

Living with ESBL – a qualitative study

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Background: Extended spectrum beta lactamase (ESBL), an enzyme produced by bacteria in normal intestinal flora, renders such bacteria resistant to many antibiotics. Some patients infected with ESBL respond poorly to antibiotic treatment, and even trivial infections may require hospitalization.

Purpose: To increase understanding of the emotional impact of ESBL-producing intestinal bacteria.

Method: This study used a modified version of Grounded theory during seven open interviews to analyze coping mechanisms for ESBL infection.

“I think I went to see her on a Thursday and on Friday she calls me at 5 o’clock in the evening and had the results for the sample I had sent, the urine sample. And then she tells me that I have to go to the nearest hospital because I have a resistant bacteria, and I have to get treatment as soon as possible...and then I became really frightened...I called my husband and said that he had to take me to the hospital because this issue with the bacteria was serious and it couldn’t wait until Monday and I didn’t know what I had, do I have AIDS or what is it?”

“...and then came all this staff with protective clothing and masks and all that, and then I felt ok what is it that I have? Because if they’re coming towards me like that and are going to treat me...how am I going to be able to be around people at all if they approach me bild like that? What do I have in my blood...just for having contact with me? I might not be able to work anymore because I can’t be in contact with another human being!”

Results: Our analysis identified a core category (i.e., being thrown into scary and unknown territory without a map and compass). All informants felt that they had received no or insufficient information from the health care system. There were many unanswered thoughts and reflections once the information had been given. Health care staff were lacking in knowledge about ESBL and the fears they exhibited as a result of that, sometimes resulting in the use of extreme hygiene measures, increasing the stigma. Such deficits led respondents to take matters into their own hands as they tried to obtain information by other means (e.g., the Internet).

Conclusion: It is to important that attending doctors provide good information to individuals infected by ESBL-producing bacteria. Moreover, such individuals must develop good life management and coping skills.