



SHORT COMMUNICATION

Digitally excluded in a highly digitalized country: An investigation of Swedish outpatients with psychotic disorders and functional impairments

Christopher Holmberg^{a,b,*}, Andreas Gremyr^{a,c}, Viktor Karlsson^a, Karin Asztély^a

^a Department of Psychotic Disorders, Sahlgrenska University Hospital, Göteborgsvägen 31, V-huset, Gothenburg, Sweden

^b Department of Health and Care Sciences, University of Gothenburg, Gothenburg, Sweden

^c Jönköping Academy for Improvement of Health and Welfare, Jönköping University, Jönköping, Sweden

Received 18 October 2021; accepted 22 April 2022

Available online 30 May 2022

KEYWORDS

Digital divide;
Digital technology;
Function impairment;
Psychotic disorders;
Smartphone

Abstract Access to digital devices and digital services increases accessibility to mental health services. We investigated access to smartphones and digital identification methods (digital-IDs) in an outpatient unit focusing on patients with psychotic disorders and functional impairments. Patients' case managers completed an online anonymous survey. Most patients (85%) did not have digitalIDs, which is required in Sweden to access digital health care. High age and living in assisted living facilities influenced patients' access to smartphones and digitalID negatively. Even in a highly digitalized society, outpatients with psychotic disorders and functional impairments have much less access to digital technology than the population on average.

© 2022 The Author(s). Published by Elsevier España, S.L.U. on behalf of Asociación Universitaria de Zaragoza para el Progreso de la Psiquiatría y la Salud Mental. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

Introduction

Online and digital services are integral to the future of mental health care as this might enable overcoming barriers to mental health care access, enables a wider dissemination of online treatment programs, and might lead to more cost-effective care.^{1–3} Not least the COVID-19 pandemic has accelerated the understanding of digitalization in many aspects of the mental health care.⁴

However, a known problem is digital exclusion, which can be defined as the issue that some persons in society does not have access to digital technology to conduct everyday tasks online.³ This exclude them from digital access to mental health care services.⁵ A meta-analysis of mobile phone

Author contributions: KA and CH contributed to the conception and design of the study. CH, VK, and KA contributed to data acquisition. CH, AG, VK, and KA contributed to the analysis and interpretation of data for the work. All authors contributed to drafting the work and approved of the version to be submitted.

* Corresponding author: Christopher Holmberg, RN, PhD, Associate Professor, Address 1: Department of Psychotic Disorders, Sahlgrenska University Hospital. Göteborgsvägen 31, V-huset, 413 80 Mölndal; Address 2: Department of Health and Care Sciences, University of Gothenburg. Arvid Wallgrens Backe, Box 457, 405 30, Göteborg, Sweden, Tel: +46 (0) 766-18 18 52.

E-mail address: christopher.holmberg@gu.se (C. Holmberg).

<https://doi.org/10.1016/j.ejpsy.2022.04.005>

0213-6163/© 2022 The Author(s). Published by Elsevier España, S.L.U. on behalf of Asociación Universitaria de Zaragoza para el Progreso de la Psiquiatría y la Salud Mental. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

ownership among those with symptoms of psychosis revealed that the rate of phone ownership was rapidly increasing over time, with 81% ownership among those surveyed in 2014 and 2015.⁶ A systematic review of mobile phone studies and schizophrenia found no evidence of any adverse events related to technology use and rather overall strong support, interest, and adherence among those with schizophrenia.⁷

However, research also indicates that people with psychotic disorders had less confidence in using the Internet than people with other psychiatric diagnoses such as depression and that older patients were more likely to be digitally excluded.⁵ With international standards, Sweden is considered to have a very high digital technological penetration rate. For example, 96% of all adult Swedes report using the Internet at least sometimes, and of these, 70% of those that are older than 76 years have used a digital health care provider.⁸ To identify oneself online, most Swedish government agencies and health care providers require a digitalID. In 2020, 95% of Swedish Internet users reported using digital-ID (Bank-ID), and also senior citizens reported a high usage (86%).⁸ Bank-ID can be used on stationary computers, laptops, or tablets and smartphones.

Thus, the access to smartphones and digitalIDs is very high in the general Swedish population. However, we do not know to what extent patients enrolled in a Swedish outpatient unit that focuses on patients with psychotic disorders and functional impairments have access to digital devices and digitalIDs. This is imperative to investigate, as it would answer whether patients with complex care needs are digitally excluded from healthcare services.

Methods

This study was conducted in a specialized referral outpatient unit for patients with psychotic disorders and functional impairments provided by a tertiary psychiatry department. The department belongs to the Sahlgrenska university hospital in West Sweden. The department of psychotic disorders is the country's largest. Around 150–160 patients are usually enrolled at this particular unit. Patients are mainly referred to this unit from other outpatient units at the department due to their functional impairments which mostly is a result of debilitating and treatment resistant schizophrenia, and multiple psychiatric and somatic comorbidities.

When comparing patients at the unit with patients at the other outpatient units within the department of psychotic disorders, several indicators confirm that they have more functional impairments. For example, 95% of patients have had their psychotic disorder for more than 10 years compared with 73% in the other units. Most (68%) of the unit's patients live in assisted living facilities compared with 23% in the other units.

At this unit, the most common psychotic diagnosis (59%) is schizophrenia (F20), 26% are diagnosed with schizoaffective disorders (F25), 8% with unspecified nonorganic psychosis (F29), 6% with persistent delusional disorders (F22), and 1% with a severe depressive episode with psychotic symptoms (F32.3). Neurodevelopmental disorders are the most common psychiatric comorbidities, with intellectual disabilities (F70–79) being the most frequent, 13%, followed by autism spectrum disorders (F80–89). More than half of patients in

the unit (57%) have more than one psychiatric diagnosis. Also, 27% of patients in the unit have diabetes compared with 13% of patients in the other units, 17% vs. 13% have a cardiovascular disease such as coronary heart disease, and 8% vs. 3% have a chronic obstructive pulmonary disease (COPD).

Instead of using self-reported data from patients, their case managers completed a digital survey assessing the patients' access to smartphones and digitalIDs. The case managers know their patients very well as they function as the main contact for patients at the unit, coordinate their care, and have regular contact with other health care sectors and their patients' assisted living staff. Each case manager is responsible for around 10–15 patients.

A meeting with all staff was organized in June 2021 with information about the project. Following the meeting, case managers were emailed written information and a link to a digital survey using Microsoft Forms.

Variables included: patient age (years), gender (female, male, other), enrollment at the unit (0–3 years, 4–15 years, >15 years), living situation (living independently with or without assistance, assisted living facility, other), access to digital-ID (yes/no), access to a personal mobile phone (smartphone, older mobile phone, no), how does the patient contact the unit (call/text, online, via assisted living staff, other), case managers' perception of patients' ability to manage digital technology (independently, with support, not at all, not sure), and how certain the case managers self-reported data are accurate (very certain, somewhat certain, uncertain).

The survey was anonymous and completed by case managers' recollections of their patients. Thus, patients were not directly involved in the study. No unique identifiable patient data were collected. Hence, this study did not need formal ethical approval according to the Swedish Ethical Review Act (2003:460). The comparisons of patient characteristics at this unit with the other outpatient units were conducted using aggregated data from the department's quality register.^{9,10}

Descriptive (frequencies and percentages) and inferential statistics were used. As missing variables were low, and they were considered missing at random, thus maintaining unbiased analyses, we did not conduct any imputations.¹¹ The only continuous variable (patients' age) was not normally distributed ($p = 0.014$, Shapiro-Wilks), hence, non-parametric tests were used for all statistical associations (Spearman's rho) and comparisons (Fisher's exact test). A p -value less than 0.05 was considered statistically significant. SPSS (v. 26, IBM Corps.) was used for analyses.

Results

Case managers recorded information for 139 patients which represented 87% of the unit's total number of enrolled patient population ($n = 159$). Newly enrolled patients were not included because case managers did not have sufficient or reliable information about them. For most patients (92%), case managers reported to be very certain or certain that their recorded information was accurate.

Of the 139 patients, 81 were male (58%). Mean age was 59 years ($SD=10.8$, min/max: 27/83), and 97 (70%) of patients lived in assisted living facilities. Most patients had been enrolled at the unit between 4 and 15 years ($n = 96$, 69%).

Of the 139 survey responses, 136 (98%) contained complete information about patients' mobile phone access. There was an even distribution regarding the access to mobile phones, with 47 (35%) of patients not having one, 47 (35%) had an old version (i.e., not smartphone), and 42 (30%) had a smartphone. Most patients ($n = 73$, 53%) contacted the unit by calling or texting (SMS) themselves, 59 (43%) of patients needed help from assisted living staff to contact the unit, and 6 patients (4%) used other methods such as writing a letter ($n = 2$), make an unannounced in-person visit ($n = 2$), or via family members ($n = 2$). Of these 136 patients, case managers reported that most of them ($n = 82$, 59%) did not have the ability to use internet services to contact the unit. However, they estimated that 38 (27%) of the patients would be able to do it if they had some assistance. Only 13 (9%) were judged to be able to do it independently.

Of the 139 total survey responses, 132 (95%) contained information about patients' access to digitalIDs, and most patients ($n = 112$, 85%) did not have a digitalID.

Spearman's rho analyses revealed that significant variables associated with mobile phone access were patients' age ($p < 0.001$), living situation ($p = 0.024$), how they contact the unit ($p < 0.001$), and how case managers perceive the patient's ability to manage digital technology ($p < 0.001$).

For access to digital-ID, significant variables were patients' age ($p = 0.004$), living situation ($p = 0.001$), access to mobile phone ($p < 0.000$), how they contact the unit ($p < 0.001$), how they contact the unit ($p < 0.001$), and how case managers perceive the patient's ability to manage digital technology ($p < 0.001$). Thus, these variables were compared using Fisher's exact test (Table 1).

Discussions

The results reveal that compared to statistics from the Swedish general population, including specifically those aged 65 and older,⁸ this group of patients with psychotic disorders and functional impairments had very limited access to smartphones and digitalID. Results also disclose that older age and living in assisted living facilities was significantly negatively related to patient's access to smartphones and digital-ID. Having a smartphone was associated with having a digitalID. Patients that had smartphones and digitalID were more likely to contact the unit digitally and were perceived by their case managers to be more digitally skilled.

Generally, digitally excluded patients with psychotic disorders refer to a lack of knowledge as a barrier to digital inclusion. Rather than using mobile phones, they prefer to use the Internet via computers.⁵ Thus, facilitating inclusion among this population means helping them develop skills and confidence in using technology, and providing them with access. Providing mobile phones without basic information and technology training may be counterproductive. In society, excluded persons may end up even more excluded if they do not get access to mobile technology.⁵

To provide a high standard of care healthcare professionals should have a holistic view of the patient. This requires knowledge of patients' circumstances, the barriers presented by their mental health difficulties, and their financial resources.¹² Previous research that has focused on patients with psychotic disorders with mild-to-moderate functional impairments found that they owned several digital devices.⁷ In contrast, our patient sample did not own several digital devices (i.e., smartphones) and did not have access to digitalIDs. This might be because our patient sample had more severe functional impairments as was indicated by the high proportion of patients living in assisted living facilities, coupled with a high prevalence of psychiatric and somatic comorbidities. Another explanation might be that many patients with psychotic disorders and functional impairments have legal guardians that manage patients' financial and administrative matters. Of note is that 13% of patients at this outpatient unit have intellectual disabilities. Our study thus contributes to this field as it focuses on a particular group of patients with psychotic disorders that might tend to be underrepresented in clinical psychiatry research.¹³

Future studies should consider using qualitative methods focusing on the patients' perspectives such as their motivations and barriers to using digital technology in health care settings. Further research about how to use a personalized learning format that reflects the individual's unique needs and preferences are also warranted. Common reasons to use digital devices among persons with psychotic disorders are to get support from family and friends, to gather information, to identify coping strategies including music to help block or manage voices, and to use technology to set reminders for medication management.¹⁴

It is also important to acknowledge that some patients might not want to interact digitally.¹⁵ Whether this stance is a result of personal values and preferences or symptoms of paranoia, healthcare organizations need to enable multiple ways of keeping in contact and providing treatments, not restricting it to digitally only.

It might be a limitation that the online survey for this study was completed by the patients' case managers and not the patients themselves. However, previous research indicates that online survey collection methods might introduce biases into the sample, masking those who are likely to be excluded.³ It can therefore be considered a strength to use case manager reported data as all their patients were represented, and not just the patients able to, or willing to, complete an online form. Furthermore, at this tertiary unit, the case managers work intimately and continuously with their patients and know them well as they regularly meet at the unit and at the patients' homes.

In summary, in a highly digitalized high-income country such as Sweden, there are still groups who are digitally excluded. The assessed group of patients with psychotic disorders and functional impairments are one of these groups. This need to be addressed on an individual level by supporting the patients according to their preferences, in order to compensate for their lack of ability and/or access to technical equipment. Furthermore, policy makers and managers in health care must be aware of this reality when implementing reforms about increasing the digitalizing of health care services.

Table 1 Comparisons between patients' access to mobile phones ($N = 136$) and digital-ID ($N = 132$) with significantly associated variables. Note that some analyses were conducted with missing data as missing variables were low.

	Mobile phone ($N = 136$)			p-value*	digital-ID ($N = 132$)		p-value*
	Smartphone ($n = 42$)	Old phone ($n = 47$)	No mobile ($n = 47$)		Yes ($n = 20$)	No ($n = 112$)	
<i>Age</i>				<0.001			0.012
27–55	23 (55%)	19 (40%)	6 (13%)		13 (65%)	33 (29%)	
56–65	12 (28%)	15 (32%)	18 (38%)		4 (20%)	41 (36%)	
66–83	7 (17%)	13 (28%)	23 (49%)		3 (15%)	39 (35%)	
<i>Living situation</i>				0.013			<0.001
Assisted living facility	25 (60%)	29 (62%)	40 (85%)		13 (65%)	28 (25%)	
Independent living	16 (38%)	18 (38%)	7 (15%)		6 (30%)	85 (75%)	
Other	1 (2%)	–	–		1 (5%)	–	
<i>Contacting the unit</i>				<0.001			<0.001
Themselves, call/SMS	36 (86%)	30 (64%)	7 (15%)		20 (100%)	50 (44%)	
Via assisted living staff	5 (12%)	15 (32%)	36 (78%)		–	56 (50%)	
Other	1 (2%)	2 (4%)	3 (7%)		–	6 (6%)	
<i>Perceived digital ability by case managers</i>				<0.001			<0.001
Independently	10 (24%)	3 (6%)	–		10 (50%)	3 (3%)	
With support	22 (52%)	15 (32%)	1 (2%)		9 (45%)	28 (25%)	
Not at all	9 (22%)	26 (55%)	46 (98%)		1 (5%)	79 (70%)	
Not sure	1 (2%)	3 (6%)	–		–	3 (3%)	
<i>digital-ID</i>	17 (43%)	3 (7%)	–	<0.001	–	–	–

* Fisher's exact test (2-sided significance).

Ethical considerations

The survey was anonymous and completed by case managers' recollections of their patients. Thus, patients were not directly involved in the study. No unique identifiable patient data were collected. Hence, this study did not need formal ethical approval according to the Swedish Ethical Review Act (2003:460).

Conflict of interest

The authors have no conflict of interests to declare.

Acknowledgements

We want to thank all the case managers for helping us complete the study. A special thanks to Cigdem Yenigün and Birgitta Magnusson.

Funding

The project received funding from the Sahlgrenska university hospital's innovation fund.

References

1. Sasseville M, LeBlanc A, Boucher M, Dugas M, Mbemba G, Tchuente J, et al. Digital health interventions for the management of mental health in people with chronic diseases: a rapid review. *BMJ Open*. 2021 Apr;11(4):e044437.
2. Santesteban-Echarri O, Piskulic D, Nyman RK, Addington J. Telehealth interventions for schizophrenia-spectrum disorders and clinical high-risk for psychosis individuals: a scoping review. *J Telemed Telecare*. 2020 Jan;26(1–2):14–20.
3. Chivilgina O, Wangmo T, Elger BS, Heinrich T, Jotterand F. mHealth for schizophrenia spectrum disorders management: a systematic review. *Int J Soc Psychiatry*. 2020 Nov;66(7):642–65.
4. Moreno C, Wykes T, Galderisi S, Nordentoft M, Crossley N, Jones N, et al. How mental health care should change as a consequence of the COVID-19 pandemic. *Lancet Psychiatry*. 2020 Sep;7(9):813–24.
5. Robotham D, Satkunanathan S, Doughty L, Wykes T. Do we still have a digital divide in mental health? a five-year survey follow-up. *J Med Internet Res*. 2016 Nov 22;18(11):e309.
6. Firth J, Torous J. Smartphone apps for schizophrenia: a systematic review. *JMIR MHealth UHealth*. 2015 Nov 6;3(4):e102.
7. Firth J, Cotter J, Torous J, Bucci S, Firth JA, Yung AR. Mobile phone ownership and endorsement of “mhealth” among people with psychosis: a meta-analysis of cross-sectional studies. *Schizophr Bull*. 2016 Mar;42(2):448–55.
8. The Swedish Internet Foundation. The Swedes and the Internet 2020 (swe: Svenskarna och Internet 2020) [Internet]. Stockholm, Sweden; [cited 2021 Sep 7]. Available from: <https://svenskarnaochinternet.se/app/uploads/2020/12/internetstiftelsen-svenskarna-och-internet-2020.pdf>.
9. Holmberg C, Torgerson J, Gremyr A. Elevated pulse pressure and its associations with demographic and clinical parameters in a clinically representative sample of outpatients with psychotic disorders. *BJPsych Open*. 2022 May;8(3):e79.
10. Holmberg C, Gremyr A, Torgerson J, Mehlig K. Clinical validity of the 12-item WHODAS-2.0 in a naturalistic sample of outpatients with psychotic disorders. *BMC Psychiatry*. 2021 Mar 10;21(1):147.
11. Kang H. The prevention and handling of the missing data. *Korean J Anesthesiol*. 2013;64(5):402.
12. Greer B, Robotham D, Simblett S, Curtis H, Griffiths H, Wykes T. Digital exclusion among mental health service users: qualitative investigation. *J Med Internet Res*. 2019 Jan 9;21(1):e11696.
13. Lally J, Watkins R, Nash S, Shetty H, Gardner-Sood P, Smith S, et al. The representativeness of participants with severe mental illness in a psychosocial clinical trial. *Front Psychiatry*. 2018 Dec 4;9:654.
14. Gay K, Torous J, Joseph A, Pandya A, Duckworth K. Digital technology use among individuals with schizophrenia: results of an online survey. *JMIR Ment Health*. 2016 May 4;3(2):e15.
15. Ennis L, Rose D, Denis M, Pandit N, Wykes T. Can't surf, won't surf: the digital divide in mental health. *J Ment Health Abingdon Engl*. 2012 Aug;21(4):395–403.