

Italo-Canadian Mothers' Beliefs Surrounding Cause and Treatment/Cure of Childhood Disabilities

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Une grille qualitative a été utilisée pour explorer les croyances italo-canadiennes, imprégnant la perception des causes, des traitements, et de la guérison d'invalidités infantiles. Un échantillon de commodité a été constitué avec la collaboration d'un centre de réhabilitation pédiatrique, situé dans le sud de l'Ontario. L'échantillon était composé de huit mères italo-canadiennes de deuxième génération, qui avaient des enfants atteints d'handicaps variant de moyens à graves. Des entrevues ont été menées auprès des mères, utilisant des questions ouvertes destinées à stimuler leurs réflexions et leurs émotions. L'analyse des données était faite en concomitance à la cueillette et consistait à effectuer une analyse de contenu. Trois catégories majeures de croyances traditionnelles en rapport à la cause ont été identifiées : (a) une punition pour des actes répréhensibles commis dans le passé; (b) un «mauvais sang» causé par les mariages entre membres d'une même famille ou une malédiction familiale; et (c) des forces surnaturelles, telles que le mal'occhio (le mauvais oeil). La catégorie de traitement majeure identifiée pour soigner les invalidités infantiles était la guérison par un processus magico-religieux. Selon les mères, ces croyances traditionnelles étaient plus fortes chez les Italo-Canadiens de première génération, notamment chez les grands-parents. Les mères exprimaient elles-mêmes leur adhésion à certaines de ces croyances, tout en acceptant très peu ou en rejetant certaines autres. À partir de cette étude, la formulation d'implications pouvant servir à la pratique serait prématurée. Toutefois, plusieurs voies de recherche à poursuivre ont été identifiées.

A qualitative design was used to explore Italo-Canadian beliefs about the cause and treatment/cure of childhood disabilities. A convenience sample of eight second-generation Italo-Canadian mothers of children with moderate to severe disabilities was recruited through a pediatric rehabilitation centre in Southern Ontario. The mothers were interviewed using open-ended questions that served as probes to stimulate their thoughts and feelings. Data analysis proceeded concomitantly with data collection, and consisted of content analysis. Three major categories of traditional causation beliefs were identified: (a) punishment for past wrongdoing, (b) "bad blood" caused by intermarriage or a family curse, and (c) supernatural forces such as *mal'occhio* (the evil eye). The major category identified for cure of childhood disability was magico-religious healing. These traditional

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beliefs were described by the mothers to be strongest among first-generation Italo-Canadians, especially grandparents. The mothers themselves expressed their acceptance of some of these beliefs, but only minimal acceptance of or resistance to others. Based on this study, it would be premature to formulate implications for practice; however, several directions for future research are identified.

The ability of nurses to provide care that is culturally sensitive relates to the quality of the information available to them on how various groups experience and manage illness and disability. Although considerable knowledge has been accumulated about certain groups, surprisingly little is known about others. For example, Italo-Canadians have a strong numerical and historical presence in Canada, yet their beliefs and practices — especially those of Italo-Canadian women — have not been documented. To begin to address this gap in knowledge, we studied the beliefs and practices of Italo-Canadian mothers related to raising children with disabilities. These mothers constituted a sample in a larger study conducted by McKeever (1994).

Literature Review

A search of the literature found no research studies into Italo-Canadians' views of disabilities or their management of related experiences. However, the findings of studies with other ethnic groups reveal that the meaning and experience of illness and disability vary cross-culturally. The following are among the various explanations offered for illness and disability in both children and adults: (a) punishment from God for past sins on the part of parents, other family members, or ancestors (Chan, 1976; Groce & Zola, 1993; Lloyd, Jones, Yoshida, & Feldman, 1992); (b) supernatural forces (Cheon-Klessig, Camilleri, McElmurry, & Ohlson, 1988; Groce & Zola; Lloyd et al.; Mikhail, 1994; Plawecki, Sanchez, & Plawecki, 1994); (c) "bad blood" — disorders are thought to be inherited through intermarriage or a curse (Groce & Zola); (d) sins or wrongdoing in a previous life (Groce & Zola); (e) bodily imbalances caused by changes in body temperature or natural factors such as air and food (Groce & Zola; Mikhail); and (f) biomedical forces (Ahmann, 1994). It is important that we understand these explanations, because they influence how families and communities respond to disabilities in children and how they relate to the children and their parents (Caulcrick, 1980; Groce & Zola). However, such information should be used with caution, because culture alone cannot explain why individuals think and act as they do (Ahmann).

Several of the studies cited above (Cheon-Klessig et al., 1988; Groce & Zola, 1993; Lloyd et al., 1992; Mikhail, 1994; Plawecki et al., 1994) found that groups that retain traditional etiologic beliefs also tend to believe in traditional cures. These can include: (a) herbal and nutritional remedies, (b) religious healing, (c) sorcery/witchcraft, (d) ritualistic healing, (e) massage, (f) poultices, and (g) folk healing. Experts in traditional healing, usually elderly women (Bushy, 1992; Cheon-Klessig et al.), are often approached first, modern medicine being the avenue of last resort (Cheon-Klessig et al.; Germain, 1992; Gordon, 1994; Groce & Zola; Mikhail). Consequently, the investigators caution health professionals against giving their patients the impression that traditional healing practices are inferior to modern medicine. When traditional practices are depreciated, the researchers add, health advice and prescribed treatments are often rejected, and "non-compliant" behaviours can be the result (Bushy; Engebretson, 1994; Plawecki et al.).

These findings suggest that cultural values can greatly influence the perception and management of illness and disability. Inattention to this fact on the part of health professionals can alienate patients, and thus negatively affect their compliance with treatment plans.

We found no research describing the cultural beliefs and practices of Italo-Canadians surrounding illness and disability, yet some understanding of such beliefs and practices can help provide culturally acceptable health care to this population. The purpose of this study was, therefore, to explore Italo-Canadian beliefs about the cause and cure of childhood disabilities.

Research Questions

Four research questions guided the study. This report will focus on the findings generated by one of the questions: What are Italo-Canadian mothers' beliefs about causes and treatments/cures of their children's disabilities?

Method

Ethical approval was obtained, and participants were accessed through an urban pediatric rehabilitation centre in Southern Ontario. Once consent had been obtained, each mother was interviewed once, in her home, for about one hour. Follow-up telephone interviews were conducted with four mothers to confirm initial findings and to obtain additional data. One mother telephoned the interviewer twice to share new information. The follow-up telephone interviews served as a validity

check for the findings; the interviewees evaluated the findings for congruence with their own experiences. The interviews continued until no further data or insights were forthcoming from the informants. All interviews were audiotaped.

To stimulate thoughts and feelings, the following open-ended questions were used during the interview:

What do you understand ____'s problem to be? What concerns do you have for your child? In your culture/ethnic group, how is ____'s problem viewed? Are there special ways in which you and your family take care of ____? Have you looked for help for ____ from people other than health professionals? Tell me about a typical 24-hour day for you. What is family life like for you?

Not all questions were asked of each respondent; in some cases, one or two questions were enough to elicit substantive details. Observations about the mother, the child, and the environment were recorded after each interview.

Data analysis proceeded concomitantly with data collection. Segments of data comprising meaning units were identified and categorized according to a system of topical categories that had been derived from the research questions. Many topical categories also emerged from the data through on-going inductive analysis in which patterns or themes were identified and tagged. As categories were identified and refined, patterns and relationships within and between them became apparent. These were tested against the data through a process of searching for positive and negative instances of the pattern (Marshall & Rossman, 1989), using *The Ethnograph* computer program.

Results

Demographic Characteristics and Socio-economic Circumstances

The sample consisted of eight women between the ages of 26 and 43 years, with a mean age of 36. A relatively small sample of mothers was recruited because cultural knowledge is group-shared knowledge, and interviews on a topic with only a small number of respondents from a selected segment are required to identify shared cultural knowledge (Evaneshko & Kay, 1982; Schatzman & Strauss, 1973).

Of the eight women, five were second-generation Canadian, while three had immigrated to Canada from Italy before the age of 13. Like the majority of Italian immigrants to Canada, all had come from rural southern Italy, along with their parents and their husbands, after the

Second World War (Iacovetta, 1992). Most came from a background of subsistence farming, in which periodic hunger and famine were not uncommon.

Seven women were married and living with the father of the child with a disability, while one was a single mother who had been married and divorced twice. Although Italian was their mother tongue, all spoke fluent English as well. All the women had been raised Roman Catholic but one had become a Muslim and another a Jehovah's Witness, both as adults. They all lived in Italo-Canadian communities.

The children with disabilities ranged in age from two to 13 years, with a mean age of seven. They had at least one and at most three healthy siblings. Their disabilities — moderate to severe non-degenerative conditions in which neither cure nor death were imminent — were: severe asthma (1), spina bifida (4), cerebral palsy (5), and a rare neurological syndrome (1).

Beliefs About Causes and Treatments/Cures

All the mothers expressed an acceptance of modern medical explanations for their children's disabilities, and reported that they routinely sought and complied with prescribed treatments. This acceptance may reflect a sampling bias, because the mothers were recruited from a rehabilitation centre founded upon the notions of scientific medicine. The traditional Italian beliefs reported below were described by the mothers to be strongest among first-generation Italo-Canadians, especially grandparents. The mothers themselves expressed tolerance of some of these beliefs, but only minimal acceptance of or resistance to others.

Causes. All mothers viewed God as the ultimate power in causing and curing illness and disabilities. The most common belief was found to be that God "brought these children into the world" to teach the parents a lesson or to punish them for their sins. For example, one mother stated that if a person makes fun of or fails "to pity someone" who is disabled or disadvantaged God may punish that person with the same affliction (B-1482). A belief in retribution can result in blaming the parents, especially the mother, for the disability: "They have to pin-point; they have to blame somebody. They have to see evidence of blaming somebody ... and the ultimate is, 'What did you do? Maybe God is upset with you?' ... It's always, 'Oh there has to be a reason'" (K-1120). While three mothers expressed self-blame for their child's disability, five denied that they blamed themselves or accepted any blame placed on them by extended family members.

The mothers also reported the belief that illnesses and disabilities can result from “bad blood” introduced into families through intermarriage. This theory is sometimes used to blame in-laws for the child’s disability: “What they [the respondent’s parents] were saying was that these defective genes came from intermarrying between families... they said, ‘It wasn’t me. It must have been his parents’” (K-1111).

Finally, seven respondents reported that supernatural forces — such as sorcery, witchcraft, *mal’occhio* (the evil eye), or superstitions — might have caused their child’s disability.

Treatment/Cures. All categories of causes were considered to be subject to God’s will; therefore, disabilities were believed to be preventable and/or curable through magico-religious healing practices designed to please God or the saints. For example, the majority of the eight mothers explained that their parents often made vows or performed rituals in honour of the Madonna or a favourite saint, hoping their prayers would be answered with a miraculous cure. Yet they were fatalistic, believing that, regardless of their vows, God alone could bestow a cure or a miracle. A comment from one mother will serve to illustrate:

My mother-in-law is very religious. She believes that God will provide miracles if you pray hard enough. She takes Anna’s picture to Saint Anne, which is a Catholic church in Montreal where miracles happen. She does this once a year. She hopes that this might heal Anna. She always brings her back holy water and leaves it in our fridge and gets Anna to drink it... she just does these things because she thinks it is something she should do. She has made a commitment to Anna to do these things. If a miracle happens, it happens. God has the ultimate control, and is the only one who can change the way things are. (B-1501)

As intimated in the above quote, the mothers expressed neither total acceptance nor total rejection of a belief in miraculous cures.

The mothers considered first-generation Italo-Canadian women experts in magico-religious healing. These older women maintained a close relationship with the Roman Catholic Church, yet many engaged in officially forbidden healing practices. To protect newborn infants from *mal’occhio*, for example, they adorned them with gold necklaces and bracelets, pinned gold ornaments on their clothing, or sewed good luck charms into their underclothing. When children were born with abnormalities, the women prayed or made incantations while burning oil and wax. They also prepared traditional herbal potions. The mothers

described some of the healing rituals of their own first-generation mothers:

They have this thing — sometimes they light a candle, and they have this dish. They put oil in it to ward off the evil eye. (J-1258)

They have rituals. You know, if you do the rosary, like, a hundred times, or whatever, and you use it, your wish will come true. (F-1510)

Seven respondents explained that their parents, especially their mothers or mothers-in-law, encouraged them to engage in rituals and prayers to cure their children. Most mothers reported that they usually went along with these rituals but did not believe in them as strongly as their parents did.

Discussion and Implications

This study explored the beliefs of Italo-Canadian mothers surrounding the cause and the cure of their children's disabilities. Three major categories of traditional explanations for the disabilities were identified: (a) punishment for past sins, (b) "bad blood" due to intermarriage or a family curse, and (c) supernatural forces such as *mal'occhio*. The major category for cure of childhood disability was found to be magico-religious healing, including prayer, herbal potions, rituals, and sorcery/witchcraft. Variations of all of these categories have been identified in studies with Asian, North American Indian, and Hispanic cultures (Chan, 1976; Cheon-Klessig et al., 1988; Groce & Zola, 1993; Lloyd et al., 1992; Mikhail, 1994; Plawecki et al., 1994).

Traditional beliefs affected how the mothers were viewed by other family members — namely, blamed for the disability. This finding supports those of other studies that beliefs about causes of disability can influence how families and communities respond to disabilities in children and how they relate to the children and their parents (Caulcrick, 1980; Groce & Zola, 1993).

The traditional Italo-Canadian magico-religious healing rituals reported in this study were categorized as such because they were all intended to please God or the saints. The practices included: making vows or performing rituals to honour the Madonna or favourite saints, using traditional herbal medicine, and adorning the children to ward off evil. These practices were considered harmless by the mothers, and they sometimes instilled in them a sense of hope or spirituality even though they did not effect a cure. Leininger (1991) believes such traditional healing practices should be accepted and accommodated by nurses who care for people from different cultural groups, in order to

establish a mutually satisfying and trusting relationship with their clients.

The finding that traditional healing rituals were performed by many grandmothers, and were generally accepted by the mothers, supports the findings of other studies that experts in traditional healing are generally elderly members of the family or the community, and that younger people seek their advice (Bushy, 1992; Cheon-Klessig et al., 1988). Another finding that supports those of studies with other cultural groups is that traditional healing is used in combination with modern medicine (Cheon-Klessig et al.; Germain, 1992; Gordon, 1994; Groce & Zola, 1993; Mikhail, 1994). However, this study, unlike others reported in the literature, found that mothers routinely accessed modern medical services rather than viewing them as a last resort. This finding may be a reflection of the fact that the majority of respondents were second-generation Italo-Canadians, whereas traditional values are usually strongest among first-generation immigrants (Isajiw, 1975).

The findings of this study are inconclusive and should not be used to develop stereotypical approaches to treating Italo-Canadian families. It would therefore be premature to conclude that they have implications for nursing practice. However, several areas for future nursing research can be identified. To more fully understand Italo-Canadian experiences in mothering children with disabilities, research could be focused in the following areas: (a) beliefs about cause and cure of disability and illness, (b) the social and material circumstances of Italo-Canadian families, (c) Italo-Canadian experiences with the health-care system, and (d) Italo-Canadian attitudes toward disabled children, including the social roles that are deemed appropriate for disabled or chronically ill children. These areas for research would be amenable to both qualitative and quantitative approaches, depending on the nature of the research question. A qualitative approach similar to the one used in this study might be enhanced by the inclusion of a larger sample size, multiple interviews, and a comparative sample.

Continued research in these directions will help nurses and other health professionals provide competent and culturally meaningful care to Italo-Canadian families of children with disabilities. However, such accumulated knowledge should not be considered static or universally applicable to all Italo-Canadians: cultural beliefs, practices, and experiences can vary greatly among the various members of an ethnic group, as well as across time, space, generations, and socio-economic and political circumstances.

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