Unmet needs for informal care among people with type 2 diabetes in rural communities in Vietnam

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ABSTRACT

Objectives: The objective of this study was to identify determinants associated with unmet needs for informal support among people with type-2 diabetes in rural communities of Vietnam in order to inform development of effective interventions aimed at bridging the gap between community members and resource constrained health systems.

Study design: A cross-sectional survey was conducted from December 2018 to February 2019 in a rural area of northern Vietnam.

Methods: From 2 districts in northern Vietnam, 806 people with type-2 diabetes participated in a survey to assess who were their most important informal caregivers (ICGs) and to measure the association between demographic and socio-economic predictors and unmet needs of informal support of relevance for diabetes self-care using bivariate and multivariate analyses.

Results: The spouse was reported as the most important ICG (62.9%) followed by a daughter or son (28.4%). 32.0% reported at least one type of unmet need for informal support. The most commonly reported unmet needs of informal care were: transport to health facilities and company when seeking formal care (20.5%), financial support related to costs of diabetes self-management (18.5%), and reminders to engage in physical exercise (14.5%). People living alone reported the highest odds ratio (OR = 4.41; CI95%: 2.19 – 8.88), followed by those being poor (OR = 3.79; CI95%: 1.25 – 11.52) and those being unemployed (OR = 2.85; CI95%: 1.61–5.05).

Conclusions: Almost one-third of people with type-2 diabetes reported at least one type of unmet need for informal care. These findings provide a basis for development of new modalities for strengthening support provided by ICGs in rural communities in Vietnam and in other low- and middle-income countries.

1. Introduction

The anticipated increase in diabetes-related disease burden and a similar increase in burden of other chronic diseases call for new and innovative approaches to treatment and care. The traditional models of health service provision are under transformation and it has recently been emphasized that it is of crucial importance that all types of care givers and volunteers, who engage in health promotion, disease prevention, treatment, and rehabilitation, play an effective role in provision of primary health care [1–3]. Particularly in resource constrained communities undergoing rapid transition of diseases patterns, informal health support should be assessed and considered as a modality for improving quality of life for both persons living with chronic disease and their families.

Diabetes self-management is regarded as an essential component in daily diabetes care concerning, for example, diet, physical activity and medications [4]. In this context, social interactions and support from non-medical staff play a vital role among people living with disease [5],
and this type of informal care can potentially reduce diabetes-related distress and improve glycemic control [6]. Specifically, informal caregivers (ICGs), such as family members, friends, and neighbors, can play an important role in self-care for people with type-2 diabetes by offering support related to issues such as visits to health facilities, provision of medication, physical activity, and emotional needs and thereby result in improved health outcomes over time [7,8].

Persons with type-2 diabetes perceive family behaviors as being supportive for diabetes self-management, as a barrier to diabetes self-management, or as equivocal behaviors with the potential to both support and impede diabetes self-management [9-12].

The vast majority of studies on ICGs and diabetes self-management have been carried out in high-income countries and, with few exceptions, focus solely on the positive health effects of informal care. Very few studies have assessed the needs of informal care of relevance for self-management expressed by the persons with type-2 diabetes themselves in low- and middle-income countries (LMICs) undergoing rapid epidemiological shifts in patterns of disease, despite strong projections that predict that the future major increase in numbers will take place in these LMICs [13].

Knowledge about unmet needs for informal support among people with type-2 diabetes is of crucial importance for informing development of interventions aimed at bridging the gap between community members and resource constrained health systems. Therefore, a cross-sectional survey was conducted in order to measure the occurrence and identify predictors of unmet needs for informal support among people with type-2 diabetes in rural communities of Thai Binh Province, northern Vietnam.

2. Methods

2.1. Study design

A questionnaire-based cross-sectional survey was conducted from December 2018 to February 2019 in a rural area of northern Vietnam.

2.2. Setting and recruitment of persons with type-2 diabetes

The study was carried out in Thai Binh Province. Located 100 km Southeast of Hanoi city, it covers an area of 1542 km² and has a total population of approximately 1.86 million people. It is divided into 8 districts and 284 communes. Two rural districts, Quynh Phu District in the northern part and Vu Thu District in the southern part of the district, were purposively selected for the project based on district hospital records showing that these two districts had the highest number of people diagnosed with diabetes. There are two district hospitals in Quynh Phu District and one district hospital in Vu Thu District. Based on lists of people who received treatment for diabetes, that were available at these district hospitals, all communities were ranked according to the number of such persons in each of the two districts. In each district, among the communities with the highest number of persons with type-2 diabetes, two communities with the closest proximity to the district hospital and two communities located farthest from the district hospital were selected for the study. Hence, a total of 8 communities were purposively selected for the study. For the analytic sample, people who were diagnosed with diabetes before age 40 years were excluded.

The sampling frame, that is, the list of persons in the 8 communes treated for diabetes at the district hospitals, included a total of 963 persons. All were invited to participate in the study. Among these, 37 (3.8%) refused to participate, 78 (8.1%) did not stay at the address reported to the hospital, or had moved away by the period of data collection. Furthermore, 42 persons were excluded from the analysis since they reported that they had been diagnosed with diabetes prior to the age of 40 years or they did not remember when they had been diagnosed. Hence, a total of 806 persons were included in the study (83.7% of persons in the sampling frame).

2.3. Interviews

From each health station in the 8 selected communes, two health workers were trained to administer the questionnaires and to conduct the interviews. The interviewers were trained in a 2-day workshop followed by field-based training and counselling. As part of the training, the interviewers participated in the pilot testing and subsequent revisions of the questionnaires.

All potential interviewees were contacted by mobile phone calls or by personal visits to request their participation and, if they agreed, fix the date and time of the interview. The interviews took place in their homes. Prior to the interview, the aim and outline of the research project were explained verbally and in writing. Those who agreed to participate signed a consent form.

2.4. Questionnaires

Data on unmet needs for informal support and selected predictors were collected using a structured and pilot-tested questionnaire. The questionnaire was in Vietnamese. The design of the questionnaire was based on a collaboration between Vietnamese and Danish clinicians and experts in diabetes care and self-management, researchers and public health providers with first-hand experience with health-related and cultural perceptions, attitudes and practices in the relevant communities. The questionnaire was pretested with persons with Type-2 diabetes and validated and subsequently revised to ensure understandability and cultural relevance of the questions.

Each interviewee was asked about who they perceived as their most important ICG of relevance for their diabetes self-management. For descriptive analyses, ICGs were categorized as: 1) spouse; 2) daughter or son; 3) other relative (e.g. parents, brother, sister, son-in-law, daughter-in-law); and 4) non-relative (e.g. other person with diabetes, friend, neighbor).

2.5. Outcome variable

Unmet needs for informal care were based on six questions regarding: 1) transport to clinic or hospital when seeking care related to type-2 diabetes and being accompanied by an ICG; 2) purchase and preparation of food of relevance for type-2 diabetes diet; 3) reminder to take medication for type-2 diabetes; 4) reminder to engage in physical exercise; 5) emotional support in relation to type-2 diabetes; and 6) financial support of specific importance for self-management of diabetes. The answering options for these questions were: 1) inadequate level of care; 2) adequate level of care; and 3) high level of care. For each dimension of informal care, ‘inadequate level of care’ was used to define a high level of unmet need for informal care, whereas an ‘adequate level of support’ or ‘high level of support’ was used to define a low level of unmet need for informal care. An overall unmet need of informal care was defined as at least two answers of ‘inadequate level of care’ to the six questions mentioned above.

2.6. Exposure variables

Possible predictors, demographic and socio-economic characteristics, and self-reported status of physical health, were selected a priori based on assumptions that these were typical determinants for unmet needs related to management of diabetes, and comprised possible modalities for interventions targeting diabetes. The demographic and socio-economic predictors included sex, age, marital status, size of household, occupational status, and economic status of the household.

For the statistical analysis of the association between exposure variables and unmet needs, age was categorized into four age groups: 1) 40–49 years; 2) 50–59 years; 3) 60–69 years; and 4) ≥70 years). Marital status was categorized into two groups: 1) living with spouse; and 2) single, divorced, widowed, or living separate from spouse. Size of
household was categorized into: 1) 1 member (living alone); 2) 2 members; 3) 3-4 members; and 4) ≥ 5 members. Occupational status was categorized as: 1) unemployed; 2) farmer; 3) being employed in small trade business, as a worker, government employee or in a private company; and 4) retired. Self-reported economic status of the household of the person with type-2 diabetes was categorized as: 1) poor; 2) medium; and 3) wealthy. Self-reported level of physical health was categorized into: 1) poor; 2) fair; and 3) good.

2.7. Statistical analysis

Data were double-entered in EPI-DATA 3.1 for quality control and errors were subsequently corrected. SPSS software package (IBM SPSS Statistics, version 25, 2017) was used for data analysis. Descriptive data were presented in frequency tables. Bivariate and multivariate analyses were used to measure the associations between exposure variables and overall unmet need for informal support. Results were reported as odds ratios (ORs) and 95% confidence intervals around the respective ORs. Predictors in the bivariate analyses, which were associated with unmet need, were included in the multivariate analysis.

3. Results

3.1. Sample characteristics

Characteristics of the persons with type-2 diabetes are summarized in Table 1. Approximately half of them were females (52.7%). Almost one-third were aged 70 years or older (30.5%), and the majority lived in a household with a medium size (49.5%). One out of nine described their household as poor (11.8%), whereas half of them lived in a household with more than two members (51.4%). One out of nine reported their physical health as being poor (37.5%) reported their physical health as being poor.

3.2. Informal caregivers

Irrespective of whether they lived with a spouse or not, a spouse was reported as the most important ICG (62.9%) followed by a daughter or son (28.4%). Among those who did not live with a spouse or did not have a spouse, a son or daughter was reported as the most important ICG (62.9%) followed by a relative (25.8%), whereas a smaller proportion (6.6%) indicated a non-relative as the most important ICG.

3.3. Unmet needs for informal care

Overall, 32.0% of the sample reported at least one type of unmet need for informal care. Overall, 11.8%, 7.1%, and 13.1% reported 1 type, 2 types and 3-6 types of unmet need for informal care, respectively.

The occurrence of unmet need for informal care for each of the five dimensions of care is shown in Table 2. The most commonly reported unmet need was transport to clinic or hospital and company during the visit (20.5%), followed by an unmet need for financial support related to costs of diabetes self-management (18.5%) and an unmet need for reminders to engage in physical exercise (14.5%). Across all six dimensions of care, women and those who lived alone had relatively high proportions of unmet need. Those who reported poor physical health presented with the highest proportions of unmet need for informal care across all six dimensions of support. The lowest proportions of unmet needs for informal care were observed for the dimension of emotional support among men (1.6%) and for those persons who reported good physical health (1.9%).

A separate sub-analysis was performed among those who lived alone. In this group, the highest proportions of unmet needs for informal care were transport to health facility and financial support (46.1% and 40.4%, respectively).

The results of the analysis of the association between selected predictors and overall level of unmet need for informal care are presented in Table 3. The results of the multivariate analysis showed that living alone (AOR = 2.31; CI95%: 1.61–5.05). Lastly, poor level of self-reported physical health as compared to good health was associated with a high risk of unmet need (AOR = 2.31; CI95%: 1.05–5.08).

4. Discussion

In the present study, we assessed who were the most important ICGs,
and the associations between demographic and socio-economic predictors and unmet needs of informal care of relevance for diabetes self-management in a rural population in Vietnam. The spouse was the most important ICG for diabetes self-management, and this finding is in accordance with other studies [8,14,15]. Among those persons with type-2 diabetes who did not live with a spouse, the most important ICG for diabetes self-management in a rural population in Vietnam. The spouse was the most important ICG for diabetes self-management, and this finding is in accordance with other studies [8,14,15].

The findings in the present study suggest that for most persons with type-2 diabetes who experience unmet needs of informal care, the request for support is restricted to one or two specific dimensions. The needs for assistance and transport when visiting health facilities and for financial support of relevance for self-management of diabetes were expressed by approximately one out of five persons.

Across all six dimensions of support, women were more likely to report an unmet need of informal support than men. Previous studies have shown that women had a higher risk to present with diabetes-related distress than men [16-18]. In Vietnam, women are often separated from their natal families after marriage, where after they commonly move to the household of their husband’s family [19]. This may result in gender-specific barriers in sharing chronic disease-related difficulties in life with their family [20]. Furthermore, in Vietnam, women often bear the main responsibility for housework and for taking care of children and elderly members of their household [21]. These responsibilities in combination with other sociocultural factors may result in a lower level of informal care offered to women due to gendered moral expectations and household division of labor.

Persons with type-2 diabetes living alone as compared to living in a larger household, being unemployed or a farmer as compared to being retired, having poor physical health as compared to good health were associated with a high level of unmet need for informal support for diabetes management. Specific needs for informal care and barriers for access to health care among those who lived alone have been reported in other studies [22,23]. Although women, as previously mentioned, were more likely to report an unmet need for a specific type of support than men, results of the multivariate analysis showed no gender differences when using an aggregated measure for an overall unmet need for informal care.

The present study included a total of 806 persons living with type-2 diabetes, which allowed detailed analyses of determinants for unmet need of informal care of relevance for diabetes related self-management. However, the study has some limitations related to design, analysis, and validity of results. Since persons were recruited using a sampling frame of persons treated with diabetes at the district hospitals, community members being referred to and treated at regional hospitals were not included as study participants. Therefore, it is not known whether the group of respondents included in the present study is representative of persons with type-2 diabetes in this population. In Vietnam, those treated at a regional hospital typically present with more severe disease as compared to those treated at the district hospitals. This would most likely result in an underestimation of the prevalence of persons with type-2 diabetes with unmet needs for informal care. Furthermore, the focus on unmet needs for informal care addressed six pre-defined dimensions of care, and it is likely that there are other types of needs of importance for diabetes self-management which have not been covered.

### Table 2
Prevalence of unmet needs for 6 categories of informal care.

| Characteristics                              | Number of individuals in each group | Number of persons who report a specific type of unmet need for informal support (% of total in group) |
|----------------------------------------------|------------------------------------|--------------------------------------------------------------------------------------------------|
|                                              |                                    | Transport to hospital or clinic and company in order to seek care for type-2 diabetes             |
|                                              |                                    | Reminder to take medication for type-2 diabetes                                                  |
|                                              |                                    | Purchase and preparation of food of specific relevance for type-2 diabetes                       |
|                                              |                                    | Reminder to exercise                                                                               |
|                                              |                                    | Emotional support in relation to type-2 diabetes                                                  |
|                                              |                                    | Financial support to manage disease                                                               |
| All                                          | 806                                | 165 (20.5)                                        | 98 (12.2)                      | 74 (9.1)                      | 117 (14.5)                     | 40 (5.0)                      | 149 (18.5)                     |
| Gender (806)                                 |                                    | 56 (14.7)                                        | 35 (9.2)                      | 12 (3.1)                      | 44 (11.5)                      | 6 (1.6)                       | 51 (13.4)                      |
| Male                                         |                                    | 109 (25.6)                                       | 63 (14.8)                     | 61 (14.4)                     | 73 (17.2)                      | 34 (8.0)                      | 98 (23.1)                      |
| Female                                       |                                    | 75 (35.2)                                        | 37 (17.4)                     | 44 (20.7)                     | 46 (21.6)                      | 27 (12.7)                     | 66 (31.0)                      |
| Marital status (n = 806)                     |                                    | 90 (15.2)                                        | 61 (10.3)                     | 29 (4.9)                      | 71 (12.0)                      | 13 (2.2)                      | 83 (14.0)                      |
| Single, divorced, and widowed persons        |                                    | 41 (46.1)                                        | 24 (27.0)                     | 31 (34.8)                     | 30 (33.7)                      | 17 (19.1)                     | 36 (40.4)                      |
| Living with spouse (n = 806)                 |                                    | 59 (18.6)                                        | 31 (9.7)                      | 19 (6.0)                      | 41 (12.9)                      | 7 (2.2)                       | 49 (15.4)                      |
| 1 member (living alone)                      |                                    | 32 (17.7)                                        | 21 (11.6)                     | 11 (6.1)                      | 24 (13.3)                      | 9 (5.0)                       | 33 (18.2)                      |
| 2 members                                    |                                    | 33 (15.1)                                        | 22 (10.1)                     | 12 (5.5)                      | 22 (10.1)                      | 7 (3.2)                       | 31 (14.2)                      |
| 3-4 members                                  |                                    | 318                                              |                                |                               |                                |                                |                                |
| 5 members or more                            |                                    | 218                                              |                                |                               |                                |                                |                                |
| Age group (years) (n = 798)                  |                                    | 42                                               | 11 (26.2)                     | 6 (14.3)                      | 5 (11.9)                       | 7 (16.7)                      | 4 (9.5)                        | 8 (19.0)                      |
| 40-49                                        |                                    | 140                                              | 41 (29.3)                     | 33 (23.6)                     | 29 (20.7)                      | 41 (29.3)                     | 16 (11.4)                      | 43 (30.7)                      |
| 50-59                                        |                                    | 296                                              | 82 (27.7)                     | 37 (12.5)                     | 25 (8.4)                       | 39 (13.2)                     | 15 (5.1)                       | 69 (23.3)                      |
| 60-69                                        |                                    | 104                                              | 8 (7.7)                       | 6 (5.8)                       | 6 (5.8)                        | 9 (8.7)                       | 2 (1.9)                        | 15 (14.4)                      |
| >70                                          |                                    | 258                                              | 34 (13.2)                     | 22 (8.5)                      | 12 (4.7)                       | 28 (10.9)                     | 7 (2.7)                        | 21 (8.1)                      |
| Economic situation of household; self-reported (n = 806) |                                    | 95                                               | 49 (51.6)                     | 25 (26.3)                     | 26 (27.4)                      | 26 (27.4)                     | 15 (15.8)                      | 39 (51.6)                      |
| Poor                                         |                                    | 638                                              | 109 (17.1)                    | 69 (10.8)                     | 45 (7.1)                       | 87 (13.6)                     | 24 (3.8)                       | 95 (14.9)                      |
| Medium                                       |                                    | 73                                               | 7 (9.6)                       | 4 (5.5)                       | 2 (2.7)                        | 4 (5.5)                       | 1 (1.4)                        | 5 (6.8)                        |
| Wealthy                                      |                                    | 302                                              | 75 (24.8)                     | 45 (14.9)                     | 35 (11.6)                      | 61 (20.2)                     | 21 (7.0)                       | 77 (25.5)                      |
| Self-reported physical health status (n = 806) |                                    | 399                                              | 81 (20.3)                     | 50 (12.5)                     | 35 (8.8)                       | 48 (12.0)                     | 17 (4.3)                       | 62 (15.5)                      |
| Good                                         |                                    | 105                                              | 9 (8.6)                       | 3 (2.9)                       | 3 (2.9)                        | 8 (7.6)                       | 2 (1.9)                        | 10 (9.5)                       |
in the present study, e.g. a specific need for interpretation of advice and counselling offered by health providers.

Efforts were made to pilot test and modify the questionnaire to match with the most relevant predictors for unmet need for informal care, current occupation, economic situation of household, and physical health status.

Table 3
Associations between selected predictors and overall high level of unmet need for informal care. Results of bivariate and multivariate analyses.

| Characteristics                      | Number of individuals in each group (% in group with high level of unmet need) | Results of bivariate analysis | Results of multivariate analysis |
|--------------------------------------|--------------------------------------------------------------------------------|-------------------------------|---------------------------------|
|                                      |                                                                                 | Crude odds ratio (95% CI)     | Adjusted odds ratio (95% CI)    |
| Gender (n = 806)                     |                                                                                 |                               |                                 |
| Male                                 | 381 (8.9)                                                                        | 1                             | 1                               |
| Female                               | 425 (16.9)                                                                       | 2.08 (1.35–3.21)              | 0.87 (0.57–1.33)                |
| Living arrangement (n = 806)         |                                                                                 |                               |                                 |
| Single, divorced, and widowed persons| 213 (22.5)                                                                       | 2.68 (1.76–4.09)              | 0.92 (0.54–1.58)                |
| Living with spouse                   | 593 (9.8)                                                                        | 1                             | 1                               |
| Size of household (n = 806)          |                                                                                 |                               |                                 |
| 1 member (living alone)               | 89 (36.0)                                                                        | 5.00 (2.70–9.28)              | 4.41 (2.19–8.88)                |
| 2 members                             | 318 (10.4)                                                                       | 1.03 (0.58–1.82)              | 1.21 (0.73–2.01)                |
| 3–4 members                           | 181 (10.5)                                                                       | 1.05 (0.55–2.00)              | 1.71 (0.98–2.97)                |
| 5 members or more                    | 218 (10.1)                                                                       | 1                             | 1                               |
| Age group (years) (n = 806)          |                                                                                 |                               |                                 |
| <50                                   | 42 (19.0)                                                                        | 1.63 (0.69–3.85)              |                                 |
| 50-59                                 | 161 (16.1)                                                                       | 1.34 (0.76–2.33)              |                                 |
| 60-69                                 | 357 (11.5)                                                                       | 0.9 (0.55–1.48)               |                                 |
| ≥70                                   | 246 (12.6)                                                                       | 1                             |                                 |
| Current occupation (n = 798)         |                                                                                 |                               |                                 |
| Unemployed/Stay at home with wife/husband | 140 (26.4)                                                                    | 4.05 (2.26–7.27)              | 2.85 (1.61–5.05)                |
| Farmer                               | 296 (13.9)                                                                       | 1.82 (1.04–3.16)              | 1.76 (1.04–2.96)                |
| Small trade, worker, government employee, private company | 104 (6.7)                                                                      | 0.81 (0.34–2.00)              | 0.73 (0.29–1.83)                |
| Retired                               | 258 (8.1)                                                                        | 1                             | 1                               |
| Economic situation of household (n = 806) |                                                 |                               |                                 |
| Poor                                  | 95 (31.6)                                                                        | 7.80 (2.66–23.84)             | 1.25 (1.25–11.52)               |
| Medium                                | 638 (11.3)                                                                       | 2.19 (0.78–6.19)              | 1.53 (0.58–4.05)                |
| Wealthy                               | 73 (13.2)                                                                        | 1                             | 1                               |
| Self-reported physical health status (n = 806) |                                             |                               |                                 |
| Poor                                  | 362 (26.5)                                                                       | 3.54 (1.85–7.97)              | 2.31 (1.05–5.08)                |
| Fair                                  | 399 (18.5)                                                                       | 2.43 (1.17–5.03)              | 1.90 (0.88–4.09)                |
| Good                                  | 105 (8.6)                                                                        | 1                             | 1                               |

a High level of unmet need defined as reporting at least two out of six dimensions of unmet need for informal care.

b Adjusted for gender, living arrangement, size of household, current occupation, economic situation of household, and physical health status.

different predictor for medical adherence, higher fruit/vegetable intake, and lower diabetes-related distress [27].

These findings suggest a potential for including spouses in a systematic approach to improve quality of life and self-management of disease among persons with type-2 diabetes in rural communities of Vietnam and other LMICs.

5. Conclusions

The results of the present study performed in rural communities in Vietnam provide a basis for improving care and support from ICGs, as reported in other studies [11,12,24,26,28]. For individuals with diabetes who live with a spouse or are single/widowed, there are apparently obvious advantages in including the spouse or daughter/son, respectively, in counselling and training activities which will support and improve self-management. Future programs developed to strengthening levels of informal care should specifically focus on people with Type-2 diabetes who live alone, are unemployed, poor, or with bad physical health and women with specific needs for assistance with transport when visiting health facilities and for financial support of relevance for their self-management of diabetes. In Vietnam, many people in rural communities are members of one or more civil society organization. We suggest testing the feasibility and effects of a network of peer-driven ‘diabetes clubs’ where individuals and their relatives can meet and share knowledge, experiences and seek advice on self-management of Type-2 diabetes with assistance from health staff with knowledge regarding the barriers and opportunities for improving informal and health system-related care of diabetes.

Statements of ethical approval

The study followed ethical guidelines developed by CIOMS (Council for International Organization of Medical Sciences). Both oral and written informed consent were obtained from all research participants and confidentiality was guaranteed. Ethical approval of the project was granted by the Ethics Committee for Biomedical Research of Thai Binh University of Medicine and Pharmacy (decision no. 11/2018, 23rd November 2018).

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Declaration of competing interest

The authors declare that they have no competing interests.

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List of abbreviations

ICG Informal caregivers
LMICs Low- and middle-income countries
OR Odds ratio

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