

# Wolf—living with SLE in a novel

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**Abstract** Living with SLE is a major task for the patients and their social environment. In modern health care, quality of life is increasingly incorporated as an important outcome. Studying novels about illness is a new method of exploring quality of life in patients with an illness. In this paper, we use the novel *A tribe of women* by Hervé Bazin as data to explore how a patient with SLE gives meaning to her illness and how her social environment reacts toward the illness and its treatment. We find that the novel—probably the only one where SLE is a major subject—offers a rich set of data on “living with SLE”. Our findings may be instrumental in encouraging health care providers to explore quality of life in patients with SLE, incorporating self-management in order to improve their quality of life, and in teaching medical students about “medical humanities”.

**Keywords** Medical Humanities · Novels · Quality of life · Self-management · Systemic lupus erythematosus

## Introduction

Having a disease is only part of the story. Being ill, living with an illness, is what matters for patients and their social environment. Increasingly, physicians and other health care providers incorporate this living with an illness into the medical management of their patients. This shows that health care providers are interested in the quality of life of their patients.

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Quality of life (QOL) is no longer merely a buzz word. Research on QOL is part and parcel of this journal as well (e.g., [27, 29, 30]) and in related journals (e.g., [5, 7, 28]). Defined as “the functional effect of an illness on the patient and its consequent therapy upon a patient, as perceived by the patient” ([24], p. 16), QOL is usually assessed with validated questionnaires. This assessment of patient-reported outcomes (PROs) encourages health care providers to include patient stories into their medical care (e.g., [25]).

The stories that patients tell to themselves, their partners, and their physicians are observable not only in the office of the doctor. Novels, poems, films, paintings, and music are additional forms in which patient’s experiences and stories can be identified. The area of Medical Humanities is the label of this field of scientific theories and empirical work, focusing on the analysis of these experiences and stories [3]. The effects of the application of the principles of Medical Humanities to medical education, medical practice, and research are being studied increasingly. Publications on this topic are cautiously optimistic, although critical reviews are in no short supply [2, 12, 20]. With regard to the domain of rheumatology, QOL is a quite developed area, both theoretically and empirically [10, 21]. Specific interventions to improve QOL have been developed and tested, as an additional form of treatment, e.g., self-management [22] and expressive writing [26].

Assessing QOL in persons with SLE illustrates the major functional consequences of this disease and its treatment, as perceived by the patient (e.g., [6]). Methods from the Medical Humanities domain have also reached SLE: research about drawings [19] and illness perceptions [6, 14] supplements QOL data in SLE research. SLE has up to now, as far as we know, not been represented in poems, films, paintings, or music. Flannery O’Connor suffered SLE and she wrote about its devastating consequences. Some authors feel that her story *A good man is hard to find* is a metaphor for her struggle with her SLE [9]. PRO, quality of life, expressive writing, and drawing research are examples of methods to explore and analyze patient experiences in living with an illness. Studying novels about living with an illness represents yet another approach to exploring these patient-reported outcomes.

## Method

In this paper, we use *A tribe of women* written in 1956 by Hervé Bazin (1911–1996) as one of the very few—if not the only—novels where SLE is an important theme [1]. We attempt to enrich the Medical Humanities domain with a novel about SLE, describing and analyzing how the protagonist lives with her SLE. We suggest that health care providers might benefit from reading novels, in that this might encourage health care providers to incorporate the patient's views about an illness in their medical management. Below, the novel is summarized with a view to focus on “living with SLE, by the patient and by her social environment”.

## Results

Life, love, relationships, sex, money, and power: combined with being ill, they are the ingredients for immersive literature. Novels can help diagnose difficult cases, perhaps even better than textbooks. In *A tribe of women*, we are confronted with the diagnosis systemic lupus erythematosus (SLE): the symptoms of this auto immune disease come tumbling at us. About how people live (and die) with the disease, how their social network braces itself against it, and what role doctors play in this all—novels definitely paint a clearer picture of this than textbooks.

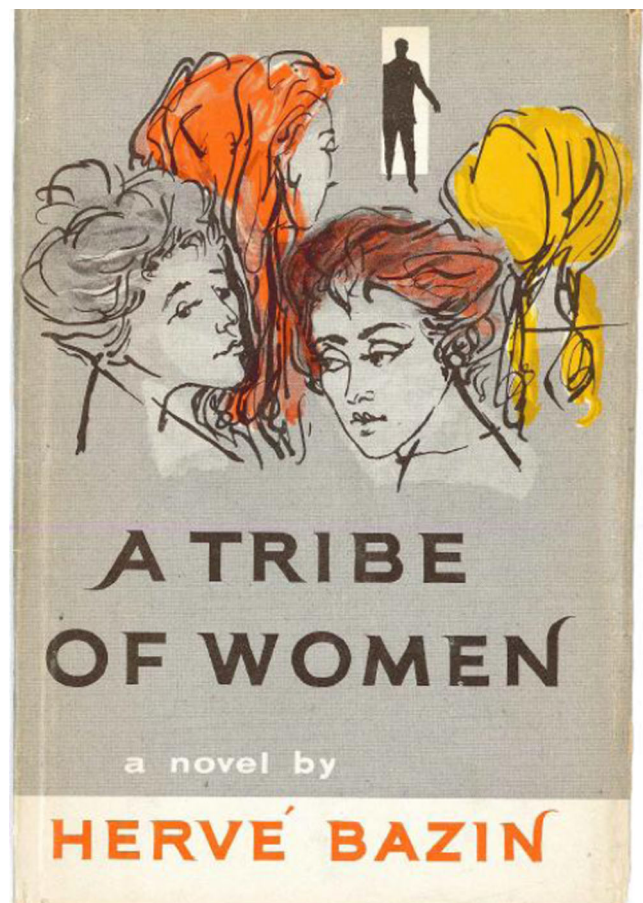
Novels about SLE (lupus, wolf) are far and few between. The title of the English translation of the book by Hervé Bazin (1911–1996) is the briefest summary: *A tribe of women* (1956). As a pack of wolves, the women guard their day to day life, their social balance, and their relations with the outside world, in their mansion in the west of France: mother, her two daughters, and the housekeeper. Husbands have passed away, moved away after divorce, or perished in war. The cover provides us with an even more beautiful, visual summary: four women staring at a man entering or leaving their home.

A new man makes his attempt. The smell of male sweat and cigarettes enters the mansion along with the lover and later on husband of Maman: Maurice is a notary in the neighboring village. New things are happening to her body as well: migraine, fever, shortness of breath, chills, and vertigo have crept their way into her life. The family doctor is at his post: “that could be anything, anything at all”. The residents of the mansion observe “his potions, his lotions, his notions” with suspicion. And indeed, it is no minor ailment: her face and upper body start crusting with devastating effects: “... a hideous bat-shaped patch that formed a kind of angry and pustular mask. Her temples burning, her elbows and knees aching, Mama complained of sudden pains in her stomach, her kidneys – pains everywhere. A bat-shaped rash which gave her a mask of anger ... pain in her stomach and kidneys ... - the rash flares up and her face is too encrusted to allow for any expression at all.” Injections with corticosteroids provide

some relief, but not for long. Berthe, the youngest daughter, makes the mistake of gifting her mother a hand mirror. Maurice is careful enough to gift his wife a powder box.

Mother is ill; Maurice continues his work as a notary. Oldest daughter Isabelle, 19, translates her jealousy regarding their relationship to the subtle seduction of the intruding man. She soon loses her virginity. The youngest daughter and the housekeeper have their suspicions about the nature of their affair, while the mother is too ill to notice. Isabelle and Maurice are in a passionate embrace in the kitchen when, upstairs, the mother dies, alone. “Her heart and kidneys were under a lot of strain”, the family doctor concludes.

Her demise shakes the very foundation of the group. We get a slight notion that the author might have thought about the *Little Red Riding Hood* when writing this, when taking the problematic relationship with his own mother into account. The facial skin rash of people with SLE has been compared to the white markings on the snout of a wolf. Maurice seduces Isabelle twenty years his junior; Maman dies, in bed. In solitude. Banal yet true: life goes on. Isabelle gives birth to a daughter. There are once again four women in the mansion. Maurice allows himself to get chased away by the pack. Being ill can bring us closer together, and tear us apart.



Cover of *A tribe of women* by Hervé Bazin, Simon and Schuster, New York, 1958 [1]

## Discussion

SLE not only impacts the afflicted patient—the tribe of women is afflicted. This, of course, holds for all persons with SLE [16, 17, 23]. The cautious diagnostic and therapeutic steps by the family physician are probably dated, although they are likely not fundamentally different from today's approach. A less dramatic outcome, it can be stated safely, is more likely today, however.

In other papers, novels about a particular illness are used to compare patients' stories with clinical reality and more formal assessments of patients' QOL, e.g., *Cancer Ward* [11] or *Indian Camp* [8]. We are unaware of another novel on SLE; therefore, comparisons between novels on SLE cannot be made. We hope our contribution to the Medical Humanities of SLE will encourage others to further explore this issue.

Recent literature on QOL in SLE illustrates patient uncertainty about various aspects of SLE (e.g., [4, 18]). Perceptions about SLE of afflicted persons illustrate that just as strongly [6, 14]. These studies illustrate the importance of stimulating future research about PRO in patients with SLE, with the overall purpose of improving patients' QOL [13, 15]. A modern approach to this issue pertains to eHealth: using internet technology to encourage patients with SLE (and other chronic disorders, for that matter) to employ self-management skills (e.g., [22, 29]). Medical Humanities is not a panacea [2], it does, however, make a contribution to a high quality care medicine for the patients with SLE and their loved ones.

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