

Governance in/of Cancer Care and Stewardship in Cancer Control: Creation of Definitions

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ABSTRACT

In the literature in the field of cancer care, especially in the literature concerning national cancer control programmes, the terms governance and stewardship in/of cancer care are used, but usually not explained or defined. Therefore, we planned a systematic literature review in order to find the definitions of the terms governance and stewardship in/of cancer care. It was planned to create new definitions of the mentioned terms in case of unsuccessful finds. A literature review using PubMed, Google and MeSH as well as an opportunistic search for extra articles and chapters from books and grey literature was performed. Most of the found and analysed articles did not give exact explanation of the terms governance/stewardship in/of cancer care or they cited older articles (published before the year 2000) where the terms are used mostly in the field of clinical governance or in the completely other fields, mostly banking, economy, religion or spirituality. Therefore, it was decided in the working group of experts from different European countries collaborating within in the work package Governance of integrated and comprehensive cancer care in the frame of the Innovative Partnership for the Action Against Cancer Joint Action project on cancer to create new definitions which we are presenting for the first time. The new definitions will facilitate the understanding of the leadership tasks in the area of cancer care and cancer control and will be particularly useful in the field of cancer programmes.

Key words: governance, stewardship, cancer care, cancer control, cancer programmes

Introduction

During the preparation of the proposal for the third European project on cancer from the group of Joint Actions (JA), Innovative Partnership for the Action Against Cancer (iPAAC JA) the need for the development of the definitions for the specific terms, governance in/of cancer care and stewardship in/of cancer care was clearly expressed by representatives of Member States. iPAAC JA is supported and cofinanced by European Commission¹. Partners from European countries that collaborate on work package, named Governance of integrated and comprehensive cancer care, dedicated to governance in the field of cancer, were in charge of preparation of the mentioned definitions. Both terms are frequently used in the literature, especially the one concerning cancer programmes, plans, strategies or leadership in the field of cancer. However, due to the lack of definitions of both terms, the understanding of the topics remains often unclear.

The World Bank defined governance in 1991 as the manner in which power is exercised in the management of a country's economic and social resources for its development². Governance in health-care is one of the key terms used by the World Health Organization (WHO). It is more precisely defined as a wide range of steering and rule-making related functions carried out by governments/decision-makers as they seek to achieve national health policy objectives that are conducive to universal health coverage^{3,4}. Governance in health does not imply only the management of resources within healthcare, but includes collaboration with other departments and agencies in the government and also with other sectors, such as the private sector and civil society, to promote and maintain population health in a participatory and inclusive manner. In countries that receive significant amounts of external development assistance, governance should also be concerned with managing these resources in ways that promote national leadership, contribute to the achievement of agreed policy goals, and strengthen national health

systems. While the scope for exercising governance functions is greatest at the national level, it also covers the steering role of regional and local authorities. This in particular applies to those countries where state administrative and political functions are strongly devolved and transferred to regional and local authorities⁴.

The WHO, in one of its most seminal annual reports, introduced also the concept of stewardship to the health sector, identifying it as one of the four major functions of health systems worldwide^{3,5}, and even more important than the other functions such as: delivering health services, financing the system, and creation of resources. The WHO defined stewardship as the careful and responsible management of the well-being of the population^{5,6}. Subsequently, a series of reports and articles further expanded the concept and defined its conceptual framework. Travis et al's framework for stewardship is arguably the most referenced and comprehensive of these in the health system literature^{6,7}.

However, all of the above described explanations of governance and stewardship are not related to cancer care, but they generally explain the meaning of both terms. Cancer management is one of the most complex disease management segments of healthcare. Given the broad scope and the multiple elements involving a great number of actors, governance in cancer is important for at least the following key reasons: management and planning of all resources needed in healthcare for cancer management, coordinate, nationally manage and sustainably finance comprehensive cancer services, including: screening, diagnosis, treatment and rehabilitation, secure adequate level of knowledge about cancer for the population, ensure stability of organizational support and financing of services supporting cancer patients beyond treatment and immediate oncological care⁴. Given the complexities of cancer management today, planning of cancer services and resources should be carried out at different levels. Its base is established with the definition of a national cancer policy or a national cancer strategy, which may coexist and either of which may be incorporated in the National Cancer Control Programmes-NCCP^{4,8}. Therefore, proper governance and/or stewardship are of key importance for the achievement of expected results^{6,7}.

The aim of this study was to search for the definitions of the terms governance and stewardship in/of cancer care in the literature or create new definitions within the working group of European experts in the frame of work package on Governance of integrated and comprehensive cancer care of iPAAC JA in case of unsuccessful search in order to facilitate the understanding of governance and stewardship in the field of cancer care.

Methods

Descriptive research methodology was used to perform a review of the literature. A systematic literature review made it possible to obtain data from various sources and thus ensure a comprehensive understanding of the research field. In our work, we used the databases PubMed,

Google and MeSH in accordance with the Priority Reports for Systematic Examinations and Meta-Analysis (PRISMA-P) 2015⁹. We used different combinations of keywords in English. When selecting the literature, we were searching for the articles published in the last 10, 15, 20 years and older than 20 years. Members of the working group prepared a keyword proposal from which the keywords used to search the literature were then selected. As part of the literature review, articles on the use of the terms governance and stewardship in cancer care were then identified, reviewed and analysed on the basis of keywords, search items. We conducted our search using keywords and analysing the titles of the articles, the abstracts and the whole articles. These articles were published in the professional literature as well as in some relevant international documents and research studies. Gray literature identified and proposed by the working group was also included and reviewed. We searched for the documents opportunistically, meaning a focused or focused search based on information found by each partner of the working group in their own country. Among the gray literature, we reviewed unpublished documents or those that are otherwise difficult to find, including various reports. Letters, information from editorials, various interviews as well as posters and articles without access to the full text were not included in the study.

At the beginning of the research it was agreed that in case of unsuccessful literature search new draft definitions would be created by the members of the working group using the terms found in the definitions from related fields, and discussed and adopted at the work package meeting with European experts on cancer from different institutions, Ministries of Health, academia, representatives of cancer organisations, cancer institutes as well as cancer patients.

Results

Regarding the literature review of the terms governance in/of cancer care the initial search in PubMed resulted in total 229 records, of which 52 remained after full text review. The initial search in Google resulted in a total of 52.200.000 records. We screened full text of first 20 records and excluded 17 records. The initial search in MeSH resulted in total of 4 records, of which one remained after full text review. We ended up with fifty six eligible studies.

Far less articles were found in the field of stewardship in/of cancer care. The search in PubMed resulted in total of only 105 records. After full text review we excluded 101 articles and 4 articles remained for the review. The initial search in Google resulted in a total of 8 records. We screened full text articles and excluded 2 records. We added some articles found by opportunistic search and we ended up with 24 studies. The search items and search results for the terms governance/stewardship of/in cancer care are presented in Table 1.

We analysed all of the found articles searching for the definitions of governance and stewardship in/of cancer care. Most articles did not give any exact explanation of

TABLE 1
THE SEARCH RESULTS FOR THE TERMS GOVERNANCE/STEWARDSHIP IN/OF CANCER CARE

Search item	Results Title/ Abstract (last 10 years)	Results Title/ Abstract (last 15 years)	Results Title/ Abstract (last 20 years)	Results Title/ Abstract (all years)	Results All Fields (last 10 years)	Results All Fields (last 15 years)	Results All Fields (last 20 years)	Results All Fields (all years)
Governance	7627	9022	10230	11128	9375	10925	12236	13148
Cancer Care	7652	8996	81514	91627	13200	15667	208280	260901
Governance in Cancer Care	0	0	100	101	191	214	226	229
Governance of Cancer Care	81	95	100	101	196	220	226	229
Stewardship	4887	5162	5532	5660	5309	5611	6020	6156
Stewardship in Cancer Care	0	0	43	43	100	103	105	105
Stewardship of Cancer Care	43	43	43	43	100	103	105	105

the terms or they cited other articles where the terms were used in other fields, mostly banking, economy, religion or spirituality. The definition of governance of care created by Organisation for Economic Co-operation and Development (OECD) in 2013¹⁰ was perhaps the most useful definition. According to OECD governance refers to how system of care is steered and managed at macro level, particularly with respect to improving its quality and outcomes. Governance seeks continuous improvement in what a system delivers and how it delivers¹⁰. However, the OECD definition concerns governance of care and not governance of cancer care.

Discussion and Conclusion

In the limited number of scientific and professional articles in the field of cancer care as well as in the key document concerning cancer control programmes, European Guide for Quality National Cancer Control Programmes¹¹, where the preparation of quality national cancer control programmes is explained, the terms governance and stewardship in/of cancer care are used⁴. However, there is a lack of explanation of these terms which complicates the understanding of this specific topic. In order to find the definitions of the terms governance in/of cancer care and stewardship in/of cancer care the literature review was carried out. We found and analysed different articles searching for the above mentioned definitions. Only few articles that we found were useful because most of the articles did not give the exact explanation of the terms in cancer care or they cited the articles where the terms are used in other areas, as economy, spirituality or banking.

Marks reasoned that governance is a notoriously slippery term. It may be associated with a set of principles, the exercise of legitimate authority through law and regulation, or processes for ensuring accountability and managing risk within organisations. It may also apply to the systematic application of procedures¹². While stewardship of the health of the population was considered a key principle of gover-

nance¹². Clinical governance is often described and explained in the literature. However, it was not helpful in the setting of definitions, as it refers to the quality of services¹³.

According to the definition of governance of care created by OECD, which is one of the few useful explanations we found, governance refers to how system of care is steered and managed at macro level, particularly with respect to improving its quality and outcomes¹⁰. Additionally, according to Stoker, governance is concerned with creating the conditions for ordered rule and collective action; the outputs of governance are not therefore different from those of government¹⁴. In a recent article on governance and cancer care in India Bhaidkar reasoned that governance plays a critical role in regulation and delivery of quality healthcare¹⁵.

Due to the lack of definitions the terms governance in/of cancer care and stewardship in/of cancer care are sometimes mixed. As explained by WHO, stewardship in health, sometimes more narrowly defined as governance, refers to the wide range of functions carried out by governments as they seek to achieve national health policy objectives¹⁶. Stewardship is explained as a political process that involves balancing competing influences and demands. It includes the maintaining of the strategic direction of policy development and implementation; detecting and correcting undesirable trends and distortions; articulating the case for health in national development; regulating the behaviour of a wide range of actors – from health care financiers to health care providers; and establishing effective accountability mechanisms. Beyond the formal health system stewardship means ensuring that other areas of government policy and legislation promote – or at least do not undermine – peoples' health¹⁶. The scope for exercising stewardship functions is greatest at the national level, however, the concept can also cover the steering role of regional and local authorities¹⁶.

Due to the lack of articles with exact definitions of the terms stewardship and governance in/of cancer care it was

decided to create new definitions in the frame of the work package Governance of integrated and comprehensive cancer care of the iPAAC JA project using the terms found in the literature, even if not directly linked to cancer care. Task leader proposed the first version of both definitions, that were created using the words and meaning from the analysed definitions used in related fields. The proposed definitions were discussed and adopted during the meeting of the work package on Governance of integrated and comprehensive cancer care at the Hungarian National Institute of Oncology in Budapest in September 2019. European experts from the partner organisations, Ministries of Health, National Institutes of Public Health and Institutes of Oncology, Universities as well as members of Organisation of European Cancer Institutes (OECI), European Cancer Organisation (ECCO), Digestive Cancers Europe, representatives of cancer patients and others, participated professionally in the formulation of definitions. Regarding the definition of stewardship in cancer care it was agreed at the meeting to use the term in connection with cancer control (stewardship in cancer control) because of the broader content meaning of the term stewardship in comparison with governance.

In this article we present for the first time the final agreed versions of definitions.

Definition of Governance in/of cancer care

Governance in/of cancer care is a continuous process of management at macro level through which Health Care Systems can provide/assure, develop and improve quality, capacity and outcomes in cancer care.

Definition of Stewardship in cancer control

Stewardship in cancer control represents the State's highest level of responsibility in the field of cancer with the aim of reaching the national health policy objectives.

In the frame of the work of the European iPAAC JA project on cancer the definitions of governance in/of cancer care and stewardship in cancer control were developed on the basis of the literature review and work within in the working group. The definitions were discussed, supplemented and adopted at the work package Governance of Integrated and Comprehensive Cancer Care meeting with European experts on cancer from different institutions, academia, Ministries of Health as well as the representatives of cancer organisations, cancer institutes and cancer patients. The definitions will be particularly useful in the field of national cancer control programmes and will facilitate the understanding of the leadership tasks in the area of cancer care and cancer control.

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REFERENCES

1. JELENC M, ALBREHT T, LIPUŠČEK T, VOJE N, HRIBAR K, Isis : glasilo Zdravniške zbornice Slovenije (2018) 19. — 2. THE WORLD BANK, A Discussion Paper (1991). Available from: <http://documents1.worldbank.org/curated/en/884111468134710535/pdf/34899.pdf> — 3. WORLD HEALTH ORGANIZATION, The World Health Report (2000). Available from: http://www.who.int/whr/2000/en/whr00_en.pdf?ua=1 — 4. ALBREHT T, FEDERICI A. Governance and financing. In: ALBREHT T, MARTIN-MORENO JM, JELENC M, GORGOJO L, HARRIS M (Eds) European Guide for Quality National Cancer Control Programmes (NIPH, Ljubljana, 2015). — 5. SALTMAN RB, FERROUSSIER-DAVIS O. WHO Bulletin 78 (2000) 733. — 6. FEDERICI A, FILIPPETTI G, OLEARI F, Italian Journal of Public Health 9 (2012) 99. doi:10.2427/6345. — 7. TRAVIS P, EGGER D, DAVIES P, MECHBAL A, Towards Better Stewardship: Concepts and Critical Issues. In: MURRAY CJL, EVANS DB (Eds) Health Systems Performance Assessment: Debates, Methods and Empiricism (WHO, Geneva, 2003) — 8. ALBREHT T, JELENC M, GORGOJO L, From 'on paper' to 'into action': development of National Cancer Control Programmes in the EU. In: MARTIN-MORENO JM, ALBREHT T, RADOŠ KRNEŠ S (Eds) Boosting Innovation and Cooperation in European Cancer Control (NIPH, Ljubljana, 2013). — 9. MOHER D, SHAMSEER L, CLARKE M, GHERSI D, LIBERATI A, PETTICREW M, Syst Rev 4/1 (2015). doi: 10.1186/2046-4053-4-1 — 10. ORGANISATION FOR ECONOMIC CO-OPERATION AND DEVELOPMENT, OECD Health Policy Studies (2013). Available from: <https://www.oecd.org/els/health-systems/Focus-on-Health-Cancer-Care-2013.pdf> — 11. ALBREHT T, MARTIN MORENO JM, JELENC M, GORGOJO L, HARRIS M, European Guide for Quality National Cancer Control Programmes (NIPH, Ljubljana, 2015). Available from: https://cancercontrol.eu/archived/uploads/images/project%20documents/European_Guide_for_Quality_NationalCancerControlProgrammesWEBw_biographies.pdf — 12. MARKS L, CAVE S, HUNTER DJ, Public Health 124 (2010) 55. doi: 10.1016/j.puhe.2009.11.006. — 13. SCALLY G, DONALDSON LJ, BMJ 317 (1998) 6. — 14. STOKER G. ISSJ 68 (2019) 15. doi: 10.1111/issj.12189. — 15. BHAIKAR A. IJMEI 4 (2018) 1815. — 16. WORLD HEALTH ORGANIZATION, Stewardship (2020). Available from: <https://www.who.int/healthsystems/stewardship/en/>

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UPRAVLJANJE U SUSTAVU SKRBI O RAKU/NADZOR U KONTROLI RAKA: STVARANJE DEFINICIJA

S A Ž E T A K

U literaturi na području skrbi o raku, posebno u literaturi koja se odnosi na nacionalne programe za rak, pojmovi upravljanje u sustavu skrbi o raku/nadzor u kontroli raka često se koriste, ali obično nisu objašnjeni ili definirani. Stoga smo pretražili literaturu kako bismo pronašli definicije pojmova upravljanje u sustavu skrbi o raku/nadzor u kontroli raka. Planirano je bilo stvaranje novih definicija spomenutih pojmova u slučaju neuspješnih nalaza. Provedeno je pretraživanje literature pomoću PubMeda, Googlea i MeSH-a, kao i oportunističko traženje dodatnih članaka i poglavlja iz knjiga i sive literature. Većina pronađenih i analiziranih članaka nije dala točno objašnjenje pojmova upravljanje u sustavu skrbi o raku/nadzor u kontroli raka ili su citirali starije članke (objavljene prije 2000. godine) gdje se pojmovi uglavnom koriste u području kliničkog upravljanja ili u potpunosti druge sfere, uglavnom bankarstva, gospodarstva, religije ili duhovnosti. Stoga je u radnoj skupini stručnjaka iz različitih europskih zemalja koji surađuju u okviru radnog paketa Upravljanje integrirane i razumljive skrbi o raku u okviru projekta Inovativno partnerstvo za akciju protiv raka dogovoreno da se stvore nove definicije koje u članku predstavljamo prvi puta. Nove će definicije olakšati razumijevanje zadataka upravljanja u području raka, a bit će posebno korisne u području nacionalnih programa protiv raka.

