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Diabetes Management in Danish Primary School: A Survey of Experiences of Parents of Children with Type 1 Diabetes

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Abstract: Supporting diabetes self-care in school is important for optimal glycemic control and mental health. The aim of this study was to investigate parental experiences of diabetes management in Danish schools, with an emphasis on the importance of school staff support in self-care. This cross-sectional study surveyed parents of schoolchildren with type 1 diabetes aged 6 to 16 years in Denmark. The parents were identified among members of the Danish Diabetes Association and were invited to complete an online questionnaire. A total of 252 parents of schoolchildren with type 1 diabetes answered the questionnaire. Only 28% of the children had a designated staff member responsible for support in diabetes self-care during school hours. Having a designated staff member responsible for support in self-care was positively associated with parental experiences of better school–parent cooperation (p < 0.001), better experience of diabetes management in school (p = 0.022 and p = 0.049, respectively). School staff support was positively associated with better parental experience of diabetes management and with some parameters of mental health in schoolchildren with type 1 diabetes and their parents in Denmark.

Keywords: type 1 diabetes; child; parent; school; support



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1. Introduction

Type 1 diabetes (T1D) is one of the most common chronic diseases in childhood. T1D is an insulin-dependent, complex, and demanding disease that requires frequent blood glucose monitoring, management of carbohydrate intake, and insulin administration to achieve optimal glycemic control, often complemented by the use of diabetes technology (e.g., insulin pumps and continuous blood glucose monitoring). Optimal glycemic control is essential to preventing acute and long-term diabetes-related complications and enhancing school performance [1–7].

Diabetes management in childhood requires consistent parental involvement and adult support, but the level of support depends on the child's age and maturity [8]. The level of support may also be influenced by diabetes duration and other co-existing conditions.

Younger children (6 to 11 years) are the most assistance-demanding age group in school, as they require consistent support in day-to-day diabetes management. The necessity of consistent support is related to the cognitive development of a child, which evolves

during the school years. Younger children are cognitively unable to both understand the cause and effect of an illness and perform complete diabetes self-care without support. Young schoolchildren mainly rely on concrete thinking, which focusses on facts and information in the immediate present [9,10]. At around 11 to 12 years of age, complex mental activity related to planning behavior and decision making develops, enabling the child to make decisions regarding diabetes management [11]. As young schoolchildren have not yet developed the capacity for abstract thinking, they need help to recognize signs of hypoglycemia, need support in counting carbohydrates and administering insulin in eating situations, and need help to learn the fundamental skills of self-care [12-14]. The child requires support in self-care up until the teenage years; for some adolescents, absolute self-care can be performed, whereas others still require continuous support [14]. However, noncompliance in diabetes self-care during school hours is also well-recognized in adolescence, a period characterized by omission of insulin administration and reduced testing of blood glucose related to the adolescent's desire to be 'normal' [10]. For children and adolescents, diabetes and diabetes management are associated with many negative emotions, psychological pain, and feeling different from others [12]. Diabetes is also associated with several mental health comorbidities [15].

The cognitive development of a younger child, the potential for detrimental self-care behavior during adolescence, and various mental health concerns call for general support in diabetes self-care for all school children in primary school, with more extensive needs found among the youngest children.

Denmark has no national guidelines for diabetes management in school. Danish national law requires schools to provide children a safe school day on equal terms with peers by offering children with special needs the necessary support [16]. If a child has special needs beyond a designated threshold (in Denmark, 9 h per week), the school can apply for additional financial support from the municipality to support the child. However, the procedure for granting support to a child with diabetes varies significantly across municipalities [17]. School nurses are not involved in diabetes care during school hours, as school nurses only have responsibility for preventive health care. Instead, the responsibility for diabetes care often lies with the child's teacher, another designated school staff member, or the parents. In Denmark, around 1700 children between 5 and 14 years of age have T1D, which corresponds to one child with T1D at each primary school [18].

The importance of school staff providing support in diabetes self-care has previously been highlighted in two Swedish studies [19,20]. Having a designated staff member responsible for support in diabetes self-care was positively associated with parental satisfaction with self-care management in school.

Parental experiences of support in diabetes management in Danish schools have not yet been studied. Therefore, the aim of our study was to investigate parental experiences of diabetes management in Danish schools and the mental health of schoolchildren with T1D and their parents, with emphasis on the importance of school staff support in diabetes self-care. We hypothesized that parental experiences of diabetes management in school would be positively associated with the level of support in school, and we also assumed that the missing national guidelines may influence parental experiences negatively overall.

2. Materials and Methods

The present study was performed as a cross-sectional online survey. The participants were invited in their capacity as members of the Danish Diabetes Association and through Facebook group announcements. Inclusion criteria for the study were: parents of a child with T1D in the age range 6–16 years attending primary school (grade 0. to 9.).

In total, 607 parents with a schoolchild with T1D, identified among members of the Danish Diabetes Association, were contacted by email with an invitation to participate (Figure 1). Forty participants were not included due to invalid email addresses. A total of 148 respondents filled out the questionnaire. One did not meet the age criterion and was excluded.

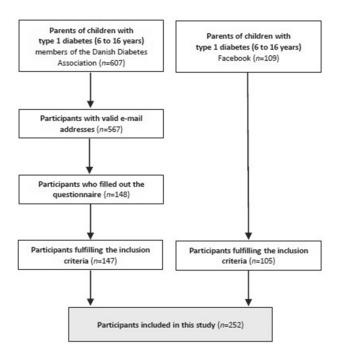


Figure 1. Flow chart of study participants.

From the Facebook group announcements, a total of 109 parents filled out the online questionnaire, and 4 did not meet the inclusion criteria.

Sociodemographic data for the respondents were compared with the background population (the Danish population in the age range 30–54 years) [21], as 98% of the included respondents were in this age group.

The questionnaire was developed by the Danish Diabetes Association and tested prior to the study by 5 parents of children with T1D to ensure the compatibility of the questionnaire's form and content with the target group. The questionnaire contained 51 questions and, in addition to sociodemographic information, assessed three main themes: (1) structures surrounding the child at school, (2) indicators of mental health (related to feelings and attitudes towards being a student with T1D) and well-being in school, and (3) being a parent of a child with T1D.

The questionnaire consisted mainly of close-ended questions; some questions used dichotomous answers (e.g., YES/NO), but more than half of the questions (27 questions) used ordinal-scale responses (e.g., to a great extent, to some extent, to a lesser extent, or not at all).

Ordinal data were presented using descriptive statistics in frequencies (%).

Sub-group analyses were performed with stratification for designated staff support (YES/NO) and the child's age (below or above 12 years). The responses were compared using the chi-squared test, with a significance level of 0.05.

3. Results

3.1. Study Population

In total, 252 questionnaires were filled out, of which 230 were complete. Characteristics of the included parents and their children are described in Table 1 (and Appendix A, Table A1) and Table 2 respectively. In 89% of the cases, the mother filled out the questionnaire. Of the respondents, 75% had completed a higher (medium or long-cycle) education, and 88% were employed. In the background population, the corresponding figures were 38% and 81%, respectively [21]. The mean age of the children was 12.04 \pm 2.47 years (mean \pm SD), and 73% were attending a municipal school (Danish Folkeskole).

Table 1. Characteristics of the study population (parents of schoolchildren with type 1 diabetes) and the background population (the Danish population 30–54 years of age). Characteristics are presented in frequencies (%). For extended description, see Appendix A, Table A1.

	Parents (<i>n</i> = 252)	The Danish Population (30–54 Years) *
Females	88.9	49.6
30–39 years	15.8	37.4
40–49 years	66.6	40.7
50–54 years	14.7	22.2
Above 55 years	2.4	-
Compulsory education ¹	1.6	15.5
Secondary education ²	11.6	38.5
Post-secondary education ³	86.0	44.7
Employed	88.0	81.1
Unemployed	6.8	16.2

^{*} Statistics Denmark (2022), 3rd quarter of 2020, ¹: primary and lower secondary education, ²: upper secondary and vocational education and training, ³: short-, medium-, and long-cycle programs.

Table 2. Characteristics of the schoolchildren with type 1 diabetes and the background population (the Danish population 6–16 years in 0. to9. grade). Characteristics are presented in frequencies (%).

	Children with Type 1 Diabetes (n = 252)	The Danish Population (6–16 Years) *
Females	56.3	48.7
6–8 years	9.8	27.8
9–11 years	29.9	30.9
12–14 years	43.5	32.0
15–16 years	16.8	9.3
Municipal school	73.1	78.7
Private or free school	24.5	18.4
Boarding school	1.2	1.3
Other school	1.2	1.6
0. to 3. grade	25.4	36.1
4. to 6. grade	42.0	31.8
7. to 9. grade	32.6	32.1
0–5 years at diabetes debut	33.4	-
6–8 years at diabetes debut	30.6	-
9–12 years at diabetes debut	31.8	-
≥13 years at diabetes debut	4.1	-

^{*} Statistics Denmark (2022), 3rd quarter of 2020.

3.2. Diabetes Care in School

For the children 6 to 16 years of age, 28% (n = 69) currently had a designated staff member to turn to for help and guidance in managing diabetes during school (Table 3).

Having a designated staff member responsible for support in self-care was positively associated with better cooperation between the school and the parents (p < 0.001) (Table 4), as 70% of parents with a designated staff member and 31% without experienced good school–parent cooperation. Parents more frequently felt comfortable with the school's ability to manage diabetes in cases with a designated staff member (85%) compared to those without (45%) (p < 0.001) (Table 4).

Table 3. Proportion of children (above or below 12 years of age) having a designated staff member with responsibility to support diabetes self-care. The results are presented in frequencies (%).

Does the Child Have a Designated Staff Member Responsible for Support in Diabetes Self-Care during School Hours?	Children <12 Years (<i>n</i> = 98)	Children ≥12 Years (n = 146)	Total (n = 244)
Yes	51.0	13.0	28.3
No	37.8	63.0	52.9
No, but previously yes	11.2	24.0	18.9

Table 4. A selection of questions and answers within the theme: Diabetes care in school. All questions are worded with emphasis on the time prior to the COVID-19 pandemic. The answers are presented in total frequencies (%) and significant associations (p < 0.05), stratified for status for designated staff member (YES/NO), are also presented.

(n = 239)	To a Great Extent	To Some Extent	To a Lesser Extent	Not at All			p
To what extent do you experience good parent–school cooperation?	41.4	35.1	17.2	6.3			
Designated staff member YES Designated staff member NO	69.7 30.6	22.7 39.9	7.6 20.8	0.0 8.7			<0.001 ***
the school engaging in having a student with diabetes?	28.0	33.1	25.5	13.4			
Designated staff member YES Designated staff member NO	54.5 17.9	33.3 32.9	10.6 31.2	1.5 17.9			<0.001 ***
that the school is meeting the child's individual need in relation to diabetes?	34.3	30.5	26.4	8.8			
Designated staff member YES Designated staff member NO	63.6 23.1	19.7 34.7	15.2 30.6	1.5 11.6			<0.001 ***
	Comfortable	Slightly Comfortable	Neither Nor	Slightly Uncomfortable	Un- comfortable	Do Not Know	p
How comfortable are you with the school's ability in managing diabetes during school hours?	38.8	17.3	11.8	15.2	14.3	2.5	
(n = 237) Designated staff member YES Designated staff member NO	69.7 26.9	15.2 18.1	3.0 15.2	10.6 17.0	1.5 19.3	0.0 3.5	<0.001 ***
the designated school staff member's ability in managing diabetes during school hours? (n = 66)	77.3	12.1	6.1	1.5	1.5	1.5	-
(n = 233)	All the Time	Often	Now and Then	Rarely	Never	Do Not Know	р
How often do you experience that your child is excluded from school events due to diabetes?	1.3	3.9	12.4	15.0	64.8	2.6	0.81
is unwantedly left alone in managing diabetes?	4.7	15.0	23.2	28.8	26.2	2.1	<0.001 ***
Designated staff member YES Designated staff member NO	0.0 6.5	4.6 19.0	20.0 24.4	30.8 28.0	44.6 19.0	0.0 3.0	

Significance level: p < 0.001 ***.

In total, 35% of parents did only to a lesser extent or not at all experience that the school was meeting the child's individual needs, and 43% of parents experienced that the child was unwantedly left alone in managing diabetes. Having a designated staff member was positively associated with perceptions of school engagement in relation to diabetes (p < 0.001) and the school's ability to meet individual needs (p < 0.001). Having a designated staff member was negatively associated with the child being unwantedly left alone with diabetes, as 45% of parents with a designated staff member never experienced the child being unwantedly left alone compared to 19% of those without (p < 0.001).

3.3. Indicators of Mental Health and Well-Being in School

Of all the parents, 86% experienced their child being happy and 88% their feeling comfortable and safe in school (Table 5). Children with a designated staff member were more frequently perceived as feeling comfortable in school compared to children without (p = 0.022), but children were perceived as being equally happy.

Table 5. A selection of questions and answers within the theme: Indicators of mental health and well-being in school. All questions are worded with emphasis on the time prior to the COVID-19 pandemic. The answers are presented in total frequencies (%) and significant associations (p < 0.05), stratified for status for designated staff member (YES/NO), are also presented.

(n = 231)	To a Great Extent	To Some Extent	To a Lesser Extent	Not at All			p
To what extent do you experience your child as being happy in school?	55.8	30.3	11.3	2.6			0.35
as feeling comfortable in school? Designated staff member YES Designated staff member NO	58.9 73.8 53.0	29.0 21.5 31.9	10.4 4.6 12.7	1.7 0.0 2.4			0.022 *
as being concerned about life with diabetes?	24.2	46.3	22.5	6.9			0.77
as being offered support in school to cope with psychological challenges of	9.5	18.2	23.4	48.9			
diabetes? Designated staff member YES Designated staff member NO	16.9 6.6	24.6 15.7	23.1 23.5	35.4 54.2			0.014 *
(n = 231)	All the Time	Often	Now and Then	Rarely	Never	Do Not Know	p
As a consequence of diabetes, how often do you experience your child as feeling excluded?	0.4	12.1	27.7	32.5	26.0	1.3	0.15
is your child absent from school?	0.4	7.8	31.6	45.5	14.7	0.0	0.32

Significance level: p < 0.05 *.

Even though the parents reported their children having a positive attitude towards being a student in school, T1D was associated with some unfavorable consequences for the child, as 40% of parents reported the child feeling excluded and 40% reported the child at times being absent from school because of T1D.

In cases with a designated staff member, 19% of parents reported children feeling excluded often or all the time, but this only applied to 10% without support (data not shown); however, the association was not significant (p = 0.15).

Parents experienced the child having concerns about life with diabetes in 71% of the cases. However, only in 28% of the cases did parents experience the school offering the child adequate help and support to cope with the psychological challenges of diabetes. Psychological help and support in school were more frequently offered in cases with a designated staff member (p = 0.014).

3.4. Being a Parent of a Child with T1D

In 85% of the cases, being a parent of a child with T1D was perceived as a challenge, and 49% of parents were often or all the time concerned about the risk of hypoglycemia

during school hours (Table 6). Parents felt the same amount of concern regardless of the level of support in school.

Table 6. A selection of questions and answers within the theme: Being a parent of a child with type 1 diabetes. All questions are worded with emphasis on the time prior to the COVID-19 pandemic. The answers are presented in total frequencies (%) and significant associations (p < 0.05), stratified for status for designated staff member (YES/NO), are also presented.

(n = 229)	To a Great Extent	To Some Extent	To a Lesser Extent	Not at All			р
To what extent do you feel comfortable having your child in school?	50.7	37.6	7.4	4.4			
Designated staff member YES	60.0	36.9	3.1	0.0			0.040 *
Designated staff member NO	47.0	37.8	9.1	6.1			0.049 *
do you experience lack of support to the child negatively affecting your work life?	14.0	32.3	30.1	23.6			0.32
do you experience it challenging to be parent of a child with diabetes?	50.2	34.5	14.4	0.9			0.14
(n = 229)	All the Time	Often	Now and Then	Rarely	Never	Do Not Know	р
How often are you concerned about your child's risk of low blood sugar?	16.6	31.9	33.6	15.3	2.2	0.4	0.49

Significance level: p < 0.05 *.

Almost half of the parents (46%) experienced that lack of support for the child during school hours affected work life negatively. Despite the implications for work life, only 34% of parents had been in contact with the municipality for help and support (e.g., loss of earnings compensation), and half of them (53%) had been awarded municipal support (data not shown).

Most parents (88%) felt comfortable about the child attending school, but this was more evident in cases with a designated staff member (p = 0.049).

3.5. Subgroup Analysis

For children below 12 years of age, 51% had a designated staff member, compared to 13% of the children above 12 years (Table 3). Results stratified for age (below or above 12 years) and designated staff support (YES/NO) showed somewhat similar associations as seen in the entire population; these are presented in Tables 4–6. However, a greater number of significant associations between designated staff support and study outcomes were observed for children below 12 years compared to those above (data not shown).

4. Discussion

The present survey investigated parental experiences of diabetes management and mental health in Danish schoolchildren with T1D, with an emphasis on the influence of designated staff support. Having designated staff support was positively associated with several factors concerning parental experiences of diabetes management in school (e.g., the school's ability to meet individual needs and the school's engagement in relation to diabetes) as well as with some mental health factors in schoolchildren (e.g., children feeling comfortable and safe in school) and parents (e.g., parents feeling comfortable about leaving the child in school). In total, 28% of children between 6 and 16 years of age had a designated staff member responsible for support in diabetes self-care.

More than half of the parents felt challenged by having a child with T1D, and almost half of the parents experienced that the lack of support negatively affected work life. Most parents (82%) were concerned about the risk of hypoglycemia during school hours, and this concern may be a common parental fear, as parents felt the same amount of concern regardless of the level of support in school. Similar results were found in a review by Smith et al., who suggested that parental fear of hypoglycemia in school persists despite school staff being adequately trained [22]. From the literature, we know that many parents experience emotional distress, which is at least partly associated with the fear of hypoglycemia [23,24]. In the present study, we had no information on the usage of diabetes technology, whether a given school was equipped with glucagon nor whether the school had procedures for hypoglycemia, and it is also uncertain whether these factors could have affected the fear of hypoglycemia. Despite the challenges and fears, most parents felt comfortable about the child attending school. Moreover, having a designated staff member was associated with a higher proportion of parents feeling comfortable about having their child in school compared to parents without support.

Most parents (71%) experienced the child having concerns about life with diabetes, and these concerns were unaffected by support in school. This indicates that concerns may be quite common for children with T1D, which is in accordance with findings from other studies, demonstrating increased risk of poor mental health in individuals with diabetes [12,25]. In an integrative review by Kelo et al., T1D in childhood was associated with sadness, irritation, psychological pain, and feeling different from others [12]. In a study by Schwartz et al., 56% of the children experienced emotional distress about dealing with diabetes in school [25]. We observed positive associations between having designated staff support and other mental health outcomes. Designated staff support was positively associated with parental experiences of children feeling comfortable in school and with children more frequently being offered psychological support to cope with diabetes-related challenges, though one may question whether schools should be required or even expected to offer psychological assistance to children with diabetes. However, although it was not statistically significant, there seems to be an unfavorable consequence of having a designated staff member, as 19% of the children with school staff support often or all the time felt excluded, according to their parents, compared to only 10% of the children without school staff support.

The present findings demonstrate positive associations between having designated staff support and better parental experience of diabetes management in school for children with T1D. Similar studies have also highlighted the importance of school staff providing support in self-care [19,20]. With this in mind, it is a cause for concern that only 28% of the children in the present study had a designated staff member to turn to for support in diabetes self-care. In comparison, in a Swedish study, 59% of the schoolchildren (5 to 16 years) had a designated staff member [20]. The stages of child cognitive development determine the need for adult support in younger children (6 to 11 years) [9]. Given this, it is an important finding that only 51% of the children below 12 years of age were supported by a designated staff member. This is in accordance with 52% of schoolchildren 4 to 13 years of age in Ireland [26], but significantly lower compared to Sweden, where 87% of the children in the lower grades (5 to 10 years of age) received support [20]. Whether the remaining 49% of the younger children in the present study were left completely unsupervised or were supported in a fragmented manner is uncertain. Consequently, parents may be forced to reduce work hours to support the child during school hours, as has been observed in a Danish study [27].

The included subgroup analyses suggest that some of the observed associations between having designated staff support and study outcomes are largely explained by parental experiences of younger children, as a greater number of significant associations were observed for children below 12 years of age compared to those above. This indicates that the importance of school staff support varies across the two age groups, which was to be expected.

The present findings show that it may be necessary to include other strategies than school staff support to improve support of and mental health in schoolchildren with T1D. Guidelines from the International Society for Pediatric and Adolescent Diabetes (ISPAD) highlight the importance of adequate training of school staff, an individualized diabetes management plan for all children with T1D, and that parents should not be expected to manage their child's diabetes during school hours [7]. Sweden complies with these ISPAD guidelines, as the responsibility for support in self-care in Sweden is transferred from the parent to the school, with an individualized action plan based on an agreement reached by the child, parents, diabetes care team, and school. A diabetes care team provides appropriate diabetes training for the school personnel and works to improve communication between parents and school [19]. Such strategies may also be applicable in a Danish context.

The present study has some limitations. The respondents were members of the Danish Diabetes Association and were primarily women with longer education and higher employment rates compared to the background population. Therefore, experiences of fathers are underrepresented, which may be explained by a lesser tendency of men to respond to questionnaires compared to women and because we know that mothers are more likely to register their children as members of the Danish Diabetes Association. Given that the sociodemographic characteristics of all Danish parents of children with T1D are unknown, it is not possible to determine whether the study sample is representative of this group (selection bias), and because the sociodemographic characteristics of non-responders are also unknown, we are unable to evaluate the study sample's representativeness compared to all invited parents.

The use of diabetes technology was not included in the questionnaire, which is a major limitation of the study given the widespread use of insulin pumps and continuous blood glucose monitoring of children with T1D.

Another limitation may be the timing of the study, which was conducted in 2020, following the first national COVID-19 pandemic lockdown in Denmark. The risk of recall bias may have been exacerbated by the lockdown, as all questions referred to the time prior to the lockdown, meaning respondents were being asked to remember situations even further back in time.

Furthermore, making comparisons of results between countries is challenging due to differences in school and health systems as well as national legislation.

In conclusion, in Danish schoolchildren, having designated staff support in diabetes self-care was positively associated with a better parental experience of overall diabetes management and some mental health factors. Despite the positive association, only 28% of the children 6 to 16 years of age had a designated staff member responsible for support in diabetes self-care. For children below 12 years of age, only 51% were supported in school, which means there is potential for meaningful improvements.

This study also highlights the necessity to include other strategies to improve support of Danish schoolchildren with type 1 diabetes. The ISPAD guidelines can be a source of inspiration.

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Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki and did not require approval from an ethics committee. According to Danish legislation, it is only required that the ethics committee is notified if the survey research project includes human biological material (Komitéloven §14, Section 2).

Informed Consent Statement: All data were anonymized and processed in accordance with Danish Law and the General Data Protection Regulation 2016/679 of the European Parliament and of the Council. Respondents were able to withdraw their consent to participate in the study at any time.

Data Availability Statement: The data presented in this study are available on request from the corresponding author. The data are not publicly available due to privacy restrictions.

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Conflicts of Interest: The authors declare no conflict of interest. The donators had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

Appendix A

Table A1. Extended description of characteristics of the study population (parents of schoolchildren with type 1 diabetes) and the background population (the Danish population 30–54 years of age). Characteristics are presented in frequencies (%).

	Parents $(n = 252)$	The Danish Population (30–54 Years) *
Females	88.9	49.6
30–34 years	6.3	19.6
35–39 years	9.5	17.8
40–44 years	31.7	19.4
45–49 years	34.9	21.3
50–54 years	14.7	22.0
Above 55 years	2.4	-
Primary and lower secondary	1.6	15.5
Vocational education and training	7.6	32.9
General upper secondary	4.0	5.6
Short-cycle programs	10.8	6.4
Medium-cycle programs	56.4	21.1
Long-cycle programs	18.8	17.2
Other	0.8	1.3
Employed	88.0	81.1
Unemployed	6.8	16.2
Other	5.2	2.7
Capital Region of Denmark	22.6	34.0
Region Zealand	20.2	14.1
Region of Southern Denmark	23.4	20.2
Central Denmark Regions	21.8	22.3
North Denmark Region	12.1	9.5

^{*} Statistics Denmark (2022), 3rd quarter of 2020.

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