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Horror and disgust: Gastrostomy feeding and identity transformation

Gillian M Craig [*]

Apart from the actual bearing and suckling of children, there is probably no act which better epitomises the maternal role than the preparation and serving of food (Newson and Newson, 1970)

Food loathing is one of the most elementary and most archaic forms of abjection (Kristeva 1982, p. 2)

Introduction

In recent years the topic of the body has taken on increasing significance in the medical and social sciences (Williams, 1997). Williams cites a range of factors responsible for the growing interest including: the role of technological innovations with the potential to transform the body, and anxieties about the impact of HIV and AIDS and other debilitating conditions. Turner (1995) has also pointed to the way 'lifestyle aesthetics' have dominated contemporary consumer culture.

Theorists have conceptualised the body as a project which is intimately connected with self and identity (Shildrick, 2005; Shilling, 1997). Feminism, both in wider society and the academy, is also implicated in the 'bodily turn' because of the way discourses of the biological body have been used to either (mis)represent women's bodies and their experiences (Ussher, 1989) or discriminate against women in education, employment and lego-political life (Weedon, 1989; Showalter, 1988). Reproductive technologies have been a particular issue for feminists in terms of women's control over their own fertility and access to such technologies (eg IVF, contraception and abortion) mediated through the regulatory apparatus of the state. This has given rise to claims that rather than benefiting from reproductive technologies, women and

women's bodies have been exploited by a male dominated science and medical profession (Stanworth, 1987). Moreover Gatens (1996) suggests feminists have failed to theorise adequately the relationship between women's bodies and the state despite women's attempts to gain autonomy over their bodies (witness various campaigns for safe and effective contraception and abortion).

The privileging of the body then sits uncomfortably with some feminists, not least because of the concern that this represents a move towards a biological determinism which has social and economic effects for those deemed to have 'inferior' bodies. Conversely, others have regarded bodily technologies as "the solution to the problem of the deviant body" (Valentine, 2001, p. 45). The metaphor of 'the cyborg' (Haraway, 1990) has been invoked for its liberatory potential in transgressing borders between "human, organism and machine" (Lykke and Braidotti, 1996, p. 5). Cyborgs, it is argued, permit a "recoding of the body and self" (Valentine, 2001, p. 59) in order to produce a subjectivity that is both trans-historic and un-gendered. As such the cyborg is embraced as a site of possibilities and political contestation (Haraway, 1990; Casper, 1995).

However the celebration of techno-bodies is rendered particularly complex when considering disabled children and their bodies. Children with neuro-developmental disabilities, for example those diagnosed as having severe cerebral palsy, are characterised as having 'feeding difficulties', including high rates of dysphagia (ie. 'abnormal' swallow reflex and oro-motor development). This means they are unable to achieve an adequate nutritional intake by mouth with consequences for their growth and development. Mothers may spend prolonged periods of time feeding a child a relatively small portion of food, such as a few teaspoons of solids. Indeed some mothers report spending between five and seven hours a day feeding a child. Mothers often describe mealtimes as 'difficult' as children can choke and splutter when feeding. In extreme cases children can turn blue as food is aspirated (swallowed) into the lungs. Accounts of children drooling, regurgitating or vomiting, both during and following mealtimes, not only challenges the idealised image of mother and child but exemplifies, perhaps, the 'sheer messiness of corporeality' (Shildrick 2005, p. 7).

Due to the risk of oral aspiration, which has been associated with respiratory distress and poor respiratory health (eg aspiration pneumonia), some professionals may caution mothers against oral feeding. Conversely others may encourage mothers to 'persevere' and

increase the quantity of food to boost growth or to feed their child more often; in short, ‘try harder’. This sets up a conflict whereby discourses of ‘nurturing’ are constructed as harmful and women are positioned into monstrous mothers for feeding (harming) their child or ‘blamed’ for failing to feed enough food to sustain the child’s growth.

Advances in medical science then offer to reconfigure a child with an alternative way of feeding through a gastrostomy tube surgically inserted into the child’s stomach to assist growth and, in some cases, provide an alternative to oral feeding. Additionally, where indicated, clinicians may recommend an anti-reflux procedure (ARP). This involves ‘tying’ the stomach to prevent its contents -- including food and acid (‘reflux’) -- flowing back up into the oesophagus resulting in heartburn, regurgitation, vomiting and the consequent risk of aspiration (where food/acid is swallowed into the airway/lungs) with consequences for children’s respiratory health.

However the prospect of a surgical intervention involving an alternative way of feeding a child raises ambivalence in mothers about the potential for change. I will suggest that this ambivalence, in part, reflects an anxiety about changes in children’s identities and embodiments constructed through the medium of feeding and associated technologies.

Abject bodies

Abjection is a theoretical explanation of the psychic processes of disgust (Kristeva, 1982) and, according to Smith (1998, p. 33), illustrates ‘the power and importance of visceral reaction as a representation of what is happening in the psyche’. Kristeva describes abjection as part of the process of separation between mother and child. In demarcating difference between self and the body of the engulfing (m)other, the child expels all that is unclean which it associates with the mother’s body in order to preserve its own ‘clean and proper’ self (Segal, 1999; Kristeva,1982). The abject is associated with all that is repulsive and, in particular, those aspects of bodily experience which threaten the integrity of the body. For Kristeva, the abject is not an object but the boundary between the pure and the impure, the clean and the unclean and life and death. This creates a fear of things without clear boundaries (Segal, 1999). Horror and disgust are therefore constructed at the interface of the ‘clean and proper’ body (Kristeva, 1982, p. 8):

It is thus not lack of cleanliness or health that causes abjection but what disturbs identity, system, order. What does not respect borders,

positions, rules. The in-between, the ambiguous, the composite (Kristeva, 1982, p.4).

Abjection is of interest to feminists because of its potential in challenging the distinction between mind and body. Cartesian dualism it is argued, supports a particular construction of the individual which, in Western liberal democracies, represents a cultural ideal; that of the autonomous, rational, and hence disembodied, male (Bridgeman, 2000; Sampson, 1977). Moreover, emotions such as horror and disgust sit uneasily within the psychic economy and disrupt the rationalist, masculinist body-machine metaphor which represents children's bodies as objects to be operated on and 'fixed'. Abjection then is a useful analytic as it disturbs the hegemonic norm underpinning medical constructions of the closed and stable body.

In this paper I analyse constructions of mothering and feeding disabled children. Drawing on examples from previous work (Craig, 2005; 2004; Craig and Scambler, 2006) I illustrate ways in which feeding technologies impact on children's identities and embodiments and relations with others. I will illustrate how mothers' attempts at feeding and caring for their disabled child and children's in/ability to feed are both rendered abject within dominant discourses of mothering.

Constructions of feeding technologies

In previous work (Craig, 2004; Craig and Scambler, 2006) I described how parental constructions of feeding technologies distinguished between the gastrostomy tube as an object (the gastrostomy -- body interface), the stoma (the hole created in the stomach where the tube is inserted) and the actual experiences of feeding by tube. I elaborate on these accounts briefly to illustrate what happens to children's identities (as known by their parents) and embodiments when, ' the material structure or function of the body' is altered through surgical intervention (Price and Shildrick, 1999, p. 276).

Going against nature

Feminists have been concerned to challenge the link between women and nature because of the tendency to naturalise and privilege particular representations of knowledge and establish universal truths (Saraga, 1998); truths which can be applied in exclusionary ways for, if something is natural, we cannot change it.

Kristeva (1982, p. 75) suggests food becomes abject 'only if it is a border between two distinct entities or territories. A boundary between nature and culture, between the human and the non-human'. Analysis of parental constructions of feeding technologies reflected a tension at the intersection of these boundaries. Their accounts suggested they both accepted and resisted 'cyborg identities' in relation to their child and both (re)produced and refused the nature/culture binary. For example, parental assertions that a gastrostomy tube was going against nature drew on a naturalised discourse and constructed a dualism between nature and medicine.

Anxieties about medical interference in nature were apparent in one mother's comment that the 'gastrostomy was not given by God', rather it was a 'human being doing it to another human being'. Here she drew on a pre-Enlightenment discourse. The Enlightenment was characterised by the shift from religion as a traditional source of authority towards science as the arbiter of knowledge (Bondi and Burman, 2001). By drawing on a pre-Enlightenment discourse this mother challenged the primacy of medicine as an expert knowledge and its attempts to dominate nature.

However mothers also acknowledged that their child needed more food and better nutrition than they were physically able to eat or drink by mouth which, presumably, was their child's 'natural' state. Parents were then faced with the prospect of going against 'nature' in order to sustain the child. Constructions of the tube as 'unnatural' or 'alien' and as an 'undesirable object' hanging out of their child's body, were weighed against the potential health benefits the technology promised to confer; that of (re)producing the effects of 'normal eating' and growth.

Parental accounts constructed different kinds of feeding technologies and associated surgical procedures along the dimensions of: temporary-permanent, reversible-irreversible and interior-exterior. These different feeding configurations underpinned anxieties about transformation and change in terms of children's identities and relations with others.

In the following account Ricki's mother constructed the gastrostomy tube in terms of its transformatory capacity relative to a nasogastric tube (tube inserted through the nose to deliver food into the stomach). Her account constructed a dualism between the temporary-permanent aspects of tubes:

"a few operations that he has had done things were being taken out from him, like cataracts or when stitches were being removed, but this is an

operation that's going to be a tube going to be put down in his stomach and it's going to be connected to him and thinking of that sort of upset us, oh Ricki's going to be fed from a tube, or something is going to be stuck to his stomach. Because the tube in his nose you can put it in and out, some days he'll have it in his nose and some days he won't, so he'll be just Ricki again." [Ricki's, mother]

The temporary aspect of the nasogastric tube (i.e. it can be removed) serves to normalise the child - 'he'll just be Ricki again' - whereas a gastrostomy tube 'permanently' attached to a child's stomach, was constructed as something that would transform the child's identity as recognised by others, especially his parents. By way of contrast, other mothers constructed nasogastric tubes as a permanent attribute of the child, given that in many cases the need for a feeding tube was firmly established shortly after the child's birth.

In the same way comparisons were made between nasogastric and gastrostomy tubes as 'fixed' and 'natural', parents used similar constructions when talking about the antireflux procedure (ARP). One mother judged the ARP to be more 'unnatural' than a gastrosotmy tube because the former was constructed as a permanent intervention (ie irreversible) while the gastrostomy was seen as a temporary one which, in theory, could be removed if the child's feeding and weight 'normalised':

"whilst the tube isn't natural, I mean it's not natural having a tube in your tummy, somehow the, the, having your what oesophagus pulled down and your tummy tied round, all sounded totally sort of unnatural, and sort of irreversible. I mean his tube [gastrostomy] can be whipped out, you know what I mean, whereas the [ARP] certainly did seem like a very permanent situation, it sounded totally unnatural." [Edward's mother]

Other surgical interventions (eg. a shunt) were also implicated in the 'othering' of children. In these accounts parents constructed difference not only through the insertion of an object into the body (corporeal alteration) but in terms of things the child would be prevented from doing: for example, not able to feed by mouth or 'burp' or 'vomit'; functions which were considered to be the natural prerogative of the child. These bodily processes of ingesting and expelling constituted normality, the absence of which demarcated difference. Interfering with these processes was constructed as a denial of normality and an infringement of the rights of the child:

"I mean he's special in a sense already that he has a shunt and a gastrostomy and then we want to make him special .. by well you can't be sick and you can't burp, and we want him to have, you know lead a normal life. So that's why I would have liked to have seen him without the [ARP] and maybe like gone to the [ARP] if it was really that bad, or if he was still vomiting a lot." [Joshi's father]

Separation and distance

Parental accounts also reflected a concern about the potential of feeding technologies and their impact on physical contact: for example, whether the gastrostomy (constructed as a 'foreign object') might deter others from 'touching' the child (eg cuddling the child). Parental constructions suggested that the 'public' fear of intimate contact with children by virtue of their disability would be intensified by the gastrostomy tube. This exemplifies, perhaps, the 'urge' to protect oneself against the polluting effects of the abject other through physical distance and separation.

However as Price and Shildrick (2002, p. 71) suggest, the avoidance of physical contact is a 'discourse that both structures and is structured by everything from psychodynamic processes to socio-political power'. This is no better illustrated than by the increasing regulation of physical contact with children in many institutional settings where 'non-touching' policies exist which serve, perhaps, to protect adults against accusations of abuse (Lipsett, 2008). Moreover, physical contact with children is itself gendered with boys more likely to be engaged in 'rough' and 'tumble' play than girls who are also constructed as delicate and fragile (Belotti, 1987).

Other mothers suggested that it was the fear of loss of intimate contact with children, which they constructed through mealtimes and oral feeding, that accounted for their resistance to tube feeding. Although mothers drew on militaristic metaphors to describe their experiences of feeding children as a 'battle' or 'war' they also constructed feeding as a time for intimacy and physical closeness. For example mothers often found it easier to sit the child on their lap in order to feed, contrary to the advice of feeding experts. In some cases mothers described feeding as an activity that both mother and child engaged in together ('she's not doing it, I'm not doing it, we're doing it together'). Physical contact therefore had to be re-negotiated within a modernist discourse of separation (Price and Shildrick, 2002) which then invited the risk of accusation from professionals that mothers were 'over-protective'.

Mother's experiences of feeding therefore revealed identity as an act of relation. Moreover, the construction of feeding as an interdependent activity ascribes a personal agency to the child otherwise elided within medical discourse which constructs disabled children as passive. The notion of interdependency challenges both the dominant discourse of separation which, Price and Shildrick (2002) argue, structures most caring relations, and the able-bodied/disabled dichotomy.

Bodily difference -- horror and disgust

Within medical discourse the word 'stoma' is used to refer to the cut or hole in the stomach where the gastrostomy is inserted. Parental accounts constructed a difference between a nasogastric and a gastrostomy tube in terms of a hole in the stomach artificially created to accommodate the gastrostomy. One parent compared it with a pre-existing hole, the nostril, which was a 'natural' opening. Some mothers drew on a discourse of disgust to describe their feelings and reaction to the stoma ('It didn't seem alright to me, I was disgusted really. I didn't like it').

Gross (1990, p. 88), drawing on the work of Lacan, suggests erogenous zones are defined in relation to 'spaces' which demarcate the boundaries between the inside and outside of the body: for example, ears, mouth and nose. These sites define what is inside the body, and therefore part of the person (subject), and what is outside the body, and therefore constitutes an object (other). The linking of the inside and outside of the body is apparent from parental accounts of gastrostomy complications including stoma-related infections. The following extract nicely illustrates one mother's abject reaction when cleaning the child's stoma and confronted with the side-effects of a surgical procedure:

'I was hysterical, absolutely hysterical, and I was I don't know what it is, what's happening, it's gone all black so I rang the nurse and she came out and she said it [the stoma] was over-granulating. And um, where I've been cleaning it, she was obviously leaking some gastric fluids which was causing it to redden, but it wasn't actually, it was this infection that was on the inside, I couldn't get in because it was one [gastrostomy tube] that you couldn't get out of the tummy, it was stuck in the tummy, and there was that. And obviously then I experienced um, um, when Cathy wasn't well, and when I aspirated back I was drawing back blood, ….like lumps of blood which panicked me as well.'[Cathy's mother]

Here the mother's sense of panic is conveyed in relation to the

uncertainty over the exact nature of the leaking material (whether food or waste) and its source: inside or outside the child's body. As Kristeva (1982, p. 9) states: "abjection is above all ambiguity". In this example the gastrostomy deconstructs the food/waste-inside/outside dichotomy. The adverse side-effects of the surgical intervention generates a further source of abjection (ie. leaky stoma) which, somewhat ironically, challenges the very aim of the surgical procedure; to effect closure on the body and render it both knowable and stable.

Although the account Cathy's mother narrated is atypical (and chosen explicitly for the purpose of illustration), gastrostomy tube/site related complications are common and can be distressing for mothers, not only in terms of the aesthetical appearance and the assumed discomfort children may experience, but also the need to learn new nursing procedures in caring for the gastrostomy site.

Parental reactions when confronted with images of tubes, scars and the stoma - sometimes oozing or infected - can be explained in terms of the way such images challenge normative constructions of children's bodies. Whereas bodily orifices (mouth, ears and eyes) are eroticised, the stoma/gastrostomy represents ambivalence because it displaces the mouth as the site where feeding and, potentially, pleasure take place. Both the stoma and the gastrostomy, constructed as medical and artificial but also associated with feeding (and assumed pleasure), create ambiguity and hence, the abject. A medical intervention involving tubes, holes and scarring serves to de-eroticise the child's body, denying pleasure to both mother and child (Craig, 2005).

Burman (1994, p. 240) argues that children who do not conform to the idealised images of childhood, such as disabled children, 'sit uneasily' within the psychic economy. Such images contravene normative expectations of children sentimentalised as pure and innocent. Thinness is often equated with ill health and sickness in young children. Being thin and 'malnourished' not only signifies illness but also adds to the construction of children as very disabled. In the same way that women's bodies are deemed to be closer to nature than men's, children's bodies are also naturalised; the surgical insertion of a feeding tube then transgresses the purity of the child.

Images of feeding technologies then create a tension as they transgress boundaries positioned at the interface of what is inside and outside the body; what is potentially lifesaving but may also incur the risk of pain or perhaps death (due to the risks involved in surgery) while at the same

time offering the potential for ‘normalising’ a child through health and weight-gain but at the risk of ‘othering’ the child by making her different (Craig, 2005).

Conclusion

Feeding technologies are designed to correct the child’s ‘deviant’ body and offer the promise of protection against those aspects of feeding and growth that are sources of abjection: for example, emaciated bodies, regurgitation and vomit. The parallel with women’s ‘leaky’ bodies is perhaps worth noting. Historically women’s bodies have been constructed as unreliable and unstable vis-a-vis their reproductive function and medical interventions have been marshalled to restore the ‘deviant’ body. Medicine then is part of the regulatory apparatus which "maintains unreliable body borders" (O’Connell, 2005. p. 219).

However the shifting and unstable nature of children’s identities, constructed through the medium of feeding interventions, suggest that rather than civilise the body, medical technologies may actually render the body less knowable and certain, particularly to the children’s parents. Science then both regulates and disrupts the body in its ability to "disturb conventional understandings of self" and others (O’Connell, 2005, p. 227).

Identity transformation may not always be interpreted negatively however as many parents wish to see their child transformed from sick to well and from poorly nourished to well nourished and therefore do consent to feeding interventions. However for families, particularly women, the decision to have a feeding tube surgically inserted into their child’s stomach is rarely straightforward. As O’Connell (2005, p. 225) states, science plays at ‘the boundaries of identity, which, although it offers a means of producing a clean and proper body, also inspires an anxious social response’.

Disability activists have criticised the way technology has been used to produce the effects of ‘normality’. Similarly, the possibility of ‘re-building’ a child (ie through health and weight-gains) raises ambivalence in parents about the potential for change. Yet to some extent disabled children are already ‘technologised’ with the insertion of grommets, shunts, and cochlear implants so why, we might ask, would a gastrostomy be any different in terms of parental acceptance of children’s ‘cyborg’ identities?

Woodward (1997) suggests that in 'Western' culture constructions of motherhood are iconified by a dominant discourse of Judeo-Christianity, the madonna and child representing an idealised image of motherhood. Idealised images of the maternal set up expectations about motherhood and desire. Feeding disabled children either orally or by tube transgresses the 'usual rules' associated with the 'nurturant' mother and, therefore, challenges the idealisation of the maternal in the (Western) cultural imaginary. These conflicts may, in part, explain why some women were ambivalent about the decision to have a gastrostomy inserted in their child. As Flax, (1990, p. 11) states: "ambivalence is an appropriate response to an inherently conflictual situation".

Moreover, children's bodies that fail to conform to standardised norms reflect badly on women's parenting skills. Disabled children are not usually held responsible for their situation, although their mothers may be. Child care manuals often give the impression that disability is something that can and should be avoided (Marshall, 1991). Consequently if a woman has a disabled child she feels responsible and is blamed. Women may also blame themselves for having a disabled child and the recommendation of a gastrostomy further questions their ability to mother for having failed to establish feeding, as signified by their child's thinness and poor growth. In previous work (Craig, 2004; Craig and Scambler, 2006) I analysed discourses of blame in relation to regimes of governmentality (Foucault, 1988) vis-à-vis the disciplinary practices which govern aspects of mothering and feeding (Rose, 1989). As such a father with an emaciated, disabled child is more likely to attract sympathy while a mother will experience blame.

So far I have demonstrated that feeding disabled children challenges the idealisation of the 'nurturant' mother and renders women's mothering as abject as they perform the dual function of mother/carer. However, although abjection can be used as a lens to both reflect upon and disrupt medicine's mechanistic and reductive view of the body and the idealisation of mothering and feeding, I am left feeling dissatisfied with the transgressive potential of abjection.

Although every society may have its own abject, this does not satisfactorily explain abject reactions towards particular groups of people and the ways in which disability, gender, race and class intersect in (re)constituting the other. Feeding disabled children blurs the 'boundary' between mothering and caring. While accepting that there are aspects of caring that may be pleasurable (and I am wary of (re)producing dominant discourses of disabled people as a burden, a point which

feminists have been criticised for in the past) there are also economic, social and psychological costs in relation to caring for a disabled child. As Susan Wendell (1999) argues, greater attention to the consequences of being abject is warranted and, as such, discourses of the body and abjection, need to be relocated within the material experiences of disability. In this context we might question whether a focus on abjection is in danger of depoliticising mothering and (gendered) relations of care. For example, women tend to be the major caregivers of children and perform care giving tasks that arguably should be done in the formal health care sectors. Difficulties accessing support such as respite care and the additional costs families incur in caring for a disabled child can also impact adversely on women's psychological health and the wellbeing of their families. The different roles women perform therefore need to be acknowledged and the policy implications of being more than 'just a mother' theorised.

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Biographical note:

Gill Craig is Lead for the Centre for Disability and Social Inclusion, School of Community and Health Sciences, City University London, UK. Gill’s teaching and research interests include the experience of disability, chronic illness and social inclusion. Her PhD examined professional and parental discourses in relation to gastrostomy feeding technologies and women’s experiences of caring for disabled children as part of a major clinical evaluation. This work was awarded a postgraduate prize by the British Psychological Society, Psychology of Women section. Other interests include maternal identities and subjectivities, abject bodies, user involvement, feminism and discourse analysis.