COMMENTARY

Positive and Negative Effects of IT on Cancer Registries

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Abstract

In the new millennium people are facing serious challenges in health care, especially with increasing non-communicable diseases (NCD). One of the most common NCDs is cancer which is the leading cause of death in developed countries and in developing countries is the second cause of death after heart diseases. Cancer registry can make possible the analysis, comparison and development of national and international cancer strategies and planning. Information technology has a vital role in quality improvement and facility of cancer registries. With the use of IT, in addition to gaining general benefits such as monitoring rates of cancer incidence and identifying planning priorities we can also gain specific advantages such as collecting information for a lifetime, creating tele medical records, possibility of access to information by patient, patient empowerment, and decreasing medical errors. In spite of the powerful role of IT, we confront various challenges such as general problems, like privacy of the patient, and specific problems, including possibility of violating patients rights through misrepresentation, omission of human relationships, and decrease in face to face communication between doctors and patients. By implementing appropriate strategies, such as identifying authentication levels, controlling approaches, coding data, and considering technical and content standards, we can optimize the use of IT. The aim of this paper is to emphasize the need for identifying positive and negative effects of modern IT on cancer registry in general and specific aspects as an approach to cancer care management.

Keywords: Cancer registry - information technology - benefit - challenge

Introduction

One out of eight deaths in the world is due to cancer. Cancer is the leading cause of death in developed countries and is the second cause of death after heart diseases in developing countries. It is estimated that by 2030, the global burden will reach 21.4 million new cancer cases (American Cancer Society, 2008). National Institutes of Health (NIH) has announced that the overall cost of cancer in 2007 was $226.8 billion of which 103.8 billion for direct medical costs and 123 billion dollars for indirect deaths costs (American Cancer Society, 2012).

Physicians, in order to study the causes of cancer, detect cancer earlier, prevent or determine the effectiveness of treatment, and specify the reasons for the treatment ineffectiveness, need to access accurate, comprehensive, and timely cancer data. Cancer registry is a valuable tool for achieving these goals (SEER Training Modules, 2013). Oncology departments in hospitals across the world are relying on data from cancer registry (Thomas, 2009). Collecting accurate, complete and standard cancer data, providing timely and accurate information to the user, better management of resources (Saskatchewan et al., 2006), patterns of diagnosis and treatment, monitoring and evaluating the effectiveness of cancer control activities, helping to define public health priorities, conducting clinical and epidemiological research, providing resource for etiologic studies (Dos Santos Silva, 1999; Etemadi et al., 2008; SEER Training Modules, 2013), evaluation of quality and outcomes of cancer care, assessing the effectiveness of cancer prevention and screening programs, monitoring environmental and social factors on cancer risk (EMPHO, 2005), monitoring incidence trends in cancer and its treatment, planning and evaluation of cancer control programs (SEER Training Modules, 2013), describing the extent and nature of the cancer burden in the society, description of incidence, mortality and prevalence (Armstrong, 1992) are some of the benefits of applying cancer registry.

Research shows clearly the valuable effects that the use of information technology and computer approach can have on the quality of effort in cancer registry. Generally, the aim of this systematic review is to survey positive and negative impacts of modern information technology on the cancer registry as an approach for cancer care management.

Cancer Registries: Necessity of an Information Technology Approach

Cancer control policies require detailed, accurate and timely information about cancer management and

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outcomes. Although cancer registry is retrospective and focused on producing accurate reports for one or more years before diagnosis (McDevitt et al., 2009), registrations are often done in parallel, in discrete forms and manually with delay, and thus the physicians' needs are not sometimes met. On the other hand, it is difficult for registrars to gain access to the appropriate physician to ask questions and to have quick access to results and information. This leads to delay in data entry and failure in timeliness and completeness of the cancer registry (Laszlo, 1985). Along with the development of electronic health and health informatics, methods and models for cancer registry were changed gradually and substantially. Nowadays the use of electronic tools and modern methods of automatic data registry to simplify and improve cancer registration, accelerate cancer registry, improve health care services, and is a valuable tool (Wei et al., 2012).

IT Benefits in Cancer Registration

Monitor rate of cancer incidence and mortality, providing regular information about the cancer burden at local, national and international level, planning priorities, promoting the use of cancer registries in cancer control, improving in research (Moore et al., 2008), ease of information use (Holden et al., 2010), fast retrieval of electronic data, quick calculation of health indicators and displaying on the color charts and maps and graphical displays of trends over the past few years (Lucas, 2008) are the most general benefits of technology in cancer registry. With the use of IT, in addition to gaining general advantages, we can reach considerable specific benefits such as: collecting information for a lifetime, creating tele medical record, patient empowerment (Mohammadzadeh, 2006), and decrease in costs and medical errors (Anderson, 2002; Brusco, 2011; Lawler et al., 2011), eliminating duplication, improving coordination of care and information among hospitals, laboratories, physicians' offices and other ambulatory care providers through an effective infrastructure for the secure and authorized exchange of health information, development of patient-centered health service (Brusco, 2011; Lawler et al., 2011), better documentation (Safdari et al., 2006; Roham et al., 2012), rapid access on relevant, comprehensive information needed (Glenton et al., 2006; Goldberg et al., 2011; Belanger et al., 2012), and improving the quality of health services (Haigh, 2004; While et al., 2011; Cresswell et al., 2012; Matheson et al., 2012).

IT Challenges in Cancer Registration

In spite of powerful role of IT, there are challenges in general and specific aspects associated with the use of technology. Some of the most common general difficulties are: threats to confidentiality and privacy (Khoumbati et al., 2010), changes in workload and the time devoted to work (Lawler et al., 2011), dependence on IT (Gustafsson et al., 2003), user attitudes, technology acceptance (Haux, 2006; Cresswell et al., 2012), user characteristics like age, economic , social and educational status (Cotton et al., 2004; Hardiker et al., 2011), lack

of ICT infrastructure, legal and administrative barriers, costs of system implementation and maintenance (Haigh, 2004; Cripps et al., 2011), the cost of updating (Haux, 2006), costly modern systems (Ammenwerth et al., 2003), sufficient investment, delays in implementation and providing electronic devices and software (Lucas, 2008). Also the most important challenges in specific aspects are: poor design and implementation, lack of system interoperability with electronic health records and other IT tools (Lawler et al., 2011), system compatibility with personal tasks (Viitanen et al., 2011), decrease in face to face communication between doctor and patient (Lluch, 2011), omission of human relationship and the negative effects of technology on relationships between individuals and social processes (Gustafsson et al., 2003), designing of E-Health services content (Hardiker et al., 2011), failure to meet targets (Lucas, 2008), problem in responsibility (Rigby, 1999), virtual information control (While et al., 2011), ill-functioning of system that leads to medical errors and negative effects on care outcomes, patients and personnel (Ammenwerth et al., 2003; Nykanen et al., 2011), mistakes in documentation (Lawler et al., 2011) e.g. data manipulation and re-writing, misrepresentation, and violation of patients' legal rights.

Conclusion

With the application of correct tactics and appropriate strategies to optimize the use of IT, one can get more benefits from IT advantages in cancer registry. Identifying authentication levels, controlling approaches, coding data, considering technical vocabulary and content standards, promoting procedures and policies, reengineering of processes, considering system flexibility so that by keeping operations standards special needs in each phase can be met, appropriate budgeting on the basis of efficient and correct information on needs, conditions and facilities, IT skills training, integrating cancer information system, user involvement, electronic system compatibility with personal tasks, support of the management policy makers and key stakeholders, technical support for the sales of IT tools, and risk analysis are some of the tactics of effective use of information technology in this field.

References

American Cancer Society (2008). Global Cancer Facts & Figures 2nd Edition. Available from: http://www.cancer.org/acs/groups/content/@epidemiologysurveilance/documents/document/acspc-027766.pdf

American Cancer Society (2012). Cancer Facts & Figures. Available from: http://www.cancer.org/acs/groups/content/@epidemiologysurveilance/documents/document/acspc-031941.pdf

Armstrong BK (1992). The role of the cancer registry in cancer control. *Cancer Causes and Control*, **3**, 569-79

Anderson JG (2002). Evaluation in health informatics: computer simulation. *Comput Biol Med* , **32**, 151-64

Ammenwerth E, Graber S, Herrmann G, Burkle T, Konig J (2003). Evaluation of health information systems-problems and challenges. *Int J Med Inform*, **71**, 125-35

Brusco JM (2011). Electronic health records: what nurses need

to know? *AORN J*, **93**, 3.

Bélanger E, Bartlett G, Dawes M, Rodriguez C, Hasson-Gidoni I (2012). Examining the evidence of the impact of health information technology in primary care: an argument for participatory research with health professionals and patients. *Int J Med Inform*, **81**, 654-61

Cresswell K, Sheikh A (2012). Organizational issues in the implementation and adoption of health information technology innovations: an interpretative review. *Int J Med Inform*, **82**, 73-86

Cotton SR, Gupta S (2004). Characteristics of online and offline health information seekers and factors that discriminate between them. *Soc Sci Med*, **59**, 1795-806

Cripps H, Standing C (2011). The implementation of electronic health records: a case study of bush computing the Ngaanyatjarra lands. *Int J Med Inform*, **80**, 841-8

Dos Santos Silva I (1999). Cancer Epidemiology: Principles and Methods. International Agency for Research on Cancer (IARC): France, 385-405 available from: http://www.iarc.fr/en/publications/pdfs-online/epi/cancerepi/index.php

EMPHO (2005). About Trent Cancer Registry. Available from: http://www.empho.org.uk/tcr/aboutus.aspx

Etemadi A , Sadjadi A, Semnani Sh, et al (2008). Cancer registry in Iran: a brief overview. *Arch Iranian Med*, **11**, 577-80

Glenton C, Underland V, Kho M, Pennick V, Oxman AD (2006). Summaries of findings, descriptions of interventions, and information about adverse effects would make reviews more informative. *J Clin Epidemiol*, **59**, 770-8

Goldberg L, Lide B, Lowry S, et al (2011). Usability and accessibility in consumer health informatics current trends and future challenges. *Am J Prev Med*, **40**, 187-97

Gustafsson E, Dellve L, Edlund M, Hagberg M (2003). The use of information technology among young adults-experience, attitudes and health beliefs. *Appl Ergon*, **34**, 565-70

Holden RJ, Karsh B (2010). The technology acceptance model: Its past and its future in health care. *J Biomedical Informatics*, **43**, 159-72

Haigh J (2004). Information technology in health professional education: why IT matters. *Nurs Educ Today*, **24**, 547-52

Haux R (2006). Individualization, globalization and health about sustainable information technologies and the aim of medical informatics. *Int J Med Inform*, **75**, 795-808

Hardiker NR, Grant MJ (2011). Factors that influence public engagement with eHealth: a literature review. *Int J Med Inform*, **80**, 1-12

Khoumbati K, Dwivedi YK, Srivastava A, Lal B (2010). Handbook of Research on Advances in Health Informatics and Electronic Healthcare Applications: Global Adoption and Impact of Information Communication Technologies. Medical Information science reference: Hershey, New York, p: 10

Laszlo J (1985). Health registry and clinical data base technology: with special emphasis on cancer registries. *J Chron Dis*, **38**, 67-78.

Lucas H (2008). Information and communications technology for future health systems in developing countries. *Soc Sci Med*, **66**, 2122-32

Lawler EK, Hedge A, Pavlovic-Veselinovic S (2011). Cognitive ergonomics, socio-technical systems, and the impact of healthcare information technologies. *Int J Ind Ergonom*, **41**, 336-44

Lluch M (2011). Healthcare professionals' organizational barriers to health information technologies-A literature review. *Int J Med Inform*, **80**, 849-62

Mc Devitt J, Comber H (2009). A proposed CORE national cancer dataset: national cancer registry, version 1.0,17 December 2009, Available from: http://www.ncri.ie/pubs/pubfiles/CoreNationalCancerDatasetv1.0.pdf

Moore MA, Shin H, Curado M, Sobue T (2008). Establishment of an Asian cancer registry network-problems and perspectives. *Asian Pac J Cancer Prev*, **9**, 815-32

Mohammadzadeh N (2006). Study of Attitudes of Iranian Medical Record Faculty Members about Effectiveness of IT in Health Information System: 2005-2006. MS of Medical Record Education Thesis. Tehran university of Medical Sciences.

Matheson A I, Baseman J G, Wagner S H, et al (2012). *Int J Med Inform*, **81**, 244-56

Nykanen P, Brender J, Talmon J, de Keizer N, Rigby M, et al (2011). Guideline for good evaluation practice in health informatics (GEP-HI). *Int J Med Inform*, **80**, 815-27

Roham M, Gabrielyan AR, Archer NP (2012). Predicting the impact of hospital health information technology adoption on patient satisfaction. *Artif Intell Med*, **56**, 123-35

Rigby M (1999). The management and policy challenges of the globalization effect of informatics and telemedicine. *Health Policy*, **46**, 97-103

Safdari R, Dargahi H, Mahmoodi M, Torabi M, Mohammadzadeh N (2004). Assessing the viewpoint of faculty members of medical record departments in Iran about the impact of information technology on health system, *HBI J*, **9**, 93-101.

Saskatchewan R, Thames S (2006). Integration of Cancer Registry Software with a Public Health Network (PHIN) Based, NEDSS Compatible Public Health Surveillance System. NAACCR, Annual Meeting.

SEER Training Modules (2013). Population-Based Registries. US National Institutes of Health, National Cancer Institute.

SEER Training Modules (2013). Importance of Cancer Registry. US National Institutes of Health, National Cancer Institute.

Thomas M (2009). Cancer Registry Outsourcing - The Benefits. Available from: http://ezinearticles.com/?Cancer-Registry-Outsourcing---The-Benefits &id=2621869

Viitanen J, Hypponen H, Laaveri T, et al (2011). National questionnaire study on clinical ICT systems proofs: Physicians suffer from poor usability. *Int J Med Inform*, **80**, 708-25

Wei K, Chen W, Zhang S, et al (2012). Cancer registration in the peoples republic of China. *Asian Pac J Cancer Prev*, **13**, 4209-14

While A, Dewsbury G (2011). Nursing and information and communication technology (ICT): a discussion of trends and future directions. *Int J Nurs Stud*, **48**, 1302-10