On the autonomy of dental patients
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Chapter 11

SUMMARY AND GENERAL DISCUSSION

1 Introduction

The overall aim of this thesis was to evaluate the implementation of the Medical Treatment Contract Act, and in particular the dentist's duty to inform his patients as well as his duty to obtain the patient's consent, in dental practice. First, the knowledge of dentists and patients and their views with regard to this act, and in particular with regard to the principle of informed consent, were examined. Second, patients' willingness to participate during the dental consultation was assessed, as well as the relation between patients' participation and both their own and their dentist's satisfaction. In this chapter the main findings will be summarized and discussed. Recommendations for continued research are given at the end of the chapter.

2 Summary of main findings

In Chapter 2 an inventory was made of the number and sort of informed consent complaints about Dutch dentists, lodged with the Dutch Dental Association in the years 1987-2000. The results indicated that the number of complaints slightly decreased after the Medical Treatment Contract Act came into effect, a finding comparable with the results from an earlier Dutch study on this topic (Lipschart-van der Linden, Eijkman & Spruijt, 1997). However, complaints about a lack of information with regard to the treatment and its consequences significantly increased. Communication problems between dentists and patients seem to play an important role in a majority of the complaints.

Chapter 3 and chapter 4 each describe research carried out to assess dentists' knowledge, their attitudes and perceived self-efficacy with regard to some major aspects of the Medical Treatment Contract Act. The results described in chapter 3 showed that dentists are reasonably informed about a fair amount of stipulations
of this act. Results concerning their attitudes and perceived self-efficacy though, were less positive. A majority of the respondents fear that the act will lead to a commercialization of the dentist-patient relationship. Also, fear for legal procedures seems to be present. Respondents' knowledge, attitudes and perceived self-efficacy were only slightly correlated, meaning that optimal implementation of the act demands both a change in dentists' attitudes and in their perceived self-efficacy. Unfortunately, because of the less than optimal response-rate (41.6%) of this study, the results may have been biased. Therefore, it was decided to replicate the study with a shortened version of the original questionnaire, assuming that this would increase the response-rate. This was indeed the case. The response-rate was about 20% higher than in the first study, indicating that the length of the questionnaire was an important factor in keeping response low. The results of this replication study, which are described in chapter 4, are more or less the same as the results of the original study, thereby increasing the credibility of both outcomes.

The aim of chapter 5 was to examine how dentists actually deal with some rights of patients in their practice. Data were collected by means of a questionnaire, sent to a large sample of Dutch dentists. Items in this questionnaire concerned the dentist's duty to inform his patients, his duty to obtain the patient's consent, the duty to keep records of patients and patients' right to privacy. It was found that the implementation of some rights of patients is still far from ideal. For example, over a third of the respondents have received complaints of patients about a lack of information-provision. Furthermore, respondents often did not obtain patients' consent to pass on information to third parties. The results furthermore showed that respondents who attended post-graduate courses on dentist-patient communication dealt better with some rights of patients than dentists who did not attend such courses.

In Chapter 6 dental patients' knowledge, their attitudes, perceived self-efficacy and self-reported behavior with regard to informed consent were examined. The results showed that, despite the fact that less than 10% of the patients is acquainted with the Medical Treatment Contract Act, a majority is aware of their right to be informed about several aspects of the treatment. Their attitudes toward informed consent however, were not that positive, and patients also indicated problems with asserting their rights in practice. Contrary to social-psychological theory (Ajzen, 1991), self-reported behavior of patients could hardly be predicted by their knowledge, attitudes and perceived self-efficacy. Therefore, it was concluded that other factors must play a more important role in predicting the extent to which patients assert their rights in dental practice.

The aim of chapter 7 was to assess the experiences of Dutch patients with regard to the information provided by their dentist. Based on a principal
component analysis of the self-constructed questionnaire, a distinction could be made between general information and information related to the Medical Treatment Contract Act. The results indicated that patients were satisfied with the general information and explanations from their dentist. However, their satisfaction with the provision of legislation-related information, such as information about the risks of the treatment, was significantly lower. It was concluded that it is necessary to educate dentists on the issue of applying informed consent in practice, for genuine patient autonomy will only be reached if patients are fully informed about all relevant aspects of the treatment.

The next three chapters studied the topic of patient autonomy from a different perspective. In chapter 8, results of research assessing patients' need for information and participation in medical decision-making were presented. In addition, possible antecedents of these preferences were studied, such as patients' coping-style and their socio-demographical characteristics. Two different samples were used, one sample of patients receiving emergency treatment and one sample of regular patients. Dental patients' need for information, as assessed with the 'Information' subscale of the Krantz' Health Opinion Survey (Krantz, Baum & Wideman, 1980) and with the subscale 'Information seeking preference' of the Autonomy Preference Index (Ende, Kazis, Ash & Moskowitz, 1989), was quite high for both samples. Although both samples of patients expressed less need for participation in decision-making, as assessed with part of the subscale 'Decision-making preference' of the Autonomy Preference Index (Ende et al., 1989) and with the Deber-Kraetschmer 'Problem-Solving Decision-Making' scale (Deber, Kraetschmer & Irvine, 1996), they did want to share some decision-making tasks with their dentist. Thus, it was concluded that it is important to define the concept 'patient participation' more clearly in future research before drawing definite judgements about patients' alleged preference or non-preference for involvement in decision-making. Finally, only weak associations were found between patients' coping-style and socio-demographical characteristics and their preferences for information and participation.

Chapter 9 dealt with the influence of patients' need for information and participation and dentists' communicative behavior on patient participation during dental emergency consultations. The results of this study showed that patients' desire for information and participation was not reflected in their overt behavior. For example, even though patients expressed a strong desire for information they did not ask their dentist many questions. Furthermore, dentists' communicative behavior, as assessed with the Communication in Dental Setting Scale (CDSS: Newton & Brenneman, 1999), was hardly related to patients' behavior during the consultation. Scores on the CDSS indicated that dentists' communicative
behavior should be improved, in order to enhance patients' right to make informed decisions.

In chapter 10, the relation between the behavior of dentists and dental emergency patients and their satisfaction with the dental encounter was studied. It was found that both dentists and patients are, in general, very satisfied with the dental consultation. Patients' satisfaction was mainly predicted by the communicative behavior of the dentist. Dentists' satisfaction though, could not be explained by their own or by the patients' behavior. In view of the legal requirements with regard to the information-provision to patients and the positive relationship between dentists' communicative behavior and patients' satisfaction with emergency consultations, it was concluded that training dentists in communicative skills remains of vital importance.

3 General discussion

3.1 Preliminary remarks

Before discussing the results of the studies presented in chapters 2 to 10, some general remarks regarding the evaluation of legislation need to be made. Ideally, the overall goal of evaluation studies on legislation should be to arrive at a sound judgement about the effectiveness of the act in question, just like, for example, studies on the effects of medical interventions or psychological therapy are aiming at drawing valid conclusions about the effectiveness of medical or psychological interventions. However, it is virtually impossible to make causal inferences about the effectiveness of legislation, because threats to the internal validity of these evaluation studies, in particular the threat of history, can never be ruled out (Judd, Smith & Kidder, 1991). In this case, history means that events that coincided with the introduction of the Medical Treatment Contract Act could have had similar effects as the act itself, such as, for example, the growing articularteness of patients. Thus, one can only speculate about the causal influence of the act per se.

A method to deal with the problem of causality in evaluating legislation is to determine the situation before the act came into effect, i.e. to assess a baseline with which the present situation can be compared. Unfortunately, in The Netherlands the legislator seldom decides to carry out base-rate measurements (Hendriks, 2000). In case of the Medical Treatment Contract Act as well, no research has been done with regard to the situation just before this act came into effect. For this and other reasons, the evaluation of the Medical Treatment Contract Act by ZorgOnderzoekNederland (ZON, 2000) was severely criticized (e.g. Giard, 2001). Against this criticism the objection has been raised that in
case of the Medical Treatment Contract Act an assessment of the baseline situation would have been useless because the act is mainly codification of already existing norms and regulations (Dute, Gevers, Friele, Hubben, Legemaate, Roscam Abbing, Sluyters & van Wijmen, 2001). The fact remains, though, that causal inferences about the effect of the Medical Treatment Contract Act could have been drawn with more certainty if a baseline measurement had been available. Therefore, in chapter 2 of this thesis an attempt was made to retrospectively gain more insight in the situation before the act came in effect by comparing the number of informed consent complaints lodged with the Dutch Dental Association, before and after the introduction of the Medical Treatment Contract Act. The aims of the other studies in this thesis, though, were merely to arrive at a sound judgement of the extent to which the principle of informed consent is applied in dental practice.

The assumption underlying the study in chapter 2 was that as a result of the Medical Treatment Contract Act, patients would become more aware of their right to information, and this in return would lead to more complaints of dental patients than before. However, the results indicated no significant differences in number of complaints before and after the Medical Treatment Contract Act came into effect. On the contrary, the total number of complaints slightly decreased after its introduction. It should be kept in mind though, that there are several bodies and authorities dealing with complaints in The Netherlands. This decentralized complaint system makes it difficult to obtain a comprehensive and systematic overview of patients' complaints (cf. Nordlund & Edgren, 1999). It is therefore recommended to develop a central register where all complaints and mediatory attempts can be filed. This would not only make research on patients' complaints more reliable, it also enhances the quality of dental care by making manifest which aspects of that care deserve further improvement.

3.2 Informed consent in dental practice

The Medical Treatment Contract Act pursues to strengthen and clarify the position of the patient, taking into account the own responsibility of the health care practitioner. In the introduction of this thesis (chapter 1), it was argued that this goal can only be attained if both dentists and patients are able and willing to implement the act's requirements in dental practice. Therefore, the first aim of this thesis was to examine dentists' and patients' knowledge, views and self-reported behavior with regard to this act, and in particular with regard to the principle of informed consent, assuming that these factors are necessary conditions for implementation to take place. From the results reported in chapter 3, chapter 4 and chapter 6, it can be concluded that problems with the
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implementation of the act will probably not stem from a lack of knowledge of dentists or patients. Both parties seem to be sufficiently aware of the principle of informed consent, although it must be stated that both dentists and patients still show gaps in knowledge about some aspects of the act. The somewhat negative attitudes and perceived self-efficacy of dentists and patients on the other hand, will probably pose a bigger problem for the implementation of the act. Thus, the optimistic view of many health care lawyers with regard to the implementation of the Medical Treatment Contract Act (e.g. Leenen, 1995; Legemaate, 1995) is not supported by the empirical evidence found in this study. Despite the fact that most possible positive consequences of the act are endorsed by a considerable part of the dentists in this study, their view that patients do not want to participate in the decision-making process and that it takes too much time to inform patients adequately poses a threat to patients' right to self-determination (chapter 3). Even though many patients may not want to participate in the decision-making process as is suggested by many researchers (e.g. Degner & Sloan, 1992; Nease & Blair Brooks, 1995), this does not mean that patients should not be given the opportunity to participate. Whether they do or do not is ultimately up to the patient, and it could be defended that patients who leave the decisions to the dentist make an autonomous decision as well. With respect to the mentioned lack of time, it remains to be seen if adequate information-provision per se does increase the length of the consultation and whether there is an unambiguous relation between the length of the consultation and its quality as perceived by patients (Hofmans-Okkes, 1991).

An essential condition for patients to be able to give their genuine informed consent is that they understand the information they receive from their dentist. However, dentists in this study indicated that they find it difficult to make sure that patients actually comprehend the given information (chapter 3). This finding is in line with the results from a study by the Royal Dutch Medical Association on the implementation of the principle of informed consent in Dutch hospitals (de Haes, de Haan, Willems-Groot, Oosterveld & Spronk, 1998). Moreover, while many studies have shown that comprehension and recall of physicians' information by patients is poor (e.g. Uden & van Dam, 1986), over half of the patients in this study pointed out that their dentist most of the times does not check if they have understood the information (chapter 7). Thus, even when dentists inform their patients according to the requirements of the Medical Treatment Contract Act, it is by no means certain if patients understand the information well enough to give their informed consent. Therefore, dentists should try to explicitly ask their patients if they have comprehended the information and, in order to facilitate patients' comprehension, they should avoid the use of medical jargon as much as possible. Other tools in helping patients to understand and recall
information is to give not too much information at once, to repeat and summarize important information and to support the information with written materials such as leaflets (Eijkman, Duyx & Visser, 1998).

Contrary to our expectations, dentists' perceived self-efficacy was hardly related to their knowledge or attitudes (chapter 3), and patients' behavior too could not be predicted by their knowledge, attitudes and perceived self-efficacy (chapter 6). Two conclusions can be drawn from these results. In the first place, a better implementation of the act by dentists demands both a change in their attitudes as well as an improvement in their communicative skills, for an improvement in attitudes will only have a marginal effect on dentists' perceived self-efficacy (cf. de Regt, de Haan & de Haes, 1998). Attending post-graduate courses on dentist-patient communication and younger age are both associated with more knowledge about and compliance with the requirements of informed consent (chapter 5). These results point to the possibilities of further educating dentists on this topic. In the second place, we are inclined to conclude that in the case of patients too, an enhancement of their attitudes and perceived self-efficacy needs to take place. In particular the finding that only a small percentage of the patients is of the opinion that it is easy to decide themselves which treatment is best for them, deserves further attention. Even though patients' attitudes and self-efficacy were hardly related to their self-reported behavior, it remains to be seen if the absence of an association between these variables is valid or the result of other factors, such as a social desirability response bias. The positive results found in this thesis on patients' self-reported behavior are at least in contrast with the results of most other studies on this topic, which indicated that patients are fairly passive during medical and dental consultations (e.g. Wanless & Holloway, 1994; Beisecker & Beisecker, 1990; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler & Till, 1989). Thus, the positive results with regard to patients' self-reported behavior should be interpreted with due caution, and it is clear that other methods which assess patients' behavior more directly are to be preferred in research of this kind.

Finally, it is worth mentioning that the Medical Treatment Contract Act is part of a governmental policy to guarantee and improve the quality of care, just as for example the Individual Health Care Professions Act. Responsibility for the implementation of these acts lies primarily in the hands of the professional practitioners and their representatives (Verdonschot, Plasschaert & Grol, 1997). Certainly in the case of the Medical Treatment Contract Act, which highlights the professional standard and the own responsibility of the health care practitioner, it is strongly recommended to specify the duties of health care practitioners in guidelines, all the more given the substantial variation in judgements between dentists (e.g. Poorterman, 1997; den Dekker, 1990). Such guidelines can aid
health care practitioners in enhancing compliance with the requirements of the act by making clear what is expected of them with regard to the information-provision to patients.

3.3 The autonomy of patients

The Medical Treatment Contract Act pursues to protect and stimulate patients' right to self-determination. Therefore, the second aim of this study was to assess to what extent they actually participate during the dental consultation. In addition, possible predictors of patients' participation were studied, as well as the relation between patients' participation and their and their dentist's satisfaction. From the results found in chapter 8 and chapter 9, it can be concluded that none of the factors studied in this thesis proved to be strong predictors of patients' actual behavior during dental emergency consultations. The influence of patients' desire for information on their actual information-seeking behavior during the consultation, operationalized as the number of questions they asked, was negligible. Also, patients' need to participate in dental decision-making was unrelated to patients' overt behavior. Furthermore, other variables hypothesized to be associated with patients' behavior during dental consultations, such as patients' coping style, their socio-demographic characteristics and dentists' communicative behavior, hardly explained any variance in patients' behavior at all.

These results may indicate that other, more treatment-related factors may be involved in the explanation of patients' information-seeking and participating behavior during the dental consultation. However, although the results of prior research on the relation between preferences of patients and their corresponding behavior are inconclusive and even contradictory, results from studies regarding patients' socio-demographic variables and coping style, all yielded consistent associations between those variables and patients' behavior (e.g. Ong, Visser, van Zuuren, Rietbroek, Lammes & de Haes, 1999; Miller, 1995). Perhaps, the lack of association between these variables is the result of using Dutch emergency dental patients in this study. This group of patients probably differs from the group of regular patients, but unfortunately, no research has been carried out to support this notion. The choice for using emergency patients in this study was very deliberate though, because the Medical Treatment Contract Act can be seen as an event-model and dental emergency consultations correspond more with such a model than regular dental consultations. To be specific, in emergency consultations the information-provision by the dentist confines itself to one visit, whereas in the case of regular patients information about the treatment may be spread out over several visits. Moreover, in most emergency consultations a decision about the treatment has to be made, which is not always the case within regular visits. Hence, in the latter case no reliable conclusions could have been made regarding
the amount of information-provision by dentists and regarding the way decisions about the treatment are made when observing just one visit. Another possibility for the lack of association between patients' coping style and their behavior during the consultation is that the instrument used in this study to assess patients' coping style (Threatening Medical Situations Inventory (TMSI); van Zuuren & Hanewald, 1993) was not developed to assess patients' coping style in a dental setting. All items in the TMSI relate to threatening scenarios in the medical setting, and it is questionable to what extent patients' coping style in such a setting can be generalized to their coping style in a dental setting. Thus, it is worthwhile to develop a new questionnaire, specifically constructed to determine patients' coping style in the dental setting.

In this study a clear discrepancy between patients' need for information and participation in dental decision-making and their actual information seeking and participating behavior was apparent (chapter 9). Patients' strong preference for information was not reflected in the number of questions they asked their dentist, and the expected relation between patients' need for participation and their actual behavior could not be established either. It could be argued that the absence of a relation between patients' preferences and their behavior is due to the use of emergency patients, who do not have such a strong relationship of trust with the dentist as regular patients, and therefore may be more hesitant to get involved in the dentist-patient interaction. It may also be the case that the observational method used in the study affected the behavior of the patients, also known as the Rosenthal-effect (cf. Hoogstraten, 1999), to become less active participants. However, observational research on this topic was deemed necessary because of the likely discrepancy between what dental patients (and dentists) say and do. Therefore, the advantages of observational research, such as its directness and its lack of artificiality (cf. Robson, 1993), were found more important than its possible disadvantages. It should also be noted that the average number of questions patient asked in this study was consistent with the average number of information-seeking comments of patients in some other studies, thereby increasing the reliability of the results (e.g. Roter, 1977; Beisecker & Beisecker, 1990).

In line with previous studies, patients' need for information exceeded their need for participation in the dental decision-making process. Also, when looking at the results concerning patients' behavior, it was found that in more than half of the cases, the dentist made the ultimate decision about whether or not to start treatment, and almost none of the patients did request a specific treatment or proposed alternative treatment options to the treatment proposed by the dentist. Therefore, the conclusion that dental patients do not want to participate in the decision-making process seems to be obvious, just as other researchers often have concluded about medical patients (e.g. Roter & Hall, 1992). The problem
with such a conclusion, though, is that the concept of 'patient participation' is often not defined, making it unclear what it exactly is that researchers imply. Deber (1994) has started the discussion on this topic by suggesting that patient participation consists of multiple factors, namely problem-solving and decision-making, and that conclusions about the level of patients' desire for participation depend on which of the two aspects is studied. The results of her as well as this study (chapter 9) indicated that patients do want to be involved in decision-making, but rather leave problem-solving tasks, such as diagnosing the case and determining the treatment options, to their health care practitioner. Thus, a true partnership between practitioner and patient means integrating the expertise (problem-solving) and values (decision-making) of both parties in the decision-making process, as is suggested by Wear (1993) too.

The Medical Treatment Contract Act clearly describes which information patients need to arrive at a well-informed decision about the treatment. However, one of the necessary conditions for adequate information-provision to their patients is the ability of the dentist to communicate properly with their patients. It is, however, doubtful that dentists' communicative behavior is adequate enough to reach the goal of true informed consent. The results of this study show at least a discrepancy between the legal prerequisites of informed consent and information given in daily practice (chapter 9). Thus, training dentists in communicative skills should be a continuous task within the dental curriculum (cf. Gorter & Eijkman, 1997). Moreover, the possibility does exist that the results concerning dentists' communicative behavior in this study are positively biased, because the group of dentists participating in this study cannot be considered representative. These dentists were presumably more than the average group of dentists interested in the topic of dentist-patient communication. Therefore, it must be taken into consideration that the results were more favorable than they would have been using a more representative sample. Regrettably, it was not feasible to conduct a study with such a sample, because many dentists approached with the request to participate in this study did not want to cooperate.

Finally, in this thesis the relation between the behavior of patients and dentists and their satisfaction with the dental encounter was studied (chapter 10). A distinction was made between patients' satisfaction and dentists' satisfaction, because it is assumed that the satisfaction of both parties will be related to different patterns of behavior. The most noteworthy outcome of this study is that dental patients' satisfaction was for the greater part predicted by the communicative behavior of the dentist, a finding consistent with the results from other studies (e.g. Roter, Hall & Katz, 1987; Kress & Shulman, 1997).

In sum, the results from chapter 8, 9 and 10 indicate that patients do want to have the opportunity to assert their right to self-determination in dental practice.
Their need for information is considerable, and a majority of dental patients also do want to be involved in decision-making tasks regarding the treatment. Although the discrepancy between their preferences for information and participation in the decision-making process, and their actual behavior during the consultation is striking, this does not mean that the dentist should not treat his patients as autonomous and capable of making decisions of their own. It does signify though, that it is important to make dentists aware of this discrepancy, so they can act more in line with the preferences and rights of their patients.

3.4 Recommendations for continued research

Although more insight has been gained with regard to the introduction of the Medical Treatment Act in dental practice, the results from this thesis do raise several new research questions as well. Most important, with respect to the etiology of patients’ behavior during the dental consultation, no important predictors were found. In order to identify factors that explain patients’ behavior to a greater extent, future studies should, among other things, make use of other, more representative samples of dental patients if possible. To enhance participation of dentists and patients in research on this topic, it is recommended to utilize less obtrusive ways to assess the instrumental and affective aspects of dentists' behavior than has been done in this study, such as scoring dentists' behavior directly without taping the consultations. Furthermore, it is necessary to identify the factors and weights of these factors patients use in making dental health care decisions in general, in order to understand better the process of informed decision-making in the dental setting. Within such studies, it should be recognized that patients are more and more becoming consumers of health care, especially within the field of dentistry where patients themselves more often pay for costs of treatment than in most areas of health care. Also, future studies must give due attention to the definition of patient participation, before drawing definite conclusions about patients’ desire for participation in decision-making. Another point that deserves further attention is the problem of patients’ lack of recall and understanding of the information received from the dentist, for patients can only assert their right to self-determination if they comprehend the information necessary to arrive at a sound decision. And last but not least, explanations have to be found for the observed discrepancy between patients’ need for information and participation in the dentist-patient interaction and their overt behavior. Identifying factors that explain this discrepancy is vital for enhancing the involvement of patients in the dental decision-making process.
3.5 Final Remarks

To accomplish a true partnership between dentist and patient, the relationship between the two should, above all, be one of trust. The Medical Treatment Contract Act does not dispute this, nor does it claim to be an instrument in establishing such a relationship of trust. This remains the responsibility of dentist and patient, independent of any act. The Medical Treatment Contract Act does, however, protect and stimulate the fundamental right of the patient to self-determination and to make informed decisions about the medical or dental treatment. Despite the obvious differences between dentistry and other health care professions, the patient's right to self-determination should be guaranteed, both in medicine and dentistry, regardless of whether patients do or do not wish to make use of that right. That decision is ultimately up to the patient, and should be respected. Given the many unanswered questions with regard to patients' need for involvement and their corresponding behavior in the interaction with the dentist, the best clinical approach at this moment remains to explicitly ask the patient about his preferences for information and participation, and to make clear that a choice is always available.
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