Acta Oncologica, 2013; 52: 883–885

informa
healthcare

EDITORIAL

My 50 years

MATTI HAKAMA

Finnish Cancer Registry, Helsinki, Finland

During the life span of Acta Oncologica cancer became from mainly an incurable disease to a curable one. In Finland, the overall cancer survival improved from 20% in the early 1950s to more than 60% in the 2000s [1,2]. The background of this progress in prolongation of life is most likely multifactorial and it is commonplace to account for it by the scientific research and technological innovations in basic biology, diagnostics and treatment. Science and technology is largely a driving force in the society at large.

The fundamental change in clinical oncology and in medicine in general, can be also seen through another paradigm. In the Nordic countries we have during the past 50 years seen a change from the clinical freedom of the doctor to decide on the method of treatment or on other actions to the treatment protocols that regulate variations in medical interventions. A further change, participation of the patient in the medical decision making, has been more and more insinuated into the oncological practice. These changes are not primarily because of the progress in science and technology but they are rather due to changes in fundamental societal and individual values, hence the term paradigm.

Paternalism

Fifty years ago I wrote with collaborators in the Finnish Cancer Registry: "The colon cancer relative survival in Finland was 31% in men and 29% in women. In the U.S. patients the survival was a little better" [3]. "Because the results of treatment were rather similar by treatment, the doctor should be allowed to decide on the treatment he (the doctor) likes best" [4].

The two papers were based on the first truly international large scale survival analysis of patients with cancer [5].

The evidence for the conclusion above was that in Finland radiation treatment was more common and survival was 25% (30% vs. 41%) poorer than in the U.S. Today such evidence would not justify the conclusion on the survival difference or on the clinical freedom attitude. Fifty years ago it was the normal, the authors or the reviewers did not question the statements.

The attitude, nowadays we call paternalism, was based on the fact that the clinician best knew the evidence and could take the specifics of the disease and the patient into account.

The attitude was little by little questioned, because there was variation in the clinical decision making, e.g. choice of treatment even if the prognostic factors were the same. Furthermore, the variation was correlated with the background of the doctor and not only with the characteristics of the disease and the patient. A WHO survey provided quantitative evidence of a large variation by speciality, age of the doctor and his continent of residence [6].

Protocols of treatment and other health services

Development of the treatment protocol (or care program or guideline) was the response to the variation that was not always justified. They are widely used until the present day. Sweden was the pioneer soon followed by the other Nordic countries. The objective in cancer treatment protocols was to maximize the patient survival given a set of disease categories that were characterized by survival differences. Quality of life is a common secondary outcome.

The treatment protocol was in Finland [7] defined as a common agreement how the patient with a given disease should be treated. The main objectives were to improve the treatment outcome (mainly survival

Correspondence: Finnish Cancer Registry, Pieni Roobertinkatu 9, Helsinki, 00130 Finland. E-mail: matti.hakama@cancer.fi

(Received 26 March 2013; accepted 26 March 2013)

ISSN 0284-186X print/ISSN 1651-226X online
DOI: 10.3109/0284186X.2013.791028

for cancerous diseases) and to promote efficient, i.e. cost effective use of resources. The guidelines were prepared by the League of Hospitals with guidance or control by the Ministry of Health and Welfare and the National Board of Health. The leadership to prepare, follow and evaluate of the protocol was typically with the public service. The protocols were prepared from the viewpoint of health administration even if the private and third sector as well as the academia were involved.

In oncology the evidence on the feasibility of the treatment protocols was based on randomized controlled trials (RCTs) on the effects of treatment on the survival of the patients and on disease characteristics. In the evidence from the trials the quality of life was, at best, a secondary outcome. However, the protocols themselves were (and are) not evaluated by a randomized trial, but there was non-experimental evidence on treatment volume and other determinants mainly related to administration, revealing the benefits of the protocol approach. One of the best examples of evidence on the usefulness of the treatment protocol approach originated from Finland [8,9]. There was a close collaboration between the clinicians in the treatment evaluation of hematological malignancies that covered about half of the central hospital districts. One of the trials on multiple myeloma did not show any survival benefit of a new treatment compared with the traditional old treatment. As all patients in these RCT areas were treated by (either of) the (two) protocol(s) and the rest of Finland followed clinical freedom, one can make inferences on the effect of the protocol as such. The improvement of survival was larger in the trial area than in the rest of Finland which demonstrated the benefit of the protocol that unifies the medical practice.

Enhanced patient participation

The enhanced patient participation is the next fundamental change in the approach to the diagnostics and treatment or to the medical practice at large. Patient involvement is somewhat in contradiction with the treatment protocols, because treatment protocols do not as such allow variation by individual patient preferences but mainly by the disease characteristics. To the best of my knowledge the only RCT on patient participation versus treatment protocol was carried out in Finland on patients with prostate cancer [10]. In the planning phase of the trial there were mentioned two major reasons of a RCT on the patient participation versus treatment protocol not to be feasible or justified. The patient, an old man, was considered not to be capable to comprehend the multifactorial decision process, to prioritize (or to weight) between the several treatment options causing survival differences and differences in treatment-induced impotence, incontinence, pain etc. The other was prejudice common in the clinical freedom approach; even if the men can participate in the decision making they elect the treatment according to the best evidence, i.e. according to the protocol, and hence, there will be no differences between the randomized arms.

The results were reassuring, the men were able to participate (one of the decision options was to allow the doctor to decide). And the men decided differently from the protocol recommendations. The treatment distributions by arm were different. The general trend was that the protocol emphasized the length of life (survival) and the patient valued also the quality of life.

The future

The trend towards patient participation is already a fact. In Finland, it was the leading principle in the new law on patient rights in 1992. Application in practice of the principle suffers from lack of balanced empirical data on all the dimensions of health, biological, physical, mental and social. If research is providing the means for practice, then the practice will be biased because of this imbalance. The scientific research provides more and better data on survival than for the other dimensions of health. In the study on prostate cancer [10] the survival by disease characteristics was numerically well known and based on RCTs. Instead, the quality of life implications by treatment were (and are) not known numerically but based on common verbal description. The reasoning is not convincing that quality of life indicators show too much variation to be empirically studied in a way that results in quantitative estimates. Also the deaths take place over substantial length of follow-up and the time of death is unpredictable. Second, the imbalance would be less if there were, say, similar amount of research on the quality of life as on the survival. Third, the survival pattern, magnitude and trend in mortality, is different from the pattern of quality-of-life indicators [11]. Therefore, data on survival cannot substitute or compensate the lack of evidence on the physical, mental and social dimensions of cancer, i.e. on effects on the quality of life.

In theory, the outcome of cancer control is a compromise at least on three dimensions: the effect on length of life, the effect on quality of life and the effect on cost. Ideally, the three paradigms described above may be seen to have one of these effects as a more leading principle than the others. The medical expertise and science seem to emphasize length of

life, survival. Invariably, survival, or its proxy, is the primary end point in RCTs. The patient seems to value the quality of life more than indicated in the treatment protocol. Health services administration must be cost-conscious. Research, science, on each of these dimensions should provide balanced (i.e. equally detailed and unbiased) results if oncology will be evidence based. In addition to these balanced facts, there remains the comparison of the dimensions with each other, how to weight or value length of life to quality of life to the cost. Therefore, the structure of the ultimate cancer control depends also on the values attached to each of the dimensions. There is not even in principle any scientific proof on how to compare, i.e. to weight the dimensions. In other words, there is no scientific means to find out what are the optimal values. On the reverse, from the present practice one can see how the dimensions were weighted in the medical practice, in the cancer control, that is, whose values dominated in the cancer control. This we can see also from the focus in cancer research, because research is the means to affect the practice, it is the evidence for medicine. At present, it seems that research is more focused on the biological characteristics of cancer than on the quality of life of the patient. The change towards patient participation in the cancer control paradigm would imply a change also in the research policy. The hesitancy to have a change is already visible in the adverse effects of the paradigm of patient participation. Commercial market style provider is replacing evidence-based (but biased) service because these providers realize people's (patients') desires also for the quality of life with the physical, mental and social dimensions in their dealings with cancer control services. Without valid research there will be the rise of alternative medicine without evidence and even quackery.

Declaration of interest: The author reports no conflicts of interest. The author alone is responsible for the content and writing of the paper.

References

[1] Pukkala E, Sankila R, Rautalahti M. Syöpä Suomessa 2006. Suomen Syöpäyhdistyksen julkaisuja nro 71. Helsinki: Suomen Syöpäyhdistys; 2006.

[2] Storm HH, Kejs AM, Engholm G, Tryggvadóttir L, Klint Å, Bray F, et al. Trends in the overall survival of cancer patients diagnosed 1964–2003 in the Nordic countries followed up to the end of 2006: The importance of case-mix. Acta Oncol 2010;49:713–24.

[3] Vainio T, Hakama M, Saxén E. Suomessa 1953–1956 todettujen histologisesti vahvistettujen syöpätapausten eloonjäämisluvuista. (Survival experience of patients with cancer in Finland, 1953–1956.) Duodecim 1963;79:38–42.

[4] Saxén E, Hakama M. Syövän leikkaus- ja sädehoidon vertailua eloonjäämislukujen perusteella (Surgery and/or radiation in the treatment of cancer. Studies on end-results.) Duodecim 1965;81:569–73.

[5] Cutler S, editor. International Symposium on End Results of Cancer Therapy. National Cancer Institute Monograph 15. 1964.

[6] Stanley K, Hansen HH. An international survey on attitudes in the control of lung cancer – A collaborative study between WHO and I.A.S.L.C. Lung Cancer 1985;1:47–55.

[7] Kittelä L, Kokkola K, Lahesmaa R, Montell R. Tutkimus- ja hoito-ohjelma hoitokäytännön kehittämisessä. (Diagnostic and treatment protocol in development of medical practice). Helsinki: Suomen itsenäisyyden juhlavuoden rahasto; 1980.

[8] Karjalainen S, Palva I. Do treatment protocols improve end results? A study of survival of patients with multiple myeloma in Finland. Br Med J 1989;299:1069–72.

[9] Karjalainen S. Equity and cancer patient survival. Acta Universitatis Tamperensis ser A vol 316. Tampere: University of Tampere; 1991.

[10] Auvinen A, Hakama M, Ala-Opas M, Vornanen T, Leppilahti M, Salminen P et al. A randomised trial of choice of treatment in prostate cancer: The effect of intervention on the treatment chosen. Br J Urol Int 2004;93:52–6, discussion 56.

[11] Holli K, Hakama M. Biological, physical, mental and social dimensions of breast cancer: Information based on routine case notes. Eur J Cancer 1993;29:2152–5.