Brian C. McSHARRY
Erzsebet F. TOTH
David E. KOCH

An analysis of the phenomenon of »chronic physical invisible illness denial«

Analiza pojava zanikanja kronične nevidne telesne bolezni

POVZETEK

Za biopsihosocialno raziskovanje doživljanja ljudi, ki so zboleli za kronično telesno nevidno boleznijo in ki je ostala nediagnosticirana celo otroštvo in adolescenco, smo uporabili Interpretativno fenomenološko metodo (»IPA metodo«) in metodologijo omejenega realističnega socialnega konstrukcionizma. Za namene te študije smo kot primer vzeli Ehlers-Danlosov sindrom. V tem kontekstu smo razvili matrico, v kateri smo analizo narativov povezali s prispevki številnih avtorjev z relevantnih področij, da bi prikazali biopsihosocialne procese povezane z zanikanjem nevidne bolezni. Upamo, da bomo s tako ponazoritvijo prispevali k pojasnjevanju tega, kakšno je doživljanje ljudi s kronično nevidno boleznijo, ki gre lahko v smeri negativnega ali pozitivnega prilagajanja. Prav tako upamo, da bomo pripomogli k osveščanju psihoterapevtov in zdravnikov, kako se nezavedno izogibajo ustrezni oceni simptomatike nevidne bolezni in s tem k zmanjševanju dolgotrajnih nediagnosticiranih primerov.

KLJUČNE BESEDE

Nevidne bolezni, Ehlers-Danlos sindrom, moralizacija, odklanjanje, psihologizacija

ABSTRACT

The Interpretive Phenomenological Method (»the IPA method«) and the methodology of limited realist social constructionism were used to examine the biopsychosocial lived-experience of those who endure chronic physical invisible illness symptomology that remains undiagnosed throughout childhood and adolescence. For purposes of this study, Ehlers Danlos Syndrome was used as an exemplar. Within this context, a matrix was developed which synthesizes the study's narratives with the scholarship

BRIAN C. MCSHARRY, MA, JD, PHD (SCIENTIFIC PSYCHOTHERAPY DISSERTATION DEFENSE PENDING SIGMUND FREUD UNIVERSITY, VIENNA), MEMBER OF THE NEW YORK BAR, MCSHARRY2@GMAIL.COM.

ERZSEBET F. TOTH, PHD, SIGMUND FREUD UNIVERSITY IN VIENNA, COORDINATOR OF THE INTERNATIONAL PHD PROGRAM, ERZSEBET.TOTH@SFU.AC.AT.

DAVID E. KOCH, PHD, LCSW, CLINICAL ASSOCIATE PROFESSOR OF SOCIAL WORK AT FORDHAM UNIVERSITY, NEW YORK, CERTIFIED PSYCHOANALYST PRACTICE, NEW YORK CITY, DRDAVIDKOCH@GMAIL.COM.

from numerous pertinent fields in order to depict the biopsychosocial process associated with invisible illness denial. By highlighting the process in this way, it is hoped that this study will prove useful in casting some light on the lived experience of chronic invisible illness, including the negative and positive adaptive avenues opened to those who develop them. Moreover, it is also hoped that by making psychotherapists and physicians more aware of their own unconscious biases against validating invisible illness symptomology, the occurrence of cases of long-term undiagnosed chronic physical illness may be minimized.

KEYWORDS

Invisible illnesses; Ehlers Danlos Syndrome, moralization; turfing; psychologization.

Introduction: The Phenomenon of Delayed Diagnosis Of Chronic Physical Invisible Illnesses

For some of those who develop chronic physical invisible illnesses, the pursuit of a diagnosis can be filled with doubt and denial. The denial of invisible illnesses can manifest on any or all of the biopsychosocial planes, and when it does it can cause unnecessary complications.

As noted by Susan Sontag (1991), the modern psychosocial default tends to be towards psychologization of invisible illness symptomology. Indeed, as Professor Skevington (1995) establishes, it would appear that even some physicians would rather deny the physical aetiology of undiagnosed invisible illness symptomology than admit that modern medical science has its limits. It is easier, that is, for some to believe that unexplained invisible illness symptomology is psychiatric in origin, than it is to believe that modern medical imaging technology is not perfect.

Within this context, the instant study was undertaken in order to understand the biopsychosocial phenomenon of invisible illness denial and to develop a meaningful way of understanding it. EDS was used as an exemplar illness because the literature and anecdotal evidence indicates that EDS is especially prone to being misdiagnosed and psychologized by general practitioners (Lumley, Jordan, Rubenstein, Tsipouras and Evans, 1994). Indeed, there is even evidence to support the perverse proposition that the more extreme the symptomology of EDS, the more likely it is that a psychiatric label will be applied (Adib, Davies, Grahame, Woo and Murray, 2005).

EDS arises from a collagen insufficiency which causes systemic hypermobility (»double-jointedness«), hyperextensibility of the skin and chronic pain. Hypermobility may be dramatic to the point that it can cause spontaneous joint dislocations and reduction (i.e. »relocation«) of the dislocations (Castori, 2012). Hyperextensibility of the skin may result in easy bruising (Hakim, Malfait, De Paepe and Sahota, 2010).

Given the foregoing, one can appreciate how EDS may create a diagnostic Catch 22 situation. When a person with undiagnosed EDS seeks medical attention, if bruising is found to be present after spontaneous joint dislocation, allegations of self-harm may follow (Levy, 2016). However, if bruising is not present and spontaneous reduction has occurred, an incredulous physician—who is unaware of EDS—may find themselves left with no objective evidence to substantiate claims of injury. Psychiatric labelling may follow (Castori, 2012).

Psychiatric labelling may also occur when symptoms of Chronic Widespread Pain (CWP), Chronic Fatigue Syndrome (CFS) and gastrointestinal malfunction are raised to a general practitioner by a person with EDS. This is because CWP, CFS, and gastrointestinal issues, when otherwise unexplained, may be indicative of a psychological issue. However, in the case of EDS patients, a physical explanation for these conditions may exist. Moreover, as Castori (2012) notes, when EDS is diagnosed and treated many of these pseudo-psychiatric symptoms may disappear.

As such, one can also readily see why the failure to determine the physical aetiology of a genuine case of EDS may lead to the development of secondary psychological symptoms associated with unjustified social disbelief and self-doubt, a phenomenon noted by Murray, Yashar, Uhlmann, Clauw and Petty (2013).

Method

Study Participant Identification and Participation

After appropriate ethics approval, respondents were solicited from the over one-thousand strong membership of a support group for those with EDS. Eighteen individuals initially responded. Of those, eight continued to follow up, and the six who had been formally diagnosed with EDS were ultimately selected. Within this context, it is worth noting that the six participants were women, and they are identified by the aliases »Sally,« »Cheryl,« »Marie,« »Shania,« »Jane« and »Susan.« They ranged from their early twenties to mid-sixties, and all but one had a third level education.

Given the data collected in this study it should be noted that the low response rate cannot be taken as indicating that a small percentage of persons with EDS have been affected by the phenomenon of invisible illness denial. Instead, an alternate explanation could include something as straightforward as being unwilling to have one's personal life pried into in connection with an experience which causes feelings of pain, anger, fear, and shame.

The IPA Method and the Methodology of Limited Realist Constructionism.

The IPA method emphasizes the development of meaningful interpretive theories from the subjective lived experience of study participants. It is not broad and thematic, but instead it is focussed, and through such focus it seeks depth and interpretation. As such, Hefferon and Rodriguez (2011) suggest that doctoral students select between four to ten data points while making an idiographic commitment. Hefferon and Rodriguez also note that by using this method the individual and the group experience can be woven together by the researcher while making the patients' voice and the interpretation of the researcher equally clear. In this context, the emphasis is not on generalisability, as such, but on the transferability of findings in light of current scholarship and experiential knowledge.

Given that the IPA method is qualitative and phenomenologically based, it has much in common with Van Manen's approach (1990). Essentially, scholarship and experience in the field are not to be ignored, but utilized. Moreover, engaging in qualitative research should be a dialectical process where open-ended questions are asked with the aid of a protocol, and the researcher follows up with related questions in order to obtain as much material information as possible (Kleining and Witt, 2000). Within this context, Biggerstaff and Thompson (2008) emphasize that the researcher should immerse him or herself in the data to the point of saturation, identifying themes and connections.

While so doing, it is imperative that the researcher acknowledge his or her own philosophical prejudices and positions, lest these inadvertently skew interpretation of the data. In that regard, the instant study uses a limited realist social constructionism approach, in order to provide the IPA method with a coherent ontological framework.

The limited realist social constructionist approach views the human being as an entity in flux and dialogue with its biopsychosocial reality (Slife, 2011). Within the area of psychopathology, in particular, this approach is useful because it highlights the fact that an honest exploration of psychopathology must be done, not in isolation looking at the individual, but as a biopsychosocial analysis:

»A social constructionist view of psychopathology does not imply that human psychological pain does not exist, or that the patterns of thought, emotion, or behaviour that we use to label psychopathology cannot be scientifically studied. It means, instead, that the notion of individually and subjectively perceived psychological suffering as disorder or disease is socially constructed, and that this must not be overlooked. A conception or theory of psychopathology does not simply describe and classify characteristics of groups of individuals, but … actively constructs a version of both normal and abnormal … Which is then applied to individuals who end up being classified as normal or abnormal« (Gelo, Vilei, Maddux and Gennaro, 2015, p. 108).

Results

Analysis of the narratives of the study participants reveals many commonalities and themes, and much depth, associated with enduring long-term biopsychosocial denial of the legitimacy of one's invisible illness.

Susan notes that in childhood her »legs and ankles kept giving way« and »giving out« but she viewed this as being merely part of who she was. When she experienced pain or joint malfunction, she simply took the pain for granted. Indeed, Shania also mentions that her parents would dismiss her complaints of pain as being merely normal growing pains.

Sally notes that from the age of two she experienced frequent joint subluxations, or partial dislocations. Yet, she says, she didn't think her body was »unusual because it was normal for me.« Jane even recollects that when she was young her hands began to routinely swell and hurt because of a bag she carried to school. But the fact that she was in pain only occurred to her later, as an adult. Her initial reaction was denial.

This conceptualization that »pain is normal for children« permeated their lives as children, and it came from both their own tendency to deny pain, and from the authority figures in their lives. It was biopsychosocial in that their bodies, their minds, and the social structure—parents, teachers and even physicians—told them that the pain they felt was normal.

In connection with this, we see reinforcement of denial through concepts of guilt and force of will, factors which hint at efforts to compel »wellness« in order to evade the social penalty of stigmatization. As such, Susan remarks that when she was young she did not dwell on pain lest she be considered a »moaner.« Indeed, she tells the story of how she once fractured her ankle but kept quiet about it for as long as possible because, she says, »I doubted my symptoms and kept them to myself so as not to make an issue out of it.«

Sally, whose father was a Marine, says that »the expectation in my family was to keep moving, to tough it out and not complain too much.« As such, she was once surprised when a physician told her that her old shin fracture had healed well, because she had no recollection of having previously fractured her shin, at all.

»I thought it was a normal part of growing up. But, then again, now you look back at things and you think about how much sense it all makes,« says Jane, who continues, »you know no different, you don't think to question it.«

However, as Cheryl points out, there came a time when she could no longer simply believe that her illness was normal, but even embarking on a quest for a diagnosis was not easy. »Of course, when you are told you are fine, you start to doubt yourself,« she says.

Moreover, one particular incident sticks in her mind in terms of the social consequences of seeking a diagnosis for an invisible illness. On her birthday, her sister, a nurse, bought Cheryl a birthday present that would »help her get all better.« It was an appointment with a psychiatrist, a gift that devastated Cheryl emotionally.

For Susan, who had eleven major surgeries before she was diagnosed, the social pressure to be »normal« and keep quiet was intense. As she puts it, she tried not to complain, »in case they thought I was a bit of a hypochondriac.« Her experience with physicians was especially difficult: »A couple of doctors made me think it was all in my head. They would say things like 'Oh you again, why are you here?' And they would make me feel like I was just moaning. I wasn't trying. They couldn't understand where it was all coming from.«

Marie tells of how when she was younger she was vomiting and not putting on weight. As a result, her mother made her see a counsellor. Marie's counsellor said that she had anorexia and stress-related temporomandibular joint dysfunction (TMJ) which were, in turn, indicative of the fact that she »wanted attention.« She was even prescribed tricyclic antidepressants. Not unsurprisingly, given that such symptoms were EDS-related, »none of them ever worked.«

Marie also tells of how she was once referred to a rheumatologist for recurrent wrist pain. When the rheumatologist could not diagnose her problem, she says that he implied that she was both a psychiatric case and a malingerer. He told her that he thought »I was just trying to get attention and I probably hated my job and was looking for an excuse to stay home.«

In connection with this, we see the two forms of social denial: stigmatization, and its obverse, masking. Stigmatization involves application of a label by society. In the context of the phenomenon of invisible illness denial, the social tendency seems to be to apply »the psychiatric case« label, especially when the condition has not formally been diagnosed by a physician.

The second form of social denial stems from the individual's unwillingness to expose him or herself to social stigma through application of »the psychiatric case« label. Those with invisible illnesses achieve this by »masking,« or hiding, their invisible illness symptomology to the greatest extent possible.

In terms of masking, Susan simply »keeps quiet« about her symptoms as much as possible. Sally says that her »masking techniques as a child were just to hide that I was hurting. I was fairly successful. [However,] as an adult, it's harder to hide because it hurts much more. I don't talk about my pain or symptoms with others very often…«

However, in terms of her friends and those who understand her condition, she says: »With friends who are more understanding, I will feel more comfortable about 'reporting out' but I rarely allow myself to vent with anyone. I feel that venting might give me a small amount of temporary relief, but the strain it gives my friendships is too costly and I fear losing my loved ones.«

Cheryl also admits to engaging in masking in order to »protect [herself] from any more judgment and hurt.« Of this she says, »Up until the age of 54, it was believed, by doctors and everyone else, that I was fine and that is what I tried to believe, too. I am great at playing pretend! Smile, act like all is fine, try to be active and get misinterpreted all the time even today!«

Marie also engages in masking behaviour and she utilizes disengagement coping techniques. Of this, she says, she prefers to avoid seeing physicians whenever possible. This is true even though she now has a formal diagnosis and a physiological explanation for her symptomology.

Masking continues even after a formal diagnosis is obtained. But, the narratives reveal that when an invisible illness diagnosis is obtained, a process of grief, frustration, mistrust, and anger, among other emotions, sets in. As part of this process, the affected person can blame themselves for not only their symptoms, but for participating in the social denial of those symptoms.

To that end, in a burst of emotion, Susan powerfully tells of when she received her diagnosis that she was: »Amazed. Suddenly I started linking everything together. Everything suddenly became very clear. I felt angry, relieved, everything made sense. I felt very angry. I wanted to tell [everyone who had disbelieved me] about what I had to do, and how I had to suffer. There was a reason. Personally, there are a lot of people who are suffering in silence and they have no one to turn to. [Many doctors] don't want to do anything that is too complex for them, so they end up blaming their patients.«

Jane also reveals the frustration and anger that emerged once she was diagnosed. She feels that she was betrayed and lied to, and she feels isolated. As a result, she says: »I think that the medical profession is hideous right now. When it came to the hospitals and the rheumatologists, I think they were useless. From sixteen to twenty-one I was not even told I had it. They did not tell me I had hypermobility or how to deal with it from when I was sixteen, even though they knew.«

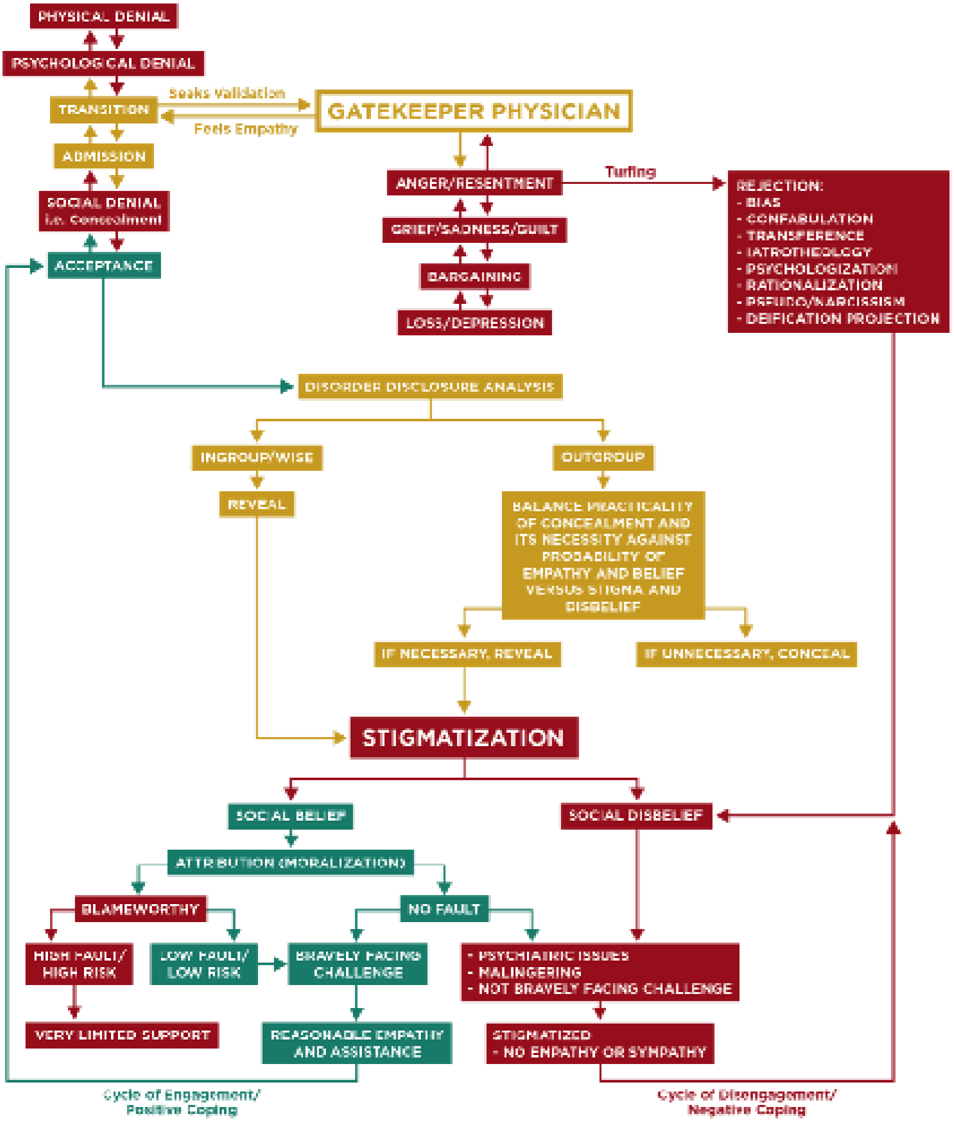
When Marie received her EDS diagnosis, she felt validated, but she recognizes that her: »anger does run deep. I wish I could get in the face of every doctor that was so nasty to me and tell them how wrong they were and shove the proof in their face. Nothing would make me feel more elated than the ability to shame these nasty unprofessional individuals that think they are superior to the lowly patients they scoff.« Marie, like many others, is so traumatized that she chooses to avoid seeing physicians whenever possible. She is tired of having her physical symptomology psychologized, especially since she has been officially diagnosed with EDS.

Moreover, Shania provides gripping evidence of the fact that the experience of denial and grief are not linear. She says that post-diagnosis she attempted to engage in bargaining her condition away as part of her effort to accept her illness: »I worked on my diet and lost 30 pounds and cut out inflammatory foods. To my disappointment at 118 pounds, I still felt pain. I definitely had Ehlers Danlos hypermobile Type III. I was someone shocked and in somewhat disbelief. I was also disappointed that there was no 'fix' for me. I couldn't change my diet or do anything to necessarily stop the effects of EDS. A few days later was my birthday and I remember crying as my friends and family sang 'Happy Birthday' to me. I told my sister who didn't understand because she or my parents don't have it. Regardless it has been an up and down journey... A little over a year later, I now have accepted the diagnosis [and] studied Ehlers Danlos...«

In the narratives of Sally, Cheryl, Marie, Shania, Jane and Susan we see a quest to find biopsychosocial equilibrium in a context where equilibrium can be frustrated and disequilibrium sometimes fostered. This quest involves a process. However, it must also be emphasized that we also see positive engagement coping and validation, as in the case of Sally. Sally says that her general practitioner initially doubted her symptomology and tended towards the psychologization of her illness. But, when she received an authoritative diagnosis from an expert in EDS, his behaviour changed. He immediately apologized for previously having doubted her and he said that he would read all of the articles available on EDS in order to learn more about her condition. She now views him as being a partner in her healthcare journey, and this partnership has helped her to engage in positive coping techniques and otherwise to adapt to her illness.

We also see Jane, who suffered little social denial at home because of the fact that her mother also suffers from the condition. This support and validation made her adaptation relatively easy, she says. In this adaptation, we also see a process.

Thus, in viewing the study participant narratives, we can see the commonalities and themes as a matrix which depicts process potentialities, the possibilities involved in the lived-experience of those who have undergone the phenomenon of invisible illness denial. This matrix can be conceived and constructed as Figure 1, below, *The Biopsychosocial Invisible Disorder Process Analysis Chart.*



Analysis and Discussion

Figure 1 shows the journey involving the lived reality of those who develop chronic physical invisible illnesses. Interpretation of this figure begins in the top left-hand corner. By beginning there, and tracing downwards, we can see that the phenomenon of invisible illness denial involves biological, psychological and social elements.

Physical Denial

In terms of the tendency of humanity to physically deny injury, the scholarship reveals that, in connection with the »survival instinct,« the brain has an inherent evolutionary ability to deny the early symptoms of illness. When the body is injured, the brain initiates a biochemical »fight or flight« reaction, and as part of this reaction a pain-inhibiting and adrenalin fuelled cocktail is released. This masks pain and fosters flight from the noxious stimulus (Banja, 2005).

Psychological Denial

Once biological denial begins to wane, psychological denial begins to wax, and the unconscious ability to deny pain begins to rise in importance as depicted by Figure 1.

As noted by Anna Freud (1993) and Elisabeth Kubler-Ross (2014) among others, unconscious psychological denial is a coping mechanism which arises in response to a perceived threat. Very few things are more threatening than chronic illness, and when the symptoms of chronic illness start injecting themselves into the psyche, the mind reacts with denial in order to give itself time to process the illness and consider its options.

Transition Phase

When the ability to deny pain and malfunction begins to fade, a person with an invisible illness may ultimately move into the Transition Phase discussed by Knafl and Gillis (2002).

This process is both non-linear and tumultuous, and during the Transition Phase the mind can experience a plethora of mutually antagonistic emotions almost simultaneously. It is in this period that those affected by an invisible illness may seek out a physician in order to obtain a diagnosis.

The Gatekeeper Physician

In modern society, physicians discharge the social function of »gatekeeper.« As gatekeepers, they are charged with the socio-political function of making a determination as to whether an individual is entitled to claim »the sick role,« as discussed by Sim and Madden (2008). If a physician validates the symptomology of an illness, then this can assist with the person receiving social support for their illness, as discussed by Werner and Malterud (2003). However, some physicians may refuse to validate the physical aetiology of invisible illnesses, and instead label the patient as having a psychiatric condition. In such a situation the sick person may be »turfed« to a psychiatrist (Stein, 1986).

In connection with this, Stein—himself a psychiatrist—explains that the phenomenon of »turfing« occurs when a physician disposes of an individual to the field of psychiatry when the physician is incapable of diagnosing the physical malady affecting the person in question. When people are turfed they may receive no social support and engage in a cycle of negative disengagement coping, in the manner discussed by Strating, Suurmeijer and Van Schuu (2006) among many others. This, of course, does not mean that when a person is turfed there is not actually an underlying physical malady—just that the physician presumes there is none because he or she cannot find one. Within this context, Skevington (1995) notes that modern scientific psychology has shown that there is a bias in the medical profession against validating symptoms when modern diagnostic testing cannot demonstrate a cause for them.

Theoretically speaking this behaviour comes from the biopsychosocial need to deny the terror of death by using medical science as a transference object, as pointed out by theoreticians such as Becker (1997) and Reiken (2015). This need to deny death and illness can lead to phenomena such as medical iathrotheology and deification projection, as well as the attraction of disproportionate numbers of pathological and pseudo-pathological narcissists to the medical profession. However, a discussion of the theoretical underpinnings of these phenomena is beyond the scope of this article. Such a discussion will instead appear in the next edition of this journal.

Social Denial: Stigmatization and Masking

Sim and Madden (2008) point out that stigmatization of the sick allows society to rationalize its ostracization of the sick due to society's fear of contagion. Indeed, the word »stigma« has its origins in ancient Greece, and it relates to how slaves were identified, or »stigmatized,« by labelling them with cuts or burns (Taylor, 1991). As Joachim and Acorn (2000) note, persons with invisible illnesses may »mask« in order to conceal their condition from others so as to avoid stigmatization. The risk in doing so is that they may become inauthentic to themselves and others. However, the benefit of masking is that the masked person can pass as normal, thereby potentially avoiding stigmatization. Not surprisingly, therefore, masking is a default, and it is engaged in for as long as physically and psychologically possible.

Positive Engagement Coping

In looking at the left-hand side of Figure 1, we can see that when the symptoms of an invisible illness are validated by a gatekeeper physician, the affected person can begin moving through the grieving process. In so doing, they can obtain at least a modicum of both individual and social acceptance and equilibrium through the initiation of a cycle of positive engagement coping.

Through gatekeeper validation, social acceptance and integration can be facilitated. In this manner, it can be seen from the left side of Figure 1 that physician validation reinforces adaptation and social integration, so as to minimize the destabilization of people with chronic physical invisible illnesses. This is based on many studies, including those of Strating, et al. (2006) and Stanton, Revenson and Tennen (2007), to name but a few.

Negative Engagement Coping

Unfortunately, the gatekeeper physician does not always appropriately diagnose and validate the symptomology of invisible illness. This situation is depicted on the right-hand-side of Figure 1. As we have discussed, a gatekeeper physician can turf the patient through a number of rationalizations, including confabulation and psychologization (Stein, 1986). Looking again at the right-hand side of Figure 1, we can see that stigmatization associated with being labelled a psychiatric case can lead to an unsupportive social network and otherwise contribute to negative disengagement coping (Gallant, 2003). This can, in turn, cause anxiety, anger, depression and social maladjustment-issues secondary to chronic pain and disbelief. Indeed, the person may also experience the psychological pain of self-doubt as to the validity of their own symptomology.

The Calculus of Social Support

Even when a person's invisible illness has been validated, it is important to note that it does not necessarily follow that they will automatically receive significant social support. This explains the fact that the default is for people to mask unless essential. When it does appear that it may be essential to disclose one's invisible illness to others, the affected individual may go through a disorder disclosure analysis. In connection with this, Crocker and Major (1989) explain that in making a determination as to whether to reveal an invisible illness to others, the affected person tends to separate others in society into an ingroup and an outgroup.

Within this context, the ingroup is represented by persons who have some knowledge about, and exposure to, the condition in question, or a condition like it. It is to this group to whom the person suffering a physical invisible chronic illness initially considers revealing their healthcare condition, because ingroup members possess special knowledge of, or experience with, the illness in question.

The outgroup is made up of normals, or persons with no known connection to, or interest in, the disorder in question. As such, outgroup members tend to be deemed as being far more likely than their ingroup counterparts to engage in stigmatization and to refuse to extend empathy and social support.

Once unmasked, the question becomes one of social denial. It is no longer an individual matter. As such, the belief/disbelief step depicted in the middle-right of Figure 1 shows a calculus that may be engaged in by members of society when attempting to determine the relative merit of an individual's claims to entitlement to the »sick role.«

If the claims of sickness are deemed to be unbelievable, then the default tends to be that the person may be deemed to be a liar, a malingerer or a psychiatric case. In such situations, no empathy is afforded and the person reporting out is stigmatized as a psychiatric case. If, on the other hand, the person's claims are deemed credible, then the social observer next considers the moral culpability of the person in connection with the symptoms of which they complain. This is the moral Attribution analysis step of which Weiner (1993) speaks and diagrams. If the complaining person is deemed to be morally responsible for their illness, such as a smoker who develops lung cancer, then the person's symptoms are moralized, and the suffering person tends to be viewed as being someone who invited their illness. In such a situation, the support rendered will be contingent upon a calculus involving the degree of blameworthiness associated with the condition, the risk of contagion, and the gravity of the harm, faced by a social observer rendering support.

In applying this calculus, we can see that a person with lung cancer from smoking will receive more social support than an intravenous-drug-using HIV patient with antibiotic resistant TB. In the case of lung cancer, smoking is viewed as a minor social evil in many societies, but it is not contagious at all. As such, the risk of harm to the person rendering social support is very low. However, in terms of moralization, intravenous drug use is seen as a great evil in society, drug-resistant TB is quite contagious, and the risk of death associated with it can be high. Consequently, a person with tuberculosis may receive some social support from some persons in society, but the support will be extremely limited.

The extent to which a person who is deemed to be morally responsible for their illness will be supported by society depends upon the degree to which they are seen to be bravely facing the challenges of their disorder. In looking at Figure 1, we can see that the analysis in this case becomes similar to the case of when the person reporting out is deemed to be morally blameless.

Specifically, even in the case of a morally blameless person who develops a chronic physical invisible illness, unlimited support does not necessarily follow. Instead, the social observer engages in a calculus with regard to the degree of support which must be rendered to the sick person as a perceived matter of ethics and morality. This process may, of course, be entirely the product of rationalization rather than one of reasoned ethics.

Within this calculus, the degree of severity of the illness is balanced against whether the affected person is perceived to be bravely facing the challenge posed by the illness. If the person is not perceived to be bravely facing their illness, then the social observer does not feel compelled to empathize with them or to otherwise offer support. In essence, they are stigmatized as psychiatric cases. If, the person reporting out is deemed to be bravely facing their health condition, then the observer may feel some degree of empathy towards them and, as a result, render support as necessary.

Conclusion

In reviewing the study in its entirety, we can see that when a person with a chronic physical invisible illness is turfed by a physician and disbelieved by society, a poor outcome can result. In such cases, disbelief and stigmatization can result in self-doubt and the implementation of a destructive cycle of negative disengagement coping. On the other hand, when an invisible illness is properly diagnosed by a supportive gatekeeping physician, the outcome may be markedly different. In such cases, an affected person may put in place an effective management strategy, resulting in the potential for a much more positive outcome.

Indeed, when a person's invisible illness has been legitimized by a gatekeeping physician, and that person is deemed by society to be bravely facing the challenge associated with his or her condition, some degree of social accommodation and acceptance tends to be afforded. This, in turn, may result in that person having the possibility of entering a cycle of positive engagement coping resulting in successful integration of their illness into their lives.

As noted previously, an analysis of the psychological theory underlying the instant work will be included in the next edition of this journal. The article in question will also include some thoughts and recommendations on potential ways of minimizing the occurrence of the phenomenon of invisible illness denial. In the interim, and as noted earlier, the fact that the six study participants were female may provide grounds for an interesting further study within the context of chronic physical invisible illness denial.

References

Adib, N., Davies, K., Grahame, R., Woo, P. and Murray, K.J. (2005). Joint Hypermobility in children: a not so benign multisystem disorder? *Rheumatology, 44*, 744-750.

Banja, J. (2005). *Medical Errors and Medical Narcissism.* Sudbury, MA: Jones and Bartlett.

Becker, E. (1997). *The Denial of Death.* NY, New York: Free Press Paperbacks.

Biggerstaff, D.L. and Thompson, A.R. (2008). Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research. *Qualitative Research in Psychology, 5(3)*, 214-224.

Castori, M. (2012). Ehlers-Danlos Syndrome, Hypermobility Type: An Underdiagnosed Hereditary Connective Tissue Disorder with Mucocutaneous, Articular, and Systemic Manifestations, *ISRN Dermatology, 2012*, 1-22.

Crocker, J. and Major, B. (1989). Social Stigma and Self-Esteem: The Self-Protective Properties of Stigma. *Psychological Review, 96(4)*, 608-630.

Freud, A. (1993). *The Ego and the Mechanisms of Defense.* London, UK: Karnac Books.

Gallant, M. (2003). The Influence of Social Support on Chronic Illness Self-Management. *Health Educ Behavior, 30*, 170-186.

Gelo, O, Vilei, A., Maddux, J. and Gennaro, A. (2015). Pathopsychology as Social

Construction: The Case of Anorexia Nervosa. *Journal of Constructivist Psychology, 28(2)*, 105-125.

Hakim, A., Malfait, F., De Paepe, A. and Sahota, A. (2010). The heritable disorders of connective tissues: epidemiology, nosology and clinical featres. In A. K. Hakim, *Hypermobility, Fibromyalgia and Chronic Pain* (pp. 3-17). London, UK: Churchill Livingstone.

Hefferon, K. and Gil-Rodriguez, E. (2011). Methods: Interpretive Phenomenological Analysis. *The British Psychological Society: the Psychologist…* 24: 756-759.

Joachim, G. and Acorn, S. (2000). Stigma of Visible and Invisible Chronic Conditions. *Journal of Advanced Nursing, 32(1)*, 243-248.

Kleining, G. and Witt, H. (2000). The Qualitative Heuristic Approach: A Methodology for

Discovery in Psychology and the Social Sciences. Rediscovering the Method of Introspection as an Example. *FQS Forum: Qualitative Social Research, Sozialforschung, 1(1)*, Art. 13, 1-19.

Knafl, K. and Gilliss, C. (2002). Families and Chronic Illness: A Synthesis of Current Research. *Journal of Family Nursing, 8(3)*, 178-198.

Kubler-Ross, E. (2014). *On Death and Dying, What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families.* New York: Scribner.

Levy, H. (2016). Ehlers Danlos Syndrome Hypermobility Type. In R. A. Pagon, *Gene Reviews* (pp. 1993-2016). Seattle, WA: University of Washington.

Lumley, M.A., Jordan, M., Rubenstein, R., Tsipouras, P. and Evans, M.I. (1994).

Psychological Functioning in Ehlers Danlos Syndrome. *American Jornal of Medical Genetics, 53*, 149-152.

Murray, B., Yashar, B., Uhlmann, W.R., Clauw, D.J., Petty, E.M. (2013). Ehlers Danlos Syndrome Hypermobility Type: A Characterization of the Patients' Lived Experience. *Am J Med Genet, Part A 161A*, 2981-2988.

Rieken, B. (2015). The Prehistory of Psychotherapy and its Implications for Psychotherapy Science: Shamanism, Folk Medicine, Philosophy, and Religion. In O. P. Gello, *Psychotherapy Research: Foundations, Process and Outcome* (pp. 9-37). Vienna, AU: Springer.

Sim, J. and Madden, S. (2008, July). Illness experience in Fibromyalgia Syndrome: A metasynthesis of qualitative Studies. *Social Science and Medicine, 67(1)*, 57-67.

Skevington, S. (1995). *Psychology of Pain.* Chichester: John Wiley and Sons.

Slife, B. (2011). The Special Issue on Ken Gergen’s Book Relational Being. *Journal of Constructivist Psychology, 24(4)*, 267-270.

Sontag, S. (1991). *Illness as Metaphor and Aids and its Metaphors.* New York: Penguin Classics.

Stanton, A.L., Revenson, T.A. and Tennen, H. (2007). Health Psychology: Psychological Adjustment to Chronic Disease,. *Annu. Rev. of Psychol., 58*, 565-592.

Stein, H. (1986). »Sick People« and »Trolls«: A Contribution to the Understanding of the Dynamics of Physician Explanatory Models. *Culture, Medicine and Psychiatry 10(3)*, 221-229.

Strating, M.M.H, Suurmeijer, T.P.B.M., and Van Schuu, W.H. (2006). Disability, social support, and distress in rheumatoid arthritis: Results from a thirteen-year prospective study. *Arthritis Care and Research, 55(5)*, 736-744.

Sugarman, J. and Martin, J. (2011). Theorizing Relational Agency. *Journal of Constructivist Psychology, 24(4)*, 283-289.

Taylor, M. (1991). Stigma: Theoretical Concept and Actual Experience. *British Journal of Occupational Therapy, 54(11)*, 406-410.

Van Mannen, M. (1990). *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy,* London, Ontario, Canada: SUNY.

Weiner, B. (1993). On Sin versus Sickness: A Theory of Perceived Responsibility and Social Motivation. *American Psychologist, 48(9)*, 957-965.

Werner, A. and Malterud, K. (2003). It is hard work behaving as a credible patient:

encounters between women with chronic pain and their doctors. *Soc Sci Med, 57(8)*, 1409-1419.