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**Prioritized outcomes to evaluate the effectiveness of atrial fibrillation
disease management: A systematic review and Delphi study.**

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INTRODUCTION

The management of atrial fibrillation (AF) is a big challenge for cardiac care providers, since AF prevalence is continuously increasing in an aging society. Adequate AF management requires implementation of and adherence to evidence-based guidelines in clinical practice (1;2). It has been argued that interdisciplinary AF expert programmes may be a vehicle to provide guideline-based AF care (3). However, for researchers, clinicians and policy-makers, it is unclear which outcomes or key performance indicators should be prioritized when assessing care delivery. Researchers want to know what the primary outcomes should be when evaluating novel AF disease management strategies like AF expert programmes. Clinicians want to demonstrate the value they add to patient care, by proving the effectiveness of their role in the provision of care. Policy-makers want to know what outcomes should be scrutinized to incentivize effective and cost-effective care (4-6).

In a search for such outcomes/key performance indicators we aimed to 1) provide a list of internationally accepted outcomes to evaluate the implementation and effectiveness of AF disease management programmes, and 2) to rank-order the outcome variables according to their perceived priority.

METHODS

Therefore, we performed a comprehensive literature review followed by a one-round Delphi study. The literature review aimed to identify and list possible outcomes of AF management. For this purpose, the databases Medline, Cinahl, Embase and CRD were searched for relevant publications from inception to March 2010. Publications were selected if the following criteria were met: (i) studies describing AF-related outcomes and (ii) written in English, French or Dutch. Publications related to other cardiovascular diseases were excluded.

The Delphi study aimed to exclude outcomes from this list that were considered less or irrelevant; to identify missing outcomes; and to rank the remaining outcomes according to perceived priority. A Delphi study is a structured group communication method to gather expert opinion about novel ideas, through the use of a questionnaire. It allows the anonymous inclusion of a large number of individuals across diverse geographically dispersed locations and expertise, and avoids situations in which a few experts might dominate the consensus process (7). Another advantage is that it is a time-saving method to ensure input from often busy and much sought-after experts.

Potential participants for the one-round Delphi were sought through literature review and personal contacts known to the authors. Eligibility criteria for the expert selection were 1) nurses and cardiologists or electrophysiologists whose expertise was focused on AF care; 2) academic and/or clinical experience within cardiology and/or electrophysiology; 3) at least 1 publication about AF; and 4) availability of valid contact information. This resulted in a panel of 36 international AF management experts (11 nurses and 25 cardiologists/electrophysiologists). These experts were invited to fill out a survey form. Respondents assessed the level of importance of the proposed outcomes using a 6-point rating scale (1=lowest relevance; 6=highest relevance). It was also possible to add other suggestions by free text space that was provided. Non-responders received up to three reminders.

Of the 36 experts invited, 14 participated (response rate=39%): 1 from Canada; 3 from USA; and 10 from Europe, comprising a total of 7 countries. The characteristics of the panellists and non-participating experts are described in Table 1.

Table 1 Professional characteristics of panellists and non-participating experts of the one-round Delphi study

Variables		Participating panellists (n=14)	Non-participating experts (n=22)
Gender	Female	4 (28.6%)	8 (36%)
	Male	10 (71.4%)	14 (64%)
Age category (years)	< 25	0 (0)	NA°
	26-35	2 (14.2%)	
	36-45	2 (14.2%)	
	46-54	3 (21.3%)	
	55-64	6 (43.1%)	
	>65	1 (7.2%)	
Working position	Stroke physician	0 (0)	1 (4.5%)
	Cardiologist	0 (0)	1 (4.5%)
	Cardiologist – Academic	4 (28.6%)	3 (13.6)
	Electrophysiologist – Academic	5 (35.7%)	11 (50%)
	Research Nurse with AF expertise	3 (21.3%)	4 (18.8%)
	AF Clinical Nurse Specialist	2 (14.2%)	1 (4.5%)
	Academic Nurse	0 (0)	1 (4.5%)
Highest level of education	Bachelor degree	0 (0)	2 (9%)
	Master degree	0 (0)	5 (22.5%)
	PhD-student	1 (7.2%)	1 (4.5%)
	PhD/Doctorate	13 (92.8%)	14 (64%)
Years of expertise in the domain of AF*	<5	1 (7.2%)	NA
	5-10	2 (14.2%)	
	11-15	2 (14.2%)	
	16-20	2 (14.2%)	
	21-25	4 (28.9%)	
	>25	3 (21.3%)	
Number of publications about AF	1	2 (14.2%)	4 (18.8%)
	2	1 (7.2%)	4 (18.8%)
	3	2 (14.2%)	0 (0)
	5	0 (0)	2 (9%)
	>5	9 (64.4%)	12 (53.4%)
Country	USA	3 (21.3%)	3 (13.6%)
	Italy	3 (21.3%)	1 (4.5%)
	The Netherlands	2 (14.2%)	1 (4.5%)
	Austria	1 (7.2%)	0 (0)
	Canada	1 (7.2%)	3 (13.6)
	Denmark	1 (7.2%)	0 (0)
	France	1 (7.2%)	1 (4.5%)
	Germany	1 (7.2%)	1 (4.5%)
	UK	1 (7.2%)	4 (18.8%)
	Australia	0 (0)	1 (4.5%)
	Ireland	0 (0)	1 (4.5%)
	Norway	0 (0)	1 (4.5%)
	Slovakia	0 (0)	1 (4.5%)
	Spain	0 (0)	1 (4.5%)
	Sweden	0 (0)	1 (4.5%)
	Switzerland	0 (0)	1 (4.5%)
	Turkey	0 (0)	1 (4.5%)

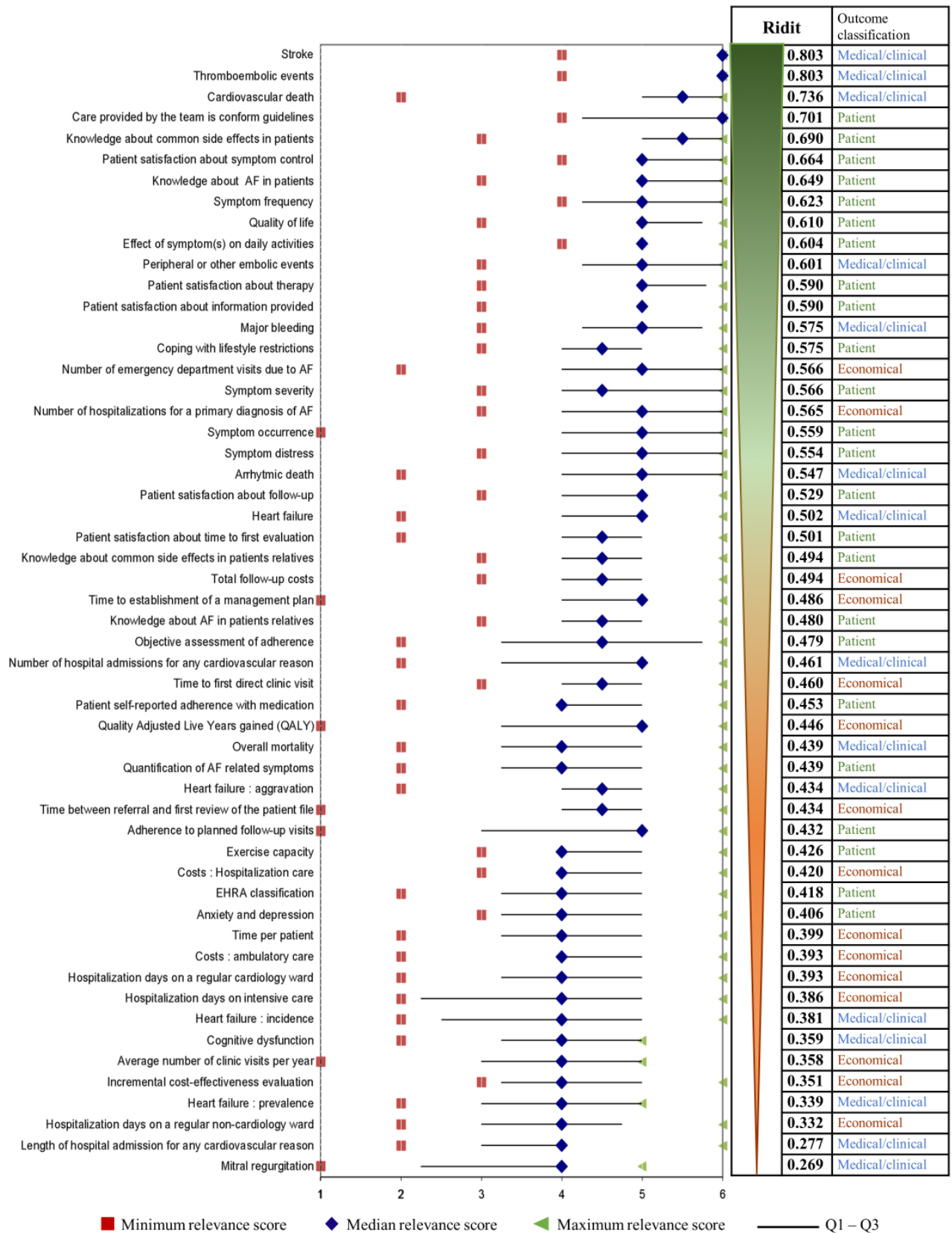
°NA=not available;*AF=atrial fibrillation

Data were analysed descriptively. Median scores, range of scores and quartiles (Q1-Q3) were calculated. Since medians do not allow apt discrimination between relevance scores, we applied RIDIT analysis, which is a more sensitive technique to analyse ordinal level data (8). A RIDIT can range from 0 to 1. The higher the RIDIT, the higher the level of relevance scored by the experts (9).

RESULTS

Based on the literature search, we made a list of 54 outcomes or key performance indicators for AF management. This list comprised 15 medical/clinical outcomes (3 morbidity- and 12 mortality-related); 24 patient outcomes (3 psychosocial; 7 AF-related symptom and symptom burden; 4 knowledge; 5 patient satisfaction; 1 exercise capacity; 4 therapy adherence-related); and 15 economical outcomes (5 hospitalization; 1 outpatient clinic; 3 patient access time/ time assessment; 1 physicians' burden; 5 cost-related). Analysis of the relevance scores showed that all outcomes received a median score ≥ 4 on a scale from 1 to 6, and 25 out of 54 outcomes received a median score ≥ 5 (Figure 1). The 10 most important outcomes for the panel were stroke; thromboembolic events; cardiovascular death; care provided by the team is conform guidelines; knowledge about common side-effects in patients; patient satisfaction about symptom control; knowledge about AF in patients; symptom frequency; quality of life; and effect of symptom(s) on daily activities (Figure 1). Additional outcomes suggested by the panellists were: myocardial infarction; time within therapeutic range during vitamin K antagonist therapy; number of lost working days for patient and family members; and patient satisfaction about information provided regarding social issues, such as travelling, driving, sexual activity and insurance.

Figure 1 Relevance scores and priority order of 54 outcomes pertinent to the evaluation of the effectiveness of AF expert programmes.



DISCUSSION AND CONCLUSION

Disease management programmes for AF aim for guideline-adherent care that results in improved clinical, patient-perceived and economical outcomes (3;6;10). Outcome studies are needed to evaluate the effectiveness of such disease management programmes. To guide future outcome studies and clinical evaluations, we developed a list of prioritized outcomes/key performance indicators, relying on existing literature and conducting a Delphi study. The latter methodology usually demands multiple survey rounds. However, because all outcomes received a median relevance score ≥ 4 , no second survey round was deemed to be necessary. It is desirable that studies in the field of AF care try to focus on the key performance indicators to enable cross-comparison and serial follow-up.

A literature update from March 2010 until September 2015 showed that by far most of the outcomes described in the recent literature overlap with the outcomes that have already been included in this Delphi study. However, this resulted in some new but hard quantifiable outcomes like ‘self-care behaviour/management’, ‘cardiovascular morbidity’ and ‘clinical stability’. Even though some potentially interesting outcomes were cited like ‘treatment-induced adverse events’, ‘cost per life year’, ‘total healthcare cost per patient’ and ‘all-cause healthcare cost (e.g. cost for inpatient stays, emergency room, outpatient facility, physician office visits,...)’.

As limitations of our study a relatively low response-rate should be noted. However, a low response was anticipated since we invited an international group of highly-qualified experts in AF management and communication was only performed by email, not in-person. Exactly for that reason, we invited a rather large group of experts in order to end up with an acceptable number contributing to the study. The characteristics of the non-participating experts do not substantially differ from those of the participating panellists. Therefore, we think that the results of the study are valid. Moreover, we did not seek input from patients, general practitioners and

healthcare entities: this may explain why most economical outcomes were ranked much lower than medical and patient outcomes.

In conclusion, the list of prioritized outcomes / key performance indicators can inform researchers, clinicians and policy-makers to assess the efficacy and effectiveness of AF disease management programmes or other interventions to improve AF care (3).

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