

Patients don't understand the purpose of clinical drug trials

August 17 2015, by Anneli Waara

Clinical trials are an important part of cancer research. Future patients depend on the severely ill to test drugs to improve treatment. But in her dissertation from Uppsala University, Tove Godskesen shows that some of these patients have a limited understanding of the purpose of the studies they enroll in.

On August 28, Tove Godskesen will defend her PhD thesis where she has looked at the reasons why cancer [patients](#) participate in clinical [drug](#) trials and whether they understand the information they have received. She shows that most patients have been adequately informed, are satisfied with their participation and able to recommend others to enroll in studies. But a small group of the patients, who also are the most ill, that had trouble understanding what participation in a drug trial entails. According to Tove Godskesen this is an ethical dilemma for clinical research that risks diluting the practice of informed consent.

It is not very likely that patients would benefit from participating in a clinical drug trial, but many still choose to enroll. Tove Godskesen has interviewed patients in so called phase-1 [clinical trials](#) where a drug is tested on humans for the first time. These studies enroll the most severely ill patients. Previous research has shown that patients often choose a risky and demanding treatment even when there is little chance of cure. Tove Godskesen's research supports these findings. She saw that patients had unrealistic expectations of cure and that they lacked understanding of the purpose of [drug trials](#):

"A new drug can give a patient with incurable cancer a hope for cure. Patients grasp at every last straw and are willing to put up with a lot of discomfort to be part of these studies", says Tove Godskesen.

Many patients appreciate the close relationship with the research nurses. They describe a feeling of receiving VIP-treatment and being well taken care of. But this is also a dilemma: If patients should be able to spend their final days according to their own wishes, it is important that they understand that these studies are not meant to cure individual patients, but designed to promote new knowledge.

Besides the interviews, the thesis includes a questionnaire to patients in studies where new treatments are compared to standard treatments (phase 3 trials). These patients are well informed, but the survey shows that 20 per cent had not received enough information or knowledge about side effects and that they did not know how to ask questions to the people in charge of the study.

These patients stated the same reasons for participating: they hoped for a cure. But they also stated helping future patients and [research](#) as a reason for participating. Men and patients over 65 often enrolled to repay the help they had received, either from a sense of duty, or because their family suggested they take part. One of the survey's strengths is the number of patients that responded: 92 per cent.

Provided by Uppsala University

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