Adolescents’ and Young Adults’ Experiences of Offense from Reading Their Health Records Online

Josefin HAGSTRÖM¹, Charlotte BLEASE², Jonas MOLL³, Hanife REXHEPI³, Isabella SCANDURRA³ and Maria HÄGGLUND⁴

¹Dept. of Women’s and Children’s Health, Uppsala University, Uppsala, Sweden
²Informatics, School of Business, Örebro University, Örebro, Sweden
³School of Informatics, University of Skövde, Skövde, Sweden

ORCiD ID: Josefin Hagström https://orcid.org/0000-0003-2835-0259, Charlotte Blease https://orcid.org/0000-0003-3657-2476, Jonas Moll https://orcid.org/0000-0002-4772-4730, Hanife Rexhepi https://orcid.org/0000-0001-8957-9853, Isabella Scandurra https://orcid.org/0000-0002-2597-1079, Maria Hägglund https://orcid.org/0000-0002-6839-3651

Abstract. Patients feeling offended by reading records online is a concern among healthcare professionals, however previously published work has focused on adult patients. Here, a survey was used to explore and compare experiences of offense among adolescents (15-19 years old) and young adults (20-24 years old). Findings indicated that while the ratio of those offended did not differ between adolescents and young adults, reasons for feeling offended did.

Keywords. Adolescents, young adults, patient accessible electronic health records, electronic health records, offense, open notes

1. Introduction

Online record access can provide many benefits for adolescents [1] and support their transition into adulthood [2]. However, healthcare professionals (HCPs) fear that readers will be emotionally harmed by what they read in their electronic health record (EHR) [3]. A recent US study found that a tenth of adults feel offended by something they read in their notes [4]. Little is known about adolescents’ experiences of reading their EHR [1], hence our aim is to explore adolescents’ and young adults’ (YA) experiences of being offended by reading their EHR online.

2. Methods

A survey designed in the NORDeHEALTH project [5] was available for three weeks to users accessing their EHR via the Swedish national patient portal. One closed-ended question was used here: Have you ever felt offended by something you read? If yes, a

¹Corresponding Author: Josefin Hagström, email: josefin.hagstrom@kbh.uu.se.
free-text comment could be provided. Adolescents (15-19 years) and YA (20-24 years) were included. The yes/no question was analyzed using a Fischer’s exact Test and free-text responses were coded with qualitative content analysis [4]. Ethical approval was granted by the Swedish Ethical Review Authority (EPN 2021/05229).

3. Results

Of 13 008 survey respondents, 218 were aged 15-19 (1.68%) and 409 (3.14%) were 20-24 years old. A quarter of adolescents (57/218, 26.1%) and a third of YA (135/409, 33.0%) had been offended from reading their EHR. The difference between groups was not significant (p=.84). About two thirds of each group noted comments (adolescents: 36/57, 63%; YA: 90/135, 67%), the most common reason for both groups being disrespect, followed by labelling for YA, and errors and surprises for adolescents.

4. Conclusions

Similar ratios of adolescents and YA reported experiences of feeling offended by reading in the EHR, yet the underlying reasons differed. Further work should consider the role of health literacy and examine disparities with adult users [4]. This may be the first study of adolescents and YA feeling offended when reading their EHR. Findings should be considered in the design of patient portals and EHR documentation guidance.

Acknowledgements

This work was supported by NordForsk via funding to NORDeHEALTH (no 100477).

References