

Social Stigma Among Stoma Patients

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ABSTRACT

Stoma is a surgical opening from an area inside the body to the outer surface of the body. Stoma is an effective treatment used for many cancerous and non-cancerous diagnosis. However, post ostomy changes, many suffers and go through a lot of psychological issues pertaining to altered body image, social stigma, decreased self-efficacy, decreased confidence, negativity and also related to physical problems such as leakage, ostomy related dermatitis, bad odour and other lot problems. The young and unmarried adults suffer more from psychological and emotional problems. The stigma and disability acceptance of patients with stoma are serious problems that are closely related to their psychosocial adaptation.

Keywords: Stoma, stigma, adaptation, psychological, emotional, physical, self-efficacy, social support, ostomy inventory.

INTRODUCTION

Social stigma is the extreme disapproval of an individual based on social characteristics that are perceived to distinguish them from other members of a society. In this condition people with stoma see themselves differently from others especially due to the different impact on them- either it be physical and psychological impact¹. Ostomy has a pervasive impact on every aspect of a patient's life; however, the major long-term impact is on psychological and social

functioning. The changes in physiological, psychological and social life influence the life style and quality of life of the individuals.²

Ostomy changes the overall lifestyle of a person, and ostomates have been identified as a chronic illness population frequently experiencing adjustment problems³. People who undergo stoma are often stigmatized in various ways leading them to impairment in all aspects of their life⁵. The quality of life is greatly impacted, people often isolate themselves from the society and prefers to be alone. The sole purpose of this review article is to see how people are stigmatized due to presence of stoma.

FACTORS ASSOCIATED WITH SOCIAL STIGMA:

People with stoma faces a lot of challenges acquiring skills to live with the altered image of body and experiences a total psychosocial transition. The negative feelings associated are such as fear, anguish, sadness, helplessness, loss of confidence, social isolation leading to prompt self-deprecating experiences, loss of health and self-esteem, and reduced self-efficacy and a sense of hopelessness and uselessness. Stoma patients experience changes in their lives especially related to their social network (work and leisure) and relationship especially pertaining to sexuality, aggravating their feelings of insecurity and fear of rejection⁷.

The original meaning of stigma refers to an individual or person being different from

others due to his or her own disease and being rejected and not accepted by the people around him or her leading to from a unhealthy environment. Yuan Jing min and other surveys found that 44.3% of patients with permanent colostomies had severe stigma, which led to poor stoma adaptation and decreased quality of life⁸.

Studies revealed that stigma has direct effect on psychological adaptation and disability acceptance, and disability has indirect relation with psychological adaptation. The adaptation process differs from individual to individual depending on the support they received from their family members and their partners. As mentioned above, stoma formation leads to altered body image in terms of appearance, function, differentiating the unity between the perceived body and self. Individuals believed that their attractiveness had decreased since the human body being the center of attraction for many and therefore expressed emotional distress recalling personal feelings around their altered body image⁹.

There are various factors leading to stoma adjustment and acceptance. Factors such as age, gender, marital status, economic status, diagnosis (whether cancer or non-cancer), duration and type of stoma are the factors which directly or indirectly influences the individuals adjustments and acceptance to stoma. Studies demonstrates that young adults suffer a lot more due to the changes in body image and with emotional issues and future economic perspectives while elderly people are more concerned in constraints to physical functions. Married couples experiences major sexual life changes, especially right after surgery or at the early stages of the disease but these changes can be resolved as soon as the couples learn to cope and adapt to the changes¹¹. Furthermore, studies have revealed that women have a lower quality of life compared to men and this is related to body image changes, fear of rejection and an inability to perform activities of daily living. Family income also have an impact

on the lives of patients due to the high cost of the materials needed for ostomy care. And people with temporary stoma accepts and copes faster then people with permanent colostomy because of the hope they have that they will soon recover and get over the stoma and the changes in body image¹⁰.

According to study social isolation is an effective predictor of health status and mortality risk. Many with stoma undergo psychological issue under which social isolation is a major one. Most quit meeting friends, attending functions and even jobs. Disinterest, giving up social activities, restriction in travel, strained personal relationships, loneliness, and a tendency toward self- isolation or wanting to be alone are of significant concern¹⁵.

ASSESSMENT OF SOCIAL STIGMA:

Stigma can be assessed using various scales. The following are some of the ways to assess social stigma:

- Social impact scale
- Perceived social support scale
- Stoma self-efficacy scale
- Ostomy adjustment inventory scale

SOCIAL IMPACT SCALE:

It is a scale used to measure stigma for individuals with various illness mostly for patients with HIV. The social impact scale consists of total four dimensions and 24 items, namely, social exclusion (9 items) and social isolation (7 items). Along with it the Fife tool can also be use to assess the stigma of patients with depression due to stoma. Internalized stigma (5 items) and no economic security (3 items), 4-point Likert scoring method to add points for summation, the higher the patient's self-assessment score, the stronger the sense of stigma^{16,17}

PERCEIVED SOCIAL SUPPORT SCALE:

Studies indicated that the level of social support is closely related to the degree of stigma, self-esteem, and expectation of patients with stoma. Less social support can

lead to psychological problems such as stigma, frustrated self-esteem, and decrease level of hope¹⁸.

Perceived social support was developed by Zimet et al. in 1987. The scale consists of 3 dimensions (family support, friends support, and other people support) and 24 items. The scale indicates that lower the perceived social support, higher the same experience by the patients.

STOMA SELF-EFFICACY SCALE:

The Self-efficacy scale was prepared by Bekkers et al.¹⁹ and was used to evaluate the self-efficacy of patients with ostomy. This scale consists of 2 dimensions one of which is ostomy care self-efficacy and the other social function self-efficacy. The scale is indicated as higher the score better the self-efficacy of patients.

OSTOMY ADJUSTMENT INVENTORY SCALE:

Ostomy adjustment inventory scale is an important tool that is being used to assess the level of social psychological adaptation of patients with ostomy. It contains 4 dimensions and 30 items, comprising of negative emotion (13 items), body function (9 items), treatment compliance (5 items), and survival anxiety (4 items)²¹. Results obtain from the inventory tool suggest that it can help plan nursing interventions to improve patient adaptation to ostomy and avoid social isolation²¹.

CONCLUSION

Stoma though considered a treatment procedure and to improve the quality of life among individuals. It is still considered a stigma among patients and some family members due the various physical and psychological impact as discussed above. Though there are and can be various methods to help them adapt and cope with the changes it is still considered a stigma to them. The factors as discussed, age²² and changes in the body image²⁵ as one of the effective factors to predict social isolation and younger patients paying more attention

to external image and frustrated self-esteem

Another study showed that external image change is not only related to the patient's age, but also to work situation, occupation type, social status, and cultural background. As discussed, patient self-efficacy and social self-efficacy are directly equivalent to the quality of life of the patients in which higher the patient self-efficacy and social psychological adaptation, it is the better adaptation and the less negative emotion, and also prevents permanent social isolation. Nevertheless, the setback of ostomy care and its effect on stigma greatly limit the improvement of patient self-efficacy. It is also seen that low level of social support leads to and exasperate stigma of patients²⁸, which endanger the safety of patients' lives but whereas high degree of social support showed good adaptation to social life and coping²⁹.

Declaration by Authors

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