

# Long-Term Adjustment of Body Function among Patients with Colostomy: A Grounded Theory Approach

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**Abstract:** *Objectives:* 1) To identify the process of long term adjustment. 2) To develop a constructivist Grounded Theory. *Design:* A constructivist Grounded Theory. *Setting:* Study was conducted in Stoma Care Centre (Ostomates India) associated with Karnataka Cancer Association, Bangalore. *Participants:* Twelve ostomates participated in the study. *Method:* Data was collected in the mentioned setting. In-depth Interviews were initiated with semi structured questionnaire and triggered question were asked to reflect the experiences. Interviews were recorded using voice recorder and transcribed and translated in to verbatim. The verbatim were read and re-read. Coding was done. Core concepts were derived with the intermediated coding. The interrelated concepts are categorized. *Results:* Long term adjustment process experienced by the ostomates derived as "Progressed Adjustment" with three phases. 1. Initial tormenting phases. 2. Self-driven phase 3. Positive resilient phase. The core process in the progressed adjustment is "Support system".

**Keywords:** Long term Adjustment, Ostomates, Grounded Theory, Tormenting, positive resilient, Support system

## 1. Introduction

A "Colostomy" cannot be termed as a "disease" but rather a disorder signifying a deviation from the usual pattern of body functioning. According to American Society of Colon and Rectal Surgeons (ASCRS), a Colostomy is a surgically created opening meant to connect an internal organ to the body surface. Every year, a sizable number of the global population undergoes Colostomy surgery that alters their normal passage of digestive waste. <sup>(1)</sup>

Colostomy associated problems is an on-going issue. Ostomates have to live with the challenges every day. The initial stages of colostomy prove to be difficult and depressing for colostomates, they are able to gradually transition to a state of adjustment, resilience and even optimism. Some of them who have accepted their altered lifestyles post colostomy even volunteer to be a part of support groups to motivate peers and strangers alike facing similar challenges. <sup>(2)</sup> The study findings of the factors that affects the long term adjustment for ostomates suggested that they have good adjustment with a mean score of  $159.5 \pm 26.2$  and the adjustment process is better with the preoperative education provided by a wound, ostomy, and support of specialist nurse. <sup>(3)</sup>

## 2. Need for the study

The permanent ostomates has to live with the colostomy till their end of the life. The researcher has visited the ostomy association, the ostomates are looking very normal unlike the ostomates admitted in the hospital. The long term ostomy has brought the ostomates to an adjustment with ostomy. This study aimed to investigate challenges faced by ostomates with respect to their adjustment towards the colostomy procedure, their long-term challenges and to explore modalities which enable them to face their challenges in terms of coping strategies and support systems

which in turn enable the creation of a safe space for them to adjust to their altered lifestyles. This study will enable us to understand the adjustment process of the ostomates on a long run to face the challenges related to colostomy.

## 3. Objectives

- To identify the process of long term adjustment
- To develop a constructivist Grounded Theory

## 4. Methodology

### 4.1. Research Design

A constructivist Grounded Theory (GT) was employed to explore the process of long term adjustment of ostomates with colostomy.

### 4.2 Setting

The study was conducted in a Selected Stoma Care Centre (Ostomates India) providing Care to the Ostomates. It is an Ostomy care centre associated with Karnataka Cancer Association, Bangalore. It is also a part of Asian Ostomy Association. Data was also collected in the Clients residence since fear of COVID-19 had reduced the movement of the high risk people like elderly. The participant were more relaxed and comfortable to interact in their residence since they don't have any hesitance and it was their own and familiar environment.

### 4.3 Sampling Technique

Purposive sampling technique was used.

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#### 4.4 Participants

In this study there were twelve ostomates participated in the study. Informed consent was taken before the interview. Semi structured questionnaire was used to collect the data in English, Tamil, Kanada based on their preference in the language. Participants were ostomates with colostomy bag for minimum 10 years were selected for the study.

#### 4.5 Data Collection Method:

Data was collected in the mentioned settings. In-depth Interviews were initiated with the question “can you tell me your experiences related to the colostomy? Coping strategies for the long-term adjustment? Trigger questions were asked them to reflect on their experiences in depth. Each interview lasted for 1 hour to 1hr.30 minutes. In depth interview were conducted and allowed the participants to open with their experiences and issues. (4) Interviews were recorded using voice recorder and transcribed and translated in to English as verbatim. The verbatim were read and re-read and coding was done. Concurrent data collection and analysis started. (5) Initial coding was started along with data collection process. Few focused coding was also derived. The researcher has formulated some of the theoretical categories. Repeated comparative analysis of the data helped the researcher to derive the categories. Gathering data was stopped with the Theoretical saturation. (5)

#### 4.6 Data Analysis

The complete interview data was translated into English. The verbatim was read line by line and around 70 initial codes were obtained from the initial coding. Core concepts were derived with the intermediated coding. The interrelated concepts are categorized from the advanced coding. (5) The researchers categorized the long term adjustment process experienced by the ostomates as “Progressed Adjustment” with three phases 1. Initial tormenting phase.2. Self-driven phase 3. Positive resilient phase. The core process that helped the ostomates in this progressed adjustment is “Support system”.

### 5. Findings

The researchers categorized the long term adjustment process experienced by the ostomates as “Progressed Adjustment” with three phases. The adjustment has taken time and it has occurred in the as different phases.1. Initial tormenting phase.2. Self-driven phase 3. Positive resilient phase. The core process that helped the ostomates in this progressed adjustment is “Support system”.

#### 5.1 Initial Tormenting Phase

The Initial tormenting period is a difficult period for most of the participants with colostomy. The majority of the participants had their colostomy with the indication of life-threatening diseases like cancer, &major accident. The participants expressed that their life would have ended with a chronic illness like cancer and irritable bowel disease but colostomy had made a change in their life in terms of relieving pain and other initial symptoms.

In addition to the chronic diseases the participants with colostomy had a new turn in their life with the challenges related to managing the colostomy bag. The participants expressed colostomy was a relief in a way, but the adjustments with the bag had become real challenge for them. The researcher has stated this initial phase of challenges and struggles faced by the participants in managing and coping up with the colostomy bag as initial tormenting phase. This phase had given those additional challenges, struggles, difficulties along with their illness in adjusting and coping with the colostomy. The participants expressed this they can end their life rather struggling with the bag.

The new life with the colostomy has imposed unavoidable restrictions in their life. They were restricted to choose their basic life needs like, restriction in choosing the food, dress, sleep, travel etc. These restrictions in basic life needs and basic life activities made the participants to draw a boundary with themselves and made to wrestle the self and as well as God. This wrestling had created an abstinent behavior to their spirituality. For some of the participants this continue wrestling with the self and wrestling with God had created a worthlessness, hopelessness, and for some of them it created a low self-esteem followed by suicidal tendency. These life experiences were taken into consideration as contributing factors, themes and concepts for the initial tormenting phase. This phase was lasted for most of the participants for one to three years and maximum of four years for some participants.

*I felt I don't need this kind of life. Even I used get suicidal thoughts also (LTC06).*

*It was a strange experience for me. (LTC07)*

*With bag initially it was difficult. I have thought it would have been better if I have died rather struggling with the Bag. (LTC09)*

*“It took maybe four to five years to cope with the challenges” (LTC01). Initially for three to four years I had a real struggle to adjust to the routine. (LTC04). After the operation my total lifestyle changed and I am not able to travel. (LTC01)*

*With bag life is very different. Initially I had pain in and around my stoma, which has reduced now. When bag is full I feel very difficult to empty it, otherwise I am fine. (LTC02)*

#### 5.1.1. Choice of Compulsion

All the participants experienced restriction and limited choices for their basic needs of life. They cannot have their own choice of food, they are unable to wear the dresses as the like, there is change in sleep cycle because the sleep time has become shorter, cannot sleep in the posture which is convenient to them. With regard to their food choices. They had to prefer a food which is odor free, which not alter their bowl movement, some food may cause constipation or loose stools, spicier food would cause skin excoriation, some food may lead to abdominal discomforts like blotting, obstructions with pain. At the end the ostomates are left with limited choice of food. This situation caused enormous modification in the food habits and choice of food items.

The ostomates expressed that they were not able to enjoy even the common food that normal people can enjoy. They have to be careful in choosing the food.

Other than food the participants expressed in the initial days they had the fear of leakage in the bag. Due to this the ostomates had constricted sleep posture and time. They are forced to choose a posture of semi fowlers position or sleeping on one side which can cause less leakage. Most of the ostomates have expressed sleepless nights due to their anticipation of the leaking or have to empty the bag at the time of the leakage around the clock.

*“I was having many food restrictions, until I cope with the bag. there are some foods that lead to altering my bowel movement. (LTC 03)*

*Some protein like pulses, egg and fish is good for health but most of the time it produces bad odor and I will find difficulty in cleaning the bag and maintaining the bowel movements regular. It also alters my whole day life cycle, like diet, and sleeping pattern. (LTC 03) ”*

*I take soft diet. I don't take too much spicy food and don't take oily foods that might cause abdominal discomfort and loose stool. I am a full vegetarian, soft diet is easy for digestion. LTC08)*

*I have to control the diet I can't eat like others. I will not eat spicy food it will cause loose motion. I will not eat green gram, groundnut, or legumes. I reduced my intake of fried items like vada and Bonda (recipe made of Dhal and lentils). Some food will cause constipation for two to three (LTC09). I was advised to take fiber rich diet. At the same time, high fiber diet causes some obstruction, I should be very careful in the intake of fiber. (LTC 03)*

*It's very difficult to control loose stools. So I have to be careful with the food. Some food will cause constipation like ragi ball (ball made of boiled millet powder), chapathi, nuts etc. Non-veg food like fish meat will cause bad odor too much dhal if we take also bad odor will come from the bag. Some food will cause abdominal pain and discomfort. We should be careful choosing the diet. We just can't eat whatever we like. (LTC06).*

*Earlier I was not able to eat some spicy food but now it is not so. LTC11.*

*It is said that fiber content is good but for me it is totally the reverse in my case if fiber content is more then I will get loose stools. LTC 12.*

*Initially after the colostomy was done, I was wearing only dhoti (loose type of wrapping cloth wear in southern part of India). It was very comfortable to change my bag and clean it. (LTC 03)*

*Before my surgery I used to wear saree, after that not wearing saree. I wear only nighty LTC2*

*After 3 months I started wearing pants before that little hesitation was there to wear pants later I got adjusted to the regular dressing pattern. (LTC08)*

*Initially when I was new with the colostomy bag it has disturbed my sleep. During sleep there will always be a tension of leakage from the bag that the bag will come out of the position. While sleeping unknowingly there will be leakage. LTC 03.*

*I turn one to one side adjust and sleep. When the bag gets full I have to wake up to empty in the night. Initially, more than ten times I was emptying the bag. Sometimes my family members will help me to empty, I feel very bad in emptying the bag. LTC02.*

### 5.1.2 Self-Bounded life

Self-bounded life can be explicated as the self-bounded restrictions that the ostomates make for themselves. These self-bounded restrictions are seen in terms of limitation in their travel, hesitant to go in public places, social gathering, family functions, regular sport activities and to the religious shrines. This concept of self-bounded life is coined by the researcher by evaluating the constrained life style of the participants. It was found that their travel is constrained, their social life is restricted they draw a boundary for themselves not travelling not visiting people, not participating in the social gatherings and activities, not meeting friends, not going out from their home at all but just bound themselves to a particular life style. One of the main reasons for this self-bounded life was the ostomates associate themselves more to the religion which they belong to, and the feeling of purity pollution in regard to the place of worship, since they carry their bag, it gives a feeling that the excreta in the bag makes them profane. This becomes one of the reasons for self-bounded life. The ostomates stop travel due the fear of finding convenient place to empty and clean the bag. They avoided the social gatherings because of the hesitation of the odor that comes from the bag. In this phase the ostomates travel more that is only visiting the hospital for their medical review.

*I used to avoid travel I will not go anywhere, sometimes as the bag fills with the motion it get bloated up for that I should clean and change the bag, i. e. if I do a night travel by morning the bag will be filled so I will avoid long travel. (LTC01).*

The colostomates has social refrainment. They restrict themselves from the society not being in a group. Participants expressed that they used to avoid social gatherings, public places such as shopping areas, churches, temples and common family function. They were embarrassed being in the social group because of bad odor and fear of leakage, unpredicted bowel elimination etc.

*I won't go out in any social gatherings. I remember those initial days of my colostomy. I was not at all going to any social gathering now. (LTC03)*

Married participants (two participant had colostomy at the age of 28 & 34) experience some hesitation in their sexual relationship. They were hesitant being intimate. They had a

fear of leaking and bad odor. The also had a fear that their partner will leave them abandon. Even the they have restricted family relationship

*Yes, after colostomy only I got married. I had little hesitation in the initial time. During my initial marriage life I was hesitant.... . my wife gave me confidence and encouraged me. (LTC03)*

### 5.1.3 Religious Abstinence

Most of the participants have a hesitation. Every religion has a concept of purity pollution in all religion they want to go to the worship place after cleansing them by having a bath. The ostomates had hesitation to perform religious rituals. They also thought that they are unclean to enter into the worship places. Some of the participants had felt that it is God's punishment or the Karma of the previous generation and they have abstained from spiritual rituals and regular prayers. They wrestling with God by asking questions like, why? why me? why these sufferings? why this has to happen to me? why god is testing us beyond our strength? to get answer for these questions they wrestle with god, like scold god, abstain themselves from all spiritual activities. They also stop going to worship places and stop offering their regular prayers because of the anger they have with God.

*Initially it makes me feel bad to perform my religious duties. (LTC03)*

*When the bag was on initially I had hesitance to go to temple and worship god. (LTC01).*

*I am a very spiritual person. After this I was upset with God. I was not going to the temple initially. I was spiritually down. Sometimes I felt very dirty with the bag outside. (LTC06)*

*I have avoided going to the mosque because we should enter the mosque in a clean way. LTC11.*

*Initially I was scolding God and comparing with others other than me All are living a normal life. (LTC01)*

*It is a difficult experience and I was asking God why God has done this to me but now accepted this situation. (LTC04)*

*Initially I was upset, asking questions to myself, why this lifestyle. LTC06*

*I spend more time with God. I will go to the temple and do a lot of prayers and Pooja. I used to think this happened because of my Karma. LTC9.*

### 5.1.4. Feeling Hopelessness and Worthlessness

With the stoma most of the participants expressed their feeling of losing their self-worth and self-esteem. The ostomates have expressed that the intrinsic worth of their self is gone which made them hopeless and unworthy of living. This led them to have psychological, emotional disturbances which are expressed by the ostomates as feeling of themselves as unworthy, they are of no use, fear of future and feel depressed. Sometimes this extension of the feeling led the participants to had a self-destructive behavior and suicidal tendencies.

*I felt I don't need this kind of life. Even I used get suicidal thoughts. (LTC06)*

*With bag initially it was difficult. I have thought it would have been better if I have died rather struggling with the Bag. (LTC09)*

*Sometimes I am cursing myself (LTC08)*

## 5.2 Self-Driven Phase

The next phase formulated by the researcher by close observance of the positive changes in the life style adapted with the long-term adjustment is self-driven phase. The participants had felt with the challenges, limitations and restriction they need to come out and turn towards the normalcy of life. They have realized that they are not the only one who is suffering, and the suffering is universal. This realization becomes the contributing concepts for self-realization provided self-confidence, made to realize existence is worth, this is not the end of the life and there is meaning for them to live. This has made them get back to their life as they were before the colostomy.

### 5.2.1. Self-realization led to self-confidence

The participant has felt at one point of time that they need to come out of their boundary. They realized by themselves have to break the boundary and come out. They realized that the suffering and struggles are common and universal. After breaking the boundary, the participants slowly resume to their daily routine and work. Most of the participants said that they have a strong will power to come back. They want to be independent of themselves. The participants to gain confidence on their self. This self-confidence has brought acceptance and pressed them to continue their life. After the long-suffering they have positive feeling and they have a will power that they will be able to do.

*What happened is happened we cannot reverse it but with this happening how we can go further. So to move further we need all the support system to reach the destiny. (LTC03)*

*I gained self-confidence. I don't want to be dependent on anybody so I started doing all my work by my own. (LTC09)*

*Initially my wife was taking care of me but now I don't want to disturb her. I should be independent all the time. I took a decision that I will not disturb anyone. I will wash my bag and I take bath by myself. (LTC08)*

*Now I feel God has given me bonus life. (LTC06)*

*We should be satisfied for what we have. We have to accept what we have (LTC05)*

*I was asking God why God has done this to me but now accepted this situation. (LTC04)*

*We have only one life and we have a destiny in this life journey, unexpected things can happen to us that can shatter our entire life (LTC03)*

*What happened is happened we cannot reverse it but with this how we can go further. (LTC01)*

### 5.2.2 Suffering is Universal

After few years with the colostomy they understood suffering is universal. Everyone on earth has different kind of suffering. Most of them had a positive feeling that suffering is not subjective. It is experienced by at different level by all the people. They also have a feeling that there are people having suffering more than them.

*Sometimes I used to think why I should undergo and why this inconvenience then suddenly I myself think no. . . no... there is no inconvenience. Everybody will have some or the other inconvenience and I have this that's all. It's not only me with this problem, there are many who have the same kind of problem. (LTC07)*

*When we compare with the people who have tough time more than me or suffer more it gives me little consolation that I am better than anyone (LTC03)*

### 5.3 Positive Resilience

After being with colostomy for many years Most of the participants has reached to the level of positive resilience. The ostomates has expressed that they have been motivated to go forward to the next level in their life and most of them don't want to be suppressed with the difficulties what they have. They have been very optimistic to resume to their work, being supportive for the family being a part of social groups. They want to be as normal as any other people. Three of the participants has expressed that they not only being positive about themselves they also had move a step ahead by serving other who had the same struggles. Positive resilience is achieved by being optimistic in midst of the struggles and challenges. This optimism is gained by a person through life experiences.

#### 5.3.1. Optimism

In this phase ostomates gain optimism about their status. The struggles which they faced in the initial phase remain with the limited intensity they make adjustments to lead a normal life with all the limited options and the challenges. Now they are independent of themselves. Their hopelessness and worthless feeling have changed and they want to live for the family. They are happy about good thing which has masked their difficulties and discomforts. The hesitancy has vanished the participants become optimistic to proceed with their life with their life conditions.

*I feel this life is very important. I have understood the value of life. (LTC06)*

*Only if I tell, others will know that I have bag, otherwise nobody will know that I have this problem or I am having a bag. (LTC04)*

*I have a positive attitude that I can manage. Our thinking should be positive and encouraging then it will not disturb us in any way. (LTC07).*

*Sometimes the odour is unavoidable. We can use some kind of perfumes and body sprays otherwise nobody can identify that I am with a bag. (LTC06)*

#### 5.3.2 Life Restored

In this phase the participants are all with the colostomy bag but the way they see themselves has changed and restored them to be normal. This is termed by the researcher as life restored phase. All the hesitation related to food, dressing, socializing, travel limitations, reluctance to go to the worship place, hesitation in sexual relationship all have taken a complete turn in their life in this phase the ostomates have a feeling that their life is restored and they come to the decision to live a happy life to the reset of the days.

*Now I am one among the normal. Only if I disclose that I have a colostomy bag nobody will be knowing. looking very normal when we see you from outside, no one can find out or say that you have a bag. (LTC03).*

*I go out and socialize I don't show that I am Ostomates (LTC10)*

*I go to church every day and I am not hesitant for what I am. God only created me and he knows my problem any hesitant. LTC04*

*I felt God understands and there is no such thing that should stop us from worshipping God LTC01.*

*I learnt to balance my emotion, we have better understanding within ourselves. I really thank God for a good life partner. The Colostomy did not affect my marital life and my sexual relationship. (LTC03)*

*Should not think of this, whatever situation I have to handle and be happy. If I am sad, all feel sad. So I am starting to get adjusted with it. I have strong will power. LTC05.*

*There is no change in my daily routine. I go to Bank; I go to my office for some work and I go alone. I go for a walk every day. (LTC07)*

*It makes me feel bad to perform my religious duties. Initially I was not comfortable but as days went by it gave me a sense that it is not the physical purity that matters the purity in mind that matters. LTC12.*

#### 5.3.3. Extended Concern

In this phase the ostomates have expressed the concern about the others with same struggles and challenges in their life. One of the ostomate had volunteered himself to serve other who are newly operated and he demonstrates the method of cleaning and changing the bag and giving suggestions for their issues with colostomy. The other ostomate has served as secretary and treasurer for few terms in the ostomy association and counselled many ostomates.

*I help others with the same problem. I give others a possible guidance who has the same kind of problem. We meet each one, give their experience and share their problems and how we solve the problems. I had been socializing and active and*

*I found helping ostomates that made a difference in my life. LTC10.*

One of the ostomate has resigned his job and doing a ministry to God by serving people in the church.

One more participant has expressed that she has involved herself in social service. She expresses that God has given her a “Bonus life” (LTC06) so she helping others with in her limitations.

*It is a second life for me. I don't want to miss it. I help poor people to avail the government facilities like chief ministers' health schemes, Education funds etc. Now I feel God has given me bonus life. I like to financially also help to others who are like me I like to counsel others. We can do everything. We should do good to others as long as we live. LTC06.*

*I was taking close part with ostomates and I had been helping people at various level. LTC 10.*

*After that seeing the things. I had to redefined the normalcy which we see with our bare eyes is not normal. The abnormal which we see is not abnormal. (LTC3)*

#### 5.4. Support System and Long-Term Adjustment

The support system in the context of the ostomates is perceived as the support that they get from a person who help and teach the ostomates to handle the colostomy bag. The ostomates have an extensive support system in the initial tormenting phase. The support system was provided by experts such as their oncologist, surgeons, stoma care nurses, volunteers from the ostomy association. This support system was appreciated invariably by all the ostomates. Most of the participants are endorsing the support system that has helped them in fixing the colostomy bag, to empty, to clean, and to irrigate by themselves. With the help of the support system the ostomates are learning to adjust well with the bag but this adjustment takes a long process. The core factor which is connects all the phases are support system.

The influence of the support system can be seen extensively from the initial days of the ostomates till their coping up. From their experience expressed by the ostomates the researcher to divides the support system as “Veiled Support System” and “Realised Support System”.

#### Veiled Support System

This Veiled Support System was experienced by the participants during the initial days. Even with the broad support system ostomates were distressed and unable to cope and adopt with the challenges caused by the colostomy bag. They had difficulty in coping with the problems related to the bag. In the initial days they had physical discomfort, psychological distress emotional trauma restricted social and family relationship. The support system was masked by the initial tormenting phase and was not appreciated in the initial days because that has not comforted or relieved their discomforts during the initial days.

#### Comprehended Support System

On later days when they retrospectively thinking appreciating the overwhelming support system which has made them to adjust with challenges faced by the bag. All of the invariably agreeing and accepting that all the above mention support system is the factor which enabled them to cope with challenges faced by them during the initial tormenting phase, infused self confidence in them and brought to the resilient phase.

##### 5.4.1. Health Team

Support from the health team plays a major in initiating the coping up mechanism and it is the expertise support which gave them a confidence. Health team give technical support to the ostomates in the initial phase with their clinical knowledge this helped the ostomates to accustom with cleaning and changing process of the bag. The health team with technical support and also give moral support which induce the confidence level of the ostomates.

*Initially in the Hospital they had given me more instructions regarding cleaning and changing routine In hospital, the nurses will clean the bag. LTC01.*

*There is a separate department for colostomy in colorectal surgery unit there the nurses will teach the technical aspects about diet, exercise that helped us a lot. The colostomy department nurses had encouraged me a lot. (LTC03. My doctors, family members supported me morally LTC06.*

*I can still remember the name of the staff and he mentioned it. (Nurse Archana who does dressing and Nurse. Sudha taught me how to change the bag) they have taken care of even small thing also. They helped us very much and made me accept to be with the bag. The coping up was due to medical help due to the help of the doctors they helped us during and post-surgery by the nurse and the doctors and the environment made cope LTC08.*

##### 5.4.2. Family and Friends

Apart from the health care personals the ostomates were also loved, cared, guarded and assured by the family members and their loved one spouse, mother, father, siblings, friends to manage and to cope up with the colostomy bag. These members of close circle volunteer to learn the stoma care, demonstration, and supervise the use of bag. The ostomates get help from the beloved ones for their psychological and emotional problems, because they associate them closely all the times.

*I got support from my colleagues and friend. My friend who knows that I have a bag also will not treat me differently so I am comfortable in my friend's circle. LTC01.*

*Most of my friends knows that I am in colostomy. So social acceptance helped me to overcome the difficulties. LTC03. My husband was helping me to clean. All my family members, mother, brothers and sisters are supporting me. My Family, father will take care of me very well. Because my father I have reached thus far. His support makes me strong. Whole family and relatives are supportive only. Brother also cooperative. LTC05.*

*I have great support; my brother and his family are very supportive. I am staying with them I am very much encouraged. They don't make me feel any time that I have a colostomy and I am very comfortable and I can be free. My friend circle also treats me well and I am very much comfortable. I am free to mingle with them and I don't have any problem. LTC06.*

**5.4.3. Peer Group Support**

The support system which is very much helpful to the ostomates are peer group support. There are supervised peer group meetings organized by the non-governmental organisation, hospitals and ostomy association has a great support. In this the suggestion were given by the experts for the minor and major problem associated with bag. The ostomates clarify their doubts with the peer group in regard with the cleaning process, diet modification, exercise to be performed. This peer group support has taught the ostomates many new things gave them confident to handle the bag.

*They teach how to use and cope with the bag and how to clean. Sometimes adverse reactions happens with the colostomy skin excoriation happens when we take hot foods they will give a gel and powder. LTC03.*

In peer group meeting the experience shared by the fellow ostomates has encouraged, lifted their emotion and gave them the confidence. It gave them the real motivation since the experience was shared out their suffering same as they face. This increased their coping level.

*We share the problems each one of us have, how they cope with the problems. LTC03.*

*Initially the suggestions given was very useful and one time we had meeting with the people who has similar kind of problem that time also we had gathered and shared some of our common concerns that also helped me a lot. Now also I have few contact whom we speak and share our thoughts. LTC01.*

*I used to come to the ostomates association and they will give guidance to care for the people with colostomy. We have some contacts as a peer group. We shared some of our concerns about the difficulties earlier. We used to come for regular meetings and get together. It was really useful. LTC05.*

*I used to attend the conference for the ostomates once in a year conducted by the ostomy association that was very encouraging. There we can meet many people like us. This helps us to share and get encouraged. LTC07.*

*The stoma clinic people helped me to get adjusted well with the bag. I gained self-confidence. LTC09.*

**5.4.4. Irrigation Process**

Irrigation process is a procedure in which a patient with a colostomy flushes the colon with water, using a tube that is inserted into the stoma (a surgically created opening in the body that connects an organ or area inside the body with the outside). This causes the colon to empty and pass stool through the stoma into a bag. The procedure should be done at the same time every day. It may allow colostomy patients to have better control over their bodies. (6) The physical problem like fear of leakage, bad odor and sleep disturbances and travel restrictions, bowel disturbances are resolved by the irrigation process. It not only relieves the physical symptoms it also gives them self-confidence to socialize and involve in the recreational activities like sport since there is no bad odor or leakage. Irrigation process was adopted by the six participants.

*I will do irrigation along with my bath after that I don't have to worry. (LTC08)*

*In the morning I do the irrigation after that, there is no problem at all. I don't feel that I have a bag. I am totally free (LTC07)*

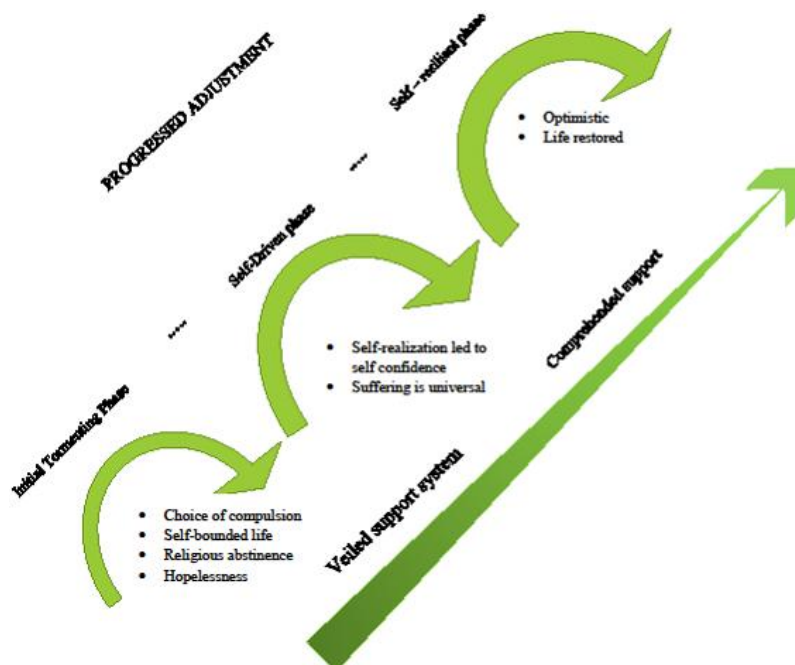


Figure 1: The process of progressed adjustment and support system

## 6. Discussion

A Study conducted to assess the lived experience with colostomy has the analysis revealed the following themes 1. Experiencing traumatic event with the sub theme of extreme emotions 2. Living with the new reality with the sub theme of personal changes 3. Efforts to improve the quality of life with the sub theme Autonomy and support. <sup>(7)</sup> From the above study first theme supports the phase emerged in present study "Initial tormenting phase". Both the themes bring out the physical, psychological, emotional sexual and religious difficulties and discomforts encountered by the ostomates. The second theme living within the new reality and the third theme Efforts to improve the quality of life with sub themes relates the second phase "self-driven that focusses on the positive acceptance, self-confidence and the support is related the support system that enabled the ostomates to cope with long term adjustment in the present study.

Qualitative study conducted to assess the specific concerns and adaptation among the colorectal survivors revealed the ostomates experiences the adjustment in related to bowel functioning clothing restrictions, dietary adjustments etc. <sup>(8)</sup> This study corelates the present study with category initial tormenting phase.

A qualitative study to conducted to assess the coping process of the patients brought out three interrelated themes struggling and suffering, learning how to live with the ostomy, and living with the ostomy. This study finding relates to the present study themes the initial phase of struggle and suffering as "Initial tormenting phase, learning how to live with the ostomy, and living with the ostomy related with other two phases of self-driven and positive resilience phase. <sup>(9)</sup>

A cross sectional study conducted on irrigation practices in long-term survivors of colorectal cancer. The study results revels that out of 101 ostomates, 50% never irrigate, 30% irrigate every 1-3 days, 4% irrigate more than once a day, 5% irrigate sporadically, and 11% were individuals who had irrigated for a period of years, and then quit. Out 33% irrigate on the regular days had given a positive comment as this process controls odour and gas, bag is not necessary to be kept all the time only a small bandage is enough to cover the stoma. Can travel without any worries. <sup>(10)</sup>

## 7. Limitations

Limitation in this study was data collected only from the ostomates. Group interview with Family members and focused group interview would have contributed more extensive data.

## 8. Implications

- Research can be conducted in future the adjustment process ostomates with reduced support system.
- The researcher has brought significant finding that the support system has brought positive adjustment. The

nurses can be given special education to care for the ostomates.

- Administrators can set up organized ostomy care centers to render support for the ostomates by educating them with regard to the care and adjustment strategies with colostomy.

## 9. Conclusion

The researchers categorized the long-term adjustment process experienced by the ostomates as "Progressed Adjustment" with three phases 1. Intial tormenting phases.2. Self-driven phase 3. Positive resilient phase. The core process that helped the ostomates in this progressed adjustment is "Support system".

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