

The mourning process in chronic illness

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Chronic illness

Defining “chronic illness” is complex. The term is often mentioned in contrast to “acute illness”. Generally, the term refers to an incurable illness for which a course of treatment has not yet been established. A person with chronic illness may cycle between periods of mild improvement and relapse. Although chronic illness does not itself cause death, it is a lifelong affliction. Diabetes, asthma, epilepsy, and kidney problems are examples of chronic illnesses.

Psychological aspect of patients

Chronically ill patients must continue to live in spite of their ailments. In addition to physical implications, chronic illnesses may have psychological repercussions, including such negative feelings as helplessness, low self-esteem, anxiety, and depression. A person diagnosed with a chronic illness knows that his or her illness is ‘forever’. Thus, an examination of the psychological aspects of chronic illness must be undertaken in order to holistically address patients’ well being.

Focusing on mourning work

This study examined the psychological dimensions of patients’ chronic illness, using the concept of mourning. Chronic illness is a form of the “object loss”. Patients with chronic illness undergo various changes, including such “object losses”, as bodily functions, social constraints, etc. Patients accept their losses by going through the mourning process. Psychological reconstruction, as a function

of the mourning process would be the basis for patients' efforts to adjust to life with chronic illness.

Two models of the mourning process

There have been numerous studies on mourning work and there are two major models of mourning work in the field of disabilities and chronic illnesses. These two models contradict each other, but both contend that the mourning process is composed of five stages: shock/impact, denial, emotional confusion, effort at resolution/focusing outward, and acceptance/closure.

The first model, often called the "stage" or "linear" model, is pervasive among researchers and practitioners. According to this model, the five stages appear in the order listed above and the mourning process progresses linearly. In this model, the process will come to the end in the span of one or two years. The second model is called the "chronic sorrow model" or the "cyclical model". In this model, the five stages are divided into two phases. Phase I include the first three stages that are repeated cyclically. Phase II includes the other two stages. Proponents of this model suggest that disabled or chronically ill people seldom progress from Phase I to Phase II. Rather, they go through a cyclical process within Phase I.

The latter model has been presented as antithetical to the former model, particularly in the realm of disabilities or chronic illnesses. Because disabilities or chronic illnesses are permanent, people with disabilities or chronic illnesses inevitably confront stressors like deterioration and difficulties throughout their lives. Their grief does not diminish or resolve, so the mourning process never ends and the patients cycle between the first three stages.

Examination of two existing models

The "chronic sorrow/cyclical model" is important because it is based on the characteristics of chronic illness. However, no studies have examined the

relationship of both models to chronic illness. This study examined the application of both models to chronically ill peoples' life stories, as related after the onset of their illnesses.

Fourteen people with chronic kidney disease participated in the study. Their ages ranged from 19 to 34, and there were six males and eight females. In recognition of possible age or developmental differences in coping with chronic illness, this study focused on specific demographic population, that of young adults.

Discussion

Two patterns of mourning could be observed in participants' life stories; A) stages of shock/impact, emotional confusion, and effort for resolution/focusing outward appear in order; B) stages of denial and emotional confusion appear in order.

(1) Nature of the mourning process: Linear or cyclic?

This study found that the five stages of mourning did not progress in a linear fashion. Stages recurred in the face of major life events or deterioration. Several stages coexisted and overlapped in some cases. These results were more congruent with the chronic sorrow model or cyclical model than the linear model.

However, the shift from Phase I to Phase II occurred among 71.4% of participants in this study. Recurrence of stages was also not limited to the first three. These results suggest that neither model were applicable to chronic illness. But some characteristics of both models could be included. Namely while the mourning process has characteristics of chronic sorrow/cyclical model, it develops stage by stage towards "acceptance/closure" when macroscopically viewed.

(2) Positive function of "denial"

"Denial", the second stage in the mourning process, is a temporally and strong psychological defense mechanism that deals with acute emotional crisis at

illness onset. It buffers initially the shock by denying or refusing the illness. “Denial” is seen as a negative stage because it may delay or stagnate the mourning process, and can become pathological if a person does not move beyond it.

The “denial” observed in this study were milder than defined and seemed to be a particular attitude or strategy towards the chronic illness rather than temporally and strong defense mechanism. Chronically ill people must deal with everyday affairs, such as domestic duties, family matters, school, work, etc. This means that their illnesses cannot always be the centre of attention. In such cases, “denial” is effective because it temporarily pushes aside the illness and enables the sufferer to deal with other priorities. This research suggests that clinicians should pay more attention to the positive function of “denial”.

(3) Closure in the mourning process

“Acceptance/closure”, the final stage of mourning, did not occur for this study’s participants and is incompatible with the linear model which specifies its occurrence within one or two years. Most studies about mourning have focused exclusively on bereavement. In the case of chronic illness, the mourning process cannot be completed in such a short time span. Longtime adjustment is needed for chronic illnesses and the process of mourning inevitably becomes longer than it is for bereavement.

A conceptual issue surrounding “acceptance/closure” should be noted. It has been pointed out that the definition of “acceptance/closure” is too ambiguous. However, this is a difficult issue to reconcile especially in the case of chronic illness. Different people respond to chronic illness differently, so a rigid definition of acceptance vis-à-vis chronic illness seems inappropriate. In this study, there were diversities among participants with regards to “effort at resolution/focusing outward”, the stage before “acceptance/closure”. Namely, each participant tried to construct the meaning of his/her illness differently. We should reconsider the meaning of “acceptance/closure” in chronic illness, paying attention to such

diversity and individuality.

Conclusion

In this study, the process of mourning in chronically ill people did not show either model of mourning to be a perfect fit. An alternative model adapted to chronically ill people is needed.

Chronic illness does not bring immediate death, but rather requires constant attention and lifelong care. The prognosis for chronic illnesses is unclear. Aggravation or developmental crises may necessitate a confrontation of the losses caused by the illness.

The results of this study show that “ambiguity” accompanies chronic illness. Therefore, comprehensive analysis of the mourning work of chronically ill people requires an examination of “ambiguity”. Accounts of the longtime process of adjustment to chronic illness are also needed, as is consideration of individual development. In constructing an alternative model of the mourning process, we should also consider developmental problems. Viewing mourning processes as an individual developmental process will help us better understand and care for patients.

References

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