

Perspectives of online outcome transparency in stroke care

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Background

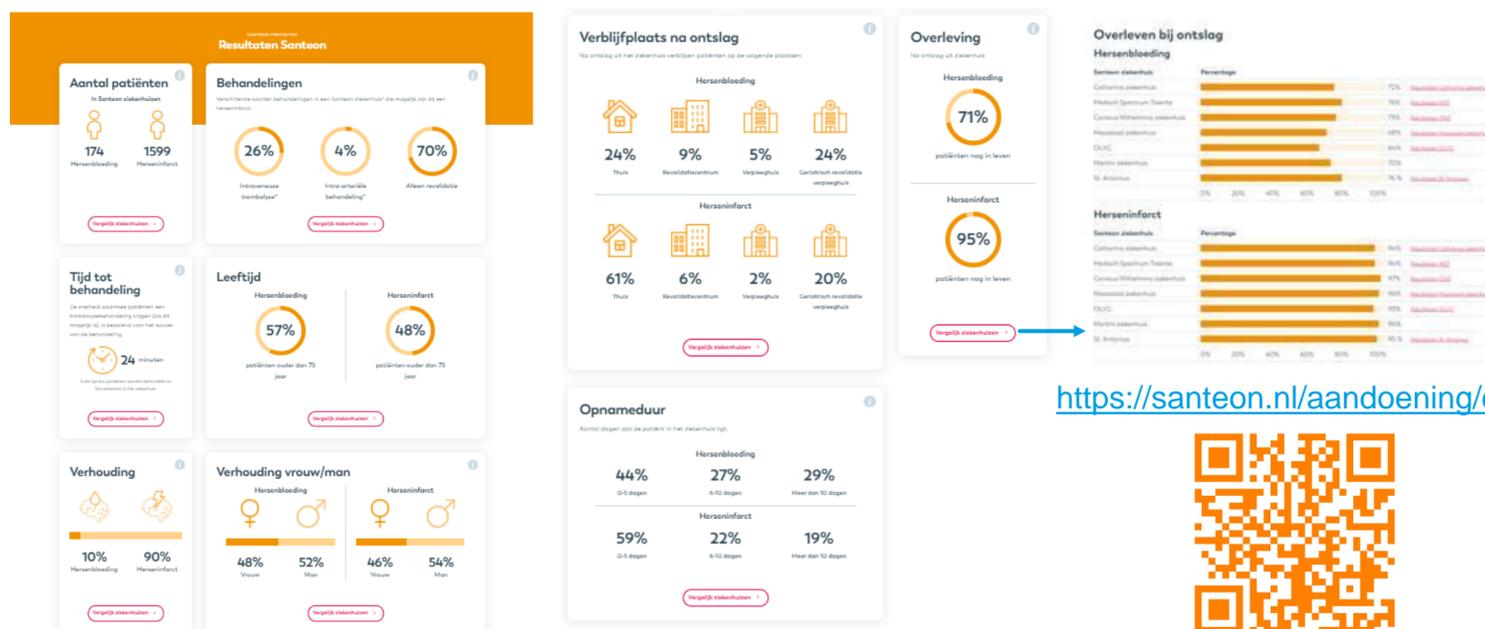
Transparency in healthcare outcomes aims at improving healthcare continuously. On a patient level, transparency can lead to a better understanding of what patients can expect of their treatment. Santeon is a Dutch group of seven teaching hospitals that uses the Value-Based Healthcare framework as its guiding principle. The patient value is defined using a scorecard, based on the ICHOM standard sets. Santeon measures and compares outcomes per medical condition in a structured, standardized manner. Santeon is transparent on outcome results, by means of publishing outcomes in a booklet. To reach a more diverse and wider population, an online infographic with outcomes on stroke care based on the scorecard was made. This was all in co-creation with healthcare professionals of the seven Santeon hospitals. Our next step was gaining insight into patients' perspectives on outcome transparency, specifically by means of an online infographic containing outcomes of stroke care.

Methods

The aim of this study is to explore which outcomes stroke patients are interested in and how these outcomes should be presented in order to be better informed on treatment and treatment outcomes. A needs assessment was conducted with stroke patients. Both quantitative and qualitative methods were used. A survey on which healthcare outcomes are important to patients was developed in cooperation with the patient association 'hersensletsel.nl'. A link to the survey was posted on the website of hersensletsel.nl. After survey completion, focus groups were conducted to further explore the preferences of stroke patients on healthcare outcomes and its presentation.

Results

Results showed that patients had a limited understanding of the concept of healthcare outcomes in general and how to interpret outcome results. Patients indicated that they preferred to be better informed about the (invisible) consequences of having a stroke such as feeling your personality has changed, feeling withdrawn and not able to find words spontaneously. In terms of presentation, stroke patients preferred outcomes expressed in persons (5 out of 10) rather than showing only actual percentages (50%).



Conclusion

Increased awareness is needed on how patients can be best informed on and empowered by outcome information. Overall, we observed that patient perspectives differed from healthcare professionals' perspectives. Further studies are needed to examine if these results will also be found in other diseases.

In terms of stroke care, next steps are:

1. developing a patient-friendly infographic focusing on (invisible) consequences
 2. identifying the extent to which (invisible) consequences are discussed in the consultation room through text mining.
- Additionally, it would be necessary to explore how to use an infographic containing patient outcomes in daily clinical practice.

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