Heart Patients' Perspectives on 30-Day ML-based Risk Predictions: Exploring Implications for Patient Self-Care and Patient-Physician Collaboration

Tariq Osman Andersen

Dept. of Computer Science, University of Copenhagen, Denmark, tariq@di.ku.dk

Stina Matthiesen

Dept. of Computer Science, University of Copenhagen, Denmark, tariq@di.ku.dk

Emil Vogt Sørensen

Dept. of Computer Science, University of Copenhagen, Denmark, tariq@di.ku.dk

This study explores heart patients' perspectives on self-care and the consequences for patient-physician collaboration when extending ICD remote monitoring with 30-day risk predictions, wearable activity tracking, and patient engagement through a patient mobile app. Two rounds of interviews were conducted in Feb-April 2022 using scenario-based walkthroughs and screen mock-ups of the mobile app. We share the very early exploration of the effects of introducing AI into the existing telecare network and study what this might mean for how patients think and act during moments of human-ai-human engagements.

1 INTRODUCTION

The area of concern of this paper is to explore the implications for patient self-care and patient-physician collaboration when introducing AI-based predictions and wearable activity data into the care network. Lethal heart arrhythmias, known as ventricular tachycardia and ventricular fibrillation (VT/VF) constitute a growing challenge to health care systems worldwide [1]. Implantable cardioverter defibrillators (ICDs) have led to major advances in the prevention of sudden cardiac death from VT/VF [12] and remote monitoring has become the standard of care for ICD patients [17]. While remote monitoring has increased survival rates [14] the care-scheme is mostly reactive i.e., taking clinical action based when disease exacerbation is rising. It is known that increased numbers of VT/VF followed by ICD treatment correlates with death and that the current way remote monitoring works is focused on detection rather than prediction. In earlier work, we have explored how machine learning can be used to develop predictive tools to support clinicians and their decision-making [11].

With this paper, we wish to turn to patients and explore their perspectives of being exposed to 30-day risk predictions and what this means for them and their collaboration with clinicians. We are interested in exploring the effects of introducing AI into the existing telecare network and study what this might mean for how patients think and act during moments of human-ai-human engagements.

2 BACKGROUND

Healthcare information systems have traditionally been designed for clinicians as end-users and the distribution of roles between patients and clinicians have supported a paternalistic and conservative view of the patient-clinician relationship. The patient was considered a passive receiver of professional advice and the clinician acted as authoritarian [4]. The consumer movement during the 1960s has, although, given the consumers' right to security, the right to be informed, the right to make their own choices and the right to be heard [10]. This mindset has influenced the way care was provided and patients are increasingly becoming active participants in their own treatment [4,13]

The development of tele- and internet-based technologies have afforded new ways of patient participation. Initially, telecare solutions like remote monitoring systems engaged patients from a distance and enabled patients to be involved in new ways, such as taking part in the diagnostic work and the decision making [13]. During the past two decades we have witnessed a boom in wearable self-care technologies and mobile applications that support chronic patients and their everyday management of their disease, which in turn, has affected the ways in which patients and clinicians collaborate [7]. According to Thompson, [16] there are different degrees of involvement of patients in their treatment ranging from non-Involved to information seeing/receptive to wishes for shared and autonomous decision-making. The focus on designing healthcare technologies and systems to support patient-clinician collaboration and trying to balance the different needs, is receiving increased attention [2,7]. This shift to involve patients more actively in healthcare through technology rests on the assumption that patients benefit from - and want and to be - actively involved in their own treatment [4].

More recently, explorations of AI and the effects on the patient-clinicians relation is considered [9,15]. The involvement of patients in a form of Human-AI team enables patients to take part in the diagnostic process in new ways. Research on AI-assisted decision-making systems show that intuition [6] and conceptual models [3] might have an impact on how outcomes from AI-based systems are understood and trusted.

2.1 Research setting

The study, from which we are reporting, is part of a larger European research and development project called SafeHeart (2020-2023) [8]. The SafeHeart project is a cross-institutional and interdisciplinary collaboration between two cardiology clinics (university hospitals in Netherlands and Denmark) and two digital health companies that specialise in patient-centered and AI-based decision-support (Denmark) and objective measurement of physical behaviours and lifestyle using wearable activity trackers (UK). Ethics approval was obtained at the two participating hospitals, and the study is conducted in accordance with the Declaration of Helsinki as revised in 2013, registered at the National Trial Registration in the Netherlands (Trial NL9218; https://clinicaltrialregister.nl/en/trial/20961).

The overall project aims to improve remote monitoring of patients with an implantable cardioverter-defibrillator (ICD) by developing an ML-based early warning system that uses data from implantable and wearable devices to identify participants at risk of developing life-threatening heart arrhythmia. The system developed in the SafeHeart project extends current remote monitoring of ICD patients. It works by patients transmitting ICD data from their home monitoring box to the clinic for review. The SafeHeart platform is an add-on system that consists of a wearable activity tracker and mobile app for patients, a web-based dashboard for clinicians, and a backend engine, which computes wearable and cardiac device data using ML algorithms to make 30-day risk predictions of severe cardiac arrythmias.

2.2 Data collection and analysis

Ten ICD patients and their relatives were invited and accepted to participate in two rounds of qualitative interviews. Informed consent was obtained from all participants. Two rounds of interviews were conducted Feb-April 2022 using scenario-based walkthroughs and screen mock-ups of the mobile app. The first interview round investigated the self-care practices of the participants, their experiences with remote monitoring and their interaction with the clinic, and memorable situations of severe symptom experiences or shock or treatment from the ICD. The second interview explored the attitudes and speculations about using the SafeHeart system. We designed a range of mobile app screen mock-ups and developed a tailored interview guide that was based on memorable situations derived from the initial interviews. The second interview round consisted of the patients and carers doing a walkthrough of the scenarios using the mock-ups while thinking aloud and discussing with the interviewer. All interviews were recorded and transcribed verbatim.

Data analysis is being carried out collaboratively using an inductive qualitative approach based on constructing grounded theory [5] supported by the qualitative data analysis software NVivo 12 (QSR International, Melbourne, Australia). For this workshop paper, we coded all interviews using open coding (i.e., line-by-line coding). At the time of writing, we are in the early analytical phase of generating insights and themes through focused coding of the interviews.

3 EARLY FINDINGS

This study explores patient perspectives and the consequences for patient-physician collaboration when extending ICD remote monitoring with 30-day risk predictions, wearable activity tracking, and patient engagement through a patient mobile app. In the following, we present insights from work in progress, and from the initial analysis emerging from interviews with two of the ten participants.

3.1 Interpretation and Trust

During discussions with one patient and her partner, we found AI can trigger patient-physician collaboration, which can lead to a doctor engaging in a dialogue around opportunities for action. This introduces new opportunities for preventive action, initiated by an AI system. However, for most patients, trust in AI-based risk predictions ultimately depend on a doctor taking part in the interpretation of the prediction and having the final say and oversight.

> *Interviewer: Getting risk assessments that are made by this computer algorithm, and based on different types of data -- how much confidence would you have in it?*
>
> *Patient: I still want people to look at it. Someone who can confirm that it is true. But I know very well that this form of intelligence can do a lot and it is found more and more in all sorts of places. But yes, a real doctor too.*
>
> *Patient's partner: Well, I dream of having a wearable like that one day, so that I can measure heart rate and everything else. It's nice to know in advance if you must do something. You get a message that you must do something or that you need to contact the doctor.*

However, some patients responded with concerns about repeated, possibly false predictions. When discussing various scenarios against historic episodes, one patient explained that he was concerned about the AI-based predictions were based on changes in his activity and behavior. For him, context matters and he considered how seemingly abnormal behavior may affect the ways in which the AI-based system reach conclusions of risk predictions.

Patient: My work involves a lot of shifts and working overtime […] there's not really a steady rhythm. It goes up and down.

Interviewer: Would you say that you fear that this system will ask you to make transmission all the time [due to changes in activity and behavior]?

Patient: yeah, but then I would also know the reason and I would take it more easy.. And maybe not make the transmission […] you could also make a transmission and write "I have worked my ass off".. I'm not sure what I would do in that situation.

3.2 Prediction and Action

One patient found that 30-day risk predictions can become meaningful when they align with existing symptom experiences. For her, the 30-day risk predictions become useful, especially when they confirm her symptoms and feelings about worsening of her condition and when experiencing something is underway. In this way, AI can help patients take preventive action, which is well sought after.

Interviewer: What do you think, now you've walked through all these mockups and scenarios about risk predictions? Has it produced anything positive or negative?

P1: Well, perhaps it's very good when you have the opportunity to find out if something is underway [severe heart arrythmia]. You can sometimes experience that you might be feeling a little bad, but then you are also confirmed about something is wrong.

3.3 Emotion and Risk

The same patient, however, speculated that the 30-day risk predictions may have a practical affordance, but sometimes they may also produce negative emotions that contest the usefulness and could lead to rejection of the system. This means that while there are affordances of receiving computed predictions, negative emotions emerge, which can affect the interpretation and use of AI-based results.

Interviewer: In this scenario the algorithm has measured low activity and therefore asks you to make a transmission. Does that make sense to you?

P: Yes, because if we say that I have plans for going travelling, and then I get this information, it could be useful. But - do I then dare to live? [..] In a way it's good, but I'm afraid I'll begin to worry more.

4 DISCUSSION

The initial analysis presented in this workshop paper suggests three things. First, AI-based prediction tools need to be carefully embedded into existing care networks with respect to the individual needs among patients. Specific attention has to be paid to the ways in which physicians can support the interpretation of 30-day risk predictions shown to patients. Ways to support collaborative interpretation is essential for trust and reliance in the AI-based systems. Second, 30-day risk predictions based on machine learning and activity trackers may be accepted during self-care practices. Especially, when the AI-based results align with patient experiences. This may mean including the patient experience before presenting the AI-based output to support trust and reliance. Thirdly, negative emotions emerging from ML-based predictions can lead to increased concerns and rejection. This may mean that when introducing AI-based predictions in patient-centered systems, there is a need for considering managing negative affect emerging from using the systems.

Our early findings complement existing work that explores the implications of embedding AI in existing care networks. Jabobs and colleagues [9] suggested that clinical decision-support tools should be designed as "multi-user systems that support patient-provider collaboration and offer on-demand explanations that address discrepancies between predictions and current standards of care." Similarly, we found that the patients' trust in using the risk predictions is contingent on their contextual situation and their own interpretation of their health state. While AI-based predictions may be informative, they are only useful to the extent in which they support the patient's mental model of the system [3] and the patients' intuition (i.e., past experiences, knowledge, pattern recognition) [6] and thereby become meaningful in the local context. This suggests that designing for trust and reliance in AI-based add-ons to existing telecare networks should recognize the strong ties to patients' individual contexts and their intuition for making AI useful in telecare networks.

REFERENCES

[1] Sana M. Al-Khatib, William G. Stevenson, Michael J. Ackerman, William J. Bryant, David J. Callans, Anne B. Curtis, Barbara J. Deal, Timm Dickfeld, Michael E. Field, Gregg C. Fonarow, Anne M. Gillis, Christopher B. Granger, Stephen C. Hammill, Mark A. Hlatky, José A. Joglar, G. Neal Kay, Daniel D. Matlock, Robert J. Myerburg, and Richard L. Page. 2018. 2017 AHA/ACC/HRS Guideline for Management of Patients With Ventricular Arrhythmias and the Prevention of Sudden Cardiac Death. *Circulation* 138, 13 (2018), e272–e391. DOI:https://doi.org/10.1161/cir.0000000000000549

[2] Tariq Osman Andersen, Jørgen Peter Bansler, Finn Kensing, Jonas Moll, Karen Dam Nielsen, Troels Mønsted, Olav Wendelboe Nielsen, Helen Høgh Petersen, and Jesper Hastrup Svendsen. 2018. Aligning Concerns in Telecare: Three Concepts to Guide the Design of Patient-Centred E-Health. *Computer Supported Cooperative Work (CSCW)* (May 2018).

[3] Gagan Bansal, Besmira Nushi, Ece Kamar, Walter S Lasecki, Daniel S Weld, and Eric Horvitz. 2019. Beyond Accuracy: The Role of Mental Models in Human-AI Team Performance. *Proc Aaai Conf Hum Comput Crowdsourcing* 7, (2019), 2–11. DOI:https://doi.org/10.1609/hcomp.v7i1.5285

[4] Jo Cahill. 1998. Patient participation — a review of the literature. *J Clin Nurs* 7, 2 (March 1998), 119–128. DOI:https://doi.org/10.1046/j.1365-2702.1998.00132.x

[5] K Charmaz. 2006. Constructing grounded theory: A practical guide through qualitative analysis (Introducing Qualitative Methods Series). (2006).

[6] Valerie Chen, Q Vera Liao, Jennifer Wortman Vaughan, and Gagan Bansal. 2023. Understanding the Role of Human Intuition on Reliance in Human-AI Decision-Making with Explanations. *Arxiv* (2023). DOI:https://doi.org/10.48550/arxiv.2301.07255

[7] Chia-Fang Chung, Kristin Dew, Allison Cole, Jasmine Zia, James Fogarty, Julie A Kientz, and Sean A Munson. 2016. Boundary Negotiating Artifacts in Personal Informatics. *Proc 19th Acm Conf Comput Cooperative Work Soc Comput* 2016, (2016), 770–786. DOI:https://doi.org/10.1145/2818048.2819926

[8] Diana M. Frodi, Maarten Z.H. Kolk, Joss Langford, Tariq O. Andersen, Reinoud E. Knops, Hanno L. Tan, Jesper H. Svendsen, Fleur V.Y. Tjong, and Soeren Z. Diederichsen. 2021. Rationale and design of the SafeHeart study: Development and testing of a mHealth tool for the prediction of arrhythmic events and implantable cardioverter-defibrillator therapy. *Cardiovasc Digital Heal J* 2, 6 (2021), S11–S20. DOI:https://doi.org/10.1016/j.cvdhj.2021.10.002

[9] Maia Jacobs. 2021. Designing AI for Trust and Collaboration in Time-Constrained Medical Decisions: A Sociotechnical Lens. In (Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems), 1–14. DOI:https://doi.org/10.1145/3411764.3445385

[10] Yves Longtin, Hugo Sax, Lucian L. Leape, Susan E. Sheridan, Liam Donaldson, and Didier Pittet. 2010. Patient Participation: Current Knowledge and Applicability to Patient Safety. *Mayo Clin Proc* 85, 1 (January 2010), 53–62. DOI:https://doi.org/10.4065/mcp.2009.0248

[11] Stina Matthiesen, Søren Zöga Diederichsen, Mikkel Klitzing Hartmann Hansen, Christina Villumsen, Mats Christian Højbjerg Lassen, Peter Karl Jacobsen, Niels Risum, Bo Gregers Winkel, Berit T Philbert, Jesper Hastrup Svendsen, and Tariq Osman Andersen. 2021. Clinician Preimplementation Perspectives of a Decision-Support Tool for the Prediction of Cardiac Arrhythmia Based on Machine Learning: Near-Live Feasibility and Qualitative Study. *Jmir Hum Factors* 8, 4 (2021), e26964. DOI:https://doi.org/10.2196/26964

[12] Kumaraswamy Nanthakumar, Andrew E. Epstein, G. Neal Kay, Vance J. Plumb, and Douglas S. Lee. 2004. Prophylactic implantable cardioverter-defibrillator therapy in patients with left ventricular systolic dysfunction A pooled analysis of 10 primary prevention trials. *J Am Coll Cardiol* 44, 11 (2004), 2166–2172. DOI:https://doi.org/10.1016/j.jacc.2004.08.054

[13] Nelly Oudshoorn. 2008. Diagnosis at a distance: the invisible work of patients and healthcare professionals in cardiac telemonitoring technology. *Sociol Health Ill* 30, 2 (February 2008), 272–288. DOI:https://doi.org/10.1111/j.1467-9566.2007.01032.x

[14] Leslie A. Saxon, David L. Hayes, F. Roosevelt Gilliam, Paul A. Heidenreich, John Day, Milan Seth, Timothy E. Meyer, Paul W. Jones, and John P. Boehmer. 2010. Long-Term Outcome After ICD and CRT Implantation and Influence of Remote Device Follow-Up. *Circulation* 122, 23 (December 2010), 2359–2367. DOI:https://doi.org/10.1161/circulationaha.110.960633

[15] Zhaoyuan Su, Lu He, Sunit P Jariwala, Kai Zheng, and Yunan Chen. 2022. "What is Your Envisioned Future?": Toward Human-AI Enrichment in Data Work of Asthma Care. *Proc Acm Human-computer Interact* 6, CSCW2 (2022), 1–28. DOI:https://doi.org/10.1145/3555157

[16] Andrew G.H. Thompson. 2007. The meaning of patient involvement and participation in health care consultations: A taxonomy. *Soc Sci Med* 64, 6 (2007), 1297–1310. DOI:https://doi.org/10.1016/j.socscimed.2006.11.002

[17] Niraj Varma and Renato Pietro Ricci. 2013. Telemedicine and cardiac implants: what is the benefit? *Eur Heart J* 34, 25 (July 2013), 1885–1895. DOI:https://doi.org/10.1093/eurheartj/ehs388