

VOICES OF PUBLIC INVOLVEMENT – THE COVERAGE OF PATIENT INVOLVEMENT IN A SWEDISH PATIENT CANCER MAGAZINE (A5843)



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Background

The purpose of the study is to examine how the involvement of patients with head and neck cancer in medical research was reported in the Swedish patient magazine "Mouth&Throat" during the period 2010-2016. The concept inclusive research referred to patients and families effective opportunities to participate, such as research partners in clinical studies, and help to identify issues in medical research.

Aim

To what extent has the concept inclusive research been discussed in the patient magazine? What aspects of user involvement have the patients themselves chosen to portray in the magazine?

Results

The Mouth&Throat Cancer Association is a member of the Swedish Disability Federation which in 2011 introduced a report which recommends user participation/inclusive research ("From the research object to co-actor"). Despite the international research and the use of the concept inclusive research in a report from the Swedish Disability Federation, the Mouth&Throat Cancer Association have not apply inclusive research in any significant way in their magazine. Only 6 numbers of the magazine during the period has highlighted the concept user participation/inclusive research. However, both the Mouth&Throat Cancer Association and the magazine have continuously reported about "patient involvement" in cancer care, patient and informant views, importance of participation and consultation in national cancer registries, as well as in the rehabilitation project where patients and relatives have been included.



Methods

The research material consists of articles published in the patient magazine Mouth&Throat. The material includes all published numbers during the period 2010-2016 (totally 29 Numbers; 608 pages).

Conclusion

The coverage of medical research is generally frequent in the magazine. Several articles in each numbers reported on treatment, medical research and meetings between medical doctors, representatives of various professions, patients and families. Awareness and interest in active patient participation to developing cancer care is considerable why it should in the future be potentials to even discuss user participation/inclusive research and patients involvement in the medical research.

Take home message

Knowledge and awareness of inclusive research and patient involvement is important for different interdisciplinary actors as medical doctors, nurses, speech therapist, hospital social workers as well as patient organizations. Cancer Magazines is a important channel for information and critical coverage of the implementation of inclusive research in reality. The Swedish magazine "Mouth&Throat" has a long tradition to publishing articles concerning coping strategies and life changes for patients and families.

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