Language, cultural brokerage and informed consent – will technological terms impede telemedicine use?

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Background. Telemedicine provides a solution to treatment of economically and geographically compromised patients and enhances the level of care. However, a problem has arisen in safeguarding patients' rights to informed consent.

Objective. To determine the impact of language, translation and interpretation barriers on gaining legally valid informed consent in telemedicine.

Methods. Forty-one key words relevant to computer terminology and concepts required to gain informed consent for a telemedicine encounter were selected and sent for translation into isiZulu, the local indigenous language of KwaZulu-Natal, South Africa. A questionnaire with the list of words was developed with three domains covering information communication technology (ICT) use, ICT terms and ethics terms. This was administered to patients at four outpatient departments in rural KwaZulu-Natal hospitals.

Results. Of the 54 participants, 50 (92.6%) did not know or understand the term 'telemedicine', 49 (90.7%) the term 'video conference' and 49 (90.7%) the term 'electronic records'. Words such as 'consent' and 'autonomy' were understood by less than a third of the participants. Only 19 individuals (35.2%) understood the word 'consent', and only 4 (7.4%) understood both the words 'consent' and 'telemedicine'.

Conclusions. Obtaining informed consent for a telemedicine consultation is problematic. Alternative ways of doing so need to be investigated.

South Africa (SA) has recently developed an eHealth strategy in which telemedicine is highlighted as a means of supporting the delivery of healthcare to rural areas.[1] In 2007, the Health Professions Council of South Africa (HPCSA) drafted proposed Guidelines for the Practice of Telemedicine in South Africa, with the requirement of written informed consent before commencement of a telemedicine encounter.[2] For consent to be legally valid, the patient must fully comprehend the procedures and acts to which they consent. The language of information communication technology (ICT) is replete with complex technical terms, some of which are used in informed consent documents and may be difficult to understand. In medicine, and by inference in telemedicine, patients prefer information in their own language, but in Africa development of technical terminology in most of the 2 000 indigenous languages has been neglected.[3] This lack of words in the lexicons of African languages may be a barrier to obtaining proper informed consent for either store-and-forward or synchronous telemedicine.

In KwaZulu-Natal, SA, the majority of the population and users of the public health system speak isiZulu with English as a second language, but proficiency in English is low.[4] The SA Constitution grants equal and official status to 11 different languages, and the majority of SA citizens speak an indigenous language. The Constitution also requires that the state takes 'practical and positive measures to elevate and advance the use of these languages'.[5] The dominant language of business and government is English, but only 35% of working-age South Africans are considered proficient

in English.[6] English is also the primary language of the Internet, and Internet use in Africa is low. Only 16.3% of people in Africa access the Internet,[7] and in SA, Internet penetration is 21%.[8]

Although telemedicine provides a solution to treatment of and can enhance the level of care to economically and geographically compromised patients, it also poses a challenge in safeguarding patients' rights. Practitioners and regulators in the developing world have also expressed concern about the ethical and legal implications of diagnosing and managing patients by telemedicine.[9]

The World Health Assembly resolution of 2005 (WHA 58.28), calling on member nations to advocate telemedicine, acknowledges the need to respect the principle of equality and differences in culture, education, language, physical and mental ability and geographical location.[10] It does not address specific ethical issues related to telemedicine, such as the lack of direct contact between patient and practitioner, confidentiality, safety, data security and informed consent, or the legal implications of cross-border, international practice of telemedicine. While the vulnerability of people in developing countries has been the focus of recent debate around ethical issues relating to the standard of care and research,[11] the debate on vulnerability has not extended to the practice and use of telemedicine.

Worthington[12] states that the 'main requirement to seek valid consent from patients before an intervention is to uphold and reinforce the concept of patients' autonomy'. This allows the patient to refuse participation and seek alternative therapies if they so choose. A central issue in informed consent is that of understanding and comprehension. This can be an elusive concept that is extremely

difficult to gauge, especially when language and translation become additional factors.[13] In SA, with 11 different official languages and a population that can be defined as having limited English proficiency, interpreters are often used in clinical interviews.[14] Studies have shown that ad hoc interpreting procedures in a clinical setting have an up to 40% rate of translation errors,[15] and where language barriers exist there is a greater chance of patient dissatisfaction and non-compliance with care.[16,17] Pachter *et al.*[18] describe a system of culturally sensitive healthcare that respects ethnic and cultural values along with linguistic considerations to enhance the quality of the interaction between the patient and the healthcare system. In the pluralistic society of SA, the impact of language and culture on telemedicine and the use of complex computer terminology in the informed consent process has not been addressed.

In SA, nurses are traditionally used to translate and in addition, advocate, mediate and negotiate on behalf of their patients. This is 'cultural brokerage', which may be defined as 'the act of bridging, linking, or mediating between groups or persons of differing cultural backgrounds, for the purpose of reducing conflict or producing change'.[19] It is assumed that the cultural broker has a suitable level of linguistic competence, which is the capacity to communicate effectively and convey information in a manner that is easily understood by a diverse audience. In the developing world, it is therefore essential to ensure that culturally competent nurses help their patients receive culturally competent care.[20]

The aims of this study were to determine whether language is a barrier to obtaining informed consent for a telemedicine encounter, by translating or transcripting (i.e. mapping the sounds of one language to the best matching script of another language) common and uncommon computing and technical terms and words into isiZulu and then assessing whether these words are readily understood by patients in rural settings.

Methods

Telemedicine informed consent documents from several countries were studied. Thirty-eight words about computer terminology and concepts relevant to telemedicine and three relevant to consent were selected. The 41 words were sent for translation into isiZulu by an IT technician, a surgeon, an isiZulu linguist and translator, and a teacher of isiZulu, all of whom are isiZulu first-language speakers, and by an English-speaking doctor who is fluent in isiZulu. Some words were not directly translatable and were transcripted or left in English if transcription was not possible. Words were then translated back into English by the IT expert to ensure reliability. A questionnaire with the list of words was developed with three domains covering ICT use, ICT terms and ethics terms. These were further grouped into words that could be translated or transcripted into isiZulu and those that were not translatable.

The study was conducted in the outpatient departments of the four rural hospitals that regularly participate in the regional telemedicine programme, as patients attending these hospitals may potentially be involved in a telemedicine consultation. Convenience sampling was used to select participants from those waiting to be seen. Subjects were engaged in conversation in isiZulu and asked if they would consent to participate. They were then asked, in isiZulu, if they understood the meaning of each word or phrase in isiZulu and of the untranslatable words in English. If they said they understood the word, they were asked to give their understanding of the meaning of

the word. Understanding of the words and terminology was reported with 'yes' or 'no' answers.

Permission to conduct the research was obtained from the KwaZulu-Natal Department of Health and the Biomedical Research Ethics Committee of the University of KwaZulu-Natal. No personal details or identifying information were collected from participants.

All data were entered into an Excel spreadsheet. SPSS version 21 was used for statistical analysis using Fisher's exact test, with a significance level of $p<0.05$.

Results

Fifty-four patients (39 female) were interviewed in four rural hospital outpatient departments. Their ages ranged from 18 to 65 years (mean 42). Most lived in rural areas, with only 8 resident in the local town. Forty-five individuals (83.3%) used a cellular phone and only 4 (7.4%) used a computer. Eight words could not be translated into isiZulu, and 45 people (83.3%) did not understand or could not explain the meaning of these English words. The two words that were transcripted were email and monitor, which were not understood by 40 (74.1%) of the participants.

Most respondents did not know or understand the terms 'telemedicine' (50; 92.6%), 'video conference' (49; 90.7%) or 'electronic records' (49; 90.7%), words that are commonly used in informed consent documents internationally and locally. Many also did not understand words that are not unique to telemedicine, such as 'confidentiality' 38 (70.4%), 'consent' (35; 64.8%) and 'autonomy' (46; 85.2%). Only 3 (5.6%) of the participants, all of whom were computer users, understood uncommon, complex computer terminology such as 'encryption', 'firewall' and 'synchronous'. The words and terminology understood by more than half of the participants are those also used when describing mobile or cellular phone technology and home entertainment systems, such as 'television' (51; 94.4%), 'video' (35; 64.8%), 'speakers' (30; 55.6%), 'network' (30; 55.6%) and 'microphone' (29; 53.7%) (Table 1).

The 19 people (35.2%) who understood the word 'consent' were significantly more likely to understand the other words than those who did not understand its meaning (Table 2).

Discussion

The National Health Act of South Africa states that 'all users of the healthcare system have the right to be informed by a healthcare provider, in a language and manner that they understand'.[21] The concept of informed consent in Western medicine is firmly grounded in recognising that patients are autonomous agents. Consent is the primary means of ensuring that the patient's right to control their own treatment is protected. Ideally consent is provided on an informed basis. In SA the requirements for legally valid consent have been set out in *Castell v De Greeff*.[22] The consenting party 'must have had knowledge and been aware of the nature and extent of harm or risk', 'must have appreciated and understood the nature and extent of the harm or risk', and 'must have consented to the harm or assumed risk'. Consent 'must be comprehensive, which extends to the entire transaction, inclusive of its consequences'.

Our study highlights the problems that are faced when attempting to obtain informed consent from patients for a telemedicine consultation using standard consent forms that contain ICT terminology. A cornerstone of true informed consent is the full

Table 1. Subjects in the sample (*N*=54) who understood the isiZulu words and phrases used in telemedicine consent documents

Term	Understood term n (%)
Telemedicine	4 (7.4)
Video conference	5 (9.3)
Autonomy	8 (14.8)
3G	13 (24.1)
Email	17 (31.5)
Security	21 (38.9)
Microphone	29 (53.7)
Network	30 (55.6)
Electronic records	5 (9.3)
Store and forward	6 (11.1)
Digital photograph	12 (22.2)
Confidentiality	16 (29.6)
Consent	19 (35.2)
Computer	21 (38.9)
Speakers	30 (55.6)
Video	35 (64.8)
GPRS	10 (18.5)
Internet	18 (33.3)
Intranet	9 (16.7)
Telediagnosis	5 (9.3)
Digital signature	7 (13.0)
Firewall	2 (3.7)
Encryption	4 (7.4)
Decryption	4 (7.4)
Latency	4 (7.4)
Synchronous	4 (7.4)
Antivirus	5 (9.3)
Trusted third party	6 (11.1)
Wireless	10 (18.5)
WWW	10 (18.5)
Television	51 (94.4)
Realtime	5 (9.3)
Non-realtime	5 (9.3)
Hacker	5 (9.3)
e-prescription	5 (9.3)
Authentication	6 (11.1)
Storage	8 (14.8)
Broadcasting	10 (18.5)
Monitor	12 (22.2)
Wi-fi	40 (74.1)

Table 2. Understanding of the remaining words among subjects who understood the word 'consent' (*N*=19)

	Understood term n (%)	*p*-value*
Telemedicine	4 (21.1)	0.012
Video conference	5 (26.3)	0.004
Autonomy	7 (36.8)	0.002
3G	11 (57.9)	0.0001
Email	13 (68.4)	<0.0001
Security	16 (84.2)	<0.0001
Microphone	18 (94.7)	<0.001
Network	16 (84.2)	0.004
Electronic records	5 (26.3)	0.004
Store and forward	6 (31.6)	0.001
Digital photography	11 (57.9)	<0.0001
Confidentiality	15 (78.9)	<0.0001
Computer	17 (89.5)	<0.0001
Speakers	18 (94.7)	<0.0001
Video	18 (94.7)	0.001
GPRS	8 (42.1)	0.002
Internet	14 (73.7)	<0.0001
Intranet	9 (47.4)	<0.0001
Telediagnosis	5 (26.3)	0.004
Digital signature	7 (36.8)	<0.0001
Firewall	1 (5.3)	N/S
Encryption	4 (21.1)	0.012
Decryption	4 (21.1)	0.012
Latency	4 (21.1)	0.012
Synchronous	4 (21.1)	0.012
Antivirus	5 (26.3)	0.004
Trusted third party	6 (31.6)	0.0001
Wireless	8 (42.1)	0.001
WWW	10 (52.6)	0.0001
Television	19 (100.0)	N/S
Realtime	5 (26.3)	0.004
Non-realtime	5 (26.3)	0.004
e-prescription	5 (26.3)	0.012
Authentication	6 (31.6)	0.001
Storage	8 (41.2)	<0.0001
Broadcasting	10 (52.6)	<0.0001
Monitor	10 (52.6)	<0.0001
Wi-fi	5 (26.3)	0.004
Hacker	5 (26.3)	0.004

N/S = not significant.
*Fisher's exact test.

disclosure of all relevant information by the healthcare provider and understanding of this information by the patient. It also implies an understanding of the meaning of consent. Of concern is that 65% of patients did not understand the meaning of the word 'consent' and 70% the word 'confidentiality'. Whether this is due to a cultural issue or ignorance is not known. While the study sample was relatively small, the participants were all potential users of a telemedicine service. Whether the same problems exist in other indigenous African languages is not known and needs further study.

The lack of comprehension of the words 'telemedicine', 'video conference', 'Internet' and 'email' by patients is a problem, as using ICT to transmit health information does carry an element of risk.[23] This lack of comprehension suggests that the formalistic requirement of informed consent set out in regulations will be impossible to meet in many instances.

Another issue is the extent to which a cultural broker or interpreter helps in the patient's understanding of a telemedicine consultation, or worsens the problem through their own lack of understanding of

the words and terminology. If the consent form is written in isiZulu, we can assume that the patient reads it or the form is read to them. The cultural broker's role changes from that of an interpreter to being a source of information to clarify issues that are not understood by the patient. A limitation of this study is that the local nurses' understanding of the terminology and words used was not assessed. This will be addressed in a future study of health service providers.

The potential effects of language barriers in SA hospitals have been explored previously, with medicolegal dilemmas of informed consent and confidentiality highlighted when using interpreters and complex medical terminology.[24] Lindegger and Richter[25] looked at similar problems when debating critical issues of informed consent in HIV vaccine trials. The consent processes used fulfilled the legal requirements of information disclosure, but may not have addressed the ethical considerations of understanding and ability to make decisions that are in one's best interests. The same applies to telemedicine terminology.

When a sentence was taken from the consent form currently used in KwaZulu-Natal for teledermatology consultations, 'I hereby give my informed consent for the use of telemedicine in my medical care', 65% of the participants did not understand the term or the translation of the word 'consent' and 91% the word 'telemedicine'. Of all 54 subjects, only 4 (7.4%) understood both words. This exemplifies the challenge of gaining legally valid and truly informed and understood consent for a telemedicine consultation. Does this mean that patients in our rural setting should be deprived of a telemedicine consultation with a specialist because the stringent consent standards set in the developed world cannot be met?

The issue of written informed consent for telemedicine remains a controversial one. The Canadian National Initiative for Telehealth Framework of Guidelines identifies differing opinions relating to informed consent for video consultation. Some say that informed consent is not required, as there is implied or tacit consent to participate in a consultation. They argue that there is no distinction between a face-to-face consultation, for which informed consent is not required, and a video-conferenced telemedicine consultation, in which video conferencing is merely 'a tool for health care delivery'.[26] Others submit that implied consent should not be extended to telemedicine and contend that written informed consent should be a prerequisite, as telemedicine is not yet a routine service incorporated into health services.[27]

It is of interest that when telemedicine becomes fully integrated into routine clinical service, the expectation of written informed consent decreases. Most radiology services in the developed world now use digital imaging with images moved electronically for reporting and storage. This is teleradiology, and written informed consent is not seen as a requirement for standard X-ray imaging.

The HPCSA guards against over-reliance on implied consent in the routine clinical face-to-face context, going as far as to state that healthcare practitioners should not take the action of a patient lying down on an examination table as permission to be examined.[28] Written informed consent is a requirement of the draft Guidelines for the Practice of Telemedicine in South Africa for all aspects of a telemedicine encounter. The World Medical Association takes a more practical approach, saying that 'consent for telehealth should follow similar principles and processes as those used for other health services' and that 'To the extent possible, informed consent

shall be obtained by the physician before starting any service or intervention.'[29] Does 'to the extent possible' cover the patient's lack of comprehension, on the basis that an attempt was made to gain informed consent?

The lack of a lexicon of technological and computing terms in isiZulu makes it impossible to ensure that the full legal requirement of a valid informed consent, as proposed by the HPCSA, will be met in most cases. It is in the interests of patients and practitioners that obstacles around the requirement for written informed consent for the practice of telemedicine in SA be resolved in a pragmatic way that is appropriate to local circumstances and in the best interests of the majority of the population. This is needed to realise the vision set out in the eHealth Strategy for South Africa, which is 'eHealth: Enabling a long and healthy life for all.'[1]

Conclusion

This study identifies the need to develop new methods for gaining informed consent for telemedicine-related activities in the SA setting. Patients do not understand technological terms in their mother tongue. While they may give 'informed consent', its validity must be questioned because of lack of comprehension of what is being consented to. With over 2 000 languages in Africa, the problem is not confined to SA or to isiZulu. Africa needs telemedicine, and pragmatic solutions are required.

References

1. Department of Health, Republic of South Africa. eHealth Strategy South Africa 2012-2016. Pretoria: Government Printer, 2012. http://www.hst.org.za/publications/e-health-strategy-south-africa-2012-2016 (accessed 5 May 2013).
2. Kekana M, Noe P, Mkhize B. The practice of telemedicine and challenges for the regulatory authorities. South African Journal of Bioethics and Law 2010;3(1):33-37.
3. Madzimbamuto F. Developing anatomical terms in an African language. S Afr Med J 2012;102(3):132-135.
4. Kamper GD, Mahlobo EB, Lemmer EM. The relationship between standardised test performance and language learning in English second language: A case study. Journal of Language Teaching 2003;37(2):164-178. [http://dx.doi.org/10.4314/jlt.v37i2.6013]
5. Republic of South Africa. Constitution of the Republic of South Africa 1996. Pretoria: Government Printer, 1996. http://www.gov.za/documents/constitution/1996/a108-96.pdf (accessed 5 May 2013).
6. Casale D, Posel D. English language proficiency and earnings in a developing country: The case of South Africa. Journal of Socio-Economics 2011;40(4):385-393. [http://dx.doi.org/10.1016%2Fj.socec.2011.04.009]
7. International Telecommunications Union. Free statistics. http://www.itu.int/ITU-D/ict/ (accessed 25 May 2013).
8. International Telecommunications Union. Percentage of individuals using the Internet. http://www.itu.int/ITU-D/ict/statistics/ (accessed 25 May 2013).
9. Hogenbirk JC, Brockway PD, Finley J, et al. Framework for Canadian telehealth guidelines: Summary of the environmental scan. J Telemed Telecare 2006;12(2):64-70. [http://dx.doi.org/10.1258%2F135763306776084338]

10. World Health Assembly. World Health Assembly eHealth Resolution (WHA58.28). 25 May 2005. http://apps.who.int/iris/bitstream/10665/20378/1/WHA58_28-en.pdf (accessed 14 March 2014).

11. Rice N, Smith PC. Ethics and geographical equity in health care. J Med Ethics 2001;27(4):256-261. [http://dx.doi.org/10.1136%2Fjme.27.4.256]

12. Worthington R. Clinical issues on consent: Some philosophical concerns. J Med Ethics 2002;28(6):377-379. [http://dx.doi.org/10.1136%2Fjme.28.6.377]

13. Levin M. The importance of language and culture in pediatric asthma care: Communication problems between doctors and Xhosa speaking parents of children at a paediatric teaching hospital. Current Allergy and Clinical Immunology 2005;18(1):8-12.

14. Wu AC, Leventhal JM, Ortiz J, et al. The interpreter as cultural educator of residents. Archives of Pediatric and Adolescent Medicine 2006;160(11):1150-1154. [http://dx.doi.org/10.1001%2Farchpedi.160.11.1145]

15. Penn C. Factors affecting the success of mediated medical interviews in South Africa. Current Allergy and Clinical Immunology 2007;20(2):66-72.

16. Woloshin S, Bickell NA, Schwartz LM, et al. Language barriers in medicine in the United States. JAMA 1995;273(9):724-728. [http://dx.doi.org/10.1001%2Fjama.273.9.724]

17. Deumert A. It would be nice if they could give us more language – serving South Africa's multilingual patient base. Social Science and Medicine 2012;71(1):53-61. [http://dx.doi.org/10.1016%2Fj.socscimed.2010.03.036]

18. Pachter LM, Sheehan J, Cloutier MM. Factor and subscale structure of a parental health locus of control instrument for use in a mainland United States Puerto Rican community. Social Science and Medicine 2000;50(5):715-721. [http://dx.doi.org/10.1016%2FS0277-9536%2899%2900323-8]

19. Jezewski MA. Cultural brokering in migrant farm workers health care. West J Nurs Res 1990;12(4):497-513.

20. Shaibu S. Ethical and cultural considerations in informed consent in Botswana. Nurs Ethics 2007;14(4)503-509.[http://dx.doi.org/10.1177%2F0969733007077884]

21. Republic of South Africa. National Health Act No. 61 of 2003. Pretoria: Government Printer, 2003. http://www.gov.za/documents/index.php?term=national+health+act&dfrom=&dto=&yr=0&tps%5B%5D=1&subjs%5B%5D=0 (accessed 5 May 2013).

22. Castell v De Greef 1994 (4) SA 408 (C) at 425.

23. Stanberry B. Legal and ethical aspects of telemedicine. J Telemed Telecare 2006;12(4):166-175. [http://dx.doi.org/10.1258%2F135763306777488825]

24. Schlemmer A, Mash B. The effects of a language barrier in a South African district hospital. S Afr Med J 2006;96(10):1084-1088.

25. Lindegger G, Richter LM. HIV vaccine trials: Critical issues in informed consent. S Afr J Sci 2000;96:313-317.

26. National Initiative for Telehealth. Framework of guidelines. http://www.cst-sct.org/resources/frameworkofGuidelines2003eng.pdf (accessed 25 May 2013).

27. Internet Health Coalition. Guidelines for disclosure, patient privacy and quality content. http://www.ihealthcoaltion.org/ethics/cod (accessed 25 May 2013).

28. Health Professions Council of South Africa. Guidelines for good practice in the health care professions: Seeking patients' informed consent: The ethical considerations. http://www.hpcsa.co.za/downloads/conduct_ethics/rules/generic_ethical_rules/booklet_9_informed_consent.pdf (accessed 25 May 2013).

29. World Medical Association. WMA Statement on guiding principles for the use of telehealth for the provision of health care. http://www.wma.net/en/30publications/10policies/t5/ (accessed 10 August 2013).