

Current developments in cancer care: including the patients' perspective—3rd European Roundtable Meeting (ERTM) June 17, 2016, Berlin, Germany

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Abstract

Purpose National Cancer Control Plans (NCCP) are necessary to improve cancer care and reduce mortality. We have reported previously on European institutional health structures and transformation of theoretical health care standards into a practical approach. For the latter consideration of the patients' perspective was considered as highly important and chosen as subject for this meeting.

Results Several European organizations have realized deficits in this area. They promote equal and timely access to cancer care since current inequities lead to disparities in cancer survival across Europe. Patients' support working groups are focussing on employment issues, financial services, psychosocial screening and support, palliative care and rehabilitation. They also identified cancer research including patients' views as highly important. Workshops during the 3rd European Roundtable Meeting (ERTM) covered the issues transparency in patient care, implementation of new knowledge and decision making in partnership with the patient.

Conclusions It was concluded that patient views and perspectives have to be considered during the whole continuum of cancer care. Access to treatment, transparency and including patients into the development process are relevant aspects.

Keywords National Cancer Control Plan · Cancer care · Patient perspective · Shared decision making · Transparency · Access to cancer care · Cancer research

Introduction

Many European countries have introduced National Cancer Control Plans (NCCP) with the goal to improve cancer care and to reduce mortality. Even though many European countries strive for this goal, organization of health care systems for cancer care differ from country to country with respect to training, governance, financing and resourcing as well as the targets and timelines for evaluation of outcome measures. Also there are huge variations of standards in cancer control and care. A number of programs were initiated to ensure focussed implementation, monitoring and evaluation of comprehensive strategies for prevention, early detection, diagnosis, treatment, after care, palliative and end of life care across all cancer types. These include the European Partnership for Action Against Cancer (EPAAC) (Martin Moreno et al. 2013) and the Cancer Control Joint Action (Cancon) (www.cancer-control.eu/).

In Germany, a NCCP was initiated in 2008 ([https://www.bundesgesundheitsministerium.de/service/publikationen/einzelansicht.html?tx_rsmpublications_pi1\[publication\]=652&tx_rsmpublications_pi1\[action\]=show&tx_rsmpublications_pi1\[controller\]=Publication&cHash=e363aa1729d](https://www.bundesgesundheitsministerium.de/service/publikationen/einzelansicht.html?tx_rsmpublications_pi1[publication]=652&tx_rsmpublications_pi1[action]=show&tx_rsmpublications_pi1[controller]=Publication&cHash=e363aa1729d)). This program was based on the concept of a nationwide network of health structures such as comprehensive cancer centers, and other in the health system participating institutions and organizations to provide equitable access to high-quality cancer care based on scientific evidence and interdisciplinary care. This initiative is driven

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by a framework of network implementation, quality control indicators and outcome measures. It was developed with a strong influence of different medical societies particularly the German Cancer Society (DKG). The DKG and the Union for International Cancer Control (UICC) initiated European Roundtable Meetings (ERTMs) with the goal of sharing ideas on applied strategies and best practice. Hereby, they try to identify key instruments for improving quality of cancer care. The previous ERTMs focussed on institutional health structures and transformation of theoretical health care standards and knowledge into a practical approach (Ortmann et al. 2015a, b). The second meeting described central procedures and communication networks in cancer centers. Among these, the description of precise patient pathways and consideration of the patients' perspective were considered as highly important. Therefore, it was decided to analyze this subject in detail during the 3rd ERTM.

Currently, a number of European initiatives have identified issues that are highly important from the patient's point of view. The European Cancer Patient Coalition (ECPC) for example represents 403 patient groups in 44 countries (www.ecpc.org). It is run and governed by patients. The ECPC promotes timely access to appropriate prevention, screening, early diagnosis, treatment and care for all cancer patients. Also, the aim is to reduce disparity and inequity across the European Union (EU). Inequalities in cancer care in Europe have mainly economic reasons. The average cancer expenditures per citizen in the EU are around 100 Euro with huge differences that range from 16 Euro per citizen in Bulgaria to 182 Euro per citizen in Germany (Luengo-Fernandez et al. 2013). Also, there are disparities in cancer survival across Europe with better figures in Northern and Central Europe compared to Southern and Eastern Europe (De Angelis et al. 2014). The access to innovative drugs is clearly different between countries in Europe. For example time periods from trastuzumab approval to reimbursement in the adjuvant and metastatic settings may vary from days to many years (Ades et al. 2014). From the patients point of view this is not acceptable.

This issue is also addressed by the association of European Cancer Leagues (ECL), which initiated a task force on equal access to cancer medicines (www.europeancancerleagues.org). Also the association founded a patient's support working group that is focussing on employment issues, financial services, psychosocial screening and support, palliative care and rehabilitation. The ECL strongly supports the Members of the European Parliament (MEPs) against cancer (MAC) to discuss cancer issues. It is the only cancer group in the European Parliament. Among the strategic goals and key issues for the period from 2014 to 2019 are assurance of equal access to high-quality treatment and care, quality of life for cancer patients

and survivors and patient involvement. The CANCON is a joint action initiative co-founded by participating institutes, organizations, universities and health care units and the EU, that started in 2014 and will continue until 2017. The main objective of CANCON is the development of a patient-centered guide, the European guide on quality improvement and comprehensive cancer control. ECPC and ECL patient support working groups have both identified the advance of cancer research and innovation as highly important. Patient involvement in research is an essential partnership. Patients have to be included in the development and establishment of biobanks and also the design of clinical studies. Since the number of cancer survivors is rising rapidly, it is important to evaluate new treatments and care protocols not only on biological outcomes such as disease-free and overall survival but also on health-related quality of life. Patient-reported outcomes have to be registered in order to evaluate quality of treatment (van de Poll-Franse et al. 2011).

Communication with the patient is of critical importance for shared decision making. Patients' expectations are cure from cancer and good quality of life. If cure is not possible, prolonged survival and good quality of life are important. If prolonged survival is not possible, good quality of life is expected. In all important parts of cancer care patient's feedback is essential.

During the 3rd ERTM three major issues were identified and discussed by the participants:

1. How much transparency is needed in patient care, how can it be implemented?
2. How does the cancer care system react to new knowledge, how fast can standardized reactions be implemented on the basis of patient needs?
3. How can a benchmark for decision making in partnership with the patient be defined?

The outcomes of the workshops are analyzed here to be shared with a wider group of stakeholders' information which is important for appropriate consideration of the patient perspective.

Transparency is needed in patient care

Transparency should be available in all parts of cancer care. The degree is dependent on how much the patient wishes to be informed and involved. Transparency means information about the disease, offering choices and explaining consequences and implications. It is not only needed for appropriate information, but it is also important for data collection. There are potential barriers against transparency, such as limited access to information and choices due to education and health literacy of the patient.

Furthermore, there might be limited regional access to medical services because of long distances and limited mobility of patients.

How can transparency be implemented? Communication should be present at all levels of cancer care. Information provided by independent sources should be available. It was found to be important to set up a pathway to define the level of transparency and information that is needed:

1. The degree the patient wishes to be informed has to be explored. Three groups of patients can be defined: A—very informed, B—intermediate, C—uninformed and/or passive.
2. The insecurity of the patient should be addressed. Individually adapted pathways should be explained.
3. Consider creating financial incentives for communication. Adequate resources for informing the patient have to be provided and thus allows interactive decision making is important assure high quality of care.
4. Different professional groups such as cancer nurses should be integrated into the information process. This multidisciplinary approach is important since each profession has its own competencies.
5. Care has to be taken for the transfer of information in a multistep approach. This stabilizes the confidence of the patient in the professional team.
6. Care should be taken to use adequate language and carefully reasoned information.
7. The patients' needs have to be considered at the strategic decision points. This is essential to decide upon the treatment strategy.

Implementation of new knowledge

Progress in cancer care results from research leading to new knowledge that improves the understanding of the disease, diagnostics, treatment, recognition of side effects and adherence to treatment. New knowledge may also lead to better self-management and self-care abilities. There is a lag time between the generation of a research result and its transfer to daily clinical practice. Also, there is a gap between basic and clinical research. To improve the situation the research process has to be analyzed, bottlenecks identified which should lead to an optimized strategy. Patient groups have to be integrated into research teams and participate in study design development. There is a lack of resources for research independent from pharmaceutical industry. Also it has to be guaranteed that new knowledge has to be transferred in treatment- and patient guidelines. A new treatment has to be evaluated. Therefore, appropriate data collection has to be set up. It is important that different institutions cooperate and exchange data that are needed to describe the patient's situation appropriately.

Decision making in partnership with the patient

The process of cancer care includes several points of important decisions. These have to be defined and adequate information is necessary for patient and care provider. Mutual respect for different positions is essential. An educational process is necessary. Decision aids have to be offered early. Principles of patient-centered communication have to be set up in cancer care institutions, and a structured decision-making process has to be implemented. It is essential to involve patient representatives. After having set up this process, patient satisfaction has to be measured by his or her feedback. The analysis of this feedback should lead to modification or adaptation of the established process.

Conclusion

The value of patient views and perspectives for the whole continuum of cancer care are highly important. Access to treatment, transparency with high level of communication as well as including patients into the development process of different parts of cancer care were identified as relevant aspects. The increasing number of cancer survivors will be a new challenge for the health care system as well as social and professional life. More awareness for the needs of this group is required.

Author contribution OO, WR and UH have contributed to manuscript writing, editing.

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Compliance with ethical standards

Conflict of interest Authors U. Helbig M.D., W. Rösler and O. Ortman M.D. declare that they have no conflict of interest.

Human and animal rights This article does not contain any studies with human participants or animals performed by any of the authors.

References

- Ades F, Senterre C, Zardavas D et al (2014) An exploratory analysis of the factors leading to delays in cancer drug reimbursement in the European Union: the trastuzumab case. *Eur J Cancer* 50(18):3089–3097
- Association of European Cancer Leagues. www.europecancerleagues.org
- Cancer Control Joint Action. www.cancercontrol.eu/
- De Angelis R, Sant M, Coleman MP et al (2014) Cancer survival in Europe 1999–2007 by country and age: results of EURO CARE 5—a population-based study. *Lancet Oncol* 15(1):23–34
- European Cancer Patient Coalition. www.ecpc.org
- Luengo-Fernandez R, Leal J, Gray A, Sullivan R (2013) Economic burden of cancer across the European Union: a population-based cost analysis. *Lancet Oncol* 14(12):1165–1174
- Martin Moreno JM, Albrecht T, Rados Krue S et al. (2013) Boosting Innovation and cooperation in European Cancer Control: key findings from the European Partnership for Action Against Cancer (EPAAC) National Institution of Public Health of the Republic of Slovenia and World Health Organization. www.epaac.eu/
- Ortmann O, Helbig K, Torode J (2015a) Improving cancer care in Europe: which institutional health structures might be beneficial and why? 1. European Roundtable Meeting (ERTM), 16th May 2014, Berlin, Germany. *J Cancer Res Clin Oncol*. doi:10.1007/s00432-014-1906-x
- Ortmann O, Torode J, Helbig U (2015b) Improving structural development in oncology: transformation of theoretical health care standards and knowledge into a practical approach—2nd European Roundtable Meeting (ERTM), May 8, 2015, Berlin, Germany. *J Cancer Res Clin Oncol*. doi:10.1007/s00432-015-2052-9
- van de Poll-Franse LV, Horevoorts N, van Eenbergen M et al (2011) The Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship registry: scope, rationale and design of an infrastructure for the study of physical and psychosocial outcomes in cancer survivorship cohorts. *Eur J Cancer* 47(14):2188–2194