Existential Concerns of Individuals Living with Chronic Mental Illness in Guam

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EXISTENTIAL CONCERNS OF INDIVIDUALS
LIVING WITH CHRONIC MENTAL ILLNESS IN GUAM

A Dissertation

Presented to the Faculty of
Antioch University Seattle
Seattle, WA

In Partial Fulfillment
of the Requirements of the Degree
Doctor of Psychology

By
Cristina Maria B. Dela Cruz
June 2013
EXISTENTIAL CONCERNS OF INDIVIDUALS
LIVING WITH CHRONIC MENTAL ILLNESS IN GUAM

This dissertation, by Cristina Maria B. Dela Cruz, has been approved by the committee members signed below who recommend that it be accepted by the faculty of the Antioch University Seattle at Seattle, WA in partial fulfillment of requirements for the degree of

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ABSTRACT

EXISTENTIAL CONCERNS OF INDIVIDUALS LIVING WITH CHRONIC MENTAL ILLNESS IN GUAM

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Individuals living with chronic mental illness experience a host of challenges associated with the symptoms of their illness. In an effort to help restore healthy functioning, mental health treatment for individuals with chronic mental illness thus focuses primarily on symptom reduction and management. Recent research exploring the lived experience of individuals with chronic mental illness suggests that apart from their symptoms, these individuals also encounter existential issues related to the self, relationships with others, temporality, making meaning out of the illness experience, and managing life with the illness. At the same time, however, this research has tended to focus on distinct aspects of chronic mental illness rather than the overall experience of day-to-day living with the illness, resulting in a fragmented view of the phenomenon. Moreover, these studies have been conducted primarily in Europe, as well as North America, Australia, and South Africa, but not in Asia or the islands of the Pacific. The goal of this study was twofold: to gain a comprehensive understanding of the lived experience of chronic mental illness in the Pacific Island of Guam, as well as to examine whether the themes found in the extant literature are applicable to individuals from Pacific Islander and Asian cultures living in Guam. Interpretative Phenomenological Analysis was used to guide the research, emphasizing the phenomenological approach to understanding the lived
experience of individuals and how they make meaning of their experience. Ten
individuals living with chronic mental illness in Guam were interviewed. The interviews
were designed to elicit descriptions of the participants’ experience of chronic mental
illness and its impact on their daily lives. Results suggest that the participants
encountered existential concerns regarding defining and knowing the self, navigating
relationships with others, trying to understand the illness, managing the illness, desiring
control, and living a meaningful life with the illness, and that the role of the family
impacted these concerns. Implications for clinical practice in Guam include both the
integration of existential-oriented psychotherapy, as well as interventions that involve the
individual’s family to optimize the family’s impact on the individual’s existential well-
being. The electronic version of this dissertation is at OhioLink ETD Center,
www.ohiolink.edu/etd
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Introduction

Objectives of the Study

Although mental health professionals may have a general sense of the kinds of symptoms individuals living with chronic mental illness experience, such knowledge does not necessarily translate to an understanding of what such individuals experience as a consequence of their psychiatric conditions. Despite the benefits of mental health treatment available through medication, therapy, and other mental health services, most often the aim of such interventions revolves around symptom reduction and management. Meanwhile, the mental health patient as an individual with worries, fears, ambitions, and hopes becomes ensnared in the mental health system and risks the erosion of an identity and personality beyond their diagnosis. Consequently, some aspects of the individual may remain buried by the focus on symptom management, leaving those with chronic mental illness without an avenue to discuss or receive assistance for other issues they may be experiencing as a consequence of and unrelated to their psychiatric condition, thereby alienating them from the very system that has been established to assist them. In an effort to better address the various aspects of mental illness, it is imperative that mental health professionals understand what individuals living with chronic mental illness experience in relation to their condition beyond their symptoms.

The overall goal of this study was to explore and identify specific existential concerns affecting the lives of individuals living with chronic mental illness in Guam. Several more specific objectives to support this endeavor included (1) to better understand the sense of self experienced by individuals with chronic mental illness, (2) to better understand how individuals with chronic mental illness experience interpersonal
relationships, (3) to better understand how individuals with chronic mental illness make meaning in their lives, (4) to explore the experiences of individuals with chronic mental illness with respect to their being diagnosed, receiving treatment, and managing their lives with chronic mental illness, and (5) to better understand the experience of living with chronic mental illness in the context of such existential themes as freedom and responsibility, isolation and desire for connection, meaning and meaninglessness, life and death.

The present study is of potential significance for the field of professional psychology, particularly in Guam, in that it provides critical knowledge garnered from individuals with chronic mental illness about the challenges they face as they engage in their daily lives with a life-long condition. Given that the source of information was those actually living with chronic mental illness on a daily basis—thus providing valuable insights into what they need in order to live more fully engaged with themselves and their world—such knowledge can further inform the development of effective treatment interventions and mental health services. Psychologists may benefit from learning about the chronic mental illness experience from the voices of those living it day-to-day; understanding the illness experience from the clients’ perspective may also be helpful when engaging them in treatment planning. Finally, the present study also contributes to the field by highlighting the importance of treating the whole individual rather than focusing solely on the illness aspect of the person. Individuals living with chronic mental illness often encounter stigmatization because of their illness; it is important for psychologists to prevent themselves from overlooking the person underneath the symptoms.
Theoretical Framework

Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2008) was used to guide the design of the study and the analysis of the data. This approach aims to explore the lived experience of those experiencing a particular phenomenon, to examine each case in detail on its own, and to look at the similarities and differences across cases. The goal is not to test or prove a hypothesis, nor to make broad generalizations, but to draw an account of what it is like for individuals who have experienced the phenomenon in question. IPA also asserts that although it is important to understand the experiences of the individual with regard to the phenomenon directly, it is also important for the researcher to provide another level of interpretation to assist with developing an understanding of the phenomenon beyond even the awareness of the individual. This does not mean that the individual’s account is incorrect or insufficient; rather, the interpretative analysis allows for additional understanding.

Following the works of such existential philosophers as Edmund Husserl, Martin Heidegger, Maurice Merleau-Ponty, and Jean-Paul Sartre, IPA incorporates phenomenology, hermeneutics, and idiography to explain the process of gleaning from interviews a deeper exploration and understanding of the lived experiences of individuals with regard to a particular phenomenon. Furthermore, IPA is used to ascertain the meanings ascribed to these experiences through a systematic analysis and interpretation of the data by the researcher (Smith et al., 2009). As IPA is steeped in the philosophies of phenomenology and existentialism, this approach seems relevant to the present study’s goal of exploring the lived experience of individuals living with chronic mental illness,
including the impact mental illness has on their existence, thus allowing the researcher to ascertain the existential concerns that arise when living with chronic mental illness.

**Research Question**

The research question was as follows: What do individuals with chronic mental illness experience as they live their daily lives in Guam? A specific focus was the existential concerns they encounter as a consequence of having a life-long condition impact their existence: that is, their interactions with themselves, others, and their world. Related questions that were addressed pertained to more specific aspects of living with chronic mental illness, such as being diagnosed, receiving treatment, being on medication, being hospitalized, receiving other mental health services, and living with chronic mental illness.
Literature Review

Existential Philosophy and Literature

In order to explore the existential concerns of individuals living with chronic mental illness, it is important to first understand the philosophical tradition of existentialism and its approach to conceptualizing human experience. This section of the literature review examines the work of five existential writers who played a fundamental role in shaping the later works of existential psychotherapists. The works reviewed include key philosophical texts and literature that helped to define existentialism. These include Søren Kierkegaard’s *The Sickness Unto Death*, Fyodor Dostoevsky’s *Notes from Underground* and *The Double*, Leo Tolstoy’s *The Death of Ivan Ilych*, Jean-Paul Sartre’s *Nausea* and *Existentialism is a Humanism*, and Albert Camus’s *The Stranger* and *The Myth of Sisyphus*.

**Søren Kierkegaard.** In his book *The Sickness Unto Death* (1849/2004), Danish philosopher Søren Kierkegaard discussed the concept of despair as it relates to human beings and their awareness of themselves and the issue of choice. He argued that despair is universal in that all human beings experience states of despair whether they are conscious of it or not, and that despair is not to be viewed as a negative aspect of living that should be avoided or eradicated. Rather, Kierkegaard posited that despair is an inherent part of the individual’s development and a sign that the individual is at a point where a choice must be made toward fulfilling his potentiality as a self, which Kierkegaard defined as the synthesis or balance between the dialectic of spirit and body. Despair is providential in that it is a time to motivate oneself toward growth and the development of the self. Rather than viewing despair as symptoms of pathology, failure,
or inadequacy, the individual is provided the opportunity to confront his despair and move toward greater balance in his life through increased consciousness of the self.

Although despair is universal, the kind of despair the individual is experiencing at a given moment and whether he is aware of the despair or not is determined by one’s level of consciousness. Kierkegaard (1849/2004) argued that individuals may not be aware or conscious of being in despair even when they claim to be in despair. That is, individuals tend to attribute feelings of despair to external events that are happening to themselves, but the external event that supposedly caused the despair is not actually the despair itself. Rather, the despair lies underneath the external event, and it is the external event that signals to the individual that he is and has always been in despair despite being unconscious of it; this despair is really about his self. Similarly, mental health issues are not the actual experiences of despair. Depression, anxiety, or other mental disorders are really signals that the individual is in despair about his sense of self and can no longer seek refuge from this despair through work, relationships, or other means used to stave off the despair. The symptoms, in and of themselves, may also have served to keep the individual from having to experience the underlying despair of the self in that the symptoms acted as a means to disguise the despair. Kierkegaard argued that external events that are seemingly more plausible as causing despair, such as grief, loss of relationships, economic hardship, and so forth, are merely what individuals tend to say are the reasons for their despair. He suggested that individuals do not recognize that the despair has always been within them, separate from these events, and that they have been blinded to this despair about the self by the distraction of external events occurring in their day-to-day lives.
According to Kierkegaard (1849/2004), the self involves striving toward a balance among the different aspects of a person, such as the emotional, cognitive, and volitional parts of human beings; this balance occurs within three dialectics: (1) infinite and finite, (2) freedom (or possibility) and necessity, and (3) eternal and temporal. These dialectics do not exist as an either-or dilemma where the individual chooses to live at either end of each of the dialectics. These dialectics occur along a continuum, and individuals make choices that fall within these continuums. When there is an imbalance among these factors, despair is said to exist. For example, an individual who chooses to live more along the infinite end of the continuum may sacrifice real-world or earthly concerns in favor of a life lived in imagination. An example of this may be the individual who develops psychotic symptoms and, thus, lives in alternate realities. Conversely, an individual who becomes embroiled with ensuring that aspects of their earthly, day-to-day living is taken care of ends up foregoing the more creative, imaginative part of existence. In either case, balance is not achieved, resulting in a state of despair, which can then be addressed by striving toward greater balance among these dialectical factors.

With regard to the second factor, when the individual places greater emphasis on freedom or possibility, while ignoring the importance of necessity, the individual experiences life as having no limits or structure and, consequently, behaves as though all endeavors in life are in and of themselves mere possibilities, requiring no follow through to achieve an end goal (Kierkegaard, 1849/2004). This is reminiscent of the pleasure-seeking individual, one who acts without regard to responsibility. On the contrary, when necessity is valued at the cost of freedom or possibility, the individual ends up feeling
chained or bogged down by the demands of what is immediate, rather than allowing himself to see beyond what is necessary and pursue personal drive or ambition.

The third dialectic pertains to the individual’s level of self-awareness involving the opposites of the continuum, the eternal and temporal (Kierkegaard, 1849/2004). As the individual becomes increasingly aware of his self, he also grows beyond the immediate and material world of the temporary and becomes motivated to move toward the eternal goal of becoming a self. Any imbalance among these three dialectics then becomes the individual’s experience of despair, such that he has failed to successfully navigate within the spectrum of each of the dialectics and establish a synthesis between the infinite and finite, possibility and necessity, and the temporal and eternal, which helps the individual to develop into a self.

Kierkegaard (1849/2004) defined the sickness unto death as being the despair that accompanies the inability to die. This aspect of despair appears when the individual is not wanting to be himself and desires to be rid of his self, but is unable to do so. Despair is thus the unrelenting torment of knowing that one cannot be rid of oneself, regardless of the attempts one makes to avoid being one’s self. Kierkegaard offered the example of a young woman who gets thrown into a state of despair when her romantic relationship comes to an end. Her despair, according to Kierkegaard, is not that she lost her lover, but rather that she lost the ability to define herself as her lover’s partner, thereby not having to acknowledge her underlying despair of not wanting to be herself. When this occurs, the young woman’s deep despair becomes overwhelming as she is left to face herself and the awareness that she cannot rid herself of her self. As such, her despair becomes her
sickness in that she is unable to annihilate the self she so desperately desired to rid herself of by becoming her lover’s partner.

With respect to wanting to rid oneself of its self and the inability to die, death can mean the physical death of the person, as well as the death of the self by becoming a non-being or non-self (i.e., nothingness). Kierkegaard (1849/2004) offered as examples the individual with psychosis and the individual who commits suicide. The emergence of psychotic symptoms is the despair over wanting to be rid of one’s self, to the point where the individual enters the depths of such self-loathing that he will find ways to overcome that despair and thus develop substitute identities or realities to avoid that despair and attempt to eradicate his underlying self. The individual who commits suicide chooses to terminate the actual existence of the self and the experience of despair. For this individual, the despair over having to be his own self became so overwhelming and tormenting that he found physical death as the only means to be rid of his self and despair.

This not wanting to be oneself is only one form of despair. Its opposite, the despair of wanting to be oneself, constitutes another form (Kierkegaard, 1849/2004). The individual with this form of despair suffers the torment of feeling forced to be a self that goes against the sense of self he desires, thus leading him to experience a state of despair over wanting to be what he considers his real self. With this form of despair, the individual’s level of consciousness of the self is much increased as opposed to the level of consciousness experienced by the individual not wanting to be himself. The individual becomes defiant against the external force which established the disliked self and is determined to break free from the expectations he feels are being imposed on his real self.
The individual wishes to be his own master and thus experiences despair over not only the inability to become the self he desires, but also the increased awareness that he is faced with the despair of wanting to be himself. In this case, the individual then becomes enraged and filled with resentment and anger toward the world and existence for imposing expectations regarding the self that he is supposed to become.

The Russian novelists: Fyodor Dostoevsky and Leo Tolstoy. In his outline of existentialism and existential philosophers, Barrett (1958) included the Russian novelists Fyodor Dostoevsky and Leo Tolstoy as significant contributors to existential philosophy despite the fact that neither were philosophers per se. Dostoevsky and Tolstoy did, however, live and write during nineteenth century Russia when the culture was undergoing much change in its landscape, which left the two novelists with the opportunity to confront and illustrate the existential issues of the time through their work. Barrett proposed that suffering, as well as the questioning of existence and its meaning, abounds when the sociohistorical context is undergoing change due to the breakdown of pre-existing social structures that once prescribed the ways in which to live. With the loss of such structures and norms, one is then left to question what life and existence mean, without any sense of guidance as to how to answer these questions. As Russia was undergoing such a breakdown of its once predictable structures and norms, it seemed only likely that its people would be faced with questions of how to deal with the changes and what these changes meant in terms of the meaning of their existence. Barrett pointed to Dostoevsky and Tolstoy as having aptly captured the existential issues that may have been present for individuals during that time in Russia.
Fyodor Dostoevsky. The works of Russian novelist Fyodor Dostoevsky reflect existential themes of freedom and free will, despair, suffering, and consciousness. In the first part of his novel Notes from Underground, Dostoevsky (1864/2009) explicated his thoughts on the cultural landscape of nineteenth century Russia, which is in many ways akin to the cultural landscape of much of the industrialized world today. Nineteenth century Russia was undergoing change as the Enlightenment period was bringing about an emphasis on reason, logic, science, and mathematics. The concern at the time was to discover the laws of nature scientifically and mathematically, thus prescribing predictable, logical, and rational ways of being in the world. It was believed that individuals desire to do what is in their best interest and that the goals they would set out to achieve would be toward the desire to do what is good for their well-being. Such, it was proposed, was the law of nature to which every individual aspired. Dostoevsky did not agree with this notion and questioned whether the effort at the time to mathematically and scientifically discover the law of nature was realistically possible and whether this aim was necessarily in the best interest of the individual in the first place.

Dostoevsky (1864/2009) argued that the essence of human nature and of the human being is free will or independent volition. He believed that the individual will not necessarily and predictably make choices to do what will bring about her well-being, contrary to what reason and logic might assume. Although the individual may choose such a path under many circumstances, she will nevertheless continue to strive toward becoming an individual with her own personality and independence. After all, according to Dostoevsky, it is the individual’s personality and independence that characterize herself. Upon closer examination of various historical events, it is fairly evident how
human beings have acted and continue to act according to their own free will. Dostoevsky explained that despite the notion that all human beings want what is good for their well-being, the individual will continue to assert her independence and free will through choices that may at times be quite opposite of what is considered best for her well-being. Dostoevsky cited acts of destruction and chaos as reflections of the push for independent volition, such as war, the torture of another human being, and revenge for being offended. He argued that the individual will even seek out suffering if only to confirm her individuality apart from the masses, thus contradicting the sense that reason and logic are necessarily the goals of all human beings.

In the second part of his novel *Notes from Underground*, Dostoevsky (1864/2009) illustrated his philosophy through the story of the Underground Man and his struggle to assert his independence and individuality. One sub-story has the Underground Man wanting to seek revenge against an officer who brushed him aside as if he did not exist. The Underground Man speaks about how he spent many waking hours toiling over how to seek revenge, though not through any malicious deed. Instead, he hoped to avenge himself by passing the officer on the street and at least bumping shoulder to shoulder with him to show the officer that he, too, exists. This event speaks to Dostoevsky’s assertion that the individual wishes to be recognized as having her own independence and personality separate from everyone else, essentially making her existence known, and that the individual will not be content to be mathematically or scientifically reduced to a mere cog among many others in a machine.

The story proceeds to the Underground Man’s experience when he decides to join his former schoolmates, whom he proclaims to despise for not being intellectual like
himself, for dinner one evening (Dostoevsky, 1864/2009). Before the evening’s end, he becomes angry with these schoolmates for their criticism of his being an intellectual, for wanting to stand apart from the common man, and for not merely accepting to live within the status quo. He again spends much time in torment and resentment of these schoolmates but at the same time struggles with feeling ashamed for believing he has embarrassed himself with his anger. He again fantasizes about seeking revenge upon his schoolmates. This incident illustrates Dostoevsky’s (1864/2009) belief that, despite any potential desire to fit well within society, which may reasonably make life easier for the individual, her natural inclination to assert her individuality and personality will nevertheless prevail, even if in the course of experiencing resentment, suffering, or despair.

In the third major event in the novel Notes from Underground, the Underground Man meets a young woman who is enslaved in a brothel. He encourages her to think about her situation, helping her to realize that she is more than a slave and that she, too, has her own independence and free will if she so chooses (Dostoevsky, 1864/2009). The Underground Man offers her his address if she is able to leave the brothel but later becomes tremendously anxious that she might actually arrive at his apartment. His anxiety stems from his perception that he deceived her into thinking he was well-off, only to risk her finding out that he is living shabbily, without money. When the woman does finally arrive at his apartment, he becomes irate and demands that she leave, but not without first insulting her. He later agonizes over having done that to her and fantasizes about chasing after her and reconciling but soon after thinks how it might be better for her that she walked away humiliated. Again, Dostoevsky (1864/2009) is emphasizing
how the assumption that all human beings will act according to reason and logic toward the achievement of well-being does not hold true and that the individual will still toil and be torn at times about committing acts that are destructive, producing suffering and despair, if only to reaffirm her existence and independent volition. For the Underground Man, his own affirmation of himself comes through the act of humiliating the woman and consequently suffering from the turmoil of having humiliated her and feeling conflicted about it. At the same time he appeases his inner conflict by believing that he provided her with the gift of consciousness in that the humiliation will serve as a reminder of her own consciousness and existence. Thus, she will no longer be a mere slave to anyone, but an individual in and of herself.

In Dostoevsky’s novel *The Double* (1846/2009), he used the character of Mr. Golyadkin to illustrate the conjecture that the individual will not be satisfied with being an unrecognizable self amid other identical selves in society. In the midst of despair over feeling humiliated for being thrown out of a party (to which he invited himself), Mr. Golyadkin soon thereafter meets his double. His double looks exactly like him, and they initially develop a seemingly friendly relationship, whereby Mr. Golyadkin sees his double as someone he could trust and conspire with against all those he despises at his work. His relationship with his double changes after his double gains employment at his workplace and quickly begins to outshine him. No one else at work notices that this new employee is an exact duplicate of Mr. Golyadkin in physical likeness, much to Mr. Golyadkin’s surprise and discontent, as he realizes that he is looked upon as merely another faceless being in the workplace. As his double begins to achieve greater status at work, Mr. Golyadkin becomes resentful of his double’s presence and begins to believe
that his double’s presence is the doing of some authority who is out to conquer him. Throughout the story, Mr. Golyadkin becomes increasingly disturbed about his double’s presence, and he unsuccessfully tries to convince his supervisors and others (including his double) that he and his double are separate individuals each with his own personality and independence. In the end, when he attempts to reveal his double as a separate individual who has been deceiving everyone, he is deemed as insane and put in an asylum.

This particular story again reflects Dostoevsky’s (1846/2009) contention that the individual will always desire to be recognized as an independent being with her own personality and will and will, thus, not be complacent to allow herself to be reduced to a non-being. The individual is driven to assert her own self, even in the face of any denial or prohibition to do so. Although society may be striving toward mathematically and scientifically dissecting the human being for further understanding of its desires and wishes in order to then formulate a prescribed rational and logical means of being, it is inherent within the individual to want to fight against this and make known her significance as an individual, even if to do so produces despair, suffering, chaos, or the destruction of self or others. The character’s admission to an insane asylum also speaks to society’s desire for conformity; to deviate from this rational and logical way of behaving would only result in the individual’s exile from society.

**Leo Tolstoy.** In his short story *The Death of Ivan Ilych* Leo Tolstoy (1886/2003) illustrates the themes of death anxiety, meaninglessness, and isolation. The story is about Ivan Ilych, a man who lives his life according to what he has always believed was the proper way to live—working hard to establish a stable and reputable career in
government service, marrying, having children, and otherwise pursuing a higher standard of living for himself and his family. His life goes according to plan for the most part, punctuated with moments of good fortune and difficulties, including promotions as well as loss of promotion opportunities, the deaths of some of his children, and struggles and triumphs within his marriage. As his life begins to peak (i.e., with a new promotion; a new house, which he furnishes to his liking; positive educational opportunities for his children; and improved relations with his wife), he succumbs to a gnawing pain in his side which, for the remainder of the story, becomes progressively worse with the cause of his illness never identified.

Ivan Ilych goes through a period of experiencing much death anxiety as he begins to fear that his illness will eventually lead to his death, despite everyone else around him refusing to acknowledge this indication (Tolstoy, 1886/2003). As the gnawing pain in his side worsens and he begins to grow weaker, he comes to believe he is dying and becomes anxious that he will soon meet the end of his existence. Ivan Ilych questions the many doctors he sees about the severity of his illness, but the doctors evade his query and respond with only conjectures as to the diagnosis of his ailment. As Ivan Ilych grows increasingly ill and weaker, he finds that his wife, their daughter, and the doctors avoid any mention of his illness and appear unwilling to admit the possibility of his dying. His only source of comfort is one of his servants, who is more open to Ivan Ilych’s pending death.

The theme of meaninglessness emerges as he starts to question his life and whether he has actually lived it properly as he had always believed he had. As he recalls his life, he sadly acknowledges to himself that all that he has done in his life has actually
been meaningless, and he becomes ever more anxious about dying. He spent his life pursuing endeavors that he believed were the proper way of engaging in life, only to later realize as he is dying that what he thought would bring him happiness did not actually do so. Ivan Ilych recalls his childhood as perhaps being the only memory of happiness he has known, and thus he feels saddened that even the high peaks in his life, when he experienced success and happiness, may not have truly been the happiest and most meaningful moments in his life (Tolstoy, 1886/2003). He then questions what is the right way to live if he had lived his life incorrectly. This causes him much turmoil as he nears his death.

The third existential theme of isolation runs rampant from the beginning to the end of the story. Upon learning of Ivan Ilych’s death, his colleagues’ private thoughts become occupied with the possible promotions and changes at work that would result from his death, and they find relief that the death had occurred to someone other than themselves (thus also revealing their own death anxiety) (Tolstoy, 1886/2003). Ivan Ilych’s wife continues to avoid admitting that her husband may be dying; his daughter seems almost annoyed that his illness is interfering with her happiness (again touching on the death anxiety theme). What Tolstoy (1886/2003) might have attempted to convey is the acknowledgement that all individuals are truly alone in the world, even in the experience of death. This may not be because people truly do not care for one another, but rather because all individuals are struggling with issues of existence as they navigate through life, hoping that what they are doing is proper, or correct, or meaningful. When confronted with the reality of physical mortality, individuals begin to fear the possibility not only of their cessation, but also the possibility that their whole life’s endeavor may
not be as meaningful as they had assumed while they were living. In the end, it is each individual who will come to terms with whether or not he lived a meaningful life, as well as the inevitable anxiety that accompanies the eventual acknowledgment that one cannot escape death and that one is truly alone in dealing with this experience.

Jean-Paul Sartre. French philosopher Jean-Paul Sartre (1938/2007b) examined the existential themes of anxiety, existence and essence, and freedom and responsibility in his book *Nausea*. This story is written in a diary format with the main character, historian Antoine Roquentin, recounting his daily activities, experiences, thoughts, and feelings in an attempt to understand his sudden sensations of fear and anxiety, which he termed as the *nausea*. Roquentin is initially bewildered by this nausea, not knowing what is causing it or why he is experiencing it. In a similar fashion to the rationalists, who attempt to dissect phenomena and experience piece by piece, objectifying all objects and people in an attempt to understand the overall phenomenon, he begins to take detailed notes in his diary of all he observes and experiences. In doing so, Roquentin’s eventual understanding of the nausea, and of himself, begins to unfold as he undergoes a transformation process and answers his own questions about existence, which then helps him to better recognize what he is doing and who he is, as well as gain a clearer comprehension of what was causing the nausea and how he has been choosing to live his life.

In his diary Roquentin describes his latest project of researching and writing about a French aristocrat named Marquis de Rollebon (Sartre, 1938/2007b). As his work progresses, he soon becomes unnerved that he can no longer distinguish between the life of Rollebon and his own life, with both Rollebon and himself merging in his mind.
Roquentin eventually realizes that he has been indulging in his fervent work on Rollebon as a means to justify or hide from his own existence. This then leaves him questioning what his existence is all about and what the purpose of his existence and of existence in general is. In another moment Roquentin sees his reflection in a mirror, only to find that he does not really recognize himself, seeing only the separate parts of his face (i.e., his eyes, his nose, his hair), not seeing his image as a whole. Within other entries in his diary, Roquentin describes other experiences he has in which he begins to see other objects and other people only as minute, distinct parts, rather than as whole figures or images. These realizations, questions, and consequent anxious feelings that he experiences soon overcome him, leaving him feeling increasingly disturbed and disgusted: feelings which he refers to as the nausea that overcomes him. He then proceeds to find answers to his questions and quell this nausea by keeping a diary detailing all he observes.

As he continues the process of noting his daily activities and observations, he eventually begins to lose interest in his work on Marquis de Rollebon, realizing that he was merely using this project to avoid examining and participating in his own existence, deceiving himself into thinking that he had been living purposefully (Sartre, 1938/2007b). He sees that one cannot live in the past, for the past does not exist, and only the present is what is existence. As the nausea becomes increasingly bothersome, he comes to recognize that the nausea he has been experiencing was stemming from his increasing awareness that the minute details of objects and people mean nothing, that the purpose of existence is nothingness. Objects and people exist just as they are, and the essence that the individual infuses into objects and people (i.e., their characteristics like
color, expression, etc.) is merely her interpretation of the underlying existence. This illustrates Sartre’s (1938/2007b) contention that existence precedes essence. Another example Sartre used to iterate this new awareness is how Roquentin believes that it is not until we reflect upon and recount our experiences that they become adventures, and that until then, the individual’s experiences are merely contingent or accidental in that experiences occur as part of existence without meaning until she brings meaning into what we do. With his new-found awareness, Roquentin eventually comes to find relief from the nausea through actively choosing to live his life, rather than abdicating this freedom to choose for fear of assuming responsibility for his life. This brings Roquentin to his other revelation concerning the notion of freedom and responsibility, which is further illustrated in his relationship with his long-time, on-and-off lover, Anny.

Anny refers to Roquentin as her milestone because she uses him to gauge if and how much she has changed over the years since they meet only sporadically after having been apart for several years (Sartre, 1938/2007b). She expects that Roquentin will remain the same despite the length of time that has passed. At one point, Anny writes to Roquentin and requests to meet after not having seen each other for five years. Roquentin deliberates on his own whether to proceed with meeting her or not, first thinking it would be best to meet with her to see if they still have feelings for each other, then changing his mind and thinking it would be better to ignore her request and miss the appointment. Through this, Roquentin realizes that he has the freedom to choose whether to meet with Anny or not, but simultaneously he acknowledges that he is ultimately responsible for whatever outcome ensues from the decision he makes. He decides to meet with Anny, only to find that she has aged and changed over the last five years. As
they talk, he realizes that she has come to similar conclusions about existence meaning nothingness, but unlike him, Anny has chosen to avoid this awareness and delve into living in the past, recalling past memories and re-reading the same old French history book she has kept, instead of forging ahead with living in the present. Roquentin, on the other hand, has decided to forego the past, believing the past no longer exists and that only the present matters, thus choosing to live more purposefully in the present rather than return to his old ways of living in history. Upon realizing this difference between them, Anny and Roquentin part ways with the assumption and acceptance that they would likely not meet with each other again in the future.

Throughout the story, Sartre (1938/2007b) infused the concepts of existential anxiety, temporality, freedom and responsibility, and meaninglessness through the depiction of Roquentin and the nausea he experiences. Sartre purported that although existence may be meaningless at its core, with meaning coming from the essence infused into existence, the individual has the freedom to choose how to address this meaninglessness through the choices she makes in the present, as long as the individual is equally willing to accept responsibility for the outcome of her choices. When the individual chooses to abdicate that responsibility, this avoidance can take the form of living in the past, or using others to define or justify one’s existence, which can reach the point where the individual eventually loses sight of who she is or what her life means. The nausea is akin to the existential anxiety that signals when a choice is necessary in the individual’s life, such that the individual can then choose which direction to take in life and subsequently become gripped by the meaninglessness of the past or live more purposely in the present.
Five years after the original publication of Sartre’s *Nausea* in 1938, Sartre published *Being and Nothingness*, wherein he described his philosophy of existentialism, intended solely for an audience of philosophers (Sartre, 1946/2007a). By that time, however, the philosophy of existentialism had become a familiar concept among the general public. As such, *Being and Nothingness* received much criticism for its complexity and incomprehensibility, while Sartre was also criticized for proposing an existentialist philosophy that appeared pessimistic, negative, and contradictory to the ideals of humanism: characterizations that were in sharp contrast to Sartre’s intent behind his philosophy. In response to the criticisms, Sartre agreed to give a lecture in Paris in 1945 wherein he clarified the salient points in *Being and Nothingness*, offering a more simplified, concrete, and toned down version of his existentialist philosophy, which was then transcribed and published as the book *Existentialism is a Humanism* (Sartre, 1946/2007a).

In *Existentialism is a Humanism* Sartre (1946/2007a) highlighted several of the main criticisms lodged against existentialist philosophy and provided responses to clarify and defend against those criticisms. One such criticism was that existentialism holds people in a state of despair and quietism, whereby people are discouraged from taking action to improve their conditions or fight against external forces which oppress or otherwise negate them. Sartre argued that existentialism does the exact opposite, instead believing that the individual exists only in action. The individual is defined by her choices and actions, which also define all of humanity; the individual must not merely obediently follow the expectations and dictates of external forces or a higher power. Rather than believing that the individual is predestined toward a particular fate or that the
individual is defined externally by social, religious, or other mechanisms in the environment or even that the individual is defined by internal, biological, or physiological states, existentialism proposes that the individual determines who she is and who she will be by making choices and taking action to enact those choices. These choices and actions in turn define the rest of humanity in that how the individual chooses to be concurrently defines how the individual perceives all other individuals to exist.

A second criticism alleged that existentialist philosophy promotes the negative features of humanity, negating the more positive, optimistic aspect of human nature (Sartre, 1946/2007a). Critics argued that existentialism sees the individual as lost, living in despair or anguish, without hope. On the contrary, Sartre (1946/2007a) contended that existentialism emphasizes a kind of optimism about the individual, in that the philosophy views the individual as free and, thus, free to choose and enact action in order to realize or define herself and humanity. Rather than instill a false sense of hope in external conditions or a higher power or force that will guide the individual toward a particular direction or fate, the hope in existentialist philosophy stems from the belief that the individual has within herself the ability to define herself and the rest of humanity because of the very freedom to choose that she possesses. Instead of relegating the individual to a relentless state of despair or anguish, existentialism asserts that these states exist in a state of consciousness, which means that the individual is fully aware of her existence and her freedom to make choices.

The third criticism made against existentialism was the seeming emphasis on the solitude and isolation of the individual, rather than the elevation of her connection with the greater community or the world (Sartre, 1946/2007a). Sartre (1946/2007a) explained
that the individual is not at all in solitude as she navigates through her existence since, as
the individual realizes and defines herself, she is also realizing and defining the rest of
humanity, thus making the individual and humanity interdependent upon each other.
This interdependence also means that the individual cannot exist without the rest of
humanity, and humanity cannot exist without the individual. Although humanity does
not dictate what the individual is to be or become, humanity is a reflection of the
individual’s choices and actions just as the individual is a reflection of humanity. The
individual is never really alone, for she is always intertwined with others.

Fourth, existentialism had been criticized for espousing a view that individuals
can do whatever they choose, based on whim and gratification, rather than adhering to
prescribed morals, such as that found in religious beliefs (Sartre, 1946/2007a). On the
contrary, Sartre (1946/2007a) argued that existentialism purports not only that the
individual has the freedom to choose her actions, as there are no prescribed guidelines or
rules for her to follow, but also that with that freedom comes the responsibility of
ensuring that when she chooses, she is fully aware that she is making choices both on
behalf of herself and the rest of humanity. This responsibility prevents the individual
from freely choosing without regard for the consequences of her choices, which places
her in the position of ensuring that her choices are based on more than mere self-
gratification or whim, that her choices are thoughtful and intentional.

Sartre (1946/2007a) also explained three existential concepts: anguish, abandonment,
and despair. Anguish refers to the individual’s conscious awareness that along with the freedom to choose comes the responsibility of not only defining herself,
but also of defining humanity. Upon realizing that she is responsible for the rest of
humanity, the individual experiences a sense of anguish over having this responsibility, which then affects how she addresses the freedom she has to make choices. The individual experiences anguish over how to define or realize herself since she knows that she then becomes responsible for how this affects others. As this anguish may be quite distressing, the individual may attempt to ignore, avoid, or otherwise conceal her anguish, yet the anguish that comes with freedom always exists within the individual.

The existential concept of abandonment refers to the sense that the individual is left without any prescribed guidelines to help her make choices when navigating her freedom, requiring the individual to be ever aware and intentional when using her freedom to make choices (Sartre, 1946/2007a). With the absence of any higher authority to dictate her decisions, the individual is held ultimately responsible for fashioning her world and her reality through the choices she makes. Although this sense of abandonment may leave her feeling anxious, this anxiety serves to motivate the her to become aware of her freedom and responsibility to make choices, as well as the consequences of her decisions. The individual may choose to avoid making choices in the face of this anxiety; her choosing to abstain from making choices is, as well, a choice in and of itself, which still entails the responsibility for the consequences resulting from that choice to not choose.

Sartre (1946/2007a) then discussed the concept of despair as the notion that the individual should not rely on hope, but rather on the probabilities of events occurring. He asserted that this does not mean that the individual’s situation is necessarily bleak due to hopelessness, but rather that she should recognize that hope is not necessary for her to make choices and take action, such that she can make choices without hoping for a
particular outcome. The individual can forego hope and look at the probabilities of certain events occurring to help herself to make choices, instead of allowing herself to get intertwined with false notions of hope that certain events will occur. Since the individual does not need to rely on hope, Sartre proposed that she can will things to happen. This does not mean that she can magically produce a desired effect but rather that she can make decisions that can lead to the desired effect. As such, the outcome will be whatever she has chosen it to be and will be produced, rather than be the result of mere hope for a desired effect. The individual has the power to produce certain outcomes and is not at the unpredictable and nebulous mercy of hope or fate.

Finally, as illustrated in his novel *Nausea*, Sartre (1938/2007b) explained the notion that existence precedes essence, which means that the individual’s existence comes before her meaning or definition. That is, the meaning of the individual’s existence comes after she exists and then chooses the purpose of her life. The individual, and things in her world, come to being first through mere existence. When she then exercises her freedom to choose, she interprets her existence by defining herself and the rest of humanity, and she consequently finds the meaning or purpose of her existence through making choices and acting upon them. The individual’s meaning or essence cannot exist without her first existing as an individual, or as a being or entity. She then finds the meaning of her existence by making choices and realizing her potentialities, creating her essence.

**Albert Camus.** French philosopher Albert Camus (1942/1988) used the novel *The Stranger* to illustrate his philosophy pertaining to the absurdity of existence, which refers to the conscious awareness and acceptance of the randomness of existence. Life is
seen as an amalgamation of present events and experiences, rather than a coherent, rational, purposeful existence as scientists and rationalists would like to believe. In *The Stranger* the main character, Monsieur Meursault, is depicted as a stranger in the world in which he lives, as he does not exist in much the same way as others and the general society do, wherein individuals follow the socially prescribed expectations regarding behavior, thought, and feeling. Instead, Meursault tends to avoid analyzing his emotions and does not get ensnared in reflecting on how he feels in response to various experiences, events, or circumstances in his life. He also tends to evade making purposeful choices in his life to the extent that he follows the route of whatever may be occurring or presented to him at any given time. This leaves many around him both loving him for his seeming indifference to the world while simultaneously leaving others around him feeling much hatred for his lack of care or feeling for anything or anyone around him.

The story opens with the death of Meursault’s mother, which requires him to travel to the care home, where he had placed her, to attend the funeral (Camus, 1942/1988). Those at the home and funeral are quietly dismayed that Meursault does not appear to be grief-stricken, nor does he seem to show any emotion when he keeps vigil along with his mother’s friends. The day after the funeral he went swimming and met up with Marie, a woman who worked at his place of employment, watched a movie with her, and returned to his home with her where they had a sexual liaison. Meursault’s behavior and actions related to his mother’s death and the day after, particularly his lack of grief or remorse, would later be questioned, as he did not react in the way others would expect of someone who had just lost his mother.
Throughout the story Meursault’s indifference to other people in his life is portrayed (Camus, 1942/1988). For example, despite how he seems to enjoy Marie’s company and appears to love her, he does not make any outright verbal proclamations of his love for her. When Marie asks him if he loves her and would marry her, he responds that it does not matter to him whether he loves her or not, but that he would marry her if that was what she wanted him to do. Marie is somewhat taken aback by his response and asks if he would have the same response if another woman had asked him the same questions. He again tells Marie that it would not matter and his response would be likewise if another woman were questioning him. Although Marie is initially disappointed by his response, she continues to love him for the very fact that he is different from everyone else in not being preoccupied with examining his feelings for anyone or anything.

Another example of Meursault’s seeming tendency to avoid making purposeful choices is revealed in his friendship with his neighbor Raymond (Camus, 1942/1988). Raymond befriends Meursault and soon requests his assistance to seek revenge on a woman who Raymond says cheated on him. Meursault agrees to do whatever Raymond requests, including writing a letter to the woman to get her to see Raymond so that Raymond can then beat and humiliate her. Meursault later agrees to testify on Raymond’s behalf at the police station when Raymond has to explain what happened between the woman and himself. Towards the end of the first half of the story, Meursault also agrees to shoot the woman’s brother if he assaults Raymond. It appears that regardless of the type of request Raymond makes and despite potential harmful consequences for any and all involved, Meursault does not think about the choices he is
making and merely follows along with whatever Raymond requests of him. Again, this demonstrates Meursault’s seeming indifference to the choices he makes in his life, abdicating the act of choosing and merely following the whims of the present experience and what it beckons of him.

Eventually, Meursault shoots the brother of Raymond’s mistress, though not in response to being provoked, but rather due to the glare and heat of the sun while they are at a beach area (Camus, 1942/1988). Meursault is put in prison and eventually faces trial. While in prison, he initially struggles with his loss of freedom but soon adapts and resumes his pattern of indifference or apathy. After several months his case goes to trial, and his character and personality are assaulted by the prosecutor, primarily in reference to his seeming lack of remorse over the murder he committed and his mother’s death from earlier in the story. Meanwhile, Meursault experiences the trial as if he is not even there or participating, as if everyone else is speaking of him and he is not permitted to say anything on his own behalf. The jury returns with a verdict of guilty, and the judge sentences him to death by beheading. Later, as he awaits word of the outcome of his appeal, Meursault contemplates his possibly meeting death by execution should his appeal not overturn his sentence. He realizes that death is inevitable, whether he was to be executed now or if he were free and lived another twenty years. Meursault acknowledges that, in either case, death is the fate of all individuals, which only reinforces his belief that existence is merely a string of present experiences and not an accumulation of past, present, and future; regardless of the path individuals choose in life, the outcome is still inevitably death, rendering the choices individuals make meaningless as the outcome will still be the same (i.e., death).
Camus (1942/1991) further explicated his philosophy of the absurdity of existence in his philosophical book *The Myth of Sisyphus*. He used the myth of Sisyphus to illustrate the absurdity of life, emphasizing that the absurdity comes with the conscious awareness of the futility of hope. The myth is about Sisyphus, who is condemned to the underworld and forced to roll a heavy boulder to the top of a mountain. Sisyphus makes repeated attempts, only to be defeated as the weight of the boulder overtakes Sisyphus’s efforts and rolls back down to the ground. This sends Sisyphus down to the bottom of the mountain in order to start all over again trying to roll the boulder up the mountain.

Camus was not impressed by Sisyphus’s sense of hope with each unsuccessful attempt to roll the boulder to the top of the mountain. Camus instead argued that hope is not what is central as Sisyphus’s repeated attempts only iterate the futility of hope and the impossibility of happiness should he ever succeed in reaching the top of the mountain, with the boulder. He likened this to the mundane routine of work when the individual goes to work day after day, performing the exact duties, with the hope of one day achieving happiness upon reaping the rewards of daily labor. The individual eventually comes to find that his efforts and his hope to attain happiness were merely exercises in futility as happiness cannot be attained in such a manner. Camus highlighted that Sisyphus experiences happiness as he walks down the mountain, knowing that he will have to start pushing the rock up the mountain yet again. In other words, it is from Sisyphus’s conscious awareness and acceptance of the absurdity of his efforts that he experiences happiness, for happiness is found in that moment of consciousness.

**Summary and critical analysis of existential philosophy and literature.** Based on the works reviewed above, existentialism appears to have several core tenets. The
notion of anxiety—whether referred to as anxiety, despair, or nausea—seems an overarching element to human existence as the experience of anxiety is the signal calling attention to the individual to examine her existence and question whether she is fulfilling her potentiality. This anxiety reveals itself within the contexts of four existential conditions.

First, existential philosophy discounts the notion of rationality, logic, or reason as being the basis of or guiding force behind the human being or human existence. Instead, the individual is believed to have free will or the freedom to make choices, regardless of whether these choices are destructive or advantageous to the self. With the freedom to choose comes the necessity of assuming responsibility for the outcome of one’s choices. Rather than relying on hope for desired outcomes to occur, the individual must realize that in making choices, she, in effect, chooses the events that will occur and lead to certain outcomes.

Second, this freedom to choose is what provides the essence of human existence. In choosing and acting upon one’s choices, the individual infuses essence or meaning into one’s life. Without this, existence is meaningless. Part of the existential issue of meaninglessness is the notion that the individual must live a life without prescribed or externally imposed guidelines as to how to find meaning in one’s life. Meaning must come from the choices the individual makes toward living her life purposefully.

Third, existentialism views the individual as existing in isolation. Following the notion that there are no prescribed guidelines as to how to find meaning or what choices to make, the individual is alone in the endeavors of meaning and choice. At the same time because the individual, in making choices, defines the rest of humanity, humanity
becomes a reflection of the individual. The experience of isolation is somewhat intertwined with the individual’s responsibility toward humanity through the choices and meaning she makes.

Fourth, existential philosophy asserts that all individuals experience death anxiety. The realization that death is everyone’s fate and is inevitable raises questions for the individual as to whether she lived her life purposefully or if she abdicated the responsibility of making choices by living in the past and, thereby, stripped her life of meaning. Existentialism emphasizes the importance of living in the present in order to realize the full potential of the individual by consciously making choices, infusing essence into existence.

Although the existential writers reviewed above share a common view of the nature of human existence, there are several subtle variations within each of their perspectives. Kierkegaard challenges us to accept despair as an inevitable part of existence and sees faith in God as the only path out of despair. Similarly, Russian novelists Dostoevsky and Tolstoy depict despair as an unavoidable part of life, as seen through the experiences of the various characters they portray with tremendous depth and honesty in their works of fiction. Although Dostoevsky’s novels tend to highlight the abnormal aspects of human nature and the despair that underlies abnormal behavior, Tolstoy’s works depict the despair underlying normal bourgeois life. Yet both writers share with Kierkegaard a vision in which despair can be overcome only through spirituality and religion (Barrett, 1958). For Sartre, despair, along with anguish and abandonment, are not so much inevitable aspects of existence but rather are associated with one’s awareness of freedom. Anguish accompanies the awareness that individuals
are free to choose and thus are responsible for defining both oneself and humanity. The feeling of abandonment arises in response to the awareness that there are no prescribed guidelines to follow when making choices. Despair results from realizing that individuals cannot depend on hope—they must instead will things to happen. Unlike Kierkegaard, Dostoevsky, and Tolstoy, Sartre’s version of existentialism is fundamentally atheistic. Individuals create meaning through their actions; there is no fundamental essence or meaning other than that which they create. Camus shares with Sartre an atheistic version of existentialism in which existence precedes essence. Unlike Sartre, who emphasizes the meaninglessness of existence, Camus highlights the absurdity of existence. For Camus, the individual’s task in life is less about taking responsibility for his choices in a world devoid of meaning and more about developing conscious awareness and acceptance of life’s inherent randomness and absurdity. According to Camus, such acceptance leads to happiness.

**Existential Psychotherapists**

Existential psychotherapy grew out of existential philosophy and reflects the key existential concepts outlined in the previous section. This section of the literature review addresses the work of four existential psychotherapists—Rollo May, Viktor Frankl, R. D. Laing, and Irvin Yalom—each of whom made a unique and significant contribution to the theory and practice of existential psychotherapy. These authors frequently cited the works of existential philosophers and novelists, including the ones reviewed above, as influential in the development of their models of psychotherapy, applying existential theory to the treatment of mental illness. The works reviewed in this section include Rollo May’s *The Meaning of Anxiety*, *Man’s Search for Himself* and *Psychology and the
Human Dilemma; Viktor Frankl’s The Will to Meaning and The Doctor and the Soul; R. D. Laing’s The Divided Self; and Irvin Yalom’s Existential Psychotherapy.

Rollo May. American psychologist Rollo May wrote prolifically about the role and inevitability of experiencing anxiety in human existence. Although the experience of anxiety was more hidden prior to the mid-twentieth century, May (1950/1977) suggested that anxiety became a more overt problem by the mid-twentieth century in large part because of the cultural changes that occurred in society with regard to the economic, political, religious, and social landscape. In previous centuries during which time social structures were more static and dictated what to believe and value, individuals could depend on these structures to guide them on how to act, to determine what was important, and to set goals to strive for individually and collectively as members of the greater society. Without these prescribed values individuals were left to navigate through their existence completely on their own, leaving them with the frightening reality that they were alone and responsible for making decisions for themselves about what they valued. People subsequently experienced fear related to meaninglessness and the annihilation of their existence as the social foundations they had previously become accustomed to became less dependable in providing the structure, values, and guidance to shape the meaning of their existence. This meaninglessness and cessation of existence went beyond the end of physical life through death and were experienced psychologically in terms of the non-existence of the self. Through the years overt anxiety became the manifestation of the fear of meaninglessness, and people began to engage in behaviors or activities that enabled them to either manage or avoid this anxiety, such as through working for monetary gain or joining social clubs. Increasing rates of social pathologies,
such as suicide, mental illness, and divorce were also linked with increasing anxiety among individuals, which May proposed were both symptoms of and products of the overt anxiety problem that began to pervade society in the mid-twentieth century.

According to May (1950/1977), culture plays an important role in understanding anxiety, meaning that it is important to examine the sociohistorical context to understand how anxiety eventually manifests as symptoms or illness within the individual and his environment. As society began to move toward becoming a culture based on capitalism and individualism, people began to experience feelings of emptiness and loneliness—two characteristics of modern man (May, 1953). With capitalism came the expectation for individuals to compete against each other in order to succeed and become superior to others. Interdependence was no longer valued; it was replaced with the value of competitive success. Since the goal was now to outdo others, the individual soon began to see his neighbor as the enemy to be overcome or conquered, which then led to feelings of loneliness for the individual, as he had to ensure his superiority. Perhaps out of reaction to the loneliness, the value of competitive success was soon replaced with the value of the individual becoming what May termed as the “organizational man,” that is, when the individual conforms to the organization so as to blend in with others around him in order to allay the experience of loneliness. As the goal became to conform, rather than stand out, the individual began to experience emptiness as he was merely conforming to external expectations, rather than living out his individual potential and uniqueness. At the same time, the individual also experienced feeling powerless to be effective in his life or in his world. As a result of the loneliness and emptiness, the
individual then developed feelings of despair, followed by a sense of apathy as a means to defend against the accompanying anxiety.

May (1950/1977) defined anxiety as occurring when the individual experiences a threat to the values that he associates with his existence, which may refer both to physical as well as psychological existence. These values are the patterns the individual has developed which offer him a sense of security, such that they become the core of his personality. When these patterns, or the individual’s core, are threatened, he experiences anxiety from being left without the patterns that have helped him to cope and overcome crises throughout his life. Feelings of helplessness also arise from not knowing how to address the anxiety or its trigger.

May (1950/1977) differentiated between fear and anxiety. He argued that fear often has an identifiable trigger or cue, providing the individual with a sense of how that trigger may be addressed, such as through fighting against or fleeing from the trigger to overcome the sense of fear. Anxiety is diffuse and vague and comes from within the individual, rather than outside of the individual, such as with fear. The individual is left confused as to what may be triggering the anxiety and how to overcome or alleviate the anxiety. Because the individual experiences a threat to certain values that the individual associates with his existence, anxiety strikes at the core of the individual who experiences the threat not only to his values but also to his very existence. The more the individual feels threatened and helpless to alleviate or overcome the threat, the greater his anxiety becomes (May, 1950/1977, 1967/1979).

The anxiety that individuals experience is actually a normal and expected aspect of existence (May, 1953, 1950/1977, 1967/1979). Each individual holds certain values
that are relative to the individual’s context or environment. When these values are threatened, and if the threat is proportionate to the value being threatened, anxiety arises. This anxiety is an inherent characteristic of existence such that all human beings are in a constant state of anxiety, and this anxiety is actually essential to an individual’s existence. It creates an opportunity for the individual to be in constant movement and forces him to confront the conflicts he experiences in life (May, 1967/1979). Existential anxiety serves as a signal that a decision to act is necessary in order for him to resolve an inner conflict that may be preventing him from progressing in his development and movement toward realizing his potentiality.

May (1950/1977, 1967/1979) added that this anxiety is considered healthy or normal anxiety by the very fact that this anxiety is an expected element of existence. Existential anxiety becomes neurotic or unhealthy anxiety when the threat is disproportionate to the value being threatened, when attempts to avoid the threat are met only by yet another threat or when the individual responds with attempts to block or avoid the consequent anxiety. Neurotic anxiety develops when the individual attempts to avoid experiencing this anxiety and avoids confronting the conflict that is occurring within himself. This inner conflict arises not only when there is a threat to the individual’s values, but also when his values are competing against or contradicting each other, leaving him feeling trapped and helpless, as well as threatened from all directions. May (1950/1977) clarified that the event which precipitated the anxiety is only the signal that there is an underlying conflict; the conflict itself is the actual source of the anxiety.

The transition from normal to neurotic anxiety occurs when efforts used to avoid or alleviate anxiety become compulsive, such that the individual repeatedly performs the
behavior that helps him to avoid the anxiety for the sole purpose of staving off the discomfort or pain of the anxiety (May, 1950/1977). Anxiety is reduced when the behavior is performed; anxiety reemerges when the behavior is prohibited. One example of how the individual may engage in compulsive behavior to avoid anxiety is when he engages in frantic activity, which is when the activity results in the relief of the anxious feelings but does not necessarily address or resolve the underlying source of the anxiety (i.e., a conflict between two competing values that are being threatened). Another example of compulsive efforts to avoid anxiety is rigidity of thinking, which offers temporary relief from anxiety, but costs the individual the opportunities to work through the anxiety by learning new ways of thinking or behaving to help him resolve the conflict of values and adapt to the new situation. These two ways of dealing with anxiety can then result in the repression of the conflict, leaving it unresolved, resulting in the eventual emergence of neurotic anxiety and the formation of psychological symptoms.

When the conflict between two competing values is left unresolved, resulting in the individual engaging in compulsive behaviors in order to avoid the anxiety, the consequence can then include the development of psychosomatic symptoms or illnesses (May, 1950/1977). When individuals are unable to cope with or address their anxiety, psychosomatic symptoms or illness develop as a mechanism through which they can alleviate or avoid their anxiety. Thus, physical ailments and psychological conditions may indicate unresolved inner conflict.

May’s interest in studying individuals who were in a crisis situation was spurred by his assumption that when an individual is experiencing anxiety-provoking situations, his reactions or psychotic symptoms reflect both how the anxiety is related to the anxiety-
provoking situation and a particular pattern within the individual’s personality. In a study involving thirteen cases of unmarried mothers in a New York City shelter, May (1950/1977) demonstrated how psychotic symptoms are manifestations of inner conflicts and neurotic anxiety. One of these mothers was Charlotte, who exhibited mild psychotic characteristics, and the results of her psychological test suggested that she was experiencing a mild schizophrenic state. Charlotte had also been described by others who knew her as having some psychological disturbance in her background. Although she manifested some psychotic tendencies, her level of anxiety was relatively low, suggesting that the psychotic symptoms she developed were a means for her to quell or mask her anxiety. The many manifestations of psychotic symptoms are likely the result of inner conflicts and the consequent anxiety that the individual deems as unbearable, and, thus, the development of psychotic symptoms becomes a means of alleviating the unbearable anxiety. May’s study indicated that the mothers usually cited increased levels of anxiety just before the onset of the psychotic symptoms but that the level of anxiety seemed to decrease as psychotic symptoms emerged, suggesting that the symptoms became the mechanism used to cope with the anxiety. Unfortunately, in such cases, the price of this way of alleviating anxiety costs the individual some sense of being in touch with or adjusting to reality.

Because May (1953) believed that existential anxiety is a normal and inherent aspect of the individual’s human existence, he argued against the notion that the goal of psychotherapy or mental health treatment should be the eradication of anxiety. He does not agree with the conceptualization of mental health being defined as the absence of anxiety in one’s life. He went further to say that such a goal or conceptualization can
become dangerous in that the individual is never challenged to grow or realize his potential through the constructive and creative uses of normal or healthy anxiety. Seeing the anxiety as an opportunity, rather than as a frightening, crippling, disempowering experience, the individual can choose to work through the conflict with the conviction that the values to be gained or learned through the experience far outweigh the values that are retained by avoiding the anxiety. To this end, May (1950/1977, 1967/1979) posited that the act of choosing or deciding is an integral part of existential anxiety; one can choose to retreat from the opportunity or to move forward despite the awareness that to do so may involve discomfort as the individual moves toward resolving the inner conflict. Rather than insight being the end goal of therapy, it is actually the act of deciding that is necessary for the client to work through his neurotic anxiety. May (1967/1979) introduced the duality of freedom and responsibility, such that the individual has the freedom to effect choices in his world, but with the corresponding responsibility to act upon those choices.

With respect to psychotherapy or mental health treatment, rather than the goal being freedom from or the absence of anxiety, May (1967/1979) saw the goal of therapy as helping the client to move out of neurotic anxiety in order for the client to work through the normal anxiety constructively, experiencing new learning and new growth with an inner core based on modified or new values that contribute to the client’s sense of existence as a person. The way in which clients can free themselves of the compulsive behaviors used to avoid anxiety (i.e., the neurotic anxiety) is by helping them to move ahead and confront their anxiety in spite of their apprehension, rather than by diminishing or even eradicating their anxiety. Clients become stronger and more integrated through
this process as they develop the ability to use normal anxiety constructively and creatively whenever confronted with inner conflicts and threats to their values. Although they may experience more anxiety without the compulsive mechanisms they have grown accustomed to using in order to avoid the anxiety, they will, instead, have developed the belief in themselves and capacity to work through the normal anxiety they encounter in their lives.

May (1967/1979) noted that if the symptoms of the client’s neurotic anxiety are eradicated without helping him to resolve the underlying conflict, such as through the sole use of medications, then the client will remain static in his development since he will not have had the experience of confronting the underlying conflict, seeing that he is able to live and use the normal anxiety of existence to help himself grow. At the same time, psychological symptoms or physical ailments that are manifest of neurotic anxiety must be considered as the individual’s attempt to preserve the self; these mechanisms that the individual employs to stave off anxiety are also a means for him to maintain centeredness amidst the anxiety. From this standpoint it is erroneous to assume that all clients seek psychotherapy or mental health treatment necessarily with the goal to get well; they may be reluctant to shed their symptoms and risk the distress of the anxiety. Instead, it is important to remember that the individual may be unwilling to let go of his compulsive behaviors until other conditions in his environment are changed. It is equally imperative to remember that the individual does possess the potential to constructively work through the underlying conflict and live with normal or healthy anxiety in his life.

Viktor Frankl. Viennese psychiatrist Viktor Frankl founded the school of logotherapy, which is a therapeutic means to healing neuroses through the discovery of
meaning (Frankl, 1969/1988). In his book *The Will to Meaning* Frankl (1969/1988) argued against reductionism or deterministic theories of the human being, believing that these schools of thought serve only to strip the individual of a sense of meaning or purpose in life, rendering the individual to living aimlessly with frustration, boredom, and apathy. He coined the term *existential vacuum* to refer to the void people live with when consumed with boredom and apathy from a life led without meaning and direction toward living one’s potential. In his theory Frankl saw the role of freedom and responsibility as central to human existence, noting that human beings have the freedom to make choices even in the face of destiny or fate, but they also have the responsibility to make those choices. Attempts to abdicate that responsibility lead to various forms of neuroses that are often seen in psychological issues. Although he is cognizant that his theory does not explain causation of mental disorders, such as endogenous depression and schizophrenia, and that logotherapy does not aim to cure mental illness, Frankl asserted that having mental illness does not declare the individual free of the responsibility to live one’s potential and find meaning, nor does it incapacitate the individual from doing so.

Logotherapy is based primarily on three core principles: the freedom of will, the will to meaning, and the meaning of life (Frankl, 1969/1988). The freedom of will is the notion that the individual has the freedom to choose how to take a stand against whatever conditions beset her even when confronted with fate or destiny. In contrast to determinism, which renders the individual as a victim of her circumstances, a central tenet of logotherapy is that the individual always has the freedom to choose how she will address her circumstances. Along with the belief that the individual has this freedom to will, logotherapy also functions on the second notion of the will to meaning. Meaning
cannot be given to the individual; the individual must take it upon herself to actively find meaning. Frankl (1969/1988) asserted that logotherapy does not aim to provide the patient with answers but rather acts as a catalyst to help the patient begin to find her own answers independently. The meaning of life refers to the notion that there is no universal meaning for all but that each individual is drawn to find her own meaning as the individual is unique in her existence every hour and every day and in every situation. It is wholly up to the individual to find meaning in her world.

According to Frankl (1969/1988) there are three avenues through which the individual can find meaning in life: creative values, experiential values, and attitudinal values. Creative values refer to what the individual contributes to the world through what she does in life, such as her work, family, hobbies, or accomplishments. This can be seen, for example, in the person who speaks of finding meaning through her career, philanthropic activities, or personal achievements. The individual can also find meaning through experiential values, or what she receives or takes from the world, such as through the appreciation of the environment’s natural beauty, or through artwork or musical compositions. The individual’s appreciation of what is bestowed upon her can present opportunities to find meaning. When creative or experiential values are unreachable or unavailable, Frankl posited that the individual can still find meaning through the stand she takes in even the most dire or destined situations, such as hardship, illness, tragedy, and even death. The individual can still choose how she will face difficulty and inevitable death through the attitude she chooses to adopt (i.e., with negativity, anger, or surrender as opposed to optimism, dignity, or purpose, despite destiny).
In his book *The Doctor and the Soul* (1946/1986) Frankl applied existential analysis to understand the psychology of mental illness outside the bounds of medical or physiological explanations. He illustrated this through the examples of four mental health conditions: anxiety, depression, obsessive-compulsive disorder, and schizophrenia. He advised that despite these illnesses having physiological causes, there remain ripe opportunities for the use of existential analysis to alleviate some of the symptoms and demonstrate for the individual the possibility of creating meaning even in the context of mental illness.

The central tenet of existential analysis is the importance of being conscious of responsibility (Frankl, 1946/1986). Being responsible (and thus making choices) is what separates humans from animals. Responsibility, in turn, is what enables the individual to make meaning of her existence. Frankl argued that individuals with psychological symptoms tend to have issues with their consciousness of responsibility, either wanting to repudiate their responsibility or becoming fearful of it, which contributes to the manifestation of symptoms of mental illness.

Although mental illness is not without its physiological and neurological bases, thus warranting the use of psychotropic medications to assist with alleviating symptoms, having a mental disorder does not necessarily negate the responsibility and ability of afflicted individuals to make choices and aspire to make meaning in their existence. Frankl (1946/1986) referred to this notion as attitudinal values. In the face of suffering and limitations, the individual maintains the ability to choose how she will exist through the suffering. One person may choose to succumb to the suffering, thus deflecting opportunities to rise above the suffering and create meaning out of her existence; another
person may redirect life goals or simply choose to change the way she perceives the illness or limitation. This can be seen, for example, in the positive attitude among some suffering from tragedy or terminal illness versus others who may turn to substance use or become reclusive in the face of difficulty.

The main goal of using existential analysis with individuals who have mental disorders is to draw out their consciousness of responsibility and acceptance of this responsibility to make choices in spite of the limitations posed by their suffering. With anxiety disorders, particularly phobias, Frankl (1946/1986) suggested that the object feared is an amalgamation of the individual’s fear of death and corresponding fear of life. The individual’s fear of accepting responsibility for the life she creates and the consequent guilt over not having moved toward living her potentiality become centralized onto a specific and concrete object she then fears or towards which she becomes phobic. Rather than attempting to help the individual confront the feared object specifically, thereby eradicating the phobia, existential analysis shifts the focus to helping the individual move toward realizing how the phobia or symptom has become a means for avoiding the responsibility of existence, thereby freeing the individual to then explore and develop that responsibility in order to create her life task and its consequent meaning.

Apart from phobias, anxiety disorders involve the guilt over not living one’s potentialities and the fear of the responsibility inherent within existence or living. The more the individual can be brought toward accepting that responsibility, the less she will experience anxiety symptoms.

Although physiological factors contribute to or cause endogenous depression, Frankl (1946/1986) suggested that there is a human element that is manifested in the
feelings of insufficiency, self-reproach, and guilt found among those suffering from this disorder. It is this human element that allows for the application of existential analysis to an illness that is biologically rooted. Frankl explained that the psychophysical insufficiencies in endogenous depression create tension within the individual between the state of her well-being with the illness and her view of her ideal self. The individual with this type of depression sees an amplified or exaggerated discrepancy between how she is and what she thinks she should be, worsening that tension and increasing her anxiety about being unable to realize her ideal self. The individual consequently perceives an inability to attain her life goal or cope with life’s tasks, losing her sense of a potential future. Depersonalization and suicidality follow when this individual’s existential tension (i.e., between what is and what ought to be) is extended to her relation with the world, such that the tension within herself extends to a tension and a retreat from reality or the external world. She believes herself to be meaningless and worthless. Her valuation of herself decreases, as does her valuation of herself in the world. In contrast, the individual suffering from mania experiences an exaggerated sense of sufficiency, believing herself capable of more than her present life task and perceiving potentialities as actual reality, becoming engrossed with planning for the future, rather than living her potentialities in the present.

With regard to obsessive-compulsive disorder, the idea of treating the individual’s attitude toward the illness, instead of merely treating the concrete symptoms, is again at the core of applying existential analysis to this condition. Frankl (1946/1986) posited that individuals suffering from obsessive-compulsive disorder tend to lack self-confidence in their instincts and ability to make decisions in their day-to-day life. They
do not trust themselves to make decisions and fear living with the consequences of their decisions, leaving them to overcompensate by seeking absolute certainty in every aspect of their lives. Since these individuals realize that it is impossible to attain that absolute certainty in all aspects of their lives, that rigidity becomes focused on particular areas wherein they can achieve that certainty in their day-to-day existence. The individual with this disorder expends the same energy needed to make significant decisions in life (e.g., choosing whom to marry or a career) onto more trivial day-to-day demands, such as repeatedly checking if a door is locked or if a stove has been turned off. Given the rigidity in their thinking, individuals with obsessive-compulsive disorder will continually find themselves caught in the binds of the resulting tension between their wanting absolute certainty and the impossibility of feeling secure in certainty. With existential analysis, the goal would be to assist such individuals with changing their attitude toward their illness, such that they come to accept the reality of uncertainty and re-learn to trust their ability to see the obvious and consequently trust themselves to make decisions.

Frankl (1946/1986) applied existential analysis to understanding schizophrenia. Individuals suffering from this particular mental illness often complain of hearing voices telling them to engage in strange or harmful behaviors, believing people are out to get them or trying to hurt them, or feeling that their thoughts are either being inserted into their minds or being broadcast to the public. Frankl argued that the common thread among such symptoms is that individuals with schizophrenia experience themselves as objects with actions being committed upon or against them by others. Such individuals exist in a passive stance, with things happening to them, rather than in the active stance, where they are the instigators of activity or behavior. Again, the goal of existential
analysis with individuals suffering from schizophrenia would be to accept their illness as such, then to change their attitude toward their illness so that they can continue to seek out their life task in spite of their illness. Although the symptoms may need to be treated with medications, the illness itself does not discount the individual from exercising her responsibility to aim toward realizing her potentiality and creating meaning of her existence.

**R. D. Laing.** Using existential analysis to illustrate how the individual’s early life experiences culminate in a split of the individual’s self from both itself and from external reality, R. D. Laing’s (1960/1969) work *The Divided Self* describes the inner world of the schizoid personality and schizophrenia. The Glaswegian psychiatrist delineated his theory using existential concepts, such as ontological insecurity, engulfment, petrification and depersonalization, the unembodied self, and false-self systems. These concepts, according to Laing, contribute to the development of the schizoid personality and schizophrenia. Alluding to the notion of the schizophrenic family, he also touched on the influence that the individual’s family of origin may have in planting the seeds for potential psychosis for the individual in later life if the integration of the self is not supported or permitted to occur in a healthy manner within the family context.

Laing (1960/1969) defined the schizoid individual as one who experiences himself as split between mind and body, where the connection between the two is precarious, resulting in the individual becoming an amalgamation of several versions of a self because he is comfortable neither in his relationship with himself nor in his relationship with others. Wherein the individual experiences the self as split between mind and body, so does the individual experience a split between himself and the world,
leaving him with loneliness and despair. Although the schizoid individual engages in odd or bizarre behavior in order to protect his self, he can still otherwise appear normal to others. Schizophrenia results when the individual, in his attempt to navigate through various versions of a self (i.e., begins to live primarily in fantasy), consequently loses touch with reality and the self; in essence, the individual dies.

The family, according to Laing (1960/1969), plays a vital role in helping the individual to develop an ontologically secure self. Such a person experiences himself as a whole person, fully integrated between mind and body, at ease within his relationships with himself and with others, autonomous, and capable of asserting his own identity even in the face of others’ expectations. At the same time the individual perceives others similarly. The family, in this case, is comfortable with the individual family member having his own thoughts, feelings, ideas, and identity in relationship with and separate from the family’s values, beliefs, and expectations. When the family fails to facilitate such an environment, and, instead, almost suffocates the individual, prohibiting him from realizing his own identity, then the individual is said to develop an ontologically insecure self.

The ontologically insecure individual perceives the other and the world as a threat to his identity, never feeling safe enough to develop an identity, or self. He believes that his world will be threatened if he develops his self (Laing, 1960/1969). The individual, instead, learns to comply with the expectations he perceives others have of him, while quietly surrendering any notion of his own separateness from others. He consequently develops resentment and hatred toward the other for having to comply with these
perceived expectations. The ontologically insecure person encounters three forms of anxiety: engulfment, implosion, and petrification or depersonalization.

With engulfment anxiety the individual with a tenuous, insecure sense of self fears being swallowed by the other, which he fears will leave him without a self, only to become a replication of the other’s self (Laing, 1960/1969). The individual’s defense of this engulfment is to isolate himself. He views his relationship with the other as involving one of two options, that is, to become engulfed by the other or to isolate oneself from the other. With implosion, the second form of anxiety, the individual has come to experience the self as a vacuum: that the reality of his self is nothingness or emptiness. Although the individual longs to fill that emptiness, he simultaneously perceives the possibility of having that emptiness filled as a threat, for being filled would destroy his self. The individual would rather experience his self as empty than dead. Third, the ontologically insecure individual may otherwise encounter the anxiety of petrification or depersonalization. In this case, since the individual believes that the reality of the other supersedes his own reality, he experiences the threat of becoming an object in the other’s view, further reinforcing his fear of not having a self or having his self die. In turn, the individual petrifies or depersonalizes the other and perceives the other as an object, for, as an object, the other does not have the power to take possession of his self or identity. Naturally, all attempts to quell each of these three forms of anxiety only serve to perpetuate the anxiety. The more the individual isolates from and depersonalizes the other, so increases the fear and insecurity of having his self objectified and destroyed.

Because the ontologically insecure person has such an unstable sense of self, identity, autonomy, and personhood, this individual is compelled to find ways to defend
against the anxieties that come with the perceived threats of losing whatever sense of self he feels he does have in order to reaffirm his existence. In response to each of the three forms of anxiety, the consequence involves a splitting between the individual’s mind and body, creating a false self and an inner or true self (Laing, 1960/1969). The body becomes the false self, acting according to the perceived expectations of others while the mind becomes the true self. The true self is the individual’s own thoughts and feelings, which he feels determined to protect from being taken away by others. Consequently, the individual soon experiences the self as an unembodied self, which refers to the split between the mind and body, as if each were a separate entity. Although having temporary moments of feeling detached from one’s body can also occur among individuals without psychosis, such persons otherwise continue to experience a connection between their mind and body, knowing that they, or their self, will die when the body dies. Psychosis ensues when the detachment is more pervasive in the individual’s experience and he develops a seemingly exclusive affiliation and identification with the mind while becoming further detached from the body. The individual exclusively identifies with the inner, true self (the mind) and ostensibly experiences the body as an object that is no longer part of his true self. The body becomes merely the seat of impersonations of all others in order to comply with their expectations and to defend against being engulfed or depersonalized by the other. Since the body is the medium through which the real world is experienced, the unembodied self is precluded from being fully engaged with that world as it no longer bears a connection with the body, resulting in the individual’s split from reality.
Since the ontologically insecure and unembodied self did not have the opportunity to develop an integrated, autonomous, secure sense of self, the individual has then had to develop an alternate self that complied with others’ expectations (Laing, 1960/1969). Never having had a chance to develop a more unified self, the individual has become an amalgamation of different selves, also known as the false-self system, in order to prevent himself from becoming engulfed or petrified by the other and having his inner, true self destroyed. Since not one of these different selves or personalities developed fully, these multiple parts all continue to operate, though further increasing the individual’s anxiety and relegating him to guard against perceived threats to a tenuous inner, true self. Given that juggling all of these different personalities becomes increasingly difficult, in addition to having to expend greater effort to guard against perceived threats and attempting to quell fears and anxiety about losing his true self, the individual becomes progressively more vulnerable to furthering the split between mind and body, as well as between the self and others. The potential for the person to develop a schizoid personality emerges.

In a schizoid state the individual can see no escape from the threats to his self, generating the detachment between mind and body (Laing, 1960/1969). As the inner self becomes seated in the mind, the individual comes to escape perceived threats via the mind, or mentally, leaving him to become only a detached observer of his body or physical being. Such an escape does not necessarily preclude the individual’s desire to participate in the world with others, which only perpetuates the feeling of dread—knowing that to participate will result in the destruction of the self, as well as the consequent need to maintain detachment from others to conceal the inner, true self. The false self then assumes the reigns of the individual’s actions and experiences, rendering
all participation of the individual in the world as unreal and dead. At the same time the individual’s true self is committed to maintaining a sense of honesty and sincerity to the point of meticulously controlling this inner identity, which is nevertheless precarious at best for having never fully developed. As a result a secondary split occurs in the individual such that any sense of identity he did possess eventually becomes lost.

The individual, out of fear of becoming engulfed or otherwise destroyed, sees a need to become ever more controlling in his relationship with others through isolation and detachment. Rather than reveal the true self, the false-self system becomes the only way of operating in the world and interacting with others, which it does through pretenses and, eventually, fantasies (Laing, 1960/1969). As the individual comes to function in the world only through fantasies, he then becomes increasingly unreal, not only in his relationship with others but also in his relationship with himself. He can then become whomever he wishes, and the inner self dies. Whatever identity he had, even if tenuous, is lost. At this point, the individual enters a schizophrenic state, having completely broken away from reality. As the individual operates only through the false-self system, believing the body to be of service only to comply with others’ expectations, he also comes to experience a sense of being an object in actual possession of others, whereby others can do harm to him. In some cases, the individual in a schizophrenic state may attempt to experience some sense of being real by attempting to cause physical pain or harm to himself in order to feel alive and gain some reassurance that he is real.

Although the individual who has developed into the schizoid personality or schizophrenic state has done so as a defense against the anxiety and dread of potentially being consumed by the other, he nevertheless desires to reach a point of feeling more
secure and integrated with himself and with the world (Laing, 1960/1969). His fears continue the cycle of the false-self system and the splitting from the self and reality. To address this in therapy, Laing (1960/1969) argued that the clinician’s role is to demonstrate an acceptance of the individual’s total being without expectations, and, in so doing, the clinician creates the main avenue through which the schizoid or schizophrenic can begin to mend the split and develop a more coherent self. The remnants of the psychosis will continue to exist within the person, as the splits in his self will endure; the apparent outward behavior associated with psychosis may be less present. The therapist’s main function is to make contact with the individual’s original self, which the therapist must believe still exists within the individual, and to convey to the individual a total acceptance of this original self without expectations (as this is what the individual fears most and which triggers the splitting) in order for the individual to begin to fuse the different parts into a unified being.

**Irvin D. Yalom.** American psychiatrist Irvin D. Yalom developed his theory of existential psychotherapy around the notion that there are four *givens* in existence; that is, there are four areas of conflict that are inherent within existence for all human beings and, therefore, are inescapable. He outlined these four givens in his book *Existential Psychotherapy* (1980), arguing that awareness of these givens give rise to anxiety and that inadequate or extreme attempts to avoid or thwart addressing this anxiety could, in turn, contribute to the development of symptoms of psychopathology. He added that the anxiety that arises is not ultimately pathological. The anxiety signals an opportunity for growth for the individual who chooses to address the anxiety in healthy ways whereas the individual who instead avoids or tries to escape the anxiety is faced with increasing
anxiety and eventual symptomatology. These four areas of concern in existence are death, freedom, isolation, and meaninglessness. He further noted that these givens are not experienced sequentially or developmentally because the individual can encounter and re-encounter any of the four givens at any time in her life.

The first of the four givens centers around the awareness of the inevitability of death and the tension this creates in the individual because this awareness is complemented by the desire to live (Yalom, 1980). This is most obviously encountered when the individual is facing death through terminal illness or is in a situation that more immediately forces her to confront the possibility of death (e.g., being on the frontlines in war, a near-fatal accident), but this does not preclude those who are not in such circumstances from experiencing death anxiety. When the individual is unable to confront her awareness of the inevitability of death and is faced with increasing anxiety about the awareness of the eventual termination of her existence, she may seek means to assuage her death anxiety. Yalom (1980) suggested that the individual may resort to developing a sense of specialness, such that she begins to believe that she has some special quality that makes her an exception to the inevitability of death. For example, an individual may dare herself to seek out dangerous situations with the belief that if she succeeds in surviving these encounters unscathed, then she has successfully cheated death from nabbing her; she has escaped death. On the other hand, an individual may leave her fate to an ultimate rescuer, such that she believes that she can merge her identity with that of another, or live for a greater cause, as a means to defy death. Although helpful in quelling death anxiety so that the individual can live day-to-day and make use of her life, both strategies may otherwise potentially restrict her from growing and living more
meaningfully when used in extremes. The individual who has taken her belief of her specialness to an extreme can consequently develop narcissistic traits whereas the individual who has developed a sense of helplessness and has merged her identity with another may then develop depression when that other person is absent or cannot offer the desired protection from her death anxiety.

The second given in existence concerns the tension found between the awareness of one’s freedom to choose and its corresponding responsibility to thoughtfully make choices without any guidance or universal laws to follow (Yalom, 1980). Inherent within existence is the responsibility to constitute one’s self and one’s world as one chooses and the freedom to decide how one will live and create meaning for one’s self and one’s existence. Individuals have the freedom to choose how to go about exercising this responsibility, as well as the freedom to abdicate this responsibility. Although societies are governed by laws and rules and individuals abide by such guidelines in order to function in their given society, there are no overarching, universal laws that dictate how the individual constitutes her own self or identity or what kind of meaning she should create for herself. The individual is left with the anxiety of having to create her identity, her world, and her meaning entirely on her own, without a navigational aid to discern for her if she is heading in a positive or negative, or right or wrong, direction. As with the coping mechanisms associated with death anxiety, healthy means of coping with the tension between freedom and responsibility promote growth and do not restrict living whereas coping mechanisms that only serve to promote avoidance of the anxiety will inevitably lead to symptoms of psychopathology. For example, an individual can develop compulsive tendencies, merely acting on a perceived external force or urge, as a
means to quell the anxiety associated with not having any pre-established guidelines to help navigate her awareness of her freedom and responsibility. In such a case, the individual relies on this external force that compels her to perform ritualistic behaviors to avoid confronting the anxiety of having to make choices regarding her existence, thus also evading the consequences associated with bearing the responsibility of choice-making. In other cases, the individual can avoid responsibility by placing the responsibility on other people or other external forces, such as with paranoid patients who explain their own desires as voices coming from an external source. The individual who claims to have lost control of herself constitutes another mechanism through which she can deny her responsibility to make choices and evade the consequences of her actions. Finally, the individual can also choose to avoid responsibility by developing a dependency on others to make choices for her rather than living autonomously.

The tension between isolation and the desire for connection constitutes the third given of existence (Yalom, 1980). The anxiety from this given arises from the awareness that one is ultimately alone in one’s existence from birth until death and that despite efforts to connect with the world through relationships with others, there still remains the awareness that one is ultimately alone in existence. That is, no one else can experience another person’s life for her: each person is responsible for her own life, and each person will face her own death entirely on her own. Although the individual may die alongside other people, such as in mass casualty situations, she will experience death in her own way and in ultimate isolation from those around her. The individual can quell the anxiety of isolation by entering relationships with others, which can be healthy when she is still able to grow and maintain her own individual being within the relationship. Coping
mechanisms can become unhealthy when the individual merges with another or fears non-existence if the other is not thinking of her. The individual needs confirmation of her own existence from another person, rather than from experiencing her own existence as real even without the presence of that other person. Two examples of psychopathological issues that emerge from such thinking include suicidality and psychosis. With suicidality, the individual believes confirmation of her existence and assurance of not being alone will come when she is remembered after her death. Psychotic symptoms, such as hearing voices, may be a means to diffuse the experience of isolation. Fusion is yet another means of dealing with the anxiety of isolation, whereby the individual develops a dependency on another and attempts to become the other. This allows the individual to lose her self in the other and avoid the experience of self-reflection and the consequent awareness of her isolation in existence.

Yalom (1980) described the fourth given as that of the tension arising out of one’s awareness of life’s meaninglessness and the desire to know that one’s life has meaning. This anxiety is usually confronted when the individual is searching for a sense of purpose or value, assuring herself that what she does in her life has worth or reason. Related to the lack of external entities providing guidance as to how to make choices amidst vast freedom, there is no universal meaning one can attribute to one’s existence, and the individual is left groundless and uncertain about the meaning of her existence. It becomes the individual’s task to create meaning for and make sense of her own existence, rather than expect an external force or entity to prescribe her life’s meaning for her. When people attempt to avoid confronting the anxiety inherent within this fourth given, symptoms of psychopathology can emerge. For example, depression may follow when
an individual becomes unable or unwilling to confront her search for meaning or purpose, leaving her to experience apathy, boredom, or a sense of emptiness about her life. At the other end of the spectrum, another individual may develop compulsivity about life, engaging in frenetic activity to avoid facing the awareness of the meaningless in existence. Other means of coping with meaninglessness, which can be healthy when not engaged in excessively, include devoting one’s life to a cause one finds meaningful or finding meaning in religious or spiritual endeavors.

Yalom (1980) emphasized that the four givens of existence are not, in themselves, pathological because the anxiety inherent within each given provides individuals with the opportunity to make choices, create meaning, develop relationships, and face death with dignity. Pathological symptoms emerge when individuals choose to avoid confronting the anxiety and seek methods of coping that prevent growth and restrict their ability to live their full potential and when these coping mechanisms become excessive. The four givens can present themselves in less manifest ways than more overt or severe psychopathological disorders as a part of the vast array of each person’s interpersonal and intrapersonal challenges and circumstances.

**Summary and critical analysis of existential psychotherapists.** All four existential psychotherapists reviewed above discuss the role of anxiety in the development of psychopathology. Symptoms of mental illness are viewed as manifestations of compulsive or excessive attempts to avoid confronting or working through the anxiety that is inherent within existence. This anxiety manifests itself as the tension that naturally occurs within the four domains of living (i.e., freedom, isolation, meaning, and death), and it acts as a catalyst for the individual to consciously make
choices that will pave the way to living his potentiality. In some cases the individual finds the anxiety too unbearable or threatening that he then employs behaviors that provide immediate relief from the anxiety. Still, the underlying anxiety gnawing at him nevertheless remains, which impels him to further engage in the behaviors that bring him relief. Examples of behaviors that provide immediate relief from the anxiety of existence include depending on others to make decisions for oneself, fusing with others for a sense of identity, isolating oneself, engaging in compulsive behaviors in an effort to feel secure, or developing alternate realities in which to live. When these behaviors are engaged in excessively, the individual can then develop symptoms of such mental disorders as depression, obsessive-compulsive disorder, and schizophrenia. The goal of existential psychotherapy is, then, to assist the individual with confronting, rather than avoiding, the anxiety, providing the individual with the opportunity to more successfully work through the anxiety by making choices and accepting responsibility for the outcome, developing a true sense of self through conscious choice, establishing a secure sense of self both independent of and in relation with others, finding meaning in existence in general and in his life, and learning to develop alternate attitudes to circumstances that he is unable to change. It is important that the individual remains consciously aware that anxiety will always be present and that the accompanying experience of discomfort is necessary to urge himself to make choices.

Although the four existential psychotherapists share similarities across their theories, there are also several key differences among them. May and Frankl, for example, saw the development of psychological issues through different lenses. May argued that psychological symptoms stem from compulsive attempts to avoid anxiety.
Frankl considered the notion of avoidance as playing a significant role in psychopathology; he asserted that symptoms emerge when the individual attempts to avoid the responsibility of having to make choices and create meaning in his life. May and Frankl have contrasting views as to what should be the goal of psychotherapy. May believed the goal should be to assist the individual with working through the internal conflict in values that is creating the anxiety whereas Frankl emphasized the importance of drawing out the individual’s consciousness of responsibility and helping him to accept that responsibility to make choices and meaning for himself.

The concept of isolation is a point of difference between Laing and Yalom. Laing developed his theory of the schizoid personality and schizophrenia based in part on the idea that individuals with these particular psychological issues choose to isolate themselves from others as a means to defend against perceived threats to the inner self. Although they may desire connection with others, isolation is employed as a protective mechanism. For Yalom, all human beings exist in isolation, and the individual seeks, instead, to avoid this isolation through relationships with others. He asserted that psychological symptoms emerge when the individual attempts to merge oneself with another, depend on another for one’s sense of existence, or develop psychotic symptoms to quell isolation. Laing saw the schizoid or schizophrenic individual as desperately wanting not to lose his self to others whereas Yalom saw the symptomatic individual as willing to surrender his self for the perceived relief of being connected with another.

The explanations of particular mental disorders also seem to differ relative to each psychotherapist’s theory. For example, Laing explained that the schizophrenic individual has experienced a split between his inner and false selves in an effort to protect the inner,
true self but to the point of splitting both from other people and from himself, resulting in the individual living in fantasies and losing touch with reality. Yalom proposed that psychotic symptoms, such as hearing voices, stems from the individual’s attempt to diffuse the experience of isolation. Frankl offered another view of schizophrenia, asserting that although this disorder has a biological basis, such symptoms as feeling persecuted or of experiencing the world in a passive stance could be an issue of not wanting to assume responsibility for the meaning in their lives. According to May, psychotic symptoms could be manifestations of an inner conflict and a means of avoiding anxiety.

Although May, Frankl, Laing, and Yalom all identify a form of anxiety in their theories of mental illness, they each define that anxiety differently. May argued that anxiety is the experience of a threat to the individual’s values such that the individual then experiences a perceived threat to his existence. Frankl’s variation of anxiety comes in the form of meaninglessness, which stems from the absence of a universal meaning for all human beings. Although Laing does not speak in terms of anxiety, his theory of schizophrenia included the sense of an inner conflict. He believed that the root of schizophrenia was the development of the ontologically insecure self wherein the individual has never had a chance to develop an identity and perceives the world as threatening to his self. For Yalom anxiety emerges with the awareness of the four givens in life, pertaining to freedom and responsibility, isolation and the desire to connect, meaninglessness and the desire for meaning, and death and the desire to live.
Empirical Studies Exploring the Lived Experience of Chronic Mental Illness

A number of studies have been conducted in recent years (Bradfield & Knight, 2008; Cookson & Dickson, 2010; Erdner, Andersson, Magnusson, & Lutzen, 2009; Erdner, Magnusson, Nystrom, & Lutzen, 2005; Jonsson, Wijk, Skarsater, & Danielson, 2008; Koivisto, Janhonen, & Vaisanen, 2003; McCann & Clark, 2004; Rhodes & Smith, 2010; Rusner, Carlsson, Brunt, & Nystrom, 2009) exploring the lived experience of individuals diagnosed with chronic mental illness, including psychosis, long-term mental illness, schizophrenia, bipolar disorder, and depression. Other studies have more closely examined specific aspects related to the consequences of living with a chronic mental illness, such as the experience of being diagnosed (Hayne, 2003), being misunderstood as an individual with a psychiatric disorder (Gaillard, Shattell, & Thomas, 2009), being medicated (Bentley, 2010; Teal, 2009), and being restrained (Johnson, 1998). One article examined first-hand accounts of individuals living with chronic mental illness (Hayne & Yonge, 1997). A review of these 15 empirical studies focused on the experiences of individuals with chronic mental illness follows below.

**Psychosis.** One study looked at the experience of the onset of psychosis among individuals admitted to a psychiatric hospital. Koivisto et al. (2003) conducted a phenomenological study to attain a description of the experience of psychosis from nine participants who were in an inpatient setting in Finland, recovering from a psychotic episode. The participants had been diagnosed with schizophrenia, schizoaffective psychosis with delusions, or manic-depressive disorder with psychotic features. They were interviewed individually and asked to provide descriptions of what they experienced and felt when in the midst of a psychotic episode. Several themes emerged from their
responses, highlighting the experience of a sense of self that seemed uncontrollable, the impact the experience of psychosis had on their relationships with themselves and others, and the relationship of situational experiences with the onset and progression of their illness and eventual hospitalization.

The first theme *uncontrollable sense of self* pertained to the participants’ experience of psychosis as a feeling of change that was outside of their control and which included emotional distress and physical pain (Koivisto et al., 2003). This theme was associated with the second theme of *self and others*. The participants’ experiences of these strange psychological changes within themselves left them feeling vulnerable and insecure, as well as ashamed and confused. As a result, they soon found themselves lacking confidence in their ability to judge or trust others, leading them to isolate themselves and become more scrutinizing in their observations of others around them. Although the participants valued their relationships with family and friends, as they felt supported and helped by them, this inadvertently led the participants to also feel increasingly anxious and guilty about what they said or did when they were having a psychotic episode. Conflicts with family and friends sometimes resulted when participants felt expected to appear capable and lively when not feeling up to par.

The third theme concerned *situational experiences* (Koivisto et al., 2003). When asked to share their experiences about the onset of their illness, the participants explained that they saw the onset of their psychosis as situational. They identified specific stressors occurring in their lives that they believe might have led to their symptoms, such as divorce and marital problems, difficulties or conflicts with colleagues at work. They became overwhelmed with helping others in their lives without taking time to care for
themselves, or they encountered difficulties earlier in their lives that they felt alone in coping with at the time. As their illness progressed, the participants described feeling exhausted as strategies they attempted to maintain themselves at work and with other life duties, as well as to meet the expectations of family and friends, began to consume all of their energy, yet they were not always successful, making it increasingly challenging to meet the demands of daily living. They experienced increased feelings of fear, anxiety, distress, insecurity, shame, and guilt. These feelings stemmed from a growing sense that they were losing control over themselves and their bodies, the latter due to sleeplessness, pain, and uncontrollable bodily functions. They talked of becoming fearful, that they were indeed becoming psychotic or going mad (Koivisto et al., 2003). The participants described feeling shameful and afraid when they were admitted into a psychiatric hospital for treatment, adding that although they were aware they needed help, they were nevertheless uncertain if hospitalization was needed, making the decision to consent to treatment simultaneously difficult and necessary.

Although Koivisto et al. (2003) provided an understanding of the experience of individuals who have had a psychotic episode, the presentation of results appeared brief and lacking in the level of depth one would expect from a study which used descriptive phenomenology to access the meaning of the experience of psychosis. General descriptions of themes were offered and specific examples from individual participants were shared, yet detailed descriptions of variations within the themes were absent. Within each description, the researchers did not indicate if all, some, or few of the participants shared the experiences highlighted within the theme. One is left questioning whether the themes or descriptions really held true for all nine participants, or if there
were divergent aspects of the experience of psychosis that were not mentioned. The researchers emphasized that the research approach they chose required sensitivity and time to establish rapport in order to engage as a co-participant with the individuals being interviewed and to experience the phenomenon as authentically as the participant. It was not clear if anything else was done apart from or within the interviews to authentically experience the phenomenon of psychosis (e.g., observations, particular interview questions asked).

**Long-term mental illness.** Other studies, in contrast, sought to understand the experience of individuals not confined in a psychiatric hospital but living with long-term mental illness as opposed to a particular moment of psychosis. Anette Erdner and colleagues have conducted research examining existential issues among individuals with long-term mental illness in Sweden (Erdner et al., 2009; Erdner et al., 2005). The aim of one study was to explore the experience of daily living among individuals with long-term mental illness who live in the community, noting how they viewed their lives, what they considered important, as well as the challenges they encountered which prevented them from leading more active lives in their environment (Erdner et al., 2005). An ethnographic approach was used for this study, including participant observation and interviews with eight adults enrolled in two rehabilitation programs for people with long-term mental illness, learning to live more independently.

Erdner et al. (2005) analyzed the data from their field notes and interviews, identifying six themes from their experiences of daily living with a long-term mental illness and interpreting these themes as hidden impediments to living an active life in their community. The first theme *you barely know who you are in relation to others*
captured the participants’ disclosures that they lacked confidence and a sense of acceptance as a member of their social environment. Although this sometimes stemmed from feeling as though they did not fit in, some of the participants admitted to consciously making themselves an outsider in terms of perceiving themselves as being unique on the one hand and inadequate on the other. This often led to conflicted feelings of sometimes wanting to be noticed and command attention to themselves, but at other times wanting to be less conspicuous.

The second theme or impediment you cannot anticipate anything in the future concerned the need for predictability (Erdner et al., 2005). Participants believed that being able to predict the course of their illness would provide them with more independence and enable them to maintain employment and routine in their lives (Erdner et al., 2005). The nature of their illness made such desired predictability unattainable, and repeated experiences of failure in attaining goals in the past left them fearful of planning ahead and hopeless in initiating change.

In terms of the third theme lack of knowledge and learning capability, the participants expressed anxiety and worry over knowledge and skills that they had previously obtained but lost as a consequence of their illness (Erdner et al., 2005). They also reported having encountered challenges with learning new skills to keep up with the demands of employment. These difficulties left the participants feeling insecure about their ability to live more independently and actively in the community.

The fourth theme or impediment earlier memories and experiences predominantly consist of difficulties related to having a history of life challenges (Erdner et al., 2005). The participants drew connections between having difficult childhood experiences or
traumas and their present situations with their illness. The participants felt unable to move beyond their past experiences in order to live more actively in the present.

A fifth impediment to living a more active life worrying about reasons for being mentally ill concerned the participants’ lack of knowledge about mental illness (Erdner et al., 2005). They shared that they were not aware of or could not recall the cause of their illness. This led participants to worry rather extensively about what could cause their illness, which left little room for them to attend to other matters in their daily lives.

Finally, it’s difficult to develop an interest in other people was the sixth theme identified (Erdner et al., 2005). The participants described how difficult it was for them to develop an interest in having contact with other people due to their lack of confidence in their ability to reciprocate in social exchanges. They reported having difficulties with initiating and maintaining conversation, as well as experiencing an absence of feeling stimulated by contact with others. Such difficulties created obstacles for the participants in terms of social engagement with others in their community.

Erdner et al. (2005) concluded that these six impediments for living a more active life in the community were also representative of various forms of alienation or existential loneliness. Individuals living with long-term mental illness find it difficult to enter into social relationships and share their daily lives with other people due to a lack of skills as well as a lack of interest. Consequently, although individuals with long-term mental illness may be aware of what they need to live an active life in the community, they often fail to meet those needs as they inadvertently continue this alienation and isolation through their conflicted feelings of wanting to fit in, yet not knowing if they really desire or deserve such attention.
As part of their ethnographic approach, Erdner et al. (2005) spent 16 days observing 23 individuals with long-term mental illness in two rehabilitation centers. Unlike the study on psychosis discussed earlier, wherein the researchers did not explicitly define how they gained an authentic experience of the phenomenon, the researchers clearly indicated what they did to help themselves gain a broader picture of the daily experience of individuals with long-term mental illness. The inclusion of a period of observation helped further the credibility of the study though it was unclear if the eight participants who were interviewed were part of the 23 individuals who were observed. If not, then the question arises as to whether the themes based on the observations were also true for the eight participants. In the analysis of the researchers’ field notes, themes seemed to be based on assumptions or interpretations made about the behaviors observed. This raises the question of how they accounted for possible misinterpretations or the individuals possibly modifying their behavior when under observation by the researchers. Knowing if such issues were checked or clarified would help the reader further evaluate the credibility of the study (Lincoln & Guba, 1985). Erdner et al. provided graphic representations of their breakdown of themes, subthemes, and examples from the interviews and observations to illustrate their data analysis process. This rich description of their data analysis helps in part to establish the transferability, or generalizability, of their study (Lincoln & Guba, 1985) such that the reader can see how sample quotes or field notes were categorized and evaluate the relevance of the results to other contexts.

In another study by Erdner and colleagues concerning long-term mental illness, photographic ethnography was used to explore the views of life among individuals living with long-term mental illness (Erdner et al., 2009). Eight participants diagnosed with a
long-term mental illness, that was cited as the cause of the person’s inability to function independently, and who were enrolled in three day centers in Sweden for individuals with long-term mental illness living in the community were given disposable cameras with which they were to take photos of objects, people, or scenes that were meaningful to them. The photos were used to facilitate interviews about the photo images and what they each represented for the participant.

Four themes emerged from the interview data, demonstrating collectively the difficulties participants encountered in relating with other people and God, as well as their consequent preference for establishing relationships with animals and objects in lieu of relationships with other people (Erdner et al., 2009). The first theme revolved around their thoughts about God and the meaning of life and death. Participants discussed their fear of death in relation to being forgotten or not being important enough to be remembered. In discussing their relationship with God, they talked of the importance of having faith in God but feeling as well that God had failed them during difficult times or that God had punished them. Such feelings about God and death echoed the participants’ experience of loneliness. The second theme meaning of relationships with others centered on the participants’ relationships with others, with many of them sharing that their present distrust of others and lack of self-confidence stemmed especially from the disharmony between their parents when they were children and that their current sense of distrust in others also resulted from misjudging others and trusting the wrong people. The third theme animals give life meaning without demands captured the participants’ disclosures that they preferred relationships with animals. The participants shared their belief that animals provide a sense of peace and ease that people do not provide and that
animals do not expect anything in return from their caregivers. The fourth theme *symbolic meaning of objects* highlighted the symbolic meaning objects had for the participants. In seeing objects as extensions of themselves, participants felt that no other person would be worthy enough to inherit their prized possessions. Their desire to own objects was symbolic of their desire to connect with the outside world, yet they make sure not to possess too many objects as this would only serve to disrupt their lives. In their holistic interpretation Erdner et al. (2009) conclude that the four themes seem to indicate that individuals with long-term mental illness desire a connection with the world, but due to their mistrust of others, they must establish meaningful connections with their world on their own terms, such as through relationships with their pets or objects.

A strength of this study was the creative use of photographs to stimulate the dialogue between the researchers and participants. The fact that the participants were given the opportunity to take photos of what they thought was meaningful to them seemed to have the advantage of ensuring that what was meaningful to the participants emerged from themselves rather than the researchers. Similar to the study on psychosis, the presentation of results seemed to indicate that all eight participants shared the same views of life or experienced the themes rather similarly with little sense of variation or divergence from any of the participants. Interviews were conducted after the photographs were developed wherein the participants were asked to describe what they thought about the pictures. It is unclear how the researchers moved the participants from speaking about the images on the photos to discussions on their views of life. There was no indication if prompt questions were used or if there was a structure to the interview portion of their method. Further information might be helpful to understand how all eight
participants had come to discuss interestingly similar topics, especially about rather specific subjects, such as God and animals.

Schizophrenia. Although the aforementioned two studies on long-term mental illness concerned individuals living with any type of chronic psychiatric disorder, other studies have been conducted that investigate issues related to individuals with specific chronic mental health conditions. Three studies in particular focused on the lived experience of schizophrenia (Bradfield & Knight, 2008; Cookson & Dickson, 2010; McCann & Clark, 2004). McCann and Clark (2004) used a phenomenological approach to explore how individuals with schizophrenia experience and find meaning in their illness. Nine young adults diagnosed with schizophrenia and living in the community in a regional and rural area of New South Wales, Australia, were interviewed and asked to describe what it was like to be a young adult with schizophrenia. Three themes emerged in the data analysis.

The first theme embodied temporality: illness as a catastrophic experience focused on how schizophrenia can affect the individual’s experience of the present and the future (McCann & Clark, 2004). Participants described how they experienced schizophrenia as frightening because the illness does not allow for predictability as to when the illness’ symptoms, particularly hallucinations and delusions, will recur. In turn, such unpredictability left participants also feeling afraid of what they might do when experiencing hallucinations and delusions, already carrying emotions of guilt or embarrassment for past behaviors or transgressions they might have engaged in during previous episodes of hallucinations or delusions. Not knowing when their symptoms might return made it difficult for participants to plan ahead, generating even greater fear
of the unpredictability and uncertainty of their future. The experience of schizophrenia proves challenging for individuals with this illness to make sense of what they are experiencing in the present, as well as to create meaning in their lives in the context of future goals or ambitions as they are uncertain as to their state of being during any period of time. This subsequently generates a sense of hopelessness about their present and their future.

The second theme embodied relationality: illness as a mediator of social relationships referred to how the experience of schizophrenia affected the participants’ relationships with others (McCann & Clark, 2004). Participants described how their illness sometimes resulted in receiving support from family while at other times led to damaged or unsupportive relationships with family members. At times behaviors they might have engaged in during periods of hallucinations and delusions resulted in feelings of embarrassment, guilt, or misunderstanding which led to difficulties in re-establishing some of their relationships. This left participants to seek support from alternative sources, such as through friends or their spirituality, the latter of which was often seen as providing warmth, comfort, and acceptance. At the same time fear of discrimination made it difficult for participants to engage fully with others around them, which also impacted their decision about whether to disclose their illness to others at the risk of rejection, resulting in their further marginalizing themselves from their social community.

The third theme embodied treatment: medications side effects as burdensome encompassed the participants’ experience of the side effects associated with their medications for schizophrenia as disruptive and burdensome to their daily living (McCann & Clark, 2004). Participants shared that they found the side effects physically
disruptive because the effects included weight gain, sluggishness, sleepiness, as well as impotence and amenorrhea. Side effects were also experienced as frightening, and participants disclosed that their body images had also been affected because they worried about appearing mentally unstable due to the side effects, which inevitably affected their ability and confidence in initiating relationships with others.

As a result of their illness and medications impacting their relationships as well as their sense of meaning in the present and ability to plan for the future, individuals with schizophrenia often risk isolating themselves either through choice or as a consequence of the illness, resulting in severed relationships. The hopelessness, isolation, and despair associated with living with schizophrenia and its unpredictability have led some of the participants to contemplate or even attempt suicide (McCann & Clark, 2004). Living with schizophrenia resulted in a lack of confidence in their own mind, causing the participants to remain vigilant in how they function in the present, always making comparisons with how they functioned in the past during times of illness and times of health and questioning what expectations they could have for their future.

McCann and Clark (2004) provided rather detailed descriptions of each identified theme, adding quotes and segments of interview dialogue to help bring the themes to life. Unlike a number of the studies reviewed in this section, McCann and Clark also highlighted some variations within the themes, such as the differences in social relationships experienced by the participants as a result of their illness. Only a brief, general description of the participants was provided, making it difficult to establish a level of transferability because some potentially significant details were absent. For example, although the article indicated that the participants were young adults who had
been diagnosed with schizophrenia, nothing is said of the participants’ age range, duration of illness, or living situation. Knowing these details may allow an estimation of how applicable the study’s findings are to other contexts (Lincoln & Guba, 1985).

McCann and Clark used bracketing and journaling before the interviews and during the data analysis process as a way to maintain an openness to the data, which helps to reassure the reader that the description of the phenomenon came from the data and not the researchers’ preconceptions or biases (Creswell, 1998).

Another phenomenological study that looked at the experience of schizophrenia was conducted by Cookson and Dickson (2010). It was specifically aimed at exploring participants’ experience, perception, and understanding of their diagnosis of schizophrenia, in addition to exploring their experience of psychosis. Semi-structured interviews were conducted with eleven adults who were diagnosed with intellectual disabilities and either schizophrenia or schizoaffective disorder and who were confined in a medium secure unit in the United Kingdom. Participants were asked to describe their experience of their diagnosis of schizophrenia or schizoaffective disorder, what they felt when they first received the diagnosis, and their understanding of what was happening to them when they were diagnosed. Three superordinate themes were identified, each with subthemes, that described the participants’ experience of schizophrenia and psychosis.

The first superordinate theme focused on reality of symptoms, which encompassed the subthemes of voices as controlling or malevolent and symptoms as a real lived experience (Cookson & Dickson, 2010). Participants described how they experienced the symptom of hearing voices as malevolent and having control over them, resulting in their feeling both fearful of and submissive to these voices. Although they
recognized that the voices were internal or contained in their head, participants often identified the voices with real people, either a stranger or someone known to them. The participants also shared that not only was the experience of hearing voices frightening for them, but it was also debilitating in that participants perceived these voices as superseding their ability to keep themselves or others safe. Although the participants were able to discern that the voices came from within their head, they nevertheless tended to attribute their hallucinations and delusions to external sources as opposed to a mental illness. Rather than risk the stigma associated with a diagnosis of mental illness, participants found it more palatable to explain that their symptoms came from outside of themselves, such as attributing them to other people or claiming they had been bestowed special gifts or powers. Alternatively, such explanations could be due to having no other available means to explain their hallucinations or delusions, rather than due to a conscious choice to avoid stigma.

The second superordinate theme making sense: a search for meaning covered the subthemes of normalization: linking past experiences to the onset of symptoms/difficulties, religious/spiritual explanations, and psychotic symptoms as a sign of illness (Cookson & Dickson, 2010). The first subtheme referred to the participants’ attempt to make sense of and normalize the experience of their psychosis and consequent diagnosis by drawing connections between the onset of their illness and earlier life experiences, such as not getting sufficient sleep, getting married or having a baby, or having had negative childhood experiences. Rather than admit to having a mental illness, participants also chose another less stigmatizing explanation to find meaning in their symptoms. Participants attributed their illness to a religious or spiritual event, such as the
devil being inside them or receiving visions of or visits from spirits. Yet, despite such explanations and attempts to make meaning of their symptoms through less stigmatizing rationales, when participants were diagnosed with a mental illness, they also demonstrated an acceptance of their symptoms as being due to an illness. The participants’ flexibility in explaining their symptoms and finding meaning in their illness highlighted their ability to view their illness through multiple lenses and integrate the different meanings they have made of their illness prior to and after contact with mental health services.

The third superordinate theme related to perceptions of being labeled, specifically noting the subthemes of acceptance versus rejection and impact of the diagnosis (Cookson & Dickson, 2010). Participants generally appeared to accept the explanation of their symptoms as being due to an illness, but they also seemed to vacillate between accepting and rejecting the diagnosis they received, the latter perhaps being due to the stigma attached to the diagnosis. Participants shared their concerns over the impact their illness had on their lives, such as fearing they would not be able to obtain employment because of the diagnosis, being subject to discrimination and stigmatization, and experiencing emotional distress upon receiving the diagnosis due to realizing that the illness is lifelong and permanent.

In contrast to McCann and Clark’s (2004) study on schizophrenia reviewed above, Cookson and Dickson (2010) provided a detailed description of the participants and setting, contributing to the study’s level of transferability (Lincoln & Guba, 1985). The researchers also included a graphic representation of the themes and subthemes; unlike with Erdner et al. (2005), Cookson and Dickson did not include sample quotes to
provide the reader with some access to review their data analysis process. The researchers reported that they used a semi-structured interview schedule, adding that the format served as a guide but still allowed the researchers to follow a natural, flexible exploration of the participants’ experiences. Sample questions were provided by the researchers as well. The presentation of results was full of supporting quotes from the different participants, providing not only a richer description of the themes but also ensuring the participants’ voices were present throughout the research (Creswell, 1998). Giving voice to the participants was especially important given the participants’ context (i.e., confined individuals with both an intellectual disability and mental illness with a history of offending) to prevent further marginalization of this group.

Bradfield and Knight (2008) conducted a phenomenologically informed case study examining the intersubjective experiences of an individual with schizophrenia, specifically looking at her experience of the self in relation to others. Seven hour-long unstructured interviews were carried out with an adult female diagnosed with Schizophrenia, Paranoid Type, living in South Africa. Open-ended questions were used to invite the participant to describe her lived experience of schizophrenia within the context of interpersonal relationships with others. The participant also provided written narratives of her experience, specifically outlining an intrapersonal dialogue between two aspects of her personality.

One theme that emerged from the data centered around the participant’s feeling of isolation, which she attributed to feelings of being misunderstood and her belief that those without mental illness are unable to empathize with her (Bradfield & Knight, 2008). At the same time, the participant added that the feeling of being misunderstood
contributed to her anxiety about her ability to communicate her thoughts and feelings effectively in such a way as to be understood by others. Such experiences led the participant to feeling unheard by those around her, resulting in her feeling unsupported and having experiences of self-doubt about the validity of her existence and the value of her contributions to social contexts. Her experiences of self-doubt further delved into existential doubt whereby the participant began to question her own being in the world.

Another theme that emerged in the participant’s descriptions related to her perceptions of being disrespected and abused by others (Bradfield & Knight, 2008). The texts provided by the interviews and the participant’s written narratives revealed that the participant possessed a limited range of ways she engaged in interpersonal transactions, such that she expected that certain people should behave in certain ways, should say certain things to her, and should ask her certain questions. When other people failed to do as she expected, the participant perceived these slights as being dominated and controlled by the other person. The participant’s rigid sense of interpersonal engagement, which is tied to an inflexible self-perception, rendered her unable to tolerate the natural ambiguity that comes with being in relation to others. She, instead, felt that she must be on one side or the other instead of being more fluid in her interactions with others. Consequently, the participant described having difficulties with interpersonal contexts that required her to engage in a manner that did not adhere to her rigid or concrete rules of engagement.

The participant disclosed that her only positive relationships were those she shared with other mentally ill people, namely fellow patients (Bradfield & Knight, 2008). She explained that these relationships have helped her to feel understood and worthy of
the other person and of the relationship itself. Feeling worthy appeared central to the participant’s experience of the relationship as positive. Generally, though, the participant expressed that she found it challenging to start conversations due to a feeling of awkwardness stemming from not knowing the other person well enough to sense the other person’s viewpoint, adding that she has experienced difficulty in getting to know others due to a perceived need to maintain some degree of guardedness and defensiveness. These factors have ultimately prohibited the participant’s ability to interact with others.

Bradfield and Knight (2008) provided an illuminating lens into the experience of interpersonal relationships using a case study design, such that they were able to focus on one individual and go into greater detail with the participant than they would have if they had used a larger sample size. The seven hour-long interviews and the written narrative provided by the participant resulted in a vivid description of the participant’s struggles in her interactions with others, shedding light on other issues related to interpersonal relationships apart from lack of social skills or the symptoms of the illness. The researchers outlined their data analysis procedures in detail, and they included quotes and portions of interview dialogue to help capture the essence of the participant’s experience. A limitation of the case study approach is not knowing how much the participant’s descriptions of her experiences are similar to or different from other individuals diagnosed with schizophrenia, affecting the study’s transferability (Lincoln & Guba, 1985). Bradfield and Knight were always careful to refer back to the participant in their description and discussion of the phenomenon, never assuming that the participant’s experiences were representative of other individuals living with schizophrenia.
**Bipolar disorder.** Other qualitative research studies have explored the lived experience of individuals living with bipolar disorder (Jonsson et al., 2008; Rusner et al., 2009). The goal of one of these studies was to understand the meaning of living with bipolar disorder from the perspective of how individuals with this diagnosis viewed their illness and future (Jonsson et al., 2008). Qualitative content analysis was conducted on data gathered through in-depth interviews with 18 adults diagnosed with bipolar disorder, living in Sweden and receiving outpatient mental health treatment. Six themes emerged from the data concerning the participants’ views about their illness and their views about the future, with four themes defining their views of the illness and two themes defining their views of the future.

The first theme *accepting the illness* captured the participants’ difficulty with accepting that they had a mental illness (Jonsson et al., 2008). Participants shared how they experienced a long-term process that involved vacillating between accepting and rejecting their illness because they found it difficult to identify as someone with a mental illness. Prejudices with regard to individuals with mental illness further complicated this process of acceptance, resulting in participants favoring a denial of their illness as they longed for a normal life. Participants added that even when they reached a state of acceptance, that state was not permanent and often took the form of simply resigning to the fact of being mentally ill for mere lack of alternative explanations for their experiences.

The second theme *being insecure in oneself* highlighted the insecurity some of the participants felt about their abilities as a consequence of the repeated disruptions to their daily living due to their illness (Jonsson et al., 2008). The difficulties they faced living
with their illness day-to-day posed limitations to their functioning and having to be
reminded of these limitations daily only served to lower their self-confidence and leave
them fearful of failing or becoming ill again. The issue of prejudices toward individuals
with mental illness resurfaced in this theme in that the participants’ awareness of how
people perceived those with mental illness generated feelings of insecurity and of low
self-esteem, which then impacted how they related with their social world. Their desire
to live without limitations made manic episodes more alluring as these periods allowed
participants to have this desire fulfilled.

The third theme *striving for understanding* referred to the participants’
descriptions of how they experienced difficulty in understanding their feelings and what
was happening to them as well as their gaining some insight into their illness upon
receiving the diagnosis (Jonsson et al., 2008). The diagnosis did not necessarily facilitate
a complete understanding of their illness because more questions arose for the
participants. The nature of the illness, with its varying symptoms and moods, appeared to
pose an additional challenge for participants as they attempted to understand their
diagnosis of illness as an explanation (which they felt was not always sufficient) for their
experiences. Participants expressed confusion over which of their feelings and
experiences were due to the illness and which were normal. Being armed with
knowledge about their illness helped to relieve at least some of the burden of having a
life-long condition.

The fourth theme *managing the illness* encompassed the participants’ disclosures
about questioning their ability to manage their illness of bipolar disorder on a daily basis
and developing a sense of responsibility over their lives (Jonsson et al., 2008).
Participants shared how increased knowledge about their illness, as well as acceptance of their condition, helped them to be more active in taking care of themselves and managing their symptoms. As they felt more effective in managing their daily living with bipolar disorder, they felt less frightened by the illness and saw how living with and managing their illness could enhance their personal growth. In order to maintain functioning, participants had to make changes to their lives, such as allowing space for less stress, planning ahead, establishing consistent and clear routines, and seeking social support.

The fifth theme *an uncertain future* concerned the limitations in functioning associated with the illness, creating a sense of worry and fear about being unable to plan ahead, achieve goals, or manage daily living (Jonsson et al., 2008). Participants shared how they feared the illness would affect their ability to attain and maintain employment or further their education, acquire financial independence or security, establish social relationships, or otherwise achieve desired goals or wishes. Their fears concerned not only the fluctuations brought upon by their symptoms but also involved fears of failure in the different aspects of their lives. Some participants addressed their uncertainty about the future by avoiding making plans or not allowing themselves dreams or wishes for their future, instead planning only for the day; others admitted to contemplating death as a solution to this uncertainty.

The sixth theme *a hopeful future* spoke to the moments of hope participants had for their future and themselves once they gained an understanding of their illness and became more accepting of it (Jonsson et al., 2008). Through taking control over their illness by learning strategies to manage their symptoms and assume responsibility for their lives, participants experienced an improvement in their well-being and held a more
positive attitude about their future. They felt more successful when it came to managing their illness and adjusted to their abilities. Consequently, they also saw themselves as valuable and contributing members of society.

The researchers provided a rich description of their participants, data collection procedures, and data analysis process, additionally providing tables showing the participants’ demographics as well as examples of their coding system, meaning units, and themes. In doing so, Jonsson et al. (2008) enhanced their study’s credibility, such that the reader is able to evaluate whether the findings reflect the data elicited from the participants’ statements. Such detailed descriptions of the method and findings also strengthened the study’s transferability, or the ability of the reader to identify similarities to or differences from other contexts (Lincoln & Guba, 1985). Although Jonsson et al. aimed to explore the core consistencies in the data, it would have also been interesting to know if any of the participants offered unique responses that did not fit neatly into any of the themes. Given that there were 18 participants, there might have been some variations or divergence in the responses that would have been equally valuable in illustrating individuals’ experiences of bipolar disorder with regard to views of life and views of the future. With a relatively large sample, using more than one quote for each description (if available) might have brought forth the participants’ voices as individuals and as a group (Creswell, 1998).

Another qualitative study focusing on bipolar disorder sought to explore the existential meaning of life with this illness through the lens of phenomenological philosophy (Rusner et al., 2009). For this study, interviews were carried out with 10 adults diagnosed with bipolar disorder and living independently in Sweden, each having a
history of institutional psychiatric care. Participants were asked to describe their experiences of living with bipolar disorder, with follow-up questions used to further facilitate their descriptions. The interview data focused primarily on the essential meaning of the lived experience of bipolar disorder, with three additional variations of that meaning.

The participants’ descriptions seemed to indicate that living with bipolar disorder requires individuals with this illness to grapple with extra dimensions in all aspects of life. Rusner et al. (2009) termed these additional dimensions *magnitude* and *complexity*. Magnitude involves an intensity of feelings and experiences that create chaos in life. Complexity refers to the complications brought about by the illness as it becomes intertwined with daily living and creates difficulties for the individual to understand what he or she is experiencing.

One variation of the notion that individuals living with bipolar disorder experience extra dimensions in all aspects of life concerned *a specific intensity* (Rusner et al., 2009). Although the highs and lows experienced by people with bipolar disorder are similar to those without this illness, the difference comes in the level of intensity of the highs and lows. For individuals with bipolar disorder, this intensity affects their ability to think, makes them more sensitive regarding themselves and their surroundings, increases or decreases their energy level, or leaves them feeling worthless or more self-confident.

The second variation of the essential meaning of living with bipolar disorder involved *a struggle to understand*, which included difficulties pertaining to trying to understand oneself, as well as other people and situations. People living with bipolar disorder appear to have difficulties with trying to understand what is helpful and what can be detrimental
in life, in addition to what is real and what is not. The challenges with understanding life with bipolar disorder are so complicated that this struggle to understand becomes a daily battle for individuals with this illness. The third variation illustrated the experience of bipolar disorder as *an illness that is intertwined with one’s whole being*. This pertained to the illness being a part of the person (i.e., their being and their identity), and the fact that it is a part that cannot be separated from these aspects of the individual. As a result, feelings of self-contempt and disappointment surface as individuals with bipolar disorder realize that to fight against the illness is impossible because this would require fighting against themselves. Some sense of relief or peace is achieved when individuals with bipolar disorder accept their illness as a part of their being, which gives them greater self-control.

Although Rusner et al. (2009) provided a fairly rich description of the experience of living with bipolar disorder, this study seemed to lack the level of detail found in Jonsson et al.’s (2008) work. Rusner et al. did not provide any graphic representations of their data analysis process, leaving the reader without a sense of how they proceeded to code the data into the themes discussed in the article. The presentation of results was written entirely in the present tense. The researchers stated that the use of present tense was intentional as a means to describe the phenomenon and not what the participants shared in their interviews. Given that a phenomenological approach was used, it seemed important to illustrate the phenomenon from the participants’ viewpoints, rather than through generalized statements regarding the phenomenon as if what the participants disclosed is necessarily true for all individuals living with bipolar disorder. Although a few quotes were included, the researchers’ descriptions were akin to those found in
diagnostic or psychopathology textbooks wherein lists of symptoms or characteristics are merely outlined. The researchers indicated that there were large variations in the participants’ responses; examples of these variations were not illustrated in the presentation of results. Unique aspects of the experience of living with bipolar disorder were omitted, consequently creating a generic understanding of the phenomenon.

**Depression.** Depression can also constitute a chronic mental illness that can impact an individual’s daily living experiences. Rhodes and Smith (2010) conducted a single case study of an adult male living in the United Kingdom who had been diagnosed with major depression. A semi-structured interview was used to elicit a description of what the experience of depression was like for him during the initial onset of the illness and in the present. The following four themes emerged from the data analysis.

The first theme *the context for depression* described what was occurring in the participant’s life prior to and at the onset of the illness (Rhodes & Smith, 2010). The participant recounted long-term difficulties, such as dealing with a struggling business, working extensively long hours then staying out at night to go drinking, and spending less time with his family and often not seeing them due to his drinking. At about the time he began to experience symptoms of depression, the participant recalled being in debt and not having paid his taxes, resulting in remortgaging in order to resolve the debt. This, the participant felt, was the end for him.

The second theme *features of depression* pertained to what the participant experienced within himself as he became depressed (Rhodes & Smith, 2010). The participant described feeling a change in motivation and in his capacity to act, such that he lacked not only the desire to do things but also the ability to get himself to do things.
He initially saw this change as not a part of his normal self, and he eventually came to question if this change was slowly creeping into his being and becoming a core part of himself.

As he began to think his depressive features were becoming a core part of himself, he described feeling helpless and vulnerable, which constituted the third theme of *masculinity and vulnerability* (Rhodes & Smith, 2010). These feelings conflicted with his previous views of himself as a strong person. The participant stated that he always strived to be a strong person because this was expected of him as a man. As such, the depression meant a dismantling of these original assumptions of his masculinity and strength.

The fourth theme that described the participant’s experience of depression related to *the horror of depression* (Rhodes & Smith, 2010). The participant recounted two images that aided in understanding how he experienced his depression. The first image was that of being *in a pit*, which represented feelings of helplessness, fear, entrapment, abandonment, and isolation, with no way for him to escape or no way out of this pit of depression. The second image was that of feeling like the *top of his head would pop right off*, which was meant to describe the feeling that the negative thoughts continued to accumulate to the point where the increased volume and toxicity of these thoughts would eventually need some sort of release. This feared release would either be in the form of an explosion of frustration or cathartic release. At the same time, the participant indicated that he also worried that this explosion meant that he was going mad or losing himself.
Rhodes and Smith (2010) provided a unique lens into the experience of depression, outlining the results in a somewhat linear fashion from when the participant began to experience symptoms to when those symptoms worsened. Unlike the previous studies, where only common themes were identified and discussed, Rhodes and Smith illustrated how the participant’s thoughts and feelings shifted and changed over the course of his illness. This seemed to bring out the participant’s voice, which further emerged through the use of many quotes and portions of the interview transcript throughout the presentation of results. Rhodes and Smith failed to mention details about their interview process, such as the number and duration of interviews and the interview questions. The researchers used a semi-structured interview approach but there were no sample questions to help illustrate how the data collection proceeded. This makes it difficult to assess the dependability, or reliability, of the study, which then affects the study’s credibility and transferability. There are limitations to knowing whether the data is really reflective of the method and not of the researchers’ biases and to knowing how applicable the results might be when compared to other contexts (Lincoln & Guba, 1985).

**Being diagnosed.** Hayne (2003) conducted a phenomenological study aimed at describing the experience of being diagnosed as having a mental illness. A narrative or conversational dialogue style was used to elicit participants’ description of what it was like for them to receive the diagnosis of being mentally ill, as well as the realization and awareness of the diagnosis as a part of themselves. Participants consisted of 14 adults living in Canada who had had the experience of being diagnosed with a mental illness. Four essential themes emerged from the data analysis, each of which touched on the impact the diagnosis had on the participants’ sense of self.
The first theme *a knowledge that knows* revolved around the experience of first receiving the diagnosis wherein participants described feeling as though the diagnosis carried an incisive power that created a sense of schism between what participants knew of themselves and what they had come to not know of themselves (Hayne, 2003). Feelings of distress and confusion arose, with participants attributing these experiences to a sense that the diagnosis was an irrefutable medical fact that indicated something about them which they were not aware of previously. Participants seemed aware that what they were experiencing as a result of the illness was strange, but having their odd behaviors labeled with a diagnosis of an illness transformed their experiences into a part of themselves that was foreign to them.

The second theme *destructive (gift) of difference* highlighted the experience of a seeming duplicity brought upon by the diagnosis (Hayne, 2003). The diagnosis label afforded participants a sense of uniqueness, as if the diagnosis of illness meant for them that they had special characteristics, abilities, or value. Participants concurrently experienced the diagnosis label as de-legitimizing, or of having been stripped of that uniqueness and having those special characteristics destroyed. The diagnosis appeared to offer some relief in the form of an explanation for what participants were experiencing as a result of their illness but left them shaken from having their awareness of themselves and sense of being as a person displaced and shattered.

The third theme *making visible the invisible* focused on a more positive aspect of being diagnosed mentally ill (Hayne, 2003). Participants shared that to have the diagnosis meant being able to receive treatment and healing as the label allowed for an identification and explanation of their strange experiences, opening the doors to the
necessary treatment to help restore them to a level of functioning in their lives. Some participants expressed feeling as if they were given life anew because they could now make sense of and understand what they were experiencing which helped reduce the confusion and fear associated with what later became known as their symptoms. They could begin to build a new life with this new awareness and re-engage in all aspects of their lives.

The fourth theme *knowledge made knowledgeable* also focused on other positive gains made from receiving the diagnosis (Hayne, 2003). Receiving the diagnosis of being mentally ill provided participants with the knowledge they needed in order to feel whole again. Although they spoke of feeling de-legitimized, they also shared that the diagnosis contributed to a sense of affirmation that their symptoms were real and could be viewed through a different lens. Participants were able to reinterpret their experiences through the framework of their illness, rather than as a losing of one’s self, which made it possible for them to seek and receive help. The language of symptoms and illness provided a way to normalize what they were experiencing, resulting in a sense of relief from confusion, fear, and turmoil over what was happening to them.

Allowing the voice of the participants to emerge through the data is always important to strengthen the integrity of qualitative research and is particularly crucial when attempting to describe the experiences of a marginalized group (Creswell, 1998). The voices of the participants in Hayne’s (2003) study were quite evident throughout the presentation of results. The integration of quotes and descriptions of what individual participants shared in the interviews resulted in a unique understanding of what some individuals with mental illness might experience when they receive a diagnosis. At the
same time the description of the participants was rather sparse (e.g., no mention of the participants’ ages or diagnoses), and there was no mention of inclusion or exclusion criteria apart from that participants must have been diagnosed with a mental illness and were able to articulate their experiences. Although Hayne might have wanted to capture a general sense of the experience of being diagnosed, that experience might be affected by whether participants had a condition that was chronic or acute, how old they were when they received the diagnosis, or how long they had had their illness. This study offered valuable insight into what it might be like to be diagnosed with a mental illness, which would be important for mental health professionals to become aware of in order to improve the ways in which they inform individuals of their conditions.

**Being misunderstood.** One study examined an aspect of living with chronic mental illness that concerns being misunderstood by others, including treatment providers. Gaillard et al. (2009) focused their phenomenological inquiry on the experience of being misunderstood when one is diagnosed with a mental illness. Their research involved a secondary analysis on previously collected interviews for a larger research endeavor about mental illness. Participants included 20 adult individuals living in the United States who self-identified as having a mental illness, reporting a variety of past and present psychiatric diagnoses including depression, anxiety, bipolar disorder, posttraumatic stress disorder, attention deficit hyperactivity disorder, antisocial personality disorder, schizophrenia, and schizoaffective disorder. Although some reported having been hospitalized for their mental illness in the past, all of the participants were living in the community at the time of the interviews. Gaillard et al. did not conduct new interviews for their study; they reviewed the already existing interview
data through the lens of their research question aimed at understanding what is the experience of being misunderstood.

Four themes of the experience of being misunderstood emerged; the first of which was protection from vulnerability (Gaillard et al., 2009). Participants shared how they were wary of telling others about their mental illness due to feeling vulnerable to the judgments and misconceptions of others. They spoke of resorting to censoring what they shared or how they behaved in public in order to protect themselves from what they believed were the consequences of being misunderstood, such as being stigmatized, patronized, or otherwise treated negatively. In the end such self-censoring also brought about feelings of frustration, resentment, and discomfort for not being able to be themselves around others or having their disclosures or behaviors interpreted as merely being a part of their mental illness.

The second theme related to the experience of being misunderstood referred to feeling like an object to be fixed (Gaillard et al., 2009). This theme captured the feeling of being treated by treatment providers as a problem to be fixed, or a case or number, rather than as a whole person. Participants described having interactions with various health care providers who seemed solely interested in treating only the symptoms of the illness with medication, otherwise discounting them as a person with lives, abilities, characteristics, and needs. In some cases, the participants observed that providers often did not make eye contact with them, failed to offer feedback, or focused more on the person’s written medical records while ignoring what the person was reporting or sharing. Such treatment from providers left participants feeling objectified and resentful.
The third theme pertained to the experience of being misunderstood as feeling *treated like a child* (Gaillard et al., 2009). Participants shared that they felt providers treated them as though they were incapable of being responsible for themselves and their mental health care, affecting their self-esteem and self-confidence. Their interactions with treatment providers often resulted in participants feeling like they were no longer in control over themselves. Instead, it seemed that health care providers lacked confidence in the participants’ ability to make decisions for themselves and often failed to acknowledge participants as autonomous adults who were fully capable of participating in their own treatment planning. In addition to feeling ignored when given simplistic advice in response to disclosures of significant feelings or experiences (e.g., take deep breaths, listen to music, develop a hobby), participants felt pressured into treatments with which they did not agree or desire. Rather than helping to direct the course of their treatment, participants inevitably felt they must succumb to the treatment providers’ agendas for them.

Finally, the experience of being misunderstood had the effect of *relentless frustration* for the participants (Gaillard et al., 2009). Whenever they felt treatment providers were misunderstanding them, participants expressed feeling frustration, anger, and emotional distress. Participants also described experiencing conflicted feelings about whether to agree or disagree with their treatment providers, frustration with having to repeatedly explain themselves only to be left still feeling misunderstood, and experiencing a sense of desperation to be understood and treated more adequately. At times, participants felt discouraged and wished to receive appropriate treatment without
having to go through a series of providers in order to find just one who would help them to feel heard and understood.

Although Gaillard et al. (2009) provided an insightful description of the experience of being misunderstood, the method they used for data analysis could arguably be considered weak with regard to the study’s credibility, or the degree to which the study was actually tapping into the phenomenon being investigated (Lincoln & Guba, 1985). Rather than directly interviewing participants about the experience of being misunderstood, Gaillard et al. chose to do a secondary analysis on previously collected data for a study that was focused on the experience of being understood. The researchers did not outline how they coded the participants’ responses or how they went about identifying responses to a research question that was different from the original inquiry. This results in some confusion as to how one can assume that an experience of being understood necessarily translates to its opposite, that of being misunderstood. Such a method of interpretation or assumption misses out on more detailed responses about being misunderstood, other descriptions of the phenomenon that were not mentioned in the original study, and the opportunity to allow the participants to share their narratives about what might have been meaningful for them with regard to the phenomenon.

Gaillard et al. reported that they took steps to assess the validity of their findings through multiple reviews from research groups at different stages of the analysis and presenting the results to one participant for another level of validation. The researchers never returned to the other 19 individuals who participated in the original study to verify if the interpretations made in the secondary analysis were accurate for them. One participant might not necessarily be a representative voice for the other 19 individuals.
**Being medicated.** Being on medication is often a part of having a mental illness, particularly if the condition is chronic and warrants such an intervention in the individual’s treatment and management of symptoms in order to assist him with daily functioning. It is often assumed that taking medication is beneficial for its assistance with managing the illness and restoring some level of functioning to allow the sufferer to live an otherwise productive life. Two qualitative studies have recently been conducted that specifically look at what it is like for individuals with mental illness to be taking medication for their condition and what this means for them (Bentley, 2010; Teal, 2009).

Following an interpretative approach, Bentley (2010) sought to explore the meaning and impact that taking psychiatric medications had on the lives of individuals living with mental illness. Semi-structured interviews consisted of 21 questions covering such topics as the effects and side effects of medication, both positive and negative experiences with taking medication, changes participants observed within themselves over time, perceived influences of family and society, and hopes and fears related to a future with medication. In addition to the interviews, participants were also asked to create a color drawing depicting their thoughts and feelings about medication and to interpret their drawings. This study involved 21 adults living in supervised residential settings in the United States who had a history of mental illness, were currently taking psychiatric medications for their illness, and who had been hospitalized in the past. Participants reported having at least one of the following diagnoses: bipolar disorder, schizophrenia, depression with psychotic features, schizoaffective disorder, posttraumatic stress disorder, attention deficit disorder, generalized anxiety disorder, dysthymia, and borderline personality disorder.
The interview data yielded a central theme about the experience of being on medication, labeled as *medication as something that incites meaning, influences identity and impacts life*, which was seen as being integral to seven variations, or typologies, of this overarching theme (Bentley, 2010). The central theme referred to the overall consequence of taking psychiatric medications, in the sense that this experience also entailed the added dimensions of individuals undergoing both physical effects as well as emotional or psychological changes in how they viewed themselves, their lives, and their illness in the context of these medications. For many of the participants, being on medication involved a paradox in that this form of treatment brought about positive benefits, such as greater clarity and increased functioning, but also led to a sense of being different or of surrendering to the illness.

Bentley (2010) referred to the first of the seven typologies as *psychiatric medication as a positive force across several dimensions of experience*. Participants reported various positive benefits to being on psychiatric medications. For example, they experienced a reduction of symptoms that were frightening, confusing, or distressing (e.g., hearing voices, racing thoughts, anxiety, paranoia). Improvements in focus and concentration, confidence, and thinking were also reported. Medication also provided a sense of assurance, offering calmness and relaxation, stability in mood, and happiness. Other benefits included helping participants to avoid hospitalization, anger, self-absorption, and other negative consequences of their illness. Still others shared that medication had helped them to feel normal, meaning that they felt more alive, more involved in interactions with others, more aware, more energetic, and better able to cope with daily life.
The second typology *psychiatric medication as a tolerated fact of life* referred to participants’ disclosures that taking medication was just a part of their lives that they must accept (Bentley, 2010). Participants shared a general sense of having accepted that they must be on medication for the rest of their lives and having resigned themselves to this fact. Although side effects are often difficult to deal with or tolerate, there seemed an acquiescence to having to endure this troubling aspect of medication. Participants seemed to view medication as beneficial in the long run, that the benefits far outweighed the negative side effects when the goal was to function day-to-day.

The notion of *psychiatric medication as primarily an internal and individual experience* comprised the third typology (Bentley, 2010). Participants described the act of taking medication as an internal experience that occurred both physiologically and psychologically because the medication affected them at both levels. Medications affect one’s neurology and bears physiological implications, including the positive regulating qualities and the negative side effects. At the same time, medications also impact one’s emotional state and the perceptions and conceptualizations one has about oneself. Taking medication is also very individual in that other people’s opinions of psychiatric medications are not at the forefront for individuals with mental illness who are needing to take psychiatric medications. Although family members or societal perspectives may have had some influence on the decision to take medication, participants disclosed that such factors had minimal impact on their attitudes toward and perceptions of taking medication as positive or negative.

The fourth typology referred to *psychiatric medication as a prominent part of the story and evolution of one’s mental illness* (Bentley, 2010). Participants highlighted how
their experience of taking medication was an integral part of the history of their mental illness. The story of when they began to take medication, what types of medication they took and the side effects they experienced, and trials and errors with medication types they experienced were intertwined with their narratives of psychotic episodes, manic or depressive episodes, onset of illness, hospitalizations, employment or relationship difficulties, and acts of violence toward others or themselves. The story of coming to accept their mental illness was also encapsulated within the story of their experiences with medications as they went through the process of finding the right ones and the right dosages.

The fifth typology *psychiatric medication as basis of gratitude and source of victory over past struggles* captured the participants’ indication of their experience of being on medication as generally positive (Bentley, 2010). Despite the negative side effects of taking medication, participants shared that the medications afforded them the ability to fight their illness and its related challenges. Upon reflection of the progression of their illness, participants described the battles they faced from instability and chaos due to the severity of their symptoms to a place of stability and safety, with the assistance of their medications. Such insight offered participants a feeling of triumph and tenacity in their long and difficult journeys with their illness.

The sixth typology characterizing the experience of being on medication was labeled as *psychiatric medication as necessary for prevention of relapse and protection of humanness* (Bentley, 2010). As part of coming to accept that taking medication was an unavoidable part of their lives, participants shared their awareness that non-compliance with their medication could result in severe consequences. The fear of relapse was
significant among participants because returning to a state of instability and non-functioning meant losing control over their lives again as they became overpowered and enslaved by their symptoms. This lack of control consequently resulted not only in instability and chaos but also in a return to a state of non-humanness as they would lose their sense of being a normal person. With medication, their sense of identity and of being a functioning person like all others was protected and preserved.

The seventh typology of the experience of being on medication focused on *psychiatric medication as a symbol of differentness and dependency* (Bentley, 2010). Although the benefits of medication were lauded by the participants, they also revealed that being on medication had some repercussions on their sense of being normal.

Participants shared that being on medication also had the effect of separating them from other people in the sense that they had to take or ingest something in order to function normally. The act of taking medication meant that they were different from others around them without mental illness. Also, the realization that they would have to be on medication for their lifetimes meant a state of dependency on an external agent that was responsible for allowing them to be normal. For some, this awareness burdened them with the struggle of accepting or denying their mental illness, which resulted in their taking control over their medication by regulating their compliance with it. For others, it meant relieving themselves of this struggle by accepting the notion of this dependency and sense of differentness as just a part of their living with mental illness, which unfortunately also sometimes brought forth feelings of sadness and loss.

This study was one of the most sound studies among those reviewed in this section. Bentley (2010) provided very rich descriptions of the participants, as well as of
the data collection and data analysis procedures. Not only were the diagnoses of the participants listed, but demographic information was also included, such as age, education level, duration of illness, number of hospitalizations, and current use of medication. The complete list of interview questions was provided, in addition to the instructions and questions given to the participants for the supplemental activity wherein participants were asked to illustrate and describe their thoughts and feelings about medication use. These descriptions help to strengthen the credibility and transferability of the study (Lincoln & Guba, 1985). The thematic descriptions were brief and the participants’ voices were scarce in the presentation of results. As Creswell (1998) emphasized, qualitative research approaches must give voice to participants to prevent them from being marginalized. Given that Bentley used a large sample size and included both an interview and drawing activity to elicit the experience of being medicated, his research could have offered much insight into the phenomenon had the participants’ voices been used more to tell the story.

Teal (2009) focused his phenomenological research on the experience of being on medication more specifically on the experience of being on a Selective Serotonin Reuptake Inhibitor (SSRI), a type of medication used for reducing depression or depressive symptoms, as a way to highlight that being on this medication alters the lifeworlds of those taking it beyond mere symptom reduction. Four volunteers, all of whom had a history of being on an SSRI, had experienced at least one post-SSRI period, and lived in the United States participated in the study. Participants provided written responses to a series of questions covering demographics, history of types of SSRIs taken and for how long, and psychiatric diagnoses. Participants also provided written
descriptions of the periods when they noticed a difference in themselves during and after being on an SSRI. All four participants were also interviewed to allow them to expound upon or clarify their written responses.

The participants’ descriptions of their experiences not only illustrated the overall experience of being on an SSRI but also revealed differences among the participants in their experience of becoming depressed as well as reasons for seeking treatment and, consequently, their reactions to being on the medication. Based on the findings the four participants were categorized in two distinct pairs: the overwhelmed-self pair and the lost-self pair (Teal, 2009). The overwhelmed-self pair reported feeling as though they largely had control over their lives and that their decision to seek treatment was spurred by specific events that were occurring in their lives prior to seeking treatment. The lost-self pair experienced feelings of powerlessness and reported that their illness or symptoms seemed more chronic. This pair also did not cite any specific triggering events that led them to seek treatment; they instead felt treatment became necessary when they increasingly felt troubled by the long-term nature of their condition.

Several phases described the impact that taking SSRIs had on the participants. The first phase was that of relief whereby all of the participants shared that they experienced a sense of calm immediately after starting to take the SSRIs, such that they were no longer upset or aroused when faced with upsetting or stressful situations (Teal, 2009). They also observed that they no longer experienced their lives or world as frustrating. Participants also described experiencing a distance from troublesome situations, allowing them to let go of assuming responsibility or of needing to have control over the various aspects of their worlds.
At the same time the two distinct pairs also illustrated key differences in terms of their experience of the distance that they soon enjoyed after starting on SSRIs (Teal, 2009). The lost-self pair was ecstatic by the existential freedom the SSRIs provided, having experienced a renewed vitality and sense of recovering and discovering themselves. The SSRIs gave them the space to rediscover their lost ambitions, as well as the courage they needed to confront previously avoided situations. The two participants in this pair experienced a surge of energy resulting from uncovering those aspects of themselves they perceived as lost or buried underneath their turmoil. They recognized new opportunities for becoming engaged with their worlds now that they were no longer inundated with compulsive distractions or concerns.

The overwhelmed-self pair, who had generally felt in control of their lives, expressed appreciation for the relief from their suffering, but they also noticed that they lacked a capacity for engaging with their world, that their emotions seemed blunted or dulled (Teal, 2009). There was no period of self-rediscovery for them because they had not previously felt their sense of self as lost before seeking treatment, nor did they experience an energizing freedom from having been imprisoned by a seemingly endless barrage of sadness or turmoil. The beneficial relief they received from the SSRIs was accompanied by a sense of having been removed from their stressful situations, which, for this pair, also prevented them from feeling engaged with their world.

In the next phase of being on SSRIs functionality, both pairs of participants became less divergent in their experiences (Teal, 2009). All four participants described being able to function and cope with stressful situations as they were calmer, more stable, and feeling better equipped to deal with situations that would have previously sent them
into distress. Teal (2009) discovered that the defining psychological structure of being on SSRIs was actually negative for the participants because the medications not only provided relief and distance but also diminished, rather than enhanced or added to, their ability to fully engage with their worlds. Participants found that although they were able to cope, they otherwise cared for little else or lacked the capacity to function beyond mere coping due to the disconnect that was consequent of the SSRIs. Previous experiences of being re-energized or of renewal eventually gave way to this diminishing effect as participants continued with their daily living on the medication. This unexpected adverse effect of disconnect brought about by the SSRIs affected the participants in the physical, emotional, social, and existential aspects of their functioning, noted by their experiencing of lethargy, apathy, disengagement, and decreased personhood.

The third phase of the experience of being on SSRIs was that of a sense of *deprivation* in their lives over the course of being on the medications (Teal, 2009). All four participants spoke of feeling dissatisfied with the disconnect and distance provided by their medications. Although they found the distance beneficial in terms of coping, they also grew more aware that they no longer felt fully connected or engaged with themselves and their worlds. The participants had reached a point where living a bland existence was just as debilitating as being unable to cope with life situations, leading them to discontinue taking the SSRIs. Quite paradoxically, participants felt that the SSRIs not only freed them from their previously oppressive states, but also barricaded them from living whole and promising lives.
The final phase of being on SSRIs *the after* noted the aftermath of the participants’ discontinuation of their medication treatment (Teal, 2009). All four participants noticed that after discontinuing their use of SSRIs, many of the aspects of living that they had begun to miss all returned, such as increased physical energy, a wider range of emotions, the ability to fully connect and engage with others, and a renewed sense of autonomy. Each of the four participants also described variations in their experiences after discontinuation of their medications. One participant from the overwhelmed-self pair (i.e., the pair who experienced a sense of control and felt their illness experiences were situational) immediately suffered a crashing breakdown and became suicidal, resulting in his resuming the SSRIs long-term in order to fulfill his goal of taking care of his family. The other overwhelmed-self participant had resumed being on SSRIs on an as needed basis, using the medication only to help her cope with significant or traumatic life stressors in order to prevent depression, otherwise discontinuing SSRI use once stable again. In contrast, both participants from the lost-self pair (i.e., the pair who lost themselves amidst what felt like a chronic condition) have remained free of being on SSRIs but each for different reasons. One participant reported having learned from the experience of being on SSRIs, now having the ability to fully engage in life but with better boundaries erected in order to cope with difficult situations. The other highlighted that despite being without SSRIs, he had been able to maintain the sense of disconnect or disengagement that he experienced while being on SSRIs, adding that the state of non-attachment enables him to engage with the world, including the positive and negative aspects, without becoming overwhelmed.
In contrast to Bentley’s (2010) study on the experience of being medicated, the participants’ voices in Teal’s (2009) study were more evident, with quotes from each of the four participants included throughout the presentation of results. Teal also enhanced the understanding of the phenomenon by illustrating the variations found both within and between each participant’s experience, rather than merely reporting only commonalities among the group. The results outlined the experience of being medicated from why the participants chose to start taking medications to why they decided to either remain off their medications or continue using them, showing the shifts in the thoughts and feelings each participant experienced throughout the process of being medicated. This, together with the inclusion of the variations in experiences, provided a detailed and meaningful understanding of what it might be like for individuals with mental illness who are taking medication. Teal demonstrated that taking medication is not merely the experience of taking pills for the benefit of symptom relief; there are deeper processes involved for the individual that need to be considered.

**Being restrained.** In addition to the experiences of being diagnosed, being misunderstood, and being medicated, living with a mental illness can, for some, also include the experience of being restrained when hospitalized. Johnson (1998) conducted an interpretative phenomenological study focused on the meaning of being restrained. Ten adults living in the United States who have had experience with being physically restrained while placed in a psychiatric unit participated in unstructured interviews aimed at facilitating their descriptions of an incident of being restrained that was significant or had stood out for them. Two themes emerged from their descriptions, both of which
illustrated not only what being physically restrained was like for them but also what it was like for them to have mental illness.

The first theme concerned their experience of being restrained as a *struggling*, which described the participants’ struggle with the staff and the rules of the psychiatric unit, as well as the struggle to free themselves from the physical restraints (Johnson, 1998). The participants also spoke of the feeling of being restrained as a consequence of their mental illness. The symptoms associated with their mental illness were often experienced as constraining, as the difficulties they faced as a result of their conditions often caused limitations, restricting them from opportunities or possibilities in their lives or within themselves. Struggling also came in the form of trying to discern which experiences were real and which ones were not. Participants shared their difficulties in trying to make sense of their thoughts, feelings, and experiences amidst their suffering.

Johnson (1998) referred to the second theme as *Why Me?* This theme captured the participants’ questions as to why they were put in restraints or under close supervision while in the psychiatric unit. The question also arose on a more existential level, with participants questioning why they were mentally ill or why were they the way they were. Feelings of powerlessness in response to being restrained or hospitalized often surfaced because participants were confused as to what was happening to them, and anger toward staff became a means of coping with their powerlessness. Their anger and powerlessness were also in reference to having had their freedom removed or feeling abandoned as a consequence of their mental illness.

The strength of this study was the abundant use of quotes from the interview transcripts to ensure that the participants’ voices were prominent in the telling of their
stories. Several weaker points of the study emerged in the data collection and presentation of results. Johnson (1998) reported that the participants were asked to describe an instance of being restrained that was significant for them and that one of the criteria for inclusion was that participants must have experienced being physically restrained. The results appeared to include interpretations regarding other experiences, such as being hospitalized and being psychotic without mention of being restrained. This potentially creates some confusion as to the interpretation of the data with regard to whether being hospitalized or psychotic can be lumped in with the experience of being restrained. Although the interview question pertained to the experience of being restrained, Johnson seems to have interpreted the data through the lens of being mentally ill, rather than through the phenomenon of being restrained. If Johnson’s goal was to gain an understanding of the experience of being mentally ill, then it seems erroneous to assume that the specific experience of being restrained can be likened to the experience of being mentally ill. One aspect of being mentally ill cannot sufficiently define the broader experience of mental illness, as the phenomenon of being mentally ill includes other aspects (e.g., symptom onset, being diagnosed, being medicated, being hospitalized, reintegrating into the community).

**First-hand accounts.** Although the above studies used original accounts from interviews conducted with volunteer participants to gain an understanding of the experience of living with chronic mental illness, Hayne and Yonge (1997) sought to explore this topic by analyzing previously published first-hand accounts, provided in journals covering schizophrenia, psychiatric services, and the mentally ill, from individuals living with chronic mental illness. Forty narratives were chosen for analysis
based on their ability to provide textually rich and in-depth descriptions about living with chronic mental illness and the meaning attributed to this experience. In order to illustrate the impact chronic mental illness has among individuals living with this condition, the 40 first-hand accounts were analyzed according to four existential *lifeworlds*, or states through which individuals experience the world or existence.

One lifeworld is that of *corporeality*, which refers to how individuals experience the world through their bodies (Hayne & Yonge, 1997). Although mental illness is not immediately or necessarily associated with physical experiences, the accounts suggested that individuals with chronic mental illness draw very physical associations with their mental illness. The brain was often linked to their mental illness, and the accounts described how the individuals had experienced a psychic pain or anguish that felt very real to them. The sense of *derealism* also surfaced, with the sense that the body which housed the self no longer felt real, was no longer a reliable or solid foundation, leaving the sufferer with a sense of identity loss or non-existence. The individuals’ accounts noted that as they recovered or stabilized, they began to enjoy physical pleasures, such as eating, sleeping, and exercising, often translating such experiences to a reintegration of the self. Taking medication was associated with this reintegration when wellness improved with this aspect of treatment.

The second lifeworld *spatiality* refers to the notion that one’s space or environment impacts one’s state of being (Hayne & Yonge, 1997). In their narratives the individuals spoke of living in a confined world as a result of having a chronic mental illness and having their agency or autonomy removed. They asserted that they did not choose to enter the state of mental illness, but they felt drawn or pulled into their illness,
feeling the absence of volition or control. They also described the space in which they found themselves, that being of mental illness, as unpleasant, suffocating, and unsafe, one that led them to having difficulties discerning the boundaries between themselves and others.

*Relationality* comprises the third existential lifeworld, referring to the relationships and connections fashioned through social contact with others, which then affirms one’s existence (Hayne & Yonge, 1997). The narratives highlighted that the most pervasive difficulty in terms of this lifeworld was feeling connected with themselves, citing a sense of self-estrangement where a schism exists between the self and its body or mind. The individuals described not being able to trust themselves, or their minds, as symptoms prevented them from being able to control what was happening to them or what they were doing, paving the way for feelings of emptiness and betrayal.

Finally, the fourth lifeworld of *temporality*, which refers to how individuals experience time in the context of life events, showed how individuals with mental illness experienced the passage of time as directly correlated with the events associated with their illness, such as hospitalizations or episodes of acute symptom manifestation and episodes of wellness (Hayne & Yonge, 1997). The accounts also illustrated how the individuals experienced a prolonged period of time between receiving the diagnosis and becoming aware or accepting of the diagnosis, with this period interspersed with fear, confusion, and uncertainty. Although they at some point had come to understand their situation, there remained an internal struggle as they cycled through periods of illness and wellness; there was some presence of hope for their future as they began to experience
longer periods of remission wherein they could remain focused on themselves and live as persons rather than merely attending to their mental illness.

The use of published first-hand accounts allowed Hayne and Yonge (1997) to gather a larger sample for their study; this method resulted in limitations to the study’s credibility and transferability (Lincoln & Guba, 1985). Although Hayne and Yonge listed the journals they searched to obtain the accounts, there is no way of knowing the reasons for the inclusion of the accounts in those journals. The accounts might have been elicited from readers for specific purposes that might have guided how the accounts were written or what aspects of mental illness were discussed. Hayne and Yonge also included in their sample 10 accounts written by family members. Obtaining information from such second-hand sources might not be accurate as they might have had biases or provided inadequate descriptions of the experience of being mentally ill, especially given that family members experience the phenomenon indirectly and usually from the point of view of being a caretaker or otherwise being affected by having an ill family member. The accounts that were published might also have been abridged versions of original narratives or might have been edited to meet the intents or purposes of the journals’ editors. These issues pose limitations as to whether the accounts used for analysis could have provided sufficient and accurate data for interpretation, and not knowing the context of the participants makes it difficult to evaluate how applicable the interpretations might be for other individuals with mental illness. Using published accounts does not offer the researchers any opportunity to follow-up with participants for further clarification, nor does it allow the researchers to observe nonverbal behaviors that might add to the richness of the accounts.
Summary and critical analysis of empirical studies. Although the above review of empirical research looked at 15 separate studies conducted in different parts of the world, most of which covered various aspects associated with the experience of living with chronic mental illness, the individual themes that emerged seem to fall within five overarching categories when analyzed collectively. These categories or themes include (1) the self, (2) relationships with others, (3) temporality, (4) meaning-making of the illness experience, and (5) management of life with the illness. The descriptions of these five overall themes also appear to reflect several key concepts found in existential philosophy and literature, such as a sense of self, freedom, isolation, and meaning-making.

The first theme the self encompasses descriptions made about the impact of living with chronic mental illness on the individual’s sense of self. This includes feeling a sense of powerlessness to the unwanted and unexpected changes and experiences associated with the illness that have encroached on the individual physiologically and psychologically. There appears to be a preference to perceive mental illness as an external event or condition thrust upon the individual rather than an internal experience of the self. The individual’s sense of identity becomes tentative, confused, or uncertain when faced with the struggle of having to accept a diagnosis of having a mental illness as one feels split between selves that are known and unknown. Meanwhile, the parts of the self that are known to the individual are often experienced as shattered or destroyed. For many, the very notion of their existence comes into question as they begin to feel that their core being has been enveloped by their mental illness and they are left wondering which parts of themselves and their experiences are real and which ones are not, or which
are really a part of the self and which are a part of the illness. Overall, the experience of living with chronic mental illness encapsulates a loss of identity and a loss of a foundation upon which the sufferer can rely for a sense of stability, control, self-confidence, and worthiness, leading the sufferer to additionally feel betrayed by and unable to trust herself.

The second overall theme *relationships with others* describes a significant consequence of the experience of living with chronic mental illness. Individuals with chronic mental illness often find it difficult to engage with other people, such that they consciously avoid contact with others. Fears of prejudice, discrimination, stigmatization, and other forms of negative treatment from others often lead such individuals to either avoid engaging with others or to censor what they say or how they behave when in public. This, leads many to feel restricted from being themselves. Feelings of shame, embarrassment, guilt, or anxiety also provide barriers to establishing relationships with others. Not being able to trust oneself due to the unpredictable or uncontrollable aspects of mental illness may also translate to being unable to discern boundaries between the self and others while previous misjudgment of others can also lead to a general mistrust of others. Alternative sources of connection are sought, such as with animals, objects, fellow mental health patients, or spirituality because these means of feeling connected with the world offer peace and comfort without the demands or fears associated with being with people who do not have mental illness.

The experience of time or *temporality* comprises the third overall theme. Individuals with chronic mental illness often experience difficulties with planning ahead due to the unpredictable nature of their mental illness from the time of onset. As such,
they tend to avoid making plans for their future, including having dreams, desires, or ambitions, for fear that they would be unable to achieve what they want and be forced to repeatedly experience failure and disappointment. Because they never know when their symptoms may recur, they are unable to make sense of their present existence as they struggle with not knowing when their present experiences are due to the illness and when they are not. Hopefulness for the future can occur when their illness is well-managed and they experience longer stretches of remission.

The fourth overall theme meaning-making concerns the difficulties individuals with chronic mental illness encounter when trying to understand and make sense of what is happening to them as a result of their condition. In addition to not knowing which of their experiences are real or not, such individuals also struggle with finding a suitable or sufficient explanation for their experiences. Fears of prejudice and stigma often lead some individuals to prefer to explain their illness as being a result of earlier life traumas, present-day life stressors, spiritual influences, or other external forces. Identifying with such explanations does not only serve to avoid the negative social consequences, but also provides a way to normalize the experiences associated with the mental illness. Being armed with the knowledge of having a diagnosable mental illness can contribute to a sense of peace and calm as strange experiences become less frightening and are instead seen as being real symptoms of a real condition. Having this knowledge can also pose a challenge because individuals with chronic mental illness are then left with the struggle of trying to understand and make sense of their experiences within the context of having an illness, particularly when they are then left wondering which of their experiences are due to the illness and which are not.
The fifth overall theme found among the studies relates to management of life with the illness. A part of living with chronic mental illness involves learning to integrate that aspect of living into one’s daily life and level of functioning. Having the illness diagnosed appears beneficial in that it paves the way to receiving treatment, which in turn helps the individual with chronic mental illness to resume a state of functioning that results in increased engagement with the world. Experiencing success in managing mental illness is associated with feelings of victory, namely for having conquered a formidable challenge, as well as a renewed sense of self. The individual appears to develop an awareness of the necessity to accept or resign to the fact that life-long treatment, though challenging, is imperative to maintaining functioning. There is also a seeming association between the importance of managing the illness and maintaining one’s humanness or sense of being normal as daily living is restored.

Although the 15 empirical studies that were reviewed provided a general understanding of the experience of living with chronic mental illness, several limitations in the studies’ methods pervade the research and thus leave some unanswered questions about the phenomenon. Two were case studies wherein one participant was interviewed. The use of case studies offers a more in-depth and detailed exploration into a phenomenon, allowing for an intensive study of one individual’s perspective or experience. The case studies reviewed above (Bradfield & Knight, 2008; Rhodes & Smith, 2010) provided detailed descriptions of two individuals’ experiences of chronic mental illness. Qualitative studies with larger sample sizes provide an opportunity to compare an individual’s descriptions to others who may have experienced the same phenomenon. As a result, researchers are able to ascertain whether an individual
participant’s descriptions of her experience are unique and specific to her particular context or similar and generic for all who share the experience. Most of the other studies that were reviewed used larger sample sizes, which did offer a sense that a number of individuals shared rather similar experiences as an individual with a chronic mental illness. These studies also lacked any indication of variation or divergence that might have emerged through the interviews but were overlooked in the attempt to identify commonalities among the participants. Consequently, one does not really get a sense of the unique experiences of particular participants nor the shifts and changes that occur in the lives of individuals with chronic mental illness. Teal’s (2009) study on the experience of being medicated with SSRIs stood out as offering a balance between using a small sample size to gain the depth found in case studies and still offering the opportunity to compare and contrast among the participants’ experiences, all of which illustrated the common themes as well as unique responses.

Each of the studies reviewed were focused on specific, isolated experiences of living with chronic mental illness (e.g., a specific symptom, a particular disorder, or a unitary aspect of treatment). Although doing so provides a window into the experience of living with chronic mental illness, focusing on solitary aspects removes these parts from the whole individual and from the overall phenomenon of what it is like for individuals to live day-to-day with a long-term condition. This approach inevitably fragments the individual into discrete parts as if the experience of diagnosis can be separated from the experience of symptoms or the experience of being medicated, as if these particular experiences can be separated from the individual. The studies that looked at the experience of particular diagnoses (i.e., schizophrenia, bipolar disorder, and
depression) did attempt to tap into the overall experience of living with a specific chronic mental illness; upon closer inspection, they still focused on particular aspects of the illness, such as views of life, barriers to living an active life, or interpersonal relationships. McCann and Clark’s (2004) study on schizophrenia and Rusner et al.’s (2009) study on bipolar disorder come close to exploring the overall experience of living with these particular disorders, though they still presented brief or general descriptions of the participants’ experiences without including the variations that might better reflect the complexity of the phenomenon. The focus on particular disorders does not necessarily reflect the experience of living with chronic mental illness because it looks at aspects of specific disorders (e.g., hallucinations, delusions, manic episodes) rather than the overall experience of living with mental illness.

In many of the studies reviewed, the researchers discussed their efforts to establish rapport to gain the trust of participants, as well as their goals to seek an in-depth, descriptive understanding of the phenomenon being studied. Many of the researchers met with participants only once and for interviews lasting no more than 90 minutes. The question arises if such limited contact or limited time with the participants was sufficient for gaining the level of depth desired in phenomenological research. Given that many of the studies described only general themes, included few quotes from interview transcripts, and omitted instances of divergence, it becomes unclear if the themes were gleaned from superficial responses to the interview questions. Many of the researchers used only one open-ended question with follow-up questions as needed, but these questions were not always included in the published articles, making it impossible
to know what attempts, if any, were made to seek greater depth or clarification from participants’ responses.

In sum, there are only a few studies that have been conducted exploring the lived experience of individuals diagnosed with a chronic mental illness. Those that have been conducted within the past decade offer much insight into many of the challenges and struggles these individuals encounter as they attempt to fashion a life for themselves with an illness that is long-term and intertwined with their existence. At the same time, more research in this area is still needed to help inform the treatment interventions used with this population in order to better facilitate their ability to live their lives in spite of their illness.

**Rationale for the Proposed Research**

Existential philosophy and literature provide a framework for conceptualizing human experience wherein individuals are free to make choices and are responsible for making meaning of their experiences and determining their own identity and development. Existential psychotherapists have developed a theoretical model applying the concepts found in existential philosophy and literature to explain and understand the development of mental health problems, particularly with regard to how struggles with existential issues can manifest as psychological symptoms and affect the individual’s sense of self and of being in the world. Qualitative research using phenomenological and existential theory has provided a window into the experiences of individuals living with chronic mental illness. The majority of these studies have focused on specific, fragmented aspects of the experience of chronic mental illness, dissecting the individual and the experience into distinct, separate parts without looking at how these isolated
aspects come together to comprise the whole person within the context of having a chronic mental illness. These studies tend to present generalized themes that fail to capture the subtle nuances of each individual’s unique experience. The majority of these studies involved limited contact with research participants, which may not have been sufficient for attaining the level of depth required in phenomenological research.

The present research study was designed to fill a gap in the literature by providing a comprehensive phenomenological analysis of the existential concerns of individuals living with chronic mental illness in Guam. The study’s aim was to allow participants the freedom to explore what they deemed to be the most salient aspects of living with a chronic mental illness while also encouraging them to describe specific experiences commonly associated with having a mental illness. This was achieved through a semi-structured interview protocol. Efforts were made to establish rapport and gain greater depth through lengthy interviews (i.e., two hours) conducted over one or two sessions for each participant. The analysis of the data included the identification of common themes but also highlighted where variations occurred to illustrate the texture and complexity of the experience of mental illness. Another goal of the present research study was to explore the relevance of the themes found in the existing literature to those found among Pacific Islander or Asian individuals with chronic mental illness and living in the Pacific Island of Guam. Prior to this research, no study of this kind had been conducted in this region of the world; it was unknown if the themes described in the literature were universal, or if individuals living in Guam experienced mental illness in unique, culturally-specific ways.
The context of Guam is unique for several reasons. First, the island of Guam is a territory of the United States (U.S.), which means that U.S. laws, standards, and sociocultural influences play a significant role in shaping Guam’s political and social landscape. Yet, Guam is geographically remote from the U.S. mainland, which arguably creates enough separation to mitigate some of its influences on Guam’s inhabitants and cultural milieu. Second, Guam’s ethnic make-up is largely different from that found in the U.S. mainland. At least 90% of Guam’s population consists of Pacific Islanders and Asians, primarily indigenous Chamorros and immigrant, as well as second and third generation Filipinos (U.S. Department of Commerce, 2004). Other Pacific Islander and Asian populations in Guam include immigrants from its neighboring Micronesian island nations (i.e., the Federated States of Micronesia, the Republic of Palau, and the Republic of the Marshall Islands) and nearby Asian countries (e.g., Japan, China, and Korea). As a result, Guam’s social and cultural environment is a rich and complex integration of influences from Guam’s indigenous culture, the surrounding Pacific and Asian regions, and the U.S. mainland. Third, the ways in which mental illness is viewed and treated in Guam have largely been imported from the U.S. mainland. Mental health professionals in Guam use the American Psychiatric Association’s Diagnostic and Statistical Manual when making diagnoses, administer psychological testing instruments normed in the U.S., and implement Western-based theories and treatment modalities to conceptualize and treat mental health problems. Whether applying the U.S. mental health system to Guam is effective or not, it is not currently known how doing so has influenced how individuals with mental illness living in Guam view themselves or their experience of mental illness.
Method

The empirical studies reviewed in the previous section were guided primarily by the use of phenomenological research. As the proposed study was aimed at exploring the lived experience of individuals living with chronic mental illness in Guam in order to understand their existential issues, the use of a phenomenological approach was deemed appropriate. This study involved in-depth qualitative interviews with adult individuals living with chronic mental illness in Guam; it followed the methods of Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009; Smith & Osborn, 2008). IPA is a qualitative approach with a central focus on understanding how individuals make sense or meaning of their life experiences; it is based on three theoretical concepts: phenomenology, hermeneutics, and idiography. Following the works of philosophers Husserl, Heidegger, Merleau-Ponty, and Sartre, IPA is based on the ideals of phenomenology wherein it is imperative to understand the human lived experience on its own terms as it is naturally expressed, rather than force experiences to fit within predefined categories.

The hermeneutical component of IPA pertains to the interpretative nature of the analysis stage of the research (Smith et al., 2009). Although the goal of phenomenology is to prevent the researcher’s personal or professional perspectives and experiences from interfering with the attempt to understand the participant’s experience, IPA recognizes that the researcher can offer meaningful insights through the detailed and systematic analysis of the participant’s narrative. The hermeneutical aspect of IPA also involves moving fluidly back and forth between discrete parts of the experience and the experience as a whole, requiring the researcher to employ an iterative approach to the
data analysis whereby the researcher will look at the data as a whole and as individual parts to help gain a deeper understanding of the experience in question, rather than through a step-by-step or linear approach. When analyzing individual statements or ideas from an interview, the iterative process requires regularly returning to the interview as a whole so as to ensure that the participant’s statements are considered within the context of the transcript in its entirety.

IPA includes the concept of idiography, which speaks to the emphasis on examining a particular case in greater detail and depth, then moving on to attending to the next case in similar fashion, to understand the experience as perceived by particular individuals in particular contexts (Smith et al., 2009). IPA emphasizes the use of small sample sizes whereby the participants come to represent a perspective of the phenomenon instead of a broader population. In contrast, the nomothetic approach, adopted by most quantitative researchers, uses large sample sizes in an attempt to establish general laws about a population. Compared with the goal of generalizing findings from a sample to a population typical of nomothetic, quantitative approaches, IPA allows for theoretical transferability wherein the reader makes comparisons among the research findings, his or her personal or professional experiences, and the research literature. This process allows the reader to evaluate the extent to which findings in an IPA study are transferable to persons in other contexts.

**Participants**

Participants included 10 adult individuals (i.e., at least 18 years old), living in Guam, who had been diagnosed with a chronic psychiatric disorder that met the criteria listed in the *Diagnostic and Statistical Manual of Mental Disorders IV-Text Revision*. 
(DSM-IV-TR) (APA, 2000). For the purpose of this study, mental illness was defined as a mental disorder diagnosed in accordance with the DSM-IV-TR and deemed to cause impairment to the individual’s educational, vocational, and/or social functioning. Chronic mental illness was defined as a diagnosed mental illness lasting at least five years. Individuals were excluded as potential participants if they were acutely psychotic or had an intellectual disability or neurological disorder that precluded them from providing informed consent to participate in the study. Individuals confined in an inpatient setting were also excluded as potential participants to prevent interference with treatment efforts to stabilize their conditions. It was preferred that participants were of Pacific Islander or Asian descent in order to reflect Guam’s ethnic landscape (at least 90% of Guam’s population is comprised of people from these ethnic backgrounds) (U.S. Department of Commerce, 2004). Individuals with limited fluency in the English language were excluded to prevent the need for interpreters, the use of which might have hindered the accuracy of the meaning of the interview questions and the intended meaning of the participants’ disclosures. English was the first language for all 10 participants. Although the researcher had previously worked at the agency through which most of the participants were recruited, the researcher had not provided psychotherapy to any of the participants, with the exception of one participant who had attended a few sessions of a support group for which the researcher served as one of the facilitators.

This study employed a sample size of 10 participants in accordance with IPA (Smith et al., 2009; Smith & Osborn, 2008). This sample size fits with IPA’s emphasis on gaining access to detailed accounts of individual experiences of the phenomenon
being studied. The use of 3-6 participants is recommended for student research using IPA; larger sample sizes may also be used in IPA research depending on the richness of the individual cases (Smith et al., 2009). There is otherwise no specific maximum number of participants recommended for IPA research. Two IPA studies reviewed earlier used a sample size of 10-11 participants (Cookson & Dickson, 2009; Johnson, 1998) while the samples used in the other phenomenological studies discussed in the literature review ranged between 4-14 participants (Erdner et al., 2009; Erdner et al., 2005; McCann & Clark, 2004; Rusner et al., 2009; Koivisto, et al., 2003; Teal, 2009).

Materials

Because the goal of IPA research is to explore the ways in which individuals perceive and understand their experiences, a flexible data collection instrument is required. The most highly recommended method for data collection in IPA research is the semi-structured interview (Smith & Osborn, 2008). This interview format encourages rapport and dialogue between the researcher and participant, requires the researcher to modify interview questions based on the participant’s responses, and allows the researcher to further investigate areas of interest or significance that may arise. Although the interview schedule consists of questions pre-established by the researcher, the schedule is intended to guide, rather than dictate, the interview. In this way, the participant and researcher work in tandem to attain deeper explorations of the topic. The importance of developing the interview schedule prior to the interview is for the researcher to identify possible areas to investigate and ways to address sensitive topics.

Seven topic areas derived from the empirical studies reviewed earlier were included in the interview protocol as a way to tap into specific aspects associated with the
experience of living with chronic mental illness. These topics were used flexibly to allow the researcher to follow the participant’s narrative while still covering each topic area. The seven topic areas were as follows: (1) initial experience with the illness, (2) the experience of living with mental illness, (3) initial experience receiving treatment, (4) the experience of being diagnosed, (5) the experience of being on medication, (6) the experience of being hospitalized, and (7) the experience of receiving other mental health services. Prompt or follow-up questions were asked when further elaboration or clarification was needed to help draw out the participants’ experiences. The semi-structured interview format allowed for each of the topic areas to be covered while being conducted in a conversational style to facilitate the establishment of rapport, as well as to allow for opportunities for further elaboration when necessary (Smith & Osborn, 2008).

The interview protocol for this study consisted of three parts (see Appendix A). The first part focused on demographics to gain a sense of the participants’ present context, including questions regarding age, gender, ethnic background, number of years living in Guam, highest level of education completed, employment status, current living situation, marital status, and number of children and their ages. The second part, which was aimed at addressing the research question, consisted of two phases. The first phase followed an unstructured interview format, which focused on the participant’s lived experience as an individual living with a chronic mental illness. This phase was open-ended, asking participants to describe their experiences living with their illness. This phase was intended to allow the participant to freely describe their experiences and the topics that were most salient for them. The second phase was semi-structured in that it asked the participants to describe specifically their initial experiences of their mental
illness and their present experiences living with their illness. Follow-up questions were included in this phase to help the researcher facilitate the interview when necessary, as well as to give the researcher ways of asking questions in a sensitive manner. The third part of the interview consisted of two phases aimed at exploring the participant’s experiences with receiving treatment for their mental illness. The first phase was unstructured, allowing the participant to share experiences that were most salient for them. The second phase was semi-structured and specifically focused on their initial experiences receiving treatment, followed by the experiences of being diagnosed, being medicated, being hospitalized, and receiving other mental health services. Follow-up questions were included in this phase as well.

**Procedure**

**Participant recruitment.** Participants were recruited from the Department of Mental Health and Substance Abuse (DMHSA), Guam’s only community mental health facility. Participants included individuals receiving outpatient services from DMHSA, who were either living on their own or with family or were residing in one of DMHSA’s residential group homes. This researcher approached the Federal Management Team, who was overseeing DMHSA at the time of the study, to obtain approval to recruit participants from among consumers who were receiving outpatient or residential services from the facility. After receiving approval from the Federal Management Team and, subsequently, the Institutional Review Board (IRB) of Antioch University Seattle, this researcher met with DMHSA’s Chief Psychologist and one of the facility’s clinical psychologists (who became this researcher’s liaison to the facility’s clinical staff, which included psychologists, counselors, and social workers) to discuss the procedures for
participant recruitment. This researcher also met with the facility’s director to finalize the approval process for access to DMHSA’s consumers for participant recruitment. A specific recruitment process was agreed upon among the Chief Psychologist, clinical psychologist, and this researcher.

Following IPA’s theoretical orientation, sampling is conducted purposively as a means to garner rich descriptions and insight into the phenomenon being studied (Smith et al., 2009). The referral method is most commonly used in IPA research whereby gatekeepers assist the researcher in identifying and contacting potential participants. To begin participant recruitment, this researcher prepared a written description of the purpose of the study, as well as the preferred demographics or characteristics of potential participants. Inclusion and exclusion criteria were outlined as well. This description was sent by email to DMHSA’s clinical staff through the liaison clinical psychologist (see Appendix B).

The researcher met individually with each treatment provider who responded to the email and recommended consumers who might be appropriate for the study, and an initial screening was conducted during these meetings to ensure that the consumers met the criteria and could be considered as potential participants. At this point, the names of the consumers were not disclosed to the researcher in order to preserve their confidentiality. The treatment providers then contacted the consumers who were deemed appropriate for the study to inform them of the study and ascertain their interest in participating. The treatment providers were given a schedule of the researcher’s available days and times so that the potential participants could schedule an appointment time that would be convenient for them to meet individually with the researcher. The
researcher then met with each potential participant to conduct a secondary screening to ensure his or her interest and appropriateness to participate in the study, as well as to review the Statement of Informed Consent and conduct the interview if the potential participant agreed to participate in the study and signed the Statement of Informed Consent.

The Statement of Informed Consent (see Appendix C) included information regarding (1) the purpose of the study, (2) an outline of the procedure involved, (3) the risks and benefits of participating in the study, (4) a statement of how confidentiality and privacy would be maintained, (5) the contact information of this researcher, the research supervisor, and the IRB Chair of Antioch University Seattle, and (6) a statement assuring the participant that there would be no penalty or negative consequences if he or she decided at any time to withdraw consent or discontinue participation in the study. Participants were also informed of how the results may be used (i.e., oral or written presentations). All participants were informed that to protect their identity, a code number would be assigned to their interview transcripts and results of the study would be reported without any identifying information (e.g., pseudonyms would be used; accounts of behaviors that have occurred in public settings would be omitted; names of family members, villages of residence, or places of employment would not be included). The Statement of Informed Consent also indicated that participation was voluntary. Although a signature line for the Public Guardian was included for any participants who may have been under such guardianship, none of the participants were wards of the Guam Office of the Public Guardian.
In total, nine DMHSA consumers met the inclusion criteria, did not have any of the concerns that comprised the exclusion criteria, expressed an interest in participating in the study, and provided written consent to participate. A tenth individual, who had also been a DMHSA consumer, contacted this researcher voluntarily by email and expressed interest in participating in the study after hearing about it through word of mouth. The researcher contacted this individual by telephone to discuss the details of the project and screen the appropriateness of this individual to participate in the study. Written consent was obtained from this participant when an interview appointment was scheduled.

**Interviews.** Interviews were conducted one-to-one with each participant in a private room at DMHSA, with the exception of the self-referred participant, whose interview was conducted in a private room at the individual’s place of employment. Interviews with each participant lasted approximately two hours. Two participants chose to meet with this researcher over the course of two 60-minute sessions while the other eight participants chose to have their interviews conducted in a single two-hour session. Participants were informed that they could stop the interview at any time to take a break, to continue at another time if they felt fatigued or needed to be elsewhere, or to terminate the interview. Participants were each compensated with a $20 gift voucher for a local merchant at the beginning of their interview and were assured that they would be able to keep the voucher even if they terminated their participation or withdrew their consent.

In addition to reviewing the Statement of Informed Consent, time was spent at the beginning of each interview session to establish rapport which was continually facilitated throughout the interview session. The interview sessions were audio recorded with a
digital voice recorder, and each participant was reassured that they could have the recorder turned off at any point in the interview. None of the participants requested that the recorder be turned off during their interview. Although an interview protocol was prepared to help guide the interview with each participant, the researcher largely followed the participant’s lead. The researcher occasionally used the protocol when needing to encourage the participant to provide more descriptive responses, to ask follow-up questions in a sensitive manner, or to assist the participant in maintaining focus on the topic being discussed. IPA supports this method of conducting semi-structured interviews, insisting that the participant should be given the opportunity to play a more directive role in the interview process (Smith & Osborn, 2008). In the present research, the participants primarily led the interviews as they shared their narratives of developing a mental illness and their recovery process. The topic areas outlined in the interview protocol were usually discussed at the participants’ introduction of those experiences in their narratives without the researcher needing to introduce them, preventing any abrupt shifts in the interviews’ direction. In cases where the researcher introduced the topic areas, this was done as a means to draw out the participants’ descriptions and only at points of the interview when it seemed appropriate for the topic areas to be introduced.

After each interview, the researcher checked in with the participant to ensure he or she felt understood, felt satisfied with how the interview was conducted, and did not experience any distress caused by the topics discussed during the interview. Participants were also encouraged to ask the researcher any remaining questions regarding the use of the information collected during the interviews. The researcher reminded participants that they were welcome to discuss their participation in the interviews with their
treatment providers, especially if they wanted to further process any experiences or reactions that may have risen during or after the interview.

The researcher transcribed each interview verbatim using Microsoft Word. A code number was assigned to each transcript so that the name of the participant would not be included. Each transcript was reviewed to eliminate information that could potentially identify the participant, such as names of family members or friends, villages where the participant had resided, or places of employment. All participants spoke English during the interviews; no translation was needed. Occasionally, participants used common phrases or words in the Chamorro language (i.e., the native language of Guam). The researcher was familiar with these Chamorro words and expressions (e.g., taotaomo’na, the Chamorro word for ancestral spirits; suruhanu, the Chamorro word for an indigenous Chamorro spiritual healer), eliminating the need for an external translator.

**Data Analysis**

Although IPA research does not require strict adherence to a specific set of procedures when analyzing interview transcripts, data analysis procedures should maintain the general principles of IPA (Smith et al., 2009). Regardless of how the researcher chooses to approach the data, it is important to maintain the idiographic nature of data analysis in IPA (Smith & Osborn, 2008). When analyzing data from multiple interview transcripts, the researcher should analyze the first case in great detail before moving onto the other cases. It is also important to keep in mind that the interpretative process occurs at each stage or step of the data analysis procedure. The focus should always remain on the participants’ ways of trying to make sense of their experiences of the phenomenon being studied (Smith et al., 2009). Rather than approaching the analysis
through external theoretical lenses, the researcher should ensure that his or her interpretations of the data emerge from the interview transcripts.

IPA research typically involves a small sample size of 3-6 participants to allow for greater depth of analysis; larger data sets of approximately 10 participants are also common (Smith et al., 2009). When using larger sample sizes, the emphasis turns to ascertaining the emergent themes for the whole group. This may be done by identifying the emergent themes at the individual level for each case, followed by an examination of all the cases together as a whole to begin mapping connections or patterns among the emergent themes (Smith et al., 2009). Although the focus of analysis then turns to the group as a whole, each group-level theme is illustrated by specific examples from each individual case, thus maintaining IPA’s idiographic nature. The data analysis procedures used for the present study are outlined below, following Smith et al.’s (2009) guidelines for data analysis with larger sample sizes.

**Step 1: Reading the first transcript.** Following IPA guidelines for data analysis, the researcher began the process by reading the first transcript thoroughly twice. The focus on one participant’s transcript at a time was to ensure that each participant’s narrative would be considered in its entirety to maintain the idiographic nature of IPA. This was also done to maintain the focus of analysis on the participant, rather than on the researcher’s assumptions about or perspectives on the narrative (Smith et al., 2009). The multiple readings of the transcript also allowed the researcher to get a feel for how the participant structured the narrative about his or her experiences of living with a chronic mental illness (Smith et al., 2009). For example, the researcher noted that many of the participants relayed their stories in a chronological format, often starting from a response
they provided when asked about demographic information. Some participants returned repeatedly to the aspects of their experiences that were affecting them most in their day-to-day lives. While reading the transcript, the researcher bracketed her own reactions, thoughts, feelings, observations, and recollections about the interview process and content so as to further maintain the focus of analysis on the participant during this stage. A common practice in phenomenological research is for the researcher to bracket, or set aside, his or her preconceived notions, assumptions, or biases about the phenomenon being studied to gain a better understanding of the participants’ experiences from their point of view (Creswell, 1998).

**Step 2: Coding domains.** Upon noticing that the participants discussed the topic areas outlined in the interview protocol despite not necessarily being directed to do so, the researcher used different-colored highlighters to mark where in the transcript each topic, or domain, was discussed. This allowed for manageability of the data, in terms of individual transcripts and as a whole, particularly as the other transcripts were eventually analyzed. This process also supported the goal of examining specific experiences associated with having a mental illness that have been explored previously in the literature (e.g., being diagnosed, being medicated, being hospitalized). In some instances, particular excerpts were double-coded with different colors to remind the researcher that although the excerpt dealt with a particular topic area (e.g., being medicated), the same excerpt could also relate to another topic area (e.g., day-to-day living). The final decision as to where the excerpt most appropriately belonged was influenced by the larger context of the interview and reflections on what the participant might have intended in terms of the meaning of that experience.
Step 3: Exploratory noting. In the next stage of the data analysis, the transcript was reviewed line-by-line to facilitate the coding of emergent themes (Smith et al., 2009). As each line was read on its own and within the context of the participant’s narrative, the researcher made descriptive notes and comments highlighting the key elements of what the participant shared, as well as more interpretative notes focusing on a deeper understanding of the participant’s concerns and experiences. In line with IPA the interpretative work was occurring at this stage as it does throughout the data analysis process (Smith et al., 2009). As was found in later transcripts, some excerpts had to be debated as to whether the interpretation was coming from the text or from psychological theory. This issue arose particularly when participants used vague, abstract, or metaphoric language to describe issues they were facing or when discussing their delusions, auditory hallucinations, fantasies, or interpretations of experiences. The resolution of the question regarding where the interpretation was coming from was attempted by returning to the transcript, re-reading the text, and ascertaining if the researcher’s interpretation could be supported by the data rather than the assumptions of psychological theory. As Smith et al. (2009) explained, the researcher’s interpretations are legitimate as long as the interpretation is derived from and can be traced back to the text being analyzed; the interpretation could be said to come from the participant’s words rather than imposed from external assumptions or suppositions.

Three levels of exploratory noting were used following IPA methods for data analysis. The first, or descriptive level, was done by commenting on how participants described or explained their experiences through words, phrases, or other descriptive statements that could be taken at face value (Smith et al., 2009). At deeper levels,
descriptive notes focused on the meaning of the participants’ descriptions. For example, when participants described the onset of their symptoms, their descriptions were first taken simply at the surface level as the beginnings of mental illness—thus, comments such as “started hearing voices” were made in the margins. The noting process was then taken to a deeper, more interpretative level, so that “started hearing voices” became “feeling lost and of control,” which was then also noted in the margin.

The second level of exploratory noting according to IPA is the linguistic level, which involves commenting on the ways participants use language to describe their experiences and articulate the meaning behind their experiences, such as through the use of metaphors, laughter, pauses, repetition, or other uses of language (Smith et al., 2009). One participant, for instance, described the experience of being hospitalized as feeling like she was being “trained for homelessness,” which was interpreted to mean that she felt abandoned, lonely, and deprived of her most basic needs. Another participant used the metaphor of “zombie” when referring to the period in his life when he struggled with the side effects from his medication. This captured not only the sense of feeling like he could not function, but also the sense of having years of his life wasted as well as or when he had no control over his life.

Exploratory noting at the conceptual level provided another avenue to make sense of the meaning the participants ascribed to their experiences (Smith et al., 2009). Conceptual noting involved moving away from the participants’ explicit descriptions, instead focusing on a broader understanding of their experiences. One way of conceptualizing the participants’ experiences came through the chronological structure some participants followed when describing their encounters with mental illness. For
example, one participant spoke about having a sense of self that was different from the self she was before receiving a diagnosis and taking medication, illustrating the changes in her sense of self over time. In another case, a participant vacillated between questioning and accepting her diagnosis, suggesting that she was struggling with trusting herself and her experiences and feeling a lack of control over her sense of self.

**Step 4: Constructing emergent themes.** In the next stage of data analysis, to find emergent themes, the transcripts and exploratory notes were analyzed for connections and patterns. To do this, the researcher created a table using Microsoft Word, which was used to categorize each of the exploratory notes and brief excerpts from the transcript based on their commonalities and differences. Each note or excerpt from the transcript was placed in a category with other notes and excerpts that shared the same meaning, and, together, they were given a title, or theme. If dissimilar from the existing categories, the note or excerpt was placed in a separate category and given its own title, or theme (Smith et al., 2009). The process of reviewing and categorizing each note and excerpt was conducted until the entire transcript was analyzed in this manner. Possible themes were assigned to each category and later refined as more notes and excerpts were added. The themes were written as short phrases meant to capture and reflect the essence of the set of notes and excerpts from the transcripts (Smith et al., 2009).

**Step 5: Coding the remaining transcripts.** The whole data analysis process—from the initial multiple readings of the transcript, to the coding of domains, to the three levels of exploratory noting, and then to the constructing of emergent themes—was subsequently conducted with each of the remaining nine transcripts. At this point, the
emergent themes were listed chronologically in the order they arose as the researcher analyzed each transcript (Smith et al., 2009).

**Step 6: Searching for patterns and connections across emergent themes.** The next stage of data analysis involved mapping and connecting the emergent themes to pull together all of the data from the 10 interview transcripts and to begin forming a picture of the experience of living with a chronic mental illness, illuminating what was both salient and enlightening in each participant’s narrative. This was attempted by an examination of the connections that arose across the emergent themes (Smith et al., 2009). The first step was to look through the list of emergent themes and identify themes that seemed to draw or pull other themes together. This helped to solidify the identification of the six domains that were used to organize and map out the relationships among the themes. The six domains reflected the main topic areas that were outlined in the interview protocol and were discussed by the participants when telling their stories. The second step was to identify patterns and connections among emergent themes within each domain to map out the themes for each topic area.

The IPA model also recommends more specific methods of examining the data for relationships among emergent themes. One such method that was used was abstraction, which is the process of joining similar themes to form a larger cluster (Smith et al., 2009). The name given to the larger cluster then becomes the super-ordinate theme. This provides a basic way of establishing connections among the emergent themes in that it involves the categorization of similar themes. For example, several emergent themes all appeared to relate to the participants’ first responses when receiving
a diagnosis. All themes that connected to this process were thus clustered together under the super-ordinate theme *initial reactions to diagnosis*.

The researcher also used the method of *polarization*, which involved searching for instances when emergent themes were different from rather than similar to other emergent themes (Smith et al., 2009). This technique was useful in highlighting the complexity of the data, illustrating that although some participants may have had similar experiences with regard to a particular domain, others had divergent or unique experiences. Contrasting experiences often occurred within as well as across participant narratives. For example, under the super-ordinate theme of *relationship with others*, all 10 participants described receiving support from others, including family, friends, or fellow consumers, which helped them through their recovery process. At the same time, 6 of the 10 participants also described *feeling rejected by others* due to their mental illness. Polarization helped the researcher to recognize these contrasting themes within the data and to highlight, rather than discount, divergent experiences even within the same participant’s narrative.

A third method of mapping the connections among the emergent themes in IPA is referred to as *contextualization*, wherein the participants’ experiences are organized in such a way as to illustrate how the themes link with key narrative moments or key life events discussed in the transcripts in order to enhance the understanding of the experiences (Smith et al., 2009). Following this approach, the researcher decided to follow the general format the participants tended to follow when sharing their experiences of living with a chronic mental illness. As many of the participants seemed to describe and frame their experiences chronologically, from the time they began to
experience symptoms to the time they were diagnosed and started taking medications, finally to their day-to-day living experiences, the researcher will present the domains in a similar format, beginning with the domain of onset of illness and ending with the domain of day-to-day living with chronic mental illness.

Throughout the process of mapping the connections between and among emergent themes, the researcher consolidated a large set of emergent themes in order to pare it down to a more manageable data set and to enable a clear presentation of the results. Part of that process involved making decisions about each theme, particularly regarding whether the theme could be merged with other related themes, or if the theme needed to stand alone to help tell the story and add texture or layers to the super-ordinate theme. Making these decisions required repeatedly returning to the transcripts to keep in mind the context of the theme. Doing this was instrumental in getting a flavor of the theme and subsequently reassigning the theme to join another or to maintain the theme on its own to illustrate divergence or complexity. With IPA the main goal is to ensure that the interpretative process remains linked to the participants’ experiences, which involves going back and forth between looking at the part against the whole and the whole against the part (Smith et al., 2009). It was not sufficient to extract an excerpt from the transcripts without later reconsidering the context to ascertain the meaning behind the excerpt nor would it have been adequate to look at the overall themes or super-ordinate themes without looking at the discrete units from the transcripts that helped to comprise the whole story. Excerpts from the transcripts along with the researcher’s exploratory notes were included in the data analysis tables to illustrate the process of looking at the individual part against the whole and the whole against the individual part. The
researcher repeatedly reviewed and revised the tables of themes and super-ordinate themes, again returning to the transcripts to ensure each theme’s meaning, until it seemed that each theme and super-ordinate theme could not be diluted or expanded further.
Results

Demographic Characteristics of the Participants

Ten individuals living with chronic mental illness participated in this study. Of the 10, six were female and four were male. They ranged in age between 27 to 60 years. Six identified their ethnicity as Chamorro, one identified as Filipino, one identified as Chamorro-Filipino, and two identified as Filipino-Chamorro. Six participants had resided in Guam all of their lives while the remaining four had lived in Guam between 17 and 48 years. Those who stated that they had not lived in Guam throughout their lifetime explained that they were either born in Guam and had temporarily resided in the U.S. mainland, or elsewhere for a period of time, or that they were born elsewhere and had relocated to Guam with their family when they were young and had otherwise grown up in Guam. Five participants completed high school, including one participant who pursued further education and earned an associate’s degree. Of the five participants who did not complete high school, one earned her General Education Development (GED) and completed one year of college. The other four attended high school but did not graduate.

Half of the participants were employed at the time of the interview though one was working as a volunteer and one was on-call until another position became open. The other half of the participants was unemployed, but one participant was retired and another was waiting to hear word of being hired. At the time of the interview, five participants were living with family members, three were living on their own, and two were living in a residential group home. Four participants were single, three were married, two were divorced, and one was a widow. Among the 10 participants, six had children and four
had never had children. To protect the participants’ identities, pseudonyms were used and identifying information, such as names of family members, villages of residence, and places of employment, were not included in the presentation of the results.

The demographic characteristics of the participants are presented in Table 1.
Table 1

*Demographic Characteristics of Participants*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Years living in Guam</th>
<th>Highest level of education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jane</td>
<td>Female</td>
<td>27</td>
<td>Chamorro</td>
<td>All life</td>
<td>11&lt;sup&gt;th&lt;/sup&gt; grade</td>
</tr>
<tr>
<td>Dolores</td>
<td>Female</td>
<td>41</td>
<td>Chamorro</td>
<td>17 years</td>
<td>12&lt;sup&gt;th&lt;/sup&gt; grade</td>
</tr>
<tr>
<td>Joaquin</td>
<td>Male</td>
<td>60</td>
<td>Chamorro</td>
<td>48 years</td>
<td>Associate degree</td>
</tr>
<tr>
<td>Gloria</td>
<td>Female</td>
<td>55</td>
<td>Chamorro-Filipino</td>
<td>All life</td>
<td>12&lt;sup&gt;th&lt;/sup&gt; grade</td>
</tr>
<tr>
<td>Nancy</td>
<td>Female</td>
<td>51</td>
<td>Chamorro</td>
<td>All life</td>
<td>1 year college</td>
</tr>
<tr>
<td>Josephine</td>
<td>Female</td>
<td>53</td>
<td>Chamorro</td>
<td>45 years</td>
<td>9&lt;sup&gt;th&lt;/sup&gt; grade</td>
</tr>
<tr>
<td>Francine</td>
<td>Female</td>
<td>38</td>
<td>Filipino-Chamorro</td>
<td>All life</td>
<td>12&lt;sup&gt;th&lt;/sup&gt; grade</td>
</tr>
<tr>
<td>James</td>
<td>Male</td>
<td>36</td>
<td>Chamorro</td>
<td>All life</td>
<td>12&lt;sup&gt;th&lt;/sup&gt; grade</td>
</tr>
<tr>
<td>Peter</td>
<td>Male</td>
<td>35</td>
<td>Filipino-Chamorro</td>
<td>All life</td>
<td>11&lt;sup&gt;th&lt;/sup&gt; grade</td>
</tr>
<tr>
<td>Carlos</td>
<td>Male</td>
<td>35</td>
<td>Filipino</td>
<td>29 years</td>
<td>10&lt;sup&gt;th&lt;/sup&gt; grade</td>
</tr>
</tbody>
</table>
Table 1 (Continued)

Demographic Characteristics of Participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Employment status</th>
<th>Current living situation</th>
<th>Marital status</th>
<th>Number of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jane</td>
<td>Unemployed</td>
<td>Group home</td>
<td>Single</td>
<td>0</td>
</tr>
<tr>
<td>Dolores</td>
<td>Employed</td>
<td>Group home</td>
<td>Widowed</td>
<td>3</td>
</tr>
<tr>
<td>Joaquin</td>
<td>Retired</td>
<td>With sibling</td>
<td>Married</td>
<td>4</td>
</tr>
<tr>
<td>Gloria</td>
<td>Employed</td>
<td>With spouse</td>
<td>Married</td>
<td>2</td>
</tr>
<tr>
<td>Nancy</td>
<td>Volunteer</td>
<td>Alone</td>
<td>Divorced</td>
<td>4</td>
</tr>
<tr>
<td>Josephine</td>
<td>Unemployed</td>
<td>With sibling</td>
<td>Divorced</td>
<td>1</td>
</tr>
<tr>
<td>Francine</td>
<td>Unemployed</td>
<td>With parent</td>
<td>Single</td>
<td>0</td>
</tr>
<tr>
<td>James</td>
<td>Unemployed</td>
<td>Alone</td>
<td>Single</td>
<td>0</td>
</tr>
<tr>
<td>Peter</td>
<td>Employed</td>
<td>Alone</td>
<td>Married</td>
<td>0</td>
</tr>
<tr>
<td>Carlos</td>
<td>Employed</td>
<td>With sibling</td>
<td>Single</td>
<td>3</td>
</tr>
</tbody>
</table>
Background Information on the Participants’ Mental Illness

Details of the participants’ mental illness were based on their responses during the interviews. Regarding the specific diagnoses, four participants were diagnosed with schizophrenia, four were diagnosed with bipolar disorder, one was diagnosed with schizoaffective disorder, and one was diagnosed with major depressive disorder. The number of years they had been living with their illness (i.e., since symptom onset) ranged from approximately 5-37 years. All 10 participants were taking medications to manage their symptoms at the time of the interview, with eight reporting that they were taking more than one medication for their illness to manage side effects. All of the participants had been hospitalized in an inpatient unit at a mental health facility at least once since the onset of their illness. All 10 participants were receiving other forms of mental health treatment in addition to medication, including individual counseling, group counseling, or a day treatment program. Half of the participants were involved in a combination of services.

Each participant’s diagnosis and the duration of his or her mental illness are presented in Table 2, and the types of mental health services each participant was receiving at the time of his or her interview are presented in Table 3.
Table 2

*Diagnosis and Duration of Mental Illness*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Diagnosis</th>
<th>Years since symptom onset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jane</td>
<td>Schizoaffective Disorder</td>
<td>11 years</td>
</tr>
<tr>
<td>Dolores</td>
<td>Bipolar Disorder</td>
<td>32 years</td>
</tr>
<tr>
<td>Joaquin</td>
<td>Bipolar Disorder</td>
<td>5 years</td>
</tr>
<tr>
<td>Gloria</td>
<td>Bipolar Disorder</td>
<td>37 years</td>
</tr>
<tr>
<td>Nancy</td>
<td>Bipolar Disorder</td>
<td>22 years</td>
</tr>
<tr>
<td>Josephine</td>
<td>Major Depressive Disorder</td>
<td>14 years</td>
</tr>
<tr>
<td>Francine</td>
<td>Schizophrenia</td>
<td>11 years</td>
</tr>
<tr>
<td>James</td>
<td>Schizophrenia</td>
<td>12 years</td>
</tr>
<tr>
<td>Peter</td>
<td>Schizophrenia</td>
<td>11 years</td>
</tr>
<tr>
<td>Carlos</td>
<td>Schizophrenia</td>
<td>29 years</td>
</tr>
</tbody>
</table>
Table 3

*Involvement in Treatment Services*

<table>
<thead>
<tr>
<th>Participant</th>
<th>History of hospitalization</th>
<th>Currently taking medication</th>
<th>Additional current treatment services&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jane</td>
<td>More than once</td>
<td>Yes</td>
<td>DTP</td>
</tr>
<tr>
<td>Dolores</td>
<td>Once</td>
<td>Yes</td>
<td>DTP, IC</td>
</tr>
<tr>
<td>Joaquin</td>
<td>More than once</td>
<td>Yes</td>
<td>IC</td>
</tr>
<tr>
<td>Gloria</td>
<td>Once</td>
<td>Yes</td>
<td>IC</td>
</tr>
<tr>
<td>Nancy</td>
<td>Once</td>
<td>Yes</td>
<td>IC</td>
</tr>
<tr>
<td>Josephine</td>
<td>More than once</td>
<td>Yes</td>
<td>IC, GC</td>
</tr>
<tr>
<td>Francine</td>
<td>More than once</td>
<td>Yes</td>
<td>DTP, GC</td>
</tr>
<tr>
<td>James</td>
<td>More than once</td>
<td>Yes</td>
<td>DTP</td>
</tr>
<tr>
<td>Peter</td>
<td>More than once</td>
<td>Yes</td>
<td>DTP, IC</td>
</tr>
<tr>
<td>Carlos</td>
<td>More than once</td>
<td>Yes</td>
<td>DTP</td>
</tr>
</tbody>
</table>

<sup>a</sup>DTP = Day Treatment Program; IC = Individual Counseling; GC = Group Counseling
Brief Biographies of the Participants

*Jane* is a Chamorro woman who was born and raised in Guam, never having resided elsewhere. She has never been married, nor does she have any children. At the time of the interview, she was 27 years old and living in a residential group home. The highest level of education Jane had completed was the eleventh grade though she mentioned in the interview that she had completed a couple of courses at the community college. Jane also relayed that she was waiting to hear word of a potential employment opportunity, adding that she had previous work experience in the area of housekeeping. Her first contact with mental health services came as a result of suicide attempts as an adolescent, resulting in her first of several hospitalizations in an inpatient unit in Guam’s mental health facility. She has been diagnosed with schizoaffective disorder and is currently taking several medications and attending a day treatment program to help her manage her mental illness. Overall, Jane has been receiving mental health services for approximately 11 years.

*Dolores* is a Chamorro woman who was born and raised in Guam though at times lived in other parts of the world as a military dependent. She estimated her length of residence in Guam as at least 17 years. Dolores was 41 years old and living in a residential group home at the time of the interview. The highest level of education she completed was twelfth grade, and she is currently employed with a community organization. Dolores explained that she had been married for 16 years until she became a widow. She and her husband raised three children though she suffered the loss of one of the children. Dolores recalled receiving mental health services as a child and teenager as a result of repeated suicide attempts, though she did not recall being formally
diagnosed with any particular mental disorder during that time. She reported that she has been diagnosed with bipolar disorder as an adult. She has had one experience of being hospitalized in the inpatient unit at Guam’s mental health facility. She is currently taking medications to help her manage her mental illness, in addition to participating in individual counseling and a day treatment program. Although she was diagnosed formally only recently as an adult, she has been struggling with symptoms of her mental illness and has been involved with mental health treatment for approximately 32 years.

Joaquin is a Chamorro man who was born and raised in Guam. He was 60 years old and living with one of his siblings at the time of the interview. He has been married for over 30 years and has four children. He and his wife relocated to the U.S. mainland several years ago, and he recently returned to Guam and has decided to remain on island at this time as part of his recovery process for his mental illness. He has lived in Guam for at least 48 years. His three adult children also reside in the U.S. mainland while his youngest child lives in Guam. Joaquin’s educational background includes graduating from high school and earning an associate’s degree. He is now retired after having worked for the military for the past several years. Joaquin was diagnosed with bipolar disorder five years previously after he started to behave erratically and experience mood swings. He has had several admissions to the inpatient ward in a mental health facility where he previously resided in the U.S. mainland but has not had any hospitalizations in Guam since returning. He currently takes medication and participates in individual counseling but has previously attended group counseling in the U.S. mainland after being diagnosed. Joaquin stated that up until five years ago, he has otherwise not had any prior contact with the mental health system.
Gloria is a Chamorro-Filipino woman who was born in the Philippines but lived in Guam all her life after her family moved to Guam shortly after her birth. At the time of the interview, she was 55 years old and living with her husband and younger child. A high school graduate, Gloria has been employed with a community organization. Gloria recalled that her first contact with mental health treatment came shortly after giving birth to her first child, having been hospitalized at the inpatient unit in Guam’s mental health facility with symptoms of postpartum depression. For the next 19 years she continued to struggle with symptoms of an undiagnosed mental illness. She sought mental health treatment again 17 years ago and was eventually diagnosed with bipolar disorder, for which she is currently taking several medications to manage. Her admission to the inpatient ward for postpartum depression was her only experience of being hospitalized. She has otherwise participated in individual counseling for several years. Gloria has lived with her mental illness for the past 37 years.

Nancy was born in the U.S. mainland but raised in Guam, having moved with her family to Guam when she was an infant. She identified her ethnic background as Chamorro though she explained that she was of mixed heritage. At the time of the interview, Nancy was 51 years old, living on her own with government assistance for housing, and in a relationship. She had previously been divorced and had four children. She completed her GED and attended one year of college. Although Nancy had been employed in the past, she is now working as a volunteer in the community. Nancy was diagnosed with bipolar disorder in 1991. She refused to try any medications at that time but participated in individual counseling. It was not until two years ago that she decided to take medication as she sought voluntary hospitalization in the inpatient unit of Guam’s
mental health facility. This was her only experience of being hospitalized for her mental illness. She has since been taking medication for her illness and continuing to participate in individual counseling. Nancy has been involved in mental health treatment for the past 22 years.

*Josephine* is a Chamorro woman who was born and raised in Guam. She has lived in Guam most of her life, apart from a brief period when she lived in the U.S. mainland more than 20 years ago when she was married. At the time of the interview, she was 53 years old, divorced, and living with several of her siblings. She explained that she would periodically move from living with one sibling to another. She has one child, who resides in the U.S. mainland. Josephine was unable to complete high school, reaching only the ninth grade due to hardships following the death of her father. Although she had been employed in the past, she had not been able to work in recent years due to multiple medical issues. Josephine sought mental health treatment following the death of her mother in 1998, at which time she was diagnosed with major depressive disorder. She continues to take medication for her mental illness, in addition to participating in individual and group counseling. She was hospitalized in the inpatient unit of Guam’s mental health facility on two occasions. Josephine has otherwise been involved in mental health treatment for the past 14 years.

*Francine* is a Filipino-Chamorro woman who was born and raised in Guam, residing in Guam all her life. She was 38 years old, single, and did not have any children at the time of the interview. She was also living with one of her siblings, though she primarily lives with her father, who was temporarily away from Guam at the time of the interview. She graduated from high school and was briefly employed in retail shortly
afterwards but had to quit due to the stress of the hours involved. She has not held employment since then. Francine was diagnosed with schizophrenia in 2001 after starting to hear voices following the death of her grandfather; she is currently taking medications and attending a day treatment program and group counseling to help her manage her symptoms. She has had multiple admissions into inpatient units in Guam and in the U.S. mainland, when visiting briefly with family. Francine has been living with mental illness for the past 11 years.

James is a Chamorro man who was born and raised in Guam, residing in Guam all his life. At the time of the interview, he was 36 years old, living on his own, with government assistance for housing, single, and without children. He had just decided to quit his job due to concerns that his mental illness would worsen from the stress of the work environment. He completed high school and earned several vocational certificates. James recalled that his first contact with mental health services began in 1994 because he had been using substances; he was eventually diagnosed with schizophrenia. He has a history of being hospitalized in the inpatient unit at Guam’s mental health facility and is taking medication and attending a day treatment program to help him manage his mental illness. James has been living with schizophrenia for at least 12 years since he was formally diagnosed with the disorder.

Peter is a Chamorro man who has lived in Guam all his life. He was 35 years old, living on his own, with government assistance for housing, and employed full-time at the time of the interview. He explained that he was legally married but that his spouse lives in another country. He added that he has a child from a previous relationship. He aspires to attain his GED as he was only a few credits short of graduating when he decided to
leave high school. Peter initially sought mental health treatment due to substance use 14 years ago and was eventually diagnosed with schizophrenia. He has a history of being hospitalized in the inpatient unit at Guam’s mental health facility. He is currently taking medications to manage his symptoms, in addition to participating in individual counseling and a day treatment program. Peter has been living with schizophrenia for at least 11 years.

Carlos is a Filipino man who was born in the Philippines but moved to Guam with his family when he was six years old. He has been living in Guam for 29 years. At the time of the interview, he was 35 years old and living with one of his siblings. He was also employed at a hotel. His highest level of education completed was tenth grade. He was single but had three children from a previous relationship. Although his children live with their mother, he has continued to visit them regularly. Carlos began hearing voices when he was a child, but his first contact with mental health services was in his adulthood when he was eventually diagnosed with schizophrenia. He has a history of being hospitalized in the inpatient unit at Guam’s mental health facility. He takes medication and participates in a day treatment program to help him manage his illness. Carlos has been living with schizophrenia for the past 13 years.

Research Findings

Each of the 10 participants willingly and generously opened their lives to this researcher and expressed a genuine desire to share their experiences. Some expressed wanting to participate in this study as a way to simply share their story with an interested individual. Others felt it was an opportunity for them to tell their story in hope of helping others to understand what it is like to have a mental illness and, in particular, what it has
been like for them in their lives. At the same time it seemed the interviews afforded participants an opportunity to take stock of where they were when they started their journey as an individual with mental illness and how far they had come in terms of their recovery process. Throughout the interviews, participants shared difficult experiences and feelings about the more challenging aspects of living with a chronic mental illness; they also took pride in their accomplishments, great and small, in spite of the challenges they have encountered.

Although an interview protocol was developed to help guide the interviews for this study, the interviews were directed largely by the participants’ responses and how they chose to share their stories of what it was like for them to live with a chronic mental illness. As they navigated through their narratives, the participants seemed to weave their stories around key events in their mental illness experience. These key events matched the domains outlined in the interview protocol, allowing their collective narrative to be structured according to six domains. These domains offer a close to a chronological structure to the experience of living with mental illness, beginning with the initial onset of symptoms and culminating in the present experience of daily living with their illness.

The six domains are (1) onset of illness, (2) being diagnosed, (3) being on medication, (4) being hospitalized, (5) receiving mental health services, and (6) day-to-day living with chronic mental illness. Within each domain, several themes and super-ordinate themes emerged that describe the participants’ experiences of living with a chronic mental illness (see Tables 4-9). Each domain and its themes and super-ordinate themes will be discussed individually.
<table>
<thead>
<tr>
<th>Super-ordinate themes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience of symptoms</td>
<td>Feeling confused</td>
</tr>
<tr>
<td></td>
<td>Feeling lost and out of control</td>
</tr>
<tr>
<td></td>
<td>Feeling insecure in one’s self</td>
</tr>
<tr>
<td></td>
<td>Accepting symptoms</td>
</tr>
<tr>
<td>Experience of others’ reactions</td>
<td>Feeling supported by others</td>
</tr>
<tr>
<td></td>
<td>Feeling rejected by others</td>
</tr>
<tr>
<td>Attempts to cope with symptoms</td>
<td>Self-destructive coping</td>
</tr>
<tr>
<td></td>
<td>Hiding symptoms</td>
</tr>
<tr>
<td></td>
<td>Using daily routines to cope</td>
</tr>
<tr>
<td></td>
<td>Receiving help from others</td>
</tr>
<tr>
<td>Explanations for symptoms</td>
<td>Symptoms attributed to loss of family members</td>
</tr>
<tr>
<td></td>
<td>Symptoms attributed to life stressors</td>
</tr>
<tr>
<td></td>
<td>Symptoms attributed to ancestral spirits</td>
</tr>
<tr>
<td></td>
<td>Symptoms attributed to substance use</td>
</tr>
<tr>
<td>Reasons for seeking treatment</td>
<td>Seeking treatment initiated by self</td>
</tr>
<tr>
<td></td>
<td>Seeking treatment initiated by other</td>
</tr>
</tbody>
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Table 5

Domain 2: Being Diagnosed

<table>
<thead>
<tr>
<th>Super-ordinate themes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial reactions to diagnosis</td>
<td>Lacking understanding of diagnosis</td>
</tr>
<tr>
<td></td>
<td>Refuting diagnosis</td>
</tr>
<tr>
<td></td>
<td>Feeling embarrassed of diagnosis</td>
</tr>
<tr>
<td></td>
<td>Seeing diagnosis as a punishment</td>
</tr>
<tr>
<td></td>
<td>Feeling excluded from diagnosis process</td>
</tr>
<tr>
<td></td>
<td>Feeling relieved by diagnosis</td>
</tr>
<tr>
<td>Secondary reactions to diagnosis</td>
<td>Accepting diagnosis</td>
</tr>
<tr>
<td></td>
<td>Struggling to accept diagnosis</td>
</tr>
<tr>
<td></td>
<td>Feeling appreciative of diagnosis</td>
</tr>
<tr>
<td>Family’s reactions to the diagnosis</td>
<td>Family did not believe diagnosis</td>
</tr>
<tr>
<td></td>
<td>Family was supportive of diagnosis</td>
</tr>
<tr>
<td></td>
<td>Family used diagnosis to stereotype</td>
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</tbody>
</table>
Table 6

*Domain 3: Being on Medication*

<table>
<thead>
<tr>
<th>Super-ordinate themes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulties with medication</td>
<td>Initial reactions to medication</td>
</tr>
<tr>
<td></td>
<td>Struggling with side effects</td>
</tr>
<tr>
<td></td>
<td>Fears related to medication</td>
</tr>
<tr>
<td></td>
<td>Struggling to find the right medication</td>
</tr>
<tr>
<td></td>
<td>Wanting to stop taking medication</td>
</tr>
<tr>
<td></td>
<td>Resigning self to being on medication</td>
</tr>
<tr>
<td>Positive experiences with medication</td>
<td>Recognizing medication’s role in recovery</td>
</tr>
<tr>
<td></td>
<td>Medication seen as supporting emergence of true self</td>
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Table 7

*Domain 4: Being Hospitalized*

<table>
<thead>
<tr>
<th>Super-ordinate themes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience of being hospitalized</td>
<td>Feeling trapped and scared by hospitalization</td>
</tr>
<tr>
<td></td>
<td>Feeling renewed by hospitalization</td>
</tr>
<tr>
<td></td>
<td>Trying to cope with hospitalization</td>
</tr>
<tr>
<td>Experience of being discharged from hospital</td>
<td>Missing sense of security after discharge from hospital</td>
</tr>
<tr>
<td>Family’s reactions to hospitalization</td>
<td>Family was apprehensive about hospitalization</td>
</tr>
</tbody>
</table>
Table 8

*Domain 5: Receiving Mental Health Services*

<table>
<thead>
<tr>
<th>Super-ordinate themes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience of accessing mental health services</td>
<td>Barriers to accessing services</td>
</tr>
<tr>
<td></td>
<td>Feeling apprehensive about accessing services</td>
</tr>
<tr>
<td>Experience of receiving adjunct mental health services</td>
<td>Adjunct services as a place of refuge</td>
</tr>
<tr>
<td></td>
<td>Feeling apprehensive about receiving adjunct services</td>
</tr>
<tr>
<td></td>
<td>Feeling frustrated with being in adjunct services long-term</td>
</tr>
<tr>
<td>Experience of mental health service providers</td>
<td>Feeling supported by service providers</td>
</tr>
<tr>
<td></td>
<td>Feeling like a burden to service providers</td>
</tr>
<tr>
<td></td>
<td>Missing service providers who leave</td>
</tr>
<tr>
<td></td>
<td>Difficulty trusting service providers</td>
</tr>
<tr>
<td>Super-ordinate themes</td>
<td>Themes</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Experience of mental illness</td>
<td>Trying to make sense of mental illness</td>
</tr>
<tr>
<td></td>
<td>Struggling with instability of mental illness</td>
</tr>
<tr>
<td></td>
<td>Coping with mental illness</td>
</tr>
<tr>
<td>Relationship with the self</td>
<td>Struggling with sense of self</td>
</tr>
<tr>
<td></td>
<td>Wanting to feel or appear normal</td>
</tr>
<tr>
<td></td>
<td>Wanting to feel in control of self</td>
</tr>
<tr>
<td></td>
<td>Wanting to feel independent</td>
</tr>
<tr>
<td></td>
<td>Experiencing a transformed self</td>
</tr>
<tr>
<td>Relationship with others</td>
<td>Feeling alone</td>
</tr>
<tr>
<td></td>
<td>Struggling with wanting to be alone vs. desiring connection</td>
</tr>
<tr>
<td></td>
<td>Deciding whether to disclose mental illness to others</td>
</tr>
<tr>
<td></td>
<td>Responding to rejection</td>
</tr>
<tr>
<td></td>
<td>Receiving support from others</td>
</tr>
<tr>
<td>Desire to find meaning</td>
<td>Regretting an unfulfilled life</td>
</tr>
<tr>
<td></td>
<td>Feeling proud of accomplishments despite mental illness</td>
</tr>
<tr>
<td></td>
<td>Wanting to help others</td>
</tr>
<tr>
<td></td>
<td>Feeling hopeful about the future</td>
</tr>
<tr>
<td></td>
<td>Feeling afraid of the future</td>
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</tbody>
</table>
Domain 1: Onset of illness. Participants discussed their recollections of when they began to experience symptoms of their mental illness. Five super-ordinate themes emerged that captured their experiences. These super-ordinate themes described the participants’ (1) experience of symptoms, (2) experience of others’ reactions, (3) attempts to cope with symptoms, (4) explanations for illness onset, and (5) reasons for seeking treatment.

Experience of symptoms. All of the participants were able to recall their experiences when the symptoms of their mental illness began to encroach upon their lives. They discussed how they began to experience symptoms typically associated with the mental disorders they were eventually diagnosed with, such as sadness, suicidal ideations, mood swings, and auditory or visual hallucinations. Beyond the listing of symptoms, the participants revealed how they felt or what they thought in response to the onset of their symptoms. Four themes emerged: (1) feeling confused, (2) feeling lost and out of control, (3) feeling insecure in oneself, and (4) accepting symptoms.

Feeling confused. Five participants disclosed that as these foreign feelings and experiences began, they found themselves feeling confused. These participants felt unable to discern why such symptoms were occurring or what the symptoms meant at the time of onset. Three out of the five participants spoke plainly of not understanding what was happening to them, knowing only that they were experiencing immense sadness or mood swings. Two participants, who were later diagnosed with schizophrenia, appeared to struggle with not understanding the source of the voices they were hearing. Francine described the confusion she encountered as she thought the voices were her neighbors talking to her:
I didn’t know where these voices were coming from. I thought it was my neighbor talking to me…. So all that cussing and swearing, and all that criticism I was hearing, really made me think that the neighbors were saying that to me, so I yelled…. [The] voices were criticizing me, but I had no idea it was the voices that I was hearing. I thought it was my neighbor…. And I was cussing at my neighbors. I was getting mad at them. They were shocked…. They were shocked, looking at me like what am I saying, they didn’t do anything.

*Feeling lost and out of control.* Seven of the participants said that they experienced their symptoms as frightening and unpredictable. There was also a sense that as the symptoms worsened, participants became fearful, not only of the symptoms, but of themselves as well. Two participants discussed how they started to feel lost in their lives or not themselves as they began to struggle with heavy sadness or mood swings, adding that they did not know what to do as their sadness began to take over their lives. Fears of acting out suicidal thoughts or feelings were prominent for three of the participants. Two participants described feeling as though they had to fight with themselves as they struggled with competing thoughts, feelings, or experiences.

*Josephine,* who was later diagnosed with major depressive disorder, described what it was like when she thought she had no control:

> Not a good feeling. Not a good feeling…. It’s like how your mind wants to go right, and your body doesn’t want to follow it. It’s a very uncomfortable feeling. It doesn’t make you at ease. It doesn’t make you relaxed because a lot of things are going on in your mind. Just like a tape-recorder. Fast-forward, rewind, fast-forward, rewind…. At first, before I knew what was going on, it was a really scary feeling.

*Feeling insecure in one’s self.* As they shared their stories about when they first experienced the onset of their illness, five participants stated that their symptoms began to assault their sense of self, with a few consequently becoming suicidal. Participants explained that in addition to dealing with the sudden emergence of symptoms, such as intense sadness or hearing voices, they also began to feel like they were no longer their
usual selves and struggled with this loss of self. *Jane* spoke of experiencing low self-esteem and engaging in self-destructive behaviors, including substance use and multiple suicide attempts. *Francine* described starting not to like herself when the voices started to criticize her, resulting in her trying to kill herself. As her depressive thoughts and feelings started to inundate her life, *Josephine* felt that she was losing her outgoing, humorous self, and she started to withdraw out of worry that people would call her “mental.” *Joaquin* described feeling that he was not himself when his bipolar symptoms intensified to the point that he was depressed and crying most of the time, behaving erratically, and unable to sign his name.

_Accepting symptoms._ Five participants described accepting their symptoms early on during the onset of their illness. This acceptance was not in reference to an awareness and acceptance of having a mental illness. It was simply an acceptance that the symptoms were a part of who they were and a part of their daily lives. For example, *Carlos* said that when he first started hearing voices as a child, he welcomed the voices as helpful guides and believed they once saved his life by warning him of a snake in his bed. *Peter*, who was later diagnosed with schizophrenia, was fully aware that he was wandering off from home and walking on the road “spaced out,” but did not know this was not considered “normal” and thus continued to roam the island. *Gloria* spoke of how she and her family seemed to accept her symptoms as status quo in their home:

I was disappearing for days from my family. Imagine, I had my son and later on a daughter. And through that period of time, my husband says it was like a totally separate life from the rest of the family. So I was wandering off, doing my own thing, and stuff like that. It wasn’t always very pleasant. I mean, I had my moments when it wasn’t so bad, and then there were other times where it was just absolutely awful…. But when I think back to those days…it almost felt like that was just the way things were. And my husband and my family kind of took it.
Experience of others’ reactions. With the onset of their mental illness came a drastic change in the participants’ moods, thoughts, and experiences. They struggled with these changes individually while they were unexpectedly finding themselves unable to trust their own senses or their sense of self. Many questions arose as to what they were experiencing and why. The symptoms were causing many changes within themselves, which were not amenable to being disguised or concealed. As a result, participants also had to deal with the reactions of others in their lives as family and friends started to take notice that their loved one was not his or her usual self. Six of the participants generally described the immediate reactions they received from others at the onset of their illness in one of two ways, which emerged as the following themes: (1) feeling supported by others and (2) feeling rejected by others.

Feeling supported by others. When five of the participants began experiencing symptoms of their mental illness, they noted that they felt cared for in some way. This sense of being cared for came in different forms but resulted in feelings of appreciation for the support participants received while they were in the process of trying to understand their emerging symptoms. Joaquin explained that his siblings were sympathetic to what he was going through, trying to find out and understand what was happening to him. They also pulled together to identify what help to get for him and where to seek treatment. James explained that his aunt helped him as he was experiencing the onset of schizophrenia, initially taking him to a suruhanu (an indigenous Chamorro spiritual healer) and eventually to Guam’s mental health facility when the symptoms continued.
Feeling rejected by others. Two other participants experienced rejection from family or friends. Just as the participants were struggling to make sense of what was happening to them as their illness began, it seems their family and friends were also struggling with not being able to understand why their loved one was behaving differently or acting out in a way they were not accustomed to in the past. Because the participants and their families did not know what was happening, conflicts arose, and participants soon started to feel rejected, abandoned, or misunderstood. Francine recalled initially feeling supported or reassured by her family when she began hearing voices. When her symptoms worsened, her family reached a point when they started to blame her for not helping herself, and they became upset with her for embarrassing the family as she began to scream and yell in response to the voices. Dolores felt her parents could not understand why she was repeatedly trying to commit suicide as a young child. When she started to experience intense depression again as an adult, eventually leading to a diagnosis of bipolar disorder, she felt that her siblings had abandoned her when she was at her lowest point. She credited a caring stranger who stopped her from killing herself for helping her when it was most needed.

Attempts to cope with symptoms. As the symptoms of a yet undiagnosed mental illness were continuing to worsen, attempts to cease or at least mitigate these strange internal happenings soon followed. Six participants discussed how they tried to alleviate or rid themselves of the voices, depression, or mood swings. Not yet knowing that they were in the throes of the onset of a mental illness, they did what they could to survive their day-to-day existence with these new changes that were occurring in their lives. Their coping strategies fell into four main categories or themes: (1) self-destructive
coping, (2) hiding symptoms, (3) using daily routines to cope, and (4) receiving help from others.

*Self-destructive coping.* As the symptoms were beginning to assault their sense of self, leading to feelings of confusion and of being out of control, three participants saw no other recourse but to try to destroy the very self that was suffering. This came in the form of multiple suicide attempts for two participants, with the third participant turning to substance use as a way to quiet her suffering. *Dolores,* who struggled with depressive symptoms, including several suicide attempts, throughout her childhood and adolescence, saw herself in adulthood again fading away within herself, no longer caring about life, after the deaths of four close family members in close succession of each other. She described how she came to try to end her life:

I was so blown lost. I didn’t care about life. I sat in a room…everyday. I wouldn’t come out…. I was…never eating, rarely eating at all. So the time came when I moved out of my brother’s house because I just couldn’t handle it anymore. I was so dumbfounded lost. So I moved out, stayed with a friend for awhile…. I split [my friend’s home]…. I was just living on the streets, being homeless, didn’t care about anything…. For a long time, and then November 20th was the night they brought me in because I was a jumper. I kept jumping in front of car after car after car waiting for somebody to hit me.

*Hiding symptoms.* Stemming from the confusion ensuing from the onslaught of symptoms, as well as having to deal with not only their own reactions but fearing the reactions of others around them, two participants described making attempts to conceal what was happening to them. *Josephine* described staying in her room and covering herself with a pillow while crying when she kept hearing voices telling her to kill herself, adding that she did not want to tell anyone about the voices she was suddenly hearing.

Hiding symptoms became a way for *Gloria* to save her marriage and family. She spoke
of pretending that she was getting better out of fear that her husband would leave her and take their children with him.

*Using daily routines to cope.* Another way of coping with the emerging symptoms of a mental illness came in the form of common daily activities that seemed reminiscent of trying to heal oneself from physically troubling ailments or stress. Two participants spoke about how they tried natural daily routines to cope with their symptoms. Much like trying to soothe a headache or migraine, *Josephine* attempted to silence the voices she was hearing by taking a cold shower and splashing water over her head. This also seemed like an attempt to wake herself from the frightening state of hearing voices telling her to end her life. *Peter* approached his beginning symptoms of schizophrenia by trying other methods that were readily available to him, such as sleeping it off and eating healthily, only to soon realize that neither of these changes in his daily habits was successful.

*Receiving help from others.* At times family members attempted to intervene and did what they thought would be helpful to alleviate the difficulties that the participant was experiencing. Much like the participants themselves, family members were not fully aware that the participants were actually experiencing the onset of a mental illness. Within their own attempts at trying to make sense of what was happening to their loved one, family members thought of ways to help relieve the stress that was happening in the home and the distress occurring within the participant. Two participants discussed the help to cope with their symptoms they received from family members. *Gloria,* for example, shared that her husband took her on a vacation in earnest belief it would help her:
So he took me on a vacation, and it was a nice vacation and stuff…and it was fine for awhile, but then it comes back and then you’re not so fine anymore.

**Explanations for symptoms.** Eight participants recalled the explanations they had for their symptoms at the time they first emerged. These explanations served as a way to try to make sense of what was happening to them and to tentatively lessen their confusion and alleviate their worry. Most often, participants identified the most immediate events as possible triggers of their symptoms. Five of the eight participants attributed their symptoms to more than one factor. Each participant spoke about very specific life events leading up to their symptom onset, reflecting their understanding of their symptoms at that time. Their explanations fell into four themes: (1) symptoms attributed to loss of family members, (2) symptoms attributed to life stressors, (3) symptoms attributed to ancestral spirits, and (4) symptoms attributed to substance use.

**Symptoms attributed to loss of family members.** The immense sadness and grief following the loss of a family member was a common explanation assigned to the participants’ emerging symptoms, regardless of whether the symptoms were depressive feelings or auditory hallucinations. *Jane* recalled attempting suicide as an adolescent due to missing her father who was incarcerated in the U.S. mainland during that time. Four other participants discussed how they began to suffer unrelenting sadness after the death of a loved one. *Dolores*, in particular, explained how she lost both of her parents, as well as her husband and daughter, all within a seven-year period. Although she had struggled with depressive feelings throughout most of her life, it was her daughter’s unexpected death that eventually resulted in her becoming so lost and despondent that ending her life seemed an enticing solution to her pain. *Josephine* had been engulfed in her ongoing grief so much that she experienced repeated nightmares of her deceased mother and
father arguing over whether she should continue to live. This was also reminiscent of the voices she started to hear that tried to coax her into ending her life.

*Symptoms attributed to life stressors.* In addition to symptom onset being associated with intense grief reactions, other life stressors were also identified as possible precipitating factors. Four participants discussed a variety of life events that they felt contributed to their developing symptoms. These life stressors included family conflicts, feeling betrayed by an intimate partner, as well as financial and health issues experienced by the participant or their family members. *Joaquin* described falling under the pressures of multiple stressful events that seemed to be occurring almost simultaneously, including his wife’s ailing health, loss of employment, and needing to financially assist his adult children. He soon found himself becoming increasingly afraid and agitated, leading to paranoid thinking, delusions, and bizarre behavior.

*Symptoms attributed to ancestral spirits.* Of the six participants who stated that the onset of their illness included auditory hallucinations, four believed that the voices were those of their ancestors’ spirits. Although the voices were malevolent at times, primarily telling participants to end their lives, all four of these participants also experienced a sense of comfort from the voices during less threatening or frightening instances. They believed that the voices were attempts from long-deceased relatives to guide or protect them. *Peter,* who identified his ethnic background as a mix of Filipino and Chamorro, explained that he initially thought the voices he was hearing were those of his Chamorro ancestors:

Well, I thought there was an outer life…after you die. There’s people watching over us, they say, in heaven. But, I always thought that…the ancestors of my mom, [the] Chamorro side, were watching over us. So that’s what I imagined…. They were trying to help me get better in life…. [The voices] were sort of like
ancestors or people that have died before, and...they came back into life as...like a ghost or something.... Well...I figured it out because I always thought that my mom’s parents and her grandparents were watching over us.... I imagined it because I needed help, as in...confidence, encouragement to do good in life.

*Josephine,* who was diagnosed with major depressive disorder, shared how she believed the flashbacks and voices she was experiencing were ancestral spirits trying to communicate with her:

> I believe, I really strongly believe in old loves ones reaching out for some kind of message or something like that.... We believe in that. I believe in that.

**Symptoms attributed to substance use.** Three participants thought their emerging symptoms were due primarily to their use of alcohol and other substances, such as cannabis or methamphetamines. These same three participants also believed that their symptoms began as a result of a combination of substance use and ancestral spirits. *James* believed that his depression and paranoid thinking came from his consumption of alcohol and long-term drug use but that **taotamo’na** (i.e., ancestral spirits of ancient Chamorros) were also making him ill with negative thoughts:

> Honestly, I’ve been using drugs. I’ve been using meth for almost more than 25 years. And I only quit three years ago. I’m serious about it.... That’s what caused me to have a mental illness. But, deep inside me, I was feeling also spirits, too.... Like, somebody’s making me sick. Like, spiritual sickness. Like, spirits of **taotamo’na** or like that.... I was always thinking the **taotaomo’na** doesn’t like me and all these things. They’re making me sick.... Like, all negative thoughts in my mind.... Paranoid.

*Peter* recalled that he had some awareness that his symptoms began after he discontinued his use of methamphetamines, but he also thought the voices were his ancestors guiding him. *Jane* did not necessarily believe her symptoms were related to her own ancestral spirits. She believed that her symptoms were due to her use of cannabis and
methamphetamines, as well as her smoking the indigenous tangan tangan plant, which she said is believed to be associated with *taotaomo’na*.

**Reasons for seeking treatment.** After their symptoms began and started to worsen, there came a point for all of the participants when something needed to be done in order to find out why the symptoms were happening and how they could be alleviated. Some participants took it upon themselves to seek help when they could no longer stave off the symptoms themselves while others needed the assistance of others to help them find the appropriate services needed to ease their suffering. The themes that emerged regarding the participants’ eventual pursuit of treatment included (1) seeking treatment initiated by self and (2) seeking treatment initiated by others.

**Seeking treatment initiated by self.** There were a variety of reasons why some of the participants decided to seek treatment, but these reasons drove five participants to take it upon themselves to find the help they thought they needed to better understand and rid themselves of their symptoms. These reasons included acknowledging a self-awareness of unusual behavior and becoming fearful of previously innocuous triggers, drowning in unbearable grief, and suddenly hearing voices. Feelings of fear and confusion about the symptoms seemed to be the most significant motivating factors for the participants to seek treatment. *Nancy* described how she admitted herself to Guam’s mental health facility when she began to feel as though she were dying:

[I was feeling] depressed. Wanting to die, or not wanting to die, but feeling like I’m dying. And it was a stage. I figured it might have been a stage that I was going through, feeling like I’m dying, then maybe next thing you know, I would wanna die because I’m feeling like I’m dying…. So I figured that might have been a stage, so me and my sister talked, and I came in and I had myself admitted.
Seeking treatment initiated by others. Five participants were so engulfed by their symptoms that they needed someone else to push them to seek treatment, whether it was a court order, a family member, or a kind stranger who intervened to prevent the completion of a suicide attempt or family members realizing symptoms were becoming so severe or uncontrollable that outside help was needed at that point. Although Dolores was in tremendous despair over the deaths of several close family members and determined to end her life, she was grateful for the stranger who stopped her from killing herself and called for help:

I kept jumping in front of car after car after car, waiting for somebody to hit me. This one guy, I jumped in front of his car, he swerved, he missed me. I said, “Fuck! What the hell?!” So this tractor trailer that I jumped in front of hit his brakes. He knew what I was gonna do. So he hit his brakes right on time. And the truck was…right…in front of me. I looked at him and said, “Why?” He goes, “Not gonna do your deed for you.” And then we’re talking. He put the triangles out because he wanted to make sure I was okay. He called the cops and I didn’t know…. And I looked at him like, “Oh, my God.” He goes, “I’m sorry.” I said, “Thank you. Thank you for calling the cops because I do need help.”

It was an ultimatum from her husband that pushed Gloria to seek treatment. She feared her husband would leave her and take their children with him after she disappeared yet again from her family, that time ending up in a neighboring island without remembering how she managed to board a plane.

Domain 2: Being diagnosed. Upon seeking treatment for their symptoms, the participants were then confronted with the experience of learning that the sudden changes in their mood or behavior, or that the voices they had started to hear, were actually symptoms of a mental illness. The participants’ experiences encompassed their own reactions to the diagnosis, as well as dealing with their family’s reactions to the diagnosis. These reactions were illustrated by three super-ordinate themes: (1) initial
reactions to diagnosis, (2) secondary reactions to diagnosis, and (3) family’s reactions to the diagnosis.

**Initial reactions to diagnosis.** Of the 10 participants, nine shared their immediate reactions to being told that they had a mental illness. It seems that most of the nine participants wrestled with the news of their diagnosis while one participant saw her diagnosis as an opportunity to finally do something about the symptoms that were destroying herself and her family. Two participants also spoke about their experience of the diagnosis process. Participants’ reactions ranged from a feeling of confusion to a sense of relief, with six main themes having emerged from their experiences. These six themes were (1) lacking understanding of diagnosis, (2) refuting diagnosis, (3) feeling embarrassed of diagnosis, (4) seeing diagnosis as punishment, (5) feeling excluded from diagnosis process, and (6) feeling relieved by diagnosis.

**Lacking understanding of diagnosis.** When first told that they had a diagnosed mental illness, six participants initially felt confused about what that meant. That confusion stemmed primarily from not knowing what their diagnosis meant in terms of their symptoms, requiring the psychiatrist to explain exactly how their symptoms were those of a specific mental illness that had a name. Although participants were fully aware they were not feeling well or behaving as their usual selves, they never expected that there was a name for an illness that they had suddenly developed. *Francine* described her surprise upon learning there was an actual reason why she was having hallucinations:

I was like, “What’s that?” I said, “What’s that? I don’t know what that means.” And the doctor goes, “Oh, that’s hallucinations.” I was like, “Yeah, yeah! I have that. I hear voices. I hear people talking to me, and… I thought it was my neighbor….,” My reaction was like, “Wow, I never knew I was schizophrenic….” I never knew that they would come across [schizophrenia] as a term for my illness.
Refuting diagnosis. Although receiving a diagnosis for a mental illness provided a medical explanation for the symptoms they were experiencing, receiving the diagnosis resulted in a wide range of reactions. The surprise, if not shock, of a diagnosis of a mental disorder seemed unbearable for four of the participants, resulting in their experience of denial and efforts to refute the diagnosis. These participants rejected the notion of having a mental illness, believing their diagnosis could not be true and finding reasons to support this belief. Jane believed her enjoyment of being around people must be proof that she did not warrant the diagnosis of schizoaffective disorder. In a similar vein Joaquin made attempts to prove to his doctors that if he was feeling well, then it meant that he could not have bipolar disorder. Nancy was experiencing problems with her neighbors the first time she was diagnosed with bipolar disorder. She immediately discounted her diagnosis, believing medicating her would not stop her neighbors from harassing her. Upon reflection, she wondered if she was too immersed in her problems that she did not see her symptoms clearly.

Feeling embarrassed of diagnosis. Being diagnosed with a mental illness brought about feelings of embarrassment or shame for three of the participants. Much of this had to do with the social stigma often associated with mental illness. At the same time this feeling of embarrassment also had traces of fears that having a mental illness meant they were now different from those around them. Although Francine finally understood that the voices she was hearing were due to a mental illness called schizophrenia, she nevertheless felt embarrassed and bad about herself because she feared her family would think her diagnosis meant she was crazy. Dolores immediately thought her diagnosis of bipolar disorder meant she was “mental,” which she explained meant for her that she was
dumb or could not function. *Joaquin* felt that the mental illness changed his circumstances in the world, describing his perception of how he was now different from others succinctly:

> Why does it happen to me when I figured…I’m okay….. It’s like I’m okay, you’re okay, and then…it’s like I’m not okay on my part.

*Seeing diagnosis as a punishment.* Two participants’ descriptions of their reactions to being diagnosed seemed to indicate that they felt they were being punished or that it reflected their character. This reaction contributed to either a desire to refute the diagnosis or to feelings of depression following the diagnosis. In addition to fearing the social stigma associated with mental illness, *Joaquin* shared that he also felt as though he was being punished for something he might have done. Although *James* has come to accept his diagnosis, he recalled quickly becoming depressed after he was diagnosed with schizophrenia, believing that the diagnosis meant he was a criminal or a bad person. Both participants’ reactions seem to hint at a sense that there may also be an internal process where they not only fear others’ reactions or feel embarrassed about being diagnosed with a mental illness, but that there is also a mechanism of self-recrimination or a questioning of one’s integrity.

*Feeling excluded from diagnosis process.* In addition to sharing their reactions upon learning that they had a mental illness, two of the participants also highlighted how they felt during the process of being diagnosed. These participants appeared to demonstrate the lack of control or power they felt at the time they were told they had a mental illness. *Jane* recalled how the psychiatrist met with her and her grandmother to discuss what was going on with her, but that her grandmother ordered her to leave the room before the psychiatrist could begin the discussion. This left her wondering what
was being discussed and why she was being left out of the discussion when it was about her, but she nevertheless complied and left her grandmother to meet with her treatment providers. Although nothing was done directly to leave Joaquin feeling omitted from the diagnosis process, he shared how the evaluation process had rendered him unable to have a say or question his diagnosis. He described how he felt excluded at each stage of the process when reports were written about him and sent from one provider to another; he could not argue or question the diagnosis because the treatment providers had the authority and had authorized the diagnosis.

*Feeling relieved by diagnosis.* Although only one participant described feeling relieved upon being diagnosed with a mental illness, this reaction still seemed noteworthy because it spoke to a sense that being diagnosed may also have a positive aspect. After years of struggling with symptoms, trying to self-medicate with substance use, and instability in her home life with her family, Gloria experienced being diagnosed as an unburdening of self-recrimination and a start to getting her life back in order. It seemed as though receiving the diagnosis gave her hope and a sense of power or control over her symptoms, which she attempted to maintain in the past but through self-destructive ways. In being diagnosed, she saw an opportunity to release herself of the guilt she carried over doing acts that she saw were destroying both herself and her family. She described the relief she felt when a psychiatrist finally gave a name to her symptoms:

So for the longest time, I felt like I was just a really bad person…. That was just like…“You’re just bad. Look what you’re doing to all these people.” And I would be in the middle of doing something stupid. And knowing I’m doing something stupid. And just continuing to do it…. So I just thought I was a bad person…just evil. And then, when I got diagnosed, when [the psychiatrist] finally came out with those words…I just felt this sense of relief. Like I’m not a bad person…. I was so glad. I went home. I told my husband. I told my daughter…. It was almost like a celebration. I told them what we were going to do. We’re
going to try these different medicines that are going to make me better. And so…it was a celebration.

**Secondary reactions to diagnosis.** After the immediate reactions participants had in response to being diagnosed with a mental illness, another phase of reactions seemed to follow. This phase particularly focused on the process of accepting or trying to come to terms with having a mental illness. A couple of participants even saw positive aspects of having a diagnosis beyond merely accepting that they now had a name for their collection of symptoms. Three themes emerged regarding the participants’ ensuing reactions to being diagnosed: (1) accepting diagnosis, (2) struggling to accept diagnosis, and (3) feeling appreciative of diagnosis.

**Accepting diagnosis.** Despite their initial lack of understanding of the diagnosis or feelings of embarrassment and desire to refute their diagnosis, half of the participants were eventually able to reach a point of accepting their diagnosis. Different paths were taken to reach that point, but the five participants concluded that receiving their diagnosis was no longer something they needed to deny or challenge. Their acceptance was not merely a resignation to the diagnosis but more a process of gaining perspective and knowledge to help them move forward with living with their mental illness. Three participants recalled that they were able to accept their diagnosis fairly easily without the initial reaction of wanting to dispute the psychiatrist’s conclusions because the diagnosis helped to explain and clarify the symptoms they were experiencing. Similarly, although Jane initially wanted to refute the diagnosis, she came to accept it after reading about it in a brochure or pamphlet that specifically described her illness. Accepting the diagnosis came easily for Gloria, as having a mental illness was a far better explanation to accept than that she was the terrible person she felt she was in the years prior to being
diagnosed. Dolores’ initial embarrassment about having a mental illness gave way to acceptance when she realized that she had been through worse medical issues in her past and still had come out of them as a strong person. At the same time she admitted that she much preferred the explanation of having a chemical imbalance than to be seen as “mental,” or unable to function.

Struggling to accept diagnosis. Not all of the participants found it easy to accept being diagnosed with a mental illness. Five participants struggled with the reality of having a mental illness, reflecting the difficulty of having to ingest this new aspect of their identity. In addition to having to cope with emerging symptoms that they initially did not understand, they also then found themselves having to readjust to how they perceived themselves and fearing how others would see them. Three participants shared how it took them a long time to finally accept being diagnosed with a mental illness. This process required the participants to re-conceptualize how they saw themselves or their symptoms, such as adapting to explanations of schizophrenia versus being visited by spirits, believing one has become a bad person upon being diagnosed, or requiring repeated reminders through counseling that one now has a mental illness. Another obstacle in accepting the diagnosis for two other participants came from receiving the diagnosis as an adult. Joaquin encountered confusion with accepting his diagnosis of bipolar disorder simply because he could not understand why he did not have the disorder throughout most of his life, but he now finds himself with a mental illness as a 60-year-old man. Nancy struggled with wondering if she has had bipolar disorder all her life but somehow managed to cope with it all these years until it became severe enough to warrant attention. She has come to accept her diagnosis, not necessarily in true belief of
her illness, but more from an absence of the anger she used to harbor, believing that having the illness may not be detrimental because she is at least able to function.

 Feeling appreciative of diagnosis. Although most of the participants described the process of coming to terms with their diagnosis, two participants specifically noted positive aspects associated with receiving news of having a definable mental illness. For these participants being diagnosed was a catalyst for the changes that transpired in how they dealt with their symptoms. It meant more than just finding out they had an illness to explain their symptoms but rather became a way to make their lives with an illness actually more livable than what they had been experiencing prior to the diagnosis. Gloria and Josephine were able to move beyond the phase of acceptance to reach a point of appreciation for having been told that there was a name for their suffering. For years Gloria had been self-medicating through substance use but otherwise continuing to experience symptoms that created conflicts with her husband and made it difficult for her to fulfill her role as a mother to their two children. She credits being diagnosed with saving her life because the diagnosis gave her and her family the ability to understand what was happening, do something about it, and get their lives back in order. In Josephine’s case, the diagnosis gave her something concrete to anchor what was happening to her. Armed with a name and explanation for why she was crying all the time and in so much anguish, she was able to start telling people what was happening with her and ease the weight of the burden she had been carrying alone for some time.

 Family’s reactions to the diagnosis. Part of the process of being diagnosed included disclosing that diagnosis to immediate family members for five of the participants. This meant that the participants also had to address some of the reactions of
their family members. The participants who shared their experiences about how their family members reacted to news of their mental illness described a mix of denial, support, and misunderstanding. These reactions were captured by three main themes: (1) family did not believe diagnosis, (2) family was supportive of diagnosis, and (3) family used diagnosis to stereotype.

*Family did not believe diagnosis.* Just as it was difficult for some participants to accept or believe their own diagnosis, it was perhaps unsurprising to learn that some of the participants’ family members also had a difficult time accepting the news that their loved one had a mental illness. As participants began to experience symptoms, family members likely went through their own process of trying to make sense of what was happening and had arrived at their own conclusions to explain what the participants were displaying. In that regard, it was understandable that some family members would also struggle with coming to terms with the existence of a mental illness within the family. Three participants described how their family members seemed to express disbelief about their mental illness, often developing alternative explanations to refute the diagnosis. *Gloria* shared how her parents refused to believe that she had a mental illness and instead blamed her husband for not taking better care of her. *Nancy* and *Carlos* seemed to receive some disbelief from their siblings about their diagnosis though it seemed as though this disbelief came from a place of wanting to see their loved one as well and functioning. One of Nancy’s sisters remarked how she felt that Nancy could not have bipolar disorder but was rather merely upset and needing to calm herself from being too angry. Her sister also attempted to normalize Nancy’s mental illness by reminding her that she had been through a lot of difficult situations in her life. Despite coming from a
family where multiple family members have also been diagnosed with a mental illness, Carlos shared that his sister insisted that he could not be mentally ill because he was able to complete application forms. Carlos commented that he had to explain to his sister that mental illness did not necessarily mean incompetence and that fully functioning individuals could still have a mental illness.

*Family was supportive of diagnosis.* In other cases participants were greeted with much support when they disclosed their diagnosis to their families. Supportive reactions ranged from expressions of sympathy to helping the participant to explain to other family members what was needed to assist the participant in treating the mental illness. Participants appeared to appreciate the support they received as they were also coming to terms with learning about their diagnosis. Three participants described how particular family members showed their support when they disclosed their diagnosis to them.

Joaquin shared that his siblings were sympathetic to his mental illness. Two of his sisters who reside outside of Guam often research his illness and his medications to better understand and guide him in his recovery while other family members have even tried to express their solidarity by looking within themselves to see if they might also have a mental illness or offering to shoulder his illness for him. Although Gloria might have received denial from her parents, her siblings have come around to support her, often asking her how she is doing or otherwise showing concern. Francine’s sister was with her when she was diagnosed, and it was her sister who discussed the diagnosis with their parents and explained what was going to happen in terms of her treatment.

*Family used diagnosis to stereotype.* Although only one participant mentioned this particular issue, it was noteworthy as it demonstrated how sometimes even well-
intentioned support could become problematic in other ways. Gloria described how her sisters started to express concern for her upon accepting the reality of her mental illness. Her sisters’ concern eventually transitioned to an assumption that her mental illness explained all of her behaviors, and this seemed to diminish or invalidate Gloria’s feelings or experiences. For example, if she raised her voice or acted differently, her sisters would quickly ask her if she had taken her medications. This did not leave much room for her to be herself without others viewing her through her mental illness; she felt that her entire self was now being defined by her diagnosis.

**Domain 3: Being on medication.** The most common form of treatment for mental illness involves the use of psychotropic medications. Medication is used to treat a variety of mental disorders, including the particular disorders experienced by the participants interviewed for this study. All 10 participants reported being on medication at the time of the interview, and they shared their thoughts on what it was like for them when they started taking medication. Two super-ordinate themes emerged from their experiences: (1) difficulties with medication and (2) positive experiences with medication.

*Difficulties with medication.* Although taking medication may help to alleviate the symptoms associated with a mental illness and make life with the disorder more bearable, the benefits do not necessarily negate or dilute the troubling aspects of being on medication for a mental illness. All of the participants discussed some of the difficulties they experienced when they started to take medication for their mental illness. Some of the difficulties stemmed from their own mixed feelings about having to take medication while the other challenges of being on medication came from issues related to the ups and
Six themes emerged from the participants’ experiences of the difficulties with medication: (1) initial reactions to medication, (2) struggling with side effects, (3) fears related to medication, (4) struggling to find the right medication, (5) wanting to stop taking medication, and (6) resigning self to being on medication.

**Initial reactions to medication.** Despite having experienced frightening symptoms that left them feeling out of control or fearful of themselves, the notion of having to take medications for those symptoms was difficult to accept. At the same time they were in the process of trying to accept and understand that they had a mental illness, participants soon found themselves having to try medications they had never heard of before. Three participants shared their initial reactions to being on medications for their mental illness, and their reactions seemed to demonstrate an underlying prerequisite of needing to trust mental health professionals. For these participants, being on medication meant more than merely ingesting several pills each day. They had to place their trust and faith in the doctors who were telling them that the medications would help them and would ease their suffering, especially when facing the unknowns of how the medications would affect them or confronting the projection of a lifetime of medication use. The first time Nancy was diagnosed with bipolar disorder, she refused to try taking medication for her illness. It was not until more recently when she felt fearful of dying that she decided to be hospitalized and finally agree to try taking medication. It was primarily because she was in a secure environment where she could be observed that she agreed to the medication treatment prescribed because she greatly feared how the medication would affect her. Joaquin recalled repeatedly spitting out the medication he was given, agreeing to swallow the pills only if his brother would be the one to give them to him. He feared
the medication’s side effect of possible suicidal thoughts and worried that the very intervention aimed at helping him would actually worsen his condition. It took much self-convincing, but he had to remind himself that the mental health professionals were trained and must know what they were doing in order for him to trust them enough to follow the medication regimen. Francine described mixed feelings of happiness and sadness to learn there was a medication for her symptoms of hearing voices, feeling relieved that there was something to help alleviate her symptoms, coupled with a sense of loss that she would need the medication for the rest of her life:

I was feeling a little bit happy and sad. Happy I’m getting the help. Sad that...I’m taking medications…. First I thought that you’ll get counseling. That you’ll get counseling, that they’ll talk to you, and you just keep talking and talking and talking. But, taking the medication, I didn’t quite know…what it really is, what it really means besides telling the doctor, and the doctor telling you how it’s going to make me react or feel. When they first gave me the med, I was like, “Wow! Feels a little bit good, it’s okay.” But when I took it, I felt like I was being secluded. Secluded in an area where I can’t do anything. Like I can’t go out anymore. I can’t go out to be with my family. I thought I wasn’t going to come out of Mental Health…. I got scared…. I thought I was going to stay here forever…. I just felt that it’s for life. I was scared… That I was going to live off the medications…. I was happy I was getting help. It was, “Oh, I’m finally getting help and the voices will stop…but I’m scared that’s the rest of my life.”

Struggling with side effects. Although medications may help to alleviate the symptoms of a mental illness, they do not necessarily come without the troubling aspect of side effects. Eight of the participants discussed the side effects they struggled with, which ranged from increased sleepiness and appetite to uncontrollable facial movements or speech impediments. More than the physical ailments brought about by the medication, the side effects also had ramifications on their ability to socialize or function, their confidence in mental health professionals, and their sense of choice in terms of their treatment. Two participants mentioned that they are no longer able to drive due to the
side effects of their medication. Joaquin added that his inability to drive has left him unable to be more independent and to socialize outside of the home, leaving him withdrawn, lonely, and depressed. Two other participants explained that they struggle with being in public as their medications’ side effects result in slower speech or uncontrollable facial movements, affecting their ability to engage socially with the world. Carlos sometimes chooses to remain home to avoid being in public so that he does not have to explain why his face moves in a “weird way,” making him look “mad.” Another two participants shared how the side effects made it difficult to function either at work or at all. James described feeling like a zombie when the side effects of his medication made him sleep excessive hours during the day and unable to do anything else, resulting in continued use of substances just to stay awake. He repeatedly begged psychiatrists for help, but none could offer relief because he needed the medication they had prescribed.

Two other participants detailed years of trying different medications, enduring unbearable side effects and the worsening of their symptoms. Gloria shared how the issue of side effects eventually becomes futile because there are no alternatives. As she sees it, the decision about being on medication becomes about whether the benefits of the medication outweigh the side effects or not, which she says really offers no choice because the alternative is to live with the unbearable symptoms of the mental illness. She also explained how she feels judged when labeled “non-compliant” by mental health professionals when refusing to take the prescribed medications due to the side effects, explaining that they do not seem to understand the full ramifications of having to choose between living with the symptoms of the mental illness versus living with the symptoms of the medications, neither of which are worthwhile options.
Fears related to medication. Apart from the issue of side effects, six participants also discussed some of the fears they have about being on medication. These fears reflected the broader issues of medication use beyond the concern over the immediate side effects that often accompany this route for treating mental illness. Four participants expressed worry over their physical health, recognizing that they are taking powerful drugs for the remainder of their lives, which may have deleterious effects on their internal organs. Mortality issues arise as they wonder how long their bodies can sustain any ill effects of their medications. Two of these participants also hinted at the irony of improving their eating habits and engaging in exercise to maintain their mental health, yet at the same time infusing their bodies with chemicals that could be damaging in the long-run. Other fears about being on medication stemmed from concerns about the future. When discussing her dreams for the future, Jane shared her concern that being on medications would prevent her from achieving her goals after hearing from one of her treatment providers that such an outcome could happen. Nancy, who vacillates between accepting she has a mental illness and searching for evidence that her diagnosis is correct, is plagued by the fear that her life could fall apart if she terminated her medication treatment. Such fears reflect the power medication holds in these participants’ lives, one that transcends its purpose of alleviating symptoms of mental illness.

Struggling to find the right medication. Upon being diagnosed with a mental illness, all of the participants stated that they were prescribed medication as a course of treatment. Four of the participants provided some insight into the sometimes lengthy and arduous process of finding the medications that provided the most relief from their symptoms with the fewest, or least disabling, side effects. The process usually involved

enduring severe side effects, periods of being incapacitated, the worsening of symptoms that the medications were intended to alleviate, and moments of helplessness and hopelessness as it began to appear that a more tolerable medication could not be found. Three of the participants expressed much appreciation and gratitude toward the psychiatrists who were finally able to relieve them of both their symptoms and the side effects that were inhibiting their livelihood. James exclaimed that he was “dancing the next day” and repeatedly mentioned throughout the interview how grateful he was to the psychiatrist who restored his life and ability to function after 12 years of feeling like a “zombie” and unable to do anything. He added that he ceased using illicit substances upon being given a medication that worked without detrimental side effects because he no longer needed the substances to stay awake and function during the day. Francine recalled feeling confused about how the medications would seem effective at first, only to have the symptoms re-emerge and worsen shortly thereafter. She also described repeated hospitalizations and threatening behavior toward her family with almost every trial of medication over the course of 11 years. Like James she begged different psychiatrists to ease her suffering, but it was only more recently that she was put on a medication regimen that she found tolerable and effective. Gloria described experiencing a host of debilitating side effects throughout the years she was on the search for the proper medication, as well as her fear of trying a new medication again when side effects emerge:

I mean, every symptom that you read on those lists seemed to happen to me. So I was always saying, “Oh, I can’t take this anymore.” And that’s why I always feel like there’s a certain point where they’ll say, “Well, you need to give it some time.” But I don’t think I should subject myself to that torture for that period of time. I used to have really bad arguments about that…. And so when you find the right one, you’re just like, “Oh, my God, I cannot stop this,” because there’s
always that fear…. And I’m not even going to, I don’t even want to take the chance. I have the choice to go back and start all over and try to find something to replace the [medication I’m currently on], and then I said, “No. It works. I’d rather not be able to drive than to have to go through that crap all over again”…. Medication’s such a sensitive thing because it’s so invasive. I think it just takes over your body…. See, you have to understand when people are saying that this medicine doesn’t make them feel good, you have to take it seriously because, in many cases, they’re the only ones who would know whether it makes them feel good or not.

*Wanting to stop taking medication.* With all the side effects, struggles, and fears associated with being on medication, it is to be expected that there would be a desire to stop taking the medications despite whatever degree of relief this treatment offers from symptoms. Two participants shared that they have had moments of wanting to cease their medication use, remaining hopeful that there will come a day when they will no longer need this form of treatment for their mental illness. Whether or not this hope can come to fruition remains to be seen, but these two participants nevertheless continue to envision a life without medications. *Jane’s* fears of having her future goals disrupted by her medications have resulted in her hoping that she might be able to find other people to help her eventually get off of her medications. There have been times when she has shyly or jokingly approached her psychiatrists about being taken off her medications. She has never seriously attempted to request that her medication prescriptions be terminated due to being reminded by her treatment providers, as well as her ongoing symptoms, that her condition requires that she remain on her medications. *Joaquin*, who was diagnosed with a mental illness only five years ago and currently struggles with the side effects of his medication, also spoke of hoping not to need his medication for much longer. When he is feeling good, *Joaquin* starts thinking that he no longer needs the medication, but mild relapses of his symptoms lead him back to realizing he still needs to
continue with his treatment. He otherwise takes comfort in the fact that his dosage is quite minimal.

Resigning self to being on medication. Despite the fears and struggles associated with taking medications for their mental illness, the fact that all of the participants reported being on medication at the time of their interviews suggests that they all eventually arrived at the decision to accept their pills or injections, even if not to their liking, and had necessarily accepted their medication routines as part of their lives. The participants seemed to have lost the freedom to choose whether to take medications or not given the alternative is a lifetime of symptoms, conflicts with family, substance use issues, and an inability to function in the world. At some point even side effects must be tolerated when the greater cost of not being on medication is to become incapacitated.

Five of the participants discussed having to resign themselves to a lifetime of medication use in order to maintain employment, engage socially with others, and otherwise stay afloat in their lives. Peter shared how he feels that having to take medication is the hardest part about having a mental illness, recognizing that he would not be able to function normally in his life if he did not take his medications regularly. After years of going on and off medication treatment, Gloria expressed feeling defeated when she had to resign herself to a lifetime of medication. She explained that she would start to feel better and think she could stop taking her medication, only to have the symptoms resurface and be reminded that her illness and need for medication will forever be a part of her life. Weariness over trying to fight the illness, going on and off medication, eventually left her to surrender to her “lot in life.” Dolores described her resignation to being on medications:
Have to [keep taking the medications] or else I’m not going to be stable…. Like now, I’m stable, but if I don’t have my meds, I won’t be sitting down here talking to you. I’d be walking around the room and around and around. Or I’ll get agitated and walk out on you…. My meds, every day, I have to take, there’s no way out of that. That’s going to be my lifetime pills…. Not fun, but, hey, that’s my cocktail mix that keeps me in place.

**Positive experiences with medication.** Although all of the participants shared the difficult experiences they have had with being on medication, nine participants also discussed the more positive aspects of taking medication for their mental illness. These positive experiences highlight the role of medication in helping participants to function and maintain a quality of life that might otherwise be impossible due to the symptoms of their illnesses. Two themes emerged regarding the participants’ positive experiences with medication: (1) recognizing medication’s role in recovery and (2) medication seen as supporting emergence of true self.

**Recognizing medication’s role in recovery.** Another perspective regarding being on medications is the recognition that, when they do work, medications can be quite effective in helping to alleviate symptoms of mental illness. Perhaps it is this realization that led a number of the participants to feel that being on medication is necessary in order to function and engage with the world. Seven of the participants explained how their medications aided in their recovery process and helped them to live beyond merely experiencing their symptoms on a day-to-day basis. Each of these participants shared their awareness that their medications help to prevent them from relapsing and experiencing greater suffering and despair. Because the medications allow them to feel better, maintain employment, and engage socially with others, participants have a reason to continue taking their medications. It seems that even with the struggles associated with being on medication, there is a sense of appreciation for what they are able to gain
from this mode of treatment. *Jane* explained how she is able to refrain from destroying her life due to her medication:

I don’t mind taking it…because it helps a lot. Without it, I probably might be out on the street again, doing some dope…committing a real crime…. My record’s been clean…. I’ll want to make it dirty if I take away all the pills.

*Josephine* credited her medications with helping her to experience a sense of control over her mental illness. She described feeling as though her mental illness had been controlling her prior to starting medication, adding that she felt she could not do anything about her symptoms. She explained that the medications gave her back a sense of control:

But with the right pills, you feel you have control…. It’s a good feeling. It’s a good feeling.

*Medication seen as supporting emergence of true self.* When the participants shared their experiences of being on medication, the concept of *self* emerged as a key aspect of mental illness and medication treatment. There appeared to be a distinction between the self that has the mental illness and a true self that transcends the illness with the help of medication. Two of the participants shared this sentiment, believing that the medications they are taking are largely responsible for their true self emerging out of their mental illness. They explained that the self that is calm and emotionally stable is their true self, unlike the self that is mired in mood swings and anger outbursts when their symptoms are at the forefront of their lives. *Nancy* clearly articulated this theme, stating that her medication has allowed her normal self to come out:

I feel the normal me is coming out. And not the upset me…. I’m going to keep on with my medication because I don’t want to lose my cool and then have a knife in my hand.
In contrast, a third participant, who also described experiencing a different kind of self when on medication, seemed to struggle with having a medicated version of her self. *Gloria* shared that she and her family noticed that she has become less spontaneous since being on medication, adding that they sometimes miss the free-spirited aspect of her personality. She has often wondered why she and others with mental illness cannot be accepted and honored for who they are, instead of being subdued by medication. As such, she sometimes feels that her self is now comprised of her medications, which does not allow her to be her real self:

And, every now and then, I’ll still have this, I’ll wake up in the morning and say, as I’m popping a pill… “Oh, no worries, Gloria. One day, you’re not going to have to do this. Once you don’t have to go to work anymore, you can just stay home and be who you are.” It’s kind of like, you have this feeling like it takes away from who you really are.

**Domain 4: Being hospitalized.** Given the chronic nature and severity of serious mental illnesses, such as schizophrenia, schizoaffective disorder, bipolar disorder, and major depressive disorder, temporary admission into an inpatient ward of a mental health facility seems almost inevitable. All of the participants reported having been hospitalized due to their mental illness. They have each been admitted into an inpatient ward of a mental health facility at least once since the onset of their illness, with seven participants having had more than one hospitalization. Eight of the participants discussed their experiences of being hospitalized. Three super-ordinate themes emerged under this domain: (1) experience of being hospitalized, (2) experience of being discharged from hospital, and (3) family’s reaction to hospitalization.

*Experience of being hospitalized.* There were various reasons why each of the participants was hospitalized for mental illness. For some, it was to seek answers as to
what was happening to them when they began to experience symptoms of what they later learned was a mental illness. For others, being hospitalized was a way to preserve life after a suicide attempt or to prevent such an attempt from happening at all. Regardless of the reason, the experience of being hospitalized can be frightening due to preconceived images derived from society’s portrayals of mental institutions, but it can also offer a sense of relief and calm knowing that help and support is readily available. Eight of the participants described the reactions they had when they were hospitalized for their mental illness. Three themes described their experiences of being hospitalized: (1) feeling trapped and scared by hospitalization, (2) feeling renewed by hospitalization, and (3) trying to cope with hospitalization.

*Feeling trapped and scared by hospitalization.* The experience of being hospitalized for mental illness can be anxiety-provoking, particularly because hospitalization most often occurs at the same time the symptoms of mental illness are severe enough to warrant the admission. Feelings of security and control are already shattered by the mental illness, but these feelings can be further splintered when having to surrender the care of oneself to others in an unfamiliar setting. Five participants described their experiences of being hospitalized as feeling trapped and scared. Joaquin explained that he felt scared when he was hospitalized because he was “not in [his] right self” and envisioned being hunted by the authorities if he tried to escape. Safety was a concern for two of the participants, primarily due to sharing the same space with other individuals with severe mental illness who they feared might have been out of control or dangerous. Concerns with loss of freedom and choice also arose for three of the participants when they recalled their experiences of being hospitalized. Peter recalled
feeling as if he were a prisoner, caged and locked up. Although her admission was voluntary, *Gloria* remarked how she was made to feel “paranoid” and to doubt herself when the nurses insisted that she have herself admitted for the safety of her baby. Reflecting on her experience, she felt that her hospitalization was not truly voluntary because she had agreed to be hospitalized only out of fear that the professionals were correct in saying she would end up hurting her child:

I agreed, I mean, it was kind of like I had no choice…. I mean, when they say it’s voluntary…. The whole thing was that, “Oh, it’s not good for you to be with your baby.” And then, that little fear thing, that, “Oh, my God, what if these people are right, that I might do something to him?” That kind…. Then I started making myself more paranoid.

*Josephine* described crying throughout most of the beginning of her hospitalization because she felt she had no control over her situation. She recalled beginning to fear that she was being prepared to “live on the street” because she was unaccustomed not to being able to freely access her belongings and to deal with the bleak conditions of residing in an inpatient ward.

*Feeling renewed by hospitalization.* At times being hospitalized while in the grips of mental illness can serve as a place of respite and recovery. It can be a period of time away from the pressures of the outside world and an opportunity to adjust to medications, receive therapy and other supports, and regroup before reintegrating into daily living outside of the hospital. Most importantly, the experience of being hospitalized provided a new outlook for a few of the participants, recognizing that they were not alone and that the negative images of individuals with mental illness as being out of control or “crazy” were not true. As they were now individuals with mental illness themselves, this meant for them that they, too, were not “crazy” or out of control. Three
of the participants recalled that their experiences of being hospitalized had a positive aspect, helping them to feel renewed while they were receiving treatment in the inpatient ward of a mental health facility. Nancy saw her hospitalization as an opportunity to give medications a try since she was now in a secure place where she could be observed if she were to experience any ill effects from the medications. She recalled feeling much better when she was hospitalized, having felt like she was dying prior to being admitted into the mental health facility. Dolores’ initial hesitation about being hospitalized due to her fears of the other consumers in the inpatient unit soon disappeared when she realized that she was not alone in her suffering. Seeing others also trying to cope with their mental illness helped her to realize she was not alone. She proudly shared how she was able to transform herself from living in a state of devastation and self-destruction to becoming an individual with hope, determination, and fierce strength within a month of being hospitalized. Francine described her experiences being hospitalized as frightening at first since she did not know what to expect from the other consumers who were there, but hopeful at the same time, for it meant getting the help she desperately needed. She admitted that she enjoyed her hospital stay because she met friendly people and was reassured when she saw that she and other people with mental illness were not “crazy.”

Trying to cope with hospitalization. The experience of being hospitalized in a mental health facility can be daunting, not knowing what to expect or what will happen. When in the hospital, consumers lose their freedom of movement and their privacy; they are restricted from seeing family and friends except during specific visiting hours. There is also the question of how long the hospitalization will last. These stressors can make being hospitalized difficult to cope with while also trying to find relief from the
symptoms of a mental illness. The eight participants who discussed their experiences of being hospitalized shared their struggles of trying to cope with living in a mental health facility. Two participants who were voluntarily hospitalized shared that they elected to leave the inpatient ward shortly after being admitted, requesting to be discharged and then returning home to family members. Four other participants, all of whom were also voluntarily hospitalized, remained in the inpatient unit until they and their treatment providers felt they were ready to be discharged. Despite any fears they might have had initially, three of these four participants eventually adapted to the hospital environment and were able to focus on their recovery. Dolores, on the other hand, suggested that her recovery was encouraged after she could no longer tolerate being unproductive and constrained within the unit. Two other participants shared the experience of being hospitalized involuntarily: Carlos due to a court order and Josephine due to a family member’s insistence on hospitalization. Josephine recalled no longer wanting to live at the beginning of her hospitalization, but she said that she eventually learned to make the best of her situation. Both she and Carlos resorted to volunteering to clean, do laundry, and engage in other chores on the unit to keep busy and help make their surroundings feel more like home. These chores served as a way to cope with, and arguably, feel a sense of control over their situation.

**Experience of being discharged from hospital.** Being hospitalized for a mental illness usually involves receiving individual and group psychotherapy, taking medication, participating in recreational therapy activities, and receiving other forms of support in order to recuperate and prepare for reintegration into daily life outside of the mental health facility. Hospitalization can also be a period of learning about oneself, meeting
other individuals experiencing mental illness, and otherwise experiencing a sense of safety and stability that had been previously eradicated by the symptoms of a severe psychiatric disorder. Being discharged from this secure environment can also elicit feelings of apprehension and loss. Although only three participants discussed what they experienced when they were discharged from the hospital, their feelings seemed noteworthy as a reminder that the experience of being hospitalized is not solely about receiving treatment for mental illness, but also about residing in a safe and secure living environment where consumers are shielded from the stresses of daily life. The one sentiment, or theme, that the three participants shared seemed to revolve around missing this sense of security after being discharged.

*Missing sense of security after discharge.* The three participants who spoke about what it was like for them when they were discharged from the hospital seemed to value and appreciate the sense of security they felt during their inpatient treatment. Being discharged seemed somewhat daunting as they resumed their lives outside of the hospital. This meant, in some respect, that they were on their own again to cope with the life stressors or symptoms that brought them to the hospital, without the security, safety, and support they once received within the confines of the inpatient ward. *Nancy* recalled experiencing some apprehension when she was discharged from the hospital, adding that she missed the inpatient unit for a while shortly after leaving the hospital. *Dolores*, who was hospitalized after a failed suicide attempt following the death of several loved ones, expressed feeling lost after she was discharged from the hospital. The hospitalization experience seemed to leave her with one thing she did know:

So after I get out of [the inpatient unit], I’m still kind of numb. I don’t know what I’m doing, don’t know where I’m going, but I know I have to live.
Family’s reactions to hospitalization. As previously discussed, a few of the participants shared how they had fears and worries about being hospitalized for their mental illness. These fears stemmed largely from not knowing what to expect from the experience, as well as preconceived notions of what it might be like within an inpatient ward of a mental health facility. A couple of the participants admitted that they feared being housed with other individuals with severe psychiatric disorders, envisioning a locked environment with individuals who were out of control or “crazy.” This created some degree of apprehension initially for these participants. Similarly, not knowing what to expect can also stir fears and worries among the family members of individuals who are hospitalized for mental illness. When discussing their experience of being hospitalized, two of the participants provided additional insight into what that experience was like for their family members at the time they were hospitalized. One particular theme emerged, which highlights the apprehension family members may have about their loved one being admitted into an inpatient ward.

Family was apprehensive about hospitalization. The two participants who discussed their family’s reactions to their being hospitalized shared that they received much support from their family members when they developed their mental illness. They each had reached a point in the onset of their illness when hospitalization seemed necessary for their safety and stabilization as their symptoms continued to worsen. Despite the fact that they would receive treatment and care in a secure environment, the participants’ family members nevertheless had their own worries and concerns about whether hospitalization was a necessary course of treatment. Joaquin shared that although his family was sympathetic to what he was going through with his symptoms,
his wife and some of his siblings questioned whether hospitalization might have been too extreme or drastic an intervention. Because it was one of his brothers who helped him to seek treatment and get admitted into an inpatient unit, his other siblings also felt upset and hurt that it was one of their own siblings who helped place him in a mental health facility. In Gloria’s case both she and her husband wanted to avoid her being hospitalized. She explained that when her symptoms were worsening, the possibility of hospitalization arose. Having already been admitted into an inpatient unit once in the past, she knew that she did not want to have that experience again. With the stigma of mental illness also playing a factor, she and her husband felt she did not belong in the hospital:

> My husband decided to quit his job and stay home with me. So he just quit…. And so he stayed home with me and took part-time jobs just so I wouldn’t be admitted into the inpatient unit. I didn’t want to be admitted, and my husband didn’t want me to either…. And it was that whole stigma thing. I wasn’t like those people that were hanging out at the [mental health facility]. I was better than that. And my husband saw that, and he was like, “Oh, I don’t want you to end up like that. No matter how bad you are, we’ll figure something out.”

**Domain 5: Receiving mental health services.** As outlined in the previous domains, mental health services for chronic mental illness typically involve diagnosis, medication, and hospitalization. Yet, there are many other aspects of mental health treatment that have a significant impact on consumers’ symptoms, recovery process, and the trajectory of their illness, as well as on their general well-being and quality of life. All of the participants discussed their varied experiences associated with receiving mental health services other than being diagnosed, taking medication, and being hospitalized. Three super-ordinate themes emerged describing these experiences: (1) experience of
accessing mental health services, (2) experience of receiving adjunct mental health services, and (3) experience of mental health providers.

**Experience of accessing mental health services.** There comes a time, following the sudden onset of symptoms, when it becomes apparent that help must be sought in order to identify the causes of the symptoms and the means through which the symptoms can be alleviated. Accessing mental health services is often a challenging experience. In some cases, individuals experiencing symptoms of mental illness may be desperate to receive mental health services, but they may run into obstacles when trying to access those services due to unfamiliarity with the mental health system or limited availability of mental health professionals. On the other hand, individuals with mental illness may be reluctant to access mental health services, even when readily available to them, due to fears stemming from preconceived notions and stigma regarding mental health services or feeling doubtful that such services will be helpful. Two themes emerged from five of the participants’ descriptions of their experience of accessing mental health services: (1) barriers to accessing services, and (2) feeling apprehensive about accessing services.

**Barriers to accessing services.** When an individual is starting to experience mood swings, anger outbursts, hearing voices, or other symptoms of mental illness for the first time, this can be frightening and confusing. With the worsening of such symptoms, the individual or their family members usually reach a point where they believe it is necessary to seek help to find out what is happening and how those symptoms can be eradicated. Finding that help can sometimes be challenging; the individual or family may not know where to go or whom to see as they enter the unfamiliar territory of the mental health system. There may already be a level of desperation for help, which is then
compounded by the difficulties associated with seeking treatment. Three participants shared their experiences of obstacles they encountered when they attempted to seek help for their symptoms. Joaquin, for example, recalled how he sought medical care when he began to experience symptoms of what he later learned was bipolar disorder. Although the physician recommended that Joaquin seek psychiatric care because there were no physical reasons for his symptoms, the physician failed to assist him in finding a psychiatrist; he did not tell him where he could go to seek mental health services. He was fortunate that he found assistance through a family member’s connection to someone who was employed in the medical field and offered to help him seek the treatment he needed. Gloria encountered challenges associated with seeking help in a small island community where resources are scarce:

It was hard finding a psychiatrist. I had health insurance. But finding a psychiatrist who could see me was just, it was a nightmare in and of itself. I was desperate to find help because my husband was threatening to leave me. And so what I did was, I went through my health insurance book and looked at it, and called everybody, and nobody was available. I mean, they were just full. And I’ll never forget it. Dr. [X]. I begged. I didn’t even know this man. He was just a name on a list, but at least he answered the phone. There wasn’t a message saying they were full or what. He answered the phone and I begged him and begged him. And finally he saw me.

Feeling apprehensive about accessing services. Seeking mental health treatment can sometimes be daunting for the individual experiencing frightening and confusing symptoms. Given the stigma and any preconceived images associated with psychiatric or psychological treatment, it is not surprising that there exists some apprehension about seeking mental health services. The individual may already feel hopeless about trying mental health treatment after having failed to cope on his or her own or to seek other sources of assistance. Two participants discussed the feelings of apprehension they
experienced when they sought mental health services for the first time. James shared that his aunt had already taken him to see a suruhanu, but the treatment offered by the indigenous healer did not relieve his symptoms of hearing voices, having paranoid thoughts, and feeling depressed. When his aunt told him she would then take him to the public mental health facility, his immediate thought was that any treatment available at the facility would not work. Carlos’ fears of being locked up at a mental health facility made him reluctant to follow through with treatment recommendations the first time he initiated seeking help. After an initial evaluation, he chose not to return to avoid any possibility that he could be confined. He later returned for treatment as a result of a court order, which forced him into mental health treatment for his symptoms.

Experience of receiving adjunct mental health services. All of the participants reported that treatment for their mental illness had involved receiving adjunct mental health services in addition to medication and hospitalization, including individual counseling, group counseling, day treatment programs, residential group home programs, or a combination of these services, either in the past or at present. Receiving such services can help to provide symptom relief but can also be beneficial in other ways, in that they can offer a sense of connection with others who are living with mental illness, opportunities to learn life skills, and a space to address personal and interpersonal problems that may also be interfering with daily living. At the same time, there may also be some difficulties associated with receiving adjunct mental health services that may consequently produce feelings of frustration and create an impediment toward improved mental health and quality of life. Nine participants shared their experiences of adjunct mental health services, and their responses yielded three themes that describe the range of
their perceptions: (1) adjunct services as a place of refuge, (2) feeling apprehensive about receiving adjunct services, and (3) feeling frustrated with being in adjunct services long-term.

**Adjunct services as a place of refuge.** Although medication may be effective in treating the symptoms of mental illness, this intervention is a relatively solitary experience because the individual with mental illness is essentially left on his or her own to maintain daily adherence to the medication regimen and endure any side effects. Symptom management does not necessarily reduce or relieve other forms of suffering that are sometimes associated with mental illness. The broader effects of mental illness can include feelings of difference and isolation from others, conflicts with family members and friends, and a general sense of instability and self-doubt. Adjunct mental health services can sometimes help to mitigate such despair by offering a source of companionship, a sense of safety and security, and a validation of one’s struggles and triumphs. Seven participants discussed how mental health services provide them with a place of refuge as they try to live with mental illness. *Jane* explained that she has lived in a residential group home for the past several years because it became difficult to return home due to ongoing conflicts with family members. She added that during times of crisis she often turns to her counselor, someone who has known and worked with her for a long time, to prevent her from making decisions that could harm her or destroy her life. *Dolores*, who also resides in a residential group home, recounted a conversation she had with a friend who suggested that she did not belong in such a home because he thought she was functioning well. She emphatically insisted to her friend that she was not high functioning, adding that she does not want to leave the home because she has grown close
to the other consumers who reside with her. Two participants likened the adjunct mental health services they have received to family or a second home due to the guidance and support they receive as they navigate their life with mental illness. Three participants described how group counseling offers a sense of connection with others who are also living with mental illness; meeting fellow consumers has helped them to feel less alone or different and allowed them to learn from others how to cope with symptoms or other stressors. *Josephine*, who often visits the cemetery to visit loved ones who have passed on whenever she is feeling depressed, shared how participating in group counseling has eased her symptoms and loneliness:

Since I joined the group, I no longer cry. No longer cry.... What really changed me is when I started joining the group. And hearing everybody’s problem, I’m not alone.... I used to think I’m the only one with a problem. But I’m not.... It feels good. It makes me feel like they’re my family now. [It’s] a supportive place for me, and it’s nice to have a supportive family.... [I tell myself] it’s going to be okay. It’s going to be okay. And if it’s not okay, with counseling, after I leave here, I’m good. Just like going to the cemetery.... Sit and talk to my loved ones and then I’m okay. But this one’s different because I have real people that answer and give me their opinion or their input.... And I’m not alone with the problem.... It’s a huge help because before, I used to think I’m the only one with a problem. But now, hearing different people with their problems, I’m not alone.

*Feeling apprehensive about receiving adjunct services.* Group counseling and day treatment programs are commonly used not only to provide mental health treatment to larger numbers of consumers more efficiently but also to allow for peer support and socialization, particularly for those consumers who may not have opportunities to feel understood and accepted as individuals with mental illness. Although the group format may be beneficial and even appreciated by some consumers, there may be other individuals with mental illness who are reluctant to participate in such treatment. Two participants discussed their apprehension about receiving treatment in a group setting.
Joaquin, who identified as Chamorro, recalled his initial discomfort when being asked to discuss his family in group counseling, adding that he felt upset about having to listen to the other group members comment on his family. The group format may be particularly disconcerting for some individuals in Guam because Chamorro cultural values emphasize respect for the family. This includes not disclosing private matters, especially about the family, due to the risk of bringing shame to the family within the community.

Considering Guam’s fairly small population, the risk can be significant as word about private matters can easily spread affect family members at their workplaces or schools or within their social groups. Due to his Chamorro cultural values, it took some time for Joaquin to feel at ease with having to disclose private matters in a public setting. At the same time he also found it uncomfortable that the group he was told to join included individuals with a variety of psychiatric disorders, such that he found himself together with individuals who displayed extreme behaviors that made it difficult for him to benefit from the experience. Jane expressed her apprehension of the group format used in day treatment programs. She explained that when another group member behaves inappropriately and is corrected in front of the group, she feels that she, too, is being perceived negatively:

So that means to me that if there’s one bad apple in the basket, the rest of the apples are bad. Makes me want to cry….

Feeling frustrated with being in adjunct services long-term. Living with chronic mental illness means not only a lifetime of symptom management but also many years of receiving a variety of mental health services as symptoms wax and wane and other related issues arise. Although long-term medication use is often associated with chronic mental illness, participation in individual counseling, group counseling, or day treatment
programs may also be needed for significant periods of time due to the severity of many chronic mental illnesses. Long-term adjunct mental health services can be beneficial in terms of offering support, guidance, and learning as the individual with mental illness encounters new difficulties and must cope with the demands of their illness while progressing through life’s stages. Spending many years participating in such services can also be frustrating or even frightening. Consumers may develop a sense of stagnation or boredom as they feel unable to move forward with other aspects of their lives. Two participants discussed their experiences of being involved with adjunct mental health services on a long-term basis. *Dolores* explained that she pushed herself to find employment and be more productive after seeing other consumers who have been involved in mental health services for many years. She imagined herself aging in the mental health system and feared that the remainder of her life would consist merely of sitting in treatment programs and nothing more. *Jane* expressed a feeling of boredom from the repetitiveness of attending a day treatment program for many years, as well as the freedom she feels when she does not have to attend the program:

Coming here everyday, doing it, repeating yourself, doing the same thing over and over and over…. It’s just something unbelievable already. I’ve been here too long. I know everybody…. I feel extravaganza [when I’m out in public]! Like so way up there that I can do whatever I want to do. I’m free. Instead of coming here.

*Experience of mental health service providers.* When living with a chronic mental illness, it seems inevitable that relationships will be forged with the various mental health service providers encountered throughout the treatment process. These providers can include psychiatrists, psychologists, nurses, therapists, social workers, and other support staff who facilitate day treatment programs or supervise residential group
homes. In some cases, service providers become almost as familiar and valuable as family members. In other cases they may actually be the closest semblance to family an individual with mental illness has, particularly those who, for whatever reason, do not have the support or presence of their real family. At the same time mixed feelings about mental health service providers may arise because they are the people primarily responsible for helping to alleviate debilitating symptoms and assist the individual in addressing the challenges associated with their diagnoses. Seven participants described their experiences of service providers through their journey of living with chronic mental illness. Four themes emerged illustrating their experiences: (1) feeling supported by service providers, (2) feeling like a burden to service providers, (3) missing service providers who leave, and (4) difficulty trusting service providers.

*Feeling supported by service providers.* Mental health service providers can play an important role in the lives of individuals living with chronic mental illness since they can be significant sources of support, comfort, guidance, and advocacy throughout the individual’s recovery process. Because they are educated and trained in the mental health field, service providers are expected to have an understanding of what individuals with mental illness experience. Individuals with mental illness learn to trust their service providers and often turn to their providers for reassurance when not feeling well or in the midst of a crisis. When sharing their experiences of their service providers, four participants described feeling supported at various times in their treatment. Joaquin explained how he had to put his trust and faith in his treatment providers as he tried to understand what was happening to him and follow through with treatment recommendations in the face of apprehension. He later learned to appreciate his
providers’ knowledge and expertise, realizing that their recommendations were for his own benefit. Jane shared how she often turns to her counselor for advice and guidance, particularly during her low moments. Carlos referred to his service providers as his brothers and sisters, illustrating how he feels supported by them particularly when he is unable to elicit the same support from his own siblings at home. James expressed his appreciation for one of his counselors for never giving up on him and being a constant source of support as he desperately tried to survive the side effects of his medications.

*Feeling like a burden to service providers.* When individuals are living with a chronic mental illness, it seems inevitable that they will make multiple trips to meet with their mental health service providers for different needs. Periodic appointments with psychiatrists are necessary to re-evaluate how the medications are working and address any issues with side effects. Therapists may be sought as new life situations arise that cause considerable distress. The assistance of social workers may be required when in need of advocacy or guidance to obtain social services. Regardless of the reason service providers fill an integral part of the individual’s life. It seems there may be times when the individual feels reluctant to call upon the assistance of their service providers for fear of burdening them further with their needs or problems. Four participants spoke of feeling like a burden to their service providers, particularly with regard to not wanting to take up their time or bother them. Jane and Carlos both explained how they go along with their psychiatrists’ recommendations regarding their medications due to not wanting to cause problems or make their doctors feel ineffective. Dolores shared how she prefers not to bother her service providers unless she absolutely needs their help; instead she tries to help herself as much as she can without having to ask for assistance. Seeing the
number of patients waiting to see the psychiatrist prevents Nancy from asking him questions about her diagnosis:

Most of the time when I see [the psychiatrist], he asks me how is everything, and I say, “Everything’s fine.” He feels that I am doing fine, too, but I never really [ask him in any questions]...I see a lot of people outside and I don’t take up too much of his time because there’s a lot of people waiting outside.

**Missing service providers who leave.** There are times when mental health providers leave Guam and relocate to the U.S. mainland, particularly as many of the providers in Guam originally come from the U.S. mainland or other countries. After learning to trust their service providers and developing a bond with them, individuals living with chronic mental illness in Guam may sometimes have to experience the loss of these providers, having to adjust to the new providers who replace the ones who have left. It may be expected that the individual will eventually become accustomed to the comings and goings of treatment providers and readily adapt to new faces. Two participants, however, discussed how unsettling it has been for them at times when they have had to deal with the loss of trusted treatment providers. *Jane* shared how she chooses not to say anything to new treatment providers upon meeting them because she has not yet developed a level of trust with them. She explained how numerous contacts are needed with a treatment provider before she can trust that provider, leaving her silent as the new provider learns how to work with her. *Gloria*, who faced difficulties when trying to find a psychiatrist, recalled how she became frightened when that psychiatrist had to leave Guam because she saw him as a means to prevent further conflicts with her husband:

It was really hard because I spent a lot of time in that period pretending everything was okay, and I was seeing this doctor, and I’m getting better, and I’m getting better, when I actually wasn’t. But I had to do that front because I didn’t
want to cause anymore problems for my husband. And I had to put on this front...look really good, and at that, when [the psychiatrist] left, I guess that kind of sent me into a tailspin because then I started to get afraid that I'm not going to be able to keep up this front much longer. And I went off the deep end then.

*Difficulty trusting service providers.* Since mental health providers can be instrumental figures throughout the process of living with chronic mental illness, it is essential that they convey an image of compassion, care, concern, and trustworthiness. Despite such an image it can be challenging for an individual with chronic mental illness to accept the most well-intentioned provider for a variety of reasons. Feelings of mistrust can arise from past instances of having been disappointed, hurt, or betrayed by others. In other cases individuals with chronic mental illness might have had negative experiences with previous providers or might have misunderstood why providers had to restrict their freedom or take away privileges for the sake of safety. Four participants discussed some moments when they questioned the intentions of the service providers they encountered, highlighting the issue of trust that seems to underlie their experiences. Two participants shared that they have sometimes questioned the motivation of their service providers, commenting that they wondered if the providers were there to help them only for the sake of an income. *Jane* stated that she will not talk to providers if she feels they are there only for the money. *Dolores* also mentioned that she has felt that some of the treatment providers she has encountered seemed to not really care about her, giving her the impression that they were merely babysitting or earning a paycheck. Although *Carlos* has felt appreciative of the assistance he has received from his treatment providers, he still finds himself hesitant to open up to his providers for fear they will not believe him. *Gloria*, who has encountered a number of treatment providers over the last 20 years, described a shift in how she perceives treatment providers. She shared her perceptions
that the treatment providers seemed more caring and made themselves more available in
the past; she feels providers now seem too focused on the clinical issues of the individual
diagnosed with mental illness and tend to ignore the rest of the person outside of the
illness.

**Domain 6: Day-to-day living with chronic mental illness.** Moving beyond
their experiences associated with the onset of their illness, being diagnosed, being on
medication, being hospitalized, and receiving mental health services, all 10 participants
discussed how chronic mental illness affects their daily life. It seems that chronic mental
illness pervades deeper aspects of the individual beyond the immediate effects of the
associated symptoms, shaping their experience of their illness, themselves, others, and
their lives. Four super-ordinate themes emerged, describing the participants’ experiences
of day-to-day living with chronic mental illness: (1) experience of mental illness, (2)
relationship with the self, (3) relationship with others, and (4) desire to find meaning.

**Experience of mental illness.** Being on medication and receiving other forms of
mental health services to alleviate symptoms does not necessarily furnish a life without
further challenges associated with having a chronic mental illness. All of the participants
shared where they were with their mental illness in the present day, having gone through
a series of struggles and triumphs throughout the recovery process since the onset of their
illness. A number of the participants seemed to wrestle with ongoing questions of why
they had developed a mental illness. Having witnessed the sudden and unexpected
emergence of symptoms, coupled with unresolved questions as to the cause of the
symptoms, several of the participants also shared their fears related to the unpredictable
nature of their illness. Living with chronic mental illness seems to translate into simply
trying to get through each day in the face of symptoms, medication side effects, and rejection from others. For many, it takes a great deal of effort just to continue with the business of getting up each morning and participating in the outside world. Three themes emerged from the participants’ discussions of their day-to-day experience of mental illness: (1) trying to make sense of mental illness, (2) struggling with instability of mental illness, and (3) coping with mental illness.

*Trying to make sense of mental illness.* When discussing the onset of their illness, as outlined in domain one, participants shared how they attempted to make sense of and attribute causes to the sudden emergence of symptoms, not knowing at that point that the symptoms were the beginnings of a mental illness. Participants attributed symptoms to the loss of loved ones, life stressors, ancestral spirits, and past substance use. When discussing the experience of being diagnosed, as outlined in domain two, some of the participants reported that they were able to learn about their illness through explanations offered by psychiatrists as well as informational brochures and pamphlets. Although participants may have learned medical perspectives on their mental illness and may have lived a number of years with their symptoms, many continue to struggle with trying to make sense of their illness long after its initial onset, vacillating among different explanations and possible causes as a means to understand what must have happened that resulted in their developing a lifelong condition.

At different points in their interviews, seven participants pondered various factors or life events that might have led to their illness. *Jane*, who mentioned that she was able to accept her diagnosis after reading about it in a pamphlet, nevertheless seemed to ponder alternative explanations for her illness. She initially shared her awareness of the
role of genetics in mental illness but later suspected past substance use, ancestral spirits, and grief over lost loved ones as causes. At one point, she contemplated the possibility that God, not genetics, pre-determines whether an individual will have a mental illness:

> When a female’s bearing a child, Jesus is writing notes already…about the way the child’s going to be. So it probably might not be genetics.

Joaquin and Josephine both mentioned that they still question how they developed a mental illness, with Josephine adding that mental illness does not run in her family the way serious physical conditions do. Although Peter no longer attributes ancestral spirits to the voices he hears, he has otherwise wondered if his self-proclaimed laziness in high school might have caused his schizophrenia. Meanwhile, Carlos explained that there was a distinction between his schizophrenia, which he attributed to depression and anger, and the voices he hears, which he believes are spirits who guide him. Nancy, who has become more open to accepting her mental illness primarily because she has seen herself calmer with medication, does not seem to question the cause of her illness. She continues to wrestle with believing that she actually has a mental illness and wonders why she had not recognized it before.

*Struggling with instability of mental illness.* Another theme discussed under domain one, onset of illness, focused on how several of the participants experienced feeling out of control when their symptoms began to emerge. Although that theme focused on the unpredictability of symptoms at the onset of the illness, it seems that the instability of the illness is an ongoing challenge for a number of the participants, particularly the fears associated with the possibility of experiencing a relapse in symptoms.
Eight of the participants discussed their fears of relapse and how the unpredictable nature of their chronic mental illness impacts their ability to live independently, maintain employment, or pursue life goals. Three of these participants explained how the instability of their mental illness has affected their ability to find or maintain employment. Carlos, for example, resigned from numerous jobs due to becoming angry and not wanting to risk getting fired if his anger ever resulted in serious altercations with co-workers. Just prior to his interview, James quit his job as he was becoming increasingly tense and angry when at work. He also shared that he has been making plans to leave Guam and his family to avoid potential triggers that could make his fears of relapse and ending up in jail come to fruition. Two participants talked about how they are reminded of the possibility of relapse whenever they take the medications prescribed for their illness. Peter succinctly explained this daily reminder of potential relapse:

Pops up once in awhile. But, it’s there, because I have to take my medication every day. So, it’s telling me if I don’t take this, I won’t function well.

Gloria described how, during the brief moment when she is taking her medications, she wonders if it will be the day she ends up relapsing. She also shared how although she likes it when other people seem to forget that she has a mental illness and see her as an accomplished person, she nevertheless always worries that something will happen to mar that image:

So those kinds of things make you feel good, and makes you feel like, “Oh, I’ve really accomplished something, now people are not looking at me that way. But there’s always that fear inside that, “Oh, my God, what if something happens and all of a sudden all these symptoms come about, and you’re no longer able to control it.

Three other participants explained how their fear of relapse has made it difficult to pursue other goals or desires they have in life. For example, Jane has decided to put off her goal
of attaining her GED, and Josephine fears living on her own due to not knowing if or when her symptoms might worsen.

*Coping with mental illness.* The experience of mental illness on a day-to-day basis seems to include doing whatever is necessary to cope with the presence of the illness as daily life continues even if symptoms are not at the forefront of experience at a particular point in time. Although participants attempted a variety of coping mechanisms at the onset of the illness—such as using drugs, attempting suicide, hiding symptoms from others, sleeping, showering, seeing a suruhanu, or taking a vacation—these efforts were primarily of an immediate nature to halt or alleviate the further emergence of symptoms. Coping with mental illness on a daily basis becomes a matter of moving past symptom management and pushing oneself to continue with living one’s life in spite of the illness.

Nine participants shared some of the techniques or methods they use to cope with their mental illness day-to-day, each noting several coping mechanisms they employ, illustrating their desire to maintain healthy living to optimize the quality of their lives in the face of their illness. Four participants discussed practical approaches to coping with their mental illness, including eating healthily, exercising, keeping up with medication, learning triggers, and developing a plan in case relapse occurs. Reading the Bible, praying, and engaging in spirituality arose as a means of coping for three participants. Nancy described how her spirituality has helped her to realize that her illness will not prevent her from living her life:

> I think what helps me is that I have Jesus Christ in my life.... In fact, when you’re spiritually filled, your way of looking at things is different. It’s calmer. It’s really beautiful. I don’t know how to explain it. So that helps a lot. Then, of course, I’m taking my medication on top of that and still feel that I’m taking care
of myself. But, if it doesn’t stop me from getting to know who Jesus Christ is, getting to know who all these people are, then what makes me think that the bipolar’s going to stop me from anything else.

Reassuring themselves that they will be fine or that they are strong seemed helpful for four of the participants. *Francine* often thinks about how people care for her and the value of her life when she hears voices or suicidal thoughts enter her mind:

> It’s really hard. Especially just thinking about how much people care for you in life, and what they would do for you in return. It’s a good deed. I mean, why take your life or listen to those voices and just go crazy, or get in trouble [with] the law, or do something crazy to yourself. You just waste your time. You mean to tell me you’re going to ruin your life because this is what the voices are saying…. Which is the one you’d rather choose? The good point, or the bad point. I would choose the good point. To listen to myself and to know what’s good and right for myself.

Three participants shared the belief that keeping busy and having a reason to get up in the morning are essential to coping with chronic mental illness. They have noticed that preoccupying their minds with employment or other activities prevents them from dwelling on their illness and worrying about relapse. *Dolores* pointedly warned of the danger of dwelling on the illness:

> I don’t dwell on my mental illness. I dwell on the good that I have for the day. Because if you sit there and you really think about it, you’re going to go crazy.

**Relationship with the self.** As discussed previously, some of the experiences participants have had with their mental illness have affected how they perceive or understand the self. At the onset of their illness, they encountered feelings of insecurity when their symptoms began to take hold of their lives and their being; upon being diagnosed with a chronic mental illness, they faced further assaults on their understanding of themselves, grappling with feeling embarrassed, defeated, or punished.

The experience of being on medication further brought about a redefinition of the self.
The process of trying to understand and define the self has continued for all of the participants even long after these earlier stages of living with a chronic mental illness. Five themes emerged that illustrate how living with a chronic mental illness impacts the participants’ relationship with the self: (1) struggling with sense of self, (2) wanting to feel or appear normal, (3) wanting to feel in control of self, (4) wanting to feel independent, and (5) experiencing a transformed self.

*Struggling with sense of self.* Despite the number of years that have passed since they learned that they had a chronic mental illness, four participants shared that they continue to struggle with questions about who they are and who they have become as a consequence of their illness. According to these participants their sense of self continues to be wrought with feelings of self-doubt, an awareness of lost aspects of an old self, confusion over whether a pre-diagnosis self was their true self, and attempts to make sense of a self outside of their mental illness. *Nancy,* who vacillates between accepting she has a mental illness and questioning its veracity, noted that she sometimes wonders if she had bipolar disorder all of her life but just never knew about it. This thought makes her question whether the person she was prior to being diagnosed and taking medication was her true self or if her mental illness had defined her self throughout her life, including the years before diagnosis. Similarly, *Gloria* shared how she continually questions who she was prior to her illness, who she has become, and who she has to be for the sake of fitting in with the rest of society:

There was a sense of sadness, like [there] was a prior life. All this color and fun things, right? And now you’re this sedate, black and blue. So, you kind of like, every now and then, you feel like you lose yourself and what your life was like before. And then you’re like, “Oh, okay, was that part of the illness, or was that who you really are?” And who you are now is made up of these chemicals that you poured into your body….. And even with work….sometimes you have these
feelings like, “Oh, am I making the right decisions here? Am I really the right person to be making these kinds of decisions?

Peter, who during his interview talked of being a straight-A student as youngster, grapples with the awareness that his illness has impacted his most prized aspect of himself:

[Mental illness] has limits. Because your mind, well, for me…some people are good with their hands. I’m good with my brain, which is the wrong thing for me because I have schizophrenia. So some people are good with their hands, working. I’m good with my brain. But because of the schizophrenia, it’s harder…. It’s hard.

Carlos described no longer being his self due to his mental illness, blaming his voices for who he has become:

Sometimes, I just want to be alone…because I’m not myself…I’m different…I’m weird. But I told the spirit voices, “I think you guys are the ones mental, not me. You guys brought me here because you make me mad.”

Wanting to feel or appear normal. Being diagnosed with a chronic mental illness creates an ever-present awareness that one is different or “not normal” compared to the rest of society. This feeling is particularly distressing due to negative stereotypes of people with mental illness as being violent, uncontrollable, or “crazy.” The experience of living with a chronic mental illness often includes promoting an image of oneself as normal in order to defy preconceived notions of the mentally ill individual. Seven participants discussed their desires and efforts to feel or appear normal. Some of these participants try to appear normal to others while others seek to reassure themselves that they are capable, intelligent individuals with the potential for normal and even successful lives.

Three participants explained that they often choose not to tell others about their mental illness to avoid being judged or stereotyped based on society’s stigmatizing views
of mental illness, with Dolores hoping to be seen as “normal and calm,” and Nancy wanting to “just let them know me as me . . . what they see is what they see.” Jane discussed how she does not like being referred to as being “sick,” adding that she does not see herself as different from anyone else who has problems. Preferring instead to be seen as “smart, friendly, and kind-hearted,” she spoke of wanting to prove to others that having a mental illness does not equate to being crazy or a menace to society. Three other participants shared how they remain cognizant of their behavior when out in public, trying to appear like everyone around them and not draw attention to themselves.

Francine described walking around the mall and smiling politely to appear friendly when someone looks at her. Gloria explained that even her choice of clothing is influenced by her fears of appearing odd or mentally ill, opting for calmer, coordinated hues and rejecting more colorful and creative options. A greater awareness of and worry about what other people will say pervades her thoughts even though she tries to fight against it:

Yeah, what would this look like to other people? I’m more conscious of that, about other people’s feelings, than I was before. It’s like, “Oh, I have to present myself in this manner. Is this appropriate?” Hello! I’ve read enough of those mental health…intakes. Oh, I know what they’re writing now, and I know, so all of those things matter, and that’s how people judge you. Before, those things didn’t matter to me…. It’s probably that internal stigma that I work so hard to stay away from, but it’s still there. And I think for the most part, it’ll be there. It’s just part of the illness that kind of goes with you, even though you’re trying so hard not to let it interfere with your daily life.

In Peter’s case, feelings of shame propel him to appear normal and sociable when interacting with other people:

I kind of get shy. I’m ashamed. It’s kind of, I’m a little bit ashamed of it, learning to live with it…. I try to play it off, my personality, just talk to them and show them that I’m still sociable…. I don’t want them to get scared.
Identifying with other individuals with mental illness who have been successful seems reassuring to Peter and Joaquin as they strive to feel capable and accomplished. Peter spoke of a poster he saw depicting people with mental illness who have become successful professionals, inspiring him to entertain the possibility that his own mental illness does not limit his potential. He also seemed to take pride in being regarded as the “most high functioning” consumer in his treatment program. Joaquin has learned to identify with famous people who have the same diagnosis, as well as with relatives who have been diagnosed with mental illness. He also frequently recalls how treatment providers have told him that individuals with his diagnosis are often regarded as intelligent, helping him to shed his self-doubt.

*Wanting to feel in control of self.* As mental illness influences thoughts, emotions, and behavior, it can leave the feeling of being out of control of the sense of self. This is often one of the most debilitating aspects of the mental illness experience. Six of the participants indicated that they struggle with trying to maintain control over their lives and themselves. Reminiscent of the experience of feeling lost and out of control at the onset of the illness, there seems to be an ongoing battle to maintain control of the self throughout the day-to-day experience of chronic mental illness.

Two participants commented that they felt consoled or comforted by the thought that their mental illness is not as severe as the mental illnesses of others. Nancy expressed that she is grateful that her illness is controllable, feeling that “it would be scary” if that were not the case. Peter feels a sense of control by reassuring himself that his schizophrenia is not as severe as he has seen in other cases, noting that he has been able to maintain steady employment unlike other consumers he knows. Recognizing that
control comes from within the self is how two other participants address their desire for control in their lives and over themselves. *Jane* shared how she has learned to accept responsibility for herself:

> It’s all with me, within me, I have to start with me. I, instead of we or us. I have to trust myself. I have to focus. And I have to accept the mental illness.

*Dolores* appears to attain her sense of control through self-reliance and inner strength:

> You just have to be strong. Be strong and not worry about what other people think of you. It’s what you think of yourself and where you’re going and where you’re headed.

*Gloria* achieves a sense of control through a more practical, logical approach. She shared how she has surrendered her former spontaneous self, having seen the consequences of the impulsivity associated with her bipolar disorder, and adopted a more analytical self that obsessively plans ahead for any potential crisis. This approach has left her feeling like the mental illness continues to have control over her, as she struggles each day to ensure that her decisions will not have dire consequences. *Carlos* expressed that at times he has wanted to rid himself of the spirits who help guide him, feeling that they sometimes overpower him and dictate his choices, thereby robbing him of his freedom to exercise choice.

*Wanting to feel independent.* Living with a chronic mental illness can also have an impact on one’s independence. The ability to live independently may be limited or impossible if symptoms are severe or concerns about relapse overshadow daily life; many adult individuals with mental illness still live with their family or in a residential group home. Even if individuals with mental illness live independently, they continue to long to feel independent and capable because having a mental illness typically renders the individual dependent upon mental health services for many years. For the remainder of
their lives, individuals with mental illness may be tied to mental health services to one degree or another, even if only for ongoing medication treatment.

Six of the participants shared their desire for a sense of independence and discussed how they experience much esteem when they are able to carry out their lives on their own. *Jane* shared how she actually does not like it when others say to her “take care.” She explained that this sends her the message that she is incapable of looking after herself, and she often feels the desire to retort that she does take care of herself: she is taking her medications as instructed. *Dolores* often tries to prove to people that she is a very strong and capable person, pointing out how she has been able to gain employment and achieve other successes in her life primarily by relying on herself, without depending on family members or mental health treatment providers. After years of being betrayed, hurt, and taken advantage of by people she has trusted, *Nancy* stated that her independence is very important to her, explaining that she has worked hard and endured much in her life that taught her to be self-reliant. Although *Josephine* expressed feeling afraid to live on her own due to her mental illness, she nevertheless dreams of one day no longer having to reside with her siblings and abide by their rules. She imagines a role reversal wherein she has a home of her own and opens her doors to her other siblings who are struggling in their lives. *Francine* described how since finding the right medication, she has gained the ability to seek help on her own, rather than having to turn to her family when she is in crisis:

I’m able to do things on my own…. I can do it on my own, not like before where it’s my family. But now that things have changed a lot, really a lot, it makes a big impact, the change…I can do things on my own. I feel more independent.
Similarly, receiving treatment for his mental illness has afforded Peter the ability to be on his own; he is now living independently in his own apartment. Feeling independent has also given him the opportunity to enjoy the sense that he is like everyone else who reaches maturity:

I like it because I’m on my own. I’m independent now…. It’s good. It’s a good feeling…. I like the way the feeling is and to live like how everybody lives when they get older.

*Experiencing a transformed self.* Going through the journey of adapting to a new life with a chronic mental illness extends beyond learning how to manage one’s symptoms. Receiving a diagnosis of a chronic mental illness can sometimes upend an individual’s view of the self, having experienced the self as one way prior to the diagnosis, then leaving the individual to redefine the self in light of this new way of conceptualizing thoughts, feelings, behavior, and experiences. Interestingly, there seems to be a transformative aspect to this process of understanding the self. All of the participants discussed how living with a chronic mental illness has produced changes within themselves, with a new self having emerged from the experiences they have had since the onset of their illness.

Four participants spoke of having developed a healthier self. Jane mentioned that she has become more reflective and observant of herself so that she can understand herself more and make improvements, adding that she has developed a healthier lifestyle by eating healthy foods and refraining from drug use. Remaining drug-free is a change that James has also made, in addition to trying to live his life better and becoming a role model for individuals living with chronic mental illness. Nancy shared that she has become more responsible with her life, including taking better care of herself by eating
healthy foods and taking her medication consistently. Transforming from someone who felt a constant need to work and be productive, Joaquin stated that he has learned to feel less guilty about resting.

Five other participants discussed experiencing a transformed self that has included gaining self-confidence, assertiveness, maturity, and inner strength. Dolores and Carlos credit their mental illness with helping them to develop a confident and strong self. Dolores has learned that changing “negative to positive always works,” giving rise to a sense of confidence even in the face of feeling sad. Being able to teach others about mental illness has given Carlos a new inner strength:

I’m glad I have a mental illness…. I became stronger…. Because if I don’t have mental illness, and I’m by myself, I would not learn how to understand other people. I wouldn’t know how to understand more. I get to understand more about mental illness, and it helps me that I can teach other people. So I can also teach my friends how to be careful with mental illness. You don’t know if you have it, but if you have the symptoms, you should get checked.

Peter and Francine talked of becoming more sociable and outgoing, unlike the earlier stages of their illness when they tended to seclude themselves and simply stay at home. Francine described seeing herself as a very different person from how she was before:

[Before] I would just stay home…and seclude myself from anybody…. I didn’t want to be with people…. [I was afraid] not only of hurting them, but also making trouble or getting hurt, or criticism…. “Oh, there’s that crazy girl. Talking. Screaming. Yelling. Making trouble. I didn’t want [to deal with that]…. I can see myself better. I’m pretty much occupied. I keep myself busy. I do more things than what I used to do before. I’m more productive. More aware. I’m more open. I feel much love in my heart for my family and others. I also enjoy talking to my friends, hanging out.

Josephine also sees herself now as being more sociable, more assertive, and mature. She had previously secluded herself, not only because of her depressive symptoms but also out of shame for having a mental illness whereas now she has learned to not care about
what others think of her and to be more straightforward. *Josephine* also shared that she now views herself as having “grown up” and become “more mature” in her self-understanding. She has also become “more peppy,” reflecting the jovial aspect of her personality that disappeared when she was in the depths of her illness. Most importantly, she has come to value being alive and no longer feels lost.

Although 9 of the 10 participants seemed to enjoy the benefits of having a transformed self that is stronger, more self-confident, and otherwise positive, *Gloria* gave a bittersweet evaluation of where she is with her self. Despite having learned to be more comfortable with who she is and no longer hiding her mental illness, she still thinks about how she has had to surrender her creativity for the sake of “being safe” in order to blend in and feel accepted in society. Her summation suggests that there was a cost involved in the development of her transformed self, reflecting a sense of sadness that the benefits received from gaining a positive self came at the high price of losing a previously valued identity.

**Relationship with others.** Chronic mental illness not only affects how individuals conceptualize the self, but also has implications for how they experience themselves in relation to others. In the previous domains, participants discussed their experiences of how others reacted to them during the onset of their illness as well as when they were diagnosed, medicated, and hospitalized. The impact of chronic mental illness on the individual’s relationships with others does not end with these earlier stages of the illness. All of the participants provided some insight into the struggles and successes they have had with regard to their relationships with family and friends as they continue to live with chronic mental illness. Five themes emerged that describe the participants’ experiences
of their relationship with others: (1) feeling alone, (2) struggling with wanting to be alone versus desiring connection, (3) deciding whether to disclose mental illness to others, (4) responding to rejection, and (5) receiving support from others.

**Feeling alone.** When an individual is struck with a serious physical illness, it is not uncommon to see family and friends come together to support that person throughout the course of the illness. Mental illness has a stigma attached to it that often results in the afflicted individual being marginalized or ostracized by society in general or even by family members or close friends who may not fully understand the illness or may have been swayed by negative portrayals of mental illness. This usually leaves the individual with mental illness feeling isolated and alone.

Six participants shared how they have struggled with or continue to experience feeling alone, having lost friends or been abandoned or misunderstood by family members. *James* spoke of how he lost friends when he was symptomatic and that his ongoing feelings of isolation have led him to want to leave Guam to try to start anew:

> I’m not happy here. And even if I try to make friends, like the next day, it’s like they don’t want to be friends with me anymore…. [The people in my village] don’t want to hang out with me anymore. That’s the part of it that hurts me. Who’s not going to feel bad? Even though I went wrong, I know I do good things, too…. I can’t find friends. I’m lonely, and I’m hurting here…. How [mental illness] affected my life—one, how things were going in my life, two, I find nobody at my door. I find I have no friends.

Both he and *Jane* expressed a sense of deep loneliness when they shared their fantasies of being lovingly missed and begged to return if they moved away from Guam and left their families behind. *Carlos* hinted at his loneliness when he explained that he does not feel alone, knowing that the spirits he hears will always be with him, even when family and friends opt to live without him in their lives. *Gloria* lost some friends as she began to
recover from her symptoms because they were no longer able to benefit from her manic phases when she would lavish money on them. She remarked how this was the point when she realized her life would be different, and she has had to learn to develop new friendships with people who genuinely care for her. Rather than attempting to cultivate new relationships with people after being abandoned by her family when she became ill, Dolores has chosen to maintain a friendship with only one friend even though she admits she experiences loneliness. Joaquin has found himself feeling lonely and withdrawn due to the limited opportunities he has to meet new people, particularly because he is unable to drive because of his mental illness, making it difficult to get around to socialize.

Struggling with wanting to be alone vs. desiring connection. There are times when living with chronic mental illness creates a dilemma between actually wanting to be alone and wanting to feel connected to others. Perhaps the desire to be alone acts as a way to quell deep, painful experiences of abandonment, rejection, or loneliness. At the same time that sense of isolation continues to simmer, creating still the want and need to relate with others. Chronic mental illness can wreak havoc with the sense of confidence, trust, and strength that is needed to forge relationships with others in the face of the risks of hurt, betrayal, and rejection that exist. All of the participants described vacillating between wanting to avoid the hurt feelings associated with relationships by being alone and the consequent desire to connect with others, stemming from the loneliness created by choosing to isolate themselves.

For example, having experienced criticism for her illness from close family members, Jane has learned to keep people at arm’s length, having become wary of trusting anyone. She spoke of seeing her family as negative and herself as positive and
admitted to secretly questioning whether she had been adopted, suggesting a sense of disconnect and difference between herself and her family. At the same time she also expressed a longing for acceptance by this same family, imagining them offering supportive and comforting words of advice or pleading with her to return to them. Similarly, *Dolores* claimed that she prefers to be alone, having been abandoned by her family when she became ill. When discussing interactions with others, her struggle between wanting to be alone and wanting connection emerged. She spoke of using her mental illness to test whether people would reject her or accept her without hesitation, as well as vacillating between wanting to remain on her own for the freedom to be herself and wanting to feel loved and cared for within the context of a relationship with another. *James’* struggle with the desire for both isolation and connection appears when he tries to express his feelings to friends, only to then reject them if they do not respond as he had hoped. Despite isolating himself from family and friends due to rejection associated with his mental illness, he nevertheless is hoping to leave Guam in order to make new connections with others elsewhere.

*Deciding whether to disclose mental illness to others.* Part of living with chronic mental illness involves making the decision about whether to disclose the illness to others. This decision is influenced by the stigma typically associated with mental illness and the fear of being judged or rejected. Each time an individual with mental illness encounters this crossroad, the risks and benefits of disclosure must be weighed because the potential costs of relationships, dignity, and privacy are at risk. If the disclosure is received positively, it can mean a feeling of acceptance and relief. If the outcome of the disclosure turns sour isolation, shame, and regret may result. With Guam being a small
community, the decision to disclose can be particularly difficult; this decision can have far-reaching implications for the individuals with mental illness and their families. Eight of the participants shared their experiences of deciding whether to disclose their mental illness to others.

Having control over whether to disclose her mental illness to others is important to Jane because she has had to deal with family members disclosing her illness to other people without her permission. She, herself, chooses not to tell others about her illness, feeling no obligation to do so. Similarly, Dolores also chooses not to tell others about her mental illness “because one, they’re either going to pity you, or they’re not going to like you…and I don’t want either.” Joaquin and Nancy have different approaches when they run into people from their past who ask what they have been doing, a fairly common occurrence due to Guam’s small size. Joaquin readily tells others about his illness, preferring to be open while Nancy opts not to disclose her illness to people who have known her in the past, wanting to be seen as she had always been known before. Josephine is much like Joaquin in that she has chosen to hide her illness no longer, feeling lighter from being open with others. Two participants have created specific ways of disclosing their illness to others in order to protect their dignity. Peter shared how he prefers to use the actual name of his diagnosis when disclosing to others, rather than merely saying he has a mental illness:

I tell them I have [schizophrenia]. I don’t say mental illness because I always worry about that…. I say I have schizophrenia, which is a nicer term to say than mental illness…. Mental illness is like when you, like people that are, I don’t want to put people down, but when people look at us, we’re like vegetables in a hospital…. [Schizophrenia] is a more scientific term…. Professional.
Carlos, on the other hand, has come to learn that trying to tell others about the spirits he hears is usually met with disbelief, leaving him to fear being perceived as “weird.” He instead is more apt to tell people that he has a mental illness.

Gloria believes she has benefitted from disclosing her mental illness; she feels pretending was actually worse than the illness itself. She enjoys no longer having to hide or pretend, instead focusing on her recovery and making something of her life and herself. This has caused her to question whether the practice of confidentiality for mental health issues might actually contribute to the stigma:

I sometimes think this whole confidentiality issue, I don’t know if it just perpetuates the stigma…. Because people are at church, they’re talking about their diabetes and stuff, and they’re talking about their cancer…high blood pressure, everything. But it’s like hush, hush, nobody wants to talk about their mental illness. Nobody wants to talk about the substance abuse in their family. Nobody wants to talk about that, and I think it just makes it worse for everybody…. I really think it’s more detrimental than anything else.

At the same time Gloria described fearing that her decision to be open could have adverse effects on her family, realizing that “coming out” about her illness might result in her husband and daughter being ridiculed or judged.

Responding to rejection. Dealing with rejection and abandonment by family and friends, along with more general stigma and marginalization within society, can make living with mental illness a deeply painful experience. Learning to cope with and respond to rejection is an integral part of living with a chronic mental illness. Six participants shared some of the experiences they have had with feeling rejected by family, friends, and others in their lives and how they have chosen to respond to this rejection.
Jane has opted to live apart from her family and explained that she continues to isolate herself from them during family gatherings by sitting on her own away from the family group. Peter explained that his cousins, as well as some friends, shut him out when he became ill. It seems that this has not deterred him from trying to reach out to them, as he described continuing to try to find ways to socialize with them, and remaining hopeful about the future:

Some of my cousins don’t acknowledge me in their life anymore…. They just totally shut me out of their lives [when I got sick]…. Before it was better. I can handle that. Later in life, I guess we’ll get better, the relationship with my family…. My friends also…some of them shut me out…but I try to gain them back by, when I work, they have barbecues and I would buy beer and just hang out.

Five participants have learned to retort to people who reject them either by standing up for themselves or responding sarcastically so as to make the other person upset.

Although these responses help participants to cope with rejection, they do not prevent them from feeling the sting of rejection. Dolores frequently stands up for herself in response to her family’s lack of concern for her but continues to feel hurt:

I sometimes think my family’s embarrassed of me…. They don’t come to see me…. My family was always embarrassed because I was a client. Only now they know me [after I’ve accomplished so many things]…. They never check on me…. I’m the one that has to contact them…. They’re proud that I made it in life. But I told them, I said, “The only thing that sucked about it was that you didn’t stand by me. You were too embarrassed to stand by me.”

Francine recalled a tense moment with her father when she had to defend herself against a remark he made that offended her:

I was singing and my dad was saying, “You’re embarrassing me. You’re embarrassing me. The neighbors can hear you. I’m embarrassed. You know, people think you’re crazy. You know, you’re retarded.” My dad said, “You’re retarded.” My tears fell. I said, “Don’t call me retarded because I’m not.” When he said that, it really made me angry…. When my dad told me that, I said, “I’m not retarded.” I told him straight, “I’m not retarded. I may have a mental illness,
but I’m not retarded. I know my rights, where I stand, and where I’m coming from. Don’t tell me I’m retarded because I’m not retarded.” I told him. I told him straight, I’m not retarded.”

Gloria was the only participant to share that she had experienced rejection in the form of discrimination when she was previously employed, having been let go from her job after requesting time off to undergo treatment for her mental illness. Her response to being fired was to file a complaint for discrimination against people with disabilities.

*Receiving support from others.* Stigma and a lack of understanding about mental illness sometimes precludes the availability of social support, leaving affected individuals with further isolation in addition to their own internal feelings of being different from mainstream society. The feelings of rejection and loneliness that individuals with chronic mental illness experience do not entirely define their experience of relationships with others. All of the participants discussed their experiences of receiving support from others whether it was support from family or friends or alternative sources of support that they have found along the way of their recovery process.

Five of the ten participants were able to receive support from particular family members even if others in their lives had opted to reject them in some way. These participants all seemed to conclude that having family support has been invaluable in their experience of living with a chronic mental illness; receiving support has helped them to feel accepted, less alone, and more secure, knowing that they have loved ones to assist them whenever needed. Joaquin, for example, who is struggling financially due to his wife’s medical treatment, has received support from his siblings, ranging from emotional support and understanding to paying for medications he is otherwise unable to afford. Gloria specifically credited her husband and daughter for getting her through
very rough times, as well as for giving her encouragement to achieve many accomplishments in her new life as an individual living with a chronic mental illness.

Francine, who has at times felt hurt when others in her family wanted to have her hospitalized, expressed how she has felt especially accepted and supported by her sister:

I have full support with my sister. She’s really a good help. She tries to understand me. She tries to be fair and not treat me like a mentally ill patient. She’s very hopeful and understanding. She’s really there 100%. And when I need help, if I need something that deals with my medicine and I need money, she’ll help me get the medication or she’ll find a way to get that medicine. She’s a very good support. Even when there’s a crisis sometimes…she’ll ask me, “Do you feel you want to stay in the hospital? Is there anything you need? What can I do for you while we’re here? We can get help for you.”

After being rejected by their families, the other five participants turned to friends and co-workers for social support, with three of these participants turning to fellow consumers to develop their support networks. James, whose aunt and only source of family support died recently, explained that his only two friends in life now are fellow consumers with chronic mental illness, who offer him the acceptance and understanding that he feels he does not receive from others. Carlos, who was able to maintain some of his friendships from before he became ill, described feeling protected by his friends:

[They’ve been] supportive… Because they know that I’m disabled. They, my friends, told their friends, “Don’t hurt him because he’s disabled. You have to excuse him.” They tell their friends about me, like, “He’s just like that, taking medication.” I never lost friends.

Desire to find meaning. Living with chronic mental illness can be all-encompassing, requiring strict adherence to medication regimens, coping with side effects, participating daily in treatment programs, trying to maintain a healthy lifestyle to prevent relapse, and addressing the challenges of social stigma and rejection from various sources. In spite of all of the energy, focus, and efforts involved in learning to live with a
chronic mental illness, there may still be an inner desire to transcend the illness and to live a life that is meaningful. Having meaning in one’s life can provide a reason or impetus to get up each morning and face the day and can offer a sense of worth or importance that may otherwise be elusive for individuals who must depend on others for assistance. Individuals living with chronic mental illness must sometimes cope with unfulfilled dreams or goals, sidelined since the onset of their illness, as well as fears about what the future holds for them. At the same time, mental illness does not extinguish the sense of hope and desire for a more meaningful existence. Nine participants discussed their desire for meaning in their lives, with five themes emerging from their disclosures: (1) regretting an unfulfilled life, (2) feeling proud of accomplishments despite mental illness, (3) wanting to help others, (4) feeling hopeful about the future, and (5) feeling afraid of the future.

Regretting an unfulfilled life. Living with a chronic mental illness poses many challenges beyond having to address symptoms and maintain stability. In some cases, individuals diagnosed with a chronic mental illness find themselves having to go through a grieving process. This may come in the form of mourning the loss of goals, wishes, or desires that may not have come to fruition, grieving over lost time, or feeling responsible that others have been negatively affected in some way by the illness. Four participants shared their experiences of regretting the loss of important aspects of their lives.

*Jane* expressed regret over having used substances in the past, believing this was one of the reasons she developed schizoaffective disorder and spent many years of her adult life in treatment:

If I didn’t use abuse the substance, marijuana, drink beer, or do ice, then I wouldn’t be here. I would be doing other things.
Similarly, Peter spoke of wishing he had not used substances in the past, attributing his heavy drug use to the eventual development of his schizophrenia. He recalled how he had been a stellar student destined for college and a bright future, a future he is now uncertain of attaining as his schizophrenia impacts the very part of him that had previously been his gift—his mind. Regret over not having been a good parent plagues Gloria’s thoughts at times, wondering how her illness, particularly during the years before she started treatment, affected her children and her relationship with them. James made reference to the time he lost as a result of medication side effects and the impact his illness has had overall in his life:

> It affected my life by sleeping a lot. The wasted years. It affected my life by losing friends. It affected my life by…what else can I say…the main thing is that hurt, man.

_Feeling proud of accomplishments despite mental illness._ Living with chronic mental illness can involve losing months or even years to the unpredictability of symptoms, the search for the right medication, the difficulty of managing side effects, and the disappointment and heartbreak of relapse. Having recognized that chronic mental illness comes with a host of challenges, it becomes important to acknowledge moments of success and achievement. Being able to accomplish goals or being applauded for good work can serve as reminders that all is not lost of one’s life because of mental illness; these reminders serve to encourage individuals to forge ahead to make new goals after grieving unfulfilled dreams of the past. Five participants talked about moments in their lives when they achieved success and felt proud that they had come a long way despite their mental illness.
Jane proudly shared accomplishments she has had in school and employment, having successfully passed two courses at the local community college and having received praise from co-workers when she had worked as an intern. She added that, at the time of the interview, she was waiting to hear confirmation of an employment opportunity; her previous internship placement now wished to hire her. She emphatically stated, “I’m not an intern anymore…I’m a real worker!” Being recognized for her hard work was also instrumental in helping Dolores to feel proud of the accomplishments she has made since becoming ill; she had been applauded by others for her talents and strength and noted that she was able to pull herself and her life together entirely on her own. James expressed pride in having been able to rebuild his life after years of struggles by ending substance use and earning a high school diploma and vocational training certificates. He stated with recognition of his efforts, “It’s hard, though…I work for this.” The sense that living with chronic mental illness is a long, uphill battle also resounded for Peter, who, unlike some of his fellow consumers, has been able to maintain employment for long periods of time:

I’ve carried my cross pretty well. I mean, I wasn’t too perfect of a schizophrenic person, but I’ve made a long ways from where I [was to] where I’m at now.

Having opportunities to feel proud of one’s accomplishments despite having a chronic mental illness has an empowering effect, as was reflected when Gloria took stock of her achievements since becoming ill:

I think that’s what made this whole thing bearable. Because I feel like I have accomplished a lot of things even in spite of this. And so I have nothing to be ashamed of. I have nothing to fear.

Wanting to help others. After years of feeling vulnerable to symptoms and fears of relapse, having to depend on others for assistance, and surrendering choice and dignity
in the face of interventions aimed at stabilization, it is not surprising that individuals living with chronic mental illness may want to do something to restore a sense of capability, volition, and worth. When the desire to find meaning in one’s life arises, the challenge then becomes identifying which route to take to feel like one’s existence is important. As they shared their experiences of living with a chronic mental illness, five of the participants described their strong desire to help others, which seemed to be an indicator of their yearning to feel that their lives are still meaningful in spite of their illness and that they have something of themselves to offer the world.

*Jane* mentioned that after she started to live a healthier lifestyle since being in treatment for her mental illness, she made attempts to be a role model for her family members. Although she has faced challenges with encouraging her family members to follow her footsteps, this has not dissuaded her from trying to pursue her overall desire to help others. *Gloria* described the changes she has undergone as a result of living with her mental illness, including how she has gone from working in retail and focusing on garnering high sales to now concentrating her energy, creativity, and compassion on helping other individuals living with mental or physical disabilities. *Carlos* shared his dream of one day having enough money to be able to help those less fortunate, believing that his mission in life is to help people and that his mental illness will not prevent this from happening, explaining, “No, it won’t restrict me because that’s from my heart, that’s what I love to do.” After having felt abandoned by her family when she became ill, *Dolores* has decided to devote her life to working with populations that are often marginalized and rejected; she now works with the elderly, troubled youth, and disabled:

> I like where I’m at. I deal with the [people] that nobody wants to be with…. They need energy to push them. So I’m like the energy behind all their energy to
push them, to let them know that it’s okay if you fail, you try again…. I didn’t have meaning in my life until I got here, got into [treatment], and learned [about outreach].

On a smaller, but no less important scale, Nancy finds meaning in her life through helping her family. She shared how important it is for her to still be able to help her sisters despite having a chronic mental illness, stating, “It makes me feel good…at least I do matter.”

**Feeling hopeful about the future.** Perhaps as a result of the various challenges associated with living with a chronic mental illness, or arguably in spite of these challenges, individuals living with chronic mental illness may continue to dream of a future in which they have overcome their difficult circumstances. Some may envision a life free of symptoms, others may yearn for practical goals such as education or employment, and still others may simply feel hopeful that their strength will continue to carry them through. Regardless of what goals they may desire, remaining hopeful about the future seems to offer a sense that the illness will not overpower or conquer them.

Six participants shared their thoughts about their futures as individuals living with chronic mental illness, illustrating the sense of hope they maintain despite the ups and downs they face as they continue their recovery. Two participants discussed their hope of living a life free of mental illness. Josephine, for example, spoke of hoping one day to return to her old self without the mental illness—the self that was without tears and not sapped of energy and zest for life—exclaiming, “If I could get through that, I’ll kiss the floor, I’ll kiss the floor, thanking the Lord!” Three participants shared their conviction that whatever the future holds for them, they cannot allow their illness to interfere or stop them from doing anything they set out to do. Dolores repeatedly talked of how her
strength has carried her through the many hardships she has had in her life, including her mental illness. Although she recognizes the challenges she faces because of her illness, she was emphatic about not letting that stop her from realizing her goals:

I have to fight for what I want. I always have a fighting battle going on. It’s always an uphill battle because of my mental illness…. But I don’t let that slow me down…. I got [a mental illness]. Who cares? I’m just going to live with it and deal with what I have to do. I’m a strong person. Nothing can knock my stride down…. I dream high. I never dream low and I always go high.

Of the six participants only two were employed at the time they were interviewed. The remaining four participants all expressed a desire to one day be able to maintain employment, suggesting that this would be a sign that they are no longer constrained by their mental illness. Francine described this sentiment when she shared how being employed would be an indicator as to how far she has come from her illness and how it would mean that she has finally risen above it:

I would love to work…. Seeing the difference of where I was before and where I am now…. Do something productive…. [It would] mean a lot to me, to help myself overcome my illness…. To not think about the bad things, but to overcome things. Not to let the world or whatever is happening come down on me, but to be strong…. I want to see the good in me, that I can do it. I mean, not because I’m mentally ill, but I know I can do it and overcome. I can do it. I can go out there and do it for myself. And even if I’m mentally ill, I can still do whatever I want to do. I can still hold a job and accomplish things in my life…. That’s one of my biggest goals, is to not let the illness overcome [me], but I overcome the illness by proving I can do it…. I’m going to keep trying until I can show myself and my family that I did it. I overcame it.

*Feeling afraid of the future.* Even with hopes and dreams of a future where chronic mental illness represents merely a sidestep on the path toward a vibrant, productive, and meaningful life, there remains the likelihood that the chronic aspect of mental illness will continue to wield some influence in the years to come. Realistically,
there will most likely be continuing challenges with each step toward recovery. Four participants shared their deep fears as they entertained thoughts about their future lives.

The genetic aspect of mental illness overshadowed two participants’ thoughts of the future. Jane, a 27-year-old woman, who started experiencing the challenges of a mental illness as an adolescent, expressed her desire to one day be in a relationship and have a child of her own. At the same time she disclosed her fears surrounding that desire; she has already started to worry about the genetic implications of mental illness:

I’m ashamed to have a relationship because of my mental illness…because I think I might pass it on or something…. If I were to have a baby…. I’m scared because of my mental illness. I’m scared that if I were to bear a baby, my mental illness might affect, genetically, the child.

Carlos, who already has three children, often worries about whether any of his children might have inherited his mental illness and finds himself monitoring them for any possible signs of the illness. Mental illness has also resulted in Dolores’s reluctance to pursue a romantic relationship because she is afraid her illness will frighten any potential partners away from her. Gloria was informed early on in her treatment that mental illness only worsens with age, causing her to give thought to living with the sense of a foreshortened future:

What was really weird was one of the social workers, years ago, made a comment that people with mental illness, as they get older, the illness progresses. And, it just kind of like gave [me] that doomed effect. Like, why the hell am I going to try then if that’s what I have to look forward to? So I kind of spent a lot of time trying to dispel that. I called it a myth. This is not going to happen to me. But I do, I think about that.

Whatever the future may hold for her, Gloria has come to realize that she has been able to live a fulfilling and meaningful life in spite of her mental illness:

I enjoy it. I feel fulfilled. I feel like if I died tomorrow, I’d be okay. I really, I’ve thought about that. I’ve thought about that. I’ve learned that the important thing
is to leave the earth better than when you first started. And I feel like the work that I’ve done and the things that I’ve done in the community, I’m okay. If I was to go tomorrow, I’m okay. I’m okay with that.
Discussion

Summary of the Findings

The main goal of the present study was to explore and identify the specific existential concerns affecting the lives of individuals living with chronic mental illness in Guam. The results of the study illustrate that the participants experienced a host of concerns and reactions with regard to specific aspects of having a chronic mental illness, such as experience the onset of the illness, being diagnosed, being medicated, being hospitalized, receiving mental health services, and living day-to-day with chronic mental illness. Although their varied experiences all had particular meanings pertaining to each of the phases associated with having a chronic mental illness, there were several core existential concerns underlying the overall phenomenon of what it is like for individuals to live with a mental illness in Guam. These core existential issues move beyond the results presented in detail in the previous section by domain, super-ordinate theme, and theme and represent another layer of interpretation. They were derived by analyzing connections among the entire set of themes across all six domains, leading to a core set of themes that ran through each of the domains, representing the core existential issues permeating the participants’ lives. In total, there were six core existential concerns that the participants encountered in their experiences of living with a chronic mental illness. These existential concerns included (1) defining and knowing the self, (2) navigating relationships with others, (3) trying to understand the illness, (4) managing the illness, (5) desiring control, and (6) living a meaningful life with mental illness.

Defining and knowing the self. From the moment symptoms of mental illness began to emerge, existential concerns regarding the definition of the self also began to
plague the lives of the participants. The participants’ conceptualization of the self was significantly altered when foreign and strange occurrences associated with their symptoms began to develop internally. These unusual occurrences affected their thoughts, feelings, and behaviors, all of which comprise the self. When symptoms struck, they affected the core of the self, leaving participants feeling confused, lost, and out of control, making it difficult to define and know who they were in light of what was happening to them.

When their symptoms were then given a name through diagnosis, participants were sent into another stage of trying to redefine their identity and experiences, as they were being told that their thoughts, feelings, and behaviors were actually symptoms of an illness and not a part of the self. Insecurities and confusion arose as thoughts, feelings, behaviors, and general life experiences were re-examined through a new lens that had to incorporate competing understandings of the self, including the self pre-diagnosis and the self post-diagnosis. All that was known about the self before was questioned as to its veracity, leaving the participants wondering who they really were and which self was real. This existential dilemma was then compounded by the experience of being on medication, which added another layer of defining and knowing the self, requiring participants to accommodate the new experience of a radically altered self due to medication while still remembering their original sense of self prior to taking medication.

The participants’ experience of the self became tenuous as they attempted to integrate the new information and experiences associated with their mental illness against the backdrop of past experiences prior to their mental illness. The participants continued to experience the push and pull of questioning who they were in relation to their illness and
themselves throughout their day-to-day lives, long after the initial stages of living with chronic mental illness.

Navigating relationships with others. The second core existential concern pertains to how the participants navigate their relationships with others. All of the participants struggled with feeling isolated and alone. Similar to the push and pull participants experienced with their sense of self as they learned to exist as individuals with chronic mental illness, there also seemed to be a push and pull with regard to their desire to connect with others versus their need to isolate in order to protect themselves from others. The participants’ longing for isolation stemmed primarily from having experienced being rejected or abandoned by family, friends, or their community at different times of their illness. At the same time, even without outright rejection by others, feelings of shame and embarrassment spurred their desire to isolate themselves.

Being diagnosed with a chronic mental illness left participants feeling different from others; the need to feel accepted and perceived as “normal” became paramount, particularly in the face of the social stigma and marginalization associated with mental illness. This affected their decisions regarding whether to tell others about their mental illness, knowing that they risked being rejected, ridiculed, or treated differently if they chose to be open about their illness. Participants also struggled with wanting to have relationships with others but also feared that they would become a burden. Because their mental illness forces them to depend on others for safety and stability, they may not see themselves as being equal parties in relationships. At some point in their illness, all of the participants maintained or developed relationships with others in which they felt supported, whether it was with particular family members, friends, or treatment
providers, and these relationships often became instrumental in their attempts to cope with mental illness in their day-to-day lives. These relationships often remained tenuous and fraught with tension. Despite the length of time they had been living with mental illness, participants continually struggled with how to navigate their relationships with others in such a way where they could protect themselves from being hurt and at the same time develop satisfying and meaningful connections in their lives.

**Trying to understand the illness.** The third area of existential concern pertains to trying to understand the illness. At the time they began to experience symptoms, the participants developed various explanations to try to make sense of what was happening to them, focusing in particular on life events immediately preceding the symptoms. They knew something was amiss with what they were experiencing, but the notion that their thoughts, feelings, and behaviors were symptoms of an illness had not yet been recognized. Unlike symptoms of physical ailments, changes in mood, feelings, thoughts, and perceptions are not readily understood as symptoms of an illness because they affect the mind more than a particular part of the body. The participants were confused as to why their thoughts, feelings, and behaviors seemed different from before, and they soon experienced distress as their internal selves were making less sense to them. Despite eventually receiving a diagnosis and an accompanying medical explanation for why they felt different from before, participants continued to struggle to make sense of their illness, even years later. The struggle to make sense of the illness became a central component of their day-to-day lives. Participants often vacillated among competing explanations for their illness: genetics, substance use, life stressors, grief, personal characteristics, ancestral spirits, and God. Participants encountered the dilemma of experiencing the
symptoms internally as a part of the self but having to understand and accept that these internal experiences were due to an illness that they perceived as an external entity. The challenge was to understand how their thoughts, feelings, and behaviors were due to an illness, as well as to understand how much of their internal experiences were due to the illness and not their own natural responses or reactions to their world. The participants faced the existential concern of making sense of the illness at the same time they were still trying to make sense of the self in the context of the illness.

**Managing the illness.** Another existential concern for participants was managing the illness. All of the participants invested a great deal of time and energy in managing their illness. Illness management included finding the right medication, remaining consistent with taking medication, and coping with medication side effects. It also included participating in a broad range of mental health services and overcoming various barriers and feelings of apprehension regarding those services. Participants engaged in daily activities, lifestyle changes, and cognitive strategies to cope with their symptoms on a day-to-day basis, such as eating healthily, exercising, learning triggers, praying, reassuring themselves, and keeping busy. Although illness management was a practical daily concern aimed at maintaining their mental health, managing the illness also impacted the participants’ daily lives in broader and deeper ways. Managing the illness did not only mean reducing the risk of relapse, but it also meant that participants were able to function, carry out daily activities and routines, and live their lives as they would if they did not have a mental illness. The more they were able to accomplish daily life tasks, the more participants achieved a sense of normalcy and felt like they fit in with the rest of society. With greater stability in their lives, participants’ experience of mental
illness could be more encapsulated such that it did not become their only source of identity.

**Desiring control.** Due to the overpowering nature of their mental illness, participants encountered the existential concern of desiring control. From the moment they began to experience symptoms, participants yearned for a sense of control over their lives. They did not feel in control of their own thoughts, feelings, and behaviors, and they attempted to regain control by alleviating their symptoms through simple coping strategies, including hiding symptoms, soothing symptoms through daily activities, such as sleeping, showering, and eating, and by engaging in self-destructive strategies, such as substance use and suicide attempts. This loss of control followed them throughout the process of entering and receiving treatment. Participants felt excluded from the diagnosis process, trapped and scared by hospitalization, and became frustrated with having to receive mental health services and be dependent on others over a long period of time. As they lost control over their sense of self and their daily lives, the participants also encountered vulnerabilities in their relationships, such that they could not assume family and friends would remain by their side as they battled symptoms and tried to gain a foothold on their illness. In sum, they felt as though they had lost control over both their internal and external worlds, which left them wanting to find areas of their lives where they could regain control over what was happening to them. For example, participants sought control over their medications, either trying to develop their own regimens or wanting to stop taking their medications altogether. Also, in choosing whether to disclose their illness to others, participants had found a way to influence how they would be perceived and treated by others. Their desire to be in control did not stop at wanting
to be in charge of their illness and its treatment. Participants also dreamed of being in charge of their lives; they took pride in being able to take care of themselves, in being independent, in seeking employment, and in having the ability to live on their own. Overall, participants were not only concerned with trying to survive each day with their mental illness, they were also determined not to allow their illness to overcome them and to live as independent and capable individuals able to direct the course of their lives.

**Living a meaningful life with mental illness.** The sixth existential concern revolved around participants’ efforts toward living a meaningful life with their illness. After dedicating a significant period of time to addressing the immediate needs of trying to understand symptoms, seeking help, and finding the right treatment, the participants seemed to enter another stage of their lives during which they strove to rise above their illness to envision the possibility of living more meaningfully, rather than merely taking care of their mental illness day by day. The process of trying to find meaning necessarily involved taking an inventory of their lives, including aspects of their lives and themselves that existed prior to their mental illness, as well as aspects that continued to exist during their illness. Participants often experienced regret and grief over a life not fully lived—not being as accomplished as they could have been, having had to surrender parts of the self in order to maintain stability, and living a life consumed by medication and treatment programs. At the same time seeing for themselves how far they had come and how many hurdles they had conquered allowed them to remain hopeful that they could still live meaningfully in spite of their illness. Although they acknowledged some fears about the possibility of losing all that they had accomplished due to relapse and uncertainty about what the future might bring, participants found solace in realizing how much stronger
they had become because of their mental illness. Knowing that they were still capable of helping themselves and others became a vital source of feeling as though their lives had meaning and value even when sometimes clouded by the symptoms and limitations associated with their mental illness.

**Findings in Comparison to Literature Review**

Another goal of the present study was to examine whether the phenomenon of chronic mental illness is experienced in much the same way among individuals living with chronic mental illness in Guam as it is for individuals living with chronic mental illness in the countries that were mentioned in the literature review—the United States, Canada, the United Kingdom, Sweden, Finland, Australia, and South Africa. Although Guam is a territory of the United States, it is also culturally distinct in many ways. Guam’s ethnic population is primarily composed of Pacific Islanders who are indigenous to Guam (i.e., Chamorros), as well as other Pacific Islanders from neighboring Micronesian islands and Asian populations from the Philippines, Japan, China, Korea, and other surrounding Asian countries. Thus, Guam’s social culture is an integration of Pacific Islander, Asian, and U.S. influences. This provides a rather different sociocultural background from those that were represented in the literature review. As no other study exploring the experience of chronic mental illness had been conducted in this region, it was important to examine if the themes that were found in other cultures would still be relevant for individuals living with chronic mental illness in Guam.

**Core existential concerns.** The six core existential concerns found in the present study do reflect the various existential tenets espoused by the existential philosophers and
theorists examined in the literature review. Discussion of the relationship between existential theory and each of this study’s core existential concerns is presented below.

**Defining and knowing the self.** As was found in the present study, the participants’ concern with defining and knowing the self was akin to Kierkegaard’s (1849/2004) concept of the sickness unto death, as well as of Laing’s (1960/1969) notion of a true self versus false self system. The participants’ struggles to define and know which parts of their self was real, as well as with wanting or not wanting to be their self, was illustrative of Kierkegaard’s despair, which is a sign that a decision or change is needed. The participants had to choose exactly how they would define their true self in the face of the dichotomies consequent of their illness (e.g., the self before and after diagnosis). As in Laing’s theory of the true self and false-self system underlying schizophrenia, the concept of wanting to protect the true self, but living their day-to-day lives through a false self, was also a part of the participants’ existential concern. It seemed important to the participants to safeguard who they were through their efforts to protect themselves from rejection, to hide aspects of their self in order to feel or appear capable and normal, to rediscover their true self hidden beneath their symptoms, and to prove to themselves that they had control over the illness, that their true self was able to conquer the external threat represented by the illness.

**Navigating relationships with others.** The participants’ existential concern with trying to navigate relationships with others echoed the theories on isolation and desire for connection that May (1953) and Yalom (1980) discussed in their works. Although both May and Yalom saw isolation as an existential given in life, the feeling of being alone is compounded for the participants as a consequence of having a condition that is
particularly isolating due to social stigma and marginalization. Similar to Yalom’s existential conflict between isolation and the desire for connection, participants found themselves caught in the dilemma of wanting to isolate themselves as a protective measure for the safety of the self and wanting to connect with others to feel a part of the world and less alone. Tolstoy’s (1886/2003) illustration of existential isolation in *The Death of Ivan Ilych* also captures the participants’ experience of isolation and loneliness; Ivan was left on his own to experience his illness and impending death. Even when participants did receive the support of family, friends, or treatment providers, the feeling of isolation still remained, perhaps, due to the very nature of mental illness as an internal experience that ultimately must be confronted alone.

**Trying to understand the illness.** The participants’ concern with trying to understand the illness is reminiscent of Sartre’s concept of existential anxiety illustrated in *Nausea* (1938/2007b). The strange internal experiences that accompanied the onset of their illness were similar to Roquentin’s sudden sensations of fear and anxiety that Sartre referred to as nausea in his novel. The participants’ endless struggle with trying to make sense of the causes and explanations for their symptoms and their illness was much like Roquentin’s obsession with trying to understand the source of his nausea. For Sartre, nausea, or existential anxiety, accompanies the awareness that existence is meaningless and individuals are free to create their own meaning. The only way to overcome such anxiety is to choose to live purposefully and to infuse meaning into existence. According to this framework, the participants in this study experienced existential anxiety when their internal thoughts and feelings no longer made sense, were no longer meaningful. The participants’ desperate search to understand their illness was driven by this anxiety in
an attempt to find meaning within their symptoms, their illness, and ultimately within their self.

**Managing the illness.** The fourth existential concern participants encountered was managing the illness, which reflects the broader concern of desiring to live as discussed by Yalom (1980). Yalom suggested that all individuals face the existential given of death anxiety and the corresponding desire to continue to live in the face of that anxiety. Although the participants were not facing physical death, being diagnosed with a chronic mental illness meant for them the death of a life they knew without the challenges associated with their illness. They experienced mourning the loss of their pre-diagnosis self and had to make substantial adjustments in order to adapt to their new post-diagnosis existence. In this light the participants’ desperate efforts to cope with their symptoms early on in their illness can be seen as attempts to reduce their death anxiety. Once in the process of recovery, participants were able to gain a sense of control over their lives through medication, mental health services, and personal efforts to manage their illness, suggesting that they had confronted their anxiety about their diagnosis. Fears about potential relapse, like death anxiety, continued to play a role in their determination to adhere to treatment recommendations and engage in healthy activities to maintain their mental health. Their efforts toward managing their illness, whether through ongoing participation in mental health services or engaging in personal activities to remain healthy, highlight their desire and determination to live fully in spite of their mental illness.

**Desiring control.** The participants’ desire for control over their illness and their lives reflects the existential concern of choice and responsibility, as discussed by a
number of the existential philosophers and theorists presented in the review of the literature (Dostoevsky, 1864/2009; Frankl, 1969/1988; May, 1967/1979; Sartre, 1946/2007a; Yalom, 1980). Throughout their experience of living with a chronic mental illness, participants often felt that they had lost control over their internal and external worlds. This created a strong yearning to have a sense of choice in their lives, but they also felt that their ability to choose was limited to such a degree that they were left with no choice at all. According to Sartre, the belief that the individual is not free to choose arises due to an avoidance of the responsibility that comes with choice. This can be seen in situations where participants could make decisions about their illness or their lives but are faced with the responsibility that comes with making these decisions. For example, choosing to discontinue their medication meant finding relief from incapacitating side effects but increasing their risk of relapse whereas remaining on medication meant stabilization and the ability to engage in the world but with the cost of unwanted physiological impairments. Similarly, participants knew that choosing to reach out to others could lead to social affiliation and acceptance, yet they also had to accept that reaching out could lead to rejection. Ultimately, the participants’ experience of daily life with a chronic mental illness was greatly impacted by their strong desire to feel in control and at the helm of what happens to them in their lives, along with the awareness that their decisions could significantly affect their well-being: that their choices would shape and define their lives.

**Living a meaningful life with mental illness.** The participants’ desire to live meaningfully in spite of having a chronic mental illness echoes the works of Sartre (1938/2007b), Tolstoy (1886/2003), and Frankl (1946/1986). Sartre posited that
existence precedes essence, and meaning is not a given in life but must be infused into existence. For Tolstoy, Ivan Ilych only discovers the true meaning of his life when his illness pushes him to the edge of death. Illness has the potential to spirit one towards meaning. Similarly, Frankl (1946/1986; 1969/1988) argued that having a mental illness does not incapacitate the individual from finding or making meaning in his or her life, for meaning is created from how we respond to our suffering. According to these perspectives, responding to the disabling condition of chronic mental illness in such a way so as to create meaning is necessary in order to transcend mere existence with the illness and move toward living a full and meaningful life with the illness. The participants at times regretted living an unfulfilled life and were fearful of what the future might bring. They also expressed a desire to have a reason to wake up each morning, take their medication, and do whatever is necessary to remain stable and healthy; in short, they desired a reason to live. Their life goals included finding employment, returning to school, and living more independently, as well as establishing connections with others and helping family or those less fortunate than themselves. Participants believed that achieving such goals would be a way toward finding meaning in their lives, but the most significant source of meaning for them was hoping that they might one day conquer their illness and live the life they had always envisioned for themselves.

**Themes of the mental illness experience.** A number of the specific themes found in the present study were similar to those found in the empirical studies examined in the literature review, suggesting that individuals living with chronic mental illness in Guam may share similar experiences to such individuals residing in other parts of the world. There were a few differences in the themes found in this study. These differences
reflected subtle, cultural nuances that seemed specific to Guam but which may be significant factors in helping to understand the experience of chronic mental illness for individuals who are members of Guam’s sociocultural milieu. Discussion of the relationship between the themes found in this study and the themes found in the empirical literature is presented below.

**Onset of illness.** When symptoms began to emerge for the first time in their lives, the participants in the present study appeared to struggle with feelings of confusion, insecurity, and loss of control as they tried to understand what was happening to them. These reactions were also found in the studies conducted in the United Kingdom, Sweden, and Finland, highlighting feelings of fear, shame, guilt, and distress that accompanied the confusion (Cookson & Dickson, 2010; Jonsson et al., 2008; Koivisto et al., 2003; and Rusner et al., 2009).

The participants in the present study provided some unique responses when trying to explain or make sense of their symptoms. In the studies cited above, the participants tended to identify situational experiences as the reasons behind the onset of their mental illness, such as divorce, employment stressors, and past traumas, including childhood abuse. When trying to understand or attribute a cause for the onset of their symptoms, participants in the present study similarly cited life stressors, but they also specifically saw the death of loved ones as largely contributing to the development of their mental illness. This coincides with some participants attributing the onset of their symptoms to *taotaomo’na*, or to ancestral spirits of long-deceased loved ones who are believed to have returned to help guide and protect them. These unique findings reflect Guam’s cultural values emphasizing the importance of the family, as well as traditional beliefs that have
been transmitted through the generations about taotaomo ’na and respecting the spirits of Chamorro ancestors.

In Chamorro culture the individual is defined and understood within the context of his or her family, or familia, which includes both immediate family members as well as extended family who share a common ancestor and comprise the individual’s clan. The familia provides the individual with a sense of identity, a support system, and social status, in addition to defining what is expected of the individual in relation to the familia. Family members that comprise the familia include parents, children, grandparents, aunts, uncles, cousins, in-laws, and godparents (Marsh, n.d.). Ancestors are also highly revered, as they were long ago when ancient Chamorros believed that they were surrounded by spirits who were able to provide protection and assistance but could also be threatening or dangerous. Today, although many Chamorros still view taotaomo ’na as protective ancestral spirits offering guidance, taotaomo ’na have become more frequently associated with malevolence, such that they have been said to cause a person to become ill (Bevacqua, n.d.; Rogers, 1995).

**Being diagnosed.** In a phenomenological study conducted in Canada on the experience of diagnosis, Hayne (2003) found that receiving a psychiatric diagnosis initially led to distress and confusion for the participants in his study; the diagnosis transformed their experiences into something that was foreign to them. Hayne also found several positive aspects of being diagnosed with a mental illness, in that the diagnosis offered individuals an explanation for their strange experiences, validation of the reality of their symptoms, and the opportunity to reframe their experiences as symptoms of an illness requiring professional help. Similarly, in the present study, participants initially
struggled with receiving a diagnosis but eventually came to accept their diagnosis as it provided an explanation for their symptoms. As in Hayne’s study, some participants felt relieved by their diagnosis because it offered them a way to talk about what was happening to them, as well as the opportunity to receive help and find relief for their symptoms. The participants in the present study also discussed reactions to being diagnosed that were not mentioned in the literature. They spoke of wanting to refute the diagnosis, feeling embarrassed by their diagnosis, and seeing the diagnosis as a punishment. Such reactions highlight the sense of shame that having a mental illness can bring about for the individual, particularly in Guam where the concept of shame plays an important cultural role. Being diagnosed with a mental illness can give rise to feelings of shame regarding what the family might think of the individual, as well as what the community might think of the individual and his or her family.

The Chamorro culture places much emphasis on the value of not bringing shame to the family through one’s actions; one is often punished or shunned for committing an act that publicly paints the family in a negative light. The code of conduct pertaining to the practice of respect and avoidance of bringing shame to the family is known in Chamorro as mamåhlao, (De Oro, n.d.; Leon Guerrero, n.d.). Respect for the family is of utmost importance in Chamorro culture, and maintaining the dignity of the family is central in governing the individual’s behavior. This cultural value stems from the time of ancient Chamorros when, in the absence of a formal governmental structure, social order was preserved by the obligations of the individual to the family, including the expectation of not engaging in behavior that could damage the family’s reputation. Bringing shame to the family often resulted in severe punishment (Leon Guerrero, n.d.). The sense that
being diagnosed with a mental illness means that one is being punished could be an outcome of this cultural value, in that the individual may perceive mental illness as being a punishment for having done something wrong or inappropriate. Unlike Haynes’s study, the participants in the present study shared not only their own reactions to being diagnosed but also their family’s reactions. Although this could be due to methodological differences among the studies, the emphasis on the family’s reaction to the diagnosis in the present study could be a reflection of Chamorro cultural values that place importance on the interdependence of the individual and the family.

**Being on medication.** Bentley (2010) suggests that being on medication is primarily an internal and individual experience, one that individuals living with chronic mental illness must tolerate as it is necessary for the prevention of relapse and to allow a sense of control, choice, and humanness. These perceptions of being on medication were shared by the participants in the present study; their experiences of being on medication also reflected the notion that medication, for the most part, is a solo endeavor because the struggles associated with medication affect the individual more than anyone else. One interesting finding related to being on medication that was discovered in the present study was the sense of the true self emerging from the alleviation of symptoms afforded by the medication and conversely, for one participant, the submergence of the true self due to having to take medication in order to fit in with the community. This is reflective of Teal’s (2009) findings, which shed light on the decisions made by individuals with mental illness to terminate or continue medication use based on their perceptions of their true versus medicated self. There was one subtle difference from both Bentley’s and Teal’s studies: the participants in the present study acknowledged the role of the
treatment provider in the experience of being on medication. For them the experience of being on medication also involved the prerequisite of trusting psychiatrists enough to start taking medication, which places much emphasis on the relationship between the individual and treatment provider. The importance of this relationship was not mentioned in either of the studies examined in the literature review that focused on the experience of being on medication. This finding may point to the key role played by the doctor-patient relationship in supporting mental health treatment in Guam.

**Being hospitalized.** The participants in the present study held negative and positive evaluations of their experiences of being hospitalized in a mental health facility, noting the feelings of being trapped and of renewal that come with confinement. Some even mentioned missing the support they received while hospitalized. Although Johnson (1998) explored the meaning of being restrained with physical restraints and not necessarily that of being hospitalized, it seems that some of his findings were echoed by the experiences that emerged in the present study. Feelings of being abandoned, powerless, limited, and angry resounded for the participants in Guam as they did for Johnson’s participants in the U.S. mainland. The collectivist nature of Guam’s culture and its emphasis on relationships, may have contributed to the positive experiences of being hospitalized, such that relationships with fellow consumers were significant in helping to alleviate feelings of isolation and abandonment.

**Receiving mental health services.** Interestingly, it seems that the presence of mental health services and mental health service providers was rather significant for the participants in the present study, such that how they perceived the treatment services they received and the treatment providers they encountered contributed to their overall
experience of living with a chronic mental illness. In the literature review there was scant mention of the experience of treatment providers, with only one study having found themes that touched on this aspect of living with mental illness, though this may reflect the lack of research specifically focusing on the experience of mental health treatment. Gaillard et al.’s (2009) study on being misunderstood highlighted how individuals who are diagnosed with a mental illness perceived themselves as being treated like a child or as a problem to be fixed. The present study, on the other hand, suggests that the participants had more varied experiences, including both positive and negative aspects, such as seeing adjunct services as a place of refuge but also feeling frustrated with being in such services long-term. Similarly, participants felt supported by their service providers and missed service providers who left but also felt like a burden to their service providers and had difficulty trusting them. Participants’ experiences of mental health services and providers also appeared to be intertwined with how they experienced more specific facets of mental illness, such as that of being diagnosed, being medicated, and even of living day-to-day with their illness.

Day-to-day living with chronic mental illness. The experience of living day-to-day with chronic mental illness for the participants in Guam was, for the most part, quite similar to the experiences described in the studies that were conducted in cultures that are dissimilar to Guam. Due to the nature of chronic mental illness, individuals diagnosed with mental illness appear to experience fears related to the unpredictability of relapse, which result in uncertainties about the future (Jonsson et al., 2008). The stigma associated with mental illness leads many individuals to censor themselves when in public in an effort to appear normal, and decisions to disclose their illness to others is
often layered with wariness and trepidation (Gaillard et al., 2009). Dreams and goals for the future usually remain unfulfilled as fears of not being accepted or being incapable of succeeding due to the mental illness pervade the individual’s thoughts, particularly as one is still left with trying to make sense of why the illness occurred in the first place (Erdner et al., 2005). Relationships are entered tentatively as feelings of isolation serve as reminders of the shame and rejection associated with mental illness (Erdner et al., 2009). For the participants of the present study in Guam, a substantial part of the experience of the illness concerned the impact of the illness not just on themselves but on their relationships with their family. As the culture in Guam places much value and emphasis on the role of the family, such that the family becomes the primary source of social functioning for the individual, any deleterious effects mental illness has on the individual’s relationship with his or her family is central to the experience of the illness in its totality.

**Implications for Clinical Practice**

The findings of the present study bear significant implications for clinical practice in Guam. As Guam is a territory of the United States, mental health treatment follows the interventions and practices that are used in the U.S. mainland in order to comply with standards and regulations set forth by the medical and mental health systems that also govern the island of Guam. Consequently, Guam mental health treatment providers prescribe the same medications and ascribe to the same psychological theories and interventions as their counterparts in the U.S. mainland. As the present study has found that individuals living with chronic mental illness in Guam seem to experience mental illness in ways that are similar to individuals living with chronic mental illness in other
countries, including the United States, Canada, and the United Kingdom, developing a new or unique model of mental health treatment is not necessarily indicated as many of the existing mental health interventions can be applied to the clinical population of Guam.

At the same time the present study has demonstrated that individuals living with chronic mental illness in Guam, like individuals with mental illness in other countries, do confront existential concerns that transcend the symptoms and immediate problems associated with mental illness. It seems imperative that mental health treatment in Guam should encompass assisting individuals with symptom management, such as medication and cognitive and behavioral therapeutic approaches, as well as existential life concerns that accompany symptom onset, receiving treatment, and living day-to-day. Treatment should not stop with medication prescriptions or clinical interventions aimed specifically at symptom reduction. The present study has shown the need for mental health treatment not merely to treat the mental illness but also to include clinical psychotherapy that focuses on treating the whole individual that is affected by mental illness. Clinical interventions should also address the specific experiences of mental illness and receiving treatment, as well as how these experiences impact the individual’s life and sense of self. This can be achieved through the integration of existential psychotherapy—along with psychotropic medication, cognitive and behavioral therapy, and other evidence-based interventions focused on symptom reduction—in Guam’s mental health treatment protocols.

Within the past decade there has been a resurgence of existential psychotherapy in clinical practice as evidenced notably by the works of Emmy Van Deurzen (2012),
Ernesto Spinelli (2007), Mick Cooper (2003), and Barnett and Madison (2012).

Although these proponents of existential psychotherapy have come out of the United Kingdom, there is also renewed interest in existential psychotherapy occurring in the United States through the works of Kirk Schneider (2007) and Ned Farley (2008), as well as the ongoing work of Irvin Yalom (2002). Existential approaches to psychotherapy have also been recently integrated with cognitive and behavioral approaches through the concept of mindfulness as seen in models associated with the third wave of cognitive-behavior therapy, including Acceptance and Commitment Therapy (Hayes, Strosahl, & Wilson, 2011), Mindfulness-Based Cognitive Therapy (Williams, Teasdale, Segal, & Kabat-Zinn, 2007), and Dialectical Behavior Therapy (Linehan, 1993).

Some may argue that individuals living with chronic mental illness, particularly those with psychotic symptoms, such as auditory hallucinations, may not benefit from existential psychotherapy due to the severity of their illness or their disconnect from reality. The present study has shown that individuals diagnosed with schizophrenia and schizoaffective disorder, as well as individuals with bipolar disorder and major depressive disorder, also experience concerns regarding their identity and relationships with the self and others, struggles with managing and making sense of their illness, as well as fears and worries about being in control and finding meaning in their lives in the present and the future. Being diagnosed with a chronic mental illness should not discount the treatment of individuals as a human beings merely because of their symptoms. In a recent publication, existential-oriented psychiatrist Daniel Dorman explained psychosis through an existential lens, highlighting the applicability and need for existential psychotherapy even with individuals experiencing psychotic symptoms:
The psychotic person’s explanations are examples of the very same struggle as anyone else’s, namely, his effort to resolve inconsistencies in order to preserve his personal identity, his I. His so-called thought disorder is largely composed of explanations designed to relieve his suffering and to make sense of his world….

If we listen to the stories of people whose suffering has reached psychotic proportions, they regularly tell us that they are struggling with the very existence of their personal identities. (Dorman, 2008, p. 239)

Although the results of the present study suggest integrating existential psychotherapy into Guam’s mental health treatment protocols to address the existential concerns of individuals living with chronic mental illness, the results also highlight the need to include interventions that address the challenges individuals with mental illness face with regard to their families. Efforts to combat the stigma associated with mental illness should be made to educate families in Guam about mental illness in order to help decrease the confusion and misconceptions about mental illness that may lead to rejection, abandonment, or discord within the family. There should also be greater efforts made toward involving the family in the clinical interventions used when treating individuals with chronic mental illness in Guam because the individual’s family can have a significant impact on how the individual conceptualizes him or herself, not only as a person with a mental illness but also as a self trying to be in the world. This may involve encouraging greater participation of family members in consumers’ treatment through family therapy, as well as including family members in treatment planning, medication evaluations, psychoeducation, residential group home activities, and other clinical interventions. As the family also serves as the primary tool for socialization in Guam, helping to maintain and enhance the individual’s integration with the family may be beneficial toward decreasing the feelings of isolation commonly experienced when one must live with a chronic mental illness (see San Nicolas, 1996).
Delimitations and Limitations of the Study

Although efforts were made to ensure that the present study was methodologically sound, several delimitations and limitations of the research design may affect the reliability and validity of the results, as well as the ability to generalize the conclusions to other populations of individuals living with chronic mental illness. Delimitations refer to characteristics of the research design intentionally chosen by the researcher to define the scope and boundaries of the study; limitations refer to shortcomings or potential weaknesses of the research design (Creswell, 1994). Delimitations and limitations often overlap, and both affect the generalizability of a study’s findings, particularly when viewed from the perspective of nomothetic, quantitative research approaches.

One delimitation of the study is that the sample size consisted of only 10 participants with specific characteristics. For example, participants were recipients of mental health services from Guam’s community mental health facility, which primarily services individuals who do not have health insurance and are typically of a lower to no income socioeconomic status. It is unclear if individuals living with chronic mental illness in Guam who are receiving services through private practices and have other resources available would have similar or different experiences with their mental illness. A second delimitation of the study is that although an interview protocol was developed, it was not implemented in a standardized fashion. In accordance with the methods of IPA, interviews were largely participant-led, and questions from the protocol were asked only as needed, serving primarily as follow-up questions when additional details were required. One limitation of the study is that there was no measure of the level of functioning of the participants. Level of functioning was based largely on the
participant’s treatment provider’s clinical opinion regarding the participant’s ability to respond to questions and offer meaningful responses. The participants’ level of functioning, or conversely, level of impairment due to their mental illness may have had an effect on other aspects of their life, which could then impact the kinds of experiences they may have associated with their mental illness. A second limitation is that participants’ recollection of past events may have been influenced by their illness, as well as by their emotions or other factors that could have impacted their ability to remember past events with accuracy.

At the same time it is important to note that qualitative research uses different approaches to evaluating the reliability, validity, and generalizability of research findings; the standards derived from quantitative research are not considered relevant or applicable due to the differences in methodology between the two approaches (Creswell, 1998; Lincoln & Guba, 1985; Smith et al., 2009). Smith et al. (2009) refer to four criteria set forth by Lucy Yardley (2008) to assess the validity and quality of qualitative research, including Interpretative Phenomenological Analysis (IPA). Yardley’s four criteria are (1) sensitivity to context, (2) commitment and rigor, (3) transparency and coherence, and (4) impact and importance.

Some ways to demonstrate sensitivity to context in IPA research include establishing rapport with key gate keepers in order to access a specified sample of participants (Smith et al., 2009). The researcher had already established rapport with the administration and staff of the Department of Mental Health and Substance Abuse through previous professional relationships. The researcher had also completed a year-long clinical internship at the Department prior to conducting the present study, providing
the researcher with prior knowledge of and exposure to the environment of the Department itself, including its consumer base and treatment programs. Another way to demonstrate sensitivity to context is through carefully carrying out the qualitative interviews, being mindful to be empathic and establish rapport to increase the participants’ comfort and mitigate any power differentials between the participants and researcher (Smith et al., 2009). The researcher made efforts to put the participants at ease and establish rapport before the actual interview commenced, as well as made reassurances that they were the experts of their experience. Sensitivity to context is further demonstrated by the researcher’s investigation of the relevant literature to the subject matter (Smith et al., 2009). An extensive literature review had been conducted prior to data collection, including a review of the philosophical and psychological theories necessary in helping to comprehend the intricacies of existentialism, in addition to a review of recent qualitative research studies focused on specific experiences associated with chronic mental illness.

The second criterion commitment and rigor can be demonstrated in IPA research through the researcher’s commitment to participants during the data collection process, as well as through the level of dedication to the data analysis procedures (Smith et al., 2009). This researcher ensured a high level of attention to the participants throughout the data collection process of the present study. Special care was taken in the selection of the participants to ensure the appropriateness of the sample for the research topic being investigated (Smith et al., 2009). In addition to outlining inclusion and exclusion criteria, several steps were taken by the researcher to screen potential participants at multiple levels, including the initial screening conducted with the treatment providers who
referred potential participants, as well as in-person screenings with each potential participant who agreed to meet with the researcher. Commitment to the participants was also ensured by reviewing the Statement of Informed Consent in detail with each participant and encouraging questions before participants signed their consent, having the participants determine the most convenient schedule to conduct the interviews, conducting interviews in a private room at the mental health facility where they receive treatment to further protect their identities, and checking in with each participant at the conclusion of their interview to see how each experienced the process. The researcher spent considerable time analyzing each transcript, with multiple reviews and adherence to the methodical data analysis procedures outlined in the Method section of this dissertation. The researcher continued to analyze the data even during the writing of the Results section as is typical in qualitative research.

Transparency and coherence refers to how clearly the description of the research process is written, and IPA research can meet this criterion through offering a detailed description of the different stages of the research process, including participant recruitment, data collection, and data analysis (Smith et al., 2009). The researcher has provided a detailed description of each of the steps taken to recruit participants, beginning with obtaining approval from the administrators of the Department of Mental Health and Substance Abuse, screening potential participants, and obtaining informed consent. The stages of data collection and data analysis were also written in depth, including how the interviews were conducted following the participant’s lead, how each interview transcript was methodically reviewed, and the process implemented to identify emerging themes from each transcript. The researcher paid detailed attention to the data
analysis process to maintain adherence to the methodological and theoretical underpinnings of IPA research, wherein each transcript is reviewed and analyzed before proceeding to the next data set.

*Impact and importance* refers to the potential for the research to contribute to real-life applicability. Smith and Osborn (2008) suggest that IPA research is of particular importance due to the nature of this type of inquiry because its purpose is to gain a deeper understanding of a phenomenon in order to contribute to our knowledge about that phenomenon, which has the potential for theoretical and practical application in the real world. The present study is of substantial importance to our understanding of individuals living with chronic mental illness in Guam because no study on this topic had been conducted in this region or with this cultural group. The findings of the present study have the potential to impact mental health treatment in Guam, as well as to enhance the education and training of present and future local mental health professionals. The present study can also be used to further the aim of combatting the stigma of mental illness in Guam’s community through greater awareness and appreciation of the humanness of individuals living with chronic mental illness.

**Recommendations for Future Research**

Although the present study was aimed at providing a comprehensive overview of the experience of living with chronic mental illness, other studies may be indicated to further the knowledge in this area. The present study relied on the participants’ recollections of past experiences throughout their lifetimes with their illness, which could have been impacted by such factors as the difficulties associated with their illness or medications or the coloring of past experiences by present emotions. A recommendation
for future research would be to conduct a longitudinal study that follows individuals with chronic mental illness over the course of their illness to obtain more direct and immediate access to the experience of mental illness.

Another area that might warrant examination is the lived experience of individuals living with specific psychiatric disorders. The present study included participants with various disorders because the goal was to explore the lived experience of chronic mental illness in general. Research exploring the experiences of individuals with specific mental disorders may yield more detailed results in terms of what it is like to experience the symptoms associated with that disorder, particularly for individuals living with the disorder in Guam. It would be interesting to learn, for example, if certain disorders are met with more or less stigma or shame among individuals living with particular disorders in Guam.

More in-depth research on the role of families with regard to the experience of mental illness in Guam would be of particular importance; the participants in the present study spoke of how their families’ reactions and responses to them appeared to play significant roles in how they experienced their mental illness and themselves. The present study did not specifically set out to understand the contextual factors of the experience of chronic mental illness in Guam, such as the role of the family. A more comprehensive exploration is recommended to understand how the experience of mental illness is impacted by the presence or absence of the family in light of Guam’s cultural context that places value on family support and where socialization occurs primarily within the extended family setting. Research by Ronald San Nicolas (1996) on working
with Chamorro families of individuals with mental illness in Guam can serve as a model for new studies in this area.

Although the present study included participants who were members of the two majority ethnic groups in Guam (i.e., Chamorro and Filipino), none of the participants came from other ethnic groups represented in Guam’s culturally diverse population. It would be of interest to examine the experience of mental illness among Guam’s Micronesian immigrant population, particularly individuals living with mental illness who recently immigrated to Guam from the Micronesian islands where western influence has been less encompassing, in order to understand their conceptualizations of mental illness and how their cultural identification impacts their experience of mental health treatment in Guam.

**Concluding Remarks**

The idea for the present study came quite naturally as an interest of the researcher to learn what it is like for individuals to live with a mental illness that has little, if any, chance of being completely eradicated, cannot be readily seen by an outsider and can have a significant effect on their lives. While working clinically as a pre-doctoral intern with individuals living with chronic mental illness, the researcher had the opportunity to get to know several of these individuals beyond their symptoms, presenting problems, and treatment goals. The researcher quickly realized that there was much more to be learned from individuals diagnosed with a mental illness than their clinical presentations, reminding the researcher that they all had lives that were not that much different from those of everyone else, complete with dreams, wishes, and goals, as well as fears, doubts, and worries. In many ways, the researcher, who was supposed to have a better
understanding of mental illness than lay persons due to years of professional education and training in clinical psychology, was just as guilty of making assumptions and at times believing preconceptions commonly associated with mental illness. Because of this, there arose a fervent desire for the researcher to make use of this research opportunity to serve as an avenue through which individuals living with chronic mental illness could teach others—mental health professionals and the community of Guam alike—about how mental illness affects the person beyond the illness’s symptoms. The researcher also felt at times that the focus of much of mental health treatment toward the reduction of the problematic symptoms of mental illness does not leave much room to assist individuals with chronic mental illness with the actual task of living with the illness. It is the researcher’s hope that the present study not only serves as a voice for the ten participants but can also spark the impetus to make changes in the ways mental illness is viewed in Guam’s community so that the stigmatization and marginalization so often consequent of mental illness is no longer an experience that must be included in the lives of individuals living with chronic mental illness, as well as encourage mental health treatment providers always to be mindful of the person whose humanity may at times be forgotten or lost amidst the illness and its symptoms.
References


APPENDIX A

Interview Protocol
Interview Protocol

Part 1: Demographics

I will begin by asking some basic questions to help me get to know you.
1. How old are you?
2. What is your ethnic background?
3. How long have you been living in Guam?
4. What is the highest level of education that you have completed?
5. Are you currently working? What type of work do you do?
6. What is your living situation right now? Do you live alone? With family? With friends?
7. What is your marital status?
8. Do you have any children? If so, how many and what are their ages?

Part 2: Lived Experience of Chronic Mental Illness

Phase I: Unstructured Interview
Next, I would like to ask you about your experiences living with (diagnosis). In your own words, can you describe for me what it is like for you to live with (diagnosis)?

Phase II: Semi-Structured Interview
Next, I would like to ask you some specific questions about your experiences living with (diagnosis).

A. Initial Experience with the Illness
Can you tell me what it was like for you when your illness first began?

Prompt questions:
1. Can you tell me what was happening in your life before your symptoms began?
2. What was happening in your life when the symptoms first started?
3. What was it like for you when your symptoms started?
4. What differences did you notice?
5. Did you notice any changes in the way you experienced yourself? If yes, how so? How did you feel about yourself? What was your understanding of what was happening to you at that time?
6. Did you notice any changes in the way you felt when you were around other people. If yes, how so? Did you notice any changes in the way people treated you? If yes, how so? Did you notice any changes in how you interacted with people? Can you describe these changes?
7. How did you explain to yourself or others what was happening to you?
B. The Experience of Living with Mental Illness
Can you tell me about your experiences living with (diagnosis)?

Prompt questions:
1. What is your view of your illness?
2. How does living with (diagnosis) affect your day-to-day life?
3. How does living with (diagnosis) affect the way you see yourself/your identity?
4. How does living with (diagnosis) affect your interactions/relationships with other people?
5. How does living with (diagnosis) affect your desire for connection with others? Do you find yourself reaching out to others or do you find yourself preferring to be alone?
6. How does living with (diagnosis) affect your view of life in general?
7. How does living with (diagnosis) affect your view of the future?
8. How does living with (diagnosis) affect the meaning of your life? In what ways do you see your life as meaningful or not meaningful?
9. How does living with (diagnosis) affect your ability to make choices in your life? In what ways do you feel that you are free to make choices in your life/to be in control of your life? In what ways do you feel that your illness interferes with your ability to make choices in your life/to be in control of your life?

Part 3: Lived Experience of Receiving Treatment

Phase I: Unstructured Interview
Can you tell me about your experiences receiving treatment for (diagnosis)?

Phase II: Semi-Structured Interview
Next, I would like to ask you some specific questions about your experiences receiving treatment for (diagnosis).

A. Initial Experience Receiving Treatment
Can you tell me what it was like for you when you first received treatment for (diagnosis)?

Prompt questions:
1. What made you decide to seek help for what was happening to you?
2. What was it like for you when you first sought help? Can you describe some of your experiences?

B. The Experience of Being Diagnosed
Can you tell me about your experiences with being diagnosed with (diagnosis)?

Prompt questions:
1. What is/are your diagnosis/diagnoses?
2. How old were you when you received the diagnosis/diagnoses?
3. What was your reaction when you were first told you had (diagnosis)? What was your understanding of the diagnosis? When you were told you had (diagnosis), what did you think? How did you feel? What was it like to realize you had (diagnosis)?

4. What did it mean for you when you were told you had (diagnosis)? Did the diagnosis help you to understand what you were going through? If so, how?

5. How has the diagnosis affected how you see yourself?

6. Have you told other people that you have (diagnosis)?
   a. If yes, how did you go about telling others? What was it like for you when you told others that you have (diagnosis)? In what situations or relationships do you avoid telling others that you have (diagnosis)? What makes you decide whether or not to tell others about your illness?
   b. If not, what keeps you from telling other people that you have (diagnosis)?

C. The Experience of Being on Medication (for participants with a history of being on medication)
Can you tell me about your experiences with being on medication?

Prompt questions for each medication:
1. Have you ever been on medication for your illness? What types of medication have you taken? How long did you take each medication? What types of medication are you currently taking?
2. Can you tell me what it was like when you first started taking (medication)?
3. What was it like for you as you continued to take (medication) over time? How did you feel? How did it affect your symptoms? What were some of the side effects? How did it affect your day-to-day functioning?
4. How did taking (medication) affect how you felt about yourself?
5. How did taking (medication) affect your interactions/relationships with others?
6. What does taking (medication) mean for you in your life?

D. The Experience of Being Hospitalized (for participants with a history of hospitalization)
Can you tell me about your experiences being hospitalized for (diagnosis)?

Prompt questions:
1. Have you ever been hospitalized because of your illness? If so, how many times, and how long was each hospitalization?
2. What were the circumstances leading to your hospitalization(s)?
3. What was it like for you being in the hospital? Can you describe some of your experiences?
4. How did being hospitalized affect your illness?
5. How did being hospitalized affect how you saw yourself?
6. What were your relationships like with treatment staff when you were in the hospital?
7. What were your relationships like with other patients when you were in the hospital?
8. What were your relationships like with family and friends when you were in the hospital?
9. What did being hospitalized mean for you?
10. What was it like for you when you were discharged from the hospital?

**E. The Experience of Receiving Other Mental Health Services**
Can you tell me about your experiences receiving other mental health services, such as psychotherapy or day treatment?

Prompt questions:
1. What other types of mental health services have you received or are you currently receiving?
2. What was it like for you receiving (mental health service)? Can you describe some of your experiences?
3. How did receiving (mental health service) affect your illness?
4. How did receiving (mental health service) affect how you saw yourself?
5. What were your relationships like with your psychiatrist, psychologist, therapist, social worker, nurse, or other treatment staff while you were receiving (mental health service)?
6. What were your relationships like with family and friends when you were receiving (mental health service)?
7. What did receiving (mental health service) mean for you?
APPENDIX B

Participant Recruitment E-mail Correspondence
Hi [Name] - Please forward my email below to the clinical staff. Thanks so much! Cristina

Dear DMHSA Clinical Staff:

I am a doctoral candidate in clinical psychology at Antioch University Seattle in Washington State, and a former CASD therapist (2000-2004) and former doctoral intern (2008-2009) at DMHSA. I have received approval from Dr. [Name], Dr. [Name] and Mr. [Name] to conduct my doctoral dissertation research with DMHSA consumers. My dissertation is entitled, "Existential Concerns of Individuals Living with Chronic Mental Illness in Guam." I am hoping to conduct one-to-one interviews with several adult DMHSA consumers who have been diagnosed with a long-term psychiatric disorder to gain an in-depth exploration of the experience of mental illness (i.e., how having a chronic mental illness impacts their views of themselves and their lives). The interview may last 2 hours and can be done in one meeting, or over the course of 2-3 meetings. My schedule is open and flexible, so I can meet at the consumer's convenience. **Each participant will receive a $20 gift card.**

I am currently working with [Name] to identify consumers who may be appropriate to participate in my study. Dr. [Name] invited me to present my research study at the Clinical Team Meeting on Wednesday (Sept. 19), and she has asked me to send an email outlining the criteria for potential participants. The inclusion criteria for potential participants include:

- At least 18 years old.
- Diagnosed with a long-term mental illness (e.g., schizophrenia, bipolar disorder, schizoaffective disorder, chronic depression) and able to articulate their experiences.
- Must have had the illness for at least 5 years.
- Must have resided in Guam for at least 5 years.
- Preferably Chamorro, Filipino, other Pacific Islander or other Asian descent with fluency in English.
- May have a co-occurring substance use disorder, but primary diagnosis must be a psychiatric disorder.
- May have mild mental retardation, but primary diagnosis must be a psychiatric disorder and consumer must be able to articulate their experiences.
- May be living in one of DMHSA's group/residential homes, living independently, or living with family.

Please provide Dr. [Name] with the names of consumers you think may be appropriate to participate in the study by Friday, September 28. Interviews will be conducted during October and November at the main DMHSA facility in Tamuning.

Thank you for your assistance.

Cristina Dela Cruz, MA, IMFT
Psy.D. Candidate
Antioch University Seattle

Telephone: [Number]
Email: [email]
APPENDIX C

Statement of Informed Consent
Statement of Informed Consent

I would like to invite you to participate in a research study on chronic mental illness in Guam. Below is an outline of the study, including the purpose of the study and the procedures to be used, as well as the risks and potential benefits of participation. If you have any questions while reviewing the information below, please feel free to ask me. After reviewing this information, if you decide to participate in the study, please sign your name at the end of this form.

1. **Title of Research Study:** Existential Concerns of Individuals Living with Chronic Mental Illness in Guam.

2. **Researcher:** Cristina Dela Cruz, M.A., Psy.D. Candidate in Clinical Psychology, Antioch University Seattle.

3. **Purpose of Research Study:** The purpose of this study is to learn about the experiences of individuals living with a mental illness in Guam. This includes how living with and receiving treatment for a mental illness affects individuals’ day-to-day lives, their understanding of themselves, their relationships with other people, their view of life in general, their view of the future, and the meaning of their lives.

4. **Procedures:** Participation in this study will involve meeting with the researcher for approximately two to three interviews, each lasting approximately 30-90 minutes. The interviews will be held in an office, therapy room, or other private space located within the mental health treatment facility where you receive services. There will be three parts to the interviews. The first part will include questions regarding your personal background. The second part will include questions about your experiences living with a mental illness. Finally, the third part of the interviews will focus on your experiences receiving treatment for your illness. The interview sessions will be voice-recorded and transcribed by the researcher. You will receive a $20 gift voucher for your participation, which you may keep even if you choose to stop participating without completing the interviews. Please feel free to ask the researcher any questions about these procedures at any time.

5. **Risks:** The risks involved with participation in this study are minimal. You might experience some minor emotional discomfort when answering questions concerning your experience of living with a mental illness. If you feel any emotional discomfort during the interviews, please inform the researcher immediately. At any time, you will have the right to take a break, decline to answer questions, end the interview, or turn off the voice-recorder. In addition, you will be given the opportunity to discuss with the researcher any emotional discomfort you experienced. If you would like additional support for any emotional discomfort that arose during the interviews, you will be referred to your current treatment provider.

6. **Benefits:** By participating in this research study, you will receive the opportunity to discuss how living with a mental illness has affected your life. Through this process, you may gain greater awareness, insight, and understanding of your experience of living with a mental illness. Participating in this study will also provide you with the opportunity to share your experience of living with a mental illness with others, thereby making an important contribution to the mental health community. By sharing your experiences, you will be helping mental health professionals and others in the community to learn what it is like to live with a mental illness in Guam. Such knowledge can help mental health professionals to develop more effective treatment interventions and other mental health services. The knowledge you share may also play an important role in reducing the stigma sometimes associated with mental illness in Guam.
7. Confidentiality and Privacy: All information provided in the research interviews will be kept confidential and secure, and will not be identified with your name. Only the researcher and the research supervisor will have access to the interview materials. To further protect your privacy, no identifying information will be revealed in any written or oral presentations of the research. When quotations from interview transcripts are used, identifying information will be changed so that you cannot be identified. For example, the researcher will disguise, alter, or eliminate personal details such as the name, age, village, school, or place of work of yourself and any other persons mentioned in your interviews.

8. Contact Information: If you have any questions regarding this research study, please contact the principal researcher, Cristina Dela Cruz (689-0663 / cdelacruz@antioch.edu), or the research supervisor, Dr. Patricia Linn (206-268-4810 / plinn@antioch.edu). For any concerns regarding this research study, please contact Dr. Alex Suarez, Chair of Antioch University Seattle’s Institutional Review Board (206-268-4810 / asuarez@antioch.edu).

9. Voluntary Participation: Taking part in this research study is entirely voluntary. If you do not take part, there will be no penalty and it will not affect any services or other benefits you might receive from your treatment provider. You are free to withdraw consent and to discontinue participation in the study at any time.

I have read and/or listened to and understand the statements listed above. The researcher has answered all of my questions to my satisfaction. I voluntarily agree to participate in this study.

Signature of Participant:_________________________ Date: ____________

Name of Participant (Print):_________________________

Signature of Public Guardian (if applicable):_________________________ Date: ____________

Name of Public Guardian (Print):_________________________

Signature of Researcher:_________________________ Date: ____________

Name of Researcher (Print): Cristina Dela Cruz, M.A., Psy.D. Candidate