Title: Egyptian Pilot Study for a Global Database of Cancer Control in Developing Countries

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Abstract:
Although 72% of global cancer mortality occurs in low/middle income (LMI) countries the evidence for cancer control planning is largely derived from published studies conducted in high income (HI) countries that may offer little practical benefit to clinicians working with reduced resources in LMIC. Reports of studies conducted in LMIC are often harder to access. The International Network for Cancer Treatment and Research (INCTR), the European School of Oncology ESO, the Egyptian Foundation for Cancer Research and the National Cancer Institute (NCI) Cairo are collaborating on a study to assess the difficulties of accessing reports published in a LMIC. A search was conducted of Egyptian medical journals (including the *Journal of the Egyptian National Cancer Institute* (2000-2007) and the *Yearbooks of the National Cancer Institute, Cairo 2000-2006*) for published reports of original research in breast cancer, bladder cancer, lymphoma, paediatric cancer and palliative care reported in Egypt 2000-2007. The results were compared with electronic searches of four databases: Medline, Embase, Scopus and PsycLit. 1392 studies met the inclusion criteria. Only 111 (8%) studies were indexed on all four databases and 708 (51%) were not indexed on any of the databases. Arrangements are being made for the database to be hosted on the University of Cairo website. INCTR is seeking to collaborate with libraries in LMI countries to build up specialized Databases of Cancer Control that could help ensure that
the outcomes of research studies relevant to populations in LMI countries are made more easily accessible for the development of evidence-based national cancer control plans
Background

The importance of making published research more accessible to health care professionals working in low or middle income (LMI) countries has been recognized (Ref 1) and several initiatives designed to encourage this process now exist (REF. 2-5). Less emphasis has been placed on ensuring that reports of clinical research conducted in LMICs are widely accessible. In 2005 the World Health Assembly adopted Resolution WHA58.22 on Cancer Prevention & Control. (REF.6) This resolution urged members states to collaborate with WHO in developing and reinforcing comprehensive cancer control programmes “specifically through the systematic, stepwise and equitable implementation of evidence-based strategies” (REF 6). Resolution WHA58.22 presupposes the existence of an accessible evidence-base of context relevant research that can be used to guide and inform the drawing up of effective cancer control plans. In reality, the most accessible evidence is largely derived from studies conducted in the high income (HI) countries. While this extensive body research has provided a sound foundation upon which to build cancer control measures in HICs, the context within which research is conducted may differ from that of many LMICs. High-, middle- and low-income countries differ widely with respect to the types and patterns of cancer, levels of cancer incidence, patient genetics, health care governance, socioeconomic status, literacy rates and behavior of populations as well as with respect to the resources they can command.

Since they are often not published in journals indexed by the major databases (REF 7) reports of studies conducted in LMICs are harder to access. Research papers published by authors working in the USA or UK accounted for 32% of the cancer research reports indexed on PubMed in 2006, while papers from the whole of Africa accounted for only 0.5% of the indexed cancer articles (REF 8). The task of gathering and assessing the value of non-indexed research evidence although challenging is not impossible. We
report the interim results from a three year pilot study jointly undertaken by the International Network of Cancer Treatment and Research (INCTR0 and the National Cancer Institute in Cairo, Egypt (NCI Cairo) and supported by the European School of Oncology and the Egyptian Foundation for Cancer Research. The purpose of the pilot study is to demonstrate how reports of research studies conducted in a LMI country can be made more accessible to cancer control planners.

Methods

The contents pages of 70 biomedical journals held by libraries in Egyptian universities or at NCI Cairo, including the Journal of the Egyptian National Cancer Institute (2000-2007) and Yearbooks of the National Cancer Institute, Cairo (2000-2006) have been searched for published reports of original research in breast cancer, bladder cancer, lymphoma, paediatric cancer and palliative care conducted in Egypt. Copies of possible relevant reports were obtained and checked against the inclusion criteria. The results are compared with electronic searches of four databases: Medline, Embase, Scopus and PsycLit. Search terms associated with the type of cancer or palliative care in the Title, Abstract or Medical Subject Heading (MeSH) fields, combined with ‘Egypt*’ in the Title, Abstract, Address or Affiliation (AFFIL) fields were used. Database searches were conducted between January and April 2008 and the results downloaded onto a bibliographic database (ProCite 5.1). The bibliographic of non-indexed publications were either keyed in by hand or, if available, downloaded from the NCI Cairo website. Animal studies were excluded.
Results

545 ‘journal years’ have been searched, and 854 papers identified of which 708 (83%) were not indexed on the four databases. 43 (61%) searches of the 70 journals have been completed. Combined with database searches 1,874 studies were identified, of which 1,392 met the inclusion criteria. There was variability in the indexing of individual studies. Only 111 (8%) of the 1392 included studies were retrievable from all 4 databases. and 708 (51%) were not indexed on any of the four databases. Searches of the J Egypt Nat Cancer Inst 2000-2007 identified 150 studies which met the included studies; 60 (40%) were indexed on Medline. The results of the searches are presented in Table 1. Totals have not been included as 48 included studies (3%) were relevant to more than one area of care.

<table>
<thead>
<tr>
<th>Area of care</th>
<th>All studies identified</th>
<th>Journal searches</th>
<th>Medline</th>
<th>Embase</th>
<th>PsycLit</th>
<th>Scopus</th>
<th>Non-indexed studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>437</td>
<td>223</td>
<td>81</td>
<td>89</td>
<td>92</td>
<td>162</td>
<td>216</td>
</tr>
<tr>
<td>Bladder</td>
<td>421</td>
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<td>113</td>
<td>98</td>
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<td>Lymphoma</td>
<td>333</td>
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<td>243</td>
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<tr>
<td>Childhood</td>
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<td>13</td>
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<tr>
<td>Palliative Care</td>
<td>83</td>
<td>41</td>
<td>21</td>
<td>7</td>
<td>19</td>
<td>39</td>
<td>29</td>
</tr>
</tbody>
</table>

Searches of the journal holdings and databases for relevant studies published in 2008 are underway. Arrangements are being made for the database to be hosted on the University of Cairo website and to be maintained by the INCTR office at the National Cancer Institute, Cairo. Where abstracts are available permission will be sought from the copyright holders to reproduce them on the website.

Discussion

Three conclusions can be drawn from the results reported above: (1) coverage by indexing on the general medical databases is, at best, partial; (2) routine searching of one or even two databases is insufficient to adequately identify studies and (3) studies conducted in developing countries may be seriously under-represented on the major databases. Less than 50% of the studies published in the J Egypt Nat Cancer Inst and NCI Cairo Yearbooks were included in the 4 major databases. Many of the articles cited in the NCI Cairo Yearbooks are published in journals not indexed by the databases. Difficulties with accessing evidence from research conducted and published in LMI countries can artificially depress national research profiles and may reduce the motivation to invest in, or conduct, research within an LMI country.

Quality is necessarily an issue. Popularly, exclusion of journals from LMI countries in the major databases supports the inference that the research they report is inherently less rigorous methodologically than that reported in indexed journals. This view does not make any allowance for the inbuilt variations in the scopes, the indexing capacity and the inclusion criteria of the major databases,
nor the chronological development of the indexing process. (When the search of Medline was performed the articles published in *J Egypt Nat Cancer Inst* prior to 2003 had not yet been indexed.) More crucially, the assessment of research quality should always be evidence-based and not anecdotal. If research standards are to be raised, systematic reviews of research methodology are needed to identify and explain shortfalls in the quality of study design, conduct and reportage. The identification of all relevant studies is a prerequisite to the conduct of good systematic reviews. (REF 9).

This pilot study demonstrates that the cooperation of professional information managers is, if not essential, at least extremely desirable in the identification and systematic review of research studies. Published reports of research lie scattered across journal holdings in different libraries and the willing collaboration of senior librarians is critical to the identification of relevant studies. It is no exaggeration to say that librarians and their fellow information managers may be the keyholders to the national research record.

The Egyptian project is a pilot study directed by INCTR and supported by the European School of Oncology and the Egyptian Foundation for Cancer Research that is designed to demonstrate the methodology behind the development of a nation-based database of cancer control within an LMI country. In a separate INCTR study funded by the Office of International Affairs at the National Cancer Institute, Bethesda MD USA, evidence relevant to the early detection, diagnosis and treatment of breast cancer in LMIC is being collected and reviewed by an international panel. It is highly probable that this tumour-specific project will also highlight the variation in coverage between the major bibliographic databases and the difficulties to be overcome in accessing reports of cancer control studies conducted in LMI countries. It would be interesting to see if these barriers also existed in different areas of treatment modality; e.g. radiotherapy, surgery or drug therapy.
INCTR and NCI Cairo plan to continue to extend the Egyptian database to all areas of cancer control, and subsequently to train appropriately qualified individuals in the conduct of systematic reviews of research methodology. The database, which will be maintained by stakeholders within the region, should:

- Provide an accessible, comprehensive evidence-base that will inform the development of national cancer control plans
- Identify gaps in the evidence base, thereby stimulating the conduct of relevant research
- Contribute to improving the standard of published research studies
- Help prevent duplication of research effort

Conclusion

The emphasis in Resolution WHA58.22 on evidence-based strategies is well placed, but there are barriers to accessing evidence created within the context of low and middle income countries that need addressing. The authors hope that the establishment of Databases for Cancer Control in Developing Countries - piloted in Egypt, then expanded in a stepwise process - coupled with the provision of training in systematic review in research methodology, will help improve patient care in LMI countries by facilitating the development of evidence-based national cancer control plans and by strengthening the culture of scientific research.
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