An opportunity for health librarians - improving on information provision for children about cancer

Dr. Janet Harrison[1], Professor Ina Fourie[2]

[1]*Centre for Information Management, School of Business and Economics, Loughborough University, Loughborough, UK*
[2]*Department of Information Science, University of Pretoria, Pretoria, South Africa*

Dr Janet Harrison: J.Harrison@lboro.ac.uk

Abstract

Introduction: A reasonable body of literature is available on children, cancer, information provision and information seeking, and the information needs and related experiences of survivors of childhood cancers. Considering the increase in childhood cancers, the improvement of chances for survival, how children are affected by the cancer of parents and siblings and importance of informed decision-making for survivors of childhood cancer, a need has been identified for a state of the art literature review on improving information provision to children about cancer.

Objectives: To identify types of research methods in deepening understanding of gaps in information provision to children about cancer. Literature on information provision to children on cancer is limited implying that they might experience unmet information needs in seeking information. A literature review can offer an opportunity for health librarians to raise awareness of the value of systematically exploring the literature to learn from children and their experiences, information needs and information behaviour.

Methods: A literature search on children and synonyms e.g.: child, toddlers, teenagers, and childhood cancer and information provision was conducted using databases from health care, library and information science, psychology and education. Publications were hand-selected for further consideration and obtaining the full-text. Only research articles in English were included.

Discussion: The review considers four scenario settings reporting research on information provision for children: children with cancer, children who's parent or sibling has cancer, public health prevention information, survivors of childhood cancers reporting childhood experiences of information provision (only when the research participants are youth or young adults). Methods of information provision include written, oral and visual information. Research approaches cover quantitative, qualitative and mixed methods research. One methodology or data collection method does not prevail in any of the four scenario settings. Discussion on methods of data collection from children, and needs for innovative and age appropriate methods do not feature strongly.

Conclusion: Based on the gaps noticed there is ample scope to identify a particular methodology for particular scenarios that can deepen understanding of the needs of children about cancer, their own cancer, the cancer of a close family member, preventing cancer, and to inform decision-making with regard to quality of life as a survivor and model the results. This, and input from health librarians can improve information provision to children about cancer.

*Key words***:** cancer; children; childhood cancer; information; information behaviour; research methods

Children and information provision

One of the most important political influences in changing attitudes and to listen to children's voices increasing their particiation in descisons concerning their own lives came from the Convention on the Rights of the Child.[1] The notion that children have different expectations and needs of literature from those of adults is well accepted worldwide. In Britain the establishment of a Children's Poet Laurate is one significant move that confirms this. It is also acknowledged worldwide that school librarians and childrens' librarians can be a good and powerful infuence in childrens's lives providing the stimulus and encouragement for improved, wider reading and literacy, and supporting their needs for information.[2]

Children and health information provision

Research demonstrates that appropriate health information provision can influence decision-making for treatment, compliance to treatment, choices on participating in clinical trails, and overall patient anxiety and psychological well-being. "The provision of information is an individual entitlement and a prerequisite to enabling children to understand their illness, make choices about their health care and be involved in decision-making processes around these choices".[3]

Given the universally recognised concept that children are not as fully developed mentally or physically as adults and should be treated in ways appropriate to them, we wanted to know if information provison for children with cancer is appropriate, if there were any known protocols, and whether methods of data collection from children were appropriate. This paper focuses mostly on the latter.

Together with the knowledge of an existing staff expertise base of health librarians it would seem a logical expectation to suggest that health librarians could be used or assist in the provison or provide working examples of conveying medical facts to children in the healthcare setting. Health librarians often work closely with nurses and clinicans and are privy to detailed case conferences about patients; they perform structured and systematic literature reviews and provide "gold standard evidence" to assist in the clincial decision making process.[4]

With an increasing number of children diagnosed with childhood cancer, or affected by the diagnosis of a parent or sibling there is an increased need for appropriate information. These include information on the diagnosis, disease, symptoms such as pain. The frustrations children report are very similar to frustrations reported with regard to cancer information provision in general, namely, insufficient information and lack of information. To address the need for the improvement of information provided to children, we decided on a global literature study to determine the status quo, and to explore opportunities for health librarians to be involved.

Children and cancer

Childhood cancers and the experiences of patients differ from adult cancers.[5] Considering the scope of childhood cancers, types, age ranges of people affected (from babies to teenagers and young adults), the research reported on children and cancer information is very limited. Especially if one considers that findings from cancer in general has shown difference in the information needs and information seeking for specific types of cancer, the role of the person seeking information, the cancer stage, age, gender, and also cultural differences.[6] Although children can get some of the cancers associated with adults, there are also many cancers that are more uniquely associated with childhood cancers such as neuroblastoma. This is a type of childhood cancer that develops in nerve tissue outside of the central nervous system. It usually begins in the adrenal gland on top of the kidney, but it can be found anywhere along the spine and also Wilms tumor, which is a tumor associated with the liver.

Children are also affected by the cancer diagnosis of parents and siblings. A considerable part of the literature on cancer information provision to children concern the prevention of cancers such as cervical cancer, and hereditary cancer such as breast cancer, parental involvement and on how parents should inform children about parental cancer or the cancer of other close family members. This plentiful provision of literature for children with parents suffering from cancer, reflects the general focus and scope of the literature; the focus being primarily on adult cancers or the adult as parent of a child with cancer and not the child as cancer patient. There is also a significant amount of literature about the information needs and information provision to the survivors of childhood cancer. For the latter, most often, but not always, research participants are then young adults with a diversity of age ranges being covered, often in the same study e.g. including teenagers as well as people in their late twenties and even late thirties.

Methods of information provision include written and oral information, booklets, and videos.
A study of information provision particularly noteworthy is Parton[7] where a visual approach had been used. Not surpringly this study concerned information for parents of children with cancer not the children. Also Hazen et al.[8] where a video approach for information provision was used; again this was to convey information to family members and not speicifcally to the children with cancer. Surprisingly in the era of "*Digital Natives* the use of websites and the Internet for conveying information did not prevail. The www.teenagecancertrust.org is however an exception to this finding.

Research question and sub-questions

The following research question guided our study:

How can health librarians contribute to provision of information to children about cancer?

In finding answers, we considered the following sub-questions:

- *What has been published on information provision to children about cancer?*
- *What type of research methods feature in the provision of information to children about cancer?*
- *Does one research method predominate in this field?*

We thus considered methods of information provision to children, as well as the research methods used to identify gaps in information provision to children about cancer. Our purpose was to reflect on the opportunities for health librarians to raise awareness of the value of systematically exploring the literature to learn from children and their experiences and to address findings from information behaviour/practice research.

Conducting the state of the art literature review

Literature search

In preparation for the study, we searched an array of library and information science, educational, health, psychology and interdisciplinary databases to which we had access. These included AIDS and Cancer Research Abstracts, CINAHL, Library and Information Science Abstracts, Library & Information Science Source, Medline, PsycINFO, and Thompson's Web of Science. We also considered specific journal titles such as: American Journal of Psychiatry, Journal of Child Health Care, Information Research, Health Information and Libraries Journal.

Search terms for the three key concepts (children, cancer and information provision) had to appear in the title, keyword and abstract fields. Singular and plural form, as well as other word forms were considered. We included synonyms e.g.: child, toddlers, teenagers, and childhood cancer, as well as giving, sharing, telling and terms for specific media e.g. video or booklets, and terms for specific types of cancer typically associated with children, e.g.: leukaemia, lymphoma, astrocytoma, neuroblastoma, Wilms, and Hodgkins disease.[5] Publications were hand-selected for further consideration and obtaining the full-text. Only research articles in English were included.

Scope of the review

The review considers four scenarios of research on information provision for children: children with cancer, children who's parent or sibling has cancer, public health prevention information, and survivors of childhood cancers reporting childhood experiences of information provision (only when the research participants are youth or young adults). Information behaviour studies have shown that role and responsibility and how a person is affected e.g. whether a patient or family member, as well as progression in a situation impacts on information needs and information seeking.[6]

Most of the studies we analysed were reporting on information provision to the children of a parent with cancer, the need to take precaution in cancer prevention such as for hereditary cancer and cancers such as cervical and prostate cancer that are approached as preventable with vaccination (for cervical cancer) and timely diagnosis through screening (cervical, breast and prostate cancer).

Findings and discussion

Types of research methods

Research approaches cover quantitative, qualitative and mixed methods research with most studies following a quantitative approach. One methodology or data collection method does not prevail in any of the four scenario settings. Discussion on the methods of data collection from children and the appropriateness of the methods do not feature strongly.

Types of research methods found in the literature included, questionnaires, diary recordings, interviews, content analysis of web-postings and observations. Studies are often limited to the traditional, namely questionnaires (print and electronic), individual and focus group interviews. Although telephone interviews are reported for young adults, interviews are mostly face-to-face. Sometimes these methods are combined with means for providing information such as a booklet, combined with a clinical interview and a questionnaire. Hardly any of the reported studies focused on age appropriate methods of data collection. This is a problem since the age ranges are often very wide e.g. 8-16 or 12-24, and sometimes even older participants for studies on survivors.

Timeline, target group for information provision, and research participants

Information provision is aimed at children as cancer patients, as persons who can prevent cancer, as affected by the cancer of a relative or as survivors of childhood cancer. Often parents or even health professionals are, however, included as participants, or even the sole participants sharing their perceptions and experiences on the information needs of children. The target group is also important in terms of the stage of cancer e.g. in treatment or as a survivor, or the role of the participant e.g. as a patient or relative. In this sense, there is a serious lack of diversity of studies with children about cancer; the scope of what needs to be studied is not nearly covered.

In terms of methods of data collection used for the scenario settings, there are some studies worth noting:

(1) Children as patients: Kauhanen et al.[9] report on the sense of an interview with a questionnaire, diaries and a physical examination to assess the impact on following the messages/information provided on exercising. Soanes' et al.[10] is an exceptional study reporting on using age appropriate techniques of data collection for various age groups about their experiences. A mosaic approach was used for 4-6 year olds, draw and write for children between 6-12 years and interviews for children older than 12 years.

(2) Public health prevention: Semi-structured focus group interviews, self-reported assessment after receiving messages with information, online surveys, and questionnaires are reported as typical methods. A card-sort game combined with pre- and post-questionnaires was more innovative.[11]

(3) Survivors: Apart from the traditional methods also noted for other scenarios, there are reports were these methods are combined with means for providing information such as a booklet, combined with a clinical interview and a questionnaire. Self-portraits combined with the use of photovoice was more innovative[12].

(4) Related to a cancer patient: The studies noted were mostly using traditional methods such as interviews and focus group interviews.

Model for research methods for information provision for children with cancer

One methodology or data collection method does not prevail in any of the four scenario settings. Discussions of methods of data collection from children do not feature strongly. There is not a clear and identifiable pattern for information provision for clincial and other healthcare staff to adopt. This is somewhat surpring as often treatment regiems will be similar for the same cancers with supporting clincial governance protocols. It would seem that age appropriate information provision and research methods on information provision is a forgotten or ignored factor in the treatment of children suffering from cancer. It is acknowledged throughout the literature that informing patients about their condition and treatment helps the take ownership of their own health and this can be benificial for both clincial staff and patients. Children should be no exception. Shillabeer[13] observed that little research had been done in the area of information provision for adolescents in the past twenty years and similarly there had been little improvement in clinical outcomes. Our initital findings from this literature review would seem to confirm this.

Opportunities for health librarians

There are many opportunities for health librarians to get involved in the provision of information to children about cancer. They can raise awareness of the value of systematically exploring the literature; as clinical librarians they can contribute to gathering evidence based medicine for use in clinical diagnosis making; they can contribute to preventative literature; they can contribute to raising awareness that existing methods of data collection on information needs are insufficient considering the difficulties in recognising and articulating information needs, and that a wider spectrum of age appropriate research methods as well as methods of information provision is needed to learn from children and their experiences of information needs and information behaviour to ultimately add to the knowledge base.

Conclusions

The most striking finding from our literature searching is the paucity of literature available concerning the information provision for children with cancer of information giving by healthcare professionals directly to children. There may be several very good reasons for this absence of literature: it is extremely difficult to interview and gain views and opinions from children who are suffering from cancer given the ethical issues surrounding treating children and gaining consent for research studies; the importance of information provision is seen as secondary to clincial intervention; children are not seen as articulate and able to express themselves clearly; and/or the information is considered to be too upsetting or difficult to translate to a child’s perspective.

Based on the gaps noticed and the paucity of research available, there is ample scope to identify a particular methodology, for particular scenarios that can deepen understanding of the needs of children about cancer, their own cancer, the cancer of a close family member, preventing cancer, and to inform decision-making with regard to quality of life as a survivor and model the results.

The identification and/or development of a model for information provision for healthcare staff to use with children suffering and coping with cancer would be invaluable; contributing to both improvement of patient knowldege and empowerment and the clinical governance agenda. This would include raising awareness of methods appropriate for research with children.

REFERENCES

1. United Nations. Convention on the Rights of the Child. 1989 [cited 12 Apr 16]. Available from: http://www.unicef.org/crc/
2. Kachel D, Curry-Lance K. Latest study: a full time school librarian makes a critical difference in boosting student achievement. School Library Journal. 2013; 59(3):28.
3. Lambert V, Glacken M, McCarron M. Meeting the information needs of children in hospital. Journal of Child Health Care. 2013;17(4):338-53.
4. Harrison J, Creaser C, Greenwood H. The status of health librarianship & libraries in the Republic of Ireland: an account of a review to inform future strategy and sustainability. Health Information and Libraries Journal. 2013; 30(2):92-109.
5. Vlok RM. The Medical Library Association Guide to Cancer Information. New York: Neal-Schuman Publisher, Inc; 2007.
6. Johnson JD, Case, DO. Health information seeking. New York: Peter Lang; 2012.
7. Panton RL, Downie, R, Truong T, MacKeen L, Kabene S, Yi Q-L, Chan HSL, Gallie BG. A visual approach to providing prognostic information to parents of children with retinoblastoma. Psycho-Oncology. 2009; 18(3):300-4.
8. Hazen RA, Eder M, Drotar D, Zyzanski S, Reynolds AE, Reynolds CP, Kodish E, Noll RB. A feasibility trial of a video intervention to improve informed consent for parents of children with leukemia. Pediatric Blood & Cancer. 2010; 55(1):113-8.
9. Kauhanen L, Järvelä L, Lähteenmäki PM, Arola M, Heinonen OJ, Axelin A, Lilius J, Vahlberg T, Salanterä S. Active video games to promote physical activity in children with cancer: a randomized clinical trial with follow-up. BMC Pediatrics. 2014; 14: 94.
10. Soanes L, Hargrave, D, Smith, L, Gibson F. What are the experiences of the child with a brain tumour and their parents? European Journal of Oncology Nursing. 2009; 13(4): 255-261.
11. Hooker L. Information needs of teenagers with cancer: developing a tool to explore the perceptions of patients and professionals. Journal of Cancer Nursing. 1997; 1(4): 160-8.
12. Yi J, Zebrack, B. Self-portraits of families with young adult cancer survivors: using photovoice. Journal of Psychosocial Oncology. 2010; 28(3): 219-43.
13. Shillabeer A. Information provision for adolescents with cancer. User Centred Networked Health Care. 2011; 169: 8-12.

,