

Stigma and the perception of bodily parts: Implications for help seeking

SIBYLLA VERDI HUGHES¹, DAVIDE PIETRONI²

¹ Department of Applied Psychology, FISPA, University of Padua, Italy

² Department of Economics, University of Chieti-Pescara, Italy

Abstract: The present paper covers the first of a four part series that will investigate the hypothesis that people may have biased cognitive representations of the body's parts (body schema) and that this may have implications for illness behaviour, disclosure, and help seeking. In fact, seeking help for medical needs varied across body parts, with test subjects less likely to seek help for highly stigmatized and private parts but likely to seek help for parts viewed as important and vulnerable. To test if we could minimize this effect, we conducted a series of interventions aimed at changing cognitive perceptions and schemas of the body on randomly selected test subjects. We compared the various interventions and measured the efficacy of each different type of intervention in changing cognitive perceptions of test subjects. Among the interventions carried out and measured were: storytelling, group work, humour, empty chair and empowering. We discuss which of these interventions produced the greatest changes in cognitive representations of the body and the implications of these findings.

Key words: Body; Stigma; Health promotion; Intervention; Private parts

INTRODUCTION

There is a lot of research that has explored individual's concepts and attitudes about their body, especially in the field of body image distortions in eating disorders^{1,2} and stereotyping of physical attributes.^{3,4} What the research seems to tell us is that beliefs about the body play a major role in the effectiveness of preventative health programs such as exercise programs, as well as in a variety of pharmacologic, surgical, medical, psychotherapeutic, and behavioural medicine interventions.⁵ However, attitudes about body parts are not limited to beliefs about the size and attractiveness of the body part in question, but more importantly, attitudes about the perceived privacy of a body part can affect the willingness to share information with others about any potential dysfunction or illness of that part. We hypothesize that the stigma that is associated with such private parts like the genitals and the anus, that are oftentimes viewed as "dirty"⁶ can have a real effect on the propensity of individuals to seek medical attention when health issues arise to the private parts in question. This unwillingness to seek medical attention, and talk to significant others about a problem that is associated with a body part that has a social stigma attached to it can have large implications for the health of individuals and when generalized to the entire population, it can carry considerable health care bills costs. It also points to the need to develop creative and dynamic programs that address this issue, raise awareness and encourage the "airing out" of these taboo subjects in order to deconstruct the social stigma attached.

On the other hand, other body parts such as the ears are viewed as less private and sexual than the aforementioned and thus are more likely to receive greater medical attention from the patient.⁷ In addition, as these body parts are viewed as neutral, any problems arising from these are more readily expressed and shared with others. In fact, we predict that for these neutral parts, disclosing medical challenges and comparing stories are frequent among individuals. These neutral body parts we define as "embarrassment free", thus medical problems such as broken bones, dental abscess, ulcers etc, we hypothesize are more freely disclosed to others than issues such as anal fissures that are viewed as highly private and "dirty." This has important medical implications.

METHOD

In our study we would like to investigate cognitive representations of the various body parts via a questionnaire administered to randomly selected individuals at the hospital of Pescara, Italy. To a certain degree, we replicated an earlier study by Klonoff & Landrine,⁸ with the difference that we

went one step further and carried out interventions on test subjects to measure if these cognitive representations can be changed over time and if this change can lead to a greater likelihood to seek help in the future. We decided to exclude from the study individuals that had already been screened for various pelvic perineology problems as they may have already received some form of formal or informal intervention or education and therefore the stigma and view they hold about the body part in question may already have undergone a change. We invited test subjects that had completed the surveys at T1 to take part in one of our interventions and then re-test their cognitive representations of the various body parts post intervention at T2 to investigate which intervention was more effective in changing body schemas and thus lead to changes in how the various body parts are viewed.

The various interventions carried out on test subjects included: storytelling, group work, humour, empty chair and empowering. These methods were chosen on the basis of their efficacy and practicality (only various sessions were conducted). Storytelling was chosen because research shows that our understanding of the narrative model is not just something acquired, but it seems to be genetically determined.⁸ In fact, already in 1985, Fisher talked about humans as being "Homo Narrans". Moreover, the way our brain responds to stories illustrates that this is an especially effective cognitive tool. In a study conducted at Washington state university,⁹ participants brain activation while reading a story was measured. The results showed that participants were living the experiences alongside the young protagonist in the story and were not just passive participants. In fact, neurons in areas related to movement correlated with the protagonists movement in the story.

Group work was chosen as an intervention modality because it enables group members to learn from the experiences of others and offer advice. In our experiments we also wanted to capitalize on this methods ability to foster working through issues together. In this manner this method provides subjects with a "peer group" of individuals that they can feel safe around to practice the new cognitive viewpoints learned.

Humor has long been used as an effective psychological intervention tool, we might all recall the physician Hunter "Patch" Adams, who used laughter as a primary tool in his treatment of cancer patients, to great success. He is just one example of many who have witnessed and reported firsthand accounts of how essential humor is to both physical and emotional health. In fact, research points out that laughing leads to increased learning, more specifically that humor produces psychological and physiological benefits that help students learn.¹⁰



Figure 1. – Farrah Fawcett.

The Empty chair technique was used with test subjects because it's been proven to be effective at facilitating integration of different aspects or "disowned parts" of individuals and their personality. In addition, it brings into the present or immediate, experiences, verbalizations and abstractions. There are various approaches that can be used,

we decided to use the corrective dialogues approach: here the subjects' distorted cognitions or maladaptive schemas are clarified and verbalized in one chair. A counter-argument is carefully developed in a collaborative manner by the therapist and the patient.¹¹ The patient then goes back and forth between the two chairs – presenting the distorted thinking and then working to correct it. The dramatic and emotional quality of this work helps to counter the issue of patients' understanding the new cognitions intellectually, but do not really feeling them to be true.¹²

Empowerment techniques were chosen for their ability to provide individuals with a sense of control and purpose over their lives. Empowerment is a way to encourage all people even those that are materially, psychologically or even physically disadvantaged to become responsible for their own condition and achieve a sense of control—individually and as a group. In fact, empowerment has been used in diabetes care and is specifically effective at helping patients discover and develop their inherent capacity to be responsible for their own life.^{7, 13, 14}

DISCUSSION

We hypothesize that subjects that hold highly stigmatized views about certain body parts are less likely to seek help and speak to others about their medical condition. We believe this leads to a decreased propensity for prevention and higher rates of somatization which could lead to less effective post operative results and greater stress and pain.^{14,15} We predict that after the interventions, the majority of test subjects will be more likely to disclose problems related to private parts and seek help in the future if problems arise.¹⁶ Testing the various interventions for efficacy will be useful to provide direction to health care providers, government and other interested parties in the design of effective health prevention campaigns. In this way we can avoid the delay in seeking treatment, and non compliance with diagnostic and treatment interventions involving certain body parts but not others.

ADDENDUM

The numbers of anal cancer cases are rising, although experts haven't been able to pinpoint why. Cultural squeamishness about certain body areas could prevent early diagnosis and treatment of anal cancer. For example patients in the

United States often hate to be examined in these areas, they like to keep their private parts even more private than in Europe. If patients hate those exams, physicians hate to do them as well and thus the examination is incomplete." Former "Charlie's Angels" actress Farrah Fawcett, 62, (Figure 1) received a diagnosis of anal cancer in 2006 and died in 2009. She brought the world's attention to a rare disease during her cancer battle which lasted for three years.¹⁷

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Correspondence to:

Davide Pietroni - Email: pietroni@libero.it

INVITED COMMENTS

Many patients with pelvic disorders have poor awareness of themselves and one's own body (body schema). This means that they still commit "Descartes' error" there is no duality between

mind and body, but only wholeness unity. There is no division but unity. What we are, how we explain it, the "narrative thought" is reflected on the emotional and somatic side and vice

versa. Bodies and body parts are invested with emotion and it is the awareness or non awareness of this that avoids confusing organic pathology from somatization and leads us to understand the difference.

Very often it happens that a discomfort of psychological origin creates long term a clinical disorder. In my opinion, the cognitive error should not be treated much like a distortion but focused and re-read with the patient in order to understand the various aspects, which according to the personal history of the subject, have made it such. And through a cognitive reconstruction that enables us to understand how the latter has told himself "reality", how this has caused certain gaps in his mind, how he built certain valences of meaning and how HIS beliefs influence him and consequently, how he feels, perceives, and behaves. In this way the symptom will assume a different value but will be revisited in a neutral fashion (without judgment). In a sort of "enlightenment", what was interpreted mainly from the organic point of view, will take on characteristics articulated to reveal, to tell, to be exhausted and perhaps to be put in the right place.

I think this is the central point to keep in mind, regardless of the type of interventions that will be chosen, from time to time and according to the subjects to be evaluated, with the aim of achieving a more full self-awareness and therefore, of their own psychological- body functioning.

Given my post- rationalist training, I do not think there is a single reality, defined and pre-existing, but many realities as many as there are individuals who experience them. I do not think there are cognitive errors, distortions or dysfunctional a priori thoughts, everyone "tells it" how they can, according to their parenting attachment, and the subsequent organization of personality and finally, their personal life history. Keeping in focus these three factors together and reconstructing them with the patient, by listening to his story, one can act on "change" or on the more harmonious and articulate re-reading of the self.

ALESSIA CARSUGHI

Psychologist, alessiacarsughi@yahoo.it

The Author's reply

It's interesting to observe how the human mind is not cognitively and emotionally equipped to overcome Descartes' error, despite our attempts to rationalize. Paradoxically, the colleague later passionately affirms that there is only wholeness (unity) and no duality between mind and body, but then invites the clinical world to avoid "confusing organic pathology from somatization"! Our approach embraces the concept that there may be cognitive distortions in our own perceptions and beliefs that may in fact restrict or impede the quality of the patients social, emotional and physical life. and when our colleague speaks of a patient who "has certain gaps in his mind" the statement seems to implicitly agree with our vision, if by gap we mean a gap between functional and dysfunctional concepts to "put in the right place". At the same time we are convinced that the human mind is not equipped to interpret any element (be it a person, event, or, in fact, a symptom) in NEUTRAL terms with no "judgment". Our mind is an extraordinary machine built to continuously emit assessments and judgments (primarily affective and then these are rationalized), the question then becomes not how to revisit the symptom without judgment but how to recondition the automatic neuro-affective associations linked to previous conditioning, thanks to a targeted and "enlightening" psychosocial intervention that combines effectiveness and efficiency/transversal (one cannot

objectively carry out a deep therapeutic intervention with each patient), Moreover as explicitly stated in our paper, we are conducting interventions with healthy people and not with existing patients. Our objective is to "educate" a random set of subjects to test if we can change their cognitive perceptions of the stigma of certain types of diseases.

This research offers interesting insights. The patient's experience with pelvic and colonproctologic issues is often loaded with meanings that go far beyond the actual disease. In everyday practice, the health care worker is often faced with "unsettling" statements with regard to the perception of the problem that, should not be ignored, and should be fully understood before by the physician or the health care worker that looks after the patient and then these statements should be "deconstructed" through dialogue or other strategies that allow a "redefinition" of the disease. How many times in fact, patients with incontinence due to dyssynergia are convinced of having to tone their pelvic muscles, totally unaware of their "real" muscle tone. Often, it happens that even in cases of mild prolapse the stories of friends or relatives "worry" the patient so much to the point where the patient is certain that "everything is falling" and if nothing is done the damage will be irreparable. On the one hand "moral" resistance prevents a serene description of symptoms and on the other "deep fears" make the imagination a sort of "black hole" that catalyzes the attention of the subject.

Dialogue, diffusion without minimizing is the prescription of this research. The chair method invites a sort of role playing where the patient gets to be the "devil's advocate". The therapist's role is maieutic, to help the person find the nature of the symptoms and often the source of them as well. One example: the anal sphincter is often very tight causing a plethora of problems in individuals that tend to "hold" on not only to feces but also to deep fears and emotions. To enable the patient to perceive and talk about what they feel with their hands, joking about the tendency to "tighten the ass" in every situation are some practical examples that make us understand the direction and the purpose of this approach as useful as it is purely pragmatic.

STELLA DE CHINO

Pelvic floor physiotherapist stelladchino@gmail.com

The Author's reply

Noteworthy comments about the experience of working with patients in a live setting without the hindrances that are often present when dealing with such cases. In our research, we reviewed the literature on the topic and started with the premise that patient and public sensitization is really one very important first step in this "chain" of events. We observed that campaigns that have sensitized people to illness such as cancer, HIV etc. have been able to not only bring to light topics of "taboo", and initiated valid discussions in the public, but also and most importantly, for front line workers have enabled individuals to learn about these conditions and thus come forward without shame and get early treatment. This along with other factors has cut down considerably mortality rates and increased life expectancy prognosis of the aforementioned diseases... Similarly we hypothesize that when something comes "out" into the light of society and is no longer hidden in the shadows, that it likewise ceases to lie in the shadow of the individual, and it is no longer so viable to become a "dark hole" where patients readily somatize.