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ORIGINAL PAPER

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Patients' attitudes on how to deal with the risk of future stone recurrences

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Abstract One hundred consecutive patients referred for active stone removal responded to a number of questions regarding their attitude to metabolic risk evaluation and recurrence prevention. Of the 74 men and 26 women all but one were interested in the cause of their disease. While 95% of the patients were motivated to change their dietary habits, only 71% were interested in pharmacological treatment. Collection of 24-h urine for risk evaluation in one or five fractions was acceptable to 94 and 84% of the patients, respectively. Only 79% wanted to collect urine during more than one 24-h period. Given the option of a recurrence prevention programme or active stone removal when or if a stone appeared, approximately half of our patients (52%) chose the first, and about one-third (29%) of them chose the second alternative, whereas as many as 19% of the patients did not express any opinion. A programme for regular follow-up in order to detect new stones early was appreciated by only 81 patients. These results show that biochemical risk evaluation and recurrence prevention is generally met with a positive attitude by most patients and that medical recurrence prevention appears to be appreciated by more than half of the patients.

Keywords Active stone removal · Biochemical risk evaluation · Patient attitude · Pharmacological treatment · Urine analysis · Urine collection

Introduction

It is well recognised that patients who have suffered the experience of one or several urinary tract stones are at risk of forming more stones. Although the 10-year risk among Swedish patients who presented with their first stone was only about 30%, this risk increased to 70% in those who had a history of more than one stone [1]. It has been estimated that the recurrence risk in a stone population is around 50% [2]. In view of the variable course of stone formation there is a wide range of severity of the disease. Some patients form stones with long intervals between successive episodes, whereas others have bothersome and frequent stone formation [2–4].

Stones that pass spontaneously usually cause considerable pain and very often require a visit to an emergency unit or even a period of hospitalisation. Stones that do not pass spontaneously might require active stone removal by ESWL, ureteroscopy or percutaneous surgery. In some patients, it is even necessary to proceed to open or laparoscopic surgery. In addition to the painful experience, stones might cause obstruction, reduced renal function, haematuria and infection problems. There are thus obviously both medical and economic reasons for rational therapeutic steps aimed at efficient recurrence prevention.

Although there is an obvious relationship between urine composition in terms of supersaturation with stone-forming salts and the crystallisation propensity and risk of stone formation [5–10], there is presently no analytical method that can be used to predict the future course of the disease reliably. Accordingly, it is not possible to identify and offer recurrence prevention only to those patients who would otherwise be chronic stone formers.

Recurrence prevention programmes comprise general and specific medical advice regarding fluid intake and diet as well as pharmacological treatment [11–14]. The patient compliance with all these regimens is, however, relatively poor [15–19]. There are probably several reasons for such an outcome. The patients are usually without symptoms between episodes of stone formation and accordingly less motivated to continue with lifelong treatment. Many patients find it difficult to adhere both to new drinking habits and to follow dietary restrictions. In addition, the treating urologist might be insufficiently

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informed about the need for and the kind of treatment for an individual patient. Moreover, the stone-removing procedures have become much easier than they used to be and pharmacological treatment might be expensive [12].

Information on what the stone formers generally think about these issues is scanty. In order to obtain a deeper insight into the patients' own thoughts about and attitudes to risk evaluation and recurrence prevention, we asked a consecutive series of patients seen at our stone unit to complete a short questionnaire.

Patients and methods

One hundred consecutive patients who were referred to our stone unit for active stone removal by ESWL completed a questionnaire comprising a set of questions as outlined below. These questions had been formulated in order to reflect the clinical handling of patients with stone disease. The form was given to all patients, during a period in 2004, provided they had knowledge of the Swedish language sufficient to understand the meaning of the questions. It needs to be emphasised in this regard that we use ESWL (with or without gentle auxiliary procedures) as the first-line treatment, essentially for all patients requiring active stone removal.

The investigation was carried out on an anonymous basis and it was thus not possible to relate the result to any specific characteristic of the patients' stone disease. There were 74 men and 26 women who responded to the questions. Of these patients, 36 had formed one stone (they thus came to treatment for their first and only stone: group A), 24 had formed two stones (group B) and 40 had a history of three stones or more (group C). All completed the questionnaire when they had been through the stone-removing procedure. The age distribution was as follows: two patients were less than 25 years old, and seven were more than 75. Of the remaining patients, 38 were between 26, and 52 between 51 and 75 years old. One patient did not state his age.

The questions given to the patients, as translated from Swedish were as follows:

1. Have you previously been given medical advice with the aim of counteracting stone formation?
2. Are you presently taking any pharmacologic agent for prevention of stone recurrences?
3. Have you previously been treated with any stone-removing procedure? If the answer is yes: were the stones removed with ESWL, ureteroscopy, percutaneous surgery, open surgery, a basket or just with a catheter inserted into the ureter?
4. Are you interested to know the cause/causes of the stone formation?
5. Are you interested in recurrence prevention measures?
6. Would you be motivated to modify your diet if such a step was proved necessary?
7. Would you be motivated to increase your fluid intake if this was proved necessary?
8. Would you consider following regular treatment with a pharmacological agent in order to counteract new stone formation or growth of residual fragments?
9. Would you be sufficiently motivated to follow any lifelong treatment programme in order to contract stone formation?
10. In order to make an attempt to determine risk factors of stone formation, would you be motivated to:
    (a) Collect the urine produced during one 24-h period?
    (b) Collect the urine produced during 24 h in fine fractions (bottles)?
    (c) Collect the urine produced during several 24-h periods?
11. Do you find it useful to be on a regular follow-up programme with X-ray examinations in order to detect and treat stones early that might have formed in the urinary tract? (for instance once a year, every second or every third year).
12. If you have the option to choose between lifelong medical treatment for recurrence prevention and repeated stone-removing procedures when new stones form, which would be your choice?
13. If the analysis of urine undertaken to identify risk factors of stone formation required *n* extra personal cost for you, would you be motivated to pay for that?

In addition to responding to these questions, the patients were asked to indicate their gender, age and number of stones formed.

Yates Chi-square test was used for statistical group comparison.

Results

The responses to the major questions recorded from all 100 patients are summarised in Table 1 and Fig. 1. Only a few patients thought or could remember that they had previously been given any medical advice, the purpose of which was to prevent new stone formation. Of those in groups A and B only four out of 60 (7%) had been given such advice. In the 40 patients in group C the corresponding number was seven (18%). Among all patients three (one man and two women) had some kind of pharmacological treatment with stone-preventive properties.

All but one patient (99%) declared an interest in knowing why they had formed stones and 96% stated that they were interested in recurrence prevention measures. Ninety-five of our patients were apparently well motivated to change their dietary habits if such a step would be useful and all patients except one (99%) would be prepared to increase their fluid intake for the same purpose.

Table 1 Response from patients in the various subgroups

Group	A	B	C	M	F
Patients in the group	36	24	40	74	26
Questions					
1. Previous medical advice	2 (6)	2 (8)	7 (18)	6 (8)	5 (19)
2. Pharmacological treatment	0 (0)	1 (4)	2 (5)	1 (1)	2 (8)
3. Previous stone removal	2 (6)	10 (42)	18 (45)	18 (24)	12 (46)
4. Interested in causes?	36 (100)	24 (100)	39 (98)	73 (99)	26 (100)
5. Interested in recurrence prevention?	34 (94)	23 (96)	39 (98)	71 (96)	25 (96)
6. Positive to dietary changes?	33 (92)	22 (92)	40 (100)	71 (96)	24 (92)
7. Positive to change of drinking habits?	35 (97)	24 (100)	40 (100)	74 (100)	25 (96)
8. Positive to pharmacological treatment?	23 (64)	18 (75)	30 (75)	54 (73)	17 (65)
9. Positive to life-long treatment programme?	27 (75)	16 (67)	28 (70)	56 (76)	15 (58)
10a. Positive to one 24-h urine collection?	34 (94)	23 (96)	37 (93)	70 (95)	24 (92)
10b. Positive to several urine fractions during one 24-h period?	32 (89)	20 (83)	30 (75)	64 (86)	18 (69)
10c. Positive to more than one 24-h urine collection?	31 (86)	18 (75)	30 (75)	59 (80)	20 (77)
11. Positive to a regular follow-up programme?	28 (78)	20 (83)	33 (83)	62 (84)	19 (73)
12. Choice of active stone removal	11 (31)	6 (25)	12 (30)	21 (28)	8 (31)
12. Choice of medical treatment	17 (47)	16 (67)	19 (48)	41 (55)	11 (42)
12. No opinion	9 (25)	2 (8)	8 (20)	11 (15)	7 (27)
13. Positive to pay for a risk analysis?	27 (75)	18 (75)	31 (78)	54 (73)	22 (85)

Patients with their first stone (A), patients who had formed two stones (B) or more than two stones (C). The answers given by male (M) and female (F) patients are shown separately. Number of patients (percent) is indicated

For a regular pharmacological recurrence prevention treatment, the motivation was lower and only 71 of our patients would consider such an alternative. As could be expected this attitude was related to the severity of the disease and whereas only 64% in group A were positive to such a treatment, the corresponding figure was 75% for patients in groups B and C. A positive response was recorded from 73% of the men and 65% of the women. The younger patients appeared to be less positive to pharmacological treatment. Only 65% of patients aged up to 50 years would consider pharmacological treatment in contrast to 76% of those patients aged above 50. Although the differences between the various subgroups did not allow for statistical conclusions, the trend seemed clear that older patients and those with a more serious history of stone formation were slightly more positive to a pharmacological treatment. For a more general lifelong recurrence preventive treatment in its widest sense, we recorded no differences between the groups.

The necessity to collect urine for analysis of risk factors seems to be well understood by our patients and 94% were obviously well motivated to collect one 24-h urine sample. This number of patients was reduced to 84

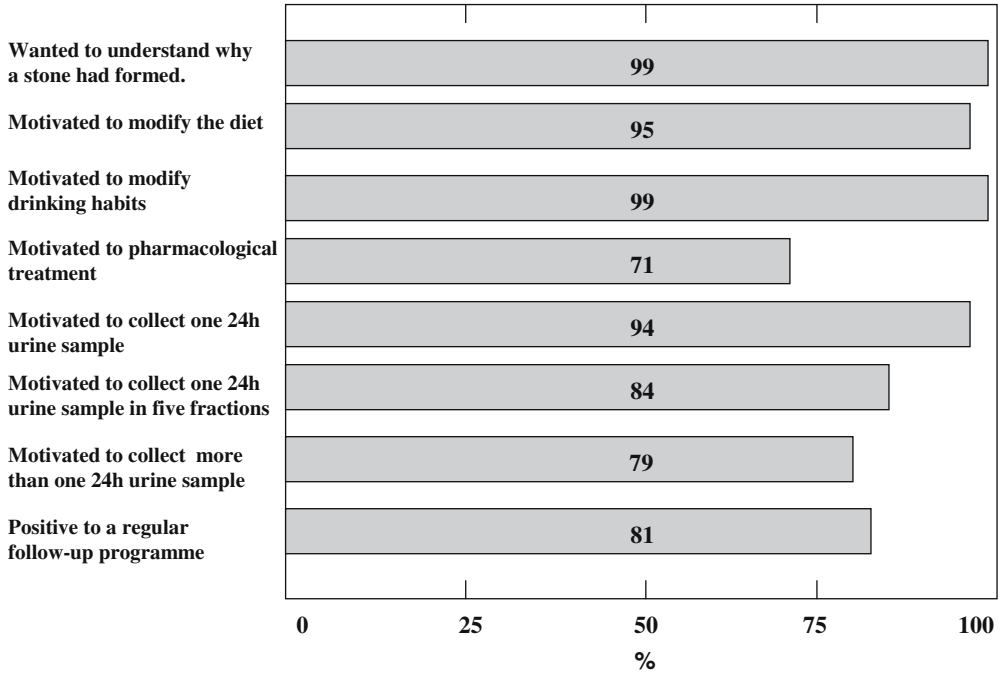

Fig. 1 Patients' attitudes to some of the most important procedures related to the prevention of recurrent stones

when the alternative was to collect the 24-h urine in five separate fractions. In the case where more than one 24-h urine sample would be necessary the number of motivated patients dropped to 79. Men generally accepted urine collection in fractions better than women with 86% of them prepared to collect 24-h urine in five fractions compared with 69% of the women ($0.05 < P < 0.10$). Both genders had a similar attitude when the alternative was to collect more then one 24-h sample. The willingness to collect more than one 24 h urine sample was not lower in group A than in groups B and C.

It is of interest to note that the case risk factor analysis would require personal expenses for the patient, in which 76% would still be interested. That level was the same irrespective of the previous stone history. Whereas, 85% of the women would accept an extra cost only 73% of the men did so. The economic tolerance was apparently better in the age group up to 50 years than among the older patients: 83 and 73%, respectively. Although of definite interest none of these differences was statistically significant.

The number of previous procedures for active stone removal was 2, 10 and 18 in patients from groups A, B and C, respectively. When we gave our patients the option to choose between a lifelong recurrence preventive medical treatment (hopefully effective) and repeated stone removing procedures if new stones occurred, 52 out of 99 patients preferred the medical and 29 the surgical (ESWL) alternative. Eighteen patients either did not respond or had no idea on how to decide. This means that of those who made a decision 64% were in favour of a medical and 36% in favour of surgical approach.

It is somewhat surprising that only 81% of the patients found a value in a regular follow-up programme. As could be expected the interest was lowest among patients in group A, 78% of that group compared with 83% in the others. Women were numerically less positive than men, 73% compared with 84%, respectively.

Discussion

The result of this enquiry showed the patients' interest in their disease with regard to the metabolic risk evaluation and recurrence prevention treatment. It also gives useful information on how the stone-removing activity should be organised. The number of patients included in the study was limited and solid statistical conclusions were not possible. Nevertheless, the recorded result might be a useful guide for planning the workup of patients with stone disease.

It is of note that all but one of our patients were interested to learn about the possible cause or causes of stone formation. Moreover, almost all patients declared that they were interested in some kind of treatment aiming at a reduced risk of stone formation. In terms of treatment most patients considered dietary and drinking recommendations as a reasonable and acceptable regimen. When the question was raised on pharmacological and/or lifelong preventive treatment, however, no more than about two-thirds were willing to accept such a treatment. This figure will certainly drop as time passes and the more or less acute stone problem vanishes from the patient's mind. The relatively limited interest in such a treatment thus seems to correspond roughly to the compliance levels reported in the literature [15–20].

The search for risk factors of stone formation by analysis of the urine composition was apparently met with a positive attitude by the vast majority of our patients. It is noteworthy, however, that whereas 94% would be prepared to collect one 24-h sample, not more than 79% found it worthwhile to collect urine for more than one day, which is a common recommendation today [21–24]. When we consider that recommendation, the reluctance of collecting urine during more than one 24-h period should be taken into account. It thus might be reasonable to start with one 24-h sample and repeat the collection only when sufficient or reliable information cannot be obtained from that analysis [25, 26]. For patients not motivated to collect urine during several days it is unlikely that the collection will be carried out with necessary care and accuracy.

It is surprising, however, that as many as 84% of the patients were positive to collect 24-h urine in several fractions. Such an approach would indeed be a useful tool in order to identify specific risk periods during the day.

The improvement of methods for active stone removal has made patients and urologists less positive to medical preventive measures. This is probably reflected by the fact that about 36% of our patients preferred active stone removal in case of new stones. Nevertheless, more than half of our patients (52%) had a positive attitude to medical prevention and would choose such an alterative before repeated active stone removal. It is also interesting to note that very few patients with a previous history of stone formation were aware of any medical advice that had been given to them. Only 14% had that experience and no more than 3% had some kind of pharmacological treatment for stone prevention.

Chandoke and co-workers [27] in 1990 asked their ESWL-treated patients about their view on metabolic evaluation and recurrence prevention. They also found a positive attitude to the metabolic risk evaluation and related medical procedures. Our experience is similar to that report. Obviously, also with the newer generation of lithotripters, there is a patients' preference for a treatment that is as little invasive as possible.

Due to a considerable recurrence rate, risk evaluation and rational preventive measures are indicated in patients with repeated stone formation. One problem is, however, that even pharmacological treatment is ineffective in many cases. Whether this is due to an inferior effect of the agent or a poor compliance is difficult to know and remains a matter of debate. Several randomised studies have shown, however, that potassium

citrate, magnesium potassium citrate and thiazides are efficient preventive agents [28–34]. Unfortunately, we still lack the ideal preventive method and there is a definite need to understand better the exact mechanisms of stone formation and to improve the risk evaluation accordingly.

In economic terms active stone removal is usually more expensive than pharmacological treatment, as long as the evaluation and treatment is reserved for patients with a severe recurrent stone disease or those with residual stone material in the renal tract [12].

Most certainly the patient's motivation for and compliance with various treatment modalities are related to the severity of the disease. The information obtained in our study gives support to such an assumption and seems to support the recommendation put forward by the EAU Health Care office that both biochemical evaluation and treatment should be used in a selective and individualised way [14, 35].

Because of economic restrictions in the health care sector it might possibly be necessary to carry out risk evaluation on the basis of a self-cost for the patient. Without mentioning any cost level, for an evaluation, as many as 76% of our patients were positive to such an alternative. This attitude might certainly vary from one country to another, but the response is noteworthy in view of the fact that the people in Sweden are used to having all such procedures covered by the health insurance system.

In conclusion, all the patients in this limited study were interested in receiving an explanation of the cause or causes of their stone formation. They also had a positive attitude to analysis of risk factors as well as to some kind of recurrence prevention, at least at the time of acute problems and active stone removal. It was obvious, however, that the extent of preventive treatment has to be individualised with great attention being paid to the severity of the disease. Otherwise the compliance will certainly be poor.

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