

# Stoma and shame: engaging affect in the adaptation to a medical device

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## KEYWORDS

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## ABSTRACT

### Objective

The objective is to understand difficulties some patients have with their adaptation to a medical device, specifically a stoma and an ostomy appliance, following gastro-enterologic surgery. A partial or total colectomy is typically performed in cases of digestive cancers, Crohn's disease, or anal incontinence. A psychotherapeutic application deduced from this understanding is described. The therapeutic approach is informed by Lacanian psychoanalysis.

### Setting

The setting is the digestive surgery services section of a large public teaching hospital in France. The clinical team conducting the interventions described perform their work with patients post-operatively.

### Subjects

Selected cases are chosen to provide brief illustrations of the analysis and the psychotherapeutic approach developed.

### Primary argument

This study focuses on the impact of the stoma and the ostomy appliance on the subjectivity of the patient and shows how the affect of shame can appear. It is noted that the affect of shame in the adaptation to an ostomy appliance has not been investigated to date. This affect can in turn have psychological effects on the gastro-enterologic treatment itself, even to the point of the patient's abandonment of ongoing care. The analysis reported here explores the recognition of shame when it might be present, and the process of accompanying the patient therapeutically, engaging the logic of the transference.

### Conclusion

Shame cannot be treated by ignorance or by indifference. A psychotherapeutic application engaging the transference between the patient and members of the nursing and psychotherapeutic team, helps patients support shame and adapt well to the ostomy bag.

## INTRODUCTION

In cases where a colostomy or ileostomy is performed as treatment for gastroenterological disease, the effect of the intervention involving a stoma<sup>1</sup> with an ostomy bag often presents some difficulties for the medical team. It is not so much that there are difficulties arising from the medical device itself, but rather difficulties for the patients who must then adjust to living with the stoma and the ostomy appliance, with its requirements of drainage and changing. Our analysis of the lived experience of patients who have received either a colostomy or an ileostomy appliance, indicates the difficulties and related affects are similar in each case. Our group has observed how a patient, who apparently does not think about the stoma and the ostomy bag, can become isolated, sometimes for some years and sometimes even resulting in suicide.

There is a small but growing focus on the question of the experience of stoma and the introduction of an ostomy appliance in the nursing literature, researching how nurses might understand, treat and care for patients living with a colostomy or ileostomy bag. The question of acceptance has been addressed in a number of studies. The intervention of the bag has been described as a 'challenge' (Popek et al 2010; Krouse et al 2009), through to identifying a 'negative impact' due to the difficulty of acceptance (Thorpe et al 2014; Ang Seng Giap et al 2013; Kimura et al 2013(a) 2013(b); Siew Hoon et al 2013; Jeanroy-Beretta 2011; Krouse et al 2007; Northouse et al 1999). These studies, however, do not address the nature of this difficulty.

A comprehensive literature search found that the issue of shame<sup>2</sup> is considered in only two articles. In one, it is given a passing mention: Johnsen et al (2009) acknowledge the significance of this 'sense of shame' for patients, as this emerged from their research, but without proposing an analysis of this sense of shame in therapeutic terms. There is one study in the French literature (Jeanroy-Beretta 2011) that offers a remarkable reading of the stoma from the point of view of a concern regarding shame and sexual modesty. Although Jeanroy-Beretta addresses the issue of what is involved in the act of looking at, or into, the stoma, she does not draw out the psychodynamic consequences. Within the psychoanalytic paradigm, Freud (1910) considered that the look is different from the organ, the eye. The look is a partial drive (Freud, 1915), with its partial jouissance<sup>3</sup>. Jeanroy-Beretta confines herself to the issue of the sight of faeces in the bag on the stomach, but misses the significance of the drive of the look. In our clinical practice, we note that what the patient typically says he or she first **sees** is the flesh of the abdomen ('my own flesh outside'), or some faecal matter, or some blood, etc; sometimes it is the bag itself.

The problems of adapting to the bag are most often linked to the impossibility of accepting the sight of the stoma on the abdomen. In turn, this impossibility is what drives carers to engage patients on the question of their perception of this sight, a perception that will be specific to each individual patient.

We find these visual perceptions to be the main ways of discovery most frequently encountered with patients post-operatively, and they invariably refer to shame. Shame concerns the look of the 'other', and the imagined view the individual has of him or herself through the gaze of the 'other'. Shame does not necessarily, or immediately, involve guilt. According to psychoanalyst Jacques Lacan (1964, p98), shame passes by the drive of the look or gaze. Therefore, the question is posed how a practitioner might work with shame, from the moment of a traumatic shock of the look that captures the patient.

Research with patients recovering from curative colorectal cancer surgery, reported by Taylor et al (2010), investigates patients' fears about cancer returning. They present a model of a movement from an initial

<sup>1</sup> See glossary for explanation of 'colostomy', 'ileostomy' and 'stoma'.

<sup>2</sup> See glossary of terms.

<sup>3</sup> See the glossary for an explanation of the terms 'jouissance' and 'the partial drive'.

disembodiment to embodiment as a process of therapeutic recovery involving a regaining of control. They propose two opposing positions – guarding and resolution. “Guarding” refers to the difficulties patients face during the transition towards recovery, involving a reaction of a kind of hyper-vigilance. Focussing on the shock of the visual sight, and the shame that the intervention of a stoma elicits, we intend to show how patients might pass from guarding to resolution.

All studies reviewed emphasise the importance of the nursing relationship developed with patients (Ferreira-Umpiérrez 2014; Thorpe et al 2014; Ang Seng Giap et al 2013; Zheng et al 2013; Landers 2012), or that of health care professionals more generally (Taylor et al 2011; Krouse et al 2009; Northouse et al 1999). However, no study explores the dynamic of the relationship, nor questions what approach would be most beneficial for the patient.

In psychoanalytic terms, a relationship between two persons, particularly where there is a perceived and apparent difference in knowledge or expertise, involves transference<sup>4</sup>, positive or negative, which is an unconscious dimension of the relationship. Transference is not addressed in the studies reviewed. One study recommends that patients have access to psychologists before and after the surgical procedure (Krouse et al 2009, p232), without addressing the issue of transference in the relationship. In the nurse–patient relationship, the two persons involved are the nurse, who is not ill, and the ill person; this is an asymmetric relationship. From a psychoanalytic point of view, if transference is not taken into account, the treatment will be ignoring an important aspect of the therapeutic process.

Evans (2007) explores the importance of transference in the nurse–patient relationship. The patient, feeling weakened by his or her illness, is often in a position of recognising the supposed knowledge of the nurse or the doctor. In Evans’ terms, with reference to Lacan, “transference, then, can be recognized by the emergence of a subject who is ‘supposed to know’” (Evans 2007, p5); the ‘subject’ here being present in the form of the nurse or doctor. The one-on-one relationship, as is the case in stoma care, encourages the health care professional to grasp what is happening in this relation with the patient. Evans (2007) claims the nature of the transference that can develop between the nurse and the patient depends on the distance between the two partners, a distance concerning the unconscious<sup>5</sup> link: “When the nurse is positioned as distant to the patient and involved with the more technical aspects of care; (*sic*) that is, as technician, it is more difficult to privilege listening to the patient, thus making it more difficult to hear the particular meaning each patient attributes to his/her illness” (Evans 2007, p2). The position of distance does not enable the therapeutic relationship; a position of an inappropriate closeness can introduce anxiety. Distance or proximity have to be evaluated in relation to each patient, because it concerns the unconscious of the patient.

As Evans explains, if and when the transference develops, the nurse who is initially a stranger to the patient, “might be positioned, for example, as someone who the subject can trust, love and respect, or the person might be positioned as someone who the subject feels they can never please” (Evans 2007, p4). These kinds of positioning indicate precisely that transference is operative in the relationship.

Our clinical practice aims to incorporate an understanding of the transference. We are concerned to reflect on the way the lived experience of patients might be affected by this medical externalisation in the case of colostomy or ileostomy. What is happening psychically regarding the introduction of these medical devices? The suffering experienced by patients guides our reflections. It appears clear that all professionals involved in surgical-related care in gastroenterology will meet such situations. However, none of the research to date

<sup>4</sup> See glossary of terms.

<sup>5</sup> See glossary of terms.

begins their study in the hospital, with the patient at the time of the discovery of the stoma on the abdomen, with the nurse who cares, nor considers how to practise care through accompanying this suffering. This is our qualitative focus.

### SHAME AND SUBJECTIVITY: THE FELT, THE SAID, AND THE SEEING

The starting point for our approach is immediately post-operative, when the patient confronts the stoma through to the time when an adaptation has been achieved. Our experience has demonstrated that there are two versions of the stoma, that of the surgical team and that of the patient. In perceiving this distinction, we follow the notion of Georges Canguilhem (1966/1989) that there are two versions of a disease, as two sides of the same knowledge. The distinction is necessary as the disease of the patient is not the anatomical medical disease. Indeed, since the early 1980s the distinction between the discourse of medicine and the narrative of the patient, building on the work of Canguilhem (1966) and Merleau-Ponty (1968), has become a prominent basis for social research focusing on medicine, health and illness. For example, Mishler (1984) developed the dual construct of the voice of medicine and the voice of the life-world.

In this way, we differentiate the medical professionals' version of the stoma from the patient's version. The medical version of the stoma is a surgical solution to a failed function of the colon, surgically creating a junction of the colon or the ileum towards the abdominal skin. A temporary stoma protects the anastomosis following a large or small bowel resection and prevents suppuration pending healing, for example in the case of radiotherapy treatment for cancer, an ostomy appliance is added. A permanent stoma usually involves the introduction of an ostomy appliance.

In the narrative of the patient, the stoma is a singular representation that the subject constructs about this experience: how he or she lived and felt is expressed in what he or she says. From the perspective of Lacanian psychoanalysis, the person who speaks is a 'subject', and the subject is a speaking-being (*'parlêtre'*), a term coined by Lacan (1975, p56)<sup>6</sup>.

Although the experience of the stoma is singular for each patient, there is an element that appears to be more or less constant and that is the affect of shame. I now offer some brief illustrations from our practice.

A patient, aged 50, suffering from colorectal cancer had a colostomy bag. He would shop in a large supermarket, but began to fear that his colostomy bag would open itself when he was out shopping and that the retained liquid would spill on him. After evoking this feared scene, he said, "people would think I wet myself." This was so outrageous for him to contemplate that he gave up his shopping outings, seized by the shame of a potential flow.

The feeling of shame refers to a shame experienced and lived by the patient. This 'felt shame' can be said to be in the background of the enunciation of the patient, which in turn re-actualises an affect of shame. In the field of linguistics, it is common to distinguish the statement, or utterance (what is said) from the enunciation (that which can be deduced from what is said) (Benveniste 1958). For this patient, we distinguish the 'felt shame' from the 'said shame'. Over the course of a period of four days, and through the psychic work between sessions, he speaks of a shame felt when out shopping. He speaks of this shame in a way that fixes the shame in a certain utterance "people would think I wet myself." The 'felt shame' can be heard by the clinician in the background of the statement. Then later in a different register he is able to say: "I am ashamed, embarrassed ...". We are referring to this as 'said shame'.

<sup>6</sup> See the glossary for an explanation of 'Lacanian psychoanalysis' and 'parlêtre'.

It is also striking that the shame, both 'felt' and 'said', in this instance is rooted in an anticipation of the gaze of others, what they might see. In our clinical experience it is most often the case that the shame has its genesis in the look. Another patient told the psychologist "it disgusts me to look. I would not be able to change it myself. It repulses me [...]".

Here the statement refers to the problematic of the look (or the eyes as the site of the look). Indeed, this patient can no longer see the side of his body where the stoma is placed; he does not look at it. He seems to make a half turn. This avoidance of the look is a constant we observe for a considerable number of patients.

The patient encounters his or her own gaze. This look "reduces him to the feeling of shame" (Lacan, 1964, p98). In this way, shame indicates or signals the expression of an affect coming from a weakness in the constitution of the specular image of the body. We find evidence for this hypothesis in the relationships felt, and said, by patients in our clinic. In other words, this is an imaginary identification, through which shame appears as the privileged affect. Generally, shame signals an effect and an affect, in terms of the representations idealised by the patient. This affect refers to a certain moral conscience of the subject.

### MOVING ON FROM THE SHOCK OF THE GAZE

Mrs. B., 78 years, has just undergone a definitive colectomy<sup>7</sup> and discovered postoperatively, without prior warning, that she now has a colostomy bag. Our first meeting takes place on day six after the operation. She is curled up in her bed, seeming gaunt, even emaciated. The nurses had warned the psychologist of a possible "syndrome of sliding" referring to a possibility the patient was giving up, mentally. In this case it meant she was no longer accepting food. Immediately after introducing myself (LD), and after a silence, she manages to say: "It's horrible," and repeats "it's horrible," while looking towards the other side of her body relative to her stoma. Her curled body seems twisted, as if she turned partially so as not to see one side of her body. She seems desperate and stunned. I stand on the side where her gaze is directed, meeting her where she can look. I say "You said to me it's horrible, it's horrible, could you explain...". She answers "I don't want to see it ... I don't look at it ...". The clinician can hypothesise this is 'felt shame'? It is starting from this look that she begins to speak about it; from the look, she chooses to speak.

In our hospital setting there are a number of different roles involved in patient care, therefore together we construct a situation of multiple transferences. While cleaning and dressing the area around the stoma for the patient, the nurses are asked by the psychologist (who manages the transference) to take a long time over this process, all the time talking to the patient – about everything and nothing – inviting him or her to speak, but also to be able to look at the stoma site in their own time, at their own rhythm. This creates a care more prolonged than usual, and in the process there is a restoring of a "bath of language" (Mannoni 1970, p240). If the patient cannot look, at least he or she can hear someone talking about the care being given.

It is important for the patient to look at the stoma and/or the ostomy bag, and for this to take place with someone. Practising in this way we often observe positive results whereby the patient appropriates<sup>8</sup> the medical device over time. But in the case of this patient, she cannot grasp it. Transference is constructed after the first meeting. I meet her for a second clinical interview; she talks about what she likes including singing, which had become her activity in the retirement home in her village.

<sup>7</sup> See glossary of terms.

<sup>8</sup> The term 'appropriate' is used here as a verb to evoke the way successful adaptation to the medical device will involve the patient being able to make the ostomy appliance his or her own, incorporating it into his or her body schema, to accept it.

She explains that she does not want to eat: "I don't want to see the bag fill itself." There was a kind of dysphagia, which led to the maintenance of parenteral nutrition. She talks about "this block", which in French is 'ça bouche'. I can also hear this as her mouth ('sa bouche'). There are two reasons for this: firstly in French 'ça bouche' (this block) and 'sa bouche' (meaning her or his mouth) sound exactly the same when spoken; secondly, the word stoma is from the word for mouth in Greek. The patient sees the stoma, the opening, and, because of anxiety, can no longer take food in her mouth. The noticeable connection between these words, in the first instance because of their homophony in French, enables the practitioner to point towards a possible unconscious process preventing the patient from eating. This modality of practice for recovery insists on the equivocation of language, a central feature of Lacanian psychoanalysis. She answers "that makes a ball in my throat." This statement designates an anxiety. I say "you feel an anxiety..." She agrees with this interpretation.

Gradually, she seems to become increasingly calm, having talked about what she likes, who she is. In the next session, in showing her colostomy bag, she says: "I'm not normal like everyone else ... I'm ashamed of what I have" – shame is present and is said. The statement joins the enunciation. She calls her colostomy "Laffreuse<sup>9</sup>", which means "the awful". Then, she tells of an event with her mother when she was a child: "I was afraid to cross an obstacle, and my mother told me gently 'go ahead'". I end the interview on this utterance: "With food, as your mother had told you, go ahead."

In parallel, the nurses continue their particular cares, more pronounced around the stoma. After three meetings, the state of abandonment has ceased. After the last nursing care, I meet Mrs B. for the fourth time. She tells me: "I've eaten a little." The mother's statement to "go ahead", which has been internalised, suffices to reactivate her ability to take food and in the same movement she can appropriate the stoma.

Then she is able to evoke what she had seen the first day, on her belly: "I saw a piece of flesh of my own flesh". Shock! Tumescence of the real body! She said "it's part of me now," touching the colostomy bag. Then she adds: "I saw the bag change." I asked her what she saw ... She places her hand with spread fingers before her mouth and, with a small smile, she said "I saw a little." I emphasise her gesture. I do the same. She smiles. The living being was re-engaged. She can leave the hospital some days later, to stay at a convalescent home.

This clinical picture shows how the solution of a medical device such as an ostomy appliance is one requiring not only a process of accommodation that is entirely singular to the patient, but also one that he or she can appropriate visually. The patient, Mrs B., re-linked this process to an utterance made by her mother. If the stoma is more or less traumatic it is because this intervention is the second time, one that repeats in some way a first time when the subject was questioning in childhood (Freud 1895). At the current point of the second time, the stoma re-actualises this first moment. Subjects succeed in answering this question in childhood, with the singular theory that they invent; but now, with the stoma, they fix it at the level of the Imaginary<sup>10</sup>.

The patient can no longer recognise him or herself in the body image from which he or she is alienated. It is a drama whereby the return of an object of the drive projects the patient into shock: a drive coming from the Real<sup>11</sup>, through the look. The return of the drive explains the shock as well as the way out of the stunned state it induces. What was unified by the specular image does not hold anymore! The patient discovers "the piece of flesh" on the belly; the breaking through of the Real. For another patient it is the sight of the faecal

<sup>9</sup> "Laffreuse" in French is not a word as such. This signifier results from combining a definite article ('la', which is 'the' in English) and an adjective ('affreuse'). While 'l'affreuse' lacks a noun, this signifier 'laffreuse' creates a noun to personify something she saw; it is a poetic way of naming, invented by her.

<sup>10</sup> See glossary of terms.

<sup>11</sup> See glossary of terms.

matter. It happens through the partial objects, as in the drive, in which the gaze is implicated each time. This sight, or image, refers to the Imaginary and may provoke a re-actualisation of shame, of submitting to the look of others. This look that the subject imagines or supposes from others, refers above all to his or her own looking. There is an alienation of the subject in the specular image (Lacan 1966). The clinician promotes the detachment from the shock, in knowing well this function of unconscious alienation. We called this detachment 'de-sideration'<sup>12</sup>. So, the patient's desire appears again and then the subject is able to say something about the shock. Another patient can name the stoma and ostomy bag, indicating a "that", to which the clinician responds, and the patient adds, "this shit" ... In this desperate look, "shit" is a signifier, found by a subject, a metonymic<sup>13</sup> signifier. Another calls it "Laffreuse", or "Moricette" or "piece of flesh". There is a passing from the stunning of the shock to the shame felt, beginning with the distressed look, to the said shame. And the subject can then name the colostomy. In this sense, the representation of the shock comes unstuck, and is able to see itself, and say itself. A "parlêtre", or speaking-being, has to use language to translate his or her feeling and to transform the shock into singular signifiers.

## IN CONCLUSION

One way of approaching psycho-pathology that might appear in the process of encountering the stoma, when this pathology is centred on the gaze, identifies the significance of the specular image of the body. With this unconscious image appears an affect, shame, and the subject is alienated to this image. The Other, as the locus of language and culture beyond the subject, must validate the mirror image of the patient, even if others have not been able to see what the patient sees. In other words, through the Other, in turn through the transference, the patient is enabled to appropriate the ostomy appliance. In clinical sessions with patients we therefore start with, and follow, their utterances to lead them toward representations that are susceptible to reducing anxiety.

Our clinical experience suggests thinking about the medical phenomenon of colostomy or ileostomy in terms of subjective structures; approaching patients one by one. Through a clinical application with a team of health professionals, engaging the affect of shame, it is possible to accompany the patient in some kind of restitution of psychic continuity<sup>14</sup>.

<sup>12</sup> Sideration in French means shock or stunned, stupefied in English. Thus de-sideration is a progressive diminishing of this shock.

<sup>13</sup> In the case of a metonymic signifier, the part stands for the whole: shit is both faecal matter collected in bag and a denotation of the stoma and ostomy bag.

<sup>14</sup> There is a double meaning here in French: "*Remise en continuité*" is a French medical term, used in gastro-enterological surgery, meaning to reconstitute the normal way of the colon, when possible.



## GLOSSARY

### **Colectomy**

surgical removal of the whole (total colectomy) or part (partial colectomy) of the colon.

### **Colostomy**

a surgical operation in which a part of the colon (large intestine) is brought through the abdominal wall, creating an opening called a stoma. The opening of the colon, is performed in order to drain or decompress the intestine. The colostomy may be temporary or permanent. An ostomy appliance, or bag, is usually worn over the colostomy opening. (See also stoma.)

### **Ileostomy**

a surgical operation in which the ileum (lowest of three sections of the small intestine) is brought through the abdominal wall creating an opening for the discharge of contents, bypassing the colon. An ostomy appliance, or bag, is usually worn over the ileostomy opening. (See also stoma.)

### **Imaginary**

a register of the subject, concerning the effects of the formative nature of the image (see Lacanian psychoanalysis).

### **Jouissance**

is a French word meaning enjoyment. However, in the Lacanian psychoanalytic field it is generally not translated into English because Lacan has a particular rendition of the term involving a state of excitation, even a traumatic intrusion, where intensification of pleasure becomes painful as it reaches a limit. Jouissance concerns that which has not been thought or represented as such by the subject, and which is experienced physiologically in the body.

### **Lacanian psychoanalysis**

an approach to psychoanalytic theory and practice developed by Jacques Lacan (1901-1981), who claimed to return to Freud. His focus is primarily on how we are '*parlêtres*', that is, how our way of being human is fundamentally grounded in the fact of language, as beings who speak. This being is a subject, with both consciousness and an unconscious, constructed through the demands of the parent(s), or caregivers, and is traversed by three registers: real, symbolic and imaginary.

### **Parlêtre**

a neologism coined by Lacan (1975, p.56), combining the notions of 'speaking' and 'being' into one word in French. He develops this concept to avoid a substantialist notion of being, such as within phenomenology, privileging rather the subject's formation through its relation to language. For this concept he draws on the work of linguists such as Ferdinand de Saussure, Roman Jakobson, Emile Benveniste, and Michel Arrivé. As such, the subject is not a substance but a fact, or effect, of language: "it is in and through language that man (sic) constitutes himself as 'subject'" (Benveniste 1958, p.259).

### **Partial drive**

the drive comes from sensations in the body, deriving its support from the corporeal orifices. The drive's aim is to circle around the object of the drive rather than achieving some imagined goal of full satisfaction. The concept of the drive is central to Freud's theory of sexuality. Both Freud and Lacan distinguish the drive from instinct, in other words it is not a fixed, biologically innate relation to an object, but rather a relation that varies between subjects and is contingent on their specific histories. For Lacan, all drives are partial drives because they only ever partially represent the sexuality of the subject.



**Real**

is a register of the subject, concerning that which is impossible to represent, to symbolise, to put into words (see Lacanian psychoanalysis).

**Shame**

in psychoanalysis shame is an affect constituted on the unconscious traces of early experiences of satisfaction or pain. It relates to the perception and meaning attributed to the look or gaze of the Other. Referring to a feeling of shame experience by Sartre, Lacan (1964, p.98) explained that the look “that surprises him in his role as voyeur” is “a look my ego imagined coming from the field of the Other.” Shame is thus situated in the imaginary register.

**Stoma**

is a generic term for a surgical opening of a tube such as the colon or ileum that has been brought to the surface on the abdomen. This term is specialised in relation to the localisation of the affected tube, thus colostomy (for a stoma of the colon) and ileostomy (for a stoma of the ileum).

**Transference**

Freud noted the influence, indeed effects that the medical doctor can have on the ill person through suggestion. Such an influence becomes possible through a process of transference involving a displacement from another situation deriving from the ill person’s past, to the current relation with the health professional. Transference is therefore a resource insofar as something, sometimes from earliest childhood, is set in motion, which is then replayed in the relationship between the ill person and the carer. “Like Freud (1900/1976), Lacan (1988) argued that transference is how the unconscious is given form” (Evans 2007, p.193).

**Unconscious**

The unconscious is a central concept of psychoanalysis, concerning a part of the topological organisation of the psychic apparatus. According to Freud, unconscious formations might mark their presence in slips of the tongue, bungled actions, dreams, symptoms, etc. Unconscious processes indicate a return of infantile theories. The unconscious is present in the transference.

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