# New Endeavors, Risk-taking and Personal Growth in the Recovery Process: STARS Study Findings

**Andrew T. Young**,
Center for Health Research, Kaiser Permanente Northwest

**Carla A. Green, PhD, MPH**, and
Center for Health Research, Kaiser Permanente Northwest

**Sue E. Estroff**
University of North Carolina, School of Medicine

## Abstract

**Objective**—To explore consumer perspectives on the role of personal growth-related risk-taking in the recovery process, to examine consumer perspectives on clinicians' roles in their decisions to take on new activities and opportunities, and to explore clinical approaches that patients identify as most helpful in making significant changes.

**Methods**—177 health plan members (93 women, 85 men), ranging in age from 16 to 84 years, participated in a mixed-methods exploratory study of recovery among individuals with serious mental illness (schizophrenia, schizoaffective disorder, bipolar disorder, affective psychosis). Participants completed four in-depth semi-structured interviews over 24 months; interviews were transcribed verbatim and coded for content by study staff. Data were analyzed using a modified grounded theory approach.

**Results**—The most helpful discussions about new endeavors 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. Knowledge gained by clinicians in the context of good relationships with patients provided a firm grounding for approaching the delicate balance of providing helpful levels of support and encouragement without pushing consumers so hard that it caused difficulties.

**Conclusions**—Enduring, strong, collaborative relationships provide a healthy framework for discussions between patients and clinicians about taking on new activities, roles or responsibilities, and increase the likelihood that new activities and opportunities will be planned and carried out in ways that promote, rather than endanger, recovery.

Historically, consensus regarding the long-term prognosis for individuals with serious mental illnesses has been dire at worst and guardedly pessimistic at best (1,2). Recent research challenges this view, and documents that recovery, albeit defined in different ways, is common (1,3–7). These definitions encompass social recovery (economic and residential independence and low social disruption) (7), complete recovery (absence of psychotic symptoms and return to pre-illness functioning) (7), and achieving well-being and a satisfying life (8). Based on accumulating evidence, and demands from consumer advocates, mental health systems are attempting to adopt recovery-based orientations and practices (9–11). In concert with these changes, mental health consumers have argued that personal

growth, including taking on new activities and responsibilities, promotes recovery and contributes to the development of full lives (12,13), even when such opportunities may increase the risk of stress-related relapse (14). In this context, resources are increasingly available to guide consumers as they evaluate risks, develop personal goals, and create plans to achieve those goals. The consumer-produced self-help book *Pathways to Recovery,* for example, offers such guidance while underscoring the value of new pursuits and the dignity of risk: "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. 43) (13).

Consumers have also argued that well-intentioned clinicians may hold them back by focusing primarily on relapse prevention, placing "people in a protective bubble, shielding them from their community and ultimately from their future" (p. 83) (15). These conservative, risk-averse approaches likely result from an array of sources, including (a) professional stigma among clinicians who see individuals with mental health problems as lacking the capacity to take on either daily or life-changing activities (16), and (b) research showing that stressors and negative life events can exacerbate symptoms and cause relapse (17–19). New findings, however, demonstrate that taking on normative roles and activities can facilitate recovery, defined as development of a meaningful life in the community (20). When consumers are employed, symptoms improve (21); when they hold competitive jobs, self-esteem increases (21) and they participate actively in the social life of the workplace, expanding and deepening normalizing relationships (22). Furthermore, those with strong, supportive social networks recover more quickly from symptom exacerbations (23), while those with better social relationships have a richer quality of life and improved functioning (24). As with those without a mental health diagnosis, parenting, too, can play an important role in the lives of individuals with mental illness, even when it proves difficult (25).

Despite these potential benefits, many such endeavors carry the risk of increased stress, challenging clinicians and consumers to find a reasonable balance between pursuing opportunities that could enhance recovery, while minimizing risk of relapse or setbacks. Little is known about how, why, or when clinicians and consumers approach these deliberations, or about the clinical practices consumers find most helpful in this process.

Using qualitative data from a longitudinal study of recovery, we explored consumers' experiences with clinicians as they considered taking on new activities, roles or responsibilities, whether or not they had felt pushed too hard or held back by clinicians, and their impressions of what was most and least helpful.

## Methods

### Setting

The study was conducted within Kaiser Permanente Northwest (KPNW), a non-profit prepaid, integrated group model health plan serving about 480,000 members in Washington and Oregon. KPNW provides comprehensive inpatient and outpatient medical, mental health, and addiction treatment services to its members.

**Study Background—**STARS (The Study of Transitions and Recovery Strategies) is a mixed-methods, longitudinal, exploratory study of recovery among individuals diagnosed with schizophrenia, schizoaffective disorder, affective psychosis or bipolar disorder. Funded by the National Institute of Mental Health, it was conducted between 2003 and 2007. Participants completed in-depth interviews at four points—two at baseline, one at 12 months, and one at 24 months. Questionnaires were completed at three points—baseline, 12 months, and 24 months. Interviews explored mental health history, personal experiences

affecting mental health and recovery, and experiences with symptoms and mental health care.

**Participant Identification, Inclusion and Exclusion Criteria, and Recruitment—** Study participants had inclusion diagnoses for at least 12 months, at least 12 months of health plan membership prior to enrollment, were age 16 or older, and planned to stay in the area for at least 12 months. We excluded those whose mental health clinicians felt they were unable to participate and those with diagnoses of dementia, mental retardation, or organic brain syndrome.

We extracted a pool of potential participants ($n = 1827$) and sent small batches of recruitment letters, beginning in November 2003, to 418 individuals (when the recruitment goal was reached). Clinicians screened out 16% of the letters we sent to them, based on their assessment that these individuals were not able to participate at that time. To balance the sample, letters were stratified according to gender and diagnostic class (affective vs. schizophrenia spectrum), and were signed by the principal investigator and the member's mental health clinician (or primary care provider when we found no mental health clinician of record). We telephoned those who did not respond. Of 418 letters sent, we contacted 350 individuals and received 127 refusals; 22 individuals were ineligible. Thus, we originally enrolled 46% of those eligible. Of these, 5 were later excluded—4 because diagnoses were in error and 1 who did not complete both baseline interviews.

**Participants—**Participants were 177 KPNW members with serious mental illness. See Table 1 for demographic and descriptive information. The enrolled sample distributions for age and sex, within diagnosis, did not differ from the study-eligible health plan population. At the 24-month follow-up, 167 of 177 participants completed interviews, 3 participants were deceased, and 7 were lost to follow-up—a 96% follow-up rate (among living participants). The study was approved and monitored by KPNW's Institutional Review Board. After complete description of the study to potential participants, all provided written informed consent prior to study enrollment.

**Interview Procedures and Qualitative Data Analysis—**Trained, experienced masters- and doctoral-level interviewers completed semi-structured interviews and followed individual participants throughout the study. Most results are based on analyses of 2 questions written for the final interview following examination of earlier interview data: (a) "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?" Prompt: "What would you have preferred s/he/ they had done?", and (b) "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?" Of 167 participants at the final interview, 157 provided codeable answers to these questions. In addition, relevant data from the prior interviews was also included in our modified grounded theory-based analytic process.

Interviews were audiotaped and transcribed, verbatim. Investigators and interviewers reviewed transcripts weekly throughout data collection to ensure transcription accuracy, appropriate interviewing techniques, and to develop and test a global, content-descriptive coding scheme. Inconsistencies were discussed and resolved by the coding team throughout the development and coding processes, and definitions revised to clarify code application when needed. Interviews were individually coded by members of the coding team using Atlas.ti (26) software. To ensure consistency across all coders, a 10% random selection of

interviews were check-coded using a subset of key codes. Two additional coders reviewed inconsistencies between primary coders and check coders; primary coders were judged accurate 89% of the time for the interviews that provided the majority of data used here (24 month follow-up).

A secondary coding scheme was inductively developed to capture data that addressed the topics explored in this paper. To develop the secondary codes, we reviewed all text provided in response to the pushing" questions as well as text that addressed these topics in other parts of the interviews. During this inductive process, we made notes describing the data we found and created code names to describe commonalities across interviews. This process produced 23 pushing/risk-taking-specific subcodes that were then applied to all relevant text. We then created reports of all text associated with each code, and extracted common themes from within these codes. In the sections that follow, we describe the most common and significant themes derived from the interviews. We also searched for disconfirming cases throughout our analytic process, and report such instances with the main themes when applicable.

Finally, one key code from the analyses reported here ("clinicians need to 'know' client") was check coded as part of the overall check-coding process; the primary coder was judged correct 85% of the time for this code; 67 passages were reviewed for this code.

## Results

### General Discussions about Risk-Taking and Recovery

First we, Young and Green, examined general discussions about the role of risk-taking in the recovery process, then searched for descriptions of being pushed too hard or of being held back unnecessarily by clinicians, and for any consequences, positive or negative, of these experiences. We then analyzed text within each code to identify emergent themes.

Among unprompted discussions addressing these topics, 8 participants mentioned the importance of taking on new activities to facilitate recovery and 13 indicated that clinicians should play a role in helping, supporting, and sometimes pushing patients to do so. For example:

> …if they're…walking, and talking, and not suicidal…[clinicians should] get them doing something volunteer…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…but I think it's good 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.

We also looked for participants' experiences of clinicians strongly discouraging them from taking risks, finding such instances among only 3 participants. The impact of these experiences, however, could be profound, as illustrated by the report of a young man who chose *not* to take this 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…she said you have bipolar, you need to accept that you cannot do these things. I was like what?…"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…[working, 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…she never did tell me things was going to be okay, that I had a light at the end of the tunnel…

We also searched for cases where people were pushed too hard or too quickly by clinicians. Eleven participants reported having had these kinds of experiences: 3 related to taking on new activities or responsibilities, 3 related to medication changes, while the others were varied. In cases where clinicians pushed too hard, participants most often reported being frustrated with the clinician-patient relationship (some terminated their relationship when the problem was significant). None reported the kinds of increases in symptoms or hospitalizations that clinicians may fear. The following examples illustrate these discussions:

> …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…she was like you need to do this, this, this and this, like 10 different things, and if you don't…I can't be your therapist…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…

> …when I was pregnant with my son, I felt like they were pushing me too much… At that time I had no energy…and I had to get up at 5…to make the bus to go to this…clerical school …and I swear I couldn't make it there hardly ever. I was so tired…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…I was so…worn out…

### Themes Related to the Roles Clinicians Play in Decisions to Take Risks

Next 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 taking on new activities and responsibilities. Most participants described collaborative processes that they found supportive and helpful. The following common themes emerged:

**Theme 1: Clinicians Need to Know Their Patients—**In one of the most common themes we found, participants articulated that clinicians should know their patients well before counseling them regarding potentially stressful endeavors. Participants expressed this view in various ways; the following is characteristic of their advice to clinicians about counseling patients:

> …try to learn the person first…learn their ways, their reactions…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…

**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 particularly true when relationships were collaborative.

> …know the person you're with, the patient or the doctor, either one…you have to establish a good relationship with them…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…The patient has to trust the doctor…

Additionally, participants reported that better communication resulted from feeling comfortable with providers.

> I've always felt…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.

Such trusting relationships were forged through careful listening by clinicians. Participants reported that clinicians who listened well developed a better sense of each client's unique situation, and thus offered more appropriate advice. Furthermore, some noted that good listening contributed to having a personal and collaborative partnership that made them feel more comfortable disclosing sensitive information that was needed to make informed decisions.

> …clinicians need to be…like your pastor…they need to listen …take them over their history, take some time…you're not just a dollar sign walking in and out …

Good working relationships between patients and providers also appeared to facilitate collaborative, in-depth discussions about risk-taking. For example:

> …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…We…connect and decide which way would be best to do this problem. …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…

### Theme 3: Clinical Guidance Aligned with Patient Capabilities and Interests—

Within these collaborative, trusting relationships, clinicians gained knowledge about patient capabilities and desires that participants felt was prerequisite for providing reliable guidance. Assistance perceived as helpful struck a healthy balance between personal growth and risk. For example:

> The doctor has to know just what your capabilities are, not what you think they are, he has to know…without discouraging you, but he has to caution…and then lead you into a life. That's asking a lot from a doctor, but do not push too hard or too little…

Moreover, participants assessed clinicians as more skilled when the suggestions they made were consistent with participants' own abilities and interests.

> [Clinician ever pushed you too much or not enough?] Never…because they're really good listeners, they're really intuitive people…very sensitive to where people are…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, even while recognizing that they *were* being encouraged by their clinician.

> 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 as a suggestion or question, participants noted that it did not feel intrusive or unwanted, and found they felt more comfortable taking the advice provided:

> They [clinicians] just put it in the way of a suggestion…[It didn't feel like a push then?] Yeah.

Finally, we found several examples where clinicians and participants worked out a means for managing potentially stressful activities. These careful, well-paced negotiations appeared to facilitate recovery. For example:

> I've never been pushed too hard…[DOCTOR] will usually, in a very subtle and kind way, explain to me when I'm trying to do too much, like…he's real influential without telling me what to do, he gets the point across and I understand.…if anything he puts the break on just a little bit, which is good, so I don't overdo it.

## Discussion

Our analyses suggest that the most helpful discussions about new activities, roles or responsibilities occur in the context of well-recognized elements of the therapeutic alliance —empathic, collaborative, mutually trusting clinician-patient relationships. Advice was most often accepted when clinicians listened well, knew their patients' capabilities and interests, and pushed gently at a pace that consumers perceived as comfortable. These findings are consistent with research showing improved outcomes resulting from healthy clinician-patient working relationships (27,28) and collaborative approaches to care (29). Furthermore, our analyses suggest that the knowledge gained by clinicians when they have forged strong relationships with patients, over time, allows a firm grounding for approaching the tricky juncture between providing helpful levels of support and encouragement without pushing so hard that difficulties arise. The need for this type of knowledge is also consistent with recent approaches suggesting that to increase community integration and foster recovery, we must work to help people with mental health problems identify and enhance their individual capacities and capabilities (30,31).

We also found that participants expected clinicians to adopt complex, well-informed, multidimensional perspectives—those consistent with enduring-rather than short-term clinician-patient relationships, significant engagement in the clinician-patient relationship, and knowledge about the patient's history, lifestyle, capabilities and preferences. We also found support for the notion that personal narratives, told and developed in clinical encounters (32,33), can provide important information that can aid clinicians and clients as they work together to make decisions about new or ongoing opportunities. In sum, our findings suggest that to promote the meaningful activities that foster recovery, clinical relationships need to encompass far more than medication management.

Our data did *not* reveal instances of undue stress or backsliding among patients who had been pushed by clinicians more than desired. Instances in which participants reported feeling pushed too much resulted in damaged clinician-patient relationships, sometimes causing consumers to leave their clinicians, but not symptom exacerbations. Although terminating with a clinician reduces continuity of care and may be 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.

### Limitations

Participants in our sample, although actively coping with serious mental illnesses, also appear to be further along in the recovery process, and have better functioning on average, than other samples—they had higher educational achievement as well as greater employment and marriage rates. Participants' ability to engage with their clinicians, and our interviewers, is likely to have been 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, leading to better functioning and clinical engagement. Similarly, although our inductive analytic process should produce an accurate representation of participants' ideas, our sample may have different perceptions of these processes than would individuals who were not as far along in the recovery process.

In addition, the terms 'push' or 'pushed too hard' in interview questions may have been interpreted differentially by participants. For example, it is possible that participants believed we were interested only in experiences with clinicians who were overly forceful in promoting their own clinical agenda. Although we cannot be sure about these interpretations, interviewers were encouraged to explain the questions and prompt to encourage answers that were more broadly inclusive. Responses suggest that most participants did reply to the questions as they were intended.

## Conclusions and Implications

Enduring, collaborative relationships provide a constructive framework for discussions between patients and clinicians about taking on new activities, roles, and responsibilities, and increase the likelihood that new endeavors can be planned and carried out in ways that promote, rather than set back, recovery. These results stress the importance of training new professionals in what are basic therapeutic skills: how to establish collaborative treatment relationships and how to support healthy risk-taking among individuals recovering from serious mental illnesses. Our findings also show the value of systems of care that help sustain long-term relationships between clinicians and consumers. Repairing current systems of care so that they encourage and sustain these kinds of relationships may deserve as much attention as the development of new treatment modalities.

## Acknowledgments

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**Table 1**

Baseline demographic characteristics.

| | *n* | Percent |
|---|---|---|
| Gender | | |
| Female | 177 | 52% |
| Male | | 48 |
| Ethnicity (totals to >100% because participants marked all that applied) | | |
| White | 177 | 94% |
| Black or African American | | 6 |
| American Indian/Alaska Native | | 3 |
| Asian or Pacific Islander | | 2 |
| Hispanic (overlaps all groups) | 176 | 1 |
| Percent reporting mixed-racial heritage (does not include Hispanic ethnicity) | 177 | 5 |
| Education | | |
| Less than high school graduate | 173 | 8% |
| High school graduate | | 19 |
| Some college or technical school | | 39 |
| College graduate | | 34 |
| Diagnosis | | |
| Schizophrenia or schizoaffective disorder | 177 | 42% |
| Bipolar disorder | | 48 |
| Affective psychosis | | 10 |
| Marital status | | |
| Never married | 173 | 22% |
| Widowed | | 8 |
| Divorced | | 17 |
| Separated | | 3 |
| Married | | 45 |
| Living with partner | | 9 |
| Prior year household income | | |
| <$10,000 | 166 | 10% |
| $10–20,000 | | 20 |
| $20–30,000 | | 16 |
| $30–40,000 | | 14 |
| $40–50,000 | | 10 |
| $50–60,000 | | 9 |
| $60–80,000 | | 5 |
| $80,000+ | | 5 |
| Source of income (all that applied, total > 100%) | | |
| Paid employment | 173 | 48% |
| Disability | | 25 |

|  | *n* | **Percent** |
|---|---|---|
| Spouse, partner, family |  | 28 |
| Retirement, pension, investments, savings |  | 26 |
| General assistance, Medicaid, TANF |  | 2 |
| Unemployment, alimony, child support |  | 2 |
| Other |  | 13 |
| Primary activity |  |  |
| Paid employment | 173 | 40% |
| Volunteer/unpaid work |  | 8 |
| School |  | 5 |
| Treatment/rehabilitation program |  | 2 |
| Craft/leisure/hobbies |  | 15 |
| No structured activity |  | 15 |
| Homemaking |  | 9 |
| Other |  | 7 |
| Had comorbid mental health diagnoses in 12 months prior to study recruitment | 177 | 41% |
| Had comorbid substance abuse diagnoses in 12 months prior to study | 177 | 27% |
| Taking psychiatric medications | 173 | 91% |
| Among those taking medications |  |  |
| Always take as prescribed | 158 | 85% |
| Quite often take as prescribed |  | 12% |
| Sometimes, very infrequently, or never take as prescribed |  | 3% |
| Medication controls symptoms? |  |  |
| Not at all | 158 | 1% |
| Some |  | 8 |
| A fair amount |  | 15 |
| Quite a bit |  | 59 |
| Eliminates all symptoms |  | 17 |
| Age (range = 16–84 years) | 177 |  |
| Mean ± sd | 48.8 ± 14.8 |  |
| Colorado Symptoms Inventory Score[1] | 173 |  |
| Mean ± sd | 16.63 ± 10.7 |  |
| SF-12 Mental Component Summary Score[2] | 171 |  |
| Mean ± sd | 40.80 ± 12.7 |  |

[1] Possible scores range from 0 to 56 with higher scores indicating more psychiatric symptoms. Means in a homeless population were 20.8 at baseline and 17.0 12 months post-baseline (34).

[2] Possible scores range from 0 to 100 with higher scores indicating better mental health; The U.S. norm for healthy individuals = 52.3 ± 7.9.