J Genet Counsel (2012) 21:726–740
DOI 10.1007/s10897-012-9495-9

ORIGINAL RESEARCH

Understanding of Genetic Inheritance among Xhosa-Speaking Caretakers of Children with Hemophilia

Gabriele Solomon · Jacquie Greenberg · Merle Futter ·
Lauraine Vivian · Claire Penn

Abstract Hemophilia A and B are X-linked recessive inherited bleeding disorders that have a profound impact on the family of affected individuals. Education is vital to enable women to appreciate the implications of being a carrier and the implications for a prospective child. Prior research has shown that cultural, socio-economic and linguistic issues in South Africa are major barriers to communication for first-language Xhosa-speakers. This exploratory study aimed to investigate the basic knowledge of genetic inheritance among this cultural group in order to promote culturally-sensitive, effective genetic counseling. Ten in-depth interviews were conducted with Xhosa-speaking mothers or caregivers of boys with hemophilia. Results suggest that the participants had a very limited understanding of the clinical management, genetic consequences and cause of hemophilia. While treatment and care by health care service providers was fully accepted, several participants believed that traditional methods would provide them with more satisfactory explanations. These findings suggest that there is a critical need for socio-culturally tailored, *language-specific* education for families with hemophilia.

Keywords Genetic inheritance · Cultural differences · Culturally-sensitive · Genetic counseling · South Africa · Xhosa-speakers · Hemophilia

Introduction

Hemophilia A and B are life-long chronic bleeding disorders that present with severe to mild bleeding and bruising. Both types of hemophilia are X-linked recessive inherited disorders that have a profound impact on the daily life of the affected individual, carrier mothers and close family members (Goldstein and Kenet 2002). Without treatment, hemophilia can lead to spontaneous internal bleeding or excessive bleeding following injuries and, in some cases lead to death. Hemophilia A is the most common form of hemophilia and occurs in 1 in 5,000–10,000 male births, while Hemophilia B occurs in 1 in 20,000–34,000 male births. (National Haemophilia Foundation (USA) (2006)).

Socio-economic and language issues in South Africa are a major barrier to communication and an obstacle to good medical care for first-language Xhosa speakers (Penn 2007). In order to provide culturally-sensitive, effective counseling, genetic counselors or medical professionals need to have a good understanding of the genetic knowledge base of this population. Beliefs about the cause of a condition are often culturally determined and in order to address any misunderstandings, health care providers should be aware of the cultural base that shapes the thoughts and actions of their clients (Cohen et al. 1998). Respect for cultural traditions also helps build a foundation of trust between counselors, health care

G. Solomon · J. Greenberg · M. Futter
Department of Clinical and Laboratory Sciences,
Division of Human Genetics, University of Cape Town,
Cape Town, South Africa

L. Vivian
Primary Health Care Directorate, Faculty of Health Sciences,
University of Cape Town,
Cape Town, South Africa

C. Penn
Health Communication Project, University of the Witwatersrand,
Johannesburg, South Africa

G. Solomon (✉)
Department of Clinical and Laboratory Sciences,
Faculty of Health Sciences, University of Cape Town,
Falmouth Building, Level 6, Room 6.26, Observatory,
7925 Cape Town, South Africa
e-mail: gabriele.solomon@uct.ac.za

professionals, affected individuals and their families (Turner et al. 2004). Of particular concern in the South African context is that circumcision is traditionally practiced as a rite of passage into manhood. Circumcision is performed by experienced "traditional" surgeons (ingcibi) who have no form of medical training. This practice can have particularly serious ramifications for males with hemophilia because of excessive and prolonged bleeding complications after the procedure. It is, therefore, essential that affected youth, parents or caretakers and traditional surgeons fully understand the risks involved in this rite (Karaman et al. 2004; Mayatula and Mavundla 1997; Zulfikar et al. 2003).

A large number of international studies have dealt with the manner in which differences in language and culture affect clinical care, especially in the USA where the effects of cross-cultural communication in non-English speaking minority groups have been examined in depth (Betancourt et al. 2004; Flores and Vega 1998; Kreps et al. 1994; Taira 1999; Tsang et al. 2003). In contrast, few studies have focused on the consequences of cross-cultural communication between patients and health professionals in South Africa. Swartz and Drennan (2000) argue that the slow progress towards achieving greater access to mental health services in South Africa has its roots in language difficulties. Few English speakers have mastered the African languages and even today are surprisingly ignorant of the local indigenous cultures (Penn 2007). Language services in South Africa's health care system remain poorly established, despite constitutional recommendations (Levin 2006a; Swartz and Drennan 2000) and an established need for such services. Language surveys, for example, suggest that fewer than 5% of the doctors at institutions studied are able to conduct the interviews in the home languages of their patients (Levin 2006a, b; Saohatse 1998, 2000). Even when health professionals are culturally and linguistically matched, interactions may take place in a language which is not the home language. The nature of the setting, power relations, the materials and the task often lead to the use of English (Penn 2007). Healthcare workers in most major hospitals in the Cape Town region mainly communicate in English or Afrikaans, while many patients speak Xhosa as their first language (Levin 2006b). Levin highlighted difficulties experienced by Xhosa-speaking parents in understanding English terms used by pediatricians in a teaching hospital (Levin 2005; Levin 2006a). Interpretation is an obvious and important factor in cross-cultural communication, and Crawford (1999) has comprehensively documented problems experienced by nurses who, often involuntarily, are obliged to take on the role of interpreters in South African hospitals. Complex concepts such as the causes of hemophilia, how blood clotting factors work together to form clots, and inheritance patterns are difficult to explain and understand and require an experienced interpreter. Interpreters, however, often are not available. Moreover, available interpreters usually are inexperienced and frequently chosen indiscriminately from among whoever is bilingual and available at the time (Levin 2005; Penn 2007).

Lay understanding of genetics has been well researched in the western world, especially pertaining to bilateral kinship systems, in which kinship ties are traced through both parents (Richards 1998). Little research however has focused on patrilineal descent systems, where kinship is traced through the paternal parents; patrilineal descent systems are common in many Asian, Middle Eastern and African cultures (Modell 1997).

Beliefs concerning the cause of a condition are often culturally determined, and recent research in South Africa has focused on identifying different models of causation and treatment seeking in South Africa (Herselman 2007; Van Rensburg and Ngwena 2001). Understanding the needs of a cultural group is essential to improve the role played by health care providers and genetic counselors (Herselman 2007; Penn et al. 2010). Historically, medical genetic counseling models from developed countries have been used to train genetic counselors in South Africa and to provide services which are based on first world standards and facilities. South African clinical genetic specialists provide such service in both tertiary institutions and at primary care level in the form of outreach clinics. A critical shortage of trained genetic professionals in many parts of the country has left a large part of the population without access to genetic specialists. However, in SA the population is culturally and socio-economically very diverse and these models may not be applicable to the rather unique environment (Penn et al. 2010). The approach to counseling in South Africa almost certainly needs to be modified in order to improve its effectiveness in this diverse, multicultural setting.

Purpose of the Present Study

There is a lack of empirical data in South Africa regarding lay public understanding of genetics among Xhosa speakers who come from a patrilineal descent system. Given the cultural and linguistic challenges and the lack of interpreters who can effectively convey complex aspects of hemophilia described earlier, the aim of the present study was to explore in more details the understanding of genetic inheritance among Xhosa-speaking caregivers of boys with hemophilia. The major research questions investigated were as follows:

- What is the understanding of caregivers about haemophilia, how is it inherited and what aspects link to support seeking?
- What are the experiences of caregivers caring for someone with hemophilia?
- How do cultural belief systems impact on this understanding?
- What barriers to clinical service can be identified?

The study design was qualitative and data were collected from in-depth interviews.

Methods

Participants

Ten participants over 21 years were recruited among first language Xhosa-speaking mothers/caregivers of boys with hemophilia A or hemophilia B. These individuals attended the hemophilia support group in Khayelitsha and/or the regular hemophilia clinics at the Red Cross War Memorial Children's Hospital and they expressed a willingness to be interviewed by an interpreter, with the investigator being present. This sample was a convenience sample drawn from a group of about 15 caregivers who attend the support groups held at a Day Hospital in Khayelitsha. Delivery of hemophilia health care in South Africa occurs through a network of hemophilia treatment centers, which function under the auspices of the National Department of Health. Children with hemophilia, under the age of 18 in the Western Cape, are referred to the Red Cross War Memorial Children's Hospital for diagnosis, counseling by specialized nurses, in some instances genetic counseling and treatment. It is a teaching hospital for child health, research and training. Ethical approval was obtained from the Departmental Research and the Faculty of Health Sciences Research Ethics Committees of the University of Cape Town before commencement of the study (Reference number: REC REF 383/2006).

This study was undertaken mainly on the Cape Flats in Khayelitsha, one of the biggest, socially disadvantaged townships in the country. The Cape Flats is a large area on the Cape Peninsula where numerous housing projects were established by the previous apartheid government. Most of the present participants were residents of this township which is made up of different types of formal and informal dwellings. Where people live informally, shelters are generally constructed from used scrap metal, corrugated metal sheets, and even plastic. These informal settlements are characterized by massive social problems such as severe poverty, unemployment, lack of adequate housing, sewerage, water and infrastructure, as well as inadequate health services (Ndingaye 2005).

Participants included six mothers, two grandmothers and two aunts. With the exception of three caregivers who were interviewed at the Day Hospital in Khayelitsha, the participants were interviewed in their homes, which often only consisted of one room. If family members were present they tended to participate and some comments by husbands (fathers of affected children) were included in this study. This afforded some additional insights into cultural perspectives. Their level of education varied from "no formal education" to a teacher's diploma. Table 1 contains a summary of the participants' relevant socio-demographic data. After interviewing 10 participants, no new data was forthcoming and data saturation had been achieved for this study.

Instrumentation

A semi-structured interview schedule (Appendix A) was developed and translated into Xhosa by an interpreter. The first draft of the interview schedule was reviewed and discussed in a focus group meeting consisting of the investigator, two project supervisors, a lay isiXhosa first-language speaker as well as an isiXhosa first-language speaker with a background in science. The objective of the focus group was to ensure that the questions would be easily understood once translated into isiXhosa and that they would be sensitive to the culture of the participants. The interview schedule included close-ended and open-ended questions. Close-ended questions were used to obtain demographic information and data that could be easily categorized. Open-ended questions were formulated to encourage free responses and allow the participants to tell their story. The questions sought to explore when the participants first became aware of their child's condition, what their understanding and concerns were as well as their own interpretation of the condition. Further questions focused on their perceptions and beliefs concerning hemophilia, whether they believed that there were any cultural explanations for this disorder the extent to which they understood the genetic implications of hemophilia, and what they generally understood by the term "inheritance."

The semi-structured interview schedule allowed for the addition, exclusion or variation of the wording of particular questions, in response to the participants, albeit without changing the meaning of the questions (Murray and Rhodes 2005). This was necessary because isiXhosa (Xhosa language) lacks words, especially for new, scientific concepts such as "DNA," "genes," "genome" and "genetic predisposition." Because certain words and ideas simply could not be translated directly, they needed to be paraphrased according to each participant's personal experiences, so that they could understand (Patton 2002).

Because the first author is not familiar with isiXhosa or the cultural life of the study group, it was necessary to employ an interpreter to conduct the interviews. The interpreter for this study did not know any of the participants and/or family members. She was in her final year of a BPsych degree in Health Sciences and Social Services with specialisation in Counselling Psychology at the University of South Africa (UNISA). She had further completed a 6 month theoretical course in HIV/AIDS Care and Counselling with UNISA. Prior to the interview process, the interpreter and first author had several meetings and practice sessions, during which the subject, aims and interview schedule were discussed. A pilot study was conducted to assess whether the interview questions

Table 1 Socio demographic and biographical data of the participants

Participant	Age	Relationship to patient	Previous Residence	Present Residence	Educt.[1] Grade	Years in CT[2]	Urban settlements	
							House	Shack
C1	40–50	mother	E.Cape[3]	Philippi	3	9		X
C2	no data	mother	E.Cape	Philippi	12	4	X	
C3	30–40	aunt	Khayelitsha	Khayelitsha	11	–	X	
C4	40–50	mother	E.Cape	Khayelitsha	T.D.[4]	11	X	
C5	no data	mother	no data	Khayelitsha	no data	no data		
C6	30–40	aunt	E.Cape	Khayelitsha	12	15	X	
C7	60–70	grandmother	Khayelitsha	Khayelitsha	8	–	X	
C8	60–70	grandmother	E.Cape	Gugulethu	none	27	X	
C9	40–50	mother	E.Cape	Khayelitsha	6	20	X	
C10	30–40	mother	E.Cape	Khayelitsha	10	19		X

[1] *Educt* education

[2] *CT* Cape Town

[3] *E.Cape* Eastern Cape

[4] *T.D.* Teacher's diploma

The researcher only became aware of the missing demographic details for C5 once the interviews had been transcribed. Several attempts were subsequently made by the interpreter to contact C5 by telephone, but without success

were clear and unambiguous and to estimate how long it would take to complete the interview. The need for an interpreter reduced control of the interview from the researcher's perspective, as it was not always possible to control the direction of the interview or to direct adequate probes. It also put extra pressure on the interpreter who had to quickly become familiar with the subject matter, the aims of the interview and the interview schedule. The first author was however always present at the interviews and as the interpreter became aware of key points she would summarize those points to the researcher to allow for probing questions to be asked. The interpreter was empathetic and friendly and established an easy and good relationship with the participants. She established rapport through positive verbal and nonverbal encouragement. Good eye contact, smiling and open body language ensured that the participant felt comfortable with the process and sufficiently relaxed to "talk back." She also developed an understanding of probing questions. The researcher acted as an observer during the interviews, taking notes of the interview process, of the environment and, if applicable, interactions between family members.

Procedure

Three interviews were conducted in a tearoom at the Site B Day Hospital and seven in the homes of participants in and around Khayelitsha. The interview venues were chosen by the participants depending on what was most convenient to them. The tea room at the Day Hospital was familiar to the participants because regular haemophilia support group meetings are held at this venue. The tea room was available exclusively to the interviewers and caregivers for the duration of the interviews. The interviews were conducted in isiXhosa by an interpreter while the first author, as mentioned previously, was present as an observer. Participants were reassured that they were free to ask questions or to withdraw from the interview at any time. The interpreter conducted the interview over approximately 45 min to an hour guided by the interview schedule (Appendix A). Interviews were audio-recorded with the permission of the participants and qualitative data were generated from the transcribed and translated audio-records as well as from participant-observation notes taken by the investigator.

Transcripts were transcribed verbatim and then translated into English. Three transcribers were employed over the course of the study and, in each case, the transcriber also translated the Xhosa transcripts into English. Ideally a translator should be a native speaker of the target language (Translation Working Group 2009). It was however not possible to employ a native English speaker who was fluent in isiXhosa for this study. Limited funding prevented the use of professional transcribers or translators and these processes were thus performed by lay people.

Analysis

Data obtained from the open-ended questions were grouped by the first author into "content areas" that were related to the interview questions. Responses to those questions represented "meaning units" that were condensed and then represented as "codes." Codes were grouped and sorted, from the bottom up, into categories until ultimately four themes emerged (Graneheim and Lundman 2004). Capture of data, selection of categories and findings were discussed with specialists in the field of Human Genetics, Anthropology and Linguistics. These discussions provided closely-monitored feedback on the research process.

Results

In the following section each theme is presented and ordered according to the sequence shown in Table 2. Table 2 also represents an overview of how data were organized into themes and categories. To ensure anonymity participants were given a code as per Table 1 (which also lists their socio-demographic and biographical data). Representative responses that reflect the experiences of this study group are provided in italics. Participants' responses were categorized under headings that corresponded to emergent themes.

It became evident in some of the translated transcripts that, as mentioned earlier, the translators were not native English speakers. Obvious spelling or grammatical errors were edited; otherwise, translated transcripts were left in their original format.

Theme 1. Interaction with Community and Extended Family

This theme refers to participants' decisions to share the child's condition and also describes from whom they might seek support. The theme is subdivided into two categories: 1) Communication with community and 2) Communication with extended family.

Table 2 Overview of categories and themes

Themes	Categories
1. Interaction with community and extended family	• Communication with community • Communication with extended family
2. Taking care of a family member with hemophilia	• Background knowledge of Hemophilia • Experiences with obtaining a diagnosis • Treatment challenges
3. General understanding of inheritance	• General inheritance • Inheritance of Hemophilia • Understanding or knowledge of genes
4. General and cultural beliefs	• Bleeding • Traditional Medicine

Communication with Community

All participants lived in either formal or informal houses in very close proximity to their neighbors and privacy was often compromised. In spite of that, many felt it was best to "keep to oneself" in the urban environment, and therefore they decided not to inform community members about their children's condition.

> C8: I don't discuss my issues with my neighbors as you are aware that in the cities each person focuses on his or her business and not other people's problems. You cannot be telling your problems to everybody that you meet.
>
> C1: No, my neighbors are not aware except for my family members. There's few of them that know about this. The parents of these children [friends] are not aware about the situation.

Communication with Extended Family

Generally the extended family members, many of whom still live in rural areas, were informed, especially if they needed to take care of affected boys in the absence of the caregiver. Some participants have migrated to Khayelitsha from the Eastern Cape out of necessity to be close to medical centers that are equipped to deal with their affected children. They do however maintain strong ties with their families in the rural areas and will visit on a regular basis, especially during school holidays. Informants seemed aware of the differences in perspective in urban and rural areas as illustrated in the following point:

> C5: No, I didn't tell them about his problem of having skin growths [swellings]. I only talked about it after I came from the hospital [after diagnosis]. Before I couldn't explain this or tell anyone about it. It's only now that I am open about his condition but before I was skeptical to talk about it. As people who come from rural areas it is difficult to talk about certain issues and start telling everybody that so and so is having such a condition. It's rare that people will take note on a child that is bleeding - it's not something that they will take serious.

Theme 2. Taking Care of a Family Member with Hemophilia

This theme refers to challenges experienced by participants in taking care of a family member with haemophilia. There are three categories: 1) Background knowledge of hemophilia, 2) Experiences with obtaining a diagnosis and 3) Treatment challenges.

Background Knowledge of Hemophilia

There appeared to be virtually no background knowledge of hemophilia among the participants. The interpreter asked what they knew about the disease or whether they had ever heard about it before, and 9 of the 10 participants responded with a straightforward "no." They had never heard of hemophilia or its symptoms until they were told about it by the doctors.

> C9: No. Even the name hemophilia, I don't hear it when they say it, even when it is explained I do not understand it.
> C8: I didn't know anything about this condition. I've never heard of it.
> C1: Never, we only heard from a doctor when he diagnosed him. We never heard about it before. Was this illness there before? When did you discover Hemophilia at the hospital?

One participant had some knowledge and remembered having been taught about hemophilia at school.

> C5: I first learnt about it at school, where we were told that it happens when the blood does not clot. I never thought I would have a [it would happen to my child] child with this disease, I just knew the name and that was all.

Experiences with Obtaining a Diagnosis

At the start of the study none of the participants were aware of a family history. During the time of the interviews a grandmother, who took care of two boys realized that both boys had the same condition after the second boy, a mild hemophiliac, had suffered a head injury. She initially believed that the head injury was the cause of hemophilia but gradually came to accept that both boys had inherited the same condition. As none of the children in this study had been diagnosed at birth, participants were initially unaware of the condition, and the children's frequent nose bleeds and bruising had caused fear and confusion for most.

> C6: He would get swollen joints and we didn't know what was happening...... we were so concerned and also scared of why he is not getting better when he gets swollen.
> C1: What used to worry me was that I thought he wasn't going to get help and also I thought he was going to die.

According to participants, there appears to be almost no awareness of hemophilia among health care workers in the rural areas of the Eastern Cape. Participants reported that clinical staff in those areas had a poor understanding of the symptoms or treatment required and that boys with hemophilia did not receive adequate care.

> C6: We originally come from Eastern Cape. He was not getting help there, and we decided that he must come here in Cape Town
> C2: … they [extended family] usually struggle because the clinics in the Eastern Cape are not able to help.
> C1: I've noticed when he played and sometimes if he fell off or he trip off and he would swell up. When I took him to the clinic, nurses at the rural clinic could not see what he was suffering from [didn't know]. My brother invited me to come to Cape Town to the Red Cross Children's Hospital. At Red Cross I was told about my son's illness and what he was suffering from.

Experiences Associated with Hemophilia Care

Hemophilia is a life-long chronic disease which imposes a heavy burden on families. Participants reported suffering from the stress of continuously being on stand-by and having to rush to hospital at a moment's notice. Their comments included mention of the unpredictability of recurrence, financial burdens, and their emotional reactions to the child's illness.

> C8: There used to be a big concern because sometimes I had to rush him to the doctors after work at around 17H00. At times I am exhausted, but I have to take him to the Red Cross Hospital because of this bleeding ….
> C2: Whenever there is a call from school I usually have to leave work immediately to see to the problem. When he gets sick I must forget about work and rush to wherever he is.
> C9: The problem with him is that his sickness just comes up, it stays off for a bit and when it comes back, it overwhelms him, he becomes very sick and I struggle because I have no means….. [Crying] It did, it has… this situation has changed my life [Sobbing]. It changed it a great deal because I cannot do anything [with a shaking voice]. Even when I crave meat from the vendor stands, when I buy it and get home to find my child sick I feel very guilty because I feel as if I should have known. When I find him sick I regret delaying at the vendor stand and buying the meat, and I would not know what I will come to when I get at home…It's his sickness and him not getting a grant for it. I don't have support in my house and if he had a grant at least, I would be able to use the money to find help and a cure for him……..

Cause of Hemophilia

Most participants were not well informed of the cause of hemophilia (i.e., it is a genetic disorder, and at the moment, there is no cure). While participants were in frequent contact with medical staff, there appeared to be a barrier in communication as the necessary facts were not effectively communicated, as depicted by the following quotes.

> C2: I don't know [what caused it]. In Grade 12 they did not get into details about it; we were just told of it as a type of cancer and nothing more.
> C8: I honestly don't know. This is something that I cannot answer, for it's only God knows as I have alluded before, nobody would know the reason why this happens; only God knows especially about this particular condition.
> C7: I thought it is because of the head injuries. He was beaten with a golf stick.
> C6: ….. no, we were not told [the cause of Hemophilia].

Treatment Challenges

Overall participants' understanding of treatment was poor, despite the fact that affected boys had visited clinics frequently and drips had to be administered on a regular basis. Many caregivers preferred to leave it up to the doctors' discretion to make treatment decisions and reported little desire to learn more about the treatment or treatment options.

> C7: I don't know his treatment and I can't really comment on his treatment as I do know nothing about it, and [I] am also not familiar with the terms since I am not a nurse nor a doctor, so I can't say this is not right for him and that is good for him.
> C3: I am not sure, because when he went to Red Cross he got something, I just cannot think what it was. …………No, he is not on any medication, but he got something when he went because of the accident [the fall]. He is not taking anything; when he goes to Red Cross he gets whatever relevant medication at the time, otherwise he is not sickly.
> C8: I can't tell you. I don't know. They inject him.

Three older affected boys, in their teens, and one participant had been taught to administer the drips themselves and were thus able to infuse blood clotting factor as needed for an injury or a spontaneous bleed.

> C2: They also taught me how to treat him so that I don't have to go there all the time for the treatment
> C6: When he feels that he played a lot or hurt his wrist he usually takes himself his medication

Theme 3. General Understanding of Inheritance

To ascertain what participants understood by inheritance, open questions were asked about their thoughts on why some people get ill and others do not, about what they understand if a condition is referred to as being inherited and from whom a condition would be inherited. There are 3 categories: 1) General inheritance, 2) Inheritance of hemophilia and 3) Understanding or knowledge of genes.

General Inheritance

Participants were asked whether they were aware of any illnesses in their family that were passed down and to share their thoughts about inheritance (descent) and about the location of genes in the body.

Several participants acknowledged that some conditions occur in families.

> C2: It [inheritance] means you got something from somebody else. Maybe when someone has some disease, it is said that they inherited it from another family member.
> C9: People do take after others; I think sometimes you take after someone whom you have never even known
> C10: When you talk of inheritance, I think of someone who has taken after some old family members who have long passed away, or close relatives, for an example from mine or his father's side….
> Interviewer: How do you mean?
> If for instance there was someone who had this problem, but someone I never even knew…..….I think it's a case of someone having a problem that another member of the family had before, even if it is not exactly the same problem. I am not sure if I am answering you appropriately…

One participant appeared confused about the question of inheritance and was unsure from whom her child would have inherited hemophilia. At the same time she made a connection to her own mother who died during childbirth. It was not clear whether she believed that genetic ties were broken because her mother died while giving birth to her.

> C5: Interviewer: Is the condition inherited?
> I don't know, maybe, I can say that, but I don't know what else to say. Where did he get this inheritance from? My life story is that my biological mother passed away when she gave birth to me. You know in the rural areas women used to bear children at home [not in hospitals] I don't know why.

When speaking about inheritance, participants referred to physical, behavioral and moral characteristics possessed by a parent and passed on to a child. One participant seemed to have the view that, given that there are two children, one will inherit from the father and one will inherit from the mother. Unfortunately, no further probing questions were asked by the interpreter to explore this perception in more detail.

> C4: I can say for example, as I have two children one of them will inherit from me. Let's say the one child is naughty and the other is sweet [well behaved]. The other one might be naughty and his dad may not have such behavior. Maybe I might be the one who is naughty and not their father. I can pick up my bad behavior from the child, and I can easily say that this child's behavior resembles my character when I was a child. That's how I know inheritance.

Participants also referred to stronger genes (or dominant parental sides of the family) and attributed physical resemblance or behavior to the parent with the stronger genes.

> C4: Let's say his daddy's genes are not as strong as mine. My strong genes will dominate the father's and the child will inherit my genes.
> C5: You do understand that it is common with us African [Black] people to hear people saying a child looks just like his father and the mother has lost the battle. What I meant is that the most powerful and strongest and dominating side is my mother's in this sense, and my dad's side is weak.

Two participants actually referred to genes when asked about inheritance. There is no equivalent Xhosa word for genes and interpreter and caregivers uses the word "i-genes" which is borrowed from English.

> C4: I'm saying that as we had an encounter with the father of my child my genes will regenerate to my child during my pregnancy period and when I give birth to him, he will be born with my genes in him and not his dad's as I have the dominant genes.

The interpreter referred to this response and continued probing: "You talked of genes that are inferior and dominant to others. Do you think that the child will not take the weak genes and is bound to take yours just because they are dominant or strong?"

> C4: Yes, I do

Another participant expressed similar ideas about strong and weak genes.

> C5: Interview Question: So I want to know if the child cannot have the weaker genes as well?
> No, I don't think so. He will take those strong ones; maybe since they are strong they will quickly be passed to the child as they are strong.

Unfortunately the interpreter did not continue probing how she thought the genes would be passed on to the child.

There were several instances where reference was made to the mother that gave birth to the child when referring to inheritance.

> C3: …something that was passed on to you by the person who gave birth to you. ……maybe whoever gives birth to you, transfers it to you through the blood, and then it only comes out at a later stage.
> C8: Interview Question: Can the child inherit from the father?
> No, he doesn't inherit from the father because he is kept inside his mother's womb…...... It's like he is sharing the same blood with his mother, he eats from her. He draws everything from his mother. It is like a drinking mother [that transfers alcohol to the child] there is something happening to the child when she drinks - such things are bound to happen. That's how I understand it that all things come from the blood.
> C8 (husband of C8): (How is the condition transferred to the child?)To be infected [contraction]? Yes, it is your blood especially if you were not treated for this and as you breastfeed he grows and it manifests itself in his body.
> C10: Interviewer: What do other people think is the cause?
> They just say that maybe I ate something wrong, so when I got pregnant I carried it with the pregnancy.

Another participant believed that the child would inherit only from the father, because he was the one that "performed" during intercourse and that "genetic material" is passed on by means of a hormone.

> C1: I would say it comes from the father's side. I think that it is the father that performs when he sleeps with the mother .... maybe there is a hormone that gets secreted when you mate.

Although this participant appeared to be familiar with the fact that certain conditions (for example, cancer) run in families, the principle of genetic disorders did not seem to be understood. She suggested the possibility of inheriting from a deceased relative, especially if the child was born after that person had died.

> C7: My father had passed away a long time ago with throat cancer, where is the connection, and the child was born in 1992? The child [my brother's] also passed away from the same illness that my father had.

Two participants were either not familiar with the term inheritance in connection with illnesses or may not have understood the question.

> C4: [When asked about inheritance of an illness]: No. I haven't heard of that one. I don't want to lie to you.

> C9: Of sickness - No I don't know, I get confused.

Inheritance of Hemophilia

Based on their responses, it became apparent that no participant had a clear understanding of X-linked recessive inheritance.

> C8: …don't know. I wouldn't know, and I cannot answer to that. Only God knows.
>
> C2: According to my knowledge it is a boy's problem, although they inherit it from their mothers. My knowledge was increased when I heard of it at Red Cross, where they drew blood from my genes, and I learnt that it is something that is apparently inherited. Even when they explained at the Red Cross, I never took it serious, I just told myself that it was going to pass, I did not think it was a life disease. I do not know, but they did some blood tests on me and they said they did not see [it] in me. I really don't know because according to them, a child inherits it from the mother.
>
> C2 (husband of C2): I initially thought it was because of the injection from the KTC Hospital doctor that was the problem, or that caused the problem. As time went [on] I also realized that there are outstanding cultural traditions and rituals that I needed, which could be causing this illness. (KTC is the name of a squatter camp near Gugulethu. The *KTC* Day *Hospital* was formerly known as the Gugulethu Maternity Obstetrics Unit)

Family History of Hemophilia

Participants were asked whether they were aware of any family history of hemophilia. One aunt recognized that there was a family history because two of her nephews were affected.

> C3: I think so, because there is another nephew (my other sister-in-law's child) who has the same problem. I think they were born with this.

Generally there seemed to be no knowledge or understanding of a family history. The following two quotes suggest a family history, but this is based on the assumption that the disorder was inherited from the paternal line. As hemophilia is an X-linked disorder, it could have only been passed on by the boys' mothers and not by the paternal relatives.

> C1: …it was his grandfather's brother, and our mother only told us when we asked. We didn't know and we were asking my mother, just to know if he inherited it from his forefathers.
>
> C10: I just heard that his grandfather, from his father's side, used to have nose bleeds, but as a man who believed in herbs, he used to treat it with traditional medicines and he would come right.

Understanding or Knowledge of Genes

Questioning on this topic was difficult because there are no equivalent Xhosa words or terms for genes. This issue was discussed during debriefing with the researcher after the interviews, and it was decided that the interpreter would try to paraphrase. The translated transcripts however revealed that on some occasions the interpreter misrepresented the word "genes" and used misleading expression by referring to "white blood cells," "cells that defend your body" and "blood cells."

> C9: Interviewer: There's sometimes talk of cells that defend our bodies from diseases. Have you ever heard of them?
>
> I don't know. I just know that they exist and don't know much
>
> C10: Interviewer: Where do you think the white blood cells are in your body?
>
> I think they are around the body.
>
> C1: Interviewer: There are blood cells. Have you heard of them?
>
> I don't know that thing. I just hear about the blood cells. I know about joints, the body parts.

Generally participants did not know what or where genes are and after some prompting suggested that they might be in the blood. Many communities use blood as a metaphor for the medium through which conditions are inherited (Featherstone 2005). People use expressions such as "it's in the blood" and "blood" links generations when people speak about blood lines and blood relatives.

> C7: I don't know, and I don't want to lie. The only thing that I know is when the child is born he/she could be like her mother or father. But I don't know how. I should think in the blood.

Theme 4. General and Cultural Beliefs

Interview questions aimed to elicit how the participants understood this bleeding disorder and how they were making sense of the condition. They were asked what their fears or worries were and what other people thought of the condition. There are two categories: 1) Bleeding and 2) Traditional Medicine.

Bleeding

Participants had no explanation as to why there were bleeding episodes, especially as they occurred without obvious trauma. Some participants thought that it was connected to the ancestors and that outstanding rituals should be performed.

> C4: Interviewer: What does this bleeding mean to you?
> I am not sure what to say. If he was a girl, I would say it had to do with periods, but because he is a boy I don't know what to think. Bleeding is not something that just happens, it happens when you have had an operation, or if you have been involved in some accident. It does not just happen. That is why I cannot explain it.
> C2: (husband): I usually associate it with some cultural ritual that must be done. I am not sure.
> C9: I know only of nose bleeding, for us in Xhosa the nose bleeding is not usually a serious or a fatal thing. According to us, nose bleeding is some sign [spontaneous] from our ancestors. Maybe they have thought of you and are now reaching out to you - Okay I hear you.

Traditional Medicine

Rituals

In Xhosa society, traditional healers appeal to ancestors for help in diagnosing problems and prescribing remedies and routinely check to see if illnesses are caused by their clients having violated cultural norms and traditions (Nattrass 2006). One boy's father suspected that his child was affected because rituals or traditional ceremonies had not been properly addressed, and he was planning to look for guidance from traditional healers.

> C2: (husband): Yes, a child would be sickly when young, and turn around to be the most helpful when old. Like my son, he is sickly now, maybe when he grows old that will stop, the illness may be a sign from the ancestors. The meaning of it could be that there is an outstanding ritual that has to be performed for the child, or for the ancestors. When a child is sickly you would not know what to do, and overlook the possibility that it is related to some traditional ceremony that is required. You only realize at a later stage when the child is not getting cured. The issue of our rituals is a delicate and difficult one; it is not easy to just get into it.

Another participant's husband also thought that the disorder was linked to some (missing) rituals, because he could not imagine what else could have caused the symptoms.

> C8: (husband): We sometimes think of that [rituals] honestly because what could be the cause of the lumps?

One participant, whose own father suffered an "African death" (believed to have been caused by witchcraft), related that the child's father also suspected outstanding rituals or ceremonies to be the cause of their son's condition.

> C4: He [child's father] says he suspects that it is because of the rituals or traditional ceremony that they have not attended to. And from my side I cannot say much because my parents died. My dad suffered an African death as a result. He died suffering from a leg problem.

Another participant recounted that rituals were performed by the child's paternal family and these rituals had improved his condition to some extent.

> C9: The reason he went to Cifimvaba [Eastern Cape] was for his family [father's side] to fix him. There was some relief after that until he came back to Cape Town. He came back with some boxes, and he was a bit better.
> Interviewer: By fixing what do you mean?
> Slaughtering. They slaughtered for him and performed cultural rituals.
> Interviewer: He came back better?
> Yes, he came back better.

A different participant expressed doubt that tradition is linked to hemophilia because her traditional healer had confirmed that all necessary rituals had been performed. She did however contemplate the possibility that some ritual may have been overlooked.

> C1: I don't think my tradition has got link to the bleeding because when I went to find out about the tradition perspective to this problem, we were not told to do any ritual because we've done all necessary rituals. Not unless there is something that we are missing, that we are not aware of, we have done everything

Traditional rituals were still very much interwoven with the daily life of most participants. It is believed that ignoring the spirits of the ancestors, who protect the living community, can cause problems that can manifest in poor health or misfortune (Wessells and Monteiro 2004). A newborn's entry into the local community, for example, is marked by a series of rituals aimed at introducing the new baby to the community and ancestors and to obtain ancestral protection against sickness (Jewkes and Wood 1998).

> C10: I sometimes think maybe there are some traditional ceremonies that need to be performed, but we have done most of those, especially those serious ones that are likely to cause this kind of problem. However, we are afraid to do some, for an example, the "cutting of the finger."

Traditional Healers

A large majority of South Africans still use traditional healers as their first source for medical advice. These practitioners, who are often also respected opinion leaders, are generally caring people who treat their clients holistically and consider all aspects of their lives (Kale 1995; Pretorius 1999). Participants were asked what kind of treatment their child should receive and whether they thought that there were possible alternatives to western medicine.

> C2 (husband): I have even mentioned to my wife that maybe I need to go away to Botswana, or maybe Johannesburg, Gauteng, or may be Durban, to "consult" [getting in touch with the traditional doctors], because I need some guidance on what this is and what its meaning is.
>
> C4: One lady suggested that I should try taking the child to a Sangoma or traditional doctor so that I can ascertain what the problem is. I told myself that I won't go there because to pay a visit there I have to pay something. I don't have money as I am unemployed…One person [child's paternal grandmother] said I should take him to a Spiritual Healer so that I can get to the bottom of this problem. She attends a spiritual healer's church. Even so I get discouraged to go there because of my church beliefs. In my church, Wesley, we do not have a Spiritual Healer……….

Discussion

This exploratory study investigated the experiences and understanding of a group of caregivers of persons with hemophilia, who came from a distinct cultural and linguistic setting in South Africa. Findings suggest that participants and their families had very little, if any, background knowledge of hemophilia. Participants also perceived their community and health care workers in rural areas of the Eastern Cape as similarly having a poor understanding of hemophilia and its pathology. Furthermore, it appears that boys with hemophilia do not receive adequate medical care in those areas. The lack of background knowledge of hemophilia within this cohort differs from that found in western countries, where there is at least some awareness. Greater awareness in western countries might be because hemophilia has affected the Royal Families of Europe for the last few centuries or because of the tragic consequences of tainted blood transfusions which spread HIV among people with hemophilia during the 1980's (Barlow et al. 2007a).

Living with hemophilia has posed a heavy burden on caregivers and their families, especially as occurrence and nature of symptoms are unpredictable. Daily life was often severely disrupted and participants had to unexpectedly and repeatedly rush patients to hospital. The participants seemed reluctant to speak to their community about hemophilia and the challenges they faced, and consequently they had little social support. Only a few reported that they were able to rely on help from neighbors during crisis situations. Some participants had migrated to Khayelitsha from rural areas in the Eastern Cape to be close to medical centers, but they continued to regularly visit and maintain close ties with their rural families. The extended family in those rural areas had generally been informed about the symptoms and dangers of the condition, especially if they needed to take care of affected boys in the absence of the caregiver. The participants' decisions to disclose seemed to be based on a "need to know." This links to the work of Beeton et al. (2007) and Cassis (2007) who found that a perceived lack of understanding of the disease by others and a fear of rejection often results in secrecy by parents or by the patient concerned. The results of a survey by Barlow et al. (2007b) in the United Kingdom similarly suggest that there is a stigma attached to having Hemophilia and that many are very careful about informing others about their bleeding disorder. Caregivers were generally deeply affected by their children's condition and, in addition to constantly feeling anxious, also incurred considerable indirect financial costs. The unpredictable nature of the disorder affected employment and employment options for some.

Caregivers of boys affected with hemophilia usually visited specialist clinics relatively frequently, an activity which should ensure a reasonable understanding of the condition. In this study, despite frequent contact with medical professionals, participants often lacked information about treatment and were unfamiliar with terms used by medical professionals. Participants generally seemed to trust medical professionals to treat symptoms and tended to leave the locus of control with them. Similarly, they seemed to have no or, at most, only basic knowledge of the cause or pathogenesis of hemophilia. Many mentioned that they wished to turn to traditional medicine to find answers to the cause of the condition.

People naturally have a fear of the unknown, and it is important that explanations given are clear and adapted to the target audience to increase their understanding and to help them come to terms with the condition. It has been mentioned previously that the dominant languages in most major hospitals in the Cape Town region are English or Afrikaans and isiXhosa speakers face the difficulty of communicating in another language. As a result they experience problems in understanding complex concepts such as X-linked inheritance, genetic causes of hemophilia, and how blood clotting factors work together to form clots. Another consequence to having to converse in a language other than their home language could be that participants are not always able to ask appropriate questions, and thus important issues remain unanswered.

Participants generally referred to inheritance in association with physical, behavioral and moral characteristics that are passed on by parents, relatives or long-dead ancestors. It was, however, not clear how they understood these traits to be passed on to children. It is possible that a more experienced interpreter using more appropriate probing questions would have elucidated their perspectives in this regard. The following exchange between one participant and the interpreter highlights some of the drawbacks associated with having to rely on an interpreter-interviewer: "…*I think of someone who has taken after some old family members who have long passed away.*" The interpreter then probed by asking "*What do you mean*?" to which the participant responded by repeating what she said before, just putting it into other words: "*If for instance there was someone who had this problem, but someone I never even knew.*" The interpreter then left it at that and did not continue to probe into the participant's thoughts regarding the mechanism by which traits are passed on from generation to generation. It also appears that the participant felt as if she were being tested and was under pressure to give an appropriate answer: "…*I am not sure if I am answering you appropriately.*" As stated previously, the interviews did not reveal whether or not participants, while they accept that certain traits or conditions are passed on from generation to generation, have any ideas about how they are passed on.

Port et al. (2008) report on the processes undertaken to provide a culturally sensitive service for the Maori people of New Zealand. They found that most of the information generated to date on the interpretation of mutational analysis has been based on a Eurocentric model. This western model of individual autonomy could not be integrated into the hierarchical tribal structure of the Maori which includes inherent rights of the collective. Similar to the Maori, the amaXhosa are a population with a hierarchical tribal structure. Furthermore, as opposed to western cultures, the amaXhosa are a patrilineal society in which the line of kinship and descent is traced through the paternal line and a man and his brother, their children and their son's children, are counted members of the same descent group.

Personal observations by the first author and review of transcripts showed that participants were reluctant to elaborate when asked about inheritance, and they may have felt apprehensive because they felt unable to answer certain questions. When asked about how they thought a condition could be inherited, several participants made reference to "the mother that gave birth to the child." There was a common notion that conditions are transferred through the mother's blood to the child. Several participants believed that while the child lives and grows inside the mother's uterus and is nourished by her, certain conditions can be passed on from her to the child. One participant made the comparison to a drinking mother, who would transfer alcohol to the child. Thus inheritance could be seen as an act of transferring a condition or problem to a child through the mother's blood or even through what she eats. While there were various ideas about how a child could inherit from the mother during pregnancy, the questioning/probing during the interviews did not elicit an explanation of how a child would inherit from the father. One participant and her husband maintained that the child draws everything from the mother and believed that inheritance is connected to the shared blood between mother and child. Another participant believed that the child can only inherit from the mother, because she carries the child in her uterus.

From a traditional healing perspective pregnancies are seen as a very delicate time when woman may have lots of problems. Women and their babies are susceptible to environmental influences and are particularly vulnerable to "evil" or "spells" during that time. The perceived heightened susceptibility during pregnancy helps to explain the notion that this is the root cause of many problems the child may develop (Abrahams et al. 2002; Sifunda et al. 2007).

It further became apparent that participants had no clear understanding of Mendelian genetics and that previous explanations of inheritance given by medical professionals had not been understood and/or accepted. This was highlighted by one participant who expressed concern regarding a family history. She did not address this point during the interview, but only raised the subject once the interview was over and everybody was ready to leave. She commented that the interview had left her wondering, whether her nephew's inherited condition could have any implications for her or her own offspring. Although she was in regular contact with clinical staff, she felt the implications of a genetically inherited disorder for the family had not been effectively communicated to her. The researcher attempted a referral to genetic counseling along with an offer to contact her regarding an appointment. She was hesitant and instead elected to note down the telephone numbers and to contact the counseling service in her own time.

Genetic diseases are family diseases, but it is doubtful that information about genetic risk was shared with relatives, because the implications were not successfully communicated to or understood by the participants. Open communication about hemophilia within the family serves an important role, especially for daughters, to discuss their actual and possible carrier status and to make them aware and prepare them for potential future reproductive issues (Gregory et al. 2007). Daughters confirmed to be carriers, may have problems deciding whom to tell and when, and they may have to deal with the guilt of passing on hemophilia (Ross 2000). Carrier daughters may also be afraid that their marriage chances will be affected and may thus be reluctant to disclose their status (Miller 1999).

Some participants reported that they were prompted by community and family members to consult traditional or spiritual healers in order to find a diagnosis or a cure. While the participants were generally willing to accept the treatment of symptoms by western medicine they continued to look for the root cause of the condition by referring to traditional methods. The consultation of dual systems among the amaXhosa has similarly been demonstrated by Sifunda and colleagues (Sifunda et al. 2007). In the traditional worldview relationships with family, relatives, environment, ancestors and ancestral spirits are all connected, and solutions to problems are sought in consideration of all factors. An illness, except common illnesses such as colds or "natural illnesses," is often ascribed to ancestor activity or witchcraft (Buehrmann 1984). Other studies have similarly shown that models of disease causation held by individuals are often in contrast with scientific concepts and may incorporate notions of bad luck, chance and fate (Walter et al. 2004). The concept of traditional medicine and traditional healing was an important part of the participants' model of health (Buehrmann 1984; Pretorius 1999), and health issues seem to be viewed and discussed not only from the perspective of western medicine but also from that of traditional medicine.

The concept of "gene" was not understood. As there are no equivalent Xhosa words or terms for genes, the interpreter initially used the word *i-genes* (borrowed from English) and afterwards tried to paraphrase the meaning. The questions referring to genes or cells seemed to intimidate the participants who might have had the impression that they were being tested. They did not know what the interpreter was referring to and were unsure how to answer. The wording of the questions may have influenced the responses, and thus it would be necessary to find more suitable isiXhosa words or expressions to ask about or ultimately explain genetic inheritance. The concepts of "genes," "DNA" or "chromosomes" are not easily understood, even when there are no language barriers. Research in the western world has shown that, although there is mention of these terms in lay accounts, most do not specify how these may be related to inherited characters, and there is generally no clear idea of what exactly is transmitted between generations (Richards 1998; Richards and Ponder 1996).

Study Limitations

As mentioned previously, there are a number of methodological limitations that should be considered in drawing conclusions from the present findings. These include the limited sample size (although data saturation was achieved), as well as the difficulties encountered in using interpreters for data collection and analysis. Finally, qualitative data are not intended to be generalized to the population of interest. Additional studies are needed to establish the external validity of these results.

Practice Implications and Research Recommendations

Despite the methodological limitations of the present study, the findings suggest that cultural and linguistic factors play a profound role in the understanding and management of hemophilia. It seems evident that there is a need for socio-culturally tailored, language-specific education for families with hemophilia, either in their mother tongue or, if that is not possible, in the presence of an interpreter.

There was little awareness about genetic diseases among the participants, and counseling by medical professionals had either not been understood or been accepted. This has important implications for health care providers and genetic counselors in general and highlights the need to revise counseling interactions in a multicultural context and to modify models of training for genetic counselors. It is essential that health care providers and counselors be aware of different cultural values and beliefs in order to meet the needs of not only many isiXhosa speakers, but diverse cultural groups in general that live with genetic conditions.

The counseling received by nursing sisters during the time of a bleed may not be remembered or understood due to the stressful circumstances, and therefore support groups could be used as platforms to educate and encourage members at a level and in a language that is appropriate for that community. To promote better care, genetic counselors might be motivated to interact with the support group members at the monthly meetings. Genetic counselors could thus play an important part in treatment centers or during support group meetings to educate, not only affected individuals, but also to inform mothers and sisters of people with hemophilia about the genetics of the disorder and the hereditary risks involved should they decide to have children. Experienced interpreters, with broad life skills and good interpersonal relationships, should be available if education or counseling in isiXhosa is not possible. Such individuals would benefit from specific training in genetic terminology and concepts. They could help explore ways of paraphrasing or explaining genetic concepts such as genes, chromosomes or mutations in isiXhosa and also examine the options of exploring a possible confusion between inheritance and infection.

Counseling sessions tailored to this group's need would give affected individuals and families a more comprehensive picture of the condition that is affecting them, the genetic implications of their condition, as well as help them make more informed decisions about their health care. In order to develop guidelines to explain genetic concepts to participants and isiXhosa speakers in general, it would be advisable to consult a range of people in different roles or positions. This may be achieved through focus group discussions with isiXhosa speaking health professionals, members of the hemophilia support group, genetic counselors, and possibly traditional healers. These discussions could help explore ways of paraphrasing or explaining genetic concepts such as "genes," "chromosomes" or "mutations" in isiXhosa and also examine the options of exploring a possible confusion between inheritance and infection.

Future research should thus identify concerns that are culturally-based and develop strategies for addressing them in a meaningful way. For example, further in-depth studies are advised as these preliminary findings suggest that counseling interactions did not adequately inform participants regarding genetic implications of hemophilia. Such studies might include, for example, the perceptions of adult males who have the condition and exploration of perceived reproductive implications among daughters from families with Hemophilia.

Acknowledgements We are grateful to the interviewer, Ncumisa Zitho, for her positive and personable attitude during the interview process and her enthusiasm in helping us understand amaXhosa culture, Anne Cruickshank (Hemophilia Nursing Sister) for facilitating participation in the Khaya Rock HF support group and participating families for their willingness to share their personal information. This research was supported by a grant from the Medical Research Council and from the South African Netherlands Research program on Alternatives in Development.

References

Abrahams, N., Jewkes, R., & Mvo, Z. (2002). Indigenous healing practices and self-medication amongst pregnant women in Cape Town, South Africa. *African Journal of Reproductive Health, 6* (2), 79–86.

Barlow, J., Stapley, J., & Ellard, D. (2007a). Living with haemophilia and von Willebrand's: a descriptive qualitative study. *Patient Education and Counseling, 68*, 235–242.

Barlow, J. H., Stapley, J., Ellard, D. R., & Gilchrist, M. (2007b). Information and self management needs of people living with bleeding disorders: a survey. *Haemophilia, 13*(3), 264–270.

Beeton, K., Neal, D., Watson, T., & Lee, C. A. (2007). Parents of children with Haemophilia – a transforming experience. *Haemophilia, 13*, 570–579.

Betancourt, J. R., Carrillo, J. E., & Green, A. R. (2004). Barriers to health promotion and disease prevention in the Latino population. *Clinical Cornerstone, 6*(3), 16–29.

Buehrmann, M. V. (1984). *Living in two worlds: communication between a white healer and her black counterparts*. Cape Town: Human & Rousseau.

Cassis, F. (2007). Psychosocial care for people with haemophilia. *Treatment of Hemophilia* 44.

Cohen, L. H., Fine, B. A., & Pergament, E. (1998). An assessment of ethnocultural beliefs regarding the causes of birth defects and genetic disorders. *Journal of Genetic Counseling, 7*(1), 15–29.

Crawford, A. (1999). "We can't all understand the whites' language": an analysis of monolingual health services in a multilingual society. *International Journal of the Sociology of Language, 136*, 27–46.

Featherstone, S. (2005). *Postcolonial cultures*. Edinburgh: Edinburgh UP.

Flores, G., & Vega, L. R. (1998). Barriers to health care access for Latino children: a review. *Family Medicine, 30*, 196–205.

Goldstein, G., & Kenet, G. (2002). The impact of chronic disease on the family. *Haemophilia, 8*(3), 461–465.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), 105–112.

Gregory, M., Boddington, P., Dimond, R., Atkinson, P., Clarke, A., & Collins, P. (2007). Communicating about haemophilia within the family: the importance of context and of experience. *Haemophilia, 13*(2), 189–198.

Herselman, S. (2007). 'Health care through a cultural lens': insights from medical anthropology. *Current Opinion in Allergy and Clinical Immunology, 20*(2), 62–75.

Jewkes, R., & Wood, K. (1998). Competing discourses of vital registration and personhood: perspectives from rural South Africa. *Social Science & Medicine, 46*, 1043–1056.

Kale, R. (1995). South Africa's health: traditional healers in South Africa: a parallel health care system. *BMJ, 310*, 1182–1185.

Karaman, M. I., Zulfikar, B., Caskurlu, T., & Ergenekon, E. (2004). Circumcision in hemophilia: a cost-effective method using a novel device. *Journal of Pediatric Surgery, 39*, 1562–1564.

Kreps, G. L., O'Hair, D., & Clowers, M. (1994). The influences of human communication on health outcomes. *American Behavioral Scientist, 38*, 248.

Levin, M. E. (2005). The importance of language and culture in paediatric asthma care: communication problems between doctors and Xhosa speaking parents of children at a paediatric teaching hospital. *Current Opinion in Allergy and Clinical Immunology, 18* (1), 8–12.

Levin, M. E. (2006a). Language as a barrier to care for Xhosa-speaking patients at a South African paediatric teaching hospital. *South African Medical Journal, 96*(10), 1076–1079.

Levin, M. E. (2006b). Different use of medical terminology and culture-specific models of disease affecting communication between Xhosa-speaking patients and English-speaking doctors at a South African paediatric teaching hospital. *South African Medical Journal, 96*(10), 1080–1084.

Mayatula, V., & Mavundla, T. (1997). A review on male circumcision procedures among South African Blacks. *Curationis.*

Miller, R. (1999). Counselling about diagnosis and inheritance of genetic bleeding disorders: Haemophilia A and B. *Haemophilia, 5*(2), 77.

Modell, B. (1997). Kinship and medical genetics: A clinician's perspective. In A. Clarke & E. Parsons (Eds.), *Culture, kinship and genes* (pp. 27–39). London: Macmillan.

Murray, C. D., & Rhodes, K. (2005). Nobody likes damaged goods: the experience of adult visible acne. *British Journal of Health Psychology, 10*(2), 183–202.

National Haemophilia Foundation (USA). (2006). *Types of bleeding disorders.* Retrieved Feb, 2009, from http://www.hemophilia.org.

Nattrass, N. (2006). *Who consults sangomas in Khayelitsha? An exploratory quantitative analysis*. Cape Town: CSSR Working Paper No. 151, Centre for Social Science Research University of Cape Town.

Ndingaye, X. (2005). *An evaluation of the effects of poverty in Khayelitsha: a case study of site* C. (Master of Arts Thesis, University of Western Cape).

Patton, M. (2002). *Qualitative redearch & evaluation methods* (3rd ed.). London: Sage.

Penn, C. (2007). Factors affecting the success of mediated medical interviews in South Africa: review article. *Current Opinion in Allergy and Clinical Immunology, 20*(2), 66–72.

Penn, C., Watermeyer, J., MacDonald, C., & Moabelo, C. (2010). Grandmothers as gems of genetic wisdom: exploring South African traditional beliefs about the causes of childhood genetic disorders. *Journal Genetic Counseling, 19*, 9–21.

Port, R. V., Arnold, J., Kerr, D., Gravish, N., & Winship, I. (2008). Cultural enhancement of a clinical service to meet the needs of indigenous people; genetic service development in response to issues for New Zealand Maori. *Clinical Genetics, 73*, 132–138.

Pretorius, E. (1999). *Traditional healers. chapter 18. South African Health Review* [Internet] [cited 2008 Feb] Available from: http://legacy.Hst.Org.za/sahr/99/chap18.Htm.

Richards, M. P. M. (1998). Lay understanding of mendelian genetics. *Endeavour, 22*(3), 93–94.

Richards, M., & Ponder, M. (1996). Lay understanding of genetics: a test of a hypothesis. *Journal of Medical Genetics, 33*(12), 1032–1036.

Ross, J. (2000). Perspectives of haemophilia carriers. *Haemophilia, 6* (Suppl 1), 41–45.

Saohatse, M. C. (1998). Communication problems in multilingual speech communities. *South African Journal of African Languages, 18*, 111–117.

Saohatse, M. C. (2000). Solving communication problems in medical institutions. *South African Journal of African Languages, 20*, 95–102.

Sifunda, S., Reddy, P. S., Braithwaite, R. B., Stephens, T., Bhengu, S., Ruiter, R. A. C., & Van Den Borne, B. (2007). Social construction and cultural meanings of STI/HIV-related terminology among Nguni-speaking inmates and warders in four South African correctional facilities. *Health Education Research, 22*(6), 805–814.

Swartz, L., & Drennan, G. (2000). Beyond words: notes on the 'irrelevance' of language to mental health services in South Africa. *Transcultural Psychiatry, 37*(2), 185–201.

Taira, D. A. (1999). Improving the health and health care of non-English-speaking patients. *Journal of General Internal Medicine, 14*(5), 322–323.

Translation Working Group. (2009) *Translation protocol for lay documents* [Internet] [cited 2009 May] Available from: http://www.eurolight-online.eu/assets/89/589EA978-AAC7-A35A-D1B529E14B7A4A00_document/translation_protocol_for_questionnaire.pdf.

Tsang, A., Bogo, M., & George, U. (2003). Critical issues in cross-cultural counseling research: case example of an ongoing project. *Journal of Multicultural Counseling, 31*(1), 63–78.

Turner, W. L., Wieling, E., & Allen, W. D. (2004). Developing culturally effective family-based research programs: implications for family therapists. *Journal of Marital and Family Therapy, 30*(3), 257–270.

Van Rensburg, H. C. J., & Ngwena, C. (2001). Health and health care in South Africa: Against an African background. In W. Cockerham (Ed.), *The Blackwell companion to medical sociology* (pp. 365–391). Oxford: Blackwell Publishers.

Walter, F. M., Emery, J., Braithwaite, D., & Marteau, T. M. (2004). Lay understanding of familial risk of common chronic diseases: a systematic review and synthesis of qualitative research. *Annals of Family Medicine, 2*(6), 583–594.

Wessells, M., & Monteiro, C. (2004). Healing the wounds following protracted conflict in Angola: A community-based approach to assisting war-affected children. In U. P. Gielen, J. M. Fish, & J. G. Draguns (Eds.), *Handbook of culture, therapy, and healing*. Mahwah, NJ: Lawrence Erlbaum.

Zulfikar, B., Karaman, M.I., & Ovali, F. (2003). Circumcision in hemophilia. An overview. *Treatment of Hemophilia.*