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**Measuring the symptomatic, physical, emotional and social impacts of dry mouth: a qualitative study.**

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Keywords:	Dry Mouth, Quality of life, Qualitative research, Xerostomia

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3 **Measuring the symptomatic, physical, emotional and social impacts of dry mouth: a**  
4 **qualitative study.**  
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10 Running title: Measuring the impact of dry mouth  
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## Abstract

### Objective

To explore the impacts of dry mouth in order to develop a comprehensive condition specific OHRQoL measure.

### Background

Dry mouth has been shown to have significant, if not more severe impacts on OHRQoL, than dental caries. Yet there remain few studies reporting on how to develop a comprehensive measure of the impact of dry mouth on OHRQoL.

### Methods

This study was a qualitative study using semi-structured interviews. Data were collected from a purposive sample of 17 people with dry mouth (14 women, 3 men). The sample was drawn to capture a comprehensive range of impacts of dry mouth. These interviews were analysed using a framework approach informed by existing functionalist approaches to OHRQoL.

### Results

Participants reported a huge range of symptoms associated with perceived dry mouth resulting in extensive impacts on physical, emotional (psychological) and social functioning. Dry mouth could also result in restrictions in social participation which, under some conditions could be disabling. These impacts were modified by psychological, social and environmental factors.

### Conclusions

If we are to measure the impacts of oral conditions it is important that this is done systematically and with reference to existing conceptual models of health. Current measures of the impact of dry mouth cover symptoms, discomfort and physical impacts along with some aspects of how people cope with the condition. This study proposes a more comprehensive approach that includes the full range of impacts people experience. Such an approach may enable us to focus on 'downstream' and 'upstream' interventions for dry mouth.

**Keywords:** Dry mouth, qualitative research, Quality of life, Xerostomia

## Background

Xerostomia can be defined as “the subjective sensation of dry mouth” and can occur even in a moist mouth<sup>1</sup>. It can be multifactorial and complex and is distinguished from salivary gland hypofunction (SGH) which refers to a “reduced unstimulated or stimulated salivary flow”<sup>1</sup>. Dry mouth may therefore be a perceived symptom of the SGH seen in systemic diseases including rheumatoid conditions such as Sjögren’s syndrome, endocrine (e.g. diabetes), neurological, and immunological disease. Xerostomia may also be perceived as a side effect of radiotherapy. Many drugs including antidepressants and diuretics may produce SGH<sup>2,3</sup>. Local causes xerostomia are mouth breathing, which may be chronic or transient, for instance during a cold. Non-salivary causes of SGH are much less common but may involve altered sensation and xerostomia in psychogenic disorders and cigarette smoking<sup>3-5</sup>. The aetiology of the condition can therefore be complex because of the interaction between psychogenic disorders and treatments for these disorders.

SGH is important because it can result in the oral cavity becoming more susceptible to gingivitis and mucositis including cracked lips along with atrophy and peeling, a dry irritated reddened tongue, periodontal disease and halitosis. There may also be altered taste perception. SGH also causes tissue friability in denture wearers due to lack of lubrication and reduced denture retention. The reported prevalence of xerostomia ranges between 10 and 47 %, with the condition being more common in older adults and women<sup>1,6,7</sup>. Long term xerostomia increases the risk of dental caries and erosion<sup>3,5</sup>. It is an important and problematic condition because it can have a significant impact on everyday life.

The typical approach to measuring the daily impacts of oral conditions is through the use of Oral Health Related Quality of Life (OHRQoL) instruments that document the ‘symptomatology’ or range of impacts of oral conditions on everyday life. The next sections of this paper evaluates the degree to which existing measures of the impact of xerostomia are comprehensive in evaluating the everyday impact of xerostomia on OHRQoL. This is achieved by first of all examining if existing measures adequately cover the range of concepts associated with predominant models of OHRQoL, that is the purpose of the next section.

### Measuring the impact of perceived dry mouth on OHRQoL

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3 Oral health related quality of life has been defined as the impact *“of oral disorders on*  
4 *everyday life that are important to people and of sufficient magnitude to affect perception of*  
5 *their life overall”* <sup>8</sup>. The impacts of oral conditions have been measured through disease  
6 specific measures including the OHIP <sup>9-11</sup>, ODP <sup>12</sup>, OHQoL-UK <sup>13</sup>, and the GOHAI <sup>14,15</sup>. There  
7 has also been a growing number of even more condition-specific measures in OHRQoL  
8 research. These include the Dentine Hypersensitivity Experience Questionnaire (DHEQ) <sup>16</sup>, the  
9 Xerostomia index (XI) <sup>17-19</sup>, The Xerostomia Questionnaire <sup>20</sup> (XQ), and the oral health impact  
10 profile for assessing health-related quality of life in edentulous adults (OHIP-EDENT)<sup>21</sup>. The  
11 development of these indices reflects the need to be able to measure the effectiveness of  
12 targeted interventions, as well as being able to detect appreciable changes over time. It is  
13 also important to be able to establish changes that make a difference to patients<sup>22</sup>.

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24 **Perceived dry mouth** has been found to be associated with worse OHRQoL <sup>18,20,23-27</sup>. Although  
25 the indicators used to measure such impacts vary dramatically in their construction and  
26 comprehensiveness. Ikebe et al <sup>26</sup> used a single item score with a yes no response to the  
27 question ‘Does your mouth feel dry when eating a meal?’ Clearly such a question is not  
28 designed to establish the full range of impacts of perceived dry mouth on everyday life. It is  
29 very likely that other impacts may be happening and these may be of more importance to  
30 patients. Most studies into the perceived impact of dry mouth on OHRQoL <sup>20,23-25,27</sup> have used  
31 either the Xerostomia Questionnaire (XQ) developed by Pai et al. <sup>28</sup> or the Xerostomia Index  
32 (XI) developed by Thomson et al. <sup>19</sup>. **Here again the degree to which these questionnaires**  
33 **comprehensively measure the full range of impacts of perceived dry mouth can be**  
34 **challenged.** If we map the items on these questionnaires into the common domains  
35 associated with conceptual models of health <sup>29-31</sup> we can see how various domains are either  
36 covered or not by these indices (See Table 1).

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48 <Insert Table 1 about here>

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50 As we can see from Table 1 the Xerostomia Index (XI) <sup>6,17</sup> focuses principally on symptoms,  
51 physical limitations and coping. Respondents are asked to choose responses such as “Never”  
52 (1). “Hardly ever” (2), “Occasionally” (3) “Fairly often” (4) and “Very often” (5) for 11 items  
53 which include the following:

- 54 1. I have to sip liquids to aid in swallowing food;
- 55 2. My mouth feels dry when eating a meal;

3. I get up at night to drink;
4. My mouth feels dry;
5. I have difficulty in eating dry foods;
6. I suck sweets or cough lollies to relieve dry mouth;
7. I have difficulties swallowing certain foods;
8. The skin of my face feels dry;
9. My eyes feel dry;
10. My lips feel dry;
11. The inside of my nose feels dry.

We can see that each of these indices are not designed to cover all of the domains in models of health. Some items in the XI refer directly to symptoms related to Xerostomia (2, 4, 8, 9, 10, 11 above) whereas others refer to specific coping strategies (1, 3, 6) as well as functional limitations (5, 7) some of which are symptomatic (2). What this means is that there is, as yet, no OHRQoL instrument available to measure, comprehensively, the full range of impacts that might accrue from xerostomia.

### **Why is this important?**

Developing *comprehensive condition specific measures* is in keeping with similar strategies adopted in other fields<sup>22,32,33</sup>. In arthritis it is established practice to have items that refer to very specific conditions, diagnostic groups, and/or specific problems that have been deemed of importance to the population group under investigation. The nature of items and impacts are however not the only things to consider. Other considerations for quality of life instruments include the need for brevity, responsiveness to change and, where relevant, coverage of the relevant constructs associated with an underlying theory of health<sup>22,33</sup>. In terms of brevity the XI and XQ are both designed in such a way that they might be used alongside generic measures of OHRQoL because they are short and to the point.

The XI has been used alongside existing OHRQoL measures. Locker<sup>23</sup> found that the XI had good construct validity, predicting chewing problems with an odds ratio 0.92. Locker pointed out that although the index was “ad hoc” it was significantly associated with all five functional and psychosocial measures and so it had good construct validity, good internal consistency and reliability<sup>23</sup>. Further work by Thomson<sup>17</sup> confirmed that the XI had good concurrent and temporal validity. Locker also *discovered that Xerostomia was found to be as good a predictor,*

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3 *if not a stronger predictor, than dentate status of OHRQoL* measured by the shortened form  
4 of the OHIP and the GOHAI <sup>23</sup>, having much more profound and extensive impacts than dental  
5 disease, something we will return to later. It may be that there are more extensive impacts  
6 from perceived dry mouth that have yet to be fully explored and measured. **One way to**  
7 **determine if this is the case is to explore existing studies on the everyday impact of xerostomia.**  
8 **The next section reports on such an analysis.**

### 14 **Qualitative studies on xerostomia**

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17 Several qualitative studies have explored the experiences of xerostomia <sup>7,34</sup>, Sjögren's  
18 Syndrome <sup>35</sup> or oral discomfort <sup>36</sup> more generally. Rydholm and Strang <sup>34</sup> conducted semi-  
19 structured interviews with 16 terminally ill patients with advanced malignancies. Their  
20 interview guide is developed from the literature and their clinical experience in working with  
21 patients with perceived dry mouth as a consequence of advanced cancer and associated  
22 treatments. These interviews were not developed with systematic reference to existing  
23 theories of health, nonetheless they provide information about the personal, social and  
24 psychological impacts of perceived dry mouth in patients at the end of life. Patients' reported  
25 terrible subjective discomfort, feeling like there was sandpaper in their mouths, as well as  
26 having dry vocal cords. They experienced a weak voice, tiredness when speaking, difficulties  
27 with eating because of dryness with chewing and swallowing taking a long time. They also  
28 experienced problems sleeping because of the need to wake up and drink water (coping), this  
29 added to their tiredness <sup>34</sup>. There were also additional impacts on their psychosocial wellbeing  
30 including losing pleasure in eating, disappointment, exhaustion, embarrassment, and shame.  
31 Some patients eventually withdrew from social contact, which in turn led to social isolation  
32 and stigmatisation. Although these impacts are extensive it would be difficult to claim that  
33 they can be separated from the underlying conditions these terminally ill patients were  
34 experiencing.

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37 Rohr et al. <sup>36</sup> also examined the experience of perceived dry mouth in terminally ill patients,  
38 finding that the discomfort from xerostomia could get completely 'out of control'. They go on  
39 to describe the physical and psychological 'discomforts' experienced by their participants  
40 alongside some of the coping strategies they had adopted, for example, getting up at night to  
41 drink water which in turn led to increased tiredness. Ngo et al <sup>35</sup> used diary methods alongside  
42 semi-structured interviews with 10 patients with Sjögren's Syndrome. Their interviews were  
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3 open ended and data analysis used a thematic approach. These findings focus on reporting  
4 the coping mechanisms participants used in their journey to diagnosis as a consequence of  
5 general functional impacts. Whilst physical, psychological and social impacts were reported,  
6 they did not focus on providing a detailed or systematic evaluation of the various impacts  
7 associated with perceived dry mouth. They argued that although the impacts were severe and  
8 multiple they were closely related to each other and it was difficult to separate them into  
9 discrete entities. An additional complicating factor was that because participants had  
10 Sjögren's Syndrome as their primary diagnosis, they tended to make sense of their perceived  
11 dry mouth within the context of this diagnosis and treatment.  
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20 This demonstrates how the subjective experience of dry mouth can be shaped by different  
21 reference points. The experience in some populations groups is associated with multi  
22 morbidity. Folke et al. <sup>7</sup> developed a grounded theory to explain how participants resolved  
23 their main concerns with Xerostomia. Their core category of xerostomia as an 'aggravating  
24 misery' clearly articulates the whole series of physical, psychological and social impacts  
25 associated with the condition. Participants reported dry itchy feelings in their mouths and  
26 viscous saliva that felt like 'burned asphalt' resulting in impaired speech. They also reported  
27 problems associated with swallowing and chewing as well as significant anxiety about their  
28 general oral health and feelings of stigmatization when not being able to eat out with friends.  
29 This eventually led to social isolation. They went on to describe how health professionals,  
30 including dentists, failed to support them with their symptoms. The range of physical, social  
31 and psychological impacts was dramatic and extensive.  
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42 Finally, Owens et al.<sup>37</sup> focused on examining the 'impairment effects'<sup>38</sup> of perceived dry  
43 mouth which are effects of particular conditions that continually impact on the individual.  
44 They examined how these effects were private and therefore entirely experienced by the  
45 individual, or if they were 'public' and therefore experienced in social circumstances. Their  
46 study provides further evidence of impairments in sleeping, eating and speaking, along with  
47 restrictions in social participation as a direct result of perceived dry mouth. A consequence of  
48 this was that participants had to demonstrate vigilance when in social situations to be aware  
49 of where they might be able to get hold of water or avoid foods that they might choke on in  
50 public. Whilst this study indicates that there are wide ranging impacts from perceived dry  
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3 mouth, it focused on the social dimension of these impacts and how this amounted to forms  
4 of social disability. There was less focus on the personal discomfort resulting from xerostomia.

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7 Table 2 summarises the domains of OHRQoL affected by perceived dry mouth in each of these  
8 qualitative studies. Those studies provide a more extensive account of the range of impacts  
9 accrued from xerostomia than existing questionnaire data. They achieve varying degrees of  
10 depth and their findings are coloured by the specific focus of each paper.  
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### 17 **What do these findings tell us?**

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20 Our analysis reveals that current indicators of OHRQoL associated with perceived dry mouth  
21 fall some way short in terms their ability to detect the full spectrum of impacts associated  
22 with xerostomia. It is with this in mind that we developed a qualitative study to carefully map  
23 the impacts of perceived dry mouth in order to develop more comprehensive indicators of its  
24 impact on OHRQoL. This study was developed in preparation for the development of a new  
25 measure of the impact of perceived dry mouth on OHRQoL.  
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### 30 **Materials and Methods**

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32 This was a qualitative study using semi-structured interviews analysed using a framework  
33 approach informed by existing functionalist approaches to OHRQoL.  
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### 37 **The research team and reflexivity**

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40 The research team included two qualified dentists, a specialist in oral medicine, a psychologist  
41 and a sociologist. All members of the research team met at several times during the conduct  
42 of the study in order to check details of the findings and to make disciplinary contributions to  
43 the data analysis. The team were aware of transdisciplinary theories of health including the  
44 biopsychosocial approach that formed the background to this study. By combining these  
45 perspectives, we were able to make sure that the resulting analysis was balanced and  
46 comprehensive. This meant making sure that the analysis went beyond symptoms to consider  
47 the wider ranging psychological and social impacts of perceived dry mouth. Whilst our  
48 interest was in securing account of the broadest range of experiences associated with  
49 perceived dry mouth we also allowed participants to articulate in their own words how their  
50 perceived dry mouth had affected their lives.  
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## Sampling and recruitment

A purposive sample was drawn to capture a comprehensive range of impacts of perceived dry mouth. This involved an email to staff at a large hospital, an advertisement in the newsletter of the British Sjögren's Syndrome Association and subsequently by snowball sampling. Respondents to these initial contacts were sent the study Information Sheet and Consent Form. They were then given a cooling off period before being contacted and asked to complete a screening questionnaire adapted from the Xerostomia inventory and the European classification criteria for Sjögren's syndrome <sup>19,39</sup>. Inclusion criteria required participants to be experiencing symptoms of oral dryness (self-determined) and to be above the age of 18.

## Conduct of the interviews

Semi-structured interviews took place at venues and times to suit participants (coffee shops and own homes) and lasted from 30- 60 minutes. Interviews initially explored the experience of xerostomia and the history of the condition before going on to explore symptoms, psychological and social impacts, including limitations (See Figure 1). Where necessary, probes and clarification were used to elicit a detailed understanding of any impacts on participants' daily lives, the strategies they used to ease their situation and how their xerostomia might have changed over time. The Interviewer remained open to participants' narratives, being flexible in switching topics and allowing the participants to speak on their underlying condition. Terms like 'dry mouth' and 'dryness' were only used when participants referred to them. This was to avoid accidentally leading participants to talk about their xerostomia in particular ways and to allow them to provide the context in which it appears *for them*. Interviews were all transcribed as soon as possible after the interviews and the audio recordings permanently deleted. Participants were given a shopping voucher for £15 to recognise their contribution and time to take part. The study was given ethics and research governance approval from the University of Sheffield research ethics committee.

<Insert Figure 1 about here>

## Data analysis

Framework analysis <sup>40</sup> was used to analyse the data. This approach to qualitative data analysis is suitable when there is a pre-existing framework for data analysis. Whilst it is often used in

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3 policy circles to address specific policy questions we used it here to analyse our data for  
4 specific fit with pre-existing and well established conceptual frameworks. The basic  
5 framework we used was based on the frameworks developed by Locker <sup>29</sup> and the  
6 International Classification of Functioning Disability and Health (ICF) <sup>31</sup> developed by the WHO  
7 and Wilson & Cleary <sup>30</sup>. Each of these frameworks is based on the same underlying  
8 functionalist theory of health but each focuses on different dimensions. So, for example,  
9 Locker's model highlights the role of discomfort and pain, while the ICF highlights the  
10 importance of social participation. The Wilson and Cleary model is a comprehensive  
11 biopsychosocial template for studying health, linking biological and physiological factors,  
12 symptoms, functioning, general health perceptions to overall quality of life. Research  
13 consistently supports its value for studying oral health, including studies of xerostomia <sup>41</sup>,  
14 housebound elders <sup>42,43</sup>. In addition to this our analysis was informed by our background  
15 knowledge of the literature on chronic illness, health psychology, coping and illness beliefs  
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All transcripts were read by the core research team (KP, PR, SB, BG) who took time to think about the core themes that were developing. While the existing frameworks guided the analysis, data were not forced to fit those themes. This allowed the refinement of the framework in a flexible way that gave priority to participants' perspectives. Additionally we constantly compared data within themes and across themes and cases. Data collection and analysis were undertaken iteratively so that themes could be chased in subsequent interviews. Data collection continued until no new themes were evident in the data. This was the point at which data collection stopped. Transcripts were indexed primarily by the interviewer (KP) but the process was triangulated by three other researchers (PR, SB and BG).

## Results

Interviews were completed with a total of 17 people with perceived dry mouth (See Table 3). Although we attempted to recruit more men we were unable to do so and whilst this could be seen as a potential limitation of the study there were no observable differences between these groups. Of these, six had perceived dry mouth as part of underlying Sjogren's Syndrome and 11 had xerostomia for other reasons, for example because of chemotherapy or medication. Participants were aged between 30-80 years old living throughout England. Xerostomia had a variable impact on participants, sometimes varying quite dramatically

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3 within the same day. What became apparent is that xerostomia had a broad range of effects  
4 on everyday life that at times were quite severe. The impacts extended throughout the  
5 models we were exploring and had important biographical dimensions as well as significant  
6 impacts resulting from attempts to cope with the condition. To encapsulate these impacts we  
7 have populated the Wilson and Clearly model with additional detail. The results of this  
8 analysis are summarised in Figure 2.

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15 <Insert figure 2 about here>

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17 From the figure we can see the sheer extent of symptomatic impacts of xerostomia. These  
18 impacts could subsequently impact on physical, emotional (psychological) and social  
19 functioning. In certain situations, perceived dry mouth could restrict social participation and  
20 in certain circumstances, this might lead to social disability. The impacts of xerostomia were  
21 modified by psychological, social and environmental factors. Psychological factors included  
22 personal biography, illness beliefs, health identity, adaptation, coping and personal blame. In  
23 what follows we briefly explore each of these elements in turn before discussing the  
24 implications of these findings for current work on the OHRQoL impacts of xerostomia.

### 31 32 **Symptoms of xerostomia**

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34 Symptoms of xerostomia were extensive and primarily characterised by their persistence and  
35 noticeability. For some these symptoms were mild whereas for other they were so noticeable  
36 that they caused significant impacts on OHRQoL. Dryness resulted in a significant list of  
37 symptoms through which the condition manifested itself including “dehydrated”, “I’m  
38 gasping”, “gnawing”, “mouth is like cardboard”, “wiped off with tissue”, “an itch” and “cotton  
39 wool in your mouth” and “no mucus”. In severe cases the dryness could cause “choking”,  
40 “retching” or “gagging”. The full list of symptoms is reported in Figure 2. Some examples from  
41 the data include Coral who reported a persistently bad taste:  
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50 *“I need to clean my mouth out every time I’ve eaten otherwise I do, I’ve got*  
51 *a bad taste of coffee now. When I go home if I don’t clean my mouth out*  
52 *there’ll still be traces of coffee in my mouth”. (Coral)*  
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56 The duration also varied, with some participants experiencing it for more than 20 years and  
57 others following on from diagnosis and treatment for other conditions. There was a  
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3 suggestion that the impact could diminish with time or with age, and that people could adapt  
4 to it:  
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8 *“When I was a teenager.. I always had mints or mouth spray you know..fresh*  
9 *breath spray. But when I got older.. I just realised that... it’s not going to*  
10 *change don’t think there is anything..there is no operation that is going to*  
11 *help me and I just put up with it really..and then I got happily married I’ve*  
12 *got an interesting job.. I don’t think it has affected my life” (Richard)*  
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17 The noticeability of xerostomia symptoms fluctuated throughout the day in different  
18 situations, in the following excerpt Allan describes how it fluctuates:  
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22 *“The difference is when I ... I don’t even notice It’s a problem when I*  
23 *have...when It’s not a problem ....this is gonna sound really stupid but.. when*  
24 *It’s not a problem you don’t concentrate on it but suddenly It’s always there*  
25 *gnawing in the back of your mind....(pauses) right now I’m just gonna have*  
26 *to have a slurp..(laughs) cause I’ve realised that it gnaws at me...”(Allan)*  
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32 Crucially the symptoms varied around how ‘noticeable’ they could be, for Jane this was  
33 coupled with a constant process of managing the condition along with the effects of the  
34 symptoms *spilling over* and impacting on other important aspects of her life:  
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38 *“I’m drinking all the time.. I always have a cup of water ..I don’t notice it as*  
39 *much but anytime I go out.. if I go out in the car I always take bottle of water*  
40 *with me.. I’m always getting so dry that I need a drink.. but my worst time*  
41 *is at night because ...it.. for some reason it wakes me up.. so . I need to have*  
42 *a drink.. its just so.. its gagging.. sort of you know... just how it affects you...”*  
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47 *(Jane)*  
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50 Here we can see that for Jane it is when the symptoms spill over into threatening her daily  
51 functioning that they become more significant. Jane went on to describe that she had not  
52 really worried about her xerostomia until she started choking. This indicates that it is when  
53 the threats associated with underlying symptoms spill over into everyday life that they  
54 generate significant social and psychological impacts.  
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3 *“Well. I can’t really say that I’ve really worried about it... I really start*  
4 *worrying and thinking about it when I started with these choking.. like you*  
5 *know whether it was connected or whether it was something to do with my*  
6 *thyroid or you know.. but I did ask my GP and again she just said she didn’t*  
7 *think it would be anything to do with that so..yeah..”(Jane)*  
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13 Also note how she develops a schema to explain her symptoms. Participants therefore often  
14 talked about how the persistent symptoms would clash with the flow of everyday life as they  
15 moved from situation to situation. Night times and on waking in the morning were particularly  
16 difficult since there weren’t enough chances to keep the mouth moist when sleeping.  
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20  
21 *“When waking up in the night it’s totally devoid of any wet, wetness (sic) at*  
22 *all- (Ginny)*  
23  
24

25 *“...because I don’t take anything and wake up in the night and your mouth*  
26 *is like cardboard!”(Petra).*  
27  
28  
29

30 A key feature was the intractable nature of the dryness, despite any use of remedies:  
31

32 *“So that’s me and sometimes I will say, I’ve got to get something to drink*  
33 *now but as I know it won’t help I just forget about it. I am aware of it, I’m*  
34 *very, very, very aware of it. (Farzana)*  
35  
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39 Following others<sup>37</sup> we found that xerostomia symptoms could be a private nuisance and  
40 therefore easy to adapt to. Xerostomia symptoms could however spill over and threaten the  
41 flow of everyday life. It was in these moments that symptoms crossed the threshold into  
42 becoming more problematic; starting to have physical functional, emotional and social  
43 impacts. This threshold should be critical to the measurement of severity.  
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### 50 **The impact of xerostomia on daily functioning**

51 When xerostomia starts to threaten the normal flow of daily life it can begin to impact on a  
52 significant range of physical and social functions. These impacts in turn have emotional  
53 consequences. The range of physical and social impacts can be seen in Figure 2. The impacts  
54 vary in severity, from being tolerable to becoming a significant source of discomfort and  
55 eventually leading to disability. In what follows we illustrate some of the physical, social and  
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3 emotional impacts of dry mouth moving from impacts that were not particularly bothersome  
4 towards impacts that could, under certain circumstances, be disabling.  
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6

7 In the following examples we can see how Farzana feels she is not speaking as clearly as she  
8 would like. This is akin to feeling the onset of a greater personal threat from the dryness in  
9 her mouth.  
10  
11

12  
13 *“I mean it has perhaps I’m not as clear when I speak. Maybe some of the*  
14 *words are more difficult to pronounce” (Farzana)*  
15  
16

17  
18 In contrast Sahasra is now experiencing real difficulties with speaking and these difficulties  
19 are starting to cause her some distress.  
20  
21

22 *“just you know.. you are tripping over your tongue sometime.. so you can’t*  
23 *articulate words in the way you want to ..and the mouth feels quite sticky..*  
24 *that’s when its worst ..it’s never actually.. physically painful.” (Sahasra)*  
25  
26  
27

28 These examples illustrate how dry mouth can develop different impacts from being largely  
29 symptomatic, psychological and social. For example, eating and swallowing could be  
30 particularly problematic. In some instance this could result in restrictions in what people could  
31 eat and in extreme cases withdrawal from eating out. Alison encapsulates the broad range of  
32 impacts very nicely when she talks about how his problems with the function of swallowing  
33 can cascade into a range of impacts. The basic impact on her swallowing function becomes a  
34 social and psychological problem in certain key situations eventually resulting in restrictions  
35 in her social participation (disability).  
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43  
44 *“Well yesterday ..err.. I was sort of.. I used to love nuts which I can’t eat*  
45 *now and used to have plenty a corn flakes and I really fancy it with nuts and*  
46 *then I thought there was NO WAY I can eat them you know... I can’t eat fish*  
47 *cakes unless I’ve got lot of sauce and very restricted. Wherever you want to*  
48 *go out for a lunch sometimes with friends it’s a problem what to eat and*  
49 *sometimes I just have a soup, because unless everywhere I go, I have to ask*  
50 *for extra gravy or if its fish sauce. Otherwise I can’t really... (mumbles)*  
51 *potatoes, chips and everything like that sticks completely and I can’t*  
52 *swallow at all unless I have got something to help it slide down. Cake I can’t*  
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3 *eat unless I have cream on it, just help it slide down. So whatever I eat it has*  
4 *to go to have something on it to slide down. Actually once I had fish and*  
5 *chips, a rare occurrence, let me tell you and I couldn't eat, I realised it was*  
6 *stuck.” (Alison)*  
7  
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10  
11 Dry mouth could impact on eating in four ways: the types of food, the time taken, the  
12 adjustments needed to be able to eat and in social situations that could become particularly  
13 problematic. The following examples illustrate the variable extent of impacts experienced by  
14 different participants.  
15  
16  
17

18  
19 *“I can't... the only fresh fruit I can eat is banana....and everything else*  
20 *stings...or its just too acidic and it stings my mouth...” (Jackie)*  
21  
22

23  
24 For Susan we can see how her problems gradually developed over time and how dry and  
25 rough foods sometimes got stuck in her throat:  
26  
27

28 *“I started finding I was getting trouble swallowing food in there and that*  
29 *was a big problem.... it is a big problem now swallowing the food.. I can't*  
30 *have any meal without a glass of water.” (Susan)*  
31  
32  
33

34  
35 Given the extent of the functional consequences of dry mouth it should not be surprising that  
36 there was a huge range of associated emotional impacts. These ranged from being anxious,  
37 annoyed, and agitated to feelings of despair and depression (Figure 2). Some of these impacts  
38 were so severe that they were reminiscent of depression, similar to that reported by Bergdahl  
39 et al. <sup>4</sup>. Fi reported feelings of failure and shame in relation to how dry mouth had undermined  
40 her ability to achieve things in the world.  
41  
42  
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45  
46 *“It has made me feel like I'm a failure made me feel very ashamed and it*  
47 *has made me feel that I can't grasp or achieve what I can potentially do in*  
48 *the real world urm.. you learnt to accept, but you have the odd moment like*  
49 *..I don't deserve this” (Fi)*  
50  
51  
52  
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54  
55 This underscores the need to better understand how dry mouth can threaten aspects of  
56 physical, psychological and social wellbeing. Fi even had emotional problems related to  
57 sleeping:  
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3 *“Choking, waking at night. It was a frightening experience that I have ever*  
4 *encountered and I really thought I was going to die (laughs)..because it*  
5 *was...when it happens for the first time like that...you just don’t know what*  
6 *is happening...” –(Fi)*  
7  
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10  
11 Additionally, participants reported feeling annoyed and anxious about having bad breath as a  
12 result of their dry mouth; as well as being annoyed at not being able to take care of their teeth  
13 properly because of problems with brushing.  
14  
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16  
17 When dry mouth threatened social relationships or social situations it became even more  
18 problematic. In such situations participants reported having to be vigilant about the effects  
19 of their dry mouth, which subsequently became a source of anxiety. Such effects might  
20 include those derived from speaking or fear of malodour in public. Joanna reported being  
21 distracted from interactions:  
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26  
27 *“at work or anything I’m doing at anytime .with friends or..yeah.. my mouth*  
28 *keeps distracting since this dryness ..yeah even while watching television..*  
29 *you know.. you do [licks lips]. Recently I was with friends in the picture.. I*  
30 *was sitting and watching the film and then I started coughing actually and*  
31 *then I had to go out to get a drink of water.” (Joanna)*  
32  
33  
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37 Richard described his vigilance about malodour at social gatherings:  
38  
39

40 *“sometimes if you go to a dance or a party where there is ...loud music and*  
41 *then you have get quite close to people to speak. I’m very conscious when I*  
42 *do that.” (Richard)*  
43  
44  
45

46 Restricted food choices and the need for liquids affected eating out or with others. Jackie  
47 found the menu’s in some restaurants were restrictive with not enough gravy or food with  
48 moisture to be able to eat.  
49  
50

51  
52 *“I do see it as a problem when I go out for a meal somewhere and I look at*  
53 *it and I think.. “Oh Gosh!! what can I actually choose of this menu?” and that*  
54 *is difficult ..when you go out somewhere...” (Jackie)*  
55  
56  
57

58 Alison reported similar problems:  
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3 *“..in fact I’m going for a lunch tomorrow in Nottingham and I’m worried*  
4 *about what the menu is going to be...” (Alison)*  
5  
6

7 Susan reported an incident where she nearly choked in a restaurant when she was eating  
8 dry food. Her attempts to ‘pass’ <sup>46,47</sup> in the social situation meant she stopped taking in  
9 enough moisture and the result was nearly choking on her food. Note how this has  
10 happened to her more than once.  
11  
12  
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14

15 *“Well it doesn’t look very nice gulping water....with every bite and you’re*  
16 *drinking at the same time really aren’t you? Most of my friends know the*  
17 *condition but I don’t particularly like it, that is why I try and choose*  
18 *something that has got like a lot of gravy or a sauce, or some extra sauce*  
19 *that I can swamp in gravy and get it down. The worse thing I’ve ever had is*  
20 *sometimes I get to swallow something, it starts to get in a bit really slowly*  
21 *and then it shuts off and I cant breathe in and I cannot breathe out and it is*  
22 *terrifying. I’m just, you know and then all of a sudden I am like (makes*  
23 *choking noises) like that and takes a minute or so. I can’t breathe. I can’t*  
24 *breathe in and I cant breathe out and that is terrifying. I feel absolutely*  
25 *exhausted afterwards. It has happened in a restaurant it was so*  
26 *embarrassing because the whole restaurant stopped, this woman on the*  
27 *other side nearly screamed when she saw, people were running out to me*  
28 *and all a sudden it came back. Very embarrassing moments....” (Jackie)*  
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42 In rare cases participants reported simply not being able to do certain things. Fi had found  
43 her mouth had become such a chore that she had given up some activities, which had led to  
44 her feeling like a failure.  
45  
46  
47

48 *“It has stopped me from a lot of things you know.... urm.. (pauses). Anything*  
49 *that involves painting because I used to do a lot of work but the chemicals*  
50 *makes your mouth dry. So I don’t paint.. just draw with a pencil now and*  
51 *colour with crayons. So that’s gone. Obviously the singing, people say I have*  
52 *a nice voice but I can’t maintain it for long, that’s the problem. (In terms of*  
53 *severity) I’ll say I have gone from 1 to 10....definitely...it has turned it right*  
54 *round. I think my mouth has become a major chore, whereas it used to great*  
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3                   *you know, it has become such a chore. That is where I find it difficult to come*  
4  
5                   *in terms with ...that is the big issue I have...u know. Tormenting!” (Fi)*  
6  
7

8 Such instances were uncommon. Most participants reported being able to do most day to  
9 day activities whilst making adjustments, but in rare instances the symptoms of dry mouth  
10 combined with social situations to generate disability in the form of exclusion from social  
11 participation.  
12  
13  
14

15  
16 Figure 2 highlights how a complex of factors both individual and environmental can act to  
17 modify the experience of dry mouth. Just as other research has shown dry mouth has a  
18 strong biographical dimension<sup>7,35</sup> resulting in the development of narratives about the  
19 condition. These narratives weave symptoms and functional impacts into attempts to adapt  
20 and cope with the condition. Others have already described these attempts in some detail  
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7,34,36,37 so there is little need to revisit these details here. Nonetheless what these narratives tell us is that there is an underlying complexity to the symptomatology of dry mouth that has yet to be fully explored, and which may not be captured in existing condition-specific patient reported outcome measures (PROMS). How these various factors may be involved is the purpose of ongoing work.

## Discussion

This paper is the first to provide a detailed conceptual map of the impacts of dry mouth in daily life (Figure 2). If we are to successfully measure the daily impacts of oral conditions it is important that this is done systematically and with reference to existing conceptual models of health<sup>29,30</sup>. Current measures of the impact of dry mouth cover symptoms, discomfort and physical impacts along with some aspects of how people cope with the condition. We propose that it may be time to consider a more comprehensive approach.

Locker<sup>23</sup> demonstrated when using the XI that dry mouth could have more severe impacts on OHRQoL than dental disease. Our data, along with that of others<sup>34,36,37</sup>, support his findings. Despite this, dry mouth receives very little attention in policy circles, despite its high prevalence and its relationship with poly pharmacy.

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2  
3 Our data have important implications for the content validity of PROMS dedicated to people  
4 with dry mouth. First, there is a need to expand our assessments to cover all the impacts that  
5 accrue from dry mouth (Figure 2). Second, whilst the current approach of using frequency of  
6 symptoms as the response framework for questions about the impact of the condition has  
7 some justification, there may be a better approach. Our participants spoke extensively about  
8 how noticeable their symptoms were and how this could lead to dry mouth becoming an  
9 ‘aggravating misery’<sup>7</sup>. Perhaps then the ‘noticeability’ of dry mouth might act as a more direct  
10 measure of the intrusiveness of these symptoms. Noticeability has been used as a focus for  
11 conditions such as vitiligo<sup>48</sup> where the scale considers the external visibility of that condition.  
12 In dry mouth the focus might lie in the public and private dimensions<sup>37</sup> to the *noticeability of*  
13 *symptoms*. This would include assessing how these symptoms grab attention and aggravate  
14 people. Future work includes panel testing of our draft questionnaire as well as longitudinal  
15 validation studies.

16  
17 Noticeability closely relates to somatic experience which in turn closely relates to how oral  
18 dryness acquires its meaning<sup>49,50</sup>. Research in psychology reveals that the same somatic  
19 experience can have varied interpretations and meaning. The attention that is paid to  
20 sensations can lead to positive or negative responses and it is argued that we should pay  
21 attention to how variation in somatic experience happens. In an experiment looking at  
22 somatic attention to physical sensations it was found that attention to physical experiences  
23 and sensations could produce positive affect<sup>49</sup>. It may well be that sensations such as dry  
24 mouth could be transformed by developing more adaptive ‘schemas’<sup>51,52</sup> for the condition.

25  
26 As we saw in our introduction, it is important to be able to establish the degree to which  
27 symptoms are clinically meaningful, including when they become especially problematic. In  
28 our study some participants explained that more often than not dry mouth was not a  
29 problem, but it was when sensations ‘threatened’ the stability of everyday life that they  
30 become anxious and worried by them. This suggests then that threat could act as a  
31 threshold for severity. This is important because by using this threshold concept in new  
32 measures for this condition, we might be able to establish which interventions work for  
33 which groups of patients. Developing such indices also has a degree of urgency since dry  
34 mouth can have profound consequences for social participation.

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3 Under certain conditions dry mouth can combine with social situations to produce disability  
4  
5 <sup>34-37</sup>. Whilst the vast majority of people with dry mouth can manage their condition privately  
6  
7 <sup>37</sup>. In some instances this was not possible and the effects could be profound, suggesting the  
8  
9 need to develop a range of interventions for dry mouth, from those focusing on  
10  
11 symptomatic control, to others removing the barriers to social participation for people with  
12  
13 dry mouth. **Policy options might include targeting restaurants to provide more welcoming**  
14  
15 **atmospheres including adapted menus for those with dry mouth.** Campaigns to raise  
16  
17 awareness of the impact of the condition could be developed. There is also some  
18  
19 justification for exploring the acceptability of symptomatic controls in social situations.

20  
21 A word of caution however. These data can only really be taken to reflect the views of a  
22  
23 small group of participants. Whilst their experiences clearly resonate with the experiences  
24  
25 of others we should be cautious in thinking that we have covered the full extent of the  
26  
27 impact of dry mouth. Likewise, it is possible that further dimensions to the condition remain  
28  
29 to be found.  
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**Table 1 Conceptual aspects of OH-QoL currently covered in condition specific measures of oral dryness/Xerostomia.**

Dimension of OH-QoL	Condition specific measures		
	Single item <sup>1</sup>	Xerostomia Index XI <sup>2</sup>	Xerostomia Questionnaire XQ <sup>3</sup>
Symptoms	√	√	
Discomfort/pain			√
Physical impacts		√	√
Psychological impacts			
Social impacts			
Restrictions on social participation			
General health perceptions			
Coping		√	
Disablement (social Isolation etc.)			

1. Ikebe et al.

2. Pai et al.

3. Thomson et al.

**Table 2 Summary of impacts associated with dry mouth reported in qualitative research**

Dimension of OH-QoL	Author				
	Rydholm and Strang	Rohr et al.	Ngo et al.	Folke et al.	Owens et al.
Symptoms	√	√	√	√	
Discomfort/pain	√	√	√	√	
Physical impacts	√	√	√	√	√
Psychological impacts	√	√	√	√	√
Social impacts	√	√	√	√	√
Restrictions on social participation	√	√		√	√
General health perceptions	√			√	
Coping	√	√	√	√	√
Disablement (social isolation etc.)	√			√	√

**Table 3 Sample Summary**

Sex	Age (years)		
Female	14	30-39	3
Male	3	40-49	5
		50-59	6
<b>Underlying cause</b>		60 +	3
Sjogren's Syndrome	6		
Multiple causes	11		

**Figure 1 Summary topic guide and plan for interviews****1. The personal history of the problem**

Explore - experience of the onset and biographical aspects of the discomfort

Illness perceptions (triggers, manifestations, intensity and duration)

Look for - lay beliefs and emotional reactions

**2. The impact on their everyday lives**

Explore how the pain/dryness feels?

Explore specific descriptors looking at how they would describe it?

Activity limitations (tooth brushing and other functional limitations)

Participation restrictions (social restrictions, situational burden)

Emotional burden

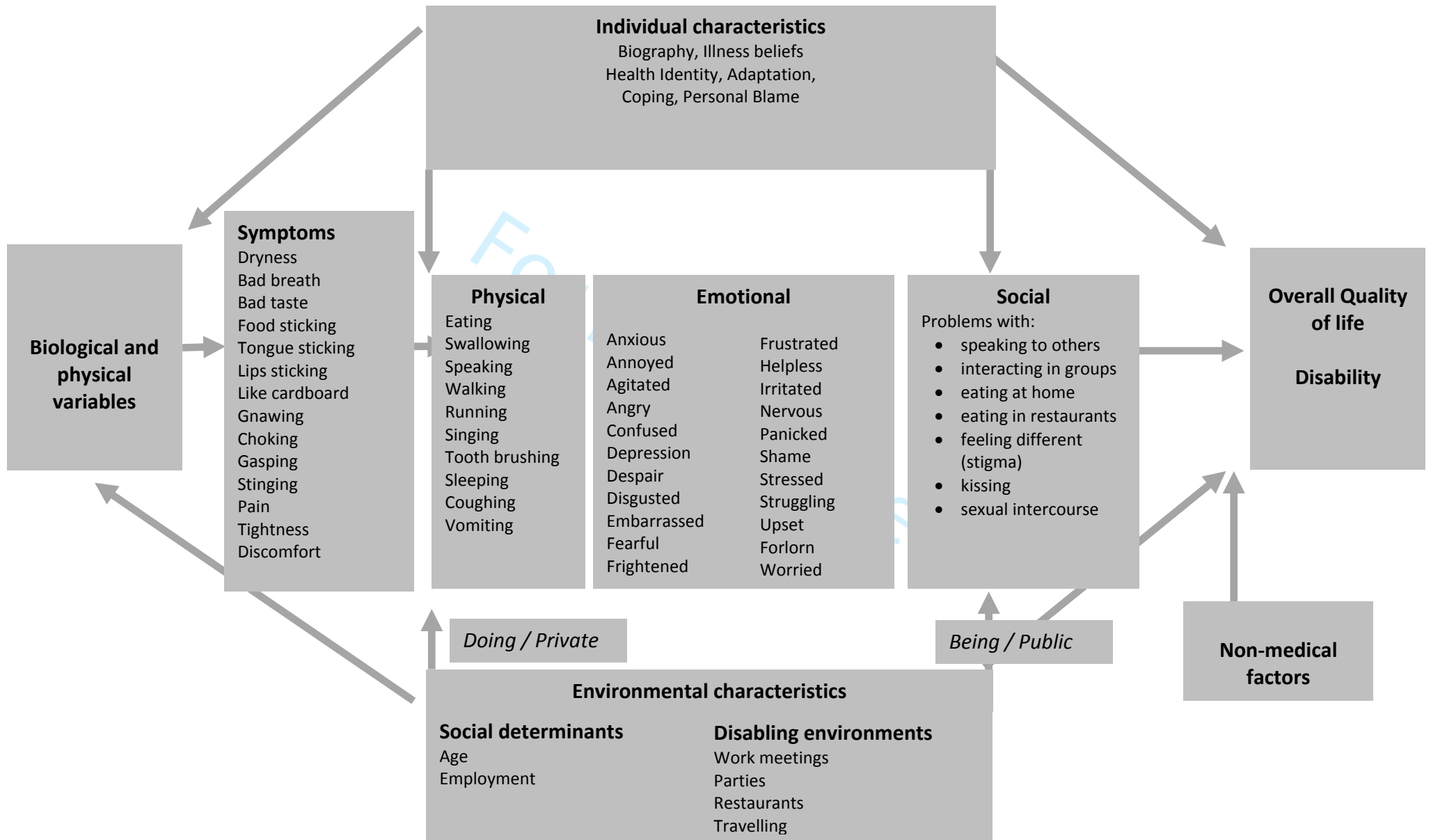
Adaptation and coping strategies

Prevention and treatment

**3. The relationship between their identity and experience of the discomfort. How does dry mouth relate to the context of their lives, has it changed anything, made differences in the way they behave/see themselves?**

**4. Explore participant preferences for oral care focus on the way preferences for toothpastes are communicated and the criteria they use for selecting a toothpaste.**

Figure 2. The interaction between personal and environmental characteristics and the impacts of dry mouth associated with the Wilson and Cleary model <sup>1</sup>.



**Table 1 Conceptual aspects of OH-QoL currently covered in condition specific measures of oral dryness/Xerostomia.**

Dimension of OH-QoL	Condition specific measures		
	Single item <sup>1</sup>	Xerostomia Index XI <sup>2</sup>	Xerostomia Questionnaire XQ <sup>3</sup>
Symptoms	√	√	
Discomfort/pain			√
Physical impacts		√	√
Psychological impacts			
Social impacts			
Restrictions on social participation			
General health perceptions			
Coping		√	
Disablement (social Isolation etc.)			

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Psychological impacts	√	√	√	√	√
Social impacts	√	√	√	√	√
Restrictions on social participation	√	√		√	√
General health perceptions	√			√	
Coping	√	√	√	√	√
Disablement (social isolation etc.)	√			√	√

For Peer Review

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For Peer Review

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