Sharing health information on Instagram: The patients' right to privacy

Leonardo S. de MORAIS*
Federal University of Pelotas

Vinícius A. DARGÉL
Pontifical Catholic University of Rio Grande do Sul

Márcia S. FERNANDES
Pontifical Catholic University of Rio Grande do Sul

José R. GOLDIM
Federal University of Rio Grande do Sul

ABSTRACT: This is a retrospective study with a qualitative-quantitative design whose main aim was how patients' right to privacy is handled by health professionals who post on Instagram images taken in restricted healthcare settings. Over a total of 1.574 free-access images analysed, 325 images violated patient's right to privacy as ruled by the Brazilian Civil Code. This finding adds evidence to the need that professionals working in intensive care units and surgical units receive a specific training on extent and implications of professional duties of confidentiality issues, and in particular the protection of patients' privacy. In addition, it is recommendable that the use of social media platforms by healthcare professionals at work should be restricted to those situations in which it may be justifiable in virtue of specific, predetermined reasons, and to condition that is fully compliant to privacy protection's requirements and the ethical principles of medical practice.

1. Overview

The popularity of social media is constantly increasing worldwide. Social media platforms like Facebook, Twitter, YouTube and Instagram provide a large panel of functionalities that allow users to collectively share data and personal information, including photos, audio, and videos. Social media platforms are frequently used by health professionals to share, in real time, images and videos that contain patient health records, patient

* Corresponding author: Leonardo S. de MORAIS | leonardostollm@gmail.com

identifiable data (Sullivan *et al*., 2012; Williams *et al*., 2014). Although Instagram is one of the most popular social media platforms[1], only few studies have explored the use of image sharing with patients depicted in healthcare settings (Moreno *et al*., 2016). In this regard, preliminary research findings have showed that psychiatric patients may be negatively affected by image sharing on social media platforms (Cavazos-Rehg *et al*., 2016; Correia *et al*., 2016; Holland & Tiggemann, 2016). The aim of our study was to observe how individuals' right to privacy is handled in Instagram, given that, to our knowledge, a limited number of studies have been conducted in this field (Rozenblum & Bates, 2013), and none of them in Brazil.

2. The right to privacy in Brazil

In Brazil, privacy is considered a fundamental right; this includes privacy as a right of the human personality, expressed in specific codes, acts or laws. In Title II (Fundamental Rights and Guarantees), Chapter I (On Individual and Collective Rights and Duties), Article 5, the Federal Constitution (CRFB) of 1988 grants fundamental rights to the inviolability of the right to life and freedom and paragraph X specifically guarantees the inviolability of privacy, honour and the image of people (Brazil, 1988).

The Civil Code (Law 10,406 / 2002), General Part, Chapter II, articles 11 to 21, states the rights to personality of all human beings. The right to privacy is acknowledged in article 21: The private life of the natural person is inviolable, and the judge, at the request of the interested party, will adopt the necessary measures to prevent or terminate the contrary to this rule (Brazil, 2002). Right to privacy includes the protection of identifiable data, image and personal information, and foresees, among the other, preventive actions directed to avoid damage as established by article 12 of the Civil Code (Brazil, 2002). In the same way, the Civil Code established, in article 187, a general clause of unlawfulness act that is exercised with manifest violation of the limits imposed by its economic or social purpose, good faith or good customs (Brazil, 2002). In this case, it would mean the unauthorized transmission,

[1] Only in 2017, the platform had 700 million active users per month. See Instagram info center at: https://instagram-press.com/blog/2017/04/26/700-million/.

dissemination or publication of information, images, data or any source of information related to the patient's medical condition.

In Brazil, privacy's protection of and confidentiality are also highlighted by the constitutional command in favour of children, adolescents and elderly. For instance, the protection of children and adolescents is regulated by the Child and Adolescent Act, Law 8.069/1990, while elderly's protection is regulated by the Elderly Act, Law 10.741/2003 (Brazil, 1990; Brazil, 2003).

Taking deontological principles into consideration, health professionals, especially physicians, must respect the confidentiality of their patients' personal and medical information as well as data and images that have been entrusted to them by patients. This obligation is emphasised in the Code of Medical Ethics issued by the Brazilian Medical Council (*Conselho Federal de Medicina* - CFM). The CFM Resolution n. 1.931/2009 (see Articles 73 to 79), as a rule, prohibits the physician from disclosing any information obtained by virtue of the exercise of the profession, except in cases in which the disclosure is due for legally established purposes. For example, if the patient consents to disclose their data, or disclosure is needed to protect concerned minors. However, it is prohibited to provide information to private subjects as insurance companies or to employers without patient's consent and to cease confidentiality' duty for reasons unrelated to professional needs (CFM, 2009).

It is important to emphasise article 75 of the Brazilian Code of Medical Ethics, which states that it is forbidden for the physician to refer to identifiable clinical cases, to display patients or their portraits in professional advertisements or in the disclosure of medical matters in general media, even with the consent of the patient (CFM, 2009). Depending on the severity and the circumstances of the case, a violation to the Code' provisions may lead concerned professionals to a temporary or permanently loss of medical license. However, the respective punishment does not interfere with the civil or criminal responsibilities provided by law.

Brazilian legislation regarding protection of personality rights, including privacy, does not distinguish between dead or alive individuals. Therefore, the duty of confidentiality by healthcare professionals is valid even after the death of the patient. This situation is regulated in the Brazilian Civil Code (Brazil, 2002: art. 12), and also foreseen by the Code of Medical

Ethics (CFM, 2009: art. 73). Nonetheless, the prohibition of sharing identifiable data, personal information and images, and of breaching confidentiality or privacy has some exceptions. Breaching confidentiality or privacy may be justified for epidemiological reasons, such as reporting diseases or when there is a potential for abuses to children, adolescents and elderly people (Brazil, 2001: 86). It is important to note that in both circumstances the health institutions and professionals with whom the information is shared have the same responsibility to preserve this information, and this communication cannot be intended as a crime report (Morais, 2013; Saliba *et al*., 2007). Its aim is indeed to inform authorities in order to allow them to take decisions with a view to protect individuals' rights.

It is worth reminding that even when a physician is called to testify in legal trial, the disclosure of information obtained for professional reasons is not acceptable according to the Code of Medical Ethics (CFM, 2009: art. 73), which protects professional secrecy and prevent professionals from revealing any information spontaneously or under intimidation. Lastly, in Brazil, the protection of confidentiality and preservation of patient information is not only a legal obligation under the civil law and the deontological code, but it is also ruled by the Penal Code. Revealing data to someone without just cause, or secrecy of which had knowledge because of its duties, ministry, trade or profession, and whose disclosure may cause harm to another, shall be punished with imprisonment from three months to a year (Brazil, 1940: art. 154).

3. Methods: a qualitative-quantitative design

This is a retrospective study with a qualitative-quantitative design. The research was carried out in August 2014 in the Laboratory of Research in Bioethics and Ethics of Science, Porto Alegre, Brazil. Images were identified through the Google search tool using the 7 descriptors listed in Table n. 1.

The descriptors were chosen because they potentially identify images of restricted access hospital areas that were published in Instagram. We selected images that were published in a 24-hour range (from 14th August, at 10am to 15th August, at 10am). A preliminary data analysis was done in January 2015. The qualitative study included only public images obtained by the Google search tool and posted by health professionals. For the analysis of

images, we used the following categories: (A) identified patient, minor or of legal age of majority; (B) identified medical act, procedure exposure; (C) restricted circulation environment, with health institution identification involved. The images were pooled and evaluated based on its content.

DESCRIPTORS IN PORTUGUESE LANGUAGE	DESCRIPTORS TRANSLATED IN ENGLISH LANGUAGE	DESCRIPTORS ALLOCATED IN GROUPS
#BLOCOCIRURGICO	#OPERATINGTHEATRE	(a) OPERCENTER
#BLOCOCIRÚRGICO	#OPERATINGTHEATRE	(a) OPERCENTER
#UTINEO	#NEONATALICU - neonatal intensive care unit	(b) NEOICU
#UTINEONATAL	#NEONATALICU - neonatal intensive care unit	(b) NEOICU
#UTIPED	#PEDIATRICITU - pediatric intensive treatment unit	(c) PEDICU
#UTIPEDIATRICA	#PEDIATRICITU - pediatric intensive treatment unit	(c) PEDICU
#UTIPEDIÁTRICA	#PEDIATRICITU - pediatric intensive treatment unit	(c) PEDICU

Table n. 1 - Descriptors used during the research

Data was organized in three groups: (a) OPERCENTER, corresponding to the 2 descriptors #OPERATINGTHEATRE; (b) NEOICU, corresponding to the 2 descriptors #NEONATALICU; and (c) PEDICU, corresponding to the 3 descriptors #PEDIATRICITU. Image counting was done using the Counter Report program by Apple®. Data obtained were evaluated qualitatively using Bardin's approach on content analysis (Bardin, 2011), and the inferences were obtained through numerical descriptions generated statistically through the SPSS® program, version 18.0.

The study has collected data using public users' profiles available on Instagram, thus not involving direct contact with individuals. The project complies with the Brazilian national standards of research ethics established by the Brazilian National Health Council (CNS, 2012; 2016).

4. Sharing health information on Instagram: results

In total, 4 765 published images were identified, and 3 191 (64.08%) of the total were published on Instagram with restricted access. Therefore, most of the images published were not included in this study. However, this does not exclude ethical considerations on the potential disclosure of these images. An image being restricted in Instagram means that fewer users have access to it, however it is not possible to ensure that the privacy of patients and institutions involved are being kept confidential.

After applying the inclusion and exclusion criteria, 1 574 images with free access were found (33.03%) of the total collected photos remained for analysis. In the first group, called OPERCENTER, a total of 459 images (29.16%) were included. Of these, 102 images (19.61%) violated the right to privacy according to provisions of the Brazilian Civil Code (Brazil, 2002: articles 12 and 21); 81 out of 459 images (24.92%) identified a hospital environment of restricted access in which the health institution was exposed; and 21 out of 459 images (6.46%) allowed identification of the medical act by exposing the procedure in some way. In the second group, corresponding to the NEOICU, a total number of 835 images (53.05%) were identified; of these, 168 (20.12%) directly identified a patient seemingly underage. In the third group, denominated PEDICU, a total number of 280 images (17.79%) were identified; of these, 55 (19.64%) violated the patient's right to privacy, according to the Brazilian Civil Code; 39 images (12%) were related to children; and 16 images (4.92%) allowed identifying the medical act by exposing the procedure.

Over a total of 1 574 free-access images analysed, 325 images violated patient's right to privacy according to the Civil Code (Brazil, 2002) and the CFM Deontological Code (2009). Of the images, 63% identified a minor patient; 11.38% exposed a medical act, with demonstration of the surgical procedure; 24.92% registered a restricted access environment, with the identification of the health institution involved.

In category 1, the images were classified as violating the right to privacy because they contained patients' details allowing them to be identified. Images containing new-borns and/or children who were clearly underage, were also classified as an image of a minor patient. In category 2, images were classified as violating the right to privacy according to the above mentioned legal provisions and deontological obligations (Brazil, 2002; CFM, 2009) because they showed tissues or human body parts during a surgical procedure. In category 3,

the images were classified as violating the right to privacy because they showed the health institution's logo and they had an exact location of the ICU or the surgical block, due to the use of check-in tools.

	IMAGES VIOLATING INDIVIDUALS' PRIVACY			
Category/Sub-category	GROUP			
	OPERCENTER	NEOICU	PEDICU	Total
Cat. 1: Images allowing patient being identifiable	0	168 (51.69%)	39 (12%)	207 (63.69%)
Sub. 1.1: patient underage	0	168 (5.69%)	39 (12%)	207 (63.69%)
Sub. 1.2: patient of age	0	0	0	0
Cat. 2: Images allowing identification of medical act	21 (6.46%)	0	16 (4.92%)	37 (11.38%)
Sub. 2.2: identification of medical procedure	21 (6.46%)	0	16 (4.92%)	37 (11.38%)
Cat. 3: Images taken from restricted access environment	81 (24.92%)	0	0	81 (24.92%)
Sub. 3.1: identification of the health institution	81 (24.92%)	0	0	81 (24.92%)
Total images	102 (31.38%)	168 (51.69%)	55 (16.92%)	
OTHER IMAGES				
Cat.4: Images compliant to privacy's rules	354 (28.34%)	667 (53.40%)	225 (18.01%)	1 246 (100%)
Sub. 4.1: images shared for sensationalist purposes	354 (28.34%)	667 (53.40%)	225 (18.01%)	1 246 (100%)
Sub. 4.2: images shared for educational purposes	0	0	0	0
Total images	354 (28.34%)	667 (53.40%)	225 (18.01%)	1 246 (100%)

Table n. 2 - Data Results

Results show that NEOICU is the setting with the highest incidence of published images on Instagram. As well, NEOICU is the setting in which underage patients may see their privacy violated more frequently (Table n. 2). In addition, some images were recorded during

high complexity medical procedures, when the patients were visibly vulnerable and sedated in environments with restricted access (ICUs and surgical centers).

5. Discussion: the patients' right to privacy on Instagram

According to available literature in this field, the kind of health information shared online varies according to the specific features of each social media platform. For example, on YouTube, content analysis surveys show that health issues are mostly shared with the purpose of disseminating information on disease's prevention campaigns (Williams *et al*., 2014). On Twitter, shared news involves predominantly alerts on new health treatments (Holland & Tiggemann, 2016). Facebook is used to promote support of colleagues and patients with health problems or rare diseases (Jain, 2009). However, it is important, to emphasise that none of the major social platforms may guarantee full protection against violation privacy breach.

Although it has been claimed that sharing images related to healthcare settings may have a fundamental role in educating professionals, promoting prevention activities and fostering health promotion (Eckler *et al*., 2010), health professionals should be aware of patient's rights as well as of the provisions of medical ethics that provide patients with specific needs of protection. From a legal point of view, Brazilian legislation (Brazil, 1988; 2002) and the Code of Medical Ethics (CFM, 2009) guarantee the right to privacy of patients also by stigmatising images-related sensationalism and personal self-promotion through sharing content taken by healthcare settings (CFM, 2015: 131). The protection of right to privacy in the Brazilian legal order includes patient' self-determination, i.e. the right to determine who can use and access data and information related to them (Fernandes *et al*., 2015). However, there is growing evidence that privacy protection in healthcare settings is deficient, especially due to frequent use of social media by healthcare professionals (McKee, 2013; Sullivan *et al*., 2012; Villas-Bôas, 2015). As a matter of fact, many training scholars and health professionals lose sight of ethical requirements associated with the profession, among which the fundamental values underlying right to privacy and duty of confidentiality.

The results of our study indicate healthcare professionals publish more images in the following hospital settings: intensive care units (ICUs) and surgical blocks (see Table n. 2).

These sites are characterised as 'restricted access' sites to ensure the integrity and control of infections in patient care and health care. More in general, the results show that health professionals underestimate image-sharing on social media platforms, which have been described as 'open public spaces' (Lévy, 2012). Therefore, it is recommended that professionals working in intensive care units and surgical units receive a specific training on ethical and legal issues ensuing from professional duty of confidentiality and the needs of protecting patients' privacy. Moreover, the use of social media platforms by healthcare professionals at work should be restricted to those situations in which it may be justifiable in virtue of specific reasons – e.g. for educational purposes –, and it is compliant to privacy protection's requirements and ethical principles of medical practice (Eshah, 2018).

Despite we metaphorically live in a 'Spectacle Society' in which 'being seen' can be more important than merely 'be' (Debord, 1967), we conclude that healthcare professionals cannot elude its pivotal role and the special responsibility they assume with regard to observing ethical principles and guaranteeing that patients' rights are respected.

6. Final considerations

The main finding of our study is that from every five images published in Instagram related to healthcare' settings, at least one appears to violate individual right to privacy. This finding adds evidence to the fact that healthcare institutions should promote a specific education of professionals in regard of images sharing, use of social media platforms at work. This kind of educational activities may improve the overall awareness by healthcare professionals on the ethical implications of their actions, which are especially relevant for the protection of privacy and confidentiality of patients' health information. This is especially due when considering paediatric patients, as insofar they are to be seen as a very vulnerable category of patients[2].

[2] The right of children and adolescents' to privacy is supported by the Brazilian Society of Paediatrics and the Brazilian Federation of Gynaecology and Obstetrics' Societies (Brazil, 1995) and is also regulated by the Statute of the Child and Adolescent 'ECA' (Brazil, 1990) and the Code of Medical Ethics (CFM, 2009). Although the Brazilian Civil Code (Brazil, 2002) establishes the civilian majority at 18 years (a definition that changes the legal requirements related to autonomy), the right to privacy is guaranteed to all human persons, including adolescents and children.

Acknowledgments

This work was supported by the Laboratory of Research in Bioethics and Ethics in Science based at Porto Alegre Clínicas Hospital (LAPEBEC/HCPA).

We sincerely thank Louise Delaney, Júlia Delaney and Aroldo A. Dargél, for the reviews and valuable comments and suggestions.

References

Bardin L. (2011) *Análise de conteúdo*. São Paulo: Edições 70.

Brazil (1940) *Brazilian Penal Code*, available at: http://www.planalto.gov.br/ccivil_03/decreto-lei/Del2848compilado.htm.

Brazil (1988) *Federal Constitution of Brazil*, available at: http://www.planalto.gov.br/ccivil_03/ constituicao/ConstituicaoCompilado.htm.

Brazil (1990) *Statute of the Child and Adolescent,* available at: http://www.planalto.gov.br/ccivil_03/leis/L8069Compilado.htm.

Brazil (1995) *Resolution n. 41 of October 13th on Rights of Hospitalized Children and Adolescents*, available at: http://www.mpdft.mp.br/portal/pdf/unidades/promotorias/pdij/Legislacao%20e%20Jurisprudencia/Res_41_95_Conanda.pdf.

Brazil (2001) *Ordinance by Ministry of Health n. 1,968 of October 25th*, concerning the notification to the competent authorities of cases of suspected or confirmed maltreatment against children and adolescents, available at: http://bvsms.saude.gov.br/bvs/saudelegis/gm/2001/prt1968_25_10_2001_rep.html.

Brazil (2002) *Brazilian Civil Code*, available at: http://www.planalto.gov.br/CCivil_03/leis/2002/L10406.htm.

Brazil (2003) *Brazilian Act. Senior Citizens' Statute. n. 10.741*, available at: http://www.planalto. gov.br/ccivil_03/leis/2003/l10.741.htm.

CNS [Conselho Nacional de Saúde] (2012) *Resolution n. 466/2012*, available at: http://conselho.saude.gov.br/resolucoes/2012/Reso466.pdf.

——— (2016) *Resolution n. 510/2016*, available at: http://conselho.saude.gov.br/resolucoes/2016/Reso510.pdf.

Cavazos-Rehg P.A., Krauss M.J., Sowles S.J., and Bierut L.J. (2016) "Marijuana-Related Posts on Instagram". *Prevention science*, 7(6): 710-20.

CFM [Conselho Federal da Medicina] (2009) *Code of Medical Ethics*, available at: http://www.rcem.cfm.org.br/index.php/cem-atual.

——— (2015) *Resolution n. 2.126/2015*, available at: http://www.portalmedico.org.br/resolucoes/CFM/2015/2126_2015.pdf.

Correia R.B. LI L., and Rocha L.M. (2016) "Monitoring potential drug interactions and reactions via network analysis of instagram user timelines". *Pacific Symposium on Biocomputing*, 21: 492-503.

Debord G. (1967) *La societé du spectacle*. Paris: Gallimard.

Eckler P. Worsowicz G., and Rayburn J.W. (2010) "Social media and health care: an overview". *PM R*, 2(11): 1046-50.

Eshah N.F. (2018) "Investigating Cardiovascular Patients' Preferences and Expectations regarding the Use of Social Media in Health Education". *Contemporary nurse*, 54(1): 52-63.

Fernandes M.S. Ashton-Prolla P., Moraes S.L., Matte U.S., Goldim J.R., and Martins-Costa J. (2015) "Genetic information and biobanking: a Brazilian perspective on biological and biographical issues". *Journal of community genetics*; 6(3): 295-99.

Holland G., and Tiggemann M. (2016) ""Strong beats skinny every time": Disordered eating and compulsive exercise in women who post fitspiration on Instagram". *The International journal of eating disorders*, 50(1):76-9.

Jain S.H. (2009) "Practicing Medicine in the Age of Facebook". *New England Journal of Medicine*, 361(7): 649-51.

Lévy P. (2012) "The Unfinished Mutation of the Public Sphere". *Signo y Pensamiento*, 31(60): 96-103.

Martorell L.B., Nascimento W.F., Garrafa V. (2016) "Redes sociais, privacidade, confidencialidade e ética: a exposição de imagens de pacientes no facebook". *Interface - Comunicação, Saúde, Educação*, 20(56): 13-23.

Mckee R. (2013) "Ethical issues in using social media for health and health care research". *Health policy*, 110(2-3): 298-301.

Morais L.S., Fernandes N.C., Genro B.P., Fernandes M.S., Goldim J.R. (2013) "Revelação de diagnóstico de AIDS para terceiros: aspectos éticos, morais, legais e sociais". *Revista HCPA*, 33(3-4): 279-85.

Moreno M.A., Ton A., Selkie E., and Evans Y. (2016) "Secret Society 123: Understanding the Language of Self-Harm on Instagram". *The Journal of adolescent health*, 58(1): 78-84.

Rozenblum R., and Bates D.W. (2013) "Patient-centred healthcare, social media and the internet: the perfect storm?" *BMJ quality & safety*, 22(3): 183-6.

Saliba O., Garbin C.A.S., Garbin A.J.I., and Dossi A.P. (2007) "Responsabilidade do profissional de saúde sobre a notificação de casos de violência doméstica". *Revista de Saúde Pública*, 41(3): 472-477.

Sullivan S.J., Schneiders A.G., Cheang C., Kitto E., Lee H., Redhead J., Ward S., Ahmed O.H., and McCrory P.R. (2012) "What"s happening?' A content analysis of concussion-related traffic on Twitter. *British Journal of Sports Medicine*, 46(4): 258-63.

Villas-Bôas M. E. (2015) "O direito-dever de sigilo na proteção ao paciente". *Revista Bioética*, 23(3): 513-23.

Williams D., Sullivan S.J., Schneiders A.G., Ahmed O.H., Lee H., Balasundaram A.P., and McCrory P.R. (2014). "Big hits on the small screen: an evaluation of concussion-related videos on YouTube". *British journal of sports medicine*, 48(2): 107-11.