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“Nobody could understand what was wrong with me”

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Systemic mastocytosis



A rare chronic hematologic disease caused by rapid division and growth of mast cells.



In Sweden, approximately 40 adult patients are diagnosed each year.



The symptoms of the disease are varied, often diffuse, and affects patients differently. E.g. rashes, GI problems, osteoporosis, anaphylaxis. This complexity often leads to delayed diagnosis.

CONCLUSION

- The time between symptom onset and diagnosis was perceived as tough.
- Systemic mastocytosis brings a complex and often unpredictable effect on the patient's daily life a long time before diagnosis.
- This study highlights the importance of getting the right diagnosis without delay.

Aim: Explore how patients with Systemic mastocytosis describe the time between symptom onset and diagnosis.

Methods: Qualitative study. Sixteen patients were interviewed. Systematic text condensation was used in the analysis process.

Findings: Three tentative categories have been found; Having symptoms with unknown cause, Dealing with it and Being a patient without a diagnose.

“It's like pushing a button and then like watching a cartoon. The power goes away, like when you empty a bottle of content, my legs didn't carry me, I tried to crawl away. Then I don't remember anymore.”

“Because nobody could ever give me an answer. I left lots of samples but they didn't find anything and they didn't really look either. Since they didn't know what it was nothing happened.”