

Gastrointestinal Nursing - vol 12 no 1 February 2014

Stigma, taboos, and altered bowel function

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Abstract

This article discusses the concepts of stigma and taboos and their relevance to bowel function and gastrointestinal disorders. The author debates the definitions regarding the concepts of stigma and taboos and considers the effects of stigma on the stigmatised and non-stigmatised person. The types of stigma experienced by individuals with chronic illness are examined and the effect of stigma in specific gastrointestinal disorders is reviewed. The interventions to try to reduce the stigma associated with bowel function and gastrointestinal disorder are also explored. It is hoped that this article will contribute to a debate on addressing the issue of stigma in the UK.

Many subjects were once considered taboo but are now discussed more freely, such as death, sexual function, and even urinary incontinence. These subjects are now debated on television or spoken about in advertisements. However, one taboo persists in the UK—that of bowel function (Kaplan, 2012). A recent spate of advertisements on television promoting laxatives make reference to constipation, but do not refer to the bowel directly or discuss bowel function; instead they refer to 'being back to your old self again'. Similarly, any advertisements for continence pads do not refer to faecal incontinence.

The need to raise awareness about colon cancer and promote its early detection and, thus, improved treatment outcomes led to the NHS endorsing a 30-second television and radio campaign in 2012. This campaign encouraged people to discuss any of their bowel symptoms with their GPs (Department of Health (DH), 2012). The Care Services Minister Paul Burstow commented that 'No one likes talking about their poo—it's embarrassing. But bowel cancer is the second biggest cancer killer so we need to get over the embarrassment and talk to someone about it' (DH, 2012). Bowel cancer causes 13 000 premature deaths annually, with 33,000 people diagnosed every year (DH, 2012).

When a topic is considered taboo, it is not discussed openly. In fact, discussion is usually discouraged or deemed inappropriate. Therefore, very often, people do not possess the appropriate vocabulary to discuss the subject. They are afraid of coming across as offensive and therefore avoid discussions altogether. This is particularly relevant to discussions regarding bowel function (Norton, 2004; Thompson, 2013). The stigma associated with bowel conditions often leads to underreporting by those affected (Yarde, 2013).

Taboo and stigma

The terms 'taboo' and 'stigma' are often used synonymously; however, this is somewhat misleading. Taboo refers to a prohibition of an act, action, person, or object, whereas stigma relates to the impact of a taboo and the perception of the person affected and others. Howson (2013) defines taboos as 'beliefs and rules which societies develop (construct) to maintain dirt in its rightful place and which in turn, represent or symbolize the social order'.

The term stigma is derived from the Greek word referring to a tattoo mark—the marks people were branded with to demonstrate their affiliation to a temple. These marks were not initially seen as a negative attribute, but in later years, they determined whether a person was a slave (Carlisle et al, 2001). Goffman (1963) refers to stigma as 'the situation of the individual who is disqualified from full social acceptance'. In his seminal text, Goffman outlines three broad types of stigma (Box 1).

Link and Phelan (2001), while acknowledging Goffman's work realised that stigma is a complex phenomenon that needed to be reconceptualised. They state that a stigma exists when labelling, stereotyping, separation, status loss, and discrimination occur within a power situation. Therefore, the process of stigmatisation occurs when people are labelled as different, which is then linked to a negative stereotype.

Since bowel function is maintained by unconscious processes (Ness, 2012), it is difficult for a person to understand how bowel symptoms have occurred. People with bowel function problems are already experiencing a sense of deviance or differentness from the norm. Therefore, approaching a health professional—a person seen to be in a position of power—can accentuate their own feelings of powerlessness and their symptoms (Carlisle et al, 2001). This creates two groups of people: the stigmatised and non-stigmatised. Strangely, when the groups interact, they are both concerned with the perception of the opposing group (Garcia et al, 2005). On the one hand, the stigmatised person may be hyper-vigilant for signs of possible rejection or being discredited and may attempt to conceal his/her stigma if possible. He/she may also utilise defensive strategies to avoid social interaction. The non-stigmatised person, on the other hand, is fearful that he/she appears prejudiced, and may try to overly compensate for this behaviour. Therefore, both groups behave differently, which can accentuate the underlying issue (Garcia et al, 2005; Howson, 2013).

Concealment of the stigma or stigmatising feature may be an option for some 'conditions' such as mental illness, incontinence, and HIV/AIDS. In these situations, for instance, the stigma cannot be seen, unlike a facial disfigurement, for example. Therefore, the person has a degree of control and choice over to whom and when they reveal their stigmatising condition (Joachim and Acorn, 2000; Quinn and Earnshaw, 2011). In Chelvanayagam and Stern's (2007) paper, on facilitating a group of women with spinal injuries and bowel dysfunction, the respondents reported experiencing both invisible and visible stigma. Visible stigma referred to the physical effects of their spinal injury, such as unusual gait or difficulty walking up stairs, whereas invisible stigma was related to bladder or bowel dysfunction. The respondents reported that deciding whether or when to reveal their invisible stigma was empowering, since it was within their control (Chelvanayagam and Stern, 2007).

Taboos and bowel function

Archaeologists discovered fossilised stool dating back 400000 years; the stool was found away from the 'clean' areas, such as the kitchen (Smith and Smith, 1987). In the UK, awareness of the links between faeces and disease became apparent after the development of the London sewage system in 1859, when death rates significantly decreased (Norton and Chelvanayagam, 2004). Elimination has always been seen as a private activity carried out in an enclosed environment (Williams, 2008).

Society demands that individuals adopt acceptable practices with regard to defecation. Weinberg and Williams (2005) refer to three sets of practice: Where the defecation is performed—a place that has to be 'socially acceptable in terms of time, location and use of receptacles' (Weinberg and Williams, 2005) The sight, smell, and sounds of defecation and the associated disgust, which must be minimised. The vocabulary or euphemisms used to describe the process of defecation. Norton (2004) discusses the idea that nurses have a 'special relationship with the bodies of their patients'. Nurses are allowed access to the private physical body and all its functioning (Thompson, 2013). Therefore, it is crucial that they demonstrate acceptance and empathy by ensuring that their verbal and non-verbal communication is appropriate. Interestingly, patients will often respond more to a nurse's facial expression than to verbal communication (Bach and Grant, 2011). When an odour is particularly offensive, it can be difficult to conceal feelings of shock and disgust, but such expressions of emotion will only exacerbate the sense of shame and stigma felt by the patient

Stigma and gastrointestinal disorders

Individuals who experience a gastrointestinal disorder frequently have symptoms concerned with defecation, whether as a direct symptom of their illness such as inflammatory bowel disease (IBD) and irritable bowel syndrome (IBS), with an idiopathic cause such as corrective surgery, cancer treatment, or the formation of a stoma. The taboo against discussing bowel function means that they frequently develop alternative coping strategies such as planning their journeys by the location of available toilets—'toilet mapping' (Ness, 2012)—or using medication such as loperamide to manage their symptoms and avoid 'behaviours' that would cause stigmatisation (Collings and Norton, 2004).

Patients with active IBD and IBS will experience pain and diarrhoea and therefore choose to be within close proximity to a toilet (Taft et al, 2011). Individuals with IBD can develop anal fistulas that can affect continence either through their formation or through the surgical intervention required to treat the fistula. In addition, the person experiences persistent anal discharge with recurrent anal abscesses (Hammond and Lunniss, 2007).

People diagnosed with IBS report a sense of stigma owing to not only their symptoms but also the lack of understanding from their family, friends, and health professionals. Unlike other gastrointestinal diseases, there are no objective measures of illness severity. Therefore, the health professional has to establish the severity of symptoms on the patient report alone (Drossman et al, 2009). Patients with IBS frequently report that they feel their condition is not being taken seriously and are often told that it is 'all in the head' (Jones et al, 2009). These experiences, combined with the increased comorbidity of psychological disorders, imply that the patient can feel stigmatised, may conceal his/her symptoms, and withdraw from social interactions (Jones et al, 2009). These experiences, combined with the increased comorbidity of psychological disorders, imply that the

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Pelvic-floor dysfunction affects one third of all adult women (Porrett, 2008). Pelvic floor weakness can cause prolapse of the bladder, uterus or bowel as well as urinary and faecal incontinence, sexual dysfunction, and constipation. This disorder is frequently reported to be both embarrassing and stigmatising (Porrett, 2008). Individuals living with faecal incontinence often report feeling stigmatised (Wilson, 2013) and are even reluctant to discuss their symptoms with a health professional (Collins and Norton, 2013).

Fear of faecal incontinence or a visible stoma appliance will influence what a person wears and the activities they engage in (Noone, 2010). In addition, the person's diet is frequently affected, and they need to be careful about what foods to eat to avoid urgency, flatus, and diarrhoea. High-fibre foods, such as bran and oat-based products, vegetables, and fruit, can exacerbate faecal urgency, increase flatus, and produce stools of a loose consistency (Wilson, 2007; Williams, 2008). However, people frequently experiment with different foods to assess what helps or worsens their symptoms.

The timing of eating is also important. It can affect eating with family and friends at home or outside and therefore affect social life (Wilson, 2007; Williams, 2008). Stomas can have a stigmatising effect on some ostomates. The patients can be reluctant to show their stoma to their partners, family, and friends and could isolate themselves from previous recreational and social activities (Owen, 2008; Noone, 2010).

Difficulty with defecation or incomplete evacuation detrimentally affects a person's quality of life (Collins and Norton, 2013). These symptoms may be complicated by psychosocial difficulties such as eating disorders, depression, or sexual abuse, which may have precipitated and now perpetuate the symptoms (Sun et al, 2011; Woodward, 2013). Sun et al's (2011) cross-sectional survey also reported that, compared with matched controls, individuals with chronic constipation were more likely to take sick leave and report general health impairment that affected work performance.

Stigma and chronic illness

People with chronic illnesses, such as IBD, report difficulties in social relationships and employment owing to ill-health and decreased satisfaction with health-care providers (Earnshaw et al, 2012). Stigma in chronic illness can be described as internalised, experienced, and anticipated stigma (Earnshaw and Quinn, 2012). Individuals with internalised stigma incorporate the negative connotations of their illness into their belief system and, therefore, feel ashamed and guilty. They may also report feeling dirty, which is often reported by people experiencing faecal incontinence or who have a stoma. Experienced stigma or enacted stigma is the perception that the person with the stigma has experienced discrimination in his/her relationships with others, in his/her personal and work life as well as a patient within the health-care system.

'Suddenly I needed to go desperately; then ... too late it was running down my legs and the shop assistant escorted me and my 5 year old daughter to the staff toilet walking behind us. I felt so humiliated and angry and it was obvious what she was thinking.' (Anecdote by patient attending author's clinical practice)

Anticipated stigma relates to the expectation a person has that he/she will be stigmatised by others. This can have a stronger detrimental effect on the person's mental health (Earnshaw and Quinn, 2012). However, anticipated stigma may have arisen from previous episodes of experienced stigma. Even if a person has not experienced any form of stigmatisation, the threat or anticipation of being discredited has been discovered to have a detrimental effect on quality of life (Earnshaw et al, 2012)

'Whilst using a public toilet, I heard two women commenting on the smell of faeces. I assumed they were referring to me, so I waited until they had left the toilets and then I scurried away like a little mouse.' (50-year-old woman with faecal incontinence)
(Chelvanayagam and Stern, 2007)

The problem with any type of stigma is that it can result in a reluctance to seek help and disclose symptoms because of a fear—real or perceived—of being labelled or discriminated against, which then validates the person's feelings of shame and disgust (Weiss et al, 2006; Earnshaw and Quinn, 2012).

Interventions to reduce stigma

Stigma is correlated with poorer patient outcomes, low self-esteem, and decreased overall health (Quinn and Earnshaw, 2011; Taft et al, 2011). Therefore, it is imperative for health professionals to recognise the implications of stigma and provide effective interventions to lessen the effect. Essentially, stigma needs to be tackled from three perspectives: the stigmatised person, health providers, and health policy (Weiss et al, 2006) (Table 1).

Intrapersonal and interpersonal level

Many people with altered bowel function report feeling isolated (Collings and Norton, 2004; Jones et al, 2009; Wilson, 2013). They report that hearing others experience similar symptoms offers a sense of normalisation (Chelvanayagam and Mott, 2005).

'Once informed of the prevalence of faecal incontinence, one patient at her second appointment recounted that she had worked out that there may be at least 4 other people in her train carriage with similar symptoms. 'I then realised I wasn't alone.' (Anecdote by patient receiving biofeedback therapy for faecal incontinence)

Discussion of symptoms without embarrassment and fear of reprisal and with a supportive health professional who listens and responds appropriately also lessens feelings of stigmatisation. Some individuals may require more formalised psychological interventions, such as counselling or cognitive behavioural therapy, that challenge beliefs and assumptions surrounding illnesses (Heijnders and Van Der Meij, 2006; Taft et al, 2011).

Self-help groups can help to demystify a condition and provide support. These groups can help individuals to develop resilience to manage their symptoms and adaptive coping strategies by sharing advice regarding management of their symptoms and access to treatment (Vassilev et al, 2011). There are a range of organisations, such as Crohn's and Colitis UK, the Ileostomy Association, The IBS Network, and Beating Bowel Cancer, that provide advice and education on gastrointestinal conditions for clinicians and patients. Some of these organisations have local support groups.

Organisational/institutional level

Although nurses and health professionals are aware of the stigmatising nature of bowel dysfunction, it can be difficult to appreciate and understand the effect of experiencing anticipated or enacted stigmatisation. However, reflecting on a personal experience may help to provide insightful and supportive care.

As stated earlier, patients with IBS do feel stigmatised by health services. Therefore, the attitudes and behaviours of health professionals need exploration, and health professionals need education regarding their effect on the person and health outcomes (Weiss et al, 2006). Provision of clear information regarding the condition and access to 'positive portrayals of people living with their illness' (Quinn and Earnshaw, 2011) are useful resources for patients and health professionals, who learn how people manage stigmatising conditions and how they can work with them collaboratively (Whayman et al, 2011).

When assessing or implementing any strategy, evaluation is required to assess whether interventions have been effective (Heijnders and Van Der Meij, 2006). On reviewing the literature, there is a plethora of information regarding the stigma of HIV and mental illness and stigma-reducing strategies for these groups; however, very few papers exist on the issues of stigma for people with altered bowel conditions. Therefore, this is an area that requires further research and development involving 'stigmatised' individuals as well as unstigmatised groups in the community, health professionals, and community leaders (Van Brakel, 2006; Weiss et al, 2006).

Community level

Misconceptions can be challenged within the community by providing education and developing local support networks. A stand within a shopping centre with information regarding bowel cancer and the importance of screening for cancer is an example of raising awareness. So are initiatives such as 'Gut Week', which remind the public about the importance of gut function and staying healthy (Norton, 2007). A celebrity disclosing their personal experience of a disorder, whether they or a family member are directly affected, can help to reduce stigma. Stephen Fry's disclosure of his lived experience of bipolar disorder has helped to demystify and reduce the stigma surrounding this severe mental illness (Chan and Sireling, 2010). A combination of both these interventions can be effective (Heijnders and Van Der Meij, 2006).

Government/structural level

Stigma reduction at the government/structural level concerns protecting individuals with a stigmatising illness, ensuring that people are not discriminated against within education and employment, and ensuring access to health care and treatment (Quinn and Earnshaw, 2011). The government is involved in the development of policies to address the issues of stigma and discrimination. However, without research evidence to inform or effective parliamentarians to lobby for change, this is unlikely to occur. Interestingly, in June 2012, two members of parliament, Charles Walker and Kevan Jones, disclosed their experiences of mental illness, which has had a direct effect both within and outside the Government (BBC, 2012).

Conclusion

This article has defined the concepts of stigma and taboos and their relationship to bowel function, gastrointestinal disorders, and chronic illness. The taboo surrounding the discussion of bowel function and the fear of being stigmatised can prevent discussion of symptoms and healthseeking, which may have fatal consequences. The paucity of literature surrounding targeted interventions to reduce stigma for gastrointestinal disorders highlights the need for further debate, investigation, and research.

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Box 1. Goffman's (1963) types of stigma

Abominations of the body. This refers to physical deformities

Character blemishes, such as dishonesty, mental illness, imprisonment, and unemployment

Tribal: race and religion.

Box 2. Reflective exercise: personal experience of stigma

Have you experienced stigmatisation as a child or adult?

Consider the physical, psychological, and social aspects: How did you feel? How did this affect your behaviour?

How did people respond to you?

What led to an alleviation of the stigmatisation and/or what was your role in this process?

Table 1. Stigma-reduction strategies

Intrapersonal level	Counselling Cognitive-behavioural therapy Empowerment Group counselling Self-help, advocacy, and support groups
Interpersonal level	Care and support Home-care teams Community-based rehabilitation
Organisational/institutional level	Training programmes (New) policies, such as patient-centred and integrated approaches
Community level	Education Contact Advocacy Protest
Government/structural level	Legal and policy interventions Rights-based approaches

Source: Heijnders and Van der Meij (2006)