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Original Research Article

Probing Problems and Priorities in Oral Health (Care) among Community Dwelling Elderly in the Netherlands - A Mixed Method Study

Babette Everaars^{1,2,3}, Katarina Jerković – Čosić², Gert-Jan van der Putten^{2,4,5}, Geert JMG van der Heijden¹

¹ACTA, Department of Social Dentistry, Academic Center for Dentistry Amsterdam, University of Amsterdam and VU University Amsterdam, Gustav Mahlerlaan 3004, 1081 LA Amsterdam

²Universtiy of Applied Sciences Utrecht, Centre for Innovation in Healthcare, Bolognalaan 101, 3584 CJ Utrecht

³ATHENA Institute, Faculty of Earth & Life Sciences, Free University, De Boelelaan 1085, 1081 HV Amsterdam

⁴Amaris Gooizicht, Paulus van Loolaan 21, 1217 SH Hilversum

⁵Department of Oral Function and Prosthetic Dentistry, Radboud university medical center, 6500 HB Nijmegen

Corresponding Author: Babette Everaars

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ABSTRACT

Background: Complex dentitions and decline in adequate oral hygiene in elderly may lead to poor oral health. This may have impact on their general health, wellbeing and quality of life. With increased longevity, the problems and needs in oral health of community dwelling elderly lead to changes in oral health care needs. We identified and prioritized problems and needs in oral health of community dwelling elderly.

Methods: The problems and needs in oral health of community dwelling elderly were elicited during focus groups and interviews. The list of problems and needs derived thereof was presented to 97 elderly who prioritized these.

Results: Overall, older people appeared to be satisfied with their current oral health, and the maintenance and care for their oral health. Cost of care was identified as a major problem in general. There are differences in current perceived problems and needs and problems and needs anticipated for the future. Perceived current problems and needs concern dental care provision and knowledge on oral health of professionals and patients. For anticipated future problems and needs the importance of daily oral care by caregivers was prioritised, while emphasis was placed on fear of losing autonomy.

Conclusion: It is important to take the perspectives and expectations of elderly into account in policy and planning of future oral health care practice, because these differ from the perspectives of dental professionals.

Keywords: oral health problems, community dwelling elderly, priorities.

INTRODUCTION

The nature of oral problems is chronic and progressive.^(1,2) Hence, the risk of more serious oral health problems increases with age. However, nowadays, many elderly retain their natural teeth until

high age. This is due to improved preventive and curative oral health care over the last decades. At older age, more complex dentitions with e.g. bridges, crowns and implants, the reduced ability to properly maintain oral hygiene and co-morbidities,

may lead to poor oral health and (oral) health complications. As a result of poor chewing function, a negative impact on eating may cause malnutrition and cognitive decline. ⁽³⁾ In addition, poor oral health may have a negative impact on speech and esthetics. As such, resulting impaired communication and social activities, easily leads to isolation and depressive disorders, and reduce of self-esteem, wellbeing and quality of life. ⁽³⁾ Besides these problems, oral diseases are also associated with systemic diseases like pneumonia, diabetes and heart diseases. ⁽⁴⁾

Together with the increased longevity, the next decades the population of elderly will steadily grow. Worldwide, the world's population of 60 years and above will double to 22% between 2000 and 2050. ⁽⁵⁾ In The Netherlands, the number of elderly (65+: 2.6 million people) will increase between 2012 and 2060 from 16% to 26% of the population, ⁽⁶⁾ of which about 25% is considered frail. ⁽⁷⁾ Currently, only 6% of the elderly in The Netherlands live in long term care facilities. ⁽⁶⁾ About 80% of the elderly in the north of The Netherlands have moderate or bad oral health when they enter a long term care facility. ⁽⁸⁾ Thus, this is a significant proportion of the increasing population of community dwelling elderly.

It is expected that over the next decades the problems and needs in oral health of community dwelling elderly will drive a change in the demand for oral health care. Currently, in The Netherlands agreement among professionals is lacking about optimal oral health (care) in community dwelling elderly. Moreover, there appears to be a discrepancy about needed care between professionals (normative needs) and patients (perceived needs). ⁽⁹⁾ To date, however, little is known about the experiences and needs of the (frail) community dwelling elderly. Therefore, the aim of this study is to identify

and prioritize problems and needs of community dwelling elderly with respect to their oral health and oral health care.

MATERIALS AND METHODS

Mixed methods were used to collect and analyse the data. We distinguished between study participants by care dependency level: pre-, low, and medium dependency, to anticipate on views and perspectives on oral health relating to dependency in self care. ⁽¹⁰⁾ We furthermore expected different views and perspectives on oral health relating to life course periods and therefore distinguished between current problems and needs and those anticipated for the future. Finally, we looked for different health care organisational perspectives on problems and needs: the care consumer level and oral health care system level. Our approach to these grouping of data will be explained below in more detail.

In a focus group we identified and explored perspectives, experiences, problems and needs in oral health (care) of community dwelling elderly (65+). Thereafter, through semi-structured interviews we gathered more in-depth information on problems and needs in oral health (care) of community dwelling elderly with different dependency levels. The semi-structured interviews were aimed at more in-depth exploration and derived possible new topics. Finally, a questionnaire among community dwelling elderly was conducted to verify, quantify and prioritize the problems and needs. In addition, respondents were invited to add new items if desired.

Collection of qualitative data

Focus group

The Nominal Group Technique with an organized structure was used to gather relevant information from the elderly (see [Appendix A](#)). Eight elderly consented to

participate in two parallel focus group sessions with four participants each facilitated by two co-authors (B&C). Three participants were invited by one of the co-authors from a practice based network on elderly research and his practice population. Five of them were recruited from the NUZO (Network Utrecht Care for Older people) and the Older people Union (ouderenbond).^(11,12) The focus group discussions were audio recorded and notes were taken on flip overs.

The focus group participants eventually turned out to be relatively independent and healthy elderly. Hence, elderly with low to high dependency levels did not participate. During analysis of the focus group data, it was recognized that saturation on problems and needs, was not yet reached, because of the lack of variety in dependency levels. Therefore, more in-depth information was gathered by semi-structured interviews.

Semi-structured interviews

From the NIVEL consumer panel, 200 community dwelling elderly (65+) were approached by e-mail if they wanted to participate in: a) a face to face interview, b) a questionnaire or c) both. Moreover,

information of three demographic characteristics were asked in this e-mail: age, oral health status (dentures, partly own teeth, full natural dentition) and care dependency level.^(13,14) In order to fit the oral health context of this study, the Canadian Study of Health and Aging (CSHA) scale for care dependency levels was adapted and categorized in no, pre-, low, medium and high dependency (Table 1).^(13,14) Participants had to choose one out of five statements which represented their dependency level the best. 68 (34%) of the 200 community dwelling elderly indicated to be interested in participation for a face to face interview. Of these, twelve were approached by phone, using convenience sampling based on dependency level (pre-, low, or medium); four per dependency level, assuming that high dependent elderly are institutionalized. One participant from the focus group indicated to be willing to share her experiences and was willing to participate for the interview. Because only one individual from the NIVEL consumer panel was medium dependent, (C) working as elderly specialist at a day care center for elderly invited three medium dependent elderly for an interview.

Table 1: Statements to indicate independency scales adapted from the CSHA scales to oral health context.^(13,14)

Dependency scale	Statement
No dependency	I feel fit and healthy and I have no chronic disease(s) and/or physical/psychological issues.
Pre-dependency	My chronic disease(s) and/or physical/psychological issues are controlled and do not affect my daily activities.
Low dependency	I am not dependent on others for care, but my chronic disease(s) and/or physical/psychological issues do affect my health. I have symptoms now and then and they affect my daily activities (like brushing my teeth).
Medium dependency	I am slightly dependent on others. For example, I need help to go to the dentist or doctor or the dentist comes to visit me at home.
High dependency	I am very dependent on others help. For example, I cannot brush my teeth by myself or wash myself. I am not able to be moved to the dentist or doctor, they have to visit me at home.

A trained interviewer (A) used an interview guide ([Appendix B](#)) and took notes when conducting semi-structured interviews at the participants' home. Interviews with the individuals from the day care centre took place in a private room in the centre. To ensure the richness of the

data, interviews were conducted in Dutch and probing questions were asked. Socio-demographics, dentition status (dentures, partly dentate, dentate) and dependency level were documented during the interview. All interviews were audio recorded and took between 30 and 60 minutes.

Collection of quantitative data

Questionnaire

From the approached 200 community dwelling elderly from the NIVEL consumer panel, 97 (48.5%) agreed to participate for the questionnaire. Problems and needs on oral health identified through the focus group and interviews were listed and presented as a questionnaire. They were asked to select five items from the list that they felt most important and to rank those from one (most important) to five (least important). They were asked to do this twice: first, for *current problems and needs*; second, for problems and needs on oral health expected *in the future, when getting (more) care dependent* (the two main themes detached from the focus groups and interviews). Both lists consisted of the same 28 items. Furthermore, demographic characteristics notably: age, gender, dentition status (full dentures, partly dentures, crowns and bridges) and dependency level (Table 1) were documented. Participants had ca. three weeks to fill out and return the questionnaire.

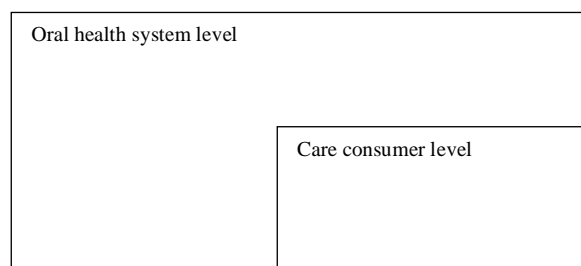
Data analysis

The focus group and interviews were transcribed verbatim and analyzed by (A). Transcriptions were written in MS Word and audio recordings were saved in Express dictate. ⁽¹⁵⁾ Transcriptions were written and analyzed in Dutch to warrant the context and interpretations. MAXQDA was used to code and analyze the transcripts. ⁽¹⁶⁾ Theoretical thematic coding was used to structure the main themes of the focus group by using two levels of an adapted conceptual framework from the WHO. ^(16,17) This framework entails three organizational levels of health care: micro, me so and macro. The three levels refer to; the patient interaction level; health care organization and community level; and policy level

respectively. Since for our data problems and needs showed considerable overlap on me so- and macro- level we combined these and labeled them into 'Oral health care system level'. We labeled micro-level as 'Care consumer level' (see Figure1). This pre-defined conceptual framework and the two themes derived from the focus group ('*current problems and needs*' and '*future problems and needs: when getting (more) care dependent*') formed the basis for the interview guide.

However, coding was an iterative process, which allowed adaptation of coding during the whole procedure.

Figure 1: Adapted model extracted from the WHO model on health organizations levels. ⁽¹⁷⁾



The questionnaire was analyzed in Excel. Per item, frequencies, means and standard deviations were calculated. The ranking of prioritization was recoded into 5=1,4=2, 3=3, 2=4,1=5, because 5 points represented the least important subjects in the questionnaire. As suggested by Guyatt (1990) we ranked items according to the product of their frequency of endorsement and the mean weight given by the respondent. ⁽¹⁸⁾

Validity, reliability and ethical considerations

Triangulation was accomplished by combining: focus groups, interviews and a questionnaire, which ensured the credibility of this research. In addition, reliability was enlarged by dividing the focus group in two sub-groups. Member-checks were carried

out during the interview, by summarizing what the participant had said and verify if interpretations were correct.

For coding and analysis of data from the focus group and interviews by A, appropriateness of codes and themes was confirmed by another researcher (B). For discrepancies about codes and themes they reached full consensus by discussion.

During this research the code of conduct for Health Research (Gedragscode Gezondheidsonderzoek) was followed. ⁽¹⁹⁾ According to the Medical research Human Subjects Act (WMO) a waiver applies for ethical approval to conduct this qualitative research. ⁽²⁰⁾ All participants were informed about the aim of the research and written informed consent was given by all participants. They were instructed to speak freely, and were informed that information they shared was only used in context of this research and that in any stage of this research their identity was kept strictly confidential.

RESULTS

Focus groups—Eight elderly between 65 and 98 years old (five women, three men) participated in the focus group. Most focus group participants were relatively fit and healthy community dwelling elderly (no/pre-dependent); some had a role as informal caregiver to relatives. No data on chronic diseases of participants was collected. Two participants had complete dentures and the others were dentate with or without partial dentures.

Interviews - In total twelve community dwelling elderly between 69 and 98 years were interviewed (7 women, 5 men). Participants had several co-morbidities like Parkinson, cardiovascular diseases and Arthritis, and were categorized in pre-, low and medium dependency levels (Table 2). One participant, who had complete dentures, needed daily oral health care by home caregivers. Other participants performed their own daily oral hygiene.

Table 2: Overview of interviewees.

Interviewee	Gender	Marital status	Age	Dental status	Brushing moments	Dental visits	General health status	Dependency Scale
1	Male	Married	78	Dentures on implants	2 x per day	2 x per year	Heart problems Herpes zoster	Low dependency
2	Male	Married	72	Dentures on implants	1x per day	1 x per year	Heart problems	Pre-dependency
3	Female	Divorced – living alone	76	Mostly own teeth	1 x per day	2 x per year	Osteoporosis	Medium dependency
4	Male	Married	72	Partly own teeth	2 x per day	2 x per year	Ciap, Diabetes	Pre-dependency
5	Female	Living alone	73	Partly own teeth	2x per day	Has not been in two years	Coeliakie	Pre-dependency
6	Female	Widow – living alone	72	Partly own teeth	1/2 x per day	1 or 2 x per year	Fibromyalgia	Low dependency
7	Female	Living alone	82	All own teeth	2 x per day	2 x per year	Arthrosis, hip dentures, shoulder dentures	Low dependency
8	Female	Widow – living alone	98	Partly own teeth	2 or 3 x per day	2 x per year	Arthrosis, hearing loss, loss of sight	Low dependency
9	Male	Married	73	Partly own teeth	2 x per day	2 x per year	Heart problems, pace maker, incidental epileptic attack	Pre-dependency
10	Female	Married	86	Complete dentures	1 x per day by homecare	None	Paralyzed half	Medium dependency
11	Male	Widow-living alone	81	Partly own teeth	2 x per day	2 x per year	Parkinson, Diabetes	Medium dependency
12	Female	Married	69	Partly own teeth	2 x per day	1 x per year	Two times CVA	Medium Dependency

Questionnaire—97 participants from the NIVEL consumer panel consented to participate on the questionnaire: 47% female, and 43% male (10% missing data). The response was 61 (62%). 12 Participants were excluded for analysis due to the following reasons: did not fill out the prioritization exercise correctly (n=5), not

perceiving any oral health (care) problems (n=6), withdrawal from participation (n=1).

Data of 49 participants were included for analysis, of which one-third (33%) were edentate with complete dentures and 10% were dentate. Of the participants, 25% were pre-dependent, 20% were low-dependent and one participant was medium-dependent (see Table 3).

Table 3: Overview and characteristics of respondents from the questionnaire.

Sex	Dental status	Dependency level	Health status
Female (n=23)	Full dentures (n=16)	Pre-dependency (n=12)	Fit and healthy (n=26)
Male (n=21)	All teeth present (n=5)	Low dependency (n=10)	Chronic disease (n=21)
Missing(n=5)	Crown(s) and bridge(s) (n=25)	Medium dependency (n=1)	Missing data (n=2)
Total: 49	Partial dentures /frame (n=12)	Missing data (n=26)	

Themes and sub-themes

Based on coding and thematic analysis of problems and needs expressed in the focus group and interviews, two main themes emerged regarding life course: ‘*current problems and needs*’ and ‘*future problems and needs: when getting more care dependent*’. Thereby also nine sub-themes derived: (1) dental care provision; (2) professionals’ knowledge on oral health (care); (3) patients’ knowledge on oral health (care); (4) costs of care; (5) oral health status; (6) autonomy; (7) self-care; (8) daily oral care provided by care givers; and (9) general health care. The sub-themes are presented in *Italics* in the text. After twelve interviews, no new codes regarding the two main themes and nine sub-themes emerged and data saturation was reached in perspective of the aim to elicit problems and needs on oral health.

The problems and needs expressed during the interviews were coded and arranged according to these two main and nine sub-themes, as well as by the level of care organization: ‘Care consumer level’ and ‘Oral health care system level’ (Figure

2&3). The lack of variation of dependency levels among study participants hampered coding and analysis of the expressed problems and needs accordingly.

It is evaluated whether the interviews confirm or add to the findings from the focus group and illustrations are given by quotes.

The main themes are discussed according to the ‘Care consumer level’ and ‘Oral health care system level’.

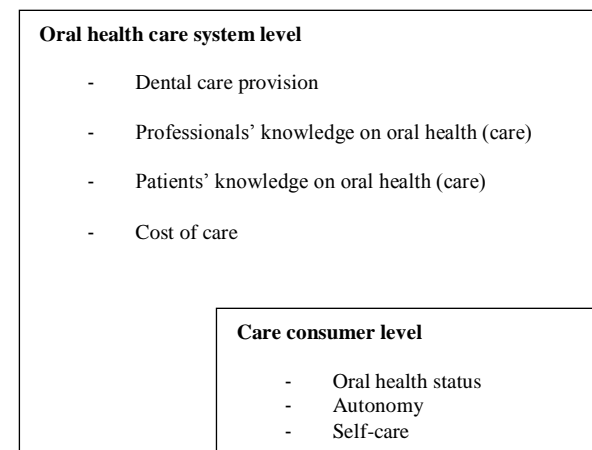
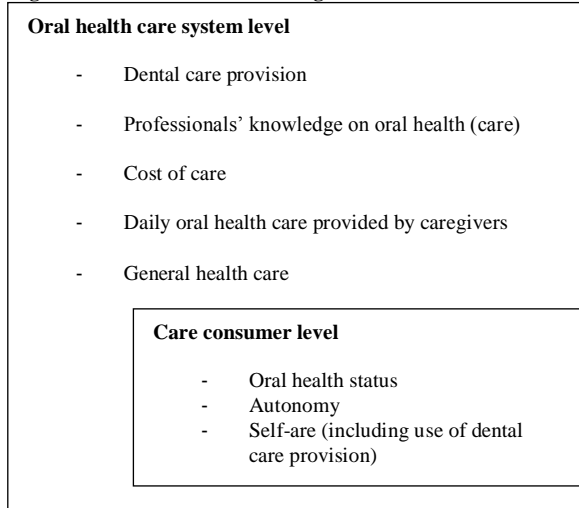


Figure 2: Sub-themes on two organizational levels within the main theme: ‘Current problems and needs’.

Figure 3: Sub-themes on two organizational levels within the



main theme: 'Future problems and needs, when getting (more) care dependent'.

Current problems and needs

'Care consumer level'

"Yes I also have a denture in my lower jaw... but it is just uncomfortable. But with what I have, I can eat without problems.... I put it in sometimes but on a certain moment it irritates me and I will put it in my pocket...It just does not fit... It is uncomfortable. I can eat.... I can eat everything I want.(focus group participant)".

The above quote indicates that focus group participants and interviewees appear to experience discomfort or problems with their *oral health status*, but do not acknowledge or report them as such. Focus group participants talked about elderly in the third person, as if it did not concern themselves, and indicated *oral health status* problems observed among other more dependent elderly, notably poor functionality of dentures, shame of oral conditions and dry mouth. One focus group participant felt she had lost control about choices in the dental treatment and therefore indicated problems with her *autonomy*.

The results of the interviewees supported the findings of the focus group: very few of the participants confirmed problems when asked

"Do you currently experience any oral health problems or needs?". The one person who participated in both the focus group and interview experienced problems with *or* *alself-care* because of her Arthrosis and sensory loss when holding the toothbrush and indicated that adapted toothbrushes were not available in the shops. Three interviewees pointed a few new topics concerning their *oral health status*: shrinking of the jaw bone, not being able to bite an apple and food impaction underneath the dentures, but they stated that they did not view these as problems.

"Yes.. I would say for five... for ninety percent.. There is always something to wish for, with dentures, it is often that something gets underneath...but these are things that are part of it. You just accept it, as long as I have no pain and can eat and drink everything...(interview 6)"

'Oral health care system level'

Focus group participants perceived the following problems with *dental care provision*: the unknown role of the dental hygienist, problems with finding a good dentist and the lack of instructions by oral health professionals. Focus group participants suggested to increase the *level of knowledge on patients and professionals*. They mentioned a lack of cooperation between different health workers (eg. general practitioner), including oral health professionals. All focus group participants indicated problems regarding *cost of dental care*; they viewed dental care as too expensive and they felt that it should be covered by their healthcare insurance. Participants expected that cooperation of oral care health professionals with other health care professionals would improve the cost-effectiveness of provided care.

Interviewees did not express problems with *provision of dental care*. They talked more about the importance to maintain oral *self-*

care, which includes the use of *dental care provision* and daily oral health care to assure an adequate functional dentition (without pain) and to keep their own teeth. They stressed the importance of *dental care provision* to prevent oral problems. However, it was recognized by the interviewer that consequences of poor oral health were unknown for most interviewees.

In the focus group all participants indicated problems to *cost of care*, while only one interviewee mentioned this and indicated that costs of oral health care actually withheld her from visiting the dentist.

"No, I think that it is really wrong that dental care is not in basic insurance, I think, yes until you are eighteen than it is insured, but after that age it is just as important. And people will quit going to the dentist. I think it is really a basic need... dental care, two times a year as minimum"(interviewee 5). Not all interviewees had an oral health care insurance. Those that had one did not experience financial barriers regarding oral health care. When they were asked, they indicated that they preferred coverage of oral health care by a basic health care insurance.

'Future oral health problems and needs, when getting (more) care dependent'

'Care consumer level'

Again, focus group participants discussed this theme as if it did not concern themselves as dependent elderly and indicated to anticipate oral health problems and needs they had seen with care dependent elderly, such as complications of oral *self-care* due to a lack of adapted oral hygiene equipment; *oral health status* problems such as discomfort of the dentures and difficulties to remove dentures fixed on implants. Loss of *autonomy* was a major concern for focus group participants and interviewees when getting care dependent, together with losing control, development of resistance, and loss

of dignity due to cognitive decline due to dementia.

"You should let people keep their dignity...give them the feeling that they can make their own decisions.. ask them what they want and what you are doing... Not in the third person to one of the caregivers: 'she should go in the chair'.. you have to say: 'Would you please go in the chair?' 'Then I can have a look in your mouth', for example... with respect... (interviewee 5)."

When interviewees were asked: *"How do you think oral health care and oral health will change if you will get more care dependent"*, they directly focused on solutions for maintenance of adequate oral health care in terms of *self-care* and use of *dental care provision*, instead of spontaneous indicating problems.

Interviewees did not seem to think about problems in maintaining daily oral health care and they appeared not aware of problems of disruption of oral care or *self-care* or its possible consequences. One interviewee expected that when she would become dependent in daily maintenance of her oral hygiene, and a homecare provider who would no longer brush her teeth, she would have to have all her teeth extracted.

'Oral health care system level'

On 'Oral health care system level', focus group participants reported problems which they had seen in their role as informal caregivers, notably with *daily oral health care by care givers* in homecare: little priority was given to oral health, a taboo rests on cleaning someone else's mouth, a lack of time and a lack of control moments by supervisors were mentioned. Some focus group participants themselves felt resistance to clean their relatives' mouth. In relation to this, they questioned whether *professionals' knowledge on oral health care* with respect to oral health care competencies and skills in

the education for home care professionals was sufficient.

According to focus group participants, more frequent and consistent oral health check-ups were needed to prevent problems. But they expected the costs of oral health care would pose a larger barrier when getting care dependent. With high care dependency, oral health care was anticipated as a lesser priority, especially without coverage by basic health care insurance. One solution mentioned for this was that oral health care would become an integral part of *general health care*, indicated that including basic oral health care screening performed by general practitioners would improve affordability and accessibility to professional oral health care. *Dental care provision* at home was also mentioned as possibility to improve access, and therefore contribute to easier oral health maintenance for more (care) dependent elderly.

As most interviewees maintained daily oral care themselves, they had no experiences with *daily oral care by caregivers*. Only one medium dependent interviewee with complete dentures received *daily oral care by home caregivers*. Similar to findings for the focus group, she mentioned that one caregiver was afraid to take the dentures out of her mouth and caregivers sometimes forget to clean her dentures.

“Yes, they (care givers) do it every day (clean dentures), but I have to take my dentures out by myself because she (care giver) finds that scary... She is afraid that I would swallow my dentures in...” (interviewee 10).”

Two interviewees also supported the findings from the focus group: a lack of control moments and supervision and insufficient *professionals’ knowledge on oral health care* and insufficient *daily oral health care provided by care by caregivers* were experienced.

Furthermore, interviewees stressed the importance maintaining an adequate level of oral health when getting (more) care dependent. The same sub-themes pointed out in the focus group appeared: *dental care provision* and *provision of daily oral health care by caregivers*. Interviewees distinguished daily oral health care by caregivers between: formal caregivers, family caregivers and nurse practitioners.

“Yes I have my wife of course.. and if I would not have my wife anymore, if I would live alone... and I would be in a wheelchair or something, I don’t know... Then would it be nice if I could get some help with it (brushing teeth) (interviewee 4).”

One interviewee disliked the idea of family cleaning her mouth.

Dental care provision at home was also mentioned by a few interviewees, while two other thought this was unnecessary and would rather prefer go to the practice. *Costs of care* was not mentioned as extra problem ‘when getting more care dependent’ by interviewees.

RESULTS OF THE QUANTITATIVE PART

The top five problems in oral health and oral health care for older people that respondents currently experienced and were prioritized the highest are: 1) dental care is not covered by the basic insurance, 2) dental care is too expensive, 3) shrinking of my jaws, 4) having a dry mouth and 5) the role of the dental hygienist is unknown. These aspects were also most often selected by the respondents and got the highest priority (see Table 4). That caregivers do not give enough instructions to older people about oral health and self care, was selected as problem by 13 participants, just as the unknown role of the dental hygienist. But the latter, was higher prioritized.

Table 4: Priorities and most selected problems by the questionnaire in the theme: ‘Current problems and needs’.

	Prioritization (N * weight)	N selected out of list of problems	Mean of prioritization (weight) (5=highly important, 1 less important)
Dental care is not in the basic insurance	113.9	32	3.6 (SD 1.5)
Dental care is too expensive	87.9	28	3.1 (SD 1.7)
Shrinking of my jaws	44.9	14	3.2 (SD 1.3)
Dry mouth	41.0	14	2.9 (SD 1.5)
Role of Dental hygienist is unknown	39.9	13	3.0 (SD 1.7)
Decrease of chewing ability	39.0	12	3.3 (SD 1.5)
Caregivers give not enough instructions about oral health	33.0	13	2.5 (SD 1.3)

The top five problems in oral health and oral health care for older people that respondents expected to perceive when they would get (more) care dependent are: 1) dental care is not in the basic insurance, 2) dental care is too expensive, 3) losing dignity in relation to oral health care, 4) having a dry mouth, 5) caregivers who have no time to clean my mouth. These aspects

were also most often selected by the respondents and got the highest priority (see Table 5).

For both the themes ‘Current problems and needs’ and ‘Future problems and needs, when getting (more) care dependent’, priority one, two, and five include the ‘Oral health care system level’, whereas priority three and four are on ‘Care consumer level’.

Table 5. : Priorities and most selected problems by the questionnaire in the theme: ‘Future problems and needs, when getting (more) care dependent’.

	Prioritization (N * weight)	N selected out of list of problems	Mean of prioritization (weight) (5=highly important, 1 less important)
Dental care is not in the basic insurance	84.0	25	3.3 (SD 1.8)
Dental care is too expensive	58.0	20	2.9 (SD 1.5)
Loosing dignity in relation to oral health care	48.1	17	2,8 (SD 1.3)
Dry mouth	44.0	16	2.8 (SD 1.3)
Caregivers who have no time to clean my mouth	45.0	15	3.0 (SD 1.5)
The influences of oral health on general health	42.0	14	3.0 (SD 1.3)
Shrinking of my jaws	35.0	12	2.9 (SD 1.2)

Out of the questionnaire, six respondents reported each one a new aspect, which were not mentioned in the focus group or interviews. These six items were: 1) to find a adequate toothbrush, 2) wear of the dentures, 3) eating too fast, 4) alteration of taste, 5) development of calculus and 6) forget to brush. These all were subsequently grouped under the sub-themes: self-care and oral health status.

DISCUSSION

This study investigated perceived *problems and priorities in oral health (care) among community dwelling older people in The Netherlands*, by means of a focus group, in-depth interviews and a questionnaire.

While during the interviews only one participant mentioned affordability of professional oral health care as a problem, the outcomes of the focus group discussions and questionnaire showed that most participants found this was the most important problem. Most interviewees had a dental care insurance as supplement to the basic health care insurance and therefore probably did not experience affordability of dental care as a problem. This was also confirmed by an article about barriers in utilization of oral health care in elderly, where having a dental insurance was a significant predictor of care utilization. ⁽²¹⁾

Focus group participants and interviewees expected the same problems in the future ‘when getting (more) care

dependent'. They mainly concerned losing autonomy i.e., maintaining preferences in oral health care, losing control of dental treatments and dignity. Losing dignity and self-esteem in relation to oral health care was also highly prioritized in the questionnaire 'when getting (more) care dependent'. These findings are supported by another study conducted in The Netherlands, investigating the impact of frailty on oral health care behavior. ⁽²²⁾ The authors argued that maintaining adequate oral health care in frail older people had mostly to do with self-worth, dignity and self-efficacy. Participants from the focus group and interviewees stressed the importance of daily oral health care by caregivers when they are not able to do it themselves. Niesten et al. (2012), confirms the importance of daily oral health care by caregivers which will contribute to feelings of self-worth and dignity in frail older people. ⁽²³⁾

Even in case of possible oral health discomfort, participants from the focus group and interviewees seem to be quite satisfied with their current oral health (care). This could be explained by the adaptation process of 'response shift': people create expectations about their lives, building on their experiences. ⁽²⁴⁻²⁶⁾ These participants seem to have certain expectations about their oral health and cope with discomfort. By accepting the discomfort, they adapt to the situation not influencing the participant's oral health related quality of life. ⁽²⁴⁻²⁶⁾ When individuals have other health problems, this might influence how participants experience their oral health. According to Sprangers & Schwartz (1999) internal standards, values and conceptualizations of life quality can change over time in a disease trajectory. ⁽²⁵⁾ Niesten et al. (2013) support these theories in frail older people by mentioning the secondary control strategies. It was stated that with increased frailty, people compare

themselves with others, their general health or their age. They adapt their judgment on what is 'healthy' by their age and oral health situation. ⁽²²⁾

Limitations and Strengths

To our knowledge this is the first study addressing individual perspectives on and priorities in oral health (care) of community dwelling elderly. In addressing our aim we used purposive sampling of participants and multiple methods for triangulation.

The sample from the NIVEL consumer panel may be rather selective and not optimal for our purpose, since it eventually did not include interviewees with either or both problems and dissatisfaction about their oral health. Also it did not provide sufficient spread for inclusion of the necessary anticipated dependency levels. This is probably due to inclusion of fit older people who are aware of their oral health. Nevertheless, saturation for the sub-themes was established. Perhaps a larger amount of data, i.e. a larger number of focus groups and interviews would allow more informative additional analysis with respect to different levels of care dependency (pre-, low, medium); different life course periods (at present and anticipated in future); and different levels of health care organization ('Oral health care system level' and 'Care consumer level').

Furthermore, conducting interviews with medium dependent older people was challenging. The higher the dependency scale of older people, the more cognitive problems like dementia were present, which made interviewing difficult. People with cognitive problems might be less capable to self-reflect on their oral health problems, which needs to be taken into account when interpreting the results. However, this was the case in only two participants in this study.

Agenda setting

When setting the agenda for oral health (care) in community dwelling older people and planning for future oral health care practice, it is important to take into account the experiences, views and expectations of community dwelling elderly. It is stated by literature, that there are differences in needs in oral health: 1) professionally defined need, 2) perceived need, 3) expressed demand, 4) and 'realistic need'.^(9,27) Thus, the perceived need and expressed demand seem to be low in the investigated population. However, the 'realistic need' is an ethical issue, balancing between what the dentist finds necessary and the wishes of the patient.

Awareness of the consequences of poor oral health on general health and wellbeing,⁽²⁸⁻³⁰⁾ may shape the perceptions of oral health from elderly, professionals and (in) formal caregivers and may motivate them to preserve oral health.⁽³¹⁻³³⁾ When oral health problems however are not a priority for elderly, a need for treatment will not be perceived, and the impact of providing treatment can be questioned for ethical and other reasons.⁽²⁷⁾ With respect to considering the need for treatment for community dwelling elderly, policy makers, researchers and (dental) professionals should take ethics into account.

Participants expect formal caregivers to maintain their daily oral health care when they are not able to do so themselves. However, in The Netherlands oral health care for community dwelling older people have to date not been properly organized. To find the most cost-effective way, which fit the needs of community dwelling older people, health services research is needed.

CONCLUSION

Our findings signify the importance of identifying problems and needs in oral health of community dwelling elderly. This

research shows that community dwelling elderly find maintenance of oral health important. Given the demographic changes in the population: views, perspectives, experience and expectations of community dwelling older people have major implications for policy and planning of future oral health care practice. It is important to take their perspectives and expectations into account when setting the agenda for oral health (care) in community dwelling older people, because these differ from the dental professionals' perspectives.

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BE: design and planning of study, collection and analyses of data, first draft; **KJ:** conception, design and planning of study, collection and analyses of data, editing of drafts; **GPF:** data collection and editing of drafts; **GH:** guarantor; design, planning and supervision of study, editing of drafts.

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Additional file 1

Appendix A – Nominal group technique used in the focus group

(i) Participants will take part in a facilitated discussion about the importance of oral health and how dental disease should be best prevented (at primary, secondary and tertiary levels of prevention). Specifically the questions to be answered will be:

- a. What aspects of oral health are important for you now?
- b. What aspects of oral health would be important to you as you loose your independence?
- c. How should we best prevent dental disease in older people?
- d. What does good dental care look like (as older people become increasingly dependent)?
- e. What would you fear happening to your mouth i.e. what negative outcomes would you want to avoid as you lose your independence?
- f. What are the important research questions to ask?
- g. How should success be measured?

(ii) Participants will first be asked to spend ten minutes on their own writing down their thoughts to the questions (a. to g.) above

(iii) Two sub-groups of participants will then be created (approximately four participants each)

(iv) In the sub-groups, each participant in turn will discuss their answers to each question, with the facilitator recording these views on a flip chart

(v) The sub-group will then be asked to discuss the responses

(vi) The responses will then be ranked by the sub-group in order of importance

(vii) The two sub-groups will then re-unite and the sub-group rankings will be presented to the large group by each facilitator

(viii) A final ranking will then be made by the whole group and after this has been undertaken the participants will be asked to distribute 100 tokens according to the perceived value of each response

Additional file 2

Appendix B – interview guide (translated into English)

Introduction of myself and the objective of the research

* Increasing community dwelling older people with natural teeth

* Research from ACTA about problems and priorities regarding oral health in community dwelling older people

* Focus on community dwelling older people perspective

'There is an increase of community dwelling older people who will keep their own dentition longer. From the ACTA we want to investigate your experiences regarding oral health and oral health care. We are interested in what you find important, so we can include that in future policy. There will be some questions about general aspects, your general health and oral health and oral health care'

Thank the participant for participation. Tell that the interview will last between 30 and 60 minutes. There might be a possibility that we will contact the participant after the interview to ask for clarification, on a time which suits the participant (till two months after the interview). Ask the participant for permission for audio-recording and for analyzing and reporting. The audio tapes will only be used for research and will be destroyed after the research. In the article, it will not be traceable which participant said what.

Let the participant read informed consent and answer their questions.

Explanation of oral health care and oral health. Oral health care indicates care which you or others (like the dentist or caregiver) will provide to keep your mouth healthy. Oral health is the health status of your mouth.

General information	
Name:	
Age:	
Profession:	
Chronic diseases:	
Marital status:	
To you perceive any personal/home care or help with cleaning?	
Tooth brushing moments a day:	
Dentist visits:	

1. General

- What do you do in daily life?
 - Daily activities
 - Partner
 - Care
 - Social life
- From the online questionnaire I retrieved some information about your health. Can you tell me how your health status influences your daily life?
 - Limitations in daily activities? Which?
 - Care seeking
 - Dependency

2. Oral health

- Can you tell me something about your (current) oral health status?
 - Satisfied, why yes/no?
 - Problems
 - Past
- What do you do to keep your mouth healthy?
 - Dentist/ dental hygienist
 - Brushing, flossing, using tooth picks
- Can you tell how your general health status influences your oral health?
 - Dependency on others
 - Physical limitations
 - Dry mouth
- What was dental care and oral health like in the past?
 - Brushing
 - Seeking dental care
 - Role of parents

- How would you describe the perfect oral health?
 - Functionality (eat/speech)
 - No pain
 - Esthetics
 - Did you accomplish this? Why?
 - What does that mean for you?
 - How could this have been accomplished?
- Are your thoughts about good oral health changed compared to the past?
 - How is this changed?
 - Experiences
 - Other problems
 - Care at home (new insights)
- Do you currently perceive any problems or needs regarding your oral health?
 - How do you experience this?
 - How should this be solved?
- Which changes have you experienced the last years in your mouth?
 - How did this happen?
 - Different care
 - Disease

3. Oral health care

- What does good oral health care looks like, to your opinion?
 - Going two times a year to the dentist
 - Brushing
 - Dental check ups at home
 - Is your demand for care fulfilled? Why yes/no?
 - Why is this important for you?
 - How should this be solved?
- Are your thoughts about good oral health care changed compared to the past? Did you have other ideals?
 - How did this change?
 - Experiences
 - Other problems
 - Care at home (new insights)
- How do you think, oral health care and oral health will change if you will get (more) care dependent?
 - Do you expect other needs?
 - Do you expect problems?
 - How should these be solved?
- Imagine, your physical and psychological capacity will decrease, whereby your oral health will worsen. How should (in) formal care and professionals take care of this?
 - Solutions
 - Force
 - Accept

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