‘You Lose Confidence in Being a Human Being, Never Mind Being a Parent’: The Lived Experience of Mothers With Spinal Cord Injury

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Abstract
Little research to date has explored the experiences of parenting among mothers with Spinal Cord Injury (SCI). The aim of the study was to explore the lived experiences of mothers with SCI. Semi-structured interviews were conducted with eight mothers and an interpretive phenomenological analysis was carried out. Two super-ordinate themes were identified. The first theme, entitled: ‘A sit-down mummy: The visibility of differences as a mother with SCI’ highlighted how mothers faced challenges when undertaking practical parenting tasks, thus making them feel less than their non-injured peers, and how they navigated the visible and physical intrusion of the wheelchairs in their relationships with their children. The second theme, entitled: ‘What kind of mother? Being a good enough parent’ reflected mothers’ heightened sense of guilt with respect to unmet expectations of the self as mother, and the contrasting positive experiences of availing of support and finding new ways to connect with their children. Clinical implications, methodological considerations and future directions are discussed.

Keywords
spinal cord injury, mothers, interpretative phenomenological analysis

Spinal Cord Injury (SCI) is a sudden life changing event which can present a multitude of physical, psychological, social and economic challenges to individuals and families. Traumatic SCI results from damage to the spinal cord following trauma, while non-traumatic SCI occurs following a loss of blood supply or compression due to tumour or infection (Eck & Marks, 2012). Between 250,000 and 500,000 spinal cord injuries occur each year (WHO, 2013). In Ireland, where the present study was carried out, the estimated incidence of traumatic SCI between 2010 and 2015 ranged from 11.5 to 13.3 cases per million population per year with non-traumatic SCI occurring at twice that rate of 26.9 per million per year (Smith et al., 2019, 2020).

Due to its often-sudden nature and depending upon the location of the injury, sustaining an SCI is a significant life event affecting multiple systems, including bodily processes, movement and functioning, as well as psycho-social processes including body image, independence, sense of self, place in society and role performance (Albright et al., 2008), including that of being a parent. Alexander et al. (2002) quantitatively examined parenting by mothers with SCI and concluded that children were not adversely affected by their mothers’ SCI and there were no differences between mothers with and without SCI on measures of marital and family functioning, self-esteem, parental satisfaction and gender role identity. However, there is a dearth of qualitative research which explores the experiences of parenting among mothers with SCI (Brennan & Swords, 2021). This is a gap that the current study seeks to address.

Parenting With a Physical Disability
Owing to the scarcity of literature on parenting with SCI, literature on parenting with a physical disability will be

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Parenting With SCI

Research examining parenting with SCI is scarce with only a handful of studies focusing specifically on mothers and fathers with SCI (Brennan & Swords, 2021). Several studies have measured a variety of indicators that relate to family life such as perceived stress and life satisfaction (Albright et al., 2008), social participation and barriers to participation (Rasul & Biering-Sorensen, 2016; Tsai et al., 2017; Westgren & Levi, 1994), parental ability and quality of family relationships (Alexander et al., 2002; Westgren & Levi, 1994) and support in the parenting role (Rasul & Biering-Sorensen, 2016). Other studies have qualitatively explored experiences of parenting among mothers and fathers (Kaiser et al., 2012), or among fathers (Duvedvany et al., 2008; Nolan, 2013; Pearcey et al., 2007 [one mother included in this sample]) or mothers separately (Aune, 2013; Casey & Nolan, 2012; Quigley, 1995).

These studies highlight societal challenges and obstacles negatively impacting those with SCI. In addition, parents experience frustration secondary to the community obstacles they face, including having to contend with judgement about their competence as parents (Kaiser et al., 2012, p. 127). However, as noted by Brennan and Swords (2021, p. 412) ‘once parents adjust to their injury, their experiences of parenting with an SCI can be nurturing, enjoyable and a fulfilling experience’ and parents with SCI do report satisfaction in their parenting role (Rasul & Biering-Sorensen, 2016). Kaiser et al. (2012) found that parents highlighted the value of non-physical contact and the provision of love, support, time and nurturance, over physical activities like playing football.

Qualitative studies specifically on fathers found that these men challenged negative perceptions and attitudes towards parenting abilities and described how an open dialogue with children about disability retained a focus on paternal strengths while also nurturing relationships with their children. (Duvedvany et al., 2008). In another study of men’s experience of SCI (Nolan, 2011), one father described having more time with his children following SCI but faced obstacles in spending quality time with them because of restrictions posed by his wheelchair, and his struggle to exert authority when required.

Research with a specific focus on mothers’ experiences with SCI is also scarce. According to Malacrida (2019), it is important to consider the experiences of mothers and fathers separately, given that parenting is a role that is strongly gendered. She argues that while the social model of disability has focused on barriers to participation in education, the labour force or the built environments, many of the challenges faced by parents with a disability occur in the private sphere and mothers with disabilities...
are disproportionately affected by these challenges. Foremost among these challenges is living up to the ideal of intensive motherhood (Hays, 1996), characterized by ‘active, involved and expert mothering’ (Malacrida, 2019, p. 470), in a context where mothers with disabilities are likely to be judged as being not good enough or inadequate in their mothering and their children are at risk of being parentified or relied upon by their parent (Prilleltensky, 2004).

Aune (2013) highlighted the obstacles and challenges facing women, including a lack of awareness within the healthcare community of mothers with SCI and an initial lack of confidence and concern about practical parenting tasks. Similar to Grue and Laerum’s (2002) findings, these mothers reported societal questioning of their parental capacity (Aune, 2013), although research has shown that these feelings dissipate as women grow in confidence as mothers with SCI (Alexander et al., 2002; Westgren & Levi, 1994), and adaptive and modified equipment has been used to support women’s independence and confidence in providing care for their children (Cowley, 2007).

One quantitative study of mothers with SCI reported satisfaction with family life, social networks and the ability to successfully carry out mothering roles as well as positive relationships with children and partners and good family functioning (Westgren & Levi, 1994). Similarly, Alexander et al. (2002) found that mothers with SCI reported comparable levels of parental satisfaction, family functioning, children’s self-esteem, adjustment and marital functioning as mothers without disabilities. Consequently, Westgren and Levi (1994) and Alexander et al. (2002) call for an end to the consistent identification of negative societal attitudes and biases towards parenting with SCI, and towards children of parents with physical disabilities (Grue & Laerum, 2002; Malacrida, 2009; Prilleltensky, 2003).

Women with SCI poignantly reflected on the contrast between expectations and experiences of parenting with SCI (Albright et al., 2008). Findings suggest that time to reflect and make changes and practical adaptations to living with SCI can be protective for future parenting roles. Overall, women reported finding ways to overcome obstacles to being mothers with SCI and reclaiming motherhood as ‘a significant life role that is crafted across a life course, reworked into details of traumatic SCI’ (Albright et al., 2008, p. 57).

The Current Study

The aim of the present study is to explore the lived experiences of mothers with SCI. Qualitative research has been previously used to gain a deeper understanding of the experiences of fathers with SCI (Duudevaney et al., 2008; Kaiser et al., 2012; Nolan, 2011; Pearcey et al., 2007). In addition, two qualitative studies of mothers with SCI have been identified (Aune, 2013; Quigley, 1995). Aune’s Norwegian study of five mothers with SCI explored how they managed everyday challenges and barriers in society, while Quigley’s US-based study included two mothers in her sample. The current study will therefore add to this small body of literature to offer insights into the lived experience and sense making of eight mothers with SCI to address the following research question: ‘what is it like to be a mother with SCI?’

Method

Design

Interpretive Phenomenological Analysis, a qualitative methodology designed to explore the personal meaning, phenomenology and sense making of personal experiences was selected (Smith et al., 2009) for the present study. IPA is both a methodology and a philosophical foundation which also provides a process to understand the complexity and qualities of that experience (Smith & Osborn, 2008). An IPA approach was considered appropriate as the research question specifically focused on the subjective experiences of being a mother with SCI.

Recruitment and Participants

Ethical approval was received from the National tertiary neuro-rehabilitation service specialising in the care of people with SCI in Ireland, and the university to which the research team was affiliated. In consultation with the medical records department and SCI multi-disciplinary rehabilitation team, 116 women were identified as receiving rehabilitation during the period 1993–2012; 43 of these women were identified as mothers. Inclusion criteria included: participants with a traumatic or non-traumatic SCI, living in their home within the community with SCI, who had completed rehabilitation and discharged home at least 1 year prior to interview, who spoke English as a first language and had at least one school aged child and no significant cognitive impairment, mental health difficulties or significant levels of neuropathic pain. Every effort was made to find a homogenous population to gain ‘a shared perspective upon the phenomenon of interest’ (Larkin et al., 2019, p. 182). Fourteen of the 43 women met the inclusion criteria and were sent a postal invitation together with participant information and consent forms.

Eight women ranging in age from 27 to 52 years (M = 41.6 years, SD = 11.3 years) participated. Time since leaving rehabilitation ranged from 2.5 to 32 years (M = 13 years, SD = 12 years). Causes of SCI included road traffic accidents, falls and surgery. Level of injury ranged from L2 to C5. Five women were married with more than
one child. Three were unmarried and had one child each. Children ranged in age from 5 to 20 years ($M = 11.9$ years, $SD = 4.76$ years). Three women had children following injury.

**Procedure**

A semi-structured interview schedule (Appendix 1) was developed through a literature review, reflective supervision with academic and clinical supervisors, an IPA peer supervision group and following feedback from a pilot interview. The researcher sought to avoid obscuring or over directing the interviews by asking broad, open-ended questions followed by a series of prompts used to elicit more specific information in relation to mothers, their children at different developmental stages, partners/ husbands, family, schools and community.

The interviews were conducted by as part of her Doctorate in Clinical Psychology. Clinical supervision in the tertiary hospital service (National Rehabilitation Hospital, Ireland) was with Dr Maeve Nolan, a Senior Clinical Psychologist in SCI with several qualitative health research projects and publications in SCI. Academic supervision was provided by Dr Elizabeth Nixon, Associate Professor in Psychology in the Psychology Department, Trinity College Dublin, Ireland with experience in teaching, supervision and publication of qualitative and quantitative health research. Each interview was followed by a short, informal debriefing conversation. Debriefing questions included asking participants about their expectations and experiences of the interview; their feelings during and after the interview; and if they wished to avail of supports. Participants were provided with contact details of researchers and relevant support organisations. Seven women chose to be interviewed in their homes, while one opted to be interviewed in an outpatient setting. Interview times ranged from 61 to 151 min ($M = 108$ min, $SD = 27$ min).

**Data Analysis**

Consistent with IPA guidelines (Smith, 1999; Smith et al., 2009) each interview was recorded, transcribed verbatim and analysed in stages and layers of analyses. A reflective diary was kept to ensure an idiographic approach to each individual’s unique experience and a parallel account of the researcher experience. Each transcript was read and reread and initial descriptive noting (e.g. ‘mother struggled to work out ways to get son in and out of car’), paying attention to what each woman said was completed. The second layer, linguistic analysis (e.g. ‘mother pauses before reflecting on the ‘daunting task’), focused on the language women used to describe their experiences. The third layer, conceptual analysis (e.g. ‘Restrictions and physical obstacles’), facilitated the emergence of a more interpretative perspective, while also ensuring that sufficient attention was paid to the participants’ account in the researcher’s interpretation.

This initial noting together with the linguistic and conceptual analysis were then transformed into emergent themes capturing the phenomenological essence of each participant’s account. The researcher’s experience and assumptions were ‘bracketed’ in order to ensure the analysis was grounded in the participants’ sense making (Smith et al., 2009). A double hermeneutic, whereby the researcher tries to make sense of the person making sense of their experience is central to IPA (Smith et al., 2009).

After completing individual analysis, patterns across cases were examined and a table of emergent themes identified. Extracts supporting each theme were selected and themes were repeatedly examined to ensure that higher order themes reflected the original subthemes. Independent data analysis checks were conducted with academic and clinical supervisors, and a peer supervision group, as recommended by Smith et al. (2009), ensured quality and validity of analysis. In order to ground the analysis in participants’ experience, super-ordinate and subordinate themes were repeatedly reviewed in the context of the interview transcripts.

Yardley’s (2000) evaluative criteria for qualitative research were applied to ensure credibility and trustworthiness of the analysis: sensitivity to context (e.g. reflexivity, bracketing off presumptions about the data; using a pilot interview and debriefings to incorporate participants’ perspectives on the sensitivity to context); commitment and rigour (e.g. pilot interview, use of supervision, reflexive diaries and peer supervision); transparency and coherence (e.g. independent checks on data analysis by supervisors, discussion of emergent themes with clinical and academic supervisors); peer supervision; impact and importance (e.g. plan to disseminate material at conferences, publications and disseminated to key stakeholders). In addition, four qualities of IPA’s theoretical underpinnings were adhered to: attending to convergence and divergence; close analytic reading of participants’ words; developing a vigorous experiential and/or existential account; and constructing a compelling, unfolding narrative to provide a reflexive, coherent and accurate interpretation of women’s sense making of their maternal experiences, while simultaneously minimising bias to tell a story of the experiences of mothers with SCI (Nizza et al., 2021).

**Results**

Two super-ordinate themes were identified, encapsulating the experience of mothers with SCI. ‘A sit-down mummy’: The visibility of differences as a mother with SCI
highlighted the process of grappling with the negative impact of visible external barriers, challenges and differences while mothering with a physical disability. The second super-ordinate theme, ‘What kind of mother?: Being a good enough parent’, captured the invisible differences and associated internal feelings of guilt, shame and struggle with the mismatch between expectations and experiences of themselves as mothers. Both super-ordinate themes relate to the barriers and differences faced by mothers with SCI and contrast with the strategies found to optimise relationships with their children. In the presentation of themes, pseudonyms have been used to protect the identity of participants.

‘A Sit-down Mummy’: The Visibility of Differences as a Mother With SCI

This super-ordinate theme capturing the visible differences impacting motherhood for participants contained two subordinate themes: (1) Going through a different door: doing things differently and (2) Unable to get close enough: Me and the wheelchair. Women grappled with external challenges experienced when completing practical tasks, making them feel ‘set apart’ and lesser than their peers while also navigating the visible and physical intrusion of wheelchairs in their everyday lives.

Going through a different door: Doing things differently. In this subordinate theme, participants described the disruptive experience of feeling different as a result of SCI. This sense of self as different was experienced on a number of levels. Physical barriers made wheelchair access challenging in the community compared to their peer group of able-bodied mothers. One woman spoke about the difficulties involved in managing a shopping trolley with a wheelchair, another spoke about missing school plays and parent-teacher meetings when schools were not wheelchair accessible. These visible obstacles and environmental barriers, irrelevant for other mothers, become challenges to be navigated and overcome, and contributed to participants’ sense of being visibly different, set apart and lesser than their peer group of mothers without SCI. Participants perceived themselves as unable to perform mothering in the same way as able-bodied peers.

Mothers with SCI, literally and metaphorically, went through different doors, thus seeing themselves as visibly different and set apart and yet, paradoxically, somehow invisible. Patricia’s friend described the invisibility of mothers with SCI in the community, when she commented on how unusual it is to see a mother who is a wheelchair user, with a child on her lap in a supermarket. Women described an unwelcome, public transformation of former selves in how they were seen, in the community. Prior to injury, Patricia never chose to sit at the front in a public place, never chose to be visible. However, since injury, she described a compromised sense of agency and a lack of choice:

‘I wouldn’t [be a] sit at the front type of person […] now I can’t get away with it. I am the girl in the chair. I can be easily spotted.’

All participants identified with the loss of identity and the interruption and disruption to the sense of self and feeling lesser in comparison with their peer group of mothers who could do things differently for their children: ‘if I was on foot, I’d bring him to do [shopping for trousers]. Them things kind of hurt me’ (Mary). In addition to the, often unwelcome, feeling of being more prominent and visible, participants spoke about the emotional impact, vulnerability, unease and frustration at the obstacles they faced outside their homes: ‘So I went in a different door. And … it was daunting without a doubt’ (Daisy). At times, when it was not possible to overcome the obstacles in the community (e.g., when a building or sports ground was not wheelchair accessible), women would heartbreakingly watch their partners, grandparents and children leave and feel the loss of missing out: ‘… very hard so it was…when they were gone, I’d be feeling it’ (Diana). The dramatic transformation of feeling different, more prominent and visible resulting from SCI is expressively described by Sheila ‘You lose confidence in being a human being, never mind being a parent.’

In summary, this theme highlighted the external barriers and challenges women faced parenting with SCI. These visible differences, barriers and challenges catapulted women into undesirable prominence, for example, by needing to be lifted upstairs by other dads, or having to navigate public spaces differently. Participants compared this to the experiences of mothers without SCI and described feeling lesser than their peers as a result.

Unable to get close enough: Me and the wheelchair. The second subordinate theme concerning visible barriers, challenges and differences in being a mother with SCI, reflected the unwelcome and invasive presence of the wheelchair in the relationship between mother and child:

‘When they started getting more able to walk, …, you couldn’t hold their hand, at least I found it really hard to hold their hands and walk with them’ (Karen).

While use of a wheelchair enabled some parenting tasks and activities of daily living, it also created a problematic physical distance which negatively impacted the relationship between mother and child: ‘that’s when I realised … I couldn’t do anything … I couldn’t get close
enough to him’ (Sheila). Women spoke about their own resentment, and that of their family, to ‘the chair’: [My children sometimes say] ‘I hate that chair’ (Patricia). The wheelchair appeared to invade and place a visible and physical barrier between mother and child. Women regrettfully expressed strong wishes to be able to have eye contact with their children, walk with them rather than running over their toes with the chair and give them hugs without the wheelchair interrupting their space.

For participants, the unwelcome and invasive presence of the wheelchair placed constraints on where they could go or not physically go within their own homes. Children (from toddler to middle childhood years) found places their mothers could not go, such as upstairs, under beds or into rooms where the wheelchair did not fit: ‘But it’s hard looking at her, knowing you can’t do it’ (Diana). Setting boundaries with their children was therefore physically challenging and amplified women’s sense of helplessness and frustration as mothers and undermined further their sense of being a ‘good enough parent.’

In summary, this super-ordinate theme highlighted visible differences and external barriers faced by women with SCI. These were heightened at times when they could not access parent-teacher meetings or other routine parenting duties. Women with SCI reported feeling set apart and lesser than their able-bodied peers. More poignantly, the very visible invisible, a minority group, side-lined by their differences imposed by SCI, yet hidden and invisible to others was another hidden difference in feelings of shame, guilt and being ‘not good enough’ as parents because of their disability, which brought a sense of shame, as a consequence of falling short of their own ideals and expectations of parenting roles. ‘Because you use a chair…there is no doubt about it but you do feel…not on a par’ (Meredith).

For Diana, her diminished capacity to fulfil the simple but profound physical tasks of dressing her child or attending school plays shattered her expectations of herself and her ideals of parenting. Women described not having a reference group of peers with SCI to help them manage their expectations: ‘I had nobody else who had gone through pregnancy and having children in a wheelchair to go back to and ask. I was going blind’ (Meredith). No longer able to fulfil her own ideals, Diana described part of herself as having been ‘killed’. Mary’s son similarly described his mothers’ experience as ‘worse than a prison sentence’. The felt sense of entrapment and limitation imposed by SCI, yet hidden and invisible to others was evident in all interviews and contributed to feelings of being different to other able-bodied women.

The subordinate theme ‘Not a good enough parent in the wheelchair’: fear of being a bad mother encapsulated another hidden difference in feelings of shame, guilt and being ‘not good enough’ as parents. These feelings gradually changed as the capacity of mothers grew enabling them to avail of social supports, nurture, communication and connection in their relationships with their children and trust their innate parenting ability.

‘It is hard to accept help but you have to’: Being a dependent mother. This subordinate theme illustrated how family and other social supports helped mothers fulfil parenting tasks, particularly in the community, thus shaping what kind of mother they would be. Support from family and carers were valued by all women, although some mothers struggled with needing such support. Some participants spoke about yet another layer of private experience resulting from feelings of dependency stemming from reliance on such support in their lives.

Participants described the struggle between balancing and maintaining a sense of autonomy while acknowledging the need for assistance from family and carers, even young children. Sheila felt that her 5 year old grew

**‘What Kind of Mother?’: Being a Good Enough Parent**

The second super-ordinate theme, ‘What kind of mother?’: Being a good enough parent, consisted of three subordinate themes concerned with invisible differences and internal challenges for women with SCI. The three subthemes themes: (1) Fear of being a bad mother; (2) Being a dependent mother and (3) Being a capable mother gave voice to women’s heightened sense of maternal guilt in relation to unmet expectations of self, and the contrasting positive experiences of availing of supports and finding a new, enhanced connection and relationship with children.

‘Not a good enough parent in the wheelchair’: Fear of being a bad mother. Overall, this subordinate theme highlighted mothers’ experiences of not feeling ‘good enough’ and the mismatch between their expectations and experiences in physically managing some practical parenting tasks. Mothers had few reference points or role models for parenting with a disability, resulting in worry about ‘what kind of mother’ they would be. Participants reported struggling with a sense of pressure and maternal guilt by not fulfilling their parenting ideals of motherhood due to the environmental obstacles and challenges they faced. One mother described: ‘I had myself as a bad mother because I couldn’t do them (tasks of parenting)’ (Sheila). Daisy described feeling ‘guilty that [she] was unable to give them everything [she] would like to give them.’ Mothers struggled with feelings of being ‘not good enough’ as parents because of their disability, which brought a sense of shame, as a consequence of falling short of their own ideals and expectations of parenting roles. ‘Because you use a chair…there is no doubt about it but you do feel…not on a par’ (Meredith).

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Participants described the struggle between balancing and maintaining a sense of autonomy while acknowledging the need for assistance from family and carers, even young children. Sheila felt that her 5 year old grew
up too quickly trying to help her: ‘I found [he] felt like he had to protect me [...] and a five year old shouldn’t have that responsibility.’ A range of such responsibilities were described including Daisy’s children lifting the wheelchair in and out of her car; Meredith’s children helping with shopping and Kate’s child who helped in lots of activities to such an extent that she thought he would be a ‘great carer’ later. In general, participants valued supports as an extension of their ‘good enough’ parenting abilities, extending their social power by virtue of extending their tribe of support. Women described how such supports extended their own parenting roles, and rather than missing out, mothers preferred to see a member of their tribe, a family member or carer, enabling opportunities for their children. ‘I’d like to think he never missed out. If I couldn’t do it with him, I got someone else to do it with him’ (Sheila).

In this subordinate theme, it was important for women with SCI to create a community of supports to act as an extension of their own ability to carry out parenting tasks and more importantly, to ensure their children did not miss out.

‘It’s the one thing you can give them whether you are in a chair or not … love’: being a capable mother Despite the physical constraints on parenting imposed by SCI, this subordinate theme reflected key strategies of trust and communication developed between mothers and children. These strategies helped women feel capable as their children listened to them, trusted them to keep themselves safe and affirmed their close bond and relationship.

Women described experiences where they had to take risks and trust themselves and their children while parenting from a wheelchair, in order to perform their role as parents and keep their children safe: ‘Your heart would be in your mouth half the time’ (Meredith). Rather than feeling stigmatised by the shame of not being good enough, taking risks and developing intuitive parenting skills helped these women actualise as the mothers they wanted to become. Their parental trust in their children’s, and their own abilities, served to fuel their own resourcefulness and confidence in their relationships with their children. Meredith described this trust in terms of strength, a way of ‘armouring’ her children as she felt she had to rely on them to be more responsible for themselves, to stay safe. The use of the word armour implies protection and power and perhaps Meredith was preparing them with such armour to brave the environment, while also ‘armouring herself’ to keep them safe. By relying on trust, mothers found ways to be ‘good enough’ parents, and to find ‘a new normal’ in their parenting relationships.

Regardless of age, open and honest communication with children became an important parenting tool in maintaining relationships. Mothers in this study spoke of the value and reciprocal nature of communication. Some mothers described not playing ‘the game’ with their children when they would hide under beds or places mothers could not go with a wheelchair and instead powerfully asserting their authority by means of communication. In communicating honestly, women gained their children’s trust, which helped transform the experience of parenting with SCI positively, and fostered an appreciation and contextualisation of their own challenges and struggles:

‘I don’t believe in keeping it back from them. No, because I think it makes it harder to deal with […] You have to gain their trust’ (Mary).

In addition to trust and communication, women in this study reached past their own resentment of ‘the chair’ to reframe it for their children, creating a value and novelty status to the wheelchair in navigating environmental obstacles. In this way, some mothers transformed the wheelchair into an enabling relationship building tool:

‘From a very, very early age [her children’s game] was to hop up on my toes and they rode on me around the house, they’d sit on my lap’ (Daisy).

This redefinition served to normalise disability, create novelty and fun and, most importantly, allow SCI and the wheelchair to become an integral part of mothers’ identities and assist the family to accommodate SCI rather than see it as an obstacle to their relationships. Rather than SCI interrupting the mother child bond, innovative ways of using the wheelchair created new constructions of their shared world and ways to engage and connect through play.

For some women, particularly those with younger children, the bed also became a shared, safe place where relationships could flourish for both mother and child, thereby creating new ways to engage creatively. In this way, Daisy strikingly described the bed as her children’s ‘playground.’ Like Daisy, Patricia described the bed as an ‘equaliser’ which enabled a special and valuable kind of closeness, crucial for a sense of connection between mother and child:

‘We would lie in bed, they would be so affectionate. When they are lying in the bed and I am lying in the bed, we are the same’ (Patricia).

These practical coping strategies were enhanced by an emotional attunement developed in relationships with children, allowing mothers to become acute observers of their children’s actions. Kate, a woman with limited hand function, movingly described the natural inclination of her
child to engage with her in reciprocal play, despite the restrictions on hand function imposed by her high level injury.

‘John had this wee toy it was like a Winnie the Pooh book but when you changed the pages you could press these buttons and make songs, like a little piano […] John came up and sat on my lap and he grabbed my hand and pushed the buttons with my finger. And he was two at the time […] I just started […] crying’ (Kate).

Participants cherished time spent with their children. Touchingly, Patricia reports ‘it’s quality time rather than, ‘Oh yeah, I will do that in a minute.’ Women reported being more present in their relationships and as summed up by Daisy: ‘It’s the one thing you can give them whether you are in a chair or not … love.’

In this study, women described feeling pivotal at home and assured of their importance within the family, following a period of stabilisation and adjustment to SCI. Crucially, this sense of importance within the family was re-affirmed by children who did not define them by their disability. In this way, children helped challenge the lexicon of disability as a de-stabilising identity and instead shaped the experience positively.

‘Even though you are in the chair you know you are the centre pivot of the house […] while we are sitting around the table, it doesn’t matter who is sitting in what chair, it’s more about the family’ (Daisy)

Women helped their children carry on with their lives, normalise experiences for them and prevent SCI negatively impacting on the quality of family life. Daisy captured this normalisation well, and very practically when speaking to her child:

‘A lot of mummies are stand-up mummies, I’m a sit-down mummy.’

In summary, the second super-ordinate theme, ‘What kind of mother?’: Being a good enough parent, outlined the invisible differences and challenges experienced by women with SCI. The subthemes: Fear of being a bad mother; Being a dependent mother and Being a capable mother combined with the feelings of invisibility and challenge described in the first theme to richly describe participants’ experiences of mothering with an SCI. Heightened emotions stemming from unmet expectations of self were in stark contrast to positive experiences of finding a new, enhanced connection and relationship with children through social supports, creating novelty and fun and practical coping strategies. These mothers availed of opportunities to meet ordinary tasks with their children in extraordinary ways, normalise their experiences and create opportunities from challenges to positively strengthen the connection and relationship between themselves and their children. Ultimately this small group of women with SCI all found new, creative ways to enable closeness in their parenting relationships and to be ‘good enough’ parents.

Discussion

This study provides an in-depth exploration of the lived experiences of being a mother with SCI, adding to the small body of previous qualitative studies on mothers with SCI. In line with the social model of disability, the eight mothers in the current study highlighted the visible (environmental) and invisible (psychological and emotional) constraints they experienced as they navigated their roles as mothers. At the same time, they also focused on the creative and intuitive ways in which they nurtured closeness and connection with their children.

The first super-ordinate theme in which mothers described going ‘through different doors’ reflected how mothers grappled with environmental obstacles which rendered them unable to perform mothering in the same way as their able-bodied peers. These challenges have similarly been reported in other studies of parenting among mothers with physical disability (Albright et al., 2008; Aune, 2013; Bergeron et al., 2012). In contrast to findings of Grue and Laerum (2002) that being a mother may provide an opportunity to feel the same as others, mothers in this study felt excessively visible and defined by having to enter ‘different doors’ both literally and metaphorically. These ‘different doors,’ or physical barriers and environmental obstacles in the community, were disruptive and compromised women’s sense of agency as mothers. Indeed, these environmental obstacles faced by mothers as wheelchair users catapulted them into a prominent and visible place not of their own choosing.

Not only did mothers experience obstacles in their community, they also experienced physical barriers in their interactions with their children. As has been reflected in other research, mothers in this study felt defined by the physical entity of the wheelchair and were not always at ease with themselves as wheelchair users (DeSanto-Madeya, 2006). Mothers reflected that the physical distance created by the chair symbolised the imposed and unwelcome physical and visible intrusion of the wheelchair into their relationships with their children. This unease is part of a process of adjustment to being a person with SCI, learning to use a wheelchair and making it part of their embodied experience through assessment and modification of obstacles and challenges (Papadimitriou, 2008).

Arising from their use of a wheelchair and the resulting obstacles they faced both in public and at home, mothers
in this study reported feeling flawed and ‘not on a par’ to other mothers, a finding also echoed by wheelchair uses in Papadimitriou’s study (2008). Thus, in addition to constraints located within their environment and external to self as emphasised in social models of disability (Nazli, 2012), mothers internalised the stigma associated with being a mother with a disability (Malacrida, 2019). These experiences were reflected in the second subordinate theme identified in this study, that of not being a ‘good enough’ parent. This sense of not being on a level playing field to other parents and the heightened sense of vulnerability negatively impacted the confidence of mothers in this study. This lack of confidence and negative perception of parenting ability by others is a finding well documented in the literature (Duvdevany et al., 2008; Grue & Laerum, 2002).

Encapsulated in this experience of not being good enough were fears about not living up to their own expectations of ideal motherhood. Mothers did not challenge the ideal construction of intensive motherhood (Hays, 1996), instead striving to be ‘supermoms’, a finding similarly reflected in the research by Kaiser et al. (2012) and Malacrida (2009). This positioning of mothers stands in contrast to fathers with SCI who have been found to challenge societal norms in order to enhance confidence in their parenting (Duvdevany et al., 2008).

In addition, mothers in this study described how their children adopted more responsibility and increased caring roles, which led them to question the extent to which the balance of dependence was appropriate in their relationship with their children, or they were a burden to others. This resonates with findings that, in contrast to their peers, children of parents with disabilities adopt responsibilities and show more empathy, concern and care for their parents (Duvdevany et al., 2005). Despite these responsibilities, and as described in previous studies (Mazur, 2008; Prilleltensky, 2004), mothers in this study report good relationships with their children and do not describe a negative impact on children’s adaptation or family functioning, consistent with Alexander et al. (2002) and Wright (2005).

Alongside their fears about not being good enough parents and striving towards an ideal of motherhood, mothers in this study also described placing a high degree of trust in their children in a process described as ‘armouring’. The phenomenological importance of ‘armouring’ suggests that establishing a trusting relationship, learning to both trust oneself and one’s child or children, facilitates mutual understanding and communication. While all parents need to learn to trust their children, it may happen earlier, or differently, for mothers with disability. Participants’ descriptions of learning to trust their children, is in sharp contrast to modern parenting practices such as ‘helicopter parenting’ where children may become over protected unintentionally by hypervigilant parents (LeMoyne & Buchanan, 2011).

As well as trusting their children, participants’ experiences of communicating honestly with children of all ages helped develop mutual confidence. Open communication about disability with children has previously been found to foster strong family relationships (Conley-Jung & Olkin, 2001; Duvdevany et al., 2008) and a lack of communication and adaptation of altered roles to negatively affect families after stroke (Kitzmuller et al., 2012). In the present study, participants shared a strong belief that despite SCI, relationships and connection transcend the obstacles and barriers to parent child relationships. These mothers utilised suitable physical and non-physical activities for mutual enjoyment, a process also described by Kaiser et al., (2012). Women expressively reflected on their bed as a ‘playground’ with their children, an ‘equaliser’ which enabled valuable closeness and connection between mother and child. In turn, these creative and pragmatic ways to connect with their children helped promote acceptance of disability, psychological adjustment to altered parental identities and lessened the potential negative impact of the physical intrusion of the wheelchair.

These findings have important implications for psychological theory around parenting with a disability. Mothers found a renewed sense of their parenting self from finding meaningful activities in which to participate with their children, a finding which resonates with the literature on adjustment to chronic illness and disability which involves the construction of new meanings and sense of self following an acquired injury (Charmaz, 2006; Kaiser et al., 2012). Identity reconstruction has been identified as an important part of living with a disability involving a re-appraisal of pre-injury and post-injury selves to find a continuity of self (Gracey & Ownsworth, 2012; Author). This study extends and deepens our understanding of the experience of adaptation for mothers within and outside the home. As women were more likely to continue to feel pivotal at home, this process of adaptation was especially important outside the home. As described by Papadimitriou (2008), women learn to adjust to the conflicting practical and emotional issues and gain practical independence in parenting with a wheelchair, while juggling the contradictory emotional societal biases and assumptions of feeling ‘not on par’ with peers.

**Clinical Implications**

Findings from this study can contribute to enhanced rehabilitation programmes for women with SCI. Rehabilitation
seeks to maximise physical functioning, prevent secondary complications and enable re-engagement in the community (Saulino et al., 2012). An in-depth awareness of the objective and subjective obstacles faced by mothers and an increased understanding of what it is like to be a mother with SCI, including the physical constraints imposed by wheelchairs, establishing roles with children and negotiating the reconstruction of self as woman and as parent is essential for rehabilitation professionals. Personal and relationship enhancement strategies that address such challenges can influence the development of targeted, interdisciplinary interventions for mothers during rehabilitation and in preparation for discharge to the community.

Beyond the rehabilitation context, this study contributes important findings for all health care settings providing service provision to women with disabilities, including those with SCI, who may hope or plan to be mothers in the future. Personal and relationship strategies may also become important for women who consider pregnancy and a potential transition to motherhood at a stage in their life following rehabilitation. This study has implications for women attending a wide range of health care settings, such as services providing reproductive health care to women, general practitioners, public health nurses and follow up clinics.

Possible clinical initiatives referred to by mothers in this study include the potential of facilitated discussions with mothers and children about SCI prior to discharge from rehabilitation. Some participants went further and suggested including children during rehabilitation, for example, inviting parents with SCI and their children to the rehabilitation setting for a day of mutual sports and recreational activities, or to attend physiotherapy or occupational therapy sessions. This was considered by mothers in this study as a way of normalizing SCI and enabling children to observe others interact with parents despite the physical constraints and changes imposed by SCI. In addition, they suggested an intervention whereby parents with disabilities would model parenting behaviours and provide an opportunity to share experiences with other parents and children struggling to adjust to the reality of SCI. Women with SCI could thereby be supported to feel like ‘good enough’ parents in the context of peer support from other people with disabilities.

Peer support has proven effectiveness for people with physical disabilities (Beverley et al., 2009). This study suggests it would be beneficial for mothers with SCI to develop early peer support opportunities, and for rehabilitation professionals to support the development of peer networks together with educational initiatives and social media and community opportunities for women during rehabilitation in order to ease the transition to community living.

Mothers in this study strongly endorsed the view that rehabilitation services have an important role to play in providing hope and guidance for women with children and those hoping to have children following injury. The overarching importance for patients of rehabilitation staff with a hopeful attitude is identified in the SCI literature (Hammell, 2007). Given that women with SCI are at increased risk of postpartum depression and anxiety in the perinatal period (Lee et al., 2021), hope and guidance within the healthcare community is even more important to women with SCI.

Brennan and Swords (2021) suggest it would be remiss to predict that all women would encounter parenting challenges following SCI. In this study, mothers expressed the wish that rehabilitation programmes would include a stronger emphasis on examples of successful parenting with SCI as women can feel isolated, trying to find solutions to overcome obstacles themselves. Although some people undergoing rehabilitation may not have children, the observation and inclusion of events and activities for parents and children through psycho-education, assistive technologies, peer and outreach support may provide positive expectations and hope for future selves. The authors developed ways of managing childcare that included provision for assistive technologies, resources and supports for parents with SCI. These client-centred service delivery models such as Hunter and Coventry (2003) maximise the ability of persons with SCI to parent.

Methodological Considerations

During recruitment, every effort was made to find a homogenous population: similarity in living at home, independent in activities of daily living, level of injury, age of children and marital status. However, the restricted pool of mothers with SCI in Ireland resulted in a small sample of eight participants where time since injury and age of children varied widely. Women who had children before and after SCI were included representing different stages of adaptation to SCI, and this is in line with other studies of parenting with SCI (Albright et al., 2008; Dvudevany et al., 2008; Kaiser et al., 2012; Pearcey et al., 2007). In the current study, due to the small population from which our sample was drawn, we recruited mothers into the sample regardless of the timing of their injury in relation to becoming a parent. For ethical reasons and in order to ensure the anonymity of our participants could be protected, in our results we did not draw attention to the timing of the injury in relation to becoming a parent. However, we acknowledge that timing of the injury is of central significance for one’s parenting experiences and should be a focus for future research.

Despite these differences, the shared concerns of mothers whether they had children before or after injury,
were married or single, employed or unemployed and irrespective of children’s age or time since injury are striking. A strength of IPA is a focus on the meaning of a common phenomenon, in this instance being a mother with SCI (Alase, 2017). However, given the length of time for some women since injury, there may have been recall bias for some participants. Although the interviewer was not known to the participants, there may have been a social desirability bias that affected how they responded to particular questions. Finally, although every effort was made to ensure credibility and trustworthiness of data analysis, member checks were not included in this research. It is recommended that such checks be included in future IPA studies to address trustworthiness.

Recommendations for Future Research

The aim of this study was to give voice to women making sense of their experiences as mothers with SCI, a voice largely unexplored in previous literature. A lack of focus on gender in the literature on parenting with a physical disability has been identified (Duvdevany et al., 2008; Kilkey & Clarke, 2010). Further qualitative studies may provide companion studies of the experiences of men as fathers with SCI and partners of people with SCI.

The body of research on parenting with SCI is limited. More research of women with higher than C5 injuries, being pregnant with SCI, as well as having children before or after injury and of children at specific developmental stages, to capture additional experiences of the impact of SCI on parenting or being parented, is warranted. Adding multiple voices would enrich the understanding of the overall impact of SCI on family members and family dynamics across the developmental lifespan of parents and children. In addition, longitudinal work may promote an understanding of how experiences and sense-making are dynamic and change over time.

While the lived experience of children was not the focus of study, the indirect inclusion of their experiences revealed something of the experience of being a child of a parent with SCI. Future research further highlighting the child’s perspective of having a parent with SCI would be an invaluable contribution to the body of research on understanding these experiences.

Conclusion

This study provides insights into the lived experience of a small group of mothers affected by SCI as they grappled with the physical and psychological obstacles and personal and perceived societal expectations of themselves as parents. The findings provide insights into the importance of reclaiming a sense of agency in overcoming the experience of difference from peers, and of finding creative ways to harness relationships with their children despite the constraints imposed by being in a wheelchair. Taken together, the themes identified in the current study provide a valuable description of how mothers balance the external and internal challenges posed by SCI with creative strategies for communication and engagement with their children. This study gives a balanced voice to the shared experience of eight women of what it is like to be a mother with SCI, which may empower and give hope to other women with SCI. Importantly, challenges in parenting with SCI do not lessen the pleasure in parenting roles.

Appendix 1

The Interview Schedule: Questions and Prompts.

Setting the scene: I am interested to find out more about your role as a parent and a mother with SCI. When people who are parents are in rehabilitation, they sometimes ask what it will be like for them as a parent with a spinal cord injury.

Questions

General question on ‘being a parent’

Tell me about your experience of being a mother with SCI; the demands; how SCI shaped being a mother; expectations; surprises; changes over time.

Prompts

Prompts (if relevant to person) Age points – becoming a mother, baby, children, teenager? – Do you think having an SCI has placed particular demands on you?

Has having an SCI shaped your role as a mother?

Has there been any aspect of parenting with an SCI that has surprised you or has been unexpected?

Has this changed over time?

(continued)
### Relationships

**Can you tell me about your relationship with your children?** Has your relationship been shaped by your experience of living with a spinal cord injury?

**What is your experience of reactions of others to you as a mother with an SCI?**

### Parenting Style

**Has your parenting style been shaped by the SCI?**

**Has your parenting style as a couple been shaped by the injury?**

**From your child’s point of view, how do you imagine they see your authority?**

### Note to researcher:

*In parenting style, implicitly examining responsiveness and control elements of parenting and challenges to parenting style, that is, establishing an authoritative, authoritarian, democratic, responsive parenting style. In discipline, implicitly examining how discipline is negotiated, that is, inductive, coercive, aggressive within the family with a spinal cord injury.*

### Discipline

**What is involved in setting boundaries, disciplining and managing behaviour as a mother with a spinal injury? (Baby, children, adolescence, late adolescence?)**

**Can you tell me any times when it was particularly challenging?**

**Do you think any aspect of your experience of setting boundaries is influenced by your injury?**

### Skills to manage and cope for mother and family

**Has anything particularly helped you cope, manage and develop confidence in your parenting role as a mother with a spinal injury?**

**In particular, what has helped you manage in doing activities? holidays?**

### What has been your experience of social supports?

**What has been your experience with schools?**

**Have you learned particular skills that have helped you negotiate your role?**

### Rehabilitation and the future

**Is there anything that could have been done during rehabilitation to prepare you better for your role as a mother with a spinal cord injury?**

**What do you see as the challenges ahead?**

**Is there anything you would like to add about your role as a parent and specifically as a mother that we have not covered today?**

### Debriefing (examples of questions asked included the following)

**Coming here today, what were you expecting to be talking about?**

**Was it what you expected?**

**Is there anything you would like to know more about?**

**How are you feeling after the interview? (Use other probes when necessary)**

**Would you like to meet with a member of the clinical team?**

As discussed, I will give you a phone call in three or four days to check in with you following today’s interview. Thank you very much for participation.
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