Non-disclosure of symptoms in primary care: an observational study

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Key messages

- 23% of primary care consultations contained elements of non-disclosure
- Joint pain & tiredness/sleeping problem were the most commonly withheld symptoms
- Further research needs to explore the outcomes of symptom non-disclosure

Background

Symptoms form a major component of patient agendas, with the need for an explanation of symptoms being a prominent reason for consultation.

Objectives

To estimate the prevalence of different symptoms pre-consultation; to investigate whether intention to mention a symptom in the consultation varied between patients and across symptoms; and to determine how patients' intended agendas for mentioning symptoms compared with what was discussed.

Method

We video-recorded consultations of an unselected sample of people aged 45 and over consulting their GP in 7 different practices in UK primary care. A pre-consultation questionnaire recorded the patient's agenda for the consultation, current symptoms and symptoms the patient intended to discuss with their GP. The video recorded consultation was viewed and all patient agendas and 'symptoms with intention to discuss' were compared with the actual topics of discussion.

Results

190 patients participated. 81 (42.6%) were female and the mean age was 68 (range 46-93). Joint pain was the most commonly reported symptom. 139 (81.8% of those reporting symptoms) patients reported intention to discuss a symptom. In 43 (22.6%) consultations, 67 symptoms (27.2%) where an intention to discuss had been expressed, remained undisclosed. Tiredness and sleeping difficulty were more likely to be withheld than other symptoms after an intention to discuss had been expressed. Of the more physically located symptoms, joint pain was the most likely to remain undisclosed.

Conclusion

This study suggests that the extent of symptom non-disclosure varies between patients, physicians and symptoms. Further work needs to explore the consequences of non-disclosure.

Keywords (6)

Consultation

Primary care

General practitioner

Doctor patient relationship

Introduction

The appropriateness of health care seeking behaviour, in the context of a health service that is free for all at the point of contact, continues to be a source of debate in UK primary care. One reason for this may be the reported long wait for general practice appointments in many areas of the country. This has raised a more general issue periodically addressed by researchers: what is the full range of clinical agendas, mentioned or unmentioned, that people bring to primary care, and are there alternative ways to address these agendas?

Previous consultation research has attempted to quantify the nature of unmentioned agendas, finding that patients do not disclose concerns in up to 40% of nursing and 25% of GP consultations in primary care [1,2]. While patient demand is at a current all-time high, some may argue that the last thing a busy clinician needs is for patients to raise more concerns during a time pressured consultation. However, clinicians cannot effect change regarding problems to which they are blind. Further study of unmentioned concerns is important in order to ensure consultations are patient-centred and effective.

Symptoms form a major component of patient agendas even if they are requesting a 'check-up'[3]. The need for an explanation of symptoms is a prominent reason for consultation voiced by patients in research studies [4,5] whether these are framed within a biomedical or a psychosocial framework [6]. Patients may be confused by policy pronouncements on this topic, as public encouragement to take some symptoms early to the doctor contrasts with advice to think twice before 'troubling the doctor' about other symptoms [7]. Evidence also points to some patients having multiple symptoms they intend to mention to the doctor, which the system may tackle

by restricting patients to one problem per consultation. At the same time other patients do not mention important symptoms such as depression, and the system tries to encourage them to be more explicit about such problems [8,9].

We investigated pre-consultation symptoms in an unselected sample of all patients who were consulting their GP and who gave permission to complete a pre-consultation questionnaire and for their consultation to be videotaped. In this paper we compare pre-consultation symptoms, and intention to mention the symptom to the GP, with actual content of the conversation in the consultation.

The aim of this study, in an unselected sample of older people about to consult with their GP in UK primary care, was to estimate the prevalence of different symptoms pre-consultation; to investigate whether intention to mention a symptom in the consultation varied between patients and across symptoms; and, among those who consented to videotaping of the consultation, to determine how patients' intended agendas for mentioning symptoms compared with what was discussed.

Method

Fifteen general practitioners (GPs) in seven primary care practices in the Midlands region of the UK nominated two of their half-day clinics to be video-recorded. When nominating the clinics, they had no awareness of who would be consulting them on those particular days.

Patients aged 45 years and over who were due to attend the nominated clinics were sent information about the study in advance of the clinic. They were informed the study was investigating patient-doctor communication and that they would be offered the opportunity to consent to their consultation being videotaped and completing a pre-consultation questionnaire. Consent was verified in a three stage process, with further consent sought immediately after the consultation, and 48 hours later by phone, to permit a 'cooling off' period.

All persons listed to attend the nominated clinics, and consenting to involvement were given a pre-consultation questionnaire about their symptoms and about reasons for seeking a consultation. All those who completed the pre-consultation questionnaire, had their consultation videotaped and gave full written consent to the study were included in the analysis described in this paper. There was no selection of patients according to reported or recorded morbidity. (A subgroup of patients whose consultation concerned osteoarthritis were subsequently interviewed for a distinctive and separate study that has been previously reported [10,11]).

The pre-consultation questionnaire included questions about the patient's current symptoms and their agenda for the consultation (Supplementary Data). They were first asked to complete a free text section indicating their main reason for the consultation, hereafter referred to as the 'main consultation agenda'. Patient participants were then asked to tick one or more of the boxes adjacent to each of 11

groups of symptoms to indicate if they had experience of the symptom in the last week, and a second box if they intended to discuss that group of symptoms with the doctor, the latter hereafter referred to as the 'symptom agenda'.

The list of symptoms was derived from data from the Consultations in Primary Care Archive (CipCA), a database of local general practice anonymised records[12] and the scoring system for subjective health complaints (Subjective Health Complaint Inventory (SHCI))[13]. The eight most common disease areas as derived from CiPCA[14] were translated into symptoms e.g. respiratory translated to 'shortness of breath and/or cough'. This list was then compared to the list of symptoms in the SHCI list. The wording of some of the eight symptom areas was changed to SHCI descriptors if it was perceived they were easier for a patient to understand e.g. shortness of breath was changed to breathing difficulty. Symptom descriptors from the SHCI list were added that were not included in the initial list of eight items e.g. sleep problems. Some symptoms were grouped together e.g. cough with breathing difficulty to produce a shorter list than the SHCI. The final pre-consultation questionnaire list consisted of 11 items (shown in Supplementary Data), shorter than the SHCI, which contains 29 items. Finally, the questionnaire was piloted with the Arthritis Research UK Primary Care Centre (ARUKPCC) Research User Group to test ease of understanding, with no subsequent changes made.

Following the consultation, all the videos were viewed by ZP and the actual topics of discussion during the consultation recorded, independent of knowledge about the content of the answers to the pre-consultation questionnaire. Thereafter all main consultation agendas and symptom agendas, as indicated on the questionnaire, were compared with the actual topics of discussion.

Free text symptoms were grouped into symptom areas or non-symptom reasons by the first author. Descriptive statistics were used to express quantitative results.

Results

200 out of a total of 252 patients approached (79.4%) consented to both completing the pre-consultation questionnaire and having their consultation video recorded. Three participants were subsequently excluded due to technical issues with the video and a further seven either withdrew consent at a later date or didn't complete the three stage consent process. Of the 190 consenters who remained in the study, five consulted twice resulting in a sample of 195 video recorded consultations; for those who consulted twice, the patient's data from their second consultation was excluded, leaving a sample of 190 matched pre-consultation patient questionnaires and video recorded consultations. A flowchart of recruitment is available in Supplementary Figure S1. Of the participants, 81/190 (42.6%) were female and the mean age was 68 (range 46-93). Characteristics of consenting patients, compared with non-consenters, and of the consenting GPs are detailed in Supplementary Tables S1-4.

Reported main consultation agenda

One hundred and eighty eight/190 (98.9%) patient participants completed a free text main reason for consultation. The most common symptom groups given as the main reason for consultation in the free text section of the questionnaire were musculoskeletal, skin problems and respiratory tract/sinus problem recorded by 41 (21.6%), 22 (11.6%) and 20 (10.5%) of the 190 participants respectively. Fifty five participants (28.9%) reported symptoms elsewhere in the free text section, while 50 participants (36.3%) recorded a 'process' issue, such as review of results or medication. 2(1.1%) did not complete this section.

Reported symptoms

One hundred and seventy/190 (89.5%) patient participants indicated they had experienced one or more symptoms in the past week, with 113 (59.5%) reporting more than one (Figure 1). 146/190 (76.8%) patients reported symptoms that were in addition to any symptom mentioned as the main consultation agenda. Joint pain was the most commonly reported symptom. The median number of symptom boxes ticked per participant was 2 (range 0-9). Of the 170 patients who reported at least one symptom, there were 139 (81.8%) who reported an intention to discuss at least one of their symptoms (a symptom agenda); 63 of the 170 (37.1%) reported an intention to discuss multiple symptoms.

Comparing main consultation agenda and symptom agendas with observed content of the consultation

Of the 188 participants for whom a main consultation agenda could be identified, 185 (98.4%) expressed this in the consultation.

However, in 43/190 (22.6%) consultations, 67 symptom agendas remained undisclosed (Table 1). The mean age of the non-disclosure patients was 69 years, and 19 (46.3%) were female, and so they were similar to the study population as a whole. All GPs but one had consultations with non-disclosure (range 0-41% of consultations per GP with observed non-disclosure).

Conversely, in 48/190 (25.2%) consultations a symptom was discussed where no intention to discuss had been expressed on the questionnaire. Joint pain, skin lesions and stress were the most commonly raised symptoms that had not been identified as symptom agendas. Six of the 44 (13.6%) consultations with non-

disclosure contained discussion of another symptom not previously identified as a symptom agenda.

In 75/190 (39.5%) consultations, patients were observed to discuss more than one of the 11 groups of symptoms during the consultation (median 1, range 0-5).

Figure 2 illustrates the pattern of reported symptoms, intention to discuss and observed discussion. Joint pain was the most frequently reported symptom on the pre-consultation questionnaire, and the most frequent symptom that patients intended to, and subsequently did, discuss in the consultation.

In Table 2 the symptom groups are ranked according to the proportion of those with symptoms who intended to discuss. Patients reporting a skin rash, cardiovascular or respiratory symptoms were most likely to also express a wish to discuss these symptoms with their GP. Conversely, patients reporting ‘stress, worries or sadness’ or ‘tiredness or sleeping difficulties’ were least likely to express a wish to discuss these symptoms.

In Table 3, the symptom groups are ranked according to the likelihood of discussing a symptom after an expression of intention to discuss. Tiredness and sleeping difficulty were the most commonly nondisclosed symptoms, followed by joint pain and headache.

Discussion

Summary

Although previous research has investigated the prevalence of symptoms in population studies, revealing the so-called symptom iceberg [(14)], this is the first study to our knowledge to investigate how patients' intended agendas for mentioning symptoms compares with what is actually discussed. Over 96% of patients in this study discussed the main (free text) issue with the doctor they intended to discuss. However, 23% of patients did not disclose symptoms they had previously expressed an intention to discuss. Our study suggests that there is substantial variation between patients and clinicians with respect to likelihood of symptoms being withheld. What our new empirical data also adds is how different symptoms vary in likelihood of being discussed. Tiredness and sleeping difficulty appear more likely to be withheld than more 'physically located' symptoms after an intention to discuss had been expressed. Of the more physical symptoms, joint pain and headache were the least likely to be discussed after an intention was expressed to do so.

Strengths and limitations

A symptom checklist may provoke a higher level of reporting and a longer agenda for the forthcoming consultation than would be the case in its absence [15]. In our study, symptom groupings from the questionnaire may not have accurately reflected the overall symptomatic story or presentation of patients in the study and the patients' intentions and expectations may have been far more 'complex' than the checklist could capture[16]. Furthermore, it is possible some symptoms may have fallen into more than one category (back or neck ache could be described as joint pain, and 'stress' could be described as a 'personal' problem). We did not record symptom

severity, chronicity or perceived importance, or the history of the patient including mental health diagnoses. It is possible we have reported non-disclosure where the researcher's interpretation of the intended symptom or agenda did not match that of the participant.

Single-observer bias may be an issue. However, measures, were taken to remove any influence of the questionnaire groupings on observer coding by the observer first observing each videotape in turn and coding each topics as it was discussed. Only after this was completed was each topic compared with the participant's responses.

The original purpose for which patient recruitment was undertaken was to select a small subgroup of people after the videotaped consultation had been completed for in-depth interviews about joint pain and osteoarthritis. This study has been reported elsewhere [11]. For the new study reported here, we have returned to the initial full screening sample of consulters, unselected in any way other than age, who completed pre-consultation questionnaires and videotaped consultations. This patient group as a whole had been informed that the study was about communication and patient experience, with no mention of specific morbidities prior to consultation and videotaping. However, the GPs were aware in advance that one eventual purpose of the study was to investigate communication and experience related to osteoarthritis and it is possible that this may have influenced the direction of content of their consultations with the full sample.

Finally, we acknowledge that the population of this sample of adults aged 45 years and over is not fully representative of the UK population as a whole, given its predominance of white retired males, and practices with no deprivation decile score less than 6 (Table S4).

Comparison with existing literature

The proportion of consultations in which there was non-disclosure in our study is similar to those from previous in-depth studies of selected patients that have evaluated patient agendas in a broader context. Barry et al [1] elicited patient agendas before the consultation by interview, and included ideas, expectations, emotional and social issues, in addition to symptoms. They found 26% patients did not raise symptoms they had reported the intention to mention, slightly more than in our larger study (22.3%). Green et al conducted a similar study with patients and nurses in woundcare consultations and identified 38% of patient concerns were unvoiced [2]. In this study, emotional issues were more likely to be withheld than concerns about physical health [2].

Symptoms may not be disclosed for a number of reasons, and non-disclosure may not always be undesirable. There are practical reasons why symptoms may not be disclosed; the patient may simply forget their intentions or change their mind during the course of the consultation. Barry et al[1] describes 'dynamism' in the consultation, the way in which patients may choose to withhold information, on the basis that some pre-consultation plans and thoughts may seem less relevant as the consultation progresses. The consultation in itself is a 'change mechanism' which cannot easily be predicted; new things emerge which deflect or suppress the originally intended plan. It may be neither the 'fault' of the doctor nor of the patient that intended symptoms are not discussed but an inevitable consequence of consultation flow. There is some evidence to support this from our finding that six of the patients who did not disclose symptom agendas ended up discussing something else instead.

There is a rich and expanding literature about persons with symptoms indicative of serious diseases such as cancer. This includes interview studies with patients after presentation but before diagnosis. These studies (for example Birt et al [17]) have explored factors related to initial delay in seeking help, and have emphasised patients' complex behavioural and emotional response to symptoms, including normalisation and subsequent reappraisal of symptoms with potentially serious import such as haemoptysis. Patient beliefs and attitudes, and patient perceived attitudes of the clinicians are also likely to be important in the act of non-disclosure. Patients may feel there is insufficient time to raise additional concerns or be anxious about wasting the doctor's time[1,7]. The nature of the symptom is likely to be important in this rationalisation and this is the first study to our knowledge of GP consultations which characterises the nature of symptoms which go undisclosed. Patients may perceive a negative response from the GP, previously identified this as a potential barrier to raising concerns about joint pain[18] or about psychosocial issues[9]. In practice, it is likely that patients consider a range of issues, including consideration of whether their reasons are good enough, their past experience with the doctor, and the 'real time' events in the consultation (the dynamism) in making a judgement about their candidacy, or eligibility to consult on a given topic or symptom [7,19].

Clinician behaviours may act as facilitators or barriers to agendas being disclosed. In the study by Green et al, nurses were observed to be reflecting on how many more visits they needed to do, at which point the patient's agenda became limited [2,20]. In our study, there was marked variation by GP in the proportion of consultations that contained non-disclosure (0-41%) suggesting that clinician behaviours were playing a role. Given that patients reported clinicians to be more accommodating than usual

during this study [10], our findings may not have entirely reflected 'normal' clinician behaviour and resulted in underestimates of non-disclosure. Conversely, some patients reported mild distress as a result of being video recorded, which may have negatively influenced disclosure [10].

Our study did not look at what the expectations of patients were in raising symptoms. A number of studies have highlighted that this often involves a search for explanations [4,6,7.] As stated previously, there is general agreement between studies that unvoiced agendas or unmentioned symptoms, as in our study, are more likely to be psychosocial. However Salmon et al, highlighted how physical symptoms often have a psychosocial dimension from the patient's perspective but that consultations are more likely to progress down a biomedical route [6,21,22].

Implications for research and/or practice

Our findings must be interpreted with caution because of the limitations on generalisability of the populations registered with participating practices and the restrictions on exploration of the full complexity of patients' symptom appraisal in a quantitative questionnaire study. However, this study of substantial numbers of patients using linked pre-consultation questionnaires and videotaped consultations enable some initial implications for practice and research to be highlighted. First, for practice, our findings serve as a reminder for clinicians to probe regarding symptoms particularly relating to sleeping difficulty and tiredness. Second, the prominence of musculoskeletal symptoms in this sample adds weight to arguments that other healthcare professionals e.g. physiotherapists, could be utilised to support frontline primary care, particularly with the given shortage of GPs. For research, the findings suggest investigation of pre-consultation interventions to empower patients to

discuss, potentially 'difficult', symptoms, as has been done for appraisal of potentially 'serious' symptoms in patients at high risk of cancer (e.g. Murray et al [23]), could be valuable. However, a number of studies have investigated the impact of patients attending with a pre-listed agenda or checklist and concluded that, although there was some evidence of increased patient satisfaction, there was no effect on other outcomes such as repeat consultations or prescribing [15,24].

Empowering patients to feel confident in expressing their concerns is just one aspect of addressing this issue, and makes assumptions that non-disclosure matters, and that patient behaviour needs to be targeted. Further consultation research, including qualitative methods, is needed to explore the outcome of unvoiced agendas, practitioner behaviours which may block or facilitate patients to disclose their full agenda and the impact of 'one problem per consultation' policies.

In summary, the issue of non-disclosure is undoubtedly complex, influenced by multiple factors and not always necessarily a bad thing. Nonetheless, understanding how symptoms are best explained and managed in the general population could improve the efficiency of primary care. We suggest that further research addressing the issue of non-disclosure of symptoms is important in the context of optimising effective and efficient patient-centred healthcare.

Ethics

The study was approved by North West 8 Research Ethics Committee (11/H1013/3)

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Disclosures

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Figure 1: Frequency of symptoms (in the past week) in consenting consulting in primary care patients aged 45 years and over, 2012

Figure 2: The number of patients reporting symptoms, the number of those patients intending to discuss those symptoms with the GP and the number of those so reporting who were observed to discuss the symptoms in primary care patients aged 45 and over, 2012

Table 1: Summary of non-disclosure and disclosure within consultations in primary care patients aged 45 years and over, 2012

	N (%) number of patients/consultations		
	Disclosure	**Non-disclosure**	**Not applicable (no agenda reported)**
Main Consultation agenda	**185**	**3**	**2**
Symptom agenda	**96**	**43**	**51**

Table 2: Proportion of those with symptoms, who also intended to discuss symptoms with GP, ranked by symptom group, in primary care patients aged 45 years and over, 2012

Proportion with symptom, who also expressed an intention to discuss symptom with GP, %, (n)	
Skin Rash	71.0, (22/31)
Chest pain/dizziness	65.5, (19/29)
Cough/cold/breathing difficulty	63.2, (36/57)
Stomach upset	60.0, (15/25)
Joint pain	55.7, (55/88)
Back or neck ache	51.6, (32/62)
Intimate/personal problem	50.0 (2/4)
Headache	48.4 (15/31)
Problems with passing urine	45.0 (9/20)
Tiredness/sleep problem	40.0 (23/59)
Stress, worries or sadness	23.7 (9/38)

Table 3: Number who were observed to discuss symptoms, expressed as proportion of those with symptom and intention to discuss, in primary care patients aged 45 years and over, 2012

	Number of patients not discussing symptom after an intention to discuss had been expressed (total sample n=190)	**Proportion with intention to discuss who did discuss %, (n)**
Problems with passing urine	1	88.9, (8/9)
Intimate/personal problem	1	50.0, (1/2)

Stress, worries or sadness	3	78.6, (11/14)
Skin Rash	4	81.8, (18/22)
Chest pain/dizziness	4	78.9, (15/19)
Stomach upset	5	66.7, (10/15)
Cough/cold/breathing difficulty	6	83.3, (30/36)
Back or neck ache	7	78.1, (25/32)
Headache	7	53.3, (8/15)
Joint pain	12	75.5, (37/49)
Tiredness/sleep problem	15	34.8, (8/23)