



Interpretative Phenomenological Analysis of Primary Caregiver's Negative Experiences of Caring to Their Intellectual Disabled Child at Home.

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Literature review: Persons with intellectual disabilities have seen profound transformation in many parts of life during the previous century, including healthcare, work, education, enjoyment, and living circumstances (**World Health Organisation, 2000**). Intellectual disability is an aberration that has far-reaching societal consequences; it impacts not only the persons who suffer from it, but also their families and society as a whole. Intellectual disability are caused by a reduction in cognitive capacity, which results in a difference in the rate and efficiency with which the individual acquires, recalls, and applies new information in comparison to the normal population.

Throughout history, it has been defined and renamed several times. Mental retardation, which was widely used until the late twentieth century, has since been supplanted in most nations by intellectual impairment. Diagnostic and Statistical Manual 5th Revision (**DSM-V**) has replaced it with Intellectual Disability. The definition of intellectual disability has been amended several times over the last few decades as people's knowledge of the illness has evolved, as well as in reaction to different social, political, and professional influences.

'Intellectual disability,' as well as comparable words like 'learning disability,' 'learning difficulties,' and 'mental retardation,' have historically been used interchangeably, causing misunderstanding in studies (**Harris & Greenspan, 2016**). The term 'intellectual disability' is adopted in this study since it is an international common language that has largely superseded the term 'mental retardation' (**Salvador-Carulla et al., 2011; British Psychological Society (BPS), 2015**). Intellectual impairment denotes developmental issues in both cognitive and adaptive functioning that must have existed before to maturity (**World Health Organisation, 2007; BPS, 2015**). People with intellectual impairments are more likely to have co-morbid physical and mental health issues that need additional assistance (**Cooper et al., 2015**).

The most popular definitions of ID are from the International Classification of Diseases (ICD- 10), the American Psychiatrist Association's Diagnostic and Statistical Manual (DSM-IV), and the American Association on Intellectual and Developmental Disabilities (AAIDD). "Intellectual disability" is a condition of functioning that begins before the age of 18, and is characterised by considerable limits in both intellectual functioning and adaptive behaviour (**AAMR, 2002**). This impairment appears before the age of 18, this description is accompanied by five assumptions that are regarded crucial when implementing this definition: Current functional limitations must be assessed in the context of community situations typical of the individual's age, peers, and culture. The assessment of validity takes into account cultural and language variety, as well as variations in communication, sensory, motor, and behavioural aspects. Definition, categorization, causes, and features of intellectual disability within an individual; limitations may coexist with strengths. One essential goal of



expressing limits is to create a profile of required assistance. The life functioning of the individual with intellectual impairment will typically improve with adequate personalized assistance provided over time. This concept promotes the integration of persons with intellectual disabilities into society depending on their talents. Today, the emphasis is on a multidimensional categorization method that considers five dimensions: cognitive ability, adaptive behaviour, health, involvement, and environment. The tests used to assess cognitive functioning as well as adaptive behaviour are well established and standardized. The concept must be understood from this multidimensional viewpoint in order for society to respond with treatments that appreciate the individual's strengths and the significance of supports to improve functioning (**Wehymer et al., 2008**).

Impacts on Caregivers

The Indian Setting Intellectual impairment, as a condition, has far-reaching negative consequences for families and carers than any other type of disability (**Baxter et al, 2000**). There is strong evidence that carers endure many sorts of emotional anguish once their children are diagnosed with intellectual impairment. Common expressions include shock, denial, rage, sadness, shame, humiliation, melancholy, retreat, ambivalence, and fear of stigma (**Blacher, 1984; Marsh, 1992; Marvinand Pianta, 1996**). **Singh et al. (2008)** discovered negative effects among one-fourth of the parents in their research sample in India, including challenges in fulfilling extra demands for physical care of the kid, health-related concerns, making professional adjustments, suffering loss of support from their spouses, and so on.

According to studies, parents may feel the effects of impairment in a variety of ways. Mothers with disabled children, for example, were shown to have higher levels of depression (**Olsson and Hwang, 2001**), carer load (**Heller et al, 1997**), and stress (**Herring et al, 2006**) than dads. According to studies, it is not only the presence or lack of disability that has a detrimental influence on the family, but also the child's maladaptive behaviour and diverse care demands (**Neely-Barnes and Dia, 2008**). Although numerous research have been conducted on the negative effects and responses of carers of children with intellectual disabilities, just a few studies have been conducted on the positive effects on carers, particularly in the Indian setting. However, relatively few studies have been undertaken in India to investigate the negative and positive effects on carers of children with intellectual disabilities, particularly in rural settings. In a developing nation, the demands of families with such children are likewise highly complicated. As a result, assessing the effects on carers of children with intellectual disabilities can aid in the development of support systems and methods to empower these families.

Caregiving moms also experience significantly more stress and hope than non-caregiving mothers, owing to their greater concern for their children's future (**Saluja & Kaur, 2013**). **Engül and Baykan (2013)** discovered that moms managed their stress by denying and disregarding behavioural tendencies. This is especially true for persons with impairments who may have complex secondary medical issues. People with disabilities account for 15% of the population, according to the World Disability Report (**WHO, 2011**), making them the biggest minority group (**United Nations, 2006**). Despite this, "people with disabilities have worse health than the general population." They are sometimes referred to as having a "narrower or thinner margin of health" (**WHO, 2011**). Studies with groups of mothers have revealed that they feel insufficient, have a larger emotional load (**Turan- Gürhopur&şler- Dalğç, 2017**),



and are more vulnerable to stress (McConkey et al., 2008; Saluja & Kaur, 2013). In Mohamed and El-Aziz's (2011) study, moms reported feeling concerned when their children were diagnosed with a handicap. While some of the moms in the research saw the circumstance as fate, others did not. Caregiving moms also experience significantly more stress and hope than non-caregiving mothers, owing to their greater concern for their children's future (Saluja & Kaur, 2013). Engül and Baykan (2013) discovered that moms managed their stress by denying and disregarding behavioural tendencies. Furthermore, Eroluzcan, and Peker (2015) discovered that moms of special-needs children had less psychological strength and worse levels of well-being and happiness than mothers of generally developing children. Another study discovered that moms perform more daily caregiving duties than dads, although the spectrum of tasks is comparable. Furthermore, moms reported much greater caring challenges, but also significantly more pleasure, than dads (Rowbotham, Carroll, & Cuskelly, 2011). This is especially true for persons with impairments who may have complex secondary medical issues. People with disabilities account for 15% of the population, according to the World Disability Report (WHO, 2011), making them the biggest minority group (United Nations, 2006). Despite this, "people with disabilities have worse health than the general population." They are sometimes referred to as having a "narrower or thinner margin of health" (WHO, 2011). To study the caregiver's insights regarding societal perception and associated stigma with their disabled child.

Research Methodology

Objective of the study: To study the caregiver's insights regarding societal perception and associated stigma with their disabled child.

Design: This design was considered as an exploratory qualitative study.

Data collection: Data was gathered through the application of semi-structured interview guide by in-depth interviews with the help of audio recorder.

Data transcription: Collected data in audio form subsequently transcribed to bilingual in respondent native Bhojpuri language and further in English language.

Participants: Participants were taken from 46 villages under randomly selected block of Mirzapur district of Uttar Pradesh. Selected list of intellectual disabled children was verified by PHC personal. In total 38 participants were selected for in-depth interview.

Sampling Procedure: With rare case objective and for this most appropriate Purposive sampling method is opted for sampling procedure.

Inclusion Criteria: Inclusion criteria stated that participants must be over 18 years of age and be the primary caregiver for their child and having experience of caring to intellectual disabled child for more than 5 years.

Exclusion Criteria: Exclusion criteria stated that primary caregivers don't have any mental illness.

The objective related to analysis of primary caregiver's experiences about the attitude and perception of the society towards their intellectual disabled child and viability of their faced associated stigma by this cause is being examined and justified with master theme '*fixed inclination*' and their associated sub-themes. The data been analyzed with idiographic method to fulfilled the requirements of the objective.

Explanations of master theme and their associated sub themes

Fixed inclination: This theme exhibits the context of caregiver's experiences related to their social exclusion and stigma faced by caregiver regarding they heaving intellectual disabled



child and gender-biased inclined behavioural pattern of society on intellectual disability were compiled under this theme. The primary caregiver's experiences of social exclusion and their associated stigma are compiled under the theme fixed inclination and that is indicated by the combination of sub theme gloomy life, stern faces and cynical society. The primary caregivers stated that they have been socially excluded by others' verbal statements and they are uncomfortable with the unusual looks from others who feel sorry for them. Most of the caregivers stated being exposed to social discrimination and even social isolation due to having intellectually disabled children.

Results are based on the in-depth interview of sample of 38 primary caregivers there are discussed some subjective attributes which impacts their outlook to their child's intellectual disability are represented in the following tables. These tables give the representation of ratio of respondent and used to give quantitative strength to data.

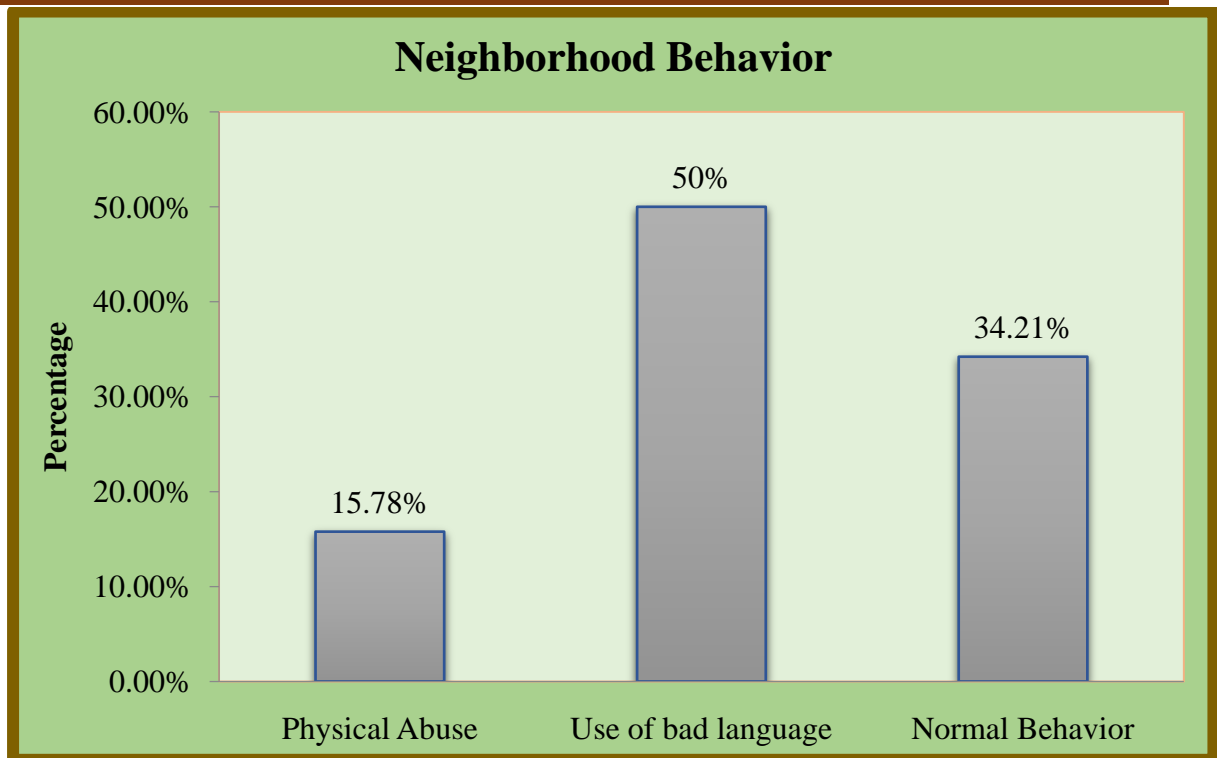
Table no. 1 represented the data of ratio on the neighbourhood behaviour towards intellectual disabled child when primary caregivers recalled about their associated stigma when they filled as isolated and self-stigmatized due to the reflection of negative attitude from adverse neighbourhood behaviour pattern.

Table – 1

Neighborhood Behavior towards intellectual disabled child

<i>Physical Abuse</i>	15.78%
<i>Use of bad language</i>	50%
<i>Normal Behavior</i>	34.21%
<i>Total</i>	100%

The table-7 is showing the percentage of neighborhood behavior as reported by caregivers of intellectual disabled children, with responses categorized as physical abuse, use of bad language, or normal behavior.



Caregiver’s inclination of hope gets ruined due to their child disability and their extreme statement on their child death prior to their death. In a rural set-up, the caregiver who have weak economic background and major financial crisis, seems her child especially her son as an asset and she hopes that he will take care of her during her bad phase or old age but due to mental disability The fact that the child is unable to do so is described by primary caregiver as a form of deep worry and despair, and their hopes are changed as a burden by those they are taking care of. during the interview the mothers talked about their struggle while taking care of their child and it was surprising in the result that the primary caregivers even expressed the self-thought that it would be better for their satisfaction and well-being of their child that their child die in front of them so that his pain will not bother him for a long time. Some statements of primary caregivers (Respondent#3,8,11,1,21,28 &34) are related to this which are found from the in-depth interview are as follows:

Liability goes longer: This sub theme associated with Caregivers’ responses with adolescence girl child and their prior concern related to their survival longevity. In set-up of rural environment where daughters are seen as a responsibility and it is understood that their responsibility regarding daughters is till their marriage, and that is all their duty. In case of their daughter intellectual disability, they will not get married; this result has made their mothers extremely distressed and sad. In such a situation, primary caregivers feel that now they will have to deliver caring responsibility in their whole life and this thing is like a burden life for them. Primary caregivers (respondent #6, 17, 24, 37&38) demonstrated their thoughts and past lived experienced like this:

[Transcribed text verbatim]

My only support is my husband who left us to abode, Now I am the only one suffering with him. I feel scared about the fact that who will take care of him after me. She will



wander around and may be die of hunger, nobody will take care of him, hence I wish her to pass away before me. (Respondent # 17)

[Transcribed text verbatim]

My entire life has been spent bearing the burden of his medicines. So, he is like burden on us and we carry this burden for whole life by despair. (Respondent # 24)

[Transcribed text verbatim]

I feel stressed about her future. Nobody will care for her as I do. I cannot trust this with my others daughters or sons-in-law to take of her, might be possible that there be misfortune with her after my death. So, I wish and pray that she passes away before us.

This will be painful but at least I can die at peace. (Respondent # 37)

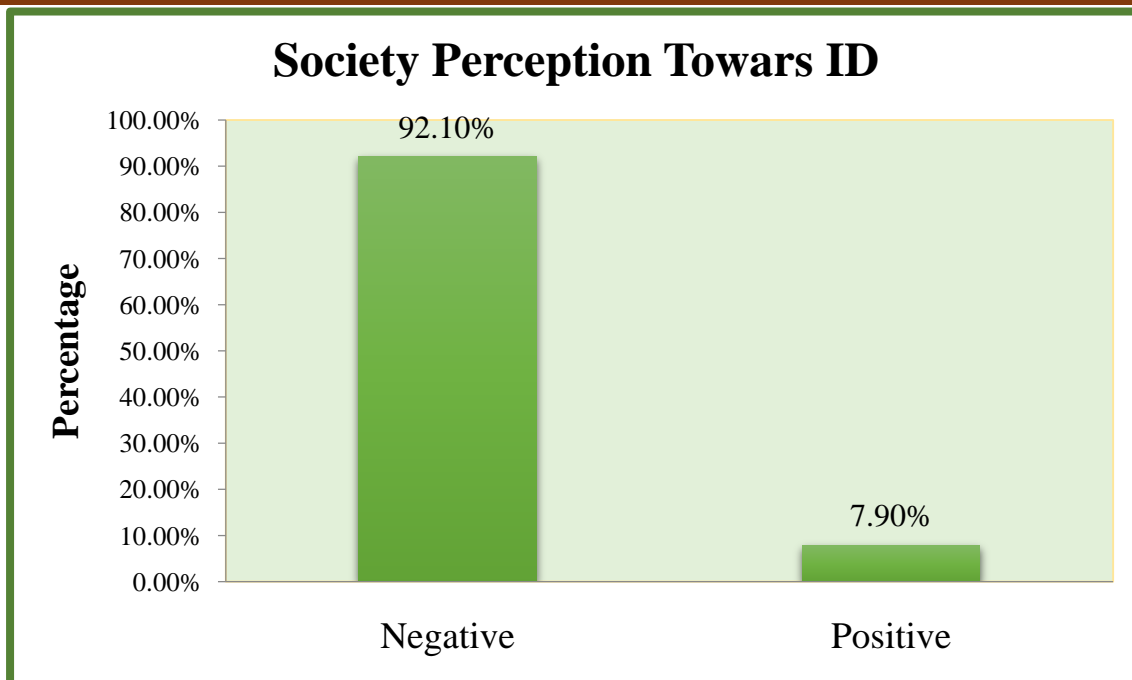
Cynical society-Society subsequent changed attitude to their child disability and social environment as determined obstacle were exposed under the sub-theme cynical change. After the disclosure of their child disability, the primary caregivers have explained the condemnable and ongoing cynical change in the persons from the society towards their disabled child and they shared their lived experience and explicated that the society is indifferent towards their child and sees it as an evil, even the society does not see and accept their child from the same point of view according to their mental condition. She feels stigmatized by this harsh behavior of the society and also finds herself guilty that sometimes she thinks that she is the mother of a child who is not good for her. This cynical change in society can be seen easily by the following table that show the higher percentage of society negative attitude towards intellectual disabled child which is tabulate on the basis of caregiver's responses on questions related to their experiences regarding society perception to their disabled child.

Table - 2

Society Perception Towards Intellectual Disability

<i>Negative</i>	92.10%
<i>Positive</i>	7.90%
<i>Total</i>	100%

The table-2 is showing the percentage of society's perception towards intellectual disability. Specifically, it indicates that 92.10% of the sample reported a negative perception towards intellectual disability, while only 7.90% reported a positive perception towards intellectual disability. It suggests that a majority of society has a negative perception towards intellectual disability, which may have negative implications for individuals with intellectual disabilities and their families. It highlights the need for efforts to promote greater understanding, awareness, and acceptance of intellectual disability in society.



[Transcribed text verbatim]

Some people have negative thoughts about such special children. I feel sorry for them about their thoughts. People should be compassionate about such kids and the society should accept them, the way they are. (Respondent # 1)

[Transcribed text verbatim]

I have another son who is younger to him, I feel anxious when people compare both the kids. Both my kids equally dear to me, and I behave equally with them. (Respondent # 10)

{Above mentioned statements of primary caregivers (Respondent #1,2&10) show the glimpse of insights about cynical change of society over after their child disability disclosure. They shared experiences of society cynical changes by their bad words and comments on disabled child potential and that is responsible for moral decline for primary caregivers.}

Table - 3

Frequency of Courtesy Stigma (filled by Care-giver)

Yes	76.32%
No	23.70%
Total	100%

The table-3 is showing the frequency of "Courtesy Stigma" filled by a caregiver. "Courtesy Stigma" refers to the stigma experienced by family members or caregivers of individuals with stigmatized conditions. The table indicates that out of the total sample, 76.32% of caregivers reported experiencing "Courtesy Stigma" while caring for someone with a stigmatized condition. On the other hand, 23.70% of caregivers reported not experiencing "Courtesy Stigma."

Stern faces: Caregiver’s expression of their experiences about adverse impact left by society with their misbehave, denial, abusing etc. oriented behavior to their intellectual disabled child and that make fade of like situation for caregivers with respect to their disabled child caring.



Following statements are demonstrate the primary caregivers' experiences related to above concerned.

[Transcribed text verbatim]

People have indulged him into chewing betels and consuming alcohol and exploit him by using his Labouré on just 2 rupees for a whole day to do their activity. No body even provides a bare minimum or feed him adequately but exploit him in the name of alcohol. (Respondent #23 with anger on people's behaviors to their intellectual disabled child)

[Transcribed text verbatim]

Once he was out in Chunar where he fainted due to eclipse so the people around have to smell shoes and pour fleshes of water over him to get him back to his senses. (Respondent #23)

{This statement of primary caregiver shows the glimpse of construct of society on the treatment of eclipse and that disease is rural background is named as 'Mirgi' aur 'jhatka'.

[Transcribed text verbatim]

Respondent # 37 recalled an accident with expression of anger" during her daughter's wedding someone from our community broke his child hand, she exclaimed that she has her patience because she does not know who did this but also mentions that God will not forgive that person who did this.

Uncertainty- The caregiver's future concern to their child disability situation in context of their longevity & survival: and primary caregiver's future thinking regarding to their child care when she is not alive were demonstrated under sub theme uncertainty.

[Transcribed text verbatim]

Looking at other kids like him, sometimes I get thoughtful about his future. I can take care of him only until I am alive. I do not know, whatever his siblings would take care of him or not. (Respondent # 17 on their child's future caring concern)

[Transcribed text verbatim]

I do not sometimes understand whether to consider myself to be luckily or unluckily about him. I only wish he could go to school like other kids, so that he could learn his living in future.

{Respondent # 22 express their cogitation about their intellectual disabled child situation and make a comparison base to normal child behavior expectation to their intellectual disabled child. Lack of knowledge is prominent factor and worked as hindrance to their child's intellectual disability.}

[Transcribed text verbatim]

Some people have negative thoughts about such special children. I feel sorry for them about their thoughts. People should be compassionate about such kids and the society should accept them, the way they are. (Respondent # 2)

[Transcribed text verbatim]

But sometimes people from neighborhood murals or make fun on him and asking him to dance Infront of everyone. We as parents feel sad about this. People tease him by indulging in activities that he dislikes the most.(Respondent #2)

Nature of acceptance- Caregivers' acceptance and gratitude to their child intellectual disabled child and amid texture of acceptance as restrains or ease and its inverse relations to case-management.



[Transcribed text verbatim]

No one else from the family ever accepts this fact, that he shall remain like this forever. Everyone else believed that as he wishes to grow old, he will start behaving normally. Now that he is 12 years old and there is no improvement in intellectual functioning. (Respondent # 6 statement shows the glimpse of knowledge as a hurdle to acceptance of the reality of the disclosure process of child's intellectual disability.)

[Transcribed text verbatim]

I was under the impression that at least one of the two sons would be like normal kids, who would take care of me during my old days but unfortunately none of them has a sound mind. Although my daughter is normal but my sons which my dependency is unfruitful because they are differently abled.

(Respondent #32 has shown the anger of her fate as well on her family, she carried out with thinking that their all two children who were with such mental condition and for this her family is responsible for this.)

Cynical change- Society subsequently changed attitude to their child disability and social environment as determined as an obstacle in caregiving were exposed under the sub-theme cynical change.

Asset as burden - Caregiver's inclination of hope gets ruined due to their child disability and their extreme statement on their child death prior to their death, explicated sense of rural setup where male child as asset that narration clearly articulated under this sub-theme. Experiences of primary caregivers which the preconceived notion of gender-based stereotype society especially in rural background, regarding male child their preference and considering him as an asset and for girl child as a responsibility that to be discharged as per their marriage time and seems them as liability. Expressions of primary caregivers' responses in these words:

[Transcribed text verbatim]

Taking care of him throughout the day cannot ensure us to take care of our needs. Hence, we husband and wife go to work at Labour sites.

[Transcribed text verbatim]

Sometimes his activities make me furious. As long as he lives, we have to take care of him either by choice or in despair.

(Respondent # 7 sharing her future concerns for their child caring)

[Transcribed text verbatim]

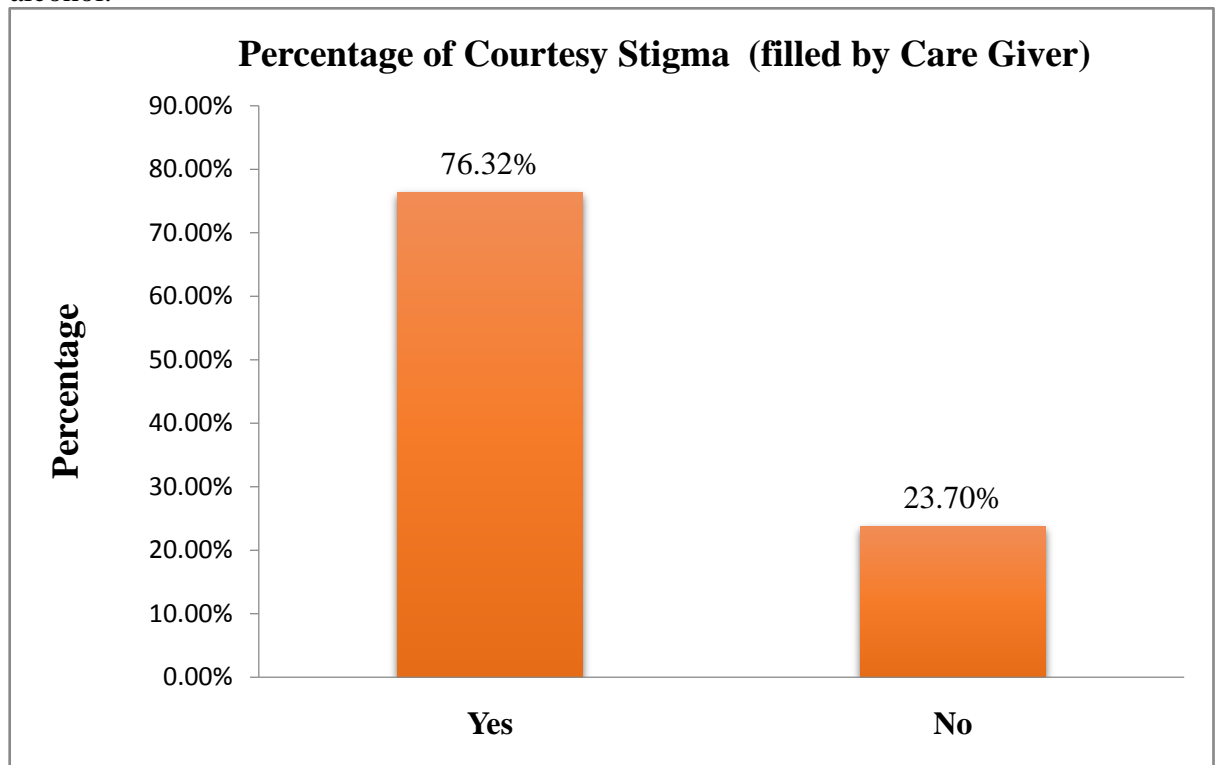
The view of the society is negative towards him owing to his dependence on others. They believe he will be a burden to the family as well on society

Harsh side of society- Caregiver's concern about adverse impact left by society includes misbehavior, denial, abusing etc. on caregivers with respect to their disabled child.

[Transcribed text verbatim]

People have indulged him into chewing betels and consuming alcohol and exploit him by using his Labour on just 2 rupees for a whole day to do their activity. Nobody even provides a bare minimum or feed him adequately but exploit him in the name of

alcohol.



Bar-diagram

This bar diagram show the high percentage of curtesy stigma among primary caregivers due to the reason of cynical changes in society perception regarding their child intellectual disability.

Discussion with existing peers' literatures

This study's purpose shows how society regards children with intellectual disabilities based on the perceptions and experiences of the primary caregivers. Under the umbrella of caregivers' perceptions of society combined with the subthemes "construct is prominent" and "cynical change," most primary caregivers described feeling cut off from society as a result of disparaging remarks and strange looks from strangers. Green (2003) discovered that the related stigma from society is extremely high for parents of children with impairments. These unfavourable perceptions about people with disabilities in India may be to blame for these attitudes (Avoke, 2002). Strong conventional ideas that devalue persons with impairments were a major influence on how primary caregivers reared their kids (Avoke, 2002; Baffoe, 2013). They must act as role models. In order to do this, caregivers should be encouraged to create Self Help Groups (SHGs) of like-minded individuals. mothers' shoulder all of the burden of caring for their children (Sato et al., 2015). In this study, primary caregivers claimed that they felt responsible to help their kids in all facets of life and that other family members, relatives, and friends had not given them enough assistance. Opportunities to share experiences and promote peer support and guidance can be provided by group talks, one-on-one listening, support groups for primary caregivers of children with similar disabilities, and other potential treatments. Financial hardship is always the aggravating element, regardless of the type of impairment. Regarding the financial effects, it was discovered that the majority of the caregivers experienced financial hardship because of the expenditures of their child's



medical care. All primary caregivers had feelings of stigmatization and isolation as a result of society's general lack of understanding with intellectual disability people in society. All of the primary caregivers claimed to be advocates for their kids, but their capacity to put up with others' disapproving looks or bluntly upsetting words hurt their emotional health and revealed a lack of societal understanding of disability. It's probable that these primary caregivers experienced '*courtesy stigma*,' which Goffman (1963) defined as the feeling of stigmatization experienced by someone who is related to a stigmatized person through the social structure (Goffman, 1963, p. 30). This has been discovered in earlier research of primary caregivers of children with disability (Green, Davis, Karshmer, Marsh & Straight, 2005) and may have an impact on the mental wellness of the primary caregivers.

Conclusion-This study revealed another set of subjective insights on gender-based preconceptions, which show the stereotype notion of society about gender-based preferences of boys over girls. This is because, in rural areas with limited financial resources, people perceive male children as an asset and a helping hand in the primary sector of employment, so when their male children's disabilities are revealed, their first concern is for their own survival. Some of the primary caregivers during their interview described societal behavior that produced a stunning result that our study distorted: labelling someone with intellectual disabled as having mental retardation or a madman and calling such a person by that name. The study's most astounding and startling finding is that primary caregivers who had their intellectually disabled child subjected to harsh social criticism were adamant that their child had been abused by family members, neighbors, and even when no one was home or nearby. Additionally, neighbors and sometimes family members refer to such children as crazy. The viability of the remarkable outcome under the sub-theme '*liability goes longer*' was asserted. Young girls' mothers claimed that their girl kid does not participate in domestic chores, despite them exerting great effort in that direction. They also spoke of their daughter's shyness and security in their concern for sex. Due to the established tendency of society's conception of girl children as liabilities to their age of marriage and the impossibility of this happening, for mothers, the relevance of their daughter's cognitive condition is not as significant as their prominent blink of stand over on. Due to their children's lack of knowledge of the notions of person, space, and time as well as their worries that they would be hurt by others, the primary caregivers had security concerns. Chang and McConkey (2008) cite four caregivers with female children who expressed anxiety that their daughters would be subjected to emotional, physical, psychological, or sexual harassment as a major finding. According to the literature, women receive insufficient official and informal support; as a result, The main issue in the area of social repercussions was discovered to be society's unfavorable perception of families with children who have intellectual disabilities. The caregivers of children with intellectual disabilities are impacted when people turn away from such marginalized groups because they will be unwilling to talk about their concerns with others owing to a perceived social stigma (Kaur and Arora, 2010). Although it takes time for a wider society to change its mentality, attempts to eradicate this stigma should begin with the parents of children with intellectual disabilities.

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