Language as a Barrier to Informed Consent and Patient Communications in South African Hospitals-A Working Paper

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Abstract

Background: The ability of healthcare professionals (HCPs) to communicate effectively is critical to the quality of healthcare. Barriers to communication arising from illiteracy and language could prevent common understanding of medical procedures, thereby putting patients at risk of providing informed consent (IC) without comprehension, and also increases medical errors, deprives patients of their constitutional rights to information, and could engender medical negligence. The National Health Act 2003 stipulates that HCPs obtaining IC, "*must, where possible, inform the user in a language the user understands and in a manner which takes into account the user's level of literacy.*" Therefore language barriers can negatively impact on healthcare services by causing errors such as misdiagnosis, non-adherence to prescribed medications, incorrect treatment, and impacts on patients' rights to IC and confidentiality

Methods: This study designed to evaluate the quality of IC obtained by HCPs at public hospitals in Durban, South Africa. A cross-sectional descriptive study was conducted to determine barriers experienced by HCPs when obtaining IC, including questions regarding language and communication during clinical encounters.

Results: Nine-hundred-twenty-seven individuals completed the study, comprising 168 medical doctors, 355 professional nurses and 404 patients. Most patients spoke IsiZulu language (55%); were unemployed (66%), with secondary education (69%). HCPs identified language, poor education, workload, and lack of interpreters, as major barriers to IC in this setting.

Conclusions: These results are consistent with those from other multicultural jurisdictions, which identify language barriers as a major challenges to IC practice. Provision of trained interpreters may assist with improving patient communications, while enhancing the HCP-patient relationship.

Keywords: Barriers, communication, informed consent, language, doctors, multilingualism, nurses, patients' rights, public hospitals, Africa.

Introduction

Cultural issues may be described as all aspects of the society that influence beliefs, opinions, and choices. These include factors such as economic globalization, religion, and politics, language and so on. It has been argued that there are complex issues that face every country regarding education, healthcare, and governance. The ability or inability to explore these cultural influences may affect decisions affecting citizens, and maybe critical to solving pervasive problems and conflicts. (Institute of Human Education, 2017). Others have argued that culture plays a crucial role in the contemporary discourse on development, and policy makers have acknowledged that the social and cultural norms of a people can influence their attitude and choices (Olasunkanmi, 2011). However, one of the criticisms leveled against traditional bioethics has been that it ignores the role of social and cultural factors in the ethicaldecision making process. This has prompted some African scholars, to see globalization (Valadier, 2001), as a form of neocolonialism and attempt by the developed world agencies to advance their biomedical agenda on resource poor countries and communities (Mbugua, 2012). Such critics have gone on to call for a truly global bioethics that acknowledges the existence of alternative ethical frameworks (Mbugua, 2009), while other commentators have argued for culturally sensitive bioethics or 'ethnoethics', described as the examination of ethical issues in biomedicine in a non-western cultural context (Lieban 1990). 'Ethnoethics' would include moral norms and issues in health care as understood and responded to by members of non-western traditional societies, which should be informative not only about cross-cultural variations in ethical principles of medicine, but also about other issues which may become defined as morally relevant or problematic in multicultural environments and traditional societies. Ethnoethical information it has been argued should contribute to the discourse of medical ethics, not only by illuminating culturally distinctive moral views and problems, but also by helping to provide a more realistic and knowledgeable basis for the exploration of cross-cultural ethical similarities (Lieban 1990, Mbugua 2012).

When applying culture in the context of South Africa, one of the first considerations would be the issue of language. South Africa is a multicultural and multilingual society with 11 official languages recognized by the constitution (Constitution of the Republic of South Africa, 1996). Further, different provinces may have different sets of official languages depending on which languages are spoken in that region. For example, Western Cape province has three official languages, namely English, Afrikaans and IsiXhosa (Swartz & Drennan, 2000), while KwaZulu-Natal province has four official languages, which are IsiZulu, English, Afrikaans and IsiXhosa (EThekwini Language Policy, 2006). The issue of language in South Africa is further complicated by the fact that apartheid and previous colonial regimes led to a situation where English and Afrikaans were the only recognized and racially enforced official languages used to provide social services including healthcare. In such a system, built around social and racial privilege, most HCPs in the higher echelons of healthcare services including medical doctors, but generally excluding nurses, were able to speak only English or Afrikaans to healthcare users or patients (Swartz & Drennan, 2000). This politicization of language was further complicated by the fact the majority of the users of public healthcare services were Black Africans, with the own indigenous languages and a limited ability to comprehend English and Afrikaans (Chima, 2015). Therefore the politics of language is not something new to South African healthcare

services, whereby the apartheid government systematically advanced the Afrikaans language by making it a requirement that individuals working in public health services were able to speak only the two officially recognized languages, English and Afrikaans, to the detriment of other African languages (Swartz & Drennan, 2000, Crawford, 1999, Deumert, 2010). Further, there it has been reported that there were no designated posts for interpreters in the health system (Crawford 1999, Swartz & Drennan 2000), thereby compounding the issue of language barriers and the ability of HCPs to communicate with their patients. However, following the emergence of South Africa from apartheid and democratic elections in 1994, there has been an ostensible shift in all aspects of South African life, including the language policy, in that other indigenous African languages including Afrikaans are officially recognized as being in constitutional terms of being of equal value with English and Afrikaans (Ethekwini Language policy, 2006, Swartz & Drennan, 2000). Further, health policies and initiatives since the advent of democracy in 1994 were designed to remedy the abject discrimination, which characterized healthcare service delivery under apartheid (Deumert, 2010). The aim has been to create an equitable healthcare system that caters to all healthcare uses without regards to race, ethnicity, income, educational levels or language. This has been characterized by introduction of policies such as the Patients Right Charter of 2002 and the Batho Pele or "people first" principles of service delivery (Deumert, 2010), as well as the enactment of new legislation such as the National Health Act 2003 and the Choice on Termination of Pregnancy Act 1996, which are designed to enhance human rights, and access to health care services for all South African citizens.

Despite these policy initiatives however, implementation still remains a concern in South Africa with access to healthcare services still varying significantly according to population group 'race' or socio-economic status, two variables which arguably overlap in South Africa (Deumert, 2010, Maphai, 1989, Chima, 2015). Another major socio-economic factor in South Africa is the issue of high unemployment, with approximately 25-30% of the population unemployed (Trading economics, 2017, Chima 2015). Further, despite these new initiatives, the historical and residual inequities within South African population groups, due to the consequences of apartheid have somehow persisted (Mhlongo & Mdingi, 1997, London & Baldwin-Ragaven, 2008, TRC Report, 1998, Schlemmer & Mash 2006, Moodley and Kling 2015). Under the current circumstances, basic health care is unaffordable, and out of reach of the majority of the population who are mostly unemployed and indigent (Chima, 2015). For example, it was reported by the 2007 South African Household survey that while over two-thirds of White South Africans have access to private healthcare, comparatively, only 7% of Black South Africans, 19% of Coloureds, and 31% of Indian South African households could afford such private healthcare (Deumert, 2010). Further, there is a dichotomy in the organization of South African healthcare services, consisting of private healthcare services patronized by about (20%) of the population who can afford health insurance, or have financial means to pay for private healthcare; compared with the public health services which are used by the majority (80%) of indigent citizens (KZN Strategic plan, 2010). This dual healthcare system is further characterized by better infrastructure in private hospitals because of commercial competition and better funding, and arguably better-educated and more knowledgeable patients and consumers of healthcare services. It was further reported that in 2006, expenditure per head on private healthcare was six times greater than public expenditure. Further, public healthcare facilities mostly patronized by the

indigent South African population groups, face massive staff shortages, overcrowding, drug, and equipment shortages. Ironically, Black South Africans are the most affected by the quadruple burden of diseases including diseases of poverty, HIV/AIDS and injuries and violence (Deumert, 2010). The dual healthcare system and other socio-economic factors may therefore influence the practice of IC in South Africa (Rowe & Moodley 2013, Chima, 2015), similar to what has been reported elsewhere (Yeo, 2004).

One must be emphasize that the problems and politics of language as a barrier to healthcare is not a uniquely South African problem. Such moral and management dilemmas in healthcare have been reported in other multilingual and multicultural African countries such as Nigeria (Antia & Berlin, 2004). Similar problems have also been reported amongst Hispanic population groups in the USA (Flores 2006, Perkins, 1999). Others researchers have also reported on the impact of language amongst patients with limited English proficiency (LEP) in the USA including Asian and Hispanic patients as well as newly arrived immigrants (Partida, 2007, Higginbotham, 2003, Clark et al., 2011). Such language barriers have been reported during documentation and obtaining IC in developed countries, even where on-site interpreter services are available and mandatory (Schenker et al., 2007). Furthermore, it has been observed that language barriers and the absence of trained interpreters for effective communication may also have a negative impact on disabled individuals such as deaf patients who require sign language interpreting for communicating with HCPs during clinical encounters, leading to derogation of such patients constitutionally guaranteed rights to health, information, confidentiality and right to be treated with respect and dignity (Haricharan et al., 2013). Finally, most African societies being culturally complex and paternalistic in nature may require that consent approval be obtained from community elders/extended family members, or men as heads of households before the actual patients or human subjects of research, can provide consent (Tindana et al., 2006, Irabor & Omonzejele, 2009). The challenge in this setting then, is to ensure that IC is truly voluntary and that community or surrogate consent is not substituted for individuals' consent, which ideally should be obtained voluntarily in the absence of coercion and other undue influences (NBAC 2000).

The relationship between multiculturalism, right to health, individual autonomy and informed consent

It has been argued that the IC doctrine is primarily based on the Western notion of individualism over the rights of the community and communalism, which is practiced in some African communities as exemplified by the Ubuntu philosophy that emphasizes communal rights and brotherhood over individual rights (Metz & Gaie, 2010). It has been argued that traditionally, the ontology of African culture is communitarian in nature (Frimpong- Mansoh, 2008). This has been characterized as 'only in terms of other people does the individual become conscious of his own being, his own duties, his privileges and responsibilities towards himself and towards other people' (Mbiti, 1969), and summarized by the maxim " I am because we are , and since we are, therefore I am" (Mbiti, 1969, Frimpong-Mansoh, 2008, Chima, 2013). It has been argued that the doctrine of IC as currently formulated favors self-reliance over interdependence, action over passiveness, rationalism over spirituality, and uncertainty and forthrightness over collective harmony (Gordon 1997, Frimpong-

Mansoh, 2008). This is by contrast to deep religious and ancestral belief systems prevalent in most African cultures, which points to an omnipotent, universalizing and fatalistic view of the world that cannot be easily controlled or influenced by mortal human beings (Mbiti, 1969, Chima, 2015b). The Western notion of autonomy, is summarized by the maxim of Cardozo J, that "every human being of adult years and sound mind has a right to determine what shall be done with his own body...,' (Schloendorf Society of New York Hospital, 1914). This is further characterized by the Cartesian maxim of "I think, therefore I am" (Frimpong-Mansoh, 2008). This viewpoint overlooks the fact that in some non-western cultures, including those in Africa, individuals may expect and even desire that others make decisions regarding their healthcare and that some individuals may not even want to receive any 'negative' information on which such decisions maybe based (Caresse & Rhodes, 1995, Susilo et al., 2013, Irabor & Omonzejele, 2009). According to Frimpong-Mansoh, the question to be asked is 'how can the requirement of voluntary informed consent be addressed in African community oriented culture' (Frimpong- Mansoh, 2008). The issues of language barriers and other considerations outlined above present challenges to ensuring that IC obtained from patients in clinical practice in South Africa is based on full information disclosure, and that it is comprehensible, voluntary and autonomous.

Methods

The materials and methods applied in this study have previously been described in detail in in previously reported aspects of this study (Chima, 2013, Chima 2015a, Chima, 2017). However, briefly this report arises from a larger cross-sectional descriptive study evaluating the quality of informed consent amongst medical doctors (Chima, 2013), professional nurses (Chima, 2017) and patients (Chima, 2015a) at randomly selected public hospitals in KwaZulu-Natal (KZN) province, South Africa. A semi-structured questioniare was used to collect information regarding IC practices from doctors and nurses at selected public hospitals in Ethekwini metropolitan municipality (Durban), (Chima, 2013, Chima, 2017). Whilst a different questioniare was used to collect information from patients attending the selected public hospitals (Chima, 2015a). The questioniare for HCPs consisted of 4 parts used to collect participant demographics, informed consent practices, including language and methods used, and understanding of information by patients, as well as challenges faced by HCPs when obtaining IC. Within the second part of the HCPs questioniare was embedded a 7 item question which asked HCPs to rank barriers to IC experienced during clinical practice as well as other questions pertaining to language and patient communication during IC as shown in Table 1. The main study instrument for patients as previously reported (Chima 2015a), was a semi-structured questionnaire in English language, which was also translated into IsiZulu, the dominant language spoken by about 81% of the population of KZN (Ethekwini language policy, 2006). This questionnaires consisted of 3 sections. The first section collected sociodemographic data; while the second part was designed to collect information on patient experiences of IC practices by HCPs during clinical encounters. Patient participants were interviewed by 3 trained bilingual research assistants. Respondents had the option of completing questionnaires either in English or IsiZulu. Selected aspects of this questioniare pertaining to language and communication during the IC process and clinical encounters with HCPs are summarized in Table 2.

Statistical analysis:

Data from questionnaires was transcribed directly into the statistical package for social sciences (SPSS,) and was later analyzed using SPSS (version 21). Descriptive statistics such as percentages, proportions, median mode and interquartile range were used to summarize the data. Scores for comprehension, understanding, information disclosure, voluntariness were worked out from the responses. Fisher's exact test was used to test for association between categorical variables and groups of patients. Pearson's chi-squared test was used to test for differences in responses between patients and HCWs (doctors and nurses) as previously reported (Chima, 2013, Chima 2015a, Chima, 2017).

Ethical considerations:

Ethical approval was obtained from a research ethics committee at the University of South Africa (UNISA). The study methodology was further reviewed and approved by the health research and knowledge management sub-component of the KZN Department of Health (a local REC). Approval was also obtained from the management of each of the hospitals included in the study. Finally, written IC was obtained from each participant after full information disclosure prior to participation in the study.

<u>Table 1: Questions related to language and communication asked by HCPs when</u> <u>obtaining IC from patients</u>

1. What are the challenges you face in the process of obtaining informed consent from a patients in clinical practice?

Please rank in order of importance (where 1 is most important and 7 is least important):

- A. Time constraints ()
- B. Work load ()
- C. Language difficulties ()
- D. Lack of administrative support e. g. interpreters ()
- E. Cultural barriers (). Please specify_
- F. Lack of education ()
- G. Medical paternalism (Doctor knows best) ()

2. What language do you use to explain/obtain informed consent from your patients?

- A.English () Yes () No () Don't know
- B. The patients local language () Yes () No () Don't know
- C. Both English and local language () Yes () No () Don't know
- 3. Which of the following methods do you use to explain/obtain consent from patients? Please tick all that apply.
- () Words
- () Diagrams () Interpreter
- () Pictures () None
- 4. Do you think your patients understand the explanations given to them? () Yes () No () Don't know () Don't think so

Table	2:	Questions	pertaining	to	language	and	communication	enquired	from	patients
giving	IC	to HCPs d	uring clinica	al p	procedures	5				

1. Languages spoken:

() English

() IsiZulu

() IsiXhosa

() Afrikaans

() Other, Please specify _____

2. Level of Education

() None

() Primary

- () Secondary
- () Tertiary

3. Occupation

- () Unemployed
- () Self employed
- () Employed
- () Other please specify _____

4. In what language was information on the treatment or procedure provided?

- () English
- () IsiZulu
- () IsiXhosa
- () Afrikaans
- () More than one language. Please specify_____
- () Other, specify_

5. Did the doctor or nurse explain the treatment that he/she would provide? () Yes () No () I do not remember

6. Which of the following methods did the doctor use to explain the treatment? Please tick.

() Words() Pictures

() Diagrams() Interpreter

() None

7. Did you understand the information provided?

() Yes () No () I do not remember

8. Did you ask any questions concerning the treatment or procedure?

() Yes () No () I do not remember

If No, Why not?

Results

The overall response rate for this study was 85%, with a total of 946 respondents including doctors, nurses and patients, out of an initial estimate of 1118 participants. After a critical review of captured data a total of 19 participants were excluded due to ineligibility. Therefore a total of 927 individuals were finally included in the study. The response rate for doctors was 47% of initial estimates, while the response rate for nurses was 95%. For patients the initial estimate was exceeded by about 5% to compensate for missing data and ineligibility.

Language, comprehension or understanding of information disclosed to patients

To examine the extent of patients understanding of informed disclosed by doctors, we asked questions about the language and methods used to obtain informed consent from patients. When communicating with patients, 64.3% (108) doctors said they used '*English language*', 44.6% used the '*patients' local language*', while 69% of doctors said they used '*both English and the patients local language*'. To enhance or facilitate understanding of information disclosed to patients, 96.4% of doctors used '*words*' or communicated verbally, 20.2% used '*pictures*', 41.7% used '*diagrams*', while 72% used '*interpreters*' to communicate with patients. When doctors were asked if they think patients understood the information given to them; 76.4% answered 'yes'; while 3.6% answered 'no'; and 12.7% answered 'don't know', while 7.3% said they 'didn't think so'.

Major barriers to obtaining informed consent during clinical encounters

Doctors and nurses were asked to rank a series of potential challenges experienced while obtaining informed consent in practice, on a scale of 1-7, with 1 being most difficult and 7 as least difficult (Table 1). The major challenges identified by doctors in this setting included 'language difficulties', ranked highest by 87.5% of doctors, 'time constraints' ranked second by 86.9% doctors, followed by 'work load' 85%, lack of education 84.5%, and lack of administrative support e.g. interpreters' 82% of doctors. The least important constraints identified were 'cultural barriers', by 79.8%, while medical paternalism (doctor knows best)' was ranked last by 78% of doctors (Figure 1). A test of statistical significance using the Kruskal-Wallis test for independent variables, showed that the 'lack of administrative support e.g. *interpreters*' was statistically significant across all clinical specialities (p < 0.013) as previously reported (Chima, 2013). Similarly, majority of nurses ranked 'language *difficulties*' as being most challenging, followed by 'work load'. Time constraints, lack of administrative support e.g. interpreters, and patients' lack of education, and non-specific cultural barriers were equally ranked as being challenging. The least difficult challenge experienced by nurses was also due to medical paternalism. There was no difference in barriers identified by different cadres of nurses' i.e. Professional (nursing sisters) and enrolled nurses (staff nurses). However language difficulties, cultural barriers, lack of education and medical paternalism showed statistically significant differences between doctors and nurses ranging from p < 0.001 to p =0.002 as previously reported (Chima, 2017). The major barriers to IC as reported by doctors and nurses are illustrated in Figure 1.

Methods of communicating with patients by nurses

Most nurses reported communicating with patients verbally using the patient's local language in 59% of cases; 39 % of nurses said they used 'English language', while 56 % reported using both English language and the local language. Other methods used to enhance information disclosure to patients included use of diagrams and pictures reported by 20% of nurses. The use of interpreters was reported by 56% of nurses, but this information was corroborated by only 3.5% of patient participants as previously reported (Chima, 2015a).

Demographic characteristics of patient respondents pertaining to language and socio-economic status

Most participants were female (68.2%), single (56%) or married (37%). The age of participants was not normally distributed (P<0.001, median = 35.5 years; range = 11-91 years). Most of patient participants in this study were bilingual with a majority of IsiZulu speakers (55%); 49% spoke English language, 8% spoke IsiXhosa, and 2% Afrikaans, closely following the language demographics for KZN province (Ethekwini language policy 2006). Other minority languages spoken by this cohort of patients included Hindi, Tamil, Tswana and Sesotho. Majority of patients had secondary education (69%), some had tertiary education (16%), primary education (12%) while 2% and no formal education. Majority of patient respondents were unemployed (66%), while 27% were employed. Majority of participants reported no monthly income (56%). Detailed demographic profile of this sample cohort has been reported previously (Chima, 2015a).

Language and communication from the patients' perspective

Majority of patients reported that IC was obtained 'verbally' (73%), 19% said 'written', while 5% said both 'written' and 'verbal' methods were used to obtain IC. According to patient participants, information disclosure to patients was rendered using 'words' in most cases (89%). English language was used in 66% of cases, while IsiZulu was reportedly used in 32% of cases. Methods used to enhance information disclosure included pictures (8%); diagrams (5%), and interpreters as reported by 3.5% of patients respectively, as previously reported (Chima, 2015a).

Understanding of information disclosed

Majority of patient participants said they understood the information provided (91%), while 8% answered negatively. When asked if they asked any questions about their treatment, 70% of patients answered 'yes', while 29%, said "no". Reasons for not asking questions about treatment elicited responses such as "doctor knows best" or "i didn't know what to ask". Others said they were already familiar with their medical diagnosis or treatment regimen. Some complained that they did not have time to ask questions because the doctors were in a hurry or too busy. "The doctor was too fast he didn't give me time to ask, he didn't have time at all."

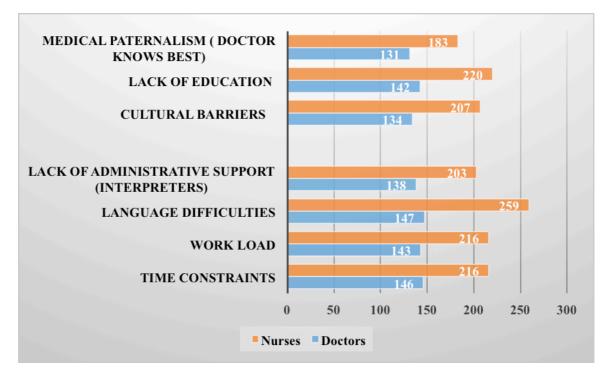


Figure 1: Barriers to IC identified by doctors and nurses

Discussion

Comprehension of information disclosed

It has been argued that although information disclosure and knowledge of that information are necessary for the comprehension of information, plain 'knowledge' is generally not sufficient. The patient or person providing IC must also have appreciation of the information disclosed. According to Van Oosten (1989) "...information as a conditio sine qua non means that information must also be appreciated." Real comprehension would involve the ability to use information rationally. Therefore for a patient to understand the information imparted by a HCP, the patient must not only be able to listen attentively to the HCP. On the other hand, HCPs must also appreciate that for information to have been communicated successfully, it needs not only disclosure, but comprehension, in that the patient must also pay attention to that information, understand it, accept, retain the information and then put that information to use in a rational manner (President's Commission, 1982). Johnston (2010) has argued that the true test for comprehension is the patient's capacity to understand information; and that the HCP needs to ascertain that the patient actually has the capacity to understand the information conveyed in a nontechnical language. Further the British Medical Association (BMA, 2009) guidelines stipulate with regards to understanding that the patient must be shown to:

- Understand in simple language what the medical treatment is, its purpose and nature and why it is being proposed
- Understand its principal benefits, risks and alternatives
- Understand in broad terms what will be the consequences of not receiving the proposed treatment
- Retain the information for long enough to make and effective decision

• Make a free choice (free from pressure or undue coercion)

Language and effective communication in the African setting

It is arguable that while the above requirements are generally applicable in medical treatment generally, the magnitude of difficulty for understanding required in multicultural and multilingual communities and developing countries could be even higher (Bhan et al., 2006), especially in multilingual countries such as the 11 official languages of South Africa, (Ethekwini language policy, 2006), or the 400 languages of identified in Nigeria (Antia & Berlin, 2004). Further, it has been previously reported that the population groups using public healthcare services in South Africa are not highly educated (Chima, 2015a). In addition, many of the patients do not speak the same primary language as the HCPs especially doctors (Deumert, 2000, Schlemmer & Mash 2006). In these types of settings it may be necessary to obtain the services of an interpreter or an intermediary such a patient advocate or other healthcare worker (HCW), to assist in putting the information in the patient's native language 'in language understandable to the patient', in order to fulfil the obligation for understanding prior to IC; consistent with the requirements in the NHA which stipulates that: "The health care provider concerned must, where possible, inform the user...in a language that the user understands and in a manner which takes into account the user's level of literacy" (National Health Act 2003). It has been suggested that language barriers can have a negative impact on healthcare services leading to errors such as misdiagnosis, failure of preventive healthcare and nonadherence by patients to prescribed medications (Flores, 2006, Haricharan et al., 2013). This could ultimately lead to accusations of negligence and award of damages against doctors and other HCPs (Schenker et al., 2007, Perkins, 1999). Issues of language difficulty and IC related to healthcare services are not limited to South Africa (Tate et al., 2016, Clark et al., 2011).

A previous report from this study indicated that the absence of appropriately trained interpreters is a major barrier to IC for doctors working in public hospitals in South Africa (Chima, 2013, Haricharan et al., 2013). In another study from Western Cape district hospital, the authors reported that language difficulties create significant problem for HCPs and could impact on patients' rights to IC and confidentiality (Schlemmer & Mash 2006). In light of the above observations it is pertinent to recall that the Council for International Organizations of Medical Sciences (CIOMS, 2002 &2016) has recommended that "...informing the individual patient must not be simply a ritual recitation of the contents of a written document. That rather, the investigator or HCPs must convey the information, whether orally or in writing, in language that suits the individual's level of understanding. That such investigators must also bear in mind that the prospective subject's ability to understand the information necessary to give IC also depends on that individual's maturity, intelligence, education, and belief system. As well as the HCPs ability and willingness to communicate patiently and with sensitivity." (CIOMS, 2002). Further, the CIOMs guidelines also recommend that: 'The HCP must then ensure that the prospective patient has adequately understood the information. The HCP should give each patient full opportunity to ask questions and should answer them honestly, promptly and completely. In some instances the HCP may even administer an oral or a written test or otherwise determine whether the information has been adequately understood by the patient' (CIOMS, 2002).

The impact of language barriers on access to quality healthcare have been partly summarized by Deumert (2010) as follows:

- 1. Avoidance behaviour- Presents who are not comfortable with communication in the language used by their HCPs generally do not have a regular source of primary care and tend to present to hospitals in advanced stages of their disease or disability as aptly illustrated by the case study of a deaf woman who missed several treatment opportunities due to the absence of a sign language interpreter and misunderstanding and mistrust of clinical instructions (Haricharan et al., 2013).
- 2. Errors in diagnosis and treatment: Quality of care is usually compromised due to language barriers leading to miscommunication and misunderstanding as reported by Flores (2006) in the USA and Schlemmer & Mash (2006) from a South African district hospital. As a consequence HCPs may request more unwarranted tests, hospitalize their patients more often, and delay initiating treatment, which may increase the overall cost of providing healthcare.
- 3. **Health education and compliance:** Patients with limited language proficiency including as LEPs usually have an insufficient understanding of their condition and usually misunderstand simple instructions or refuse to take prescribed medications leading to non-adherence and noncompliance with medication and HCP instructions or advice.
- 4. Informed consent, confidentiality and other rights: Language barriers also impact on patients constitutionally protected rights to full information disclosure and respect for autonomy as well as the rights to confidentiality, right to health, and cultural rights to communicate in a language of their own choosing (Haricharan et al., 2013, Ethekwini language policy, 2013, Schlemmer & Mash, 2006, Constitution of the Republic of South Africa, 1996).

Conclusion

This study's results are consistent with others from other multicultural and multilingual jurisdictions which indicate that one of the major challenges to obtaining IC practice include language barriers. Therefore, there is a need for a trained cadre of interpreters within public healthcare services to assist with local language translation and improve patient understanding and IC practices amongst local populations including the disabled and other vulnerable population groups. The provision of trained interpreters may assist with minimizing language barriers, improved patient communications and overall quality of healthcare service delivery, by minimizing workload for other HCPs who are usually engaged as 'ad hoc' interpreters in public hospitals in Africa, in the process of "cultural brokerage". Generally South African patients want to better communication from HCPs and want to participate in informed or shared healthcare decision-making. Other major cultural factors militating against IC apart from language, include poverty and low education, and increased workload for HCPs. One can conclude that there is need to further educate patients and HCPs regarding on patients' rights to communication in their preferred language as enshrined in the Constitution, as well as other legal requirements of IC as stipulated in the National Health Act 2003. This will enhance the HCP-patient relationship, increase respect for patient's rights to confidentiality, autonomy and human dignity. Future research should focus on informed and shared healthcare decision-making in

order to improve preventive healthcare services in Africa. Finally more continuing education workshops and seminars are required to educate South African doctors and nurses on the key elements of IC to meet required international standards consistent with local laws.

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References

Antia, B.E., & Berlin F.D.A. (2004). Multilingualism and healthcare in Nigeria: A management perspective. *Communication & Medicine* 1, 107-117.

Bhan, A., Majd, M., & Adejumo, A. (2006). Informed consent in international research: Perspectives from India, Iran and Nigeria. *MUMJ* 36-41.

British Medical Association (2009). *BMA Consent Toolkit*. Retrieved from: http://www.bma.org.uk/-/media/files/pdfs/.../consenttoolkitdec2009_full.pdf (Accessed 20 February 2016).

Carrese, J.A. & Rhodes, L.A. (1995). Western bioethics on the Navajo reservation: Benefit or harm? *JAMA* 826-829.

Clark, S., Mangram, A. Ernest, D., Lebron, R., Peralta, L. (2011). The informed consent: A study of the efficacy of informed consents and the associated role of language barriers. *Journal of Surgical Education* 68, 143-147.

Chima, S.C. (2013) Evaluating the quality of informed consent and contemporary clinical practices by medical doctors in South Africa: An empirical study. *BMC Med Ethics* 14 (Suppl 1) S3.

Chima, S.C. (2015a) "Because I want to be informed, to be part of the decisionmaking": Patients' insights on informed consent practices by healthcare professionals in South Africa. *Nig J Clin Pract* 18, S46-S56.

Chima, S.C. (2015b). Religion politics and ethics: Moral and ethical dilemmas facing faith-based organizations and Africa in the 21st century-implications for Nigeria in a season of anomie. *Niger J Clin Pract* 18, S1-S7.

Chima, S. C. (2017). Understanding and practice of informed consent by professional nurses in South Africa: An empirical study-Brief report. The Asian Conference on Ethics, Religion & Philosophy 2017 March 22-27 Kobe Japan ACERP Official Conference Proceedings 2017) 89-102.

Crawford, A. (1999). 'We can't all understand the whites' language': An analysis of monolingual health services in a multilingual society. *Int J. Soc. Lang.* 136, 27-45. Constitution of the Republic of South Africa, 1996.

CIOMS (2016) International ethical guidelines for health-related research involving humans. Geneva: CIOMS-WHO.

Department of Health KZN (2010) KwaZulu-Natal Strategic Plan 2010-2014.

Deumert, A. (2010). 'It would be nice if they could give us more language'-Serving South Africa's multilingual patient base. *Soc. Sci. Med.* 71, 53-61.

Ethekwini Municipality (2006). EThekwini Language Policy. Retrieved from: http://www.durban.gov.za/Resource_Centre/Policies/Documents/eThekwini%20Lang uage%20Policy.pdf

Flores, G. (2006). Language barriers to healthcare in the United States. *N Engl J Med* 355, 229-231.

Frimpong-Mansoh, A. (2008). Culture and voluntary informed consent in African health care systems. *Dev World Bioeth* 104-114.

Giesen, D. (1994). Right to healthcare? A comparative perspective. *Health Matrix* 277-295

Gordon, E. (1997). "Multiculturalism in medical decision-making: The notion of informed waiver *Fordham Urb L J* 1321-1362.

Haricharan, H. J., Heap, M., Coomans, F., London, L. (2013). Can we talk about the right to healthcare without language? A critique of key international human rights law, drawing on the experiences of a deaf woman in Cape Town, South Africa. *Disability & Society* 28, 54-66.

Higginbotham, E. (2003). Legally speaking: How to overcome a language barrier. *Modern Medicine* Oct. 1, 66, 67. Retrieved from: http://www.modernmedicine.com (Accessed 22 April 2018.

HPCSA (2008) National Patients' Rights Charter Pretoria: HPCSA, 2008.

Institute for Humane Education (2015). Cultural issues. Retrieved from: http://humaneeducation.org/become-a-humane-educator/what-is-humane-educator/cultural-issues/ (Accessed 17 November 2017).

Irabor DO and Omonzejele P "Local attitudes moral obligation customary obedience and other cultural practices: Their influence on the process of gaining informed consent for surgery in a tertiary institution in a developing country" 2009 *Dev World Bioethics* 34-42

Johnston, C. (2010). *Medical Treatment: Decisions and the Law*. London: Bloomsbury Professional.

Leiban, RW. (1990). Medical anthropology and the comparative study of medical ethics. In *Social Science Perspectives on Medical Ethics* Weisz, G. (Ed), Philadelphia: University of Pennsylvania Press.

London, L. & Baldwin-Ragaven, L. (2008). Human rights and health: Challenges for training nurses in South Africa. *Curationis* 31, 5-18

Maphai, V.T. (1989). Affirmative action in South Africa - genuine option? *Social Dynamics: A Journal of African studies* 15, 1-24

Mbiti, J.S. (1969). African Religions and Philosophy London: Heinemann

Mbugua, K. (2012) Respect for cultural diversity and the empirical turn in bioethics: a plea for caution. *J Med Ethics Hist Med* 5, 1-5.

Mbugua, K. (2009). Is there an African bioethics? *Eubios J Asian Int Bioethics* 19, 2-5.

Metz T and Gaie JB "The African ethic of Ubuntu/Botho: Implications for research on morality" 2010 *J Moral Educ* 273-290

Mhlongo, S.W. & Mdingi, S. M. (1997). Informed consent. Informed consent is light years away for black African patients. *BMJ*, 315, 252.

Moodley, K, & Kling, S. (2015). Dual loyalties, human rights violations, and physician complicity in apartheid South Africa. *AMA J Ethics* 17, 966-972.

National Bioethics Advisory Commission *Ethical and Policy Issues in Research Involving Human Participants* (NBAC, Washington DC 2000).

National Health Act 61 (2003). Cape Town: Government Gazette. Vol. 469 23 No. 26595.

Olasunkanmi, A. (2011). Development in Africa: The need for a culture-sensitive approach. *J Sociology Soc Anth* 2, 97-101.

Partida, Y. (2007). Language barriers and the Patient encounter. *Virtual Mentor* 9, 566-571.

Perkins, J. (1999). Overcoming language barriers in health care. *Popular Government*, Fall, 38-44.

Presidents Commission (1982) Making healthcare decisions: A report on the ethical and legal Implications of informed consent in the patient- practitioner relationship" *Report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research Making Healthcare Decisions*. Washington DC: US Government Printing Office, Volume 1.

Rowe, K., & Moodley, K. (2013) "Patients as consumers of health care in South Africa: the ethical and legal implications" *BMC Med Ethics* 15.

Schlemmer, A. & Mash, B. (2006). The effects of language barrier in a South African district hospital. *SAMJ* 96, 1080-1087.

Schenker, Y., Wang, F., Selig, S.J., Ng, R. Fernandez, A. (2007). The impact of language barriers on documentation of informed consent at a hospital with one-site interpreter services. *J Gen Intern Med 22 (Suppl 2)*, 294-299.

Schloendorf v Society of New York Hospital 105 NE (NY 1914) 92.

Susilo AP et al "Nurses role in informed consent in a hierarchical and communal context" 2013 *Nurs Ethics* 413-425

Swartz, L. & Drennan, D. (2000). Beyond Words: Notes on the 'irrelevance' of language to mental health services in South Africa Transcultural Psychiatry, 37, 185-201.

South Africa. (1996). Choice on Termination of Pregnancy Act.

Tate, R.C., Hodkinson, P.W., Meehan-Coussee, K., Cooperstein, N (2016). Strategies used by prehospital providers to overcome language barriers. *Prehosp Emerg Care* 20, 404-414

Tindana, P.O., Kass, N., & Akweongo, P. (2006). The informed consent process in a rural African setting: A case study of the Kassena-Nankana District of Northern Ghana" *IRB* 28, 1-6

Trading Economics (2017). South Africa Unemployment Rate 2000-2017. Retrieved from http://www.tradingeconomics.com/south-africa/ unemployment-rate (Accessed 3 November 2017).

Truth and Reconciliation Commission Report (1998) *Institutional hearings: The health sector*. Cape Town: CTP Book Printers.

Valadier, P. (2001). La mondialisation et les cultures 'Globalization and culture' *Études* 11, 505-515.

Van Oosten, F. F. (1989). *The Doctrine of Informed Consent in Medical Law* (LLD Thesis). Pretoria: University of South Africa.

Yeo, S. (2004). Language barriers and access to care. Annu Rev Nur Res 22, 59-73.

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