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Version: Version of Record

Link(s) to article on publisher's website:
http://dx.doi.org/doi:10.1080/09638288.2017.1300339

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Disability and Rehabilitation

ISSN: 0963-8288 (Print) 1464-5165 (Online) Journal homepage: http://www.tandfonline.com/loi/idre20

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To cite this article: Catherine Louise Willson, Josie Tetley, Cathy Lloyd, Michele Messmer Uccelli & Sara MacKian (2018) The impact of multiple sclerosis on the identity of mothers in Italy, Disability and Rehabilitation, 40:12, 1456-1467, DOI: 10.1080/09638288.2017.1300339

To link to this article: https://doi.org/10.1080/09638288.2017.1300339

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DISABILITY AND REHABILITATION, 2018
VOL. 40, NO. 12, 1456–1467
http://dx.doi.org/10.1080/09638288.2017.1300339

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RESEARCH PAPER

The impact of multiple sclerosis on the identity of mothers in Italy

Catherine Louise Willson[a], Josie Tetley[b], Cathy Lloyd[a], Michele Messmer Uccelli[c] and Sara MacKian[a]

[a]School of Health, Wellbeing and Social Care Faculty of Wellbeing, Education and Language Studies, The Open University, Milton Keynes, UK; [b]Department of Nursing in the Faculty of Health, Psychology and Social Care, Manchester Metropolitan University, UK; [c]Italian Multiple Sclerosis Society Research Foundation, Genoa, Italy

ABSTRACT

Purpose: This paper reports on one of the themes that emerged from the analysis of the study, regarding the perceived influence of multiple sclerosis (MS) on the identity of mothers in the socio-cultural context of Italy.

Method: In-depth interviews were conducted with 16 women at various stages of MS, with follow up interviews with seven of the women. Phenomenology guided the methodology and the analysis was conducted using interpretative phenomenological analysis.

Results: Through the research the *value of motherhood* to the women who participated emerged. The findings illustrated how many strove to *maintain control* of their MS, which led to some making comparisons of themselves and other mothers and *feeling different*. Some women described how they adjusted their roles and found strength in being mothers but others spoke of their feelings of *loss*. Most women described *living in the moment*, appreciating the present and living each day as it came. Another significant experience was fear of *stigma*, both realized in the form of "pity" from others, and the perceived and actual associated stigma for their families. This contributed to why some women were reluctant to *disclose* their condition. The mothers who took part in this study differed in how they perceived their *disabled identity*.

Conclusion: Although this study was conducted in the socio-cultural setting of Italy, the findings have implications for professionals working with disabled mothers and women with MS in Italy and beyond; including recognizing the value associated with fully identifying oneself as a mother, rather than solely focusing on *doing* mothering tasks.

ARTICLE HISTORY
Received 15 June 2014
Revised 22 February 2017
Accepted 23 February 2017

KEYWORDS
Multiple sclerosis; motherhood; identity; Italy; qualitative; self

➤ IMPLICATIONS FOR REHABILITATION

- Professionals need to be mindful of the value of motherhood for women with multiple sclerosis.
- Professionals should support women who feel like they are battling with maintaining control of their multiple sclerosis, who may be adjusting their identity as mothers; recognizing that they may be influenced by the stage of their multiple sclerosis and whether they were diagnosed before or after having their children.
- Women can have feelings of loss related to their ability to fully participate in their children's lives and professionals should work with women to help them identify the value of their mothering role not only in physically participating in activities but also in being emotionally and physically present as a mother.

Introduction

Multiple sclerosis (MS) is one of the leading causes of disability [1,2] and the most disabling neurological condition affecting young adults [1,3] in Europe and North America [4]. MS is a condition that is most commonly diagnosed in those aged 20–40 years, with women being two to three times as likely to have the condition as men [5], which suggests that a large number of people with MS will be women of childbearing age. There is, however, a paucity of qualitative studies that consider the maternal experiences of women with MS [1], as well as a general scarcity of studies that consider the life role of motherhood for people who are disabled [6].

In considering motherhood, it is important to recognize that culture and society influence perceptions of motherhood and there is an absence within the literature of studies that focus on the experiences of disabled mothers in Italy. In a country which has been slow to take on board initiatives to improve equality and rights of disabled people [7,8] and in which social policy favors a patriarchal family model [9], Italy is an unexplored cultural context in which to reflect on the lived experience of disabled mothers. This study therefore brings a novel perspective to the literature, through exposing the lived experience of disabled mothers in Italy, focusing on women who were living with MS.

The existing literature

A literature search was carried out on parenting and disability. The search terms "parent" and "mother" and their synonyms were used; in combination with the term "disabled" and its synonyms. A number of databases were searched, including Alternative

CONTACT Catherine Louise Willson Willson-c@sky.com Localita Fraia 3, Tiglio Alto, Barga 55051, Italy
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Medicine (AMED), Academic Search Complete, CINAHL, MEDLINE, psycARTICLES, and psycINFO. Searches of the Open University library catalog and the Disabled Parents Network (www.disabledparentsnetwork.org.uk) and other organizations that focus on parenting, such as the Maternity Alliance and Mums Net, were also carried out. Using the above key words, an absence of literature on disability and parenting was found, therefore, the search was extended to identify research on parenting for specific impairment groups, such as MS, rheumatoid arthritis, spinal injury, as evidence indicates that the majority of literature on disabled parenting is in relation to specific impairments [10]. In order to ensure that no existing work had been conducted in Italy on the experiences of disabled mothers, with the aid of an internet search engine to translate the keywords, a WorldCat search limiting the language to Italian was conducted. The following key words and translations were used: maternita (motherhood), madre (mother), madri (mothers), invalidita (disability), handicap (handicap), la sclerosi multipla (MS), genitore/i (parent/s), and bambino/i (child/ren). All possible combinations of these terms were used and no Italian language published studies were found that looked at any issues concerning disabled parenting.

From this search of the literature, it became clear that there is a paucity of evidence in this field, with the existing literature predominantly emerging from the United Kingdom, the United States of American, and Canada. Within the literature, there appear to be two distinct approaches to the subject of disability and parenting; the first of these is presented from a medicalized perspective, often conducted by medical or health professionals and aimed at other professionals on how to support disabled parents [e.g., 11] and often implies links between parental disability and negative family outcomes [12,10,13]. The other body of literature presents the views of disabled people themselves, highlighting barriers they face in their parenting role and these studies largely consist of interviews and focus groups with disabled parents, to allow experiences to be shared directly. Generally, there is limited published research on disability and parenting and the studies undertaken have mainly focused on parents with learning disabilities, rather than those with progressive physical impairments or chronic disease. Within the general literature on disability and motherhood there is a small, but growing body of literature on the experience of disabled parents, primarily due to efforts from within the disability movement [14]. While the existing studies on disabled parenting which draw on the direct experiences of disabled parenting come from a range of different cultural and national contexts, making it difficult to draw direct comparisons, there appear to be some commonalities. These are that the attitudes of professionals and society as a whole affect the autonomy and empowerment of disabled parents and influence how practical support and social policy are implemented. The accounts of disabled people frequently describe the barriers they have to face, in exerting their right to parent children.

Olsen and Clarke proposed that:

> Whereas the essential support needs of disabled parents are no different from those of any parent … the additional barriers faced by disabled parents can make these needs more difficult to meet … [10, p.63].

The implication is that all parents have the basic same needs for support, but having these needs met is more complex for disabled parents due to the barriers they face on account of their impairments.

There are a limited number of studies that consider motherhood issues for women with MS. Those that exist largely concentrate on pregnancy and its effect on the disease [15], or instead emphasize the different types of MS [16], rather than being empirical studies that consider lived experience and the barriers that mothers with MS face.

One study that does consider issues of motherhood for a woman with MS is that of Finlay [17]. She undertook a qualitative case study using existential phenomenological analysis and found that initially the participant operated as two selves, a woman with MS, who raged and despaired at her diagnosis; and a woman who chose to prioritize her role as a mother; giving up her job and career, to focus her energy on ensuring the lives of her children were as unaffected as possible by her impairments. What was particularly pertinent about Finlay's study was the woman's ability to keep her diagnosis and impairments hidden from her family, due to the lack of externally evident signs of any impairment. The implication is that as there are negative links between being a disabled person and being a mother, not disclosing a disability may avoid stigma. However, while Finlay's study was a single case study, the issues raised about motherhood suggest it would be appropriate to expand studies beyond a single participant.

The research reported in this paper was undertaken in Italy and the literature available indicates that in this country's context, disability has continued to be defined by issues related to the context of social welfare legislation, in that disability is linked to benefits and welfare, rather than within the parameters of equality rights [7]. It is further suggested that Italian families supplement underdeveloped welfare services by providing social support within the family [18] and a number of studies indicate intergenerational support in Italy is stronger than that in other European countries [19,20]. This cultural expectation from family members to provide care and support to other family members in time of need largely falls to women [18,21,22]. Therefore, for many women in Italy, the expectation is that they adopt the role of informal carers, providing support to family members who need it; both children and older relatives. Within the context of this study, this is relevant when exploring the experiences of disabled mothers, who may need to be "cared for" as well as have a role of "caring for" others and is linked to how mothers identify themselves within the cultural milieu.

With the Catholic Church having a significant role to play in moderating the political agenda in Italy [22], the influence of the church and its values on the identity of the mothers was also of relevance and was explored in the study. Additionally, with the endurance of a patriarchal social model, with inequality for women prevailing [23] and a "gender blind" political agenda [24, p.198], the impact of cultural expectations of women in Italian society on their roles as mothers, particularly as disabled mothers, will add to the literature on the experiences of disabled women, from a cultural environment which has not yet been reported on within the discourse of disability and parenting.

Method

Study design

Building on the evidence from the existing literature, this study focused on the lived experience of disabled mothers with MS. It explored issues affecting the experience of being; as both a mother and a disabled person. In order to gain this insight, a phenomenological methodology was used to explore how the participants made sense of their lived experience [25], as mothers living with MS in Italy. Through using a phenomenological approach, the study aimed to move beyond description to interpretation; with the researcher attempting to make sense of the participants making sense of their own experiences living as disabled mothers

[26]; what has been referred to as a double hermeneutic approach, based on Heidegger's founding principle of moving the study of phenomena beyond description to interpretation [27].

More specifically an Interpretative Phenomenological Approach (IPA) was chosen which provides the potential to provide detailed investigation of interwoven topics [27]. Ethical approval for the study was obtained through the Open University Human Research Ethics Committee and the study was accepted by the scientific committee of the Italian MS society.

The study participants

As an English speaking woman conducting a study in Italy, there was a need for the researcher to identify a means of recruiting participants, due to a lack of familiarity with the language and setting of the fieldwork. A local organization was used to access the participants [28], and professionals within the rehabilitation department of the MS Society (Associazione Italiana Sclerosi Multipla) assisted with recruitment to the study.

Opportunistic purposive sampling [29] was used to identify potential participants, as purposive sampling is a common framework applied to recruitment in qualitative research studies [30]. This enabled the researcher to find participants who had experience of the phenomena of the study [25], that is, mothers who were living with MS. The following inclusion criteria were applied to selecting the participants:

- The participants were known to the MS Society Rehabilitation Service.
- The participants were women who had a diagnosis of MS.
- The participants were a mother to at least one child aged 18 years or younger, who was still living at home.

Sixteen participants were recruited. In order to consider a range of experience and possible disease-related variation [31], five women were recruited from three impairment level groups (together with a pilot participant).

Group 1 – women with a diagnosis of MS, who had some level of impairment which impacted on their everyday function. This group incorporated women who were still mobile without aids, but were borderline, for needing aids to assist them with everyday tasks.

Group 2 – women who had a greater degree of physical impairment, which regularly impacted on their everyday function.

Group 3 – women who were severely physically impaired and were regular wheelchair users.

IPA studies vary in the number of participants, with 10 participants being the optimum recommended maximum sample size [32], but more commonly fifteen participants have been the mean number of participants described within the collective IPA literature base [32]. The sample chosen for this study was, therefore, at the higher end, being 16 in number, including the data collected from a pilot interview. However, selecting this number of participants allowed the researcher to examine in some detail convergence and divergence of experience within the sample [32]. Furthermore, due to the diversity of potential impairments encountered with MS, it was hoped that the study findings would not only be pertinent to those living with this condition or working within this field but would have relevance for a wider audience, particularly in the sphere of other long-term conditions.

IPA studies should try to ensure the sample group is as homogenous as possible [32–34], to enable detailed exploration of a phenomena within a specific group, clients with a particular diagnosis serving to provide a suitable example [33]. The sample for this study was similar in relation to the long-term condition that they were living with; the status of the participants as mothers; and their cultural similarity of living in Italy. As MS is a chronic condition, with impairments varying from person to person, it would have been difficult to provide further homogeneity to the sample, other than by specific selection by impairment type, which would have led to a more medicalized focus on impairment and disability, which the researcher wished to avoid. Furthermore, by recruiting women at different stages of severity of MS, the study captured not only the experiences of women whose impairments could be hidden from the external world but also those whose MS was more progressed and had evident impairments. This enabled the researcher to explore the different dimensions of impairment; to evaluate perceptions of barriers on women's ability to participate in their children's lives and whether their impairment level related to how women viewed their experiences as mothers.

Table 1. Participants' profiles.

Interview	Group	Aware of diagnosis prior to pregnancy	Children's age and gender	Marital status
Silvia	1	Yes	Boy age 16 and girl age 14	Married
Leona	1	No	Boy age 10	Second marriage
Sonia	1	Yes	Girl age 6	Married
Erica	1	Yes	Twins boys age 8	Married
Rosa	1	Yes	Girl 12 and boy age 8	Married
Delia	1	No	Boy age 16	Married
Laura	2	Yes	Boy age 7	Married
Maria	2	No	Boy age 8 and girl age 15	Married
Julie	2	No	Girl age 10	Married
Patrizia	2	No	Boy age 15 and girl (adult)	Married
Ottavia	2	No	Two girls age 9 and 5	Married
Alessandra	3	Yes	Girl age 2	Married
Francesca	3	No	Girl age 16	Separated
Elisa	3	Yes	Boy age 11	Married
Cristina	3	No	Boy [24] and Girls age [21] 12	Married
Fiorella	3	Yes	Girl age 14	Separated

The above groups were categorized by using the Expanded Disability Status Scale, a commonly accepted scale for assessing impairment in MS. The Expanded Disability Status Scale measures from 0 to 10 on a progressive scale from no neurological impairment to death [5] and is the scale used to record the level of a client's MS on the Associazione Italiana Sclerosi Multipla database. The groups were, therefore, further defined using this measure, with the women in Group 1 being those at level 4.5, 5, or 5.5 on the Expanded Disability Status Scale, Group 2 being at level 6 or 6.5, and Group 3 at level 7, 7.5, or 8. The profile of the participants is shown in Table 1 and pseudonyms were used to protect their confidentiality. Silvia participated in a pilot interview, but due to the depth of her story, this was included in the analysis. Table 1 also indicates whether or not the women knew they had MS before they had their children, with half having prior knowledge and the remaining eight women not being aware of the MS prior to embarking on motherhood. This information was not intentionally taken into account in recruiting participants, but was a factor that transpired during the interviews and then within the analysis.

Data collection

As the aim of the study was to explore the lived experience of the participants, and in line with recommendations for IPA studies, face-to-face semi-structured interviewing was used for data collection [33,34]. Interviews of this type offer a flexible approach to understanding experience which helps to maintain a contextual focus [33]. The research was designed and implemented by a

primary researcher; the lead author of this paper. An Italian-speaking interviewer conducted all the interviews, thereby becoming a coworker in the study [35]. In addition, a British and Italian team of researchers and practitioners supported the recruitment, analysis, and reporting processes.

The interview questions were formulated to explore the lived experience of disabled motherhood in Italy, further informed by the literature review and were open-ended, to allow for expansion of responses. The questions were first tested by the primary researcher undertaking a pilot interview with an English speaking mother with MS, in England; then a second pilot interview was carried out by the Italian interviewer, along with the researcher. The purpose of this was to establish the logistics of the interview process and the cultural applicability of the questions, which had been previously discussed and translated by the interviewer and the researcher, facilitated by a bilingual speaker from the Associazione Italiana Sclerosi Multipla. Following this, no changes to the questions or practical elements were felt to be appropriate, consequently single interviews with each of the women were carried out, with some then participating in a further single follow up interview ($n = 7$). The purpose of the follow up interviews was to further explore some of the issues that had been identified from the first interviews of all the women, as well as enabling the researcher to check that her interpretation and understanding from the first interviews accorded with the women's experiences. The interviews mostly took place in the women's own home, with the exception of two that took place in the offices of the Associazione Italiana Sclerosi Multipla at the women's request, due to practical considerations. The duration of the interviews varied, ranging from about 40 min to over 2 h.

The interviews were conducted by an Italian occupational therapist, with the primary researcher, an English speaking occupational therapist, also present. The interviews were audio-recorded and transcribed verbatim into Italian by a transcriber, who was an independent person who took no other role in the study. The transcriber also acted as a translator, translating the text from Italian into English, to enable the researcher to conduct her analysis on the English scripts. Being aware of the responsibility to "maintain the integrity and credibility of translated qualitative data" [36, p.266] the researcher had a sample of three interviews back-translated, which was undertaken by a native Italian speaker with a good command of English, who had no other role in the study. In this way, the researcher employed one strategy of assuring the accuracy of the written translated word, as well as undertaking second interviews with some of the participants to seek respondent validation of the initial data analysis, what is also referred to as "member checking" [28]. No issues of concern with the translations were identified through either the back translation of the scripts or the member checking during the second interviews.

Data analysis

Following data collection, it was necessary to conduct an interpretation of the data, to avoid "merely a static description" [37, p.780] of the participants' experiences. To facilitate this, IPA was chosen as the method of analysis, as it has the potential to answer in-depth questions regarding individuals' experiences [38]. IPA is concerned with a detailed examination of lived experience, what that experience means to the participant and how they make sense of it [33]. In line with IPA, the research focus was on the perceptions and views of the participants [32] and IPA facilitates this by using a staged approach to analysis. Smith et al [32] suggest that there are six stages to analysis: reading and rereading, initial noting, developing emergent themes, searching for connections across emergent themes, moving on to the next case and finally, looking for patterns across cases.

To fulfill the initial stage, the analysis involved involved reading and rereading of the English transcripts, and cross-referencing to the Italian transcripts if the wording in the English was found to be particularly thought-provoking. One example of this was the use of the word "suffer" in the English transcripts, which seemed to be an intense and emotive description of experience. The Italian transcript confirmed the word "soffrire" had been used which confirmed that the participant was indeed describing her experience as suffering. Through examining such specific wording and reading and rereading both the English and Italian scripts, this ensured that the analysis of the data was an immersed and active process [32]. During this process, notes and comments were made on the data in the scripts, highlighting words and sentences on the transcripts and making notes in the margins of the pages. The primary researcher also at times listened to the Italian audio recordings, to enable recollection of emotions as they were expressed at the time of the interviews. The transcripts were analyzed in the order that the interviews had taken place, rather than being considered in relation to the three groups in which the women were categorized, on account of the level of their MS.

Following this stage of the analysis, the interrelationships, links, and configurations from the initial notes were explored and identified. Practically, this was undertaken by transferring notes and quotes from the transcripts onto post-it notes and placing them onto a large surface individually. These were then grouped into larger clusters, enabling progression onto identifying emergent themes. This process was repeated from the start, dissembling then reassembling the post-it notes, to see if similar groups emerged. These three steps of reading, note taking and assembling of notes into groups were repeated for each transcript.

After this stage, in order to identify connections across the themes, a process of abstraction was used, this involved "putting like with like and developing a new name for the cluster" [32, p.96] by grouping the post-it notes from all the interviews, through identifying links between the themes. The use of polarization, looking for "oppositional relationships" [32, p.97] also aided this, as did numeration; looking for the frequency in which emerging themes arose within the transcripts.

By reviewing the themes and sometimes relabeling them, overarching superordinate themes were formed to the groups of sub-themes. Finally, the superordinate and sub-themes were written up into narrative accounts, to provide a detailed interpretation of the themes, based on the actual narratives of the participants [34], with quotes used to substantiate the findings.

The role of the researcher

One of the ways in which IPA differs from other phenomenological approaches is in regard to recognizing and reflecting on the role of the researcher in the study and the analysis of the data [34]. Indeed the role of the researcher as an insider/outsider is a much debated topic in qualitative research [39]. James [40] suggests though that through using reflexivity, a researcher can hold a dual role of both insider and outsider. James' background, analogous to that of the researcher, involves perspectives as a subjective clinician, what James suggests is an inside role, and an outside role as an objective researcher. Similar to the experience of other researchers [e.g., 39], the role of the primary researcher in this study did not naturally fit either within the insider or outsider categories. The gender of the researcher was inarguably the most evident category to render her position as an insider but status as

Table 2. Superordinate themes and sub-themes for self and identity.

Superordinate themes:		
Self and identity	Challenges and support within society	Relationships with others
Sub-themes of self and identity:	*Quote:*	
Value and centrality of motherhood	*"Motherhood is truly the … the best thing that has ever happened to me!"*	
The struggle to maintain control over MS	*"you need to fight the disease, try to become stronger than it"*	
Disabled identity	*"I do identify myself [as disabled] … yes, and the reason is that I have my problems"*	
Stigma and the dilemma of disclosure	*"people who don't know you … look at you with pity, you can see it! I mean, faces talk!"*	
Feeling different	*"Sometimes I don't even feel myself anymore! This disease has this effect on me"*	
Loss	*"I missed playing with her a lot … I've missed those things … and I think she's missed them as well"*	
Living in the moment	*"You live in the present moment, it's better"*	

a "straniera" or foreigner, who required a native speaker to enable her to conduct the interviews, undoubtedly substantiated the researcher's position as an outsider. However, the researcher's experiences of working with many disabled mothers, including those with MS and being a mother herself who had had personal experience of disability, were not overtly recognizable to the participants and, therefore, perhaps precluded her from further insider status. IPA incorporates the researcher's subjectivity [40] and takes account of their experience and its role in comprehending and making sense of reported experiences [38]. Finlay [41] suggests that reflexivity is a tool to analyze how subjective and intersubjective elements have influenced the research and that there is a tension between bracketing these preexisting understandings and drawing on them as a source of insight. She and others encourage researchers to engage in reflexive thinking to redress this balance [42,43]. Although some have posited that reflexivity is an optional tool in IPA [44], others have argued that reflexivity is a vital element to all qualitative methods [43].

On a practical level, reflexivity involves the researcher keeping a reflexive dairy to record details of the nature of emerging interpretations [45]. Being reflexive in one's study can also involve referring to colleagues and mentors and keeping a log of thoughts and ideas throughout the analysis [25,34]. Likewise, the use of field notes also assists with providing an audit trail, which is a necessary element to demonstrating the trustworthiness of a qualitative study [34]. It is important to recognize the difference between reflection and reflexivity, particularly as they are often used interchangeably within the literature [41]. Finlay defines the two concepts as being on a spectrum, with reflection being the "thinking about" at one end, and reflexivity at the opposite end, involving "immediate, continuing, dynamic, and subjective self-awareness" [41, p.533]. She suggests that this reflexive analysis should commence right from the outset of the research study, with the researcher examining their motivations and assumptions [41].

In the context of this study, the primary researcher's assumptions and personal and professional experiences of disability had arisen from the culture of the United Kingdom and the existing literature on the subject. Thereby having conducted the fieldwork in Italy, in a culture unfamiliar to her and with a lack of available literature on the experience of disability in this context, the researcher was able to enter the field with a greater degree of "openness and wonder" [42, p.536] than researching within the familiar field of the United Kingdom would have allowed. The ability to be reflexive took the form of briefing and debriefing the interviewer pre- and post-interviews, enabling the researcher to share and reflect on her thoughts, once she had had time to collate her thoughts in a reflexive diary. Likewise, discussion and reflection of thoughts with the supervising team enabled the researcher to maintain a continuous reflexive approach.

Having had a stroke as a young mother at the age of 27, the primary researcher was aware of her pre-conceptions of disabled mothering, which were also influenced by her clinical work. However, in acknowledging and reflecting on these preexisting perceptions of disability and motherhood, as is consistent with IPA, she had perhaps overlooked her existing understanding of her own cultural and social upbringing as a woman and in her role as a mother. Using IPA to explore the experiences of women in their mothering role in Italy, having entered the study expecting to highlight the barriers the women faced and the discrimination they were subject to, both as women and as disabled people, the researcher instead gained a different conceptualization of life as a disabled mother in Italy.

From the analysis of the data, three overarching superordinate themes were identified, one of which was "Self and Identity", which will be reported on in this paper. Table 2 shows the three identified superordinate themes and the underlying sub-themes for self and identity, with a quote to demonstrate each sub-theme.

The following sections will describe the sub-themes in more detail with quotes to indicate how the women's reported experiences led to the development of these sub-themes in the analysis.

Value and centrality of motherhood

A key finding in relation to how the women identified as mothers with MS was the immense value placed on the role of mother. This was evident regardless of the stage of the women's MS and whether they were diagnosed before or after having children. All the participants indicated the huge value they gave to this role:

> it's the best thing in the world to have a child! I mean, for me, mmm, I can't imagine my life without children! … [my son is] such a priceless … limitless source of joy! (Erica).

In discussing the importance of the role of mother, a number of women made reference to how they prioritized the role of motherhood over other roles and sometimes they even dismissed the existence of their MS to give precedence to their identity as a mother first. Rosa told us that she did not think much about her MS, instead focusing on other goals related to looking after her children. This put to the forefront managing her children's needs, rather than her own. Sonia, who was a busy working mother, told us

> all the other things don't count as much and … I do not want to say, at the end of my life, that I was a good, or capable [professional], I want to say that I was a good mother! That's truly the most important thing to me, even if it doesn't seem that way because I do so many other things, but it is my main priority, no doubt about it! (Sonia).

The value placed on the role of motherhood may also have been influenced by a more conventional approach to the centrality of this role in Italian society. This was reflected by comments made in terms of motherhood as defining femininity:

> a woman is a woman when she has a child (Julie) and a life without being a mother doesn't … doesn't make sense! (Fiorella).

All the women expressed the importance of their role as mothers, and this role of motherhood defined how they described themselves as a person, thereby contributing to their identity. They often placed their MS in a secondary position, being relegated to lesser importance than the esteemed role of mother. A further sub-theme expanded on this positioning of MS further; considering the presence of MS in the everyday lives of the women and their feelings about how MS manifested itself on a day to day basis and these descriptions led to the development of a further sub-theme of maintaining control.

The struggle to maintain control over MS

Some women spoke of using positive thinking and how they strove to "maintain control" of their MS, seeing MS as being less invasive, rather than being dominant in their lives. Yet for other women, their self-perception as mothers showed that their MS was more intrusive

> Being a mother with multiple sclerosis, mmm I am … I feel absent! Many times I've felt absent in caring for my children, with … with the house! Yes, I … .the disease has really … .really beaten me down! (Patrizia).

The power of MS in their lives and how they felt about the control they had over their condition arose in the accounts of a number of women, regardless of their level of impairment. Despite being one of the women who had the least impaired function, according to the Expanded Disability Status Scale measure, Silvia expressed how she felt her MS governed her life

> I have to do what the disease wants! (Silvia).

For Silvia, MS appeared to impact on her identity as a mother and had a dominant role in her day to day life. Other women also spoke of how they sought to retain control over their MS, portraying a battle between their perseverance and the presence and potential progression of MS.

Many of the women who did not know their diagnosis before becoming pregnant, expressed anger at having MS and the subsequent loss of control they had over their lives:

> I mean, it's hard to understand, you want to do something, but you can't do it, not because anyone prohibits you from doing so, it's the disease that prevents you, and against this disease you are powerless (Maria).

Ottavia also spoke about her MS as being in a position of power, alluding to the conflict between her and her MS. She compared her MS with an "*evil twin*" which sometimes allowed her to do things and sometimes did not, with her personification of her MS sometimes winning, showing its strength. The presence of MS in the lives of some of the participants thereby challenged their ability to maintain control of how they participated in daily tasks, causing them to question or compare themselves to their former identity.

Finding and having the strength to manage MS was sometimes spoken of as something that was found from within, developing a mentality of positivity. Other participants spoke of how they gained strength from others, particularly their children and how they strove to remain positive and transmit this positivity to those around them. For Alessandra, this was related to how she portrayed her strength to her daughter:

> but would else should I do? Should I cry? No! I have a daughter who has to live with me and see me with a smile, not crying! (Alessandra).

Many of the women who were not aware of their diagnosis when they had children spoke of how their role as a mother superseded any shock or apprehensions they had when they were diagnosed, instead focusing on their children. The focus shifted from managing the symptoms of their disease, to being concerned with ensuring their children's needs were met, concentrating on their identity as mothers:

> I don't know where I'd be now, what I would be doing … if I'd have the strength to keep on going and do all the things I do. It is also because of them! Because they need me! (Silvia).

For the women who made comments about the source of their strength coming from within themselves, more of them knew their diagnosis before having children, suggesting that they had developed some inner resilience to manage the battles between having MS and being mothers, as opposed to those who were diagnosed post-childbirth, who were more likely to comment on finding strength from their children.

Within the sub-theme "maintaining control", the issues discussed were around how much control women felt over the presence of MS in their lives, both in accepting and in reacting to their diagnosis, but also with living with MS on a day to day basis and how this defined their identity as disabled mothers. How women identified themselves as disabled mothers was another sub-theme that emerged in the analysis.

Disabled identity

In the process of analyzing the interviews, it was interesting to find that some women talked about themselves as being disabled mothers explicitly and others referred to themselves as being like any other "normal" mother. For example, Julie told us with regard to her relationship with her daughter:

> I mean, she considers me normal! As a person, she considers me normal, I only have … she only sees that I have something wrong with my legs, I mean, the problem's with my legs but it's really in my head, in many other places, but I think I've done a good job! Despite being sick.

Whether or not women talked about themselves as being disabled or "normal" was often linked to the perceived stigma in being disabled and to whether or not the women were open about their MS, or sought to hide their impairments. To allow further exploration of how women viewed disability in relation to their own identity, in the follow up interviews, the women were specifically asked about whether they saw themselves as a disabled person, and all said that they did. Alessandra revealed some oscillation between defining herself as disabled or as "normal"

> Only because I can't walk and because I have difficulty getting around and going to pick my daughter up … only because of that. As for the rest, no, absolutely not. I identify myself [as disabled] only when I find myself facing a barrier, only in those cases, otherwise, no. I feel like a completely normal person (Alessandra).

Sonia was reaching the stage where she was considering using a walking stick to aid her mobility. In response to being asked whether she identified as a disabled person she told us

> Unfortunately I do now … for more or less a year I have considered myself truly disabled, in the true sense of the word, because I am 'not able' to do certain things and so, yes, I feel limited … limited and disabled … (Sonia).

Unlike Alessandra's disabled identity, Sonia's description of disability is more in keeping with a medical model definition, where disability is attributed to impairment, rather than to external factors. Silvia, the other woman in the least impaired group interviewed for a second time, spoke of how she no longer went to the shopping center because of her difficulty walking and her

current levels of fatigue, and that *her* inability to do tasks was why she defined herself as being disabled.

The way in which the women identified themselves as being disabled varied, which appeared to be related to their level of impairment. The women who were frequent wheelchair users identified the environmental barriers which defined them as disabled people. For the women with lesser impairment, their definition of themselves as disabled people related more to their perceived physical limitations, rather than the outside influences on them as people with impairments. There was a shift away from internalizing the concept of disability, to attributing the cause of disability to external factors, as the women's impairments progressed. In view of how women identified themselves as disabled people, consideration as to how they disclosed their impairments is also relevant to consider and issues of disclosure arose as another sub-theme.

Stigma and the dilemma of disclosure

Stigma, the notion of being disqualified from full social acceptance through being discredited on account of a personal attribute [46], arose in many women's accounts. This was in relation to both the mothers themselves and for other family members and their descriptions of stigmatizing attitudes towards them were often linked to pity, which led to some women not disclosing their impairment. Some women were also reluctant to accept equipment as this was seen as being akin to dependence, rather than facilitating independence

> I live in a house with three floors, however, I don't have any intention of putting in a stair lift or something like that because, while I am still able, I intend to make the most of what I have, I mean, I don't want to live like a … that's just what we'd need! (Cristina).

Although being determined to do as much for herself as possible, couched in this statement is the suggestion that by having equipment in her home, Cristina would be identifying herself as being disabled and that by accepting this, it would cause upset, rather than enhance her life.

Fiorella, who was a full-time wheelchair user, described stigmatizing attitudes of others that impacted on her relationship with her daughter. Fiorella's story implied that her daughter was fearful of the stigma associated with disability and hence did not want others to be aware of her mother's disability nor to be associated with it publicly herself. Fiorella told us

> when she was in middle school, she didn't want me to come to meetings with the teachers, like I've always done, I've always gone, because she was ashamed of me! She even said it, 'I don't want you to come because all my classmates will see you, my friends will see that you're in a wheelchair!' (Fiorella).

The fear of stigma for their children was expressed by other women, not only those women who were wheelchair users

> sometimes maybe I'll think to myself 'oh, and what if I run into, my kid's friends … and they see that I walk with a crutch or that … ' I mean, I feel bad for them, you know? (Silvia).

How children were felt to perceive their mothers, who outwardly presented as being disabled, seemed to be linked to the ages of the children when the mothers became wheelchair users, and whether their children had grown up around their parent's increasing impairment. How confident the women were in identifying themselves as disabled mothers also related to whether they struggled with issues around stigma in relation to their MS. For Alessandra and Elisa, their children had grown up with them as wheelchair users and neither woman showed any fear of stigma for their children:

> he's always seen me [like this], he's not embarrassed of me … I have never been embarrassed! And I think that is how it should be for everyone! (Elisa).

Other women spoke about how when people looked at them, even if it was intended to be with compassion, it made them feel pitied and influenced decisions not to disclose MS:

> I don't divulge the fact that I have MS much. For the precise reason that you can be pi– … pitied 'oh, poor thing!' … it's as if you're dying!!! (Leona).

The women who experienced more understanding and less stigmatizing attitudes from others seemed to feel more able to divulge their diagnosis, although some women disclosed their MS through necessity rather than choice

> he … mmm … obviously because he didn't know or in joking he might push me and perhaps … playing! I might lose my balance and I told him not to push me mmm because I could fall, then he asked me why and so I explained what I had and, anyway, he understood. (Delia).

The women appeared to be caught in a trap of disclosing their disability and feeling pitied, and not disclosing and therefore not having their needs recognized. The desire to remain strong and continue to retain independence and their identity conflicted with the need to call on assistance when it was needed and necessitated a shift in how the mothers defined themselves and their identity. Fear or realized stigma was implicit in many participants' experiences, no matter what stage of their MS. Stigma also seemed to relate to how some women and their children made comparisons and adjusted the women's identity as disabled mothers, mainly to themselves pre- and post-diagnosis of MS and a further sub-theme of "feeling different" arose.

Feeling different

Many women, regardless of their level of impairment, felt different and manifested a new identity as a woman with MS:

> What I did before was something totally different; it's a second life, this is. (Patrizia).

The issue of comparison was most discernible for those women who were not aware of their MS before having children, or when their MS become apparent after the birth of a successive child. That is, they compared their mothering role and their identity as a mother between each of their children (born before and after diagnosis) and some evaluated things they had done with their older children, which were more difficult to do with their younger children.

For the five women with the greatest level of impairment, who perhaps were more likely to identify discernible differences between their pre- and post-MS selves on account of being more impaired, three commented on how their children compared or questioned tasks they could do. Fiorella and Francesca both had teenage daughters who had openly questioned them on whether they would participate more in activities with them if they did not have MS. Francesca's daughter asked her

> but now that you're sick won't you do anything? (Francesca).

Indeed for the women who had more advanced MS, issues of comparison were raised more by those with older children who could remember their mothers prior the progression of their MS, than those whose children were younger when they became impaired. As well as the women with more than one child making

comparisons of their mothering role by describing different experiences of being a mother with and without the presence of MS, some women also compared their role of mother with other women:

> You arrive really tired, having climbed all those stairs … you arrive so tired … I see all the other mothers smiling, happy … laughing and talking … and I can't! I feel … different (Julie).

Many women, because they compared their roles with other mothers, emphasized that they went to great lengths to make sure their children did not miss out on participating in activities, in order to ensure that they met their perception of the required mothering "standards":

> I've always, I've done everything that the other mothers have, I haven't done anything less! Even if I've forced myself, perhaps arriving home exhausted, but I've always taken him all over … I've always helped him to do whatever he needed to, I've never made him miss out on anything … (Delia).

Delia's account indicates that despite it causing her to feel exhausted, she continued to uphold her role and identity as a mother by taking her son to activities. Other women delegated tasks to other family members, but this renegotiation of responsibilities led to a feeling of loss of role for many women.

Loss

Some women spoke about how they felt a sense of loss, having feelings of regret, both because their children saw them managing the symptoms of their disease, but also through the realization that they had missed out on activities with their children. Many women strove to ensure that this sense of loss was minimized for their children, making sure that they did not miss out on activities, even though this could come at a personal cost:

> Do you know what it was like for me to be there in the wheelchair and watch my husband go on all the rides with the children? And me just sitting there … you have no idea what it felt like! But I had to do it! (Maria).

On this family trip Maria felt loss at not being able to participate in these activities with her children, though her husband was able to fulfill this role, and her comment "I had to do it" suggests that she felt obliged in her role as mother to let her children have this experience, even though she knew she would be not able to participate in the way she wanted to. Maria felt a loss in her identity as a mother as she was not able to take part in the task as she wanted to and had to watch her husband fulfill what she felt to be her role.

Other women also similarly spoke about missing out on everyday activities and although this was the case both for women who knew and did not know their diagnosis prior to having children, it was only evident in reports of the women who were more impaired, probably because of the environmental barriers which prevented them from participating in tasks.

As well as talking about their feelings of loss at not being able to participate in activities with their children, women also considered that their children would feel that they had missed out:

> I missed playing with her a lot, not physically playing with her, going to the park, running together, kicking a ball around, si … those are silly things! Chasing each other … I've missed those things! And I think she's missed them as well (Julie).

Again the women seemed to be expressing that being unable to participate in everyday activities with their children impacted on how they identified themselves as mothers and a loss of what they perceived to be an expected part of being a mother. Such activities that would be assumed to be everyday to most mothers, sometimes proved to be problematic in a wider sense, beyond the home. Alessandra was not able to go into her daughter's nursery school due to the steps, which had a knock on effect to her mothering role. The inability to access her daughter's nursery led to a further sense of loss for Alessandra, who realized she did not know her daughter's day to day life in school:

> I don't even know where they keep the … mmm … I don't know, the slippers when they arrive at the nursery school! I don't know anything! And it makes me feel really bad! (Alessandra).

In describing feeling "really bad", Alessandra is recognizing that her identity as a mother is not consistent with what the other mothers are experiencing as she is denied access to knowing things about her child's life, due to the inaccessibility of the nursery. Within the sub-theme of loss, the mothers spoke of how they realized they could no longer do tasks, either that they had done with older children, before their MS led to their impairment, or because they looked back and recognized that tasks previously done without a thought, were no longer possible. This led to a direct sense of loss for the women, feeling not only that they had missed out on activities with their children but also to concern as to how their children might perceive a sense of loss. Many women had, therefore, striven to fully engage their children in activities, despite knowing they would not be able to participate themselves, to prevent their children realizing any loss. Often tasks were delegated, but delegating tasks to others did not necessarily remove the feeling of loss. The women who spoke about their own loss and concern for their children feeling a sense of loss were women who were more impaired (groups 2 and 3). It is, therefore, likely that losses were influenced by other barriers, such as environmental and attitudinal barriers. However, it also suggests that women in these groups took time to look back and reflect on their roles as mothers, considering their past as well as their present situation. In this way, the women were adjusting their identity as mothers. Whether women lived in the past, present or looked to the future arose as another sub-theme.

Living in the moment

As the prognosis of MS is variable, some women were mindful of the ambiguity of their lives and spoke about how they lived in the moment, appreciating the present:

> Live for the day … live for today and don't think about tomorrow! (Leona).

Other women also spoke of how they tended to live in the present, but sometimes also conjectured on what the future may hold:

> I'm much more focused on living in the moment than thinking about the future … I don't see the future as a thing … in the sense that, having a wonderful present, living in a wonderful present anyway both are … I think that the future will also be … perhaps different, but not worse! Only different! (Ottavia).

While living in the moment was important, some women spoke of how they thought about the past, many instead tried to appreciate what they had and to focus on the present. Rosa told us she lived:

> Not the past, especially because I forget about when I've been unwell, about when … mmm, no, I forget about those things! I think about today, when I'm well! And tomorrow … .tomorrow, we'll see! And as for yesterday when I wasn't well, who cares? It has passed! I've gotten through it! (Rosa).

As can been seen from the above examples, there was a tendency for most participants to live in the present moment, due to the unpredictability of MS and the uncertainty as to what the future may hold. That said, some women considered their futures and were indifferent to it, and others thought about the future in relation to their disease progression, with three of the women contemplating the impact on their families. For example, Delia talked about how her MS would impact on her role as a grandmother and Laura thought about how she may not be able to assist her son in the future in the way that she would like to

> … the biggest fear that I have is ending up in a wheelchair. In that case I don't know how much help I'd be to my son …

Some women also thought about the past, sometimes dismissing these thoughts as they knew they would be too upsetting to deliberate, or they were keen to focus on the present. Patrizia told us how she thought about the past and the time when she was well

> … I'd give ten years of my life just to be well [begins to cry again, sobbing] … ten years of my life to have one month as I once was …

The above examples demonstrate how, for some women, they struggled to identify themselves as mothers or even as grandmothers in the present and future, so avoiding thinking about their future identity as a mother, and either focused on the present day, or deliberated on how they used to be.

Discussion

Within this study, all the participants highlighted the enormous value they assigned to their mothering role. This may be because of the huge emotional investment placed on having children in Italian society [47] and it is possible that roles and expectations about motherhood in this socio-cultural context accentuated the positive and negative aspects of the experiences the mothers described. Studies suggest that people with long-term conditions redefine their life priorities [48] and the findings of this study give reason to suggest that the positive associations of motherhood also impacted on the significance and priority the participants gave to their mothering role. This may be particularly related to the fact that motherhood has an important role in Italy in terms of the structure of Italian family life and the over-riding patriarchal paradigm within Italian society [22].

Like some of the women in Payne and McPherson's study of mothers with MS [1], some of the women in the study alluded to their notion of an ideal mother and how they viewed they fell short of this archetype. This was evident in the number of women who spoke about making comparisons, either with non-disabled mothers, or with themselves prior to being diagnosed with MS. The tendency to compare and for some, to feel different, indicates that the women in the study were comparing themselves against a personification of an ideal mother and some women thereby felt a sense of loss. These women were perhaps less adjusted to their changing roles and self-identity and the women who spoke of loss were mainly the women from the middle group (who were the women who had a degree of physical impairment which regularly impacted on their everyday function), suggesting they were in the process of adapting their roles as their condition progressed. For women who delegated childcare responsibilities to other family members, this could challenge traditional role boundaries. This accords with the findings of Farber's study with disabled mothers, in which role sharing could cause conflicted feelings; with women being grateful for support, while it also emphasized to them their loss of role [6].

Within this study, issues around modifying the mothering role were evident and some women appeared to have adjusted to their disabled mothering role more than others, who reported feelings of loss and difficultly controlling the intrusion of the MS in their lives. However, it is recognized that adjustment is not a straightforward linear process [48] and although not explored in this study, in future research account could be taken of how long the participants had been living with MS and how they managed their identity as a mother.

For the women who were the most impaired, they had a somewhat stoical attitude towards dealing with their MS. They were more likely to attribute the source of their disability to external barriers, rather than focusing on disability being due to the impairments themselves. For some of the least impaired participants, adjustment to MS was more complex, with women battling to manage and sometimes concealing the symptoms of their MS and trying to maintain the status quo in their lives. At some point, the participants claimed their identity as disabled women [49]; shifting from their preexisting identity before they had been diagnosed with MS.

More of the women who spoke about their anger at having MS and their loss of control in their lives were women who did not know their diagnosis when they became pregnant. This would suggest that the women who did know their diagnosis had more time to prepare for motherhood and the potential need to share and delegate roles, and, therefore, were able to maintain more control over elements like this in their mothering role. The women who knew their diagnosis prior to having children may, therefore, have been more emotionally prepared for the challenges they would face in being disabled mothers within this cultural context. They would also have been more equipped with the means to deal with the physical challenges the environment would present them with and had considered the role other family members may have to play in providing support to them. In contrast, the women who did not know their diagnosis had made the decision to enter motherhood without this prior knowledge and chance to consider the challenges they would face and assess their own ability to cope with these. They were, therefore, faced with reconsidering their motherhood role as being disabled mothers, which was not something that they had anticipated prior to becoming pregnant. This study offers a unique contribution to the literature, by comparing the timing of diagnosis, pre- and post-childbirth, in relation to how women felt about their roles as mothers with MS. This was particularly so with regard to women who spoke of feelings of loss, as although studies have considered issues of loss for people with MS [50,51], no empirical research has specifically explored these issues for parents with MS in relation to the timing of diagnosis. Due to the unpredictable nature of MS, continual adaptation is needed and there has been little research into how people adapt from an occupational perspective [52], that is, how people might modify their life roles.

Whether the participants shared their diagnosis of MS with others varied and reflects the negative attributions many women associated with having such a label attached to them. Grytten and Måseide's study with people with MS suggests that non-disclosure is a way of maintaining control [53], which has some resonance with the findings of this study. Some women concealed some of their impairments or were reluctant to disclose their disease, which suggests negative attributes were associated with having MS. This hesitancy in disclosure also substantiates Finlay's study findings which recognized the dilemmas for women in sharing their diagnosis with family members [17].

Some women spoke of how they were reluctant to accept aids and equipment, what could be referred to as "stigma symbols"

[46]. Linking the use of equipment with reinforcing their persona as disabled people thereby caused some women to refuse aids that would facilitate their independence. The women were demonstrating a perceived stigma, assuming that they would be discriminated against by others if they outwardly showed signs of being disabled, by using assistive equipment, which was in part related to the attitudes of other people. For some of the mothers, the stigma was related to how their children would perceive them and how the children themselves would be treated as being children of disabled mothers. However, the accounts of the most impaired women in the study, who were least physically able to access the social world around them, suggested that they were less fearful of stigma in their lives. These women had delineated their life roles differently and did not express regret at any loss of status, instead redefining themselves: *"I don't think I'm a mum with multiple sclerosis, I'm a mum…" (Alessandra)*. These women had developed what Taft et al. call "stigma resistance behaviors (sic)" [54] in that they appeared to be relatively unaffected by "internalized stigma" [55] and had moved to a position of self-acceptance as mothers with MS. It may also have been that the children of these mothers had adapted similarly and no longer feared, at least within the boundaries of their family relationships, the stigma attached to disability.

Many of the study participants spoke of how they lived in the present, appreciating their current lives, rather than thinking about the past or pondering the future. This tendency to live in the present and thereby value positive moments [48] may also have contributed to the reported experiences of those women who were comfortable with their roles and spoke of mainly positive experiences of mothering. These women were content with the significance of "being" a mother rather than solely focusing on "doing" tasks and did not feel an obligation to present as "normal" [48]. The women had successfully maintained their roles as mothers, not necessarily through physically participating in activities with their children, but through being present: physically, emotionally, and intellectually. In this way, these women had become more empowered in renegotiating or maintaining their life roles, which was a factor in how the women defined their identity as mothers.

While this study offers a unique insight into the experiences of disabled mothers in Italy, it should be acknowledged that there are some limitations to the research. The study used a relatively small sample to highlight the experiences of disabled women, but considered the experiences of these women in some depth. Therefore, the study can only assert to report on the experiences of these women who have MS. Nevertheless, a number of themes identified relate to issues around being a disabled woman in general, rather than only being relevant to the experience of living with MS. Additionally, the study took place in a confined geographical area of Italy. Recognizing the differences in welfare provision across the country, women in other areas of Italy may report different experiences. This applies to the socio-cultural differences, but may also impact on the women's experiences of environmental barriers, which were pronounced for the women in this study, but may be less significant from women living in geographically different regions.

It is also acknowledged that by seeking to investigate the lives of women with varied levels of impairment, the sampling criteria were not wholly accurate. This was because although the women were selected according to their Expanded Disability Status Scale score and allocated into the respective group criteria accordingly; some women had not been seen by a neurologist nor had their Expanded Disability Status Scale score upgraded for some time. This meant that some of the women, namely some in groups 1 and 2, may have in fact been in the group of women with a higher level of impairment. Some of the findings related to "self and identity" may also have been influenced by the length of time the women had lived with their MS. Although disease duration was not specifically explored within this study, as this information was not systematically collated, factors around how long the women had been symptomatic from their MS did emerge in the interviews. Additionally, the type of MS the women had was not recorded, which may have impacted on their experiences.

The literature that considers disabled women's experiences has tended to focus on the lives of women who chose to have children when they were already disabled [see for example 14,32], with rare commentary from women who experienced motherhood pre- and post-onset of an impairment. In exploring the experiences of women with MS, this study has given an insight into the experiences of women who knew their diagnosis pre-pregnancy and those who were unaware of their diagnosis or who were asymptomatic prior to pregnancy, revealing diverse experiences. Unlike this study, research that has been conducted with women with MS regarding maternity has tended to focus on the impact of pregnancy on disease progression [15] rather than on the lived experience of being a mother with MS.

For future studies, a more systematic exploration of disabled mothers' experiences in varied cultural contexts could be carried out, to allow comparison of the lived experience of disabled motherhood in different socio-cultural environments.

Conclusion

This paper highlights some of the practical challenges and psychosocial factors for mothers with MS and the impact on their identity. The findings have implications for professionals working with disabled mothers and women with MS in this and wider socio-cultural contexts. These include recognizing the value of the motherhood role, the effect of impairments on the ability to participate in mothering tasks and subsequent feelings of difference and loss, the desire to feel in control, and the fear of stigma, which all have potential impact on women's identity as mothers.

While the mothers in this study were subject to stigma, poorly resourced by social policy and statutory services, and disabled by environmental and attitudinal barriers in society, what also transpired was the enormity of the value of the mothering role and its impact on the disabled women and their identities. Many women had found what they regarded as an acceptable balance in maintaining their mothering role despite all the barriers and discrimination they faced, some with more support than others, but all of them aspiring to maintain their mothering role and prioritizing this. This study has investigated a relatively unexplored area of academic enquiry and it is hoped will have some impact and increased awareness of exposing the lived experience of disabled mothers in Italy.

Acknowledgements

Participant recruitment was facilitated by the Italian MS Society. Marina Usai assisted with the conduct of the interviews. Tamara Reiter transcribed and translated the interviews.

Above all the research team express their thanks to the study participants, for willingly giving up their time and sharing their stories.

Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

Funding

This research study was financially supported by a fellowship from the Fondazione Italiana Sclerosi Multipla, Genoa, Italy.

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