Of love, fears and dreams: Narratives of wives of soldiers disabled in war

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ABSTRACT: *Context* The long drawn-out war in Sri Lanka, though now ended, has resulted in a high incidence of war-related injuries and disabilities and an arguably high, yet unaccounted incidence of trauma. There is at present some research, though very limited, documenting the effects of trauma on self-image among soldiers following war-injuries or disabilities in Sri Lanka (Fernando & Jayatunge, 2012; Jayatunge, 2008). There has been no focus on exploring the potential impact of a serviceman's or servicewoman's war-related disabilities on their significant partner within the Sri Lankan context. What is the lived experience of wives of soldiers disabled in war in Sri Lanka?

Methods This study explored the potential emotional and psychological effects of war and disability on relationships post-war in a phenomenological study documenting the lived experience of female partners. It focuses on the narratives of five female partners of military servicemen wounded in war, collecting data through observations, semi-structured-interviews and dramatherapy techniques of image, artwork and letters. To understand the narratives of the participants, the researcher used models of disability and constructions of gender and masculinities to underpin data collection and analysis.

Results Three main themes and five subthemes emerged through an inductive (Data-driven) and deductive (theory-driven) analysis using the principles of Framework Analysis (Ritchie & Spencer, 1994). The main themes were fears, love and dreams, while the subthemes included reaction, abandonment, reliance, resilience and sacrifice and blessing.

Discussion Factors connected to disability and gender which permeated the narratives of the participants represent a tension between female normative traits, roles and responsibilities and the leadership role of primary caregiver and breadwinner assumed by women following their husband's war-related disability. The women

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appear to navigate through masculinist spaces while simultaneously facing negative societal reactions to disability. The findings may be useful to be considered in discussions of psychosocial support for soldiers disabled in war and their partners at the level of policy and practice.

KEYWORDS: disability, soldiers, wives, narratives, gender

The end of a thirty year conflict in May 2009 has resulted in a generation of Sri Lankans disabled and arguably traumatized by the experiences of war. Available statistics estimate that between 80, 000 to 100, 000 people were killed during the course of the war (ABC News, n.d.) with the exact number of casualties and those wounded said to be high but unknown. Jayatunge (2008) asserts that the prolonged war has 'changed the psychological landscape' (p. 140) of the country. The incidence of post-traumatic stress disorder (PTSD) remains unknown, although thought to be high (Jayatunge, 2008). There is very limited research on the effects of PTSD and the influence of trauma on self-image among soldiers following war-injuries, or as a result of disabilities in Sri Lanka (Fernando & Jayatunge, 2012; Jayatunge, 2008). That said, there is on-going debate on the relevance and limitations of the PTSD construct as a 'trauma lens' for defining a psychological condition or experience in disparate cultural contexts (Bracken, 2002; Chakraborty, 1991; Kirmayer, 1996; O'Brien, 1998; Marsella, Friedman, Gerrity, & Scurfield, 1996; Pupavac, 2001, 2004; Summerfield, 1999, 2001, 2004) particularly with regard to a 'charity model' response from society (Galappatti, 2003). Trauma (be it war-related or otherwise) does need to take account of the cultural context that influences life experiences (Batista Pinto-Wiese, 2010), given the strong effect of religion and socio-cultural beliefs on how Sri Lankans contend with disabilities.

Disability can be defined as 'the loss or limitation of opportunities to take part in the everyday life of the community on an equal level with others due to physical and social barriers' (Yeo and Moore, 2003, p. 572). In Sri Lanka, disability has been conceptualized primarily within a religio-cultural paradigm, synonymous with explanations of 'karma' or 'god's will'. There is perceived societal stigma attached to

persons with disabilities and their families, particularly with regard to marriage prospects and community participation. It can be argued that these previous negative perceptions of persons with disabilities are, to some extent, changing as a result of the large number of civilians and particularly members of the armed forces who were disabled by war-related injuries. This is evident in the focus on service-provision and medical care for military personnel wounded and disabled in war, during and following the immediate aftermath of the war. Nevertheless, the medical intervention and rehabilitation services may be said to be 'charitable' endeavours rather than viewing disability as a rights issue.

With regard to gender, the statistics reported for the mid-year population in 2012 revealed a population of 48.5 percent male and 51.5 per cent female residents in Sri Lanka in an estimated 20.328 million (Central Bank of Sri Lanka, 2012). However, this advantage is not mirrored in the position of women viz a viz in upper management or in political representation in parliament. In spite of boasting the statistic of the first female Prime Minister, the representation of women in government continues to be at a very low percentage (Kodikara, 2009). The increasing access to education to all children has resulted in a literacy rate of 93.2 percent for male and 90.8 per cent for females respectively in the country (Central Bank of Sri Lanka, 2013), although some have questioned the veracity of this finding. In stark contrast to the number of female students entering local universities which stands at around 55% (Haraldstad, 2012), the current labour force is comprised of just 30% of women in the country; one of the lowest in the region (Daily Mirror, 2014). In 2012, 6.2 per cent of women were said to be unemployed, with conversely only 2.8 per cent of their male counterparts not in employment (Central Bank of Sri Lanka, 2012). Of the factors contributing to this marked discrepancy between the level of education and that of employment are limited child care facilities and a 'culture of masculinity', making the corporate world arguably a 'masculine space'. Although the corporate world and the political arena continues to be dominated by men, the conflict has resulted in an emergence of female-headed households, particularly in the North and East of Sri Lanka (Goonesekere, 2009), with a potential change in traditional roles and power dynamics within relationships. Extending this to men disabled in the war, arguably, this would impact on the roles and responsibilities traditionally imbued by men and women within heterosexual relationships and of notions of power and subordination within a culturally patriarchal society

'Masculinity' is defined as 'simultaneously a place in gender relations, the practices through which men and women engage that place in gender and the effects of these practices in bodily experience, personality and culture.' (Connell, 1995, p. 71). It refers to a stipulated set of social roles and behaviours imbued by men within a particular society at a particular time in history (Kimmel, 2000). These prescribed roles are based on gender rather than biological sex, with a diverse range of masculine identities formed within society reflecting a process of socialisation. A recent report undertaken by CARE (2015) document masculine norms and attributes in Sri Lanka, which impact on and function as risk factors for sexual and gender-based violence. The claim by Connell (1995) is of a pluralist notion of many 'masculinities', with evolving views of masculinity within the social sciences, history and psychoanalysis affected by its associations with colonialism and the global economy.

Disability and gender are intertwined with the socio-economic and cultural context. It is acknowledged that disability requires to be considered as an element of a cultural matrix, influenced by factors such as gender and political and economic status. The notion of 'abelism' (Campbell, 2009) appears to permeate the constructs of disability within Sri Lankan society. Connected to disabilities, in Sri Lanka, sexuality and sexual and reproductive rights of persons with disabilities have not received sufficient acknowledgement or a platform for extensive discussion. It is within this backdrop that this study hopes to document the lived experiences of wives of soldiers disabled in the war. This paper is divided into three sections. Section one briefly details the methodology employed within this study. In section two, I present the themes and subthemes that emerged from the narratives of the participants, reviewing these themes from a lens of culture, constructs of disability and stigma, feminist theories of deconstructing and reconstructing the 'feminine' and ideas on 'masculinities' and with consideration for socio-economic views of poverty and its intersectionality with gender. The paper ends with brief concluding comments in section three.

Methods

This study focused on documenting the experiences of women married to military serviceman wounded and disabled[1] in war. Due to the lack of previous local

research, the three data collection methods of in depth interviews, observations and dramatherapy techniques were selected to collect narratives of five women married to soldiers disabled by war-related injuries. Semi-structured interviews were favoured as the lack of strict structure will enable the narratives to be narrated from the participant's viewpoint, rather than determined completely by the researcher. The researcher is a female speech and language therapist and dramatherapist working with both children and adults with communication difficulties with a growing research interest in the intersection between disability and gender.

Participants

The participants were between 18 to 42 years of age. Two of them had been married prior to their partner's injury and the other three had married subsequent to their partner sustaining an injury in war, which had resulted in a disability. Relevant demographic details are provided in table 1 together with information on the partners in figure 1.

Table 1: Demographic details of the participants

Participant[2]	Age in years	Education	Employment	Years of married life
Inoka	18	O/L*	Unemployed	1 year
Gayani	42	A/L**	Seamstress/owns a little clothes shop	19 years
Lalani	24	O/L	Part-time worker at a clothes factory	1 year
Sarani	21	O/L	Unemployed	4 years
Nilanka	32	A/L	Part-time worker at a clothes factory	10 years

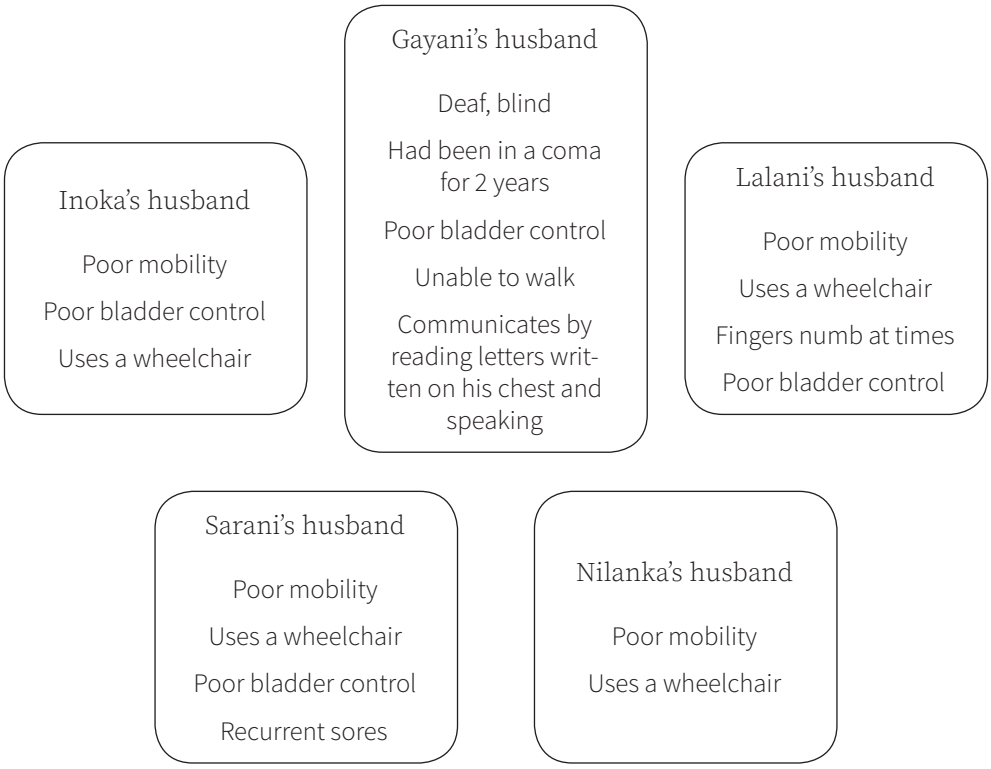
*O/L = Ordinary Level Examination is a National Examination taken by students at 16 years of age.

** A/L = Advanced Level Examination is a National Examination taken by students at 19 years of age and is the entry requirement to local universities.

Partners of soldiers who are residents at a run-stay rehabilitation facility run by the government were invited to take part. Information sheets outlining the purpose of the study and the expectations of the participants were offered. Wives of soldiers at the rehabilitation facility who expressed an interest in taking part in the study were contacted. All participants wishing to be part of the study gave written consent prior to data collection. Ethical approval for the study was gained from the Ethics Review Committee of the Faculty of Medicine, University of Kelaniya, Sri Lanka. The

main ethical consideration of maintaining confidentiality was addressed through the use of pseudonyms in order to protect the identity of the participants.

Figure 1: Information on the participants' partners



Data collection

The five participants were visited at their homes in the south of the country. Semi-structured interviews were carried out in the participants' first language of Sinhala to uncover the lived experiences of the participants. An interview guide influenced by models of disability and constructs of gender and masculinities was used with each participant. The topics included the perceptions and explanatory models of disabilities; perceived familial and societal views on disability; support structures; impact of the war-related disability of everyday life, and the influence of the disability on gender roles and responsibilities.

The interviews were between 60 to 90 minutes in duration. As an adjunct to the interviews and as the subject under discussion was very sensitive and personal, dramatherapy activities of image work, art and writing were offered, providing a

level of distance, as needed. Two of the participants were open to image work while one requested to write down her thoughts. All the participants were also observed at their homes for between 2–3 hours.

The five participants' husbands stayed at a rehabilitation centre far from their hometown and received visits from their family either weekly or less frequently. The soldiers visited their homes infrequently, once in 2–3 weeks or in one case, once a year. Three of the participants lived with their in-laws. One was hoping to build a house, one was in the process of getting financial support from the government to build her own house while the other was looking to make some renovations to her mother-in-law's house to make it accessible for her husband. One of the houses was on top of a hill making it inaccessible to a wheelchair user. Of the two participants remaining, one had a small house which was incomplete, the building of it has ceased when her husband was wounded. The other participant owned her home, which was a two-stored building, having built it on her own following the injury to her husband.

Data analysis

The interview data was audiotaped and transcribed verbatim. The data was anonymised using pseudonyms prior to analysis. The data was translated as required from Sinhala to English for the purpose of publication. Every effort was made to retain the authenticity and 'voice' of the participants by translating the data into colloquial Sri Lankan English (Gunesekera, 2005).

The interview data were analysed using the key principles of Framework Analysis (Ritchie & Spencer, 1994). Framework analysis was chosen due to the distinct yet interconnected stages of familiarization; identifying a thematic framework; indexing; charting; mapping and interpretation, making it a robust data analysis method. It was deemed appropriate also as it allows for themes to develop from the research questions and from the accounts of the participants without fracturing the individual participant's narrative (Rabiee, 2004). All the available data in the form of the audio recordings, interview transcripts and field notes from the observations and therapy activities were reviewed. The concepts that emerged from the comprehensive reading of the transcripts were used to inform the formation of the thematic framework. The themes that emerged were used as labels for codes.

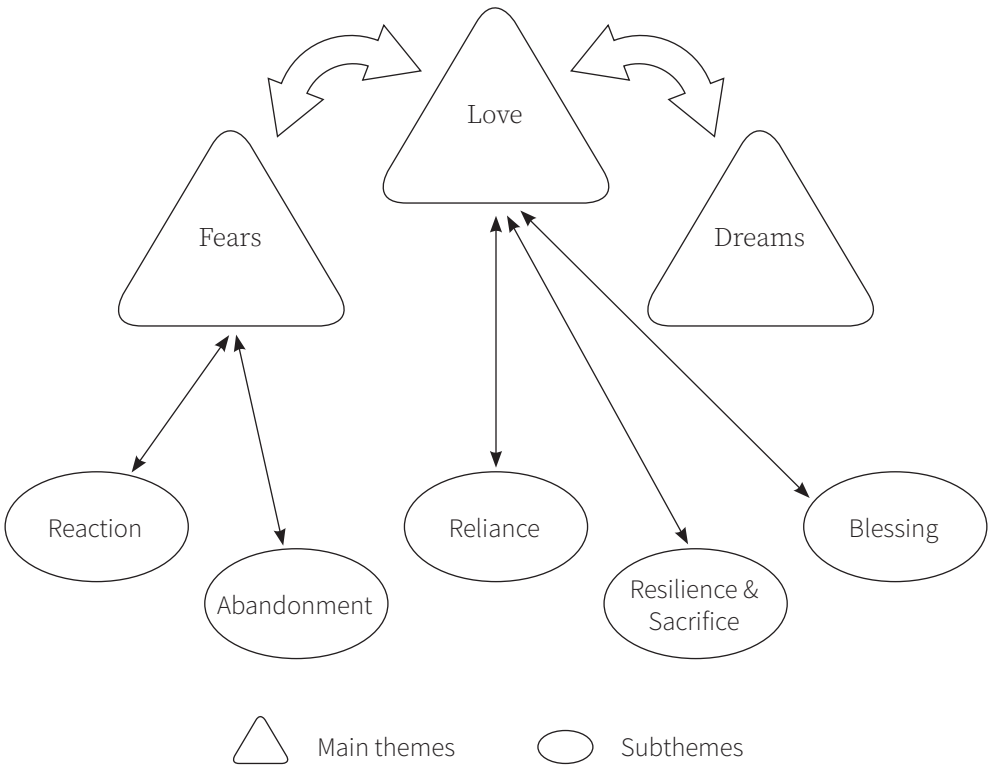
A matrix chart was compiled using the codes, and applied to the whole data and data from all the transcripts pertaining to each theme transferred to the chart.

One transcript was randomly selected for initial analysis and analysed independently by a linguist and by the researcher. While the researcher was guided by theories of disability and gender within analysis, the linguist adopted an inductive data-driven approach. Following analysis, the two coders met to discuss and determine a coding framework, which was then used to code the rest of the data. An outline of the key findings follows.

Results & Discussion

Three main themes and five subthemes connected to theories of gender and masculinity and to constructs of disability emerged through the data. Three main themes of fears, dreams and love were identified with the latter emerging as the overarching theme (Figure 2). In addition, five subthemes of reliance, reaction, courage and sacrifice, abandonment and blessing were identified within the narratives of the participants.

Figure 2: Main themes and subthemes



Love

This theme which permeates all of the narratives refers to the care and devotion of the wife towards her husband in the face of opposition. The participants had made a choice to marry a soldier disabled in the war or to continue their relationship following the injury, in spite of the weight of opposition from family members and deep-rooted societal stigma. Addressing the ubiquitous and primal nature of stigma, Corfield (2011) alleges that 'stigma is the projected and socially-accepted negative interpretation', in this case, of disability.

Lalani, who was in the first year of marriage became very emotional while talking about her family. She narrated the events leading to her decision to run away from home to get married due to objections from her mother and brothers. She explained as follows:

> I was so sad when my mother forbade me from seeing him. She said that he was not an appropriate man for our family, that he is not good enough to be my husband as he cannot look after me. It was very hurtful to hear those words. I know who he is. He is good enough for me. I don't mind that he cannot walk. I decided to run away with him. I got (gained) him… (Crying) but I lost my family.

One factor which fuelled the opposition from families reflected negative perceptions of disability, which was the suggestion that the person with disabilities was 'not an appropriate man' for their daughter or sister as he would be unable to 'look after her'. Viewed through a gender perspective, the soldier now disabled by war-related injuries was seen as lacking in some way or 'less than' a man, incapable of fulfilling his traditional gender role of protector and provider (Corker & Shakespeare, 2002; Shakespeare, 1999; TARSHI, 2010). It disallows for multiple constructs of masculinity as 'a diversity of identities amongst and within different groups of men – leading to the notion of different versions of masculinities' (Kimmel, 2000 in CARE, 2015, p.12).

Lalani continued her narrative of family rejection, explaining her brothers' views, which within disability discourse were of discrimination. Through a disability lens, a soldier wounded and disabled in the war was viewed through a medical paradigm of having a "defect" (Kaplan, n.d., Shakespeare, 1999). This view of dis-

ability as an 'impairment' or 'deficit' or as an aberration from the 'norm' or 'ideal' body intersects with notions of 'abelism' (Campbell, 2009) and masculinity (Addlakha, 2007) as the subtext is of the young soldiers wounded in war being seen as 'less than whole' and therefore unable to match the requirements of a male partner within a heteronormative relationship (Connell, 1995).

Lalani recounted:

> Miss, you don't want to hear what my brothers said. They say that they are worried about what my relatives will think. They think that X has tricked me into marrying him. They have shouted at me to end the relationship saying that I will bring disgrace on the family. But I like X. I wanted to be with him, so I ran away with him.

The notion of being 'tricked' into marriage was also echoed by Inoka whose parents had reported similar objections to her relationship at first as Lalani's mother. Inoka noted that her father forbade her from leaving the house but that she managed to visit her partner, running away with him to get married against her parents' wishes. Explaining this, she said:

> When my father heard about my affair, he was furious. He forbade me from going anywhere. He did not even allow me to go to the temple alone. When X got wounded, I think my father was worried about what the neighbours would say if I got married to a disabled person. He kept saying that X has tricked me into a relationship because I am young. I managed to meet X and I agreed to run away with him.

Another factor influencing the reported negative perceptions of family members, in this instance, in-laws, was the suspicion that the women were willing to live with a man with disabilities due to his state pension or for financial security. The connotation here is an inability to allow for the possibility that a young woman without disabilities would choose to marry or continue to live with a person with disabilities, unless there was some external reward. There appears to be a differential valuing of life based on ability or a devaluing of worth based on perceived ability/disability. As Sarani clarified:

> I am not sure why his mother thought that I was after his money. I went against my family to be with him because I care about him. But nobody seemed to believe this.

These factors intersected with the idea that it is inconceivable to accept love as a potential reason for the women choosing to live with their partner with disabilities. All five women talked about how much they 'cared' for their partner and chose to marry or continue to live with their partner. Gayani put this succinctly when she said, 'he is still my husband, even if he can't see or hear or walk. I care about him. I will not leave him.'

Reaction

Family reaction

This theme denotes positive or negative reactions to marrying a person with disabilities, in this event, a soldier with war-related disabilities. The reaction was from family, other men or the general public and includes non-acceptance of the relationship and ambiguous, changing or predatory reactions. The negative response to disability appears to eclipse the arguably 'heroic' status imbued by war veterans reflecting societal stigma towards disability. The participants experienced the reaction of their families to their marriage to a soldier disabled in the war as primarily negative, reiterating notions of 'abelism' (Campbell, 2009) and stereotypes of the 'able-bodied male' and able-bodied privilege. The three participants who got married after their partner became wounded in the war narrated a comparable experience of facing a negative reaction from their families. This resonates with the cultural model of disability through its lens of 'cultural' interpretations and stigmatisation, which in turn informs our notions of self and sexuality. It offers 'a system for interpreting and disciplining bodily variations' and provides 'a set of practices that produce both the able-bodied and the disabled' (Garland-Thomson, 2002, p.5). Lalani who has been married for one year recounted her past, explaining how she disregarded her family's wishes and got married to her husband. Explaining this, she said: 'My family don't like him. I secretly ran away with him. They still don't like it…because he is disabled. My brothers have never visited. My mother has

never seen him…I want to leave that past behind me'. She was resolved to leave what she explained was a 'bitter past' behind her and look to create a 'new' life for herself with her husband. Through her own decision to 'run away' and to 'leave that past behind', Lalani is arguably challenging the notion of ableism and gender stereotypes in her making a life-changing decision about her own life, within a culture of patriarchy.

There were questions raised on the inability of the soldiers to assume expected traditional social roles within a heterosexual relationship. Sharing a somewhat comparable experience to Lalani, though more nuanced, Inoka described how she experienced her family's reaction to her marriage as follows:

> My family did not like him at first. They like him now. I don't think it is because he is disabled. I think it is because they did not know him. But I don't know…they may be concerned about my future.

The 'concern' about Inoka's future may stem from her husband's perceived inability to fulfil his traditional 'masculine' role as 'protector' and 'provider' within marriage. Her husband, experiencing a war-related disability is viewed as 'differently able' or 'not good enough' to be in a partnership with a person without a disability. This may feed into the religio-cultural explanations of disability as due to karma or God's will, with the subtle suggestion of persons with disabilities as 'lacking in' good fortune.

Lalani's and Inoka's narratives reflect a deeply embedded view of disability within Sri Lankan society as innately negative. The reaction of Lalani's family, therefore, is of concern for her, as she is deemed to have married a man unsuitable as he is unable to provide for her as a non-disabled man arguably could, devaluing him as being not on par with a man without disabilities. The perspective of the woman's family is in-line with the religious or moral model of disability, though arguably a diminishing view, which contends that disability is due to misdemeanours or retribution for 'sins' of a previous life, resulting in pity and marginalization (Addlakha, 2007; Anthony, 2009; Ghai, 2002; Kaplan, n.d.).

Sarani's story is also of a negative reaction, but from her husband's family rather than from her own. Explaining this, she recounted that, 'He got wounded 3 months after we started our relationship. I did not tell my mother. He asked me to

go away with him and I did.' She spoke at length of how her in-laws believed that she was 'after his money', reporting that,

> His mother does not like me. She thinks I'm after his money. My parents did not like it at first because he is disabled, but are alright now.

She explained that she was saddened by the reaction of her in-laws and the overall lack of acknowledgement of all that she was doing to take care of her husband. Reinforcing the notion of 'abelism', the reaction to a relationship of a woman with a man with disabilities appears to be to cast the woman in a very stereotypical and derogatory role of a 'gold digger'. The subtext of this narrative is the view that a man with a disability cannot be considered worthy of an adult relationship leading to marriage and that a person with disabilities, in this case the man, would not be able to fulfil the perceived expectations of 'maleness'. Therefore, the compensation or payback is the husband's money or his state pension. Sarani's concern appears to be that her own 'sacrifice' of being her husband's caregiver remains unacknowledged. In this, she imbibes the traditional role of a female as 'caregiver'. Contrasting the experience of women with disabilities to that of men in the Middle East, Abu-Habib (1997) asserts that 'Men with disabilities commonly marry – often an able-bodied woman, who subsequently serves as a lifetime carer' (p. 74), suggesting that men with disabilities are able to lead a 'quasi-normal' life. Inoka's self-proclaimed 'sacrifice' to become the primary caregiver to her husband embodies concepts of a 'lifetime carer'.

Reaction of other men

The women perceived a 'predatory' reaction on the part of other men towards them, epitomizing a sense of male entitlement within a patriarchal society. The younger participants felt a sense of vulnerability, particularly in public spaces due to being married to a person with disabilities together with their age and also possibly due to their youthful appearance. As their husbands were wheelchair-users, these young women felt that other men doubted that they were in a fulfilling sexual relationship, or assumed that they were unhappy and therefore open to an extra-marital relationship. Inoka, the youngest of the five women felt particularly

vulnerable and preyed upon, and shared her thoughts as follows:

> I notice men looking at me. They know my husband is disabled. I am aware of my vulnerability…the pressure from others. I tell my husband even if someone looks at me. Then he will not distrust me.

This view underscores a particular construct of masculinity speaking to notions of male entitlement. It promotes the view of men as strong and aggressive, with a sense of prerogative and privilege in heteronormative relationships within a patriarchal culture. Due to the fear of being preyed upon and to counter any suspicions harboured by her husband, Inoka does not go to work, to the temple or to visit her family or friends. She spends all her time at her husband's sister's place, looking forward to her husband's visits or to her visits to the residential centre.

Another explanation may be deeply-held constructs on disability and sexuality, in this event, of the soldiers with disabilities incapable of satisfying sexual relations with their partner. The embodiment of masculinity within bodily performance results in the vulnerability of gender in the face of an inability to sustain performance, such as in the case of a physical disability (Connell, 1995, p.54). Historically, persons with disabilities have been portrayed in society in two paradoxical portrayals as asexual, a rejection of their sexuality (Cheausuwantavee, 2002; Mona & Shuttleworth, 2000; Fiduccia, 1999), a sexually disenfranchised group in society (Milligan & Neufeldt, 2001) or as over-sexualised (Albrecht, 2005) with the participant views reflecting the former as held by men in society. As Finger (1992) asserts, 'Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about – and formulate strategies for changing – discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction' (p.9). So, while the narratives of the participants suggest society's notion of asexuality in relation to their husbands, it also covertly refers to the sexual agency or lack thereof in connection to these women who are excluded or marginalized from realizing their sexuality and reproductive rights.

That said, Addlakha (2007) argues that sexuality and sexual and reproductive rights have been seldom voiced in the literature in India, which mirrors the situation in Sri Lanka. As she notes, 'Sexuality is an area of distress, exclusion and self-

doubt for persons with disabilities' (Addlakha, 2007 in TARSHI, 2010, p.5). While there is limited available literature on all aspects related to persons with disability, the narratives by these women of how they experienced the comments and dialogues and their interpretation of the discourse reinforces the view of persons with disability as asexual, as lacking a right to sexual wellbeing.

Although there is an acknowledgement of a disenfranchisement among the sexes, women with disabilities are said to be particularly vulnerable due to 'the double burden of ableism and sexism' (Addlakha, 2007 in TARSHI, 2010, p.5). That said, a disability is viewed as impacting on self-perceptions and societal concepts of manhood and masculinity (Addlakha, 2007). The traditional societal expectation or stereotype of a man as aggressive, self-reliant and the breadwinner of the family is at odds with the perceived dependency of men with disabilities (Shakespeare, 1999; Tepper, 1999a, 1999b). It also reinforces the stereotype of the male partner in a heteronormative relationship as dominant, as the 'protector' of the woman's honour; as able to fight and ward off other suitors.

Gayani, the oldest of the five, also explained a sense of vulnerability that she felt. Her husband is unable to walk, and had lost his hearing and vision as a result of the war. The medical authorities are also unable to assess his mental health status. As Gayani reflected, 'Sometimes he shouts and I feel that he thinks he is still at war. In his mind, he is still fighting. He cannot abandon the war'. He visits his home once a year for the New Year celebrations in April. Gayani lives with her 4 children and narrated how she had to become the breadwinner of the family following her husband's injury. 'Men in the neighbourhood compare me to their wives and say how industrious and courageous I am. They try to win my heart but I am careful. They are the very people who sent nasty letters once I got this land because they are jealous'. Her words reflect the vulnerability of a woman even within a strong female-headed household. While the reported higher propensity to sexual abuse and exploitation has been documented (Beck-Massey, 1999; LaBarre, 1998; Nosek, 1996), there is little on the potential vulnerability felt by a woman (particularly a young woman) with a partner with disabilities within a patriarchal society with the double burden of ableism and sexism. Although socialized into portraying a practice of 'desexualized subjectivity' (Shildrick, 1996; Shildrick & Price, 1996), the narratives of these women indicate the points of resistance that enable them to affirm their right to choose and to their sexuality. As an extension of the social

model, which asserts that persons with disabilities are agents of resistance rather than 'victims' (Shakespeare, 2000), these women appear to resist oppression and thereby challenge existing social structures.

Abandonment

The theme of abandonment concerns feelings of neglect, isolation and ostracism experienced by the participants. This sense of feeling let down was said to be from the participant's immediate family and from the wider society. The reason for abandonment from the immediate family appears to be a lack of acceptance of the disability and due to a devaluing of diversity or stigmatisation of variation. Garland-Thomson (2002) contends that understanding of physical variation within the binary of desirable or undesirable undervalues diversity, resulting in the internalisation of a certain idea of the self. The self-worth of the person with disabilities was articulated within terms of what he was unable to do, rather than from a point of ability, resistance and resilience. Therefore, a recurrent concern was the questioning of the motive for a woman without disabilities to choose to marry a soldier with war-related disabilities. The explanation favoured was that the women got into, or continued to be in the relationship for monetary gain. The soldier's family members appeared to hold this view, with the women's families fearing for the quality of life of their daughters.

By his or her family

Gayani continued to share her story of abandonment from her husband's family. She explained how she was supported by the army and continued to receive her husband's pension. This money, she said, is in dispute as her mother-in-law too is making a claim for it. 'His mother has not come to see him since the accident. His mother is demanding Rs. 10,000 a month. I can't afford it. I have to send my four children to school, feed them and maintain the house. I also have to pay up my loans. I started a little shop this year and I am managing it.' Contesting this claim to the soldier's pension underlines Gayani's mother-in-law's refusal to acknowledge the legitimacy of Gayani's marriage to her son. It highlights the adage of 'in it for the money', which again unwittingly underscores notions of 'abelism' (Campbell,

2009). In spite of this, Gayani has built a house for her family and a little clothes shop in a single room in front of her house where she sells children's clothes that she has sewn herself. She has also bought herself a motorcycle, which she uses to travel into the city to get her supplies of cloth and thread, with no reliance on others.

By society

Viewed through a disability lens of diverse perspectives over the decades, the religious or moral model explains disability as resulting from retribution for misdemeanours from a past life or bad karma (Addlakha, 2007; Anthony, 2009; Ghai, 2002; Kaplan, n.d.). This has been noted to lead to societal isolation. According to Addlakha (2007 in TARSHI, 2010) '…the law of karma decreed that being disabled was the just retribution for past misdeed. Pity, segregation, discrimination and stigmatisation became normalised in the management of persons with disabilities. Such constructions of the disabled by the non-disabled have the dual effect of not only justifying the complete marginalisation and disempowerment of a whole population group, but also leading to the internalisation of such negative stereotypes by disabled persons themselves' (p. 11). Two of the women reported feeling forgotten and neglected by wider society. Nilanka said that, 'No one remembers the wounded soldiers. We are on our own now'. Akin to this, Inoka shared mixed feelings about her husband's involvement in the war, feeling both pride and sadness. 'No one cares for them now. No one remembers the war. People have forgotten. They don't remember if there was a war or what has happened to the soldiers. I feel proud of him and a little sad. If he didn't join the army, this would not have happened isn't it?' A sense of regret, in this case, of their husband joining the army, featured in both Nilanka's and Inoka's explanations of feeling abandoned by society.

Through their response to this reported societal reaction, to leaving their families and breaking family ties to be in a relationship with the soldier with disabilities, these women in fact postulate a social model of disability. Through their resistance of social pressure, with social structures that are oppressive and deny equality and full access of participation in society to persons with disabilities (Shakespeare, 2000). It is society that 'disables' and persons with disabilities, and in this

case partners of persons with disabilities are not 'victims' but agents of resistance, countering oppressive societal structures (Shakespeare, 2000).

Reliance

This theme refers to the participant's perceived need in their partner's life. This was described as unidirectional with the man needing or depending on the female partner. On the one hand, this view dovetails with that of the normative 'feminine' roles of undertaking domestic chores and taking on the role of caring for her partner (Addlakha, 2007). On the other hand, the physical and unfamiliarity with supporting a person with a disability and medical needs and therefore the level of dependency could be argued to challenge traditional constructs of gender identity. Disability has been conventionally viewed as characterised by 'vulnerability, powerlessness and dependence' (TARSHI, 2010, p.54). This image is in stark contrast to characteristics afforded to masculinity such as aggression, being the main wage earner and self-reliant, making it 'doubly stigmatising for men with disabilities' (TARSHI, 2010, p.54). All five women shared stories of their partner's reliance and dependence on them. As Inoka put it, 'everything is difficult for him…going to the toilet is difficult…many things. I help him with everything'. Sarani too conveyed similar thoughts saying, 'I wait at home and do all his work for him…to help him. I lift him to the chair. I clear his catheter'. Lalani extended these thoughts further relaying a sense of pride in being able to support her husband. "I help him get to the chair. I can lift him. I feel proud of myself'. Lalani is a petite woman challenging views of masculinity with regard to courage and strength and her ability to physically support her partner.

Similarly, Nilanka, who subjectively appears physically vulnerable was still able to support her husband as he is a wheelchair-user who experiences poor mobility. She too spoke at length about her husband's level of dependence. Nilanka explained how her husband needs support with all activities of daily living, saying that, 'he needs my help with everything. I help him to the toilet, to have a bath, to get dressed, to eat. I am not complaining. This is my role now. My duties as a wife'. Her view fits in with the normative feminine role of wife and homemaker. Gayani extended this idea of dependency, expanding it to include her children. She explained in much detail how her husband is 'totally reliant on the family'

when he visits home. Given that he has lost his eyesight, hearing and mobility, with some questions about his psychological state and wellbeing as a result of the war, Gayani explained how she and her daughters support her husband during the day as follows:

> When he was first brought home on a visit, I had to help him. I was afraid that I might hurt him. Now my daughters and I have learnt how to help him. It is not easy as he is heavy and he can't see, so he can't help us to lift him, and he can't hear, so it is difficult to know what he is thinking.

Gayani noted how all financial transactions, the building of her home and the establishment of her shop and her new entrepreneurial role as dressmaker and breadwinner had propelled her to take on a more dominant role:

> I have become tough, miss, like a man. I got this house done and the shop constructed all by myself. I bought a motorbike and travelled to the city to get building materials. Some of the men in the village try to flatter me but I take no notice. They think I am vulnerable because my husband is totally disabled and can't protect me. I am tough, miss. I shout at the men. I am protecting my daughters.

The narratives embody the paradigm shift observed with the feminization of poverty within female-headed households as a result of the war (Goonesekere, 2009). This is in contrast to the presumed norm of a male-headed households or "stereotyped roles in society" (Hyndman, 2008, p. 105). The contention within Gayani's discourse is how her experiences have shaped her personality with her being cognisant that she needs to take on the persona or 'masculine characteristics' of aggression, as she says, 'like a man', to be seen to be tough, not as 'vulnerable' as her husband can no longer fulfil his traditional male role of 'protector' (Shakespeare, 1999), which in turn she imbibes in her role of protecting hearth and home, suggestive of self-reliance, a trait usually connected with masculinity (TARSHI, 2010).

Blessing

The theme of blessing denotes elements of good merit that would befall a per-

son who engages in good deeds such as self-sacrifice in looking after someone who is physically and emotionally dependent. Though religious in nature, this explanatory model of disability within a charity or welfare model promotes feelings of sympathy and dependence requiring the 'charity' or assistance of others (Khanna, 2004). Arguably, this philosophy permeates much of the work currently undertaken by civil society organisations in Sri Lanka echoing a 'stigma-collective paradigm' (Cheausuwantavee, 2002). Connected to the theme on reliance, three of the participants also interpreted the opportunity to support their husbands within the framework of religion, Buddhism to be specific. Inoka asked me the following question twice in order to get confirmation for the idea of gaining good karma for caring for someone who is ill or disabled, which was a view she subscribed to: 'It is a blessing for me to care for him, isn't it?' I wondered whether this repeated question carried with it an underlying doubt or if it reflected her need to be validated.

Inoka went on to explain that she learnt on her own how to care for her husband:

> Miss, it is 'ping' (good merit) for me to be able to care for him like this. Nobody showed me how to but I can help him in the bathroom. I am just worried whether I can continue to do this. He may need other help in the future.

Nilanka too spoke in explicit terms, stating clearly her belief in gaining merit for supporting her husband as 'I will gain 'ping' (good merit) for looking after him'.

Resilience and sacrifice

This theme constituted a sense of resilience and sacrifice – in the face of objections and control from partners. This again connects with internalised notions of duty and domesticity for women (Khanna, 2004). The constructs of masculinity as 'protector', 'aggressor', the person offering 'financial security' (Shakespeare, 1999) are challenged in the light of women having independence to work and be financially secure, with opportunities for interpersonal relationships with the opposite sex. This appears to threaten the man's sense of masculinity and self-worth, with possible concerns of not being 'whole' or 'able'. This in turn appears to be masked by aggression in-line with 'masculine' constructs of demanding that women do not work and/or have minimal contact with other men. Viewed within a medical

model of disability that pathologises the body of the person with disabilities, the body is thought of as diseased, broken and not whole in comparison to the norm of an 'able body' or ideal (Khanna et al., 2004). That said, it appears that this 'dominant' role of exerting power over the actions of the woman, which is seen as a traditionally masculine trait is maintained through the disallowing of particular relationships or opportunities.

The younger women talked about how they were not going to work thereby sacrificing a life of potential independence to look after their husband. This is what Inoka had to say:

> I am not working. I don't do anything. It can be difficult to get leave on the days my husband is at home, so I am not working…I wait to support him. He comes home once in 2–3 months for a few days.

However, with time, in conversation, it was revealed that yet another reason for not working was that her husband was unhappy with her having any contact with other men. This dislike or by extension insecurity felt by the husband was also echoed within Lalani's experience as 'He (her husband) does not let me go to work fulltime. He does not like me associating with other men in the village' and that of Sarani as 'He does not let me travel or work'. Unable to talk about this part of her story, Gayani opted to write down her thoughts. I gave her distance and sat a little away from her while she wrote on page after page for approximately 20 minutes. Her written narrative includes the following text:

> Although my husband is there (she has cut out the word 'there'), I cannot put his loss into words. But because of my four beautiful children, I have the strength to face anything. I am a person who has suffered a lot. From the day my husband got shot, we have suffered a lot.

I visited Gayani just after the New Year and her husband had been brought home from the residential facility. While Gayani narrated her story, I could see her husband writhing on the bed, while his daughters dropped by to see if he was alright. Noticing that her husband seemed restless, Gayani left the interview to tend to him. I watched as one of her young daughter's wrote with her finger on her father's

chest, which is the communication system available to them as he has lost both vision and hearing. I saw how he touched his wife's hair and face and then with what appeared to be a mischievous smile touched his wife's body. Gayani managed to calm him down and I felt that I was privy to a very private intimate tender moment. This observation was a counterpoint to the discourse on sacrifice, albeit an incident from a meeting, which occurs once a year.

This incident was a reminder and challenge to the widely prevalent view of the asexuality of persons with disabilities (Addlakha, 2007; Cheausuwantavee, 2002; Mona & Shuttleworth, 2000; Fiduccia, 1999). It highlights the intricate negotiations between disabled masculinity, desire and feminization that Gayani appeared to experience at that moment. In a world where sound and sight are impaired, touch appears to have remained as a powerful medium of communication.

On her return to the table, Gayani went on to document her emotional journey and her resolve to start working and to support her family of four children.

> There are times when I get angry. I want to look after him without him suffering. There were times when I was fed up. All our dreams were shattered…6 months before early retirement. His pay got cut and we became destitute. Some people wait till they get a hand-out. Being a woman does not mean that I cannot (work)…I am the breadwinner now.

Her words echoes the feminization of households and underscores the resilience of young women made to inhabit patriarchal spaces and the changes in the power differential between husbands and wives. Gayani's words and her resolve to be a breadwinner is in contrast to the dependence on hand-outs within a welfare model.

Fears

This theme denotes concerns about the future; about one's physical and financial ability to continue to be the main caregiver to a person with disabilities in the face of increasing dependence. The strong bidirectional link between poverty and disability has been noted in the literature (Elwan, 1999) and have been reinforced by the findings in this study. Disability places people in a vulnerable socio-economic

position, particularly within resource poor countries where persons with disabilities are at the lowest rung of the financial ladder. Although pleased that they are able to care for their partner, these women were concerned about the future and about their ability to continue to be able to support their husbands. Overall, there was an anxiety about what the future holds. Nilanka shared her concerns for the future displaying her commitment for the long haul saying, 'I wonder if there will be a time when I cannot look after him…I am worried'.

Gayani too shared similar fears for the future, even though her husband only visited her at home once a year. She said:

> We cannot look after him at home. He is better off at the centre. He is only brought home once a year for Avurudu[3] (tears in her eyes). … I wonder if I can manage to look after him even once a year as things get worse.

While needing to live in the 'here and now', particularly as a result of the high level of dependency of the soldiers with disabilities, the women all appeared to be burdened by thoughts and concerns about their ability to continue to take care of their partners in the future as presumably, the level of dependence and care required will increase. Again, this concern underlines the shift in the gendered expectation of taking responsibility for the future and of being the main income generator. Connected to this is the lack of financial security expressed by Sarani who appears to be balancing her husband's request of not working with the reality of financial needs:

> I don't work. The money he gets from the army may not be enough in the future. He already has bladder problems and gets sores often. His family is poor. They don't help us.

Dreams

The theme of dreams contain the hopes held onto for the future. This included the desire to start a family, for children to succeed and for the possibility of building one's own home. All three of the younger women mentioned their yearning to start a family. Looking through a series of postcards I had presented to her, Lalani

said that she was drawn to one particular image. Explaining her choice, she said, 'I like this picture…My hope is to start a family (eyes well-up with tears)'. She also discussed her vision of making an accessible home so that her husband could be as independent as possible. 'We are making changes to the toilet so on his next visit, he will not have to use a chair outside. We need to collect money to complete it', she said. There was acknowledgement of the influence of financial constraints on the quality of life of persons with disabilities.

Inoka talked about her desire to build a little home for her family and to start a family. Sharing her dreams, she said, 'I want to see him. If he does not come home, I go to see him. I am waiting to be free to live happily[4]. If I look sad, it is too sad for him…so, I don't show it We want to have a place of our own someday soon; I hope…I would like to have a baby.' Sarani who was spending much time babysitting her two nephews said that she would 'like to have my own'. Like Inoka, she was concerned about not having her own space as well as the lack of an adequate income. She explained: 'We took a loan and bought this property. We have applied for help to the army. We want to build an accessible little home.'

Talking of one of her moments of successes, Gayani related how the support from the army had enabled her to build her home at a time when she had no idea where to go or to whom she could turn to. Communicating this, she said:

> I can face any sadness because they (army) made us a house. We now have a land and house to call our own. One of the fears I had was that my children would not have a place to live. But now we have a place of our own.

The need to own a place of their own and be less dependent on in-laws and to feel like a 'real' family echoed through the narratives of the women. It is suggestive of the potential negative consequences on the sexual and gender identities of the soldiers and their partners post-injury. As one of two participants with children, Sarani articulated this desire clearly saying 'we both want to be a real couple; to have a small house of our own and to start a family'. This need to be a 'real' family expressed by Sarani resonates with the narratives of the others. This need to be viewed as a 'real' or by extension, a 'non-disabled couple' or 'normative couple', may be connected to notions of stigma prevalent within society.

Gayani wrote at length about her dreams of success for her four children. She

said that she lives for them, to support their education and to look after her husband to the best of her ability. Continuing to write in her last page, Gayani states:

> There are a lot of things. But there is not enough time to write everything. My only wish is to be able to teach my children well and to look after my husband well and live the rest of my life well.

As I was leaving, Gayani got her daughters to come and speak to me and worship me, as is the local custom when you meet a teacher or an elder. Gayani's parting words were:

> My daughter drew this picture[5]. She wants to give it to you. She is such a talented artist. I want her to study hard and be successful (tears in her eyes). This is my only wish.

Conclusions

Overall, the narratives of the five participants generated three main themes and five interconnected subthemes. The overarching theme across all the narratives was love. These women have and continue to experience negativity from their families and report feeling a sense of abandonment from society; they live in relative poverty, display extraordinary courage, sacrificing their lives to care for their husband and children; they try to forget an unpleasant past and dare to dream of a future with hope.

The main limitation of this study is the small number of participants. The paper reported on the narratives of five women, which reflected their lived experience as recounted by them. While the researcher was able to make a few observations, these were limited to a few visits and was not in depth documentation across time. Further research studies should include a larger cohort of participants to enable the identification of themes relevant to a larger number of women, which in turn could influence policy-makers to review the psycho-social support offered to partners of soldiers wounded in the war. It is acknowledged that stigma is a complex phenomenon warranting in depth, nuanced representations of stigma and the stigmatisation process. It would also be of benefit to undertake longer

term ethnographic studies, looking at the interaction between and the influence and interplay of hierarchies, gender and socio-economic background on acknowledging and dealing with disability. Such studies have the potential to expand our understanding of the multi-layered nature of disability and gender.

Endnotes

1 It is acknowledged that the servicemen themselves may or may not define themselves as 'disabled'. Four of the five army officers described themselves as 'disabled'; the other had lost his sight and hearing and so, it was not possible to verify this.

2 Pseudonyms are used throughout to safeguard confidentiality.

3 'Avurudu' refers to the Sri Lankan New Year celebrated in April by Sinhala and Tamil-Hindu people.

4 She is living with her in-laws at present.

5 A picture of a monkey on a tree.

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