Patients’ Experiences of Demanded Access to Online Health Records

Annika BÄRKÅSa,1, Anna KHARKOa, Rose-Mharie ÅHLFELDTb and Maria HÄGGLUNDa

aDepartment of Women’s and Children’s Health, Uppsala University, Sweden
bSchool of Informatics, University of Skövde, Sweden

ORCiD ID: Annika Bärkås https://orcid.org/0000-0002-1209-7714, Anna Kharko https://orcid.org/0000-0003-0908-6173, Rose-Mharie Åhlfeldt https://orcid.org/0000-0002-8607-948X, Maria Hägglund https://orcid.org/0000-0002-6839-3651

Abstract. Patient-Accessible Electronic Health Records (PAEHR) is particularly controversial in mental healthcare. We aim to explore if there is any association between patients with mental health conditions and the experience of someone demanding access to their PAEHR. A chi-square test showed a significant association between group belonging and experiences of someone demanding access to the PAEHR.

Keywords. Mental health, patient accessible electronic health record (PAEHR)

1. Introduction

Patient-Accessible Electronic Health Records (PAEHRs) are becoming more widespread but have been particularly controversial in mental healthcare. Studies report that clinicians are concerned that PAEHRs in mental healthcare may harm patients. In contrast, patients with psychiatric conditions report that reading their clinical information from mental healthcare enhances understanding of their mental condition or remembering their care plan [1]. A Canadian study has reported that care partners wish to support their family member who receives mental healthcare, such as having access to the family members’ PAEHR to help e.g. schedule appointments, renew medications. The care partners in this study emphasized the importance of privacy [2]. It is essential to explore if patients in mental healthcare have experienced that such privacy boundaries have been overstepped. This study aims to explore if there is an association between patients with mental health conditions and the experience of someone demanding access to their PAEHR.

2. Methods

This survey was designed within the research project NORDeHEALTH (NordForsk Project #100477). The survey was distributed in the Swedish PAEHR for three weeks from January 24 2022. The survey responses were anonymous. This paper focuses on

1 Corresponding Author: Annika Bärkås, email: annika.barkas@kbbh.uu.se
two participant groups; the Mental Health Group (MHG), which includes respondents self-reporting experience with mental healthcare, and the General Group, in which participants reported any other healthcare. Data analysis was performed in Jasp (v 0.16.2) and included descriptive statistics and a chi-square test.

3. Results

The total number of respondents included in this study was 12,334. In the MHG, 25 to 34-year-old women were overrepresented. A chi-square test showed a statistically significant association between group belonging and the experiences of someone demanding access to their PAEHR ($\chi^2(2, N=12334) = 112.79, p < .001$). In both groups, the majority responded that they have not experienced someone demanding access; however, the proportion of those who had experienced this was larger in the MHG.

Table 1. Responses to the item “Have you experienced that family, friends or another have demanded access to your health record that you did not want to share?”

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>MHG (n=3131)</th>
<th>General Group (n=9203)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Someone demanded access?</td>
<td>Yes</td>
<td>82 (2.62%)</td>
<td>58 (0.63%)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>2888 (92.24%)</td>
<td>8861 (96.28%)</td>
</tr>
<tr>
<td>Don’t know/don’t remember</td>
<td>161 (5.14%)</td>
<td>284 (3.09%)</td>
<td></td>
</tr>
</tbody>
</table>

4. Conclusions

A small proportion of participants in both groups stated they had experienced someone demanding access to their PAEHR; however, with more affirmative responses in the MHG than the General Group. It is not known what the circumstances of such demands were. Notably, younger women were overrepresented in the MHG. One hypothesis could be families who are worried about their young adults’ well-being and, in the role of careers, demand access to their “children’s” PAEHR. Another theory could be about excessive control from domestic partners [3]. Future studies should explore why patients with a mental health condition are more likely than others to have experienced someone demanding access to their PAEHR.

References

