

Losing Our Stories:

Early Experiences of Individuals Facing Mental Illness

**Patient and Community Engagement Research Study
Final Report**

**Susan Adams
Esther J. Halton
Oaitse Hellard
Susanna Matte Koczkur
Barb Sarsfield
Edamil Araujo**

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Introduction

“There is no greater agony than bearing an untold story inside you.”
Maya Angelou

What everyone has in common that they can all produce is a life story. In order to have relationships we’ve all have to tell little pieces of our story. It’s a story dependent on personal experiences and how your character exists within them, other characters within our story, pieces accumulated and pulled together into layers of who we are.

Life is amazingly intricate as there are lots of things going on and in order to hold onto our experience, we try to make meaning out of it. Our stories give us a meaning for ourselves as well to share within our community and allowing us to be the author (McLean). We have a place within our circle, or as one participant said, “My tribe.”

Background and Literature Review

This project is part of the internship undertaken within the Patient and Community Engagement Research (PaCER) training at O’Brien Institute for Public Health, Community Health Sciences, and Cumming School of Medicine. We consulted, in regards to this study, with Dr. Elena Petrov and Keri Murray, Mental Health Therapist. This initiative is supported by Alberta Health Services.

This research is a qualitative study undertaken by trainees who have relevant patient experiences in the topic studied. The purpose of this project is to explore the early experiences of individuals when they face changes at the beginning of their mental illness. This study is intended to give voice to the individuals’ memories, knowledge and perception of this initial time period, as they share their stories (Gold, 2007).

This study was conducted using the PaCER method, in which researchers and participants are peers (Marlett & Emes, 2010). This is a patient engagement research method with a peer-to-peer perspective. This methodology provided a platform where the participants expressed their experience in their own words, using the patient’s language, which gave those who face mental health, concerns an opportunity to assert this subject in a normalized conversation with their peers.

Research has demonstrated that individuals are concerned with the issues of stigmatization and quality of life changes when they consider contacting others for help (Rüsch et al, 2013), and thus people are often highly selective when they seek help (Boydell & Gladstone, 2006). For example, Oliver et al (2005) described that the number of people who seek help from a counsellor during initial mental health stress is only 14%, while others preferred a contact with their GP. Evidence-based research in psychiatry has demonstrated that people with early changes in their mental health tend to significantly delay their search for help (Anderson, Fuhrer & Malla, 2010). Addington et al (2002) stated that the average time between the initial experience with mental illness and the first effective treatment is often very long, about one to two years. The authors also commented that most research does not specifically identify what happens during this time period of changing health prior to the first contact with health care providers.

It is more likely that an individual will seek help through sharing with a friend or family member, depending on their held beliefs about psychiatric assistance, their knowledge, and the attitudes towards mental health issues in their social community (Rickwood et al, 2007). Individuals often find it difficult to share the language to express their feelings with those they have little or no pre-established relationship, such as a counsellor or doctor. Mental health counsellors and doctors use a clinical language that is not representative of individuals' own stories (Gold, 2007).

Medical and treatment-focused approaches that are common within health care system are also dominant in current research. The prevalent research discourse is concentrated around the individual's role as a patient within the mental health care system, practically ignoring those personal experiences that do not fit into the picture of patient-system interaction. The systematic review by Singh and Grange (2006) demonstrated the general focal points of interest in research on early detection, early intervention, effective diagnostics, and timely treatment. Both quantitative and qualitative research favours clinical approaches that focus on seeking medical care, "first contact" with medical care, clinical outcomes related to help seeking delay, and other concepts that are highly medically oriented (see a recent systematic review by Anderson, Fuhrer & Malla, 2010). Examples of the language used in research on this topic include such concepts as help seeking, pathways to mental health care, referral sources (Anderson, Fuhrer & Malla), and other terms oriented at medical treatments. One example of this language is the expression "muddling through" in a study by Pescosolido et al (1998), used to signify the initial time period of mental health concerns. Research literature that is based on qualitative methods, such as patient interviews and interpretive analysis, also often uses clinical and labeling terminology. For example, researchers refer to an individual's seeking and receiving help as an "illness career," or refer to illness-related behaviour as "deviance" (Pescosolido et al, 1998; Biddle et al, 2007).

When individuals experience mental illness, issues of stigmatization and labelling have a significant impact on their choices. Deegan (1993) stated that being labeled devalues and dehumanizes people, to the point that during their recovery process they will be recovering not

just from the mental illness, but also from being labeled. However, these issues are under-represented in current clinically focused research.

Deegan (1993) found that most conversations in treatment are experienced by patients as focused on the illness, its symptoms, therapy and medication, but ignoring the stories about the individuals' early lived experiences. Deegan described how significant it would be if a peer would come and say, "I know you can't see a way out right now. But I've been where you are today ... and I'm here today to tell you that there is a way out" (p. 7). Deegan argued in her article that through the understanding of the person's self-stigma, attitudes and beliefs, we can document the language of the experiences and stories of help-seeking choices.

To give voice to individuals' lived experiences, new models have been developed in research that aims at engaging patients in sharing and analyzing their experiences as researchers. In these new roles, patients collect and analyze data within patient-controlled research studies. For example, Domecq et al (2014) compared two qualitative studies, one with patient engagement and another one without engaging patients. The authors found that the first research study was described by many as paramount and essential. A recent scoping review (Beresford & Croft, 2012) stressed the importance of the new emerging trends of patient involvement in research. Similarly to these new, internationally recognized models of research, PaCER uses a methodology that enhances the peer-to-peer view that allowed us to achieve meaningful results based on patient perspective (Marlett and Emes 2010). This method aided in shifting the roles of patients in their understanding, expression and participation in their care.

Very little research has been published on early experiences of individual's mental health concerns and help seeking outside of patient-healthcare interactions, pathways to care and traditional service-recipient patient role within the mental health system (Boydell & Gladstone, 2006). This gap was addressed through exploring individual lived experiences and the collective insider knowledge of people living with mental illness. This special knowledge is neither present in research nor shared with mental health care system (Better-Johnston et al, 2011).

This project was important, as patient engagement research methods help fill the knowledge gaps in the area of early experiences of individuals facing mental illness. Through exploring patients' stories and finding collective language, this study allowed the researchers to capture the voice of individuals' experiences and highlight their beliefs and understandings of their early mental health changes.

Engagement Methods

Our study began with a number of focused ideas specific to our participant target group and to us as experienced patients. We planned to ask a question about the early period of mental health changes which was not asked of us personally nor those with whom we share this early experience. We wanted to ask further questions that would broaden the discussion with a variety of individuals with nonspecific mental illnesses. In order to know what specific questions were helpful in our investigation process, we held a SET focus group to find out what

we needed to know. Our participants helped us to rearrange our prompts and eliminate questions that hindered or confused the memory process. The difficult part of our study was finding the best way to prepare participants to reflect to these earlier periods and what prompts would be helpful in sharing their stories.

Our plan of engaging individuals who identify as having a mental illness allowed for varied and comfortable dialogue and a shared understanding of experiences. Accessing individuals who had not yet shared their mental health concerns with anyone or who did not identify as having a mental illness at the time of the study would have narrowed our recruitment to initial visits with a general practitioner and emergency settings.

Connecting with participants as mental health patients ourselves was a crucial point of opening what is often a difficult conversation. We connected with our participants in an open manner, not only through our shared early experiences, but also because we understood the difficulty of having this conversation others.

We followed the SET COLLECT REFLECT structure and philosophy outlined in Grey Matters (Marlett & Emes, 2010), using a Focus Group's transcriptions for analysis, and narrative interviews lasting approximately 60 minutes each for the COLLECT component. We analyzed the interviews using the narrative format described below to allow the stories to emerge. We wanted to ensure that we had captured the collective voice in a process using quotes and descriptions of participant's experiences.

Recruitment

For this study the recruiting methods we used were:

- Posters at Doctor's offices, Universities, Hospital and other Health care facilities
- Presentations to targeted groups
- Word of mouth
- Personnel contracts

Our study's Ethics Proposal had planned on placing the recruiting poster "*Break the Silence*" in Hospital Area (Foothills Hospital, Rockyview Hospital, Sheldon Chumir Mental Health, Peter Lougheed Centre and South Health Campus), Clinics, Doctors offices and Urgent Care in Calgary.

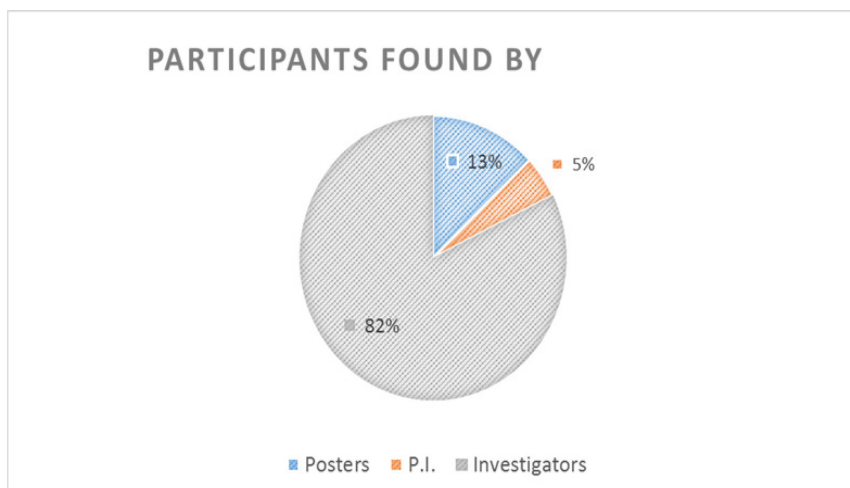
In total 58 volunteers signed up to participate in our research study, "*Early Experience of Individuals Facing Mental Illness*". All participants fit our criteria of:

1. Over 18 years of age
2. Speak Fluent English
3. Self-identify as someone who has experienced a mental illness

Volunteers were diverse in their mental illness diagnoses, race, age, religion, education, sexual orientation, income and profession. The total number of individuals participating in the research study was 13, three men and ten women. The ages ranged from 23 to 57 years old.

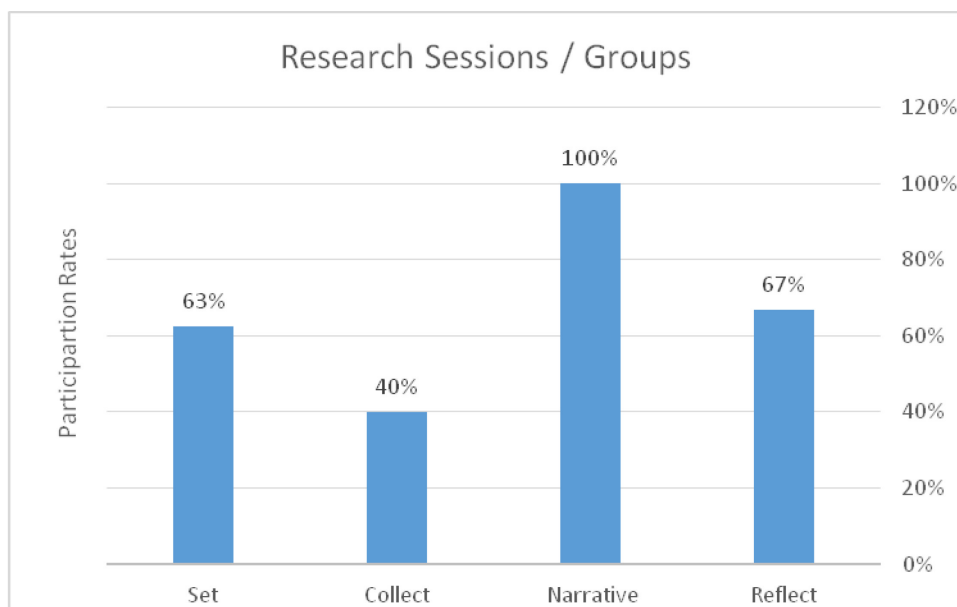
A drop in centre for adults with mental health diagnoses, *Prairie Winds Clubhouse* in Claresholm (a town 140 km south of Calgary) connected with our research project as a result of a nurse sharing our poster with the staff. Although we heard back numerous times from the staff and the administrators of the Clubhouse we never received personnel contact from clients. The clients asked the administrators and staff to call to sign up for them. Part of our protocol required individuals to sign up themselves. After many failed attempts to get even one person on the phone or to use our email recruitment address, one of our interns travelled to the club house where ten (10) clients readily signed up with another dozen clients who would decide on the day. On the day the session, we went to the Club house in Claresholm, although 8 of the 10 confirmed were in the club house at the time, only four (4) clients chose to attend the study. We found most experiences of recruitment with individuals for this study to mirror this pattern of 'sign-up but reluctant to attend', a common and required extra effort in repeated communications.

Personal contacts from our research interns accounted for 82% of our study volunteers. We recruited 58 potential participants. The results of recruitment sources were: 13% from poster, 5% passed from past PaCER subjects given by our principle investigator and 82% from personal contacts. One of the research interns provided over 80% of the list.



Graph 1: Breakdown of the methods of Recruitment finding participants for the Early Experience of Mental Illness, by percentage, from the use of Posters, P.I. (Principle Investigator), and Research Interns (Investigators)

We followed the SET, COLLECT, REFLECT structure set out in *Grey Matters*, (Marlett and Emes, 2010). In each phase the number of participants signed up for the Focus Group was always lower than confirmed. Only the Collect Narrative Interviews had 100% participation (See Graph 2). The narrative interviews required a shorter time commitment (1 to 2 hours) and were conducted in 'one on one' meetings versus a full day focus group session.



Graph 2: Percent of Participant Attendance for each type of session, out of the total that signed up and confirmed. This comes from a Set -> Collect -> Reflect research method, with the one-on-one Narrative-Collect sessions separated from the group Collect sessions.

SET Focus Group

The SET focus group had six participants including four women and one man. All had experienced the initial period of a mental illness.

Our location of the Calgary Central Library was changed three days prior to our scheduled date. We were able to secure a room at the Elbow Park Community Centre. This location was smaller and less inviting for comfort and lighting. We provided stress relieving items and activities to the table as well as the Kleenex packages and writing materials to offer ways to react to any anxiety the group's conversation may have created.

Once we had the required forms signed, we reviewed the purpose of the study and the method of Patient and Community Engagement Research. We used the following guideline for our investigation:

- Pose the guiding question: Can you share with us the initial period when you were thinking or feeling different?
- What was it like for you when you started to notice these changes?
- What actions did you take? (see or talk to anyone)
- What would have made you feel safer?

The participants had little difficulty sharing their individual stories prior to responding to the research question. The dialogue was captured by two recorders, flipchart note taking and process note taking during both the morning and afternoon sessions.

We tried to redirect conversations to the initial period of mental illness experiences as it was natural to add portions of diagnosis and post diagnosis stories. A complication to sharing stories of those diagnosed is the use of psychological jargon and clinical terminology. The participants indicated it took a while to remember the early experiences and that sharing the overall experiences helped them to reach back to this initial period. (This approach garnered a great deal of participation and data but it required more work in collecting and managing it?) Despite our concerns about participants stress level during the group conversation the stress relieving items were not used and some participants did not appreciate their presence as it seemed like an indication we assumed they couldn't handle telling their stories.

COLLECT Phase

To collect data our study designed two means of meeting with participants. We held a Collect Focus Group with a total five participants and five research interns. We also conducted Narrative with four individuals. All focus group discussions and narrative interviews were recorded and transcribed. All participants named or given pseudonyms gave permission for the information to be shared within our data.

Focus Group

The COLLECT Focus Group was held in the town of Claresholm south of the city of Calgary. The location was chosen for its access to recruiting from the Clubhouse members who identified as having a Mental Illness, convenience of a space within the building to meet and offer to provide a full lunch.

The planning from a distance and the travel issues for the focus group turned out to be more complicated for the research team to manage and the actual session began an hour and a half late. The number of reserved participants did all attend even though the location and familiarity of the Clubhouse made it easy to access.

We began with signing necessary forms and sharing information about our PaCER project. The focus group session was recorded and flipchart and process notes were taken. Our focus group began with participant introductions and stories after which we began using the following guide:

Guiding Questions:

Can you share with us the initial period of time when you were thinking or feeling different?

What was it like for you when you started to notice these changes?

What actions did you take?

What would have helped your situation during this time?

Summary of the information from the participants by reviewing the flipchart notes taken during the morning session.

Discussion to explore, define and refine the process and data. Develop key topics for use in further data collection interviews.

The conversation began easily within a relaxed and comfortable room and meeting setting. Each person knew each other from their membership and shared their full stories without hesitation. Once we began the investigation process, we were able to use prompts as planned with methods of redirecting conversation to stories of early experiences and had more success in modelling the use of nonclinical language and asking for clarification when clinical terms were used. We found the question of, what was it like for them and can you tell me more about what that was like, helped participants to go back to that time and remember, using more lay terms, their experiences prior to their subsequent diagnosis and treatment.

Through the COLLECT Focus Group the research question and the prompts used were effective. The attention to directing the story from the clinical story back to the time period when participants first experience changes in their mental made a difference in bringing forth these memories. This experience and that of the SET Focus Group established the parameters for our preparation and direction in our Narrative Interviews.

Narrative Interviews

The narrative interview component originally had eight participants agreeing to participate. Due to time management, intern changes and data needs four participants were interviewed; three females and one male. Each narrative interview was conducted by one interviewer and a process note taker and held in a location chosen by the participant. One interview was held over the telephone due to time and accessibility. The interviews were recorded and lasted from 30 minutes to over an hour. Each participant gave permission to use their stories and where ever they are referred to or quoted and named, pseudonyms have been used.

We each used the following questions to open conversation about experiences during this initial period of their mental illness.

Can you share with us the initial period of time when you were thinking or feeling different?

What was it like for you at that time?

Can you tell us/me, what was the thing you thought of doing?

What was it like when you knew others noticed or you shared these changes?

What would have helped your situation during this time?

One to one interviews were held in a location and at a time chosen by the participants which allowed for a comfortable and open conversation to share rich and full stories. The focus was on the one story of the participant giving a great deal of time and scope in responding to the research question. Upon transcribing the stories we were able to draw out specific scripts that spoke most to the research question. Each participant shared their full stories, commonly from the time of diagnosis of mental illness and back to their initial early experiences. The prompts were adjusted so to focus on that time period once their current story was fully told.



REFLECT Focus Group

A REFLECT Focus Group was held at the TRW Building, Foothills University of Calgary Campus. We invited all those participants who had been involved sharing their stories with in the process of this study. Five participants attended the session; two males and three females.

At this session we presented the participants with eight common threads in script form and with quotes from the data collected during the COLLECT focus group and narrative interviews. They were each taped to the walls so that participants were able to review and use post-it

notes to highlight or comment about the written form of the scripts or to add ideas about them. We used the following questions and direction to share our analysis and findings with participants so they in return could provide their most accurate accounts and true reflections of their experiences.

We began presenting and discussing the main findings from the data during the morning period of the focus group. We recorded the session. We also took flipchart notes and process notes during this part of the session. In the afternoon we then reviewed their flip chart notes and opened the conversation with the following direction:

Discussion of whether: research resonates with participant,
 research has met original goals,
 findings can be used and disseminated to others,
 further research is necessary regarding these findings.

The session provided lengthy conversation and sharing of their individual opinions and findings regarding the data and its analysis. The conversation also gave way to ideas about the overall difficulties they had during their experiences in relation to the available resources and understanding of others and themselves. The information gathered regarding the scripts presented and participant's review of the data were transcribed and analyzed by the research interns. We also discussed the need to share the stories within the context of this study and ways in which they felt it could be presented and/or published.



Data Analysis

Participants were more likely to register to be involved in the study than attend the focus groups. However, those who signed up for Narrative Interviews were readily available to participate. Given the nature of subject matter may account for the numbers of participants changing their minds about attending. According to feedback from participants and the research interns, all identified as having a mental illness, the issues of sharing with unknown people and their own mental health status contributes to their ability to be involved.

The diversity of mental illnesses shared among the participants was felt to add to the depth of the experiences and subsequent data gathered from shared stories.

SET Phase

Our experience from the SET Focus Group gave us insight into what individuals required to be actively involved in the process. We learned two significant things from our SET focus group through our review, mentorship from both research and field practitioners. Firstly we knew we would have to clear message to prompt participants to share what it was like them during this time as opposed the clinical description of what happened. While the whole story needed to be shared we needed to redirect the conversation. We felt modelling the language in our story sharing and using our early experiences briefly would help participants.

Secondly the participants gave us direction in using prompts that better sparked their memory and felt comfortable responding. The prompts were rearranged and the last prompt referring to what would have helped you to feel safer was rejected. Participants felt that it was not a relevant issue during this initial period of their mental illness. They recommended we ask what or what didn't help individuals during this time and what it was like for them to go through these changes.

COLLECT Phase

The COLLECT focus group was held south of the city of Calgary at the Prairie Winds Clubhouse where people in the mental health community gather and socialize. We had decided to use the Clubhouse for several reasons. We knew there were accessible space and a provided hot lunch saving us both time and budget expenses. We would also have direct access to many individuals who may be interested in participating in our study.

The planning from a distance and the travel for the Focus Group turned out to be more complicated for the research team to coordinate and the actual session began an hour late and did incur travel costs. The participants did know each other and there was easy to begin the conversation. The stories all began with each person sharing their story. After modelling story examples and prompts from the interns, we were able to discuss the early experiences in their mental illness. The greatest challenge remained finding the participants own words to describe their story without the jargon and medical terms. When we reread transcribed notes and flip

chart notes we determined the stories in the second half of the focus group that covered the earliest experiences as people found common events and prompted each other's memories of this initial period.

We initially found common themes in the data which we separated into 24 separate ideas. This data was reviewed and we decided to re-analyze the transcripts to listen for common stories shared most often during the afternoon session. Using a narrative analysis process, we found six scripts that represented the stories shared and also matched within the 24 separate ideas found in the coded data. The use of narrative analysis helped us to interpret the large amount of data in the way that best represented the common threads shared by the participants at this Collect Focus Group.

Three **Narrative Interviews** were conducted by an Interviewer and a Process Note Recorder for approximately one hour in length. One interview was conducted over the telephone for a 30 minute period of time. The conversation from the telephone narrative interview yielded less data and scripts. Participants giving interviews had more time to begin at sharing their mental health journey. They each began with their current status and diagnosis and shared their early experiences when given specific prompts about this initial period. Then the story would develop from there and back to their current status. The one on one interview and length of time provided led to full stories with opportunity to recall and revisit these memories. Each Interviewer or Intern was able to use the recordings to document the participant's stories. We used the Narrative Analysis format to write a script from the predominant story in the interview data.

After reviewing the transcribed interviews, we found 22 separate scripts that represented the stories from the participants following the process outlined in Grey Matters (2010). We first read the scripts to look for the emerging threads using the participants coded names for each of their quotes used. We found eleven scripts that shared similar story fragments and participant quotes.

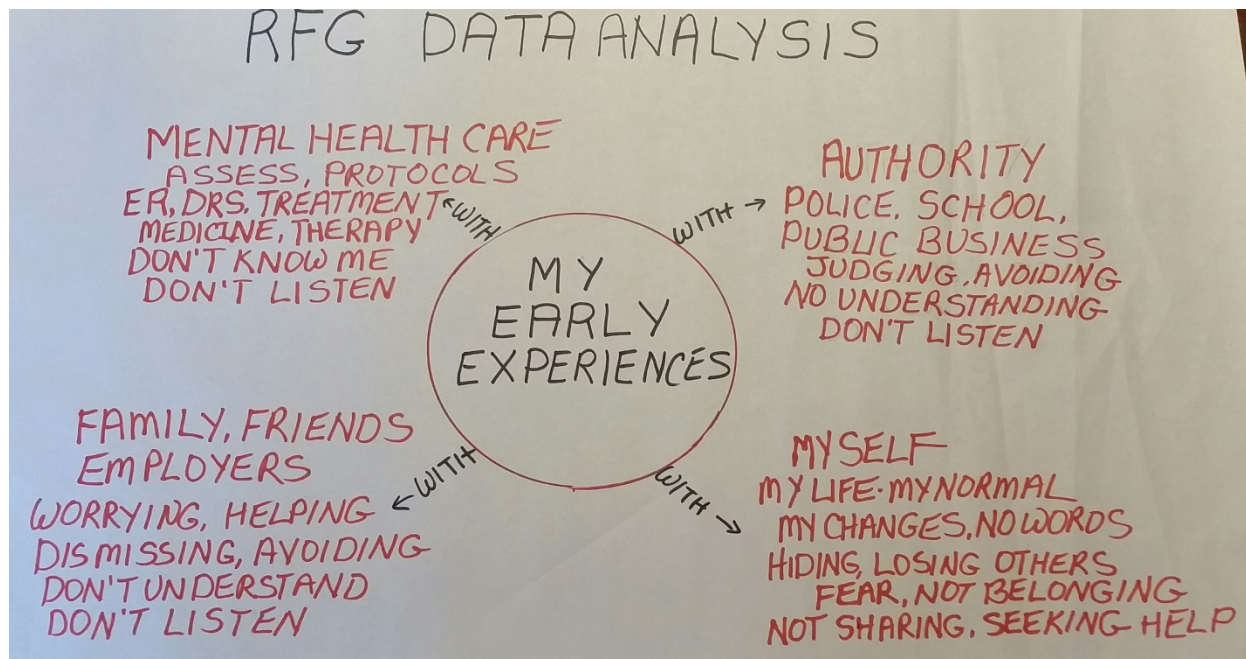
We then reviewed the six scripts from the CFG data and identified the common threads with the eleven narrative scripts. We looked for script content and quotes that could develop an overall storyline. After further analysis of each script and the story focus, we found eight scripts that reflected the experiences most shared by all participants.

REFLECT Phase

The eight scripts developed from the collected data were presented to the participants at the Reflect Focus Group. The participants were highly active in this phase of engagement and note that they were well represented by those involved in narrative interviews. The review of the data gave way to continued analysis of each script and its relevance to their own stories. There was discussion about how the sense of self changed instantly upon an intervention and mental illness diagnosis. Before the crisis people accepted their story of who they were but as they experienced changes they felt alone and frightened of losing their sense of self and where they

belonged. Others were viewed as bystanders and some bullies as they struggled to face their mental illness. The stories shared resembled the process of interacting with people who they thought should have understood and with others who were without knowledge. Their experiences with others was painful when they realized they could not share without being judged which silenced them until forced to through a crisis or offers of help.

They developed a diagram which outlined this experience during this phase leading to their mental illness diagnosis.



The loss of their 'tribe' was the most frightening part of facing their mental illness. They felt their life story changed once they were treated for a mental illness. As one participant shared, "No one asked me this question of what it was like when I first noticed something different." They felt who they were before their mental illness was unimportant and lost. It was clear in the data that the loss of their own sense of self was the greatest threat during this time. The group experienced a coming together in shared experiences during the Reflect Focus Group and a clear sense of ownership of the data analysis and its representation to the community they felt in need of understanding it. The bystanders needed the information so to stand up for the mental health community.

Narrative Analysis

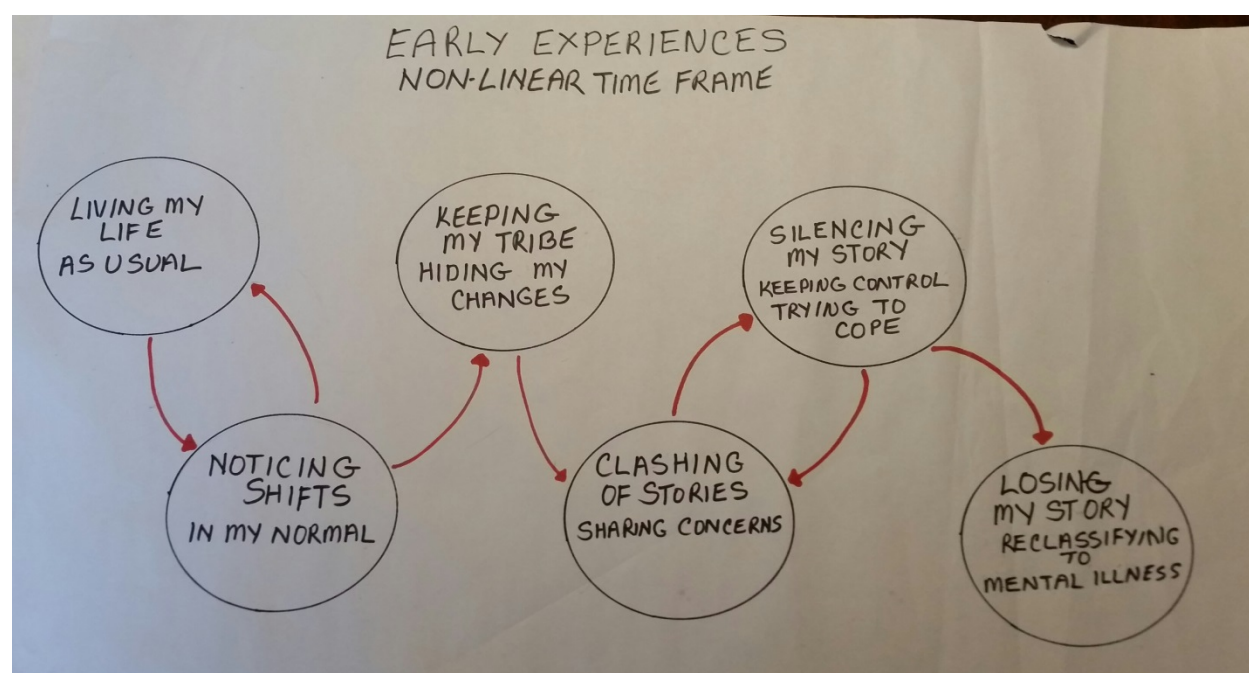
We, research interns and instructors, further analyzed these eight scripts to consider the question of a timeline, or an order of scripts that provided a clear pattern of stories. By finding elements of each script as a point in time of the participant's experience we discovered a continuous pattern that leads toward a mental illness diagnosis. These points of time were

developed as we reviewed the data from the scripts as a nonlinear story frame. From the understanding of a life story that each participant maintained (McLean) to the experience of changes in that story and onto a point of a new story of mental illness, each individual participant's story aligned with the nonlinear points of time.

Would the participants have a different experience if while facing these changes they could have shared their concerns, have them heard and validated by someone who would not reject or judge them. This would be the 'utopia' of scenarios during this initial period and was rarely experienced. Participants often tried to share or were confronted by others more than once and for some over a long period of time. The difference between the participant's story of the changes and its interpretation of those changes by others often clashed as one being a shift in their life as usual to one of an abnormality to be fixed. They were discouraged and fearful of how others changed towards them or what might happen to them.

When some participants shared turning points in their experiences it involved others, 'bystanders' who chose to ask what was happening or listened to their story. These turning points resulted in participants experiencing periods of problem solving and further help seeking. The participant's original story of their life and where they belonged was the motivating factor in hiding concerns. If their original story could be preserved at this time, engaging in 'help seeking behaviour' for mental health changes may occur sooner or with less occurrence of crisis.

We determined the result of our critical story reviews from the data of shared experiences, using the analysis process described above, we were able use patient engagement research to establish a common story of early experiences of individuals facing mental illness.



Articulating Experience

Using the methodology as described above in Engagement Methods we identified general story scripts. Each of the scripts is presented along with our experiences as research interns and as mental health patients. These general scripts convey the journey over time wherein participants experienced a process of stops and starts or cycling their individual story of mental illness. It is the period of time where their life story of 'my normal' shifts and this nonlinear journey is reflected within their scripts. The quotations within the following scripts were drawn from the narrative interviews and focus groups as described in the data analysis section.

Once stories are inserted into the greater social and cultural picture they become master stories for people to follow in life such as in learning, achievements, relationships, success and happiness. For our participants this meant they needed to belong and fit into the master story. (McAdams) That overarching script is the marker others use to set expectations and standards for a "normal" in the bigger story. Using these expectations causes difficulties for those whose stories don't fit or veer off from any of these markers. The master story does not work well for those who are different or 'don't belong'. When the participant shares differences, people living within this master story respond with conditions that they change to match a recovery ending or be identified as 'abnormal'. Once an individual has been labelled with a mental illness they are reclassified within the master story. Success is then determined by the quality of their redemptive story.

1. Life as Usual: *I was good at my job and others told me they were impressed by my work. I worked more than anybody I knew.*

It is a time when all is usual, moving along as it 'always has been' and 'my story' is about 'my normal'. This is what 'as usual' was for participants before they noticed any changes in their mental health and how they managed their life. It is a vision or their story of who they were and how they belonged within their tribe.

Matt was a cabinet maker who was single and living on his own. When he shared what his life was like before he was confronted by others about his mental health he said, "Counting things had been 'normal' my whole life." Matt felt his behaviour wasn't a problem. He enjoyed his work and his family. Counting helped him to feel calm when he worried.

If an individual faced difficult times they discovered ways to manage their feelings. Sally, a woman who lived alone found ways to cope with times of sadness. "When I was feeling 'down' I could be alone with my cat for comfort. I would not feel embarrassed."

There were participants who felt they had to work at fitting in because sometimes they felt different from others. Participants shared they mostly felt they belonged within their circle of

family and friends. Life as usual was much like those around them and they didn't question themselves.

As a student, Jeff felt people looked at him as a good person and likable. "It's very important for me to get others to like me." The stories shared indicated it was important to belong and in control of everyday life and their story.

2. Noticing a Shift in My Normal: *As I watch myself sitting here with these people I am certain something feels different. There is something about me that doesn't fit in at this moment.*

When something shifts in the narrative of 'my normal' it becomes noticeable but not easily described with words. Initial changes could involve daily life activities or interacting with others. For some participants it was a sense of a 'un-named' feeling that was different.

Some found sleep more elusive and sometimes to the point of interfering with functioning. As it became worse the concern grew. Margaret knew that once sleep became more difficult the harder it was to keep it together, "before I ended up having panic attacks, I wasn't sleeping well at night during the week and then I would sleep the whole weekend." Matt always worked but one day he realized he had difficulties doing it. "I was a cabinet maker and cried - I couldn't do it no more."

Some participants began to notice conversations with others were different or they weren't being understood. A student, Mindy would have conversations with others that would feel like conflicts and then she would be afraid to clarify her experience about the conversation. She found ways to justify her experience with negative assumptions about others. "I was afraid to voice anything and I would just snap at others." Mindy knew her negative ideas about people were making it difficult to be with them.

Jeff felt he was an intelligent and calm young boy who was well liked. He began to find it difficult to sustain his role within his circle of friends. He was fighting messages in his mind of, "you are a loser and didn't really belong." His story was shifting. "I was worried a lot – going to school and feeling like an outsider. I didn't feel that anybody saw who I really was."

The changes that were encountered happened gradually for some people but it was sudden and more obvious to others in the study. Those sudden changes were more difficult to understand and manage.

Some changes were subtle and as mentioned earlier, difficult to find words to describe. Patricia described a childhood wherein she had times of knowing she was different and it was very surreal as she describes it as, "I'm standing up in the classroom looking at them gathered and thinking why aren't I down there, why was I not included. It was because I was so disconnected and I missed a lot of stuff." Feelings of watching the world around you and not being

connected to it were experienced at times. As they were temporary it was difficult for Patricia to understand its significance to her mental health during this period.

These initial thoughts of something shifting arched over months for some and through years for others who had no concerns about their 'normal' until moments when changes interrupted it. Each participant's journey during their early experience is nonlinear periods of "life as usual" and 'finding my normal" and can occur recurrently

3. I Need My Tribe: *Something is wrong and I don't know what might happen if others knew. I'd Rather Hide than Be Alone.*

As individuals realized they were experiencing significant changes they felt concerned about what might happen if others knew. Changes were not always understood but it was during this time period when there was a need to pretend or regain their 'normal'. Mary, as a transgendered child shared, "I couldn't exist as a girl and had to act like a boy to be treated normal." This was a time of struggling each day to be someone she wasn't in order to belong at school.

A person's own story about who they are is the story they know and known by within their tribe. Struggling to find their 'normal' is to remain who they are and their membership in this community. The tribe is part of the participant's support system or resistant resources (Antonovsky¹) which provides continuity and reliability in the face of stressors such as changes in their mental thoughts and behaviour.

The fear of rejection was a dominating thought during this phase of the early experiences of mental illness. To hide their concerns and *thereby* themselves, they felt they could manage to keep things quiet and normal. When Mindy entered adolescence she felt her thoughts became different and strange. "I learned that I was wary of people and social interactions and I isolated myself." She wanted to find a way to be like others but she never felt comfortable with her friends.

Jeff feared that his mental health changes would risk his role within his family and circle of friends. He said "it was better to be with 'your tribe' than to be alone." This need to belong was felt to be linked to their changing sense of self. The less 'normal' they thought they might be the more they had to hide their changing thoughts and/or behaviours.

4 A Clash of Stories: *This is a big deal...this is about me, my story and my life. I shared my concerns but it was awful. I saw how they looked at me differently.*

People prefer to hear stories that inspire or are familiar to the bigger master story which guides them and their expectations. (McAdams) Stories that are negative but end with positive outcomes or redeeming scripts are comfortable for most to hear. The stories that are negative and hold little control over the outcome or circumstances are felt to have no redeeming endings. (Pasupathi) These stories are difficult to share and difficult to hear. This does not give

an individual a positive or redemptive view of their story and demonstrates how they no longer belong.

When it became difficult to keep the changes in their mental health hidden or when someone else shared they noticed something was different, an interaction revealed a moment when participants remember wanting to share but they didn't have the words for it.

They each had their own 'normal' and wanted to share what had changed for them but the others listened with their own understanding of what is 'normal'. At that time the story sounds uncomfortable so others reject it as it does not seem redemptive to them. Jeff shared, "fixing means something is broken. No one wants to be told they are broken." When Jeff sought advice from a family doctor he was told "suck it up buttercup." His experience of connecting with someone about his sadness confirmed for him that his problem set him apart and on the outside of the master story.

Out of concern, Patricia's Aunt felt she was not doing well saying she was "not thriving". Pat was impulsively eating and had concentration problems at school. The Aunt urged Patricia's mother to take her to the family doctor. After seeing her, the doctor said to her parents, "take her home because she just needs to grow up." The problems Patricia was having grew into disconnecting from others and she struggled to attend school. Pat said, "My Mom actually sent me to a lady in another town because she told my Mom she could fix me and she had me doing all these weird chants and stuff."

Family often did not know what to do to help when concerns were shared. They too did not have the words or understanding to hear the story. As they had their own idea of what was 'best or normal' they did not ask what it was like or what was going on.

Mary shared her story of being bullied with a teacher and he told her, "Well Mary, it's better to cry in your own misery." He did not believe her claims of distress. He dismissed her problem which she felt was a way of dismissing her importance. She felt those who should have known what to say or do, did not and she felt sorry she had shared anything.

The experience of bringing their story to others, in essence who they are at this time, and finding their concerns would be translated through a master story of what is normal and what fits and what doesn't. Their story doesn't fit and therefore, they hear they don't fit.

Participants felt sharing their concerns and experiences with others resulted in being dismissed or 'fixed' and understood then they were in trouble and that their story was up for grabs. It is a clash of stories and a very painful experience for those in this initial period of mental illness.

What did help during these initial periods of mental illness was to share their story with another that resulted in being heard. When their concerns were heard by another, they offered things to think about, or acknowledged that this thing they thought was really weird was actually not strange to them or they have words of acceptance and validation. 'Bystanders', a term

participants used often, were those in their life who stepped forward to offer support without judgement and had the most impact.

Mary felt at times there was something wrong with her because teachers didn't like her. No one stood up for her until one person, a bystander, asked her how she was doing. "I did find one remarkable teacher in high school, it changed everything." This teacher asked her how she was when she was visibly distressed and asked her to tell him what was happening. She felt comfortable sharing her story as no one ever asked her this before. Mary felt this teacher was a refuge for her, someone who knew her story and accepted her. It got her through the bullying and loneliness.

The first time Jeff went to university he had a big breakdown. He said "I didn't go to my exams. I kind of ran away." When he went to talk with the Dean she heard him share his concerns and she decided to make an exception for him. He shared, "She wiped my transcripts and she also said why don't you go see the psychiatrist on campus?"

When an individual is afraid of how people might react to their concerns, and they keep it to themselves they miss the comfort of others and the support or feedback. When they are able to share the experience turns into one of refuge and provides other possible outcomes, thereby changing the story into one of redemption. There is hope in finding a story accepted by someone else. There are ways to connect that don't threaten to take away your story or limit your personal agency in the process (Adler).

5. **I'm Silenced.** *As I come out to others with my concerns and there is a clash with them, I realize I'm the only person that I can rely on right now. I am told "how to fix it" or "to get over it", so I really know it's not life as usual anymore. I want to take it back.*

Many individuals never have the conversations they want or imagine sharing with someone. The participants were clear that in these initial periods of mental illness they searched for understanding for something they had no words for and isolated themselves the more they experienced these changes. *"All of this doesn't even account for all the conversation you plan to have, or elaborately imagine having and never have. The path from outside to inside and back out is winding, dark, and full of switchbacks," Chelsea Beck (Atlantic, Life Stories)*

The process of sharing bits of your story to have it judged/misunderstood can feel rejecting and frightening as it is hard to un-tell a story that does not fit with others. It can feel like changing your direction on your journey without a compass to reset your story once it is told. The reaction to the story may validate a person's idea that they cannot share these concerns without jeopardizing their story and who they are in their tribe.

Participants shared ways they learned to cope and find control while they continued to retreat or hide their story. Being silenced by those who question their status leaves them to creating

ways to self-manage their mental health changes. The methods of coping vary from ordinary activities to self-medicating or cutting themselves to relieve the internal stressors.

Participants reflected that they were never asked what it was like for them to be going through these changes and if someone had, they thought their fear of losing who they were and stay a part of their tribe... As others need, they too need to feel respected, equal and warmly accepted to hold onto their dignity and strength to reach out to risk sharing their story of mental illness. As Antonovsky (1990) theorized “The stronger a person’s Sense of Coherence, the more successfully will she or he be able to cope with the inevitable, continual, built-in stressors in human existence.

Margaret finally went to see her doctor at the behest of her employer. Her doctor told her he was diagnosing her formally with major depression so it would be easier for her than her actual diagnosis of Schizophrenia. She said the doctor to her, “I would be better for me not telling anyone.” While Margaret received treatment initially she felt shamed and silenced by the experience. It would also be accurate to note that her doctor was silenced by his belief and the stigma of certain mental illnesses as compared to others. The silencing exploits the need for a redemptive story to give acceptance to what is labelled otherwise as a negative or stigmatizing story. (McLean)

Some early experiences for participants required very creative ways to interrupt the frequency or impact. Margaret found she could put the chanting in her head at bay by listening to music. She said she used ear phones “when the chanting started the music would help half the time – gives me a break.” She was not allowed to use the music when she was in her mother’s home as they thought it rude. She is now living independently and says, “Now I have my own place and the music is always on.” Other participants shared the helpfulness of having a pet nearby for comfort and many utilized walking, pacing, and food (less or more) helped them to cope.

There were also methods of coping used that caused harm and/or concern from others for participant’s well-being. Pat discovered two means of coping with her sense of disconnecting from the world and herself. She managed by using self-harming and bulimia. She shared “I controlled it by throwing up and remember feeling ‘wow’”. Other means of coping included using alcohol and drugs to ease the concerns and manage the changes they were experiencing.

Jeff’s experience of sharing his mental health changes left him more alone and isolated. “I learned quite quickly that the only way of achieving some kind of safety was to be invisible and remain invisible.” For someone who has this difficult mental illness story that’s hanging on more and more, and they can’t tell it to have it validated, is a painful experience. This silences the individual and their story.

6 Losing My Story: *Not until the last day, the last moment did I want to accept I could not manage what had been going on. It was a crisis that brought help to me, unwelcomed at the time but so very necessary. I lost the hold of my ‘life as usual’.*

During this period, participants experienced a crisis or an intervention brought about through help seeking efforts by themselves or by others. The encounters and experiences shared by participants were varied and included different periods of stops and starts. Some reached out to seek help as they felt their mental illness was too difficult. Others experienced sudden intervention due to an event that jeopardized their safety.

Mary became active in her community, an activist who was admired and participated with many groups. She appeared to others as doing well. Because of this role she felt it was necessary to hide her persistent depression. Mary still struggled with a past abuse at school and continued to experience feelings of despair and hopelessness caused by not being believed at the time. "I didn't feel there was a possible future for me." After many ups and downs, self-medicating with drugs and food addiction to cope, her depression increased and resulted in a suicide attempt. It was upon her hospitalization that she realized her story would change from LGBT activist to the reclassification of mentally ill patient.

One participant, Patricia spent her second day of university in the hospital. She explains that during the evening before, she had been running around the streets because things were chasing her. She wanted to kill herself. "...and the river was calling my name for me to drown myself." She phoned Good Samaritans and they ended up taking her to the hospital. They released her after one week and without medication or a diagnosis. "I thought somehow I could fix it if I just waited it out. I was pretty sure I could do it." Patricia's mental illness persisted and she was diagnosed soon thereafter and treated.

Other participants had less of a crisis initiated intervention and more of a planned search of help in the best ways they could at the time. Jeff tried to continue working, "I was too overwhelmed. I was going to work and pretending I wasn't dying all the time." He used alcohol and marijuana to self-medicate. All of his life he was thinking of suicide. He was full of pain, rage and fear. He could no longer control his story and knew he needs help. He thought maybe he could try something different and contact his family doctor. After his first medication failed to help him he had to return for further help and a therapist. He said, "They made me a more functional dysfunctional person." Jeff understood he was not fitting into the master story and tried avoid being reclassified as mentally ill. His concern remained feeling like he did not belong in his tribe.

It is difficult to let go of a life story that shapes who you are. A crisis or event that highlights the mental illness of the participant forced them to face a new story about themselves. With intervention, medical treatment is undertaken to respond to the mental illness. Participants experienced this as both necessary and threatening. Soon their life story had changed and this new story required them to be judged as different, a reclassification of their place in the master story. Adding a mental illness story to their own changes their membership status in their tribe or community. They had to put their life into the hands of others who they may not trust and who will assess them, provide treatment and a diagnosis. To accept this change they must let go or surrender their story and begin adapting to a different identity within their community.

During this period of feeling most vulnerable, they were most reliant on others who they often did not trust. They were strangers for the most part who were making decisions and changing their life. Many participants shared that once they experienced this point of crisis they no longer shared their 'life as usual' story nor were they asked. Most narratives shared by participants began with sharing their mental illness story before remembering to the time of their most early experiences of changes, when they still held onto their life story.

Conclusion

"We must always take sides. Neutrality helps the oppressor, never the victim. Silence encourages the tormentor, never the tormented."
~ Elie Wiesel

The scripts lay out a time line of stops and starts on a journey from 'life as usual story' to a surrendering of the same. It moves participants from living their story as they've known it and shared it within their circles of support and community, through self-assessing, hiding, sharing, and silence and to a mental illness story that becomes a greater part of who they are at the point of intervention.

Initially participant's stories focused on a medical diagnosis and the clinical language describing their thoughts, behaviours and sense of self. After this starting point in conversation, the narrative grew regressively to include an experience of self in the context of 'before diagnosis', when thoughts and choices were about life as usual or how they coped to hang on to their own presence in their community. We noted that those within their circles, bystanders and those reacting to mental health changes could act as defenders and listen to the individual, validating their acceptance in the tribe and the value of their personal story. This study gives voice to the individual's story about the loss of the presence within their life story and the inside knowledge of how it directed and impacted their early experiences.

Impact Potential

The PaCER Internship team created a report to share our findings within and outside the Mental Health Community throughout Alberta, and Canada wide. The research question is one that not been asked of participants when they were first treated or diagnosed. It was difficult for them at first to remember their story prior to their diagnosis. The findings also point to answering the questions 'What Would Have Helped?' and critically 'Where as a community do we go from her?'

The findings from our research show a pattern that directly correlates with a variety of individuals with different types of mental illness pointing to an inherently proportionate relatable account of a nonlinear timeline which is more defined in our analysis. Within our analysis our findings speak to a time when individuals facing mental illness experience 'Losing

their Story.’ Because the research around ‘Early experiences of Individuals Facing Mental Illness’ is not a question that is asked the corresponding findings has great impact potential.

Throughout this research and data analysis there has been an expressed need for hindsight reflecting back to an early shift of change within their mental health. The scripts outline a path that leads to a point where individuals come face to face with mental illness, a critical point in losing their story. These findings can normalize the conversation about initial changes, engaging bystanders (family, community, doctors etc.) within the system and empowering those individuals to keep and retell their story. Their personal stories are validated and protected as they must adjust to adding a new chapter about mental illness.

The impact of these findings would be to change the experience for those individuals facing mental illness from one of hiding and silence to having a safe and open dialogue with others which affirms their concerns and protects their story. Identifying the point of the story frame that has the greatest negative impact, the clash of stories, would be beneficial in training and awareness of early experiences of mental illness. Understanding this initial period of change can possibly change the outcomes of intervention, drastically lowering health care and public costs, reduce stress on the system, loss of productivity, as well as the individuals recovery.

Publications and Presentations

This PaCER team will write a scientific report to share with key stakeholders with various fields and backgrounds within the Mental Health Community. As a team we will create presentations and dissemination, based on our research report, and target audiences. Different audiences as proposed by participants from the research study are as follows; clinics, media outlets, news affiliates, outpatients, any medical staff, and creating a video for publication within and outside of the Mental Health Community. After completing the report and developing interest within the Mental Health Community we will target a journal for publication in 2016. After a journal has been located for publication we will then rewrite a portion of our scientific report in an article suitable for peer reviewed journal publication.

We feel it is important to share the voice of the Mental Health Community and our findings within this research method with various and broad audiences to empower others in the early stages of their mental illness

Personal Reflections

Susanna Matte Koczur

I thought I knew exactly what my PaCER program experience had provided me as a research intern. As I began to write about the findings of our study, in particular, the Articulating Experience, I had a fresh awareness about myself as a patient. Writing the scripts brought

thoughts about my own journey and I asked myself why I had been reluctant to share it. Then I found, randomly, a story I wrote ten years ago, as a mental health patient that formed a belief in this study and my experience in PaCER in a way I had not expected.

Initially my interest to sign up for the Patient and Community Engagement Research program was for an opportunity to expand ways of meeting new people and learning something new. I hoped my past career in community non-profit services would be of help to me and to the program. I can't say I thought my experience as a mental health patient twenty years ago would have been more important. I always gave that story second bidding to my bigger story.

Working with my PaCER team was a process of learning together in class and learning how to apply what I knew from my earlier work skills along with my experience as a patient. It began with creating a working group from those students interested in pursuing research in the area of mental health. Initially we debated over the topic of the research but I was soon convinced as to the issue and developed the question we wanted answered. We had to sort out the roles of our team get to work learning new skills. My classmates modelled patience and generosity for me and hopefully me for them. We all contributed different skills, comfort in sharing experiences and offered each other support while getting our project done. It was good to find a passion in learning, discover that I love research, and more importantly a value for what I can 'bring to the table.'

I enjoyed all roles in the research process. Team leading and developing the research protocol were challenging but I learned a great deal. The facilitation, note recording and even transcribing were roles I found rewarding. The narrative analysis process marked a turning point for me. The data we had carefully collected and processed became alive once I learned how to apply the narrative analysis. The data thematically spoke to many voices about experiences but the narrative analysis told the story of those experiences. With guidance from our instructor, the final narratives gave me an understanding of the collective voice in a story frame. I felt a deep obligation to the participants to honour their stories in the context of our study. Writing the findings was truly a moment that settled what patient engagement research meant to me.

After ten years of being a mental health patient, an illness with many twists and turns, I had an opportunity to join a Digital Storytelling Project (2006, U of C). In a brief short story I added my story of mental illness that I never imagined writing or sharing with others. It was the beginning for me in rewriting my story and reclaiming who I had been before my illness. It inspired me to take a class in life writing to start another new chapter in my story. I did not share this digital story with anyone else and the story faded from my memory.

When I came across my digital 'Story', after another ten years, I was moved as I read it. It was clear and poignant that this story was about losing my story just as it was framed in our research findings. I had felt connections to the stories that patients, both interns and participants, shared and I could see how the study applied to all the patient stories. I did not expect to find myself at the core of the study as I read about a time when I was desperately trying to hang on to my own story, the experience of hiding it and the importance of getting it

back.” I realized I was unwilling to share my story because I was not willing to lose it again. The last sentence in my Digital Story is, “Instantly, I am heard...there is light...and I can be seen and in that moment.... my story is alive.”

For me PaCER is a ‘living’ research experience that you cannot remove yourself from as a patient. It is the reason the research is truly a collective voice of the narrative. Nothing has been more rewarding in my career or as a patient.

I thank my instructors for this generous opportunity and I look forward to participating in further PaCER projects.

Barb Sarsfield

I showed signs of a mental illness as a small child. It was over 30 years later when I had a major breakdown and was hospitalized. That happened 24 years ago. I have almost recovered 100% and have a wealth of experience in the mental health system both as a patient and a worker.

In the fall of 2014 I came home one day to find a message from an old boss of mine to call her. When I returned her call I found out she was helping recruit for a new type of research. I figured it would be at most 3 days long. I told her I was interested and she gave me a phone number. I called that phone number and was told it was a University course in which I would learn how to conduct research.

I was invited to an information session where I could question the instructors and current researchers about the course. With all my questions answered I applied for the PaCER course and got accepted as an intern. When I started the course I had no idea just how time consuming the course is or where it would lead us not only in research but in future opportunities for every PaCER Intern.

This past year of study has been a tremendous gift for me. I only knew one intern before the classes started. The friendship between the two of us has become much closer and I now have four more good friends. To top it off I have learned a new research methodology.

The first semester was particularly tough for me. I had taken business and computer courses from college. My concentration problems showed up. I never passed half of them. The instruction this time was great and they let me learn hands on.

I found the methodology very interesting because it is such a ground breaking course. I tell people about my mental health issues as part of my job. I am an outreach worker as well so I work with people who have mental health concerns. As such I have learned how to observe the actions of people which helped me in the observation lab.

The next method lab we studied was how to write up open ended questions we could use in our recruiting interviews. Our team was already working well together and we practiced the

interviews and writing open ended questions about early experiences with mental health changes.

The focus group lab was a challenge for the whole group. PaCER interns had help from an in-class demonstration, verbal instruction, and the GREY MATTERS book which holds the recipe. I had the most fun learning how to do a narrative interview. The labs were a lot of fun. We had to learn how to gently probe further into a person's story to get the story within the story. My greatest challenge came with my emotions. I had to learn how to shut my emotions off and not make the participant's stories mine. With the help of my team mates I was able to do that.

The only role I did not try was taking the flip chart notes. I acted as a facilitator. I need to learn and practice that role a lot as I am not used to directing group conversations. With time that will improve. I took process notes. I found it hard not to jump into the conversation. The instructions I received from our field mentor really helped me do that job very well. I also was an intern participant. I found that role very easy because I tell my story as part of my work with the agency I work for. My favorite role is interviewing people to find the story within the story.

This year I have had the opportunity to work with a fantastic team. We faced obstacles and challenges as a team and were able to overcome everything that was thrown our way.

Our amazing instructors helped us to understand and apply everything we learned in the course. Without their help and the help of our field mentor Eda I'm not sure I would have been able to make it through the course. Now I have a bright future ahead of me.

I am excited for the opportunities that have come about because of this course. I look forward to actually doing the research and to someday in the near future teaching the course. I have felt honored to be a part of this course. It was and still is a huge learning curve for me. I have thoroughly enjoyed every aspect of this past year.

Oaitse Hellard

My experience with PaCER was unexpected. Having my own personal journal experience with mental illness, in the back of my head I always wanted to do research and have it reviewed by key stakeholders and possibly make changes to the health care system. It never occurred to me that this research was in my reach and when I was approached I was excited. Even though the work and learning has been long and hard, and have had some hard lessons along the way, I still feel just as excited about this research team as I did the first day. I look forward to receiving my certificate in January, and being hired to further my career. I look forward to the flexibility this work has around my schedule, as well as being able to collaborate with other individuals not just with mental health but others that have experience in the health care system.

When the mental health Pacer internship group which began with six researchers, we started looking at possible research questions, and as we brainstormed we came up with the question around “What happens during the early and initial stages before a mental illness is diagnosed.” As we examined this question we realized throughout our journey and recovery of mental illness none of us had ever been asked this question. And as I delved deeper into processing this question, I found because I had never been asked this question, I had a difficult time recalling this time period. When I found the answers I had several ‘a-ha’ moments. This led me into a better understanding of myself, better conversations with my family, and better conversations within the mental health community. Bringing a great impact on understanding the beginning, the middle, and end of my mental illness allowed me to regain my story. As we progressed into the research the focus groups and the narrative interviews we learned a lot about ourselves, and as a group how to work together to complete our research.

The very first focus group we facilitated we learned that location is important, as well as keeping the focus group simple. In the first set focus group we had fidget toys and stress balls to help individuals get through a five hour day. The response from the Participants was negative and they felt somewhat patronized by the items that they perceived that they couldn’t get through the focus group without these items. In this group I wrote quotes each participant on flip chart notes. Over lunch the participants were asked to look over flip chart notes that were posted all over the room, and were to add sticky notes of their own personal reflection to the flip chart notes. Then in the afternoon, they were asked what questions worked, and what didn’t work, so as to guide us on the questions for the collect group.

So for the second collect focus group we kept it simple, and chose a big open space. The second focus group was at Claresholm, where the individuals new each other and felt comfortable opening up. I facilitated this group in the morning. We decided to split up the roles more to give other interns a break, and this was a great experience. There were long moments of individuals explaining their first experience, and the research group at first thought this was taking too much time. After conferring with our mentors Dr. Petrov, and Dr. Murray they let us know that actually this was a better way because in order to remember experiences early in the lifespan individuals have to tell a long story to recall events accurately. Then in the afternoon, was again time for reflection on the posted flip chart notes.

Then we completed four narrative interviews individually, where we transcribed each interview, and learned to collect ideas from both the transcribed collect group and the narrative interviews. The third reflect focus group is where we take the final scripts we’ve identified as a common threads. We then discuss with the individuals from the other focus groups and narrative interviews collaborating on the direction of research and if we are on the right path.

During the third focus group, the reflect focus group, was a turning point for me. The group as well as I felt energy of hope, and energy of regaining their story, a passion was ignited to analyze their findings, and share it with the world. For the first time I felt a community of empowered normally marginalized group of individuals ready to take the systemic issues in the

world around us. What a powerful feeling, and what a powerful research project we have taken on. I'm honoured to have been a part of it, happy to regain my story, and to tell others to regain theirs.

Esther J. Halton

My overall experience with the Patient and Community Engagement Research program (PaCER) was fantastic and I loved the research. This is not an area of study that I would have predicted that I would end up in. However, the experience was exciting, meaningful and very rewarding leaving me with ideas, desires and initial plans that I am contemplating to expand into more research in this area of the human condition.

I found my way to the PaCER course through a medical professional that I was working with. Very little information was given about what PaCER was and even after checking out the web site I was unsure but I was intrigued and interested in pursuing the research. The material presented in the class was a new intriguing way of looking at a specific type of research for me. Having the ability to get out the depth, width, volume and reliability from a small but more deeply studied group was a new paradox to me that did make sense and I wanted to know and understand more.

My background was technical, working in the chemical engineering world. I had been doing chemical research and later worked as a senior management evaluating opportunities for our system separation group to team on research projects. I headed up the interface between the research group and the companies working with us.

My journey to look at mental health from a personal bent started ten (10) years ago, when I went from a high functioning busy professional, with no personal experience dealing with mental health illness to an individual who encountered severe mental health illness. My mental break came as result of three major life events happening and my past ability to push through any trying event was unsuccessful with these events.

Coming up with an area of research for our group was the first task. I wanted to look at the very early time with only personnel concern but before external awareness or diagnosis. Our literature search found no research in this area.

As we worked with the data and our results, I unexpectedly started to reflect back on my own experience. As was shown in our research (see diagram 2) the non-linear story line between "Normal" and that first "Shift in Normal" I cycled between these areas trying to act normal when not feeling "Right".

My research colleagues were a diverse, interesting group. The last five (5) of the original seven (7) team members were a kind, hardworking, inventive and encouraging group that was a pleasure to be involved with. Formally, my experience with numerous academic and volunteer

group situations could be challenging. We did not encounter with our team. There were ebbs and flows where at times some members did more but it was not the same person doing more throughout the course of time.

The drop from seven (7) intern researchers to four (4) interns doing research throughout the entire process is not surprising given the nature of the mental health illness. We saw a similar situation from our focus groups with a large percentage drop out on the day of the study. Only Narrative interviews saw no withdrawal from the participants. I believe the shorter time requirement and the one on one situation (versus the group situation) made it feel safer and not as large of commitment. Unlike other health issues, mental illness still carries shame, blame and guilt (SBG). My personal three demons (SBG) were brought more in line while working with others and hearing their stories. Through the processes of coding, focusing on the data, writing of the analysts and developing the concepts my own story became clearer and filled with less shame.

Furthermore, every aspect of the research process from concept development, running meeting, facilitating, recording (process and flip charts), analyzing, writing etc. was exciting for me to be part of these studies.

Instead of just learning a new powerful method of research as the only results, I encountered a powerful method that has the ability to change, challenge, and focus medical care that can result in better outcomes, less cost and a more cohesive medical system. I look forward to more opportunities to continue developing my skills with additional research.

Thank you for developing and running this course.

Susan Adams

I have been a part of the mental health system for nearly 20 years. Although there were signs before that, unfortunately that was as long as it took to get in the system. I am both a patient and a worker in 2014 a former boss of mine contacted me about the possibility of taking part in PaCER. I had never heard of such a thing and became connected to the program as an intern.

When I started the course, I had no idea what a tie commitment the course would be. A lot went wrong with my life from my mother's death to my Dad's health problems, to my own health problems and a move at a very undesirable time of year. Life is what happens when you are making other plans.

The course has been a tremendous challenge to me with everything going on. My own computer skills were lacking (it had been a long time since I took a course at the university level and things had really changed).

The research was very interesting, especially the focus groups. I wish I had tried other roles, but I was process recorder. I had to keep my mouth quiet and focus better.

I really enjoyed the time with PaCER and short of saying that I will upgrade my computer skills; I'm not sure where my PaCER involvement will lead to. Great Team and mentors and teachers!

PaCER Mentor, Edamil Araujo

Being a mentor is a rewarding experience. It's a two way sharing process, in which as a mentor you share your knowledge, and at the same time you learn from your mentees.

It requires an open mind and courage to change perspectives when looking for non-trivial answers. I have been a mentor many times during my life, but this was my first experience as a PaCER Mentor.

During this year I have been mentoring a team of Pacer students, helping to develop the project Early Experiences of Individuals Facing Mental Illness. One of the findings, as a result of this project, was that all participants in one way or another relate to the fact that as you face mental illness you have the perception that you are losing your story.

In that sense, mentoring this team has been specially rewarding to myself. The reason is I have witnessed each person in this team, which once has had that perception of story loss, rebuilding one more chapter of their story during the PaCER course.

As the team graduates, this chapter ends with them becoming better patients, advocating for themselves and helping other patients to express their voices. Now they start a new chapter not just as a patient, but mainly as a patient researcher. A very good one!



PaCER
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Recruitment Poster

Early Experiences of Individuals Facing Mental Illness

Break the Silence

Share your early experiences
when things began to change

This study is conducted by
 Patient and Community Engagement Researchers (PaCERs) –
trained researchers with lived experience of mental illness.

You are invited to participate in any of the following ways:

- Focus group (5 hours): Lunch and parking provided
- Individual interview (up to 1 ½ hours)

For more information please contact:

Esther (403) 813-4704

*The University of Calgary Conjoint Health Research Ethics Board has approved this
 research study. Ethics ID: REB15-1420*

Morgan Kocik Photography

Ethics ID: REB15-1420

Title: Early Experiences of Individuals Facing Mental Illness

PI: Svetlana Shklyar

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