RESEARCH COMMUNICATION

Setting Research Priorities to Reduce Burden of Cancer in Iran: an Institutional Experience

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Abstract

Objective: The aim of this study was to draw a set of priority areas of cancer research in order to utilize these priorities as broader policy for decision-making on a comprehensive cancer control program at the national level in Iran. Materials and Methods: A steering committee consisting of scientists from the three major areas of clinical, basic research and public health sciences recommended a qualitative study of ranking an exhaustive outlines of cancer science topics by cancer scientists throughout country. Scientists were identified through Medline search and contacting cancer research centers all over the country. An exhausting outline of cancer science topics was modified and posed to Iranian cancer scientists. Doing research on each outlined topic was judged based on its state of being necessary, appropriate, practical or yielding in the Iranian societal context. An electronic system of communication was developed and all scientists were asked to rank each topic based in order of 1 to 5. As the areas of expertise of scientists were diverse, the participants had the option to rank the outlined topics that they think suitable to their areas. Results: Out of 135 identified scientists, 108 participated of whom 56 were clinicians (M.D's with university appointment), 35 basic scientists and 17 epidemiologists and public health scientists. As the top first five areas of research priorities, the overall assessment indicated as research topics: 1) cancer surveillance and registration as the first priority; followed by 2) exogenous factors in the origin and cause of cancer; 3) surveillance - patient care and survivorship issues; 4) issues of end-of-life care; and 5) cost analyses and health care delivery of cancer services. Conclusion: The study concluded that research on infrastructure of cancer control programs, cancer registration, service delivery and patient quality of life bears higher priority in Iran.

Asian Pacific J Cancer Prev, **12**, 2365-2370

Introduction

Cancer is the third cause of mortality in Iran after cardiovascular and traffic injuries (Khosravi et al., 2007). While there is limited well defined cancer registries in Iran to draw a comprehensive cancer map of the country, recent data(Mohagheghi et al., 2009) indicates an age adjusted incidence of 165 per 100000 men and 141 per 100,000 women in the population of Tehran, that is fairly a representative population of the whole country in terms of cancer risk and incidence.

Breast cancer is the most frequent cancer among female with annual incidence of 31 cases per 100,000 population and stomach and other GI cancer are the most frequent cancers among men as well as women (Mohagheghi et al., 2009). The cancer trend in Iran follows those of other countries with a rising of cancers related to western lifestyle such as colon, prostate, breast, lung, bladder and decreasing sign of cancers of esophagus, and stomach, though the latter is still number one among male population (Yazdizadeh et al., 2005).

The World Health Organization (WHO) has forecasted the magnitude of cancer incidence in the developing countries at an alarming scenario if these countries do not develop their own set of preventive measures and comprehensive risk reduction strategies (Shibuya et al., 2002). Among the complex paradigm of a comprehensive national cancer control program (CNCCP), lay an important module that addresses the research needs of other modules of a successful CNCCP (Orem and Wabinga, 2009). The research module in a comprehensive national cancer control program must be responsive to the evaluating needs of all the modules of the program while keeping the flow of knowledge

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and advances in sciences cancer into the national arena. Priority-setting of research activities is one of the most challenging and difficult issues faced by the CNCCP and its decision-makers. The prioritization of researches is inevitably value-laden and political (Goddard et al., 2006; Ham, 1997), requiring professional capabilities, credible evidence, strong and legitimate institutions and fair processes as well as political will (Sabin and Daniels, 1997; Norheim, 2008). Research prioritization toward more rational, effective, and achievable matrixes of burden, needs, cost effectiveness, and disparity management is a necessary component of a NCCCP program that draws consensus among all the stakeholders and policy makers (Garvey et al., 2011).

In 1998, a group of Iranian scientists established a network of cancer researchers in order to develop better means of communication, resource sharing and effective research management as well as to prevent inefficiency and wasting of resources available to cancer research and scientists in Iran. The network's inclusion of wide range of cancer science disciplines as well as its rich out to cancer scientists all over the country resulted in serving as a liaison body to give advice and consultation to the policy maker in the ministry of health as well as other governmental and nongovernmental institutions. The network letter on was officially recognized as the research module of the Iranian Comprehensive National Cancer Control Program. Part of the mandate of the network was to develop comprehensive sets of priorities in cancer research that not only provide directive policy for the other sectors of the CNCCP but also provide decision making framework for different advisory committees of the network' own establishments. As part of the CNCCP' mandate to develop priorities of research in cancer sciences, a stirring committee consists of several scientists suggested a comprehensive priority setting activities that takes into consideration the three domains of 1) the goal set by the government in "the National Road Map of Sciences and Technology" developed by the government, 2) the burden of specific cancers in the country as published by the government and 3) the views of the major stakeholders involved in CNCCP specially the Iranian scientific community as the elite group. It was envisaged that the final product of any priority setting should be as objective as possible and it should provide quantitative tools of assessment for policy makers and the network's numerous expert advisory committees. This paper reports the result of a qualitative study among Iranian scientist as the major stakeholders of the CNCCP to draw cancer research priorities.

Materials and Methods

A steering committee consisting of scientists from three major area of clinical, basic, public health sciences of cancer at a brain storming session recommended three sets of activities; 1) to identify all Iranian scientists who been interested in cancer research, 2) to develop a exhausting outline of all areas of cancer science's, and 3) to develop a means to pose the outline of cancer science areas to all the identified scientists asking their opinion on feasibility, practicality, achievability, and appropriateness of research in any of the outlined area. For the purpose of this study, an Iranian cancer scientist was defined as person holding a post graduate degree with at least one published paper on one of the cancer scientific subjects or be a faculty at any cancer research centers affiliated to the National Network of Cancer Researches. The study included all the scientists reported as faculty at the research centers plus scientists who were identified through a comprehensive search of Medline and Iran Medex (an index of Farsi medical literature). The search strategy included keyword of cancer, neoplasm, metastasis, carcinogen, carcinogenicity, malignant, carcinoma, sarcoma, leukemia, lymphoma, and melanoma in the title plus the word Iran in abstracts. The identified published papers were used to trace and contract the scientist either through his email if it was included in the paper or use his/her institutional affiliation for obtaining his email for next steps. To develop an exhaustive nomination of all cancer science subjects, the slightly modified Common Scientific Outline (CSO) main and sub-categories were used as a classification scheme to relate areas of cancer research to participating scientists. The CSO is a classification system organized around seven broad areas of cancer scientific domains including; 1) 1biology, 2) etiology (causes of cancer), 3) prevention, 4) early detection, diagnosis and prognosis, 5) treatment, 6) cancer control/survivorship and outcomes research, and 7) the scientific model systems. The CSO was developed by group of cancer research funding agency from United States, the United Kingdom, and Canada to manage the portfolio of cancer research (The International Cancer Research Portfolio (ICRP), 2010). Based on the CSO, an interactive questionnaire that included all the CSO' major and sub-categories was developed. A total of 35 questions were incorporated in the questionnaire. For each question, examples of research questions were provided as explanatory paragraph to increase objectivity of the questions content. Each scientist were supposed to express his opinion on a scale of 1 to 5 (1 giving higher value compared to 5) whether a research being done in any of the scientific outline is necessary (defined as a research that there exists societal needs of carrying such research), or is it appropriate (defined as a research that can fulfill some needs of societies), or is it practical (defined as a research that if carries out can be successful to reach its goal considering societies capabilities and resources), and or yielding (defined as a research that if carries out will yield a solid and achievable outcome). To apply the questionnaire, an electronic system of delivery (delivery of the questionnaire to participant using their email) with contact management (e-mail management), capability of trace of response (who returned the questionnaire), and

Table1. The Five Subcategories with Highest Scores for the Three Groups of Scientists

Scientist Category	CSO's subcategories	No*	Mean±SD Score
Public Health			
	Resources and Infrastructure Related to Cancer Control, Survivorship, and Outcomes Research	14	4.59±0.81
	Behavior (influence of behavioral and social factors)	15	4.43±0.93
	Chemoprevention	16	4.42±0.72
	Exogenous Factors in the Origin and Cause of Cancer	15	4.38±0.81
	Vaccines for cancer prevention	17	4.29±0.74
Clinical			
	Resources and Infrastructure Related to Cancer Control, Survivorship, and Outcomes Research	54	4.10±0.91
	Surviellance- Patient Care and Survivorship Issues	56	4.08±0.99
	End-of-Life Care	54	4.06±0.92
	Exogenous Factors in the Origin and Cause of Cancer	54	4.05±0.95
	Cost Analyses and Health Care Delivery	53	4.00±0.94
Basic Science			
	Resources and Infrastructure Related to Cancer Control, Survivorship, and Outcomes Research	30	4.16±0.99
	End-of-Life Care	25	4.05±0.82
	Technology Development and/or Marker Discovery	32	4.03±0.94
	Cost Analyses and Health Care Delivery	26	3.96±0.97
	Exogenous Factors in the Origin and Cause of Cancer	35	3.95±0.95

* Number of respondents

(interactive responding) a capability to answer partially in different time was developed. The questionnaire was applied in Farsi language. The participants had the option to answer parts of questionnaire that suites their area of expertise or to answer all the questions if he or she desires. If the participant did not return any response in a week of delivery, three more weekly reminders were sent in a period of four weeks. No more attempts were made if no answerer were received after the third reminder. Collected data were analyzed using a weighted scheme based on participants' area of expertise. The scored assigned to the outlined were averaged for each outline and ranked as area of higher priorities.

Results

A total of 135 scientists were identified by the Medline search and through contacting centers after eliminating duplicates. Out of 135 people, 108 scientists return the questionnaire. The remaining either did not answerer or the sent email bounced back. Among the respondents, 45 were male and 63 females. The distribution of the respondents based on field of specialty showed close to 56 were clinician (M.D with university appointment), 35 identified their self as basic scientist (non MD's with Ph.D. degrees in basic sciences such as genetic, molecular biology, anatomy, and physiology) and 17 as public health scientists (epidemiologist, health care administration specialist, environmental scientists, and social medicine disciplines). The first five fields of CSO that were ranked as high priority area differed among the three groups (Table 1). While of the three group give highest priority scores to cancer surveillance and registry as the first priorities, For clinician patient care and clinical surveillance, and economic aspect of cancer as well as end of life issues score higher priorities compared to other groups. The basic scientists scored higher priorities to end of life issue, discovery of markers, and etiologic study of exogenous hazards. The public health group scored high priorities to etiologic study of exogenous hazard, chemoprevention, and social and behavioral aspects of cancer risk as well as vaccine related to prevention of cancer (Table 1). The overall assessment of the given priorities indicated as the 1) Cancer Surveillance and Registry as the first priority followed by 2) Exogenous Factors in the Origin and Cause of Cancer, 3) Surveillance- Patient Care and Survivorship Issues, 4) Issues of End-of-Life Care, and 5) Cost Analyses and Health Care Delivery of cancer services as the top first five areas of research priorities with scores of more than 4 out of 5. The least priorities scores (less than 3.61)) were belong to 1) Complementary and Alternative Approaches for Supportive Care of Patients and Survivors, 2) Interventions to Prevent Cancer: Personal Behaviors that Affect Cancer Risk, 3) Biologic basis of Cancer Initiation: Alterations in Chromosomes, 4) Complementary and Alternative Treatment Approaches, and 5) Nutritional Science in Cancer Prevention Table 2.

Discussion

We applied a qualitative approach to set priorities for cancer research. We developed criteria to score a research topic raise in different setting at national and or institutional level. Our approach and developed list of scientific outlined and their assigned scores while can stand independently of other influencing factors such as economic or value laden in context of priorities setting it can be easily incorporated into any scheme or policy making decision framework to draw priorities of cancer researchers in Iran.

There are varieties of methodology in setting research priorities (Baltussen and Niessen, 2006; Youngkong et al., 2009; Baltussen and Niessen, 2006); all the

Table 2. The List of Priorities and the Scores Assigned for all Subcategories

CSO's subcategories	No*	Mean±SD Score
Resources and Infrastructure Related to Cancer Control, Survivorship, and Outcomes Research	100	4.19±0.92
Exogenous Factors in the Origin and Cause of Cancer	105	4.07±0.93
Surviellance- Patient Care and Survivorship Issues	102	4.04±0.99
End-of-Life Care	94	4.04±0.94
Cost Analyses and Health Care Delivery	93	4.00±0.96
Behavior (influence of behavioral and social factors)	99	3.95±0.98
Chemoprevention	105	3.91±1.04
Vaccines for cancer prevention	109	3.87±0.99
Localized Therapies - Discovery and Development	92	3.84±0.93
Combinations of Localized and Systemic Therapies	88	3.83±0.92
Technology Development and/or Marker Discovery	98	3.78±1.00
Localized Therapies - Clinical Applications	91	3.76±1.03
Biologic basis of Cancer Progression and Metastasis	101	3.71±0.99
Systemic Therapies	94	3.68±0.93
Technology and/or Marker Testing in a Clinical Setting	99	3.68±0.92
Biologic basis of Cancer Initiation: Ontogenesis and Tumor Suppressor Genes	99	3.63±0.95
Technology and/or Marker Evaluation with Respect to Fundamental Parameters of Method	99	3.61±1.00
Interactions of Genes and/or Genetic Polymorphisms with Exogenous and/or Endogenous Factors	107	3.61±0.97
Ethics and Confidentiality in Cancer Research	97	3.57±1.06
Education and Communication for cancer control	96	3.57±1.11
Endogenous Factors in the Origin and Cause of Cancer	106	3.50±0.83
Biologic basis of Normal Functioning of cell	101	3.46±1.01
Complementary and Alternative Prevention Approaches	100	3.42±0.98
Complementary & Alternative Approaches for Supportive Care of Patients and Survivors	90	3.36±1.00
Interventions to Prevent Cancer: Personal Behaviors that Affect Cancer Risk	102	3.33±0.89
Biologic basis of Cancer Initiation: Alterations in Chromosomes	97	3.31±1.07
Complementary and Alternative Treatment Approaches	89	3.29±1.03
Nutritional Science in Cancer Prevention	95	3.03±0.99

* Number of respondents

methodologies try to address and be responsive to the three main elements of a priority setting (Baltussen et al., 2006); 1) magnitude of the problem that is subject of prioritization translated as burden of that subject on the society or 2) some measure of economic impact, cost effectiveness, and resource availability, and 3) acceptability by the major and influential stakeholders that could range from public health administrator to just basic scientists. Of the main steps in setting priorities (Viergever et al., 2010) include identification of the stakeholders and a methodology to develop judgmental criteria for choosing and ranking competing issues of subject of priorities, and a framework to present the result of priority setting. The methodology in each of these steps includes group discussion, brain storming session, interviews and surveys of stakeholders (Youngkong et al., 2009). The judgmental criteria include subjective opinion of stakeholders and ultimately a means of presenting result of a priority setting activity could range from a rank ordered subjects to rank ordering of criteria that could direct policy makers on selecting the right action or program as the most prior. Successful priority setting is a desirable goal for decision makers; however there is no agreed upon definition for successful priority setting, so there is no way of knowing if an organization achieves it. A review of research priority setting in developing countries reported that 17 out of 18 papers publishing result of priority setting activities sets their criteria's involving different stake holders (Youngkong et al., 2009). In any plan of priority setting stakeholder are the subjective part of the spectrum that include disease burden and economic aspect of the subject of prioritization. The stakeholders' contribution in a priority setting is translated into choosing between competing values adding an ethical dimension to the task of priority setting plus introducing disparity dimension into priority setting (Singer and Mapa, 1998).

Being a complex task, priority setting methodologies has been under scrutiny and evaluation especially during last 20 years. In 2008, World health organization, published the result of a workshop on priority setting in Health research (WHO, 2008). The workshop developed, reviewed and summarized the methodology that have been used in priority setting and recommended "eight guiding principles" that their implementation would enhance a priority setting plan of action. The eight guiding principles included; 1) objectivity, transparency, validity, and reliability, 2) a systematic and thorough mapping of the national context, resources and restrictions, 3) specificity of methodology, 4) utilization of the best available information and data, 5) the translation of the result into investment and utilization by appropriate body, 6) incorporating a forecasting a forward vision in its context, 7) envisaging the limitations of the methodology used, and 8) a act capacity building and participatory enhancement. Our main method of priority setting included somehow all the eight recommended guidelines. In this study we reported the part of activity that deals with the main stream of stakeholders, cancer scientists. The process of sharing and participation of scientist was enhanced by sharing most of scientist who are interested and professionally doing research in cancer. This fact of wide rich out has implication of both objectivity and transparency. The process of ranking and scoring different subjects related to cancer ensured elements of participatory and capacity building. The method of data collection was electronic based, which has its own pro and cons, as argued earlier (Pereira et al., 2011; Ross et al., 2011). The fact that let the participant engaged in answering series of questions in a convenience of their time gives added value to the aim of methodology (ref) that is utilizing as much thought and input from participant.

To be inclusive of all aspect of cancer research, the CSO scheme was used. The CSO scheme not only includes all of cancer research topics but also its categorization of outlines merit scientific relevancy. The CSO classification is in fact a comprehensive classification and outline of cancer science and it has been used to measure the quality and quantity of cancer post graduate education (Mosavi-Jarrahi et al., 2011). The fact that, three main groups of cancer scientists, clinician, basic scientists, and public health scientist participated in our study ensures that our stakeholder's spectrum may have been greatly enhanced. The result of our study was tabulated as 27 area of research rank ordered based on priorities set by our participant. This tabulated and ranked topic ensures simplicity and objectivities of utilization of the result of the study. The tabulated list of topic by no means can alone be used for choosing subject of a priorities but as it was mentioned, this study complement two other domains of a priority setting; disease burden and national goals in the National (Iranian) Road Map of Sciences and Technology.

Our study may suffer from the fact that not all the stakeholders were included into our study. However, combining our result with those of disease burden and national goal will decrease the magnitude of this deficiency as the other two have already included comprehensive stakeholder participation.

Looking at the ranked outlines of result, it gives the impression that developing infrastructures of cancer control program (cancer registry, treatment services, and patient's quality of life) are the main concern and ranked high score in being subject of research this fact grant a sense of objectivity as theoretically, development of infrastructure bear an inherent aspect of priority.

In conclusion, our study developed rank ordered of cancer research priorities that can be used in different setting. The National Networks of Cancer Researches as a professional body that provide consultancy to the policy maker in the country would benefit most from results of this study.

Acknowledgement

The investigators appreciate the efforts, recourses, and the help that the Iranian scientific community provided toward achieving the aim of this study.

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