Evidence Based Library and Information Practice

Evidence Summary

Information Needs of Cancer Patients are Influenced by Time Since Diagnosis, Stage of Cancer, Patients' Age, and Preferred Role in Treatment-related Decisions

A review of:
Kalyani, Ankem. "Factors Influencing Information Needs Among Cancer Patients: A Meta-Analysis." Library & Information Science Research; 28.1 (2006) 7-23.

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Abstract

Objective – The author aims to study the aggregate influence of demographic and situational variables on the information needs of cancer patients, in order to inform the provision of information to those patients.

Design – Meta-analysis.

Setting – Research articles published in the *MEDLINE* and *CINAHL* databases.

Subjects – English language studies published between 1993 and 2003. An initial search set of 196 studies from *MEDLINE* and 283 studies from *CINAHL* were identified. Following rigorous assessment, 12 studies met the inclusion criteria.

Methods – A comprehensive search of the databases was conducted, initially combining "neoplasm" with "cancer patients" using the Boolean "or". These results were then combined with five separate searches using the following terms; information need(s), information seeking, information seeking behaviour, information source(s) and information resource(s). This identified in total 479 English language articles. Based on a review of titles and abstracts, 110 articles were found covering information resources or the information needs of cancer patients. These articles were then subjected to the further inclusion criteria and limited to studies which included: analysis of information needs and/or information sources of cancer patients; adults as subjects of the research;

and application of quantitative research methods and relevant statistics.

This eliminated a further 35 papers. Twelve of the remaining 75 studies were selected for meta-analysis based on their use of the same variables measured consistently in comparable units. The final 12 studies included various forms of cancer, and no distinction was made among them. All 12 studies appeared in peer-reviewed journals.

Main results – The meta-analysis found there was consistently no difference between the information needs of men and women. Five subsets were identified within the meta-analysis, and findings for each can be stated as follows:

- The younger the age of the patient, the greater their overall need for information was likely to be.

- During treatment, the time elapsed from the diagnosis to the information need was not significant. Once identified, the information need remained constant.

- During treatment and post-treatment phases, the time elapsed from the diagnosis to the information need made no significant difference, with the information need remaining constant and continuing into the post-treatment phase.

- The stage of cancer made no difference to the need for information. Those patients in the advanced stages of cancer required an equal amount of information to those in the early stages of cancer.

- The individual patient's preferred role in treatment-related decisions made a difference to the information need. Patients who took an active role in treatment-related decisions had a greater need for information than those who did not take an active role.

Conclusion – Findings from this meta-analysis can be used to guide information provision to cancer patients, specifically taking patient age and preferred role in treatment decision-making into consideration. Further research into the reasons behind the lower information needs among older patients is called for by the author.

Commentary

This is a timely piece, at least in the UK, as the consideration of the information needs of patients and greater patient involvement in healthcare libraries is very much on the agenda. Many libraries, traditionally involved in the business of information for providers rather than consumers of healthcare, are now finding themselves wrestling with the challenges of providing patient information. For many this is uncharted territory, and Ankem's meta-analysis provides us with an excellent navigation tool.

Meta-analysis is a statistical technique to combine the results of different research studies in order to ascertain the overall effectiveness of particular procedures or interventions. Most commonly used in healthcare, this study is one of the first examples of meta-analysis being used in library and information science, and is perhaps a baptism of fire for newcomers to the technique, assuming levels of knowledge which may not yet be there. Ankem has published a related piece "Approaches to Meta-Analysis: a Guide for LIS Researchers", which discusses the methodology specifically in relation to this article. That guide complements this well, providing explanatory background reading,

and having access to it puts the reader at a distinct advantage.

A common criticism of published research is that at times there just isn't enough detail, and we are left trying to fill in gaps where further explanation would have avoided such frustration. That is certainly not the case here, where the reader can at times feel overwhelmed with detail. As such, this is heaven for those familiar with research methodology, but for the librarian with a less confident grasp of statistical techniques this may be more of a challenge and consequently of more limited use.

As meta-analysis is dependent on the quality of the systematic review upon which it is based, the author's reasons for going into such detail throughout are necessary and understandable. It is laudable that the researcher doesn't just focus his search on *MEDLINE*, but also broadens scope to include *CINAHL*, the *Cumulative Index of Nursing and Allied Health Literature*. Inclusion of *EMBASE* would have been even better, as this would have broadened the scope further with the potential to identify research not included in *MEDLINE* and *CINAHL*. It is difficult to fault the explanation of the methodology as we know exactly which search terms were used, which fields were searched, and how Boolean operators were employed. It is a delight to read the documented detail of such a thorough literature search. Initial search results of 196 studies in *MEDLINE* and 283 in *CINAHL* were ultimately reduced to 12 studies which meet the final inclusion criteria. Once again, the detailed methodology leaves no room for doubt as to how this process evolved. The decision to limit the search to English language material could possibly be seen as a shortcoming as it may not have identified ***all*** relevant studies. However, this really is a tiny quibble and of no great concern as healthcare research has demonstrated that excluding languages other than English from meta-analyses makes no difference to overall results (Moher).

The greatest frustration with this study is that is it seems to ignore the various types and formats of information. We have no idea what information was delivered to the patients, how they received that information, how it was used, or the format in which it appeared. Is the information face-to-face delivery from the caregiver, patient information leaflets, digital media, generic, personalised, or some other form? However, the author again sidesteps any criticism as, in fact, the original systematic review has provided material for three articles.

> [this] article published in Library & Information Science Research covers a meta-analysis of the level (low versus high) of information need among cancer patients. The second article [Ankem 2005] published in LIBRES is a systematic review of the kinds of information these patients needed. The third article [Ankem 2006], the one most recently published in Information Research, is a systematic review of the information sources cancer patients used. (Ankem)

In essence, different data sets within a large pool have been analyzed to explore different but related themes. The author could perhaps aid the reader by making it clearer in this piece that it is one of a triptych of articles. While this is not an evidence summary of the other two articles, it is foolish to ignore them and treat this one in isolation as the three together give the reader a much richer picture. For example, we don't learn about the types of information needed by cancer patients here, as that is a main focus of the article published in LIBRES (Ankem). Interested readers should most certainly seek out the

additional two to thoroughly immerse themselves in the data.

For the librarian working in research this is 16 pages of paradise, 10 pages of which are packed with meticulously detailed methodology and results. Those working on the hospital enquiry desk may be frustrated that, with less than 2 pages of discussion, the possible implications of the results seem almost an afterthought. How we should apply Ankem's findings to plan the strategic delivery of services is far from clear, and to get the full picture the reader really does need to obtain and digest the additional two equally weighty articles. Those less-inclined to digest the three would do well to seek out a systematic review covering very similar subject matter (Rutten) conducted over the longer time-scale of 1980-2003. In addition to the databases searched for this meta-analysis, the Rutten systematic review also includes articles from *Social Science Citation Index* (*SSCI*) and *PsycINFO*. Rutten and colleagues do not nearly include the amount of methodological detail, nor go as far as the meta-analysis we have here; but they do discuss type and source of information, and suggest practice implications. The busy librarian may find this "one-stop shop" as useful in actually planning services as Ankem's thorough three-part exploration.

In conclusion, this meta-analysis is a terrific journey with a great deal to look at along the way, but is the destination worth it? Yes, without question. Some may feel that this is a long climb up a hill to find a view, which they were fairly sure was likely to be there anyway, but they would be hard-pressed to find a more meticulous and organised tour guide. The conclusion that younger cancer patients and those actively involved in treatment-related decisions have a greater need for information than others is unlikely to be a great surprise to anyone working in the field of cancer care. What we now unquestionably have is a high-quality examination of the literature to support that model.

Works cited

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