

Everybody S*s: How Defecation Stigma Reduces Care Quality in Dementia**

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Abstract

This article aims to highlight how stigma around defecation can reduce quality of dementia care. The article contains a scoping review of available literature on the topic. Literature was organised into three themes: The Origins of the Stigma, the Purpose of Stigma and the Care Context. Stigma regarding faecal incontinence has the potential to impact quality of life of people with a dementia and contributes towards the invisible work of unqualified care workers. This paper discusses issues that have not been previously examined. By shining light on what is a difficult and distasteful topic, the paper aims to raise awareness of how stigma around faecal incontinence could reduce the quality of care being provided for individuals with a dementia.

Background

Defecation is something that every single person experiences; everybody defecates (Tortora and Derrickson, 2017). The absence of regular defecation implies a severe medical issue that warrants medical treatment or lifestyle changes to improve (Waterham et al., 2017, Munch et al., 2016). This literature review shows that despite the act of defecation being experienced by every human being on the planet, there exists an astonishing amount of stigma surrounding the topic that prevents us from openly discussing the subject with others. This means that when experiencing issues such as faecal incontinence (FI), symptom management becomes increasingly difficult. For the context of this article, FI refers to the involuntary excretion of stools (Forbes, 2015) or inappropriate faecal expulsion, meaning defecation that takes place outside of the bathroom and in an inappropriate receptacle or location (Andrews, 2017, Russell et al., 2017) This article also refers to formal carers, which in this context means care staff working in a nursing or residential home who are educated up to level 4.

Dementia

For individuals living with a dementia, FI can be a common issue. Dementia is understood to be progressive brain damage caused by a multitude of diseases that affect the brain (Innes and Manthorpe, 2013, Stokes et al., 2014, Cunningham et al., 2015). Progressive cognitive decline means the ability of the brain to control defecation and urination in a socially acceptable manner often becomes compromised, leading to urinary and FI (Drennan et al., 2012). FI in people living with dementia can present as “inappropriate voiding”, meaning defecation outside of the socially acceptable vessels or times (Andrews 2017; Russell et al 2017).

The monitoring of bowel movement for individuals living with a dementia is an important part of care provision. Due to communication issues that tend to be intrinsic to dementia, individuals may find that they are unable to effectively communicate when they need to open

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their bowels. This can lead to long term issues such as constipation (Nazarko, 2011).

Monitoring bowel movements helps to identify issues such as constipation that can go on to cause distress reactions, infection, sepsis, death and indicate other health problems (Svedas and Wise, 2012, Oates and Price, 2016, Jones, 2015, Ha and Kim, 2014, Newton, 2012, Javed et al., 2017).

This article collates evidence from a variety of articles showing how the stigma surrounding FI has developed through the ages and how this could potentially have a direct impact on the way in which dementia care is provided.

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Methodology

This article takes the form of a scoping literature review. The research was conducted by searching through all databases available through the University of Worcester system.

Appropriate articles were found to come from: Taylor and Francis Online, Proquest Central, CINAHL Complete, Wiley-Blackwell Full Collection, Academic Search Complete and SAGE Journals Online.

All searches had the same basic inclusion/exclusion criteria. Content type was limited to: book/e-book, book chapter, government document, journal/e-journal, paper, and publication. All results were restricted to being in the English language and peer-reviewed items only to increase the levity of the research papers used. Newspaper articles and book reviews were excluded from results to minimise opinion-based papers surfacing in the results. Articles included were directly related to the searched keywords: dementia; faecal incontinence; stigma, historical attitudes; and societal attitudes. No age limit was applied to literature as the intention was to collate a variety of sources.

Where possible, multiple spellings of the search terms were included to encompass both English and American results. For example, the search (**societal attitudes**) AND ((**faeces**) OR (**feces**)) netted results from both English and American researchers. Geographic location was only confined to England or the United Kingdom when large amounts of results were found.

In total, 27 articles were included for review. These articles were then organised into collective emerging themes as shown in figure 1.

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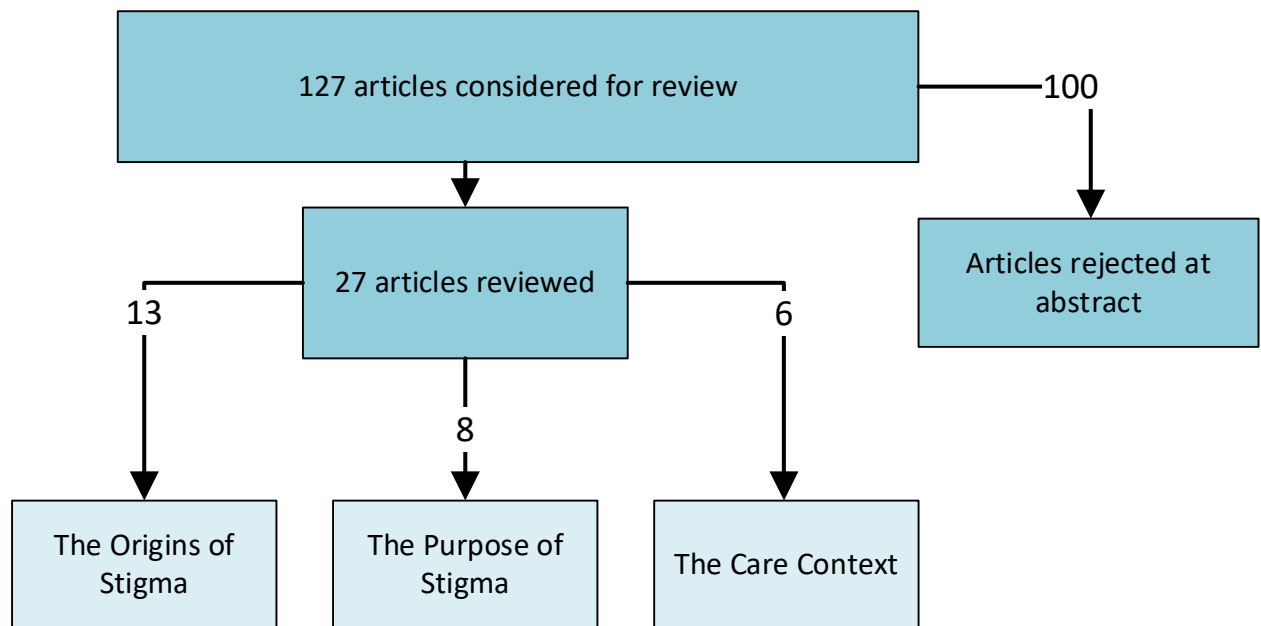


Figure 1

Language is very important when evaluating defecation stigma. Andrews (2017) argues that whilst needing to be direct it may be beneficial to use vernacular terms such as “poo” rather than faeces or stool to ensure the comfort of all involved. This coyness surrounding faeces is reflected in television advertisements; items such as toilet paper that are used by everyone are advertised whilst the actual act of defecation is conspicuous by its absence (Kama and Barak-Brandes, 2013). Wilson (2015), Ladegaard (2013) and Ramsey (2016) discussed how humour can help to ease discussions around defecation and faeces; although this is true for many challenging topics (McDavitt and Mutchler, 2014). Using taboo words that wider society finds offensive also infer a more emotional or shocking meaning which serves to make the topic easier to recall, hence the title of this article (Madan et al., 2017).

Limitations

This methodology was chosen as the authors were aiming to collect and synthesise literature relevant dementia, FI and stigma. Due to this, the methodology is automatically limited as the authors are imposing their own biases on the searches by using the lens of stigma to view

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resulting literature. The review was also limited by a lack of dementia-specific literature surrounding FI and literature that discussed only FI.

Discussion

The resulting information was organized into three themes: 1) the origins of the stigma; 2) the purpose of stigma; and 3) the care context.

The Origins of the Stigma

Historical articles are less hesitant about defecation when they explore Roman archaeological ruins that are prevalent in the UK (Cary and Scullard, 1994). Historically, latrines were often arranged in group formations with little or no barriers between each individual seat (Magness, 2012, Hobson, 2009). Communal toilets were a common feature in Roman settlements (Hobson, 2009); indicating that previously defecation was not seen as a private and shameful behaviour. Historically, defecation was not viewed with the distaste that it is currently viewed with today.

One sociological theory that attempts to explain this change in societal attitudes is the civilised body and embodiment. In this context, embodiment refers to the view of the mind as situated in the body – the idea that locating the mind in one’s body gives essential context and understanding to what is happening in the mind (Scmalzl et al., 2014). Shilling (2012) adapts the previous idea of the Civilising Process (Elias, 2000) to contextualise the way in which we form our social norms. Shilling describes the civilised body as being one that internalises accepted norms and behaviours due to fear of being shamed and embarrassed in modern society. Reflecting the idea that wider society imparts stigma to the act of defecation, Shilling’s (2012) theory of the civilised body explains that this stigma is internalised to prevent being ostracised and to encourage the idea of ourselves as contributing citizens of

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society (Kelly and Innes, 2013). This then affects an individual's sense of citizenship. Citizenship is intrinsic to our sense of personhood and being denied this can cause severe depression and isolation (Kitwood, 1997). Thus, setting ourselves apart by not responding appropriately to the stigma associated with defecation leads one to an "uncivilised" body; potentially causing mental health conditions and causing a dissociation between the mind and body (Kama and Barak-Brandes 2013).

Literature highlights the discovery of bacteria as a cause for illness as a catalyst for changing beliefs about defecation (Kama and Barak-Brandes, 2013, Tomes, 1990, Humphreys, 2014). Despite aversion to bacteria, research shows that a lack of bacteria could be as dangerous as too much. Lorimer (2017) classes these "epidemics of absence" as causes of illnesses such as inflammatory bowel disease and depression. One common infection that can be caused by lack of microbes in the gut is *Clostridium Difficile* (*C. Diff*). A controversial treatment for this infection is that of faecal microbial transplantation, or faecal transplants. This treatment has a success rate of 85 per cent, compared with just 26 per cent success with antibiotics (Spector and Knight, 2015, Bokjanova and Bordenstein, 2016). Despite the success of faecal transplants for treating recurrent infection public perception remains that the process is disgusting and distasteful (Spector and Knight 2015). Uptake of the treatment is therefore lower.

Using Goffman's (1963) theory of stigma, we can see that the advancement of society and recognition of faeces as a potential contaminant may have led to the idea of FI now being seen as "uncivilised" and therefore being seen as an undesirable attribute.

The Purpose of Stigma

Goffman (1963) uses stigma to refer to attributes that are "deeply discrediting" (p. 12). Some literature infers that stigma is not an intrinsic part of humanity but something we learn in an

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attempt to be accepted by wider society (Goldberg, 2017, Chelvanayagam, 2014, Hanschmidt et al., 2016, Vogel et al., 2013, Swaffer, 2014). This could mean that the stigmatisation associated with dementia and FI is wider society's way of ensuring we are accepted; individuals who experience dementia and FI are seen as the "out" group by which we measure our own social status and show that we are part of the "in" group.

This is evidenced by Hyde et al (2014) who argued that moving into residential care (RC) itself is a form of segregation used to hide unpleasant attributes from wider society. This, coupled with research showing that FI is often a catalyst for moving into RC (Andrews 2017), shows that the stigma associated with ageing and inappropriate bowel function has colossal ramifications on older adults. These personal ramifications are ignored by wider society as once in RC, the issues of FI and dementia are "out of sight, out of mind".

Hyde et al (2014) go on to describe the disparity between the way in which "residents" want to be treated and how they are actually treated once in RC. The authors explain how personhood is denied and residents are treated as a series of bodily functions, evidencing that despite being segregated into a specially adapted environment, people continue to be stigmatised. This is without considering the potential presence of dementia and the stigma associated with that (Swaffer, 2014). Some individuals in RC are therefore subject to multiple stigmas or oppressions such as age, residency, cognitive impairment and FI. These multiple stigmas serve to separate such individuals from others and enable those who are included to cement their places in society.

The Care Context

Ostaszkiwicz et al (2016) discussed a culture in which formal carers are subjected to courtesy stigma due to the provision of personal care for individuals they are supporting. As reflected by Fenton and Miller (2013), this courtesy stigma then becomes internalised by the

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formal carers as they are looked down upon by wider society despite performing a necessary and emotionally beneficial action. Todd and Woodward (2018) evidenced this by looking at the experiences of nurses assisting patients with bowel movements. Nurses reported “pulling rank” to avoid having to deal with faeces, forcing staff lower in the organisational hierarchy to complete the unwanted tasks. This could be a continuation of Goffman’s (1963) idea that we use stigma to cement our place in society – individuals who are already marginalised and subjected to courtesy stigma force individuals less superior than them to take on the burden of this stigma, meaning that nurses who maintain a professional distance from faeces have a higher societal standing.

Stigma around FI could potentially impact the way residential and nursing care are viewed. Research suggests that up to 50% of individuals resident in care homes experience FI (Goodman et al., 2017). However, there is currently almost no evidence recording how FI is distributed between the two types of care. Many people believe that as FI often implies a higher level of dependency it is more prominent in nursing care, despite Goodman et al. (2013) finding in their study that up to 66% of residents in their sample of residential homes experienced FI. This misbelief could result in unqualified care staff being unable to take pride in their work; they are an under-valued and unrecognised portion of society that complete their work in anonymity. They are less likely to receive the respect afforded to qualified staff who also deal with FI. As unqualified staff are generally not recognised as dealing with FI they are not likely to receive much training around management. Much of the training in continence care is aimed at qualified nursing staff (Ostaszkiwicz, 2006, Paterson et al., 2016). There is a gap in research and training for formal carers in continence management.

Care workers who are being excluded by society due to courtesy stigma not shared by their superiors could sub-consciously begin to impart the stigma on the individuals they are supporting to attempt to cement their own place in society. This sub-conscious stigma could

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present in facial expressions, which can be very difficult to control (Sarabia-Cobo et al., 2016). Chelvanayagam (2014) argues that individuals who are being supported with their defecation often respond more to facial expression than to verbal communication; something as simple as wrinkling your nose and therefore acknowledging the offensive smell is likely to cause the individual to feel embarrassment and shame. By expressing negative emotions in this way, Goffman (2003) argues that one encourages the recipient to become defensive and to protect themselves, potentially adding to pre-existing emotional difficulties associated with receiving personal care. Therefore, the courtesy stigma imparted on staff could encourage them to pass that stigma onto people with a dementia. When this is displayed as body language and sub-conscious comments, it is likely to predispose individuals being supported towards being defensive, embarrassed and upset. This emotional distress directly impacts the quality of life of those being supported, meaning that the quality of care being delivered has decreased and is no longer optimal.

Imparting stigma on individuals being supported should naturally be highlighted and tackled. In the “Culture of Care Barometer” (Rafferty et al., 2015) frequently used in hospital and care home settings states that in high-performing settings “unacceptable behaviour is always tackled”. However, there is no definition of “unacceptable behaviour”. Stigma surrounding defecation is so engrained in society it may not even be recognised as an undesirable behaviour.

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Conclusion

Absence of defecation implies a significant health problem; the stigma surrounding this act can be seen as irrational and unreasonable considering the frequency at which the human race defecates. The necessity for stools to be monitored in people living with dementia to maintain their quality of life means that issues carrying out observations can have drastic consequences. Inaccurate recording of bowel movements in people with dementia can lead to inappropriate treatments for constipation and diarrhoea; for example, anti-diarrhoea medications being administered when the individual is already constipated (Waterham et al 2017; Munch et al 2016). This can cause grave consequences such as distress reactions, infection and decreased quality of life (Svedas and Wise 2012; Oates and Price 2016; Jones 2015).

Wider society continues to view defecation as distasteful and repulsive (Ostaszkievicz et al., 2016, Norling et al., 2015, Emmanuel et al., 2017, Chelvanayagam, 2014). This is due to a multitude of factors including sociological phenomena such as the civilised body (Shilling 2012) and biological advances in medicine and prevention of disease (Kama and Barak-Brande 2013). However, even when advances in medicine indicate how useful defecation and faeces can be, this is met with resistance due to the stigma imparted upon the act and its product (Spector and Knight, 2015, Chuong et al., 2015).

This stigmatisation has led to the internalisation of defecating as something which should be viewed as disgusting. The strength of the stigma in wider society causes individuals to internalise the idea that even though defecation is a natural and healthy function of living that everyone experiences; it is one that should be hidden away from others to prevent association between oneself and defecation.

People living with dementia are already stigmatised due to the cognitive impairment they experience (Swaffer, 2014, Kitwood, 1997, Gove et al., 2014). As a result of this, they are

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subject to an ever-evolving disengagement from society in which RC becomes a form of internment (Moody 2010 pp. 9-10; Andrews 2017). In the context of dementia, the stigma associated with defecation and potential FI adds another layer of separation between the individual and wider society. This stigma is one of the reasons individuals are separated from society into RC (Andrews 2017).

This stigma around defecation and faeces interweaves into care culture. Defecation stigma becomes a tacit knowledge that permeates the care environment. This stigma is so intrinsically subtle that the individuals receiving care are part of a culture that perpetuates the idea that defecation is a repulsive, sordid act; individuals receiving care are unknowingly colluding to the shame agenda. Care workers may not even realise when they replicate and disseminate this stigma. They do this via their facial expressions when confronting faeces. These show the individuals they are supporting that they are disgusted by their action (Chelvanayagam 2014; Czymoneywicz-Klippel 2011; Sarabia-Cobo et al 2016; Goffman 2003). This visible disgust causes emotional distress in the individual being supported and directly contravenes what carers and supporters of people with dementia should be practicing (Nursing and Midwifery Council, 2015). This could be causing emotional harm to vulnerable and already stigmatised individuals and worsening their quality of life through an inability to hide disgust felt towards defecation.

This stigma could then translate as an inability to effectively use the tools provided to categorise stools. Carers may not look at the stool thoroughly. They may give it only a sparing glance, raising questions about the ability to then accurately describe and record the resulting stool. Lack of careful observation can then lead to the stool being incorrectly categorised and inappropriate treatments being prescribed. Due to the stigma surrounding defecation, medications which are contraindicative to the individual's medical condition may be prescribed. As a result of this, the individual could then experience distress reactions as a

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result of the worsening condition (Svedas and Wise 2012; Ha and Kim 2014; Newton 2012). In extreme cases, they could potentially experience sepsis; which can be fatal in vulnerable adults (Jones 2015; Javed et al 2017). Unrecognised and unacknowledged defecation stigma could, potentially, lead to the preventable death of a vulnerable adult in care.

Further Recommendations

There is, however, work being carried out that helps to reduce the stigma associated with FI. The FINCH study, carried out by Goodman et al. (2017), identified six theories for testing that could potentially improve the way continence care is delivered in RC homes. The report concluded that value must be placed on the work carried out by RC workers and the challenges associated with this in order to improve management of continence care. There is also a large amount of research around urinary incontinence; so much so that the topic of urinary incontinence seems to have lost much of the stigma and embarrassment that has previously been found alongside the topic. The NHS recently changed the way they refer to urine and faeces to make it more palatable for society (Wilcox, 2019). Areas for further research include:

- How episodes of FI impact provision of front line care
- Prevalence of FI in residential and nursing homes
- Training opportunities for formal carers
- Methods of destigmatising faeces

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