

# Importance of risk communication and decision making in cardiovascular conditions in older patients: a discussion paper

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## Abstract

**Atrial fibrillation and aortic stenosis commonly present doctors and patients with difficult decisions about the risks and benefits of treatment options and are both often inappropriately undertreated. Patients may be confused by risk information and doctors may be aware of patients' limitations and use this to manipulate choices to the ones desired by the doctors. This paper examines the importance of risk communication and discusses difficulties that can arise in decision making in these two common cardiovascular conditions.**

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Atrial fibrillation and aortic stenosis are conditions that increase in frequency with age and are problems that provide both doctors and patients with difficult decisions about the risks and benefits of treatment options.<sup>1,2</sup> The frequency of encounters both in general practice and hospital practice will increase with an ageing population and may become more challenging because of increasing patient expectations and the change in style of medical practice. In the last 2–3 years there has been a clear move away from the “doctor knows best” paternalistic type of practice to one involving a greater degree of partnership where patients are better informed about the risks, options, and outcomes of treatments in order to enable decision making to be shared with medical staff.<sup>3</sup> This change in style of practice has been encouraged by the Government in the UK as it potentially reduces health inequalities and leads to a better outcome of individual care.<sup>4</sup>

The results of studies suggest that patients with atrial fibrillation and aortic stenosis are often inappropriately undertreated.<sup>5–8</sup> The manner of risk communication from doctors to patients often assumes that patients are able to understand the risk information provided, that they can convert fractions to percentages and

## Key messages

- Atrial fibrillation and aortic stenosis provide both doctors and patients with difficult decisions about the risks and benefits of treatment options.
- Lack of transparency of risk information needs to be addressed to improve the quality of decision making in these conditions.

vice versa in order to compare risks, and that they have an appreciation of the likelihood of a favourable outcome or adverse event occurring or could be made to understand this by making simple analogies with previous life experiences such as throwing dice or playing card games. If such assumptions are incorrect, as suggested by the articles by Lloyd<sup>9</sup> and Edwards and Elwyn<sup>10</sup> in this supplement, it is relatively easy to appreciate how a patient may become confused by risk information. This confusion could lead to a decision that may not produce the most favourable outcome for the individual patient. Alternatively, doctors may be aware of patients' limitations and use this to manipulate choices to the ones desired by the doctors. Communication between doctors and patients may be further compromised by commonly occurring conditions in old age such as dementia and hearing difficulties.

This paper examines the importance of risk communication and discusses the difficulties that can arise in decision making in two common cardiovascular conditions.

## Atrial fibrillation

### THE CLINICAL PROBLEM: THE RISKS

Atrial fibrillation is a major risk factor for stroke and causes a large number of stroke events, particularly in older patients. Studies have noted that overall some 17–18% of patients with a stroke are in atrial fibrillation.<sup>11–13</sup> The prevalence of atrial fibrillation in a general practice population increases sharply with age as does the incidence of stroke (table 1).<sup>14</sup> Stroke events occurring in the presence of atrial fibrillation also show a similar sharp rise with age and the percentage of strokes that are directly attributable to atrial fibrillation, and could potentially be prevented by removing this risk factor, is such that several hundred strokes in patients over 75 could be prevented by appropriate intervention and risk reduction (table 1).<sup>15</sup>

The outcome from a stroke event is worse in patients who have atrial fibrillation than in those in sinus rhythm, with higher rates of

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Table 1 Atrial fibrillation (AF) and stroke: prevalence, incidence, and attributable risk

	Age (years)			
	60–69	70–79	80–89	90+
Prevalence of AF in general practice (%) <sup>1</sup>	1.5%	5.3%	6.6%	8%
Stroke events occurring in presence of AF (%) <sup>15</sup>	8.5%	18.8%	30.7%	
Stroke events attributable to AF (%) <sup>15</sup>	2.8%	9.9%	23.5%	
	65–74	75–84	85+	
Incidence of stroke (per 100 000) <sup>14</sup>	690	1428	2009	

death, disability, and need for long term institutional care.<sup>11-13</sup> In a multicentre European study 32.8% of patients in atrial fibrillation were dead at 3 months compared with only 19.9% not in atrial fibrillation.<sup>12</sup> One third of events are associated with a total anterior circulation syndrome.<sup>12</sup> The severity of the initial stroke event is the explanation for the poor outcome following strokes associated with atrial fibrillation.<sup>13</sup>

#### THE THERAPEUTIC INTERVENTION: THE POTENTIAL BENEFITS

Anticoagulants and antiplatelet agents reduce the risk of stroke associated with atrial fibrillation with warfarin reducing the risk by 62% (95% CI 48 to 72) and aspirin by 22% (95% CI 2 to 38) compared with placebo.<sup>16</sup> Pooled data from primary prevention trials found warfarin reduced stroke rates from 8.1% to 1.2% per year in patients over the age of 75 who were at high risk because of additional risk factors.<sup>17</sup> In the secondary prevention European Atrial Fibrillation Trial the risk of stroke was reduced from 12% per year to 10% per year by aspirin and 4% per year by warfarin.<sup>18</sup> Although there are potential benefits with aspirin and warfarin, there are also significant bleeding risks, especially in older patients.<sup>19-20</sup> In one study aspirin was found to produce an intracranial bleeding rate of 0.8% per year and warfarin 1.8% per year in patients over 75 years of age.<sup>21</sup> The baseline rate for intracerebral bleeding is around 0.1% per year.<sup>19</sup>

#### THE DECISION: RISK COMMUNICATION

Many of the general practice based decision, risk, and preference studies relating to atrial fibrillation and anticoagulation have noted that patients can be reluctant to take warfarin even when it may be in their best interest.<sup>22-24</sup> The attitudes of general practitioners, particularly around safety issues and inconvenience, may have a significant influence on the community initiation of anticoagulants.<sup>5-25</sup> These concerns are not unique to general practice and hospital based physicians also have concerns that patients in trials are not the same as those encountered in routine everyday practice and that, with a population of frail older patients, the inconvenience and bleeding risks may not outweigh stroke prevention benefits.<sup>26-27</sup> There are, however, differences between hospital and general practice, with anticoagulants tending to be used more often in hospital for stroke prevention, and in one recent study 167 of 172 (97%) high risk patients in atrial fibrillation attending a hospital outpatient clinic were persuaded to take warfarin.<sup>28-29</sup>

It is not clear why there should be differences between hospital and general practice, but there could be several explanations. The manner of risk communication may be different and influenced by the doctor's own risk and benefit perceptions that themselves have been positively or negatively influenced by the type of patient encountered and any previous adverse experiences with warfarin or aspirin. Strokes prevented by warfarin will obviously not be seen but bleeding episodes, particularly

You've done well to recover from the small stroke event associated with the irregular heart rhythm. It is possible to prevent further episodes and there is a choice between two treatments. Warfarin, rat poison, is good and will reduce the risk of stroke from 12% to 4% over the next year but you will need to be careful with drinking alcohol, a blood test will be needed every few weeks or months, and it can cause bleeding. This last point is of concern to doctors as there is about a 10-20 fold increase in risk of bleeding into the brain and causing a stroke. The alternative is aspirin. It is not quite as good as warfarin but it does reduce the risk of stroke by about 20% and you do not need any blood tests. Bleeding risks are minor compared with warfarin. It also comes in a sugar coated version that is kinder on the stomach. Which treatment would you prefer?

Box 1 Risk communication in atrial fibrillation: version 1.

if fatal, in general or hospital practice will be noted. Similarly, hospital doctors will usually have a more frequent exposure to strokes related to atrial fibrillation and the devastating nature of many of these events. Such experiences are less likely in general practice; an average of fewer than five patients are seen each year with stroke by a GP, only one of whom is likely to have been in atrial fibrillation. How the risks and benefits are presented to an individual patient in a discussion, as illustrated in boxes 1 and 2, and how they are perceived and interpreted by patients will influence their preferred choice. The papers by Lloyd and Edwards and Elwyn in this supplement explore these issues in detail.<sup>9-10</sup>

The presentation of the information and framing of risks may be more positive in hospitals than in general practice. Hospital doctors may be more paternalistic than general practitioners and simply manipulate the risk information conveyed to patients in a similar format

You've done well to recover from the small stroke event with the irregular heart rhythm. It is possible to prevent further episodes and there is a choice between two treatments. Warfarin is good and will reduce the risk of stroke by 66% over the next year. It stops eight strokes in every 100 patients given the treatment. You will need to be careful with drinking alcohol and a blood test will be needed every few weeks or months. Warfarin can occasionally cause bleeding into the brain to cause a stroke itself, however the chances of this happening are really very small and in 982 patients in 1000 this does not happen. The alternative is aspirin. It is not quite as good as warfarin but it can reduce the risk of stroke by about 20%. It can cause bleeding including about a twofold increase in brain bleeding causing a stroke. Which treatment would you prefer?

Box 2 Risk communication in atrial fibrillation: version 2.

to that in boxes 1 or 2, depending on what they feel should be the appropriate treatment for an individual patient. Different methods may be used in hospital from general practice to aid understanding of the risk and the likelihood of events occurring or not by using analogies such as the likelihood of choosing a certain card or cards from a pack. There is no evidence that any of these might be the explanation for differences between hospital and general practice, but nor is there evidence that they are not influential on patient choice.

The presentation of risk information as cumulative risk for year on year effects could elicit a different patient choice from that made when a patient is presented with risk information relating to a single year. For an older person over 75 whose life expectancy is about 10 years or less, it might perhaps be preferable to provide the lifetime risk estimates of surviving without a stroke rather than presenting the information as a repetitive yearly gamble. Research has found that the presentation of overall cumulative outcomes after five individual gambles, related to money rather than stroke avoidance, is more likely to entice someone to play than just giving the outcome of the single one time only gamble and the choice to play five successive times.<sup>30</sup> If the 12% per year risk of another stroke event following a transient ischaemic attack or stroke with atrial fibrillation is constant in each subsequent year while taking no treatment and this is reduced to 4% a year with warfarin, then after 1 year there is an 88% chance of not having a stroke with no treatment and a 96% chance of not having a stroke if warfarin had been taken. However, following 5 years of no treatment there is a 53% chance of not having a stroke compared with 82% if warfarin had been taken. Would this cumulative format of information presentation influence choice?

Further research on risk communication and shared decision making in relation to atrial fibrillation is clearly required as many elderly people with atrial fibrillation would accept treatment to prevent stroke.<sup>22</sup> The fact that very few people who have a stroke in association with atrial fibrillation are taking either aspirin or warfarin suggests that patients are perhaps not being involved in the decision process or that there are difficulties with risk communication that need to be identified and resolved.<sup>12</sup>

### Aortic stenosis

#### THE CLINICAL PROBLEM: THE RISKS

Thickening of the aortic valve is a common finding, being present in approximately 25% of people over the age of 65.<sup>31</sup> The process is progressive and severe degenerative aortic valve disease occurs in 1–3% of the elderly.<sup>32</sup> Not all patients are symptomatic but, when symptoms do begin, the prognosis is poor. The mean survival of aortic stenosis presenting with angina is around 5 years, reducing to 3 years with syncope and only 1–2 years with heart failure which is the presenting symptom in a third of patients.<sup>2</sup> In a group of 50 patients at the Mayo Clinic who had symptomatic severe aortic stenosis the 1, 2, and 3 year survival without

intervention was 57%, 37%, and 25% respectively compared with age and sex matched control survival of 93%, 85%, and 77%.<sup>33</sup>

#### THE THERAPEUTIC INTERVENTION: THE POTENTIAL BENEFITS

Surgical replacement of the aortic valve is potentially curative with the long term outlook being as good as the normal population for those surviving surgery.<sup>34</sup> The alternative treatment of percutaneous balloon valvuloplasty is disappointing in older patients with significant complication rates and no survival benefit.<sup>35</sup> Surgical intervention is not without significant risks, particularly in patients over 80 with an average early 30 day postoperative mortality of 9.2% for valve replacement alone rising to 20.9% if coronary artery bypass grafting is required in addition to valve surgery.<sup>36</sup> There are also risks to the cerebral circulation and an Oxford study noted stroke complications post-operatively in 17% of patients and more recently there have been reports of late cognitive decline with bypass surgery.<sup>34 37</sup>

#### THE DECISION: RISK COMMUNICATION

As a patient, would you take the gamble of surviving for just over a year on the toss of a coin coming up heads? Do the odds seem better if at 3 years the chance of being alive depends on drawing a spade from a pack of cards? Would you be willing to die from surgical intervention on the roll of a die if it came up as a 6 if you knew that throwing a 1 to 5 would give you a 90% or more chance of living another year and about a 75% chance of being alive in 5 years?<sup>34</sup> The psychology of preferences would suggest that patients should exhibit risk seeking preferences in relation to decisions around aortic valve disease because of the gloomy prognosis without intervention.<sup>38</sup> Are patients really given a choice or are they directed to medical treatment, perhaps to the relief of both patient and surgeon by the type of risk discussion shown in box 3? Placing the risks in a more positive frame indicating a 80–90% survival and an 80% chance of not having a stroke may favourably alter the decision towards intervention. Even though surgical risks are high at 10–20%, the decision analysis for an 87 year old woman would suggest medical treatment to

Even at 80 you can have surgery on your narrowed aortic valve that is causing the chest pain and breathlessness. There is a choice of treatment and it is rather like being faced by two doors at the end of a corridor. If you go through the medical door you can keep taking tablets to control symptoms and there is an even chance of being alive in 2 years. If you go through the surgical door there is a 10–20% risk of dying from the operation and about a 1 in 5 risk of a stroke. If you survive the operation and all goes well, which hopefully it will, you can expect to live for another 6 or 7 years. Would you like to have the operation or keep taking the tablets?

Box 3 Risk communication in aortic stenosis.



be the preferred option only if surgical mortality was over 70%.<sup>39</sup>

From personal anecdotal experience, even if surgical intervention is stated in the most favourable terms, there are some patients who feel that the gamble is difficult to wage. It is not clear why older people are unwilling to gamble to trade off 1 or 2 years of pain and breathlessness for a potentially better than average, relatively symptom free life expectancy. It is possible that some older people feel that they are already living on borrowed time and any extra time is a bonus. Alternatively, there could be an unwillingness to pursue an option at this stage of life that brings rewards but only in several years time. Patients may feel that the proportion of life expectancy lost is too great if surgery fails. The proportion of life expectancy lost increases with increasing age if surgery results in death; a 2 year life expectancy out of the possible 6 or 7 years remaining in an 80 year old man with aortic stenosis and failure may not be worth risking, whereas in a 65 year old with a life expectancy of 15 years the 2 year survival on medical treatment makes the surgical option very attractive.

Aortic stenosis is not perceived as a malignant condition, yet the prognosis is worse than that of many cancers. If the same prognoses, risks, and benefits were applied to a cancerous condition, would doctors and patients reach the same decision not to intervene in so many cases? Factors that deter physicians from referring older people for surgery are by no means clear. There is the concern that resource reasons relating to limited surgical capacity influences discussions and deters many surgical referrals even though there has been a dramatic increase in recent years in the numbers of patients over 80 undergoing aortic valve replacement.<sup>34 40 41</sup>

### Conclusions

Atrial fibrillation and aortic stenosis are common problems that pose some interesting questions about risk communication and decision making that require further research. The lack of transparency of risk information for patients caused by using absolute risks, relative risks, percentages, odds, and fractions, often all in the same discussion, needs to be addressed as this can deliberately or accidentally lead to positive and negative framing effects that have major influences on intervention decisions. The quality of decision making in these two conditions can only improve with greater clarity in the language used in risk communication.

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