Western and Traditional Medicine: Cultural Beliefs and Practices of SA Muslims with regard to Down Syndrome

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ABSTRACT

The aim of the study was to investigate the beliefs and practices of caregivers and traditional healers within the South African Muslim community regarding Down syndrome. An exploratory-descriptive research design was utilized which incorporated individual interviews with 10 caregivers of persons with Down syndrome as well as 10 traditional healers from the South African Muslim community. Common beliefs emanating from both groups relating to the cause of Down syndrome included the notion that this condition was genetic in origin and that such children were perceived to be gifts from God. Others attributed Down syndrome to a punishment from God or the result of curses from people. Treatment included the use of inscriptions from the Quran, water that had been prayed over and herbal medicines. Some caregivers seemed reluctant to approach Western health care professionals due to negative past experiences. The main reasons for consulting traditional healers were cultural beliefs and pressure from family members, their holistic approach and the personal nature of their interventions. Collaboration between allopathic medicine and traditional healing was advocated by almost all of the traditional healers. These findings underline the need for culturally sensitive rehabilitation practices in speech-language pathology and audiology; and collaboration between western health care practitioners and traditional healers.

Key Words: Muslim traditional healers; Down syndrome; cultural beliefs

INTRODUCTION

Differences in socio-cultural experiences, ethnic histories and family backgrounds are likely to influence people's worldviews regarding the aetiology of illnesses and disorders, and the particular healing methods followed by individuals (Battle, 2002). In terms of worldviews, there has been a tendency to distinguish between two main types of health conventions, the so-called modern approach that is located within a Western medical paradigm and the traditional approach, which is based on indigenous belief systems (Hall, 1994). Western biomedical or allopathic medicine is rooted in Anglo-Saxon and Judeo-Christian value systems (Tjale & de Villiers, 2004) and initially tended to view disease as a form of biological malfunctioning, with ill health manifesting in chemical, anatomical or physiological changes (Ross & Deverell, 2004; Tjale & de Villiers, 2004). Healing was perceived as the scientific process of treating disease through appropriate medical, surgical and chemical interventions (Chalmers, 1996). However, more recently, there have been attempts by the World Health Organization (WHO, 2002) to integrate the biomedical model with a social model to form a biopsychosocial model which considers bodily functions and structures, activities performed by an individual, level of participation in societal activities, and the influence of personal, and environmental factors on functioning, disability and health. A major cause of the pre-eminence of Western medical practice, specifically in South Africa, was its connection with the colonialis and later apartheid regimes which stressed the superiority of Western medical practice (Tjale & de Villiers, 2004:2).

Within traditional medicine, the terms diseases, disorders, disabilities and ailments are often used interchangeably and are generally seen as arising from natural, social, spiritual or psychological disturbances that create disequilibrium expressed in the form of physical or mental ill health. Traditional healing endeavours to restore harmony and equilibrium through natural, spiritual and psychological healing while the concepts of curing and healing are also often used interchangeably (Du Plessis, 2003). However, the problem involved in distinguishing between Western biomedical and traditional healing systems is that in the process they tend to become polarized and the one system is often viewed as superior to the other. For example, the late Edward Said in his canonical text on Orientalism (1995) discussed the skewed view of the Other, including the Islamic world, which was based on Western cultural hegemony. Despite the existence of cultural hegemony, in many countries, people from all socio-economic and educational strata often utilize both biomedical approaches as well as traditional practices, creating a medical syncretism that integrates both models and has implications for treatment or management of disorders and compliance with therapy (Muela, Ribera, Mushi & Tanner, 2002).

South African speech-language therapists and audiologists are expected to render culturally sensitive and appropriate services to families from diverse cultural, linguistic, religious and ethnic groups. Hence, they need to be aware of the beliefs and practices of these different groups in relation to health, illness and disability, and ways of restoring well-being. One community that forms an essential part of the fabric of South African society is the Muslim community. However, it is acknowledged that not all Muslims form part of a homogeneous community; nor do they share the same cultural ideologies in relation to health and healing, illness and disability.

Down syndrome is a disabling condition that affects over two million people worldwide (The National Down Syndrome Society, 2004). In South Africa, many children with Down syn-
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acquired great wisdom. The illness of one individual is usually seen as a predicament affecting not only the nuclear family but also members of the extended family, and one is expected to respect the advice given by older family members. During such times, one is also expected to make use of the agents that God has provided. This includes a responsibility to seek adequate medical (or other) advice. In this regard, western health care professionals and/or eastern traditional healers may be consulted (Bayanzadeth et al., 1997).

There are three main groups of Muslim traditional healers: Firstly, there are Moulanas who are spiritual healers that occupy an essential and honoured position within the Muslim culture and are consulted by many South African Muslims for psychological, medical and social problems. They are defined as pious Islamic scholars who are well learned in all aspects of the religion of Islam. Secondly, there are Hakeems, also known as Muslim physicians, who are also consulted by the South African Muslim community. Their services include the providing of ointments and mixtures, which are made from herbs that are known to have beneficial healing properties and are designed to restore imbalances in the body humors i.e. blood, phlegm, bile and spleen. In addition, gift healers, who are blessed with supernatural powers, also assist the South African Muslim families with healing/treatment of various illnesses and disabilities (Desai, 1998).

Although accurate figures are not available regarding the number of South African Muslims who consult with Muslim traditional healers, it is estimated that approximately 8 out of 10 Black South Africans consult with various types of traditional healers in conjunction with or in preference to western trained medical practitioners (Keeton, 2004). The World Health Organization (WHO) also recognizes traditional healing as an integral part of the primary health care system in developing countries (World Health Organization, 1978:429). Consequently, several studies have focused on traditional healers' approaches to various disorders. For example, in terms of African traditional healers, Du Plessis (2003) investigated their approaches to HIV/AIDS; de Andrade & Ross (2005) explored beliefs and practices in relation to hearing impairment; while Platzky & Girson (1993) focused on stuttering.

According to Dagher & Ross (2004) beliefs regarding the causation of birth anomalies are not always grounded in empirical science, but are often understood from a magico-religious or cultural perspective (Tjale & de Villiers, 2004). For example, Badat (2003) interviewed a group of Moulanas from the Gauteng Muslim Community regarding their approaches to cleft lip and palate. A common belief was that cleft palate is God sent and should not be questioned. Participants in her study acknowledged the existence of various superstitious beliefs and practices in the Muslim community. For instance, if a pregnant woman handled a sharp object during the time of an eclipse, her baby was likely to be born with a birth anomaly. In Badat's (2003) study, emphasis was also placed on prayer and tarweez, which is an inscription from the Muslim Holy Scriptures written on a piece of cloth and usually worn in the form of an amulet. However, despite the relatively high prevalence of Down syndrome worldwide, and the fact that many speech-language therapists and audiologists render services to these individuals and their families, few, if any studies have focussed on the approaches of South African Muslim traditional healers and caregivers in relation to this condition. For these reasons the study aimed to investigate the beliefs and practices of caregivers and traditional healers within the South African Muslim community in Gauteng regarding Down syndrome. It was anticipated that this research would have important implications for
cross-cultural awareness and culturally sensitive rehabilitation practices for various disciplines functioning in multicultural settings; improved referral systems and collaboration between western trained health care professionals and traditional healers; incorporation of cultural issues surrounding health and illness into the training curricula of health care professionals; and further research. It was also felt that the study was both relevant and timely, given the recent promulgation by the South African government of the Traditional Health Practitioners Bill in 2004, which is designed to incorporate traditional practitioners into the formal healthcare system and regulate their practice (Keeton, 2004).

METHODOLOGY

Aim

The aim of the study was to investigate the beliefs and practices of caregivers and traditional healers within the South African Muslim community regarding Down syndrome.

Objectives

Objectives with respect to the caregivers were:
1. To obtain information regarding the time of diagnosis, the person who conveyed the diagnosis, and participants’ understanding of the term Down syndrome;
2. To probe personal and cultural beliefs regarding the aetiology of Down syndrome;
3. To elicit views regarding the management of Down syndrome with regard to the use of traditional healing, medical approaches, speech-language therapy and audiology and other paramedical interventions;
4. To ascertain whether caregivers had consulted with medical doctors, speech-language therapists and audiologists and other paramedical professionals; and to explore their experiences with these western trained professionals.

Objectives with respect to the traditional healers were:
1. To elicit from the traditional healers, personal and cultural beliefs about the aetiology of Down syndrome;
2. To examine the various methods used by the traditional healers to manage/treat Down syndrome;
3. To probe attitudes of traditional healers towards allopathic medical practitioners and collaboration with western medicine;
4. To explore the views of traditional healers regarding the reasons for being approached by caregivers in relation to Down syndrome.

Research design

An exploratory-descriptive research design, incorporating a two-group, parallel study was employed. The rationale for adopting an exploratory-descriptive design was that it allowed exploration of a relatively unchartered area, while providing the opportunity for obtaining a rich and detailed description of Muslim traditional healing in relation to Down syndrome (TerreBlanche & Durrheim, 1999). The two group, parallel study, enabled the researchers to conduct individual interviews with a group of caregivers and a group of traditional healers and thereafter to compare the findings and extract differences and similarities from the data. Due to time constraints, triangulation or the use of multiple methods (Denzin & Lincoln, 1998) was not undertaken and other methods of data collection were not selected.

Participants

A purposive, non-probability sample of 10 caregivers of children with Down syndrome as well as 10 traditional healers was recruited from the Lenasia, Gauteng area. Within the purposive sampling paradigm, “snowball sampling” was employed. Prospective participants within the Muslim community were approached. They in turn were asked to obtain permission from other potential participants before giving their contact details to the researcher. Advertisements were also placed in the local community newspaper and on the Islamic radio station, inviting members of the Muslim community to volunteer for participation in the study. However, it is acknowledged that using a volunteer sample may have introduced sources of bias.

Participant Inclusion Criteria

The participants were required to be South African Muslims, as they were likely to have an understanding and knowledge of the community’s cultural beliefs that influence their decisions. Confirmation of the diagnosis of Down syndrome needed to have been made by a medical practitioner. The 10 caregivers needed to be direct and primary caregivers of the child with Down syndrome and could be any member of the affected individual’s immediate family.

The traditional healers needed to be specifically trained or to have acquired some years’ experience in traditional healing so that they would be able to comment on the type of traditional healing approaches adopted in relation to Down syndrome. They also needed to have been consulted with respect to at least one person with Down syndrome.

Description of Participants

The caregivers were all female and were all of Indian extraction. Eight of the caregivers were mothers, one was a sister and one was a grandmother to the person with Down syndrome. The ages of the caregivers ranged from 21 to 80 years. Five of the individuals with Down syndrome were males and five were females and their ages ranged from one to 30 years.

The traditional healers comprised five Moulanas, two Hakeems, two spiritual healers and one herbalist. Nine of the healers were male and one was female. In terms of ethnic group, eight were Indian, one was Black and one was of mixed descent. The period of time spent practising traditional healing ranged from two to 22 years.

Research instrumentation

The study incorporated two semi-structured interview schedules presented in the form of individual interviews. Copies of the interview schedules for the caregivers and traditional healers are set out in Appendices A and B respectively. Several of the questions were adapted from studies by Bham & Ross (2005) and Badat (2003) and included both open and closed-ended items. Both schedules were divided into two sections, namely a section on biographical information and a section on information pertaining to beliefs and practices in relation to Down syndrome.

Content validity of the interview schedules appeared to be demonstrated as sufficient aspects covering the content of the topic were investigated. In addition, a university researcher who was familiar with the area of traditional healing scrutinized the interview schedules. This person was of the opinion that the schedules...
had face validity as they appeared “on the face of it” to measure what they purported to measure.

Research Protocol

Pre-testing the interview schedule

After ethics clearance was obtained from the University Ethics Committee for Research on Human Participants, the interview schedules were pre-tested on persons with similar characteristics to the target group. These persons were excluded from participation in the final study. Due to difficulties experienced in recruiting sufficient participants, pre-tests were conducted with only one Moula na and one caregiver. The pre-tests indicated that the interview was fulfilling its purpose as the participants stated that they understood all the questions. Thus no amendments were made.

Data collection

Following the pre-test, the information sheets and consent forms were sent out to the prospective participants. The researcher contacted both caregivers and traditional healers by telephone and invited them to participate in the study. Individual appointments were made and thereafter, interviews were carried out with the traditional healers and caregivers. In order to comply with Muslim traditions, the researcher who conducted the interviews attended herself in the appropriate Muslim dress for a female, which is a cloak and a head scarf, and was accompanied by a male figure to all interviews with persons of the opposite sex. She also used the appropriate greetings on arrival and on terminating the interviews.

Interviews with caregivers and traditional healers:

All the interviews with the caregivers took place in the comfort of the participants’ homes and at times that were convenient for them. Most of the interviews with the traditional healers were conducted in places where the traditional healers usually consulted with their patients. These areas were in the yards or gardens, close to the traditional healers’ homes or in their offices. At the beginning of the interviews, participants were shown pictures of children with Down syndrome so as to ensure correct recognition of the syndrome. Although the original intention was to audiotape the interviews, participants tended to be suspicious of and resistant to this procedure. Hand written field notes were therefore made of all the responses provided by the participants. Data collection continued until 10 caregivers and 10 traditional healers had been interviewed, because at this point data saturation appeared to have been achieved. According to Leininger (1994 in Maxwell & Satake, 2006), saturation implies that the researcher has performed a “thick” description in an exhaustive effort to extract as much meaning as possible from the data until no more can be said about the topic.

Data Analysis

The closed-ended items were analysed using descriptive statistics involving simple frequency counts, while semantic content analysis was applied to the open-ended questions in order to highlight common themes expressed by participants. Content analysis is a research method for assembling and analysing the content of a text (TerreBlanche & Durheim, 1999). Morse (1994) has divided content analysis into two types, namely semantic content analysis (manifest) and inferred content analysis (latent). Semantic content analysis is used to convey what the participants have said, while Inferred Content Analysis infers or goes beyond what was said or written.

Neuman (2003) emphasises the need to ensure the trustworthiness or truth value and authenticity of the qualitative framework (comparable to the positivist notions of validity and reliability) by adopting the criteria developed by Guba & Lincoln (1989), namely credibility, transferability, dependability and confirmability. By using semantic rather than inferred content analysis, the researcher aimed to establish credibility (paralleling internal validity) of the data as representing the “real world” as perceived by the participants. In terms of transferability (which is comparable to the positivist construct of external validity or generalizability), it was anticipated that the information obtained from this study would be applicable to other therapy situations as well as to professionals who encounter clients from the Muslim community in South Africa. In order to enhance dependability (the alternative to reliability) of data analysis, the same person conducted all the interviews and systematic steps adapted from TerreBlanche & Durheim (1999) were followed. These steps included: firstly, familiarization and immersion, which involved putting into simpler terms by means of reading through, making notes, drawing diagrams and brain storming to obtain a general idea of the findings; secondly, inducing themes, which implied inferring general rules or classes from specific instances in a bottom up process; thirdly, coding, which encompassed the making of different sections of data as being instances of or relevant to one or more of the researcher’s themes; fourthly, elaboration, which involved synthesising information in a linear sequence; and fifthly, analysing data, interpretation and inspection which included going back to all the above steps to make sense of the data. In order to reduce researcher bias and establish confirmability (or objectivity) of the data, correspondence checking advocated by Pretorius & de la Rey (2004:31) was undertaken, whereby the primary researcher’s categorization of themes was checked by her research supervisor for correspondence. Once agreement had been reached regarding categorization of themes, these were quantified.

RESULTS AND DISCUSSION

PART ONE: Results from the interviews with the caregivers

Orientation to the syndrome

Time of diagnosis

Eight out of the 10 caregivers stated that their children were diagnosed at birth. However, one participant stated that the first diagnosis was made during her pregnancy via an amniocentesis test. Another mother reported that her son was only diagnosed about six months after birth.

Persons who made the diagnosis

The entire sample that was interviewed stated that their children were diagnosed with Down syndrome by either a gynaecologist or a paediatrician.

Understanding of Down syndrome

Nine of the participants appeared to be aware of the main features and characteristics of children with Down syndrome. Responses included: ‘Genetic disability with one less chromosome, Mongolian; Low ears with weak muscle tone; Dry skin and prone to upper respiratory tract infections; Floppy child with stump fingers and two segments on the baby finger: Two years slower than normal children. Some have a leaking heart and some are mentally retarded’. However, a mother of a four-year-old child with Down...
syndrome admitted that she did not understand the meaning of the term Down syndrome.

**Genetic counselling**

Seven of the 10 participants informed the researcher that they had not been for genetic counselling. One mother gave the following reason for refusing to go for genetic counselling: 'As a Muslim I had a child and was never going to abort, thus I found it meaningless. After my Down syndrome son I had two perfectly normal twins.' In contrast, one mother found that the genetic counselling was useful. 'My father finally accepted my son, as my father was very sensitive and defensive and said if anyone saw my son they would laugh.'

**Beliefs of caregivers regarding the cause of Down Syndrome**

**Personal beliefs regarding the aetiology of Down syndrome**

It should be noted that the participants tended to regard terms such as "heal" and "cure" as synonyms, while concepts such as "illness, disorder, disease, ailment and condition" were used interchangeably. A common belief mentioned by five of the participants was that all illnesses and birth conditions were due to God's will. This belief was similar to findings by Bham & Ross (2005) that many of the Muslim participants whom they interviewed felt that strokes were due to God's will.

Two participants were convinced that the child was a gift from God and one most willingly accept it and not question, 'Why me God?' One mother stated: 'This is a heaven special child and only fortunate people get these children.'

A further two participants attributed the cause of the condition to genetic factors and understood the scenario of Trisomy chromosomes. Inter-marriage was also related to genetic factors, as one of the participants felt that if marriages occurred between husbands and wives who were too closely related, the risk of having a child with Down syndrome was high. One participant felt that the age of the mother or father was one of the causes of Down syndrome. This idea is supported in the research literature as the maternal age related risk for Down Syndrome is lower at age 20 (one in 1734 births), but higher at age 35 (one in 386 births) (Harper, 1998).

**Cultural beliefs regarding the aetiology of Down syndrome**

In addition to personal beliefs regarding the aetiology of Down syndrome, caregivers were also asked if they were aware of the existence of any cultural beliefs in their communities relating to this condition. Four of the participants explained that according to their culture, having a child with a disability, such as Down syndrome, was regarded as a punishment from God. Punishment was directed to the mother, who was perceived to have committed wrong deeds in her past life. One caregiver emphasised that these were cultural beliefs, not Islamic beliefs. Furthermore, cultural beliefs assumed by the community were found to be closely linked to beliefs held by many of the participants themselves. This finding was consistent with the results obtained by Bham & Ross (2005). Several of the Muslim caregivers and traditional healers whom they interviewed mentioned cultural beliefs regarding stroke being a form of punishment.

Four of the participants also suspected Jadu (evil curses) from family and friends. One participant added: 'These beliefs are myths which need to be eradicated from our thought patterns.' In line with these findings, Dagher & Ross (2004) noted that the African traditional healers in their study believed that cleft palate was caused by ancestors, spirits and witchcraft. In a similar vein, three participants mentioned that many people in their culture were unaware of the cause of Down syndrome. For example, one participant noted, 'These ignorant people often laugh at my son.'

**Management of Down syndrome**

Six of the caregivers reported that they had consulted traditional healers regarding the management of their children with Down syndrome. Several of the participants explained that many of the elderly members of their communities and families insisted on the use of traditional healing. This finding was in line with the views expressed by those of Tomoeda & Bayles (2002) who maintain that in collectivistic cultures such as those of Indian Muslims in South Africa, members of the family group tend to exert a direct influence on decisions about treatment options.

One caregiver noted that her son was constantly being admitted to hospital and that doctors had told her that he was not going to live long. She then approached a Moulana who gave her the tarweez and advised her to read a few verses from the Quraan in order to improve his condition. 'I was happy with the results as my son's condition improved and he also stopped crying so much'.

Another caregiver mentioned that she took her granddaughter to a Moulana. She reported that the Moulana had read from the Quraan for her granddaughter and thereafter her speech had become clearer. In this respect, it should be noted that traditional medicine has been shown to have several benefits, including reduced anxiety through a shared, unquestioned belief in the powers of the healer (Hammond-Tooke, 1989).

One of the participants explained that she did not approach traditional healers as she and her husband felt that one should ask God directly for help. She added that she and her husband read from the Quraan on a daily basis and they had seen tremendous improvement in their daughter's health. Another participant shared a similar view and encouraged people to read the Quraan daily, as it contained shifa (cure) and a mercy for all mankind.

One participant was convinced that her daughter was a gift from God and that she had to accept her the way she was. Another participant explained that her brother was physically disabled and this factor motivated her to take care of God's creatures herself and not seek cures for disabilities.

One participant informed the researcher that a Hakeem had provided him with a herbal ointment to strengthen his son's legs. "Soon after treatment my son started walking. He also provided my son with a syrup for his constipation and this too was useful and I have lots of faith in this Hakeem". Another participant reported that he approached a Hakeem, not to cure his son of Down syndrome but merely to get her remedy for his heart condition. She provided a diet to follow which included goat's milk and some herbal powders. The father noted that his son lost weight and he then discontinued the diet and was not satisfied with the healer's management. Another participant explained that her Hakeem had provided her with a herbal mixture in a liquid, but her son, who was very small at time, did not drink it. Thus she was not sure if it would have been effective.

**The caregivers' attitudes towards western medicine**

**Approaching Medical Doctors**

Six of the caregivers stated that they had approached medical doctors. These participants were convinced that the doctor...
could assist them with this medical condition. One of participants explained that the doctor she approached was very encouraging and provided her with advice and management strategies. Another participant reported that her doctor introduced her to other mothers/caregivers of children with Down syndrome, which helped her deal with her feelings towards her child and contributed to more effective care and management of the condition.

Four parents stated that they had independently searched the internet and read books to assist them in the management of their children. They found the doctors to be unhelpful in terms of giving advice, and lacking in counselling skills regarding dealing with parents’ feelings. Another mother informed the researcher that her doctor had told her that her baby was going to be deaf. However, she explained that she and her husband used to read from the Quraan and that her daughter hears perfectly well. Consequently, she no longer takes the doctors’ theories or their prognoses in respect of her child seriously, but perseveres with faith.

**Approaching Paramedical Professionals**

Of all the participants who were interviewed, nine stated that they had approached speech-language therapists to assist in the remediation process of their children with Down syndrome. Among the nine children who did attend therapy, seven were currently attending, either privately or at schools. All nine caregivers stated that they had experienced success in therapy. However, one mother explained that she terminated therapy as she felt that her son had reached a plateau at the age of 12 years. Examples of useful aspects of therapy included buying toys that depicted everyday routines in order to facilitate basic identification; encouraging the child to vocalize and to expand his or her sentences; avoiding baby talk; and using gestures to complement verbal input. The impression gained was that caregivers had insight into the speech-language therapy services provided for their children and had implemented the advice of speech-language therapists. The one participant who did not approach a speech-language therapist noted that her daughter started talking spontaneously and she therefore did not find the need for speech-language therapy intervention.

None of the participants mentioned using audiological services.

Five of the caregivers reported that they had consulted with other paramedical professionals including physiotherapists, occupational therapists, paediatricians, cardiologists and counsellors. Those that had approached these paramedical professionals reported being satisfied with their services. However, two of the caregivers mentioned that they did not find the need to seek professional help as their children were developing adequately. Caregivers articulated the viewpoint that they felt more secure and relaxed about going to professionals who understood their culture and their use of alternate remedies.

**PART TWO: Results from the interviews with the traditional healers**

Ten traditional healers were interviewed, all of who reported that they had treated children with Down syndrome.

**Beliefs regarding the cause of Down syndrome**

Participants’ views were elicited on the causes of the Down syndrome as it was felt that the cause would reflect societal beliefs about the condition. Five of the participants were of the opinion that the aetiology of Down syndrome could be attributed to genetic factors. One of the participants added that when family members inter-marry this behaviour also causes the child to be born with some kind of anomaly.

Five of the participants attributed Down syndrome to God’s will. They noted that babies that are born with such a disorder are all in God’s (Allah’s) hands and we should avoid questioning God. Furthermore, such an experience was considered a ‘test’ for the parents. ‘Keep in mind that sickness is given to the patient as a trial for the patient himself or herself and for their family’. This finding was consistent with the Islamic belief that the reward in the life to come is based on how one reacts to a ‘test,’ namely how one treats a disabled child (Sakr, 1996). One participant also mentioned in passing that abortion, amniocentesis and sterilization were contrary to the teachings of Islam.

A further theme that emanated from the responses of four of the participants related to cultural beliefs in curses, also known as Jadu, and evil eyes or evil spirits (Jinn) from other people. Hall (1994) suggests that some people are believed to have native powers, which they utilize together with medicines or charms to inflict hurt on others. Campbell (1998) maintains that supernatural and magico-religious belief systems distinctive to each culture, are often alien to and not easily understood by allopathic practitioners.

Two out of the 10 participants attributed the condition to an imbalance between hot and cold in the body, which caused the child to be born with Down syndrome. This imbalance was referred to by the Hakeems as a disequilibrium in the body’s humoral system. It was believed that this imbalance could have occurred during the mother’s pregnancy. They believed that the practice of looking at the symptoms in isolation, provided only short-term relief, rather than long-term healing. They thus advocated a multi-dimensional approach, which took into account an understanding of patients themselves, their life contexts and life styles, and finally the ways in which their spirit-mind-body interacted with each other in an attempt to achieve balance and healing, thereby attempting to establish homeostasis of the spirit-mind-body. In this way one could heal the whole patient and not just alleviate the symptoms. This type of approach appeared to be devised from Unani Tibb or Tibb, which is a holistic healing system based on the philosophies of Hippocrates, the father of western medicine (Sykiotis, Kalliolas & Papavassiliou, 2006), and the well known Islamic scholar, philosopher and physician Ibn Sina. Tibb is a type of natural medicine which takes into account the individual’s body, mind and soul. Tibb was practised about 150 years ago and is the foundation on which modern medicine is based. Unani Tibb is recognized in South Africa, largely due to it being cost effective and providing an effective understanding of the aetiology of illness. The principles of Tibb are in accordance with the Quraan and the teachings of the Prophet Muhammad (Sina, 2004).

It was clear that the traditional healers who were interviewed were concerned with the reasons why a particular disease has occurred and that the search for causality was perceived to be one of their greatest assets. In contrast with the finding that the traditional healers who were interviewed, were concerned with the reasons why a particular disorder had occurred, Green (1988) suggests that western medical practitioners tend to show more concern with control as opposed to considering the root of the problem. The importance of holistic healing highlighted by the two Hakeems, is also shared by many Black South African traditional healers, who believe that if the mind is healed the body takes care of itself (Dagher & Ross, 2004). This assumption contrasts with that of western medicine, which contends that if the body is healed the mind takes care of itself (Hall, 1994). One of the Hakeems noted that he usually asked himself the following questions derived from Selzer (2004) during his consultations, namely: ‘1) What does a symptom mean? 2) How should it...
be listened to? 3) What does this patient’s symptom mean in this particular patient as opposed to another patient? 4) What does this symptom tell us about the totality of this patient from the symptom’s picture? 5) How can I as a practitioner, be of the greatest help to this person in his wholeness, and assist his soul­mind body complex to achieve its healing?’ (Selzer, 2004:10).

One of the participants stated that the ruh (soul) asks God to be born in that state, i.e. with Down syndrome. He added that God provides healers and parents with the knowledge to cope with a child with Down syndrome. He further noted that God pun­ishes the parents by giving them a child with Down syndrome, so that the parents can become more conscious of God and become more loving.

A female spiritual healer attributed the aetiology of Down syndrome to a virus, and believed that something had gone wrong in the mother’s womb. She explained that it was a natural develop­ment and that there was a negative influence, which disturbed the development of the foetus.

Information regarding management of Downs syndrome

Three Moulanas indicated that they would provide the pa­tient with a tarweez (an inscription of verses from the Quraan on a piece of paper). A tarweez is usually worn around the neck or attached to the child’s clothing. The tarweez serves to provide the child with protection against any evil and eradicates any evil pro­jected onto the child. One of the moulanas noted, ‘For every ill­ness there is a cure, and Muslims are encouraged to believe in the unseen’. This participant also encouraged people to approach medical professionals for treatment as God has made them available in order to help people. Another participant noted that he had used tarweez to help stabilize the child, and the child then started “thinking and talking”.

One Moula mentioned that he gave his patients oils, which were either part of a mixture or on their own to be applied to the body and head. In addition, he provided them with five different types of seeds. He encouraged them to drink almond milk, which he first prayed over. The Moula also mentioned the use of holy water (water that he prayed over), which he provided to most of his patients. Another method that he used was to advise his patients to put salt on their bodies at night, as it ‘cools the body and makes life easy’.

The same Moula mentioned the use of honey in combina­tion with hot water. He emphasised that honey was a cure for many illnesses as stated by the prophet Muhammed.

The Hakeems reported that they would examine the patient and establish which humour was blocked or not functioning opti­mally. Treatment included changing a certain aspect of the tem­perament of one of the four humours by providing herbal medica­tion. This herbal medication often consisted of an infusion of powders that assisted in balancing the humours, attempting to harness the body’s energy to treat itself.

One of the Hakeems noted that when the illness was evi­dent from birth as in children with Down syndrome, eradicating or achieving homeostasis of spirit-mind-body was impossible. In­stead they assisted these children by providing medication in the form of herbs that minimized the degree of the problem. He ex­plained that he had once provided a child with Down syndrome with a herbal balm to aid his joint/walking pains as the leg was very cold. Another point that he mentioned was that children with Down syndrome often struggled to talk as ‘the tongue was drier and colder than it should be’. He therefore provided medication to increase the moisture and heat on the tongue and this process helped to increase blood flow to the tongue. He believed that this action made the tongue more mobile, thereby promoting speech production. In addition, he stressed the fact that treatment was ‘holistically based taking into account the mother’s pregnancy, the child, the effect of the condition and his environment’.

Herbal treatment was identified by two of the participants. A herbalist noted that he provided a child, with Down syndrome who had a severe hearing problem, with a herb mixture in the form of porridge, which the child had to eat every morning. He also provided him with a mixture, which he had to take in the morning and at night. The herbalist stated that this child used to be hospitalised every month, but after his treatment, doctors were amazed at his improved health. His main medicines were made from plants, herbs and powder of seeds and roots, juices, leaves and minerals. On probing the specific herbs that the healer pre­scribed for children with Down syndrome, he replied that it was his secret. Hammond-Tooke (1989) suggests that many herbalists possess knowledge of natural substances, which have an authentic remedial effect but are not always willing to share this knowledge out of fear that this knowledge will be appropriated by others - which highlights the need to protect the intellectual property rights of traditional healers.

One participant emphasised the fact that no matter what approach to management or treatment a person pursued, success and recovery were all in God’s hands. Two of the participants believed that spiritual healing was a necessary procedure that had to be implemented as part of the treatment of Down syndrome. Firstly, permission is sought from God to work on the child. Thereafter they scan the body from the spiritual realm and then intervene via touch therapy.

Many traditional healers believed that the cause of Down syndrome was due to evil spirits that had possessed the mother and the child. The spiritual healing is a process that helps to dispel the evil spirits and cleanse the patient. Another spiritual healer mentioned that she would meet both the mother and child and then clear the mother of evil spirits that she had been carrying during pregnancy. She noted that her treatment, which included a combination of touch therapy, reiki, automatic writing and mas­sage, helped to remove any negativity within the child or mother and assisted with various difficulties.

One participant noted that counselling of the parents forms an integral part of his treatment. He demonstrated to the parents how to approach their child with love, and comforted them by assisting them to deal with their spiritual needs.

Views of traditional healers regarding the reasons for being approached by caregivers of children with Down syndrome

The issue of culture and pressure from family members was strongly emphasized by eight participants. One healer noted that the elderly members of the Muslim community tend to feel that alternative methods of healing should be attempted. He ex­plained that many of these elderly people have a strong belief that some ailments are caused by unseen forces. They also believe that religion holds a cure for many ailments, and can improve the well being of the child. Another participant shared a similar view and stated that ‘many people have faith in what their grandparents believed as they grew up strong and healthy’. This theme was articulated by four of the healers.

One of the participants remarked, ‘We work with uncondi­tional love. Many of our people maintain that modern doctors are generally in a hurry and they do not give enough time, care and..."
One of the participants expressed the view that he would like to work with doctors and therefore advised parents to approach practitioners and collaboration with western medicine. The traditional healers' attitudes towards allopathic medical treatments were somewhat dubious about the feasibility of this approach. They felt that for every disease there was a cure, thus alternative methods should be encouraged, including medical doctors' approaches to healing. However, one Moulana supported collaboration with western medical professionals as he felt that a disorder can be both spiritual and medical. Therefore, in line with these findings, it has been noted that some traditional healers take a keen interest in primary health care training provided by modern formal medicine.

In contrast, one of the Hakeems stated that he did not refer to medical doctors as most of the patients that came to him had often given up hope and lost faith in medical doctors as they had not experienced success with allopathic medicine.

Five of the participants had referred their patients to speech-language and hearing therapists. One participant reported that he had not referred to a speech-language therapist, because whenever a child had presented with a speech or language problem, his treatment had proved successful and with time the child started to talk in long sentences, understand better and his thinking power increased.

Nine of the participants reported that they did not consult with other medical or paramedical professions. The time factor was noted to be one of the reasons for not consulting with other western trained professionals. The herbalist stated that he did not approach other professionals, as he preferred to control the child's condition with the use of herbs.

The entire group of traditional healers who were interviewed supported collaboration with health care professionals and expressed a keen interest in learning about modern medicine and the roles of the various team members involved in the rehabilitation of the child with Down syndrome. They also felt that there was a need for the modern world to be acquainted with traditional healing and that western professionals should respect this form of healing. For example, a spiritual healer stated that she would do her work and they (medical doctors) would do theirs and the combined effect was likely to produce optimal results for the patient. One participant stressed the fact that Islam proclaims that we believe our hands are good at healing. Many people perceive my approach as a lower level and one that is more affordable. There has been a revolution in that many people approach traditional healers. The herbalist stated: 'Herbalists can help cure things, such as bone fractures and we can also help control illnesses such as diabetes. Therefore we are successful like the doctors in treating people. Likewise, we are able to control and manage conditions such as Down syndrome'.

Three participants emphasized that when all else fails within the world of modern medicine, people tend to go back to their roots in order to find a cure. This finding is similar to the assertion by Campbell (1998) that traditional healers are usually well respected, accepted and trusted by their communities because they are culturally and religiously congruent with their own beliefs and practices.

One traditional healer expressed the view: 'They come for security; dependent on you for a cure …They usually come and see us to alleviate them from guilt. They want some kind of reinforcement that it is not their fault'. Finally, one participant stated: 'They think they've been cursed'.

The traditional healers' attitudes towards allopathic medical practitioners and collaboration with western medicine

Nine out of the 10 traditional healers who were interviewed reported that at some point they had advised the parents of children with Down syndrome to approach a medical doctor. One of the participants expressed the view that he would like to work with doctors and therefore advised parents to approach medical practitioners. A spiritual healer reported that she had received a prophecy to work with doctors. Another participant articulated the opinion that if his treatment was unsuccessful he then referred to doctors. In line with these findings, it has been noted that some traditional healers take a keen interest in primary health care training provided by modern formal medicine (van Wyk, van Oudshoorn & Gerick, 2003).
SUMMARY OF MAIN FINDINGS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

Summary of main findings

In summary, common beliefs that emanated from both the caregivers and the traditional healers with reference to the cause of Down syndrome, included the notion that this condition was genetic in origin and that such children were perceived to be a gift from God. Other frequent responses attributed Down syndrome to a punishment from God and also a result of Jadu (curses from people). Common treatment/management approaches mentioned by both the caregivers and the traditional healers included the use of tarweez and water that had been prayed over which was provided by Moulanas and spiritual healers, and herbal medicines prescribed by Hakeems. Both groups emphasized the need to treat children with Down syndrome with patience and unconditional positive regard, and to focus on their strengths. Some caregivers seemed reluctant to approach medical doctors relative to traditional healers and this reluctance was attributed to their negative past experiences with medical practitioners. Furthermore, nine of the caregivers had approached speech-language and hearing therapists compared to five of the traditional healers. Both groups reported making limited use of other paramedical professionals. The main reasons given for consulting traditional healers were cultural beliefs and pressure from family members, their holistic view of management, and the personal nature of their approaches. Collaboration between modern medicine and traditional healing was advocated by almost all of the traditional healers.

However, these findings need to be critically evaluated. A critique of the study revealed several limitations.

Limitations

Firstly, theorists such as Bhopal (1997) have questioned whether research in ethnicity and health is racist, unsound, or important science. It is the contention of the present writers that such research can potentially enhance awareness of the beliefs and practices of different groups in relation to traditional healing. Secondly, as the researcher who conducted the interviews was from the same religion and part of the same South African community as many of the participants, they took for granted the fact that she was acquainted with their cultural beliefs and practices, and consequently failed to elaborate and provide explanations for many of their answers. Thirdly, as some cultural beliefs were seen to be sacred or even offensive to caregivers or the children concerned, participants were initially reluctant to admit having such beliefs for example, Jadu and the evil eye, and instead seemed to furnish socially desirable responses. Only once the researcher was able to establish rapport with the participants, were some of them able to admit that they subscribed to such beliefs. A third limitation related to the fact that participants were unwilling to allow the researcher to tape-record the interviews. She was therefore compelled to make hand written notes, which occasionally tended to detract from the flow of the interviews. Fourthly, little information was given regarding the type of herbs used for treatment. Presumably, the traditional healers felt that the researcher might expose their secrets to pharmacists and other persons who might appropriate their knowledge. The fifth limitation was related to the failure to use triangulation, which would have added rigor, breadth, and depth to the investigation (Denzin & Lincoln, 1998).

Triangulation refers to the process of “enhancing the value of a theory by using multiple methods and perspectives to investigate the truth” (Maxwell & Satake, 2006:7). A further limitation relates to the lack of generalizability of the data. However, a counter argument is that the issue of generalizability is irrelevant to research of this nature as the purpose of the study was not to obtain generalizable findings but rather to elicit a rich and thick description of the phenomenon under investigation.

Recommendations

Despite these limitations inherent in the research design and methodology, important recommendations can be made in respect of culturally sensitive rehabilitation practices in speech-language pathology and audiology; collaboration between western health care practitioners and traditional healers; theory and future research.

Culturally sensitive rehabilitation practices in speech-language pathology and audiology

Although the findings cannot be generalized to the entire South African Muslim community, they suggest that some members of this community tend to place a great deal of emphasis on cultural and religious beliefs. It is therefore recommended that speech-language therapists and audiologists need to adopt culturally sensitive practices when managing children with Down syndrome from this community as cultural beliefs may influence how people perceive affected individuals and how they are treated or managed. For example, the Muslim belief that disability is from God, may impact on the management process and needs to be taken into consideration when undertaking diagnostic evaluations and planning therapy interventions with this client population. In addition, information on treatment recommended by traditional healers is useful to western health care professionals, as they need to be aware of other forms of treatment that parents may be utilizing as these interventions might be useful or harmful when used in combination with modern medical treatment methods. Furthermore, the finding, regarding the influence of elderly and extended family members, has implications for both counselling and therapy in terms of the guilt which may be felt if certain remedies are not implemented or traditional healers are not consulted. Such findings also underscore the importance of involving the extended family in therapy and adopting family-focused interventions.

Collaboration between western health care practitioners and traditional healers

The fact that almost all of the traditional healers who were interviewed supported collaboration with health care professionals and expressed a keen interest in learning about modern medicine, highlights the need for collaboration between the these two systems of medicine. However, the finding that very few of the traditional healers made referrals to paramedical professionals was possibly related to the fact that the participants were not knowledgeable about the services provided by these practitioners. There would thus appear to be a need for these paramedical professionals to create public awareness of their services and the roles they can potentially play with respect to children with Down syndrome.

Moreover, approximately 80% of South Africans make use of traditional healers and an estimated 250 000 and 300 000 traditional healers are currently practising in South Africa. This widespread use of traditional medicine has to do with issues of affordability, cultural acceptability and accessibility (Du Plessis, 2003). It
is therefore recommended that western health care practitioners be educated regarding the roles of traditional healers and the medicines they use, so that there can be greater collaboration and mutual respect. The South African health ministry is currently looking for ways to incorporate informal medicine into the formal health sector, and the recent promulgation of the Traditional Health Practitioners Bill (2004) is designed to facilitate this process.

Theory and Future Research

This exploratory-descriptive study represents an effort, in some small measure, to enhance theoretical understanding of the South African Muslim community’s multifaceted approach to health, illness and disability. However, while respecting these cultural beliefs and practices, one cannot endorse their effectiveness without further evidence-based research. Moreover, in view of the fact that the small sample size and the use of snowball sampling precluded generalization of results to the broader population of caregivers and traditional healers, it is recommended that this research be replicated on a larger, more representative sample. Given the point raised by one of the traditional healers regarding the apparent contradiction of such practices as abortion, sterilization and amniocentesis, with the teachings of Islam, future researchers need to explore the views of traditional versus western health care professionals regarding the ethics of traditional healing and western health care in relation to these practices. Finally, it would seem to be an opportune time to begin the process of monitoring the implementation of the new Traditional Health Practitioners Bill in South Africa and assessing its effectiveness in promoting collaboration between western medicine and traditional healing over the next few years.

In conclusion, the findings that several participants attributed Down syndrome to genetic factors as well as God’s will, and many of the traditional healers had referred patients to western professionals, suggests a degree of medical syncretism whereby “biomedical knowledge transmitted in health messages coexists, interacts and merges with local pre-existing ideas and logics” (Muela et al., 2002:403). Moreover, the fact that Muslim humoral medicine is partly rooted in the writings of Hippocrates, the father of western medicine (Sykiotis et al., 2006), coupled with the finding that many of the caregivers in the present study utilized both eastern and western medicine, and all the traditional healers who were interviewed were in favour of collaboration, suggests that these two systems do not necessarily represent incommensurable paradigms but can potentially fulfill complementary functions. Hence, both approaches need to be taken into consideration by speech-language therapists and audiologists seeking to render culturally sensitive services to clients from the South African Muslim

REFERENCES


APPENDIX A

Interview schedule for caregivers

Section A – Biographical Information

Gender of caregiver:
Age of individual with Down syndrome:
Relation of caregiver to individual with Down syndrome:

Section B – Information relating to Down Syndrome

Orientation to the syndrome

1. When was _________ first diagnosed with Down syndrome?
2. Who made the diagnosis?
3. What do you understand by the term Down syndrome?
4. Has anyone explained the features of this syndrome to you? Please explain.
5. Have you received any genetic counselling?

Beliefs regarding causation

6. What do you believe is the cause of Down syndrome?
7. What do people in your culture generally believe causes Down syndrome?

Management of the syndrome

8. With regard to the person with Down syndrome that you take care of, did you approach any traditional healer such as a Moulana or Hakeem?
9. If yes, what advice, treatment or management did he or she recommend?
10. Did the advice/management that he or she recommended meet your expectations? In other words were you satisfied?
11. If you did not approach a traditional healer, was there any reason for not approaching a traditional healer?
12. Did you approach a medical doctor?
13. If so, please describe the advice/management approach that he or she recommended and your degree of satisfaction with such advice.
14. Did you consult any other medical or paramedical professionals?
15. If so, please state which professionals you consulted and describe the management approaches they recommended.
16. Did you approach a speech-language and hearing therapist?
17. If so, please describe the advice/management that he or she recommended and your degree of satisfaction with such advice.
18. If you did not consult with a speech-language and hearing therapist, was there any reason for not consulting such a professional?
19. Are there any other views or comments you would like to share with me in relation to caring for a person with Down syndrome?

APPENDIX B

Interview schedule for traditional healers

Section A – Biographical Information

Gender:
Type of healer:
Number of years practising as a healer:

Section B – Information relating to Down syndrome

Beliefs regarding causation

1. What do you believe is the cause of Down syndrome?
2. What do people in your culture generally believe causes Down syndrome?

Management of the syndrome

3. Have you ever been consulted regarding a child with Down syndrome?
4. If yes, please can you explain the type of advice, management or treatment that you provide for such children?
5. Have you ever advised parents of children with Down syndrome to approach a medical doctor?
6. Have you ever referred any of these children to a speech-language and hearing therapist?
7. Have you ever consulted with any other medical or paramedical professionals with regard to children with Down syndrome?

General

8. Do you feel that traditional healers and western trained professionals such as doctors and therapists can work collaboratively to treat/manage children with Down syndrome? Please explain.
9. What are the reasons you think parents/caregivers of children with Down syndrome consult with you instead of, or in addition to, western medical practitioners?
10. Do you have any other views or comments you would like to share with me in relation to the treatment or management of individuals with Down syndrome?