

Avoidance hierarchies and preferences for anticoagulation—semi-qualitative analysis of older patients' views about stroke prevention and the use of warfarin

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Abstract

Objective: To examine older patients' preferences regarding the use of warfarin to prevent atrial fibrillation related strokes when faced with cumulative probabilities of treatment risk and benefit.

Design: A semi-qualitative researcher administered questionnaire and interview.

Subjects: 81 patients attending a general elderly medicine outpatient clinic.

Results: Up to 50% of participants would decline warfarin treatment when shown both cumulative benefits of stroke risk reduction and risk of intracerebral haemorrhage. Principal themes highlighted concepts of gambling and trade offs relating to risk and benefit. Attitudes about stroke and negative perceptions of intracerebral haemorrhage were major contributory themes in the decision to refuse warfarin treatment.

Conclusion: Older people use very individualistic health beliefs in judging how to trade risks to preserve quality of life. Carefully explaining risk information and listening to elders' views and reasoning is likely to result in a more informed choice regarding the use of anticoagulation in stroke prevention.

Keywords: stroke, anticoagulation, risk, patient preferences, elderly

Introduction

Recent reviews have highlighted the rising prevalence of atrial fibrillation (AF), and the importance of reducing consequent stroke risks through the use of anticoagulant therapies such as warfarin [1, 2]. The efficacy of warfarin is well proven, but surveys of current practices suggest anticoagulation remains an underused treatment, with only 23% of those eligible receiving treatments in community studies [3, 4]. Considerable variation exists in clinicians' use of anticoagulants in AF management, due to difficulties in monitoring therapy and perceptions of harm through bleeding risks [5, 6]. In attempting to address these concerns and assist decisions about anticoagulation, decision analysis tools have been developed [7, 8].

Whilst the underuse of warfarin has been highlighted, little has been described regarding patients' preferences about the use of warfarin. Primary care studies involving patients with AF found that <40% of those eligible would prefer anticoagulation, even when the reduction in strokes over a 1 year

period was demonstrated both verbally and diagrammatically [8, 9]. The aim of this study was to complement these findings by examining treatment choices of older patients when given information about the *cumulative* benefits of warfarin on stroke risks over a 10 year period, and qualitatively examine the themes that surrounded these decisions.

Methods and sampling

Recruitment and use of crowd figure pictogram

The advantages of pictorial information when communicating risk have been previously described [10]. The crowd figure pictogram used to aid understanding by older people in an earlier study was used to represent stroke probability both visually and numerically in this study [11]. Patients aged 65 years and above attending an elderly medicine outpatient clinic at St James's Hospital were assessed by one of the researchers (RF) for entry into the study, excluding

those with significant audiovisual or cognitive impairment. The Local Research Ethics committee approved this study.

Questionnaire

Those participating answered a researcher-administered questionnaire based around a scenario of a patient with AF and a recent ischaemic stroke, with an estimated annual stroke risk of 12% [12]. This offered two treatment options, ‘Treatment P’ (Placebo: risk of stroke 12%/year) and ‘Treatment J’ (Warfarin: risk of stroke 4%/year), based on a 65% stroke risk reduction with anticoagulants [13, 14].

Participants were shown pairs of pictograms that numerically and visually displayed the number of strokes suffered in both treatment arms at 10 years, and were asked to choose which treatment they would opt for. They were then asked to reconsider their treatment choice when faced with additional information about ‘Treatment J’. This introduced the necessity of tablets, the need for 2, 6 or 12 weekly blood tests and restrictions on alcohol. The risks of intracerebral haemorrhage (ICH) with Treatment J, based on 0.1, 1, 2 and 4%/year at 10 years were shown pictorially as 1, 10, 18 and 34 people suffering ICH [15]. Respondents were encouraged to discuss their decisions about treatment in more detail, with responses transcribed for subsequent qualitative analysis.

Qualitative analysis

As this study aimed to examine particular themes surrounding patients’ perceptions and decision making in warfarin and stroke prevention, content analysis techniques were selected as an appropriate method of data analysis [16]. This involved generating a set of predetermined codes (e.g. perceptions of stroke, risk ‘language’ and communication, balances of risk and benefit, views about alcohol) relating to the research questions, which were then read alongside qualitative data to reveal important themes.

Rigour and trustworthiness were ensured during data collection and analysis by the use of open and closed questions to explore decisions during discussion of treatment choices, using the technique of methods triangulation [16]. This revealed discordant or alternative themes during data analysis, and these were recorded to enhance interpretation.

Further information about the study questionnaire and crowd pictogram can be found on the journal’s website (<http://www.ageing.oupjournals.org>)

Results

The study was discussed with 102 eligible subjects, and 81 consented to participate—45 male and 36 female, age range 66–97 (median 81 years); 76 agreed to discuss their choices in detail. 14 participants had suffered stroke or cerebral haemorrhage previously, and 16 (20%) knew a family member with stroke or ICH. Eight (10%) were taking warfarin.

Table 1. Effects of risk of treatment-induced ICH on number (and %) of respondents choosing Treatment J

0.1%/year (1 person after 10 years)	1%/year (10 people after 10 years)	2%/year (18 people after 10 years)	4%/year (34 people after 10 years)
80 (99%)	53 (66%)	49 (61%)	39 (49%)

When shown the pictograms demonstrating risk of stroke after 10 years, all 81 participants (100%) chose treatment J (Warfarin). The effects of additional information about treatment-related haemorrhage, and of the need for alcohol restriction and regular phlebotomy on these decisions are shown in Tables 1 and 2.

Attitudes to risk—gambling, trade offs and guarantors (Box 1)

The principal theme emergent in the analysis was the use of risk ‘language’ by patients to discuss their choices, encompassing both qualitative and quantitative terms referenced back to the pictorial data. A similarly frequent theme encompassed choices based on guarantees of successful treatment, and deciding whether to trade off risks against avoiding strokes. This was echoed in responses about decision making that used analogies with gambling and uncertainties about treatment successes.

Box 1 – Gambling and guarantees

- ‘I’d stick with this one [treatment J] because of the number of strokes. Chances of stroke are less—I don’t think there’s a choice’ (Patient 48, aged 84)
- ‘If you could guarantee me an extra 10 years extra life, I’d go for the treatment—but you can’t. You’re gambling, but more gotten through with J. Statistically more are OK with treatment J . . . I’d take my chances on that’ (Patient 43, aged 77)
- ‘It’s a gamble—strokes could be minor, bleeding could be worse’ (Patient 53, aged 81 years)

Perceptions of stroke and bleeding (Box 2)

A heterogeneity of themes and views emerged regarding strokes and risks of treatment-induced cerebral haemorrhage. Overall views of stroke were negative, often referring to personal experience of strokes or witnessing the effects of stroke on friends and family, with an overall wish to avoid stroke, reflected in the initial uptake of Treatment J.

The themes that surrounded perceptions of cerebral haemorrhage also drew heavily on personal experience, with bleeding described as ‘final’ or ‘permanent’. When faced with increasing risks of treatment-related ICH, this perception of finality led to the drop in uptake of warfarin as seen in Table 1.

Table 2. Effects of alcohol and blood testing on number (and %) of respondents choosing Treatment J

Daily tablet	2-weekly bloods	6-weekly bloods	12-weekly bloods	0 units of alcohol daily	1 unit of alcohol daily	2 units of alcohol daily
76 (94%)	68 (84%)	75 (93%)	80 (99%)	72 (89%)	77 (95%)	79 (98%)

In this setting, suffering a stroke was generally regarded as less perilous than the finality of cerebral haemorrhage.

Box 2 – Strokes and cerebral haemorrhage

- 'With a stroke you're finished seen lots of my family and friends with a stroke—it's terrible' (Patient 4, aged 80)
- 'Bleeding into the brain—isn't that fatal? Happened to someone I know' (Patient 72, aged 78)

Balancing risks of treatment

- 'Chance with a stroke—might be treatment with this. My father died with a cerebral haemorrhage, and sister-in-law had a stroke—always a chance' (Patient 16, aged 89)
- 'Had a brain haemorrhage before . . . terrible, but strokes are awful and disabling. I couldn't make a choice' (Patient 63, aged 81)

Other themes—tablets, alcohol and blood tests (Box 3)

Of the 76 patients interviewed, 46 (61%) were either abstinent or stated they would give up drinking in order to prevent strokes. Analysis revealed a clear theme that linked cessation with guarantees of successful stroke prevention. Other themes pointed to difficulties in stopping drinking with nine (11%) respondents declining stroke prevention treatment through wishing to continue to drink. Views about phlebotomy were equally varied with themes of trust (through regular monitoring of treatment) and perceptions of inconvenience. Again, the relatively high uptake of Treatment J (Table 2) was contextualized within guarantees of successful treatment and stroke prevention. Views about medication arose infrequently, and tended to be mentioned by those who preferred not to take tablets.

Box 3—tablets, phlebotomy and alcohol restriction

- 'Had a stroke before . . . not all tablets are bang on—some disagree with you. I don't like tablets, I prefer not to have them' (Patient 43, aged 77)
- '2-weekly bloods—no way and I'll have to leave my husband' [has dementia] (Patient 9, aged 82)
- 'I'd give up my evening drink . . . had a stroke before . . . wouldn't like to go through it again . . . has altered my life' (Patient 11, aged 85)
- 'I like my beer' (Patient 7, aged 79)

Guarantees

- 'I'd have a blood test every day to prevent a stroke – strokes are deadly' (Patient 2, aged 90)
- 'If it stopped me from having a stroke, I'd make do with a cup of tea' (Patient 44, aged 74)

Discussion

Despite the proven efficacy of warfarin in reducing the risk of AF related stroke and its widespread use in clinical practice, the views of patients regarding this subject are largely unknown. We have shown that when older patients are

provided with numerical and pictorial information about the cumulative benefits of warfarin in reducing stroke risk over a 10 year period, over 50% would decline it when supplied with additional information about the risks of intracerebral haemorrhage. Personal health beliefs about stroke, cerebral haemorrhage, alcohol cessation and phlebotomy were all major themes in formulating these decisions.

Previous studies have reported patients' difficulties in understanding verbal expressions of risk [17, 18], and considerable misunderstanding about the role and effects of anticoagulation has been described amongst patients taking warfarin [19]. Patients taking warfarin already rarely appreciated that this was the same as 'Treatment J', suggesting that communication and/or understanding of risks and benefits may have been limited in some cases prior to making the decision to commence treatment.

However, pictorial information was easily understood in this study and used by patients to decide what level of risk they were willing to take. The heterogeneity of the decisions and responses seen in this study is important. A key component of medical decision making is patient involvement, and one of the major challenges of discussing risk with patients is a lack of personalized information. In this study, patients were able to express clear preferences through references to the pictorial risk information and then qualify their responses by drawing on personal experiences of stroke and ICH in discussions about trading risk and treatment choices.

Understanding elders' preferences and decisions is particularly important, as they often alter their decision making when unwell [20]. Whilst sociological literature suggests that individuals' attitudes towards risk and decision making are in part formed during their formative years [21], it is clear that life changes accompanying ageing also have considerable impact. Self-perception of ageing, illness, changing roles and diminishing responsibilities all contribute to a highly individualized, complex decision process [22, 23] which may differ considerably from the partnership decision model shared with younger patients.

We acknowledge that a possible weakness of this study is its relatively small size, though it is comparable with primary care trials with between 56 and 97 participants [8, 9]. It would be of interest to repeat this study in a community setting and also in a group known to have established atrial fibrillation to see if these findings are generalizable in a larger elderly population. Whilst this study did not set out to record comorbidities of respondents, it is interesting to note that non-stroke illnesses suffered by participants rarely emerged in the data review, highlighting that perceptions of stroke and bleeding were major themes in decision making.

The study showed that older people use personal health beliefs and express willingness to trade risks to preserve quality of life. Similarly, by exploring patients' preferences for anticoagulation and stroke prevention qualitatively, this study reflects the value of narrative-based analysis in understanding how decisions are made [24]. Even accounting for the wide variation in physicians' management of AF [5], we suggest that the 'underuse' of warfarin in stroke prevention is unsurprising. We would suggest that by carefully listening to the

views and reasoning of older people in response to both short-term and long-term risk information, better and more informed choices will be able to be made when warfarin is being considered for stroke prevention in atrial fibrillation.

Key points

- Despite the benefits of anticoagulants in reducing strokes related to atrial fibrillation, community studies report that <25% of those eligible receive warfarin.
 - Older people are able to express clear preferences about avoiding strokes when given risk and benefit information about warfarin and stroke prevention.
 - Many would refuse anticoagulation through very negative perceptions of the risk and effects of cerebral haemorrhage.
 - Understanding these views helps explain the apparent underuse of warfarin.
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