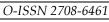
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RESEARCH PAPER

Exploring Parental Beliefs and Intervention Strategies for Children with Disabilities

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ABSTRACT	

This study delves into parental beliefs regarding disabilities and their consequential impact on intervention strategies for children with various disabilities—Hearing Impairment, Visual Impairment, Mental Retardation, and Physical Impairment. Utilizing a qualitative approach, the research sought to gather comprehensive insights into these beliefs. The sample comprised purposefully selected parents of children with disabilities, employing semi-structured interviews to extract nuanced information. A total of 40 parents, 10 from each disability category, were part of this study. The findings unearthed a profound understanding of parental perspectives on their child's disability, societal encounters related to their child's condition, specific intervention strategies adopted, and parental satisfaction with the chosen interventions. Moreover, the study uncovered diverse fears concerning the future of both genders, influencing parental perceptions of disability, some viewing it as a reward while others as a punishment, thereby impacting the selection of interventions.

KEYWORDS

Belief Systems, Disability, Interventions, Role of Beliefs in Selection of Intervention

Introduction

Beliefs intricately weave the fabric of our reality, shaping how we perceive existence. Our individual belief systems serve as guiding lights, aiding life decisions and framing our comprehension of the universe. In this complex interplay, the system of signs molds our perceived reality, heavily influenced by these beliefs. Each perception finds its foothold within a system uniquely constructed by the individual, making understanding a sign reliant on deciphering these established systems.

Literature Review

A belief system, a nexus of interlinked supportive beliefs, spans religious, ideological, and philosophical realms, intertwined into a tapestry often challenging to revise entirely (Gloves, 2011). Disabilities, particularly, harbor deeply entrenched beliefs, casting profound shadows on individuals' lives, shaping perceptions and decision-making processes. Discussions on perception necessitate delving into these belief systems (Domenech & Selva, 2015).

Crafted through maturation, belief systems hinge on five information-gathering methodologies. Among these, critical thinking stands as a solitary beacon of rationality,

seeking evidence for causation, grounding belief systems on logical foundations (campbell, 1996). Tradition, authority, association, and revelation intertwine to sculpt belief systems, effortlessly seeping into our consciousness, whether through familial legacies, revered figures, societal affiliations, or mystical encounters—a concoction of personal insights, molded by diverse influences.

Perceptions regarding disability dance across diverse spectrums within different communities (Munyi, 2012). Parental attitudes materialize as a compass guiding the navigation of disability perceptions. In certain regions, cultural beliefs intertwine deeply with disability, as in the case of Pakistan, where the birth of a child with disabilities is often viewed as a divine test of familial morality (Jegatheesan et al., 2010). Amidst these beliefs, familial roles entwine, with siblings stepping in as guardians, nurturing a sense of responsibility within the social fabric.

Defined as an interplay between impairments, activity limitations, and participation restrictions, disability affects nearly 10% of the global population, with 80% residing in developing nations (World Report on Disability, 2011). International efforts aim to integrate disabled individuals into society, propelled by agreements such as the United Nations Declaration on the Rights of Disabled Persons (1975) and specific regional initiatives, steering policies on education, employment, and societal inclusion.

Yet, misconceptions linger, attributing disability to evil forces or sin, leading to fractured familial ties or laying blame on higher powers (Moller, 2012; Bowers, 2004). The paradigm shift toward understanding disability within the social construct unfolds, differentiating the social model from the medical or charitable models, advocating for inclusive societal practices (Oliver, 1983; Groce, 1999; Mutua and Dimitrov, 2001).

Cultural beliefs wield significant influence in shaping perceptions, with diverse cultures harboring unique interpretations of disability. From reincarnation beliefs in Asian cultures to religious associations in Turkey, cultural narratives intertwine with disability perceptions (Danseco, 1997; Diken, 2006). These beliefs, entwined with superstitions and past ideologies, often influence present-day practices and attitudes (Wright, 1973; Abosi, 2002).

Spirituality and religion, while distinct, intricately weave into beliefs regarding illness and disability (Zhang and Bernette, 2001). The journey toward intervention, defined as strategic actions addressing disability, emerges as a nuanced interplay of cultural beliefs and personal convictions.

This research seeks to unravel the mosaic of disability beliefs and their profound influence on intervention strategies. Embedded within every decision lies a belief, shaping the course of interventions. Whether in the realms of early childhood support or specific methods targeting disabilities, interventions mirror the amalgamation of beliefs and pragmatic actions.

The focus of this study is to understand 1) parents belief of disability, and 2) effects of these beliefs on the way of dealing/ type of intervention employed for dealing children with disability.

There is always a belief behind deciding on any intervention. For very young children who are at risk of child abuse, early childhood intervention will provide support and educational system. Such services are focused on children having developmental

disabilities or delays. In this study intervention is the employed way or specific method to deal with specific disability.

Theoretical Framework of Study

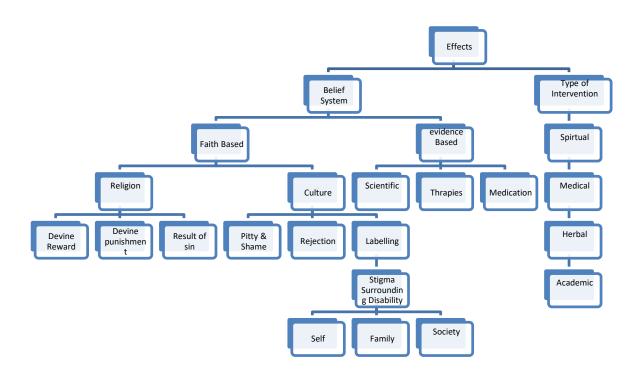


Figure 1

Material and Methods

In the pursuit of unraveling the intricate web that enshrouds the role of parental beliefs in shaping interventions for children with disabilities, this study embarked on a journey guided by meticulous research aims. Grounded in Yin's insights (2003), the choice of research design aligned seamlessly with the investigation's objectives. The quest for a deeper understanding led to the adoption of an exploratory research design, a pathfinder into uncharted territories, seeking profound insights where prior knowledge remains scant.

The qualitative approach, chosen with careful consideration, resonates with an interpretive stance, delving into the depths of parental beliefs. This methodology, renowned for its holistic view, uncovers meanings nested within the participants' perspectives, fostering a canvas that paints vivid contexts and opinions (Hoefl, 1997; Richards, 2003). Interviews, the quintessential research instrument, embody Kvale's notion (1996), sculpting an avenue to apprehend the daily experiences and contexts of research participants.

Purposive sampling, the cornerstone of participant selection, sought richness in information, aligning with Patton's and Dornyei's assertions (2002, 2007). The deliberate selection of willing and interested participants further amplified the depth of understanding. Accessibility, a guiding principle in selection, steered the researcher toward parents of school-going children, ensuring a more approachable avenue for

discussion while respecting the reservations of those outside formal educational structures.

The qualitative lens, per Denzin and Lincoln's assertion (2005), focused on understanding the phenomena in their natural settings, portraying vivid interpretations of the meanings ascribed to them. To navigate the labyrinth of research questions, semi-structured interviews emerged as the beacon, criticized for time consumption yet revered for its expansive scope and depth (Silverman, 2000).

The selection criteria, rooted in the biological parents' roles in treatment and intervention, curated a diverse sample from various disability categories. With meticulous precision, ten parents from each disability group participated, contributing to an in-depth exploration of each disability's unique nuances.

Thematic analysis, the lodestar of data exploration, paved the way through unstructured terrains, organizing disordered narratives into coherent themes (Howitt & Cramer, 2011). This systematic yet challenging journey through data culminated in a comprehensive understanding, with quotes from participants illuminating the findings.

Embedded within this meticulous exploration lay ethical considerations, ensuring consent, confidentiality, and participant comfort throughout the study. The sanctity of each participant's rights and identities remained sacrosanct, fostering an environment of trust and mutual respect.

As the tapestry of parental beliefs unfolds in the context of disability intervention, this qualitative journey delves deeper, seeking to uncover insights that illuminate the path toward more holistic and effective interventions.

Ethical Considerations

To participate in the interviews, the formal consent was also taken from the elected participants. For a researcher, taking the respondent's permission "ensured that the participants are conscious of their rights and it also saved the researcher from any afterward delays" (Dornyei, 2007). On the other hand, they were guaranteed that the only reason of the consent form was knowledgeable approval and its purpose is not creating any obligations and they are having the authority to leave at any point if they felt uncomfortable due to any reason. The researcher made it clear to them that the only purpose of this study is to research about phenomenon and their identities will be confidential. All the participants who expressed willingness to participate were selected as participants. A schedule was drawn and interviews were arranged according the availability and compatibility of each participant. The participants were also confident that their sharing will be kept confidential and they will be having absolute authority of leaving if they felt uncomfortable at any stage of the study.

Results and Discussion

Table 1
Demographic Characteristics of the Participants

Demographics of respondents	Frequency	Percentage
Gender		
Male	18	45
Female	22	55
Total	40	100

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Age Category		
Below 20 years	2	5
20-40 Years	22	55
40-60 Years	12	30
60-80 Years	4	10
Total	40	100
Child's Disability		
Hearing Impairment	10	25
Visual Impairment	10	25
Physical Disability	10	25
Intellectual Disability	10	25
Total	40	100
Educational Background		
No Formal Education	28	70
High School	8	20
Inter/Bachelor	4	10
Total	40	100

First Major Theme: Parents' Perception about Disability

This segment delves into the responses to the primary research question: How do parents of children with disabilities interpret or explain the concept of disability? Throughout the interviews, a prevailing awareness of the term 'disability' emerged among the parents, embodying varied interpretations. While many viewed disability through a divine lens or as an acquired condition, others expanded the scope to encompass financial constraints, limited medical facilities, and a shift from sympathy to developmental perspectives.

First Sub-Theme: Meaning of Disability

Within this major theme, disability was often perceived as synonymous with dependency, a trial from God, and an irreversible condition. Parents frequently described it as a situation where an individual relies on others for daily tasks, seen as a test from Allah, or an unchangeable state. Some conveyed it as a burdensome condition for the whole family, intertwining financial hardships and social struggles. "Disability is when you are not able to do something ultimately leading to poverty and dependent life" (parent participant, Individual interview). The thought of the disability is somewhere attached to the theme of trail from God and is supposed to be an examining condition for parents and family. "Disability is a trail and successors are going to be rewarded" (parent participant, Individual interview).

Second Sub-Theme: Causes of Disability

Parental beliefs regarding the causes of disability ranged from genetic factors to nutritional deficiencies, poor medical care, cousin marriages, and even the influence of the evil eye. A father responded "Genetics from mother side cause this as she was deaf and dumb. People make me feel that I have taken a wrong decision of getting married with a disable woman" ((Parent Participant, Individual Interview). Divine reward or punishment was also considered as a potential cause. Despite the varied opinions, the quest for understanding the cause of disability stemmed from a desire for future preventive measures.

Third Sub-Theme: Disability Curable/Treatable or Irreversible Condition

While opinions diverged, a significant portion of parents believed in the treatability of disability, seeking interventions for their children's betterment. However, financial constraints hindered some from seeking medical treatments, leading to a belief in the irreversibility of disability. Mixed opinions stemmed from personal experiences and beliefs, shaping their decisions regarding interventions. "Yes, disability is curable and I suggest if someone find his child with any issue like this, he should not waste time in hesitations and confused decision" (Parent Participant, Individual Interview). On the other hand, some parents think that it is an irreversible condition. "No it is not curable" (Parent Participant, Individual Interview). Strange thing with this case is that he had never consult any doctor as he had a firm belief that it is not going to cause any betterment or something positive.

Fourth Sub-Theme: Parents' Experiences of Society's View of Disability

Parents encountered diverse societal views regarding their child's disability, often reflecting societal stigmas and misconceptions. While many parents were resilient to external opinions, some internalized societal beliefs, causing self-reflection and occasional discomfort. Negative societal attitudes left an indelible mark on parental experiences. "People make me feel that I have taken a wrong decision to get married a deaf woman" (Parent Participant, Individual Interview). Another participant added, "Yes, our surroundings are having this type of opinion that we are having disabled children due to some of our own sins" (Parent Participant, Individual Interview).

Fifth Sub-Theme: Divine Reward or Punishment

Parental perceptions of disability oscillated between viewing it as a divine trial, neither purely a punishment nor a reward. The majority considered it a trial from Allah, acknowledging that fulfillment of responsibilities might lead to an ultimate reward. This nuanced view reflected their experiences and belief systems, blending the notions of reward and punishment into a concept of a trial (aazmaish). Interviewing the parents showed that people are having mixed opinion. One participant added; "We cannot call it punishment but it is something very difficult. No doubt she is very lucky for us but looking after her is very difficult as compare to other children" (Parent Participant, Individual Interview).

The multifaceted nature of parental perceptions elucidates the complex tapestry of beliefs surrounding disability. From divine trials to societal stigmatization, these insights uncover the intricate layers shaping parental understanding and responses to children with disabilities.

Table 2 Parents Perceptions of disability

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Theme	Response of Parents	Number of Respondents	Response of Parents	Number of Respondents	Response of Parents	Number of Respondents	Total
Meaning of Disability	Dependency	12	Trail period	18			40
Causes of Disability	Genetics from Mother side	10	Cousin Marriage	18	Delayed medical Facilities	12	40
Disability treatable/ Irreversible condition	Treatable	20	Irreversible condition	20			40
Society's view of Disability	Negative	40					40
			20				

Ultimate Reward/ Trail/	Trail	22	Punishment	18	 	40
Punishment						

Second Major Theme: Types of Intervention

This section scrutinizes responses to the secondary research question: What interventions did parents employ for their children? It delineates the critical aspects related to identifying, sharing, and implementing specific strategies for the betterment of their children.

First Sub-theme: Time of Identification

Identification of disabilities varied significantly based on the type of disability and parental experiences. In some instances, parents noticed delays in their child's responses, leading to later identification, while others identified physical impairments at birth. The delay in identification often stemmed from initial denials or attributing the disability to other factors, such as the evil eye. One participant added; "She was 4 months old and we came to know about her disability from her response. When we call her name or clap for her, she never give us response as a normal child and just keep playing with down head. We consult a doctor when she was about 18 months old." (Parent Participant, Individual Interview).

Second Sub-Theme: Sharing and Response of Spouse

The timing of sharing the identified disability with a spouse was influenced by the compatibility of the couple. Often, mothers were the first to identify the disability and faced varying responses from their spouses. Responses ranged from immediate consultation with a doctor to denial, advising patience, or attributing the issue to a temporary phase, especially in cases involving girls. One respondent shared her views; "I immediately share with my husband and he said that we must need to consult to a doctor" (Parent Participant, Individual Interview).

Interviewing the parents of children with Physical impairment researcher analyses from the collected data in this category mostly participant got the idea at the time of birth as disability was more visible as compared to other categories of disability. In physical impairment area, identification was easier as compared to other areas. Sharing again remains a matter of compatibility. One mother shared; "I discussed with my husband when she was around three months old and he said that you must ignore this as she is going to be better with the passage of time" (Parent Participant, Individual Interview).

Third Sub-Theme: Adopted Specific Strategy

Parents adopted diverse strategies for intervention, driven by the availability of resources and the family's social and financial conditions. While some pursued medical consultations and physical therapies, others resorted to spiritual remedies or peer consultations. However, dissatisfaction with medical approaches was apparent, with some parents feeling misled or discouraged by medical professionals' negative prognoses. The utilization of home remedies and herbal treatments also preluded medical consultations, showcasing a lack of confidence in conventional medical interventions. One respondent shared her views; "I immediately share with my husband and he said that we must need to consult to a doctor" (Parent Participant, Individual Interview).

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Fourth Sub-Theme: Satisfaction with Intervention Strategies

Parents who consulted specialists expressed dissatisfaction with medical treatments, citing inadequate guidance or negative projections. Conversely, those who opted for education-related interventions, despite physical impairment challenges, displayed confidence and perceived it as beneficial for their children's future. The gap between identification and consultation, particularly with specialized pediatric care, revealed deficiencies in the medical field's efficacy regarding disabilities and their treatments.

The diverse interventions adopted by parents underscore the complexity of navigating the landscape of disability interventions. From medical consultations to spiritual remedies, this exploration elucidates the multifaceted approach taken by parents, underscoring the need for more comprehensive and effective interventions within the medical realm.

Table 3
Type of Intervention

Theme	Response of Parents	Number of Respon dents	Response of Parents	Number of Respondents	Response of Parents	Number of Respondents	Total
Time of Identification	Bith_06 Months	20	06-12 Months of age	10	12-18 Months of age	10	40
Age at the time of Sharing with spouse	Immediately	10	After few months/ When issue was visible	15	Share only when it cannot be hidden	15	40
Adopted Specific Strategy at early stage	Visited nearby Doctor	10	Spiritual Treatment	15	Herbal Treatment / Home remedies	15	40

Third Major Theme: Satisfaction with Selected Intervention

Understanding the impact of chosen strategies on children's well-being is crucial. In conversations with parents, their satisfaction with specific interventions emerged as a critical factor for the betterment of their children. Some parents expressed contentment with their decisions regarding their child's education. "We made the right decision by sending her to school at the age of 4, and we noticed positive changes in her behavior. I'm highly satisfied with the education system," shared one parent.

The confidence in schooling as a beneficial intervention for their children was evident. "At 3.5 years old, I decided her education was the best strategy for her improvement," mentioned another parent confidently. Conversely, some parents refrained from adopting any intervention due to the belief that their child's condition would not improve. "We didn't seek any intervention," stated a father.

There were instances where couples pondered over their decisions, considering whether medical consultation could have made a difference. "I'm confused; perhaps consulting a doctor would have helped," regretted a parent.

Overall, the data indicated a prevailing satisfaction among parents regarding the efficacy of education for their children. "Education was the right decision, and it's helping him now," attested one participant. Another parent echoed this sentiment, stating, "Education is aiding her; she's interacting and communicating her needs effectively now."

Interestingly, families relying solely on spiritual treatments expressed confidence in their approach, despite the lack of visible improvement. "Spiritual treatment is the most powerful; it was the right decision," affirmed a parent.

The analysis revealed that parents were content with their children's education and perceived it as instrumental in their improvement. Different categories of disability prompted various approaches to handling the situation. Parents' beliefs about the treatability or irreversibility of disabilities significantly influenced their decisions, impacting their child's education and social interaction. Those believing in the treatability of disability tended to opt for schooling, displaying greater confidence in their child's future. Conversely, those perceiving disability as irreversible were hesitant about their child's education, perceiving them as burdensome to the family. Additionally, beliefs attributing disability to sin often led to seclusion of the child, limiting social interaction. Ultimately, these parental beliefs shaped the interventions chosen for their children's disabilities.

Table 4
Satisfaction with selected Type of Intervention:

Type of Intervention	Response of Parents	Number of Respondents	Response of Parents	Number of Respondents	Total
Medication	Satisfied	8	Not Satisfied	2	10
Herbal Treatment/ Home Remedies	Satisfied	7	Not Satisfied	8	15
Spiritual treatments	Satisfied	6	Not Satisfied	9	15
School as Intervening Strategy:					40
Schooling	Satisfied	25	Not Satisfied	15	40

Fourth Major Theme: Expectations from Special Needs Children

Exploring the concerns and expectations of parents regarding the future of children with disabilities unraveled a prevalent sense of apprehension. Irrespective of their satisfaction with the chosen interventions, many parents harbored deep-seated fears about their children's futures.

For parents, especially of boys with disabilities, concerns regarding their future skills and economic prospects were palpable. Even with acquired skills, parents were less confident about their sons' abilities to navigate societal expectations and secure stable economic statuses. However, the concerns surrounding girls with disabilities were notably heightened. Parents expressed profound worries about their daughters' social protection

and prospects of marriage. Among mothers of girls with disabilities, the issue of marriage emerged as a particularly alarming concern.

The anxieties surrounding the future were more pronounced for parents who had both a girl and a boy with disabilities. They seemed to harbor even greater worries about their daughters' prospects compared to their sons'. The fear of the unknown and concerns about societal acceptance and integration were heightened in these cases.

Despite varied interventions and strategies, parents' apprehensions about their children's futures, especially related to societal acceptance, economic stability, and marriage prospects, remained pervasive. These apprehensions were more pronounced for girls with disabilities, magnifying the complexities faced by their parents in envisioning and securing their future well-being.

Table 5
Expectation from Special Need Children:

Theme	Response of Parents	Number of Respondents	Response of Parents	Number of Respondents	Total
Future Of Children with Disability	Depressing	30	Hopeful	10	40
Fear Related to the Economic Status of child	Dependent on others	35	Independent	5	40
Fear Related to safety of Child in Case of Boys	Need to take care of them	14	May be able to manage themselves	4	18
Fear Related to safety of Child in Case of Girls	Safety Issue is Alarming	22	May be able to manage themselves	0	22

Conclusion

The study's findings shed light on prevailing beliefs concerning disability, its causes, and interventions among parents of children with disabilities. Notions often connected to disability, such as the evil eye or attributing it to a mother's actions, were identified. These findings align with studies conducted in Sub-Saharan African nations, indicating similar perspectives (Jackson & Mupedziswa, 1988; Monk & Lee, 2008; Dart, 2006).

Parents commonly described disability as a challenging period granted by a higher power, attributing it to a trial in life, aligning with perspectives shared by Lee & Yuen (2003) on disability being a spiritual punishment.

Internationally, studies have revealed a trend of people viewing those with disabilities with lower esteem (Owusu, 2018). While most parents expressed negative views toward society's perception of disability, some shared more complex and mixed beliefs. The findings unveiled a coexistence of optimistic and pessimistic attitudes within the sample. According to the parents, community responses to disabilities tended to be either negative or neglectful. These negative societal views exacerbate problems for parents of children with disabilities (Lightfoot, 2010). Groce (2005) suggests that a society with positive perceptions toward disabilities can lead to favorable intervention strategies, whereas negative societal beliefs may result in adverse intervention models. Changing

negative opinions requires local community engagement and education to align with universally accepted standards.

The evolving beliefs about disability, especially as perceived by parents of children with disabilities, indicate a shift toward advocating independent lives rather than solely relying on sympathy (Junaidi, 2020).

Recommendations

Data analysis which discovered the perceptions of parents beliefs about disability, for the betterment and to take advantage of the existing situation for the persons with disabilities, following recommendations are being Forwarded:

The medical field should take a more active and positive role in addressing disabilities. Comprehensive check-ups for mothers and children during prenatal, perinatal, and post-natal stages are crucial. Early identification and intervention based on medical assessments can mitigate the impact of disabilities. Certifying these check-ups can significantly reduce future financial burdens compared to post-disability spending.

Media should be instrumental in reshaping societal perceptions about disabilities. Leveraging its influence, media can reshape views by presenting opportunities for people with disabilities positively. Media's ability to influence public opinion can aid in dispelling superstitions and misconceptions regarding disabilities. Encouraging the portrayal of professional individuals with disabilities in the media can motivate and reshape public perceptions.

Addressing the prevailing culture of denial within families regarding disabilities is crucial. Acceptance of disabilities should be encouraged, dissociating them from superstitious beliefs. Emphasizing that disabilities are not the result of an individual's actions but rather a natural occurrence can foster acceptance and positive development in children with disabilities.

Governments should implement policies that promote job opportunities and quota systems favoring individuals with disabilities. By enhancing job quotas, governments can create better prospects and opportunities for individuals with disabilities, thereby elevating their expectations and societal integration.

By implementing these recommendations, society can strive toward inclusivity, fostering positive perceptions and better opportunities for individuals with disabilities.

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