
Towards a More Inclusive and Ethical Intervention

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Abstract

In this paper I describe ways of obtaining the experiences of people suffering from mental health issues and discuss some of the ethical issues and controversy in psychiatry.

Keywords

Mental illness, medical anthropology, informed consent, ethics

ACM Classification Keywords

K.4.2 Social Issues: Assistive technologies for persons with disabilities.

Introduction

Who makes up the mental health community? Certainly the people receiving mental health treatments are an important component. But actually including them in the design process of technology used for mental health care has been problematic. User-centered design has been mentioned as a way to give “disabled people” dignity, but in the same breath it is stressed that the agenda of the potential user and the disability rights movement should not be setting the research goals or evaluation criteria. The work of participatory action research, which directly involves individuals with disabilities throughout the process, is relegated to

being part of a “sociological research agenda”[1]. Coyle et al, stressing a therapist-influenced agenda, emphasize the difficulties in applying participatory and user-centered design models because of the difficulty for HCI researchers to gain access to clinical settings [2].

But I feel that this is giving up too easily and that different frameworks should be considered to help us think outside-the-box. Since we are dealing with issues involving stigma, power dynamics, and a historical legacy of abuse, neglect and even genocide, we all inherently become part of a sociological research agenda. Becoming aware of the larger social context and listening to people alienated by the current system can tell us where problems exist and where there is the most opportunity for intervention and change.

Participant Observation

Immersing oneself in a culture firsthand has been a traditional strength of what is called participant observation. It has a particularly strong tradition in psychiatry with one of the earliest recorded examples performed by reporter Elizabeth Cochran, also known as Nellie Bly. In 1887, Bly feigned insanity in order to gain admittance to a lunatic asylum in New York, but then acted “normal” after she was admitted. Her expose of the harsh conditions forced the asylum to implement reforms and increased the budget for care of the mentally ill in New York by one million dollars a year[3].

Almost a century later, psychologist David Rosenhan did a similar experiment along with seven other

collaborators. They spread themselves out among different psychiatric hospitals with a complaint that they heard the words “empty”, “hollow” and “thud”. All eight were admitted, seven with a diagnosis of schizophrenia and one with a diagnosis of manic-depression with psychotic features, with an average stay of 19 days (range from 7-52 days). Despite exhibiting their normal behavior once they were in the hospital, they were only “detected” by fellow patients who often assumed they were journalists or professors due to their notetaking (labeled pathologically as “writing behavior” by nurses). Aside from the obvious oversight on the part of the staff, Rosenhan also stressed the depersonalization which created feelings of powerlessness in patients as well as the hierarchal structure of the ward where the low-status attendants spent the most time on the wards while doctors spent very little time with patients.

More conventional means of obtaining access have been used by a number of social scientists. Sociologist Erving Goffman did fieldwork at several federal mental institutions from 1954 to 1957. His resulting work *Asylums* focused on the nature of total institutions and conflicting roles played by the doctors and inmates [5]. Anthropologist Tanya Luhrman did a study from 1989 to 1994 focusing on psychiatrist resident training, especially the tension between psychodynamic therapy and biomedical psychopharmaceutical models. The rise of managed care during her study led to an increased reliance on medication over therapy, which she claimed had a big impact on the perspectives and choices of the residents [6].

Patient Narrative

Narratives written by people with mental illnesses are another rich source of information. Dr. Gail Hornstein, who researches the contributions patients have made to psychology, has compiled a bibliography of over six-hundred such titles on her web site [7] She refers to patient memoirs as a type of “protest literature”, like slave narratives or witness testimonies protesting their involuntary hospital confinement or even elaborating their own theories about the cause of mental illness [8].

Most consistent with the theme of witness testimonies are stories from what is called the “psychiatric survivor’s movement”, people who experienced what they perceived as unfair or even damaging treatment by the psychiatric system. Mind Freedom, a mental health activism group, sponsored an oral history project with thirty-six participants. Themes that emerged from the analysis were: trauma, social control, oppression and recovery [9].

A very different type of testimony comes from Australian “consumer academic”, Cath Roper [10]. Nurse and co-author Brenda Happell recognized the growing expectation by the Australian government to encourage consumer collaboration and that nurses played a huge role in this as the largest professional group within mental health. Her response was to create a formal teaching position for a consumer academic to educate psychiatric nurse trainees about the people they would be serving. Roper and Happell discuss the challenges of integrating that perspective into their department in one of the few accounts where consumers and mental healthcare professionals speak together as equals.

Ethics and Informed Consent

Those that choose to involve “vulnerable subjects” directly in their research face a tougher battle than their colleagues who design the technology first and then find someone else to evaluate it on the user. Restrictions set in place by institutional research boards were inspired mainly by abuses such as the Holocaust. In addition to the atrocities against the Jews, an estimated 350,000 mentally ill in Hitler’s Germany were sterilized between 1934 and 1939 and 70,000 were killed in six psychiatric extermination camps until public protests caused Hitler to withdraw his approval in 1941. Historians relate that psychiatrists continued their “euthanasia” programs at local German hospitals killing another 100,000 mentally ill patients, with another 40,000 killed in occupied France [11].

Psychiatry continued to be used as a tool of violence by the Soviet Union during the cold war era with the hospitalization and torture of dissidents. The World Psychiatric Association (WPA) responded by ousting the Soviet psychiatrists from its organization and creating a psychiatric code of ethics in the 1977 Declaration of Hawaii [12]. Despite this, the WPA was criticized in recent years by both the American Psychiatric Association and psychiatric watchdog groups for responding slowly to allegations of psychiatric imprisonment and forced treatment of student leaders and Falon Gong members by the Chinese government [13].

In the United States, ethical concerns remain over denial of patient autonomy and informed consent. In one particularly extreme 2007 New York court case, “Simone D”, a Latina immigrant who had endured over 200 electroshocks against her will during the course of

two years, finally won the right to refuse electroshock treatments [14]. Multiple other court cases have cropped up against pharmaceutical companies, who have been accused of suppressing evidence of potentially dangerous drug side effects and not testing adequately for long-term effects or addictive potential which can create drug withdrawal symptoms worse than the original problem being treated[15][16].

Probably the largest current mental health controversy in the U.S. is over the increased psychiatric diagnosis and drugging of children. Recent deaths have drawn attention to the increased use of multiple drugs to treat behavioral problems, many times prescribed "off-label"(i.e. not approved for use by children by the Food & Drug Administration) [17]. Children are also being diagnosed for conditions which were previously thought to emerge in adulthood; bipolar disorder has been diagnosed in close to one million children, supposedly making it more common than diabetes and autism combined [18].

The condition that still receives the most attention with respect to school-aged children is ADD/ADHD. In a 2004 report, the United Nations Committee on the Rights of the Child expressed concern that ADHD was being misdiagnosed, resulting in overprescription of psycho-stimulant drugs [19]. The US Drug Enforcement Administration raised similar concerns, calling the dramatic increase in Ritalin prescriptions for ADD a "quick-fix bogus medical practice" and noting that the US had become the only country in the world where children were prescribed such a high amount of stimulants[20].

It is obviously not the job of HCI researchers to police other professions, but it is important to ask questions and make sure that our potential collaborators are practicing ethical and socially responsible healthcare. I would go so far as to suggest that as much care to selecting a collaborator as would be taken if one were choosing that person for one's own treatment.

Discussion

If we want to work towards reducing stigma ourselves, we need to start by changing our own attitudes and humanizing the people we are designing for. People suffering from mental health issues do not go around with their diagnosis on their forehead or exist exclusively in clinical settings. They may include your secretary who stays up all night worrying because her daughter hasn't called in a week or your cousin who contemplates suicide after he loses his job.

There has been an increasing amount of discussion in the mental health arena about the necessity for consumer involvement in research. The American Psychiatric Association mentions the ethical costs of excluding willing individuals with mental illness from participating in research, calling their unjustified exclusion from research a form of discrimination. [21]

Consumer empowerment is frequently cited as a goal, resonating with the goals of patient empowerment put forth in goals for participatory design in healthcare. The main challenges to PD put forth by Kensing et al [22] are the complicated power relations and politics between the multiple professional groups--physicians, nurses, pharmacists, and administrators—in addition to patients. Clearly this would be even more complicated in mental healthcare with the additions of

psychologists, social workers and therapists so it would be easy for the patient's voice to be drowned out. Moreover for patients with a more serious diagnosis, there is the additional complication of coercion and forced treatment where it is assumed they don't know what is in their best interests.

Given the current domination of the biomedical model in psychiatry, it is tempting to use existing healthcare tools to promote wellness and preventive healthcare in the mental healthcare domain. Chronic disease management tools such as those designed for diabetics [23] or dialysis patients[24] could be particularly effective in bipolar disorder where an episode may be triggered by a disturbance in sleep patterns[25] and where sometimes medication levels in the bloodstream must be monitored to make sure they don't reach toxic levels. They could possibly also aid in diagnosis when conditions such as food allergies and hypoglycemia could exacerbate or be mistaken for a psychiatric condition. Perhaps persuasive technology could be harnessed to convince a "recalcitrant patient" to stay on their medications. Then again, that patient could respond by blogging to the world about why they don't want to be on medications or asking peers on online forums how to get weaned safely off the medication they're already on.

Extending technology such as that being used for senior citizen independent living [26] might facilitate a return to the community for someone on a psychiatric ward. But even if it were possible, what would it mean for people whose symptoms might include "paranoia" to know that they really are being watched and monitored closely even in their own home? What would it mean for a schizophrenic in a future where it really is

technologically possible for their television or medicine cabinet to talk back to them? While questions such as these were covered in a satirical but eerily plausible manner online [27], issues such as privacy and civil liberties will certainly come to the forefront as we figure out how to implement ubihealth applications into the home space.

My original interest in this topic came about because of my involvement in a project on emotional tracking in the workplace where people with any history of mental health treatment were excluded from taking part. While I appreciate the need to protect "vulnerable subjects", I also feel that failing to actively solicit their viewpoints could cause greater harm in the future in denying them a voice and failing to address their concerns or needs.

Conclusion

In this paper, I have tried to give a glimpse into some of the complexity of the mental health system in the hopes that greater knowledge will result in more meaningful intervention. In too many places in the world, basic human rights are still routinely denied to people in mental healthcare settings so it is good to reflect on the possible impact technology could have.

As one ex-psychiatry patient put it: "the decisions in the mental health world have been made by professionals using their knowledge of empirical techniques in science. And these techniques don't really address the soul and the spirit and the wants and needs of the people that have these sorts of problems" [28]. Trying to approach intervention from the point of view of the end user and giving attention to the wider social context makes us better able to understand the

problems that exist and widens the opportunities for making a true impact.

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