Workplace Stigmatism: The voices of mothers with disabled children

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Abstract
This qualitative study highlights the kinds of workplace stigma confronted by mothers of disabled children. It explores the forms of stigma that may be subtle yet could be detrimental to the mothers. This study also demonstrates how mothers are affected by and respond to workplace stigma. Five Malaysian mothers representing a variety of work structures and situations were engaged in the in-depth, semi-structured interviews. Text analysis reveals clear evidence that mothers are subjected to stigmatising treatments, consequently playing a significant role in their workplace engagement, career aspirations, and confidence.

Keywords: Workplace, Stigma, Mothers, Disabled Children

1.0 Introduction
Stigma occurs when someone receives disapproval for some condition or behavioural choice (Zhuang et al., 2018). It is a typical experience for persons with disabilities due to their lack of abilities and unique needs. Goffman (1963) argues that stigma affects those possessing the stigmatising characteristics and spreads to close family members with whom the bearer of negative differences associates (Green et al., 2005). Mothers are more likely to experience stigma than fathers as they are intimately closer to their children, and the childrearing roles are expected to fall primarily on the mothers.

UNESCO (2019) highlights that mothers who give birth to children with disabilities face many challenges. They are blamed for the disabilities and stigmatised by many people (ibid). Caring for a disabled child takes on an entirely different significance, and it is exceptionally challenging when the child experiences permanent functional limitations and long-term dependence (Raina et al., 2005). The stigma associated with workplace domains would further exacerbate the state of challenges the mothers confronted.

Many countries, including Malaysia, subscribed to the Sustainable Development Goals (SDGs) of the United Nations. One of the targets of SDG 8 is to promote full and productive employment and decent work for all women and men, including young people and persons with disabilities (United Nations, 2022). The International Labour Organization (2022) defines decent work as productive work for women and men in conditions of freedom, equity, security and human dignity. According to the European Commission (2022), there are
several features of work that can be considered decent. One of the features is related to equal opportunities and treatment for all and encouraging social integration.

The number of disabled children is gradually increasing worldwide (Anderson et al., 2007). In Malaysia, the registration of children with disabilities has surged tremendously over the past few years. 114,933 and 196,846 registrations were reported for 2016 and 2019, respectively, suggesting an approximate increase of 71 per cent (Department of Social Welfare, 2016; 2019). Considering these patterns, more female employees caring for disabled children are expected to participate in the future workforce, which denotes a pressing concern that necessitates understanding the employment trajectories of mothers with disabled children, Malaysia, in particular. This study intends to sensitise issues to stigma-related threats in the workplace, an aspiration parallel to the premise of decent work as mandated by the United Nations. Specifically, it will explore the forms and responses to workplace stigmatism within the purview of women employees with disabled children.

2.0 Literature Review

2.1 Stigma: An overview

Susman (1994) defines stigma as an adverse reaction to the perception of a negatively evaluated difference (Green et al., 2005). McLean and Halstead (2021) conceptualise stigma as a mark of disgrace associated with a particular attribute that does not meet society’s normal standards. In a more general perspective, Montenegro et al. (2022) describe stigma as the negative attitudes and beliefs held by an individual or society towards individuals deemed to have shameful characteristics. Ali et al. (2012) and Mitter et al. (2019) highlight that stigma occurs through a combination of stereotyping, prejudice and discrimination in the presence of an imbalance of power between different groups, fueled by social, economic and political differences.

Werner et al. (2012) provide valuable notions to differentiate stereotypes, prejudice and discrimination and how the three related to stigma. Stereotypes are collective opinions known to most members of a social group – they are attitudes about a larger of people and can be either positive or negative (Krueger, 1996). Prejudice involves an evaluative component and includes a negative emotional response toward the stereotyped group (Eagly & Chaiken, 1993). The response to prejudice leads to a behavioural reaction to discrimination (Crocker et al., 1998), including avoidant behaviour, increased social distance, hostile behaviour and withholding help (Corrigan, 2002; Weiner, 1995). Therefore, Werner et al. (2012) view stigma as a behavioural chain that starts from the stigmatising mark, progresses through attitude structures and results in discrimination. Ali et al. (2012) point out that the experience of stigma may involve overt acts of abuse or discrimination, or maybe more subtle, such as being denied the right to make choices or having over-protective families. Hence, it is typical for perceived stigmatised experiences associated with deleterious consequences on well-being such as feelings of hardship, psychological suffering, poor quality of life and low self-esteem (Mourya et al., 2016).

2.2 Stigma, disability, and family members

People with disabilities are one of the most socially excluded groups and encounter stigma (Ali et al., 2012). Similarly, McLean and Halstead (2021) highlight that individuals diagnosed with disabilities are well-known to encounter stigma and barriers that affect their everyday lives. Family members are reported to experience stigma based on their association with the stigmatised individual (Mourya et al., 2016). Like individuals with disabilities, family members who feel stigmatised experience increased emotional distress and social isolation (Green et al., 2005). Some studies demonstrate the association between stigma experiences and sorrow among parents of a person with a disability (Mourya et al., 2016). According to Manor-Binyamin & Schreiber-Divon (2020), stigma affects not only the person with the disability but also his or her family, especially the mother. Disability is therefore considered a concept that is also experienced by mothers and other family members (Ryan & Runswick-Cole, 2008). The experience of any form of stigma can profoundly affect a parent's quality of life, notably the mother. Mothers of children with developmental disabilities who experienced high levels of stigma are reported with low levels of psychological well-being (Bangia & Ghosh, 2017). Green (2005) points out that stigma's emotional consequences can socially debilitate mothers of children with disabilities.

2.3 Working mothers with disabled children

Mothers are the primary caregivers as they spend more time than fathers on childcare (Ejiri & Matsuzawa, 2019). Due to the complex limitations in self-care functions and extensive healthcare resources over time (Raina et al., 2005) associated with disabled children, mothers are reported to experience difficulties managing their employment and caregiving responsibilities (Scott, 2010). Some studies document the competing demands of the workplace and care work of mothers with disabled children (Anderson et al., 2007; Scott, 2018). UNICEF (2019) highlights that flexibility in the workplace are scant among Asian (Chopra & Zambelli, 2017). Malaysia is highly known for its continuous overwork practice and culture (Fong, 2017), aggravating the struggles of the mothers in integrating their paid work and care roles. Consequently, the mothers are prone to reduce their working hours or leave their employment (Ejiri & Matsuzawa, 2019). It is, therefore, not surprising to find that mothers with disabled children are at greater risk of lower income and non-employment than mothers of typically developing children (Chou et al., 2018).

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2.4 Workplace stigma

Zhuang et al. (2018) define workplace stigma as showing devaluation of a co-worker's contribution, expressing verbal and nonverbal disapproval toward them, or ostracising them from social contact. The stigma may lead members of stigmatised groups to strive to overcome doubts surrounding their group membership. Some may disengage or exit if they perceive they cannot change others' attitudes or if the challenge is too great, too stressful, or simply too aversive (Van Laar et al., 2019). Ample evidence shows that workplace stigma affects career and well-being (Brouwers, 2020). It makes workplace stigma a significant problem that deserves more attention. Overcoming workplace stigma, therefore, should be made a priority. Ensuring a stigma-free work environment would undoubtedly benefit individuals, employers, and society (ibid).

A study has found that mothers of disabled children perceived themselves to be stigmatised in the school and community environments (Gill & Liamputtong, 2011). For working mothers, the stigmatised experiences would be more significant as they are subjected to an additional domain of environment, i.e., the workplace. As stigmatisation can lead the mothers to get more emotionally distressed, become isolated, and subsequently affect their caring roles in meeting the child's needs, the issue thus, warrants an urgency to address and intervene (Duran & Ergün, 2018).

3.0 Methodology

This study frames on a qualitative approach with an application of in-depth, semi-structured interviews to obtain a true representation of the participants' experiences. The principal researcher recruited five working mothers through her social media accounts on Facebook and Instagram. All mothers signed the consent forms for participation in the study, permitting audio recordings of the face-to-face interviews. Each interview session lasted between 40 to 90 minutes.

<table>
<thead>
<tr>
<th>No.</th>
<th>Coding name</th>
<th>Age</th>
<th>Profession/Sector</th>
<th>Diagnosis of disabled child</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Rai</td>
<td>41</td>
<td>IT Executive/Private Sector</td>
<td>Autism Spectrum Disorder (ASD)</td>
</tr>
<tr>
<td>2.</td>
<td>Haz</td>
<td>39</td>
<td>Senior Executive/Private Sector</td>
<td>Cerebral palsy (neurotransmitter disease)</td>
</tr>
<tr>
<td>3.</td>
<td>Naz</td>
<td>41</td>
<td>Lecturer/Private Sector</td>
<td>Mild autism</td>
</tr>
<tr>
<td>4.</td>
<td>Azi</td>
<td>43</td>
<td>Nurse/Public Sector</td>
<td>Down Syndrome</td>
</tr>
<tr>
<td>5.</td>
<td>Rod</td>
<td>49</td>
<td>Chief Clerk/Public Sector</td>
<td>Down Syndrome</td>
</tr>
</tbody>
</table>

Table 1 shows that the five mothers were between 39 to 49 years of age. They were engaged in private and public sector professions, representing a variety of work structures and situations. The mothers were caregivers for a disabled child with various disabilities, including autism spectrum disorder (ASD), cerebral palsy (neurotransmitter disease), mild autism and Down syndrome.

The interview data were analysed using the principles of thematic analysis, which uses codes as a template for data analysis (Guest et al., 2012). According to King (2004), thematic analysis works well with small datasets or when researchers know the issues they are searching for.

4.0 Findings

The analysis reveals clear evidence that the mothers are subjected to stigmatising treatments, consequently playing a significant role in their workplace engagement, career aspirations and confidence. Two salient forms of stigmatisation are found where mothers are associated with negative connotations and seen as (1) incapable and (2) taking advantage.

4.1 Mothers are incapable

Some mothers expressed that they were perceived as less capable due to mothering a disabled child. As one of the mothers (Haz) described: ‘If I late for work, delay in work submission or request for the absence of leave, they would always presume it was due to the commitments of my child. After 14 years in broadcasting, I was transferred to a corporate planning department. They claimed that the transfer is better considering the less busy nature of the corporate planning. They see me as incapable of coping in the broadcasting environment, considering my caring role to my child’. At this point, Haz expressed her sense of despair: ‘I have previously always enjoyed my work in broadcasting. What am I expected to do in this department (corporate planning)? After many years of working with the company, I felt useless’. Another mother (Naz), a lecturer in a private university, explained that she was occasionally late for office meetings scheduled in the early morning as she had to drive her child to a support school some distance away from her workplace. As a result, she has been labelled as an unpunctual person. With frustration, Naz said that the labelling affected how people perceived her role as a department leader.

4.2 Mothers are taking advantage

Managing work and family in the case of a child with disability is enormously complex, mainly when the child is diagnosed with severe functional limitations and requires long-term medical attention. Azi, a nurse at a public hospital, regularly applied for time off to accommodate her child's hospital appointments. There were occasions she was questioned about the appointment's authenticity: ‘You had time off last month...yet you are requesting another one for this month?’...‘They adamantly perceived me as taking advantage of the time off benefit’, says Azi with a colossal disappointment. In a somewhat similar situation, Rod (a chief clerk) shared a brief remark...
she received from her supervisor when she applied for a quarantine leave related to her child: ‘...As long as you do not do what people say (taking advantage)’. Rai (IT executive) highlighted that in a few unexpected situations, she had to bring her child to the office (for a short while). She articulates: ‘At least... they can see that I am not making stories and excuses for my sudden leave of absences’, another circumstance that clarifies the stigma of taking advantage associated with mothering a disabled child.

It is interesting to note how some mothers regulate their work engagements and career aspirations in response to the workplace stigma. Rai stated that she would never expect high marks for her annual performance appraisal as she was fully aware of her limited contributions compared to her co-workers. She also reported never thinking about advancing her career, emphasising that employment was merely a necessity to provide for her living. Azi highlights an enticing note: ‘You will be subjected to the mercy of other people.’ She said she must speak to her boss and colleagues to seek their understanding of her time off to accommodate her child’s hospital appointments. Naz echoed the merciful aspect as she also needed to seek her boss’s (i.e., the dean) approval for her morning classes to start slightly later due to his son’s commitment.

5.0 Discussion
The findings provide compelling evidence of identical workplace stigmatism regardless of the work structures and sectors. The mothers have to deal with the negative connotations (prejudice) due to their mothering role for children with disabilities. The findings also show that the mothers appear to legitimise the stigmatising norms they experienced and regard their treatment as sensible. According to Scott (2018), mothers of children with disabilities adjust employment duties, compromise their expectations concerning wage work, and seek empathic supervisors because of the challenges of juggling demanding care and wage work, which is consistent with the findings reported in the study. Some mothers cannot work in jobs commensurate with their aspirations, and they internalise a feeling of incompetence as workers (ibid), thus explaining how the mothers in the study responded to the workplace stigma by acknowledging their limited contributions compared to their fellow workers. Raina et al. (2005), however, highlight that failure of the workplace to understand the mothers’ caregiving obligations from having a child with disabilities may uniquely affect their job performance, career aspirations and confidence.

The mothers demonstrated resilience in response to the stigmatising treatments, another essence of the study findings. The age maturity of the mothers (between 39 to 49 years) might explain the existence of resilience. Gooding et al. (2012) discovered that older adults were more resilient, especially regarding emotional regulation ability and problem-solving, compared to the young ones. Some studies revealed that parents show resilience in the face of stigma by trying to keep their lives as normal as possible and working hard to integrate their children into the community (McLean & Halstead, 2021). Though the parents are aware of the stigma towards themselves and their children, they prevent it from affecting them by maintaining a sense of integrity (Grant et al., 2007). McLean and Halstead (2021) argue that it is essential that parents of children with disabilities display resilience and maximise their protective ability. Through their study, Choi and Yoo (2015) demonstrated that parents with lower levels of resilience reported higher levels of depression and stress, leading to poorer outcomes for the family.

6.0 Conclusion & Recommendations
This qualitative study presents issues of workplace stigma confronted by working mothers of disabled children. The analysis revealed that the mothers are subjected to negative connotations regarding their capabilities given their mothering roles for a disabled child. Workplace stigma is unhealthy for organisations. Given the crucial evidence of workplace stigma reported in the study, practitioners and policymakers should strongly consider specific structural interventions to reform the employment trajectories of mothers with disabled children. Most important, such reformation of the employment trajectories will support the agenda of decent work mandated by the SGD 8 of the United Nations.

It is imperative to note that this study was primarily based on the narratives of only five working mothers of children with disabilities. Future research should consider recruiting a larger sample to position more substantial evidence regarding workplace stigma experienced by mothers of disabled children. A diverse sample of different demographic profiles of age, race and employment type would be beneficial to provide meaningful data to understand the workplace stigma further. Abdul-Ghani et al. (2021) highlight that stigma and knowledge about disabilities differ across groups. Ryan and Runswick-Cole (2008) state that parenting a child with physical impairments will, in many ways, differ substantially from parenting a child diagnosed as being on learning impairment. These signify an indication for future research to study other types of impairments to clarify the workplace stigma confronted by mothers. Since flexibility in the workplace is claimed to be scant among Asians (Chopra & Zambelli, 2017), an attempt that delves into a comparative study of neighbouring countries of Malaysia, such as Indonesia, Thailand and Singapore, would be fruitful.

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Paper Contribution to Related Field of Study

This study offers an essential consideration to the literature on the workplace stigmatism of Malaysian mothers with disabled children. Research on stigma in family members of people with disabilities remains limited. The current study adds to a small but growing body of research on disabilities that focuses on the family members, i.e., mothers. The study also contributes to the limited literature on working mothers of children with disabilities in non-Western communities (Manor-Binyamini & Schreiber-Divon, 2020). It is aligned with the concerns that mothers of children with disabilities in developing countries are neglected populations facing hidden challenges (Jafree & Burhan, 2020). There is scarce empirical data on the challenges experienced by mothers in reconciling paid work while caring for a disabled child (Brennan & Brannan, 2005). Extensive literature debating the harmful effects of care work on maternal labour force participation (Scott, 2018). Nevertheless, researchers have paid less attention to the workplace domains that may facilitate or hinder a mother’s ability to manage work and family, especially for mothers caring for children with disabilities. Most important, very few studies explicate the workplace stigma of mothers with disabled children.

References


