



## Original Research

## Perceived knowledge on type-2 diabetes of informal caregivers in rural communities of Thai Binh, Vietnam: Implications for health education

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## ABSTRACT

**Objectives:** Informal caregivers' (ICGs') knowledge has substantial influence on the quality of caregiving. This study aims to identify caregivers' perceived knowledge status and analyse associations between their characteristics and perceived knowledge on how to care for individuals with type-2 diabetes (T2D).

**Study design:** Cross-sectional study.

**Methods:** Data were collected using a face-to-face survey with ICGs and perceived knowledge was evaluated on the 5-point Likert scale (ranging from 0 to 4).

**Results:** Between April and July 2019, 1238 eligible ICGs were enrolled in the study. The mean age of participants was 48.3 years, about half (48.8%) were males and the majority (83.3%) were spouses or children of the person they cared for. ICGs mean knowledge score on overall activities was 2.48 (SD = 0.90); the highest score was seen for diet preparation (2.74 ± 0.85) and lowest for foot care (1.76 ± 1.45). Multivariate analyses showed that the following ICG characteristics were significantly more likely to result in a low level of T2D-related knowledge (mean score ≤2): age <40 years, educational level below high school, farming occupation, low economic status and caring for an individual with mild or moderate T2D.

**Conclusions:** The level of perceived knowledge on T2D among ICGs was particularly low for the care of T2D complications. Development of targeted and tailored educational interventions for ICGs is recommended.

## 1. Introduction

Diabetes has a significant impact on the physical and mental health status of patients [1,2]. The prevalence of diabetes in 2030 is estimated to increase to 552 million people worldwide, and the majority of those with diabetes live in low- and middle-income countries, including Vietnam [3,4]. In Vietnam, in 2017 there were approximately 5.76 million people with diabetes, which corresponds to a population prevalence rate of 6% [5]. Support from informal caregivers (ICGs), usually the spouse, children, siblings or other relatives (e.g. nephews, nieces), plays an important role in improving the quality of life of those with T2D [6,7]. Furthermore, in addition to information obtained from the healthcare system, ICGs are likely to provide an important source of T2D-related knowledge to the patient [8,9].

Recent research indicates that ICGs can provide good support when they have profound insight into issues pertinent to caring for persons with T2D (e.g. assisting in decision-making, accessing resources related to the patient's condition and care plan, and monitoring the patients' treatment and wellbeing) [10,11]. Nevertheless, ICGs often feel that their knowledge on these issues is inadequate [9,12,13]. A reason for this apparent lack of knowledge is that most intervention programmes are directed at the patients only, without involving family members [14, 15].

To date, there has been very little information available on the knowledge of ICGs related to their caregiving activities for persons with T2D in low- and middle-income countries, including Vietnam. Consequently, this study aimed to identify ICGs' perceived knowledge status, and analyse associations between their sociodemographic

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characteristics and perceived knowledge on how to care for individuals with T2D in the rural communities of Thai Binh province, Vietnam.

## 2. Methods

A cross-sectional survey using a face-to-face questionnaire was conducted between April and July 2019 in two rural districts of the Thai Binh province of Vietnam. Thai Binh province is located in the North of Vietnam, covers an area of 1542 km<sup>2</sup>, has approximately 1,860,000 inhabitants living in seven rural districts and has one capital city. Two rural districts of the province were purposely selected for the survey; namely, Quynh Phu district in the northern part of Thai Binh, located far from the capital city of the province, and Vu Thu district in the southern part of Thai Binh, located next to the capital city of the province.

### 2.1. Sampling and participants

The study sample was based on the intervention research project 'Living Together with Chronic Disease: Informal Support for Diabetes Management in Viet Nam', which includes a component to identify the perceived knowledge status and knowledge requirements of ICGs caring for individuals with T2D in Vietnam.

Participants of the present study were caregivers providing informal care to individuals with T2D who were being treated at the district hospitals within the two selected districts during the survey period. In each selected district, the four rural communities with the highest number of T2D patients were chosen; a total of eight communities were selected for the survey. T2D patients were asked to name their two most important ICGs, who were subsequently enrolled in the current survey; if a person had only one ICG, only one would be enrolled.

The selection criteria of ICGs were as follows: age  $\geq 14$  years, sufficient mental and physical health status, and willing to participate in the survey. In total, within the eight selected communities, 1307 ICGs were invited to participate in the study. Among them, 66 (5.1%) refused to participate in the survey; furthermore, 3 (0.23%) were excluded from the analysis as a result of missing responses in the questionnaire. Hence, a total of 1238 ICGs were finally included in the study (94.7% of individuals in the sampling frame).

### 2.2. Questionnaire

The questionnaire and consent forms were in Vietnamese. The questionnaire was designed, pre-tested with ICGs ( $n = 25$ ) and validated by experts (specialising in internal medicine, clinical pharmacology, family medicine and public health) to ensure all questions were easy to understand and culturally relevant. The questionnaire had two parts: the first part consisted of sociodemographic information of ICGs; and the second section contained questions on perceived knowledge related to caregiving activities of ICGs for individuals with T2D.

This study aimed to determine whether ICGs feel knowledgeable, and whether and how their sociodemographic characteristics are associated with perceived knowledge. In the analysis, the independent variables were the sociodemographic characteristics and the dependent variables were the perceived knowledge of ICGs on T2D caregiving activities.

### 2.3. Sociodemographic characteristics

The key sociodemographic variables used in this study were age, gender, relationship to person being cared for, education, occupation, economic status, length of caregiving time, severity of T2D and living in the same house as the person being cared for. Economic status was self-reported by respondents and categorised into three levels (low, middle and high); low economic status was identified when respondents reported that they were in the 'poor' or 'near-poor' categories. The severity of T2D was categorised into three levels (mild, moderate and

high) and was self-reported by ICGs and/or with reference to related information from medical records.

### 2.4. Perceived knowledge

Perceived knowledge of ICGs was assessed by seven questions. These questions focused on three groups of common caregiving activities for persons with T2D: behaviour change (e.g. diet, smoking and physical activity), medication adherence and complication care (e.g. foot ulceration, anxiety and hypoglycaemia control). The following seven questions were included: 'Do you have sufficient knowledge regarding the following issues in caring for persons with T2D: 1) diet preparation; 2) smoking cessation; 3) physical activity; 4) medication adherence; 5) foot care; 6) anxiety control; and 7) hypoglycaemia control?'. The response options to these questions were based on the 5-point Likert scale ranging from 0 ('definitely not') to 4 ('definitely'). Mean knowledge scores could range between 0 and 4; higher scores indicated a higher level of knowledge. A range of mean knowledge scores  $\leq 2.0$  was defined as a low level of knowledge, whereas a mean knowledge score  $> 2.0$  was defined as a high level of knowledge. When measuring of internal consistency, the alpha coefficient for the seven questions was 0.88.

### 2.5. Statistical analyses

Data were double-entered in the software EPI-DATA (version 3.1, 2008) for quality control and errors were subsequently corrected. The SPSS software (version 25, 2017) was used for data analysis. Descriptive statistics were applied to describe the status of ICGs' sociodemographic characteristics and perceived knowledge. Multivariate analysis was used to analyse the associations between the sociodemographic characteristics and perceived knowledge of ICGs. To identify covariates used for multivariate analysis, initially, a bivariate analysis based on a conservative p-value of  $< 0.20$  was conducted. Three covariates (gender, length of caregiving time and living in the same house as the person being cared for) did not meet the cut-off point and were consequently excluded. All the other covariates were included in a full multivariate model. The unadjusted odds ratios (OR) and adjusted odds ratios (AOR) for a low level of knowledge were calculated. The association was regarded as being statistically significant when the 95% confidence interval (CI) did not contain the value 1.0.

### 2.6. Ethical approval and participant consent

The research was approved by the Ethical Committee of Thai Binh University of Medicine and Pharmacy, Vietnam. Data analyses, management and storage were carried out according to the rules and regulations currently applied in Vietnam and Denmark. All study participants were explained the aims of the survey and, if they agreed to participate, they were asked to sign a written consent form prior to completing the survey. Participants could withdraw from the study at any time. Surveys were conducted in separate rooms recommended by the ICGs to maintain their privacy.

## 3. Results

Between April and July 2019, a total of 1238 ICGs who met the selection criteria were enrolled in the survey. The mean age of ICGs was 48.3 years (standard deviation [SD] = 15.1); 604 (48.7%) were males; 1149 (83.3%) were the spouse or child of the person they care for; and 663 (53.6%) completed at least high school. Other participant characteristics are presented in Table 1. Regarding the types of caregiving activities, the majority (72.9%) of ICGs reported that they supported diet preparation, and more than a half (56.3%) helped to control hypoglycaemia for the person that they care for. It is important to note that none of the ICGs in this study were health professionals.

On the 5-point scale, with values ranging from 0 to 4, the mean

**Table 1**  
Sociodemographic characteristics of informal caregivers of persons with type-2 diabetes (n = 1238).

Characteristic	n (%) <sup>a</sup>
Age in years [mean (SD)]	48.3 (±15.1)
Female	634 (51.2)
Relationship to person with T2D	
Spouse	483 (39.0)
Daughter/son	666 (53.8)
Other relationship	89 (7.2)
Education	
Secondary school or less	575 (46.4)
High school	338 (27.3)
University/college	325 (26.3)
Current occupation	
Farmer	311 (25.1)
Worker	233 (18.8)
Retired	133 (10.7)
Unemployed, housewife, small trader, student	561 (45.3)
Low economic status	42 (3.4)
Length of caregiving time (>5 years)	657 (53.1)
T2D at severe status	829 (67.0)
Living in the same house <sup>b</sup>	857 (69.2)

SD, standard deviation; T2D, type-2 diabetes.

<sup>a</sup> Unless stated otherwise.

<sup>b</sup> Living together in the same house with the person they care for, including some of the time.

knowledge scores of ICGs on specific caregiving activities were found to be lowest for foot care (mean = 1.76, SD = 1.45), and ranged from 2.40 to 2.74 for other caregiving activities. The mean knowledge score on overall caregiving activities was 2.48 (SD = 0.09). ICGs T2D-related knowledge was found to be lowest (mean score  $\leq 2$  points) for T2D complication care activities, including foot care (n = 730, 59.0%), anxiety control (n = 545, 44.0%) and hypoglycaemia control (n = 471, 38.0%). In addition, the largest number of ICGs with no knowledge on related activities were also found for foot care (n = 416, 33.6%), anxiety control (n = 109, 8.8%) and hypoglycaemia control (n = 98, 7.9%). Other findings on the perceived knowledge of ICGs are shown in Table 2. The majority (87.5%) of ICGs reported that they lacked T2D-related knowledge. Furthermore, more than half (54.9%) of ICGs did not feel confident caring for persons with T2D and the majority of ICGs (82.8%) felt that they required more information to be able to provide better support.

In the bivariate analysis, ICG ‘worker’ occupation was not associated with knowledge level on caregiving activities when compared with ‘farmer’ occupation; however, ‘worker’ ICGs were significantly less likely to have a low level of knowledge than ‘farmer’ ICGs in the multivariate analysis (adjusted odds ratio [AOR] = 0.59; 95% confidence interval [CI] 0.38–0.90; p = 0.015). In multivariate analysis, the

**Table 2**  
Perceived knowledge of informal caregivers on caregiving activities (n = 1238).

Caregiving activities	Knowledge score mean (SD)	Low level of knowledge <sup>a</sup> [n (%)]	No knowledge <sup>b</sup> [n (%)]
Specific activities			
Diet preparation	2.74 (0.85)	390 (31.5)	21 (1.7)
Smoking cessation	2.59 (1.05)	443 (35.8)	81 (6.5)
Physical activity	2.60 (1.06)	467 (37.7)	86 (6.9)
Medication adherence	2.71 (1.15)	396 (32.0)	97 (7.8)
Foot care	1.76 (1.45)	730 (59.0)	416 (33.6)
Anxiety control	2.40 (1.07)	545 (44.0)	109 (8.8)
Hypoglycaemia control	2.57 (1.13)	471 (38.0)	98 (7.9)
Overall activities	2.48 (0.90)		

SD, standard deviation.

<sup>a</sup> Mean knowledge score  $\leq 2$ .

<sup>b</sup> Mean knowledge score = 0.

following sociodemographic characteristics of ICGs were significantly associated with a low level of knowledge on caregiving activities: age <40 years, educational level below high school, occupation as a farmer, low economic status and caring for an individual with mild or moderate T2D status. Other findings on associations between characteristics of ICGs and their perceived knowledge are shown in Table 3.

#### 4. Discussion

T2D-related perceived knowledge among ICGs was generally low, particularly on the care of T2D complications. Factors significantly associated with a low level of knowledge on caregiving activities were an educational level below high school, occupation as a farmer and low economic status. These findings are in line with other studies where ICGs often feel that their knowledge is inadequate [9,12,13], most likely because most interventions and care programmes are directed at the patients only, without involving family members [14,15].

Among ICGs who enrolled in the present study, most were the spouses and children of the person they care for, and their mean knowledge scores on caregiving activities were particularly low on the care of T2D complications, including foot care, anxiety and hypoglycaemia control. Jeffcoat [16] reported that diabetes increases the risk of developing several major health problems; in addition, this study suggests that the level of morbidity and mortality due to diabetes, and its possible long-term complications, could cause significant healthcare problems for both the family and society. Spouse caregivers are particularly vulnerable, often because of older age, low education, lower income and social isolation [17]. Access to systematic and easy-to-follow training is therefore crucial for the well-being of ICGs and the effectiveness of the care they are providing [18]. In our study, the majority of ICGs reported a lack of knowledge on caregiving activities. Furthermore, the high rates of ICGs with a low level of knowledge on caregiving activities seen in the current study supports results from Masami et al. [19], where more than two-thirds (254/376; 67.6%) of adult residents in Vietnam either did not understand or had never heard of diabetes.

Among the seven surveyed caregiving activities, foot care had the highest rate (59.0%) of ICGs with a low level of knowledge. This supports recent research in the US, the UK and Europe, where 66% of diabetic foot caregivers stated that they were fearful of making mistakes and 38% expressed a need for training in this issue [20]. It could be explained by the fact that foot ulceration in T2D patients is a serious problem because its outcome is often poor (healing is slow and a high proportion of ulcers does not heal in spite of intensive treatment).

The low level of knowledge on hypoglycaemia control (38.0%) was also concerning and is in line with results from a recent study in Germany, where nearly one-third (32%) of ICGs were unable to list any correct treatment measures in the event of mild hypoglycemia [21]. Hence, this knowledge problem appears to be equally persistent in both middle-income and high-income countries. Insufficient glycaemic control increases the risk of microvascular complications (retinopathy, nephropathy and neuropathy) in patients with T2D [22,23].

Physical well-being can be improved through physical activity and glycaemic control [24], [25] and regular physical activity reduces the risk of all-cause mortality by 30% and can increase life expectancy by up to 7 years [26,27]. However, 37.7% of ICGs in the present study had a low level of knowledge on how to help T2D patients improve their physical activity.

Improved knowledge on foot care, hypoglycaemia and physical activity should be prioritised in education intervention programmes aimed at T2D patients and their ICGs.

In the present study, ICGs with an education level lower than high school were significantly more likely to have a low level of T2D-related knowledge compared with ICGs with other educational levels; thus, priority should be given to these ICGs when designing interventions in the community. This supports recent studies by Kirkland et al. [28] and Silva et al. [29], where people with higher levels of education are more

**Table 3**

Results of multivariable analysis examining sociodemographic characteristic variables associated with a low level of knowledge of informal caregivers (n = 1238).

Characteristic	Number in each group (% with the low level of knowledge)	Bivariate analysis		Multivariate analysis	
		Unadjusted OR (95% CI)	p-Value	Adjusted OR (95% CI)	p-Value
Age (years) (ref: $\geq 60$ )					
<40	160 (40.2)	1.89 (1.38–2.59)	<0.001	2.31 (1.35–3.94)	0.002
40–59	153 (38.4)	1.40 (1.03–1.91)	0.034	1.25 (0.82–1.89)	0.302
Gender (ref: male)					
Female	204 (51.3)	1.00 (0.79–1.27)	0.983		
Relationship to persons with T2D (ref: spouse)					
Son/daughter	237 (59.5)	1.42 (1.10–1.84)	0.006	1.18 (0.78–1.76)	0.430
Other	26 (6.5)	1.06 (0.65–1.75)	0.808	0.83 (0.48–1.45)	0.515
Education (ref: >high school)					
<high school	214 (53.8)	2.20 (1.60–3.01)	<0.001	1.58 (1.05–2.39)	0.029
High school	115 (28.9)	1.91 (1.35–2.71)	<0.001	1.32 (0.88–1.98)	0.185
Current occupation (ref: farmer)					
Worker	102 (25.6)	1.00 (0.71–1.41)	0.991	0.59 (0.38–0.90)	0.015
Retired	23 (5.8)	0.27 (0.16–0.44)	<0.001	0.47 (0.26–0.85)	0.012
Unemployed and others <sup>a</sup>	137 (34.4)	0.42 (0.31–0.56)	<0.001	0.40 (0.28–0.57)	<0.001
Economic status (ref: high)					
Low (poor/near poor)	19 (4.8)	2.15 (0.83–5.55)	0.114	3.35 (1.11–10.10)	0.032
Middle	369 (93.2)	1.23 (0.57–2.54)	0.609	1.42 (0.60–3.34)	0.424
Length of caregiving time (ref: >5 years)					
$\leq 5$ years	178 (44.7)	0.88 (0.69–1.11)	0.284		
Severity of T2D (ref: severe)					
Mild	209 (52.5)	12.23 (7.45–20.08)	<0.001	11.60 (6.92–19.44)	<0.001
Moderate	169 (42.5)	4.87 (2.98–7.95)	<0.001	4.71 (2.84–7.80)	<0.001
Living in the same house (ref: no)					
Yes	268 (67.3)	1.14 (0.88–1.47)	0.322		

CI, confidence interval; OR, odds ratio; T2D, type-2 diabetes; vs., versus.

<sup>a</sup> Including housewife, small trader and student.

receptive to health education campaigns. In addition, higher education can also lead to more accurate health beliefs and knowledge, and thus lead to better lifestyle choices, better skills as well as greater self-advocacy.

In our study, ICGs who were farmers and those who had low economic status were significantly more likely to have a low level of knowledge on their caregiving activities. This can be explained by the fact that in rural Vietnam, the majority of 'poor' or 'near-poor' ICGs have an education level less than high school and work as farmers; these individuals often spend more time than other population groups earning money for daily living, thus lack time to access information on diseases, including T2D.

The economic burden on ICGs has been reported in some studies. ICGs appear to be at higher risk of financial difficulties themselves when they provide informal support to persons they care for [30,31]. Because diabetes is a chronic disease that requires regular treatment, daily medication, hospitalisation or other complications, the cost for treatment is a heavy economic burden for patients and their families in Vietnam [5].

The present study has several limitations. Firstly, the study was designed as a cross-sectional survey; thus, it might not be exempt from causality inferences or possible biases that impact the resulting values. Secondly, the fact that ICGs' knowledge was self-perceived may lead to the answers being exaggerated and/or they may be embarrassed to reveal private details in answering questions. However, this study also has several strengths, such as the large sample size (1238 ICGs), which gives more reliable results with greater precision and power in data analysis, and there was only a very low rate (5.3%) of ICGs who refused to participate in this study, thus reducing the risk of selection bias.

The results of this study suggest that to enhance knowledge of ICGs on caregiving activities, targeted and tailor-made training should be considered. The approach and contents of educational interventions should be appropriate for the sociodemographic characteristics and knowledge requirements of ICGs, with priority to those with a low level of T2D-related knowledge. Education topics should focus on areas where

ICGs had the lowest mean knowledge scores. By participating in training, ICGs would obtain a broader knowledge of related contents and how to apply them. This approach is supported by recent studies where ICGs were eager to get more information about the conditions they were caring for and were willing to take part in educational programmes offered to them [32],[33,34]. This calls for intervention studies with a participatory design, where T2D patients and ICGs are involved as co-designers, using their decision-making powers and incorporating their needs and values to the design process and the final programme.

In summary, the level of T2D-related perceived knowledge among ICGs was particularly low for the care of T2D complications. ICGs aged <40 years, working as a farmer, with low education and economic status, and caring for individuals with mild or moderate T2D showed a low level of T2D-related knowledge. Development of targeted and tailored education interventions for ICGs is recommended.

### Ethical approval

Ethical Committee of Thai Binh University of Medicine and Pharmacy, Vietnam (Decision 11/2018, November 23, 2018).

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### Competing interests

None declared.

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