# For the Records - Learning About Mental Illness

Doris Rusch, Depaul University Anuradha Rana, Depaul University



Example URL: <a href="http://www.workingexamples.org/example/show/637">http://www.workingexamples.org/example/show/637</a>

For the Records is an interactive documentary about mental health, particularly OCD, ADD, eating and bipolar disorder. Including short films, interviews, photo essays and games, it aims to increase understanding of these disorders. People with lived experience of the represented mental health issues have been actively involved in the conceptualization and design of the project. For the records is an interdisciplinary effort bringing together DePaul's cinema and game development program as well as the School of Nursing. An intended application area of this project is mental health education.

#### Seed

## The Vision

"For the Records" is an interactive documentary on four young adults who live with mental health issues such as Attention Deficit Disorder (ADD), Bi-polar Disorder, Eating Disorder (Anorexia Nervosa) and Obsessive Compulsive Disorder (OCD). It includes interviews, short films, photo-essays, and experiential games, embedded in a website that affords ludic exploration. The various media components create a coherent whole, provide context to each other and illuminate complementary aspects of what it is like to live with mental health issues.

"For the Record" leverages the potential of an interactive format and playful engagement to create phenomenological authentic possibility spaces that shift the mode of reception from mere "witnessing" to "embodied experience." To ensure experiential accuracy, our four subjects have been strongly involved in the creative and production process, took leading roles on the game development teams, and participated in the films.

We consider "For The Records" as a prototype for a much larger project that covers a wider range of mental health issues, builds community and is used widely in various contexts, including Universities, Counseling Centers and Youth Centers. The games we have created for this project are already being used in the classroom as instructional tools for nursing and medical students. We want to explore more application areas of this project for medical education and health communication. To better understand how we need to design for different purposes and audiences, we have a user study with 110 participants set up and ready to go that investigates design principles of games for mental health, their impact on players and potential therapeutic value.

## The Problem We Are Trying To Solve And Why It Matters

"For the Records" addresses inadequate understanding of mental illness as one of its main issues. "Understanding" in this sense relates to comprehending the fullness of experience, not merely the cognitive understanding of symptoms or physio-psychological mechanisms. Lack of experiential understanding may contribute to stigma and often burdens relationships between people with mental health issues and their social environment. This can complicate the already difficult task of constructively dealing with such disorders, leading to feelings of helplessness, frustration and anger on the side of friends, family and providers of people struggling with mental illness, and fueling the experience of stigmatization, isolation and disconnectedness on the side of the afflicted.

"For the Records" hopes to provide a space for "shared experiences" in order to increase understanding, promote support and constructive relationships, and alleviate stigma.

## **Sprout**

## Our Process And How The Idea Evolved Throughout The Project

For the Records is a project conceived by game designer Doris C. Rusch and documentary filmmaker Anuradha Rana. The goal is to create an interactive, transmedia documentary that provides an inside view into the lived experience of Obsessive Compulsive Disorder (OCD), Attention Deficit Disorder (ADD), Eating Disorder (particularly anorexia nervosa) and Bipolar Disorder. We decided to use different media (film, interviews, photo essays, soundscapes, written stories and interactive experiences / games – all embedded in one website and grouped into topic areas) to provide different entry points for different audiences and to leverage the strengths of each medium to get at another aspect of the lived experience.

We did not arrive at this approach directly. We initially focused on creating a support platform that could aid in community building. During this research process, we realized that one of the major obstacles in creating a supportive community and providing the resources that could help those facing mental health issues was a lack of empathy and understanding from those who weren't. This also contributed to the stigma surrounding people with mental health disorders and is a potential cause of the friction between the afflicted, their friends and family, society at large and even sometimes health care providers. This led us to question how we could use the specific characteristics of different media, particularly the benefits of games and the embodied experiences they provide, to give people with mental health problems a voice? How could we create something that captured what it feels like?

It soon became clear that we had to work closely with people who had lived experience and involve them actively into the conceptualization and design process of all media pieces. Anything else would have been disempowering and overreaching. We started with contacting NAMI, who generously allowed us to conduct interviews during their annual NAMI Walk last Fall, and drawing on our personal network. We were able to get five individuals with lived experience of mental health concerns involved who lived in Chicago and were able to interact with the productions on an ongoing basis. The fact that these individuals could serve as our subject matter experts is one of the reasons that we chose to focus on OCD, ADD, bipolar and eating disorder, besides the pervasiveness of these issues in a university setting.

To create the various media, we split into a game development and a film group. The games group was further divided into four teams, each with 3-8 students and DePaul alumni. The film group similarly formed four teams, each responsible for the production of one film and overlapping to conduct interviews with people interested in sharing their experiences, recording first-person narratives, filming 'vox-pops' (street interviews) and capturing visual moments that could illustrate a feeling expressed in a conversation.

The idea was that each topic area (ADD, OCD etc.) should be centered around one person's lived experience and include an interview, a short film or photo essay and a game sequence. Salient aspects of the individual's lived experiences should become motifs that remained consistent across media. Each piece should be connected to the others of one topic area, providing context and complementary perspectives. For OCD, the main motif was compulsive ritual performance. Our ADD pieces focus on the issue of self-worth and doubt that accompany the necessity for medication to focus. Eating Disorder centers on the body as the target of perfection, but also the source of healing (through dance!). Our approach to bipolar disorder concentrates on feelings of alienation from self and others in both manic and depressive state.

361

## Interesting Patterns And Insights We Discovered Along The Way

## **Metaphorical Game Design and Game Comprehension**

There is a strong, metaphorical component to all the media pieces we created to capture the experience of mental health issues. We are trying to make inner processes visible and tangible and since inner processes are abstract (i.e. they cannot be directly observed or delineated from a physical reality), metaphors are a great way to make them concrete. We follow Johnson and Lakoff's definition of metaphor: "The essence of metaphor is understanding and experiencing one kind of thing in terms of another." (1988, p. 5). While metaphors are powerful tools to communicate otherwise incommunicable concepts, they are not always easily understood. They might be the only way to represent what is going on "inside", but that does not mean that they do not require further explanation. One of our biggest challenges was and still is to find the right balance between staying true to the metaphors that arose from our conversations with people with lived experience and presenting these metaphors in a form that others can grasp them. There is evocative power in a subjective and artistic piece, but there is also the risk of it not being understood. We added quotes from our subject matter experts to clarify the motifs and meaning in the various media pieces. Perfection, the game on eating disorder, even includes a "what it means" page which spells out the metaphorical meaning of all its elements and facilitates interpretation of everyone's individual playthrough and interactions with these elements.

## **Abstraction and Patterns in Film Structures**

Memory plays a big role in the structure of each film. The idea that our memories integrate so much more than actual events, coloring them with our emotions, subsequent experiences, and interpretations, allows for the films to be tools for reflection. The films use quotes excerpted from exhaustive interviews conducted with each of our experts. Depending on the style of the piece, these quotes appear as text, as a voiceover narration, or as a combination of both. In *Re-embody* (Eating Disorder), we made a conscious attempt to use snippets of conversations and/or brief snatches from interviews as opposed to complete thoughts or opinions. This structure lent itself to the idea of memory and thought, how that leads to acceptance and growth depicted through the pensiveness of the dance sequence. In *Ritual* (OCD), we chose to focus on one ritual, combining live action with animation, to linearly narrate one specific memory about trying to stay 'clean'. The abstraction came in the form of creating a silhouette of the character, removing their face, and adding animated 'germs' in order to take the experience from the personal to the relatable. Similarly *The Lost Month* (ADD) uses animation to depict the work that starts to follow our character and the pills he refuses to take, consequently shutting himself off from the world for an entire month.

#### **Patterns in Experiential Structures**

In terms of game design, one of the most interesting insights from this (and previous mental health game) projects is that there seem to be distinct experiential structures associated with different kinds of mental health issues. ADD, Depression and bipolar disorder lend themselves to be modeled as "states". The game captures snapshots of the experiences. The game may model more than one state and there can be a pattern to the state changes (e.g. from manic to depressive to neutral and back to manic etc.), but this pattern is "hard coded" (states are timed and change when the timer is up) rather not modeled systemically. The experiences of OCD, eating disorder and addiction, however, seem to share a more systemic structure. To break out of the (broken) system, these games require a perspective change, a reinterpretation of behavior and the re-learning of behavior / adoption of new behaviors. Their shared experiential gestalt is one of addiction / compulsion.

The games that model states more directly impose a designer's perspective on the player, whereas the games modeling systems leave players more freedom in regard to how they want to play the game. E.g. FLUCTuation, the game on bipolar, evokes two distinct experiences in manic and depressive state and the game determines how long the player remains in each phase. Perfection, however, can be played in different ways. There is more room for exploration. Players never have to succumb to the eating disorder modeled in the game. If they take good care of their garden despite the game's prompts and suggestions, they can reach "Imperfection", the game's true win state. A player study we are about to conduct on all four games with patients, their friends and family and therapists intends to shed light on how different experiential structures impact the games' communicative potential and ability to effectively make a point.

## **Audience**

Noteworthy are also the various responses to the media pieces from different audiences. The games, particularly, tend to polarize. Therapists (or those in training) seem to struggle to accept the lived experiences modeled in the games. In our informal playtests we observed frustration in this audience due to the fact that some games can-

not be won (how do you "win" depression or bipolar disorder?). Friends and family members as well as patients themselves showed more positive responses. To gain a better understanding of the games' impact on different audiences we are going to conduct a user study with therapists, patients and friends and family members.

The short documentary webisodes, interviews and photo essays provide context for one another and also allow a 'way in' to the interactive game sequences for those who struggle with the idea of games vis-à-vis 'mental health'. Beyond that, these particular pieces of media allow the audience to sit back for a moment and observe. They allow a passive interaction as opposed to the more active engagement immediately required by the game sequences. Viewers can navigate through the various media at their own pace, based on their own growing interest (or lack of it!) Links to resources and first person accounts fill in informational gaps. The website hosting all the media will also utilize excerpts from the interviews as transitional pieces, to create an emotional resonance to the overall piece, to capture moments that can unravel an individual experience and by sharing them, unlock the experience for others to empathize with.

## Therapeutic potential

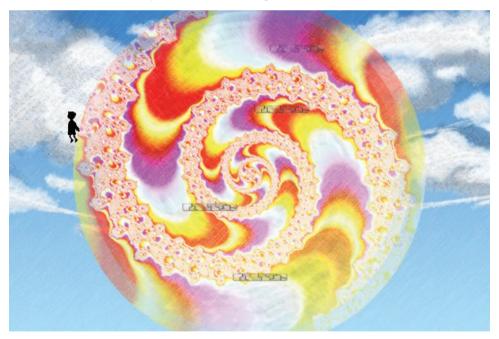
A particularly striking insight was the potential therapeutic value of being actively involved in the media creation process. The game as well as the film teams did not just draw on external subject matter experts to inform concepts and designs, but people with lived experience were also members of the film and development teams (some in leading creative positions). They reported that being able to express themselves with the goal of making their experiences more accessible to others had an empowering effect. This seems worthy of further exploration and would fit well with existing trends in expressive arts therapy.

## Some Of Our Initial Concepts And Designs:

#### **Games**

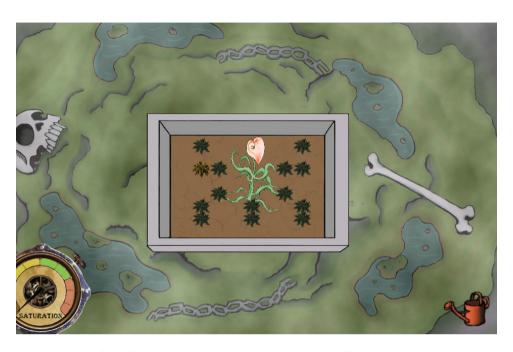
## Fluctuation (BiPolar Disorder)

http://fortherecords.org/fluctuation.html



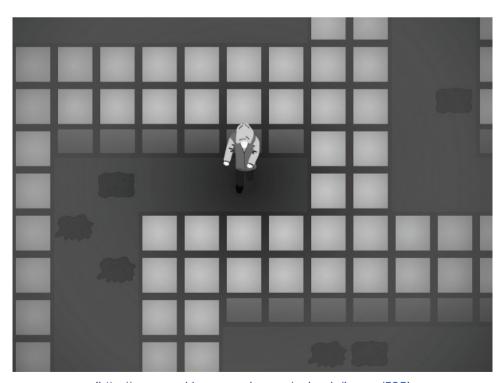
(http://www.workingexamples.org/uploads/Image/583)

Perfection (Eating Disorder)
<a href="http://fortherecords.org/perfection.html">http://fortherecords.org/perfection.html</a>



(http://www.workingexamples.org/uploads/Image/584)

Into Darkness (OCD)
<a href="http://fortherecords.org/into\_darkness.html">http://fortherecords.org/into\_darkness.html</a>



(http://www.workingexamples.org/uploads/Image/585)

For The Best http://fortherecords.org/for\_the\_best.html



(http://www.workingexamples.org/uploads/Image/586)

**FILMS** Ritual (OCD) http://www.workingexamples.org/uploads/Image/581



For The Records - OCD from Isthmus Films (http://vimeo.com/isthmusfilms) on Vimeo (https://vimeo.com).

The Lost Month (ADD) (http://www.workingexamples.org/uploads/Image/582)



(http://www.workingexamples.org/uploads/Image/587)

# **Reembody (Eating Disorders)**



(http://www.workingexamples.org/uploads/Image/588)

Reembody from Isthmus Films (http://vimeo.com/isthmusfilms) on Vimeo (https://vimeo.com).

## Homeless (BiPolar Disorder)



(http://www.workingexamples.org/uploads/Image/590)

Depression from Isthmus Films (http://vimeo.com/isthmusfilms) on Vimeo (https://vimeo.com).

## **INTERVIEWS**

Nami Excerpt 1 from Isthmus Films (http://vimeo.com/isthmusfilms) on Vimeo (https://vimeo.com).

Nami Walks Excerpt 2 from Isthmus Films (http://vimeo.com/isthmusfilms) on Vimeo (https://vimeo.com

## **Iterations On Initial Concepts and Designs**

Game design is by nature iterative and so all designs changed over time.

**Perfection** (game about eating disorder) had completely different imagery and metaphors in the beginning. The underlying structure remained quite consistent throughout the design process, but it took us a while to arrive at the garden metaphor. In the beginning, the game was set in a sterile science lab and as the guardian of the lab you had to prevent contamination. This metaphor was not rich enough to sustain all the necessary elements. The garden as multi-dimensional gestalt (with its weeds and worms, the need to be watered and the flower as object of idealization etc.) had more in common with the body and body image to allow for a more coherent design. Towards the end of the project we redid almost all art assets to emphasize the changes in the garden and make it clear that there is an alternative ending to the Perfection ending.

**FLUCtuation** (game about bipolar disorder) underwent several iterations to get the game "feel" right. The jumping mechanic in manic phase had to spiral out of control rather than be uncontrollable from the start. Manic phase had to start as an exuberant and joyful experience. Depressive phase was fine tuned to convey the emptiness and isolation of depression. We also had to redesign the "depth meter" several times in depression phase, but it is still such an idiosyncratic element that player's do not understand its meaning without explanation. The "depth meter" shows the player's progress towards the surface (at least initially). It soon becomes unreliable. Its purpose was to communicate the desire to know how long the depression phase will last, and the impossibility of predicting it.

It's for the Best (game about ADD) focused strongly on getting the core mechanic right: the pacing of the assignments that flutter onto the screen and the effect of pressing the pill. Playtests revealed that there had to be a stronger sense of negative consequence when you didn't take the pill. We thus let unfinished assignments clutter up the screen and grow into heaps in the background, to evoke the experience of being progressively overwhelmed. To avoid confusion about the game's message (it is not against medication, but about what it feels like if you are

367

told by your parents that you have to take it), a video epilogue was created in which the designer explains the game's personal background. "It's for the Best" is probably the most straightforward of the four games, which can be attributed to the fact that the game already existed as an analogue prototype (produced in a game design class) long before development of the digital version was even in planning.

The process of creating each film roughly ran the same broad course. During our initial research, we sent out emails to mailing lists and people who could help recruit subjects with lived experience. We reached out to organizations like NAMI (National Alliance for Mental Illness), Chicago Hearing Voices, Websites such as 'CaptainAwkward', Dean of Students, the Counseling Center, and the School of Nursing at DePaul University, to spread the word about the transmedia project, and talked to everyone we could think of, including faculty at other universities in and beyond Chicago.

We conducted video, audio, Skype, and written interviews with people in Chicago and across the US during late Fall, 2013. Word of mouth helped a lot as well, as after the initial push of announcing the project, people reached out to us and spoke of their experiences. All of these interviews helped propel the documentary shorts in a general narrative direction and helped us then narrow our focus to specific incidents from peoples' lives for each piece. This was different from the original outlook for the project, but ultimately felt more 'true' to the stories we were about to tell.

For instance, we had initially planned to focus more heavily on 'groupthink'. We wanted to conduct numerous interviews and find the patterns that flowed through each of them, find a narrative that emerged organically and use that as the core for the films. We hoped to create short pieces that represented the thoughts and feelings of more than one person. This changed quite drastically to focusing on individuals, allowing their experience to form the core of each piece and use the individual films as one little piece of a larger puzzle. So while the format changed, the intention remained the same. Production for each of the first three pieces was completed in 2013, with the fourth piece currently in production. Post-production on all pieces will be completed by the end of July 2014.

**Ritual** (OCD): Ritual explores the idea of cleansing or healing rituals that permeate the life of an individual experiencing OCD. It follows a faceless character as they enter their home, only to see themselves as germ-ridden interlopers in a pure space. Over the course of the three minute film which features live action and animation, the character leaves behind germs, like Ritual, on everything they touch until they take a shower, their ritual, and are cleansed physically. However, all it takes is a phonecall from the outside world to start the cycle again, unless our character can overcome the need for the ritual.

**The Lost Month** (ADD): Through a first person narrative, *The Lost Month* uses live action and animated transitions to explore the emotional state of being with, and without, medication. "You learn how to learn," stresses our main character, but with a diagnosis of ADD, one takes a pill to learn. The film addresses the loss of self and identity that comes after being on medication for the majority of one's life.

**Re-embody** (Eating Disorder): Using dance as a metaphor, Re-embody explores the progression of healing as a body discovers that it holds the unconscious secrets to rebirth, housed in physical memories that surface when the mind can be stilled. The experiential game, Perfection, and quotes from the content expert's interview, provide context to this short film, and help us empathize with the challenges faced by an individual with an eating disorder as they seek to overcome it.

**Homeless** (BiPolar Disorder): is a photo essay that explores depression, a manifestation of BiPolar Disorder. Audio narration of person living with depression is juxtaposed with black and white photos of people on the street with their backs turned towards the camera. "My father believed that anybody seeking therapy was inherently weak." The piece addresses the stigma that is attached to mental illness and the lack of understanding that surrounds it.

# How We Aim To Reach Our Audience And Promote Adoption Of "For The Records"

So far, we have been focusing on the DePaul University community as our testbed. We have the support of Counseling Services and Dean of Students office. We are about to negotiate the use of the interactive documentary as part of freshmen orientation and similar events.

A very exciting development is that DePaul's School of Nursing is very interested in "For the Records". There are already four faculty members who are using it in the classroom, to start discussion with nursing students about mental illness. The value of our approach to educators is that other than a textbook, the different media pieces are subjective expressions of what living with a mental illness is like. The games particularly enable a deep, experiential understanding, which is often lacking in mental health education.

We regard the current interactive documentary as a prototype. Our goal is to test its use and impact in the DePaul community and beyond while acquiring funding to do it all over again, covering a broader range of mental health issues and identifying a strategy for broader dissemination. We are further in the process of conducting a bigger user study right (Summer and Fall 2014) now at DePaul University focusing on mental health care providers and patients. The goal is to investigate potential application areas of the project in therapy settings as well as the project's resonance and usefulness as a communication tool for people with lived experience.

## **Scaling The Project For Impact**

When we first started talking about "For the Records", we saw it as the beginning of a movement. Our goal is to cover a broader range of "unusual" human experiences (not just the four topics we are covering right now!), give more people a voice to express themselves and get more institutions and universities involved in the production and dissemination of content. We hope to broadly increase understanding of mental health concerns, foster dialogue and alleviate stigma and to build community in the process by adding a way for people to post their own stories, videos, games, comics, sound pieces.

**Note:** This work was submitted as a Working Example paper, so we are publishing it as such, although the conference presentation was a Well Played session.