Unmet Needs for Informal Care Among People With Type 2 Diabetes in Rural Communities in Vietnam.

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54 Abstract

55

56 BACKGROUND

57 From a diabetes management perspective, informal care has proven at least as important as care
58 from health professionals when targeting poorly controlled diabetes. The objective of this study was
59 to identify determinants associated with unmet needs for informal support among people with type-
60 2 diabetes in rural communities of Vietnam.

61

62 METHODS

63 A cross-sectional survey was conducted from December 2018 to February 2019 in a rural area of
64 northern Vietnam. From 2 districts in Thai Binh Province, Vietnam, 806 people with type-2
65 diabetes participated in a survey designed to assess who were their most important informal
66 caregivers (ICGs) and to measure the association between demographic and socio-economic
67 predictors and unmet needs of informal support of relevance for diabetes self-care using bivariate
68 and multivariate analyses.

69

70 RESULTS

71 The spouse was reported as the most important ICG (62.9%) followed by a daughter or son
72 (28.4%). 32.0% of the people with type-2 diabetes reported at least one type of unmet need for
73 informal support. The most commonly reported unmet needs of informal care were: transport to
74 health facilities and company when seeking formal care (20.5%), financial support related to costs
75 of diabetes self-management (18.5%), and reminders to engage in physical exercise (14.5%).
76 People living alone reported the highest odds ratio (OR) for unmet need of informal care (OR=4.41;
77 CI95%: 2.19-8.88), followed by those being poor as compared to being wealthy (OR=3.79; CI95%:

78 1.25-11.52) and those being unemployed as compared to being retired (OR=2.85; CI95%: 1.61-
79 5.05).

80

81 CONCLUSIONS

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

86

87 Keywords: Type-2 diabetes, informal care, unmet needs.

88

89

90 INTRODUCTION

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

100

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

109

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

113

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

120

121 Knowledge about unmet needs for informal support among persons with type-2 diabetes is of
122 crucial importance for informing development of interventions aimed at bridging the gap between
123 community members and resource constrained health systems. Therefore, a cross-sectional survey
124 was conducted in order to measure the occurrence and identify predictors of unmet needs for

125 informal support among persons with type-2 diabetes in rural communities of Thai Binh Province,
126 northern Vietnam.

127

128 METHODS

129

130 Study design

131 A questionnaire-based cross-sectional survey was conducted from December 2018 to February
132 2019 in a rural area of northern Vietnam.

133

134 Setting and recruitment of persons with type-2 diabetes

135 The study was carried out in Thai Binh Province. Located 100 kilometers Southeast of Hanoi city, it
136 covers an area of 1,542 km² and has a total population of approximately 1.86 million people. It is
137 divided into 8 districts and 284 communes. Two rural districts, Quynh Phu District in the northern
138 part and Vu Thu District in the southern part of the district, were purposively selected for the
139 project based on district hospital records showing that these two districts had the highest number of
140 people diagnosed with diabetes. There are two district hospitals in Quynh Phu District and one
141 district hospital in Vu Thu District. Based on lists of people who received treatment for diabetes,
142 that were available at these district hospitals, all communities were ranked according to the number
143 of such persons in each of the two districts. In each district, among the communities with the
144 highest number of persons with type-2 diabetes, two communities with the closest proximity to the
145 district hospital and two communities located farthest from the district hospital were selected for the
146 study. Hence, a total of 8 communities were purposively selected for the study. For the analytic
147 sample, people who were diagnosed with diabetes before age 40 years were excluded.

148

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

156

157 Interviews

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

162

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

167

168 Questionnaires

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

173

174 Outcome variable

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

186

187 Exposure variables

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

193

194 For the statistical analysis of the association between exposure variables and unmet needs, age was
195 categorized into four age groups: 1) 40-49 years; 2) 50-59 years; 3) 60-69 years; and 4) ≥ 70 years).
196 Marital status was categorized into two groups: 1) living with spouse; and 2) single, divorced,

197 widowed, or living separate from spouse. Size of household was categorized into: 1) 1 member
198 (living alone); 2) 2 members; 3) 3-4 members; and 4) ≥ 5 members. Occupational status was
199 categorized as: 1) unemployed; 2) farmer; 3) being employed in small trade business, as a worker,
200 government employee or in a private company; and 4) retired. Self-reported economic status of the
201 household of the person with type-2 diabetes was categorized as: 1) poor; 2) medium; and 3)
202 wealthy. Self-reported level of physical health was categorized into: 1) poor; 2) fair; and 3) good.

203
204 Statistical analysis

205 Data were double-entered in EPI-DATA 3.1 for quality control and errors were subsequently
206 corrected. SPSS software package (IBM SPSS Statistics, version 25, 2017) was used for data
207 analysis. Descriptive data are presented in frequency tables. Bivariate and multivariate analyses
208 were used to measure the associations between exposure variables and overall unmet need for
209 informal support. Results were reported as odds ratios (ORs) and 95% confidence intervals around
210 the respective ORs. Predictors in the bivariate analyses, which were associated with unmet needs at
211 a 5% level or lower, were included in the multivariate analysis.

212
213
214 RESULTS

215
216 Sample characteristics

217 Characteristics of the persons with type-2 diabetes are summarized in Table 1. Approximately half
218 of them were females (52.7%). Almost one-third were aged 70 years or older (30.5%), and the
219 majority lived with a spouse (73.6%). One out of ten respondents lived alone (11.0%), whereas half
220 of them lived in a household with more than two members (49.5%). One out of nine described their

household as poor (11.8%), whereas the majority described their household as having a medium level of wealth (79.2%). More than one-third of the persons with type-2 diabetes (37.5%) reported their physical health as being poor.

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 (67.6%) followed by another relative (25.8%), whereas a smaller proportion (6.6%) indicated a non-relative as the most important ICG.

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.

245 The lowest proportions of unmet needs for informal care were observed for the dimension of
246 emotional support among men (1.6%) and for those persons who reported good physical health
247 (1.9%).

248
249 A separate sub-analysis was performed among those who lived alone. In this group, the highest
250 proportions of unmet needs for informal care were transport to health facility and financial support
251 (46.1% and 40.4%, respectively).

252
253 The results of the analysis of the association between selected predictors and overall level of unmet
254 need for informal care are presented in Table 3. The results of the multivariate analysis showed that
255 living alone as compared to living in a household with five members had the highest odds ratio for
256 overall level of unmet need for informal care (OR=4.41; CI95%: 2.19-8.88) followed by being poor
257 as compared to being wealthy (OR=3.79; CI95%: 1.25-11.52) and being unemployed as compared
258 to being retired (OR=2.85; CI95%: 1.61-5.05). Lastly, poor level of self-reported physical health as
259 compared to good health was associated with a high risk of unmet need (AOR=2.31; CI95%: 1.05-
260 5.08).

263 DISCUSSION

264
265 In the present study, we assessed who were the most important ICGs, and the associations between
266 demographic and socio-economic predictors and unmet needs of informal care of relevance for
267 diabetes self-management in a rural population in Vietnam. The spouse was the most important ICG
268 for diabetes self-management, and this finding is in accordance with other studies (8, 14, 15).

269 Among those persons with type-2 diabetes who did not live with a spouse, the most important ICG
270 was a son or a daughter.
271

272 The findings in the present study suggest that for most persons with type-2 diabetes who experience
273 unmet needs of informal care, the request for support is restricted to one or two specific dimensions.
274 The needs for assistance and transport when visiting health facilities and financial support of
275 relevance for self-management of diabetes were expressed by approximately one out of five
276 persons.
277

278 Across all six dimensions of support, women were more likely to report an unmet need of informal
279 support than men. Previous studies have shown that women had a higher risk to present with
280 diabetes-related distress than men (16-18). In Vietnam, women are often separated from their natal
281 families after marriage, where after they commonly move to the household of their husband's
282 family (19). This may result in gender-specific barriers in sharing chronic disease-related
283 difficulties in life with their family (20). Furthermore, in Vietnam, women often bear the main
284 responsibility for housework and for taking care of children and elderly members of their household
285 (21). These responsibilities in combination with other sociocultural factors may result in a lower
286 level of informal care offered to women due to gendered moral expectations and household division
287 of labor.
288

289 Persons with type-2 diabetes living alone as compared to living in a larger household, being
290 unemployed or a farmer as compared to being retired, having poor physical health as compared to
291 good health were associated with a high level of unmet need for informal support for diabetes
292 management. Specific needs for informal care and barriers for access to health care among those

293 who lived alone have been reported in other studies (22, 23). Although women, as previously
294 mentioned, were more likely to report an unmet need for a specific type of support than men, results
295 of the multivariate analysis showed no gender differences when using an aggregated measure for an
296 overall unmet need for informal care.

297
298 The present study included a total of 806 persons living with type-2 diabetes, which allowed
299 detailed analyses of determinants for unmet need of informal care of relevance for diabetes related
300 self-management. However, the study has some limitations related to design, analysis, and validity
301 of results. Since persons were recruited using a sampling frame of individuals treated with diabetes
302 at the district hospitals, community members being referred to and treated at regional hospitals were
303 not included as study participants. Therefore, it is not known whether the group of respondents
304 included in the present study is representative of persons with type-2 diabetes in this population. In
305 Vietman, those treated at a regional hospital typically present with more severe disease as compared
306 to those treated at the district hospitals. This would most likely result in an underestimation of the
307 prevalence of persons with type-2 diabetes with unmet needs for informal care. Furthermore, the
308 focus on unmet needs for informal care addressed six pre-defined dimensions of care, and it is
309 likely that there are other types of needs of importance for diabetes self-management which have
310 not been covered in the present study, e.g. a specific need for interpretation of advice and
311 counselling offered by health providers.

312
313 Efforts were made to pilot test and modify the questionnaire to match the local context with regards
314 to gender issues, terminology, and cultural norms and values. However, there was still a risk of
315 responder bias, specifically regarding the motivation to disclose that there are daily problems and
316 challenges related to a life with a chronic disease. On the condition that responder bias was equally

317 distributed between the groups being compared, this type of non-differential misclassification of the
318 outcome would not have affected the observed associations.

319

320 Although efforts were made to include the most relevant predictors for unmet support, residual
321 confounding, e.g. alternative measures for severity of disease, size and character of social network,
322 individual variations in resilience, co-morbidity, and spouses with chronic disease, may also have
323 influenced the observed statistical associations; though it is difficult to comprehend how specific
324 types of confounding would have affected the findings.

325

326 It was not assessed whether persons with type-2 diabetes perceived that ICGs impede diabetes self-
327 management as reported in other studies from high-income countries (9-11). Future research needs
328 to be done to assess whether certain types of informal care tend to challenge or obstruct diabetes
329 related self-management.

330

331 In the present study, it is not known whether a high level of unmet need for informal care in this
332 population actually results in a higher risk of negative diabetes related health outcomes as compared
333 to individuals with lower levels of unmet need. However, results from several studies, with the
334 majority performed in high-income countries, indicate that supportive social support measures are
335 associated with improved health among persons with type-2 diabetes (7, 24, 25), specifically with
336 regard to self-management related to diet, exercise, blood glucose testing, HbA1c levels, and
337 adherence to medication (8, 10, 26). Another study has demonstrated that greater closeness with
338 informal care partner is a significant predictor for medical adherence, higher fruit/vegetable intake,
339 and lower diabetes-related distress (27).

340

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

344

345

346 CONCLUSIONS

347 In conclusion, the results of the present study performed in rural communities in Vietnam provide a
348 basis for improving care and support from ICGs, as reported in other studies (11, 12, 24, 26, 28).

349 For individuals with diabetes who live with a spouse or are single/widowed, the results suggest that
350 there are obvious advantages in including the spouse or daughter/son, respectively, in counselling
351 and training activities which will support and improve self-management. Persons with type-2
352 diabetes who live alone, are unemployed, poor, or with bad physical health should specifically be
353 considered as highly vulnerable groups with a high level of unmet need for care addressing all six
354 dimensions of support. Results from the present study also suggest that women with diabetes have
355 specific needs for assistance with transport when visiting health facilities and for financial support
356 of relevance for their self-management of diabetes. Family members and health providers need to
357 be aware of the need for assistance and transport when barriers to self-management of diabetes and
358 should take action and improve support for transport and assist in reducing the individual economic
359 burdens related to a life with diabetes. Furthermore, this underpins the importance of future
360 educational programmes, with focus on diabetes self-management, to be tailored to target the
361 specific needs for informal care.

362

363 In already overburdened resource-constrained health systems in LMICs, strengthening support and
364 health care offered by ICGs may appear as a cost-effective intervention which will result in
365 improved quality of life for both individuals living with disease and their family members.

366
367 List of abbreviations

368 ICG: Informal caregivers

369 LMICs: Low- and middle-income countries

370 OR: Odds ratio

371

372

373 Declarations

374

375 Ethics approval and consent to participate

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

381

382 Consent for publication

383 Not applicable.

384

385 Availability of data and material

386 The datasets during and/or analysed during the current study available from the corresponding

387 author on reasonable request.

388

389

390 Competing interests

391 The authors declare that they have no competing interests.

392

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399 Ministries of Health of Denmark and Vietnam.

400

401 Authors' contributions

402 All authors contributed to the development of data collection tools and training of interviewers.
403 DKT and DHTB participated in data collection. DM analyzed the data. DM and NDT developed the
404 first version of the manuscript. All authors contributed to subsequent revisions and editing of the
405 manuscript.

406

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