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Participation of chronic patients in medical consultations: patients' perceived efficacy, barriers and interest in support

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ABSTRACT

Aims: Chronic patients are increasingly expected to participate actively in medical consultations. This study examined (i) patients' perceived efficacy and barriers to participation in consultations, (ii) patients' interest in communication support and (iii) correlates of perceived efficacy and barriers, with an emphasis on differences across providers' disciplines.

Methods: A representative panel of chronic patients ($n = 1314$) filled out the short Perceived Efficacy in Patient-Provider Interaction scale and were questioned about barriers to participation and interest in communication support. Potential correlates included socio-demographic (age, sex, education, living situation), clinical (discipline care provider, type of illness, comorbidity, illness duration, functional disabilities, health consultations in last year) and personal characteristics (information preference, health literacy, level of general patient activation).

Results: Most patients felt efficacious in consultations, although 46% reported barriers to participation and 39% had an interest in support. Barriers most frequently recognized were 'not wanting to be bothersome', 'perception there is

too little time' and 'remembering subjects only afterwards'. Patients most frequently endorsed relatively simple support. Patients perceived the least barriers and were least likely to endorse support when seeing a nurse. In multivariate models, consistent risk factors for low efficacy and perceived barriers were low health literacy and a low general patient activation.

Conclusions: Many chronically ill patients feel confident in medical interactions. Still, a significant number might benefit from support. Often this concerned more generally vulnerable patients, that is, the low literate and generally less activated. Relatively simple supportive interventions are likely to be endorsed and might overcome frequent barriers.

INTRODUCTION

In modern Western society, patients have well-defined rights, but are also considered to have responsibilities, that is, they are increasingly expected to be in charge of their health and to act as autonomous, well-informed care consumers. This shift towards patient empowerment and self-management is clearly reflected in the patient-provider relationship. Whereas medical consultations used to be provider-centred,[1] a more patient-centred style is advocated nowadays. Communication and decision making should incorporate the individual patient's perspective.[2, 3] Particularly in the setting of chronic illness, patients are increasingly regarded as members of the care team.[4, 5] Obviously, this redefined view on the patient-provider relationship places patients in a more active and participatory role in consultations.[2] Little research has examined if chronically ill patients actually feel up to this task. Street and Millay[6] defined patient participation in medical consultations as the extent to which patients influence the interaction as well as the health-care provider's beliefs and behaviour by, for example, asking questions, expressing concerns and stating preferences. Given the complexity and significance of the topics discussed in medical consultations as well as patients' vulnerable position, such participation is not self-evident and barriers might exist. The framework of Feldman-Stewart[7] suggests that patients' communicative behaviour is influenced by patients' emotions, values, beliefs, skills, and needs. Barriers to active participation could, for example, be patient's tension (an emotion), the wish not to be 'difficult' (a value), the perception there is too little time (a belief) and the inability to recall questions (a skill).[8-10]

Empirical studies examining patients' perceived efficacy in the interaction as well as barriers to participation are limited and often solely focused on patients with cancer.[9, 11, 12] Such insight is, however, valuable. First of all, it might inform clinicians about the nature of patient-perceived difficulties in the interaction and might point to ways of increasing efficacy. An efficacious patient enhances the effectiveness of communication, that is, patient-perceived efficacy in medical communication has been shown to be related to patients' knowledge about the disease,[13] diagnostic delay[14] and health outcomes.[15] Second, insight into patients' perceived efficacy and barriers could demonstrate the necessity of supportive interventions and the best format to intervene.

Interventions to facilitate patient participation are increasingly targeting patients instead of (only) doctors. Several reviews[16-18] demonstrated that such patient-targeted interventions increase patient participation. Most interventions are motivated

by the empirical observation that patient participation is limited and the assumption that patient participation is beneficial.[16] Few studies, however, assessed patients' perceived efficacy, the nature of the barriers to participation and patients' perceived need for support. In addition, few studies have examined risk factors to identify subgroups of patients who might benefit most from support.

Most known risk factors for patient passivity are based either on correlates of observed patient behaviour[19, 20] or on moderators of the effect of supportive interventions.[21, 22] For instance, there is evidence that male, lower educated and older patients are more passive communicators.[19, 20] Whether the same factors are related to patients' perceived efficacy has not been investigated extensively. As noted by Street *et al.*,[23] observed and perceived communication are not necessarily highly correlated and both measures provide valuable information.

One potential predictor is the discipline of the care provider that is, whether patients consult a medical specialist, a general practitioner (GP) or a nurse. As these disciplines differ with respect to the nature and severity of the problems discussed, the duration and strength of the relationship, as well as the context in which the communication takes place, differences in patients' perceptions of communication can be expected.[24] For example, the general assumption is that patients find it easier to talk with a nurse than with a doctor. Yet, few studies actually made the comparison and some empirical studies suggest that also nurses' communication could be improved.[25, 26]

In sum, this survey among chronically ill patients aims to examine (i) patients' perceived efficacy in communicating with their main care provider and the extent and nature of perceived barriers to participation; (ii) patients' endorsement of patient-targeted communication support of varying modality and intensity; and (iii) correlates of perceived efficacy and barriers, with an emphasis on cross-discipline differences.

METHODS

Sample

Data were collected through the National Panel of people with Chronic illness or Disability (NPCD), a study on the consequences of chronic illness in the Netherlands. Panel members were recruited from a random sample of general practices drawn from the Netherlands registration of general practice. Inclusion criteria were as follows: diagnosis of a somatic chronic disease, aged ≥ 15 years, being non-institutionalized, being aware of the diagnosis, not being terminally ill (life expectancy > 6 months), being mentally able to participate and having sufficient mastery of Dutch. The panel is a representative sample of the non-institutionalized chronically ill population in the Netherlands.

Eligible patients were invited by their GP to fill out questionnaires twice a year. Their GP provided data from their medical files at inclusion. The NPCD is registered with the Dutch Data Protection Authority; all data were collected and handled in accordance with the privacy protection guidelines.

For the current study, a questionnaire was sent to 1669 patients in April 2011. We included patients who filled out at least one variable of main interest (perceived efficacy, barrier(s), interest in intervention(s)).

Data collection

The scales reported in this paper were combined in one questionnaire. All panel members received a paper questionnaire, yet they were offered an online version. A small number of members were surveyed by telephone to overcome difficulties with reading or writing due to their disability.

Perceived efficacy, barriers and interest in support

Patients were asked to indicate the provider mainly responsible for their current treatment or monitoring. When answering subsequent questions, they were asked to think of the indicated provider.

Patients' *perceived efficacy* in interacting with their main care provider was assessed using the short 5-item version of the Perceived Efficacy in Patient-Doctor Interactions (PEPPI-5) scale.[27, 28] Patients indicated on a 5-point Likert scale (1 = not at all confident, to 5 = completely confident) how confident they were that they, for example, knew which questions to ask or were able to make the most out of the visit ($\alpha = 0.95$).

Perceived barriers were assessed with a list of 17 barriers introduced by the phrase 'I sometimes find it difficult to say something in a conversation with my care provider, because...'. Barriers were adopted from the literature[8, 9] and a previous study,[12] or added on the basis of the researchers' hypotheses. Barriers included emotions (e.g. 'feeling tense'), skills (e.g. 'not finding the right moment to bring something up'), values (e.g. 'not wanting to be a difficult patient') and beliefs (e.g. 'believing subject is not important enough').[7] A sum score was calculated ($\alpha = 0.87$).

Similarly, patients' *endorsement of interventions* to support them in communicating with their care provider was assessed with a list based on the literature,[16] used in a previous study.[12] The interventions were introduced by the phrase 'I would benefit from...'.

Potential correlates

Possible correlates were partly based on previous literature,[19, 20, 28, 29] while others were included more exploratively. Socio-demographic, clinical and personal characteristics were examined.

Socio-demographic characteristics

Patients reported their *age*, *sex*, highest educational level and living situation. Educational level was categorized into low (vocational training), middle (high school) and high (college or university). Living situation was dichotomized into living alone vs. living with other(s).

Clinical characteristics

Patients indicated their main care provider (medical specialist, GP, hospital or practice nurse, or different care provider).

Chronic diseases were registered by the GP using the International Classification of Primary Care[30] and categorized into cardiovascular diseases, rheumatic diseases, cancer, diabetes (type I and II), neurological diseases, asthma or COPD, chronic digestive diseases and other chronic diseases. Comorbidity was defined as the presence of more than one chronic disease (yes/no). The illness duration of the disease first diagnosed (in years) was calculated. As the distribution was positively skewed, illness duration was categorized into 0–5, 5–15 and >15 years.

At inclusion, patients reported the presence and severity of long-term functional (sensory or motor) disabilities,[31] which were categorized into (i) mild, (ii) moderate and (iii) severe.

Patients indicated the number of contacts with care providers over the past year with the GP, various medical specialists and nurses. If patients indicated they had a contact, but did not report a number, we assumed they had 1 contact. If patients reported at least one contact, subsequent missing data were considered as 'no contact'. Hence, the total number might be an underestimation. Number of contacts was categorized into 0–5, 6–10 or more than 10 contacts.

Personal characteristics

Patients' *information preference* was assessed with the item 'how much information do you usually want about your disease or treatment'[32, 33] on an 11-point Likert scale ranging from 0 (the least possible) to 10 (as much as possible). As the distribution was highly skewed, responses were categorized into a preference for 'limited' (scores 0–6), 'extended' (scores 7–9) and 'complete' (score 10) information.

Patients' *health literacy* was assessed with the 3-item Dutch translation of the Set of Brief Screening Questions (SBSQ-D),[34, 35] measuring patients' ability to read and understand medical information using a 5-point Likert scale (0–4). As the distribution was highly skewed, responses were dichotomized. A cut-off with high sensitivity was adopted (≤ 9).[35, 36]

Patients' general *level of activation*, that is, their knowledge, skills and confidence in managing their health (care), was measured with the Dutch version of the short Patient Activation Measure (PAM).[5, 37, 38] The PAM consists of 13 items asking about beliefs, knowledge and confidence in engaging in a wide range of health management behaviours such as medicine use and lifestyle change. The PAM scores result in four levels of activation[39] using empirically derived cut-off points.[5] Higher levels are indicative of stronger activation.

ANALYSIS

Descriptive statistics were applied to present the level of perceived efficacy as well as the presence and type of perceived barriers and endorsed supportive interventions for the total group as well as separately for the three disciplines. Cross-discipline differences were tested using F-test, Kruskal–Wallis, Mann–Whitney and chi-squared tests. If significant, post hoc comparisons were conducted. These tests were purposefully not controlled for possibly confounding patient characteristics, as we were interested in cross-discipline differences irrespective of their source. Lastly, the relations between socio-demographic, clinical and personal characteristics on the one hand and perceived efficacy (ANOVA) and barriers (negative binomial regression) were examined univariately. If significant, post hoc comparisons were conducted. Indications of effect sizes were provided by Cohen's d (>0.2 is small, >0.5 is medium, >0.8 is large) and odds ratio's (large >2.0 or <0.5). Significant correlates ($P < 0.05$) were entered into multivariate models. Both univariate and multivariate predictive analyses were conducted on the sample with complete data only ($N = 939–1023$).

RESULTS

Sample characteristics

In total, 1373 patients (82.3%) returned the questionnaire, of whom 1314 were eligible (Table 1). Most participants filled out the paper version (95%). A minority filled out the questionnaire online (3%) or was surveyed by telephone (2%). Mean age was 63.4 years. Most frequent diseases were cardiovascular or respiratory diseases. Half had more than one disease. Median illness duration was 7.2 years, with large variation. Respondents' main care provider was most often either the GP or a medical specialist. A majority reported no or mild functional disabilities. The number of health contacts in the past year varied greatly. Respondents' information preference and health literacy were high. Two-third were in the highest two levels of patient activation.

[TABLE 1]

Perceived efficacy and barriers

Patients' perceived efficacy in interactions with their main care provider was generally high (Table 2). One-fifth felt less efficacious. Half of the patients did not recognize any barrier in interactions with their main care provider. Barriers most frequently recognized (>20%) were 'not wanting to be bothersome', 'the perception there is too little time' and 'remembering subjects only afterwards'. Barriers recognized by relatively few participants (<7%) were 'fearing the answer to my question', 'looking up to the doctor', 'feeling embarrassed about a subject' and 'expecting an annoyed/offended response of the provider'.

[TABLE 2]

Patients' perceived efficacy did not differ across care disciplines ($p_{\text{difference in mean}} = 0.78$; $p_{\text{difference low/high}} = 0.19$). Yet, patients seeing a nurse reported fewer barriers than patients seeing a GP ($p_{\text{difference in median}} = 0.04$; $p_{\text{difference yes/no}} = 0.04$.) or a medical specialist ($p_{\text{difference in median}} < 0.01$; $p_{\text{difference yes/no}} < 0.01$). Specifically, they less often reported the perception 'there is too little time' ($p_{\text{compared to specialist}} < 0.001$; $p_{\text{compared to GP}} < 0.01$). Patients seeing a GP more often reported they find it hard to participate because 'the subject is burdensome to talk about' ($p_{\text{compared to specialist}} = 0.02$; $p_{\text{compared to nurse}} = 0.04$). Patients seeing a medical specialist more often reported they hold back because they 'expect an annoyed or offended response' ($P = 0.03$), and less often reported 'feeling embarrassed about a subject' ($P = 0.02$) compared to patients seeing a GP. These latter two barriers were, however, uncommon.

[TABLE 3]

Interest in support

Over half of the patients did not endorse any of the supportive interventions (Table 3). Interventions frequently endorsed (>20%) were a question prompt list (QPL) for personal use or provided to the doctor prior to the consultation and information about how to prepare and communicate. Infrequently endorsed (<7%) were modelling videos and personal advice and practice.

Compared to patients seeing a nurse, patients seeing a medical specialist were more likely to endorse a supportive intervention ($P = 0.02$). Patients seeing a specialist more often thought they would benefit from a QPL, both for personal use ($p_{\text{compared to GP}} < 0.01$; $p_{\text{compared to nurse}} < 0.01$) or sent to the doctor ($p_{\text{compared to GP}} = 0.03$; $p_{\text{compared to nurse}} = 0.03$), a preparatory conversation with a nurse ($p_{\text{compared to GP}} = 0.01$; $p_{\text{compared to nurse}} < 0.01$) and a personal coach ($p_{\text{compared to GP}} < 0.01$; $p_{\text{compared to nurse}} < 0.001$).

Correlates of perceived efficacy and barriers

Perceived efficacy. None of the socio-demographic characteristics were univariately related to perceived efficacy (Table 4). The efficacy of patients with no or mild disabilities was significantly higher than that of patients with moderate disabilities ($d = 0.2$, $p_{\text{post-hoc}} < 0.01$). All personal characteristics were significantly related to efficacy. Patients with a preference for complete information and with high literacy reported significantly more efficacy than patients with a preference for less than complete information ($d_{7-9} = 0.3$, $P < 0.001$; $d_{0-6} = 0.4$, $P < 0.001$) and low literacy ($d = 0.3$, $P < 0.001$). Efficacy was significantly different at all levels of patient activation ($0.2 < d < 0.9$, $P \leq 0.001$). In the multivariate model, only the effect of the personal characteristics remained.

[TABLE 4]

Perceived barriers

Univariate analyses (Table 5) showed that female patients and patients with a lower educational level were more likely to report barriers than male patients ($P < 0.001$) or patients with an intermediate or a higher educational level ($P < 0.001$). Besides seeing a doctor or medical specialist, the presence of a gastrointestinal disease ($P = 0.02$), more than 10 health contacts in the past year ($p_{0-5} < 0.001$, $p_{6-10} < 0.01$), an illness duration of <15 years ($p_{0-5} < 0.01$, $p_{5-15} < 0.01$), moderate ($p_{\text{low}} < 0.001$) or severe disabilities ($p_{\text{low}} < 0.001$) and a low literacy level ($P < 0.001$) increased the odds of reporting barriers. The odds of reporting barriers decreased with each level of patient activation ($p_{1\text{vs}2} < 0.001$; $p_{2\text{vs}3} < 0.05$); only level 3 did not differ from level 4 ($P = 0.07$). Effects were large for functional disabilities, health literacy and patient activation level. In the full model, all effects remained, except for the effect of educational level and number of health contacts.

[TABLE 5]

DISCUSSION

The current study is the first to demonstrate in a representative sample that many chronically ill patients feel able to adopt an active and participatory role in interactions with their care provider. Still, half of the patients reported at least one barrier to participation, and a considerable group was interested in communication support.

The top 3 of barriers were 'not wanting to be bothersome', 'the perception there is too little time' and 'remembering subjects only afterwards'. Applying the framework of Feldman-Stewart,[7] the first barrier could be considered a value, the second a belief and the third a (lack of) skill. Regarding the first barrier, despite the modern emphasis on patient empowerment and autonomy, still one in five patients feel they should be co-operative and not too demanding. The same belief was reported in other

studies.[10, 12] This stance might reflect the, perhaps reduced but still existing, dependent position of patients in relation to their doctor. Health professionals who personally became ill[40] observed that when becoming a patient, it is much harder to be a critical and assertive consumer. With regard to the second barrier, it is hard to establish whether the belief there is too little time is a subjective perception, an objective observation or, most likely, a combination of both. Dutch general practice visits last on average only 10.2 min,[41] and consultations with medical specialist probably are not much longer. Observational studies indeed show that patient participation is more limited in short consultations.[24, 42] Beisecker and Beisecker[43] demonstrated that in shorter consultations, less information seeking occurred. Moreover, only in longer consultations, patients' information needs predicted actual information seeking. Both the perception there is too little time and the wish not to be bothersome might result from the patients' subjective interpretation of non-verbal and environmental cues, such as physician that is seemingly in hurry or annoyed, as well as a full waiting room. Future research should look into the effect of such cues on patient participation, as they might put up important barriers. Lastly, the inability to remember one's personal agenda during the consultation suggests that communicating to a doctor and absorbing information requires mental energy which may result in the neglect of one's personal goals in the conversation.

The current study is one of the first to confirm the assumption that patients find it easier to talk with nurses. One explanation for the nurse–doctor difference might lie in the finding that patients seeing a nurse less often reported the perception 'there is too little time'. Besides that nurses might have more time, nurses are also more often female than male, which might make them more patient-centred communicators.[44] More research should look into these cross-discipline differences, as these might give valuable insight into communication aspects that matter to patients.

In addition to the care providers' discipline, consistent and strong independent correlates of efficacy and barriers were health literacy and patient activation. Previous studies related health literacy to observed patient participation.[45, 46] The current study shows that low literate patients not only *act* differently, but also *feel* less confident and perceive more barriers in the communication. A recent study[47] demonstrated that when lay people were not sure about their understanding of medical terms, they were less confident about interacting with a fictive care provider. Hence, low literate patients appear at double disadvantage, as they not only experience problems in understanding oral information but they are also less able to make sure their concerns and questions are addressed.

The finding that low patient activation was a strong risk factor is perhaps not surprising. Patient activation in chronic illness involves many aspects, such as self-management of symptoms and preventive behaviour, but also active involvement in medical decision making and collaboration with care providers.[5] Our findings confirm that the profile of an activated patient includes high confidence in interacting with the care provider. Similarly, perceived efficacy in the patient–provider interaction was found to be strongly correlated with perceived self-management skills among arthritis patients.[28] One could argue that such communication confidence is a necessary prerequisite for being an activated patient. Reversely, being a passive or non-adherent patient might also be the cause of patient insecurity in the interaction. Regardless, self-management interventions aiming to activate chronically

ill patients should include the enhancement of communication efficacy. For example, helping patients with diabetes to elicit information from their doctor was reported to result in better blood sugar control.[48]

Besides low literacy and patient activation, other – less strong – correlates of efficacy and barriers to participation were identified. For example, female patients reported more barriers than men. Oppositely, in studies observing actual communication, male patients often behave less active than women,[20, 49] which again stresses that observed behaviour does not necessarily correspond with perceptions. Post hoc analyses showed that female patients more often reported the 3 most frequent barriers (forgetting, too little time, wish not to be bothersome) than men. Yet, they also more often reported that feeling tense, embarrassed, burdened or fearful of the provider's response hindered their participation. This suggests that negative emotions such as fear and shame are more likely to act as a barrier to participation for women than for men, possibly because women are also more likely to experience such so-called powerless emotions.[50] The finding that a higher level of disabilities strongly predicted perceived barriers is not easily explained and requires further, perhaps qualitative, examination. Possibly, a high level of functional disabilities complicates the content of communication (e.g. there is more at stake and care is more complex), which might make participation hard. The finding that patients who have been ill more than 15 years report fewer barriers might have several reasons as well. The illness and communication about the illness might become less salient over time, or patients might have gained experience and become empowered.[51] Remarkably, age did not independently predict self-efficacy or barriers. The general assumption is that submissiveness increases with age and often a negative relation between age and participation is reported.[19] Yet, others[28] reported a positive relation and reasoned that age might come with more communication experience.

The current study has several strengths, including the large, diverse and representative sample of chronically ill in the Netherlands as well as the availability of a wide range of patient information. Some limitations need to be mentioned. First, the list of barriers presented to patients was based on a study among patients with cancer.[12] Even though we provided patients with the option to add barriers, which only a few did, the list might not have been comprehensive or applicable to all populations. Furthermore, we did not take into account that perceived efficacy, barriers and support needs might differ depending on the subject of conversation. Patients seem to benefit the most from support when communicating about difficult subjects.[16] Third, we had no information about recent contact with the *indicated* care provider. Some patients commented they were not in contact with their care provider, which might make answering the questions difficult. Lastly, we had no information on mental comorbidity, which could be an important predictor of perceived efficacy in the interaction.

IMPLICATIONS

This study informs health-care providers about the nature of frequent barriers to patient involvement in communication. The findings point to ways to lift those barriers in the consultation room. For example, care providers might facilitate participation by explicitly addressing the importance of patient participation, by negotiating a reasonable agenda at the outset of the consultation and by encouraging patients to write down their questions. Future research should look into the factors

that shape patient-perceived barriers to participation in more detail, for example with respect to the influence of non-verbal cues and the nature or the level of difficulty of the consultation. In line with earlier findings,[12] the study results show that patients are likely to endorse relatively simple supportive interventions, such as a question prompt list (QPL). A QPL can normalize an active patient standpoint, educate patients in agenda setting and prevent patients from forgetting their own agenda during the consultation. The body of evidence for an effect of QPL's on patient participation is growing,[16, 52] yet research outside oncology is warranted.

CONCLUSION

Taken together, this study shows that many chronically ill patients feel confident in the interactions with their provider. Still, half report barriers, and a considerable group has an interest in support. Relatively simple supportive interventions are most likely to be endorsed and might be most needed by, among others, low literate and generally inactive patients seeing a doctor. Patient participation in medical conversations should never be forced upon patients. It should, however, be facilitated by offering patients who feel less confident the necessary support.

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CONFLICT OF INTEREST

There were no conflict of interests, financial or otherwise.

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TABLES

Table 1. Socio-demographic, medical and personal background characteristics

| | |
|------------------------------------|-------------|
| Characteristic | |
| Age M(SD) | 63.4 (12.7) |
| Sex (%) | |
| Male | 46.0 |
| Female | 54.0 |
| Educational level (%) | |
| Low | 35.4 |
| Intermediate | 41.3 |
| High | 23.2 |
| Living situation (%) | |
| Alone | 21.4 |
| With other(s) | 78.6 |
| Main care provider (%) | |
| Medical specialist | 38.4 |
| General practitioner | 43.7 |
| (Practice or hospital) Nurse | 12.6 |
| Other care provider | 5.2 |
| Chronic diseases (%) | |
| Cardiovascular disease | 29.1 |
| Respiratory disease (Asthma, COPD) | 25.4 |
| Musculoskeletal disease | 24.0 |
| Cancer | 9.6 |
| Diabetes mellitus | 24.7 |
| Neurological disease | 10.4 |
| Chronic gastrointestinal disease | 6.5 |
| Other chronic diseases | 29.2 |
| Comorbidity (>1 disease), % | |
| Yes | 48 |
| No | 52 |
| Illness duration in year, median,% | |
| 1–5 years | 34.9 |
| 5–15 years | 47.2 |
| >15 years | 17.9 |
| Functional disabilities (%) | |

| | |
|---|------|
| No or mild | 66.3 |
| Moderate | 25.2 |
| Severe | 8.5 |
| Number of health contacts past year (%) | |
| 0–5 | 40.7 |
| 6–10 | 27.9 |
| >10 | 31.5 |
| Information preference, range 0–10% | |
| 0–6 | 14.2 |
| 7–9 | 51.4 |
| 10 | 34.4 |
| Health literacy, range 0–12, median% | |
| 0–9 | 29.7 |
| >9 | 70.3 |
| Activation level (PAM) % | |
| Level 1 | 16.7 |
| Level 2 | 18.3 |
| Level 3 | 33.5 |
| Level 4 | 31.5 |

The total sample sizes range from 1212 to 1314 due to occasional missing values

Table 2. Perceived efficacy in medical interactions and perceived barriers to participation

| | Total sample | Medical specialist | General practitioner | Nurse |
|---|--------------|-----------------------|----------------------|------------|
| Perceived efficacy medical interactions mean (SD), range 5–25 | 19.9 (3.6) | 19.8 (3.6) | 20.0 (3.6) | 20.1 (3.5) |
| Rounded mean Likert scale score of 1–3 | 20.8% | 20.4% | 22.5% | 15.8% |
| Rounded mean Likert scale score >3 | 79.2% | 79.6% | 77.5% | 84.2% |
| Number of barriers, median, range 0–17 | 0* | 0 ^{1,**} | 0 ^{2,*} | 0 |
| 0 barriers | 54.0%* | 50.2% ^{1,**} | 54.3% ^{2,*} | 64.4% |
| >0 barriers | 46.0% | 49.8% | 45.7% | 35.6% |
| Type of barriers%, ranked on frequency | | | | |
| Remembering subject only afterwards | 26.2% | 29.3% | 24.5% | 24.3% |

| | Total sample | Medical specialist | General practitioner | Nurse |
|---|--------------|------------------------|------------------------|-------|
| Perception there is too little time | 20.6%*** | 25.5% ^{1,***} | 20.6% ^{2,***} | 9.6% |
| Not wanting to be bothersome | 21.3% | 19.7% | 24.1% | 17.8% |
| Feeling tense | 19.4% | 20.6% | 19.5% | 13.8% |
| Belief subject not important enough | 16.7% | 16.3% | 17.1% | 14.3% |
| Not knowing how to discuss subject | 13.9% | 14.1% | 13.5% | 13.0% |
| Not finding the right moment to bring something up | 13.6% | 14.1% | 13.6% | 12.3% |
| Uncertainty about own understanding | 11.3% | 12.5% | 11.0% | 7.7% |
| Burdensome to talk about subject | 10.5%* | 8.4% ^{3,*} | 13.2% ^{2,*} | 7.0% |
| Not knowing what is expected of me | 9.5% | 10.5% | 8.2% | 9.8% |
| Belief provider cannot provide solution/answer anyway | 9.0% | 10.8% | 8.3% | 4.6% |
| Not knowing what to ask | 9.8% | 10.9% | 8.0% | 10.3% |
| Belief subject is not part of this provider's task | 8.4% | 8.6% | 7.6% | 7.1% |
| Looking up to the provider | 5.8% | 6.8% | 5.8% | 3.2% |
| Expecting an annoyed/offended response of provider | 5.6%* | 7.8% ^{3,*} | 4.4% | 3.2% |
| Feeling embarrassed about a subject | 5.3%* | 3.6% ^{3,*} | 6.9% | 2.6% |
| Fearing the answer to my question | 5.1% | 4.3% | 6.4% | 2.6% |
| Different remark about barriers | 6.4% | 6.3% | 6.4% | 3.7% |

1. The total sample sizes range from 1140 to 1270 due to occasional missing values.
2. Significance indicators in total sample column refer to the significance of omnibus test of group differences.
3. *P < 0.05; **P < 0.01; ***P < 0.001.
4. 1Significant difference between medical specialist and nurse.
5. 2Significant difference between GP and nurse.
- 3Significant difference between medical specialist and GP.

Table 3. Endorsement of support interventions to facilitate participation

| | Total sample | Medical specialist | General practitioner | Nurse |
|---|--------------|-----------------------------|----------------------|-------|
| Intervention endorsement | | | | |
| 0 | 60.7%* | 56.5% ^{1,*} | 62.7% | 67.8% |
| >0 | 39.3% | 43.5% | 37.3% | 32.2% |
| Type of interventions%, ranked on frequency | | | | |
| Question prompt list for personal use | 30.1%** | 35.1% ^{1,**,2,**} | 26.2% | 23.5% |
| Question prompt list provided to doctor prior to consultation | 20.5%* | 23.9% ^{1,*,2,*} | 18.3% | 15.6 |
| Information about how to prepare and communicate | 20.1% | 22.0% | 19.6% | 14.0% |
| Preparatory conversation with nurse prior to consultation | 15.5%** | 19.5% ^{1,**,2,*} | 13.4% | 8.6% |
| Personal coach to prepare, accompany and evaluate | 11.8%*** | 16.6% ^{1,***,2,**} | 9.1% | 5.3% |
| Personal advice and practice | 6.7% | 8.3% | 5.7% | 5.3% |
| Modelling videos | 6.1% | 7.6% | 5.2% | 2.6% |
| Different remark about supportive intervention | 5.3% | 6.5% | 4.6% | 1.9% |

1. The total sample sizes range from 1153 to 1227 due to occasional missing values.
2. Significance indicators in total sample column refer to the significance of omnibus test of group differences.
3. *P < 0.05; **P < 0.01; ***difference P < 0.001.
4. 1Significant difference between medical specialist and nurse.
2Significant difference between medical specialist and GP.

Table 4. Correlates of perceived efficacy in patient-provider interaction (ANCOVA)

| Predictor | M(SD) | Univariate | | Multivariate | |
|----------------------------------|-------------|------------|------|--------------|---|
| | | F | P | F | P |
| Age | | 0.196 | 0.66 | | |
| Sex | | | | | |
| Male | 19.8 (3.5) | 0.000 | 0.99 | | |
| Female | 19.8 (3.7) | | | | |
| Educational level | | | | | |
| Low | 19.5 (3.8) | 1.937 | 0.15 | | |
| Intermediate | 19.9 (3.6) | | | | |
| High | 20.1 (3.3) | | | | |
| Living situation | | | | | |
| Alone | 19.8 (3.8) | 0.069 | 0.79 | | |
| Together | 19.9 (3.5) | | | | |
| Chronic diseases | | | | | |
| Cardiovascular disease | 19.7 (3.6) | 1.206 | 0.27 | | |
| No | 19.9 (3.6) | | | | |
| Respiratory disease | 20.11 (3.4) | 2.014 | 0.16 | | |
| No | 19.8 (3.7) | | | | |
| Musculoskeletal disease | 19.8 (3.7) | 0.003 | 0.96 | | |
| No | 19.9 (3.6) | | | | |
| Cancer | 20.1 (3.8) | 0.369 | 0.54 | | |
| No | 19.8 (3.6) | | | | |
| Diabetes mellitus | 20.1 (3.7) | 1.660 | 0.20 | | |
| No | 19.8 (3.6) | | | | |
| Neurological disease | 19.3 (3.8) | 2.423 | 0.12 | | |
| No | 19.9 (3.6) | | | | |
| Chronic gastrointestinal disease | 19.2 (4.3) | 1.942 | 0.16 | | |
| No | 19.9 (3.5) | | | | |
| Different chronic illness | 19.9 (3.4) | 0.263 | 0.61 | | |
| No | 19.8 (3.6) | | | | |
| Comorbidity | 20.0 (3.7) | 0.857 | 0.36 | | |
| No | 19.7 (3.5) | | | | |
| Illness duration | | | | | |
| 0-5 years | 19.6 (3.6) | 1.086 | 0.34 | | |

| Predictor | M(SD) | Univariate | | Multivariate | |
|---------------------------|-------------------------|------------|------|--------------|------|
| | | F | P | F | P |
| 5–15 years | 19.9 (3.5) | | | | |
| >15 years | 20.1 (3.7) | | | | |
| Functional disabilities | | | | | |
| No/Mild | 20.1 (3.5) ^a | 4.026 | 0.02 | 0.884 | 0.41 |
| Moderate | 19.4 (3.8) ^b | | | | |
| Severe | 19.5 (3.8) | | | | |
| Number of health contacts | | | | | |
| 0–5 | 20.0 (3.6) | 0.961 | 0.38 | | |
| 6–10 | 19.9 (3.5) | | | | |
| >10 | 19.6 (3.8) | | | | |
| Discipline | | | | | |
| Medical specialist | 19.7 (3.6) | 0.616 | 0.54 | | |
| GP | 19.9 (3.6) | | | | |
| Nurse | 20.1 (3.4) | | | | |
| Information preference | | | | | |
| 0–6 | 19.1 (3.6) ^a | 11.395 | 0.00 | 7.517 | 0.00 |
| 7–9 | 19.6 (3.4) ^a | | | | |
| 10 | 20.6 (3.8) ^b | | | | |
| Health literacy | | | | | |
| Low | 19.1 (3.6) | 20.503 | 0.00 | 6.307 | 0.01 |
| High | 20.2 (3.5) | | | | |
| Activation level | | | | | |
| Level 1 | 18.0 (3.7) ^a | 34.343 | 0.00 | 26.650 | 0.00 |
| Level 2 | 19.2 (3.9) ^b | | | | |
| Level 3 | 19.9 (3.1) ^c | | | | |
| Level 4 | 21.2 (3.3) ^d | | | | |

1. Models included an intercept, Total N = 1023.
Categories with different superscripts differed significantly, at least $P < 0.05$.

Table 5. Correlates of the number of perceived barriers to participation (negative binomial regression)

| | Univariate | | | Multivariate | | |
|------------------------------|------------|------|-------------------------------|--------------|------|-------------------------------|
| | Wald | P | Odds ratio (95% CI) | Wald | P | Odds ratio (95% CI) |
| Age | 0.950 | 0.95 | 1.00 (0.99–1.01) | | | |
| Sex (Male) | 11.778 | 0.00 | 1.43 (1.17–1.76) | 14.056 | 0.00 | 1.45 (1.20–1.77) |
| Educational level (Low) | 28.263 | 0.00 | 1.00 ^a | 4.709 | 0.10 | 1 |
| Intermediate | | | 0.64 (0.52–0.81) ^b | | | 0.80 (0.64–1.01) |
| High | | | 0.54 (0.42–0.69) ^b | | | 0.79 (0.61–1.01) |
| Living situation (Tog.) | 3.802 | 0.05 | 1.25 (1.00–1.57) | | | |
| Chronic diseases (No) | | | | | | |
| Cardiovascular disease | 0.106 | 0.75 | 1.04 (1.67–2.13) | | | |
| Respiratory disease | 0.000 | 0.99 | 1.00 (0.80–1.25) | | | |
| Musculoskeletal disease | 3.739 | 0.05 | 1.26 (1.00–1.59) | | | |
| Cancer | 1.256 | 0.26 | 0.82 (0.58–1.16) | | | |
| Diabetes mellitus | 0.656 | 0.42 | 0.91 (0.72–1.15) | | | |
| Neurological disease | 0.011 | 0.92 | 1.02 (0.76–1.35) | | | |
| Gastrointestinal disease | 5.499 | 0.02 | 1.47 (1.07–2.04) | 4.975 | 0.03 | 1.45 (1.05–2.02) |
| Different chronic illness | 0.037 | 0.85 | 1.02 (0.82–1.27) | | | |
| Comorbidity (No) | 0.000 | 0.99 | 0.99 (0.82–1.22) | | | |
| Illness duration (0–5 years) | 7.993 | 0.02 | 1 ^a | 7.747 | 0.02 | 1 ^a |
| 5–15 years | | | 0.98 (0.79–1.22) ^a | | | 0.88 (0.71–1.09) ^a |
| >15 years | | | 0.66 (0.49–0.90) ^b | | | 0.64 (0.47–0.88) ^b |

| | Univariate | | | Multivariate | | |
|-----------------------------------|------------|------|-------------------------------|--------------|------|-------------------------------|
| | Wald | P | Odds ratio (95% CI) | Wald | P | Odds ratio (95% CI) |
| Functional disabilities (No/mild) | 44.506 | 0.00 | 1 ^a | 11.759 | 0.00 | 1 ^a |
| Moderate | | | 1.75 (1.41–2.17) ^b | | | 1.41 (1.12–1.77) ^b |
| Severe | | | 2.28 (1.71–3.04) ^b | | | 1.54 (1.12–2.11) ^b |
| Health contacts (0–5) | 16.705 | 0.00 | 1 ^a | 1.784 | 0.41 | 1 |
| 6–10 | | | 1.18 (0.92–1.51) ^a | | | 1.12 (0.87–1.43) |
| >10 | | | 1.63 (1.28–2.08) ^b | | | 1.18 (0.92–1.52) |
| Discipline (medical specialist) | 7.091 | 0.03 | 1 ^a | 11.166 | 0.00 | 1 ^a |
| GP | | | 0.86 (0.70–1.06) ^a | | | 0.93 (0.85–1.14) ^b |
| Nurse | | | 0.62 (0.42–0.89) ^b | | | 0.57 (0.41–0.79) ^b |
| Information preference (0–6) | 4.300 | 0.12 | 1 | | | |
| 7–9 | | | 0.90 (0.66–1.23) | | | |
| 10 | | | 0.74 (0.53–1.03) | | | |
| Health literacy (low, 3–12) | 65.841 | 0.00 | 0.45 (0.37–0.54) | 28.608 | 0.00 | 0.55 (0.48–0.69) |
| Activation level (Level 1) | 75.788 | 0.00 | 1 ^a | 33.955 | 0.00 | 1 ^a |
| Level 2 | | | 0.59 (0.45–0.78) ^b | | | 0.71 (0.54–0.94) ^b |
| Level 3 | | | 0.44 (0.34–0.57) ^c | | | 0.54 (0.42–0.68) ^c |
| Level 4 | | | 0.34 (0.26–0.44) ^c | | | 0.50 (0.38–0.65) ^c |

1. Models included an intercept, Total Nbarriers = 939; Total Nsupport = 950. Categories with different superscripts differed significantly P < 0.05.