

TURKISH MOTHERS' INTERPRETATIONS OF THE DISABILITY OF THEIR CHILDREN WITH MENTAL RETARDATION

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The purpose of this paper was to understand how Turkish mothers make meaning of the disability of their children with Mental Retardation (MR). Thirteen Turkish mothers who had at least one child with MR were the participants of the study. A qualitative interpretive framework was used for collecting and analyzing the data. The data were gathered through semi-structured interviews. Mothers' beliefs on the nature, causation, and treatment of the disability of their children were the main focus of the interviews. Some parents did not believe their children had a disability or misunderstood the nature of disability. Although most were aware of their children's developmental limitations, they, at the same time, perceived the condition of the disability as temporary. Both traditional and modern (bio-medical) beliefs were held by most of the mothers on the causation of the disability. Mothers identified traditional beliefs, especially the religious ones, as the most popular causal agents. Most mothers sought help from both modern and traditional agents. Mothers, who held strong traditional beliefs regarding the causation of the disability of their children, held strong traditional treatment beliefs and valued more traditional treatment practices rather than bio-medical ones. Among the traditional treatment practices, most mothers required help from religious agents. Regarding future expectations of Mothers on the situation of their children, mothers wanted their children be less independent, and for this reason, they sought a more individualized education for their children. Implications, limitations and directions for future studies are also discussed.

The importance of parents' involvement in the entire process of special education services has been recently recognized in both policy and practice levels in Turkey. For example, recent special education laws, such as KHK-573, highlight and strongly encourage parental involvement in services provided for their children with disabilities. In order for more positive outcomes for children and their parents be achieved, special education practices depend primarily on the quality of the interactions between professionals working with parents and their children with disabilities. At this point, a good understanding of families' socio-cultural background plays a crucial role on establishing positive interactions between professionals and parents. Among families' socio-cultural background/characteristics, parents' beliefs or understanding of the disability of their children seems as the most important factor that directly influences their interactions with professionals and their decisions regarding services provided to their children with disabilities. The current study focuses on understanding Turkish mothers' beliefs regarding the disability of their children.

The impact of socio-cultural influences on child development has been recognized in conceptual models and approaches of child development. Among these models, ecological model (Bronfenbrenner, 1979) and transactional model (Sameroff & Fiese, 2000) put a great emphasis on the child within his/her immediate context including family, community, and social services. According to these models, the child's family context with socio-cultural background is perceived as the most significant factor influencing the child development. There is a strong relationship between the characteristics of the child's immediate environment and child development. Parents in the child's immediate environment are the ones who play the most significant role on the child development. In addition to these conceptual models, Relationship-based approaches (Bertacchi, 1996; Moss & Gotss, 1998) enlighten the importance of the relationships between parent and professionals/service providers, between parent and child, and between child and professionals/service providers. According to these approaches, special education services must be provided by considering the socio-cultural background of the family in order to get expected outcomes for the child with disability and his/her family, such as improving parent-child interactions (Burnett & Meares, 2000).

Although parents' participation in special education practices are currently being valued in Turkey, parents' involvement and parents' traditional or socio-cultural beliefs have not been recognized enough while providing services to the children and their parents. Instead, modern/medical explanations and interpretations of the disability have been strongly supported by professionals. In addition, professionals' decisions have shaped the type of services for children with disabilities and their families. However, several studies reveal and support the fact that parental beliefs play critical role on parents' choices of services and interactions with professionals who work with them. The results of several cross-cultural studies or literature on parental beliefs on the disability of their children also show that parents may believe, hold, and practice both modern (bio-medical/western) and traditional (religious, folk, superstitions, etc.) beliefs/perceptions regarding the disability of their children (Garcia, Perez, & Ontiz, 2000; Hanson, Lynch, & Wayman, 1990; Mardiros, 1989; McCallion & Janicki, 1997; Nicholls, 1993; Reiter, Mar'i, & Rosenberg, 1986; Ryan & Smith, 1989; Stahl, 1991; Steinberg & Davila, 1997).

Even though the special education services have been provided based on mostly professionals' perspectives so far in Turkey, it is rational that both professionals and parents might not share all the same values, beliefs, or practices even when they come from the same cultural backgrounds. In order to achieve anticipated outcomes, professionals' roles have to be changed toward cooperating with families on behalf of the child (Wayman, Lynch, & Hanson, 1990). At this point, understanding, respecting and being sensitive to cultural contexts of children with disabilities and their parents are the essential roles that professionals have to have and show for the success of the special education services. From the cultural contexts of parents, beliefs held by parents about their children affect parents' behaviors beginning with seeking help, setting goals, and cooperating with the professionals regarding their children. In short, beliefs held by parents shape their behaviors toward the entire process of special education. Therefore, culturally competent professionals who understand, respect, and be sensitive to cultural contexts of children with disabilities and their parents are required for better outcomes of special education services.

One of the key factors to get successful outcomes from the services provided to children with disabilities and their families seems to be the establishment of positive relationships between professionals and parents of children with disabilities. Professionals working with children with disabilities and their families play a key role to establish these positive interactions. They are the ones who provide various services, such as assessment, referral and placement, planning, and implementing the programs. Parents' beliefs regarding the disability of their children directly influence their decisions about beginning with their willingness to seek help, their communication styles, the amount and type of their participation that they choose, goals they may select, and the family members who may be involved. At this point, the lack of knowledge and respect about the parents' beliefs regarding the disability of their children might negatively affect the communication between parents and professional who gets usually a western-style pre-service education (Stahl, 1991).

As previously indicated, active parental participation in goal setting and implementation of the programs designed for children with special needs is currently highly valued in Turkey. Parents are encouraged to speak out and to put more inputs into the services provided for their children and themselves. As belief systems change very slowly, professionals engaged in caring for children with disabilities have to take the beliefs of parents into consideration in order to see the child and his/her family as a whole and understand better their socio-cultural context. This seems as a must to have more positive interactions between professionals and parents of children with disabilities.

This paper intended to investigate how Turkish mothers make meaning of the disability of their children with Mental Retardation (MR). It provides significant amount of information to put into practice of special education services in Turkey. In addition, by providing an international (Turkish) perspective, it is believed that this study extends the knowledge base of cross-cultural studies regarding understanding parental beliefs on the disability of their children.

Method

Participants

Participants of the current study were purposefully chosen 13 Turkish mothers who had at least one child with MR. There were two reasons why mothers who had a child with MR were chosen to be interviewed. First, children with MR were particularly the focus group because children with MR are the largest and the most popular group by getting the most the special education services in Turkey. Therefore, by including this group the beliefs regarding the most popular group in Turkey were addressed in this study. Second, mothers were preferred to be interviewed because it is the mother who has the primary responsibility and plays the most significant role in child-rearing practices as well as homemaking practices in Turkey. Although the socio-economic contexts for women in Turkey have been rapidly changing, more and more women have been attending, continuing, and getting degrees from higher level of educational institutions, still mothers, especially those who have low socio-economic status and have little education, have been expected to stay at home to take care of children in Turkey.

All mothers who had a child with MR in Bolu in Turkey were asked to participate in the study. Thirteen mothers volunteered to participate in the study. Mothers' age ranged from 29 to 50. Seventy percent of mothers had only elementary school

diploma, which was a 5-year basic education, whereas 30 % of mothers had no education. All of the mothers were housewives and majority of them, approximately eighty-percent, had low income. Participants were also identified themselves as Muslim.

The ages of children with MR ranged from 4 to 18. Eight of the children were male, five of them female. Only one child was diagnosed with severe MR while six children had mild and six children had moderate MR. Only one child was currently not getting any education and services since he lived in a village with his parents. Two children were attending a self-contained classroom in a regular elementary school. Two children were attending an inclusive classroom in a regular elementary school. One child was attending a private day care center. Seven children were attending a separate public school for students with moderate MR.

Data collection and analysis

Since the current study aimed at understanding mothers' beliefs/views regarding the nature, causation, and treatment of the disability of their children with MR, and future expectations from their children, a qualitative interpretive framework (Miles & Huberman, 1994) was used for collecting and analyzing the data.

To understand mothers' beliefs and expectations the data were gathered through semi-structured interviews. Each mother was interviewed orally once. Interviews were conducted at the Bolu Research and Counseling Center, a government agent organizes and provides free special education services to children with disabilities and their families. The center is operated by the Department of Education in Bolu. Interviews were conducted by a Psychologist, who has a Masters degree in Special Education and had been working at this center for years providing special education services to children with disabilities and their families. Each interview lasted about 30-45 minutes and was completed in one session. Interview questions were aimed at understanding mothers' beliefs regarding the nature, causation, and treatment of the disability of their children, and also understanding their expectations from their children and their children's current educational services.

All interviews were audio-taped by using an audio recorder. Audio-taped interviews were fully transcribed into written texts. These written texts were then inductively analyzed to identify the recurring patterns or common themes that frequently cited by mothers and cut across the data. Children's individual files were also reviewed and included in the study in order to gather data on children's demographics, the disability condition, and the past and current special education services.

Results

Interview questions focused on three fundamental concepts, which have been recognized and studied in several cross-cultural studies regarding parental beliefs on the disability (Garcia, Perez, & Ontiz, 2000; Mardiros, 1989; Reiter, Mar'i, & Rosenberg, 1986; Ryan & Smith, 1989; Stahl, 1991; Steinberg & Davila, 1997). These were the nature, causation, and treatment of the disability. Questions were asked to understand mothers' beliefs regarding these three essential concepts. After inductively analyzing the interview transcripts, the following common categories under three essential topics emerged.

Mothers' interpretations of the nature of the disability

Mothers were initially asked to describe, define, or characterize the nature of the disability of their children. When asked about the term or medical label for the

disability of their children, only four of thirteen mothers identified the specific medical label for the disability of their children.

Abilities of Children and No Disability. Almost all of mothers were aware of the difficulties their children had or the disability condition of their children and almost all mothers described the child's problem in terms of limitations imposed upon the child because of the disability. The disability was not seen as the problem per se by most mothers. The child's health, ability to communicate, and fulfill basic tasks of self-care were identified problems dealt with by the family. However, interpretations of the beliefs of the mothers regarding the nature of the disability of their children showed that some mothers didn't believe that their children had a disability whereas some believed that the disability of their children was temporary.

Some of the mothers put a great emphasis on not believing the fact that their children had a disability. Although all of children were diagnosed with MR, four of the mothers didn't believe that their children had a disability. One of the mothers, who described her child's developmental delay very well, stated that *My child has a good memory; I don't believe my child has a disability.* Another mother, who described her child's lack of cognitive abilities such as problems with processing the information, expressed that *I know my child is a slow learner, lazy and under achieved; but, when you tell him not to do something, he listens to you and stops what he is doing. I don't believe he is mentally retarded.* Another mother by emphasizing only the limitation of her child's language ability also stated that *My child has a normal IQ, but can't talk only...that's the only problem my child has.*

Language Delay and Temporary condition. Language delay was the most recognized difficulty of their children and seen the source and solution of the other difficulties that their children had. Temporary condition was another key point that some mothers underlined. Most mothers believed that whenever their children start talking, everything will be taken care of. One of the mothers, who recognized the delay on her child's development early and took to a physician, stated that *My child's current condition is temporary. The only problem my child has is the language. If he starts to talk, he will definitely be okay.* Another mother also said that *He just can't talk, that's the only problem. He has good memory. It is temporary. Doctor also said it was temporary.*

Mothers' interpretations of the causes of the disability

Several questions were asked to understand what causal agents mothers thought that caused the disability of their children. Interpretations of the beliefs of the mothers regarding the nature of the disability of their children revealed that mothers held both bio-medical and traditional beliefs as regards the causation of the disability of their children. Some of the major causal agents indicated by mothers and cut across the interview data are as follows;

Bio-medical causes. Bio-medical causes were identified by all of the mothers. Lack of oxygen, which the baby had right after the birth, was given as a cause by three mothers. One of the mothers, who didn't know she was pregnant until eight-month of her pregnancy, believed that *X-rays and shots caused her child's disability.* Another mother stated that *I had fears of telling my husband about my pregnancy. I finally told my husband that I was pregnant when I was 5-month pregnant. I was under high depression during my pregnancy. That (high depression) must be the cause.* The failure of nurse during delivery, delivering the baby with vacuum, postmaturity, and

marriage with someone from close relatives were also seen as other causal agents by mothers.

Religious causal agents. Although all mothers could identify the bio-medical cause of the disability of their children, they also constantly highlighted various religious causal agents. God and Fate, the Spell, the Evil spirit, and becoming pregnant on Holy days were the most stressed causal agents by mothers in the study.

Fate and God. Fate and God were underlined as causal agents by almost half of the mothers. One of the mothers stated *It is our Fate. It is God's decision, and we have nothing to do with it.* Another mother also emphasized that *We have recognized my child's developmental delays before he was one-year old. We believed it was our Fate; it was God's choice for us. Therefore, we didn't take our child to the doctor.*

The Spell. The Spell also was thought as a cause of the disability of their children by some of the mothers. One of the mothers interestingly stated *When my daughter was one-year old, he started showing abnormal behaviors such as wakening in the middle of the night, showing too much fear. We took her to a Holy Man, who, we believe, has a strong religious background in Islam and could fix our child. The Holy man said to us that somebody cast a Spell for my husband and me to get us divorced. However, this Spell worked on our daughter instead of us, he stated. In this Spell, person or people who cast the Spell took our daughter's diaper, prayed and blowed on, then they buried it. When the diaper started to disintegrate, the Spell started showing its power on our daughter. That's why my child is having all these difficulties.*

Another mother expressed that *We bought a brand new blanket for our newborn when he was born, one of our neighbors ripped down one side of this blanket at the same day while visiting us to see our newborn. We recognized right after our guest left the house. We believe that was a Spell that makes our son has a disability.*

The Evil Spirit. Some of the parents put a great emphasis on the role of the Evil Spirit on the causation of the disability of their children. One of the mothers stated that *When we recognized the disability of our son, we went to see a Holy man to find out the reasons. The Holy man asked me whether I was going out of house without praying first, without pouring the water which the child was washed, or without pronouncing the formula in Islam. He continued, if so, these are the causes of my child's disability because I was struck by an Evil Spirit.*

The Holy Days. Some parents stressed the power of the Holy days on the causation of the disability of their children. Although they didn't directly confirmed that having sex on some Holy days might cause the disability of their children, they call attention to this belief by stating it as a common belief held by the society in which they live. One of mothers stated *when a mother becomes pregnant on either Monday or Friday, especially Friday, the child will have disability when s/he was born.*

Role of Parents. Some parents also believed that parents and their characteristics played important roles on the causation of the disability of their children. Two of the mothers stated that drinking problems of their husbands influenced significantly their pregnancy, so on having a child with disability. One of the mothers underlined that *My husband's alcohol problems made me too scary; I was under too much depression during my pregnancy. That's why my child had this disability.* Two of the mothers, who were above 35 when they had the baby, also concerned their age as a causal agent of the disability of their children.

Folk beliefs/Superstitions. Almost half of the parents drew attention to the folk/superstition beliefs on the causation of the disabilities. Most of the parents, who said that they didn't believe these beliefs, in the interviews still considered them and practiced them in their daily lives as they stated. One of the mothers stated *I was too sorry about my neighbor's child, who had autism, during my pregnancy. I think that might be one of the causes of my child's disability.* Some of other folk/superstition beliefs commonly believed in their society and stated by other mothers in our study were as follows; *When a newborn was kissed too much from his mouth, the child shows language problems, and when s/he was kissed too much from under his foot, s/he could not work., or When a pregnant looks at a bunny or eats a bunny, her child will be one with bunny lips, or When a child drinks uncooked milk, the child might become disabled or have academic problems at the school.*

Mothers' interpretation of the treatment of the disability

Mothers were asked to express their beliefs regarding their past treatment practices when they learned their child's situation, their current treatment practices, and their future expectations about their children and the services their children have been receiving.

Although most of the mothers used modern treatment methods or prescriptions by taking their child to the bio-medical/educational professionals, they gave more emphasis to and sought help from religious agents. These religious agents were, as the mothers in the current study indicated, were a Hodja, a devout Muslim man who is respected for his knowledge of Islam and who may perform a specific duty within an Islamic community, a grave or a tomb where a holy man is buried, and the holy water from *Zamzam*, a famous well very near the Kaaba in Mecca. Although their children were getting formal education from different educational institutions at the time the study was conducted, most of the mothers in the current study were sought help from the religious agents stated above in the past and were still seeking help from them at the time the study was conducted.

Interpretations of interviews revealed that traditional treatment methods, especially religious ones, were chosen, practiced, and followed carefully by parents. They were thought as helpful agents in recovering their child's disability. One of the mothers, whose child was in a self-contained classroom for students with MR, stated that *When we learned that our son had a disability, we first took our son to a Hodja to cure our son's disability, specifically to make him to be able to speak. The Hodja, the holy man, put the mosque's key into our son's mouth and turned three times while praying special Suras of the Koran.* Another mother reported that; *In order to make our daughter child to be able to walk, we followed a Hodja's prescriptions, in which we had to make our daughter drink three sips of water for parakeet, or the water from Zamzam. As Hodja stated, we also have our daughter drink these waters from a bell for cows.*

One of mothers believed strongly that a Hodja's readings of Suras of Koran helped her daughter to walk independently. She cited that *We sought help for my daughter from a Hodja as soon as we recognized our daughter's disability. Hodja gave us a Muska, a written charm, to follow. He started also reading a sura (the sura of Yasin, the thirty-sixth sura of the Koran usually recited either when someone is on the verge of death, or after someone has died) of the Koran for 115 days. After a while, our daughter started walking.*

Mothers' future expectations regarding the situation of their children

Mothers were also asked to indicate their future expectations from the educational institutions and from their children's development, such as what would they like to see in the next future to happen in their children's life. Almost all of mothers expressed that although they were happy with the current education that their children were receiving, they also indicated the need of more individualized education programs for their children. Almost all of them pointed out that they did want their children be less dependent in their daily life. Most of them stressed out the need of independent life skills for their children, and wanted to see their children know how to walk and talk in a group, how to read and write, how to use money and shop independently, get a diploma and have a job, and finally stand on their own feet with less dependency. Almost all mothers were all worried about the future of their children if something happens to mothers. That was the reason of their desire for the less dependency of their children.

Conclusions

The current study aimed at investigating Turkish mothers' beliefs about the disability of their children. The focus was given to the mothers' beliefs on the nature, causation, and treatment of the disability of their children. Results indicated on the nature of disability, some parents did not believe their children had a disability or perceived the condition of the disability as a temporary one even though they recognized and identified their children's developmental limitations such as developing at a slower rate. On the causation of the disability, while both traditional and modern (bio-medical) beliefs were held by most of the mothers, traditional beliefs, especially the religious ones, were the most popular causal agents identified by the mothers. As literature indicated, the relationship between the beliefs on causation and beliefs and practices on the treatment of the disability was seen in the current study too. Although most mothers sought help from both modern and traditional agents, mothers, who held strong traditional beliefs regarding the causation of the disability of their children, held strong traditional treatment beliefs and valued more traditional treatment practices rather than bio-medical ones. Most of the mothers sought help from religious agents. Mothers wanted their children be less independent, and for this reason, they sought a more individualized education for their children.

Implications

As the results of the study indicated mothers held diverse and strong traditional beliefs regarding the disability of their children. The beliefs they held shaped their reactions regarding seeking help or treatment practices. Most parents put a great emphasis on traditional treatment practices because of their strong traditional beliefs regarding the recovery of the condition of their children. It is most likely that a mismatch occurs between professionals and parents' beliefs or ideas when providing special education services. Professionals' attitudes and approaches play key roles to reduce the effects of this mismatch. The first step for professionals seems to realizing parents' beliefs. In order to realize and derive a meaning from them, initial positive communications with parents are required. The home visits, phone or face-to-face interviews with parents by using active listening techniques might be helpful for professionals to recognize parents' beliefs and to be familiar with family's home context. Since most parents might try to cover their strong traditional beliefs and practices from professionals, establishing a trustworthy relationship might help professionals to provide parents several opportunities that will bring the most positive outcomes for the child and family.

The awareness of professionals on socio-cultural backgrounds of children and their parents might be the starting point for getting positive outcomes from the interactions between parents and professionals. The skills for becoming aware of socio-cultural backgrounds of children and parents must be provided to professionals. However, most of the pre-service programs for preparing professionals to work with children with disabilities and their families seem to be inadequate in preparing professionals to be able to work with diverse groups who might hold diverse bearing beliefs from professionals. Professionals must be prepared well at pre-service level or must get ongoing in-service training to deal efficiently with the barriers when providing services to children with disabilities and their families, especially to those who are with little education, coming from low socioeconomic levels, and held strong traditional beliefs. Encouraging parental involvement more into the decisions regarding the special education services provided to the children and their parents might help to obtain more positive outcomes from the services. Parents could be encouraged by seriously considering their ideas about the current and future educational expectations for their children. When setting goals and preparing individualized education/family service programs for the child and family parents' expectations or ideas must be respected and reflected in these programs.

Having positive interactions between special education professionals and parents who have a child with disability are considered one of the key elements of gathering positive outcomes from special education services providing children with disabilities and their parents. Parents' beliefs regarding the disability of their children might be a barrier to having positive interactions and consequently getting successful outcomes from the services. As the current study indicated, mothers might hold both common and diverse beliefs regarding the disability of their children. Understanding these beliefs would bring great insights into the interactions between professionals and parents and would result with more successful outcomes for children with disabilities and their families.

Limitations and directions for future studies

This study has several limitations. Therefore, these limitations should be considered when results are interpreted. First of all, sample size seems too small. Although the current study is titled as Turkish mothers, results should not be generalized to whole Turkish mothers or culture. Since Turkey is composed of several different cultural groups and can be thought as melting-pot by showing similar cultural characteristics; but, at the same time, still hold different beliefs representing different cultural groups. Therefore, more studies with different groups are needed to understand these difference beliefs.

Secondly, almost all participant mothers had little education and all were housewives. This aspect should be carefully taken into account while interpreting the results. Future studies are needed to understand beliefs of mothers who have higher educational degrees. Finally, the level of mothers' religious practices should be considered while interpreting the results. Although the level of mothers' religious practices was not considered, it should be included in the future studies.

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