

## ARTICLE

**BETWEEN 'FORCE' AND 'CHOICE': PRACTICES OF (GOOD) CARE IN EATING DISORDERS TREATMENT**

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**Abstract:** Respecting patients' choices is an increasingly celebrated ideal in healthcare. If this logic of choice is absent – the argument goes – care is just a form of force enacted on patients by healthcare professionals. Drawing from the existing literature and from fieldwork in a treatment centre for Eating Disorders in Italy, this paper shows how it is necessary to disentangle the idea of good care from its immediate association with patient choice. Since for these patients will is complexly entangled with need, good care here means being able to enact the practical requirements of care even when patients, at that very moment, would refuse them. The key issue is the modality in which caregivers do this: the kind of affection, dedication and 'being present' that they display.

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**Introduction – Logic of Choice vs. Logic of Care**

Individual choice – and the entitlement that patients have to choose as regards their own treatment – is an increasingly celebrated ideal in healthcare. Patient choice is seen as the paradigm towards which we should all tend, while trying to move away from treatment practices that are now framed under the notion of force. If this logic of choice is absent – the argument goes – care is just a 'soft form of force' enacted on patients by healthcare professionals (Mol 2008: 1-3). Mol has widely written on the risk of mobilizing a logic of choice without considering the specificities

and intricacies of the illness in question. She shows how in the case of Diabetes a logic of choice easily leads to poor care, since it does not liberate patients from the passivity in which they are supposedly forced, while shifting the weight of what goes wrong on the patient's shoulders. For this reason, she calls instead for mobilizing a 'logic of care' (Mol 2008: 8,9).

Drawing from the existing literature and from fieldwork in a residential treatment centre for Eating Disorders in Italy, this paper will unravel 'the specificities of care' with reference to the daily life of patients with Eating Disorders, and show how it is possible – and necessary – to disentangle the idea of good care from its immediate association with patient choice and 'tender love' (Mol 2008: 2,5). These elements are not irrelevant in the care of Eating Disorders; on the contrary, they are fundamental. However, as long as good

care is associated with patient choice and tender love, it can be framed as something opposed to what are actually good treatment practices. In the case of Eating Disorders, good care is definitely something that cannot be forced on patients. Force here does not work. But neither does patient choice.

In her ethnography about Diabetes treatment, Mol (2008) points out that in care there is not only a contrast between 'choice' and 'no choice', but also between these two, united in a logic of choice, and a different alternative, that of care, which is in contrast with neglect. She brings the example of a psychiatric patient who does not want to get out of bed in the morning and go to breakfast. If healthcare professionals were supposed to act following a logic of choice, i.e. to respect the patient's desire, they would have to leave him in bed. Which in the case of someone suffering from a psychiatric condition such as depression might well mean all day. It is not easy to disagree with the observation that the patient in question would not be receiving what one imagines as good care. But how to define good care? The problem is that the ideal of good care is incorporated into practices and does not speak for itself: the aim then is to articulate its specificities (Mol 2008: 2).

In the logic of choice – Mol explains – the central question is whether people are able to make choices or not: maybe healthy people are, while people with a disease are not; maybe some people with a disease are, but not all of them; or maybe everyone can choose under the right conditions (Mol 2008: 8). This is why instead of focusing on the abilities of people, Mol calls for focusing on the practices in which people are involved; and instead of asking who should make given choices, she calls for taking a step back and for considering in what kinds of practices 'situations of choice' do arise (ibid.).

### **The Logic of Care in Eating Disorders Treatment – Desire and Need**

Mol's argument is definitely relevant to the case of Eating Disorders treatment. Eating Disorders such as Anorexia and Bulimia Nervosa are egosyntonic psychiatric disorders: i.e. the behaviours, values and feelings that stem from the disorder are in harmony with the needs or goals of the patient's ego, consistent with the patient's ideal self-image. This means that they are extremely difficult to treat, and that giving a patient suffering from an Eating Disorder the freedom to choose will not help her/him, as this might easily lead to chronicization or even death. Anna Lavis (2016) has recently written a Think Piece that reflects on the desire to maintain an existing illness, based on the narratives of individuals diagnosed with Anorexia Nervosa. Whereas anthropologists have always tended to frame illness experiences as unwanted and undesirable, by considering accounts of individuals living with anorexia Lavis asks instead how anthropology might critically approach illness and its suffering when both are entangled with desire: 'What forms does the desire to hold onto illness take? What does desire do in the context of living with anorexia? And how might this desire be approached ethically in both anthropological analysis and clinical practice?' (Lavis 2016: 69).

While many patients suffering from Eating Disorders acknowledge that theirs is a distressful and serious illness, they also express an ambivalent desire to maintain it. Desire has been widely analysed in relation to Eating Disorders, especially in psychoanalytic literature, but this way of thinking privileges the visual rather than the lived body: it frames emaciation as the end goal in Eating Disorders, caused by a desire to return to childhood and/or by the 'slenderness imperative' that dominates our society (Bordo 1993). Although highlighting the cultural

context of the illness is important, the focus on emaciation frames the Eating Disorder as a means to a desired end rather than the object of desire itself. Whereas patients' words – 'anorexia is just the way I do things' – call for a shift in analytic perspective, drawing attention to the processual nature of Eating Disorders (Lavis 2016: 70,71).

Individuals suffering from an Eating Disorder often talk about their illness as 'helpful' and 'protective', as something that 'looks after you', communicating the sense of being cared for by the illness. As such, although self-starvation can be clinically framed as an expression of a lack of self-care, informants' narratives depict it as a modality of self-care that is at the same time a response and precarious solution to pain (Lavis 2016: 71). In a way, therefore, for those with Eating Disorders the eating problem is not the problem, but the solution. It is an attempt to reorganize the self as a possible solution to suffering (Orbach 1993: xxii,xxvi; Marucci and Dalla Ragione 2007: xxiv). Kleinman has argued that caregiving is a basic response to the context of danger and uncertainty that defines the human condition (AAAI Conference, Maynooth 2016); it seems that the same holds for Eating Disorders as a particular and contradictory form of 'self-care'. Indeed, individuals explain that their feeling of being 'looked after' by the illness emerges from the way in which the disorder offers a still and 'safe' space, a 'cloud away from everyone else'. Desire in this case is thus about holding on to an existing illness in order to get through life. The eating disorder offers a way to move through the world by withdrawing from it; this is why individuals know it is harmful, feel it is painful, and yet they may want to maintain it (Lavis 2016: 72). The idea of maintaining the eating disorder as a way of being in the world illuminates how recovery can be frightening, and that holding onto it may have a lot to do with need. This blurring of the boundaries between desire and need shows that 'desire' does not

adequately take account of the complexity of individuals' relationships with their illness, and the slippages of agency inherent in these relationships. Holding onto the eating disorder may be something that is wanted and actively worked upon by the individual, but also unwanted and painful at the same time, because it is likely to be about 'seeking out ways of living within compromised conditions of possibility, rather than an expression of preference' (Lavis 2016: 72). This calls for an anthropological reconceptualization of desire as not necessarily implying choice or agency, but also ambivalence and need (ibid.). It is in this sense that '[...] agency is created, not as an inherent quality of which individuals may have more or less but as an aspect of situations in which people may find themselves, and how this effect is created by attributions of responsibility' (Laidlaw 2010: 148).

Against this background, the rest of the paper will attempt to explore how the desire to remain ill is and should be engaged within treatment in order to go beyond the binaries of cure vs. treatment failure, and what forms of care such a rethinking might mobilize (Lavis 2016: 73). Where to draw the line between respecting patients and neglecting them by failing to recognize the complex entanglement of their desires and needs? Up to what point should healthcare professionals insist when a patient refuses to eat? But most importantly, *how* should they insist?

#### **Nutritional Therapy – When Eating is a Torture (and how to make it less so)**

Harbers, Mol and Stollmeyer (2002), in their work on feeding within the care for the elderly with Dementia, point out the inadequacy of both the ethicists' 'will perspective' and the biomedical 'natural course perspective'. In the former perspective, not feeding a person who refuses to eat is seen as a way of respecting his/her

will; in the latter, lack of appetite and thirst is seen as a symptom of Dementia. Dementia – the argument goes – is a disease and the need for food and drink disappears as the disease progresses. Therefore if a patient dies as a result of fasting, this should not be understood as a consequence of (lack of) human intervention, but as ‘natural death’ (Harbers, Mol and Stollmeyer 2002: 211). The inadequacy of both perspectives is even more poignant in the case of Eating Disorders. How to talk about ‘will’ and ‘natural course’ in the case of an illness that seems to be so strongly tied to the person’s will – think about the self-discipline that is necessary to fast and overly exercise – but whose ‘natural course’ involves the loss of one’s will under the will of the illness – even once the person has decided that she wants to undergo treatment, she literally cannot eat nor stop exercising unless forced by someone else – ?

From this inadequacy comes the need to refer to a third way of relating to patients and their daily lives: this involves a caring relation in which it is important ‘to mean something to someone’ and undesirable to neglect them (Harbers, Mol and Stollmeyer 2002: 211). As in the care for the elderly with Dementia, in the day-to-day care of individuals suffering from Eating Disorders eating and drinking depend on more than just the will of individuals and the natural course of their illness. What matters are the carers, the way they attend to patients, and the ‘materialities’ employed by them in this attending: tables, chairs, plates and food itself. By describing care as ‘a socio-material practice’, it is thus possible to cross the binary between ethical and biomedical versions of ‘the good’ (Harbers, Mol and Stollmeyer 2002: 208,214).

The setting of my fieldwork was a public inpatient treatment centre that I call ‘Palazzo Alberese’, located in a small town in central Italy. It accepts both adolescents and adults with diagnoses of Anorexia and Bulimia Nervosa. The centre employs a

multidisciplinary approach that is based on the coordination of psychiatrists, nutritionists, endocrinologists, psychologists, dieticians, philosophers, a dance-movement therapist, a drama therapist, educators and nurses, plus an administrator who deals with insurance coverage and other bureaucratic matters. One of the many care practices that caregivers need to ‘force’ on patients during their stay, the one that is most feared and hated by patients, is nutritional therapy – which is meal times. Meal times in this kind of treatment centres are ‘key events’: they structure the day and its rhythm, but patients are never keen to eat or drink. This is why ‘a system of encouragement’ needs to be in operation, constituted not only by explicit and verbal encouragement, but also by a lot of implicit encouragement incorporated into other ways of caring (Harbers, Mol and Stollmeyer 2002: 216).

First and most visible is the context of nutritional therapy, i.e. the space – both structural and affective space – where patients eat their meals. The list of things that matter is endless: ‘Words of encouragement. The setting of the table...[...]. A whole gamut of practicalities, of simultaneously social and material ingredients’ (Harbers, Mol and Stollmeyer 2002: 217). As Harbers and colleagues point out, in both ethical and medical discourses food and drink are seen in an instrumental way; but in a context of care, and especially in a context of care for Eating Disorders, food and drink are not only means for physical survival: ‘They are also media for care – they do care. They taste good or bad, have a nice or gruesome texture. They are, not as delegates of people, but all by themselves, objects of longing or aversion’ (ibid).

The programme explored by Warin in her ethnography of inpatient treatment for Eating Disorders in Canada, for instance, included the condition of eating alone in one’s own room – whose bathroom had been previously

locked to prevent patients from throwing food away or vomiting. The idea here was that patients had to focus on the task of eating with no distractions: 'No one will be present while patients are eating meals. Meals must be eaten before visitors can be seen and must be completed within 30 minutes. TV and radio to be switched off while eating' (Warin 2005: 106). Moreover, there was a conflation of practices and spaces, with things normally associated with sociality becoming private: the bedroom, the toilet and the place for eating were the same space. In this way, the single room of the psychiatric ward reproduced the spatial configuration and the social relations that patients had been practicing at home to support their eating disorder, recreating the social isolation that is central to maintaining it. And patients still managed to enact dysfunctional behaviours such as hiding food in the ceiling panels, draining apple juice into bed pans and spreading butter between newspaper sheets or duvet covers (Warin 2005: 105-109). Since Eating Disorders are characterized and sustained by a range of dysfunctional behaviours – eating very little, skipping meals, exercising, binging, purging, taking laxatives and diuretics – most of which are performed in secret, the idea of most treatment regimens – based on behaviour modification – is that intense monitoring and surveillance of patients is absolutely necessary to eliminate such behaviours (Eckermann 1997: 157,158). However, one also has to remember that Eating Disorders themselves are strongly based on self-control and self-surveillance (Bell 2006: 285). It is in this sense that Malson (2008: 27-42) argues that the institutional treatment for anorexia is 'anorexia-like': it relies on the same technologies of monitoring as does the illness itself, turning therapeutically intended regimes into anorexogenic environments. And the more treatment is experienced as controlling, with staff mainly having a surveillance role, the higher the risk of

rebellion and struggles for control (Ryan et al 2006, cited in Vandereycken 2011: 293). It is evident that these spaces have strong negative effects on patients, so that they inevitably fail in their therapeutic function.

In contrast, the dining room of Palazzo Alberese – a typical sixteenth century villa located in the centre of a small town – is a spacious and bright room with three windows decorated by vividly coloured curtains. At the centre of the room there is a big oval table where up to eight patients can sit; towards the windows at the back of the room there are two square tables, for four patients each; on the opposite side a single table facing the wall is reserved – as a therapist explains to me – for 'particularly difficult patients'. Patients are assigned a different seat every meal, but always trying to keep a disposition so that the most problematic patients do not influence each other. Walls are full of paintings, drawings and pictures that former patients donated to the centre as a gift when they were discharged. There is also a big yellow cardboard with illustrated rules to be followed during the meals: done by former patients, it essentially lists in a funny and joking manner some typical dysfunctional behaviours to avoid – e.g. 'Do not break food in tiny pieces', 'When you peel the fruit, do not peel the pulp away too'. There is always music being played on a radio/cd player during meals. The only element that feels awkward in such a homey context is the way food is presented, which really makes you think about the infamous nasty food of hospitals. Food in fact comes from a cooperative that provides food for schools, companies, and hospitals, and arrives at the centre already individually packaged in the right portions for each patient. Therefore, what you see on the tables is not plates, but sealed plastic packages. A patient – Maria – admitted that the way food is presented is 'a bit cold and impersonal', that 'a proper plate would feel more convivial and help a bit', but that the kitchen of the treatment centre does

not meet the sanitary regulations required for preparing warm meals. Here it is evident, as Mol (2011: 475) writes, that 'taste is not just in the food. The surroundings in which people eat also affect how they appreciate it', including the efforts that carers put into serving and feeding patients. Staff members know that the food provided is not as good as it could be – on top of being food, which for patients is enough to create anxiety – so they actively try to 'make it taste better' (ibid.). In the words of a patient:

*I like the fact that staff members try to lessen the tension by turning the music on, by making jokes and creating some conversation...because many of us find it more difficult if we have to stay in silence just looking at our plate. Because then you experience it as an imposition. Whereas trying to create a more convivial atmosphere...I think it helps (Maria).*

Rules about meals tend to be very strict in inpatient facilities. Gremillion's account of an Eating Disorders treatment centre considered to be at the forefront in the US reports that not finishing one's prescribed calories for the day meant having to complete it with a nutritional supplement – nutritional supplements are renowned to be disgusting – within an assigned period of time. Failing in this would lead to an 'NG backup' – i.e. forced-feeding through a nasogastric tube (Gremillion 2003: 17). The nasogastric tube, inserted through the nose and pushed down to the stomach, physically separates the nutritional qualities of food from its taste: patients can thus be provided with nutrients without tasting the food, which is what affords them a sense of vitality (Mol 2011: 472,478).

At Palazzo Alberese lunch and dinner should theoretically last 45 minutes. However, there is flexibility and they often last for an hour – or even more – because carers are ready to spend all the time needed to help patients who have difficulties and are reluctant to eat.

Patients are controlled and sometimes scolded if they display dysfunctional behaviours, but mostly in a gentle and joking way. The rule says that they should finish everything in their plate, but there is room for compromises depending on the patient's condition, especially the first days of stay, that are the hardest. Here the adoption of an all-round and affectionate care is considered a key element for a successful recovery. One of the educators pointed out that sometimes this means being willing to help certain patients wash their bodies when they take a shower, because they feel such a strong discomfort while they are gaining weight 'that they cannot even touch themselves'. Another therapist often stressed the fact that the treatment approach succeeds only 'if we really take care of the girls at 360°, as if they were our own daughters'. She also pointed out that this requires a great effort on the part of the staff, and that after a while it becomes very tiring. Indeed, staff members need to assume 'diluted roles' (Deiana 2012: 60), since they have to approach patients alternately as health professionals, monitors while eating, games companions and confidantes.

### **Conclusion – and the Way Forward: Looking for the Right Balance between Involvement and Detachment**

It is evident how in the case of Eating Disorders enforcing treatment cannot work. But this does not mean that one should condemn altogether the stubbornness that caretakers put in looking after patients to make sure that they are not abandoned in the name of the holy grail of patient choice. Care for sure means listening to and respecting patients' will. However, given that for those who live with an Eating Disorder will is complexly entangled with need and with the fear to lose the only thing they feel in control of – namely their body – 'good care' here means being able to enact the practical

requirements of care even when the patient, at that very moment, would refuse them. The key issue is the modality in which caregivers do this, the kind of affection, patience, dedication and 'being present' that they display: 'So much depends on those concrete things: the doing, the feeling, the shadings, the symphonic complexity, the inadequacy, the living at every moment and over what can be such a long journey of the incompleteness yet the presence of a caregiver' (Kleinman 2009: 293). Being ready to stay in the lunch room with a patient for three hours if that is the necessary time for her to finish her meal – and being ready to stay there not only as a watchdog, but also as a friendly hand that supports her and makes her feel safe, that is an example of good care I believe. The problem is that it is extremely difficult to make a patient eat while having at the same time this truly present attitude. Caregivers often have to stand by girls who look desperate in front of 40 grams of pasta with tomato sauce, tears coming out at every spoon they put in their mouth. And yet they need to stay there and make them keep eating. It is a torture – not only for the patients, but also for the caregivers.

From this last point, it is clear that there is a need to investigate more on the way caregivers enact their 'diluted roles' (Deiana 2012: 60), especially on what they do to reach the 'right balance' between emotional involvement and detachment from patients. Those who work in an inpatient Eating Disorders unit have much more contact with patients than any other kind of professional caretaker. They thus feel more than others the tension that exists 'between care and work – between the individualized demands of compassion and sympathy and the impersonalized, routine demands of the efficient workplace' (Brody 1992: 66, cited in Gremillion 2003: 138). A kind of unconditional affection is expected from members of the treatment team, but unlike patients' natural parents, staff members are required to

express this care while they are presiding over treatment practices that often look antithetical to caretaking attitudes. Many staff members express difficulties in enforcing the unit rules while maintaining caretaking roles with patients, as the necessarily 'harsh' aspects of their job get in the way of connecting with patients emotionally, and vice versa. The key is to learn 'to set boundaries appropriately' and to have 'some detachment from the behaviour' (Gremillion 2003: 144,145), something that requires constant exercise:

*[When I first started working at Walsh], I used to literally sit in my car and imagine letting go all of the kids, not taking them home with me. It had to be that visual, concrete kind of exercise to set some boundaries....Once, we were having this major thing where all the kids were pushing [the rules at mealtimes] [...].What I chose to do for myself was just imagine I was a clock [...] And when the time was over, the meal went away! And it wasn't personal. It wasn't me setting a limit... [I did this] because it was getting very frustrating [...]. And I needed some kind of distraction for myself, so I wouldn't get angry, overly rigid, punitive" (Gremillion 2003: 146).*

In this account, the risks of emotional involvement with patients are perceived to be both caring too much – i.e. wanting to take patients home – and becoming punitive. Staff members are thus expected to reach for a middle ground: they need to mitigate the potentially overcontrolling and punitive aspects of treatment as well as temptations to engage in excessive forms of maternal caretaking (ibid.). Similarly, at Palazzo Alberese I heard some staff members talking in a critical way both about a colleague who was 'too emotionally involved' with one of her patients, and about another one who was too harsh and punitive with non-collaborative patients, especially during meals. They were negatively judging the former for being unable to see that her patient was

'manipulating' her in order not to gain weight; and the latter for being unable to recognize that patients' dysfunctional behaviour was not something personal but part of the illness, and therefore had to be taken 'with emotional distance'. This was the only way not to feel frustrated and react in a way that would simply harm them.

Staff members can explain very well how maternal attitudes can lead to over-involvement or punitive behaviours towards patients, but not so well what constitutes a good nurturing attitude (Gremillion 2003: 149,150,153). This surely consists in finding some balance between emotional involvement and detachment, but where this balance exactly lies is not clear; what is clear is that reaching it requires time and constant exercise. An ethnography of daily care for patients suffering from Eating Disorders should thus involve storytelling about the activities of healthcare workers – how they perform and experience their caring work, their intentions, their concerns – and about 'the activities of things' (Harbers, Mol and Stollmeyer, 2002: 219) mobilized by them – tables, plates, cutlery, tastes, temperatures, textures, music, gazes, jokes – as intended by carers and as experienced by patients. These stories should articulate the situations in which healthcare workers feel they are intruding and crossing the line of enforced treatment, the occasions when there are tensions with patients and within themselves – and should therefore point out the different ways in which 'the good' for the patients is sought (ibid.), sometimes reached, and sometimes lost.

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**Notes**