“Poetry in Yarn”—Making Sense of Life Experiences in the Shadow of Schizophrenia

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Personal Particulars

Head over heels in love
and fiercely, nakedly desired
Beautiful, young, gifted, admired
A life seething with romantic love
Having the world’s absolutely poshest job
tastefully handled alongside the sweetest, cutest kids
Tender mother
Devoted lover
Married to a prince on a white steed
Faithful in friendship
Popular, sought-after, indispensable to others
Finances in order
Slim and slender into old age
To the end of life, in sparkling spirits
Endlessly mourned
I got nothing of all that
I got a whole other life

Introduction

The poem Personal Particulars by Annika Malmqvist, written in her late 30s, is a distilled narrative about how a life story influenced by a diagnosis of schizophrenia in early youth changes one’s expectations of a normal life course. For a person who suffers from mental illness, the concept of the imagined, perhaps, idealized picture of her/his life plan is disrupted. An important aspect of the poem is the notion of “a whole other life.” The author is telling us what life is not about. Clearly, “the other life” remains silent or not spoken of, a silence reflected in the knowledge field of mental illness. This phenomenon is also described by Foucault1 as the psychiatric monolog of reason.

Once a person becomes a psychiatric patient, their identity from then on becomes either that of a mental patient, an ex-patient, or a survivor.2 Their life is interpreted by their interaction with psychiatry, and their mental illness influences all the other life events. Even the popular concept of recovery is a reference to the medical model.2 However, Adame and Knudson3 do stress the existence of an alternative narrative developed within the survivors’ movement. It actually seems to be a challenge to ex-patients to formulate a narrative that does not start with medical language or the discourse of the medical model. Adame and Knudson explain that the survivor movement has developed “an alternative discourse of the good life that exists outside of the dichotomies of illness and health and transcends the counter-narrative and the medical model” (p. 176).

Annika Malmqvist (AM), one of the authors of this article, was diagnosed as schizophrenic in her early 20s and considers herself a voice hearer and an ex-mental patient. Now on her own, after being widowed, she lives in an apartment in Stockholm in Sweden, with her 4 cats. This text has a life course perspective in the sense that Annika can be viewed as the story’s vehicle, ie, she formulates a story of “the other life.” The story is about how AM was treated as a child and how she later on, during her adolescence, became mentally ill. The aim is to present a narrative about how she makes sense of her life experiences in relation to her creative embroidery work in the shadow of having been diagnosed as schizophrenic. We do not know enough about people who are diagnosed as schizophrenic in their youth in relation to how they perceive their life course related to creative art work, even though art scientists34 and others have focused on the issue.5

Research Approach

The 2 authors have known each other for over 2 decades because we have worked together within the patient movement for psychiatric patients in Sweden. We have initiated various kinds of networks and self-help groups, including hearing-voices groups. We have strived in our work to break the silence that Foucault describes in his history of psychiatry. There is one difference between us though: one of us has an insider perspective, as an
activist and a former mental-health patient (AM), while the other has an outsider perspective, as a professional social worker and researcher (LBK). In this joint project, we wished to explore the field of mental illness and artwork. The authors will alternate their pronouns. Sometimes we write we, meaning both authors. We started with taped, informal conversations to document Annika’s experiences. These talks were then transcribed verbatim. One of us (LBK) clearly took the position of researcher; however, during the research process it came out that Annika had been an object of research during her childhood and had felt herself extremely violated in this situation. Anything that in the remotest way risked repeating this must be avoided. At the same time, in the words of the Swedish author of fiction and drama Gunilla Linn Persson, researchers are “freeloaders on the patient’s couch.” Because we are coauthors of this text, we are jointly responsible for it even if we have different experiences and skills. However, the differences should not be exaggerated; in qualitative research, there is no clear line between professional and participant.

The 2 authors met on a regular basis over a 2-year period, always under the ethical premise of informed consent; Annika could withdraw at any time, and she was participating on her own terms. Working together, we also gradually realized how yet another story developed, not one of being a mental patient (our focus) nor about recovery, but of “lived experiences” based on a phenomenological perspective. AM is exploring her own life, while LBK is writing from a researcher’s perspective, taking an unbiassed, theoretical approach. Writing together was not only emotionally challenging but also liberating—for both of us. AM told her story, while LBK asked questions and transcribed; the final product is the result of the efforts of both over time. Not all of the discussions were recorded; each of us took additional notes, which we then developed, keeping each other updated by e-mail. In the same way, we have adjusted the text jointly as it has evolved. This process really does not differ much from traditional scientific work when 2 researchers work together.

From her insider’s perspective, AM points out that her method involved sometimes ignoring conventions or what is perceived as “good taste” and going her own way. LBK shares this perspective. We do agree that taking the road less travelled has a price, which might involve being criticized or misunderstood. AM hopes that researchers and professionals in the fields of psychiatry or social work can benefit from at least some of her experiences, while LBK hopes that their procedure will inspire other researchers and therapists.

Annika’s Reflections on Her Life—“Not Doing”

AM grew up with a younger sister in a middle-class family. Annika was long considered by conventional psychiatry as having an incurable mental condition. She was 21 when she was diagnosed as schizophrenic, over 50 years ago. She spent long periods in closed psychiatric care, receiving high doses of antipsychotics. But she completed her academic studies and earned a bachelor’s degree in literature. For a while, she went through therapy to deal with the psychiatric and sexual abuse she experienced at the hands of both of her parents. When she was no longer in an acute psychotic phase, she was considered to be capable of working but had difficulty making her way to the labor market, where she was bullied because of her status as a former mental patient. Looking back, Annika says she never really understood how the “healthy world” worked. She was more or less defenseless in her relationships at work because she didn’t always understand what was expected of her. Instead, she started volunteering in the patient rights movement. A few years ago, her husband passed away. She has many relatives, but no one close to her who is still alive. The following is Annika’s own description of her life experiences:

In my 20s I developed a condition called schizophrenia. My prognosis was the worst possible, and for many years I was the only person who had any hope for my future. I dealt with it by writing; maybe I believed that writing could heal not only my self, but also my future readers. Language was vital in my life, both as a path to health and as a way of banishing the causes of my unhappiness.

I believed that my illness had something to do with language. And that was both wrong and right. As a gifted child, not only linguistically but in all other ways, I was drilled by my super-intellectual parents to develop into something truly great to show off to the world. I repressed the fact that I was also subjected to sexual and other forms of abuse in my home at the same time, but I still felt that something was terribly wrong. I was so vulnerable and so trapped – developed – wrapped up like some sort of package, that as a three-year-old I confronted my parents with this linguistic construction: Can you help me against you?

My one escape, the only thing I could think of, was not doing.

I achieved not doing through four short sentences that throughout my life have come to me in a visionary way. Don’t walk away from me was the first one, which erupted out of intolerable pain. I lived with it for many years until the next vision that beset me. I’ve come home. This was when I had escaped my lifelong psychosis, but was still searching for a firm footing.

A few years later, my life was again shattered through the loss of my life partner. That’s when the next sentence developed: I will survive. The hard part was hard, but I would survive. Now I’m going through gerotranscendence (Tornstam’s theory of gerotranscendence states that the way we view our lives changes over time from a materialistic to a transcendental attitude, which is expressed among other things in greater self-awareness and the realisation
that things that once seemed desirable no longer are, such as financial success and social climbing). *I'm finally free and completely open. That's when I hear the words: Let it hurt. Nurture your pain and sorrow so that they can nurture you. I don't write anymore. I embroider. My life and my work are in my hands. I have gone into and out of so many dead-end streets, and the person I finally met was my self. So I took hold of me. I found health in my own hands. Not doing became doing. My own springboard.

**Embroidery as a “Liberating Force”**

Annika's embroidery began on a whim. Her first attempt was a simple project following drawn patterns, but she soon realized that she could develop her own free-hand embroidery combining various techniques. Ten years ago, when Annika broke her foot in an accident, she was convinced the pain would kill her. But the municipality's support to individuals with psychological disorders helped her get back on track. It was about this time that she began embroidering again, in an attempt to “find calm.” If her embroidery was originally related to mastering her anxiety and fear, its purpose shifted into serving as a distraction from the grief and loneliness of having been widowed. However, the creative process was never about expressing deep feelings of grief: “I don’t really have any need for that.” Rather, she needs an outlet for a new-born desire for activity: “Above all, I had a huge amount of energy I needed to expend. And I still do. ... Embroidery gives me that power; it's like a liberating force.” Thus, creativity has a healing effect, which she has compared with “stitching up a wound.” It is particularly healing because Annika is “creating something new while remaining constantly anchored in the present.”

Embroidery provides a source of joy and satisfaction, particularly because her creativity continues to grow: “You come into a state of flow, of well-being. An enjoyable experience.” For Annika, flow is about that instant when a creative endeavor “feels just right” because both halves of her brain are communicating with each other. At other times, one hemisphere dominates and she feels “internally divided.” Perhaps this is what is meant by a split personality or schizophrenia, she explains. Schizophrenia is an expression of a survival strategy, de facto isolating oneself from the world because of one's vulnerability. Personally, AM is tired of what she describes as vulgar perceptions of schizophrenia as impossible to cure or even to recover from. The flow experience is described as an enjoyable subjective state of mind of being creative and focused. When Reynolds and Prior interviewed women who had turned to crafts after being chronically ill, several of them spoke of strong feelings of flow, which is usually associated with “when the person uses high-level skills effectively to cope with meaningful challenges and to pursue clear goals” (p. 789).

**When I See Something I Didn't See Initially**

There is a relationship between Annika’s inner world and her creativity:

Of course there's a connection, but it’s not always a sure thing that it will reach the conscious level. This becomes clear when I show a piece to someone else, and they ask or comment, “What were you going for here?” I don’t always know, but the question makes me see something that I didn’t see before.

To illustrate this reasoning, she shows a brightly colored work of embroidery. A line of black threads cuts straight across it. Someone asked her what the black line meant, and Annika couldn’t answer at first; then she realized. The black line was the crucial element of this embroidery because “apart from being beautiful, it also contains a dramatic flair.” Others have described her work as having a strong charisma, saying that her creativity is derived from painful experiences. In fact, her creations are “poetry in yarn.” What she embroiders is her life: “In the past I wrote poems in words, but the words began to hurt. I twisted my ankles in the footsteps of language.” Language is oral, but the work of our hands is something else—something that heals childhood traumas, she explains.

Terrible memories were awakened during psychotherapy. For a long time she was afraid to move her lips and pronounce the vowel sounds o, u, or eu because she was terrified that “something would happen,” or as Annika explains it, “the body remembers.” She related these physical memories to the sexual abuse by her father. Because he studied her early linguistic development for his master's degree, she felt “picked apart in the world of language away from me. Or they controlled my language as it was developing. I feel as if they took my language away from me. Or they controlled my language, made it what they wanted. That realisation was a painful discovery.

**It Should Be Magical**

When Annika creates *Poetry in Yarn*, it is “completely my own.” Embroidery is her true language, the language “I wasn't allowed to have.” Her words express some of what she experienced, but not all:

After a defeat I often wanted vindication, sometimes using language as an art form. But now I listen to others and discuss. I have definitely stopped putting on airs with words. If I feel something non-genuine gathering on my tongue getting ready to leap out, I close my mouth instead.
Viewers are affected differently by Annika’s work depending on their “own baggage.” One acquaintance said, “I can’t look at your embroideries. They create such anxiety in me.” Annika explains, “That may be so, but that shows that there is great power in them.” Creation comes solely from within, but she tries not to be too technical, preferring a challenge: “I try not to always make it beautiful. If I realise that I’m doing something I already know, I stop immediately. Otherwise you can’t evolve.” The risk then is that her embroidery becomes a style. The main goal of her works is not beauty, but attraction: “It should be magical, something that creates an experience. … But I try to avoid falling into any kind of style.” Other friends who embroider may have “excellent technique and good materials, resulting in something incredibly beautiful—but slightly uninteresting.”

During the years Annika spent at a mental institution, she “survived” by writing. Today she prefers embroidering. Having another form of expression than writing feels liberating, even if her poetry was at times “a lifeline”: “My language was never really completely mine; my own language was stolen from me and researched to death in my early childhood.” Embroidery, however, serves as a sort of cleansing from the spoken word. But Annika has never embroidered during a psychotic phase. “What is interesting with embroidery is its slowness. When you are psychotic, you can’t do things slowly.”

I Can Be Interdisciplinary in My Design Language

Annika emphasizes that she must never lose her distance while embroidering—which can happen during a psychosis. The risk is that “you somehow sew yourself into the embroidery. And that isn’t the intent, because I’m meant to be only the originator. What I am doing is creating something separate, an object. So it must not blend in with me.” Thus, she compares a less-than-optimal attitude to her work with slipping into a psychosis: “I guess that’s the difference between a good, healthy way of reacting and a psychotic experience, which can be incredibly strong, but is nothing that can be built on in the long run.” However, where is the boundary between herself, her work, and the things she sews into her works?

I suppose that’s what I don’t know. My hands guide me and I follow them. I don’t really know where they’ll end up. I can be interdisciplinary in my design language, the thing they call creating or developing, but it has to happen in a more or less healthy way. Or else it won’t happen at all.

I have a lot of faith in my subconscious will, strength, intuition. If you set out to create something great, a masterpiece, that’s really the same mentality as when you are striving for some kind of status symbol. That’s not honest.

Annika recently started an embroidery group called Free-range Hens for others who have been mental patients. Ten or 15 people get together each week at one of the municipality’s meeting facilities to find inspiration for creativity. Several of them have many years of experience as patients and suffer from severe mental illness. Asked what it’s like to talk about her embroidery, Annika says, “I know absolutely nothing about where it will go from here, and I don’t want to know—it’s exciting. But one thing I know I’d like to do—I’d like to work with this full-time.”

Poetry in Yarn—Opportunities for Healing

Embroidery, or the act of creating poetry in yarn, offers opportunities for healing. But, as Annika says, she doesn’t want to sew herself up in the work. When words began to hurt, she started creating poetry in yarn. She compares embroidering with stitching up wounds, allowing her to “create something new” while remaining “in the now,” but her work is also a part of herself. Creativity means being part of a flow, which in one way is like being in one’s own world. The destructive face of being in one’s own world is being psychotic. Embroidery, on the other hand, is a language all its own. Uncorrupted by the language of others. Verbal language, in contrast, can be seen as corrupted, even sullied. Annika’s narrative demonstrates a valuable distinction, from being controlled to expressing oneself on one’s own terms. When Annika was affected by her father’s studies in early childhood, it steered her language development in the direction he wanted. As the object of his study, she was robbed of her own language, and by extension subjected to another form of abuse. Difficult life experiences must be processed later in life, so they can be left behind and transformed into insights. The metaphor of “stitching up wounds” in order to heal becomes overexplicit in this context. Rather, Annika is developing the language she wants.

Looking back on her poem Personal Particulars, Annika finds that she would not have written it in the same way today. Even if the idea behind the poem is brilliant, the text is far too intellectual. “But as an idea it’s good. But how girly can you get? Just sitting there waiting for something to come to you! I lived with those ideas for a long time. And also with the idea that you have to be successful.” Annika says, she fell into the Western myth of the value of success: “Life took from me everything I thought was indispensable, to make me who I am.” Annika relates her experience of life to her embroidery, which is about never striving to create perfection—that meaningless attempt to capture the wind or “strive for a status symbol.”

Conclusion

When a human being suffers from mental illness, people usually do not focus on the individual’s resources or strengths; rather, they observe all the imperfections or deviances. This concentration on shortcomings influences how those individuals see themselves through the
eyes of others (op.cit.). But through creation, something happens—designated as flow,10,11—that quality of living in the moment, without thinking of one’s flaws. By creating, an individual becomes something more than just ill and at the same time has an opportunity to be healed through the creation process. When the art scientist MacGregor1 studied mental patients’ creations, he concluded that these works have no intention of mediating the way out of mental illness. But they are opportunities to order one’s world and existence. In other words, the works are the result of a certain state of mind, an expression of one’s personal feelings and apprehension of the world: “This is who I am and what I feel inside. This is how I perceive the outer world. Have we anything in common?” (p. 316). Consequently, the pieces are created out of an inner necessity, out of a desire to explore one’s inner life, and out of a desire to communicate.

Annika’s personal development can be connected to reconciliation with one’s life experiences in the shadow of mental illness, ie, schizophrenia. It is not so much about recovery, in the sense of “covering up” earlier bad experiences and feelings that initially led to the mental illness, but about reconciling oneself with one’s experiences and about the necessity to discover painful experiences (see also Rhodes).12 Annika’s embroidery and creativity can be viewed as storytelling in and of itself. The essence can be captured in MacGregor’s statement above, “this is who I am, and this is how I feel.” In every creation, Annika conveys a bit of herself, emphasizing that her hands are guiding her, so she never knows how the work will progress, much less what it will look like when finished.

In Summary

Reynolds and Prior emphasize awareness of the importance of creation that a meaningful occupation affects how we deal with illness and disability, influencing how we view our existence. Annika is conveying an alternative story. Her narrative is no longer about what she is not, or what she might have been. Instead, it focuses on her experiences and on understanding her life experiences in the shadow of a diagnosis of schizophrenia. But most importantly, this is based on a different framework than the old one of social inadequacy and mental illness. Embroidery can be viewed as an act of resistance—the ability to express oneself on one’s own terms—as well as an opportunity to create one’s own world, uncensored and free from insult. If language dissected her and created a feeling of being sliced open, the work of her hands creates value and guides her in her efforts. Annika is the mistress of her own creativity, her creations and creative world on her own terms, offering a new interpretation of her life story.

Our hope is that we will appeal to readers not only on an intellectual level but also on an emotional one. We close here with Nussbaum’s reference to Nietzsche, describing art as an opportunity for healing: “permitting the spectator to view her own life and her own body as pleasing in their very vulnerability” because it “helps people to embrace their own lives … (and) it helps them to embrace the lives of others” (p. 353).

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References