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Innovating care for people with sarcoidosis using a machine learning-driven approach

Vivienne Kahlmann¹, Astrid Dunweg¹, Heleen Kicken², Nick Jelicic³, Johanna M. Hendriks⁴, Richard Goossens², Marlies S. Wijsenbeek^{1†} and Jiwon Jung^{2,4*†}

Abstract

Introduction Understanding patients' everyday experience is essential to improve patient centered care in sarcoidosis. So far, patient perspectives are based on survey- and qualitative research.

Aim We aimed to assess patient-driven perspectives on their care trajectories using a novel machine learning-driven approach (MLD).

Methods We used the largest Dutch sarcoidosis patient platform as the data source of patient stories. The patients' stories were extracted with permission. We applied topic modelling (to generate topics among the posts), and sentiment analysis (to find tone of voice in the topics). To validate the findings, we read the top 50 most relevant posts of each topic. An in-depth patients' disease trajectory map was made.

Results Based on 4969 forum posts, 30 final topics and 10 upper themes were generated, which formed the basis for the "patient journey-map" which shows patients' perspective across the care pathway. Important decision moments could be identified, as well as care "tracks" at home and hospital and topics associated with positive or negative emotions. Most patients' perspectives were about symptoms (mainly negative sentiment), disease-modifying medication (mainly neutral sentiment), and quality of life (negative, neutral and positive).

Discussion A major part of living with sarcoidosis takes place outside the view of the hospital, but this part often remains invisible. MLD is an innovative approach, providing a comprehensive overview of patients' perspectives on health and care. Integrating, these findings in the design of health care delivery has the potential to improve patient-centered care.

Keywords Interstitial lung disease, Sarcoidosis, Quality of life, Artificial intelligence, Innovating care, Patient perspectives, Patient-centered care

[†]Marlies S. Wijsenbeek and Jiwon Jung share last authorship.

*Correspondence:

Jiwon Jung

j.jung@erasmusmc.nl

¹ Centre of Excellence for Interstitial Lung Diseases and Sarcoidosis, Department of Respiratory Medicine, Erasmus University Medical Center, Rotterdam, the Netherlands

² Faculty of Industrial Design Engineering, Delft University of Technology (TU Delft), Delft, the Netherlands

³ University Library, Erasmus University of Rotterdam, Rotterdam, the Netherlands

⁴ Surgery Department, Erasmus University Medical Center, Rotterdam, the Netherlands

Introduction

Sarcoidosis is a systemic inflammatory disease, most commonly affecting the lungs, but any organ can be involved. The clinical presentation of sarcoidosis is variable and the disease course often unpredictable. In most patients spontaneous remissions occurs, while others require immunosuppressive treatment. Symptom burden is often high, even if there are no signs of sarcoidosis inflammatory activity [1, 2]. Sarcoidosis can significantly impact daily activities, including work participation, family life and social engagement, thereby



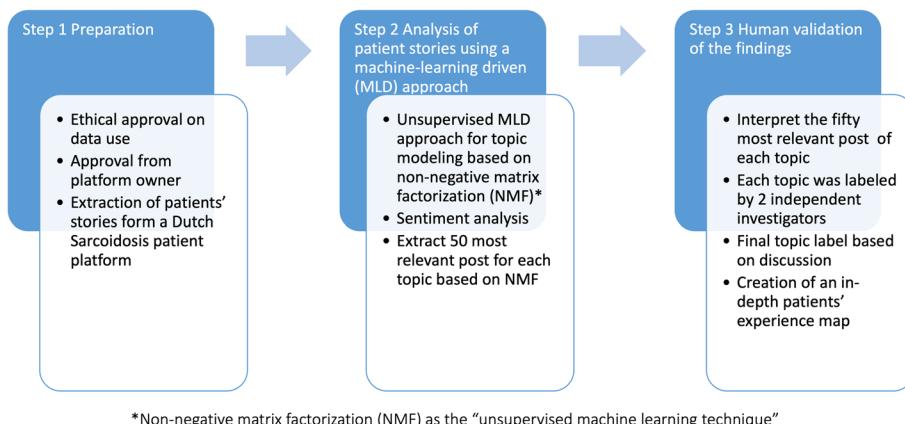


Fig. 1 Stepwise methodological approach to create a patient journey map

diminishing quality of life (QoL) for both patients and their families [3–5].

Understanding how people feel and function every day is essential to improve patient centered care in sarcoidosis. As a major part of living with sarcoidosis takes place outside the view of the hospital, this part often remains invisible for healthcare providers. It is important to acknowledge that patients and healthcare providers have different views on important treatment outcomes. For patients the most important treatment outcome is quality of life, while physicians prioritize measurements that are more physiological oriented such as pulmonary function [6].

A few survey- and qualitative studies have provided valuable information on the needs and perceptions of patients with sarcoidosis; however, these approaches did not assess patients' daily life experience data from their own narratives [3, 4, 6, 7]. Furthermore, conventional qualitative studies, focus groups and interviews, are limited by sample size, labor intensive and could lead to socially desirable answers towards the interviewer. Survey studies often make use of predefined questionnaires and Likert-scales and are not able to capture in-depth and extensive description about the patients' struggles and needs in their daily life experiences.

Machine learning driven approaches (MLD) for text modeling enable analysis of a vast collection of data. A MLD approach enables exploring non-prompted patients' experiences based on their own narratives. Moreover, the MLD approach is easily repeatable and facilitates timely updates to patient perspectives as the field evolves. In this study, we aim to assess patient-driven perspectives of patients with sarcoidosis on their care trajectories by using a MLD approach [8].

Methods

The design and conduct of this study were a collaboration between user-experience designers, data-scientists, clinicians, nurses, and a patient panel. Using a MLD approach we assessed online patient stories [8]. This method consists of three steps: (I) preparation of the data, (II) MLD analysis and (III) human validation of the findings (Fig. 1). Hereafter, we created a patient journey map, which outlines the care pathway and highlights the experiences of patients. The patient journey map was discussed during co-creation sessions with stakeholders (clinicians, specialist nurses, and a patient panel). Ethical approval was obtained by the local ethics committee.

Step 1. Preparation of data source, patient stories

We extracted anonymized patient stories from the largest online Dutch sarcoidosis patient platform, with approval from the platform owner. The online platform consisted of written patient stories without a specific format. After extraction of the forum posts, we pre-processed the data (e.g. eliminating stop words, changing all terms to lowercase, and transforming the posts into a term frequency inverse document frequency (TF-IDF) matrix). We did not make the distinction between main post and replies to the posts, because they may equally include important relevant stories from different patients.

Step 2. Analysis of patient stories by MLD approach

We used an unsupervised MLD approach called topic modeling. This is a text mining technique to classify different text documents in sets, called topics, by detecting patterns of words. We performed topic modeling with a technique called Non-negative Matrix Factorization (NMF) to find latent topics in the posts. The optimal number of topics was pre-defined on 40 topics, because

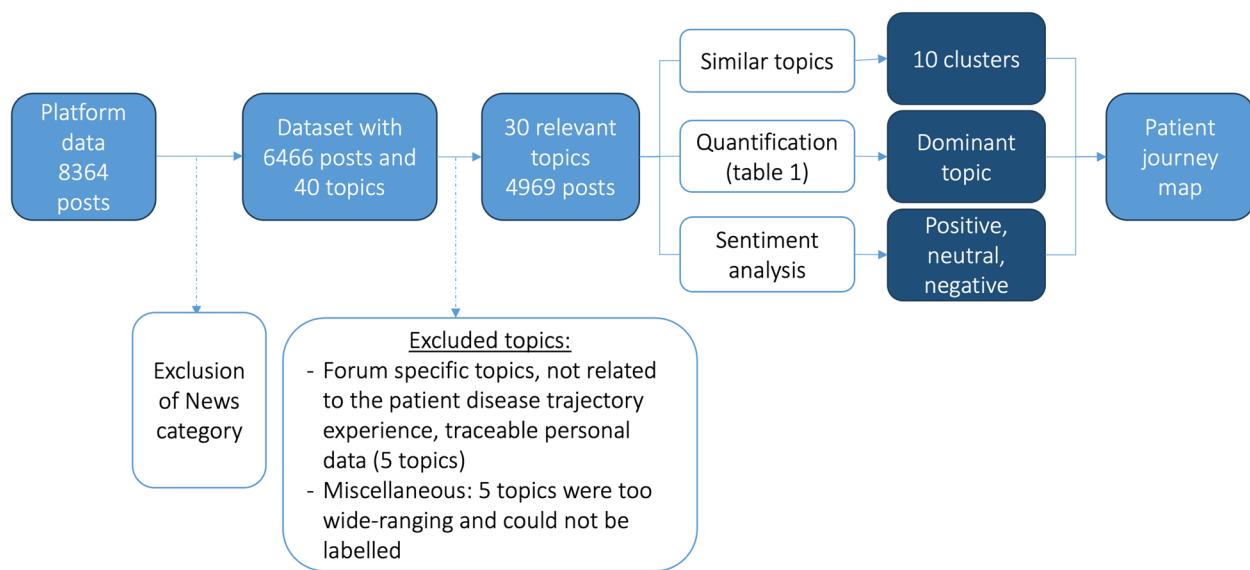


Fig. 2 Study flowchart

this number of topics could be manually checked and would avoid overlapping or too wide-ranging topics. With NMF one post can relate to multiple topics with varying degrees of relatedness. Each post was assigned to the most related topic together with other related posts. Topic modelling provided most relevant keywords and counted how many posts belonged to a specific topic. Furthermore, the 50 most relevant posts for each topic were identified and extracted, so these posts could be manually checked in step 3. Subsequently, a sentiment analysis was performed to determine the overall sentiment of the individual topics (e.g. positive, neutral, or negative).

For the sentiment analysis, we used a multilingual model, XLM-RoBERTa, which was fine-tuned as outlined by Barbieri et al. [9].

Step 3 Human validation of findings

Two independent investigators (AD and HK) validated the findings by reading the keywords and 50 most relevant posts for each topic. The two investigators labeled the topics independently. When they disagreed on a label, a third investigator (VK) reviewed the topic, and the final label was agreed upon through discussion. A topic was classified as miscellaneous if no consensus could be reached after a third researcher reviewed the topic. The miscellaneous category was defined as posts within the topic being incoherent, with no identifiable main theme. Topics that were gender or age specific, or not related to the patient disease trajectory experience were excluded

from further analysis. Similar topics were grouped into clusters.

To create the patient journey map, the topics were aligned with specific stages of the sarcoidosis care pathway. The patient journey map was reviewed during several co-creation sessions with the involved stakeholders.

Results

On December 22, 2022, we extracted 8,364 posts from the Dutch Sarcoidosis patient community platform. Figure 2 presents an overview of our study steps. The posts were created between 03–03–2008 and 12–12–2022; and were mainly written by patients and sometimes by family members. We applied topic modelling; five topics were excluded from further analysis as they were either forum specific (e.g. topic about features of the website), not related to the patient disease trajectory experience (e.g. congratulating/greeting each other) or included traceable personal data (e.g. pregnancy with sarcoidosis). The 35 relevant topics, containing 5,718 posts, were labeled (Table 1). For five topics no main theme could be identified, these topics, containing 749 posts, were labeled as miscellaneous. For instance, one of these miscellaneous topics included post on adjustments in daily life (e-bike), lifestyle interventions, vitamin B12 deficiency, and angiotensin converting enzyme. Finally, the topics were manually clustered into 10 clusters (Fig. 2).

Table 1 Results of the topic modeling and researchers' label of each topic

Clusters and topics	Nr of posts	Percentage out of valid posts
1. Symptoms	1183	23.8%
1.1 Challenge and impact of small fiber neuropathy	192	
1.2 Describing unexplained symptoms	183	
1.3 Experiencing variation in symptoms per season	163	
1.4 Impact of sarcoidosis on eyes and vision	165	
1.5 Losing or gaining weight	178	
1.6 Sharing general experiences about symptoms	149	
1.7 Strategies to relieve symptoms	153	
2. Disease modifying medication	796	16.0%
2.1 Benefits and side effects of anti TNF alpha inhibitors	220	
2.2 Benefits and side effects of immunosuppressive medication	203	
2.3 Differentiating between symptoms and side effect of medication	200	
2.4 Benefits and side effects of steroids	173	
3. Impact in daily life	568	11.4%
3.1 Balancing rest and activity to manage fatigue	187	
3.2 Benefits of sports and exercise	164	
3.3 Managing sleep and sleep disorders	148	
3.4 Living with sarcoidosis	69	
4. Other medication	498	10.0%
4.1 Weighing risk and benefits of vaccination	177	
4.2 Effect of different types of pain medication	174	
4.3 Effect of methylphenidate on fatigue	147	
5. Non-pharmacological interventions	418	8.4%
5.1 Effect of nutrition and diets on inflammation	146	
5.2 Sharing information about life-style intervention	138	
5.3 Strategies for maintaining physical and mental wellbeing	134	
6. Sarcoidosis and work	351	7.1%
6.1 Issues with work ability assessment	186	
6.2 Balancing between work and sarcoidosis	165	
7. Diagnosis and prognosis	346	7.0%
7.1 Challenges in diagnostic process	176	
7.2 Navigating in the complexity of diagnostic process	170	
8. Causes and mechanisms of disease	320	6.4%
8.1 Questioning about the cause and treatment	161	
8.2 Exploring impact of vitamin deficiencies on sarcoidosis	159	
9. Emotional support	317	6.4%
9.1 Looking for peer support	165	
9.2 Expressing empathy and understanding	152	
10. Alternative treatment	172	3.5%
10.1 Sharing experiences about alternative medicine	172	
Total	4969	100.0%

Most frequently mentioned topics and clusters

As shown in Table 1 the most frequently mentioned topics were about symptoms (23.8%), disease modifying medication (16.0%), and impact in daily life (11.4%). Patients described general experiences about symptoms and strategies how to relieve symptoms. Furthermore,

they mention the struggle to cope with the uncertainty of living with sarcoidosis, and questioned whether unexplained symptoms were related to sarcoidosis or not. Specifically mentioned were small fiber neuropathy and the impact of sarcoidosis on eyes and vision.

The second-largest cluster centered on disease-modifying medication. Patients shared experiences about benefits and side effects of steroids and other immunosuppressive medication. In addition, they discussed whether symptoms are likely to be caused by sarcoidosis or could be a side effect of medication. The third-largest cluster included topics on impact on daily life. Patients discussed how to keep balance in life, manage fatigue, benefits of sports and exercise and experiences with managing sleep and sleep disorders.

Patient journey map

To visualize patients' experiences with the current care pathway, we created a patient journey map based on the MLD analysis of the platform (Fig. 3). Additionally, the map highlights the sentiment of the posts, represented by the color of each box. Most of the topics had a neutral or negative sentiment. The sentiment of the topics on symptoms, balancing sarcoidosis and work, and causes and mechanisms of the disease was mainly negative. Peer support, sports and exercise, balancing rest and activity to manage fatigue and sharing experiences about alternative medicine were alluded to with positive sentiment.

Co-creation sessions and patient's feedback

The patient journey map was validated during co-creation sessions with clinicians, a nurse specialist, and a patient panel. Based on the discussion during the co-creation sessions the importance of providing patients comprehensive education about their disease was highlighted.

Patients

- 'Patients will always have questions regarding their illness'
- 'The patient journey map is very helpful for doctors so they can see what is important for patients'

Healthcare providers

- 'Probably we should do more about explaining the disease, but we only have 15 min'

Discussion

This is the first study to apply an MLD approach to analyze patient forum posts and develop a patient journey map derived from the narratives of patients with sarcoidosis. Using this approach, we were able to assess unsolicited patient needs and perceptions of patients with sarcoidosis, outside the scope of the hospital. The most frequently discussed topics focused on symptoms,

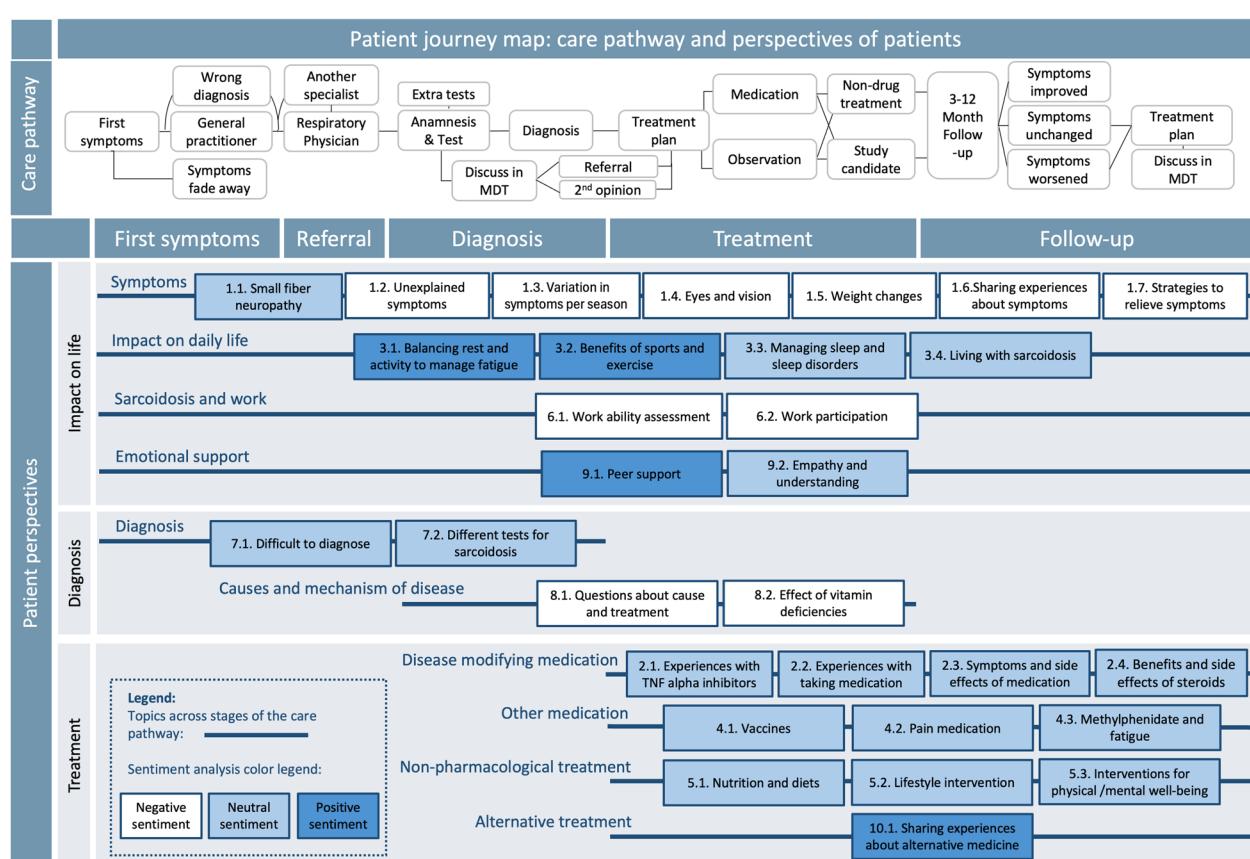


Fig. 3 Patient journey map

disease modifying medication and impact on daily life. Overall, patients consistently expressed a clear need for better disease education and a holistic management approach.

The MLD approach facilitates efficiently analyzing a large dataset such as in this study of online stories of patients. This enabled us to explore patient perspectives outside the scope of the hospital and include patient driven and everyday-life data, in contrary to survey studies and questionnaires, which are often using predefined questionnaires that could lead to socially desirable answers and are often limited in sample size. MLD could potentially not only yield novel information on patient needs but could also be used to efficiently map changing patient perspectives and needs, for instance if novel management options would become available.

The current study revealed that most patient stories focused on symptoms and expressed a negative sentiment, highlighting a substantial symptom burden among patients with sarcoidosis. This mirrors findings of several studies that symptoms often have a significant impact on quality of life [2, 10, 11]. Patients were uncertain whether symptoms were related to sarcoidosis or a side effect of medication. Also, non-organ related manifestations, such as fatigue and small fiber neuropathy were discussed. Disease modifying medication was the second-largest cluster and was also associated with a neutral sentiment. Patients were discussing benefits and side effects of disease modifying medication. Overall, many patients wanted more information about symptoms, available treatments, and their potential side effects. The lack of insufficient disease education is also reported in previous studies in round 41% patients [3, 12]. Many patients access the internet to obtain information; however, this information is often insufficient [13].

Adequate information is a prerequisite for shared decision making, which is strongly advocated for in the current guidelines [14]. Nevertheless, in clinical practice shared decision making still strongly depends on the treating physician or specialist nurse. In the stakeholder meetings in our study, healthcare providers acknowledged that ideally, they would offer more comprehensive disease education, however, time constraints make this challenging. Optimal ways and tools to provide tailored education and facilitate shared decision making deserve more attention in the sarcoidosis field. Digital solutions, such as online self-management tools and care programs [15, 16] hold promise to improve access to education and improve self-management and shared decision making. However, implementation and use of such tools may pose other challenges in its turn [17].

In general, our findings align with scientific literature, which is reassuring that with a less labor-intensive

method patient perspectives can be captured. Nevertheless, our method also identified some topics that are less frequently mentioned in surveys and interview, such as, an unmet need regarding counseling on diets and lifestyle interventions. In sarcoidosis, the prevalence and impact of malnutrition is currently unknown. Whereas inflammation can lead to weight loss, treatment with corticosteroids often leads to weight gain [18, 19]. Assessing nutritional status and the effects of dietetic support in patients with sarcoidosis offers an opportunity to optimize patient-centered care and mitigate associated comorbidities. Furthermore, patients questioned how diet and vitamin deficiencies—particularly vitamin B12, D, and calcium—affect inflammation. However, no data currently exist on the role of nutrition in managing sarcoidosis. In other chronic inflammatory diseases, such as rheumatoid arthritis (RA), it has been suggested that diets, in particular mediterranean diet, omega-3 Fatty Acids, could reduce inflammation and symptoms [20–22]. If this also hold potential for patients with sarcoidosis remains to be elucidated.

The impact of living with sarcoidosis on work-related aspects was also addressed by patients in our study. Patients discussed challenges with work ability assessments and shared their experiences of balancing work and the disease. This corresponds with findings of previous Swedish study, in which patients with sarcoidosis experienced a reduction in workability, leading to a financial loss of 8%, which persisted up to five years after sarcoidosis [23]. Another study demonstrated that 37% of the patients perceived a lack of attention during workability assessments and 38% disagreed with the assessment outcome [24].

A recent expert opinion statement recommended that workability assessment should be based on a patient-centered, holistic approach, which incorporates the personal experiences of living with sarcoidosis, and highlighted the need for additional guidance to reflect these patients' perspectives more accurately [25].

This study focused on collective patient experiences, rather than on individual trajectories, therefore information could not be analyzed chronologically for individual patient trajectories. Future research could employ dynamic topic modeling or temporal clustering, to further elucidate of how patient experiences evolve over time. We particularly used TF-IDF combined with NMF for its interpretability, transparency, and computational efficiency, allowing for clear theme extraction from large datasets. While advanced techniques like transformer-based models (e.g., BERTopic) capture deeper semantic nuances and context, they come off with trade-offs, such as reduced interpretability and increased computational demands. Future research could compare these advanced

techniques to assess whether they better capture subtle semantics at the cost of interpretability. For sentiment analysis, we selected XLM-RoBERTa, an unsupervised multilingual transformer-based model, due to its training on diverse language datasets (including Dutch), which also provides strong cross-lingual capabilities. For future studies, we propose an opportunity to measure the model performance by generating pseudo-labeled data from a patient forum and to conduct additional fine-tuning of the model.

Our study also has several limitations. As this was an anonymized study of online patient stories, patient characteristics are lacking. Although patient journey mapping enables to analyzing a large-scale data set, there is a selection bias of patients who like to share their experiences online, this could be depended on certain patients' characteristics, such as, educational level, or socio-economic status, which in other fields have been associated with online access. We also encourage future studies to incorporate multi-source data, such as follow-up questionnaires, to validate the findings from the patient journey map. Furthermore, social media platforms are often nation specific, and the result of this study gives an overview of patients' experience in the Netherlands. In addition, the MLD technique is not always perfect in grouping post in a medically and human logical way. For instance, posts mentioning blood were all grouped, whilst these contained stories about oxygen diffusion, iron deficiencies and hemoptysis. Human overreading categorized these groups as miscellaneous currently. Whereas the technique is not yet ready to use without critical human appraisal, one could envision that the MLD algorithm could improve when further trained with human feedback. Furthermore, the pre-specified number of 40 topics might have led to a loss of granularity on scarcely mentioned topics that could still be relevant. On the other hand, quantification of topics also allows prioritization when designing care pathways. Collaboration over the walls of our medical faculties with technical universities, AI scientist and implementation specialist will be needed to fully utilize and optimize the potential of techniques as MLD, sentiment analysis and care pathway design and implementation.

In conclusion, MLD is an innovative approach to analyze a vast collection of patients stories from their own narratives. MLD can provide a comprehensive overview of patients' perspective on health and care. Integrating these insights in future medical health care pathways for patients with sarcoidosis has the potential to improve patient-centered care and patient empowerment.

Abbreviations

MLD	Machine learning driven approaches
NMF	Non-negative Matrix Factorization

(TF-IDF) matrix Term frequency inverse document frequency
QoL Quality of life

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Authors' contributions

VK, AD, HK, NJ, MS, and JJ contributed to the study concept and design. VK, AD, HK, NJ, and JJ verified, analyzed, and interpreted the data. VK, AD and JJ drafted the article. VK, AD, HK, NJ, JMH, RG, MS and JJ critically read and revised the manuscript for important intellectual content.

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Data availability

The data will be made available upon reasonable request to the corresponding author.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the Human Research Ethics Committee of the Delft University of Technology. As this was a retrospective study with anonymized web-based data no informed consent of the patients was required. Consent for the use of data was obtained from the platform owner.

Consent for publication

Not applicable.

Competing interest

The authors declare no competing interests.

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