



Original research

Higher patient assessed quality of chronic care is associated with lower diabetes distress among adults with early-onset type 2 diabetes: Cross-sectional survey results from the Danish DD2-study

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ABSTRACT

Aim: Among adults aged 20–45 years with type 2 diabetes mellitus, we examined the perceived quality of chronic care, and its associations with (i) sociodemographic and clinical characteristics, and (ii) diabetes distress.

Methods: In total, 216/460 (47%) completed a self-administered survey assessing sociodemographic characteristics, patient assessed chronic illness care (PACIC-20, scale of 1–5) and diabetes distress (PAID-20, scale of 0–100), and 197 had full quality of care data for assessment. We obtained clinical data from national registers and used linear and logistic regression models to examine associations.

Results: The mean (SD) PACIC score was 2.6 (0.9) (score range 1–5). Lower PACIC scores were associated with female sex and current unemployment, and with receiving diabetes care in general practice compared with hospital outpatient clinics [mean difference: –0.4 (95% confidence interval (CI) (–0.7 to –0.2)]. People with upper quartile PACIC scores were less likely to report high diabetes distress compared with people with lower quartile PACIC scores [odds Ratio 0.3 95%CI (0.1–0.8)].

Conclusion: Higher quality of care was associated with lower diabetes distress among adults with early onset type 2 diabetes mellitus, but respondents reported less than optimal quality in several core areas of chronic care.

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1. Introduction

The increasing number of high-risk younger adults with type 2 diabetes poses a significant challenge for health care systems worldwide [1]. Adults with early-onset (age approximately 20–45 years) type 2 diabetes are characterised by higher prevalence of cardiovascular risk factors [2–4] and worse psychosocial outcomes [5,6] than older people with type 2 diabetes. This underlines the need for high quality and lifelong chronic care in this group. However, recent studies have found low screening [7] and inadequate treatment of risk factors [8], as well as insufficient adherence to medication [9] and to eye screening [10] in adults with early onset type 2 diabetes. The concurrent heavy burden of psychosocial prob-

lems and self-management barriers identified in this high-risk population [6,11,12], indicates a need for improved chronic care services.

The Chronic Care Model (CCM) was developed to guide quality improvements in chronic care [13]. It outlines the structures needed to enable collaborative care between a “proactive and prepared” health system and an “informed and activated” patient [13]. The Patient Assessment of Chronic Illness Care (PACIC) questionnaire was developed to assess patient reported receipt of care and its congruence with elements of the CCM [14]. In people with type 2 diabetes, a higher PACIC score is associated with higher patient empowerment [15], higher patient activation [16], more self-care behaviours [17], and better glycemic control [16], and CCM guided diabetes care interventions have demonstrated positive outcomes [18]. Assessing quality of care using the PACIC may therefore be an important first step to improving outcomes in adults with early-onset type 2 diabetes.

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Diabetes related emotional distress (diabetes distress) is a key patient reported outcome [19]. It is associated with poor diabetes related health outcomes [19,20] and with comorbid depression [21]. It reflects the emotional burden from living with and managing diabetes balanced against available coping resources [19]. CCM-congruent health care could be a source of such coping resources and might therefore be associated with lower diabetes distress levels. However, it is unclear how PACIC may relate to diabetes distress, particularly adults with early-onset type 2 diabetes.

There is little data on patient assessed quality of chronic care among younger adults with type 2 diabetes. Previous studies report service utilisation levels or health outcomes, rather than patient reported quality of care. We recently reported on the clinical and psychosocial characteristics of adults with early-onset type 2 diabetes in a Danish context [3,11]. In the current study, we examined the perceived quality of chronic care, and its associations with (i) sociodemographic and clinical characteristics, and (ii) diabetes distress among adults with early-onset type 2 diabetes.

2. Subjects, materials and methods

2.1. Study population

A cross sectional survey was conducted among members of the Danish Center for Strategic Research in the Type 2 Diabetes (DD2) cohort [22]. Since 2010, the ongoing DD2-cohort study has enrolled individuals with newly diagnosed type 2 diabetes mellitus from clinical practice and hospital outpatient clinics in all parts of Denmark and linked baseline data with data from national registers [23]. Enrolment procedures and baseline data from 2016 have previously been published [22,24]. When a person is diagnosed with type 2 diabetes as part of routine clinical practice, the clinical provider subsequently invites this person to join the DD2 cohort. If informed consent is obtained, clinical examination data are collected and blood samples are drawn. These data can subsequently be linked with national register data [24]. Of the 7053 participants enrolled on 1 November 2016, 460 people aged 20–45 years were sent a letter with information about the survey and a link to an online questionnaire (using SurveyXact). This was followed by a reminder letter in January 2017, which included a paper version of the questionnaire. In total, 216/460 (47%) individuals sent a response. We subsequently excluded those who had not responded to any of the PACIC items ($n = 6$) and those who did not report a diabetes consultation during the past 6 months ($n = 13$) (the quality of care questions refer specifically to this period). This resulted in a study population of 197 participants.

2.2. Survey measures

Self-reported sociodemographic data included educational level, employment status, cohabitation status, and country of birth. The educational level was re-coded into three categories: low (0–10 years), medium (11–15 years), and high (>15 years). Perceived quality of chronic care was measured by the 20-item PACIC questionnaire [14]. This asks how often participants had experienced specific types of care during the past six months with response options ranging from '1 = never' to '5 = always'. The PACIC score was calculated by averaging the 20 item scores. A higher score denotes higher quality of chronic care. There are no formal recommendations for how to handle missing data in the PACIC questionnaire. As the number of items missing was low, we calculated a mean of non-missing items for all participants. Previous validation studies have questioned the originally proposed five factor structure [25,26]. We therefore reported on the overall PACIC score and individual items. Diabetes distress was measured using the 20 item Problem Areas

in Diabetes Scale (PAID-20) [27]. Respondents rated the 20 potential emotional problems from '0 = not a problem' to '4 = serious problem'. The PAID score is calculated by summing the item scores and multiplying them by 1.25, generating a total score between 0 to 100. This was calculated for the $n = 182$ participants with data on all PAID items. Scores ≥ 40 indicate "high diabetes distress", which is a frequently used cut point [28].

Macrovascular complications and hospital-diagnosed retinopathy were identified in the Danish National Patient Registry (DNPR). Based on diagnoses recorded in the DNPR during the past ten years, we calculated the comorbidity burden using the Charlson Comorbidity Index (CCI) [29]. We excluded diabetes from the score, as this constitute the index condition. We also captured psychiatric conditions from the DNPR and selected diagnoses registered within three years prior to the survey date in order to reflect more current life conditions. We collected information on use of medication from the Danish National Prescription Registry. Glucose lowering drugs were categorized into: "No GLDs", "Non-insulin only", and "Any insulin use" (insulin alone and in combination with other GLD).

We assessed diabetes care provider use by asking participants where they had primarily received their diabetes care during the past 6 months, with response categories "at my general practitioner", "in a hospital outpatient clinic", or "no consultations". We also asked participants to indicate if they had attended any other type of diabetes care service.

2.3. Statistical analysis

We calculated medians with interquartile ranges for age and type 2 diabetes duration and proportions for categorized variables. We used linear regression analysis calculating mean differences with 95% confidence intervals (CI) to estimate associations between the overall PACIC score and each of the explanatory variables before and after adjustment for age and sex. We used logistic regression analysis calculating odd ratios (OR) with 95% CI to compare the odd for having high diabetes distress between groups with different PACIC score levels. We grouped the PACIC score into quartiles and used the lowest quartile as reference group in the logistical analysis. We adjusted the OR for age and sex (model 1) and for presence of macro-vascular complications and retinopathy, comorbidity, as well as for glucose lowering drug type (model 2). Statistical analysis were performed using SAS version 9.4 (SAS institute, Inc., Cary, North Carolina).

3. Ethics

The ethical considerations and official approvals of the DD2-study have been published previously [22]. For the survey study, written information was provided to participants, along with a statement about voluntary participation. The study was approved by the Danish Data Protection Agency (number 2015-57-0002). The Central Denmark Region Committees on Health Research Ethics confirmed that the present study does not need ethical approval according to Danish law (journal number 1–10-72-189-16)

4. Results

4.1. Background characteristics

The median age of participants was 42 years and median duration of type 2 diabetes was 5 years; 52% of the cohort were men (Table 1). In total 21% of participants did not use any glucose lowering drugs, 62% used non-insulin drugs, and 17% used insulin. In terms of diabetes complications, 10% had a previous diagnosis of

Table 1
Characteristics of 197 adults aged 20–45 years with type 2 diabetes and perceived quality of chronic care (PACIC score) and associations with sociodemographic and clinical characteristics.

	N (%)	PACIC score (range 1–5)		
		Mean (SD)	Crude Mean difference (95% CI)	Age and sex adjusted Mean difference (95% CI)
Total study population	197 (100)	2.6 (0.9)		
Sociodemographic characteristics				
Women	95 (48.2)	2.5 (0.8)	Ref	Ref
Men	102 (51.8)	2.7 (0.9)	0.28 (0.03 to 0.53)	0.31 (0.06 to 0.56)
Age (years), median (IQR) ^a	42.1 (38.2–44.4)		–0.03 (–0.05 to 0.00)	–0.03 (–0.06 to –0.01)
20–39 years	69 (35)	2.8 (0.9)	Ref	
≥40–45 years	128 (65)	2.5 (0.9)	–0.01 (–0.01 to 0.00)	–0.01 (–0.01 to 0.00)
Education level				
Primary school (0–11 years)	28 (14.5)	2.7 (1.0)	Ref	Ref
High school and vocational school (12–15 years)	110 (57.0)	2.6 (0.9)	–0.15 (–0.54 to 0.23)	–0.14 (–0.52 to 0.23)
University level (>15 years)	56 (28.5)	2.6 (0.8)	–0.18 (–0.60 to 0.23)	–0.07 (–0.48 to 0.34)
Employed				
Employed	136 (69.7)	2.7 (0.9)	Ref	Ref
Unemployed	42 (21.5)	2.4 (0.9)	–0.35 (–0.65 to –0.04)	–0.35 (–0.66 to –0.04)
Current student	17 (8.7)	2.4 (1.0)	0.06 (–0.46 to 0.58)	–0.05 (–0.55 to 0.45)
Living with others				
Living with others	143 (72.6)	2.5 (0.9)	Ref	Ref
Living alone	54 (27.4)	2.7 (1.0)	0.21 (–0.08 to 0.49)	0.12 (–0.16 to 0.41)
Danish born				
Danish born	184 (94.4)	2.6 (0.9)	Ref	Ref
Foreign born	11 (5.6)	2.9 (0.9)	0.32 (–0.23 to 0.86)	0.30 (–0.24 to 0.83)
Clinical characteristic				
Diabetes duration (years), median (IQR)	5.2 (3.4–6.5)		–0.02 (–0.06 to 0.02)	–0.00 (–0.04 to 0.03)
Macrovascular disease, no	189 (95.9)	2.6 (0.9)	Ref	Ref
Macrovascular disease, yes ^b	8 (4.1)	2.6 (1.0)	–0.00 (–0.64 to 0.64)	–0.02 (–0.65 to 0.61)
Hospital diagnosed retinopathy, no	178 (90.4)	2.6 (0.9)	Ref	Ref
Hospital diagnosed retinopathy, yes	19 (9.6)	2.9 (0.9)	0.35 (–0.07 to 0.78)	0.32 (–0.10 to 0.74)
Glucose lowering drugs				
No glucose lowering drugs	41 (20.8)	2.6 (1.0)	Ref	Ref
Non-insulin drugs only	123 (62.4)	2.5 (0.9)	–0.11 (–0.44 to 0.21)	–0.09 (–0.41 to 0.24)
Any use of insulin ^c	33 (16.8)	2.8 (0.8)	0.17 (–0.26 to 0.60)	0.15 (–0.27 to 0.57)
Comorbidity				
CCI = 0	166 (84.3)	2.6 (0.9)	Ref	Ref
CCI = 1	20 (10.2)	2.9 (0.8)	0.29 (–0.12 to 0.70)	0.37 (–0.04 to 0.78)
CCI ≥ 2	11 (91.9)	2.2 (1.1)	–0.41 (–0.96 to 0.15)	–0.36 (–0.90 to 0.19)
Psychiatric disorder ^d , no	181 (74.1)	2.6 (0.9)	Ref	Ref
Psychiatric disorder, yes	16 (8.1)	2.8 (1.1)	0.19 (–0.27 to 0.65)	0.23 (–0.23 to 0.69)
Antidepressant medication, no	165 (83.8)	2.6 (0.9)	Ref	Ref
Antidepressant medication, yes	32 (16.2)	2.4 (1.0)	–0.29 (–0.63 to 0.05)	–0.20 (–0.55 to 0.16)
High diabetes distress (PAID > 40)				
High diabetes distress (PAID > 40)	51 (26%)			
Health care services				
Hospital outpatient clinic	51 (26.6)	2.9 (0.8)	Ref	Ref
General practice	141 (73.4)	2.5 (0.9)	–0.47 (–0.76 to –0.19)	–0.44 (–0.72 to –0.16)
Diabetes education, no				
Diabetes education, no	101 (51.3)	2.5 (0.9)	Ref	Ref
Diabetes education, yes	96 (48.7)	2.7 (0.9)	0.11 (–0.14 to 0.36)	0.18 (–0.07 to 0.43)
Consulted a dietician, no				
Consulted a dietician, no	80 (40.6)	2.5 (0.9)	–0.13 (–0.39 to 0.12)	–0.10 (–0.36 to 0.15)
Consulted a dietician, yes	117 (59.4)	2.6 (0.9)	Ref	Ref

Mean differences with 95% confidence intervals calculated using linear regression analysis.

Ref: reference group (Alpha in the linear regression model). IQR: Interquartile Range. CI: Confidence Intervals. PACIC: Patient Assessment of Chronic Illness Care, 20 items, score range 0–5. PAID: Problem Areas in Diabetes Scale, 20 items, range 0–100. CCI: Charlson's Comorbidity Index.

^a Mean difference per year.

^b Diagnoses included angina pectoris, acute myocardial infarction, diabetic foot wound, and procedures such as coronary artery expansion and thrombolysis in the brain.

^c Use of insulin in combination with other glucose-lowering drugs or insulin only.

^d Diagnoses included Schizophrenia and related disorders, mood disorders, neurotic, stress-related, and somatoform disorders, eating and sleep disorders, specific personality disorders.

retinopathy and 4% had macrovascular complications. Most participants (73%) received diabetes care in general practice (Table 1), and less than half (49%) had attended any kind of diabetes education besides their usual diabetes consultations.

4.2. Quality of chronic care

The overall mean (SD) PACIC score was 2.6 (0.9). The types of care participants reported receiving least often during the past 6 months were item 9 “given a copy of my treatment plan” and item 16 “contacted after a visit to see how things were going” (84% and 81% reported never or little of the time respectively) (Fig. 1). The type of care most often received was item 5 “satisfied that my care

was well organized” and item 1 “asked for my ideas when we made a treatment plan” (18% and 21% reported never or little of the time respectively). In 11 of the 20 PACIC items, more than 50% of participants reported rarely (reported never or little of the time) receiving that type of care (Fig. 1).

4.3. Association between quality of chronic care and sociodemographic characteristics

A higher PACIC score was associated with male sex [mean difference 0.31 (95%CI 0.06–0.56)] (Table 1) and with younger age [mean difference per year –0.03 (–0.06 to –0.01)]. A lower PACIC level was associated with being unemployed [mean difference –0.35 (95%CI

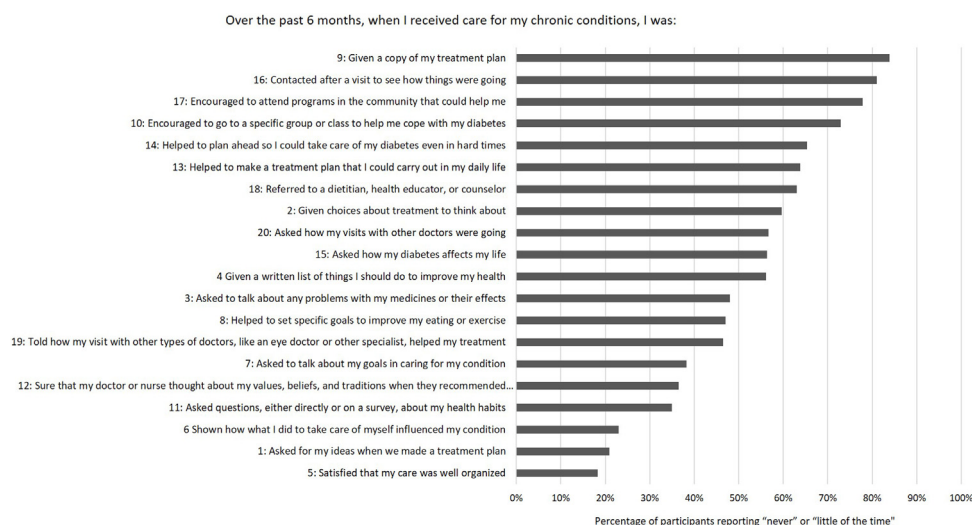


Fig. 1. Item level results of the Patient Assessment of Chronic Illness Care (PACIC) among 197 adults aged 20–45 years with type 2 diabetes. Percentage reporting “never” or “little of the time” (versus “some of the time”, “most of the time” or “always”).

–0.66 to –0.04)], but not with education level, cohabitation status, or country of birth.

4.4. Association between quality of chronic care, clinical characteristics and health care services

We found no associations between the PACIC score and duration of diabetes, diabetes complications, glucose lowering drug use, other comorbidities, psychiatric diagnoses, or antidepressant medication (Table 1). People who had attended diabetes consultations in general practice reported a lower PACIC score compared to people receiving diabetes care in hospital outpatient clinics [mean difference –0.44 (95%CI –0.72 to –0.16)] (Table 1). No differences were identified between those who had attended diabetes education or consulted a dietician compared to those who had not attended these health care services (Table 1).

4.5. Quality of chronic care and diabetes distress

In total, 26% of participants reported a high diabetes distress level (Table 1). There was a trend, with those reporting higher levels of quality of chronic care reporting lower levels of diabetes distress (Table 2). The odds of reporting high diabetes distress was 73% lower in people with the highest-quartile PACIC scores compared to those with the lowest-quartile PACIC scores [odds ratio 0.27 (95%CI 0.09–0.80)] (Table 2).

5. Discussion

Among adults with early-onset type 2 diabetes, we found an overall mean PACIC score of 2.6 (0.9) and a large variation in the quality of care received. In 11 of the 20 PACIC items, more than 50% of participants reported rarely receiving that type of care. Our results also show that lower reported quality of care was associated with female sex, current unemployment, and receiving diabetes care in general practice. People who reported higher quality of care were less likely to report high diabetes distress.

There is little evidence on patient reported quality of care among younger adults with type 2 diabetes. A recent meta-analysis examining PACIC levels in older people with diabetes [30] found a pooled PACIC score of 3.0, i.e. higher quality of care than in our study. The meta-analysis [30] also showed a 0.2 lower mean PACIC score in study populations with mean age below 65 years compared with

mean age over 65 years. This suggests that younger people may perceive lower levels of care. However, the effect did not persist after adjustment, and like our study, a number of studies found lower PACIC scores with increasing age [26,31]. Yet other studies found no age differences [17,32]. Our examination of sociodemographic and health status subgroups only identified an association between unemployment and lower reported quality of chronic care. As diabetes care in Denmark is free of charge, the costs of treatment is less likely to explain this finding. Rather, psychosocial problems may affect the rating of quality of care in this group. In contrast to our study, a previous study found higher PACIC scores among unemployed people [33]. In general, observational studies of PACIC levels have shown few and diverging associations with sociodemographic and clinical characteristics [30], indicating that this association may be specific to e.g. context and measurement methods. While it seems likely that people with a more severe condition and with comorbidities receive more specialised and frequent and thus more CCM congruent health care – a hypothesis also expressed by the developers of the PACIC questionnaire [14] – this was not confirmed in our study, nor in a number of other studies [17,34].

In contrast with our study, a previous large cross-sectional study [35] did not find a significant difference in PACIC scores between those with high and low diabetes distress levels. Other studies however, found associations between a higher PACIC scores and higher patient empowerment, self-efficacy, and perceived self-care competence [15,31], which may mediate lower distress levels. Indeed, higher diabetes self-efficacy has been associated with lower diabetes distress [36] among younger adults with type 2 diabetes, and higher empowerment levels have been associated with lower diabetes distress [35] in an older type 2 diabetes population. However, in our study, only those with the highest PACIC scores (those in the top quartile) experienced significantly lower diabetes distress. If we assume that this relationship is causal, this suggests a need to improve the quality of care offered to a large proportion of adults with early-onset type 2 diabetes. However, considering the cross sectional design, it is also possible that people with high diabetes distress level rate their quality of chronic care differently, due to different expectations and feelings of insufficient support. Even so, the result indicate an unmet need expressed by those with high distress levels.

In Denmark, hospital care often involves more consultations with a broader range of health care professionals, than typically offered in general practice. This could explain why younger adults

Table 2
Association between perceived quality of care and diabetes related distress among 197 adults aged 20–45 years with type 2 diabetes.

PACIC quartiles	N	Proportion with high diabetes distress (PAID \geq 40)	Odds ratio for reporting high diabetes distress (PAID \geq 40 versus PAID < 40)		
			Model 1 OR (95% CI)	Model 2 OR (95% CI)	Model 3 OR (95% CI)
1st (1.00–1.88)	48	38	Reference	Reference	Reference
2nd (1.90–2.50)	48	28	0.70 (0.29–1.67)	0.78 (0.32–1.90)	0.73 (0.29–1.80)
3rd (2.55–3.20)	50	28	0.60 (0.24–1.51)	0.61 (0.24–1.56)	0.64 (0.25–1.65)
4th (3.25–5.00)	51	12	0.23 (0.08–0.65)	0.26 (0.09–0.77)	0.27 (0.09–0.80)

Odds ratios calculated using logistical regression models. Model 1: Crude estimates Model 2: Adjusted for sex and age. Model 3: Adjusted for sex, age macrovascular complication status, hospital diagnosed retinopathy, glucose lowering drug type, and comorbidities (Charlson Comorbidity Index).

PACIC: Patient Assessment of Chronic Illness Care, 20 items, score range 1–5. PAID: Problem Areas in Diabetes Scale, 20 items, score range 0–100. OR: Odds Ratio. CI: Confidence Interval.

receiving hospital care reported a higher PACIC score than those receiving care in general practice. The previously mentioned meta-analysis [30] also found a higher PACIC level among those receiving care from several healthcare professionals and in several settings compared with those receiving care from a general practitioner only. This indicates that cross-disciplinary and specialized care is associated with higher reported quality of care among people with diabetes. Consequently, care for adults with early-onset type 2 diabetes could be improved by offering additional specialized services, involving different health professionals, as for example suggested in the 3 Dimension of Care (medical, psychological and social) Study [37]. Furthermore, our results suggest that services should focus on the special needs in different groups; e.g. women, currently unemployed people, and those with high levels of diabetes distress. Item level results from our study further suggest a need to increase the numbers attending diabetes self-management education and improve the referral, and follow up between services. Finally, health care providers could improve quality by supporting younger adults in planning ahead and balancing diabetes management with other challenges in life.

Previous studies of people with early-onset type 2 diabetes give further insight into their special health care needs. For example, in a study among young adults (18–39 years) with type 2 diabetes in Australia, 68% agreed with the statement that young adults with type 2 diabetes have different health care needs than their older counterparts, and 62% agreed that most type 2 diabetes information and services are targeted at older people. In qualitative studies, young adults report that services were inflexible, that their general practitioner was not up-to-date on new research and treatment [38], and that special information and support needs were not met [39]. Finally, a mixed methods needs assessment [40] found that knowledge about available services, low perception of personal risk due to young age, social norms, social support, and self-efficacy are essential factors to consider when developing services for younger adults with type 2 diabetes to improve their health and quality of life.

5.1. Strengths and limitations

This study is the first to evaluate quality of chronic care using a validated patient-reported questionnaire linked with clinical information from high quality national registers in the emerging priority population of adults with early-onset type 2 diabetes. The cross-sectional design enabled us to provide a status in a hard-to-reach priority group, but impeded conclusions about cause and effect of associated factors. The sample size yielded wide confidence intervals, with a risk dismissing clinically relevant differences as non-significant. Further, there was a risk of inaccurate estimation for variables with very low cell counts, e.g. macrovascular complications. There was a relatively low representation of people in the younger end of the age range 20–45 years in our survey sample. This is probably a reflection of the age distribution of people with type

2 diabetes in Denmark, (i.e. higher prevalence in older age), and in the DD2 cohort. Consequently, our study may provide less information about quality of care problems among the youngest groups, e.g. 20–30 years-olds. In the whole of the DD2-cohort people receiving care in hospitals, compared to general practice, are overrepresented [24]. However, the 30/70% distribution between hospital outpatient clinics and general practices reported in our study, is close to the general 20/80 distribution in Denmark. This suggests that our survey results reflect a relatively representative mix of patient cases. Despite that, selection bias might still have occurred, for example by higher representation of well-educated patients or of patients from more proactive and engaged clinics. Although the PACIC scale is well validated [25,42], no previous studies have validated the instrument specifically among younger adults, who may have different expectations or views of health care. For example, Noël et al. [43] point out that the PACIC questionnaire does not cover essential modern advances in health care, such as electronic communication with health care providers, or home health monitoring devices. The PACIC tool may therefore not sufficiently capture all relevant aspects of health care quality in the target group.

6. Conclusion

We found a large variation in perceived quality of care among adults with early-onset type 2 diabetes in Denmark, and we identified less than optimal quality in several key areas of chronic care. In particular, lower quality of care was reported by women, currently unemployed people, people with high diabetes distress, and finally, among those followed in general practice (vs. hospital outpatient clinics). There is considerable potential to improve the quality of chronic care among younger adults with type 2 diabetes.

Author contribution

AB, NHJ and HTM conceived the study design and research questions. AB, NHJ, and SKN performed the statistical analysis. AB, NHJ, FB, and HTM interpreted the results. AB drafted the manuscript and NHJ, FB, and HTM provided feedback. All authors critically revised the manuscript for important intellectual content and approved the final version.

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Conflict of interest

None.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pcd.2020.02.003>.

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