

Ethical Concerns in Accessing Healthcare Information from Social Media By Patients with Terminal Diseases, Opportunities and Challenges: Kenyan Experience

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Abstract

This paper investigated the ethical concerns in accessing healthcare information from social media by patients with terminal diseases, opportunities and challenges: Kenyan experience. It had 3 objectives to: a) determine ethical concerns in accessing healthcare information from social media; b) evaluate the opportunities patients with terminal diseases have in accessing healthcare information from the social media; c) investigate the challenges patients with terminal diseases have when accessing healthcare information from the social media. The study was desk review; that involved identifying and scanning relevant literature, analysis of the secondary data; creation a reference list and organization of the documents. The study findings were: all the articles 100% confirmed core ethical issues in accessing healthcare information: patients' anonymity, confidentiality, privacy, physicians' professionalism, and data protection; 98% agreed on imperative response by physicians to patient concerns. Social media presents opportunities to patients: 51% access, and shared (50%) healthcare information; 44% made decisions; 46% were empowered and their capacity build; 51% accessed experts advise; 48% joined social support-groups. There were challenges in accessing healthcare information: 50% accessing misinformation; 36% technological illiteracy, 48% personal data security. The study concluded that social media enables accessing and sharing of healthcare information. However, for effectiveness ethical concerns like: patients' confidentiality and privacy, physicians' professionalism, and protection of patients' data. Stakeholders need to work together to eliminate the ethical issues and challenges faced by patients using social media as a source of healthcare information.

Keywords: social media, healthcare information, terminal diseases, e-health, technology

Introduction

Growing number of literatures have shown that social media has revolutionized the healthcare infrastructure and systems (Tegegne et al., 2022; Poonam et al., 2020). For example, social media has changed how patients search for and disseminate and share healthcare information either between patients or among professional and a patient (Royal College of General Practitioners, 2013). Thus, social media enables the citizens to access and disseminate information whenever and wherever globally. World over, individuals and communities have continued to realize the need for accessing timely, relevant and accurate healthcare information particularly those with terminal cases. Since the advent of internet, social media plays a critical role in availing healthcare information online to attempt to answer general questions that patients with diverse ailments might have (Khan & Loh, 2021). In this regard, social media provides unlimited access to healthcare information to patients and infrastructure to a space to address medical ailments outside the offices of experts and healthcare providers (Farsi, 2021). The chances for patients to consult healthcare providers directly are limited by factors like high cost, and the ever-widening ratio between doctors and patients. Thus, patients and their relatives use social media technologies as an alternative to access healthcare information, and to share relevant ideas, experiences and useful information about their conditions with others suffering from similar ailments (Denecke et al., 2015). According to Gravili (2013, p.1), use of social media for sharing of information and ideas has tremendously increased,

The use of social media allows an instant sharing of ideas, opinions, knowledge and experiences, and it creates a new “spacetime” dimension that translates in a new way (additional) to "cure" patients. This new form of communication improves services to patients, providing simpler processes and developing a user empowerment through an efficient and transparent access to information. One report¹ estimates that nearly half of European healthcare users in Spain, Italy, France, Germany and the United Kingdom (approximately 47% of the total population) used the Internet to find health information in 2010, and that Facebook is their fourth most popular online source for health information

Employment of social media for sharing ideas, opinions, knowledge and experiences cannot be emphasized since it is of global dimensions; nonetheless, the platform is accepted now as a new dimension to “cure” patients. Moreover, the new platform has been used to improve service delivery, and patients’ empowerment. However, without due considerations, users of social media as the source of medical healthcare information may lead to more problems, for example, Denecke et al. (2015, p.146) warn that,

Exploiting medical social-media in healthcare applications requires a careful reflection of roles and responsibilities. Availability of data and information can be useful in many settings, but the abuse of data needs to be prevented. Preserving privacy and confidentiality of online users is a main issue, as well as providing means for patients or Internet users to express concerns on data usage.

Therefore, there should be a careful reflection in regard to the roles and responsibilities whenever appropriating medical healthcare information from the social-media sources; by thus it is possible to prevent any form of abuse among the users particularly their privacy and confidentiality (McInnes & Add, 2018).

According to Kenya Gazette (2019, Section 841 A, B and C), it is open for any interested person to establish social media in Kenya for the purpose of communication. However, the users must ensure published or shared content in the social media should not be degrading or intimidating to the recipient. Additionally, the content should not be prejudicial to all users in the basis of religion, politics, race, gender, ethnicity, nationality or ethnicity. Therefore, the content should remain fair, accurate and unbiased in nature. As far as the usage of any content from the social media including using the medical healthcare information, both the user and the content publisher have a role and responsibility to prevent the content from any form of abuse and preserve the privacy and confidentiality of the online users of the information.

Literature Review

The concept of social media denotes online-based tools accessed through simple gadgets like the mobile tools and computers (Grobler and Ames, 2016); they are used to disseminate and share ideas, personal opinions and information, and experiences. Sometimes short video or images or audio clips may be used to share the relevant information (Royal College of General Practitioners, 2013). Accessing healthcare medical information from the social media has got its own demerits and risks (Chauhan et al., 2012); for example, some of the information accessed may be of poor-quality thus being of very limited help to the patient. Furthermore, the low-quality information may be damaging to the image of trust of the medical professionals (Bernhardt and Gold, 2014). Additionally, Peck (2014) argues that due to lack of protection for the patients' privacy and confidentiality (Denecke et al., 2015), therefore, the patients' data may be abused thus breaching the patients' privacy; sometimes medical professionals have gone through messy legal processes sued by dissatisfied or aggrieved patients (Grajales et al, 2014). However, with careful and critical reflections by all the stakeholders, social media platform remains useful for dissemination and access for healthcare information quickly and widely thus reaching thousands of users in record time; the shared information can make all the difference in informing the citizens of risks, preventive measures, and possible interventions (Farsi, 2021; Cheng & Wang, 2021). Besides individual patients, more recently Governments have leaned towards social media during times of diseases outbreak (McInnes & Add, 2018; Chauhan & Coffin, 2012). For example, podcast audios and YouTube videos have been employed to disseminate health information, additionally, social media has been used as an infrastructure for sharing information about disease outbreaks, finally social media in some occasions has been adopted as an official platform for providing content to the citizens about disease outbreak (Khan & Loh, 2021; Jin et al., 2018).

Ethical concerns in accessing healthcare information from social media

There is consensus that the concept of ethics is well-defined as the discipline that deals with what is construed to be good and bad and bearing the moral duty and obligations; therefore, the concept and principles therein are applied as the litmus paper to define what is good or bad within the parameters of moral duty and obligations (Peck, 2014). Used in the context of medical world; it seeks to promote patient-centered practices. Dimensional approaches have become popular in pursuant to citizens' wellness; in this regard, social media has emerged as one of the newest tool and technological infrastructure attaining more popularity among patients with varied diseases and healthcare practitioners; for example, Facebook, Instagram, Blogs, LinkedIn, and Twitter are being used world over to disseminate and share information fast and widely among all stakeholders (Grobler & Ames, 2016). However, the users cannot afford to only focus

on the benefits accrued from utilizing social media while ignoring the underlying ethical and professional implications (Chen & Wang, 2021).

Patients' confidentiality

Patients' confidentiality stands out as one of the most distinctive and recurring issue highlighted by both patients and medical practitioners. Key elements of patients' confidentiality include respect for the patients' personal privacy and rights, and personal data or information (Peck, 2014). It is a good and professional practice to protect patients' information from any improper disclosure at all times; whenever there is breach of confidentiality, patients may claim hefty damages in legal courts. Therefore, all the stakeholders need to protect patients' confidentiality. For example, Kidd (2022) outlines some of the basic ethical practices in medical health practices:

- Healthcare practitioners have the responsibility to protect the patients' confidentiality both online and offline
- Practitioners should not make comments about patients whether online or offline
- It is the role and responsibility of the practitioners to vet their posts to audit anything that may depict the patient negatively
- The practitioners should be weary of any traces of misinformation; therefore, all content should be true and useful to the users

In this regard, Tegene et al. (2022) affirms that respecting patients' confidentiality is essentially a fundamental ethical and legal responsibility to be at all times observed by the healthcare professionals. Additionally, observing patients' confidentiality remains critical and a foundational cornerstone in promoting good attitudes, excellence, professionalism and ethical consideration particularly among the healthcare professionals (Kidd, 2022).

The opportunities presented by the social media in accessing healthcare information

According to Poonam et al. (2020), social media presents great opportunities in the healthcare framework, for example, in the improvement of the desired healthcare outcomes; for example, the development of professional network, creation of personal awareness through dissemination and sharing of information, empowerment and motivation of patients especially those with terminal cases (Tegene et al., 2022). Additionally, social media helps in the provision of timely, relevant and true health information to those needing it. Glasdam et al. (2022) tabulates the opportunities derivable from using social media:

- Sharing of vital information in the quickest possible way; thus, unlimited access
- Social media serves as a profession-promoting channel
- Professionals gain and share critical information among themselves
- The social media presents an opportunity for developing social support for all practitioners
- The professionals share experiences and information particularly from those working in unique circumstances.
- More approachable for the patients who have fear for medical doctors
- Social media lightens the mood by creating hope for those with terminal cases

Therefore, social media presents an opportunity to the professionals of bringing together the public, patients, and health professionals through sharing information and critical conversation around healthcare matters; and the chance to improve and enhance citizens' health and wellbeing (Poonam et al., 2020). Equally true, social media presents the patients with unique opportunities like: access of information related to diseases, treatment and management; benchmarking of experiences, access to support groups, dissemination of personal health management or curative stories, sharing information about curative and effects of medicines.

The challenges patients experience in accessing healthcare information from the social media

Undeniably, social media, has continued to influence citizens' lives in all manner of everyday life. For example, Naseri and Sheikhtaheri (2015) state that:

- 75% of the adults use social media to access basic information
- About 80% of the young people in European Union countries use social media

Therefore, the constituency of social media users cannot be ignored or taken for granted. Regarding the provision of healthcare, social media has continued to play a significant role, for example: the provision of medical education; consultative and curative services, facilitation of interaction and collaboration among diverse stakeholders like healthcare teams, customer, and policymakers. Finally, social media has been used to engage the public to demystify terminal diseases to end undue fear and stigma; in this regard, homecare services have been made more robust courtesy of the contribution of social media (Dizon et al., 2012; Naseri & Sheikhtaheri, 2015; Glasdam et al., 2022).

Despite the positive social recompences of utilizing social media in access, sharing and dissemination of healthcare information; the users experience many challenges (Chen & Wang, 2021; Farsi, 2021). Therefore, a burgeoning literature (Khan & Loh, 2021; Tegegne et al., 2022; Farsi, 2021; Kidd, 2022) have in common tabulated the common challenges of utilizing social media as follows:

- Most of the information from the social media lack of reliability
- The accessed information may lack privacy and confidentiality thus exposing the patients negatively and by thus risking their health more
- Due to misinformation, inaccurate medical advices have reached the unsuspecting consumers thus leading to more adverse health consequences
- The society is awash with unvetted information overload; for the untrained mind the access of such information may lead to negative health behaviours and health consequences
- The overreliance on social media may make the patients to refuse consultation with healthcare experts and providers
- More often, there is no follow up on the users' conditions; it is therefore difficult to establish or monitor patients' application of the accessed healthcare information, and the results and interventions if any.

In this regard, without interventions to these challenges, all the known advantages of utilizing social media in promoting healthcare information may in the end endanger patients and reverse the hard-gained success in the healthcare community (Gravili, 2013).

Users' roles and responsibilities in accessing healthcare information from social media

According to Sceptor and Kappel (2012), the impact of social media in all levels of our society is both instantaneous and powerful and can go either way: profound or profanity. Therefore, carrying messages that can be profound or profane. Thus, according to the two say,

...it is hardly an overstatement that social media is transforming the way that people communicate. Just a few years ago, it was almost unimaginable that social revolution or political upheaval would be tweeted about by those actually experiencing it for millions around the world to read in real time. In most cases, social media carries messages far more mundane, but in their own way, they are just as powerful because such communication has changed how the world is seen and experienced. Social media has become one with the fabric of society and while it may undergo constant evolution over its lifespan, it will remain part of the world in which we live for the foreseeable future.

In order to promote sustainable benefits accrued from social media, all the stakeholders' roles and obligations are needed for a better future in the healthcare industry.

A blanket condemnation of all social media is irresponsible in principle (Farsi, 2021); therefore, the healthcare providers using the platform need to be more critical in choice of the available networking sites such as blogs, video sites, and online chat platforms and forums (Grobler and Ames, 2016). Thus, practitioners need to identify, and only use the platforms that uphold sound professionalism, responsible, reliable, credible, vet information received before publishing, and have been recognized by other social networks. In this regard, the patients accessing these social outlets will have more confidence in applying the information sourced (Kidd, 2022). In this regard, healthcare practitioners have to be cognizant of their professional obligations while utilizing social media. Moreover, it is fair to be sensitive of any potential negative consequences of using incredible social outlets because their professionalism may be compromised, while the patients' behaviour may be at risk. Finally, the practitioners have a role and responsibility to develop relevant and effective policies to promote and enhance higher professional standards, protect patients from any harm, maintain good relationship between the patient and service providers; and finally uphold the patients' privacy and confidentiality, respect of their dignity, rights and freedoms. Cronquist and Spector (2011) warn that all healthcare practitioners should be weary of any inappropriate social media that may in the end promote unprofessionalism, unethical conduct, moral turpitude, misinformation and mismanagement of patients' information, and immoral practices. For effective policies a more participatory approach among all the stakeholders in the healthcare industry; thus, popular participation is paramount to ensure the reflection of all voices and interests across the board. In this regard, effective policies should bear the following characteristics: demystify the undue myths about social media, act as a guideline to all manner of practices and appropriate use of social media, responsive and proactive in handling patient-experts' issues, and maintenance of professionalism (Tegegne et al., 2022).

Data/Methodology/propositions

This was a descriptive desktop study. The researcher identified 315 journal articles guided by relevant themes: ethical considerations in accessing healthcare information, confidentiality, anonymity and protection of individual' data, professionalism and patients' dignity. A total of 21 journal articles were selected based on their relevance and suitability of the

study; they were critically reviewed. The collected data was categorized and finally analyzed; the emerging patterns were used to answer the research questions.

Findings/analysis

Table 01: Determination of the ethical concerns in accessing healthcare information from social media

Ethical issues raised	Number of journals	Percentages
All the journals' articles agreed that ethical considerations. Should be observed: anonymity, confidentiality, privacy, physicians' professionalism	21 journal articles	100%
20 journal articles agreed on imperative response by physicians to patient concerns.	20 journal articles	95%

Table 02: Opportunities presented by social mediato patients with terminal cases

Were able to access important information	11 journal articles	52%
Able to share experiences	10 journal articles	48%
Access experts' advice	09 journal articles	43%
Able to join social support groups	08 journal articles	38%
Had capacity building	12 journal articles	57%

Table 03: Challenges experienced by the patients with terminal diseases in accessing healthcare information

Accessing misinformation;		36%
Technological illiteracy		50%
Lack of access to the internet	11 journal articles	52%
48% personal data security.	10 journal articles	48%
Healthcare information complicated to lay people	14 journal articles	66%
Threat of misinformation	12 journal articles	57%

Conclusion

Social media is now an important part of the lives of many individuals living with terminal diseases. Indeed, the field of digital healthcare has greatly advanced and widened its reach globally. Patients enjoy ease of access to information, and services. For example, they use social media to share their day today experiences with their doctors and support groups they belong to, or to search for information about accessing treatment for their conditions. However, despite the many opportunities' individuals living with terminal diseases may access through the social media; there is therefore need for the patients to be very careful because their data, privacy and confidentiality may be abused unknowingly. All the stakeholders in the healthcare industry have the responsibility to work together closely to ensure the affected are not exploited through misinformation, or by being weighed against any unanticipated risks, and abuse of data is prevented. There is consensus that availability of data and information is useful to all the stakeholders, but prevention of data abuse, preservation of privacy and confidentiality of those individuals seeking access of healthcare information is paramount.

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