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Has patients' involvement in the decision-making process changed over time?

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Abstract

Objective To get insight into the changes over time of patients' involvement in the decision-making process, and into the factors contributing to patients' involvement and general practitioners' (GPs) communication related to the Medical Treatment Act (MTA) issues: information about treatment, other available treatments and side-effects; informed decision making; asking consent for treatment.

Background Societal developments have changed the doctor–patient relationship recently. Informed decision making has become a central topic. Patients' informed consent was legalized by the MTA (1995).

Design Data of two cross-sectional studies, the First (1987) and Second (2001) Dutch National Survey of General Practice, were compared.

Setting and participants General practice consultations; 16 GPs and 442 patients in 1987; 142 GPs and 2784 patients in 2001.

Methods Consultations were videotaped and rated using Roter's Interaction Analysis System and observer questionnaires; pre- and post-consultation patient questionnaires; and GP questionnaires. Descriptive analyses and multivariate, multilevel analysis were applied.

Main results Most patients reported to have received the information they had considered as important prior to the consultation. There were discrepancies in involvement in treatment decisions and in giving information about other available treatments, side-effects and risks. GPs who were more affective and gave more information, more often involved their patients, especially younger patients, in decision making. In 2001, more informed decision making was

observed and the GPs asked consent for a treatment more often, but they less often asked for the patients' understanding.

Conclusion Patients' involvement in decision making has increased over time, but not in every respect. However, this does not apply for all patients, especially the older ones. It should be questioned whether they are willing or capable to be involved and if so, how they could be encouraged.

What is known

The doctor–patient relationship has changed during the last decades. Informed decision making has become a central topic in doctor–patient communication.

What is new

Patients consider it as important to get information from their GP and to (co)decide about treatments. This happens not always as often as they want. General practitioners' (GPs) information-giving and affective talk influence patients' involvement in decision making. Older patients are least involved in the decision-making process. Patients' involvement in decision making has increased since 1987, but not in every respect. In 2001, GPs still give little information about other available treatments, side-effects and risks.

Introduction

Communication has always played an important role in medicine. Recent changes in the relationship between doctor and patient have even augmented its significance.[1–3] These changes have been induced by several societal developments, such as the strengthening of patients' position in health care, and the change from the traditional supply-induced care into a more demand-induced care. The growing availability of medical information sources has enabled patients to get more information about medical care.

Informed decision making has become a central topic in doctor–patient communication.[4] Patients could be encouraged to take on the task of understanding the relevant information and to share their values and views with doctor,[5] if this is in accordance with their wish. The principles of shared decision makings have been described and reviewed.[6] The skills have been elucidated and discussed.[7]

Shared decision making is based on the assumption that it is acceptable, important and probably therapeutically favourable to involve patients in the decision-making process,[8] and strengthen patients' autonomy.[9] These may be important issues for enhancing patients' satisfaction, compliance and understanding, which in turn possibly influence patients' health status positively.[10]

In the Netherlands, the right of patients on informed consent for treatment has been laid down in the 'Medical Treatment Act' (MTA, 1995). The law is an elaboration of the changing power balance during the last decennia and guarantees a more equal relationship between caregiver and patient. The aim of the Act is to clarify and strengthen the legal position of the patient, taking into account the own responsibility of the caregiver for acting as a good caregiver. According to the law, the caregiver should put into practice the following issues: inform the patient about the examination and treatment, alternatives for the examination and treatment, possible side-effects and risks; share the decision-making process with the patient; ask the patient's consent for examination and treatment. By fulfilling the patients' 'right to know' informed shared decision making could be reached.

Whether the healthcare practice has followed the law has recently been evaluated in some studies in the Netherlands by means of patient questionnaires. It appeared that the Act is

known and complied with fairly. The Act has contributed to the strengthening of the patients' legal status, while the caregiver's own responsibility was also justified.[11] Another study showed that most patients are informed by GPs about treatment (92%), side-effects (72%) and other available treatments (68%).[12]

So far, it is not known whether patients consider the main issues of the MTA important and how often they are performed by the GPs. Neither the influence of GPs' actual communication on the decision-making process, nor the changes over time has been investigated.

The added value of the present study is, first, that the importance of the MTA issues as well as the GPs' performance of these issues was measured. Secondly, the influence of GPs' communication on patients' involvement in decision making is studied by means of video observations of GPs' actual practising of the issues related to the MTA, in real-life consultations. Thirdly, a comparison is made between 1987 and 2001 to investigate the changes in time of GPs' communicative behaviour and patients' involvement in decision making.

Patient involvement has been measured until now in many different ways, and a recent review of the literature revealed that there was a lack of validated tools for this purpose.[13] The degree of patients' involvement in the decision-making process was defined in the present article as 'the degree to which the doctor allows or encourages the patients to decide about management options and disclose their preferences and concerns'. The instrument based on this definition aims at the process of patient involvement, and has been validated in earlier communication studies.[14,15]

Patients considering the decision-making process as important are expected to be more often involved in this process, as patient preference is a cornerstone of shared decision making.[16] Further, the more the doctors give information to their patients and communicate affectively, the more they are expected to involve patients in the decision-making process.[8] At the patients' side, assertiveness shown by asking more questions to the GP may result in a higher involvement in decision making. Also, a new problem presented and a treatment during the consultation may influence patients' involvement.[16,17]

Research questions

This article addresses the following research questions:

1. To what extent do patients consider issues on informed decision making as important and to what extent do GPs perform these issues?
2. Which factors contribute to the involvement in the decision-making process?
3. Has GPs' communicative behaviour and patients' involvement in the decision-making process changed over time?
4. To what extent has the realization of the MTA issues changed over time?

Methods

Design

Data were derived from the Second Dutch National Survey of General Practice (2001).[18] Additionally, for the third and fourth research question, data were used from the First Dutch National Survey of General Practice (1987),[19] to study the changes before and after the establishment of the MTA. The second survey was representative for the population of Dutch general practitioners,[20] but the representativeness of the 1987 data set is limited, because less GPs participated in this survey.[21]

On a random date, consecutive patients consulting the GP's office were informed about the study. They were not informed beforehand. They were asked to consent to the videotaping of their consultation. If they agreed, they signed a consent form. The privacy of the collected data was laid down in privacy regulations, by which ethical consent was safeguarded.

In the first survey (1987), consultations of 16 GPs and 442 patients were videotaped;[21] in the second survey (2001), 142 GPs and 2784 patients participated. For the present study, only patients of 18 years and older were included. In total,

data of 297 and 1787 consultations (first and second survey respectively) were used.

Measurement instruments

GP questionnaires

General practitioners' age and sex were derived from questionnaires within the framework of the basic First and Second Dutch National Survey of General Practice.[18,19]

General practitioners (only those participating in the second survey) registered after each videotaped consultation – among other things – the influence of psychosocial aspects on the health problem(s).

Patient questionnaires (only Second Dutch National Survey of General Practice)

The patients filled in questionnaires before and immediately after the consultation. The questions included demographic characteristics (sex, age, education); patient's health problems (ICPC coded);[22] first or follow-up consultation for the presented problem. The relevance and GPs' performance of communication aspects was measured by the QUOTE-COMM (quality of communication through the patient's eyes).[23,24] Before the consultation, the patients reported per item how important communication aspects were on a four-point scale (1, not important; 2, rather important; 3, important; 4, utmost important). After the consultation they filled in whether the GP had performed according to these aspects, also on a four-point scale (1, not; 2, really not; 3, really yes; 4, yes). The scores were dichotomized in the analyses of the first research question only. The following communication aspects were included: information about treatment; information about other available treatments; information about possible side-effects and risks; involvement in decision making; GP takes the final decision.

Observation protocol (First and Second Dutch National Survey of General Practice)

Verbal behaviour during the videotaped consultations was measured by observers by means of Roter's Interaction Analysis System (RIAS), which is a well-documented, widely used system in the USA, UK and the Netherlands[20,23,25,26] This observation system distinguishes instrumental (task focused) and affective (socio-emotional) verbal behaviour of doctors and patients, reflecting the cure–care distinction. The unit of analysis is the utterance or smallest string of words. All utterances are assigned to mutually exclusive categories. The RIAS categories are mutually exclusive and exhaustive. The present study included the following categories:

1. GPs' information giving (included counselling) regarding medical/therapeutic subjects;
2. GPs' affective communicative behaviour (social talk, encouragements, concerns, empathy, reassurements);
3. GPs' asking for understanding;
4. GPs' asking for the patient's opinion;
5. Patients' question-asking about medical/therapeutic subjects.

The 'Observer-Video-Pro' computer program of Noldus was used for the observation study.[27]

Observer questionnaire (First and Second Dutch National Survey of General Practice)

The observer questionnaire was tested beforehand on reliability, and validated items were used. The observers of the second survey rated the videotapes of both the first and second survey, on the following items:

1. MTA issues: information about other available treatments; information about side-effects and risks of treatments; information about prescriptions (as side-effects and dose); written information (as leaflet); GPs' asking consent for treatment (no/yes);
2. patient involvement in the decision-making process (a five-point Likert scale; 1 = poor to 5 = excellent). This instrument was validated[14,15] and showed highly significant relationships with specific aspects of patient involvement;
3. performance of treatments or diagnostic procedures, e.g. giving injection; blood pressure measurement; PAP smear (no/yes).

Interobserver reliability

The interobserver reliability of the ratings was calculated on the basis of 20 consultations (one per GP) that were selected at random beforehand. In both studies, the interobserver reliabilities were good to excellent: between $r = 0.72$ and 0.96 per category.

Controlling variables

At the GP's level, the controlling variables were sex and age. At the patient's level, these were sex, age, educational level (low = no/primary school, average = secondary school, high = higher vocational training/university), first consultation (vs. follow-up consultation) for problems presented (no/yes), consultation length and patients' psychosocial problems (no/yes), derived from data of GP, patient and observer questionnaire.

Data analysis

Analyses were carried out using the Statistical Package for Social Sciences (SSPS, version 11.5, SPSS Inc., Chicago, IL, USA). To answer the first research question, descriptive analyses were done (*t*-test and chi-squared test).[28] For the purpose of the second question, multivariate, multilevel analysis was performed to analyse the influence of GP and patient factors (two different levels) on GPs' communication.[29] Multilevel analysis was necessary to account for the clustering of patients within GPs. A significance level of ≤0.05 (one-sided) was applied.

For the third question, differences between the two surveys were tested for significance adjusted for clustering by using multilevel linear regression analysis.

Results

Response rates

In the second survey, the response rate of GPs and patients was high (73% and 88% respectively), and 95% of the patients filled in the questionnaires. Non-response analysis of age, sex and type of insurance showed hardly any bias resulting from patients' refusal. The response rate of GPs in the first survey was 10%. No information was available on the response rate of patients in the first survey.

Study populations

In both surveys, three-quarters of the GPs were male, and 60% of the patients were female (Table 1). The doctors as well as the patients of the first survey (1987) were younger than those participating in the second survey (2001). The problems mostly presented were – in hierarchical order – musculoskeletal, circulatory, skin, respiratory and psychosocial problems (25–10%). Most patients had an average educational level (62%), 22% had a low and 17% a high educational level. In 82% of the consultations a treatment was performed.

Relevance and performance of MTA issues

Most patients (2001) considered receiving information from the GP important, especially about the treatment (93.9%, Table 2). Four of five patients wished to be involved in the decision-making process, but, at the same time, many would leave the final decision to the doctor (80%).

Most patients received the information about the treatment as they had wanted (92.3%). The final decision was also often taken by the GP

Table 1 Sociodemographic characteristics of general practitioners (GPs)[1] and patients (18 years and older)[2]

	1987	2001
GPs		
Number	16	142
Male (%)	75.0	76.1
Age (mean, SD)	39.4 (6.5)	47.8 (5.8)*
Patients		
Number	210	1787
Male (%)	38.7	40.4
Age (mean, SD)	43.2 (19.2)	48.8 (17.2)*

* $P < 0.05$.
[1]Source: GP questionnaire.
[2]Source: patient questionnaire.

Table 2 Discrepancies and correspondences between relevance and performance: patients considering Medical Treatment Act issues (not) important and Medical Treatment Act issues (not) performed by the general practitioner (GP) (numbers and percentages)[1]

	Information about treatment ($n = 1505$)		Information about other available treatments ($n = 1294$)		Information about side-ef fects and risks ($n = 1266$)		Involvement in decision making ($n = 1348$)		Final decision taken by GP ($n = 1366$)	
If important:	1413	93.9	1048	81.0	1076	85.0	1100	81.6	1093	80.0
Performed	1304	92.3	541	51.6	394	36.6	696	63.3	895	81.9
Not performed	109	7.7	507	48.4	682	63.4	404	36.7	198	18.1
If not important:	92	6.1	246	19.0	190	15.0	248	18.4	273	20.0
Performed	75	81.5	87	35.4	44	23.2	120	48.4	181	66.3
Not performed	17	18.5	159	64.6	146	76.8	128	51.6	92	33.7

The values are expressed as n (%).
[1]Source: patient questionnaire.

(81.9%) if this was the patients' wish. Discrepancies between relevance and performance especially concerned the involvement in the decision-making process (63.3% was involved following their wish), information about side-effects and risks and, to a lesser extent, about other available treatments.

There were also discrepancies with respect to issues that patients considered as not important but that still were performed. Examples of this 'overuse' are receiving information about the treatment and involvement in decision making.

Factors influencing the patients' involvement in the decision-making process

Information giving and affective talk of the doctors (2001) was related to a higher involvement in decision making (Table 3). Younger patients and those presenting a psychosocial problem were more often involved in decision making than the older patients and those presenting a somatic problem. Patients were less often involved in decision making when a treatment or diagnostic procedure was performed. The importance attached by patients to this involvement and patients' question asking was not related to patient involvement, neither GPs' and patients' sex and GPs' age.

The explained variance at the GP level was 37% and at the patient level 10%.

Changes in GPs' communicative behaviour and patients' involvement in the decision-making process over time

Compared with 1987, the GPs did not give more information about medical and therapeutic aspects in 2001 (mean utterances 29.7 and 34.5 respectively; Table 4). In contrary, asking whether the information was understood well by the patient occurred more often in 1987 than nowadays. The GPs involved the patients in the decision-making process more often in 2001 than in 1987, but the difference is small.

In 2001, the GPs asked patients much more often for consent to perform treatments or diagnostic procedures: in 2001 in 20.6% and in 1987 in 1% of the consultations (Table 5). No other differences were found between 1987 and 2001.

Discussion

The results of this study indicate that most patients consider it important to be informed by GPs with respect to the main issues related to the MTA of 1995. They want information about the treatment, possible other available treatments and side-effects and risks of treatments. Information about treatments was nearly always given, independent of the importance patients attached to this aspect. However, the patients'

Table 3 Factors contributing to patients' involvement[1] (scale 1–5) in the decision-making process in multivariate multilevel analyses; regression coefficients and standard errors (*n* GPs = 142, *n* consultations = 1787)

	Regression coefficients	95% BTI
GP level		
Sex (1 = female)[2]	−0.043	−0.182–0.096
Age (years)[1]	−0.004	−0.013–0.006
Patient level		
Sex (1 = female)[3]	−0.002	−0.092–0.088
Age (years)[3]	−0.005*	−0.007–−0.003
Educational level[3,a]		
Average	0.087	−0.035–0.209
High	0.130	−0.023–0.283
Psychosocial problem (0 = no, 1 = yes)[4]	0.277*	0.116–0.438
Treatment (0 = no, 1 = yes)[4]	−0.189*	−0.281–−0.097
First consultation (0 = no, 1 = yes)[3]	−0.077	−0.165–0.011
Relevance of (co)decision[3,b]	0.002	−0.045–0.049
GPs' affective talk (freq.)[5]	0.004*	0.002–0.007
Patients' medical questions (freq.)[5]	0.011	−0.004–0.028
GPs' medical information giving (freq.)[5]	0.004*	0.001–0.007
Consultation length (min)	0.009	−.0008–0.025

* $P < 0.05$.
[1]Source: observer questionnaire.
[2]Source: general practitioner (GP) questionnaire.
[3]Source: patient questionnaire.
[4]Sources: patient questionnaire/observer questionnaire/observation protocol.
[5]Source: observation protocol.
[a]Reference group = low educational level.
[b]1 = not important, 2 = rather important, 3 = important, 4 = utmost important.

Table 4 General practitioners' (GPs) communicative behaviour (mean frequencies and standard deviation), patients' involvement (mean and standard deviation) and consultation length in 1987 and 2001[1]

	1987 (*n* = 210)	2001 (*n* = 1787)
GPs' utterances[2]		
Medical/therapeutic information	29.7 (23.6)	34.5 (21.8)
Ask for understanding	6.6 (5.9)	1.2 (1.8)*
Ask for opinion	1.0 (1.8)	0.3 (0.7)*
Involvement in decision making[3] (1 = poor, 5 = excellent)	3.0 (1.0)	3.4 (0.9)*
Consultation length (min) [4]	10.3 (5.2)	10.0 (4.8)

* $P < 0.05$.
[1]Significance was tested by using multilevel analysis.
[2]Source: observation protocol.
[3]Source: observer questionnaire.
[4]Source: observation protocol.

Table 5 Realization of Medical Treatment Act (MTA) issues in 1987 and 2001 (number of consultations and percentages)[1]

	1987 (*n* = 210)		2001 (*n* = 1787)	
MTA issues	*n*	%	*n*	%
Information about other available treatments	39	18.6	295	16.6
Information about side-effects and risks of treatments	31	14.8	320	18.0
Information about prescriptions	92	43.8	821	45.9
Written information	2	1.0	28	1.6
Asking consent for treatments	2	1.0	366	20.6*

*$P < 0.05$.
[1]Source: observer questionnaire.

preference for information was not always fulfilled. The GPs gave less information than some patients wished beforehand about side-effects and other available treatments. Apparently, these patients did not ask for more information of their own accord. Another reason may be that they have changed their mind about the relevance of specific communication aspects and did not need the information anymore, or the consultation worked out differently than they had expected beforehand. The present findings are in agreement with earlier studies, showing that

patients expressing preferences for some form of decision making did not necessarily act following these preferences.[6,23,30]

More than half of the patients (60%) were not involved in the decision about a treatment, at least in their own view; most of them had a preference to be involved, but not all of them. GPs should be aware of overburdening these patients who do not prefer to be involved in decision making. They should ascertain just what information their patients want before scaring them with informed consent.[31] Further, it should be questioned whether GPs should always fulfil the patients' need of information. Not every patient is willing or capable to take a decision or to share in decision making, in spite of having received good information. This may change depending on the patients' perceived lack of knowledge, low self-efficacy or fear,[17,32] and also on the problem presented, patients' age and social class.[16]

Older patients were involved in decision making less often than younger patients, which is in line with findings described in earlier studies.[33,34] Schneider[35] found that doctors were able to estimate the preference for shared decision making presumably on the basis of the patients' age and education. This may be favourable for older patients who want to be involved in the decision-making process. An appurtenant benefit might be that the doctor support older patients' ability to manage their health problems and their confidence in self-efficacy by giving them more responsibility in the consultation room. This may be important in view of the growing number of elderly, especially patients with chronic diseases, in the near future.

Information about medical and therapeutic issues seems to contribute to the decision-making process, irrespective of the influence of other factors on this process, as was found earlier.[7,8,30] This is an understandable finding, because knowledge is necessary for taking a deliberate decision with consequences for the patient's own health. Moreover, knowledge may contribute to a better compliance to treatment, and, therefore, also to a better health status.[10] From this viewpoint, the establishment of the MTA was a logical step for aiming at well-informed patients sharing in decision making. Further, an affective communication style of doctors increases the involvement of patients in the decision-making process. This is an expected, but still important finding, as, patients need both a caring and a curing doctor to meet their wishes to 'know and understand' as well as 'to be known and understood' and, in line with it, to share in the decision-making process.[3,20,23]

When a new health problem is presented or a treatment is performed, patients are more often involved in decision making. This is rather logical and confirms earlier studies.[16,17]

As expected, the communicative behaviour of the GPs about issues related to the MTA has changed. Compared to 1987, the GPs in 2001 more often involved their patients in the decision-making process, but asking for understanding to the patient was less often done in 2001. Moreover, today's GPs more often asked consent for a treatment or a diagnostic procedure to their patients than their colleagues in 1987, who almost never asked for consent. To increase asking consent, doctors should be allowed to offer patients a simplified form of consent.[36] However, some other aspects of patient involvement, as medical information giving have not increased over time, and information giving about other available treatments and their possible side-effects and risks, is still lacking. So, patients' involvement in decision making has increased over time, but not in every respect.

There are some strength and weaknesses of the study. The second survey includes many consultations, more than ever has been included. So, data of this second survey are representative of the GP population. Data of the second survey used in the present study were useful for comparative purposes, but the representativeness of the 1987 data set is limited. Besides, there was a large discrepancy between the two sample sizes. Therefore, the observed historical change to increased patient involvement in decision making should be treated carefully. Still, the results give a first insight in

the changing patient involvement in decision making.

Further, the instrument used to measure patient involvement was validated, but is a subunit within broader assessments. Elwyn *et al.*[13] concluded in a review study that this type of instruments do not measure accurately, because they do not give a detailed assessment of patient involvement in shared decision making. The new instrument they developed, the OPTION scale, does respond to this demand.[5] The present study had already started when this new instrument was available, but is seems valuable to use the OPTION scale in the future.

From a recent evaluation study it appeared that caregivers have difficulties to translate legal rules into practice.[37] Moreover, often patients do not know their legal rights. Solutions could be found in implementation strategies as education of and information giving to both caregivers and patients. Cornerstones of these processes are transfer of knowledge, creation of a broad base, influence of attitude and behaviour of caregivers and patients, and possibilities offered by the organizational context and future developments.[37]

Intervention studies have shown that GPs are able to acquire the skills to implement shared decision making.[38,39] The results with regard to the explained variances suggest that informing and involving patients may be a consistent doctor style, rather than a response to patients' preferences.

Skill development in this area should be incorporated in postgraduate education.[38] Moreover, the increasing patient participation is seen as ethically justifiable.[38,40] However, it has been questioned whether the training costs offset the benefits.[40,41] Nevertheless, the promotion of patient involvement appears likely to continue.[38] In view of this process, GPs should be aware of the possibility and desirability of involving patients in the decision-making process.[31,42]

Supplementary information

Additional information accompanies this paper at: http://www.nivel.nl.

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