

# Palliation is rarely a topic in studies on advanced cancer

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End-of-life aspects, the corresponding terminology, and the relevance of palliation in advanced cancer are often not considered in publications on randomized controlled trials (RCTs). This is the result of an analysis by the German Institute for Quality and Efficiency in Health Care (IQWiG), which has now been published as final report.

Together with external experts, IQWiG analysed studies on four solid tumours as examples: glioblastoma, [lung cancer](#), [malignant melanoma](#), and [pancreatic cancer](#). For this purpose, the research team evaluated publications on RCTs investigating the use of disease-modifying treatments such as chemotherapy or radiation therapy. Studies on purely symptomatic interventions (e.g. colostomies) were not included.

## Only 40% of studies name superior treatment goals

The research team included a total of 100 study publications; 25 for each of the four indications. Even though the median survival time for these four types of tumours is usually 24 months at most, in the introductory description of the study setting, only 71% of the publications provided clear information on the advanced phase of disease.

A superior patient-relevant treatment goal was only named in about 40% of the publications. This does not refer to the study outcomes, but to what was clinically intended with the respective intervention and what patients could hope for. Most cases (30 out of 38) referred solely to an

increase in life expectancy; two referred solely to quality of life or symptom control.

## **PROs are clearly underrepresented**

Accordingly, the primary outcome recorded in the studies was almost exclusively overall survival or a surrogate parameter such as progression-free survival or tumour response.

Patient-reported outcomes (PROs), which also include quality of life, were not investigated as the primary outcome in any study. They were merely named as secondary or tertiary study outcomes, and only in 36, that is about a third, of the publications. In 31 cases results for PROs were reported in the primary publication. In the remaining five, these findings were presumably provided only in later publications, and thus generally in less prominent journals.

## **Weighing of benefit and harms not always comprehensible**

In most publications authors addressed the benefit-harm ratio of the respective interventions. But the importance of side effects for patients was appropriately reflected and presented only in 22 out of 88 of these publications, and instead played down by certain formulations in 53. All authors drew a corresponding conclusion, but this was comprehensible on the basis of the study results reported beforehand for only 48 of the publications.

## **Terms are used differently**

The report also aimed to clarify terms within the context of "curation" and "palliation". However, this was not possible as these were used

inconsistently in the publications analysed and rarely defined.

For instance, the meaning of "salvage therapy" is unclear. "To salvage" means "to rescue", which could lead patients to assume that the treatment they are undergoing will "rescue", that is "cure" them. However, precisely this case is no longer realistic in the specific treatment situation.

## **Specific treatment situation not adequately represented**

Stefan Lange, Deputy Head of IQWiG and one of the authors of the report, sums up: "Our investigation showed that the specific treatment situation of patients in whom the end of life is foreseeable is inadequately represented in publications.

And this deficit is serious, as physicians also refer to the results of clinical studies in their conversations with patients. Both can only conjointly make good decisions about treatment options if they receive complete and unbiased information on the expected benefit and harm.

This is particularly important in diseases that are expected to lead to death in the foreseeable future, especially as therapy usually places a burden on patients. Many of those involved, physicians, researchers and also industry representatives, repeatedly emphasize that quality of life is of paramount importance for this patient group. It is thus all the more incomprehensible that this aspect is still clearly neglected in studies."

## **Process of report production**

The present [final report](#) was generated in collaboration with external experts within the framework of the general commission. To promote

the Institute's scientific independence, the Federal Joint Committee (G-BA) awarded a general commission to IQWiG in December 2004 and extended it in 2006 to cover information on the quality and efficiency in the [health care](#) system. This allows IQWiG to independently select and work on topics. In contrast to other types of reports, no commenting procedure is held for these reports.

The executive summary provides an overview of the background, methods and further results of the report.

Provided by Institute for Quality and Efficiency in Health Care

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