

Information for Children about Cancer

“An Opportunity for Health Librarians”

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What's this all about?

- Introduction - analogy
- Defining the population – if we say children...
- Defining the disease – if we say cancer...
- Link between information provision and research methods
- Types of information provision for children with cancer
- Types of research methods used in information provision for children with cancer
- What can librarians do?
- Conclusions
- Future research

Introduction - cancer the crab - analogy



Introduction – the crab – analogy (cont.)

Crabs

They live in all the world's oceans, in fresh water, and on land, are generally covered with a thick exoskeleton

Have a single pair of claws

- Usually walk sideways... But some species walk forwards and backwards; some crabs can swim

Different colours

Look ugly, not a pretty sight, not easy to love and care for (?)

Children with cancer

All live on land, all have a skeleton, some can walk, some can swim, different nationalities, different cultures, different ages, different languages

Cancer changes their bodies, look different, cognitive abilities, anxiety, depression

- Late effects...

Different disease impact, stages, treatment, disease trajectories...

Different to adults – childhood stages of development important (**crabs walk sideways, lobsters don't**)

Schools

If we say children...



Babies, toddlers,
young children,
preteens,
teens/adolescents,
TYAs, young
people, young
adults... age groups
not well defined...
(5-8; 8-12; 8-20;
25+)... different
groups in one
study
Small scale studies

Being an
adolescent/teenager
is hard enough...

If we say children and cancer...

- Children with cancer (patients)
- Children who's sibling or parent has cancer
- Public health prevention information
- Survivors of childhood cancer
 - (Children as research participants; young adults)
 - Late effects, issues of fertility

Children with cancer

- Isolation, stigma - often in their own “world” in a “shell”
- Perceived as difficult or hard to talk to; need to crack the hard shell
 - Difficult to crack shell
 - Should they be informed about disease and prognosis(?)
 - Too young to participate(?)
 - Difficult to penetrate their minds(?)
 - What do they want, or think... what do they need(?)

Lived realities

If we say childhood cancer...

- Some similar to cancers affecting adults
- Other cancers unique to children
- Examples: leukaemia, lymphoma, astrocytoma, neuroblastoma, Wilms, and Hodgkins diseaseacute lymphoblastic, acute non-lymphoblastic, non-hodgkin's lymphoma, primitive neuroectodermal tumor, ependyoma, osteogenic sarcoma, erwing's tumor, rhabdomyosarcoma, fibrosarcoma, retinoblastoma, germ-cell tumors, epithelial...

Our concern

Considering the complexity of context... **Why...**

so few reports on information provision for children about cancer?

mostly very traditional research methods?

mostly very traditional methods of information provision?

children are often not the research participants?

Link: Information provision, research methods,... countering analogy

- Information provision
 - Informed about diagnosis, disease, treatment, life style
 - Communication, learning
- Information provision should be informed by research findings; research methods shape data collected and findings
- Apart from addressing problem... research should contribute to new knowledge

Types of information provision

- Medium, device, content, language, reading level, accessibility
- Traditional: one-on-one, brochures, leaflets, books
- More-innovative: CD-ROMs, videos, animation film, combination (scrapbook, newsletter, peer visitation, speaker's bureau), animation film about treatment, YouTube style videos, cartoon booklets, webisodes on coping with chemo

Types of research methods

- Quantitative, qualitative, mixed methods
- **Questionnaires, individual interviews, focus group interviews**, video with family, diaries, card sort system, video ethnography of imaginal coping, drawing, virtual reality computer games

Findings

Differences between patients, parents & healthcare professionals

No evidence of clearly defined:

- protocol or guidelines for healthcare professionals to provide information to children – especially as patients
- search terms for children and cancer...
- age ranges of children... (cont.)

Findings (cont.)

Plenty of evidence of research for information provision for children

- with a parent/family member with cancer (e.g. mothers with breast cancer)
- as childhood cancer survivors

Literature review revealed a paucity of articles for information provision for **children with cancer**

What can be learned from other fields?

Early childhood education reports a variety of age appropriate methods:

- Q-methodology
- Delphi studies
- Checklists
- Participatory research
- Bonded design

Studies with children from age of 3...

What can librarians do?

Raise awareness of the problem from a different perspective:

- user (information) needs
- information behaviour studies
(Need to work with experts in health communication providers of psychological support)

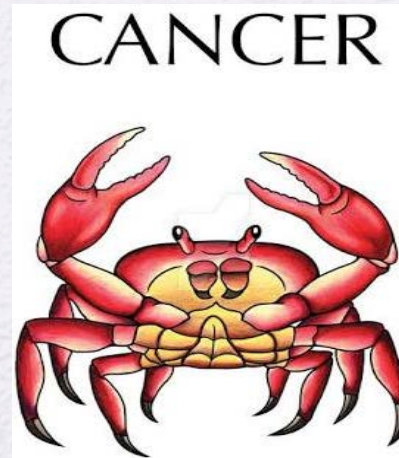
Systematic reviews can point out the problem

Systematic reviews of related fields such as early childhood education (cont.)

What can librarians do?

Proxy searches – searching on behalf of....

- *Health information literacy training*
- *Information “packages”; pointers to Web resources including Medline Plus information packages*
- *Good example: Vlok, R.M. (2007). The Medical Library Association Guide to Cancer Information. New York: Neal-Schuman Publishing Inc.*



Conclusion

Research methods influence what we learn

Findings influence what we do – information provision

Information provided and the means of information provision influence the decisions children make, how they cope. It can reduce anxiety and improve quality of life

What are they missing if we do not understand what they want, and how they want to know/learn about it?

Future Research

Develop a comprehensive model and/or guidelines of research methods for healthcare professionals to study information provision for children about cancer (especially children with cancer)

- from an information behaviour perspective
- from a library service/user needs perspective

Audits of country specific information provision to children about cancer

Questions
Thank you for
listening.

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