Mobile health services (mHealth) in haemophilia: opportunities and risks

Ana-Belén del Río-Lanza^{a, b} (adelrio@uniovi.es)

Ana Suárez-Vázquez^a (<u>anasv@uniovi.es</u>)

Leticia Suárez-Álvarez^a (lsuarez@uniovi.es)

Víctor Iglesias-Argüelles^a (viglesia@uniovi.es)

^a Biomedicine and Health Cluster, Business Administration Department, University of Oviedo, Oviedo, Spain

^b Spanish Federation of Haemophilia, Madrid, Spain

CORRESPONDING AUTHOR AT:

Ana-Belén del Río-Lanza

Address: School of Economy and Business, Business Administration Department

Avenida del Cristo s/n, 33071 Oviedo. Asturias. Spain.

Telephone: +34 985 10 28 27 FAX: +34 985 10 37 08

e-mail: <u>adelrio@uniovi.es</u>

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Mobile health services (mHealth) are the joint use of mobile communication devices, internet and wireless technologies for health care. The World Health Organization has shown its support of mHealth as a means to confront the challenges that the health systems of every country face [1]. There is a great interest in using mHealth as a means of improving medical care and delivering and extending it to those in countries with a less developed medical infrastructure [2,3].

For patients with rare and chronic illness, such as patients with haemophilia, mHealth is especially valuable when they live far from a Haemophilia Treatment Centre (HTC). In developed countries, most people with haemophilia undergo prophylactic therapy at home [4]. The introduction of home care therapy has meant that health care professionals are dependent on the patient to inform them of their infusion practices, frequency of bleeds, outcomes and adverse events. It is clear that good record keeping is an essential component of home-based haemophilia care. Using new technologies to provide relevant information where is needed with the appropriate health care professionals is possible and, actually, is being highly demanded.

There are several reasons why mHealth is also gaining momentum: (a) the continuous advances of mobile technology; (b) the enormous penetration of internet and smartphones; (c) the extension of the functionalities of those devices; and (d) the habit of using new technologies for multiple activities such as shopping or social network communication. In accordance with the Mobile Health Market Report 2013–2017, with more than 97,000 health-related mobile applications and approximately 1,000 new applications being published every month, it is expected that mHealth will grow by more than 25% per year [5].

However, the implementation of mHealth is weak or tentative in most countries. The field of health care presents risks and opportunities different from those of other fields. This is because health care has traditionally been associated to interactions between people (health care professionals-patients) which require physical or personal contact. It is also necessary to consider that health care requires specialized knowledge and that many of the services of health care professionals are difficult for the patients to appreciate and evaluate, even after having received them. Given these peculiarities, we have analyzed the preference and the intention of use of mHealth by patients with haemophilia.

We carried out an online survey of 181 Spanish patients of all ages diagnosed with haemophilia A or haemophilia B, with or without inhibitors, and with regular replacement treatment for haemophilia. In the questionnaire, a mHealth service was described and respondents asked different questions regarding the motivations of use, the perceived risks, the social influence, the preference and the intention of using mHealth. Responses were

measured on a five point Likert scale. Figure 1 shows the variables used to explain the intention of using mHealth.

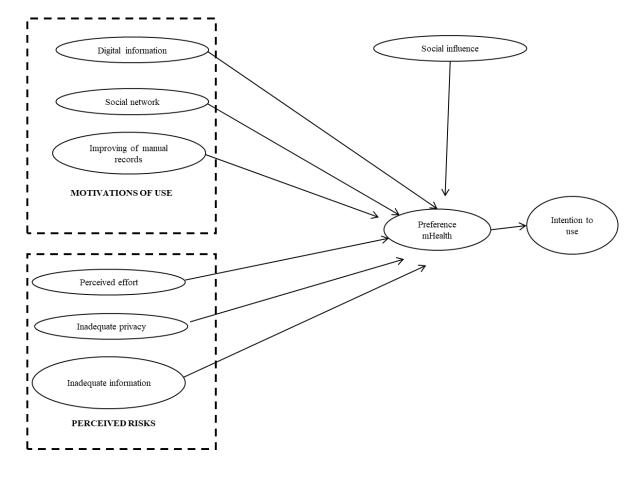


Figure 1. Proposed variables to explain the intention of using mHealth

We used structural equation modeling (SEM), by means of the EQS 6.2 software, to study which variables encourage and which variables restrain the intention of using mHealth. Our results suggest that the information on health put forward by health care professionals can attract interest in mHealth. mHealth service providers should involve health care professionals in using these technologies before and after attending a patient, i.e. offering and publishing information, recommending webs or other internet sites, using mHealth during clinics. It is also convenient the use of different formats such as texts, photos, graphs or videos. HTC can develop an important role encouraging patients to use mHealth.

Regarding the motivations for using social networks, patients do not consider the use of mHealth as a platform to be in contact with other people with haemophilia. It seems they are comfortable with their regular channels of communication (for example, phone calls or text messages, emails or meetings organized by patient associations).

If the use of mHealth to register health data is taken into account, it has been observed that the patients perceive certain difficulties or inconveniences in manual or paper records. However, these difficulties do not influence significantly in the degree of preference towards mHealth. This suggests the convenience of presenting electronic records as a complement, rather than a substitute, for paper records. It would seem advantageous that the patients not only know the functions of mHealth but also that they compare the manual registry of data with the registry through mobile technologies. The strategies to encourage the use of mHealth should pursue a progressive change without ever forcing the patient to stop using paper records.

With regards to the risks that mHealth entails, it appears the effort from the side of the patients would not be a restraint to mHealth. Nevertheless, it would act as a sign that the data are going to be accurately registered and will allow to extract relevant information for the correct monitoring of their illness. An excessive appearance of simplicity of the instrument may send out a message of little use or of mistrust. This is not incompatible with the convenience that the instrument be developed to try to simplify the use, since over-

complexity could give rise to another undesired effect, the abandonment in the use of the application.

Likewise, in the context of mHealth, previous studies [6] verified that the privacypersonalisation paradox existed and that privacy concerns negatively influence the adoption of the intention of mHealth services. However, our work suggests that privacy concerns do not significantly affect the intention of use of a mHealth. It must be taken into account that haemophilia is a disease in which there are many treatment decisions and usually there are not "evidence-based indications to unequivocally identify a superior treatment option" [7, p. 801]. Therefore, it makes sense that privacy concerns do not pose an obstacle to use mHealth.

Another risk of mHealth is that the information published in the social network by health care professionals or patients can be sometimes inadequate when it is not up to date or contains errors. It is observed that the opinion that the use of mHealth offers information of little interest, because it is not up to date or contains errors, discourages patients from using mHealth. This suggests the possibility of using signals to certify the reliability and truthfulness of mHealth.

Finally, regarding the social influence, our study shows that peers play an important role in the acceptance of mHealth among people with haemophilia. We suggest developing actions in which the peers declare and make visible to others the benefits of using mHealth.

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It would be interesting to extend the study to other countries. Technological opportunities (web 5.0, cloud, wearables, gamification, big data analytics), social opportunities ("wired lifestyle", "connected lifestyle", "bring your own device"), and health opportunities (precision medicine, remote care, social-health empowerment) favor mHealth use. Thus, mHealth is deeply affecting the health ecosystem and is able to increase the effectiveness and effectivity of health care services. However, it is important to highlight the risk of focusing on the technology instead on trying to increase the value for the patient. Creating value for the patient requires a great understanding of the opportunities and risks that the patients perceived in the use of mHealth. Our study suggests that there are tools of mHealth that can be relevant for program developers or for health care professionals but that do not have interest for the patients with haemophilia. The same happens with potential barriers for the use of mHealth. Therefore, investing in mHealth requires a previous knowledge of users preferences -both of health care professionals and patients- regarding how mHealth can better influence health care service and improve communication between the agents of the health ecosystem.

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References

- 1 Heerden AV, Tomlinson M, Swartz L. Point of care in your pocket: a research agenda for the field of m-health. *Bull World Health Organ* 2012; **90:** 393–94.
- 2 Becker S, Miron-Shatz T, Schumacher N, Krocza J, Diamantidis C, Albrecht UV. mHealth 2,0: experiences possibilities and perspectives. *JMIR Mhealth Uhealth* 2014; 2: e24.10.2196/mhealth.3328.
- 3 Khair K, Holland M. Managing hemophilia: the role of mobile technology. *Smart Homecare Technol Telehealth* 2014; **2:** 39–44.
- 4 Franchini M. The modern treatment of haemophilia: a narrative review. *Blood Transfus* 2013; **11**: 178–82.
- 5 Jahns R, G, Houck P, Mobile Health Market Report 2013; 2013 –2017. Available at: <u>https://research2guidance.com/wp-content/uploads/2015/08/Mobile-Health-</u> <u>Market-Report-2013-2017-Preview.pdf</u>. Accessed October 10, 2016.
- 6 Guo X, Zhang X, Sun Y. The privacy–personalization paradox in mHealth services acceptance of different age groups. *Electron Commer Res Appl* 2016; **16:** 55–65.
- 7 Athale A, Giguere A, Barbara A, Krassova S, Iorio A. Developing a two-sided intervention to facilitate shared decision-making in haemophilia: decision boxes for clinicians and patient decision aids for patients. *Haemophilia* 2014; **20**: 800–6.