

Psychological Issues in Ostomates.

ABSTRACT

Stoma surgery, be it temporary or permanent, it is an intrusive operation, with outcomes that can impact seriously on daily life, not just in the immediate post-operative and recovery period, but for the rest of their lives. There are changes in bodily function, altered body image, physicality and personal care needs (ref). These changes require acceptance and adaptation and can necessitate a re-ordering of daily life, socially, emotionally and in terms of work.

Assessing the patient's needs through the trajectory of diagnosis, surgery and a stoma, is not just important during the treatment phase but needs to continue through the lifespan. Traditionally, patient outcome measures after bowel surgery have included overall self-efficacy, checking for stoma complications, clinical health status, function and psychological status. However, over the last three decades there has been increasing recognition that Quality of Life (QoL) which is now regarded as a key measurement, needs further consideration. Patients report difficulties when explaining to healthcare professionals the challenges they face, and their reactions as they try to make the adjustments to their new normal of life with a stoma. The transition process by professionals from active care to post care treatment using a long term health plan that not only takes the patient through the first five years (accepted time span if there has been a cancer) can be critical to wellbeing for the rest of their life. This article examines some of the previous research into QoL and looks at stoma patients perceptions of their outcomes from recent research.

Key Words.

Stoma, psychological issues, Clinical Nurse Specialists (CNS), Body image.

Introduction.

For all patients, regardless of diagnosis, treatment and outcomes the impact of the changes and experiences that accompany the onset of illness can be frightening and challenging. Although treatment may address the original medical problems, the outcomes can include short, medium and long term health issues. In addition, where major surgery such as stoma formation is needed, the physical changes can also be accompanied by psychological problems that are hard to resolve. Indeed, evidence suggests that over 20% of stoma patients experience long term significant psychological challenges and concerns, that unrecognized can affect and impact not only on the patient, but also on their family, friends and work situations (Notter and Chalmers 2012; Black 2018).

It is impossible to separate psychological and physical self, from who we are and what we do. Our daily activities of work, play, family and friends are perceived through our actions and interactions, with our bodies integral elements everything we do, including our relationships with others. Fundamentally implicated in all lived experiences, any action that impinges on, or affects the mind and/body affects individuals lives. When medical help is sought and the diagnosis results in surgery, as individuals change their roles to become patients, they have to face the reality of the outcomes of what may be radical and/or major surgery. Firstly, in becoming a stoma patient the diagnosis initiates a process in which the individual has to come to terms with their bodily changes that will happen and interpret the symptoms and try to understand the disease in their own body. It has to be accepted that in the early recovery stage, learning coping mechanisms and new skills to cope with a stoma is not easy, patients can easily become overloaded as a result of issues of physical weakness and the effort involved in trying to recover. The situation is compounded by what is for some, a perceived loss of independence, confidence and dignity (Black 2004). Then too, the accompanying changes in body image can lead to patients "mourning" for their lost body part, and for some, these psychological effects are recognised as being greater than the physical effects (Di Gesaro, 2016).

There is evidence that there is considerable reluctance from both the healthcare professional and patient to discuss any of these problems even if the patient still has recourse to a specialist stoma care nurse (Vonk-Klaassen et al., 2015; Notter and Chalmers 2012; Black 2018). Clinical documentation and patient reports indicate that for many patients, despite the long known need for improvements in support, the same concerns and challenges repeatedly arise, and that these problems are often not identified by healthcare professionals (DoH 2007). It is evident from over three decades of research that regardless of medical advances and varying reasons for surgery, the challenges remain unchanged,

as does the urgent need for reform and revision of the services (Black 1992; Notter 2002; Black 2004; DoH 2007; Notter and Chalmers 2012; Black 2018). However, patient response is individual, and therefore, for changes in services and information offered to be successful, service providers need to recognize the different ways in which patients cope with disease and its resultant outcomes. Black's (2018) phenomenological study identified five different coping styles that stoma patients use. Information and guidance based on these could be developed to help support and empower patients to take control of their own lives to reach the best possible Quality of life.

Background

Over two decades ago Bekker et al's (1995) seminal study of patients' ability to cope, and their expectations of life after stoma surgery included self-efficacy, task performance and adaptation. They used the Psychological Adjustment to Illness Scale (PAIS-SR) at 4 and 12 months after surgery, identifying that ability for self-care after surgery was influenced by sense of self, and support. Patients with strong feelings of self-efficacy who received good support and developed strategies for adaptation had fewer post-surgical psychological problems, coping better with the physical changes. These findings are still evident, patients demonstrating poor psychological adaptation saw their lives much more negatively (Black 2018). Black's (2018) study found participants describing their '*world had collapsed*' or that they had been '*cast adrift*'. Also, that as Finlay (2011) reported the physical changes in mobility and motility had adversely affected their sense of self and self-worth. For these patients, the physical pain accompanying what they saw as their body being '*damaged by surgery*', led to them seeing their body as '*alien... it's not me anymore*'. This change in self-perception is not new (Svenaeus, 2001), and, for patients to adapt to the changes and have the best possible quality of life, there needs to be professional support and guidance from diagnosis onwards.

Lack of recognition of the psychological impact and its potential adverse effect on lifestyle, may in part be because traditionally, patient outcome measures following bowel surgery, have focused on specific medical complications, stoma problems, clinical health status, and physical function (Vonk-Klaassen et al., 2015). This needs to change, to assessing all aspects of need throughout the long trajectory of bowel surgery, stoma formation, recovery and the after treatment phase. For a patient to have the best possible chance of positive life adjustment, psychological care needs to begin at diagnosis and continue throughout the

lifespan. Timely and appropriate information can help adjustment (and hence quality of life), yet, the most frequently cited unmet needs are practical advice and short, medium and longer term coping information (Vonk-Klaassen et al., 2015. Adams et al, 2009). Information is available during treatment (from specialist nurses), but time after time, research indicates there is a strongly expressed need for information after cessation of therapeutic intervention (Black 1992; Notter 2002, DoH, 2007; Notter and Chalmers 2012; Black 2018). The absence of long term accessible guidance has resulted in patients having to seek information through comparison, they have made their own contacts with other patients through personal and social media, or in some instances patient support groups. Such social comparisons enable individuals to use external (to them) patient images to evaluate their own progress along disease pathway. If these contacts are perceived to be progressing well in their disease trajectory, they are seen as offering an 'upward comparison' while those whose condition is worse are seen as giving a 'downward comparison' (Suls, 2012). Where a patient can compare themselves favourably with others, it appears to support positive adjustment to the diagnosis of disease, resultant surgery and long term outcomes. Those who make an 'upward comparison' can then in their own turn, help other patients struggling to adapt (Suls, 2012).

Within each society, changes in body image are perceived differently as each social group has their own perceptions of health and illness, with accompanying issues and taboos (Chelvanayagam, 2014). While the body in health is often taken for granted, in the presence of illness, it brings the realization that it can no longer be relied on, but has 'failed' leaving the individual vulnerable to internal disharmony, and conflict, unable to maintain the role they once unthinkingly held (Sutherland et al 1952, Douglas 1966, Holden & Littlewood 1991, Bekkers et al 1996, Black 2000, Helman 2007, Black 2017. Polidano et al., 2019). This change in body (and body image) accompanying stoma formation surgery can be compared with a social or cultural rite of passage. The individual crosses a barrier from which there is no return, but unlike rites of passage which are positive and purifactory, the surgery is prophylactic, and by some is seen as retrogressive (Black, 1992, 2000). The individual's status within society is not being enhanced or restored, but redefined as they pass through a transitional social state to their permanent altered form, which may well cross social taboos. Patients report experiencing anxiety and fear of being '*found out*' as no longer being able to fit within '*normal*' behaviour, transgressing accepted patterns and practices for elimination. Such beliefs are cultural phenomena, but for many fear of social exclusion is part of the challenges faced by the individual as they try to find ways to modify their

behaviour, hide what they see as their stigma and return to their culture and society from whence they came (Goffman 1968, Holden & Littlewood 1991, Black 2000, Kilic et al 2007, Black 2012, 2018. Polidano et al., 2019).

Methodology

A qualitative approach was used for the studies by Black (1992) (2004) and the latest study Black (2018) which developed the coping styles patients use to cope with their altered lives, as this focuses on words and languages rather on statistical values, with an inductive relationship between theory and research (Cresswell, 2014). Descriptive phenomenology is epistemological in nature, involving systematic investigation of consciousness to explore the lived experience of the individual (Giorgi, 2009). The assumption is that while the lived experience is individual, it is possible to explore and seek for the essence of this within specific groups (Giorgi, 2009). Using in-depth interviewing each individual is asked to describe and explore their past and current experiences of the phenomena being studied, together with their accompanying interactions with others. The focus is on describing the individual's lived experiences with the aim of providing rich and detailed descriptors in which no one essence is prioritised over others, and all interpretation is within praxis (Giorgi, 2009; Cresswell 2013). Phenomenological research can help the health care professional to increase their cognisance of individuals' challenges and needs, enabling them to offer appropriate support and guidance (Van Mannen 2014).

Key comparative findings.

Reviewing the findings of the research by Black (1992), Notter (2002) and Black (2018), two main themes were found to cross the decades, these were psychological problems and long term effects of the physical changes and challenges that arose after stoma formation. These also described separately were in reality linked, with those who had been able to overcome the psychological issues coping better.

Clinically Significant Psychological Problems.

The development of significant psychological problems can occur immediately after surgery, during the transition period or later, and for some may remain for the rest of their lives (Borwell 1997, White 1997, Black 2000, Black 2018). The suggestion by White (1997) over two decades ago, that patients who expressed dissatisfaction with pre-operative information

experienced more clinically significant psychological symptoms, has been found repeatedly in studies since then (PROMs 2012; Black 2018). These problems include alienation, the expression of feelings of difference after their stoma surgery, and loss of self-esteem and confidence. For others there are feelings of shock and disgust on first sight of the stoma, reactions reported to be elevated in individuals who have not been prepared pre-operatively for what to see or expect, and those for whom the surgery results from an emergency situation (Wade 1989; Persson & Hellstrom, 2002; Black 2004, Borwell 2009; Mols 2014; Burch & Black 2017). It is at this point post-surgery that the individual has to accept their body has 'failed' them, necessitating surgical intervention, over which they had no actual control over and which permanently altered their body and its functions (Notter and Chalmers 2012; Black 2018). This loss of autonomy is difficult for many patients, while extremely grateful for the surgeon's expertise, nevertheless the reality of the outcomes can be hard for learn to live with. The challenge this brings can be seen to have remained unchanged across the decades

... its things you've never seen in your life before...a ...stoma something you've never heard of.... It's all strange and has got to be learned (Black 1992)

and

It's not normal... one day I was myself... now I got this 'thing' on my stomach ... I'm different...I'll never be me again...' (Notter 2002)

similarly

..." this is not normal is it...this... coming out of my abdomen...it should be coming out of my bottom... how do I learn to live with it..." (Black 2018)

For a minority, the feeling of rejection of their 'new' body is so strong that they find it impossible to accept or relate to the stoma, referring to it as something that belongs to the surgeon who created it rather than being part of their own body (Notter and Burnard 2006; Van Mannen 2014). In extreme instances, patients totally dissociate themselves, as illustrated by the patient who, when asked about his stoma responded used third party, objective language

*..."well there **it** is ...**it** looks ok but I don't ask **it**... I don't care... (Black 2018)*

When the specialist nurse went on to ask where 'there' was, he pointed to the empty chair beside him and went on to state

*it's on the chair there... **the thing**...I suppose I have to do it each day [change the stoma bag] but I try not to...I don't want people thinking **it** is part of me of who I am" (Black 2018)*

For such patients, without professional help to accept and adjust to life with a stoma, quality of life will be affected and their lifestyle restricted. Therefore, it has to be a cause for concern that this patient had not been recognized as having acceptance and adaptation issues at the time of surgery. Instead he had gone on to develop entrenched negative views and did not even want to seek psychological help, seeing his problems as unchangeable as they were totally related to the stoma that he had rejected. Only once the need for help had been accepted could effective support be offered to him, but it has to be accepted that such delayed help may not ever be totally successful (Van Mannen 2014) For some patients, the feelings of anger, anxiety and depression are compounded if they struggle to cope with the physical effects and altered body functions following surgery. The intensity of emotional reactions appears to be related to both the physical evidence of the surgery (the stoma) and the assigned importance of fitting within accepted social norms (Polidano et al., 2019). Factors affecting adaptation include, but are not limited to, the disease process, diagnosis, treatment and medical and nursing care, both in the hospital and on return to the community (Black, 2000).

The long term effects of the physical changes and challenges of living with a stoma

The social taboos that surround body matter elimination in Western cultures are legion, with each individual's feelings about body matter elimination embedded deeply within the psyche. There are strong prohibitions in Western societies on the uncontrolled passage of urine and faeces. Frequently referred to as unpleasant, smelly and dirty, faecal elimination is not seen as an appropriate subject for public discussion (Black 1992; Chelvanayagam, 2012). Thus, the individual with a stoma may see themselves as a person who is being made to transgress social expectations and personal responsibilities, which adds to the difficulty of coming to terms with their changed body and body image, the stoma and the accompanying loss of control of continence (Annells 2006, PROMS 2012, Burch & Black, 2017). Accepting the changes requires refocusing and reassessment by the patient

'I'd been changed forever... there was no going back... it wasn't easy...but I had a family...I had to try...(Notter 2002)'

Only then could they continue their social and private roles and responsibilities and not become a marginal member of that society (Polidano et al., 2019). When bowel surgery including stoma formation is mooted as a surgical procedure, the individual's body image changes forever. The patient can feel that their body has become objectified, that they have lost their with personal autonomy with their personal bodily functions altered beyond acceptability (Black 2018). When looking to their future, patients report feelings of shame, disgust, anger, resentment and intense disappointment as they see their hopes and dreams 'disappear' (Notter and Chalmers 2012).

'... I couldn't take it in... I thought how on earth will I manage ... what am I going to do ... I was devastated.. the diagnosis was bad enough... but this ... '
(Black 2018).

Learning to cope at the technical level is learning to accept and control what they see as pollution of their body, their personal environment and the associated uncontrollable phenomena of crossing social taboos. They have had made public, what are seen as very private activities. If patients can learn to cope with the physical changes and manage their body 'technically', then they can continue with what they see as normal life performing their public role as if they are 'still the same as I was' (Black 2018). In this context, coping can be conceptualised as adaptation following illness, and includes the use of cognitive and motor activities to preserve external knowledge and awareness of their identity, in their own eyes compensating for what they see as their irreversible impairment (Polidano et al., 2019). Although this does not make the challenges associated with living with a stoma disappear, it does help hold them in check.

For some, even when they appear to have mastered the care needed, they do not have the self-confidence to believe they have been successful

".....every one tells me I don't smell..... I know I do..... I know they are not telling me to protect me" (Black1992)

This patient was adamant that her belief that it was impossible to prevent what she referred to as '*bad smells*', family and friends had tried to reassure her, but she was adamant, and needed long term guidance and support to overcome her fear of crossing social taboos. In other instances it was hard to determine whether the main concern sat with the patient or his/her partner as the following illustrates

..... "The smell seems to permeate the whole house and my wife always has a tin of air freshener everywhere.....in every room..... it's most embarrassing when visitors are here..... she always has the windows open" (Black1992)

Further discussion elicited the information that the partner had been excluded from advice and discussions before and after surgery. It was difficult to ascertain the extent to which odour was a problem, it wasn't ever discussed, so possible solutions had not been sought. This fits with Notter and Chalmers (2012) finding that families reported being 'left out' of discussions, and expected to cope as best they could, when in reality, they too needed help and guidance.

Managing the knowledge that others know about their changed physical status requires a sophisticated coping behaviour. Many patients make every effort for concealment from their 'audience' of all evidence of 'dirt' and the notion that faeces which many described as 'dirt' are looked after in private. In trying to hide their efforts for control, the individual often aims for ideal standards, which they maintain in public by the sacrifice of some of their private standards. At the inter-subjective level of coping, the individual constructs schema and rhetoric's to make sense for themselves of what has happened and vocalise the plethora of questions and concerns

....."Am I going to be able to wear nice clothes again? Will I be able to go on holiday? Am I going to want to go out and meet people and do my shopping again...I felt different. I....in hospital it was ok, but when I got home and tried going out I felt different.....exposed you could say.....that everyone knew what was under my clothes" (Black 1992)

This quote illustrates the frequently stated fear that everyone will know that they have a stoma, and although reported three decades ago, all these issues are still evident today, and continue to restrict day to day activities (Black 2000, Borwell 2009, Nichols & Reimer 2011, Burch & Black 2017; Black, 2017, 2018).

...how can I use universal changing rooms when I go to get a new dress or whatever...if they all see a bag of s...t hanging on me they will all run out...is this is what is going to define me forever now?" (Black 2018)

For some it is the combination of factors that is hard to overcome, coping with issues such as their diagnosis and the pain following surgery can be accepted and understood by family and friends. However, while in private they may have learned to cope, some of the resulting physical manifestations that are not in their eyes suitable for social sharing can lead to major changes in life and lifestyle.

..... "I coped with the pain, I coped with the diagnosis, but how can I be expected to carry on my job with this awful smell and the continual noise..... I'll have to give up my job and stay at home..... We will never be able to go on holiday again"(Black 1992)

And more recently

“It is the fear that there may have to be someone else who will have to change the bag for me ... I pray I can go on coping ... I stay at home ... I’m afraid the bag will swell if I go out... make people stare at me” (Black 2018)

Such anxieties impact on long term family and social interactions adding to the risk of increasing social isolation. This in turn impacts on anxiety, which itself is affected by fatigue, pain, and the challenge of having to overcome these issues in combination with exacerbation of other co-morbidities. Ways need to be found to prevent this negative cycle adding to the challenges faced by patients, who in many instances are also facing the long term reality of the diagnosis that led surgery. It is essential that information and support are developed to meet the needs of this group of patients, and to do this all guidance has to be in a format that can be tailor-made for each patient, accepting that one style does not work for all.

Individual coping styles

The research by Black (2018) was developed because of the consistency of the findings which as indicated above show that the same issues persist. The cultural construction of illness is a personal and social adaptive response. The malfunctioning of the body and the psychological process involved becomes disease, while the psychosocial disruption becomes illness. Illness will invoke cognition, valuation of the symptoms and possible breakdown of family and social interaction. Therefore, illness shapes disease into behaviour and experience, created by personal, social, and cultural reactions to the disease. Van Mannen (2014) argues that the individuals can be seen as being out of step with their bodies after surgery and that these processes create explanations (explanatory model) to help patients recover a relationship with their psycho-physical wellbeing that lets them move on.

All societies create these explanatory models to help construct reality and impose meaning on situations seen as unknown and challenging, but may be hazardous if accepted as reality, rather than a way of organizing and explaining alterations in normal functioning. In health care the different rationales supporting these models can be difficult to reconcile in practice. Each patient’s individual, explanatory model comes from their response to a particular episode of illness and is not necessarily the same as general beliefs about illness held by the individual’s particular society, which may be idiosyncratic, changeable and influenced by culture. By contrast, the medical model which provides treatment is based on learned scientific evidence which offers strategies to deal with each particular set of symptoms. The

doctor and patient, each using their own explanatory model, need to interact to try to understand and interpret the other's model, recognising the individual's subjectivity (regarding their disease) and the doctor's objectivity (regarding the disease process). Led by the medical model, the clinical process, is seen as a way for the individual to adapt to worrying news and circumstances with the adaption process often reflected by the words 'managing; 'coping', and 'adapting'.

However, the way the individual constructs the news given to them about their diagnosis is a personal and social adaptive response, and the terminology of the medical model has different meaning for different individuals. Black's (2018) study illustrates the range of individual difference. It revealed 30 consistent descriptors/ feelings from the participants in the sample, which needed to be collated and combined into a format that would enable specialist nurses and other health professionals to offer patients appropriate information and guidance throughout their life span. These thematic insights, based on interviewee's stories are insight cultivators reflection and interpretive process (Van Mannen 2014) Therefore, further iterations of the analysis processes were used to refine the descriptors with emergence of five distinct categories or coping styles. (Table 2).

Reducing	Reducing	Reducing	Categorisation/ coping style
Searching for reassurance	Constant worry	Physical sensations perceived as disease progression	ANXIOUS PRE-OCCUPATION
Overwhelmed by diagnosis	No active coping strategies	Self blame and burden to others	HELPLESSNESS and HOPELESSNESS
Minimisation of disease	Undertake distraction techniques	Maintain life as if everything is normal	AVOIDANCE
Lack of control	Acceptance	Fate will decide	FATALISM
Surgery and stoma seen as a challenge	Information sought to help with treatment	To keep life as normal as possible	FIGHTING SPIRIT

Table 2. Utilization of coping styles

Each of these different coping styles has implications for health professionals For each group the three main issues that arose have been illustrated by quotes from participants.

Anxious Pre-occupation: Participants reported that they constantly worried about the stoma. Every time they looked at it and every time they had any symptom at all for them, there was and the possibility of recurrence. Insomnia was a problem for some of them and they lay awake until the early hours feeling exhausted, but when they got up, they worried even more, including the fear that they wouldn't ever sleep properly again. Worry is a natural, instinctive reaction to bad news. However, for those in this group, even after five years they still worried about all aspects of life. They worried that any perceived pain was a recurrence, that they smelt from the stoma, that others would think they were incontinent. There appeared to be nowhere they could go for reassurance about their worries. Ending active treatment is a life event as much as diagnosis was, but support for all these worries is lacking.

<p>Searching for reassurance</p>	<p><i>• I go to my GP but he seems to have little time for me and he makes me feel I am time wasting....I go to the group meetings but there is never anyone there to ask....they are not medical....I have my yearly old age check but the practice nurse is so young she doesn't seem to know much about what I am talking about.....she asks about my stoma but does not look at it.</i></p>
<p>Constant worry</p>	<p><i>•I lie awake at night wondering if the cancer will come back again...if it occurs the third time that will be the end...I cant go through that again I'm too old.....will I die tonight or will I have another day with all this worry</i></p>
<p>Physical sensations perceived as disease progression</p>	<p><i>•how will they know if it has come back....would it show... does the pain in my side mean it has come back.....I weigh my self every day to see if I have lost weight....no I'm not trying to loose weight heaven forbid but that would be a sign wouldnt it</i></p>

Helplessness and hopelessness. For some of the interviewees, the original diagnosis was overwhelming, even though they had a feeling about what they were going to be told. The barrage of information coming at them is overwhelming and they are not able to form coherent coping strategies to deal with the diagnosis and treatment regimen. For many the thought of having a permanent colostomy was so overwhelming and they felt that they would never be able to continue with their life as they knew it. They saw themselves as a burden to their spouse and that that no one would want to be near them as they would always smell (Black, 1989,2000).

Overwhelmed by diagnosis	<ul style="list-style-type: none"> • <i>It has been a very difficult way....I was told I had a bowel cancer but could not believe what I was hearing.....they must be talking about somebody else.....they(the hospital) did the op.....but did not have to have one of those awful bag things.....but 6 yeras later they say I have bowel cancer again.....does anyone know what they are doing any more I ask you(pt shouting).....Ihad to go to a specialist hospital in London who deals with things like this and had a Professor somebody or other.....would he be any better....no because he gave me a bag for good.....heaven help us!</i>
No active coping strategies	<ul style="list-style-type: none"> • <i>I was given poison [researcher asks patient to qualify] you know that , that chemo stuff.....it was every week.....I had enough after 18 weeks and stopped.....my veins were so bad.....I don't like the stoma, never have and never will.....i refuse to change it every day.....I wait for a leak or it is so full.....the special nurses told me how to do it and when to do it but what do they know.....I refuse to empty it (the appliance) when I am out and do not take any spares with me.</i>
self-blame and a burden to others	<ul style="list-style-type: none"> • <i>.. all my family have had cancer and I suppose it will come again.....I have not spoken to the family they are not interested anyway and have their own lives (refuses to discuss close family support or if he has a wife)..... death does not bother me....why should it.....I was an engineer in Iraq so I know what is to come.....just another burden for the family.</i>

Avoidance Cancer patients and/or family members often report being ashamed of their anxieties about their own or their loved one's diagnosis and treatment, even when they have been told that they are "cured". They have received major input from professionals and support from family and friends, so once active treatment is complete they report thinking that they should now 'feel OK' feeling ashamed of themselves that they 'cannot put it all behind me and move on'. They state that and they do not want to upset their family and friends by expressing their ongoing anxieties. They feel this would be an unfair burden to place on others, but fret that they are holding up their own recovery. While many can overcome this, for some this will continue through their lives and they will undertake activities to avoid family and friends asking how they are or how they are coping. Even after many years post treatment discharge some still employ distraction techniques to avoid the discussion of how they feel and how they are doing.

<p>Minimisation of the disease threat</p>	<ul style="list-style-type: none"> •yes of course I realise there is always a possibility of recurrence but I shall keep up my activity and eat well....it is not something I will worry about until it happens....I am sensibleI will not be complacent
<p>Undertake distraction techniques</p>	<ul style="list-style-type: none"> •when I reached the five year mark and was discharged friends said I should do the cancer runs and raise money for research.....why.....I am okI'm off to do the things that I want to do that I had to put on hold.....I'm better.....what else is there to say.... I dont want to dwell on what happened
<p>Maintain life as if everything is normal</p>	<ul style="list-style-type: none"> •It is over a long time ago....I am well and carry on with my life....everyone always tells me how well I look and I agree with them....but....it is always there at the back of my head.....but I just move forward all the time

Fatalism Goodhart and Atkins (2011) suggest that low mood or even depression are one of the most common side effects of cancer. Although none of the interviewees expressed thoughts of depression or treatment for depression at any time, it seems clear from the patient quotes that there could be an element of depression arising from the situation the individual has found themselves in. one indicator of this is the report of fatigue without any obvious cause. Fatigue, also one of the common late onset symptoms of cancer is still evident. Often with diagnosis and treatment the individual can be stretched to their limit and beyond and often grieving does not take place. The bottling up of all these symptoms can lead to a fatalistic attitude and feelings.

Lack of control	<ul style="list-style-type: none"> • ...she was so furious with the surgeon you know....he had(the surgeon) ruined her life..yet it was me in the bed...I was the one having to go through all this entailed and I didnt know what was going to happen.....When the stoma nurse came to teach me she would (Pts wife) say tell her (the SCN)that I am not helping you with this...I felt so embarrassed by her behaviour
Acceptance	<ul style="list-style-type: none"> • we rubbed along for 10 years after the end of my treatment....I have not seen anyone since being written off by the surgeon.....not exactly written off but you know what I mean....the fatigue is the worst.....I wish I could do more but no-one would know who I was now if I asked for an appointment, who do I ask then?....We have seperated now.....she could'nt cope.....thats what serious illness can do to a family (appears tearful) I try and cope...how could someone leave you when you have a life threatening illness?....I don't know.....I wish I could talk to someone.....there are so many things I need to ask
Fate will decide	<ul style="list-style-type: none"> • one day the SCN turned up at the door....it was about 3 months after surgery and she(SCN) had taught me to irrigate.....she always said she would pop in if she was that way.....I felt embarrassed as it was afternoon and I was in my pyjamas and dressing gown....why.....because my wife had gone her sisters to stay and I couldn't be bothered....the SCN looked a bit surprised but did not say anything.....she asked if my wife had accepted the stoma now....no if anything she was worse... she asked if I thought counselling would help her and offered to to talk to the Macmillan psychologist for me...it would be a good idea but whether she will accept it I don't know

Fighting Spirit: Although it is very common to have worries after being diagnosed with cancer and body image change, many individuals can have a “fighting sprit” from diagnosis and through treatment and onwards as they return to their normal lives. They do not want to “wallow” in self pity and have the temperament to continue their life styles and jobs. They will often search for any other forms of treatment to be able to confidently discuss regimens with their doctor and how they want their treatment to progress. Once finally discharged they are able to continue their inquiring into cancer and will often want to help others who may be finding it hard to move on in their lives after treatment.

<p>Cancer and stoma seen as a challenge</p>	<ul style="list-style-type: none"> •when I was diagnosedI thought ok, well, how am I going to approach this.....we enjoy our life (with his wife)and love our holidays abroad and no way are they going to stop.....I am sure people who have stomas go away when they are well.....they do don't they?.....I must look into how to do this.....I go to stoma days (open days) and talk to the companies.....I need to find what will suit me bestI have seen over the years how the bags change.
<p>Information sought to help with treatment</p>	<ul style="list-style-type: none"> • when I felt better afterwards (after the surgery) I investigated on the computer what might happen next.....I had heard of chemo and wanted to be prepared.....I wrote for literature from those people who deal with colostomy. [Colostomy Association].....I knew I was going to see another doctor [oncologist] in six weeks and wanted to be prepared with questions.....I suppose all the patients are like me.....keen to know what goes on.....well it was only the best [the oncologist's news] and I was back on track.....no chemo or side effects to put up with.....but mind you I would have taken and put up with whatever he threw at me.....I have had excellent treatment from the GP and hospital
<p>to keep life as normal as possible</p>	<ul style="list-style-type: none"> •I am a lay preacher and I will continue.....my health is good at present..... we have been married 60 years and I definitely expect some more(years).....I had no psychological or emotional problems.....I back at Am Dram. [Amateur Dramatics] now and the choir.....yes there was fear of the unknown but nothing seems to be unknown these days with a computer.....its a minor inconvenience.....my bum in a different place now where I can see it.

The following extracts illustrate how these coping styles can manifest themselves when common and recurrent issues are considered. The starting point has to be the first sight of the stoma after surgery. The patient may look at their abdomen and stoma in a detached way or even as a curiosity and feel an existential amazement that what they are seeing is part of them (Van Mannen 2014). After surgery and the raising of a stoma, patients will often state that their body is rebelling when the stoma bag leaks and while trying to change the appliance the stoma keeps working, spilling its incontinent output all over the floor. As one participant graphically described:

... "The nurse slowly removed the bag and kept asking if I was ok...I was dreading it ... wondering what I would see...all I could see as she removed it was poo pouring out like a river of chocolate...at any other time I could have joked about the chocolate...but I just felt so embarrassed for the nurse...she was frantically mopping me and the floor with paper towels...as fast as she did there was more and more...luckily another nurse came into help...every time I saw the poor nurse I felt so embarrassed". **Coping style: anxious pre-occupation**

It is essential that this ongoing anxiety and embarrassment are addressed or permanent anxiety and worry can develop. Everyone has a special relationship with their body, if they are unhappy with the way they look, they can try and change their external image but they cannot hide from their surgically altered body (Merleau-Ponty 1962; Palidano et al., 2019). One participant had joined a support group with the hope of accessing advice and help from

those who had already been down the path he was now walking, but had not known how to raise his concerns

“...I go to the group meetings ... but there is never anyone there to ask”

Coping style: anxious pre-occupation

If not addressed this fear can even impact on perceptions of consultations with health professionals, with the result that they gain less from their main link with services. . For some participants the solution had been to focus on creating an external reality that they believed was acceptable, while keeping their own reality secret for fear of rejection:

I keep it a secret from everyone that I have a colostomy” I don’t like meeting other people so I don’t go out. When I have to I dress carefully making sure my abdomen is well covered and protected and pray that I do not have a lot of wind to swell the bag and people may stare at me” **Coping style: avoidance**

The anxious pre-occupation by patients, that they would be marginalised by their community, once their condition is known, impacts on their willingness to participate in social interactions.

These comments are typical of patients for whom bodily functions such as excretion are not acceptable social subjects. As they expect others to share their perceptions, they place negative inferences on professional interactions, not raising what they see as un-acceptable phenomena such as odour, noise and flatus even with those who as with the support group may be experiencing similar issues. For some, this sense of no longer *‘fitting’* into society begins at diagnosis, when without experience of what life will be like after surgery, they only see the worst possible outcomes, seeing themselves as social pariahs. This kind of initial response is not unusual, as Kelly (1985) first illustrated when he gave a graphic description of his shock and rejection when he first saw his stoma, the terms he used were mirrored by the participants in this study:

...”I said I did not want to be smelly and [have to] avoid social situations ... I felt as if it was the end of my life and [I] would be seen as a leper” **Coping style: helplessness and hopelessness**

It has to be a cause for concern that in the decades since Kelly’s (1985) surgery, societal attitudes have changed so little that patients are still afraid of the stigma they could incur from people at work and socially knowing they have had surgery resulting in a stoma:

...” I don’t know how I am going to be able to handle work...I have to stand up and give regular talks...just look how my bag blows up and the noise...well...it will show under my suit jacket and everyone will notice...what am I going to

do...I can't retire I don't want to I'm too young ... I need to find ways to look normal" **coping style: Avoidance**

While total rejection of what they see as a distortion of their body image may be relatively rare, the participants in this study showed that for some patients anxiety continues body in terms of elimination of bodily fluids through different orifices, changing social boundaries

*..." this is not normal is it...this... coming out of my abdomen...it should be coming out of my bottom...how can I use universal changing rooms when I ... get a new dress or whatever...if they all see a bag of s***t hanging on me ... they will all run out...is this what is going to define me forever now?"* **coping style: Fatalism**

Ways need to be found to help them adjust, recognising that they cannot return to their former state, but need to define and accept entrance to their new status, as the following quote from a pragmatic and realistic patient suggests:

..."Well I thought...what do we have here...I had no idea what it was going to look like...I presumed just a hole in my abdomen...not this red thing...but let's be sensible...at the end of the day it's just my bum in a different place" **Coping style: fighting spirit**

Coping with such disconcerting changes, needs to be discussed with the specialist stoma care nurse if long-term issues such as the above issues are to be avoided. Health care professionals need to develop tools to recognize the different coping styles and adapt their approach accordingly to plan individualised longevity care plans. There will be challenges to implementation, but there are indicators that holistic care and services can be both cost-effective and used to improve care and quality of life for this group of patients. However, it is essential because in addition to improving health well-being and quality of life, it is recognized that stoma patients that find adaptation to their new way of life difficult will more often experience long-term physical, social and economic consequences, which in turn leads to an extensive use of health services.

Conclusion & Recommendations

The quotes used from the study by Black (2018), illustrate that all the interviewees reported some form of past or present psychological, psychosocial and physiological problems which they felt that no-one addressed. Specialist nurses are key members of the multidisciplinary team and their perspectives are essential to inform future developments in long term care provision for stoma patients and not just in the early months after surgery. However, while some participants felt that their CNS could and did, discuss many of the issues that had arisen, others stated that their CNSs were diffident and not able to discuss key issues. There

was also a group who had little contact with CNSs, and reported that general nurses lacked time to sit and discuss on going issues, while others reported nurses stating that they had no specific training and education in bowel and stoma issues.

The findings presented here have clear implications for nursing practice, the CNS has clear resonance with theories and practice of nursing, where the essence of specialised nursing knowledge is directed towards helping individuals regain health. CNSs can use their skills, expertise, education and training in stoma care to provide physical and emotional support for the patient and family, coordinate care services and to inform and advise patients on clinical as well as practical issues, leading to positive patient outcomes. It is clear from the literature and the interviewees that the CNSs in stoma care are key workers treating and managing the health concerns of stoma patients, working to promote health and wellbeing in the patients they care for. They can also reduce treatment costs, increase efficiency, drive innovation and provide valuable information for service redesign as well as enable multidisciplinary care and communication between different teams (Macmillan, 2018). Therefore, although there are currently no clearly defined pathways for this change, nurse specialists in colorectal and stoma care are well suited to prepare and deliver care for life plans which will need to be delivered mainly in the community or GP practice.

This article supports that there needs to be an adaptation in the way individuals are supported and that the five shifts in care needed using Patient Recorded Outcome Measures (PROMS, 2012) are still not in use, but should urgently be considered for implementation they are:

1. A greater focus on recovery, health and well-being after cancer treatment.
2. Holistic assessment, information provision and personalised care planning.
3. Supported self-management
4. Away from clinical follow up to tailored support that enables early recognition of the consequences of treatment and the signs and symptoms of further disease.
5. Measuring experience and outcomes

However, originally the PROMs (2012) did not go beyond the finalisation of treatment and the discharge of the patient, as one patient put it “abandoned to fall into the great black void.” Therefore, the recommendation from this study these measures should be used for life span care.

Key Points.

Stoma care nurses need to be able to offer the stoma patient a care for life plan to support the patient in their longevity.

Current models of care are not currently meeting the needs of the stoma patient.

The General Practitioner needs to be more proactive in the care of the patient who has a stoma.

It is clear from the recent research that many stoma patients feel that the stoma care nurse is not easily available, if at all, when the patient perceives they have a problem and needs help and information.

CPD Reflective questions.

How do you think your service you currently offer could be improved to offer a better service for your stoma patients?

Do your stoma patients often say that it is hard to contact the service?

Consider some of your patients that may have had a stoma 5 or 10 years ago. When did you last see or hear from them? Are they managing their lives in the way they would want?

As interviewees in the study said their GP or Practice nurse had little time for them or just said they couldn't help, how could you improve this situation for the patient?

REFERENCES

- Adams E, Boulton M, Watson E. (2009). The information needs of partners and family members of cancer patients: a systematic review. *Patient Education and Counselling*. 77,179-186.
- Annells M.(2006). The experience of flatus incontinence from a bowel ostomy: a hermeneutic phenomenology. *Journal of Wound Ostomy Continence Nursing*.33:518- 524.
- Bekkers M, van Knippenberg F, van den Borne H, van Berge-Henegouwen G. (1995). Psychosocial adaptation stoma surgery:A review.Journal Behaviour Medicine.18(1):1-31.
- Bekkers M, van Knippenberg F, van den Borne H, van Berge-Henegouwen G. (1996). Prospective Evaluation of Psychosocial Adaptation to Stoma Surgery: The Role of Self Efficacy. *Psychosomatic Medicine*. 58:183-191.
- Black P. (1992). Body Image after Enterostomal Therapy. M.Sc thesis. London.Steinberg Collection.RCN.
- Black P. (2000). *Holistic Stoma Care*. London. Balliere Tindall.
- Black P. (2004). Psychological, Sexual and Cultural Issues for Patients with a Stoma. *British Journal of Nursing*. 13 (12):692-697.
- Black P. (2012). How should we support patients with colorectal cancer and a stoma? *Journal of Gastrointestinal Nursing*.10 (8):5.
- Black P. (2017). Supporting patient care with appropriate accessories. *British journal of Nursing*.26 (17):S20-22.
- Black P.(2018). Lost after transition: the development of a conceptual framemwork and model for patients with colorectal cancer and a stomach have completed therapeutic interventions. Birmingham City University. <http://www.open-access.bcu.ac.uk/id/eprint/8906>.
- Borwell B. (1997). Psychological considerations of stoma care nursing. *Nursing Standard*. 11:49-55.
- Borwell B. (2009). Rehabilitation and stoma care: addressing the psychological needs. *British Journal of Nursing*. 18 (4):S20-S25.
- Burch J, Black P.(2017). *Essential Stoma Care*. Harrow, London. St Mark's Academic Institute.
- Chelvanayagam S. (2014). Stigma, taboos, and altered bowel function. *Gastrointestinal Nursing*, 12. (1). 16-22
- Creswell JW. (2014). *Research design: qualitative, quantitative and mixed methods approaches*. Sage.
- Department of Health. (2007).*Cancer Reform Strategy*. London. Department of Health.
- Di Gesaro A. (2016). The psychological aspects of having a stoma: a literature review. *Gastrointestinal Nursing*. 14. 2. 38-44
- Douglas M. (1966). *Purity and Danger*. Harmonsworth, England. Penguin.

- Finlay L. (2011). *Phenomenology for Therapists: Researching the Lived World*. Sussex.UK. Wiley-Blackwell.
- Giorgi A. (2009). The descriptive phenomenological method in psychology: A modified Husserlian Approach. Duquesne University Press,
- Goodhart F. Atkins L. (2011). The cancer's survivors companion. Hachette Digital
- Goffman E. (1968). *The Presentation of Self in Everyday Life*. London. Allen Lane.
- Helman C. (2007). *Culture, Health and Illness*. London. Wright.
- Holden P, Littlewood J. (1991). *Anthropology and Nursing*. London. Routledge.
- Kelly M.(1985). Loss and grief reactions as responses to surgery. *Journal of Advanced Nursing*.10:517-525.
- Kilic E, Taycan O, Belli A, Ozmen M. (2007). The Effect of Permanent Ostomy on Body Image, Self Esteem, Marital Adjustment, and Sexual Functioning. *Turkish Journal of Psychiatry*.18 (4):1-8.
- Merleau-Ponty M. (1962). *Phenomenology of Perception*. London. Routledge and Keegan Paul.
- Mols F. (2014). Living with the physical and mental consequences of an ostomy: a study among 1-10 year rectal cancer survivors from the population based PROFILES registry. *Journal of Psycho-oncology*.23:998-1004.
- Macmillan Cancer Support. (2018). Macmillan Clinical Nurse Specialists:the role. London. Macmillan.
- Notter J. (2002). *'I'm different now'*. *The Quality of Life of Women Following Restorative Proctocolectomy*. Ph.D Thesis. University of Wales College of Medicine.
- Nichols T, Riemer M. (2011). Body Image, Perception, the Stoma, and Peristomal Skin Condition. *Journal of Gastrointestinal Nursing*. 9(1):22-27.
- Notter J, Chalmers F. (2012). Living with a colostomy: a pilot study. *Gastrointestinal Nursing*. 10(6). 16-24.
- Notter J. Bernard P. (2006). Preparing for loop ileostomy surgery : Women's accounts from a qualitative study. *Journal of International Nursing Studies*.43. (2). 147-159
- Persson E, Hellstrom AL. (2002). Experiences of Swedish men and women 6-12 weeks after ostomy surgery. *Journal of Wound, Ostomy and Continence Nursing*.29:103-108.
- Polidano K. Chew-Graham CA. Bartlam B. Farmer AD. Saunders B. (2019). Embracing a 'new normal': the construction of biographical renewal in young adults' narratives of living with a stoma. *Sociology of Health & Illness*. 42 (2). 342-358
- PROMS (2012). Patient Reported Outcome Measures Survey. *Quality of Life of Cancer Survivors in England: Analysis of Patients Free Text Comments: Final Report*. London. Department of Health.

Sutherland AM, Orbach CE, Dyk RB. (1952). The psychological impact of cancer and cancer surgery: Adaptation to a dry colostomy: preliminary report and summary of findings. *Cancer*.5:857-872.

Suls J. (2012). Social comparison processes: implications for physical health. In Friedman HS (Edt). *Oxford Handbook of Health Psychology*. DOI: 10.1093/oxfordhb/9780195342819.013.0012

Svanaeus F. (2001). The phenomenology of health and illness. In S.K.Toombs (Ed), *Handbook of Phenomenology and Medicine*. Dordecht:Kluwer Academic. 87-108.

Van Mannen M. (2014). *Phenomenology of Practice*. California,USA. Left Coast Press

Vonk-Klaassen SM. de Vocht H. den Ouden MEM. Schuurmans MJ. (2015). Ostomy-related problems and their impact on quality of life of colorectal cancer ostomates: a systematic review. *Quality of Life Research*. 25. (1). 125-133

Wade B. (1989). *A Stoma is for Life*. London. Scutari Press.

White C. (1997). *Living with a Stoma*. London. Sheldon Press.

