Volition as Narrative: Understanding Motivation in Chronic Illness

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This paper expands the current concept of volition in the Model of Human Occupation. The present version views personal causation, values, and interests as traits that determine choices to engage in occupations. Through a detailed investigation of the life histories of two persons with psychiatric disorders, this paper illustrates how volition is embedded in a personal narrative. Two features of narratively organized volition are highlighted: (a) how narrative places decisions and actions within a plot, thus giving them meaning in the context of a whole life, and (b) how the personal narrative motivates the person by serving as a context for choosing and action. Thus, the paper illustrates how persons seek to narrate their lives and live their life narratives.

In this paper, we present the results of an investigation of two persons whom we came to know during their stay in a partial hospital program. They participated in a series of semistructured research interviews conducted by the first author that explored their past, present, and anticipated experiences. The interviews began with the request to hear their life stories, as the purpose of this investigation was to examine how persons narratively structure their understandings of themselves and their lives.

As our understanding of their lives developed, more specific questions sought to gain an insider’s view of their experiences. The two patients were encouraged to tell the stories that they deemed most important to share. Consequently, their stories were spontaneous and varied in form and construction.

All interviews were audiotaped and transcribed into the computer program Ethnograph (Seidel, Kjolseth, & Seymour, 1988). Colleagues familiar with qualitative research methods and narrative theory assisted with content analysis to minimize bias in the interpretation of themes. In analyzing the data through identification of themes and peer review sessions, we sought to accurately characterize the stories as the patients saw them and to understand how they comprehended themselves through narrative.

Tom

Neatly dressed in blue jeans and tennis shoes and a sweat shirt emblazoned with his alma mater’s university emblem, Tom presented his résumé as data for this study. Achievements leapt off the textured gray paper: He was a 1981 high school honors graduate, school newspaper editor, National Honor Society President, Quill & Scroll President, and debate club member; he spent his summers writing for a city-wide student newspaper and gained advanced journalism training. Five years later, he was class valedictorian of a prestigious private university, received a degree in journalism, and had successful internships in two major city daily newspapers. Nine months after college graduation, he began work as a city reporter on a daily paper; in 16 months he landed an envied job as a bureau reporter on several beats for a big city paper. At the beginning of the study, having been out of work for 8 months, Tom worried about getting a job and about the embarrassment of his departure from what promised to be a brilliant career:

I want to go to my college and look at their placement office job listings. But I’m putting it off because it’s awkward, you know, there’s always a chance of running into professors, or people that you used to know, and have to explain what you’re doing and why you’re looking for a job and that kind of stuff.

Tom also agonized over how to explain glaring gaps of time at the end of his résumé:

In groups we could never really find a good solution. We decided...
that you couldn't really tell the truth because of the stigma involved and you couldn't necessarily lie effectively if you are talking about many months of unemployment.

Despite the dilemma of how to explain his unemployment, Tom dragged himself to an interview for editorship of a monthly political newsletter, although the job was several rungs below investigative journalism. In a subsequent interview he jested about the interview experience:

Interviewer: So, how did you account for the gaps?
Tom: I said I had leprosy. Ha!
Interviewer: Did you?
Tom: Yeah.
Interviewer: I bet that was convincing?
Tom: Yeah, I said I was in prison... No, I came up with another illness, an eye problem which I actually had 5 years ago. And I went blind for awhile. So, I knew a lot about that illness and I could talk about it in the interview— and I pretended that it happened. God! It was very nerve-wracking to have to do something like that.

But this lie worked, and Tom was offered the job about a month later. At the subsequent interview he jested about the interview and continued to talk about the lie he used to get the job and to explain his unemployment. 'It was a really sad, sad day at the end of the quarter when my Mom and I went and we took all my stuff from the dorm room home. I went into the hospital January 2, 1982 because I had become delusional and the depression was getting worse. I was there for 3 months and it really messed up my academic career for awhile."

Despite this first episode, Tom went back and completed college. Although his journalism jobs have mostly ended with exacerbations of bipolar disorder, he struggles on:

It's awful! It's like, you know, a little ant crawling up a hill, and you just kick him down every so often, and he'll... he'll climb back up and continue — but it's gonna take him a long time. I'm just trying to get back on any track that I can. Because once you get another job, you could just as easily lose it — like you lose the last one. Every time you lose a job it becomes harder to get another one. You have to explain the last one. You have to keep a positive attitude and think that you will find a job and that somehow, if you do go through another episode, that it won't be bad, or that you'll be able to catch it early enough that you'll cut it short somehow. You can't predict these things. You know, you stop predicting.

And so Tom lives primarily in the "now" that comes between manic depressive episodes.

Thelma
Thelma introduced herself to her occupational therapist by reading her résumé aloud as part of her clinical assessment. She also produced a 25-year-old picture from her high school graduation that showed her as a young black woman who was "thin with pretty hair." The photograph recalls a time when she was on the student council, the honor society, the Spanish Club, and the Girls Athletic Association.

Not expected to become a breadwinner, she entered a junior college instead of a university like her brother. Nevertheless, she majored in Spanish and aspired to be an interpreter for the United Nations. She worked part time in an office for 2 years to support herself in college. After dropping out, she worked in several factory jobs and at a bank but she "never worked more than 2 years anywhere." Her résumé chronicled 6 years of work over a 14-year span, ending 11 years before the beginning of this study.

Like Tom, Thelma experienced her first episode of bipolar disorder while in college. She told the story in a typically breathless, uninterrupted blast of conversation:

"My doctor wouldn't let me go to school. He said it was too much on my brain — to study and go to school. Even if I had a part-time job, it was gonna be too much on me. I would be taxing myself and get sick again and be in the hospital. So I had to stop going to school when I was 21.

In Thelma's view, bipolar disorder ruined her plans to "get a career, have a family and live happily ever after." It
simply "never did happen." Instead, her "hopes and dreams went down the tubes!" She confessed, "I'm overweight and I can't get my hair to grow back in!" Along with career hopes went her dreams of family life:

I thought, you know, eventually--I know I can't have 'em now, but years ago--I thought to have kids was--I can see now that, that was out of the picture too. I feel like I got cheated out of my life though! I can't really blame it all on mental illness, but it was part of the reason why I didn't get married and have a family--cause I thought that when you meet somebody you want to be with the rest of your life, you should level with him and tell him, you know. You can't keep Lithium a secret, you know, you got to put it somewhere in the house. He'll come across it eventually--"What's this, why you taking it for?" And if you don't go through a relationship with honesty, there's no use going through it--cause it's going to come out eventually--and most men don't like you to be lying to them--especially if you're gonna spend the rest of your life with them. And most men want family, you like it or not, most men would like to have at least one kid to say "I had kids," or something you know, so. My life got all screwed up.

Thelma came into the partial hospital every day and proudly pinned on her housing authority identification badge as a symbol of independence. Her independence is achieved at the expense of living in an environment in which she does not feel safe or free to be herself. She does not interact with anyone else in the building except her sister, who lives on another floor. She described her periods of isolation:

I've stayed in the house as long as 6 months and won't go anywhere. I'll eat popcorn and pop for breakfast, lunch, and dinner. I won't go outside except to check the mail and go back upstairs. I just read and watch TV and go to bed. I don't communicate. I don't even answer the phone.

For Thelma, life in the outside world is a constant struggle for survival in a milieu that does not welcome her kindly. When she does venture out, she must be back in her own apartment by 9:00 p.m. or she is not safe walking in the halls. Few others have been allowed to enter her apartment. Thelma does leave the world of her apartment a few times each year for a familiar destination:

I've been in and out of the hospital numerous times, too numerous to mention. I can't even count. I'm behind closed doors most of the year.

Thelma seems swept up in the ebb and tide of moving between her small apartment and the hospital. In the end, nothing else seems to be on the horizon:

Maybe I'll get to work eventually. I don't know. I have a funny feeling that's a pipe dream that'll never come true. My skills aren't that great. It's not worth my Social Security Disability to go out there and work until my next episode. If I ever get a job I'd have to pay full fee for my apartment. I don't see any red roses or white picket fences coming up, so the future's pretty much what it's always been: a few hospitalizations and having to pay bills—the same old, same old.

Narrative as Volitional Process

Tom and Thelma's stories are windows into their experience. Although it is obvious that such stories help people to communicate their experience to others, we assert two additional points: (a) the process of narrating stories enables people to understand themselves and their worlds, and (b) people not only tell, but also seek to live, their life stories. These views of the role of narrative go beyond what is currently formulated in occupational therapy theory concerning self-knowledge, motivation, and choices for action. Such a view of the nature of personal narratives has the potential to fill in critical gaps in the current conceptualization of motivation offered by the Model of Human Occupation (Kielhofner, 1985). Within this model, choices for action are explained by the concept of volition. The volition subsystem is the composite of three traits: personal causation, interests, and values. These traits are conceptualized as stable domains of self-knowledge that produce motives for choosing action. That is, personal causation, values, and interests represent an assemblage of memories, beliefs, and anticipations that the person possesses about self and the environment. These enduring images influence how the person is motivated. For example, persons whose personal causation includes the belief that they can control life events make plans and pay attention to feedback to achieve desired goals. Persons who feel, instead, that life events are externally controlled (i.e., by others or by outside circumstances) will plan less and have less need for feedback on the consequences of their behavior. Thus, one's sense of internal and external control is not only a set of beliefs about whether one can influence life events, but also motivates one to behave in particular ways.

This view of motivation is modeled on thinking that was dominant in the field of ego psychology when the model was developed just over a decade ago. In the Model of Human Occupation, as in ego psychology, it was emphasized that these inner traits were strong influences, if not determinants, of behaviors. Much research based on the Model of Human Occupation followed this line of reasoning, attempting to show relationships between volitional traits and behavior (Kielhofner, 1984; Kielhofner, 1986a, 1986b). Although that research provided some evidence that volitional traits had an influence on adaptive and maladaptive behavior, it relied on patterns of convergence and divergence among whole groups of persons studied. It did not account for the ways in which unique configurations of traits came together in each person's circumstance. Thus, the trait conceptualization is more helpful in thinking about classes or categories of persons than it is in thinking about the unique circumstances of a particular person.

Another important characteristic of the focus on traits is that it emphasizes structure over process. Although the Model of Human Occupation has sought to achieve, through its basis in systems theory, a more balanced view of the relationship of structure and process, it still relies heavily on the view of traits as internal structures determining behavior. Although the model has
Knowing Self

Self-knowledge depends on the ability to incorporate many fragments of past experience into a coherent whole (Schafer, 1981; Taylor, 1989). As Gergen and Gergen (1983) noted, present identity is “not a sudden and mysterious event, but a sensible result of a life story” (p. 255). Moreover, our self-images have as much to do with who we are becoming as with who we are presently (Kerby, 1991). This means that our attempts at self-understanding must relate an array of past, present, and potential life events into systematic wholes. This is not so to say that all of life coheres neatly into a single story, but that, whenever we seek to make sense of chunks of our life or to apprehend where we have been and are headed, we use stories to do so.

Tom’s story provides a challenge to his achieving a sense of coherence. His present view of life differs radically from the one he had in high school when his sights were set on becoming a big-city reporter. Now he is grateful to find any relevant job that will allow him to work and support himself. In his narrative, Tom bridged the distance between his adolescent dreams of greatness in journalism and his current aspiration to hold down a less demanding job in the less prestigious trade publications:

One of the keys is that you realize that you don’t have to move ahead—that you can stay in the same place, that it’s not such a terrible thing to give up ambition to some extent. You don’t have to share the same amount of ambition as your friends. I’m realizing that I have to sort of stop thinking of myself in the same peer group that I used to. My peer group was once all my college friends who are now climbing their ladders in their respective newspapers, whatever, publishing companies. I really think that if I keep comparing myself to them it’s only gonna make me angry and envious and hostile. So, really, now what’s emerging as my new peer group is all the other people with chronic illnesses who like me are just having to do the best that we can. I think you learn to scale down what you expect, but that doesn’t mean that you stop enjoying life—it just means that you have to find enjoyment in other things.

The discontinuities, incongruencies, ironies, and conflicts that occur in Tom’s life find meaning and coherence in the story of his struggle against bipolar disorder. Within this story, his willingness to abandon his original dreams allows him to avoid the possible tragedy of life ruined. Instead, Tom, as the protagonist, evokes characteristic perseverance and humor to continue the struggle against the tragedy that bipolar disorder would otherwise visit upon him.

Interestingly, within the story we can see that Tom maintains important continuities. The mastery and achievement of a successful career is replaced by mastery of the disease process and achievement of a liveable life in spite of it. Writing as an investigative reporter metamorphoses into writing in a trade journal. Thus, both transformation and continuity exist in his story. The events, motives, and actions in Tom’s story depend on the narrative plot for their meaning. The first episode of illness was not the beginning of the end, but the beginning of a lifelong
struggle. Early ambitions are not futile dreams, but aspirations that must be modified to adapt to the reality of chronic illness. The meaning of illness onset or youthful aspirations is found in their relationship as episodes in the entire story.

That each event in the life story both contributes to and draws its significance from the overall story can also be seen in Thelma's narrative. The young Thelma, thin with pretty hair, active and self-determined, smart and college-bound, is transformed by her account into a chronically ill, unemployed and unemployable, overweight and undesirable woman whose hair is falling out. According to Thelma's story, she has been cheated out of her dreams of having a family and a career.

In a sense, both Tom and Thelma are what Bateson (1990) labeled refugees with undetermined futures; they have been displaced from their life courses by the discontinuities inflicted by bipolar disorder. But their individual stories cast different meanings on the experience. Tom may be on "plan F" now, but he still believes in the possibilities of regrouping and taking charge of life. Thelma thinks she is resigned to her fate; in her words, "As soon as I got sick the whole bottom fell out." Moreover, Thelma sees that bipolar disorder has fractured and isolated her from relationships:

It shakes the hell out of the foundation. It really does! You're never a whole person anymore. People look at you [as] "nut head" and this and that. Aw, it's just terrible! Sometimes you just meet a new bunch of friends and not even mention you have mental illness. The less they know about you, the less they can get into your business; it's terrible! Or folks know you're in and out of the hospital. "She's a nut head, fruitcakes!" and on like that. They don't take you seriously or anything. They get a new scoop on you and everybody knows about it before the next morning all about your past and your present, terrible; there's no peace, no peace.

For Thelma, life is clearly ruined with "no roses or white picket fence coming up" in the future. In the end, she knows that her story is going to be the "same old, same old" thing that includes more hospitalizations, more isolation, and more struggles to find happiness and contentment. She already lives in the ending of her story — there is no new chapter, just a long-drawn-out tragic ending.

Tom and Thelma's stories make their various volitional decisions clearer by locating them in a plot. The narrative plots tie together a series of actions and experiences that occur over the life span, becoming more than a string of disconnected events (Catani, 1981; Gergen & Gergen, 1988; MacIntyre, 1981; Mattingly, 1991a; Mattingly, 1991b; Mattingly, in press). Indeed, stories give decisions and actions meaning and context. Tom's decisions to keep seeking work, to modify his career goals, to pursue his interest in writing, and to relinquish what he can control while using his skills are all understood by the story. Thelma's hopelessness, her choices to isolate herself, her lack of goals for the future, and the lethargy of her interests similarly belong to a meaningful aggregate.

The story achieves something that the trait approach cannot — making a whole of the parts.

Experiencing and Narrating

Tom and Thelma's stories also demonstrate an interesting relationship between experience and narrative. As currently articulated in the Model of Human Occupation (Kielhofner & Burke, 1985) traits are assumed to be the accumulation of experience — for example, accrued successes summing to a feeling of efficacy. However, such a model must assume a linear relationship between experience and memory. In contrast, Barclay (1986) noted that the task of our autobiographical work is not correctness in detail, but maintenance of the integrity of our life story. Memories must be constituted to be compatible with existing self-knowledge. As the life story develops and changes in response to new events, the meaning of actions or events in the past may change. What once was brave may now be foolhardy; what was rash may be a stroke of genius. For example, Tom's early ambitions would become sources of frustration if not abandoned; Thelma's family and career goals would become false hopes.

Bateson (1990) explained that composing a life involves a continual re-imagining of the future and reinterpretation of the past to give meaning to the present, remembering best those events that prefigured what followed, forgetting those that proved to have no meaning within the narrative. (pp. 29-30)

Thus in Tom and Thelma's stories, what is at stake is not the accuracy of historical facts, but the meaning that emerges out of the overall narrative. As Schafer (1981) argued, the story that is told at any time is the only story that makes sense to the narrator to be telling.

Volitional Narratives and Action

More striking than how Tom and Thelma's stories reveal a great deal about their volition is how their stories motivate them. Tom's belief that he can achieve an acceptable life, salvage his capacities, and pursue journalistic interests also moves him to action. Tom enacted this story by interviewing for, and being offered, a job on a trade publication within the broader field of journalism.

Thelma, on the other hand, remains locked in her story that her life has been ruined:

I can't think of what I would excel with. I don't know. I type pretty good. I could do stuff like that. That wouldn't be so good, just typing all day long for somebody like term papers and stuff, assignments here and something small or something. That would sort of dwindle down to nothing.

In the context of this volitional narrative, Thelma showed no motivation to try to use her skills. There is no hope of salvaging things in a life where things just "dwindle down to nothing." In fact, she revealed her volitional
reasoning in her stories about the future:

I wouldn't mind going back to school if I knew it would help me, but I don't know. Sitting in the classroom all those weeks and months and not getting anything out of it, it would be a very sour experience. And if I ever got a job I got to pay full fee for my apartment. I don't want to be making the wrong move and then I'll be stuck with nothing, you know. I don't want to open up any doors I couldn't close.

Opening up the possibility of things getting worse by attempting to make them better dominates Thelma's deliberations:

It's hard getting a job out there. You see, you may get one and then you may get sick again, or have a relapse. You're out in the cold again trying to get back on disability. You might not even get as much as you have now. I've got to weigh the situation very carefully before I go out there and bite the dust again.

Clearly Thelma's volition is dominated by a narrative in which any attempt to make life much better carries the risk of a further downward slide that makes life even worse. Thelma's narrative exhibits the full context of action that gives skills meaning in the composition of her life. Belief in skills does not translate mechanistically into job-seeking behaviors in a story that also includes the injustices of the welfare system, prejudice against mental illness, and the unpredictability of bipolar disorder. Fragmented traits and circumstances take shape within the context of her life story and, as with Tom, it is the story that does not motivate her.

These stories illustrate how personal narratives elucidate the past, present, and future of the storytellers' lives and direct the composition of their lives as they seek to live the story they are telling. However, telling need not always precede doing. Rather, telling the story is implied in living it and the actual act of telling it is unnecessary for the story to proceed (Mancuso & Sarbin, 1983; Kerby, 1991). As one's life story unfolds, one may tell the story to oneself and others. This creates a continuous interchange between telling and living the life story. Or, as White (1988/1989) argued, behavior is a form of authoring oneself.

The personal narrative requires that one's behaviors become a logical extension of the action and plot of the life story. Tom is living his story of working his way back out of his last manic episode, finding work, and maintaining some semblance of continuity in his career. During the time he was interviewed for this study, he proceeded to compose several chapters of his life. At the beginning of this study he was in a patient role, recovering from a manic episode and living with his mother. During the study he reauthored himself into the roles of volunteer, job seeker, and finally employee living on his own.

Thelma is in the process of composing her life story as well. She lives a ruined life that does not move forward. She neither creates nor tells new chapters. Instead, she revisits past attempts at moving forward into new roles that were unsuccessful while managing to catch a few random pleasures along the way. Thelma's life story remains the "same old, same old" thing as she remains in the same roles.

Conclusion

The purpose of this study was to examine the value of a narrative approach to understanding volition. Narrative provides a complementary way of viewing motivation and choice that overcomes some of the limitations of the trait approach. Although traits are useful in explaining and predicting choices for action, they do not account for the actual cognitive/emotional process by which persons view themselves and make decisions. The existing concept of volition is expanded by the idea of narrative that offers an explanation of how self-attrition, motives, and intentions are formed and play out in interactions with the world. Thus, volitional process involves the telling and living of a personal narrative situated in a cultural and historical context. The dynamic volition of real life includes the experience of events occurring in a real sequence and in a real life story. Volition in action, which is replete with ambiguity, can only be formulated and understood in the life narrative. Moreover, human actions and decisions take place within that same personal narrative with its inconsistencies, incongruencies, ironies, and conflicts.

The trait approach helps us understand that Tom is more internally controlled than Thelma, and it is helpful to predict how each might interpret experience and choose action. However, the narratives that Tom and Thelma related give us an understanding of their sense of personal control, well beyond a simple quantification or characterization of this personal causation trait. In their stories we come to understand the context in which Tom and Thelma draw different conclusions about their ability to control their lives. In their stories we encounter conflicts, regrets, hopes, and fears that surround and enliven each one's sense of personal causation. In the stories, the personal causation of Tom and Thelma are more personal and comprehensible. And finally, the stories of Tom and Thelma illuminate how and why they are choosing their courses of action.

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References


