Patient Preference and Patient Empowerment

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Overview

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1. German Heart Foundation & its medical consultation service

2. Patients‘ problems/concerns related to NOACs

3. Patients‘ preferences – case studies from medical consultation service & implications

4. Conclusion

German Heart Foundation

- Founded in 1979 by leading cardiologists
- NGO, registered association
- Currently 96,000 members (mostly patients & caregivers)
- Main income sources: donations, membership fees, legacies - **no funding/support by the industry**
- Organs: Board, Scientific Advisory Board, Board of Trustees, General Assembly
- 32 staff members in the Frankfurt office, 112 voluntary representatives

Empowering patients by …

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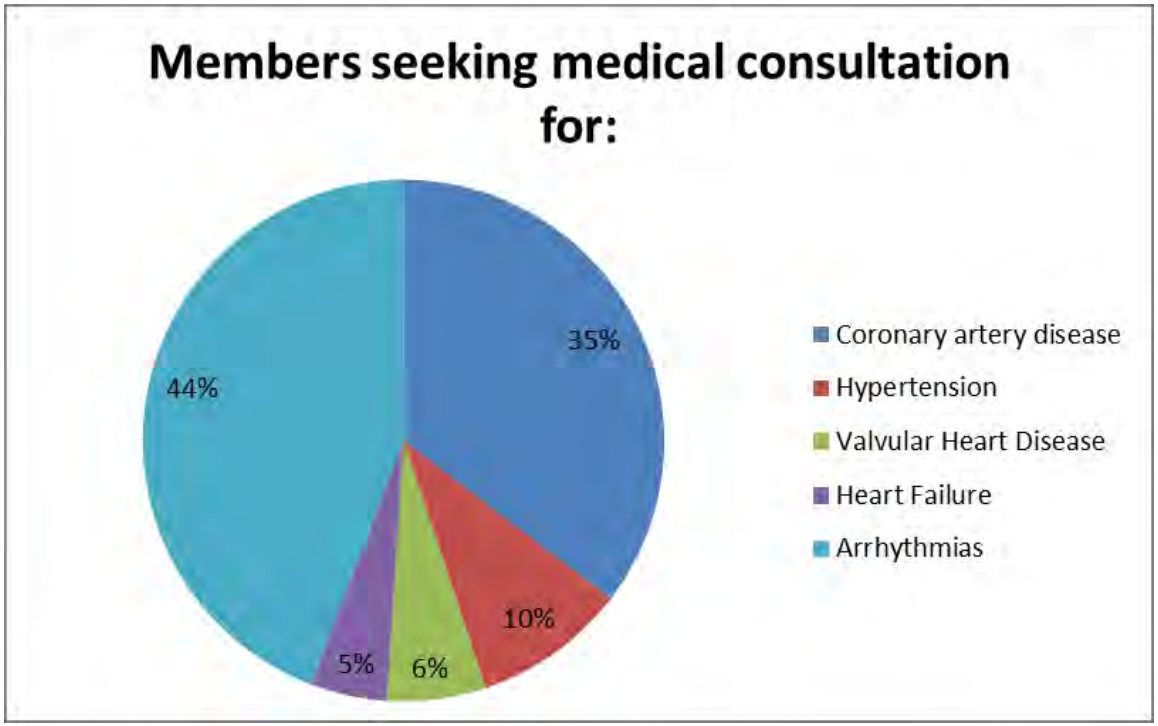
- Helping them to understand their diagnosis.
- Providing them with up-to-date information on their treatment options and thereby enabling them to discuss options with their physician/make an informed choice.
- Educating them (and the general public) about the benefits of a heart-healthy lifestyle.
- Encouraging patients to ask questions, to get a second opinion.
- Offering advice how to find a specialist/clinic.
- Encouraging patients to become their own advocate and to take responsibility.
- Message: Keep an eye on your heart!

Education and information services

- Website: www.herzstiftung.de
- Monthly E-Mail-Newsletter
- Members‘ journal „Heart Today“ (circulation: 150.000 /quarterly published)
- Information service/brochures/leaflets/identification cards/emergency certificates
- Seminars and lectures (November = „Heart Weeks“, more than 1000 events nationwide)
- **Medical consultation service (by mail/phone)**

Medical consultation service



Medical consultation via online form, June 2016, total number of requests: 147

Patients' concerns/problems related to NOACs

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- Patients have great concerns about bleeding risks, less about stroke risk.
- Patients have concerns regarding drug interactions, especially with NSAIDs, and side effects.
- Patients get differing information from different medical specialists regarding procedural management.
- Patients question the indication and/or dosage.
- Triple therapy is an issue for CAD patients with AF.
- **Patients often have preferences, but their preference is not always taken into account.**

Concerns in online patient support groups

NOACs – patients‘ preference I.

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„I’m facing a tooth extraction and possibly also a colonoscopy. From what I’ve heard, the **procedural management** with NOACs is so much easier, so I’d like to switch from Marcumar (Phenprocoumon) to Eliquis (suffered a stroke in 2015 and was diagnosed with atrial fibrillation). My GP gave me a prescription for 2 x 5mg. I think this dosage is too high and might result in a higher **bleeding risk**. My twin-sister takes 2 x 2.5mg only. I’m 72 years old and my weight is 52kg.”

(Female, no information about renal function)

NOACs – patients‘ preference II.

„My 81 year old mother-in-law is suffering from atrial fibrillation. For stroke prevention she has been prescribed Marcumar (Phenprocoumon). She is complaining about the **frequent INR tests**, apparently it‘s difficult for her to stay in the range. We have therefore asked her **GP** about the possibility of prescribing a NOAC. He refused arguing that there is **no antidote** for it and any bleeding could therefore not be stopped. Does he have a point? Or is it because of his age (70) that he’s not open minded about new drugs? What shall we do?“

NOACs – patients‘ preference III.

„My father‘s GP wants to switch him from Phenprocoumon to Eliquis because his last INR was 3.1. For years he‘s been in the correct range, no problems at all. **GP says**, with the new drug **no more tests** are required – but my father is not immobile, visiting the doctor‘s office is fine for him (I think **he’s feeling more secure** when being seen regularly). Are there any other reasons for switching him to a NOAC? I‘d rather like him to continue Phenprocoumon since he was doing fine on that."

NOACs – patients' preference IV.

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"Had a stent placed in 2011, first episode of atrial fibrillation one year later. Only have an episode about every two years, lasting 10-18 hours, converts with antiarrhythmic drugs at the hospital. Since I do not have many risk factors for stroke, I was advised to take ASS 100mg only. After my last AF episode however this changed and the cardiologist now strongly recommends Lixiana 30mg - which I unwillingly agreed to. Do I really need to take it? I'd rather stay on ASS, I have a **very active lifestyle** (mountain biking, hiking, skiing) and am afraid of bleedings."

(Male, 65 years, CHA_2DS_2-VASc Score according to information additionally provided is 1).

NOACs – patients‘ preference V.

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“I take Marcumar and have recently had **trouble staying in my INR range**: it’s fluctuating between 2.0 and 4.0. My GP has suggested to take Xarelto 15mg instead. I have searched the **web and media** for information on this new drug and have read about serious side effects and a lawsuit in the U.S. There was also a rather negative documentary on TV. What would you recommend?”

(Male, 76 years, no information why he is on an OAC, no information about method of INR monitoring)

Patients' values & preferences

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Patients report various reasons for their choice:

- Convenience/easier handling of NOACs (no monitoring, no bridging, etc.)
- Difficulty staying in the INR range with VKAs
- (Presumed) Side effects/drug interactions
- Antidote availability
- Lifestyle
- Media
- Having to go with physicians' preference: costs, antidote availability, lower bleeding risk, …

Conclusions

- Patients have various concerns and also preferences with regard to anticoagulation.
- Patients‘ preferences should be taken into account (→ greater adherence!).
- On patients‘ side better education about bleeding versus stroke risk is needed.
- On physicians‘ side better education and cooperation is needed regarding periprocedural management. Better education is also needed in terms of indication & dosage.

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Thank you very much!