Health Service Research

Unravelling sexual care in chronically ill patients: the perspective of GP practice nurses; Health Service Research

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Abstract

Background. Assessment of sexual health is important in chronically ill patients, as many experience sexual dysfunction (SD). The general practice nurse (GPN) can play a crucial part in addressing SD.

Objective. The aim of this cross-sectional study was to examine to which extent GPNs discuss SD with chronically ill patients and what barriers may refrain them from discussing SD. Furthermore, we examined which factors had an association with a higher frequency of discussing SD.

Methods. A cross-sectional survey using a 48-item questionnaire was sent to 637 GPNs across the Netherlands.

Results. In total, 407 GPNs returned the questionnaire (response rate 63.9%) of which 337 completed the survey. Two hundred and twenty-one responding GPNs (65.6%) found it important to discuss SD. More than half of the GPNs (n = 179, 53.3%) never discussed SD during a first consultation, 60 GPNs (18%) never discussed SD during follow-up consultations. The three most important barriers for discussing SD were insufficient training (54.7%), ‘reasons related to language and ethnicity’ (47.5%) and ‘reasons related to culture and religion’ (45.8%). More than half of the GPNs thought that they had not enough knowledge to discuss SD (n = 176, 54.8%). A protocol on addressing SD would significantly increase discussing during SD.

Conclusions. This study indicates that GPNs do not discuss SD with chronically ill patients routinely. Insufficient knowledge, training and reasons related to cultural diversity were identified as most important reasons for this practice pattern. Implementation of training in combination with guidelines on SD in the general practice could improve on the discussing of sexual health with chronic patients.

Key words: barriers, chronically ill patients, general practice nurse, general practitioner, sexual dysfunction, sexual health
reduce their workload and in advance of a possible shortage of GPs in the future, the Dutch government introduced a new profession in the Netherlands, a general practice nurse (GPN). After successfully completing an university degree, they were licensed to support the GP in their daily practice (4, 5). GPNs are either specialized in mental health care or somatic care (hereinafter general medical care). The GPN-general medical care offers basic psychological guidance. The most important task of the GPN-general medical care consist of performing routine check-ups in chronically ill patients. The most common chronic diseases in the general practitioner’s (GP) practice are diabetes, cardiovascular diseases and asthma/chronic obstructive pulmonary disease (COPD) (6). These chronic diseases are associated with a wide array of sexual dysfunctions (SD); decreased sexual desire, erectile dysfunction and side effects of medication prevalent in man and decreased desire, pain during intercourse and relationship problems prevalent in women (7–11). Other diseases causing SD include renal failure, numerous neurological diseases and depression (12, 13). Therefore, it is important to assess the sexual health and possible SD of chronically ill patients. In 2011, 75% of the Dutch General Practices employed a GPN and as a result the direct patient contact of the GP with their chronically ill patients is constantly declining (14). The biggest shift is seen in the management of diabetic patients, in which the GPN-general medical care has taken over more than one-third of the follow-up consultations from the GP (3).

Due to their increasing contact and check-ups with chronically ill patients, the Dutch GPN could play an important role in detecting and counselling of SD. The aim of this cross-sectional study was to identify the current role of GPNs in SD counselling and to examine to which extent the GPN discussed SD with their chronically ill patients. In addition, the present study focussed on guidelines concerning the discussion of SD within the practice. Furthermore, the study identified possible barriers that retained GPN’s from discussing SD, their level of knowledge on SD in chronic patients, and their point of view on who should be responsible for addressing SD with chronically ill patients.

**Methods**

**Study design and survey procedure**

For this study, the data were obtained by using a questionnaire. In total, 637 Dutch GPNs across the Netherlands received a questionnaire by post. The work addresses of the GPNs were obtained from the websites of the General Practices, where they are employed. These were found through ‘www.zorgkaartnederland.nl’, an independent website founded by the National Patient Federation listing all Dutch GPs and their practices. The Netherlands has approximately 12 000 GPs working in 5000 general practices. The first 20 GPs of each letter of the alphabet were selected for the study. From each practice, two GPNs were selected, one GPN-general medical care and one GPN-mentatal health. If a practice did employ only one specialisms, that one specialism was selected.

In September 2016, the questionnaire was send to 631 GPNs accompanied with an information letter. After the initial mailing, a reminder was send to non-responders after 2 and/or 3 months. The responses that were used in the study were processed anonymously.

**Instrument development**

The questionnaire was designed by the authors and was based on questionnaires used in previous studies to evaluate sexual health care (15–18). A literature review was performed to compose the content of the questionnaire. The questionnaire was pilot tested by six GPNs in the region of the LUMC (Leiden University Medical Centre), who inspected the questionnaire on lay-out, comprehensiveness of the question, linguistics and length. After the pilot, some linguistic ambiguities were removed and two answer options about the GPNs current profession were added. The final questionnaire consisted of 48 questions including demographic information, items on GPNs practice patterns regarding informing, discussing and counselling of SD, their perspective on who should be responsible for discussing SD, and possible barriers to discuss SD. Furthermore, the survey questions focussed on the GPNs level of knowledge, received education and tools to improve the discussion of SD. On the front page of the questionnaire, there was an opt-out possibility for the GPNs to not participate in the present study.

**Statistical methods**

Data analysis was performed using IBM SPSS statistics 23 (SPSS Inc., Chicago, IL.). Demographic information and answers to the questions were described using descriptive statistics. The Pearson’s chi-square test and Cochran–Armitage trend test were used to calculated bivariate associations between categorical data, specifically which factors have an association with a higher frequency of discussing SD during consultations. Two-sided *P*-values of <0.05 were considered statistically significant.

**Ethical considerations**

Since this study did not involve patients or interventions, no formal ethical approval is needed in the Netherlands. Written informed consent was obtained from all individual participants included in the study.

**Results**

**Response**

Six hundred and thirty-seven GPS were sent questionnaires and 407 (63.9%) responded. Three hundred and thirty-seven respondents agreed to participate in the study, however not every participant answered every question completely, which may cause N to differ. Valid percentages were used to express the distribution of answers from those answered the questions. Seventy respondents declined participation. Reasons for withdrawal were ‘no time’ (*n* = 47, 67.1%), ‘not enough experience’ (*n* = 20, 28.6%), ‘not interested to participate’ (*n* = 17, 24.3%) and ‘unspecified reasons’ (*n* = 8, 11.4%). Stated as ‘unspecified reasons’ were, e.g. ‘not enough interaction with these kind of patients’ (*n* = 3, 4.3%) and ‘personal reasons’ (*n* = 1, 1.4%).

**Key Messages**

- Many chronic diseases are associated with sexual dysfunction (SD).
- The general practice nurse (GPN) has an essential role in their care.
- GPNs do not discuss SD routinely.
- Training and SD guidelines could improve discussing sexual health.
Participants' demographics

Table 1 shows that the majority of the participants were female (n = 299, 88.7%) with the mean age of 47 years (range 23–66). Two hundred and five respondents (60.8%) worked as a GPN-general medical care and 129 respondents (38.3%) were employed as a GPN-mental health support, 3 GPNs (0.9%) were specialized in both general medical care and mental health support. The largest percentage of GPNs had between 6 and 10 years of experience in their current profession (n = 105, 31.5%) and almost half of the GPNs worked in a general practice were multiple GPs work (n = 176, 52.2%). Twenty-five participants (7.5%) were currently engaged in additional training an additional course or training in sexology.

Discussing SDs with chronically ill patients

Two hundred and twenty-one GPNs (65.6%) stated that discussing SD with chronically ill patients was important, the other respondents viewed this as ‘rather important’ (n = 77, 22.8%) very important (n = 37, 11.0%), or ‘unimportant (n = 1, 0.3%). Table 2 shows the various discussion of SD frequencies. The GPNs were asked how often they discussed SD with chronic ill patients. More than half of the GPNs (n = 179, 53.3%) “never or rarely” talked about SD with the chronic patient during their first consultation. Sixty GPNs (18.0%) discussed it ‘never or rarely’ during follow-up consultations. GPNs with more years of experience were more likely to discuss sexuality during follow-up consultations (P = 0.001). The GPNs observed that more than half of their chronic ill patients almost never talked about sexuality spontaneously (n = 178, 53.1%) and when sexuality was discussed the partner was not present in 72.2% (n = 241) of the consultations. If sexuality and SDs were discussed, the most common subjects in male patients were: decreased desire (n = 237, 70.3%), erectile dysfunction (n = 236, 70.0%) and side effects of medication (n = 173, 51.3%). In female patients, the majority of the questions were about decreased desire (n = 219, 65.0%), pain during intercourse (n = 185, 54.9%) and relationship problems (n = 159, 47.2%).

Barriers

When the GPNs were asked about possible reasons that withheld them from the discussion of SD with their chronic patients, ‘insufficient training’ (n = 182, 54.7%) was the barrier they most agreed on. Furthermore, ‘reasons related to language and ethnicity’ (n = 153, 47.5%) and ‘reasons related to culture and religion’ (n = 153, 45.8%) were also major barriers. All barriers are listed in Table 3.

Providing information and counselling

A quarter of the GPNs (n = 81, 25.6%) reported that patient information regarding SD was available at their practice. They could hand out information brochures (n = 44, 54.3%) or refer their patient to a specialized website about SD (n = 27, 33.3%). Other options included referral to www.thuisarts.nl, a generic website founded by the Dutch society of GPs (n = 12, 14.8%), E-Health modules (n = 3, 3.7%), DVDs (n = 2, 2.5%) or applications for mobile devices (n = 2, 2.5%). GPNs who stated that information was available, discussed SD more often during follow-up consultations (P = 0.038). Furthermore, when asked what kind of patient information they would like to have, the majority preferred information brochures (n = 277, 82.2%) or addresses of specialized websites on SD (n = 201, 59.6%). Ninety-six GPNs (28.3%) wanted to recommend E-Health modules about SD, 67 (19.9%) applications for mobile phones or tablets, 8 (2.4%) DVDs. One hundred and one GPNs (31.0%) gave tips about other forms of intimacy to their patients. These tips included, e.g. caressing and hugging your partner, massages and talking about intimacy with your partner.

Knowledge and education

The majority of the respondents felt competent to inquire whether SD is present within their patient population (n = 215, 66.2%). When the GPNs felt competent, they discussed SD more frequently during the first consultations (P = 0.012) and follow-up consultations (P < 0.001). In addition, they thought that discussing of SD is more important (P = 0.002). On the questions ‘Do you have enough knowledge to discuss SD with chronically ill patients?’ six GPNs (1.9%) answered ‘a lot of knowledge’ and 41.7% (n = 134) stated ‘sufficient knowledge’. More than of the half respondents (n = 176, 54.8%) thought that they had not enough knowledge to discuss SD and 1.6% (n = 5) answered that they had no knowledge at all. A higher level of knowledge was associated with a higher frequency of discussing SD during consultations (first consultations: P = 0.022; follow-up consultations: P < 0.001). Most GPNs reported that there was insufficient attention to SD during their GPN training (n = 267, 84.2%). The majority of the GPNs (n = 281, 85.2%) wanted to increase their knowledge on SD. Preferred ways to increase their knowledge were an additional course or training (n = 238, 84.7%), specialized websites (n = 127, 45.2%), E-Health modules (n = 125, 44.5%), information folders (n = 95, 33.8%) and applications for mobile phones or tablets (n = 34, 12.1%).

| Table 1. Respondent characteristics |
|-------------------------------------|
| Sex (N = 337)                       |
| Male                                |
| Female                              |
| Age (years) (N = 335)               |
| Mean (range)                        |
| Current profession (N = 337)        |
| GPN-general medical care            |
| GPN-mental health support           |
| Both GPN-general medical care and mental health support |
| Years in current profession (including training) (N = 333) |
| 0–11 months                        |
| 1–2                                |
| 3–5                                |
| 6–10                               |
| 11–15                              |
| >15                                |
| Type of clinic/practice (N = 425)   |
| General solo practice (1 GP)        |
| General duo practice (2 GPs)        |
| General group practice (multiple GPs) |
| Health centre                      |
| Cooperation of health workers for the primary care |
| Located outside the general practice |
| Followed an extra training/course in sexology (N = 335) |
| Yes                                 |
| No                                 |
| **N** (%)                          |
| 38 (11.3)                          |
| 299 (88.7)                         |
| 47 (23–66)                         |
| 205 (60.8)                         |
| 129 (38.3)                         |
| 3 (0.9)                            |
| 7 (2.1)                            |
| 31 (9.3)                           |
| 77 (23.1)                          |
| 105 (31.5)                         |
| 63 (18.9)                          |
| 50 (15.0)                          |
| 75 (22.3)                          |
| 91 (27.0)                          |
| 176 (52.2)                         |
| 82 (24.3)                          |
| 1 (0.3)                            |
| 25 (7.5)                           |
| 310 (92.5)                         |

*Multiple answers could be given to this question.*
Organization and accountability

A protocol that pointed out who was responsible to assess SD in chronically ill patients was present according to 20% of the GPNs (n = 67), 68.7% (n = 230) reported ‘no protocol’ and 11.3% (n = 38) was unaware of the existence of a protocol. There was an association between a higher frequency of discussing SD during follow-up consultations and the presence of a protocol (including responsibility) (P = 0.003). GPNs opinion on who should be responsible for discussing SD with chronic patients is illustrated in Figure 1. The majority of the respondents (n = 300, 89.0%) stated that this should be the task of the GP, followed by the GPN-general medical care (n = 210, 62.3%) and GPN-mental health support (n = 117, 34.7%).

Tools

When asked which tools could help the GPNs in improving discussing SD, almost three-quarter stated information brochures (n = 246, 73.0%) or an extra training (n = 226, 67.1%). One hundred and twenty-six GPNs (37.4%) choose for E-Health modules and 89 GPNs (26.4%) internet websites. Other options were ‘easier ways to direct patients to another healthcare worker’ (n = 70, 20.8%) and ‘better treatment options’ (n = 53, 15.7%), applications

Table 2. Discussion of SD frequencies

| How often do you discuss SD with chronic patients during the first consultation (N = 336) | Never, N (%) | Less than half of the cases, N (%) | In half of the cases, N (%) | More than half of the cases, N (%) | Always, N (%) |
|---|---|---|---|---|---|
| 179 (53.3) | 96 (28.6) | 23 (6.8) | 23 (6.8) | 15 (4.5) |
| How often do you discuss SD with chronic patients during follow-up consultations (N = 334) | 60 (18) | 132 (39.5) | 53 (15.9) | 63 (18.9) | 26 (7.8) |
| How often do you discuss SD with chronic patients in the following age categories | | | | | |
| 16–35 years (N = 308) | 162 (52.6) | 69 (22.4) | 24 (7.8) | 30 (9.7) | 23 (7.5) |
| 36–50 years (N = 325) | 78 (24.0) | 119 (36.6) | 42 (12.9) | 50 (15.4) | 36 (11.1) |
| 51–65 years (N = 327) | 51 (15.6) | 131 (40.1) | 57 (17.4) | 46 (14.1) | 42 (12.8) |
| 66–75 years (N = 329) | 81 (24.6) | 127 (38.6) | 39 (11.9) | 48 (14.6) | 34 (10.3) |
| 76 years or older (N = 324) | 147 (45.4) | 104 (32.1) | 30 (9.3) | 19 (5.9) | 24 (7.4) |
| How often do you discuss SD with chronic patients in the following groups | | | | | |
| Male patients (N = 335) | 51 (15.2) | 126 (37.6) | 63 (18.8) | 57 (17.0) | 38 (11.3) |
| Female patients (N = 334) | 85 (25.4) | 132 (39.5) | 51 (15.3) | 38 (11.4) | 28 (8.4) |
| How often do patients present SD spontaneously (N = 333) | 178 (53.1) | 135 (40.3) | 18 (5.4) | 4 (1.2) | 0 (0.0) |
| How often is the partner present when SD is discussed (N = 334) | 241 (72.2) | 82 (24.6) | 7 (2.1) | 1 (0.3) | 3 (0.9) |

Table 3. Barriers for discussing SD

| Reasons not to address SD | Agree, N (%) | Undecided, N (%) | Disagree, N (%) |
|---|---|---|---|
| Insufficient training (N = 333) | 182 (54.7) | 68 (20.4) | 83 (24.9) |
| Barriers related to language and ethnicity (N = 326) | 155 (47.5) | 84 (25.8) | 87 (26.7) |
| Barriers related to culture and religion (N = 334) | 135 (45.8) | 88 (26.3) | 93 (27.8) |
| Could not find a suitable moment to discuss SD (N = 321) | 138 (43.0) | 68 (21.2) | 115 (35.8) |
| Insufficient knowledge (N = 333) | 134 (40.2) | 95 (28.5) | 104 (31.2) |
| The age of the patient (N = 334) | 122 (36.5) | 70 (21.0) | 142 (42.5) |
| Presence of a third party (N = 333) | 96 (28.8) | 82 (24.6) | 155 (46.5) |
| Patient does not bring up the subject of SD spontaneously (N = 333) | 92 (27.6) | 82 (24.6) | 159 (47.7) |
| I feel uncomfortable to talk about SD (N = 320) | 81 (25.3) | 95 (29.7) | 144 (45.0) |
| SD is not a problem for the patient (N = 332) | 82 (24.7) | 121 (36.4) | 129 (38.9) |
| Patient is too ill to talk about SD (N = 331) | 75 (22.7) | 85 (25.7) | 171 (51.7) |
| Insufficient time (N = 334) | 66 (19.8) | 70 (21.0) | 198 (59.3) |
| Patient is not ready to discuss SD (N = 331) | 59 (17.8) | 107 (32.3) | 163 (49.8) |
| Afraid to insult the patient (N = 333) | 56 (16.8) | 56 (16.8) | 221 (66.4) |
| No connection the with the patient (N = 329) | 52 (15.8) | 64 (19.5) | 213 (64.7) |
| Sense of shame (N = 334) | 45 (13.5) | 95 (28.4) | 194 (58.1) |
| Age difference between yourself and the patient (N = 333) | 44 (13.2) | 54 (16.2) | 235 (70.6) |
| Sex is private (N = 333) | 26 (7.8) | 84 (25.2) | 223 (67.0) |
| Patient is of the opposite sex (N = 333) | 23 (6.9) | 44 (13.2) | 266 (79.9) |
| Responsibility of someone else (N = 331) | 23 (6.9) | 86 (26.0) | 222 (67.1) |

aAgree contains the answers ‘totally agree’ and ‘agree’.
bDisagree contains the answers ‘totally disagree’ and ‘disagree’.

Medical care (n = 210, 62.3%) and GPN-mental health support (n = 117, 34.7%).
Figure 1. GPN opinion on responsibility for discussing SD. 1General practitioner. 2GPN-general medical care (with sub specialisms of diabetic care, asthma/COPD care and cardiovascular care). 3GPN-mental health support. 4Psychologist. 5Doctor’s assistant. 6Patients own responsibility. 7Partner of patient. 8Includes the answers: e.g., ‘everyone who is involved with the patient’ and GPN sexology.

for mobile phones or tablets (n = 42, 12.5%) and information posters in the waiting room (N = 39, 11.6%).

Discussion
This study is the first to provide extensive data on the role of Dutch GPNs in discussing SD with chronically ill patients. Although most GPNs acknowledged the importance of discussing SD with their chronic patients, only a small percentage of them do so routinely during consultations. This is a distressing finding, because the patient population, both GPN-general medical care and GPN-mental health care serve, consists of chronically ill patients. Chronic diseases are associated with a wide array of SD, which can result in lower quality of life (8–12). Our finding that patients aged 16–35 years are less likely to be asked about SD, might indicate that GPNs assume that younger people are not likely to be affected by SD, which however, is not consistent with the literature (9–11, 19, 20). Our finding that patients aged 76 years or older are also less likely to be asked about SD, might indicate that GPNs assume that older people with SD do not have a need for help. However, most patients want to discuss their SD, and they prefer that the health professional bring up the topic (11, 19, 20). Moreover, the value of discussing SD is high for patients throughout the lifespan and regardless of the type of SD (10, 19, 20).

An important factor contributing to discussion of SD turned out to be the knowledge of the GPN about this topic. However, the self-reported level of knowledge among Dutch GPNs was regarded insufficient. This study indicates the importance of knowledge, experience and training when providing sexual health care. These findings correspond with previous research among Dutch clinical and English practice nurses, in which nurses who reported a lack of knowledge and training refrained from discussing sexual health (16, 18, 21–23). The insufficient training and knowledge among GPNs indicate insufficient attention on SDs during GPN education, an omission recognized both nationally and internationally (18, 24, 25). Present findings, endorsed by previous research, emphasize the necessity of implementing additional training and knowledge significantly, because this will improve the discussion of SD (18, 23, 26, 27). Both the present study and previous studies showed that GPNs acknowledged the need for an additional sexology training (18, 28). By incorporating educational models on how to assess sexual health, (e.g., PLISSIT-model and BETTER-model) into current GPN training, skills of nurses may be improved (29).

Reasons related to language, ethnicity, culture and religion were the other main barriers that withheld GPNs from discussing SD. These results are in line with studies among GPNs and GPs in Great Britain (28). The lack of cultural competence could underlie these results and training in this subject was desired (30). Cultural competence is the ability of organizations to provide care to patients from different cultures, and thus their varied perspectives, values and behaviours about health and well-being (31). However, evidence is lacking on the effect of this type of training both for GPNs as GPs as they provide care to the same patient population.

Organizational adjustments within the general practice could also help the GPN to discuss SD with chronic patients more frequently (20). Guidelines should be created concerning the assessment of SD in chronic patients. Furthermore, more information should be available in GPNs practice to hand out to patients; a helpful tool in discussing identified by the GPNs themselves (20). Besides information brochures, E-Health modules could also be brought into practice.

Organizational adjustments may take time and money to implement. Experts in the field recommend more immediate instruments for discussing sexual health (32). First of all, the GPNs must attempt to secure the patients’ trust and openness. Furthermore, questions about sexual health should be asked in a professional and straightforward manner, without losing sight of empathy. To begin a conversation, the GPN could talk about illnesses and medications that are known to have a negative impact on sexual health. By using this method, the conversation can be altered to the medical history of the patient and makes the patient feel like they are not the only one who are suffering from an SD (32).

Strengths and limitations
This survey was the first to evaluate the practices of the GPN regarding discussing SD with chronically ill patients. The response rate was 63.5%, but there could have been a response bias. The GPNs who responded may be more likely to be familiar with addressing SD with chronically ill patients, or to find the subject of SD important. In addition, the self-reported character of the questionnaire could lead to social desirable answers. In the present study, a non-validated questionnaire was used, as validated questionnaires did not assess the main objectives of the study. For future purposes, validation of the instrument will be conducted.

Conclusions
The present study showed that GPNs considered discussing SD with their chronic patients as an important part of their job. However, this study also indicates that only a small percentage of the GPNs implement this notion in their consultations with the chronic patients. This may be due to a lack of experience and guidelines on SD, insufficiency in knowledge and training, and reasons related to cultural and ethnic diversity. The results emphasize the need for training in assessing SD in chronic patients, in which the aspect of cultural diversity should be taken in account, organizational changes in the general practice and more tools such as information brochures for patients about SD.
Declarations

Funding: There are no funders to report for this submission.

Ethics approval: Since this study did not involve patients or interventions, no formal ethical approval is needed in the Netherlands. Written informed consent was obtained from all individual participants included in the study.

Conflict of interests: All authors declare no support from any organization for the submitted work; no financial relationships with any organizations that might have an interest in the submitted work in previous years, no other relationships or activities that could appear to have influenced the submitted work.

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