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Risk is not a four letter word: social integration and developmental growth

Barbara Dickey, PhD^{1,2} and Norma C. Ware, PhD^{1,3}

¹Department of Psychiatry, Harvard Medical School, Boston, MA

²Cambridge Health Alliance, Cambridge, MA, USA

³Department of Global Health and Social Medicine, Harvard Medical School, Boston, MA

Abstract

Individuals facing recovery from serious mental illness confront social challenges stemming from discrimination and the structure of our economic safety net. Although research has contributed to significant advances for individuals with the most serious mental illness, questions about the social nature of their world remain largely unasked. How can persons with mental illness move from community isolation to community integration? Building on earlier research, this paper uses qualitative data to address developmental challenges as impediments to community integration for young people with serious mental illness. Sixty transcripts from unstructured, in-depth interviews with psychiatrically disabled persons moving toward social integration were content analyzed to demonstrate possibilities for developmental growth in the context of living-learning communities. Data are organized and presented in three conceptual categories drawn from developmental theory: (1) risk-taking; (2) reciprocal relationships; and (3) self-determination. Based on the results, we suggest that attention to the challenges of developmental growth should complement current evidence-based and best program practices for young adults with mental illness.

Keywords

serious mental illness; social integration

INTRODUCTION

Developmental challenges facing young adults with mental illness

Young adults whose lives have been interrupted by a psychiatric hospitalization face developmental challenges as part of recovery. Erik Erikson, in his classic study of youth in crisis, made the point that adolescent ego development “demands and permits playful, if daring, experimentation” and “leaning over precipices” for vital adult strength (Erikson, 1968, p. 164). Through his work and the work of those who followed him, developmental psychology has offered the well-known stage theory of social and emotional growth. Without completing the tasks of one stage, it is difficult to successfully engage in the work

of the next (Erikson, 1950, 1968; Piaget, 1953). Although developmental theorists have elaborated different aspects of each stage, there is general agreement on what constitutes successful passage from adolescence to adulthood: the emergence of an individual identity as the precursor to successful educational and occupational stages that follow. With identity development comes the imperative to test limits, to try out new role-related behaviors and to establish autonomy and competence within a safe environment. For young adults who have mastered this stage, the next challenge is to successfully develop reciprocal relationships that accompany satisfying productive work and social integration. However, when psychotic illness interrupts adolescent and young adult development, opportunities for limit-testing and “trial runs” are all too often lost (Hopper, 2012).

Consumers’ vision of mental health system reform for recovery and social integration

Consumers’ vision of a better mental health system is focused less on *what* services are provided and more on *how* they are provided (Corrigan & Phelan, 2004; Deegan, 1997; Fisher, 2011; Mead & Copeland, 2000). Advocates have insisted that services must be more than reducing symptoms and improving daily functioning (Hogan, 2003). These services must facilitate gains in personal empowerment and a sense of agency (Corrigan & Phelan, 2004; Fisher, 1994; Deegan, 1997). Consistent with this vision is a consumer-centered study that defined social integration as a process through which individuals develop and exercise capacities for interpersonal connectedness and citizenship (Ware, et al., 2007). This process may be disrupted in young adults with mental illness. Interrupted developmental growth hinders recovery and isolates individuals at the very time their emotional and functional improvement rests on interactions with others. It is this conundrum of pulling away from personal relationships when they matter most that Ware et al. (2007) articulate: why many individuals with psychiatric disabilities may be said to be *in* the community, but not *of* it.

Mental health policy reform

A vision of system reform among clinicians and policy-makers is less focused and ranges across a broad landscape of professional disciplines, disorders treated, and philosophical belief systems. The underlying imperative is meeting the functional needs of the persons with the most serious mental illness, and providing support for living in the community. To improve quality of care, research on clinical effectiveness has identified best practices to meet evident psychosocial and rehabilitative needs. Best practices have been developed pragmatically, *in situ*, to address health and human service needs that hinder recovery. Reform efforts include active rehabilitation programs known to have good outcomes. They emphasize support for work and education (Becker et al., 2011), promote illness management and healthy living (Mueser et al., 2002; Tandon, 2011; Tosh, Clifton, & Bachner, 2011), ensure a safe living environment (O’Hara, 2007) and encourage active participation in the community in which one lives (Ware et al., 2007; Ware, et al. 2008; Bond, et al., 2004).

Living-learning communities

Earlier research by Dickey and Ware (2008) suggested that therapeutic communities might offer one path to community integration. Living in community is an age-old form of habitation and collective action. Today, intentional communities are less common and there

is an assumption that community as citizenship and participation in service of common, rather than individual, good is idealistic. Nevertheless, informal communities can be found everywhere. Recent scholarship describes the benefits of community groupings in social capital terms, i.e. mutual assistance, norms of reciprocity, trustworthiness and social networks. These communities are animated by belief in the power of personal relationships (Gladwell, 2008; Bruhn & Wolf, 1979, 1993; Putnam & Feldstein, 2003).

For individuals with mental illness, the notion of living in one's community means not just living outside an institution, it means finding a community that encourages being in relationship with one another (Deegan, 1997). It is thought that such communities, both intentional and informal, provide the immediate learning experiences that lead to individual growth and change. Through a 'living-learning' culture, accountability is strengthened and becomes a therapeutic agent (Rapaport, 1960).

Conceptual framework

While best mental health practices have good outcomes in real world settings, they do not directly address interrupted developmental growth for young adults with serious mental illness. Using qualitative data, this paper will examine aspects of living-learning environments that offer opportunities and challenges for growth and a smoother passage to adulthood, pointing the way to greater social integration. Guided by the work of developmental psychologists ((Erikson, 1950, 1968; Piaget, 1953), three conceptual building blocks characteristic of developmental growth structure our investigation: (1) risk-taking, (2) reciprocal relationships and (3) self-determination. Our focus is the positive aspects of living, working and loving in one's own community (Ware et al, 2008; Deegan, 1997).

Risk-taking—Attorney Steven Schwartz, who brought the Northampton State Hospital class action suit to the State of Massachusetts (Brewster Consent Decree, 1978) argued for closing the hospital to afford patients the “dignity of risk,” i.e., the opportunity to take personal chances that facilitate long-term growth. For young adults, these risks are not just desirable, they are a developmental imperative. Creating one's own identity, learning who we are and how we fit into our world, comes not from solitary introspection or from how our parents and peers imagine us to be. Instead, experiences with life's vicissitudes reveal strengths and weaknesses, building self-knowledge that is intrinsic to developmental growth from adolescence to adulthood. It is in meeting challenging opportunities that a young adult discovers unknown or unacknowledged strengths.

2. Reciprocal relationships—Reciprocal relationships are those with a mutual exchange that benefits both parties in equal measure. Relationships with a power differential can have lasting importance in one's life (e.g., parents and their children). However, the self-limiting nature of one-way relationships between two adults by its very nature stops short of plumbing the depths of our social beings. A reciprocal relationship must extend beyond mutual enjoyment and respect. It must engender trust, making the deep connections necessary for accepting each person's vulnerabilities and for holding each other accountable.

3. Self-determination—A life well lived is one characterized by making choices about lifestyle, voicing preferences about means of reaching one's goals, and sharing decision-making in clinical, legal and financial situations where expertise is offered but final decisions remain one's own (Deegan & Drake 2006). Feeling competent to make those decisions comes with what Erikson (1950) calls "ego identity" – assured self-identity, the state we all aspire to as adults. The evolution of one's sense of one's self, to feel comfortable in one's own skin, comes from navigating the complexities of our social world, not just from achieving certain rehabilitation goals. Self-determination is not just saying yes or no to choices offered by others – it grows out of motivation driven by interwoven layers of risk-taking, of trial and error, of consequences good and bad that come from earlier decisions. It is not just being able to make decisions about how to spend today, but also about considering trade-offs between today's gratification and longer-term personal goals.

METHODS

Sample and data collection

This paper is the fourth in a series of articles based on a qualitative study of social integration for persons with psychiatric disabilities (Ware et al., 2007, 2008; Dickey & Ware, 2008). Study participants were adults who had met Social Security Administration criteria for psychiatric disability, but who, in the judgment of the investigators at the time of the study, had taken significant steps toward greater social integration (Ware et al, 2007).

Data collection was informed by a "capabilities" conceptual approach to human development (Sen, 1985; Nussbaum, 2000) and included individual, in-depth interviews with study participants. Interviews were unstructured, exploring experiences of social integration particular to each interviewee. Interviews were conducted by study investigators in private settings and audio-recorded with permission. Typically, interviews lasted about an hour. Following each interview, an exact transcript was produced. Study data were collected in public and private mental health services settings in four northeastern states of the U.S. and in Quebec, Canada. Sites were selected which had a self-described orientation toward recovery from mental illness and social integration for service users. Participating sites included a consumer-run drop-in center focused on relationship development, a scattered-site housing program, a psychiatric rehabilitation program, a center for psychoanalytic treatment of psychosis, a residential and employment program aimed at "re-defining community," and a therapeutic community. Additional information on data collection for this study is reported elsewhere (Ware et al., 2007, 2008)

Analysis

Strategies for analyzing qualitative data are not simply pulled "off the shelf" but rather custom built to fit each investigation (Creswell, 1998; Miles & Huberman, 1994). In this case the primary author used a directed content analytic approach (Hsieh & Shannon, 2005) to identify and extract from the sixty transcripts text corresponding to the organizing concepts of the analysis: (1) risk-taking; (2) reciprocal relationships, and (3) self-determination. Each concept is elaborated based on the interview data illustrated through quotes from interviewees representing how they experience each concept. The study was

approved by the Committee on Human Studies at the Harvard Medical School and by the Institutional Review Board at the Nathan S. Kline Institute for Psychiatric Research. Informed consent was obtained from all study participants with an approved consent form.

RESULTS

Risk-taking

Risk-taking as part of emerging adulthood does not have to be life threatening or even physically dangerous. For our interviewees, it meant testing new behaviors and trying on new roles that, for the individual involved, represented personal risks. For some, simply attending an Alcoholics Anonymous meeting felt like a very big risk. Traditional emphases on treatment and achieving and maintaining “stability” leave little room for taking risks. When getting up every day feels like a challenge, taking on something new is more than just a hurdle to overcome. New activities present a risk with the possibility of failure, albeit with the possibility of learning from that failure. But succeeding is its own reward. In the following excerpt, an interviewee describes what for him felt like a “risk” in “coming clean” at an Alcoholics Anonymous meeting:

“If you don’t come clean and tell all your weaknesses, your faults, things that scare you, worry you, unnerve you, you will never be able to get through any situation if those things can be used against you. You have to come clean.”

[male, 2003]

Another interviewee describes taking a risk by “coming clean:”

(invited to go on a church trip, he said to the leader) “I am going to tell you a little something about me. I’m a little compulsive and it may take me a while to take showers in the morning, and I’m afraid I won’t be here on time.” She said “We will work with you – don’t worry about it. Don’t let that keep you from going on the trip”. I said “are you sure about that?” Then she said yes, I like you because you are enthusiastic and you want to go.”

[male, 2005]

This young man, now self supporting and living independently, took on a big challenge when the opportunity arose – driving a tractor:

“It wasn’t [as if] I had grown up on a farm, I’d run .. a tractor like once or twice, to be honest with you. But I had enough experience to be able to take a challenge, you know, and there was a risk. I could’ve rolled the tractor, but I think risk is . . . not a four-letter word. It’s a necessary element to recovery.”

[male, 2004]

Reciprocal relationships

Interviewees created reciprocal relationships in informal communities. For example, one interviewee and her husband lived in a church apartment, participated in church activities and exchanged hours of work at the church for rent payments. Interviewees often mentioned how joining Alcoholics Anonymous (AA) or a church helped them to reduce their isolation,

and in turn, how this led to seeing the importance of giving to others as a way of helping themselves. The possibility of stigma makes developing relationships difficult. However, acceptance by others can pave the way for friendship, as we see below:

“People care about you [at church]. They ask how you are doing. Everyone’s got a smile. No one’s grouchy. When we talk about how our week went, it shows everyone’s got problems. No one criticizes you or judges you. That’s what I like about it. There are no judgments.”

[male, 2003]

“ . . . people greeted me with smiles, were glad you’re here [AA], sit down, would you like coffee. They welcomed me, they accepted me unconditionally.”

[Female, 2003]

Participating in everyday activities with others can build solidarity and social relationships, as well a sense of “being like other people,” as seen in the following excerpt:

“When you get out there and start chopping wood and making maple syrup with Jon and Jeff [staff] its like hanging out with the guys, you know, you’re working, you’re hanging out, you’re having a good time, you’re just like everyone else.”

[male, 2004]

There is no way to know from these comments if deep and trusting friendships developed although the potential is there. One church goer described a retreat some years before that resulted in very close friendships that still existed. Another interviewee seemed to be well along the path of reciprocity.

“ I don’t feel a need to tell my friends at church that I’m mentally ill because when I get to know them better and tell them, they don’t seem to even care because it was like they already knew me, it was sort of beside the point.”

[female, 2003]

“Sometimes you wanna say, well I suffered more than that person, but it goes away after awhile, all that washes away, because eventually you get down to the person, and you say well what, what can I do to help that person, or how does that person help me”

[female, 2004]

Self-determination

Small steps over the course of recovery add slowly to each individual’s sense of agency. Agency can be taking control of one’s life through healthier living: better diet, exercise, knowing when to rest and when to avoid stressful situations. Paid employment –another step toward self-determination – was often a goal that could only be partially realized for this group of interviewees, but volunteer activities were welcomed. In Alcoholics Anonymous (AA), volunteering to be a sponsor to someone else struggling with alcoholism was for some a big step toward sobriety and the sense of personal control it brings. These examples illustrate discoveries of the importance of taking self-determination in “small steps”.

“You’ve got AA that says “one day at a time’. When a challenge would come, how am I going to get through this? And then I realized, you just take it a chunk at a time.”

[male, 2003]

“I think I started gaining confidence again, and I think as my confidence built back up, I started creatively thinking of my situation, and what things could I do now to better that situation. . . . I was overweight. I realized, you know, I gotta get physically back in shape. I need to lose some weight.”

[male, 2004]

Sometimes the small step is just the realization that more steps lie ahead:

“I think what it meant to take control of my life was to realize that I’ve gotta work. I don’t think before I really had a work ethic. I could work hard when I needed to, but I didn’t realize that living requires more than just punching the clock in for a few hours.”

[male, 2004]

DISCUSSION

This paper presents qualitative data depicting developmental experiences of risk-taking, reciprocal relationships, and self-determination for persons with psychiatric disabilities working toward social integration. The data serve to simplify and ground potentially complex theoretical ideas. Such grounding makes it possible to think deeply about program policy without having a complete understanding of the theory that drives the relationship between risk taking, reciprocal relationships and self-determination. The three concepts presented here lay the descriptive foundation for further systematic investigation. The findings point to three challenges facing investigators who may want to pursue this line of inquiry: (a) the limits on risk tolerance, (b) the difficulties of measuring therapeutic outcomes linked to complex concepts and c) finding informal communities that welcome those with mental illness.

Limits on risk tolerance

Mental illness sometimes clouds judgment and caregivers or professionals charged with the safety of those in their care typically lean in the direction of protection. Furthermore, the goal of insurance companies and the risk-adverse public sector is to limit exposure, even when the risk is low. The consequence, all too often, of reducing risk is the functional equivalent of living life within a policy and procedure manual. Imaginative programming, innovative new directions, exciting opportunities, and joyous celebrations of success too often go by the board if there is an increased exposure to liability. More importantly, staff are not able to encourage the type of risks other young adults take for granted, undermining goals of independence and sense of agency. Faced with this dilemma, it is not enough to argue for public programs to strike a balance between liability exposure and the ordinary risks of everyday life lived to its fullest. Administrators and clinicians need to be active in pursuing partnerships with non-clinical environments that welcome those on the path to

social integration, those that allow participants to be, in the words of one interviewee, “just like everyone else.”

Difficulties of measuring therapeutic outcomes

When studying the effectiveness of specific rehabilitation interventions, especially those that follow a manual, all characteristics of the intervention (and of the participants) are spelled out in detail. Multiple trials of specific interventions with positive outcomes provide the evidence-base that leads to its designation as the preferred intervention to mediate specific functional deficits. But the study of concepts that are the consequence of more complex living patterns, especially those we have defined as essential for developmental growth, becomes a challenge. Among the difficulties in studying so-called healing processes is that they do not easily yield to objective measurement: risk-taking, reciprocal relationships, and self-determination. Not only are these concepts difficult to operationalize, but we do not know how these concepts are related nor do we know just how much each contributes to social integration

Finding informal communities

Rehabilitation programs are too often over-subscribed, private programs are expensive and the stigma of being labeled a “chronic mental patient” lingers, despite efforts to dispel pejorative description. Furthermore, the very nature of professional interventions may limit integration of rehabilitation with needed social recovery skills in community settings. The organizational structure of stand-alone programs works against developing more organic interconnected environments. Pescosolido (2008) pointed out that there is no need for the delivery of social support services to be limited (or paid for) by public agencies. Our findings are consistent with this observation: almost all of the quotes in this paper reflect experiences in Alcoholics Anonymous, religious or therapeutic communities rather than public rehabilitation programs.

AA—One well-known community for those with addictions, Alcoholics Anonymous (Wilson, 1936), has some organizational characteristics similar to therapeutic communities. AA is non-hierarchical, non-coercive and non-professional with sober alcoholics serving an organizing role at the local level. Established almost 80 years ago, it remains a powerful experience for members. Becoming and remaining sober arises from the support of group members following the 12 step program and from the bonds of relationships generated.

Religious Organizations—With a range of explicit operating principles, religious organizations typically portray themselves as welcoming communities open to everyone, and almost all are, but affiliation does not guarantee a reciprocal response (Leff & Warner, 2006). Nevertheless, most organized religious groups offer a community with the same characteristics of AA: “joining” is voluntary, worship and communal activities are available, but not required. Almost all religious groups are, except for the leader, not hierarchical.

Local organizations—In addition to intentional communities, natural communities form themselves around local interests: community gardens, choral groups, sports teams, hiking and biking clubs. Vermont’s Me2 classical orchestra, led by a Julliard-trained competition-

winning conductor with bi-polar disorder and a history of hospitalization, performs with individuals with mental illness and the people who support them (Gram, 2013). The best community environments follow the same principals as therapeutic communities: acceptance, communal rather than individual benefits, lack of strong top-down hierarchy, and willingness to give and take reality checks about relationships. Encouraging and supporting community activities outside of the mental health system should be an essential part of treatment planning.

CONCLUSION

At its heart, the value of life in community rests not on its presumed clinical effectiveness, but on the reciprocal relationships that embody human dignity. Both formal and informal communities provide opportunities to find new connections with others and, with each new opportunity for connection, deepen the understanding of how to initiate and maintain new relationships. Thus, the lessons learned are linked to everyday experience in the context of personal relationships. Growth within community becomes the impetus to broaden the circle of opportunity for active participation in the larger social world.

The bonds of community are the source of dynamic and reciprocal social interaction. These interactions build social capital, the dense network of relationships which generates trust, and, in turn, provides the basis for collective problem-solving in everyday life. For each of us, social encounters are shaped by the same capacities necessary for social integration. These encounters fit with consumer arguments for reforms that emphasize relationships and agency over specific skills. More important, it is the universal nature of these capacities that brings the moral dimension to the path of recovery. They are, in the words of anthropologist and psychiatrist Arthur Kleinman (2006), “what really matter.”

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