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From Personalised Predictions to Targeted Advice: Improving Self-Management in Rheumatoid Arthritis

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Abstract. Rheumatoid arthritis (RA) is a chronic inflammatory autoimmune disease, that can lead to joint damage but also affects quality of life (QoL) including aspects such as self-esteem, fatigue, and mood. Current medical management focuses on the fluctuating disease activity to prevent progressive disability, but practical constraints mean periodic clinic appointments give little attention to the patient's experience of managing the wider consequences of chronic illness. The main aim of this study is to explore how to use patient-derived data both for clinical decision-making and for personalisation, with the first steps towards a platform for tailoring self-management advice to patients' lifestyle changes. As a result, we proposed a Bayesian network model for personalisation and have obtained promising outcomes.

Keywords. mHealth, personalised prediction, rheumatoid arthritis, Bayesian networks

1. Introduction

Rheumatoid arthritis (RA) is a chronic inflammatory autoimmune disease, causing swollen, painful joints, and characterized by fluctuating inflammatory activity [1]. The long-term prognosis has changed significantly over recent years, largely due to aggressive early treatment with combination medications aiming to achieve remission and prevent disability [2]. However, outcomes remain varied and may affect not only physical functioning but also psychological aspects such as self-esteem, role, relationships, control perceptions, and mood [3].

Recently, mobile health (mHealth) applications have targeted this challenge and have an active role in patient-centered healthcare [4]. By enabling people to access and share their health information, mHealth applications can empower individuals to take a more active role in self-managing their health and well-being [5]. They can increase disease acceptance [6] and self-management [7] capabilities, with regular use related to behavioral change and health improvement [8].

Although clinicians are actively assessing the broader impact using quality of life (QoL) instruments, which measure the patient's evaluation of life across different

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domains such as having a positive outlook on life, having a good social network and living conditions, the definition and measurement of QoL is not standardized [9]. It is not clear whether disease-specific QoL tools (e.g. the RAQoL scale [10]) are applied effectively in mHealth applications to capture the processes behind patients' changing priorities and adjustment to their long-term conditions impacting on QoL outcomes [11]. The National Institute for Clinical Excellence recommends that access to a multi-disciplinary team should provide the "opportunity for assessments of the effect of RA on patients' lives (such as pain, fatigue, physical activities, sleep quality, self-care, financial status, belonging and social activities, QoL, and mood)" [12]. However, there is little evidence that the psycho-social aspects of RA are formally assessed in clinical practice or that health services are equipped to support these issues in a personalised manner.

Bayesian networks (BNs) are a promising technology that may be able to provide this support. They are directed acyclic graphs consisting of a set of variables and their dependencies [13]. They can combine expert knowledge with data, but also be used when no data is available. The structure of a BN represents the knowledge about a problem which is usually elicited from the experts or taken from literature. The underlying probabilities in the BN allow one to model the embedded uncertainty of a given problem.

Here, we developed a BN model producing personalised predictions for self-management in RA through a patient-centered process. The aim is to provide a holistic patient-centered support system, leading to greater patient participation and improved health outcomes and reduced economic costs. QoL is supported in three different ways: independence in terms of physical functioning and financial resources; empowerment in how to manage life; and participation in the experience of belonging in a social context [14]. The proposed model also reflects on disease acceptance, to be a process whereby patients begin to make choices that maximize their QoL, and estimates the probability of flares happening associated with functional disability, disease duration, functional deterioration, pain, morning stiffness and fatigue [15].

Although the personalisation aspect in self-management for RA is researched relatively broadly, to the best of our knowledge there is no study investigating the uncertainty involved in understanding the needs for a long-term interaction with an mHealth platform from the patients' perspective.

2. Method

For this study, we developed a knowledge-based BN model for personalised prediction, where the structure of the model shows the variables and their causal or associational dependencies derived from the literature.

To build the BN structure, firstly, we determined the main variables for self-management in RA. This was done by first engaging with members of a Patient and Public Involvement (PPI) group. Informal interviews and discussion led to knowledge elicitation based on both research and patient-centered publications on the issues raised. A series of patient personas were developed describing fictional patients and scenarios around their lives. These were used in a formal focus group with PPI members to elicit further information around the important issues, with changes validated by follow up discussion with PPI members.

We used expert knowledge to specify the probabilities of the BN variables as no data was available. The probability elicitation was simplified using 'ranked nodes' as defined in [13].

As the proposed BN model receives evidence about a patient and predicts the output variables, we used interviews from a formal semi-structured interview study (AtTRA) about life with RA as a basis to initially validate the model from a patients' perspective. We developed 6 patient 'scenarios' directly from the interviews. We coded these scenarios and attained the evidences and expected state of output variables in a blind way. From these, inputs to the BN were extracted matching the patient scenario. Outputs were obtained from the BN and compared with the corresponding description in the scenarios.

3. Results

Key variables that emerged from established literature and interviews included QoL, disease acceptance, flare-up, pain, morning stiffness, and fatigue. We grouped these variables into four groups: disease activity, QoL characteristics, lifestyle choices, and disease manifestations as well as two additional groups representing the risk factors namely personal factors and environmental factors.

As shown in Figure 1, the evidence variables or input variables are displayed by orange ovals. The white dashed oval shows a synthetic variable which combines its parent variables and simplifies the model. The white ovals represent the output variables, namely: Flare-up, Current Disease Activity, Overall Disease Activity, Disease Acceptance, Independence, Participation, Empowerment, and QoL. Flare-up has three states: None, Mild, and Severe. Current Disease Activity and Overall Disease Activity have four states: Remission, Low, Moderate, and High. The rest of the output variables have three states of Low, Medium, and High.

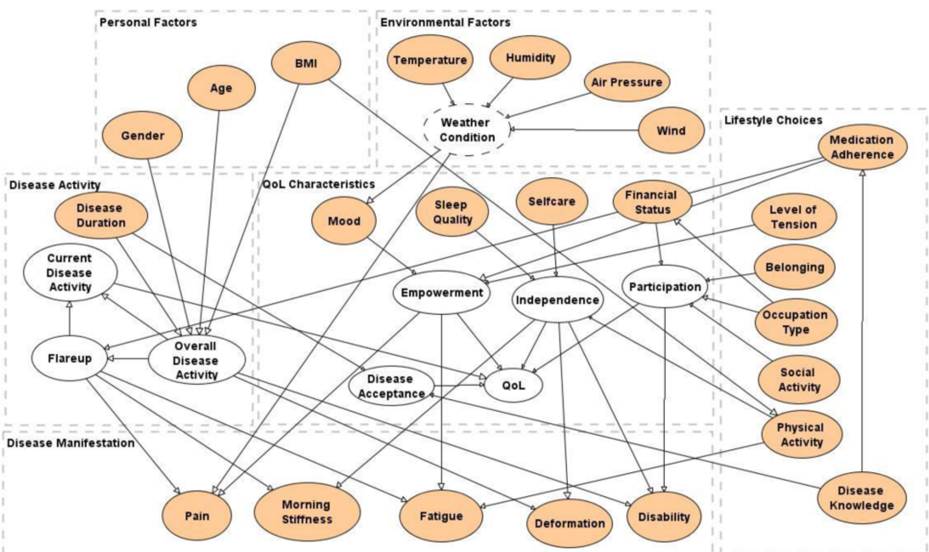

Figure 1. BN model for personalisation in self-management of RA.

The outputs of the BN and the expected states for two of the scenarios - a mild case and a severe case - are shown in Table 1 for illustration purposes. The comparison between the predicted and expected states indicates that the proposed BN model is highly consistent with the information from patient interviews.

Table 1. BN outputs and expected states for mild and severe scenarios.

Output Variables	Mild Case		Severe Case	
	BN Prediction	**Expectation**	**BN Prediction**	**Expectation**
Flare-up	None	None	Severe	Severe
Current Disease Activity	Remission	Low	Moderate	Moderate
Overall Disease Activity	Low	Low	Moderate	Moderate
Disease Acceptance	High	High	High	High
Independence	Low	Low	Medium	Low
Participation	Medium	Low	Medium	Medium
Empowerment	Medium	Medium	Low	Low
QoL	Medium	Medium	Medium	Low

4. Discussion

Our results are only indicative given the small number of scenarios and with limited personal/environmental factors covered. However, they suggest the proposed BN model is on the right track on understanding the uncertainty in RA. It has the potential to form the basis of a prediction system by bringing external and patient-derived data into the clinical decision-making cycle. It would do this by generating personalised predictions for disease status and QoL aspects. This offers a promising direction to increase the efficiency of health service delivery by tailoring healthcare to patients' individual needs.

The proposed approach does not allow firm conclusions about the exact contribution of each factor to the BN model's predictions. Future studies will shed further light on the usability of the proposed BN based approach. In the context of self-management, the ability to indicate and predict which advice will work best for a certain person at a certain time and in a certain context may be possible. From a methodological point of view, alternative approaches and techniques for data collection from the patient may have the potential to further increase the precision of the prediction model.

Current medical management focuses on the fluctuating disease activity to prevent progressive disability, but practical constraints mean periodic clinic appointments give little attention to the patient's experience of managing the wider consequences of chronic conditions. Instead, patients must rely on generic resources, such as those provided by patient associations, to gradually learn how to adapt their lives to RA. Our initial validation suggests that our BN has potential to help in this regard, pointing patients at appropriate advice in a timely way.

5. Conclusion

In this paper, we presented a BN model that predicts QoL factors based on a patient-centered knowledge acquisition process. It forms the basis of a system to give advice to patients based on its predictions of the QOL issues most needing attention. It thereby has the potential to increase the response rate to a smartphone-based targeted advice platform in terms of disease acceptance and adherence to lifestyle changes. We are in the process of designing a prototype of such a system. This approach is in line with the precision medicine initiative. The proposed model could also be used to identify relationships between multiple behavioral factors to enable the assessment of opportunities and risks associated with RA. This could, for example, be used to flag patients ready for tapering or to conduct individual targeted preventive actions towards high-risk patients.

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