

## YOUTH EXPERIENCES OF LIVING WITH MENTAL HEALTH PROBLEMS: EMERGENCE, LOSS, ADAPTATION AND RECOVERY (ELAR)

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### ABSTRACT

Current understanding of youth aged 15-24 experiencing mental health problems is limited. Through a qualitative analysis of the subjective experiences of 7 male and 6 female youths, 4 core categories emerged as stages that described the participants' process of mental illness: emergence, loss, adaptation, and recovery. Results showed that youth experiencing mental health problems felt stigmatized and labelled, and experienced multiple losses of identity, family, career choices, and educational and social standing. Participants reported that having mental health problems disrupted their transition from adolescence to young adulthood; however, these data reveal how youth adapt and recover. Implications of the findings in this study will be useful in identifying youth-focused interventions that may help professionals assist youth more effectively in their recovery process.

The impact of mental illness on transitional youth is, from their perspectives, largely unknown (Leavey, Goering, Macfarlane, Bradley, & Cochrane, 2000). Yet, according to experts in first-episode psychosis, the majority of serious mental illnesses emerge at this critical stage in young peoples' lives (Malla, Norman, & Voruganti, 1999). For example, three out of four cases of schizophrenia emerge between the age of 17 and 25 (Hambrecht et al., 1998; U.S. Department of Health and Human Services, 1999) taking from its sufferers their most productive young adult years (US Department of Health and Human Services, 1999). Therefore, it is critical for professionals to gain a clear understanding, from the youths' perspective, of how best to assist them in their recovery and reintegration processes. Qualitative data provided by youth with mental health problems can reveal information helpful for policy-makers, planners and providers of the mental health service system in developing and delivering a more youth-focused service system tailored to age-appropriate developmental needs.

Erikson's (1980) developmental stages of *identity versus role confusion* and *intimacy versus isolation* provide a useful framework for understanding the transition from adolescence to young adulthood and the challenges for youth with mental health problems in achieving "typical" tasks. Meeting the developmental tasks of each stage is critical in forming a solid foundation for adult mental health (Erikson, 1980; U.S. Department of Health and Human Services, 1999; Stover & Hopkins, 1999). Even for the healthiest youth, achieving typical developmental milestones can be difficult (Health Canada, 1997a; Health Canada, 1997b). When youth experience a mental health problem, it has the potential to be life-altering because of interference with or delay of psychosocial development (Leavey et al., 2000; McGorry, Edwards, Mihalopoulos, Harrigan, & Jackson, 1996). Transition-aged youth with mental health prob-

lems may have unique developmental needs (Schwab-Stone & Briggs-Gowan, 1998) that become complicated by the negative effects of mental health problems, specifically in the areas of family, friendship, career, intellectual functioning, and the ability to form and sustain close intimate relationships (US Dept of Health and Human Services, 1999).

A critical issue that faces youth with mental health problems is the negative social stigma associated with mental illness. Group behaviour and social functioning are essential elements in the evolutionary process of social integration and maturity. Neuberger, Smith and Asher (2000) believe that groups work to promote their members, and when one member becomes a threat, that person is stigmatized and forced to become an outcast. Individuals with mental illnesses are seen as having "blemishes of character" (Biernat & Dovidio, 2000, p. 88). Group members may avoid persons with a "spoiled identity" (Goffman, 1963) because of the fear of "stigma by association" (Neuberger, Smith, Hoffman, & Russell, 2000) or, as Goffman coined it, "courtesy stigma" (1963). Instead of being enabled by social support to seek help and recover, the young person may be tempted to "conceal or disguise" the mental health problem (Goffman, 1963). One way to destigmatize the self is to "eliminate the stigmatizing condition" (Miller & Major, 2000, p. 252) but this is an unrealistic task for someone with a mental health problem, since individuals do not choose to have an illness any more than someone suffering from a physical illness does. Since many social and biological factors—such as age, gender, sex, race, culture, family, disability, sexuality, socioeconomic status, education, and religious beliefs—influence a sense of well-being and mental health in the transitional-youth age group (Health Canada, 1999a; Health Canada, 1999b; US Dept of Health and Human Services, 1999; Jurich, Bollman and Moxley, 1976; Stover & Hopkins, 1999), understanding the effects of stigma is critical in identifying barriers to recovery.

If youth with mental health issues do not find positive images that depict their situation or receive encouraging feedback from their peer groups, building or rebuilding a healthy sense of self can become an onerous task. In their research, Davidson and Strauss (1992) found that the rediscovery and reconstruction of a sense of self are essential to recovery. In a review of the existing evidence of peer support among individuals with severe mental illness, Davidson et al. found that peer support groups may improve symptoms, promote larger social networks, and enhance quality of life. Therefore, healthy environments in which to recover may include consumer-run peer groups established within clinical and rehabilitative settings (Davidson Chinman, Kloos, Weingarten, Stayner, & Tebes, 1999).

## METHOD

### Aim of Study

To explore and describe the phenomenon of the process of becoming, living with, and recovering from mental illness as experienced by transition-aged youth.

### Sample

The research group was a convenience sample. The sample size was determined based on it being large enough to produce repeating or common themes that were not occurring by chance (Colaizzi, 1978). Originally, there were eight youth interested in participating in the research; however, through word of mouth after the research interviews began, six more youth signed up. One person was unable to participate

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because of being actively psychotic; therefore, thirteen transition-aged youth were interviewed: six female and seven male. At the time of the interviews the youngest participant was a seventeen-year-old male and the eldest a twenty-three year old female. All participants had DSM diagnoses and were taking prescribed medication as an intervention for their mental health problem. All participants were clients of the youth psychosocial rehabilitation program and most attended full time.

### Diagnoses

Based on DSM-IV-TR (American Psychiatric Association, 2000) criteria, the diagnoses of the participants included: schizophrenia, psychosis, delusional disorder, obsessive-compulsive disorder, depression, suicidal ideation, eating disorder, anxiety disorder, bipolar disorder, mood disorder, post-traumatic stress disorder, personality disorders, and learning disabilities. Of note, five participants had a diagnosis of schizophrenia, of those, three were female and two were male. Seven of the thirteen participants had received multiple diagnoses; for example, one male participant had had eight different diagnoses over a ten-year period. No current use of illegal or recreational substances was reported.

### Research Questions

The primary research question was: What is the experience, meaning, and developmental effect of being diagnosed and living with a mental health problem for transition-aged youth (15 -24)? The following interview schedule was used:

1. Can you remember what it was like for you when you were first diagnosed with a mental health problem/illness?
2. What is it like for you now?
3. How did you (or someone else) first recognize that you had a problem?
4. What kind of issues did you have to face when first diagnosed?
5. What kind of issues do you face now?
6. What kind of personal changes (within you) have you experienced since being diagnosed?
7. What kinds of changes have happened (around you) in your life since becoming aware of your mental health problem/illness?
8. Can you describe how being diagnosed with a mental health problem has affected your: (a) friendships/peer group, (b) family relationships, (c) independence from family of origin, (d) sexuality, (e) sense of self/identity, (f) academic pursuits, (g) career?
9. Did you get the support you needed in getting help for your mental health problem/illness?
10. Did you experience anything helpful in your process?
11. Did you experience anything unhelpful in your process?
12. What parts of this story would you have liked to be different, if any?
13. If you were talking to another young person facing a diagnosis of a mental health problem/illness, what would you tell her/him?

A qualitative grounded theory approach was used to investigate the phenomenon of transition-aged youth experiencing mental health problems. This methodology optimised the possibilities for exploration and description of the voice and lived experience of transitional youth with mental health problems (Kirby & McKenna, 1989). This study investigated how youth with mental illness described their lived experiences and how they created meaning from those experiences (Emerson, Fretz,

& Shaw, 1995). Interviews consisting of 13 questions were conducted with participants. These questions formed a semi-structured interview process to elicit “everyday” data to assist in understanding the worlds in which the participants were living (Giorgi, 1985; Osborne, 1990; Colaizzi, 1978). The interview was open-ended to allow participants to use their own language and concepts in responding to the questions (Emerson et al., 1995) and to facilitate the process of participants articulating and focusing on their experiences of living with mental health problems. Strauss and Corbin suggest that the act of asking a research question is an act of identifying the “phenomenon to be studied” (1990, 1994, 1998), so that the researcher can contextualize and explain the phenomenon under investigation (Strauss & Corbin, 1998). Grounded theory derives its name from the practice of generating theory from research that is “grounded” in the data (Babchuk, 1996).

### **Procedure**

#### *Ethical Review*

An ethical review process was undertaken and approved through the University of Toronto.

#### *Setting*

This research study took place in a large urban Canadian community, at a psychosocial rehabilitation centre focused on youth. The centre works toward improving the quality of life for young people (aged 16-24) experiencing mental health problems. It accomplishes this through a client-responsive model, in an atmosphere of respect and mutuality.

#### *Recruitment*

A recruitment poster was placed in areas where potential participants could read and consider the information privately and/or ask questions of the agency staff and/or director. The director and staff of the program helped with the recruiting process. Copies of the abstract of the study, the questions, and recruitment letters were sent to the agency for distribution to potential participants.

#### *Inclusion/Exclusion Criteria*

Agency staff screened potential participants to ensure that they were not actively psychotic, mentally incapacitated, organically impaired, or actively using substances. Participants were required to be between 16 and 25 years of age, diagnosed with a DSM-IV-TR (American Psychiatric Association, 2000) disorder, able to acknowledge their mental health problem, and able to describe their experiences in English.

#### *Informed Consent*

The participants in this study were all capable of giving informed consent; participation was strictly voluntary and unlinked to the provision of services at the agency.

#### *Introduction Information Group*

The director of the program and the researcher set up a “pizza and pop” information group event to introduce the researcher to any youth interested in participating in the study. The researcher offered to provide reasonable reimbursement for transportation such as bus fare or parking costs. During this session, the researcher provided participants with full details regarding the intent of the study using a written statement and a verbal description. Questions from participants regarding any part of the study were discussed as fully as possible at this time. Ten clients attended.

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### *Interviews*

Interviews were semi-structured and ranged from forty-five minutes to two hours. They were conducted during regular hours at the youth program, in a familiar, relaxed, and safe environment for participants. At this time, expectations regarding time commitment, audio taping, consent process, and storage of collected data were discussed and potential risks and benefits of the study were identified. Clients were assured of their right to terminate their involvement at any time during the process and their ability to contact the researcher at any time by telephone and confidential voicemail. Consent forms were signed.

### *Debriefing/Validating Data Focus Group*

After the data were collected, organized, and analyzed, participants were invited to participate in a validation and debriefing focus group. Eight of the thirteen participants gathered to hear the analysis and provide feedback on how their stories were represented. During the focus group, each participant reviewed the common themes for accuracy. No new information was gathered regarding themes at this time and participants gave their approval of the researcher's representation of their data.

### *Locating the Researcher*

The researcher did not know the participants prior to this study, but did have prior knowledge of the phenomenon being studied. In order to allow the data to speak for themselves and prevent prior knowledge from interfering, Osborne (1990) recommends that one consider and deconstruct one's biases and preconceived notions of the subject. This ability to deconstruct and articulate one's preconceptions of the data through "rigorous self-reflection" is called "bracketing" (Osborne, 1990). As a professional engaged in mental health service delivery the researcher has observed and became aware of the limited documentation on the experiences of transition-aged youth (17-24) diagnosed with mental illness. The researcher has participated and facilitated in the development of community and hospital mental health services where clients were invited to the planning table; however, clients sometimes felt confused, left out and/or marginalized during the process. Consumers and families of people with mental illness have often stated that the services offered to them, while well intentioned, fell short of being helpful and meaningful to people experiencing long-term mental health problems. These experiences in planning and designing service delivery systems led the researcher to believe that the best way to understand people's needs is to ask them. Therefore, the researcher wanted to investigate and reflect the lived experiences of transitional youth using a qualitative methodology.

## ANALYSIS

The data were first analyzed using open coding. Themes and categories emerged from the data by using constant comparison methodology. Further analysis of the data revealed sub-themes that could be viewed as "properties" and "dimensions." Properties give the detail and dimensions give the range or variation by which the properties or details of the categories can be understood (Strauss & Corbin, 1990, 1994, 1998). Common meanings were identified in the "aggregate" material. In order to move from meanings to themes, the researcher had to "leap from what is given in the meanings to themes given with them" (Colaizzi, 1978, p. 59). Themes were checked with the original interviews in order to validate them, being tolerant of ambiguity. As Colaizzi states, "What is logically inexplicable may be existentially real and valid . . . and [one] must refuse the temptation of ignoring data or themes

which don't fit" (1978, p. 61). Therefore, the researcher did not filter or omit information because it may not have been an obvious "fit" with the themes, sub-themes and categories identified in the findings since "any relevant new data that emerge from these interviews must be worked into the final analysis" (Colaizzi, 1978, p. 62). After the main categories were identified, linkages between these categories and areas of overlap were made by mining the data to establish the points of connection, to establish areas of overlap, and to identify closely related properties and dimensions. This was accomplished by reading/rereading and coding the material, determining that no new themes were emerging, in order to form a sense of the themes and sub-themes of each category or stage (Strauss & Corbin, 1998).

## RESULTS

### Emergence

#### *Problem Getting the Correct Diagnosis*

Recognizing a mental health problem was often an extended process, which is not congruent with an accurate or timely diagnosis. One respondent mentioned that his initial experience of having a mental health problem was at the age of six and that he did not receive an official diagnosis until he was 14-years-old. While acquiring a diagnosis was part of emergence and subsequent intervention, misdiagnoses or several efforts to find the right diagnosis often served to muddy the problem.

They got a psychiatrist to talk to me, and he thought there might be a slight chance that I, that I am sick or something. So he diagnosed, he thought I was schizophrenic. And I took medication. Then after I got discharged from the hospital and I went back home and I went to see a psychiatrist, another psychiatrist, and I got another diagnosis . . . and from that moment on I took the medications and got diagnosed again. (N7 Female)

My doctors didn't know what all was going on with me, because all I have, a lot of things together, they didn't find, for one year they didn't find what it was. (N10 Female)

. . . at first the doctors thought that I was schizophrenic, but then they said no, and then they said I had dissociate disorder...and then after, they said, "No, that's not it either." And then I went to [name of hospital] and my doctor...now, says that I have bipolar, so that's how I got my...my diagnosis, as being bipolar. Yeah. (N7 Female)

#### *Labelling*

Being labelled as mentally ill was problematic for many participants. Four females and four males reported having some trouble accepting the label of mental illness. One respondent described how it felt be regarded as "crazy" (N7 Female). Another participant internalized the images and metaphors reflected from society's stereotypical view of mental illness and described the effect on her self-image.

Sometimes I don't like myself because, having to go through a mental illness is such a bad thing that I label myself and look down on myself. Like the way I see other people who have illness, like this is a very stereotypical view, but I think bad of other . . . like not to say to these people that I think that they're all bad because they have a mental illness, but just in general, when I think of mental, when I say the word "mental illness" it reminds me of bad, just bad in that . . . eww! Bad, who'd want that? . . . Diabetes is okay, but not mental illness. It's a very personal, personal problem. (N13 Female)

Nobody wants to know that you have a mental illness . . . what I'm saying, I don't want anybody to know I have a mental illness . . . 'cause a lot of people think you're crazy or disturbed. (N 13 Female)

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### *Stigma*

Six females and three males identified a negative change in social status after being diagnosed with a mental illness. Those participants also felt they were treated “differently” once their friends and family found out they had a mental illness. Some participants stated that their families treated them as though they were no longer capable of making “proper decisions.”

. . . accepting it in my mind, you know, I still haven’t accepted it, I know, like it’s very hard to accept something when you used to be okay and you used to be fine. You’re normal. . . . Not . . . to say what’s normal. You know what I mean. What’s normal in society? There’s so many people that vary so differently in the way they . . . characterize [mental illness]. (N13 Female)

I just feel that I’m sad that I have a mental illness, because . . . for one thing I’m just sad because I don’t want something bad. I see mental illness as bad, a bad omen, and especially since society used mental illness as something crazy or disturbed people have. Like they have those TV movies where, you know, a person is compulsively doing this and they’re thinking about spiders and spiders crawl on them. They make it so drastic, these illnesses, that people see it just as bad. (N13 Female)

### **Loss**

#### *Loss of Identity*

Loss of identity in this context was a sudden descent into a sense of self foreign to what they formerly knew; in some cases a complete loss of knowing the self occurred. It was now difficult to see themselves outside the illness. One male felt very self-critical and self-deprecatory because of not being “normal” anymore.

The safety of waking up and “knowing who you are” which most people take for granted had suddenly vanished. (N4 Female)

Identity. I don’t . . . I can’t really settle on what I am [since getting the illness] because I’m always trying to get better and see things in a different way, things that are from reality, not from fantasy. (N8 Female)

Well, if I didn’t have this thing [mental illness]. Like, wrong with me. . . . I would be like a normal kid. (N2 Male)

#### *Loss of Independence*

Some respondents indicated that they were still dependent on their families. Perhaps one of the most significant effects of the illness for respondents was the continued or extended dependence on family for housing, financial support, and emotional support. This dependence, at their age and stage of life, reduced their optimism about their (future) independence.

I always want to move back in [to my parents house], but I’m too old, I should be independent by now. (N5 Male)

Ninety per cent . . . I’m very dependent on my family. I don’t like being away from them for more than two days. I depend on them for a lot, like, you know, to pay my ODSP, to tell them, I have to report how much I make from my café, to the ODSP, and my mom always has to remind me which, like, to get it into the government before a certain day, you know, like, your apron’s downstairs, or you know, like reminders. Like, it’s like she has two heads, one for herself and one for me, and I feel bad, because I know that shouldn’t happen, shouldn’t be that way. But I’m just more dependent. (N13 Female)

*Loss of Academic Functioning*

Four respondents mentioned that they wished they could have continued in the schools that they were attending pre-diagnosis. Participants were very concerned that their scholastic career had been interrupted and wished that their education had not been so adversely affected by the mental illness. Most participants were still struggling to finish high school at an age when most young people without a mental illness would either have been in a university or college program, and/or be employed.

This illness, yeah. It interferes with my schoolwork and it's a really tough subject with me, because I . . . school is very vitally important to me . . . like it's interfering . . . and it's disturbing, because I used to do so well. Before I got ill I was doing so well. (N13 Female)

My marks plummeted after [the illness . . . I was getting 78 and 77 in two courses . . . I was on the average of what other people were getting, then I shut down . . . and nobody knew why all this was suddenly happening to me. My thoughts clouded over my brain so I couldn't think clearly. (N13 Female)

*Loss of Family Status*

Mental illness had negative effects on the family of origin. Two females and three males found that their families treated them differently after they were diagnosed. Another participant stated that his family members were more careful around him when discussing a potentially difficult situation.

[They] treat me differently since I got diagnosed with an illness. I think subconsciously, yeah. They don't realize it either, because they're overprotective. They want me home by a certain time. (N2 Male)

My family, my aunt and some of my uncles, like my uncles used to worry, were strict and get angry all the time. Like before I start to get sick. After I got sick, people were so nice, they never gets angry at me, like they just laugh . . . now they just laugh (indiscernible) when there is something wrong, he just laugh. They said we can't talk to you right in front of you because you will get upset or you might get bad[ly] influenced by that or [get] sad sometime, and so therefore we don't talk everything in front of you. So like, we're trying to help you by not talking right in front of you, and stuff like that. Then I said, Okay, I understand." (N12 Male)

*Loss of Friends*

Generally, the diagnosis seemed to have a negative effect on participants' friendships.

Yeah, I notice that I changed a lot between friends and to . . . doing stuff together. But, the thing is now, like, I used to have like more than 30, 40 friends, like, I say now, I mean, they're involved with gangs and stuff, so . . . like I used to have many friends, now I have one, how many . . . two, three. . . . So I just kind of, like . . . not I'm more better, I'm different, you know. Like now I feel like a different person, but still like, I'm not that person that I used to be. I'm not as popular as I used to be. . . ." (N12 Male)

*Interrupted Intimate Relationship Development*

Almost half of the participants were not sexually active, and reported that they felt too emotionally vulnerable at this stage of their lives to be intimately involved with another. Two females and two males said they were interested in pursuing or "trying out" a romantic relationship sometime in the future, but that right now they had more "important" things to do, such as concentrating on finishing their education, establishing some career goals, and pursuing work/making a living.



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Well, I don't think it's really ever going to happen [dating]. If I continue being fucked up, sorry, if I continue being screwed up, like, I'm not going to get one [girlfriend]. Like if that . . . if that . . . 'cause feeling stays with me my whole life, like I know I'm never going to get one. Like it's just inevitable. (N2 Male)

Will they think [potential date] I'm normal? Will they suspect that I have something? Will they, you know . . . I'm not going to tell them anything. . . . (N13 Female)

### *Interrupted Career Development*

Participants indicated that their careers have been limited due to mental illness. Only half of the females and none of the males were working, but four females and two males expressed a desire to work in the future. Pre-illness, some participants dreamed of becoming doctors. Another participant, who was twenty years of age at the time of the interview, stated that he wanted to become an engineer; however, he was having trouble finishing grade eleven in a special education class.

Yeah, I wanted to be a doctor, and it didn't work out because of my illness. (N6 Male)

I want to take engineering, because my mom, she sort of said that she can get me work, like right connection, she might get me work, she has connections there at her . . . work as a draftsman, so she can help me become, you know, the (indiscernible) teaching me. So she, I think it's good if I take engineering in college. . . . (N3 Male)

## **Adaptation**

### *Coping Strategies*

*Medication.* Adaptation involved specific coping strategies such as taking medication regularly. The majority of the participants stated that medication was a critical factor in addressing their "disorganized thoughts" (N2, Male). In fact, all the participants stated this as the number one method of maintaining mental stability and a sense of self-control, even if they did not particularly like taking the medication.

The sooner on the medication, the faster the medication will help you and it'll help you right away and you'll stop getting the thoughts. (N13 Female)

*Asking for Help.* Respondents felt that a key coping strategy was gaining a sense of insight into their own mental states by being cognizant of symptoms and knowing when to seek help.

I would tell you that if you think there's something different about you than before, or if someone notices anything different about you, that you should go to a doctor, talk to him, he or she, and if he or she agrees that there might be a slight chance of something wrong, then do as the doctors say and go see a psychiatrist. (N7 Female)

*Change in Social Relationships.* After being diagnosed, some males and females sought out entirely new friends because former high school peers had distanced themselves. Participants' sense of self-esteem seemed less negatively affected if they did not pursue friends that had abandoned them. Respondents who said they were able to find friends or community post-diagnosis had joined a peer-support group at the community youth mental health program that focused on youth-directed psychosocial support. Three males and five females felt connected to this peer-support group because of the opportunity to establish friendships. Some participants said they felt that creating and maintaining positive relationships was the key in their recovery process.

... and we're all friends, you know ... we're good friends, we know that ... we're special to each other ... like you know, we have that kind of relationship that we're in a youth group so we support each other, kind of thing. (N13 Female)

I've made completely new friends. My old friends, I don't keep in touch with very much, because I deal with it, that's part of my past, and I don't really want to be part of it. (N9 Male)

### *Acceptance*

Participants felt that a key aspect of adaptation was learning how to accept their mental illness and start learning how to deal with this new reality. A turning point in participants' healing processes seemed to occur when they received a proper diagnosis and treatment intervention. Once participants' symptoms were under control, they were able to begin the process of understanding that their mental illness was not their "fault." At this point, participants were able to start distinguishing between the self and the illness by accepting and adapting to a new identity and learning to work from a new frame of reference.

I own the illness; the illness doesn't own me. (N13 Female)

I have to mature way faster to understand myself and how to help myself ... I know myself a lot more. I know that, and now it means that there is a time where you can get illnesses, mental illnesses, and like, you can get mental illnesses and there can be something wrong with you mentally. Like I never thought of mental illness before I had my problem. I never thought that you could get a mental illness, and so now I know that I have to take care of myself mentally by taking my medication every day, by talking to a psychiatrist, to someone about your problem so that you feel better, so that people can help you solve [your problems]. (N13 Female)

Accept yourself. Still a person, you can do whatever you want, it doesn't matter what mental illness you have or ... let your life, you can still do it. (N9 Male)

*Adjustment.* Participants stated that, after the onset of mental illness, they had to alter their self-expectations because of the change in their overall ability to function. Some still felt a sense of loss, but had accepted a new or changed state and wanted to move on with their lives. The ability to create a new sense of life meaning seemed to come from the process of adaptation or adjustment to the change in their mental health status. This was achieved by adapting and learning new skills post-diagnosis in order to respond effectively to social environments. Participants had learned how to cope with the loss, confusion, and pain of alienation and were now oriented toward their future, a development which offered a sense of hope. They also seemed to have appropriate insight into their limitations, and could use that knowledge in a positive way, establishing goals, working, or continuing in school.

I'll never fulfil the expectations I had of myself before (indiscernible) one time, but not now. And I can never ask the same from myself. (N10 Female)

Like, my goals used to be set really high, get high marks, go to university. Now it's just graduate high school and maybe go to college. (N9 Male)

I'm not as angry in having an illness as I used to be, not as angry, like "Why me?" any more. I don't ask "Why me?" as much. I still do. But not as much. (N13 Female)

### **Recovery**

Recovery involved emerging from the onset of mental illness and re-establishing a social identity. The participants accomplished this process by creating a new self-

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identity in relation to their mental illness and their friends. They were much more accepting of themselves and addressed having a mental illness in a matter of fact way.

Keep believing in yourself, trying not to lose self-esteem, self-confidence. Stick to the friends you have and just open up to them and let them know, you know, this is something I'm going through and it's not normal, we know, and I know, and . . . just try and stick with them, and you know, pursue long-term relationships. (N11 Female)

### *Conditions for Recovery*

*The Right Medication.* Three females and four males said that being on and staying on the right medication was key in helping them remain stable.

[You] must remember to take medication that is right for you and speak up to get it changed if it is not. (N4 Female)

. . . you need meds . . . listen to the psychiatrist and take the meds . . . but before you take the meds, ask if there is side effects to the medication and what's it for, and ask what is your diagnose [sic]. And don't be afraid to ask questions, because it's really important. It's always important 'cause you know for yourself what's going on. And so then, after knowing all that information, if you need it, then you take the medication because you know it's going to help you. It's going to stabilize you. (N7 Female)

*The Right Therapist.* Three females and two males thought that having the right therapist who would focus on a person's particular problems and help them find solutions was very important to their self-esteem. In fact, participants often found it a validating and empowering experience to tell their stories in a safe, non-judgmental environment.

This is the first time anyone has asked me about my life; the psychiatrists only want to know about medication or my symptoms. (N13 Female)

I was close to my social worker. She gave me a lot of . . . she actually was more of a psychiatrist to me. She's the one that asked me, "Well, why do you think you do this?" or "Maybe you do this 'cause of this." She gave me a lot of coping strategies to deal with my anxiousness [sic], like she would like, tell me to list all the characteristics, good characteristics, what I like about myself and focus on those. Like what are the good characteristics I have. (N13 Female)

*A Good Doctor.* Participants stated that, in order to sustain a sense of recovery, it is necessary to have a good doctor who listens to the client and accepts him/her for who they are. The participants indicated that the therapist's role was quite separate from the doctor's role in that they expected to be able talk to the therapist in a non-hierarchical manner but that the doctor was the expert on medication. Doctors were expected, however, to listen to side-effect concerns and take the young person seriously.

[The doctor] said okay, I can prescribe a better medication, and he gave me the rundown of the . . . this is a fairly new medication, it deals with chemical imbalances, this that. If the doctor's willing to explain all of that to you, well, to me, I make up my . . . okay, he's doing something right. I can follow that. You know, as long as he bring it down to me, from my level, and I understand it, I will follow it. That is what I mean by a good doctor. (N1 Male)

He's a really good doctor. I don't like seeing psychiatrists or psychologists because it makes me feel like a . . . that I have problems. (N5 Male)

*Family Support.* One female and three males stated it was important to have ongoing family support.

You know, it's been wonderful, my parents support me . . . like all they did when they learned about my . . . that I had this illness, was read up on it. They read tons of books. They know more about it than I do, and I have the disorder. So I'm just very lucky to have such supportive family. (N13 Female)

Because my mom, she's the one who actually has faith in me, faith, and what I do. (N3 Male)

It is evident that family support, if available, could have a critical role in the process of recovery.

*Community-Based Youth-Centred Support.* Five female respondents (male participants commented on this only when prompted) emphasized that a key factor in their recovery and stability was that they became part of a community-based program focused on youth with mental health problems. An important aspect of this program was the "drop-in" where they could gain social support and feel they had a safe place to relate to one another. One participant felt it was important to have a place to access her peers.

. . . just talking to . . . just talking to the kids, you know, talking to other people my age, a little older, a little younger than me, having . . . you know, relating to each other, having common ground, 'cause we both have illnesses. So it helps me to deal with my illness better, and you know, suggestions they have for me, and I have suggestions for them, that I give them on how to deal with your nerves and cope with your anxiousness. (N13 Female)

And also what helped in [community youth with mental illness program], was that people are all ages, and I can communicate with people. (N4 Female)

#### *Reintegration*

Participants seem to be aware of their situations regarding their social selves. When in a state of recovery, participants reported a strong sense of hope for the future and that they had the capacity to keep learning how to cope with their new realities.

Not being able to totally 100 per cent accept having an illness, still. Same things, but to a lesser degree, like I have the same kind of issues, but to a less degree. Like I'm better now with these issues because I've matured and I've grown up from then. Right? (N13 Female)

#### *Volunteering*

Young people expressed an interest in volunteering so they could give something back to their communities and feel good about themselves by. Six out of 13 participants either had volunteered in the past or were currently volunteering in their communities. Each of those six spoke of their voluntary work as a positive experience, giving them a chance to relate to others in need and changing the focus from their "mental illness," to their role as a volunteer.

Yes, I volunteered at [name of facility]. It's a senior home . . . and I wheelchair them around. At the beginning, I was doing laundry . . . and then they put me on the 5th floor in the serious . . . the ward where the residents are most troubled. Like they have Alzheimer's. And I was with them, and that was a really good experience, because I found, like I was so giving. I wanted to help them. And I felt that I was giving them the help they wanted, like keeping them company, wheel-chairing them around. Just . . . just keeping them company and they'd smile at you...when you said something to them, 'cause nobody pays attention to them. The family, relatives don't really come. But there are relatives that come but not very often, and they feel, you know, one of them cries because, like she doesn't know why she cries but she cries, it's just Alzheimer's. A lot of things . . . different people do different . . . you know, act differently . . . So? But it was, it

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was a really good experience for the . . . I was only up on the 5th floor for a couple of weeks, but it was enough to see the whole picture of how these people need to be cared for, and loved, especially loved. (N13 Female)

That's more kind of helpful for me, to be able to help other teenagers. But the thing is, I want to tell more teenagers not to go into the problems or, you know, like the stupid way I did. . . . After I got my mental illness, I want to help people. (N12 Male)

### *Hope for the Future*

Participants felt that a sense of hope for the future was important, rather than dwelling on the past or the social and intellectual losses sustained through the process of becoming ill.

I would say that life goes on. That anything can happen, so, . . . um. We cannot be smashed, we cannot be defeated. Um. There's always something in a person that will make them want to triumph, no matter what happens, and that there is some source of life, there is some angel, there is some power grown out of all the turmoil and all the negatives and all the lies, there's always a path leading to . . . truth. That's about it. (N4 Female)

. . . in the end . . . life is . . . like, just knowing that yesterday, like . . . I can't change yesterday, because that's like yesterday. It's over. I'm too old for yesterday and too young for tomorrow, so I'm living now. And I have to make tomorrow. . . . (N1 Male)

## A CONCEPTUAL FRAMEWORK

Four general categories or stages of emergence, loss, adaptation, and recovery clearly emerged from the data. The participants experienced mental illness as a biological and social process from which one needs to develop strategies to recover. The articulation of these stages will potentially assist others in understanding the processes that young people experience when becoming mentally ill, adapting and recovering. These stages are not to be understood as static or linear in nature. Rather, the stages are dynamic and an individual can move forward or backward. An individual may progress and regress because each person's journey through these stages is influenced by their own sets of experiences, strengths, and weaknesses. Individuals may not move through all stages and may experience more than one at a time. The following definitions are to be understood as categories or stages that emerged from these data, and are used to form a framework and context for the interpretation of the social and behavioural experiences of the illness process, as well as to provide information on positive routes to recovery.

### **Emergence**

This category encompasses how participants experienced their process of becoming mentally ill. They experienced becoming labelled and stigmatized as their differences emerged. They also described problems getting a diagnosis, which in turn caused delayed early intervention. These difficulties often delayed the recovery process and sometimes left participants feeling confused.

### **Loss**

This category involves the process of experiencing multiple losses of one's former sense of self or social identity. Participants in this stage experienced losses surrounding identity, independence, intellectual functioning, family status, and social

standing, with subsequent interruptions in sexuality and career development. Participants described feeling unable to participate fully with their typical peers in age-appropriate activities, such as dating and making career/education choices.

### **Adaptation**

This stage encompasses the process of creating a new sense of meaning by adapting to or accepting an illness identity. In this stage, learning new biopsychosocial coping skills is required. These include accepting medication in order to maintain stability, gaining an ability to recognize symptoms and ask for help, and learning how to create positive changes in social relationships. Participants described moving to a place of acceptance about having a mental illness. This helped them to adjust to their new realities and start looking for ways to move beyond the illness.

### **Recovery**

Recovery involves emerging from the onset of a mental illness and re-establishing a social identity. This includes a process of forming a new self-definition and finding ways to decrease the impact of a problematized illness identity. Participants stated this was accomplished by regaining some social reintegration and by identifying strategies needed to maintain a state of recovery. Strategies included volunteering, having the right therapist, having a good doctor, family support and being on the right medication. Meeting peers experiencing mental health problems at the community-based youth-centred program assisted participants in gaining and maintaining a strong sense of hope for the future.

## **DISCUSSION**

As stated earlier, youth with mental health problems potentially experience delay or disruption in meeting their developmental milestones (Leavey et al., 2000; McGorry et al., 1996). In this study, the participants were aware of what they were going through and felt able to articulate their needs and address their age-related developmental tasks in ways that were non-threatening. For example, volunteering allowed the focus to be on their abilities rather than on their disability, and limiting their current intimate relationships in order to focus on other developmental tasks, such as work and school successes, reduced their vulnerability to stress and feelings of inadequacy. It can be deduced then that youth in this study were trying to meet their milestones, just differently. Davidson (2003) coined the term "outside schizophrenia," in which a person gains a sense of agency and belonging through increased community involvement. Davidson stresses the importance of friendship, of developing coping strategies, and of defining the self as a means by which to move outside the illness. He emphasizes finding and recreating an identity and a role in society.

There was a delay in meeting typical milestones, such as getting work, graduating from high school, entering university and forming intimate relationships. However, the participants dealt with health-related issues that were much more complex than those of their healthier peers, which made their life-cycle issues more difficult. These participants had to learn how to negotiate institutions and systems; make treatment decisions about medication and hospital admissions; articulate their mental health needs; cope with adversity, loss, and grieving; and, finally, recover. Compared with their typical peers, the participants had to advance through the life-cycle stages more rapidly. During the process of becoming mentally ill, the participants may have been forced to form an adult identity in an abbreviated fashion,

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meaning that, instead of thinking of these youth as having a developmental delay, we might consider them developmentally different. They might have islands of age-appropriate developmental skills in some areas but have challenges in other areas.

Stigma seems to be the major barrier to participants' ability to reintegrate into the social world, based on reactions to their mental illnesses. It leaves them feeling "different," the antithesis of what these youth want to feel at this developmental stage. Understanding the social aspects of stigma and its effects on youth with mental illness is important because ultimately it has potential implications for their development (Leavey et al., 2000; McGorry, et al., 1996). Youth need to be integrated and attached socially so that they can move into adulthood feeling a sense of autonomy, attachment, and productivity (Erikson, 1980; Davidson, 2003). When those feelings are interrupted, it leaves youth potentially vulnerable to a sense of marginalization and isolation from family, friends and society. The social experience of mental illness is significant because of the potential negative effects that stigma can have on the prognosis of the mental illness itself (Leavey et al., 2000; McGorry, et al., 1996). Social stress could accelerate or worsen the mental illness, due to the young person now focusing on surviving the social loss caused by the illness. Davidson (2003) described this process as "inside schizophrenia," referring to one's being lost in a downward spiral of the mental illness, including having a particular sensitivity and magnified feeling of not belonging.

Embedded in these data are implications for improving intervention and treatment programs for youth with mental illnesses. One of the primary issues emerging is that interrupted development and the loss of crucial relationships, overlaid by stigma, are key obstacles youth face in their path to recovery. Hence, health care providers, policy-makers, governments, and service systems need to focus their efforts on developing pathways and mechanisms for early and appropriate treatment interventions for youth. Gaining access to treatment, getting the correct diagnosis, and being prescribed the correct medication will assist youth in a prompter recovery process (Leavey et al., 2000; McGorry et al., 1996; McGorry, 1995; McGorry, 1992; Lincoln & McGorry, 1995). Equally important is attending to social losses and providing opportunities for youth to develop the skills needed to surmount the social disruption, losses and stigma. In terms of recovery, youth need to be enabled to gain a sense of hope and belonging in order to avoid the despair and social isolation of being "inside schizophrenia" (Davidson, 2003).

### Limits

These results are based on a small sample and should not be generalized to all youth experiencing mental health problems across class, occupation, education, race, age, sex and gender or severity of illness. Future studies will require the recruitment of a wider range of participants in greater numbers to further test the ELAR framework (emergence, loss, adaptation and recovery) when considering youth with mental health problems and their recovery process.

### FUTURE RESEARCH

These results indicate a need for further research supporting better practice models that are focused on developmental stages, in order to tailor treatment and rehabilitation services to assist youth in their recovery processes. Better practices should acknowledge emergence and loss experiences of youth and offer direct assistance for mitigating some of the bio-psychosocial impacts associated with the

onset of mental health problems, using adaptive coping and recovery strategies. A youth-centred mental health care system with a strong peer component becomes very important in assisting youth to meet their developmental and identity needs, in addition to their medical needs, in the process of their recovery (Davidson et al., 1999). The stages of emergence, loss, adaptation, and recovery have the potential to assist individuals and service providers in understanding the illness process by providing a framework and context from which to interpret the illness, social and behavioural experiences and routes to recovery.

### RÉSUMÉ

Nous savons peu sur les jeunes âgé(e)s de 15 à 24 ans aux prises avec des troubles mentaux. Suite à une analyse qualitative des expériences subjectives de 7 jeunes hommes et de 6 jeunes femmes, 4 grandes catégories ont fait surface comme stades qui décrivent le processus ayant mené à la maladie mentale des participants et participantes: émergence, perte, adaptation et rétablissement. Les résultats ont indiqué que les jeunes aux prises avec des troubles mentaux se sentaient stigmatisé(e)s et étiqueté(e)s, et qu'ils connaissaient des pertes à plusieurs niveaux, liés à leur identité, leur famille et leurs choix de carrière, de même qu'à leur niveau d'instruction et à leur position sociale. Les participants et participantes ont rapporté que leurs troubles mentaux perturbaient leur vie, causant en particulier une cassure au moment du passage de l'adolescence au stade de jeune adulte. Ces données révèlent toutefois comment les jeunes s'adaptent et s'en sortent. Les implications des conclusions de cette étude peuvent servir à déterminer des interventions spécifiques aux jeunes qui pourraient leur aider dans leur processus de rétablissement d'une façon plus efficace.

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