Evaluation of patients' knowledge about anticoagulant treatment

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Abstract

Objective—To develop a questionnaire to evaluate patients' knowledge of anticoagulation.

Design—Anonymous self completed questionnaire study based on hospital anticoagulant guidelines.

Setting—Anticoagulant clinic in a 580 bed district general hospital in London.

Subjects—70 consecutive patients newly referred to the anticoagulant clinic over six months.

Main measures—Information received by patients on six items of anticoagulation counselling (mode of action of warfarin, adverse effects of over or under anticoagulation, drugs to avoid, action if bleeding or bruising occurs, and alcohol consumption), the source of such information, and patients' knowledge about anticoagulation.

Results—Of the recruits, 36(51%) were male; 38(54%) were aged below 46 years, 22(31%) 46-60, and 10(14%) over 75. 50 (71%) questionnaires were returned. In all, 40 respondents spoke English at home and six another language. Most patients reported being clearly advised on five of the six items, but knowledge about anticoagulation was poor. Few patients could correctly identify adverse conditions associated with poor control of anticoagulation: bleeding was identified by only 30(60%), bruising by 23(56%), and thrombosis by 18(36%). Only 26(52%) patients could identify an excessive level of alcohol consumption, and only seven (14%) could identify three or more self prescribed agents which may interfere with warfarin.

Conclusion—The questionnaire provided a simple method of determining patients' knowledge of anticoagulation, and its results indicated that this requires improvement.

Implications—Patients' responses suggested that advice was not always given by medical staff, and use of counselling checklists is recommended. Reinforcement of advice by non-medical counsellors and with educational guides such as posters or leaflets should be considered. Such initiatives are currently being evaluated in a repeat survey.

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Introduction

Oral anticoagulants, such as warfarin, are widely used for preventing and treating vascular and thromboembolic disease. The

therapeutic range is narrow,¹ and complications, such as life-threatening bleeding and re-thrombosis, can occur if patients are over anticoagulated or underanticoagulated. The efficacy of warfarin can be adversely affected by many factors, including the patients' concurrent drug treatment, change in diet or alcohol intake, and physical illness.²⁻³ It is therefore essential that patients are well advised and fully recognise the risks of anticoagulant treatment. Previous reports indicate that patients receiving oral anticoagulants commonly do not know the potential complications and risks of their treatment.⁴⁻⁵ The objectives of this study were to develop a questionnaire to determine patients' reports of information received and to evaluate patients' knowledge of anticoagulation treatment.

Methods

The study site was a 580 bed district general hospital with an anticoagulant clinic attended by over 60 patients a week. The hospital's guidelines on managing anticoagulation were drawn up by the consultant haematologist, based on those issued by the British Society for Haematology⁶ and after discussion at the hospital physicians' audit meetings.⁷ They recommend that patients undergoing anticoagulant treatment should be given a standard information card⁸ on anticoagulation and should be counselled by the ward doctor on six items before discharge. These items include the mode of action of warfarin, adverse effects associated with over or under anticoagulation, what drugs to avoid, what action to take if bleeding or bruising occurs, and alcohol consumption. In addition, the calendar method as outlined in the current Department of Health anticoagulant treatment booklet⁹ should be explained. This simple method was developed to improve compliance and entails patients ticking off on a calendar the days on which warfarin is taken. Although not outlined in the guidelines, doctors in the anticoagulant clinic should reinforce the information on these six items at the patient's first clinic attendance and should also distribute the anticoagulant treatment booklet.

We designed a questionnaire based on the six items of advice outlined in the guidelines for patients to complete after their first appointment with the anticoagulant clinic's doctor. The questionnaire asked patients for personal and clinical details, what information they had been given on each of the six items, and the source of this information. Patients' knowledge of the information contained in the Department of Health booklet was tested with a "quiz" section with multiple choice questions

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in which patients were asked to tick the true, false, or don't know options. The questionnaire was piloted in the clinic, and the final questionnaire (appendix 1) was found to be suitable, according to the Fog density index, for use by respondents who had received six years of schooling.¹⁰

Seventy consecutive patients newly referred to the anticoagulant clinic were recruited to the study over six months. All were given an anonymous questionnaire by the doctor in the clinic at the first consultation. The doctor explained the purpose of the study to the patient, who was asked to complete the questionnaire at home and return it by post. Reminders were sent out by post two weeks later.

Results

STUDY POPULATION

Of the patients recruited to the study, 36(51%) were male; 38(54%) were aged less than 46 years, 22(31%) were aged 46–60, and 10(14%) were aged over 75. Fifty (71%) of the 70 questionnaires administered were returned. Of the 50 respondents, 40(80%) spoke English at home, six (12%) spoke another language, and four (8%) did not specify. Nineteen respondents (38%) were retired, 11(22%) were in full time employment, 11(22%) either were claiming state benefit or were unemployed, and nine (18%) gave no information. Thirty eight (76%) had been recent inpatients at the study hospital and six (12%) at another hospital, five (10%) were referred from the outpatient department and one (2%) from their general practitioner.

CLINICAL DETAILS

Of the 50 respondents, 29(58%) reported having venous thromboembolic disease, six (12%) heart disease or surgery, five (10%) stroke, eight (16%) multiple or other diagnoses, and two (4%) did not specify. Seventeen (34%) patients had been receiving anticoagulant treatment for fewer than two weeks, 16(32%) for two to three weeks, and the remaining 17(34%) for more than four weeks. In all, 34(68%) of patients expressed concern about receiving anticoagulant treatment. Nineteen (38%) would have liked more medical advice, but only five (26%) felt unable to obtain sufficient medical advice.

Thirty two (64%) patients reported taking other medicines and of these, eight (16%) were currently taking drugs that can adversely affect anticoagulation treatment. These drugs had been self prescribed in one patient, prescribed by other hospital doctors in six patients, and by the general practitioner in the remaining patient.

PATIENTS' REPORTS OF INFORMATION RECEIVED

Apart from the calendar method, most patients reported receiving clear information on each of the six items (table 1). Among the 38 inpatients in the study hospital, however, only 19(50%) reported having been given an information card and 10(26%) reported

Table 1 Patients reporting clear advice given on six items from any source (n = 50)

Items	No (%) of patients
Calendar method	22 (44)
How warfarin works	38 (76)
Action if bleeding or bruising occurs	25 (50)
Problems with anticoagulant treatment	31 (62)
Drugs to avoid	37 (74)
Alcohol	41 (82)

receiving clear advice on three items or more from the ward doctor. This compares with 19/50(38%) respondents who reported receiving such advice from the doctor in the anticoagulant clinic. Of the 50 respondents, only 10(20%) reported other sources of information, which included ward nurses, other hospital medical staff, general practitioners, and written literature.

PATIENTS' KNOWLEDGE OF ANTICOAGULATION

Although 46(92%) of patients correctly answered that warfarin "thinned" the blood, knowledge of the possible side effects of poor control of anticoagulant treatment was low (table 2). Only 27(54%) patients were able to identify correctly three or more of the six genuine effects from a list of 13 conditions, and 18(36%) chose one or more of the seven unrelated conditions. In the quiz 33(66%) patients correctly reported that a new treatment could affect anticoagulant treatment, but only 26(52%) knew that changing the dose of concurrent treatment could also affect anticoagulation. Patients' knowledge of self prescribed treatment which can affect anticoagulant control was mixed (table 3); from a list of 11 self prescribed agents, only seven (14%) patients were able to identify three or more of the six agents which could adversely affect anticoagulation and, 11(22%) patients named as harmful one or more of the five "safe" agents listed.

Forty one patients reported having been clearly advised on alcohol (82%), but, only 26(52%) patients could correctly identify an excessive level of alcohol consumption, and 19(38%) patients thought that alcohol would not affect anticoagulant treatment.

Discussion

This study used patients' reports to evaluate the completeness of counselling about anticoagulation given at the study hospital and the

Table 2 Patients identifying conditions associated with poor control of anticoagulant treatment (n = 50)

Condition	No (%) of patients
<i>Associated effects</i>	
Blood in stools	20 (40)
Nose bleeds	26 (52)
Prolonged bleeding	30 (60)
Bruising	23 (56)
Blood in urine	18 (36)
Blood clots	18 (36)
<i>Non-associated effects</i>	
Sleeplessness	5 (10)
Weakness	9 (18)
Loss of appetite	7 (14)
Ringing in the ears	4 (8)
Nausea	7 (14)
Nervousness	7 (14)
High blood pressure	9 (18)

Table 3 Patients identifying self prescribed agents which should be avoided when taking anticoagulants (n = 50)

Self prescribed agent	No (%) of patients
<i>To be avoided</i>	
Aspirin	40 (80)
Cough medicines	9 (18)
Nurofen	11 (22)
Codliver oil	4 (8)
Garlic capsules	2 (4)
Health shop remedies	7 (14)
<i>May be used</i>	
Vitamin C	0 (0)
Throat lozenges	2 (4)
Optrex	1 (2)
TCP (Trichlorophenol)	0 (0)
Antacids*	8 (16)

*The safety of antacids in warfarin treatment is controversial.

outcome of such counselling in terms of patients' knowledge. Recent inpatients at the hospital reported receiving little information on the risks and complications of anti-coagulant treatment from the ward doctors. According to patients' reports, the doctors in the anticoagulant clinic were better at giving advice, but as the questionnaire was administered at the first clinic appointment, patients would be expected to have better recall of information given at this time.

This study also highlights a substantial gap between the information patients reported having received and the outcome in terms of their knowledge of anticoagulant treatment. For example, even though most patients reported having been advised on the problems associated with oral anticoagulants, only a small proportion were correctly able to identify most of the adverse events and some patients were confused about other side effects. This lack of knowledge was apparent despite virtually all patients knowing that warfarin "thins" the blood.

Patients' knowledge about anticoagulation was disappointing and there are two possible explanations for these findings. The first is that ward doctors at the study hospital are not giving all the information recommended in the guidelines. Previous audits of inpatient management and of the referral process showed poor compliance of ward doctors with other aspects of the guidelines on anti-coagulant treatment,^{11 12} and compliance with the recommended counselling may also be poor. In this study 14% of patients had been prescribed treatment which can interfere with warfarin, which accords with the results of a previous study which showed poor knowledge among doctors of which drugs can interact with oral anticoagulants.⁵ A lack of knowledge among medical staff may contribute to a reluctance to advise patients about the risks and complications of anti-coagulation. More widespread dissemination of guidelines to medical staff is required, with specific instructions on counselling patients receiving anticoagulation.

The second explanation, supported by the gap between patients' reports of advice received and their knowledge, is that patients are unable to understand and retain the advice they are given, as shown in previous studies.^{13 14} The poor quality of doctor patient

communication has been well described in other chronic conditions,¹⁵⁻¹⁷ and training in communication skills for doctors has received little emphasis in medical schools until recently.¹⁸ More effective communication arises from understanding patients' expectations, involving patients in negotiating their treatment plan,¹⁵ and continuity and accessibility of staff.¹⁵ Better levels of patient knowledge may also be achieved if information is reinforced by simple measures such as repetition or using written material.¹⁹ The availability of a non-medical counsellor, such as a clinical pharmacist or nurse practitioner, has also been shown to increase patients' knowledge about medical treatments.^{20 21} Non-medical staff may be better able to offer continuing support, to talk with the patient, and to ensure that written information has been read and understood.²²

The relative importance of the two explanations for the poor level of patients' knowledge was not addressed in this study. That would require independent observation of the consultation or inclusion of the doctors' perspective and would be difficult to replicate in routine practice. Our questionnaire focused on the patients' perspective and could be repeated at the study hospital to evaluate changes in practice or adopted for use at other sites.

This study's aim was not to relate patients' levels of knowledge to clinical outcome. A previous small study was unable to demonstrate a relation between a structured programme of education and rate of complications or therapeutic control.²³ Therefore, patient education forms only one part of effective anticoagulant control; we are currently developing methods to audit other aspects of management.

Recommendations

To improve patients' knowledge it is important to focus on the process of giving information. To increase the number of patients being counselled about anticoagulant treatment by ward doctors, the guidelines have been disseminated through the computer system and through the development of condensed guidelines in the form of practice points.²⁴ For doctors in the anticoagulant clinic a checklist for counselling has been incorporated into the clinic history sheets for all new patients. Doctors often omit important items of advice,²⁵ and the checklist can act as an "aide memoire" (appendix 2).

To reinforce counselling and to provide ongoing education a trained health care assistant asks each patient attending the anticoagulant clinic five key questions. These questions highlight the most important potential complications; changes in medication, hospital admission, episodes of bleeding or bruising, attendances at the accident and emergency department, or forthcoming surgery. The assistant also distributes and explains written information in the form of a leaflet which focuses on these key points.

The use of written educational guides may also successfully alert patients to the possible

risks and complications of treatment. Such guides, including posters and leaflets, have been instructive in other conditions and promote positive changes in patients' well-being and improve compliance.¹⁸⁻²⁶ Clear explanation of the rationale for and potential problems with anticoagulant treatment may help to improve patients' compliance with advice given. For the anticoagulant clinic at the study hospital, a poster and a patient leaflet based on the information contained in the Department of Health anticoagulant treatment booklet⁹ have been devised.

The questionnaire was successful in evaluating the level of patients' knowledge

about anticoagulant treatment. A repeat survey of patients at the anticoagulant clinic is being performed to evaluate the effects of changes in practice at the hospital. The questionnaire proved easy to administer and has been shortened to concentrate on the important aspects of education, which are reinforced at each visit. The method has also been adapted and is currently being used at other clinic sites in North West Thames region.

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Appendix 1

Patient questionnaire

Section A: This section tells us about your general health and the anticoagulant treatment (for example, warfarin or phenindione) that you are now receiving

- 1 Since starting anticoagulant treatment, would you say that your general health has:

(Please tick)

Improved ☐ Worsened ☐ Stayed the same ☐

- 2 How long ago was your present anticoagulant treatment started?

Less than 1 week ☐

Between 1-2 weeks ☐

Between 2-4 weeks ☐

More than 4 weeks ☐

Can't remember ☐

If more than 4 weeks, please state how long _____

- 3 As far as you know, which of the following are reasons for your present anticoagulant treatment?
(Please tick Yes, No, or Not sure for each item)

	Yes	No	Not sure
a Deep venous thrombosis (DVT) – blood clot in leg vein	☐	☐	☐
b Pulmonary embolus (PE) – blood clot in lung	☐	☐	☐
c Heart disease	☐	☐	☐
d Heart surgery	☐	☐	☐
e Stroke	☐	☐	☐
Anything else? _____			

- 4 About your present anticoagulant treatment:

- a Have you wanted to approach anyone for medical advice?

Yes ☐ No ☐

- b Have you been able to?

Yes ☐ No ☐

- c If YES, who? _____

- 5 Do you worry about being on anticoagulant treatment?

A lot ☐ A little ☐ Not at all ☐

If so, what are your concerns? _____

- 6 Please list ALL medications, tablets, and remedies you are taking now. Please include those obtained with and without a prescription (eg from your GP, hospital, health shops and chemists). Please also state whether taken regularly OR only when you think you need to

Name of preparation	(Please tick one or other)		For how many weeks/months/years have you been taking it?	Started by whom? (eg GP, hospital, anticoagulant clinic, self, pharmacist)
	Taken regularly	Taken when needed		

Section B: The questions in this section are about the time you spent in the ward as a patient at Central Middlesex Hospital

- 1 Were you recently an inpatient in a ward at Central Middlesex Hospital?
Yes ☐ No ☐

Please answer question 2 only if you started anticoagulant treatment while in the ward at Central Middlesex Hospital

- 2 a When you left the ward were you handed a white card "Advice for patients on anticoagulant treatment"?
Yes ☐ No ☐ Not sure ☐
- b Was the information on the card:
Too complicated? ☐
Too simple? ☐
Just right? ☐
- c Please state any problems you had with the white card:

Section C: The questions in this section are about the information you may have been given about your anticoagulant treatment

- 1 a Were you told *how* anticoagulant treatment works, and was this clear to you?
Yes, and clear ☐ Yes, but not clear ☐ No ☐
- b Who told you?
Doctor in the anticoagulant clinic ☐ Doctor in the ward ☐ Don't know ☐
Who else (for example, GP, nurse, other clinic staff) Please state: _____
- 2 a Were you told of the *problems with anticoagulant treatment*, and was this clear to you?
Yes, and clear ☐ Yes, but not clear ☐ No ☐
- b Who told you?
Doctor in the anticoagulant clinic ☐ Doctor in the ward ☐ Don't know ☐
Who else (for example, GP, nurse, other clinic staff) Please state: _____
- 3 a Were you told what to do if you *have a nosebleed or are bruising*, and was this clear to you?
Yes, and clear ☐ Yes, but not clear ☐ No ☐
- b Who told you?
Doctor in the anticoagulant clinic ☐ Doctor in the ward ☐ Don't know ☐
Who else (for example, GP, nurse, other clinic staff) Please state: _____
- 4 a Were you told of the *calendar method* to check your anticoagulant treatment, and was this clear to you?
Yes, and clear ☐ Yes, but not clear ☐ No ☐
- b Who told you?
Doctor in the anticoagulant clinic ☐ Doctor in the ward ☐ Don't know ☐
Who else (for example, GP, nurse, other clinic staff) Please state: _____
- 5 a Were you told what *drugs to avoid*, and was this clear to you?
Yes, and clear ☐ Yes, but not clear ☐ No ☐
- b Who told you?
Doctor in the anticoagulant clinic ☐ Doctor in the ward ☐ Don't know ☐
Who else (for example, GP, nurse, other clinic staff) Please state: _____
- 6 a Were you given *advice on drinking alcohol*, and was this clear to you?
Yes, and clear ☐ Yes, but not clear ☐ No ☐
- b Who told you?
Doctor in the anticoagulant clinic ☐ Doctor in the ward ☐ Don't know ☐
Who else (for example, GP, nurse, other clinic staff) Please state: _____

Section D: This section is a miniquiz because we would like to find out how well patients have been informed about anticoagulant treatment and the problems it may cause

- 1 How does warfarin work?
(Please tick Yes or No for each statement)
	Yes	No
a Warfarin does not affect the blood	☐	☐
b Warfarin thins the blood	☐	☐
c Warfarin thickens the blood	☐	☐
- 2 Could starting a new treatment or any other preparation affect your anticoagulant treatment?
Yes ☐ No ☐ Don't know ☐
- 3 Could changing the dose of a treatment you are already taking affect your anticoagulant treatment?
Yes ☐ No ☐ Don't know ☐
- 4 The following are statements about any patient drinking alcohol when receiving anticoagulant treatment
(Please tick Yes or No for each statement)
	Yes	No
Alcohol does not affect anticoagulant treatment	☐	☐
Alcohol must be avoided totally	☐	☐
8 units of alcohol a night is OK (for example, 4 pints of beer or 8 glasses of wine)	☐	☐
1 unit of alcohol a night is OK (for example, ½ pint of beer or 1 glass of wine)	☐	☐

- 5 Of the list below, which drugs should be avoided when receiving anticoagulant treatment? Please do not be alarmed, some of the drugs listed below should not be avoided
(Please tick True, False, or Don't know for each item)

	Don't know	True	False
Aspirin	☐	☐	☐
Cough medicines	☐	☐	☐
Nurofen	☐	☐	☐
Antacids (for example, Rennie, Settlers)	☐	☐	☐
Optrex (eye solution)	☐	☐	☐
Codliver oil	☐	☐	☐
Garlic capsules	☐	☐	☐
TCP/Dettol	☐	☐	☐
Vitamin C tablets	☐	☐	☐
Throat lozenges	☐	☐	☐
Health shop remedies	☐	☐	☐

- 6 Which of the following could be possible side effects of taking the wrong (too little or too much) amount of anticoagulant treatment? Please do not be alarmed, some of the items are wrong
(Please tick True, False, or Don't know for each item)

	Don't know	True	False
Blood in stools	☐	☐	☐
Nose bleeds	☐	☐	☐
Sleeplessness	☐	☐	☐
Prolonged bleeding after cuts	☐	☐	☐
Bruising without injury	☐	☐	☐
Weakness	☐	☐	☐
Loss of appetite	☐	☐	☐
ringing in the ears	☐	☐	☐
Nausea	☐	☐	☐
Blood in urine	☐	☐	☐
Nervousness	☐	☐	☐
Blood clots	☐	☐	☐
High blood pressure	☐	☐	☐

Patient details **CONFIDENTIAL**

So that we can be sure that this questionnaire reaches a cross section of patients we would appreciate the following information

- a Are you replying on behalf of:
Yourself ☐ Somebody else ☐

- b If somebody else, please explain:

- i) Your relationship to the patient: _____
ii) The reason your help is needed: _____

If you are completing this form on behalf of the patient please answer the following questions as they apply to him/her

- b Are you (the patient):

Male ☐ Female ☐

- c Which of the following age groups are you (the patient) in:

Under 16 ☐
16-30 ☐
31-45 ☐
46-60 ☐
61-70 ☐
71 and over ☐

- d What language do you (the patient) speak at home?

English ☐ Other (please specify) _____

- e Which of the following best describes your (the patient's) employment status?

Employed full time ☐ Employed part time ☐
Unemployed ☐ Long term sick leave or benefit ☐
Student ☐ Retired ☐

Thank you very much for taking the time to complete this questionnaire

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Appendix 2

Checklist for patient counselling

Please tick to confirm that the use of the yellow Department of Health anticoagulant treatment book has been explained to the patient ☐

Please tick the boxes to confirm that you have counselled the patient on the following items:

- 1 Compliance (the calendar method) ☐
- 2 Rationale for treatment ☐
- 3 Mode of action of warfarin ☐
- 4 Obtaining supply of warfarin from general practitioner ☐
- 5 Possible effects of poor control of anticoagulation
 - Bleeding or severe bruising ☐
 - Recurrence of thromboembolism ☐
- 6 Appropriate action if bleeding or bruising occurs ☐
- 7 Appropriate action if patient has diarrhoea or is vomiting ☐
- 8 Starting new treatment *and* changing dose of current treatment ☐
- 9 Self prescribed drugs:
 - Avoid aspirin ☐
 - Avoid Nurofen ☐
 - Avoid health shop remedies ☐
 - Ask pharmacist, doctor for advice ☐
- 10 Alcohol intake ☐
- 11 Contraception, pregnancy, and hormone replacement therapy (if relevant) ☐
- 12 Surgical procedures (including dental work) ☐
- 13 Injections ☐
- 14 Leisure activities ☐

Counselled by: _____ Date: _____

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