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Is Consent Not a Consideration for Instant Messaging?

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Abstract: Background. Recently there has been a steady increase in the use of Instant Messaging (IM) as a means of providing health and healthcare services. This growth has been particularly rapid during the ongoing COVID-19 pandemic. Many reports indicate informal services using IM, in particular WhatsApp, have arisen spontaneously, in the absence of any formal guidelines and little consideration of consent. This study documents the consent practices of healthcare professionals using IM for clinical activities in District Hospitals in KwaZulu-Natal, South Africa and compares these practices with the literature. **Methods.** As part of a larger audit of telemedicine activity in KwaZulu-Natal a survey questioned clinicians' use of IM, including consent practices and awareness of regulatory guidelines. Concomitantly multiple electronic databases were searched for papers on WhatsApp use in clinical service. Inclusion criteria were: papers written in English, reported on WhatsApp in clinical use or potential clinical use, and addressed consent. **Results.** The survey confirmed anecdotal reports of widespread informal use of WhatsApp in District Hospitals. Most clinicians were unaware of regulatory guidelines, and few obtained consent for taking photographs or sharing of images and information with colleagues for consultation. The literature review found that consent was mentioned in only 28 papers. Of these 11 reported that written consent was obtained, of which 5 were for taking photographs and 4 for sharing information with colleagues. **Discussion.** The survey showed that more than half of the respondents who used IM did not consider this to be telemedicine, with the corresponding ethical requirements governed by national guidelines, thereby risking legal exposure. However, South Africa's regulatory guidelines do not align with common clinical practice. The literature shows that the majority of doctors shared patient information by IM without obtaining any form of consent. **Conclusion.** Practical guidelines are urgently required in South Africa and worldwide that balance practical conduct of medical care with sound contemporary ethical principles. Prudent guidance will ensure clinicians do not inadvertently breach patient privacy and confidentiality laws whilst permitting continued health-related use of instant messaging.

Keywords. Instant Messaging, WhatsApp, consent, legal, regulatory, ethical

1. Introduction

The COVID-19 pandemic has seen a rapid increase in the use of telemedicine as a means of providing services while maintaining social distancing and complying with lockdown

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restrictions. Instant messaging (IM) and videoconferencing have been the most reported modalities. IM is the use of information and communication technologies (ICT) for text-based communication in which two (or more) persons participate in a single conversation using computers or mobile devices and the Internet for connectivity. Given that 'ICT for health' is ehealth (or now digital health), IM use within the health sector for clinical communications constitutes ehealth or digital health, and is a form of telemedicine. WhatsApp is the most used IM application globally [1], and for the purpose of this paper is used as an exemplar of IM. A PubMed search of the first 11 months of 2020 (January to November, inclusive), returned 273 papers on WhatsApp use, which is more than the total number of papers published over the previous three years and almost half of the all the papers on WhatsApp in PubMed.

A 2016 review of the use of WhatsApp in clinical practice found that consent was only mentioned in five of 58 papers and only obtained in three papers [2]. Many of the reviewed papers were from the developing world, and reported informal services that had arisen spontaneously and in the absence of formal guidelines for the use of IM in clinical practice. As a consequence, the lack of information on consent may reflect different ethical imperatives in the developing world. Subsequent papers from the developed world [3-6] have confirmed widespread informal use of WhatsApp and that consent remains an issue [4,7].

Consent for the use of IM in telemedicine has to address several issues: the sharing of private health information with another health professional or, in the case of chat groups, several people; the storage and security of this information on the sender's and recipients' phones; the secure transmission of the information; and compliance with any local privacy laws and telemedicine regulations.

There has been limited telemedicine activity in KwaZulu-Natal (KZ-N), a Province in South Africa, for nearly 20 years. The only formal telemedicine service provided by the KZ-N Department of Health, which is responsible for the provision of health services to over 80% of the population of more than 11 million people, is a teleradiology link between some regional hospitals and the tertiary care centres. A videoconference based teledermatology service has been run by the local medical school for many years [8]. There are no specialists at District Hospitals and there is anecdotal evidence of the use of informal, IM based telemedicine within and between doctors at these hospitals, and with specialist colleagues elsewhere in both the State sector and private practice.

The Health Professions Council of South Africa (HPCSA) is a statutory body tasked with, among other things, overseeing and regulating the ethical practice of medicine in South Africa. It has produced 'General Ethical Guidelines for Good Practice in Telemedicine' with onerous requirements for written informed consent for telemedicine [9,10]. Given that the use of IM for telemedicine was not considered when these guidelines were developed, and the limited evidence of patients consenting to IM use, there is need to understand current consent practice.

The aims of this study were to: document the consent practices of health professionals using IM for clinical activities in District Hospitals in KZ-N and to compare these with the literature.

2. Methods

2.1. Survey

As part of a larger audit of telemedicine activity in KZ-N a 24 item questionnaire was developed that addressed demographics, use of telemedicine in its different modalities, services for which it is used, services for which it is needed, consent and awareness of the HPCSA guidelines. The questionnaire was pre-tested by five people involved in telemedicine and medical informatics and questions were modified where necessary to avoid ambiguity. This paper reports, specifically, the respondents' consent practices and awareness of HPCSA guidelines when using IM for telemedicine.

The survey was carried out in late 2019, before the COVID-19 pandemic, at 25 of the 37 District Hospitals in KwaZulu-Natal, as District Hospitals do not have resident specialists. This study was undertaken at the request of the KwaZulu-Natal Department of Health eHealth Steering Committee. Ethics approval was obtained from the University of KwaZulu-Natal and the KwaZulu-Natal Department of Health ethics committees. All respondents consented to participate.

2.2. Literature review

In January 2019, the electronic databases PubMed, Scopus, Science Direct and six databases within EbscoHost - CINAHL with full text, Health Source Nursing/academic edition, Index to legal periodicals, PsycARTICLES, PsycINFO, and MEDLINE were searched for papers on WhatsApp in clinical service. The search term used for PubMed was "WhatsApp" [All fields] and for the other databases (("WhatsApp") AND ("telemedicine" OR "telehealth" OR "ehealth" OR "e-health" OR "mhealth" OR "m-health")) All fields. The search strategies differed because PubMed is restricted to biomedical related papers.

Inclusion criteria were: papers written in English, reported on WhatsApp in clinical use or potential clinical use, and addressed consent. Titles and abstracts were reviewed and papers that met the inclusion criteria were then reviewed. Book chapters, conference proceedings that were not full length papers, and papers on the use of WhatsApp for behaviour change, education, appointment reminders or medication adherence were excluded. All decisions on inclusion and exclusion were made by consensus of all authors. Data extracted included, year of the publication, country of origin, clinical service described and all information related to consent.

3. Results

3.1. Survey

There were 185 respondents from 25 District Hospitals, of whom 143 were doctors and 42 were allied health care providers (AHCPs). IM and/or chat was used by 136 (95%) of doctors for consultation, second opinion, and advice in a range of clinical services and by 40 (95%) of AHCPs for clinical activities and administrative functions. The specialties performed most by doctors were; dermatology, paediatrics, orthopaedics and burns, and for AHCPs were; dermatology, paediatrics, orthopaedics, burns, and

radiology. Seventeen doctors used only WhatsApp chat groups. More than half of doctors who used IM and chat groups for clinical purposes did not consider this use to be telemedicine.

Respondents were asked if they were aware of guidelines for telemedicine practice from any of: the HPCSA, the South African Medical Association, the World Medical Association, the Medical Defence Union, or the National Department of Health. The question required a 'yes' or 'no' response for each option. Nearly two thirds (65%) of respondents did not answer the question. Only 18 (13%) of doctors using IM were aware of the HPCSA guidelines. Of the 18 who were aware of the guidelines and the requirement for written consent only two obtained written consent, five verbal consent, two considered consent to be implied, one did not obtain consent for IM and eight did not respond to the question about what form of consent was obtained.

Sixty-seven doctors (49%) who used IM, but were unaware of the HPCSA guideline requirements for consent, completed the question on the type of consent they obtained for IM. Only seven (5%) obtained written consent, and 46 (31%) obtained verbal consent, including 15 (11%) reporting that consent was verbal and implied. Nine doctors (7 %) considered consent to be implied. Five did not obtain consent for IM. Overall, fifty-nine doctors (43%) using IM did not respond to the consent question. Of the 17 respondents who only used chat groups, just one obtained verbal consent and one felt that consent was implied. Fifteen (88%) of those only using chat groups did not answer the consent question.

3.2. Literature review

The searches returned 590 unique papers. After review of the titles and abstracts, 167 met the inclusion criteria and after full text review, 28 papers that addressed consent remained. Of the 28 papers, only 11 reported that written consent was obtained of which 5 were for taking photographs [2,6,11-13], and 4 for sharing information with colleagues [2,14-16]. Three papers reported obtaining verbal consent [12,17,18], one of which was for sharing patient information [17]. Fourteen papers reported that consent should be obtained for taking photographs and/or sharing information with colleagues [4,12,19-30].

Although one study found most doctors considered that consent was required prior to taking a photograph [4], another reported only 42% of doctors obtained consent for smartphone camera use [6]. Another study reported that 63.2% of general dental practitioners did not obtain any form of consent from their patients for sending clinical materials for second opinion. The remainder obtained verbal consent [18]. In the Republic of Ireland, the General Medical Council's guidance is clear on using visual and audio recordings of patients, stating recordings can only be made if appropriate consent is gained and documented. Despite this, 97% of doctors at a teaching hospital in Ireland shared patient information by IM without obtaining any form of consent [6].

Medico-legal providers recommend documenting consent in patient notes when sharing images on mobile phones [4]. Three papers mentioned the need for keeping a record of informed consent [21, 28], even if it was only verbal [6], and it was suggested that consent could be documented by submitting a photograph of the signed consent [21]. In an Australian study only half of respondents considered that consent needed to be documented in the patient notes or entered onto a hospital consent form [4]. Overall, there was uncertainty about any record keeping of informed consent [31], and general confusion existed regarding what consent was required when sharing patient information [4].

4. Discussion

The survey confirmed anecdotal reports of widespread informal use of WhatsApp in District Hospitals in KZ-N in a variety of clinical specialties for both one-to-one consultation and one-to-many chat groups. Chat groups were commonly used by both doctors as well as AHCPs for both clinical activities and administrative functions. Most clinicians were unaware of the HPCSA General Ethical Guidelines for Good Practice in Telemedicine (HPCSA guidelines), and its requirement for written consent and few of those who did, complied.

Ideally a patient should consent to a teleconsultation. Considering IM as another mode of teleconsultation, patients should consent to: any photograph being taken and stored on a local device; sharing of the image(s) with a doctor or group of doctors with accompanying clinical information; transmission of this content over the internet; and storage of that information on a device at the distant site. As a part of the consent process patients should be made aware of the security measures taken to maintain confidentiality and security of their data. The need to gain consent for all of these processes has been identified [32] but no reviewed paper discussed them.

Even though telemedicine was clearly defined in the questionnaire, more than half of doctors who used IM and chat in clinical practice did not consider their use of IM to be telemedicine. The implications of this are that these doctors would not see the need to comply with the HPCSA guidelines. This could have serious legal, regulatory and ethical implications in the event of a breach of patient privacy and / or confidentiality [7]. Conversely, abiding by current HPCSA guidelines is problematic, as noted below, and does not align with common clinical practice.

In Section 4.6.3 of the HPCSA guidelines [9] it is required that informed consent be in writing. Only two doctors, who were aware of HPCSA guidelines, obtained written consent, while most said consent was usually verbal or implied, similar to a study where only 36.7% of general dental practitioners obtained verbal consent from patients for sending clinical materials for second opinion [18]. This is also in line with a study of the consent practices of doctors and nurses conducting face-to-face consultations and then referring patients for further investigations or second opinions in KZ-N [33].

Further results from the survey showed that some respondents considered consent to be implied and six reported not obtaining consent. The implication of nearly half of respondents not answering the question on consent may be that they did not want to make known their lack of compliance, not only with the HPCSA guidelines [9], but also the Health Act of South Africa, Act 61 of 2003 [34].

Section 4.6.3 of the HPCSA guidelines [9] also requires informed consent to include the documentation of security measures taken for the use of telemedicine. In practice this creates a number of problems for doctors using IM. The security measures for IM are highly technical and difficult to translate into local languages [35], and a study in KwaZulu-Natal showed that only 35% of patients understood the meaning of the word consent in their mother tongue, isiZulu, and only 7% understood the word telemedicine [35]. Overall, the literature did not report on informed consent including security measures taken.

Section 4.6.3 of the HPCSA guidelines [9] further requires that the patient be informed as to who will be accessing their information. Again, this creates a number of practical problems. The doctor is sending patient information, text images and in some instances video and audio data to either an individual or a group of doctors. Ethically the patient should explicitly consent to this being done [25], with the exception of when the

healthcare practitioner can justify the disclosure (which, arguably, is the case in every instance, since clinicians have a patients best interests as their focus). Although the survey did not address messages sent to a chat group nor the concern of improper disclosure, the literature shows that consent is seldom gained for sharing information [2, 35] and that confusion exists regarding what form of consent is required when sharing patient information [4].

In terms of the HPCSA requirements, both the referring as well as the consulted specialist must keep records of all electronic communications of a patient consultation for filing in the patient record. Again, the survey did not specifically ask how doctors stored patient data or kept records but medico-legal providers recommend documenting consent in patient notes when sharing images on mobile phones [4]. Three papers mentioned keeping a record of informed consent even if it was verbal, and it was suggested that consent could be documented by submitting a photograph of the signed consent form [21]. In one study only half of the participants (doctors or medical students) considered consent needed to be documented in the patient notes or entered onto a hospital consent form [4].

Consent is the expression of the fundamental ethical principle of autonomy. The lax consent practices of doctors as evidenced in this paper, and in many parts of the world, when using IM in clinical practice is a major concern that needs to be addressed.

5. Conclusion

Instant messaging is widely used in KZ-N, South Africa, and even prior to COVID-19 its use for telemedicine services had been rapidly growing globally. This study shows evidence of widespread uncertainty, even confusion, regarding what type of consent (explicit vs implied; written vs verbal) is required when sharing patient information using IM. This has created a laissez faire approach to consent and health-related IM use.

Within South Africa the HPCSA guidelines are not helpful in this regard being formulated prior to development and use of IM in healthcare. These guidelines urgently require updating by balancing practical conduct of medical care with sound contemporary ethical principles. This need also requires addressing elsewhere in the world. Prudent guidance will ensure clinicians do not inadvertently breach patient privacy and confidentiality laws whilst permitting continued health-related use of WhatsApp and other instant messaging applications.

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