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Impairment effects, disability and dry mouth: Exploring the public and private dimensions.

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Abstract

Existing accounts of dry mouth concentrate on the medical and almost completely neglect to consider its social dimensions. Simultaneously, debates on disability have highlighted an apparent split between the individual (medical) and social models of disability. The concept of 'impairment effects' aims to address this dichotomised approach. Impairment effects consider the everyday impact of people's impairments on their lives in conjunction with the disabling impacts encountered through their relations with society, and society's relations with them. The present study indicates that identity and self became entangled with impairment effects and a form of disablism. The authors argue that impairment effects are, at times, a useful concept but in some instances may actually over complicate things. By analysing the public and private dimensions of a chronic condition such as dry mouth we have been enabled to explore the boundary between public and private lives. As a consequence, using public and private accounts may assist us to better locate the point where impairment ends and disability begins.

Introduction

The emergence of the social model of disability has led to heated debates over the origins and nature of disability (Snyder and Mitchell, 2001). It has been described as too simplistic, a political doctrine rather than a scientific model (Shakespeare and Watson, 2010, Thomas, 2010, Scambler and Scambler, 2010) and a model that essentialises the social dimension over physical and psychological aspects of impairment (Corker 2002, Terzi 2004). It has also been criticised for the tendency to construct disability as a form of social oppression, "It assumes what it needs to prove: that disabled people are oppressed" (Shakespeare 2010, p.270), a position that is hard to sustain when it comes to emotional or psychological impairments (Thomas, 2010, Shakespeare and Watson, 2010).

Central to these criticisms, it has been argued that the social model of disability has failed to fully grasp the importance of impairment (Morris 1998). Impairment has been defined as; "[…] lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body" whilst disability is viewed as produced by society rather than something within, or a product of the body, and imposed on top of impairment (UPIAS and Disability Alliance 1975). There is a reality to disability that comes from impaired bodies that is hard to deny and the experience of particular impacts are highly nuanced and personalised (Crow 1996). More recently there have been moves to acknowledge this in research (Thomas 2010). Acknowledging impairment and more importantly opening it up for closer inspection has several important consequences; first of all, it becomes apparent that the relationship between disability and impairment needs to be made the explicit focus of research; and secondly, there is an important individual dimension to impairment (Shakespeare and Watson, 2010). The disability rights movement have made noticeable progress in challenging discrimination and marginalisation and linking civil rights and political activism through issues such as housing, work, transport, education, finances, and disabling barriers, which exclude

disabled people from fully participating in mainstream society (Barnes and Mercer 2010). Yet, despite these gains, it is now recognised that there is a need to go beyond the current overly dichotomised approach (Shakespeare and Watson, 2010).

One attempt to overcome this dichotomisation is the use of the term 'Impairment effects'. Impairment effects are defined as "*the direct and unavoidable* impacts that impairments (physical, sensory, intellectual) have on individuals' embodied functioning in the social world. Impairments and impairment effects are always biosocial in character [...]" (Thomas, 2010, p. 37). 'Unavoidable impacts' imply that even if social barriers were removed, which the social model of disability suggests as a necessary condition for removing disability, then the impact of impairment would still remain. The concept of impairment effects seeks to make room for impairment within disability studies (Thomas 2010, 1999). They can be explored by looking at "factors and processes which serve to restrict activity ('doing'); and factors and processes which undermine psycho-emotional well-being ('being') (Thomas 2010, p.37).

In contrast to the aims of disability studies in considering impairment effects, the majority of dental research tends to simply report on emotional and functional dimensions (Macentee and Stolar, 1994, Macentee et al., 1997) without detailing the relationship between impairment and disability or between private and social dimensions of meaning. As a consequence, there is a risk that the approach in oral health science has not adequately considered the historical and social conditions that have combined to shape the experience of oral disease. Likewise, this field of research has yet to adequately consider how the social model of disability might be applied to garner a better understanding of oral conditions.

One particular oral condition that receives very little attention is that of dry mouth. Dry mouth affects one quarter of adults and forty per cent of older people (Nedefors et al., 1997, Pajukoski et al., 2001). It can be a severe condition where lack of lubricating saliva manifests as discomfort, soreness and the reduced ability to speak, chew, swallow, taste or sleep. It is also associated with

persistent dryness, risks of infection in the oral mucosa, decaying teeth, and inflammation of the gingivae. The most commonly accepted definition of dry mouth is "[…] the subjective sensation of dry mouth" (Orellana et al., 2006). Although this definition appears to minimise dry mouth, the condition has been described as "an aggravating misery"; resulting in the most profound impacts on quality of life (Folke et al., 2009). Profound functional impairments have been described as a consequence of the condition including; continuous oral discomfort (Thomson et al., 2006), burning mouth (Ni Riordain et al., 2010) eating and speaking difficulties (Napeñas et al., 2009), problems with wearing dentures (Ikebe et al., 2005), and deteriorating oral health as a result of the dryness (Folke et al., ibid). Folke's study in particular, also describes how some people withdrew from social life, not as a result of society's perceptions of their dry mouth, but as a direct result of the severe and persistent impact that dry mouth had upon their oral health and oral health related quality of life.

Using the social model of disability and the concept of impairment effects may enable us to view an existing condition in a way never previously considered. Furthermore, impairment effects may enable us to explore the tensions that exist between the social model of disability and impairment. We decided to use empirical evidence about the often overlooked condition of dry mouth in order to tease out these tensions.

Method

The aim of this study was to explore people's subjective experiences of dry mouth. A purposive snowball sample was drawn from one national association and one support group described below, and within a network of the research team's institution self- identifying as experiencing dry mouth. Participants were self- selecting and an initial screening questionnaire was used to assist in grouping participants in order of severity. Data was then collected by face-to-face open-ended interviews. Participants were all over eighteen years of age. A range of experiences were collected with participants having had dry mouth from two to twenty years.

Eighteen participants were interviewed; two males and sixteen females. Six participants (four female, two male) were recruited from the 'British Sjögren's Syndrome Association' (BSSA) which supports people with a chronic autoimmune syndrome in which invading lymphocytes attack moisture-producing glands of the body, causing symptoms such as vaginal dryness, dry mouth, throat, and eyes (Daniels and Fox 1992). The remaining twelve people reported dry mouth with no additional co-morbid symptoms.

Ethical and research governance approval was obtained from the University of Sheffield Research Ethics committee. An aide-mémoire was used to guide the interviewer and help maintain focus (see Appendix 1). During the interviews terms like dry mouth and dryness were only used whenever the participants made reference to the symptoms. Participants were initially asked about their experiences relating to their mouth. The interviewer used probes and clarification to elicit a clearer and more detailed understanding of the participant's experience of dry mouth. The interviews were transcribed verbatim as soon as possible after the interview and the tapes destroyed after transcription as requested by participants. Anonymity of participants was preserved by avoiding identifying information where possible during the interviews and excluding any further identifying information from the transcripts. Participants were given pseudonyms to protect their identity.

Data Analysis

A thematic experience analysis was carried out on the transcripts and field notes (Reissman 1993, 2008, Bold 2012), which focused on the participants' accounts of their lived experiences of dry mouth (Squire 2008). This style of analysis whilst identifying themes within the data also sought to contextualise them (Gubrium and Holstein 1997, 2009), and focused on the relationship between people's stories and the quality of their experiences (Clandinin and Rosiek 2007). For example, people with dry mouth provided stories where they described and reflected on the changes in their lives. Analysis used the social model of disability as a lens through which to view the data. We also, however, viewed dry mouth as a category of impairment which is similar to Thomas (2007, p.14),

who argued that 'chronic illnesses/diseases' are categories of impairment. It is important, however, to acknowledge that the experiences of adults with dry mouth also include what Thomas (1999, 2007) referred to as 'impairment effects' – for example the necessity to undertake daily procedures for dry mouth, sometimes during working hours, or during socialising (dining out or interacting socially). We also drew on accounts in the illness literature (Bury 1982, Bury 1991, Bury 2001, Williams 1993, Williams 2000, Pinder 1995, McRae 1999) to identify evidence of public and private accounts in relation to dry mouth (Cornwell 1984). Our reasoning was that these accounts can help decipher where the structural dimension to illness accounts might begin (Gibson and Boiko, 2012). In some respects then we sought to explore how and when the impairment effects of dry mouth were entangled within a social dimension. We were also interested in tracing the places and spaces where the social model of disability might become relevant to explain some experiences with dry mouth.

Dry mouth, impairment effects and the social model of disability

Impairment effects around speech, sleeping, work, eating, and self-care were prominent in the data. What we found however was that it became quite difficult to accurately assess the boundaries between impairment effects which restricted activity and participation; "doing", and impairment effects which undermined psycho-emotional well-being; "being". In what follows we aim to illustrate how the various impairment effects in relation to dry mouth had private and public dimensions. As we shall see, these dimensions became increasingly important in demarcating the boundary between private impairment and those dimensions of impairment which were inherently social and where some social action might be beneficial.

Negotiating work; dry mouth, impairment effects, and identity

The ability to negotiate their working environment was important for some participants. Some discussed the barriers to different types of work, and, in particular, having to alter their expectations of what they wanted to achieve.

> **Sally:** *"[…It has stopped me from a lot of things...you know.... urm… (pauses) yeah anything that involves... painting... because I used to do a lot of work but the chemicals makes your mouth dry... so I don't paint ... just draw with a pencil now...and colour with crayons so that's gone...obviously the singing... people say I have a nice voice but I can't maintain it for long...that's the problem...urm (pauses) also ...talking… you know ...I used to do assistant teaching […]so your dreams and aspirations of what you wanted to be...are not gonna happen... [...]." (p. 14)*

Sally's dry mouth had direct and unavoidable consequences for what she could and could not do. These impairments effects are also effects on her 'doing' and 'being'. They are, however, almost exclusively private. Her inability to paint anymore and the problems she has with singing are personal losses. The personal nature of this account and the impact of dry mouth is striking. In fact, most of the narratives concerning the impact of the condition were striking because they were inherently personal. So whilst work is often described as one of the key arenas where people express their identities (Christiansen 1999), it is simultaneously a place within which people may deal with who they are and who they might become (Watson 2008). Within this arena, people may experience impairment effects. The problem is that the impairment effects of dry mouth are almost entirely 'silent'. This stems from a condition without a recognised social dimension and is determined by the collision of impairment effects with the structure of their work, and subsequently individuals experience a 'robbing' of their identities. In this case, we have a work environment that involves working with chemicals which exacerbate the impairment effects associated with dry mouth. It is well established that occupations are a source of gaining social approval and displaying

competence through 'impression management' (Goffman 1959). Work is therefore to some extent defined by norms structured by the institutions and organisations of society which individuals negotiate, but which as we can see assign different levels of meaning (Castells 1997). There is something very poignant about Sally's private loss as a consequence of dry mouth, and yet can it be realistically argued that these losses are a consequence of some failure of companies to provide odourless paints to enable people like her to maintain their work. More significantly, by studying her loss as a private loss are we perhaps being reminded of a boundary around which action could be taken?

Take the case of sleep, or lack of it that can happen with a dry mouth, which can impact on work, or the ability to work. In the following examples, the range of impacts in relation to sleep varied from not waking to waking up to five times a night.

> **Kath:** *"[...] I always have a drink beside my bed and I probably wake up… it depends… sometimes I might wake up… 4 or 5 times a night to have a drink or you know it depends it might even be just a couple[…]"* (p.1)

Having to wake up to five times a night might be considered severe, but sleep deprivation also has a profound impact on performance and psycho-emotional well-being (Orzel-Grylglewska 2010, Pilcher and Huffcutt 1996). The following excerpt from Lizzie indicates how impairment effects clash with important social conditions. In essence this is the space where private and public worlds may collide.

> **Lizzie:** *"[…]the thought process and I know that my concentration is shattered because I'm not sleeping through the full 8 hours because I'm waking up 5 times to have a drink… so it does have an impact[…]" (p9) "my sleep is affected… and I would say that is probably the main issue. Because when you are sat in the office, the tiredness…" (p.10)*

Norman gave up work because he could not cope with the extra mouth maintenance and concentrating on work.

Norman: *" [...]and you just can't go for your natural sleep, […] I used to love my sleep...and now this is interrupted by maintenance ...you feel like you are robbed [...] interrupts the sleep and the potential of going to sleep[...]sleep is a gift...." (p.8)*

In these excerpts the maintenance of the mouth resulted in disrupted sleeping, in four other examples people reported 'choking', and 'gagging' in their sleep which they described as the 'panicky' and 'alarming' effects of their dry mouth. These were clear examples of impairment effects that stopped people from 'doing' sleep and from 'being' rested; a disruption that brought a dramatic 'dys-appearance' which is also a private account because it is the way the body is experienced by an individual (Leder 1990). Bodily dys-appearance calls for attention and action by the individual, their family, and health care professionals. Dys-appearance then becomes transformed into a public account of dis-appearance through the diagnostic actions of medical professionals and interventions to reduce pain or cure a condition. Although in these cases it is unclear as to what type of intervention may actually enable people not to choke or gag in their sleep. Here the concept of impairment effects is useful, but it is easier to identify the boundaries as to when the private account of bodily dys-appearance becomes transformed into a public account of bodily dis-appearance through the diagnostic and curative actions of medical professionals.

What we may also need to consider is how the body appears in this relationship. There is a disparity between the social and physical surroundings that people inhabit and their embodied biological needs and capacities; people's experiences of the external world they know has become altered and ways of interacting with others have become restricted by their internal experiences of dry mouth. The conflict between the internal and external has been termed 'crisis' (Schilling 2008, pp. 16-19) because the routinised habits of daily life become contested and disrupted, with major or minor consequences that can sometimes have an impact on identity. A crisis of identity may occur when an individual doubts their capacity because their confidence in their body and their world has become compromised.

In some cases, participants experienced dramatic effects on their ability to perform at work. It is here that the social model of disability becomes useful. It can be argued that although there is an impact from disrupted sleep, the loss of Norman's identity was not because of a deskilling or an inability to carry out work-related tasks, but because of an inability to meet social expectations about behaviour within a work context. This is similar to other studies (Edwards and Straszinsky 1995, Arthur 2000, Decker et al., 2002, Moss and Teghtsoonian 2008) which document the failure of the workplace to adapt to a change in employee health status with the main priority being an early return to work. Indeed, three people in the present study gave up work because of a combination of their dry mouth, the time off for appointments, and the debilitating effects of sleep loss.

The problem for us was that it became very difficult to ascertain the boundaries between impairment effects and disability. Thomas's (2010) distinction of "being" and "doing" seemed to almost overcomplicate the situation by bringing new concepts that did not seem to add anything to our understanding of what was happening. In some respects then we have sympathy with Shakespeare and Watson (2010) who argued that these distinctions might end up over complicating an already complicated situation. This difficulty became even more acute when it came to the nature of the impacts of dry mouth on speaking.

The flow of speech; dry mouth, impairment effects, and the social model of disability

Problems with speech were common for many participants in this study. The following examples indicate the very public nature of impairments involving speech and therefore the direct influence of social barriers to those who are experiencing these impairment effects. There were also, however, more private barriers in relation to the impairment effects of dry mouth, which could not be explained by employing the social model of disability.

> **Mary:** *"[…]you have to keep stopping to talk and have your drinks, so then you lose your flow of what you're saying because you're interrupting yourself by drinking so it's taking away the*

natural flow of what used to come out of your mouth, […] but since the dryness I don't talk with the flow […] it has spoilt that tremendously.[…]" (p.7).

Dry mouth clearly inhibits Mary's flow of speech; her account indicates that in some respects she expected the interviewer to be able to identify with the problems that could result from this lack of flow. In this respect then she seems to be indicating that such 'flows' are part of what we would expect and that having to stop and drink in the middle of speaking would inhibit this activity both for herself and for others. In the next example, Freda's account of her experience with dry mouth seemed to indicate an acceptance of medicalised and societal discourses about dry mouth.

Freda: *"my mouth gets generally dry when I talk to someone… you know…and then occasionally I get some pain...which is only occasional because it comes and goes…like I got to pay attention for my sudden dryness…like if it is too dry it makes me cough you know… […]." (p. 11).*

Six participants discussed the difficulties of trying to speak, the tiredness associated with the continued effort, in terms of their psycho-emotional well-being with words such as 'embarrassing', 'upsetting' and 'frustrating'. Hilda uses all three words in her account:

Hilda: *"[…] It's a bit like having a very sore throat [...] you keep trying to swallow […] it is a horrible thing to have... […] Even now I've been talking for a while and it's becoming worse so I need to spray my mouth or suck a lozenge... I find it… it makes me very tired […]... It's upsetting and frustrating and also embarrassing... It's very embarrassing... […] If it's particularly bad you know and I think that it's dry all the time there isn't a minute of the day when it isn't dry...* […]" (p 1-2).

As soon as we open our mouths we are subject to value judgements by others (McArdle 2001). These judgements may be related to our accents, vocabulary, or level of verbal articulacy. People with dry mouth experience a hidden impairment because it is not until they begin to articulate that

their impairment becomes obvious. It is important to note that there is almost a complete failure in the oral health related literature to acknowledge the potentially discrediting nature of impacts on the flows of speech. Speech is an intensely social experience, it is therefore almost entirely public, when someone stumbles or slows because of one impairment effect or another it can have a devastating consequence for their identity (Goffman 1961).

One qualitative cross sectional study identified that people with communication impairments felt that they were more likely to experience barriers to schooling, employment, and relationships (Parr et al. 1997) and many people felt detached and isolated as a result of their interactions and their encounters with different people's attitudes. In this study, nine people with dry mouth also reported feeling socially isolated and preferred to restrict their social circle to people who knew them and accepted their difficulties associated with dry mouth. We can relate this to the social model of disability and how society views people who do not conform to accepted levels of articulacy, but we can also use Thomas's concept of 'impairment effects because in this case we have unavoidable impacts relating to dry mouth. However, we struggled to identify where the boundaries between impairment and disability lay in these cases.

One example of our struggle is documented in the notes whilst carrying out the early stages of the thematic analysis.

> **Analysis 1:** "One issue is trying to consider the barriers in relation to impairment effects of dry mouth. This is proving difficult to explain by employing the social model of disability, and again by separating impairment from people's experiences. For many participants the need to integrate self-care routines into their daily and working lives is an inescapable everyday consequence of having dry mouth. It is an impairment effect not a socially imposed restriction. Using the social model of disability means that we would not focus on individual experience or illness because it moves the focus away from social structures that create barriers. The experiences of people with dry mouth would then become marginalised

because they would be missing from the social model discussion. Using work as an example we can use the Equality Act (2010) to support our case but it becomes difficult to identify exactly when impairment becomes disability and when disability becomes impairment. ”

Eating; dry mouth, impairment effects, pleasure and hardship

All twenty-two participants linked eating, and eating out, to socialising and the impact that dry mouth had on what was once viewed as a pleasurable event.

> **Norman:** *“To avoid disruptions, when you’re out in a restaurant, so you then adopt what’s on the menu to suit your mouth rather than what you’d like[…] you end up adapting and changing things and it becomes laborious and you lose the enjoyment factor* (p.8)

> **Lizzie:** *“[…] but often when I have a meal out...urm...I started asking for...like the jug of water... which is sort of thing that the British don’t very much offer with the meal….in fact in France when you eat you often get a jug of water...Eating is the thing that comes first…and then its social…and then finally…interacting with people […].” (p.10)*

There are two dimensions here in relation to impairment effects; the first relates to the embodiment of struggling to eat foods and how this affects people in social situations. Here, food is not just simply eaten; the consumption of food is shaped and conditioned by symbolic meaning, and social practices: ‘a shared meal has cultural importance in terms of intimacy, group identity, socialisation, initiation, and reinforcement of hierarchy’ (Corbett 2009, p.89). The second dimension is concerned with how impairment effects associated with chewing and swallowing are in opposition to the accepted level of moisture in meals. Here, there is an increased salience of issues relating to the experiences of people with dry mouth and their relationship with food. For some, dining-out became an ordeal rather than something to be enjoyed. What should be a bodily pleasure has in some cases become a bodily hardship for people with dry mouth.

Disabling practices; dry mouth, impairment effects and culture

Some people mentioned surveying the social arena in order to feel comfortable when at events, or how they felt robbed of time through self-care, bouts of ill health, daily treatment, and regular medical interventions.

> **Rosemary:** *"[…]it was just too exhausting to do anymore...it was a difficult time […]....it was dealing with the medication the side effects of the medication as well as family and so on and it was very very hard....and there was less time I had to worry about myself because then it was too much...it was like really the first ten years they were practically lost years to me...because it was so exhausting and I lost those ten years more or less...[…]"*

Rosemary's excerpt clearly outlines impairment effects; if we address any social barriers away for Rosemary the effects and impact of her impairment on her everyday embodied functioning in her social world would still remain. In this case the social model of disability and its focus on social oppression is of little use. If we now turn to Brenda who talks about the impact of dry mouth but then discusses the impact of the social arena:

> **Brenda:** *"[…] I get very tired...and the impact that it has on life… it's called the robbing disease...it robs your time with maintenance [...] if an Essex girl spends two hours to put her make up on … I'm not an Essex girl, I have to spend hours just to sort of look normal […] when you are at a wedding or something like that you have to stay clear of the flowers...because you get flowers at the wedding you know...they are gonna set you off dry mouth...and prickly eyes so you tend to look where its less fussy...so I end up near the door...or somewhere where nobody wants to sit...because its less fussy...so you look and case the joint as they say […]". (p.11)*

The presence of flowers at a wedding whilst being culturally acceptable, and in some cases associated with emotions, had a direct impact on Brenda because her dry mouth was exacerbated

when close to flowers, making her extremely wary of flowers at weddings. She was clearly adapting to the social space at the wedding seeking out spaces that were 'less fussy'. In order to participate, Brenda was forced to survey the social arena and sit where the flowers would not escalate her symptoms; what was culturally acceptable and indeed desirable was disabling for Brenda.

As a consequence, Brenda emphasised being 'robbed of time' because of the additional practices involved in maintaining her mouth. Here, impairment effects clash with important social conditions in essence where the space of private and public worlds may collide. In these spaces the impairment effects are almost entirely private; the assumption that there will be flowers at a wedding seems so obvious that it is not contested. As a consequence Brenda does not challenge anything about this because she is adapting to social norms. This is critical, her public account indicates that not only is it to be expected that there should be flowers but that it is envisaged that everyone should adapt to this social norm. If we use the social model of disability then we could claim social oppression but, we can also argue that it is not productive to explore dry mouth in this way. In this respect the concept of impairment effects becomes of greater use, but only when we look closely at where they appeared whilst simultaneously tracing the manner in which the private and public dimensions of accounts of these effects were handled by those concerned.

Discussion

This analysis of dry mouth has explored the emergence and appearance of impairment effects in relation to dry mouth. In so doing we have sought to trace how these combine within the accounts given by those experiencing these effects to observe what this means in terms of either a private problem or a public concern. Existing accounts of dry mouth within dentistry almost completely neglect to explore these social dimensions even though we are aware that it affects one quarter of adults and forty per cent of older people (Nedefors et al. 1997, Pajukoski et al. 2001). Dental research has so far failed to recognise that there are important social dimensions to the embodied experience of dry mouth. Even though dry mouth is widely accepted by the dental community,

people experiencing it must negotiate significant areas of uncertainty in relation to how they manage their lives, identities, and how their illness is viewed by others. Furthermore, there have been no attempts to expose this problem and even less to try and support people with the diagnosis, making it appear that dry mouth is a contested illness of little consequence.

Nevertheless, what we have to be careful of here is not to conflate disability with illness, and if we suggest that dentistry focuses on impairment and disability as illness then we run the risk of portraying all people with dry mouth as suffers who as a consequence need constant medical surveillance and intervention. Furthermore, it would be inaccurate to claim that everyone with dry mouth experienced being continually unwell because this does not take into consideration variation between people with dry mouth. What the biomedical accounts in dentistry fail to consider is how the individual self experiences impairment and disability. Interpreting not only the symptoms but also including patient descriptions of bodily sensations may improve the diagnostic categorisation of dry mouth within dentistry.

What we have found within this study is that identity and the individual self became entangled with the concept of impairment effects and a form of disablism. Just what this actually is, is a key question that remains to be understood. Contrary to the assertion of some disability activists as 'giving too much weight to subjective meanings and too little attention to wider structural forces' (Barnes and Mercer 1996, pp., 5-6), by analysing the public and private dimensions of living with the impairment effects of a chronic condition such as dry mouth we can observe the direct disabling consequences of the individualism that lies at the heart of managing one's mouth.

Nettleton (1988, 1992) has demonstrated that the history of the mode of governance of the mouth is generally associated with the history of changes in the mechanisms of power that moved from sovereign to disciplinary mechanisms to identity maintenance. In other words, the dominant mode of mouth maintenance is through individualised mechanisms. In some respects then, it is not surprising that when we encounter situations where impairment effects associated with the mouth

clash with public assumptions about orality; that those who experience the most profound impairments appear to accept that these are *their impairments* and that this to some extent revolves around personal responsibility for the illness. People with dry mouth appear to be involved in permanent self-care routines at the level of self which makes the impairment effects of dry mouth highly salient, whilst their public identity may change in terms of the obviousness of the disease to others.

Social model advocates argue that focusing on individual experiences of illness or impairment moves the focus away from societal structures highlighted by the social model of disability (Barnes 1998). Yet here without focusing on these impairments and how they make a public appearance we would not be able to determine that when it comes to the impairment effects of the mouth we are in fact looking at largely hidden modes of disability. For people with dry mouth, barriers to employment are firmly linked to the impairment effects, but also intersected with the social model of disability, so for many the only solution was to give up work. In some respects then there is a need to raise awareness of the impact of dry mouth on people's experiences. The employment of people with dry mouth needs to take into consideration the accommodation of bouts of ill health, daily treatment, and regular medical appointments. Employing the social model of disability as a lens means that we could suggest that it may be difficult for people with dry mouth who experienced a high level of impairment effects to claim the status of 'disabled' in place of 'sick' in the workplace. What could be considered is the phrase 'reasonable adjustments' from the Equality Act (2010) to appropriately accommodate the impairment effects of dry mouth by making the work environment more flexible; extended time allowed for personal care and medical appointments, and a general awareness of the uncertainty of the condition for people.

By considering impairment effects in relation to dry mouth, then, we have been enabled to explore the boundary between public and private lives. Being aware of the public accounts direct the focus towards the potentially stigmatising effects of illness. For example, speech was affected in varying

degrees for all participants with dry mouth; some people lost the ability to articulate and this resulted from their dry mouth. The difficulties associated with speech in everyday life can be discrediting (Goffman 1961), and assumptions can sometimes be made about those who appear to possess verbal skill deficits as marking the absence of intellectual proficiency (Edgerton 1967). Participants highlighted the reactions of others to their impairment; many preferring to restrict their social circle to people who empathised with their condition, and who they did not have to explain their inability to communicate fluently. Not only can "a word without saliva" be "a word without pleasure […] like living with a drought" (Sreebny 2000, p. 141), it may also lead people to mistrust the situation, themselves, and others and eventually lead to withdrawal from social contact (Folke et al. 2009). By becoming aware of these effects we might be able to raise awareness of the impact of the condition amongst professionals and the public.

Another public space that we might like to focus activity on is associated with eating as a form of entertainment, self-presentation and a mediator of social relations (Finklestein 1989). The socially accepted practices and customs associated with eating may differ from culture to culture, from environment to environment, and from food to food (Mintz and DuBois 2002). Within this study, impairment effects associated with chewing and swallowing seemed to grate against the assumptions about levels of moisture in meals and how certain styles of cooking contain more moisture. Other styles of cooking do not contain enough moisture which can be disabling for some people with dry mouth. Menus that identify meals that have sauces or high moisture content are an obvious area that might be considered worthy of more attention.

The importance of considering the public and private dimensions associated with impairment effects and how these might intersect with disability demonstrates that oral health related research needs to move beyond the dominant medicalised approaches which tend to focus purely on individual experiences and impacts. The principal risk of the present approach is that it may well reinforce the hegemony of management of the mouth in that oral conditions are problems to be managed by

individuals experiencing them. These problems will remain problems that society should not concern itself with; as non-problem problems (Gibson and Boiko 2012). In this respect, then, the wider social status of the mouth conditions the degree to which oral problems are seen as social or individual problems. For example, in the case of dentine hypersensitivity these accounts resulted in assessments that it was a non-problem problem, one that required self-care (Gibson and Boiko 2012). Such research indicates that there may be important social dimensions to oral conditions that we have yet to explore. We need to recognise that if we do not explore the social dimensions then we may be engaging in research that constructs disabling barriers. Recognising this need is an important step in moving towards a more detailed awareness of the relationship between oral conditions, the social environment, and how these relate to embodied functioning in everyday life.

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Appendix 1

Interview Aide-mémoire

HISTORY, ONSET, PROGRESS, PERCEPTIONS, LAY BELIEFS

- **How and when did you notice** it FIRST?
- **When did it start**?
- When does it **come/ go? How often?**
- **How long** does it last?
- **How has it changed** over time?
- **When** is it **better/ worst**?
- Explain the **feeling of dryness**?
- What ASPECTS OF YOUR **DAILY ROUTINE** are affected?
- **BOTHERSOME** to you?
- **EMOTIONAL REACTION** to this dryness?
- **DIFFICULTY** - it is?
- **DIFFERENCE** felt when **present/ absent**?
-

Impact on DAILY LIFE – FUNCTIONAL LIMITATIONS

- How are your **daily activities limited?**
- **Do they prevent you** from doing things? (**EATING, SLEEPING, SPEAKING, BRUSHING, SWALLOWING**)
- Do they **restrict your social life or taking part in things**?
    - **Visiting friends**, others etc
    - **Dinner parties** (forget - **speaking w/o frequent sipping of water** etc.)
    - **Discussed them with friends**?
    - **What do they think**?
- Are you **worried that you can't do things** because of dryness?
- **Do you do anything to prevent** feeling dry?

- **How do you relieve dryness**?
- What **care product** do you use? **Has it helped**? **(Any Specific TOOTH PASTE?)**
- **Did you discuss it with your Dentist**? **When? Why**? Has it helped?
-

GENERAL HEALTH PERCEPTIONS and OVERALL QUALITY OF LIFE

- Made **difference in the way you live**?
- Has it **changed the way you look at mouth** in general?
- Does it **affect you overall**?
- Has it **made you feel ill**?
- Is it a **nuisance or a problem in your life**?
- Does it **make you feel miserable, irritable and depressed**?
- Does it **make you feel different from others**?