

To Tame a Volcano: Patients with Borderline Personality Disorder and Their Perceptions of Suffering

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The aim of the study was to investigate life situations, suffering, and perceptions of encounter with psychiatric care among 10 patients with borderline personality disorder. The results are based on a hermeneutic interpretation of narrative interviews in addition to biographical material (diary excerpts and poems). The interpretation revealed three comprehensive theme areas: *life on the edge*, *the struggle for health and dignity—a balance act on a slack wire over a volcano*, and *the good and the bad act of psychiatric care in the drama of suffering*. These theme areas form a movement back and forth—from despair and unendurable suffering to struggle for health and dignity and a life worth living. Common beliefs regarding these patients among personnel and implications for psychiatric care are discussed in relation to the results.

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BORDERLINE PERSONALITY DISORDER (BPD) is a psychiatric health problem with a reputation of being difficult to deal with and treat. Patients suffering from BPD are characterized by identity problems and unstable relations, lack of impulse control, emotional instability, and feelings of emptiness, often in combination with anxiety, depression, and substance abuse (American Psychiatric Association [APA], 1994). Suicide rates

are prominent; long-term follow-up studies suggest that 3%–13% die from suicide (McGlashan, 1986; Paris, 2002; Stone, 1993) and a Swedish study found BPD diagnoses behind 19 (33%) of 58 suicides committed by adolescents and young adults (Runesson & Beskow, 1991). Health-related quality of life is shown to be extremely low among these patients (Perseius, Andersson, Åsberg, Samuelsson, submitted for publication). To a very great extent, it is women who are suffering from the disorder (Widiger & Weissman, 1991). The literature on the epidemiology of BPD is scarce, but an American review suggests a prevalence between 0.2% and 1.8% in the general population and 15% among psychiatric outpatients (Widiger & Weissman, 1991). These findings correspond well to those of a recent Norwegian study (Torgersen, Kringlen, & Cramer, 2001) that found a 0.7% prevalence of BPD in a large community sample. A Swedish study found a 28% prevalence of BPD among psychiatric outpatients (Bodlund, Ekselius, & Lindström, 1993). Patients with BPD often evoke uneasiness and attitudes of being troublesome and manipulative among the staff involved in

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the treatment (Linehan, 1993). The treatment dropout rates are prominent, and figures as high as 40%–50% within 6 weeks have been reported (Kelly et al., 1992).

Thus, BPD appears to be a serious health problem. The repeated suicide attempts and acts of deliberate self-harm (DSH) among patients with BPD reveal something about the magnitude of suffering that they are struggling with. But how is suffering experienced by the patients themselves? How do patients with BPD experience their life situation and their encounters with psychiatric care?

The aim of this study was to find some answers to these questions, which to our knowledge have not been investigated before. Being able to better understand how patients understand, we believe, is an important step toward improved care.

THEORY

The analysis in the current study is largely structured by the theories of health and suffering developed by Eriksson (1994); Lindholm and Eriksson (1993). Eriksson sees suffering as an inseparable part of human life. It has many faces and many characteristics but lacks an explicit language. There are different forms of suffering in health care: suffering related to illness, suffering related to life circumstances and existential issues, and suffering related to care (Eriksson, 1994). Eriksson also makes a distinction between endurable and unendurable suffering. The unendurable suffering paralyzes human beings and takes priority over possible life goals, preventing them from growing, whereas endurable suffering is compatible with health and growth as human beings (Eriksson, 1994). The ultimate purpose of caring is to alleviate suffering, to help sufferers along the path from an unendurable suffering to an endurable one. A human being who suffers needs validation of his/her suffering and time and space to become reconciled to the suffering (Eriksson, 1994). Lindholm and Eriksson conceptualize the encounter between a suffering patient and the caring professions as a drama in three acts. In Act 1 (confirmation of suffering), the patient meets the carer and hopefully receives confirmation and validation of the suffering. Act 2 (being in suffering) is shaped by the extent to which the carer can give support and help the patient endure and accept the suffering, to give the patient time and space to suffer and stay with him/her and share the

suffering. Act 3 (becoming in suffering) is shaped by the extent to which acceptance and reconciliation are achieved. Then, there is a possibility of a new understanding, further growth, and development. However, if acceptance is not achieved, there is a risk of disappointment and bitterness (Lindholm & Eriksson, 1993). Alleviating a human being's suffering implies being a co-actor in this drama. When health care fails to encounter and care for the sufferer efficiently, it often adds to the suffering and Eriksson's third form of suffering, suffering of care, occurs.

SUBJECTS AND METHODS

Subjects

In 2000, we were asked if we could help evaluate a clinical development project in southern Sweden, in which an outpatient psychosocial intervention for self-harming patients with BPD was used. In the evaluation, we focused on the patients' own worded experiences from the intervention by using interviews. (For details on the intervention and evaluation, see Perseius, Öjehagen, Ekdahl, Åsberg, & Samuelsson, 2003.) In relation to the aim of the present study, we asked questions about life situations and experiences of suffering among the informants. The interviews were amplified by biographical material produced spontaneously by the informants prior to the study.

Patients who had been in the psychosocial treatment for 12 months or longer ($n = 11$) were asked to participate after having the aims and the procedures of the study explained to them. One patient refused participation (without giving any reason) and was therefore excluded. The informants were 10 women aged 22–49 years ($Mdn = 27$ years). All 10 informants had a BPD according to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Axis II* (APA, 1994) as it was an inclusion criterion for the intervention. Other characteristics regarding psychopathology, rates of suicide attempts, and acts of DSH were collected through information given by the informants themselves. Regarding psychopathology, the informants reported that they suffered or had suffered from the following disorders: depression ($n = 9$), anxiety disorders ($n = 9$), eating disorders ($n = 3$), and social phobia ($n = 2$). Several informants also mentioned having suffered from a substance use disorder. Regarding their history of suicide attempts (intentional, acute, self-injurious

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