What you should know about tumor reductive surgery in advanced ovarian cancer – Clinical recommendations from a patient perspective

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Introduction: Little is known about the connection between tumor reductive surgery and quality of life in patients diagnosed with epithelial ovarian cancer (EOC). It is therefore unclear whether it is the surgery or the disease itself that is the main factor affecting the patients quality of life. The aim of the current study was to examine information requested and perceived about tumor reductive surgery in patients with newly diagnosed advanced EOC. Engaging the user perspective ensures focus on areas considered relevant and important by patients.

Materials and Methods: Participants were recruited through the The Norwegian National Gynaecological Patient Organization. They had all received surgical treatment for advanced ovarian cancer at Norwegian hospitals. Main topics in the focus group interviews was to explore the experiences of surgery. One focus group was formed and interviews were moderated by two members of the research team using a semi-structured interview format. A total of three sessions with this focus group has been done. The focus group interviews were audiotaped and transcribed using a meaning condensation analysis. Preliminary findings were shared with the participants for validation before further analysis.

Results: Five women were asked and agreed to participate in the focus group interviews. Two major themes was found, but with different experiences. These themes were (a) communication gap between the time of diagnosis and surgery, and (b) insufficient information given about surgical sideeffects



doctor you may contact at any time during the time for diagnosis to surgery

You should know your life will never be the same again

You should know that at one point you will be thinking: is it worth the suffering and the torture?

> You should know the consequences and side effects of the surgical procedures

healthy

You should know your social life will never be the same again. And that it is time consuming thinking about what others are saying about you and your state

You will be living in a vacuum

from the time from diagnosis to

surgery – and its normal

Conclusion:The focus group discussions revealed weaknesses in information given before treatment of advanced ovarian cancer. Guidelines on how to inform the patients should include user involved research.





