

# **Diabetes prevalence among older people receiving care at home - associations with symptoms, health status and psychological well-being**

Running head: Diabetes prevalence among people receiving care at home

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## Novelty statement:

- Knowledge on the prevalence of diabetes among older persons receiving care at home is scarce.
- The prevalence of diabetes was 24%, and among those with diabetes, 14% were unaware of their diagnosis, and reported significantly poorer health status than those with known diabetes.
- Diabetes deserves increased case-finding efforts and allocation of resources to alleviate symptoms and burden of inadequate diabetes care at home.

## **Abstract (250 word)**

*Aims.* To determine the prevalence of diabetes among older people receiving care at home, and to explore differences in sociodemographic and clinical characteristics, symptoms, health status, quality of life and psychological well-being between different diabetes categories defined by glycated haemoglobin (HbA1c)  $\geq 48$  mmol/mol [6.5%] and/or self-report.

*Methods.* A community-based sample of 377 persons receiving care at home in Western Norway participated in a cross-sectional survey. Instruments included the MMSE-NR, Symptom Check-List, WHO Quality of Life-BREF (WHOQOL-BREF, two global items), EuroQol EQ-5D-5L/ EQ-5D-VAS, and WHO-Five Well-Being Index (WHO-5). Participants were grouped into four categories: no diabetes, only self-report, HbA1c  $\geq 48$  mmol/mol [6.5%] and self-report, and only HbA1c  $\geq 48$  mmol/mol [6.5%].

*Results.* Median age (interquartile range) was 86 (81-91) years and 34% were men. We identified 92 participants (24%) with diabetes. Diabetes was more prevalent in men compared to women (34% vs 20%, **age-adjusted p=0.005**). Among persons with diabetes, 14% were unaware of their diagnosis. There were significant differences in symptoms between the diabetes categories, with more symptoms (abnormal thirst, polyuria, genital itching, nausea, excessive hunger, perspiring, cold hands/feet, daytime sleepiness) among the groups with elevated HbA1c. Significant differences in WHO-5, WHOQOL-BREF and EQ-5D-5L between diabetes categories were identified, with poorest scores in the group with undiagnosed diabetes.

*Conclusions.* **There is a high percentage of older people with diabetes receiving care at home who are** unaware of their diagnosis. Diabetes deserves increased case-finding efforts and allocation of resources to alleviate symptoms and burden of inadequate diabetes care towards those receiving care at home.

*Keywords.* Elderly, epidemiology, screening

## Introduction

The prevalence of blood glucose lowering drug use increases with age (1), and both older age and diabetes increase the risk of disabilities (2). In Norway, the peak prevalence of blood glucose-lowering drug use in men is at age 76 years (12.4%) and in women at age 80 years (9.9%) (1).

Alterations in the health care system and in epidemiological patterns will presumably increase the number of people with diabetes receiving care at home, but knowledge of the prevalence of diabetes in such care is scarce. Internationally, the reported prevalence of diabetes among those receiving care at home has been estimated to be 27% in a US study and 30.6% in Germany (3, 4). In Norway, Jorde and Hagen (5) estimated the combined prevalence of diabetes amongst persons receiving care at home and in nursing homes to be 20.2%. Given the trend of rapid increase of number of people with diabetes worldwide, and diabetes as the leading cause of death and disability, further studies are needed to determine the prevalence of diabetes in populations that include very old people.

The ultimate goals for home care services are to maintain quality of life and functional status and to replace expensive hospital care and nursing homes with care delivered in the persons' home (6). However, home care service staff do not always have information about the patient's diagnoses and vital clinical information (7). Older people with diabetes are often characterized by progressive cognitive and functional decline (8) and poor psychological well-being (2, 9), all negatively influencing diabetes management. Older people with diabetes are at increased risk of urinary incontinence, cognitive and behavioural disturbances as well as falls due to hypoglycaemia episodes (10). Thus, diagnosed or undiagnosed, older people with diabetes living at home may have symptoms of diabetes affecting their general health and psychological well-being.

In order to manage their diabetes and compensate for higher risk of comorbidity and mortality, people with diabetes need closer follow-up and assistance compared to those without diabetes. One study in the US have already explored demographic and social characteristics of people with diabetes receiving care at home in the United States (11), as well as the individual's perspective in terms of unmet care needs (12). However, to our knowledge there are no published studies in which diabetes prevalence among people receiving care at home have been studied alongside clinical and self-reported information in order to explore diabetes care in the home care services. Awareness regarding the prevalence of diabetes and the association between diabetes and psychological well-being is needed in

order to adjust resources and increase competence in home care services. Thus, our aims were to:

- Determine the prevalence of diabetes, defined as glycated haemoglobin (HbA<sub>1c</sub>)  $\geq$  48mmol/mol [6.5%] and/ or self-report, among older people receiving care at home.
- Explore differences between diabetes categories (no diabetes, self-report only, HbA<sub>1c</sub>  $\geq$  48mmol/mol [6.5%] and self-report, and only HbA<sub>1c</sub>  $\geq$  48mmol/mol [6.5%]) regarding sociodemographic and clinical characteristics, self-reported symptoms, health status, overall quality of life and psychological well-being.

## Participants and Methods

### Study population

The study population was recruited among those receiving care at home, aged 65 years and older and living in the city of Bergen, Western Norway between May 2014 to March 2015. At the time of sample identification from the municipal electronic health records, this comprised 3,666 persons. Based on a power calculation for a t-test comparing the mean World Health Organization's Five Well-being index (WHO-5) between persons with and without diabetes with an allocation ratio of 1 to 5 and standard deviation 20, the required sample size was estimated to be 228 in order to detect a 10 point difference with 80% power and 5% significance level. Due to the frailty in this population, a previously reported low participation rate (30%) in a similar population sample (5), and in order to get sufficient statistical power to allow for adjustment for age and gender, 1,100 persons were randomly selected by stratified sampling according to the population size in each of the municipality's 10 zones. Registered nurses with knowledge of the people screened each identified person. Exclusion criteria were terminal/palliative care or serious medical condition, transfer to permanent residency at a nursing home, no longer receiving care at home after the random selection or severe cognitive impairment (The Norwegian Revised Mini Mental State Examination, MMSE-NR < 9). In addition, 113 persons died between the time of sampling and start of the study. In total, 677 persons were found eligible for participation. See supplemental Figure 1 for flow diagram of recruitment and exclusions. After initial information by a home care services' nurse, one of the three trained study nurses asked for consent and collected the data. With 298 persons declining participation and 2 excluded during or after data collection (1 with MMSE-NR<9 and 1 withdrawal), 377 persons (55.7%) were finally included. Of these, four did not

complete the full questionnaire and were therefore excluded from some analyses (see Table 3 and Table 4).

## Measures

HbA<sub>1c</sub> was measured in a capillary blood sample, and a structured interview using a self-reported questionnaire was conducted. The questionnaire was initially piloted on five persons, confirming the comprehensibility of the content and the feasibility of the procedure for data collection. All data were collected from May 2014 to March 2015 in the persons' homes.

HbA<sub>1c</sub> was obtained by analysing capillary blood samples spectrophotometrically using a DCA Vantage™ Analyzer (Siemens Healthcare Diagnostics AS, Norway). Three machines with identical settings and reagent kits with identical batch and LOT numbers were used. To ensure precision and accuracy of the machines, both internal and external quality control tests were performed regularly throughout the data collection period. In accordance with the WHO recommendations (13), HbA<sub>1c</sub> of 48 mmol/mol [6.5%] or higher was used as diagnostic criteria for diabetes. Although two measurements above the cut-off are usually recommended for a clinical diagnosis of diabetes in asymptomatic individuals, one such measurement is usually considered sufficient in epidemiological studies. Self-reported and unknown diabetes were identified by the question “do you have, or have you ever had, diabetes?” This question has shown satisfactory validity and reliability (14).

The MMSE-NR, a 30-item questionnaire, revised and translated into Norwegian (15), was used to assess cognitive status. A score greater than or equal to 27 indicates normal cognition.

The Symptom Check-List (TSCL), a 19-item questionnaire regarding symptoms such as headache, abnormal thirst and excessive urination was used to assess symptoms associated with diabetes. Respondents reported symptoms within the last week from 1 (never) to 5 (every day). The questionnaire has been translated and used in previous studies in Norway (16). Symptom score was calculated both as the total number of symptoms present the last week and as the mean of the 19 items.

Two global items from the WHO Quality of Life-BREF (WHOQOL-BREF) (17); Overall quality of life and General health were used. Both are rated on a five point Likert scale with higher scores indicating better overall quality of life or general health. The questionnaire has been translated into Norwegian and has shown satisfactory psychometric properties (18).

The EuroQol EQ-5D-5L (19) was used to measure health status. The instrument consists of five items measuring general health status such as mobility, self-care, usual activities, pain/discomfort and anxiety/depression, measured on a Likert scale from 1-5 with higher scores indicating more difficulties in task performance, and elevated pain or anxiety. The response to these five items jointly formed an overall health status, which was further translated into a EQ-5D-5L utility index value summarizing the health status from below zero (a condition worse than death), 0 (equivalent to death) and up to 1 (full health) (20). As per august 2016 there are EQ-5D-5L value sets available for seven countries, where value sets from England (20) were used due to the nearest proximity with Norway. EQ-5D also comprises a visual analogue scale (EQ-5D-VAS), measuring self-reported health status from 1 (worst possible health) to 100 (best possible health) on the day of the survey.

The WHO-Five Well-Being Index (WHO-5) was used to measure psychological well-being (9) by means of five positively worded items reported on a six-point Likert scale ranging from 0 (not present) to 5 (constantly present). An overall score was calculated as the sum of the five items and rescaled to values ranging from 0 (worst thinkable well-being) to 100 (best thinkable well-being). WHO-5 has been shown to be a psychometrically sound measure of well-being (21) and the construct validity has been evaluated as satisfactory (9).

We measured internal consistency of multi-item questionnaires with Cronbach alpha coefficients for persons with and without diabetes; the coefficients were 0.72 and 0.68 for TSCL, 0.74 and 0.64 for WHO-5, 0.77 and 0.67 for EQ-5D-5-L, respectively.

### Ethical considerations

The Regional Committee for Medical and Health Research Ethics approved the study (2013/2258/REK vest). Each individual was informed of the study, asked to give consent, and informed that they could withdraw their consent at any time. Confidentiality was assured by using identification numbers. In the case where an elevated HbA<sub>1c</sub> was identified, the information was sent to the person's general practitioner.

### Statistical analyses

Diabetes was defined as either self-reported diabetes or HbA<sub>1c</sub>  $\geq$  48 mmol/mol [6.5%]. Diabetes prevalence with 95% CI was estimated for the total sample, for men and women separately, and for 10-year age groups using an offset-only Generalized Linear Model (GLM) with identity link and binomial distribution. Differences in prevalence between men and

women were also tested for significance using GLM with gender as a covariate with adjustment for age.

Descriptive statistics were used to compute frequencies and percentages for categorical variables and means and standard deviations (SD) for continuous variables. Comparisons between diabetes categories (no diabetes,  $HbA_{1c} \geq 48\text{mmol/mol}$  [6.5%] and self-report, only self-report and only  $HbA_{1c} \geq 48\text{mmol/mol}$  [6.5%]) were performed using Exact Fishers Chi squared test (categorical variables) and one way ANOVA (continuous variables). Levene's test for homogeneity of variance showed non-significant difference in variance between groups for all analyses. Inspection of normal Q-Q plots of standardized residuals showed small deviations from normality. To confirm the results from the ANOVA we therefore did a non-parametric Kruskal-Wallis test. The Kruskal-Wallis tests yielded the same conclusions as ANOVA and we have therefore only included the results for the ANOVA-analyses. We adjusted for age and sex using binary logistic or multinomial logistic regression (categorical variables) and ANCOVA (continuous variables). When testing the 19 symptoms from the Symptom Check-List we corrected the obtained p-values for multiple testing using the Benjamini-Hochberg procedure (22). All analyses were performed with SPSS software (Version 23; IBM Corp., Armonk, NY, USA) except for correction of p-values for multiple testing which was done using the multtest procedure in SAS version 9.4 (SAS Institute Inc., Cary, NC, USA).

## Results

The median age (IQR) for the participants was 86 years (81-91) and 34% (n=127) were men. Information available to compare participants with those excluded and those who declined participation included age (85, 85 and 86 years, respectively;  $p=0.21$ ) and gender distribution (men: 33.7%, 39.1% and 24.5%, respectively;  $p< 0.001$ ). Although gender distribution was significantly different between participants and non-participants, the percentage of men in the study sample and the total eligible sample (N= 1100) was not (33.7% versus 33.3%). Only one person was excluded due to an MMSE-NR score below 9. Mean MMSE-NR score in the total sample (N= 377) was 23.8 (4.4) with non-significant difference between people with and without diabetes ( $p=0.50$ ).

We identified 92 participants with diabetes (24% [95% CI: 20, 29]). Diabetes was more prevalent in men (34% [95% CI: 26, 42] compared to women (20% [95% CI: 15, 25]), (age adjusted p-value 0.005, not shown in tables). Especially for women, the prevalence of diabetes declined with age. Table 1. summarizes the prevalence according to gender and ten-

year age groups. The number of diabetes cases identified by 1) only self-reported was  $n= 27$ , 2) both self-reported diabetes and  $HbA_{1c} \geq 48\text{mmol/mol}$  [6.5%] was  $n= 52$ , and 3) only  $HbA_{1c} \geq 48\text{mmol/mol}$  [6.5%] was  $n= 13$ . Among the 27 participants with only self-report, a diabetes diagnosis was verified in 23 when checking against medical records, leaving 4 who **were** not verified. Figure 1 shows the number of persons in five-year age groups by diabetes status.

Sociodemographic and clinical characteristics are shown in Table 2, stratified by diabetes categories. We found that 21 of the 27 persons with self-reported diabetes and an  $HbA_{1c}$  below  $48\text{mmol/mol}$  [6.5 %] were pharmacologically treated for diabetes, of whom five were using insulin. Further, among the persons with diabetes, 14 % had elevated  $HbA_{1c}$  without being aware of this diagnosis, with  $HbA_{1c}$  ranging from 48-68  $\text{mmol/mol}$  [6.5- 8.4 %]. For the two groups with elevated  $HbA_{1c}$  combined the values ranged from 48-107  $\text{mmol/mol}$  [6.5 -11.9 %] with 75 % below 64  $\text{mmol/mol}$  [8%], and 40 % below 53  $\text{mmol/mol}$  [7%].

There were significant differences in self-reported diabetes-related symptoms between the diabetes categories, with the two groups with elevated  $HbA_{1c}$  reporting the highest number of symptoms (Table 3). **Pairwise comparisons for total number of symptoms and mean symptom score showed significant differences between the group without diabetes and the group with both self-reported diabetes and  $HbA_{1c} \geq 48\text{mmol/mol}$  [6.5%] (Supplemental Table 1 and 2).**

Further, we found significant differences in psychological well-being (WHO-5), overall health perception (WHOQOL-BREF 1item) and health status (EQ-5D-5L index value) between diabetes categories (Table 4); those with undiagnosed diabetes reported lower psychological well-being, poorer overall health and health status compared to the other categories. Pairwise comparisons showed significant differences between the group with undiagnosed diabetes and all of the three other groups for EQ-5D, but not for the other outcomes (Supplementary tables 3-7).

When collapsing all three groups with diabetes into one group and comparing this with the group without diabetes we found significantly higher number of symptoms (**unadjusted**  $p<0.001$ ), higher mean symptom score (**unadjusted**  $p<0.001$ ), poorer WHOQOL-Overall health (**unadjusted**  $p=0.03$ ), poorer EQ-5D-5L (**unadjusted**  $p=0.03$ ) and poorer WHOQOL-overall quality of life (**unadjusted**  $p=0.045$ ) in the diabetes group. There were no significant differences between these two groups with regard to EQ VAS (**unadjusted**  $p=0.15$ ) and psychological wellbeing ( $p=0.12$ ).



## Discussion

The overall prevalence of diabetes among people receiving care at home was 24%. About 42% of men age 76-85 years had diabetes, indicating an increased need for diabetes treatment resources. The overall prevalence is similar to the prevalence reported for those who received care at home and in residential care homes combined in Tromsø, Norway (5), and in Dresden, Germany (4). In contrast, Caffrey et.al (3) found a prevalence of 30.6%, exceeding the 95% CI found in our study. It is possible that the diabetes prevalence of 24% found in our study may be underestimated, as a high proportion of the persons excluded were frail. Because older people with diabetes have an increased risk of mortality compared to same-age persons without diabetes (23), the lower prevalence of diabetes in the oldest age group in our study could be due to survival bias. In addition, we found **a higher prevalence of diabetes in men in our study population (in the age group 86-102 years the prevalence in men was 30% and in women 14%, Table 1)**. A possible explanation is that men with diabetes have an increased risk of late complications compared to women (24, 25) and hereby are more prone to receive care at home earlier than women. Furthermore, women with diabetes have a significant higher excess mortality compared to men (26) and are thus perhaps underrepresented in higher age groups in the home care services. In the youngest age groups there were no participants with  $HbA1c \leq 6.5\%$  only (undiagnosed diabetes). We believe that this is a chance finding due to the low number of participants in this age group. These are rather young people compared to the regular receivers of care at home. However, due to their poor health status one explanation might be that they receive care at home based on an extensive diagnostic examination and thus having been made aware of their diabetes.

There are significant differences in the living situation between participants with and without diabetes. The proportion living alone is higher among persons without diabetes compared to persons with diabetes. This might be due to a selection mechanism through which persons with diabetes who live alone and have functional decline, to a larger extent get transferred to residential care homes. They do not have carers who can compensate for their decreasing ability to manage their diabetes (27).

We found that 14% of persons with diabetes were unaware that they had the diagnosis indicating the need for more intensive case-finding efforts (screening and referral for diagnosis). The proportion of diabetes-cases that was undiagnosed is considerably lower than what is estimated for the general population (1, 23). The fact that our study is based on a

population receiving health care service might explain this, as they are more likely to have been screened for diabetes.

Compared to persons with known diabetes, a higher proportion of persons with undiagnosed diabetes reported symptoms related to hyperglycaemia such as abnormal thirst, genital itching and vertigo. These are all symptoms that may be avoided with appropriate diagnosis and treatment for diabetes. As the symptom burden of diabetes may impair quality of life and functioning (28), it is important to uncover diabetes and thus prevent symptoms.

In contrast to findings reported by Jørgensen et.al. (29), those with undiagnosed diabetes reported significantly poorer health status than those with known diabetes. The former group also reported poorer overall health and psychological well-being compared to the other diabetes categories, however this difference was not statistically significant. Total mean WHO-5 score for the group without diabetes and those with undiagnosed diabetes were 62.5 and 48.9, respectively. This difference is considered clinically significant (9). Moreover, with a score under 50, those with undiagnosed diabetes are characterized as having poor well-being, and further assessment for clinical depression might be indicated (9). Compared to results from The Diabetes Attitudes, Wishes and Needs second study (DAWN2) where a mean WHO-5 score of 58.0 (SD 23.4) were found, the group with HbA1c  $\geq$  48 mmol/mol [6.5%] and self-reported diabetes in our study showed similar results (57.9 [SD 22.9]).

### **Clinical implications**

Preventing long-term complications in a population of older people may not be the primary priority in most of these elderly and care-needing people receiving care in their homes. Treatment and care should primarily focus on avoiding burdensome symptoms and promoting overall health and well-being. We argue that an increased focus on finding persons with undiagnosed diabetes receiving care at home for treatment and care is important. Moreover, allocation of more resources to alleviate symptoms and burden of inadequate diabetes care could prevent diabetes related symptoms and improve psychological well-being. Promoting high quality care calls for competent personnel, capable to implement reliable screening instruments and relevant risk assessment tools to better identify disease burden and long-term care needs.

### **Strengths and limitations**

As far as we know, this is the first study examining the prevalence of previously known and unknown diabetes among people receiving care at home in Norway and assessing the impact

of diabetes on symptoms, health status, overall quality of life and psychological well-being. The random sampling from all ten municipality zones in Bergen increases the representativeness of the sample and the use of HbA<sub>1c</sub> values as diagnostic criteria ensures a valid definition of diabetes.

Limitations of the study include the observational nature that precludes conclusions concerning causal relationships. Furthermore, we did not collect information on diabetes type, duration of diabetes, medications other than glucose lowering medications, other factors that could affect HbA<sub>1c</sub> (such as anaemia and other disturbances in erythropoiesis), medications that might influence glucose metabolism (e.g corticosteroids), vascular complications or comorbidity status and frailty. People receiving care at home will have a significant disease burden and long-term care needs which all counts when symptom burden and quality of life is measured. Given this, the severity of diabetes, measured by long-term complications would have given more details in describing the participants' health status.

Mean MMSE-NR score in the sample was low, at 23.8, and as cut-offs of 23/24 have been used to indicate cognitive impairment (30), one could question the reliability of the questionnaires in the present study. However, MMSE-NR is a measure of cognitive function, not a diagnostic test, and a score below 24 merely indicates that further testing should be performed. Only 4% of the study population had MMSE<15. A low score may also be due to loss of hearing, poor eyesight or other factors (15). Other limitations are that almost half of our researched population were excluded because of terminal/palliative care or serious medical condition, transfer to permanent residency at a nursing home, dead or no longer receiving care at home after the sampling. The exclusion of these persons from the final study population may have caused an underestimation of the prevalence of diabetes. The study was originally powered to compare only two groups: Those with diabetes versus those without. Since we have further divided the diabetes group into three categories the sample size for some groups are small, especially the group with high HbA<sub>1c</sub> and no self-report (n=13). The study therefore does not have sufficient statistical power to detect differences between this and the other groups, **especially for single symptoms in Table 4 where the number of events are very low for some of the symptoms**. Finally, the number of comparisons done in the analyses is high and this may have resulted in some chance findings. We have adjusted for multiple testing in the post-hoc tests after ANOVA and also when comparing multiple symptoms between groups, but there is still a risk of Type I error, especially for tests with p-values close to 0.05.

In conclusion, we found that having diabetes, either diagnosed or undiagnosed, was associated with more symptoms and poorer health status in this community-based study of people receiving care at home. The prevalence of diabetes was high, 24%, and 14% of those classified as having diabetes were previously undiagnosed. Diabetes constitutes a large burden of disease among those receiving care at home and deserves increased case-finding efforts and allocation of resources to alleviate symptoms and burden of inadequate diabetes care in people receiving care at home.

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## Conflict of interest

Author MP declare the following potential conflicts of interest: consulting fees from Becton Dickinson, Calibra, Lilly, and Novo Nordisk; advisory panel of Calibra and Lilly; research grants from Novo Nordisk; speaker for Novo Nordisk and Valeritas. The remaining authors declare that they have no conflict of interest.

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## References

1. Strom H, Selmer R, Birkeland KI, Schirmer H, Berg TJ, Jenum AK, et al. No increase in new users of blood glucose-lowering drugs in Norway 2006-2011: a nationwide prescription database study. *BMC Public Health* 2014; 14: 520.
2. Wong E, Backholer K, Gearon E, Harding J, Freak-Poli R, Stevenson C, et al. Diabetes and risk of physical disability in adults: a systematic review and meta-analysis. *Lancet Diabetes Endocrinol* 2013; 1: 106-114.

3. Caffrey C, Sengupta M, Moss A, Harris-Kojetin L, Valverde R. Home health care and discharged hospice care patients: United States, 2000 and 2007. 2011 27 Apr.
4. Coll-Planas L, Bergmann A, Schwarz P, Guillen-Grima F, Schulze J. [Quality of care among older adults with diabetes mellitus: comparison between community-dwelling adults attended to by home care services and nursing home residents in Dresden]. *Z Arztl Fortbild Qualitatssich* 2007; 101: 623-629.
5. Jorde R, Hagen T. Screening for diabetes using HbA1c in elderly subjects. *Acta Diabetolog* 2006; 43: 52-56.
6. Thomé B, Dykes A, Hallberg IR. Home care with regard to definition, care recipients, content and outcome: systematic literature review. *J Clin Nurs* 2003; 12: 860-872.
7. Bowles KH, Pham J, O'Connor M, Horowitz DA. Information deficits in home care: a barrier to evidence-based disease management. *Home Health Care Manage Pract* 2010; 22: 278-285.
8. Sinclair AJ, Girling AJ, Bayer AJ. Cognitive dysfunction in older subjects with diabetes mellitus: impact on diabetes self-management and use of care services. All Wales Research into Elderly (AWARE) Study. *Diabetes Res Clin Pract* 2000; 50: 203-212.
9. Topp CW, Ostergaard SD, Sondergaard S, Bech P. The WHO-5 Well-Being Index: a systematic review of the literature. *Psychother Psychosom* 2015; 84: 167-176.
10. Sinclair A, Dunning T, Rodriguez-Mañas L. Diabetes in older people: new insights and remaining challenges. *Lancet Diabetes Endocrinol* 2015; 3: 275-285.
11. Resnick HE. Diabetes among recipients of home health services in the United States. *Home Health Care Manage Pract* 2012; 24: 234-241.
12. Lee JS. The unmet needs of the elderly with diabetes in home health care. *Soc Work Health Care* 2007; 45: 1-17.
13. WHO. Use of glycated haemoglobin (HbA1c) in the diagnosis of diabetes mellitus. Abbreviated report of a WHO consultation Geneva: WHO; 2011.
14. Midthjell K, Holmen J, Bjørndal A, Lund-Larsen PG. Is questionnaire information valid in the study of a chronic disease such as diabetes? The Nord-Trøndelag diabetes study. *J Epidemiol Community Health* 1992; 46: 537-542.
15. Strobel C, Engedal K. MMSE-NR. Norwegian revised mini mental status evaluation. Revised and expanded manual. 2008.
16. Iversen M, Hanestad BR. Educational needs, metabolic control and self-reported quality of life; A study among people with type 2 diabetes treated in primary health care. *Eur Diabetes Nursing* 2005; 2: 11-16.
17. WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med* 1998; 28: 551-558.
18. Hanestad BR, Rustøen T, Knudsen Ø, Jr., Lerdal A, Wahl AK. Psychometric properties of the WHOQOL-BREF Questionnaire for the Norwegian general population. *J Nurs Meas* 2004; 12: 147-159.
19. Herdman M, Gudex C, Lloyd A, Janssen MF, Kind P, Parkin D, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res* 2011; 20: 1727-1736.
20. Devlin N, Shah K, Feng Y, Mulhern B, Van Hout B. Valuing Health-Related Quality of Life: An EQ-5D-5L Value Set for England 2016 [cited 2016 October 7]. Available from: <https://www.ohe.org/publications/valuing-health-related-quality-life-eq-5d-5l-value-set-england>.
21. Hajos TR, Pouwer F, Skovlund SE, Den Oudsten BL, Geelhoed-Duijvestijn PH, Tack CJ, et al. Psychometric and screening properties of the WHO-5 well-being index in adult outpatients with Type 1 or Type 2 diabetes mellitus. *Diabet Med* 2013; 30: e63-e69.

22. Benjamini Y, Hochberg Y. Controlling the false discovery rate: a practical and powerful approach to multiple testing. *J Roy Stat Soc B Met* 1995; 289-300.
23. International Diabetes Federation. *IDF Diabetes Atlas*, 8th edn. Brussels, Belgium: International Diabetes Federation; 2017.
24. Molvær AK, Graue M, Espehaug B, Østbye T, Midthjell K, Iversen MM. Diabetes-related foot ulcers and associated factors: Results from the Nord-Trøndelag Health Survey (HUNT3)(2006–2008). *J Diabetes Complications* 2014; 28: 156-161.
25. Pugliese G, Solini A, Bonora E, Fondelli C, Orsi E, Nicolucci A, et al. Chronic kidney disease in type 2 diabetes: lessons from the Renal Insufficiency and Cardiovascular Events (RIACE) Italian Multicentre Study. *Nutr Metab Cardiovasc Dis* 2014; 24: 815-822.
26. Allemann S, Saner C, Zwahlen M, Christ E, Diem P, Stettler C. Long-term cardiovascular and non-cardiovascular mortality in women and men with type 1 and type 2 diabetes mellitus: a 30-year follow-up in Switzerland. *Swiss Med Wkly* 2009; 139: 576-583.
27. Sinclair AJ, Armes DG, Randhawa G, Bayer AJ. Caring for older adults with diabetes mellitus: characteristics of carers and their prime roles and responsibilities. *Diabet Med* 2010; 27: 1055-1059.
28. Ludman EJ, Katon W, Russo J, Von Korff M, Simon G, Ciechanowski P, et al. Depression and diabetes symptom burden. *Gen Hosp Psychiatry* 2004; 26: 430-436.
29. Jorgensen P, Langhammer A, Krokstad S, Forsmo S. Diagnostic labelling influences self-rated health. A prospective cohort study: the HUNT Study, Norway. *Fam Pract* 2015; 32: 492-499.
30. Sheehan B. Assessment scales in dementia. *Ther Adv Neurol Disord* 2012; 5: 349-358.

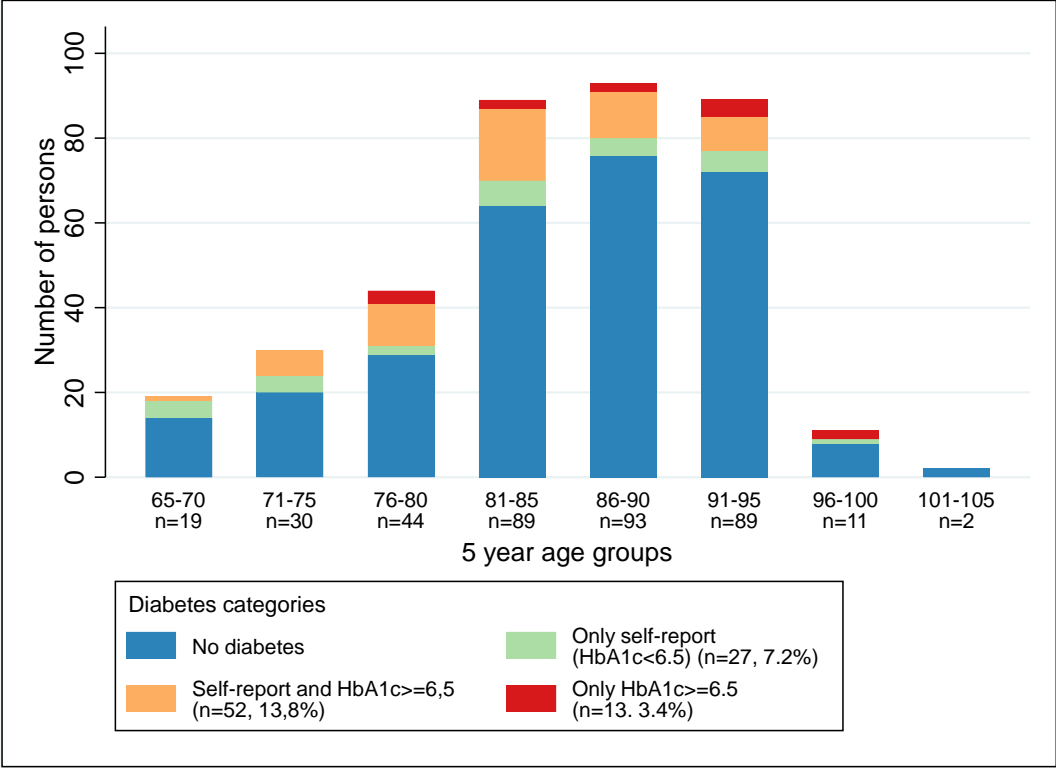
**Table 1:** Prevalence of diabetes (self-reported and/ or HbA1c  $\geq$  48 mmol/mol [6.5%] by gender and ten year age groups

	Total		Age group (years)					
			66-75		76-85		86-102	
	N Diabetes/ N total	Percent (95% CI)	N Diabetes/ N total	Percent (95% CI)	N Diabetes/ N Total	Percent (95% CI)	N Diabetes/ N Total	Percent (95% CI)
<b>Total</b>	92*/377	24 (20 to 29)	15/49	31 (18 to 44)	40/133	30 (22 to 38)	37/195	19 (14 to 25)
<b>Men</b>	43/127	34 (26 to 42)	5/21	24 (6 to 42)	21/50	42 (29 to 56)	17/56	30 (18 to 42)
<b>Women</b>	49/250	20 (15 to 25)	10/28	36 (18 to 54)	19/83	23 (14 to 32)	20/139	14 (9 to 20)

Proportions and confidence intervals are estimated using an offset-only Generalized Linear Model with identity link and binomial distribution.

\* only self-report; n= 27, self-report and HbA1c  $\geq$  48 mmol/mol [6.5%]; n= 52, only HbA1c  $\geq$  48 mmol/mol [6.5%]; n= 13

**Figure 1:** Number of individuals with diabetes in each age group by diabetes category (N=377)





**Table 2:** Sociodemographic and clinical characteristics by diabetes category (N=377)

	No diabetes		Diabetes		P*	P-adjusted**
		Only self-report (HbA1c < 48 mmol/mol [6.5%])	HbA1c ≥ 48 mmol/mol [6.5%] and self-report	Only HbA1c ≥ 48 mmol/mol [6.5%]		
<b>n</b>	285	27	52	13		
<b>Age, Mean (SD)</b>	86 (7)	83 (9)	83 (7)	87 (7)	<b>0.03</b>	<b>0.06</b>
<b>Age, median (IQR***)</b>	86 (81-91)	82 (75-91)	84 (79-88)	86 (81-93)		
<b>Gender, n (%)</b>						
Men	84 (30)	10 (37)	28 (54)	5 (39)		
Women	201 (71)	17 (63)	24 (46)	8 (62)	<b>0.01</b>	<b>0.02</b>
<b>Living situation, n (%)</b>						
Living alone	240 (84)	19 (70)	29 (56)	9 (69)		
Living with others	45 (16)	8 (30)	23 (44)	4 (31)	<b>&lt;0.001</b>	<b>0.002</b>
<b>Education, n (%)</b>						
Primary school	160 (56)	20 (74)	28 (55)	2 (15)		
High school	78 (27)	4 (15)	14 (27)	4 (31)		
≥ 4 years higher education	47 (17)	3 (11)	9 (18)	7 (54)	<b>0.01</b>	<b>0.004</b>
<b>HbA1c, mean (SD)</b>						
mmol/mol	38 (4)	42 (3)	61 (14)	52 (6)	NA****	NA
%	5.6 (0.3)	6.0 (0.3)	7.7 (1.3)	6.9 (0.6)	NA	NA
<b>Using insulin, n (%)</b>		5 (19)	26 (50)		0.007	0.008
<b>Using non-insulin diabetes medications, n(%)</b>		16 (68)	34 (64)		0.80	0.73
<b>Non-pharmacological Treatment/ Diet only, n(%)</b>		9 (33)	7 (13)		0.07	0.04

All reported percentages are column percentages. Four persons had missing values on the question about non-insulin medication and percentages are calculated among those who had valid values. \*Oneway-ANOVA for continuous variables and exact Fishers Chi squared test for categorical variables \*\* Adjusted for age and sex (where applicable)

using logistic regression for all outcomes except for education where multinomial logistic regression was used and for age where ANCOVA was used. \*\*\*IQR=interquartile range. \*\*\*NA=Not applicable.

**Table 3:** Self-reported symptoms (TSCL<sup>a</sup>) associated with diabetes, by diabetes category (N=373)

	No diabetes	Diabetes			P*	P-adjusted**
		Only self-report (HbA1c < 48 mmol/mol [6.5%])	HbA1c ≥ 48 mmol/mol [6.5%] and self-report	Only HbA1c ≥ 48 mmol/mol [6.5%]		
n	282	27	51	13		
Symptoms <sup>b</sup> , n (%)						
Headache	63 (22)	7 (26)	19 (37)	4 (31)	0.22	0.27
Urinating at night	144 (51)	15 (56)	36 (71)	7 (54)	0.16	0.13
Abnormal thirst	49 (17)	6 (22)	19 (37)	6 (46)	<b>0.01</b>	<b>0.02</b>
Blurry vision	84 (30)	5 (19)	22 (43)	5 (39)	0.19	0.18
Polyuria, daytime	57 (20)	12 (44)	23 (45)	3 (23)	<b>&lt;0.001</b>	<b>&lt;0.001</b>
Palpitation	39 (14)	3 (11)	12 (24)	2 (15)	0.38	0.39
Genital itching	28 (9.9)	5 (19)	11 (22)	4 (31)	0.05	0.06
Nausea	32 (11)	5 (19)	15 (29)	4 (31)	<b>0.02</b>	<b>0.02</b>
Vertigo	119 (42)	9 (33)	22 (43)	8 (62)	0.46	0.45
Vomiting	6 (2.1)	0 (0)	1 (2.0)	0 (0)		
Exhausted	107 (38)	15 (56)	24 (47)	6 (46)	0.30	0.36
Excessive hunger	11 (3.9)	2 (7.4)	10 (20)	0 (0)	<b>0.01</b>	<b>0.02</b>
Abnormal perspiring	30 (11)	3 (11)	14 (28)	3 (23)	<b>0.04</b>	0.05
Tremor	59 (21)	7 (26)	17 (33)	2 (15)	0.30	0.35
Cold hands or feet	100 (36)	11 (41)	28 (55)	2 (15)	0.05	0.05
Daytime sleepiness	195 (69)	20 (74)	46 (90)	11 (85)	<b>0.04</b>	0.06
Joint pain	105 (37)	11 (41)	21 (41)	6 (46)	0.90	0.91
Sensation of tingling and needles	46 (16)	6 (22)	16 (31)	4 (31)	0.11	0.13
Weakness, loss of consciousness	12 (4.3)	1 (3.7)	6 (12)	1 (7.7)	0.22	0.22
Total number of symptoms present	4.5 (3.2)	5.3 (3.40)	7.0 (3.7)	6.0 (3.8)	<b>&lt;0.001</b>	<b>&lt;0.001</b>
<b>per person, mean (SD)</b>						
Mean score, <b>mean (SD)</b>	1.6 (0.5)	1.7 (0.5)	2.0 (0.6)	1.9 (0.5)	<b>&lt;0.001</b>	<b>&lt;0.001</b>

<sup>a</sup> TSCL= The Symptom Check List, 19 variables from 1-5 with higher score indicating more frequent symptoms.

<sup>b</sup> Presence of symptoms defined as experience of symptoms at least one day during the last week presented as n (%). \* Exact Fishers chi squared test for single symptoms and one-way ANOVA for total number of symptoms and mean symptom score (mean of 19 items). \*\*Adjusted for age and sex using logistic regression for single symptoms and ANCOVA for total number of symptoms and mean symptom score. All p-values adjusted for multiple testing using the Benjamini-Hochberg procedure. **P-values not reported for vomiting because of low number of events.**

**Table 4:** Self-reported health status (WHOQOL Overall Health, EQ-5D-5L, EQ-VAS), quality of life (WHOQOL Overall QOL) and psychological well-being (WHO-5) by diabetes category (N=377<sup>a</sup>)

	No diabetes		Diabetes		P*	P**
		Only self-report (HbA1c < 6.5%)	HbA1c ≥ 6.5% and self-report	Only HbA1c ≥ 6.5%		
n	285	27	52	13		
WHOQOL Overall Health <sup>b</sup> , mean(SD)	3.3 (0.9)	3.3 (0.9)	3.1 (0.9)	2.7 (1.0)	<b>0.04</b>	<b>0.03</b>
EQ-5D-5L index value <sup>c</sup> , mean(SD)	0.9 (0.2)	0.9 (0.2)	0.8 (0.2)	0.7 (0.3)	<b>0.004</b>	<b>0.04</b>
EQ VAS <sup>d</sup> , mean(SD)	65.0 (21.6)	60.9 ( 24.0)	62.2 (24.5)	56.9 (26.8)	0.45	0.54
WHOQOL Overall QOL <sup>b</sup> , mean(SD)	3.5 (0.9)	3.6 (1.0)	3.21 (1.0)	3.1 (0.8)	0.06	0.06
WHO-5 <sup>e</sup> , mean(SD)	62.5 (19.0)	65.3 (20.9)	57.9 (22.9)	48.9 (19.6)	<b>0.03</b>	<b>0.02</b>

\*Oneway-ANOVA \*\*Adjusted for age and sex using ANCOVA

<sup>a</sup> n=373 for analyses of EQ-5D-5L and EQ VAS. <sup>b</sup> 1-5 scale, higher scores indicating better general health or quality of life. <sup>c</sup> EQ-5D-5L index value, 0-1 scale, with higher score indicating better health status. <sup>d</sup> EQ VAS, 0-100 scale, with higher score indicating better self-reported health. <sup>e</sup> 0-100 scale, higher scores indicating better psychological wellbeing