

AN ABSTRACT OF THE THESIS OF

Andrew T. Young for the degree of Honors Baccalaureate of Science in Biology presented on May 6th, 2008. Title: Risk Taking, Social Stigma and Recovery from Severe Mental Illness.

Abstract approved:

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Objective: To explore patient perspectives on the role of personal growth-related risk taking in the recovery process, and to identify social stigma's role when consumers approach and evaluate new endeavors. **Methods:** 177 Kaiser Permanente Health Plan members participated in a mixed-methods study of recovery among individuals with serious mental illness (schizophrenia, schizoaffective disorder, bipolar disorder, affective psychosis). Participants completed 4 in-depth interviews over 24 months. Data were analyzed using a modified grounded theory approach. The author sub-coded and analyzed interview content, then extracted major themes to identify relevant text. **Results:** The most helpful discussions about risk-taking occurred in the context of healthy, collaborative, mutually trusting clinician-patient relationships. Advice was accepted when clinicians listened well, knew patients' capabilities and interests, and pushed gently at a pace that was comfortable for patients. Concerns about social stigma were not observed commonly in this sample, however two participants independently discussed stigma despite not being directly asked about it. **Conclusions:** Enduring, strong, collaborative relationships provide a healthy framework for discussions between patients and clinicians about taking on new activities, roles or responsibilities. The importance of clinicians' awareness of social stigma is underscored by decades of research findings that correlate with the author's results.

Key Words: Mental Health, Severe Mental Illness, Risk, Social Stigma
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Risk Taking, Social Stigma and Recovery from Severe Mental Illness

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I understand that my project will become part of the permanent collection of Oregon State University, University Honors College. My signature below authorizes release of my project to any reader upon request.

Andrew T. Young, author

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This thesis work is dedicated to my parents, Drs Jeff and Laretta Young.
Thanks for your continued support of my education, goals and life in general.

Preface

After deciding to transfer to Oregon State University to pursue the Biological Sciences as part of a pre-medical curriculum, I began to look into ways to develop my understanding of medicine. As part of my learning process at OSU, I realized I needed to understand more about medical research. I began an internship at the Kaiser Permanente Center for Health Research, and have now worked there for more than two years. I have contributed to several projects designed to improve care for people with mental health and substance use disorders. The research was conducted at the Kaiser Permanente Center for Health Research (CHR), in Portland, OR. The main study whose data I worked with was called STARS, which stands for Study of Transitions and Recovery Strategies. The study was funded by the National Institute of Mental Health, and took place over four years with about 180 Kaiser Permanente Health Plan members diagnosed with severe mental illness. STARS aims to isolate factors that promote recovery from severe mental illness, such as schizophrenia, schizoaffective disorder and bipolar disorder.

As part of my work at CHR during the years prior to my UHC thesis research, I developed an interest in learning about the doctor-patient relationship. Furthermore, recovery from severe mental illness may hinge on the quality of the doctor patient relationship. After considering my interest in this aspect of recovery from severe mental illness, my supervisor and project principal investigator Carla Green, PhD MPH suggested that I work on a paper that involves this topic in some way. By this time, I had been working with the interview data for more than 2 years, and had a few ideas that would involve the doctor-patient relationship.

Of primary interest to me was the aspect of taking on new roles, responsibilities and activities during the recovery process from severe mental illness. Additionally, this dimension of recovery depends (in part) on the strength and quality of the doctor patient relationship.

I narrowed down my topic to ‘risk taking and social stigma in the recovery process from severe mental illness’, because it aligned well with my interests for my thesis work. Additionally, as an employee at CHR, I had access to data and mentors that could help me formulate my project. During the interviews conducted previously by trained interviewers, participants were asked about their experiences related to taking on new activities, roles or responsibilities and whether or not their clinicians pushed them toward these ventures. Additionally, participants were asked about the way in which they were pushed to take on these new risks, and what ways they thought were most effective for this type of encouragement. These questions were ideal for my analysis about risk taking and social stigma during recovery from severe mental illness.

I developed a method for analyzing and extracting themes from the primary interview data, using a software program designed for qualitative data. This ‘coding’ was done primarily by myself, and inter-rater reliability was tested among other research staff. Relevant text was selected, and then a code was placed into the text using the software program called Atlas. In total, I developed 23 codes to capture one-dimensional content that illustrated themes within the data. The software program then allowed users to ‘query’ a document set (one complete round of interview transcripts) for any of the codes used for the data. The program would then output all relevant text that coded according to the search performed. This data was then analyzed by the author, and themes were developed using a modified grounded-theory approach.

My research was conducted at the Center for Health Research during the 2007-2008 academic year. I have written a paper as first author and submitted it to *Psychiatric Services*, a peer-reviewed academic journal in the field of Psychiatry. The primary readership is clinicians, and the author revised and re-submitted the paper twice for publication, most recently in April 2008.

My role at CHR has evolved throughout several years of internship and employment, and has culminated with taking the lead on a publication. As I began to increase my interest, responsibility and capability for research at CHR, so did my plans to incorporate the work into my Honors College thesis. My study findings are presented in context along with other parts of my research conducted at CHR.

Risk Taking, Social Stigma and Recovery from Severe Mental Illness

Introduction

Clinicians have been pessimistic about the long-term prognosis for individuals with serious mental illnesses for years. Though research over the past two decades has shown that recovery is common, [1-5] low expectations and the desire to prevent failures that may undermine confidence or self-esteem, or produce instability or relapse, may lead doctors to discourage their patients from taking on new activities, roles or responsibilities. In addition, social stigma may influence the way that consumers conceptualize risk taking and approach decisions about new endeavors [6]. Social stigma, in the form of hurt, discouragement, or lowered self esteem can come from various sources [6].

In an increasingly recovery-oriented mental health care system, however, consumers see taking on normal activities as important avenues for personal growth that promote recovery and the development of a full life. Furthermore, many patients with severe mental illness have argued that though well-intentioned, doctors' efforts to stabilize their lives and shelter them tend to place "people in a protective bubble, shielding them from their community and ultimately from their future (p. 83)" [7]. Awareness of potential social stigma associated with community reintegration, or the possibility of failure when taking on new activities may contribute to some consumer's isolation [6], yet recent research supports patient claims that taking on normal roles and activities is an important part of the recovery process [8]. Symptoms improve when patients are employed and consumers who hold competitive jobs experience an increase in self-esteem [9], and can participate actively in the social life of the workplace [10].

Furthermore, patients who are recovering from severe mental illness that have healthy, supportive social networks are able to recover more quickly from symptom exacerbations [11], and those who have better social relationships have better functioning and higher quality of life [12]. Lastly, while potentially difficult, parenting can play a significant and important role in the lives of individuals with severe mental illness [13]. Thus, taking on opportunities, or ‘risks’ that increase those meaningful activities, improve interactions and contacts with family and friends, and enhance social support, may help facilitate recovery.

Despite potential benefits, pursuing many of these opportunities also involves taking risks and accepting stresses that are characteristic of new roles or responsibilities. Also, patients must be prepared to accept failure as a possible outcome. Patients increasingly emphasize, however, that accepting these risks that are inherent to the process can facilitate recovery, particularly if they are undertaken with thoughtful planning. In the patient-produced self-help book entitled *Pathways to Recovery*, for example, the authors state, “we have to take risks because the biggest risk in life is not to risk at all. We may avoid suffering, but we won’t learn, change or grow.” (p. 47) [14]. The book provides guidance to patients about evaluating risks and developing a personal vision about their goals, and how to create a plan to achieve and evaluate their progress.

As patients take responsibility for their treatment and lifestyles, doctors work to promote recovery and personal empowerment, and the mental health system moves toward recovery-focused services, it becomes increasingly important to understand how clinicians and their patients approach, evaluate and balance the risks that may be necessary to promote personal growth. By learning about patient perspectives during this risk taking process, and how they perceive, evaluate and approach these situations,

doctors will have a deeper understanding of how to foster that process during treatment. A better understanding of how social stigma affects the way that consumers approach and evaluate new endeavors will facilitate better relationships for clinicians and their patients, as doctors will be acutely aware of important issues carefully weighed by their patients. Social stigma's scope extends beyond mental illness, however.

Social stigma is prevalent for many forms of illness, including chronic physical illness [15] and obesity [16]. Mental illness comprises another important dimension where social stigma can play an important role. Social stigma has been associated with mental illness for many centuries, where individuals have a depressed status in their community due to their illness [17]. Previous studies have indicated that social stigma may be due to a variety of factors [18], yet understanding how it effects the way that patients conceptualize risk taking will deepen the collective understanding of stigma and its manifestations. Stigma may play an important role when consumers approach and evaluate new risks. On a smaller scale, individual experiences can help to illustrate specific issues that consumers deal with regarding stigma.

Many consumers worry about how others will perceive them, avoid telling others about their condition, and have reported experiences where offensive or demeaning comments have been directed at them regarding their mental illness [19]. For example, in Prince et al's study, participants reported that persons with psychiatric illnesses are likely to experience devaluation and discrimination from members of their community [20]. Furthermore, personal narratives have developed the idea of self-stigmatization where consumers torture themselves mentally out of shame, guilt or embarrassment about their illness [21]. The experience of social stigma is not limited to consumers; their families may also be affected. Significant social stigma can be experienced by family members,

and the family's burden can contribute to shame and ostracism for the consumer [22], [23]. In addition to family burden and stigmatization, there are other serious consequences of social stigma that are important to acknowledge.

Prejudice and social distance are common themes for stigma experienced by consumers with severe mental illness [24]. Furthermore, social distance may be influenced by several different kinds of prejudice, which are in turn influenced by the belief that persons with mental illness cannot care for themselves, and the degree to which this belief is held depends, in part, on the familiarity of the believer with severe mental illness [25]. Homeless and mentally-ill persons can face 'double stigma' [26], and social stigma may interfere with mental health service use and participation [27]. In sum, the stigma associated with mental illness, and the resulting social rejection can harm the self esteem of consumers [28], [29].

In light of the possibly negative experiences consumers may have because of stigma and mental illness, certain roles or activities may be avoided to keep from worsening their stigma due to a failure they experience. Thus, it is important to examine the role that social stigma plays when consumers approach and evaluate new risks with their clinicians.

By using qualitative data from a longitudinal study of recovery, the author will address these questions using patient perspectives to illustrate themes. Patient's unique experiences with risk taking, times when they were pushed or held back from new activities, and their impressions about what was most and least helpful to them during these times, follows.

Methods

STARS Study

The STARS study was conducted within Kaiser Permanente Northwest, a non-profit prepaid, integrated group model health plan that serves about 480,000 members in southwest Washington and Northwest Oregon states. Kaiser Permanente provides comprehensive outpatient and inpatient medical, dental, mental health and addiction treatment to its members.

STARS Study Background

STARS is a longitudinal, mixed-methods, exploratory study of recovery among individuals with serious mental health problems (schizoaffective disorder, schizophrenia, affective psychosis or bipolar disorder) funded by the National Institute of Mental Health. Participants completed in-depth interviews and questionnaires at four different time points over two years. Two of these interviews were done at baseline, one at 12 months, and one at 24 months. The interviews were designed to explore mental health history, personal experiences affecting mental health and recovery, and experiences with mental illness, mental health care, and symptoms.

Participant Identification, Recruitment, Inclusion and Exclusion Criteria.

STARS study participants had diagnoses of schizoaffective disorder, schizophrenia, affective psychosis or bipolar disorder for a minimum of 12 months. Additionally, participants had at least 12 months of health plan membership prior to study enrollment, were age 16 years or older, and planned to stay in the local area for at least 12 months. We excluded those who mental health clinicians felt they were unable to participate and those with diagnoses of dementia, mental retardation, or organic brain syndrome.

The study team then extracted a pool of potential participants ($n = 1827$) and sent recruitment letters (in small batches over about 10 months, beginning in November 2003) to a total of 418 individuals, at which time the recruitment goal was reached. All letters were signed by the study principal investigator, as well as the individual's mental health clinician. Clinicians screened out 15.8% of the letters we sent to them for signature, based on their assessment that these individuals were not able to participate in the study at that time. To balance the sample, letters were stratified according to gender and diagnostic class (mood vs schizophrenia spectrum), and were signed by the principal investigator and the member's mental health clinician (or primary care provider when no specialty mental health visits were recorded). The primary investigator is Carla Green, PhD MPH, a senior investigator at the Kaiser Permanente Center for Health Research in Portland, OR. Those who did not respond to the recruitment letter received follow-up telephone calls. Of 418 recruitment letters sent, 350 individuals were contacted, 127 refusals were received, and 22 individuals were found to be ineligible for the study. Overall, 46% of those that were eligible were enrolled.

Participants

Study participants were 177 Kaiser Permanente members, 92 of whom were women (52%) and 85 were men (48%) with serious mental illness. The enrolled sample distributions for age and sex, within diagnosis, did not differ from the study-eligible population of health plan members. The age of participants ranged from 16 years to 84 years, and the average age at baseline was 48.8 ($SD = 14.8$) years. Racial category information was also collected from the study sample. Participants were given the opportunity to indicate more than one racial category: 94.4% (167) reported being White, 5.6% (10) Black or African American, 2.8% (5) American Indian/Alaska Native

and 1.7% (3) Asian/Pacific Islander. Overall 4.5% (8) reported being of mixed race and 0.6% (1) reported Hispanic origin. Additional demographic and descriptive information have been published elsewhere. At the 24-month follow-up, 167 of 177 participants completed interviews, 3 participants were deceased, and 7 were lost to follow-up. The overall follow-up rate among living participants at the final interview was 95.9%.

Compliance

The STARS study was approved and monitored by Kaiser Permanente's Research Subjects Protection Office (RSPO). After complete description of the study to participants, all provided written informed consent prior to participation. All study team members completed the required HIPAA and Kaiser Permanente RSPO trainings. For Andrew Young's ancillary research for this thesis project, he completed both RSPO training and OSU Collaborative Institutional Training Initiative (CITI) RSPO trainings. A compliance review discussion was completed with the Kaiser Permanente HIPAA compliance officer as well as Dr. Carla Green. Mr. Young applied to, and was approved by the Kaiser Permanente Northwest IRB for his study, and also applied to the Oregon State IRB, receiving approval on 02/08/2008.

Qualitative Data Analysis and Interview Procedures

Interviews were semi-structured; most results presented here are based on a modified grounded theory analysis of 2 questions included as part of the 24-month interview. The first question posed by interviewers to participants was: "Sometimes people feel like their clinicians either push them to take on too much, or to move toward taking on responsibilities too fast. Other times, people may feel like their clinicians either don't push enough or hold them back when they're ready to move forward....Could you tell me about times you felt like your mental health clinicians

didn't push you enough or pushed you too fast?" The following prompt was provided for interviewers to use as needed: "What would you have preferred s/he/they had done?"

The second question was: "Do you have any advice for clinicians/counselors about when and how to push people to take on more, and how to know when the time is right or wrong to push them?" We also included information that emerged in the context of the three prior interviews when it addressed topics explored in this paper.

All interviews were audiotaped and transcribed, verbatim. The study interviewers and investigators reviewed transcripts weekly throughout the data collection period to ensure transcription accuracy and appropriate interviewing techniques, including probes, and to develop a general descriptive coding scheme. Interviews were then coded using the software program Atlas.ti [30], enabling researchers to select relevant text conforming to the coding guidelines, then extract themes for a given code or codes. Following completion of preliminary coding, we developed a secondary detailed coding scheme that was specific to emergent topics in the text that addressed being pushed or held back by clinicians, as well as participants' experiences with clinicians during times they were taking on, or considering, new activities or responsibilities. This secondary coding scheme contained 23 sub-codes; all relevant text was coded using this coding scheme. We then extracted common themes from codes with more complex pattern content, and identified examples illustrative of codes with relatively one-dimensional content. In the sections that follow, we describe the most commonly discussed and important themes derived from the interviews. Check coding was completed throughout the coding process to ensure coder consistency, and inconsistencies were discussed and resolved by the coding team and code definitions were revised to clarify code application when needed.

For Mr. Young's additional thesis research during the 2007-2008 academic year, interview content coded under the 'risk-taking' code was analyzed for discussions related to social stigma. All relevant text was analyzed by Mr. Young.

Results

General Discussions About New Activities, Responsibilities, Risk-taking and Recovery

We began by looking for general discussions about the role of risk-taking in the recovery process from severe mental illness, and how the concept of stigma influences the way that participants approach these new endeavors. Additionally, the author searched for descriptions of being pushed too hard by clinicians to take on new activities or responsibilities, of being held back unnecessarily by clinicians, and for any consequences of these experiences. The interview text was analyzed to identify themes that addressed risk-taking related to new or expanded activities or opportunities.

Within general discussions of this topic, several participants ($n = 8$) independently discussed the importance of taking on new activities to facilitate the recovery process, while 13 indicated that clinicians should play a role in helping, supporting and sometimes pushing patients to do so. For example,

...So it's a case by case thing, if they're [people with mental illnesses] walking, and they're talking, and they're not suicidal, I'd say at least get them doing something volunteer, but you always need to be doing something...and every job is different...If it's a real remedial job they can do that, if they have a real difficult job then maybe they need to do volunteer work for a while before they can do their job. It just depends, but I think it's good to get them out there doing something, to get us doing something ... you don't want us sitting around because if we sit around and lay around, we don't get better, it takes longer. I think we need more push.

Additionally, we searched for experiences where participants were discouraged by their clinician about taking risks. Interestingly, we encountered instances of participants feeling discouraged by clinicians when they wanted to take on normal life roles and responsibilities, however this was found among only 3 participants. The impact of these

experiences, however, could be profound for the participant, as illustrated by the following quote from a young man who decided not to take his clinician's advice:

Straight up, that's why I went home, she [psychiatrist] said you can't have no job, you cannot go to school, you need to be on SSI, and you cannot have a girlfriend or nothing like that because you are just crazy, basically what she said, she said you have bipolar, you need to accept that, that you cannot do these things. I was like what? Even then I was like "What the hell? No way." Then she said...you need to be on these pills for the rest of your life, you cannot have a job, you cannot do this stuff.

I'm doing it now, you know, I'm doing it now [working, having a relationship with a girlfriend] and I'm feeling really good about it, and so yeah, I have had an experience like this, and I didn't really like it at all...I can look at myself and say I did make the right decision, cause I could be sitting here right now just being numb, but I'm not because I made that decision to step my foot out...and get positive responses from positive things. I would never be able to do that if I was numb, never, ever, ever, and she never did tell me things was going to be okay, that I had a light at the end of the tunnel, she never told me that.

Furthermore, we searched for instances where participants were pushed too hard or too quickly by their clinicians. 11 participants reported having these kinds of experiences, and 3 were related to taking on new activities or responsibilities, 3 were related to medication changes, and the remaining experiences were varied. Within the cases where clinicians pushed participants too hard, participants most often reported being frustrated with the clinician-patient relationship (some left their clinician when the problem was significant), but none reported the kinds of increases in symptoms or hospitalizations that clinicians fear. The following quotations from participants further illustrates this point:

Yeah, well, there was this one therapist I had, and she's no longer my therapist, but (laughs) she gave me an ultimatum...She wrote me this letter and I had no idea she was going to do this, and she was like you need to do this, this and this, like 10 different things, and if you don't do it, I can't be your therapist any more...and that didn't fly with me at all, I'm like "This is bullshit and I'm not doing anything on this list," so yeah, that was the end of our relationship. That was really hard too, because I'd known her for like 4 or 5 years...

Interviewer: Can you tell me about any experiences where you may have had when you felt like your provider pushed you when you weren't ready to be pushed?

Participant: That's exactly what happened to me...when I was pregnant with my son, I felt like they were pushing me too much...At that time I had no energy...whatsoever and I had to get up at 5 in the morning in order to make the bus to go to this, what do you call it, clerical school or something, and I swear I couldn't make it there hardly ever. I was so tired...but I went through it and maybe it's best that I did have that structure in my life at that time, because I would have just slept I guess, but there was one period in there...that I slept for like 3 days straight and I had a fever, because I was so...worn out...

Interviewer: So at that time you felt the clinician pushed you too fast?

Participant: It was too fast at that time...

Lastly we searched for examples where social stigma was mentioned in the context of taking on new risks, but found only one example.

Themes related to the Roles Clinicians Play in Decisions to Take Risks

After searching for examples of the general experiences discussed above, we examined all interview text for emergent themes related to working with clinicians during the process of making decisions about taking risks that could lead to personal growth, or of taking on new activities and responsibilities. Additionally, we searched for examples that illuminate the way that social stigma relates to how participants approach and evaluate risks. Most participants described collaborative processes that they found to be supportive, and helpful. Descriptions of common themes with examples follows:

Theme 1: Clinicians Need to Know Their Patients

One of the most common themes in the interviews was that clinicians need to know their patients deeply when counseling them about taking on activities or responsibilities that could be stressful. Participants expressed this theme in various ways; the following example is characteristic of these discussions:

Interviewer: Any advice that you have for clinicians about knowing when to push somebody, how much to push them?

Participant: To try to learn the person first.

Interviewer: What do you mean?

Participant: Learn, learn their ways, their reactions and so forth, because what one person can probably take and accept, it's possible there's another person right around the corner that can't even deal with it in that same manner, so you take the time to learn...

Additionally, by knowing their patients well, clinicians will be more likely to be aware of important issues that should be considered before consumers approach new risks. For example, it may be useful for clinicians to help patients as they assess how others in their community view them when they try new endeavors. Consumers

concerned about social stigma, as was this participant, may need additional support if they are to take on new activities, roles or responsibilities.

Participant...there were times I felt, in the past, that people just thought I was disabled and not able to take care of anything, not able to do anything with my life, like I was less than a person, like I was sub-human, not as good as they were because I had a mental illness, like I was on the same level as a homeless person who was talking to themselves all the time, that didn't know how to bathe, and groom themselves, and I'm not like that.

Theme 2: Careful Listening and Mutual Trust Provide the Foundation for Collaborative Discussions and Decision Making

Participants reported that as clinician-patient relationships developed, so did a mutual trust that fostered more fruitful discussions and decision making. This seemed to be particularly true when relationships were collaborative in nature.

...I would just say know your patient, know the person you're with, the patient or the doctor, either one, just get to know them. It's almost like you have to establish a good relationship with them, and being able to trust, trust has a lot to do with it...you have to trust the person. I don't know if that's the doctor being able to trust the patient, being able to do more, because it works both ways I think. The patient has to trust the doctor...

Also, participants reported better communication with their doctors as a result of feeling more comfortable with them.

I've always felt, in general, very secure with him. That's made it easier not only to communicate with him, but to hear what he has to say and to trust what he has to say. It's not that he is just reciting something that he has read out of a book and tells every single person that comes in the door the same story.

These trusting relationships were forged through careful listening. Participants reported that clinicians who listened well developed a better sense of each patient's unique situation, and thus could provide better and more appropriate advice. Furthermore, some reported that good listening contributed to having the kind of personal and collaborative partnership that made them feel more comfortable disclosing the sensitive information that was sometimes needed to make good decisions.

I think that clinicians needs to be kind of like your pastor at your church sometimes, they need to listen, ...take them over their history, take some time, and like I said, you're not just a dollar sign

walking in and out ...if you're going to be a doctor...you've got to make it more than just "I'm just another patient coming through that door," ...they've got to really take the time to get to know these people and realize what works for them, and don't, if there's a sensitive subject, don't push it, because eventually all it's going to do is make that patient not come back.

Additionally, strong working relationships between patients and providers appeared to foster more collaborative, in-depth discussions about risks and risk-taking.

For example:

Interviewer: ... Have you ever had any experiences like that [being held back]?

Participant: Just that last one, my first doctor told me I couldn't drive, and [PSYCHIATRIST] pretty much tells me maybe we should not do this right now, and it's not saying don't get a job at all, it's saying you're not doing well right now, so let's put it off for a month and talk about it again, so she doesn't push me, but she also doesn't take away things from me either. She always is saying she wants me to be outgoing and stuff, but she doesn't really push me much. We kind of connect and decide which way would be best to do this problem.

Interviewer: So it sounds like she maybe suggests some of those things to you -

Participant: Yes, but she doesn't force them on me, at least not that I can remember. Lately, she will say okay, how do you feel about this, do you think we should not, not work right now, but she says if you feel like you want to, and you want to try, she'll back me up pretty much.

Theme 3: Clinical Guidance Needs to be Aligned with Patient Capabilities and Interests

It was in these close relationships that clinicians gained knowledge about their patients' capabilities and desires that participants saw as prerequisite for providing guidance that could be relied upon—that which was perceived as helpful and struck a healthy balance between personal growth and personal risk. For example:

The doctor has to know just what your capabilities are, not what you think they are, he has to know...like you think "I'm going to get better and I'm still going to be a rocket scientist", and he has to know [that] "No, this is not in the cards," without discouraging you, but he has to caution, he has to be cautious and then lead you into a life. That's asking a lot from a doctor, but do not push too hard or too little, and he has to know how to do that.

Moreover, participants reported assessing clinicians as more skilled when the suggestions they made for change or risk-taking were aligned with the patient's abilities and interests.

Interviewer: ... Could you tell me about any times your mental health clinician either pushed you too much or didn't push you enough?

Participant: Never...because they're really good listeners, they're really intuitive people, they're very sensitive to where people are in their lives, and very careful about checking with me in a number of different ways, conversationally, to make sure the path we've planned was beneficial.

Theme 4: Pacing and Clinical Approach Affect Patient Perceptions and Evaluations when Being Pushed

When the clinician was able to encourage the client at the right pace, participants reported not *feeling* pushed to take on new responsibilities or changes, even while recognizing that they were being encouraged by their clinician.

Interviewer: ...the clinicians you've worked with, can you think about times where you feel like they just didn't push you, or held you back in any way?

Participant: No, they never pushed me too much, never stressed me out, and they never held me back, they just let me progress in little steps to get better into recovery.

When the push came in the form of a suggestion or question, participants noted that it did not feel intrusive or unwanted, and felt more comfortable taking the advice provided:

Interviewer: You had mentioned you have experienced when physicians have tried to push a little bit, when you've had those experiences, can you comment at all about how they went about doing that, and what was good about that, what wasn't?

Participant: They just put it in the way of a suggestion, it wasn't really that type of thing.

Interviewer: It didn't feel like a push then.

Participant: Yeah.

Finally, we found a number of good examples where clinicians and participants worked out a delicate balance for managing potentially stressful activities. These careful, well-paced, negotiations appeared to facilitate recovery in important ways. For example:

Participant: I've never been pushed too hard with [health plan] from any clinician, and [DOCTOR] will usually, in a very subtle and kind way, explain to me when I'm trying to do too much, like when I tried to join the National Republican Party as a representative in the neighborhood, but when he sees me taking on too many projects that really aren't in my goal area, just busy work, he's been able to, he's real influential without telling me what to do, he gets the point across and I understand. And then I realize too, it's not everything I thought it would be to be so busy on different committees, or different jobs, and if anything he puts the break on just a little bit, which is good, so I don't overdo it.

Risk Taking and Social Stigma Findings

After searching the interview data for relevant discussions about social stigma in the context of risk taking, we found a single example where a participant independently discussed stigma.

Participant...there were times I felt, in the past, that people just thought I was disabled and not able to take care of anything, not able to do anything with my life, like I was less than a person, like I was sub-human, not as good as they were because I had a mental illness, like I was on the same level as a homeless person who was talking to themselves all the time, that didn't know how to bathe, and groom themselves, and I'm not like that.

Thus, this person's experience with self-stigma highlights the importance of understanding the crucial juncture between self-stigma, and taking on new activities, roles or responsibilities.

Discussion

Our findings suggest that the best discussions about risk-taking occur in the context of healthy, collaborative, mutually trusting clinician-patient relationships. This type of advice was most often accepted when clinicians listened well, knew their patients' capabilities and interests, and pushed gently with a pace that was comfortable for their patients. These findings are consistent with research showing improved outcomes resulting from healthy clinician-patient working alliances [31], [32] and collaborative approaches to care [33]. By knowing their patients well, clinicians will be well aware of social stigma concerns facing consumers as they approach and evaluate new endeavors. Furthermore, our data suggest that the knowledge gained by clinicians when they have forged strong relationships with patients provides a firm grounding for approaching the delicate balance of providing helpful levels of support and encouragement without pushing so hard that it causes difficulties.

We also found that study participants expected clinicians to adopt complex, well-informed, and multidimensional perspectives on their problems—the kind of perspectives that are more consistent with long- rather than short-term clinician-patient relationships, and that are consistent with significant engagement with the patient and knowledge about

the patient's history, lifestyle, capabilities and preferences. These findings suggest that to promote recovery, clinical relationships need to encompass far more than simply medication management.

Unexpectedly, our data did not reveal instances of damaging mental health outcomes among patients who had been pushed too hard by clinicians. When participants reported feeling pushed too much, those instances resulted in damaged clinician-patient relationships, sometimes causing consumers to leave their clinicians, rather than symptom exacerbations. Although leaving a clinician reduces continuity of care, and is thus a negative clinical result, it differs significantly from the direct negative effects on symptom levels that clinicians may fear. Finally, although we found a few examples where participants felt inappropriately held back by their clinicians, this was uncommon in this sample.

Interestingly, social stigma was only discussed by one participant in the sample. We hypothesized that social stigma would affect risk-related decision making, but stigma did not emerge as a theme in our data on this topic. We did not directly address social stigma in the interviewing process, however, and it is possible that more direct exploration of the topic would produce additional information. The single example of stigma we found underscores the potential importance of addressing stigma-related concerns in clinical settings.

We did not ask about stigma directly, thus it is difficult to know what would have been said had different questions been implemented during interviews. However, our findings suggest that for patients who are receiving good care and who have good self care, social stigma is not a critical component of the risk taking process in the context of the questions asked. This possibility is not something we can confirm in our study, but

an idea that may drive future work. These results underscore the importance of future research to directly address this aspect of risk taking, and to better understand the role that social stigma plays in the decision making process.

Limitations

Participants in our sample, though actively coping with serious mental illnesses, appeared to be more recovered and have better functioning, on average, than other samples—they had higher educational achievement as well as greater employment and marriage rates. Their ability to engage with our interviewers and their clinicians is likely to be affected by their recovery status, so our findings may have been influenced by this difference; it is also true that participants' recovery may have been facilitated by the good clinical relationships reported here, which can lead to better functioning and clinical engagement.

In addition, the use of the prompts 'push' and 'pushed too hard' may have lead to various interpretations by the participants when asked about their experiences with this concept in the interview. Without further clarification and discussion with participants about their exact interpretation of those words, it may be difficult to draw precise conclusions about the way that participants conceptualized the relationships between pushing, risk taking and recovery. For example, participants may have assumed that interviewers were interested in times when clinicians were forceful in implementing their own agenda for the participant's recovery plan, while ignoring the consumer's needs or concerns. Or, perhaps consumers discussed pushing in contexts where clinicians failed to assess barriers to their patients' proposed goals. Lastly, participants may have focused on examples where clinicians proposed ideas that the clinician and consumer agreed could

be frightening to the consumer. It is possible that participant's interpretation could reflect any of these three situations, and thus we cannot be certain about how precisely consumers conceptualized pushing and risk taking without additional interviews.

Conclusions and Implications

Social Stigma Implications

Social stigma is prevalent for disabled persons and individuals with severe mental illness [15, 19]. Thus, it is important that public policy makers, politicians, clinicians and citizens are familiar with the impact of social stigma on the lives of persons with chronic or severe illness. While discussions of social stigma were not common in our sample, it is possible that other populations could yield different results. Future research in this field should explore the specific relationship between taking on new activities, roles and responsibilities, and social stigma by asking targeted questions during interviews. With this methodology, future studies will be able to explore risk taking in the context of social stigma.

Mental Health Recovery Implications

Strong, collaborative relationships provide a healthy framework for discussions between patients and clinicians about taking on new activities, roles, and responsibilities, and increase the likelihood that new activities and opportunities can be planned and carried out in ways that promote, rather than endanger, recovery. These results stress the importance of training new professionals in how to establish collaborative treatment relationships and in how to support healthy risk-taking among individuals recovering from serious mental illnesses.

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