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# Title Page

## Oral care, loss of personal identity and dignity in residential care homes

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### **Author Contributions**

IJ and MM conceived the study. IJ, MM and RJ planned the study, carried out data collection, analysis and writing of the manuscript.

### **Data availability statement**

The data that support the findings of this study are available from the corresponding author upon reasonable request.

### **Conflicts of interest**

This study was supported by funding from GSK. The authors whose names are listed immediately below certify that they have NO affiliations with or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent-licensing arrangements), or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript.

**Data availability Statement**

## **Abstract**

**Objective:** UK National Institute of Clinical Excellence (NICE) guidelines recommend that care staff who provide daily personal care to residents: "Understand the importance of residents' oral health and the potential effect on their general health, well-being and dignity." The aim of this study was to explore residents' views and perspectives of dental care in care homes in order to understand how to deliver this care.

**Method:** Care homes were identified using care home inspection reports for Wales, UK. Care homes for older people with residents having mental capacity to consent were invited to participate. Data were collected using semi-structured one-to-one interviews with care home residents, care home managers and oral health care leads. Interviews were audio recorded, transcribed and analysed using a thematic approach to data. Analysis was assisted by NVivo 10 software. Data collection was completed when no new themes emerged.

**Results:** This analysis presents findings from 26 interviews with residents, across five care homes. Going into care was associated with a loss of identity. Having teeth and looking after teeth (natural teeth or dentures) was part of keeping that identity. All prioritised privacy, pride and independence above effective oral hygiene. Oral hygiene was viewed as a very private event. Carers adapted oral care, to balance time constraints, care, privacy, and dignity. Teeth were a part of personal pride to the extent that two residents said they did not want to die without dentures in their mouths.

**Conclusion:** While oral care is important to residents, dignity and privacy are often more important; care routines and practices are adapted around this. Carers need to adopt an individualised, pragmatic, and sensitive approach to oral care to account for personal dignity when looking after residents to be able to provide appropriate oral care in accordance with guidance. Members of the dental team need to support carers to provide effective oral care which allows dignified and effective care.

# Manuscript

## 1 Introduction

Many residents who live in care homes have poor oral health and poor oral hygiene<sup>1,2</sup> and report more oral health impacts than those who live in their own homes<sup>3</sup>. For residents, this poor state of oral health can affect general health, function, nutrition, and personal and social well-being<sup>4-6</sup>. Furthermore, many older adults have treatment needs alongside complex health issues, making treatment more difficult.

The importance of oral health in care homes was highlighted in 2016 when the National Institute of Clinical Excellence (NICE) issued guidance<sup>7</sup> which described the need to; “Understand the importance of residents’ oral health and the potential effect on their general health, well-being and dignity”.

The guidance<sup>7</sup> and the systematic and economic reviews developed to underpin this work,<sup>8-11</sup> highlighted the potential for improvements in oral health through provision of good oral care. The review of barriers and facilitators of care for the NICE guidance identified the skills, knowledge and attitudes among care home staff, and care home organisational structures including policies and resources, which were important for the support of residents’ oral health. Support from friends and family, and dental teams and the residents’ behaviour, health and attitudes have also been identified as being important factors to consider when working to improve oral health<sup>9</sup>.

Despite the NICE guidance for oral health in care homes, a report by the Care Quality Commission (CQC)<sup>12</sup> in England in 2019, identified significant ongoing issues with oral health care and infrastructure in care homes, with their report emphasising the need for oral health to be an integral part of care and not just an afterthought.

These calls for improvements in support for oral care for residents have been made alongside a greater focus on the needs of the individual, and health and care services are becoming increasingly orientated towards supporting independence. There is also evidence to indicate that person-centered care approaches, which focus on the identity and needs of the individual, can help to maintain dignity and improve both health and care for older adults and residents<sup>13-15</sup>. Therefore, person-centred approaches may support and facilitate improved oral care in accordance with NICE guidance.

However, this approach towards daily personal care for residents is not without challenges for oral health. Surveys have shown that most residents report that they clean their own teeth, but when residents do clean their own teeth, many do this ineffectively<sup>16</sup>. Therefore, individuals who wish to be independent may have poorer oral health. Furthermore, whilst there is motivation to provide care, studies of carers and nurses have highlighted that some find it difficult to provide oral care,<sup>17-19</sup> which may mean that support is not offered when needed.

As more people enter care homes with a mix of natural teeth and dentures, there will be an increase in the number of people who need oral care. Importantly there will also be a significant increase in those requiring some support to maintain their oral health and, because this care involves intraoral tooth brushing, this is likely to take more time. Many of these people may wish to and be able to carry out some self-care<sup>16</sup>. As such, person-centred oral care needs for people living in care homes are likely to increase and become more difficult over time. To deliver person-centred oral care in line with care guidance<sup>7</sup>, it will be necessary for care teams to develop an understanding of what is important and matters to residents.

## **1.1 Aims and objectives**

This primary aim of the study was to explore care home residents' views and perspectives of oral care in care homes.

The objectives were to; explore oral health care routines and experiences of oral care; illuminate perspectives of support for oral care within the care home setting; generate an understanding of the meaning of oral health for residents and capture perspectives on which aspects of oral health and care matter and which do not matter to residents.

## **2 Method**

The study was undertaken in Cardiff, the capital city of Wales, UK. The study used an inductive qualitative approach using semi-structured interviews and a thematic approach to data.

### **2.1 Ethics**

Ethical approval was obtained prior to commencing the study from the School of Dentistry Research Ethics Committee, Cardiff University. Advice was also sought from the UK

National Research Ethics Service who confirmed that no further approval was required. In the reporting of this data all names of participants have been replaced with pseudonyms to protect residents and staff anonymity.

## **2.2 Selection of Care Homes**

Care homes were first identified using the Care and Social Services Inspectorate Wales (CSSIW) home inspection reports for the city of Cardiff. Care homes providing care for young adults, those with learning difficulties and those catering for residents, with no or very limited mental capacity were excluded from the study. Using these criteria, a sample of 14 homes were identified. Care homes managers were contacted by telephone to inform them about the study and invite them to take part. Those that were interested in taking part were visited by a member of the research team to deliver a study information pack, answer any queries and to discuss suitability for the study and participation<sup>20</sup>.

## **2.3 Resident recruitment**

Recruitment was initially undertaken by the care home. Staff informed residents about the study, emphasising that it was voluntary and that they were under no obligation to take part. In some cases, with appropriate consent, family members were also informed. Residents who indicated they were willing to take part in the study were then introduced to a member of the research team. Further written and verbal information was given to the resident about the study and at this stage verbal consent was obtained. For residents to consent, the researcher had to assess that the resident was able to understand that participation was voluntary and able to engage in a simple conversation around the topic of oral health care. This was done whilst informing them about the study and having a “friendly chat”. This assessment, in combination with confirming consent was undertaken again immediately prior to the interview process.

## **2.4 Data collection – residents**

Data were collected via semi-structured one-to-one interviews over a six month timeframe using a pre-determined interview guide, <sup>20</sup> questions for staff mirrored those used for residents. The location of the interviews was tailored to the resident’s needs and where they were most comfortable. For some this was undertaken in their own room, for others, this was a quiet area of the care home. Two members of the research team were always present for the resident interviews; led by one researcher, with the other making

notes and sometimes interjecting to clarify understanding of what was being discussed. Confirmation of interpretation took place throughout the interview process.

The study used an inductive thematic approach based on Braun and Clarke<sup>21</sup> Interviews were audio recorded, transcribed and analysed, line-by-line assisted by NVivo 10 software. Data collection was deemed complete when no new themes emerged from the residents' data. Data from staff interviews was managed using the same approach and data triangulation was used to compare findings from residents and staff.

## **2.5 Data collection – care home personnel**

The main focus of this study was the residents, however, at least one member of staff from each participating care home were invited to take part in an interview. This was either the care home manager or a carer identified who had a lead role in oral health care.

Whilst all participating care homes agreed for a member of staff to be interviewed, because of the demanding nature of the care home setting and associated time pressures, securing interviews with care home personnel was more challenging. Therefore, a flexible approach was taken to maximise participation with interviews being conducted at the care home or by telephone. All interviews were recorded and transcribed verbatim.

Reflective notes were made immediately after the interviews by the lead interviewer (an experienced researcher with no previous background in older adult research). The two researchers who were present for the interview discussed the content, meaning, and interpretation of the issues discussed, notes were made and themes developed. All researchers read all transcripts independently. Furthermore, weekly update meetings were held with the research team to consider the questions, triangulate data and refine analyses. Potential bias (e.g. influences on participant responses and perspectives and experiences of the research team) was also considered during discussions. This was a continuous process.

## **3 Results**

Five care homes were purposively selected and willing to take part in this study; a total of 26 interviews were carried out with residents from five care homes. A further four interviews were conducted with staff; these interviews raised similar themes and were used to test and explore the context and triangulate residents' accounts. Residents reported varying degrees of health problems with medical and physical health issues. A few had minor issues with mental health. All resided permanently in either residential



care homes (73.1%, n=19) or in nursing homes due to more complex health needs (26.9%, n=7). 84.6% (22) of participants were female.

Several themes were identified from the data including a sense of loss of personal identity, privacy and pride.

## 4.1

**Loss of Personal Identity** All responses were influenced by being in care. Residents described moving into care as entering a new phase of their life, almost living another existence to their pre-care home life. The loss of personal identity was an overarching theme and associated with subthemes, including a loss of an independent life and existence, being on a slippery slope (declining health and increasing needs), and a feeling of powerlessness (resigned to being in care and being caught in the care system).

*Annie: "You feel as if you're hemmed in because you haven't got a key to the front door"*

*Maude: [I fell at home and] well that's when they sort of discovered I was around and then you see, I was in my nineties you see, so that was it, the ball was rolling, then they got me!*

Having teeth and looking after teeth (natural teeth or dentures) was connected to keeping hold of a part of residents' personal (pre care home) identity and preserving part of themselves.

*Betty: To me, it's all I've got left of my teeth but I'm trying to keep them..... I want to die with some [teeth] left in my mouth.*

The sense of loss is echoed in the residents' words 'it's all I've got left'. Residents described looking after teeth in the context of maintaining their appearance and their old identity. Some of the residents expressed a fatalistic sense of being resigned to the scrapheap, suggesting that people did not want to bother with them and their care. They also felt that dental services did not really have any interest in them anymore because of their age.

*Elizabeth: I was going to go privately and see if I could get a better [denture] fit, but she [the dentist] said there's no point, there is no room [in the mouth for a new set of teeth]. Whether it was the people who made them or the people who didn't want to bother with them because sometimes with old people, it's an awful thing to say but they don't want to bother with you. It's a cruel thing to say but it is true, and I think you'll find as you go through the old people you'll find that happens.*

This fatalistic description of being abandoned without care provides a view of the dentist-patient interaction from the patient perspective.

## 4.2 Privacy and pride

Oral care and privacy was a theme which ran through the interviews for residents and staff. For most oral hygiene and dentures were seen as private and personal. When residents were asked about what they thought other people (residents) did in relation to oral care, the majority stated that they did not know, and it was not their business to know.

*Carer: To me it's privacy, that's what they want and that's what I would expect myself.*

A few of the residents highlighted the uncomfortable issue of people taking their dentures out during dinner. Residents did not like looking at other people taking their teeth out in public situations such as the communal dining area and some said they felt it was antisocial. The vast majority indicated that they would be unhappy to do this themselves. In alignment with this, for the majority, oral hygiene was an event that occurred in the privacy of a resident's room or bathroom.

Some of those who took their teeth out at night described feeling embarrassed about their dentures and chose to hide their teeth in a drawer rather than having a visible denture in a cup, beside the bed. Residents also reported that they kept dentures out of sight due to a sense of disgust towards their teeth when outside their mouth.

*Frances: I throw them into the drawer as don't want to look at them. [Takes bottom teeth out at night time]*

Many residents did not wish to be seen without their dentures, this view was often expressed with strong emotions. These residents were embarrassed by their personal appearance without dentures, and were uncomfortable with the idea of being seen without their teeth, by others including care home personnel. This was to such an extent that some opted to wear their teeth while they slept, 'just in case'. One resident indicated that she continued to wear her dentures at night so that carers could understand her speech, should she need them during the night. However, when probed, she suggested that her concern went beyond a practical communication issue and was connected to personal pride and not wanting to be seen without her teeth.

*Olive: I'd prefer to be seen with them [my dentures] really. Interviewer: So that's why you sleep with them?*

*Olive: Yes, I suppose it is the main reason. Yes I've got to admit to that.'*

## 4.3 Oral care, dignity and independence

Oral hygiene was part of residents' independence and, for many, this was viewed as a very private event. Carers did not provide intra-oral care but said that they did clean dentures for residents. Carers and residents described the balance between care, privacy and independence in relation to oral care.

***Gwyneth: I clean my teeth every morning, I clean them at night but I don't like taking them out at night, it's because I'm proud I suppose, I'm afraid of dying and no teeth in my head. . . Yes, yes [I take my dentures out] about two nights a week.***

***Interviewer: and the rest of the time do you leave them out at night?***

***Gwyneth: I can't get on; I can't sleep if they're not there.***

***Interviewer: but you have them out for two nights a week so they're really clean?***

There was a form of negotiation between carer and resident to provide appropriate oral care support, whilst respecting the dignity and privacy of the residents. As reflected in the quote below from a staff member.

***Care Home Manager 2: We try and encourage residents to take them [dentures] out by night. And obviously have them washed and soaked. Um, but we do find with some of them. . . dementia residents they don't like to take them out.***

Some of the residents who were embarrassed about taking their dentures out at night, negotiated a compromise. Some residents removing their dentures for a short period of time to allow staff to soak them, instead of removing their teeth overnight, whilst others relinquished their dentures overnight for just a couple of times a week.

#### **4.4 Holistic oral care and maintaining personal identity**

The feeling that dentures or the existence of even some of their natural teeth "completed them" or "made them whole" was apparent from the resident interviews and echoed in the staff interviews. While oral care was evidently difficult for some residents, there was a sense of it being beneficial in relation to holistic and person-centred care.

***Oral Health Lead 1: As I said before everyone's different. Some of them do like to put them into soak. I've got a lady in the morning, I'll go into her, she'll take. . . she likes to sleep with them. She'll take her teeth out, she'll pop em in the pot, bit of Steradent. She'll leave them there 10-15 minutes, she'll potter, she'll have a wash, she'll get dressed, um, then before she puts her make-up on, she gets them back out and then she puts her lippy on. She's good to go.***

According to staff, for some of the residents, oral care was part of 'putting on the face',

often part of the beauty and make-up regime and keeping a sense of the person. For both residents and carers, oral care was more than just a part of washing and dressing, it was part of helping residents to feel good about themselves.

*Care Home Manager 2: Yes, and she likes to have a bit of makeup on a good day and it does make a difference if you've got teeth. She feels better, she comes out in the dining room, so she feels better now.*

## 5 Discussion

This study captured the experiences of older adults living in residential care. Fundamentally, going into care was a significant change in the lives of residents and was associated with a loss of identity reflecting reports in the wider literature<sup>22</sup>. Residents felt that their mouth and oral care was part of maintaining both their appearance and their identity. This was also reflected in comments from carers who indicated that oral care was part of the overall appearance and wellbeing of residents. These statements echoed views and the narratives of studies exploring the significance of the mouth and describing how teeth formed part of an individual's identity<sup>23,24</sup> and self-worth<sup>25</sup>. The present study explored this further, in relation to the transition into a care setting, which was considered to strip residents of aspects of their personal identity. The mouth was something they could hold onto and so retaining that aspect of their identity was particularly important for them. Oral hygiene was personal and was viewed as a very private event, which was, at times, embarrassing. This sense of embarrassment has been reported as a barrier to seeking help with dental care<sup>26</sup>. Both carers and residents, expressed the view that being helped could feel undignified and similar to the narratives in the wider literature, this was a further barrier to the acceptance of help with personal care<sup>27</sup>. Carers comments also reflected this need for privacy in relation to oral care, with many describing how they adapted oral care to balance time constraints, care, privacy, and dignity. These responses emphasised the importance of minimising personal and social discomfort and improving the acceptability of help when supporting those in care.

Dignity has been described as "respecting an individual's uniqueness and their personal needs."<sup>28</sup> and this concept is supported within the legislation which describe dignity in care in the context of supporting autonomy<sup>29</sup>. However, findings of the present study have highlighted challenges of supporting autonomy and self-care whilst also providing effective care in accordance with the guidance.

Tooth loss is understood to have an emotional impact on older adults, and the literature<sup>30</sup> suggests that dental health and care was of particular significance to residents. The residents and carers discussed how they negotiated oral care practices

such as the removal of dentures or the delivery of oral care. For example, guidelines indicate that oral hygiene should be provided regularly, and dentures should be taken out at night <sup>7,31,32</sup> but while residents knew this, they often kept their dentures in. This was so important to some of the residents, that they indicated they preferred to sleep with their teeth in, just in case they died or needed help in the night. These compromises, for example negotiating with residents to leave teeth out for a few hours or leaving only one of the dentures in, were made to prioritise dignity, privacy, pride, and independence steering away from guidance for effective oral hygiene <sup>7</sup>. Residents were more prepared to receive help with oral hygiene and care, for example giving dentures to their carer to clean, when these compromises were made. Consequently, dental teams and carers need to be aware that residents and carers may have very personal reasons for not complying with recommended guidelines for oral care. Living in a care home does not take away an individual's right to determine how they manage their personal care. Therefore, this aspect of personal dignity should be considered when developing an individualised, pragmatic, and sensitive approach to oral care for residents.

## **6 Conclusions**

Residents feel that the mouth is an important part of their identity and maintaining this is important, particularly as going into care is associated with a loss identity. However, mouthcare is deeply personal, and while maintenance and care of the mouth is important, dignity and privacy are often more important to them.

Members of the dental team need to support carers to provide individualised, dignified and effective oral care. Care should not be a one fits all approach. Carers need to adopt an individualised, pragmatic, and sensitive approach to oral care to account for personal dignity when looking after residents. It is recommended that all residents who need support with intra and extraoral care are offered the support they need, and this is delivered in a dignified way. The discussion about what the residents want and what matters to them is important for respecting patient wishes, negotiating oral health care needs and overcoming the barriers to care.

## **7 Recommendations**

Strategies, programmes and training for oral health in care homes should consider privacy, dignity and approaches for supporting the needs of the individual.

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