



iHealth: The ethics of artificial intelligence and big data in mental healthcare

Giovanni Rubeis

Department General Health Studies, Division Biomedical and Public Health Ethics, Karl Landsteiner University of Health Sciences, Dr.-Karl-Dorrek-Straße 30, 3500 Krems, Austria

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ABSTRACT

The concept of intelligent health (iHealth) in mental healthcare integrates artificial intelligence (AI) and Big Data analytics. This article is an attempt to outline ethical aspects linked to iHealth by focussing on three crucial elements that have been defined in the literature: self-monitoring, ecological momentary assessment (EMA), and data mining. The material for the analysis was obtained by a database search. Studies and reviews providing outcome data for each of the three elements were analyzed. An ethical framing of the results was conducted that shows the chances and challenges of iHealth. The synergy between self-monitoring, EMA, and data mining might enable the prevention of mental illness, the prediction of its onset, the personalization of treatment, and the participation of patients in the treatment process. Challenges arise when it comes to the autonomy of users, privacy and data security of users, and potential bias.

1. Introduction

E-health has become a major topic in mental healthcare within the last decade. Apps for mobile devices such as smart phones and tablets as well as internet-delivered services are already used as treatment options. Digital solutions can be used for diagnosis and risk assessment, therapeutic interventions, or relapse prevention. There is some empirical evidence for the effectiveness of e-mental health applications regarding various endpoints like prevention (Sander et al., 2016), symptom reduction (Firth et al., 2017), adherence (Pihlaja et al., 2017), reduction of hospitalization and total hospital days (Bell et al., 2017), and cost-effectiveness (Massoudi et al., 2019). The latest step in this development is the introduction of Artificial Intelligence (AI) and Big Data analytics, which are still in the exploratory stages of therapeutic use. According to some commentators, AI- and Big Data-based approaches to e-mental health create a new paradigm in mental healthcare, which is referred to as intelligent Health or iHealth (Berrouiguet et al., 2018; Briffault et al., 2018). iHealth provides more contextual data from the patient's personal environment by combining patient self-monitoring and self-reports, monitoring via sensors (either wearables or stationary), and data mining technology. Thus, iHealth is seen as an opportunity for enhanced real-time self-monitoring, integration of assessment into the patient's environment, and data mining to support decision-making and the personalization of treatment (Berrouiguet et al.,

2018). iHealth utilizes established techniques of e-mental health and combines them with data mining tools. The innovative aspect is integrating and processing data from different sources. Data from patient self-monitoring and self-reports can be combined with real-time data from the patient's environment provided by ecological momentary assessment (EMA) as well as data from the electronic health record (EHR) and observations by clinicians. iHealth could be used for a better risk assessment, stratification and predication, tailoring of treatment to the individual needs of each patient, preventing the onset of episodes or symptoms, and for empowering the patient's self-management. By focusing on the complex connections between individual symptoms and behavior with specific situations and the environment of the patient, iHealth may be used to overcome some of the issues patients are confronted with in daily life (Briffault et al., 2018). Collecting and processing individual data may furthermore help to understand the specific needs of groups and individuals with a complex help-seeking behavior that are otherwise underserved. However, it has to be noted that the evidence base regarding iHealth in particular and digital interventions in general is often unclear. This lead some commentators to regard these technologies as overhyped and their benefits and effectivity as unfounded (Carr, 2020; Foley and Wollard, 2019).

In the following, an ethical analysis of the iHealth-paradigm in mental healthcare is conducted. An ethical analysis at this early stage is important in order to provide a framework for evaluating the approach

E-mail address: giovanni.rubeis@kl.ac.at.

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before it is widely implemented. This may help to establish guidelines for the implementation of iHealth in clinical practice.

2. Methods

I follow the three crucial aspects of iHealth defined by [Berrouiguet et al. \(2018\)](#): enhanced real-time self-monitoring, integration of assessment into the patient's environment, and data mining to enhance decision-making and thus personalize treatment. Thus, the ethical analysis focusses on self-monitoring, EMA, and data mining in the context of mental health and identifies the specific ethical implications of each procedure or method.

In order to obtain the material for the analysis, a search was conducted using the online databases Pubmed/MEDLine, PsycINFO, and The Cochrane Library with the search terms “data mining”, “self-monitoring”, and “ecological momentary assessment” in combination with (AND) “psychiatry” and “mental health”. Due to the rapid developments in the field, only papers from the past five years were included. Study protocols, papers providing only descriptions of interventions or apps, and methodological or theoretical papers without outcome data were excluded. No language restrictions were made. Doublets and erroneous results were removed. Abstracts of remaining papers were scanned. 29 papers were included ([Table 1](#)).

[Morley et al. \(2020\)](#) identify epistemic, normative, and overarching ethical concerns in regard to AI in mental health. Epistemic concerns focus on inconclusive, inscrutable, or misguided evidence that leads to misdiagnosis or missed diagnosis. Normative concerns are connected to surveillance and privacy issues as well as threats to autonomy. Overarching concerns target the framing of specific groups as being morally irresponsible regarding their own mental health. In the following, I will focus on the normative concerns as the context of the ethical analysis. Several of these normative aspects have been addressed in general research on the ethics of AI and e-mental health, e.g. threats to autonomy ([Fiske et al., 2019](#); [Morley et al., 2020](#)), privacy issues ([Martinez-Martin and Kreitmair, 2018](#); [Wykes et al., 2019](#)), and bias ([Fiske et al., 2019](#); [Martinez-Martin and Kreitmair, 2018](#)). The following ethical analysis will build upon this existing research and apply its results on the specific constellation of iHealth, i.e. the combination of self-monitoring, EMA, and data mining. The aim of the paper is to analyze the specific ethical implications that are connected to each of these practices ([Fig. 1](#)).

3. Results

3.1. Self-monitoring

Self-monitoring, i.e. active collection of data by the user ([Bartels et al., 2019](#)), is an established method in mental healthcare. It provides data that allows to study mood regulation, predict the onset or episodes of a disorder, or select the best-suited mood stabilizer for the patient ([Ortiz and Grof, 2016](#)). A consistent, valid, and timely self-monitoring is also considered crucial for effective self-management, self-insight, and initiation of behavior change ([Bakker and Rickard, 2018](#); [Bartels et al.,](#)

Table 1

Results of database search.

| Search term | Pubmed | PsycInfo | Cochrane library |
|--|--------|----------|------------------|
| Self-monitoring AND psychiatry | 225 | 134 | 6 |
| Self-monitoring mental health | 186 | 258 | 172 |
| Ecological momentary assessment AND psychiatry | 419 | 269 | 5 |
| Ecological momentary assessment mental health | 219 | 308 | 34 |
| Data mining AND psychiatry | 258 | 69 | 0 |
| Data mining AND mental health | 204 | 162 | 5 |

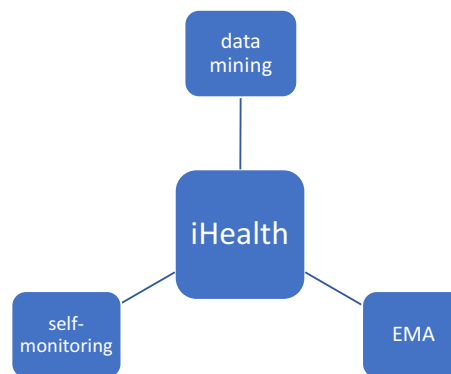


Fig. 1. iHealth according to Berringuet et al.

[2019](#); [van Os et al., 2017](#)). Apps and wearable sensors enable real-time data collection and transfer, which circumvents the recollection bias often associated with retrospective patient self-reports ([Bartels et al., 2019](#); [van Os et al., 2017](#)). Typically, the experience sampling method (ESM) is used whereby patients get prompts several times a day reminding them of assessing their mood, diet, activity, possible alcohol or drug consumption, medication, suicidal thoughts, symptoms, or stress ([van Os et al., 2017](#)). This data is crucial for mental health promotion and prevention as well as clinical decision-making, e.g. finding the right dose of medication ([Bartels et al., 2019](#); [van Os et al., 2017](#)). A crucial aspect here is the within-person approach to diagnosis and treatment which allows to analyze individual symptoms and patterns over time instead of comparing it with the average case ([van Os et al., 2017](#)), thus enabling a more personalized treatment.

There is some empirical evidence for the effectiveness of digitally-enhanced self-monitoring for a variety of disorders, such as depression ([Dogan et al., 2017](#)), bipolar disorder ([Faurholt-Jepsen et al., 2016](#)), borderline disorder ([Tsanas et al., 2016](#)), or eating disorder ([Tregarthen et al., 2019](#)), and different outcomes like symptom reduction ([Bakker and Rickard, 2018](#)) and medication adherence ([Kassianos et al., 2017](#)). However, when it comes to user experience, results are mixed. In their survey study, [Hartmann et al. \(2019\)](#) found that regarding self-monitoring tools, the duration of usage is limited and overall usage is poor. Especially repetitive and monotonous data input over a long time period negatively affects motivation and engagement. [Dogan et al. \(2017\)](#) found in their systematic review that to some users, permanent monitoring means gaining control over their own lives, improved self-management, and an overall empowerment. Others however find the responsibilities of self-monitoring overwhelming and consider it as a constant reminder of their illness. Some users report increased anxiety and feelings of being watched due to constant surveillance.

3.2. EMA

EMA has been successfully used as a tool for assessing symptoms and behavioral patterns of patients within their daily environment ([Moore et al., 2016](#)). Since mental disorders are highly heterogeneous, dynamic constructs that vary between individuals and fluctuate over time, EMA can be used for targeting the dynamic individual differences and improve treatment ([Smith and Juarascio, 2019](#)). Data on momentary affects, mood, activity, sleep patterns, or behavior can be obtained from a natural setting, which in some cases may outperform retrospective self-reports ([Li et al., 2019](#); [Moran et al., 2017](#); [Russell and Gajos, 2020](#); [van Genugten et al., 2020](#)). Self-reports may be difficult for certain patient groups, e.g. patients with bipolar disorder ([Li et al., 2019](#)) or schizophrenia ([Moran et al., 2017](#)), because mood, functioning, or working memory is often instable. In some contexts, EMA is used as an assessment tool, although the evidence is limited ([Moran et al., 2017](#)). Real-time data from daily-life enable detecting dynamic relations

between state variables and can be used for symptom assessment, monitoring indicators for relapse or treatment effects, managing daily functions, facilitate learning skills, and empowering self-management (Bell et al., 2017; Moore et al., 2016). Since data is collected over a given time period, temporal patterns and momentary processes affecting behavior can be detected, which increases ecological validity and generalizability (Engel et al., 2016).

Digitally-enhanced EMA may include wearable sensors like actigraphy sensors for sleep and accelerometers for physical activity, electrodermal activity (EDA) for physiological arousal via skin conductance, and GPS data (Russell and Gajos, 2020). This enables detecting neurocognitive, neurobiological, and physiological functioning as moderators or predictors (Smith and Juarascio, 2019). Clinical outcomes of EMA are well-documented for various mental disorders regarding different endpoints. The systematic reviews of Bell et al. (2017) and Bos et al. (2015) suggest that EMA may lead to better outcome prediction, relapse prevention, reduced hospitalization rates and total hospital days, better clinician adherence, low drop-out rates, better self-management and psychosocial daily functioning, and cost-reduction. However, it has to be said that as is mostly this case with digital interventions, the evidence base is limited.

3.3. Data mining

Data mining refers to exploring and modeling large amounts of data by detecting patterns and employing learning algorithms (Dipnall et al., 2016; Góngora Alonso et al., 2018). Data mining tools can be used for combining information from the EHR, data from self-monitoring and EMA, individual genetic data, vital functions, disease-related molecular biology data, and scientific data from studies or clinical drug trials (Becker et al., 2018; Berrouiguet et al., 2019; Schubert et al., 2018). Based on data from various sources, algorithms detect early symptoms of mental illness and predict their onset or disease progression (Góngora Alonso et al., 2018; Wang et al., 2019). Fields of application are risk assessment and identification of different risk groups, determination of mood trajectories, suicide prevention, and prediction of treatment outcome and relapse risk (Becker et al., 2018; Berrouiguet et al., 2019; Góngora Alonso et al., 2018). Data mining in mental health aims at a more personalized treatment based on individual health indicators and contextualizing them with scientific data (Wang et al., 2019). Early interventions based on predictive models may also reduce hospitalization, costs, and psychological burden of users (Góngora Alonso et al., 2018).

4. Discussion

iHealth offers the opportunity to improve mental health treatment and increase quality of life of patients. The prevention of mental illness, the prediction of its onset, the personalization of treatment, and the participation of patients in the treatment process can be enabled through the synergy between self-monitoring, EMA, and data mining. However, the analysis of each of these three elements shows several ethical concerns (Table 2).

4.1. The ambivalence of autonomy: needs and resources of users

A crucial aspect of iHealth is empowering user autonomy through self-monitoring. However, a self-management approach may not benefit certain user groups. The type of mental disorder or the individual manifestation may severely limit the capabilities for self-directed action. In these cases, it has to be made sure that the extent to which self-monitoring and other tasks of self-management are applied matches with the individual needs and resources of the patients. Another aspect is digital literacy, which cannot simply be ascribed to all users in the same way (Morley et al., 2020). Therefore, it has to be ensured that the technology is adapted to the user instead of the user having to adapt to technology.

The patient as user is supposed to be enabled to gain control over their own mental health and to actively participate in a treatment specifically tailored for them. But a closer look shows that autonomy is an ambivalent concept here. This ambivalence arises in two regards: Firstly, self-monitoring may blur the line between autonomy and self-disciplining (Lupton, 2013). Lupton (2013) points out that self-monitoring can be understood as empowerment because it enables patient engagement and facilitates better access to medical services. Patients feel included in the medical process, gain insights into their condition, and can contribute to the treatment actively. At the same time, self-monitoring can have a disciplinary effect, forcing patients into a certain routine dictated by the technical equipment (Lupton, 2013). This contradicts personalization, one of the presumed main advantages of iHealth. When users have to adapt to technology instead of technology being applied according to their individual needs and resources, personalization and autonomy are undermined.

Secondly, in many mental disorders, (re)establishing patient autonomy is a goal rather than a precondition of treatment. Autonomy cannot be presupposed in every case. Some users might be limited in their ability of autonomous decision-making or action. Self-monitoring or self-reports might overstrain this particular user group. Autonomy, although a desirable feature as such, may differ from user to user and has thus to be evaluated carefully. Assessing this risk is a core task of mental health professionals, which is why competence and liability are crucial aspects of the therapeutic alliance in an iHealth setting (Luxton, 2014). Given the emotional vulnerability of patients, empathy is another important aspect of the therapeutic alliance. The therapeutic process involves emotional interactions and expressing experiences and emotions on behalf of patients. Dealing with these manifestations of strong emotions is not only important for therapy success. Failure to respond to strong emotions can even lead to harm for the patient (Luxton et al., 2016). It is unclear whether technological systems can be sophisticated enough to detect the often-subtle manifestations of emotions and whether patients are willing to interact with these systems in the same way they would with a human therapist. There is a risk that technology does not address the specific needs and resources of patients in a way that therapists are able to. The increasing substitution of human contact through human-machine interaction may thus have a negative impact, especially when decision-making is framed as a straight-forward activity that simply implies data analysis (Morley et al., 2020).

Furthermore, the potential of digital health technologies for empowerment depends on the concept of autonomy that is referred to

Table 2
Ethical opportunities and challenges of different elements of iHealth.

| Element | Opportunities | Challenges |
|-----------------|---|--|
| Self-monitoring | <ul style="list-style-type: none"> • Potential for more personalized treatment • Active engagement of patients | <ul style="list-style-type: none"> • Ambivalence of autonomy: autonomy – disciplining, autonomy – individual capabilities |
| EMA | <ul style="list-style-type: none"> • Holistic, personalized, dynamic approach to mental healthcare | <ul style="list-style-type: none"> • Personal privacy: medicalization • Data privacy: big data divide |
| Data mining | <ul style="list-style-type: none"> • Combining data from different sources • Contextualizing individual data with scientific data | <ul style="list-style-type: none"> • Datafication • Bias |

(Schmietow and Marckmann, 2019). Concepts of autonomy vary in scope and degree, which makes it difficult to use the label “empowerment” in a general sense. Some commentators abandon the term empowerment altogether in order to avoid raising false expectations. Morley and Floridi (2020) reject the conceptual framing of empowerment regarding mHealth due to the lack of empirical evidence for an empowering effect. Practitioners have to make sure that the fitting treatment option is selected according to the needs and resources of patients. Thus, it is important that a therapeutic alliance accompanies the use of technology that aims at self-management. In addition, patient perspectives could be integrated into AI design by following a participatory design approach that acknowledges individual needs and resources (Carr, 2020). Participatory design as an inclusive dialogue between experts and citizens could enable the inclusion of experiential knowledge of users, which in turn could empower user autonomy.

4.2. Personal privacy – data privacy

According to Mittelstadt and Floridi (2016), the privacy risks of invasive monitoring technologies can be divided into two types. The permanent monitoring, surveillance, and collection of data in the user's daily environment implies a massive intrusion into their personal privacy. One result is the medicalization of the home environment, since the omnipresent monitoring devices are constant reminders of the user's mental health condition. This may be experienced as a severe burden by users (van Genugten et al., 2020). At the same time, data mining and surveillance technologies also affect the data privacy of users. Big Data tools are inherently data-hungry and need large data sets in order to provide useful results. The sheer scope of data collected poses the risk that users are unable to oversee what data is used for what purpose. Since data can theoretically be stored for an indefinite time, the loss of control over one's own data becomes even more severe. It is also sometimes unclear to users which persons have access to the data and for what reason or purpose. Compared to the traditional “in office”-situation of face-to-face treatment, there are more possibilities for data to leak or get lost (Luxton et al., 2016). Additionally, the available data stems from various contexts and is more sophisticated, intensifying privacy and data security issues in a qualitative manner. Since legislation often lags behind technical developments, loopholes and grey zones may exist that facilitate unethical data use, e.g. commercial use without explicit user consent. The loss of control over one's data has been defined as Big Data divide, which exists between entities that control the means of data collection, storage, and use, and those who provide data (Mittelstadt and Floridi, 2016). The latter may not have sufficient knowledge of the processes involved or possess sufficient access to their own data. This might create new forms of inequality within mental healthcare. Furthermore, Martinez-Martin and Kreitmair (2018) have pointed out that the loss of control over one's data may affect the patients trust in confidentiality with severe consequences for the therapeutic alliance.

Privacy issues should be dealt with by implementing transparent and universally applicable regulations (Wykes et al., 2019). This is mainly a matter of policy making (Martinez-Martin and Kreitmair, 2018), but there are additional ways to deal with privacy issues. One approach is granular consent (Kim et al., 2017), which is a re-formulation of informed consent in a digital setting. Usually, users consent to an oftentimes complicated and opaque data policy of a certain application or system as a whole. Granular consent implies that the privacy policy of the product has to define the aims of data collection and processing and make transparent which persons have access to which data. Users can then decide to which types of data use they give their consent and to what extent. This approach could give users some control over their own health data, thus decreasing the privacy-related ethical risks.

4.3. Datafication and bias

Ethical issues arise in the context of two major requirements of data

mining. Firstly, data mining often requires reduction, simplification, and coding (Abbe et al., 2016) This datafication may undermine the uniqueness of patient experiences. Secondly, data has to be pre-processed, meaning that variables have to be defined so that the systems can derive them from the data (Becker et al., 2018). In this respect, the risk of bias arises.

Datafication might force mental health professionals to translate patient information into a pre-configured scheme, thus reducing individual characteristics to standardized categories. Reducing complex relations and health narratives to quantifiable data points may be forced in order to make healthcare interventions more cost-efficient (Dillard-Wright, 2019). Collecting and processing data may not only be used to classify the individual but also to standardize behavior (de Laat, 2019). This is especially the case when AI-based technology and Big Data applications are used for risk assessment and prediction. By sorting individuals into different groups according to standardized categories and targeting them for specific treatment, the focus shifts from the individual to the group (de Laat, 2019). As a result, personalization as a main goal of iHealth might be undermined.

Bias has widely been discussed in the context of AI and Big Data (Boddington, 2017; Challen et al., 2019; Mittelstadt and Floridi, 2016). One type of bias that may result from increased data use is confirmation bias, whereby mental health professionals overemphasize the evidence that support their initial diagnosis. Automation bias signifies the increasing reliance on automated systems and the non-critical acceptance of machine decision-making. Both types of bias may counteract the intended precision and personalization of diagnosis as well as therapy intended by iHealth. Additionally, there is a risk of bias that is inherent in the mechanisms of data procession and therefore much harder to detect. The increased integration of scientific data into the treatment process makes treatment more dependable on the quality of said data. It is a well-known fact that several minority groups are underrepresented in large cohort studies (Carr, 2020). Given the fact that generalization is a crucial factor of data mining, algorithms may mostly be built upon data from studies on majority groups (Carr, 2020). This opens the door for discrimination and a widening of the existing gap in providing mental health services for different patient groups (Fiske et al., 2019). An important aspect in this regard is decontextualization (Mittelstadt and Floridi, 2016). In many cases, meaning and context have to be detached from data due to the need of standardizing said data, including the social context in which data is generated. Thus, contextual factors are often ignored or lost due to the classificatory framework of data procession. This is referred to as the “signal problem”: data is treated as representation of certain facts, although signals from specific communities or groups are missing (Mittelstadt and Floridi, 2016). Decontextualization may lead to ontic occlusion, where certain aspects of a phenomenon are over-emphasized and others ignored as a result of using a specific interpretative framework. As a result, the personalization of treatment, which is a major goal of iHealth, is undermined.

When it comes to iHealth, a twofold concern arises. Not only is there a risk of discrimination and the exclusion of several societal groups. These issues also undermine the very potential of the technologies in questions. Data mining can be an important tool for coping with the complexity of mental disorders where genetic, epigenetic, behavioral, environmental, and social determinants interact (Schubert et al., 2018; Tai et al., 2019). By processing the complexity of the data involved, data mining could provide models that support health professionals in clinical decision-making. But in order to achieve this, there must be a focus on these determinants in order to avoid ontic occlusion. This is important when processing the data of an individual patient, but it is also crucial regarding the training data that these systems are based upon. Training data are often biased due to the social or institutional context from which they were derived (Carr, 2020). When certain groups are not represented in the training data, the systems might develop a bias against them or simply be unable to deal with these groups. Thus, social,

gender, and ethnic determinants play a crucial role in this regard. When selecting training data, a crucial criterion for evaluating their quality should be whether these determinants are made transparent (Walsh et al., 2020). An additional approach could be to make the interpretative frameworks as well as the parameters for data inclusion or exclusion transparent. This could enable practitioners to avoid an undue reductionism and facilitate a more personalized treatment (Gianfrancesco et al., 2018).

5. Conclusion

The ethical analysis has shown that although iHealth has great potential for actualizing a more personalized and effective treatment, several ethical concerns arise. These are mainly the ambivalence of autonomy and the question how technology may fit the needs and resources of individual patients, the threats to personal and data privacy, and the risk of datafication and bias. The ethical issues have to be dealt with on several levels: On a policy-level, regulations have to be implemented that ensure quality standards as well as the control over one's own health data in the specific context of mental health. An important contribution in this regard on which guidelines could be based is the Canada protocol, a check list for ethical aspects of AI in mental health and suicide prevention (Mörch et al., 2020). On a research and development-level, social determinants of health data have to be taken into account when building interpretative frameworks. On a practitioner-level, it is crucial to ensure that the technology use fits the needs and resources of the individual patient, which requires some kind of therapeutic alliance.

To the best of the author's knowledge, this is the first ethical analysis of iHealth as a coherent concept in mental healthcare. It provides an overlook of ethical aspects, but has several limitations. This analysis makes general statements about the outcomes of iHealth-technologies for mental disorders. Further research is needed that focusses on different patient groups and analyzes their specific risks and benefits. Similar approaches already exist for digital mental health in general, e.g. the scooping review by Wies et al. (2021) with a focus on adolescents.

Another aspect that could not be discussed here is the possibility of technology-enabled care coordination, meaning that iHealth could be used for creating cross-sectoral delivery of mental health services and improving pathways to care. This potential of digital mental health technologies has already been tested and needs further exploration (Iorfino et al., 2021).

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