ISSN 2413-2640 eISSN 2519-0334

Girma et al.

## **ORIGINAL ARTICLE**

# KNOWLEDGE AND PRACTICES ON DIABETIC CARE AMONG THE CAREGIVERS OF CHILDREN WITH TYPE 1 DIABETES MELLITUS: A CROSS SECTIONAL STUDY

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## **ABSTRACT**

**Background**: Diabetes mellitus care in children requires parental support and involvement as young children cannot independently handle all of their diabetes cares; the diabetic cares given to these children entirely depend on the knowledge and skills of the care givers. This study was conducted to determine the knowledge and practices on diabetic care and associated factors among the caregivers of children with type 1 diabetes mellitus attending the follow-up clinic at Jimma Medical Center, Southwest Ethiopia.

Methods: Institution-based prospective cross-sectional study was conducted from July 10 to October 10, 2022. Data was collected using a structured questionnaire and analyzed using statistical packages for social sciences software Version 25.0. Bivariate and stepwise multivariate analysis was performed to test associations between the dependent and independent variables.

**Results**: One hundred fifty-eight caregivers of children with type 1 diabetes mellitus participated in the study; over half of the participants (93, 58.9%) were females. Over half of caregivers have a poor level of knowledge (56.3%) and practice (58.6%) about diabetes cares. Participants residing in the urban area are found to have better knowledge (p<0.001; 95%CI:1.81-6.86), whereas being female caregiver (p=0.03; 95%CI:1.04-4.22), attending diabetic education sessions (p=0.035; 95%CI:1.17-79.66) and, those who had good diabetes knowledge (p=0.04; 95% CI:1.03-4.04) were found to have a better practice.

**Conclusion**: The knowledge and practices of caregivers regarding diabetic care among caregivers of children with type 1 diabetes mellitus were found to be low. Structured diabetes care education should be given to all caregivers to improve their knowledge and practices.

**Keywords:** Type 1 diabetes; caregivers; knowledge; practice

Citation: Girma B., Berhane M., Knowledge and practices on Diabetic care among the caregivers of children with type 1 Diabetes mellitus: Across sectional study. Ethiop J Pediatr Child Health. 2023;18 (2):119-130

Submission date: 02 September 2023 Accepted: 13 December 2023 Published: 29 December 2023

## INTRODUCTION

The primary management strategy for a child with type 1 diabetes mellitus (DM) aims to achieve optimal glycemic control to reduce the risk of long-term complications of DM while preventing acute complications and maintaining the highest possible quality of life(1). The key factor to achieving good glycemic levels is the person's daily self-management of his/her condition. The key self-management activities specific to diabetes care in individuals living with diabetes are regular physical activities, appropriate dietary practices, daily foot care practice, compliance with the treatment regimen, sick day guidelines and recognition, treatment, and prevention of diabetes complications like hypoglycemia and diabetic ketoacidosis (DKA)(1-4).

However, most of these self-care activities are too challenging for young children to complete on their own. Therefore, it is the responsibility of their caregivers/parents to provide diabetes care to children with type 1 DM. Thus, education about diabetes care practice for a child and adolescent with diabetes must be provided to the entire family. Emphasis should also be given to integrate age and developmentally-appropriate self-care into the child's diabetes management (1).

Several studies have shown that caregivers' knowledge and practice of diabetes care have a direct effect on the glycemic level of children and the occurrence of both acute and chronic complications of diabetes(5–8). Despite this fact, recent studies conducted in low and middle -income countries indicate that many caregivers

lack the necessary knowledge and practice regarding various aspects of diabetes care, which could have an adverse effect on their children's overall diabetes control and associated complications (9–11).

Hence, this study was conducted with the objectives of determining the knowledge and practices of parents/caregivers of children with type 1 DM regarding diabetic care and associated factors. This will be helpful in designing subsequent interventions to improve the diabetic care for children with type 1 DM.

## Methods and materials

Study Area and Period: The study was conducted at the chronic follow-up clinic of Jimma Medical Center, a tertiary hospital, Southwest Ethiopia from July 10 to October 10, 2022. There were a total of 173 children and adolescents with type 1 diabetes mellitus on regular visits at the pediatric follow-up clinic of Jimma Medical Center out of which 5 were on follow up only for less than 3 months; 158 of them were included in the study.

**Study design:** Institution-based cross-sectional study design with prospective data collection was employed.

Sample size and sampling technique: To calculate the sample size, we used single population proportion formula with the assumption of 95% level of confidence, 5% marginal error, 5% non-response rate and taking proportion of caregiver knowledge level of 45% from previous studies done in Addis Ababa (12). Since the source population consisted of less than 10,000 respondents, the sample size

was adjusted by using correction formula. This revealed a final sample size of 122. However, as the sample size was manageable and also to improve the precision, we decided to include all participants fulfilling the inclusion criteria to participate in the study.

All primary caregivers of children (age less than 18 years) with type 1 DM on treatment and care for a minimum of 3 months who gave consent to participate in the study were consecutively included into the study. Those primary caregivers of children who have been on treatment for less than 3 months, caregivers who were not primary caregivers, and those who refused to participate in the study were excluded.

Data collection method and procedures: A structured interviewer-administered question-naire was used to collect all relevant information from study participants. The information collected included socio-demographic information about the caregiver, diabetes-related characteristics and clinical conditions of the caregiver, knowledge about diabetes care, and practice of diabetes care.

The diabetes knowledge test (DKT) was utilized to assess general knowledge of diabetes and components of diabetes care. DKT was developed and tested for reliability and validity by the University of Michigan researchers(13), which was adopted for this study in the context of the Ethiopian diet(12). DKT consists of 23 questions which have been shown to adequately estimate a general patient's/caregiver's knowledge of diabetes related to the 5 domains

of adherence to diabetes self-management(13). The total graded questions contained 23 questions, and each correct answer was scored as 1 and each incorrect answer was scored as 0. Then the scores of all items of knowledge were summed up, the mean score was calculated, and this mean was used to categorize participants into those who have poor (scored below the mean) and good knowledge (scored mean or above).

Data about diabetic care activities were collected using the tool "Adherence in Diabetes Questionnaire for the Parent/Caregiver Version (ADQ-P-C)" (14). The tool was adapted to the context of the study area according to the Ethiopian National Diabetic Management Guideline (2). Among the 19-item questions they used, six of them did not apply to our setup, so we decided to use only 13-item questions. The ADQ 13-item instrument quantifies five areas of practice related to adherence to type 1 DM care recommendations; which are insulin administration (3 items), dietary management (3 items), blood glucose testing (4 items), foot care (1 item), and exercise (2 items). Then a 4-point Likert scale with anchors 1=never, 2= sometimes, 3=almost always, and 4=always was used.

Scoring system: 4 points were given for always, 3 for most of the time, 2 for some time, 1 for never, and 0 for I don't know. Those with scores greater than or equal to the mean were categorized as having good diabetic care practices and those with scores less than the mean were categorized as having poor diabetic

care practices. For each domain of practice, the same thing was applied (15). The questionnaire was translated into local languages (Amharic and Afaan Oromo) and then, back translated to English to check for consistency before data collection.

## **Data Processing and Analysis**

The collected data were checked for completeness and consistency and then cleaned, coded, and entered into EpiData version 6.0. The data were then exported to, cleaned, and analyzed using Statistical Package for Social Sciences (SPSS) version 25.0. Descriptive analysis was used to describe the basic characteristics of the study participants. The mean and median were calculated for continuous variables. The association between variables was tested using binary logistic regression. Multivariate linear regression analysis was performed to determine the factors independently associated with caregivers' diabetes care knowledge and practices. A p-value of less than or equal to 0.05 was considered statistically significant. The degree of association between dependent and independent variables was reported using the adjusted odds ratio (AOR) and 95% confidence interval (CI).

Ethics Approval: Ethical clearance was obtained from the Institutional Review Board of Jimma University (Ref. No. IRB 1574/33/14), and permission was obtained from the authorities of the hospital. Written informed consent was obtained from each study participant before enrollment into the study.

## Results

One hundred and fifty-eight (94.0%) of the targeted 168 caregivers of children with type 1 DM attending a follow-up clinic at JMC participated in the study; the remaining participants either refused to provide their consent (4, 2.4%) or did not show up during the data collection period (6, 3.6%). The mean age of the caregivers was  $39.33\pm10.25$  (mean  $\pm$  SD) years . Of the 158 primary caregivers who participated in the study, over half of the study participants were females (93, 58.9%) and children's mothers (86, 54.4%). (Table 1)

Table 1. Socio-demographic characteristics of caregivers of children with type 1 DM in JMC Jimma., Ethiopia, 2022 (n=158)

| Variables          | Categories           | Frequency | Percent (%) |
|--------------------|----------------------|-----------|-------------|
| Age (years)        | <20                  | 3         | 1.9         |
|                    | 20-30                | 35        | 22.2        |
|                    | 31-40                | 64        | 40.5        |
|                    | >40                  | 56        | 35.4        |
| Sex                | Male                 | 65        | 41.1        |
|                    | Female               | 93        | 58.9        |
| Relation with the  | Mother               | 86        | 54.4        |
| child              | Father               | 47        | 29.7        |
|                    | Guardian             | 25        | 15.8        |
| Marital status     | Married              | 128       | 81.0        |
|                    | Unmarried            | 11        | 7.0         |
|                    | Divorced             | 8         | 5.1         |
|                    | Widowed/widower      | 11        | 7.0         |
| Residence          | Urban                | 65        | 41.1        |
|                    | Rural                | 93        | 58.9        |
| Educational status | Can't read and write | 59        | 37.3        |
|                    | Primary (grade1-8)   | 40        | 25.3        |
|                    | Secondary (9-12)     | 39        | 24.7        |
|                    | College and above    | 20        | 12.7        |
| Occupation         | Housewife            | 63        | 39.9        |
|                    | Farmer               | 60        | 38.0        |
|                    | Employed             | 19        | 12.0        |
|                    | Merchant             | 5         | 3.2         |
|                    | Daily laborer        | 11        | 7.0         |
| Family Monthly in- | ≤1000 ETB            | 28        | 17.7        |
| come               | 1001-2500 ETB        | 62        | 39.2        |
|                    | 2501-5000 ETB        | 39        | 24.7        |
|                    | ≥5000 ETB            | 29        | 18.4        |

The majority of the children with type 1 DM were diagnosed before reaching 5 years of age (140, 88.6%) and had been on follow-up for less than 5 years (123, 77.8%). Only a few of them (18, 11.4%) had other family members

with diabetes. The majority (145, 91.8%) of caregivers (145, 91.8%) have received diabetic education, almost all of them receiving the education from the Hospital (140, 96.6%). (Table 2)

Table 2. Diabetes-related characteristics and clinical conditions of the caregivers of children with type 1 DM attending follow-up clinic, JMC, Jimma, Ethiopia, 2022.

| Variables                     | Categories | Frequency | Percent (%) |
|-------------------------------|------------|-----------|-------------|
| Presence of family members    | Yes        | 18        | 11.4        |
| with DM                       | No         | 140       | 88.6        |
| Age of the child at diagnosis | <5 years   | 123       | 77.8        |
| of DM                         | 5-10 years | 30        | 19.0        |
|                               | >10 years  | 5         | 3.2         |
| Duration on flow up           | <1 year    | 17        | 10.8        |
|                               | 1-5 years  | 106       | 67.1        |
|                               | >5 years   | 35        | 22.2        |
| Care givers got diabetes edu- | Yes        | 145       | 91.8        |
| cation/advice                 | No         | 13        | 8.2         |

The mean and standard deviation of knowledge score among caregivers towards diabetic care was  $8.48 \pm 3.58$ ; and only 43.7% of caregivers had good knowledge. Caregivers had better knowledge regarding the most accurate way of monitoring diabetes (104, 65.8%) whereas the worst response was seen with regard to effect of exercise on blood glucose lev-

el (37, 23.4%). Only less than half of the respondents (67, 42.4 %) had good practice towards type 1 DM. Caregivers had better practice with regards to administering insulin at the right times (111, 70%), while the worst response was observed with regards to routine blood sugar monitoring (50, 31.2%). (Table 3)

Table 3: Overall responses of caregivers for the specific questions under the knowledge and practice domain JMC, Jimma, Ethiopia, 2022

| Variables  | Proportions | <b>Proportions of responses</b> |  |  |
|--|-------------|---------------------------------|--|--|
|  | Wrong       | Correct                         |  |  |
| Knowledge questions Glycosylated hemoglobin (hemoglobin A1) is a test that measures your average blood glucose level for the past 6-10 week:   | 109 (69.0%) | 49 (31.0%)                      |  |  |
| Which is the best method for testing blood glucose?  | 54 (34.2%)  | 104 (65.8%)                     |  |  |
| What effect does unsweetened fruit juice have on blood glucose?  | 95 (60.1%)  | 63 (39.9%)                      |  |  |
| Effect of infection on blood glucose   | 95 (60.1%)  | 63 (39.9%)                      |  |  |
| You realize just before lunchtime that you forgot to give him/her insulin before breakfast. What should you do now?  | 110 (69.6%) | 48 (30.4%)                      |  |  |
| If your child is beginning to have a low blood glucose reaction, what he/she should do?  | 69 (43.7%)  | 89 (56.3%)                      |  |  |
| Cause of low blood glucose   | 47 (29.7%)  | 111 (70.3%)                     |  |  |
| If your child takes his morning insulin but skips breakfast, his blood glucose level will usually decrease   | 72 (45.6%)  | 86 (54.4%)                      |  |  |
| Cause of high blood glucose  | 69 (43.7%)  | 89 (56.3%)                      |  |  |
| For a child in good control, what effect does exercise have on blood glucose?  | 121 (76.6%) | 37 (23.4%)                      |  |  |
| What is the recommended procedure for low blood sugar (hypoglycemia)?  | 71 (44.9%)  | 87 (55.1%)                      |  |  |
| What is best way to take care of your child's feet?  | 111 (70.3%) | 47 (29.7%)                      |  |  |
| Signs of ketoacidosis  | 106 (67.1%) | 52 (32.9%)                      |  |  |
| Practice questions  Take the appropriate of invalidation that the health are appropriate or a single state of the same and the same are side of the same are | 47 (20 70/) | 111(70.20/)                     |  |  |
| Take the amount of insulin that the healthcare provider prescribed   | 47 (29.7%)  | 111(70.3%)                      |  |  |
| Taking insulin at the right times  | 46 (29.1%)  | 112 (70.9%                      |  |  |
| Alternating injection sites to avoid lipohypertrophy   | 102 (64.6%) | 56 (35.4%)                      |  |  |
| Detect and respond to early signs of low blood glucose   | 54 (34.2%)  | 104 (65.8%)                     |  |  |
| Detect and respond to early signs of high blood glucose  | 59 (37.3%)  | 99 (62.7%)                      |  |  |
| Attend regular check-ups at the diabetes clinic as your health care provider recommended   | 109 (69%)   | 49 (31%)                        |  |  |
| Monitor blood sugar as often as your healthcare provider asked you to  | 108 (68.8%) | 50 (31.2%)                      |  |  |
| Check feet daily for signs of problems such as ulceration, blisters  | 78 (49.4%)  | 80 (50.6%)                      |  |  |
| Exercising or participating in some form of physical activity (Working in the field such as farming, fetching water, Playing with peer groups such as football or handball)  | 65 (22.9%)  | 93 (77.1%)                      |  |  |
| Remembering to carry "fast sugar" (e.g., carry sweets, sugary biscuits or bread, or the like) to prevent hypoglycemia  | 70 (44.4%)  | 88 (55.6%)                      |  |  |
| Follow an eating plan recommended by a health professional/Eat a balanced diet   | 61 (42.5%)  | 97 (57.5%)                      |  |  |
| Limiting the amount of food she/he eats that contains a lot of sugar or fat (for example cheese, cured meats, sweets, red meat)  | 76 (40.9%)  | 82 (59.1%)                      |  |  |

The caregivers' residence had statistically significant association with the care givers' knowledge of type 1 DM; the caregivers who reside in urban areas were 3.84 times (AOR=3.53; 95% C.I: 1.81-6.86) more likely to have better knowledge as compared to those from rural areas. On the other hand, the care givers' gender, attendance of diabetic education, and diabetes knowledge level showed statistically significant associations with

their practices; diabetes care practice level was found to be 2.09 times higher in female caregivers (AOR=2.09; 95% CI: 1.04-4.22 ), 9.48 times in caregivers who attended diabetes education (AOR=9.48;95% CI: 1.17-79.66 ), and 2.04 times in caregivers who had good diabetes knowledge (AOR= 2.04;95% C.I: 1.03-4.04 ) than their counterparts (Tables 4 and 5).

Table 4. Multivariable logistic regression model to identify factors associated with the level of knowledge of respondents JMC, Jimma, Ethiopia, 2022.

| Variables                               | Category                    | Knowledge Level |            | AOR (95%CI)      |
|---|-----------------------------|-----------------|------------|------------------|
|   |                             | Good n (%)      | Poor n (%) | -                |
| Residence                               | Urban                       | 40(61.5)        | 25(38.5)   | 3.53(1.81-6.86)* |
|   | Rural                       | 29(31.2)        | 64(68.8)   | 1                |
| Educational status                      | Can't read and              | 21(35.6)        | 38(64.4)   | 1                |
|   | write<br>Primary (grade1-8) | 16(40.0)        | 24(60.0)   | 0.97(0.39-2.42)  |
|   | Secondary (9-12)            | 18(46.2)        | 21(53.8)   | 0.67(0.24-1.85)  |
|   | College and above           | 14(70.0)        | 6(30.0)    | 1.76(0.48-6.45)  |
| Family monthly income                   | ≤1000 ETB                   | 7(25.0)         | 21(75.0)   | 1                |
|   | 1001-2500 ETB               | 21(33.9)        | 41(66.1)   | 1.34(0.48-3.72)  |
|   | 2501-5000 ETB               | 21(53.8         | 18(46.2)   | 2.21(0.67-7.22)  |
|   | ≥5000 ETB                   | 20(69.0)        | 9(31.0)    | 3.67(0.96-14.00) |
| Attended diabetes ed-<br>ucation/advice | Yes                         | 66(45.5)        | 79(64.5)   | 3.75(0.93-15.13) |
|   | No                          | 3(23.1)         | 10(76.9)   | 1                |
| Duration of follow up                   | <1 years                    | 5(29.4)         | 12(70.6)   | 1                |
|   | 1-5 years                   | 46(43.4)        | 60(56.6)   | 2.13(0.63-7.21)  |
|   | >5 years                    | 18(51.4)        | 17(48.6)   | 3.41(0.88-13.19) |

AOR: Adjusted Odds ratio, 1: the reference group, \*variables that showed statistically significant association with the dependent variable at p < 0.05

Table 5. Multivariable logistic regression model to identify factors associated with the practice level of caregivers towards diabetic care, JMC, Jimma, Ethiopia, 2022

| Variables                                | Category             | Level of practice |            | AOR (95%CI)        |
|--|----------------------|-------------------|------------|--------------------|
|  |                      | Good n (%)        | Poor n (%) | -                  |
| Age of caregivers in years               | <20 years            | 2(66.7)           | 1(33.3)    | 1.73(0.13-22.13)   |
|  | 20-30 years          | 19(54.3)          | 16(45.7)   | 1.68(0.66-4.32)    |
|  | 31-40 years          | 26(40.6)          | 38(59.4)   | 1.13(0.49-2.65)    |
|  | >40 years            | 20(35.7)          | 36(64.3)   | 1                  |
| Gender                                   | Male                 | 20(30.8)          | 45(69.2)   | 1                  |
|  | Female               | 47(50.5)          | 46(49.5)   | 2.09(1.04-4.22)**  |
| Educational status                       | Can't read and write | 22(37.3)          | 37(62.7)   | 1                  |
|  | Primary (grade1-8)   | 15(37.5)          | 25(62.5)   | 0.67(0.27-1.67)    |
|  | Secondary (9-12)     | 22(56.4)          | 17(43.6)   | 1.00(0.37-2.74)    |
|  | College and above    | 8(40.0)           | 12(60.0)   | 0.68(0.21-2.17)    |
| Family monthly income                    | ≤1000 ETB            | 10(35.7)          | 18(64.3)   | 1                  |
|  | 1001-2500 ETB        | 22(33.5)          | 40(64.5)   | 0.72(0.24-2.11)    |
|  | 2501-5000 ETB        | 19(48.7)          | 20(51.3)   | 1.19(0.33-4.31)    |
|  | ≥5000 ETB            | 16(55.2)          | 13(44.8)   | 1.44(0.36-5.82)    |
| Attending diabetes education/counselling | Yes                  | 66(45.5)          | 79(54.5)   | 9.48(1.17-79.66)** |
|  | No                   | 1(7.7)            | 12(92.3)   | 1                  |
| Knowledge                                | Good knowledge       | 38(55.1)          | 31(44.9)   | 2.04(1.03-4.04) ** |
|  | Poor knowledge       | 29(32.6)          | 60((67.4)  | 1                  |

AOR: Adjusted Odds ratio, 1: the reference group, and \*\* variables that showed statistically significant association with the dependent variable at p < 0.05.

### Discussion

With the current study, we aimed determine the knowledge and practice level of the caregivers of children with type I diabetes mellitus and associated factors at a tertiary hospital located in one of the Low and Middle Income Countries. This is particularly important in order to understand the situation in the local context and address the existing gaps with regard to the knowledge and practices of diabetic care

with an ultimate goal of improving the cares given to this group of patients and hence, reduce the associated complications and improve the quality of care of the patients.

Care givers' knowledge is crucial in determining the cares they give to their children with diabetes mellitus which in turn affects the glycemic control of the children(5–8). Consistent with studies done in Ethiopia (12) and Sudan (10), caregivers participating in this study had

poor level of knowledge and practices regarding their children's diabetic cares. This indicates the need for continuous awareness creation activities by healthcare workers taking care of these children with an ultimate goal of improving the cares of such children. Healthcare workers taking care of these children need to regularly assess the knowledge of caregivers (and the children themselves when applicable) and their practices with regard to diabetic cares on every visit or encounter and provide them with the necessary information and feedback so that they have an adequate knowledge and also transcribe the knowledge they acquired to practices which will ultimately improve the cares given to the children.

Apart from the information received from healthcare workers, access to other sources of information regarding care of children with diabetes is important in improving the knowledge and practices of care givers is important. In this study, participants from urban residence were found to have a better mean knowledge score level compared to residents from rural area. This is similar to other studies conducted in Egypt (9) and Ethiopia (12). This difference could be explained by the better access to potential sources of information (radio, television, internet, etc.) in urban areas compared to rural areas.

On the other hand, there was a significant association observed between the gender of the caregivers and their practices regarding diabetic cares; female caregivers were two times more likely to have good practice. This might be due to the fact that most of the time, mothers as caregivers, might be spending their time with the children and providing diabetic care to their children; more than half of the caregivers in our study were also mothers. This finding is supported by findings from other studies conducted in India (5) and Bangladesh (8). Even if all family members of children with DM need to receive the necessary education in order to improve the cares provided to the children, these findings might indicate whom to target for such interventions to get the maximum benefits from the intervention. As is expected and is seen in other studies (8,9,16), attending diabetes education sessions is found to be associated with better practice of diabetic care in the current study, indicating the need to provide continuous education for caregivers in order to improve caregivers' practices. Having good knowledge level is positively associated with having good diabetic care practices reinforcing the need to improve caregivers' knowledge. The fact that the study relied reported caregiver's knowledge and practice, which may not reflect their actual performances can be taken as the limitation of the study.

In conclusion, the caregivers' knowledge and practice with regard to diabetic cares in this study is poor. Urban residence was associated with good knowledge whereas caregivers' gender, attending diabetes education and caregivers' knowledge were associated with good

practices. Healthcare professionals taking care of children with diabetes should regularly and continuously educate caregivers in order to improve the knowledge and practices of caregivers.

## **Declarations**

Ethical considerations: Ethical clearance was obtained from the Institutional Review Board of Jimma University (Ref. No. IRB 1574/33/14), and permission was obtained from the authorities of the hospital. Written informed consent was obtained from each study participant before enrollment into the study.

Authors' contributions: BG conceptualized the idea, designed the methods, developed data collection tools, supervised the data collection, conducted the data analysis and drafted the manuscript. MB supported the study design, reviewed the study protocol and tool and reviewed the draft manuscript. BG and MB reviewed and approved the final version of the manuscript.

Competing interests: The authors declare that they don't have any competing interests relating to the work.

Funding: The study is funded by Jimma University Institute of Health, Post graduate and research Coordinating office. The funder had no role in the design, implementation and reporting of the study.

Acknowledgement: We would like to thank Jimma University Institute of Health, Post graduate and Research Coordinating Office for financially supporting this study. Our heartfelt gratitude also goes to all the caregivers of children with type 1 diabetes who volunteered their time and consented to participate in the study. We would also like to acknowledge all those who have supported us during the data collection.

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