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Facilitating Knowledge Exchange and Transfer: Some Key Issues

Abstract:

A critical issue for knowledge exchange and transfer is how best to inform patients so they can make the most well informed choices concerning their treatment alternatives particularly when faced with serious or life threatening medical conditions.

The example of treatment for breast cancer is used to demonstrate knowledge exchange and transfer issues relevant to patients. Some barriers to knowledge exchange and transfer are discussed:

- understanding the language and jargon of biopsy reports
- acquiring adequate knowledge given the speed with which the patient needs to make a decision concerning initial surgical and follow up interventions
- the currency of information provided in the information sheets and booklets provided and on the web
- understanding of the pros and cons of alternative interventions
- the weighting given to relevant pieces of information
- finding critical pieces of information relevant to decision making
- obtaining timely information concerning breast reconstruction in the case of mastectomy

Most of these issues remain critical throughout one's treatment for cancer (and indeed for many other health conditions) but another very critical element for the patient is:

- Knowing the right questions to ask

This paper provides some examples concerning information that is relevant to patient decision making; questions about these issues may not be asked by patients and this information may not be provided routinely by clinicians.

Information provided to patients needs to better address the questions that patient's ask and also questions that the patients' should ask! There must be more effort to explain the medical jargon, and a more adequate coverage of issues pertinent to patient decision making particularly when speed is of the essence. The information needs to be updated for currency on a regular basis.

Clinical online tools for adjuvant therapy for cancer are readily available. The development of an online tool to assist patients' with initial surgical decisions for breast cancer could also be considered. For those considering mastectomy further information concerning breast reconstruction should be made available prior to initial surgery.

Welcome Remarks:

Welcome to our 13th conference. We wish to acknowledge the traditional owners of the land we are meeting on, the Ngunnawal people. We respect their continuing culture and the unique contribution they make to the life of this area.

Many thanks are due for the support from our:

- **Sponsors**
 - Office for an Ageing Australia; Mental Health and Suicide Prevention Program; Palliative Care Section; Asthma, Arthritis and Branch Support Section of the Department of Health and Ageing
 - Eli Lilly Australia Pty Ltd
 - The Pharmaceutical Alliance
 - Community Care Branch and Veterans and Veterans' Families Counselling Service of the Department of Veterans' Affairs
 - The Motor Accidents Authority of NSW
- **Collaborators**
Centre for Advances in Epidemiology and Information Technology, The Canberra Hospital and the School of Clinical Medicine, Medical School, ANU College of Medicine and Health Sciences, The Australian National University
- **Speakers, Participants and International Guests**

Shortly Professor Neil Aaronson (Netherlands) will examine the challenging task of transferring patient-reported outcomes from clinical research to clinical practice. Professor Suzy Skevington (UK) will also examine how health professionals actually make use of quality of life information. They will be followed by a panel of experts. Professor Kathy Eagar, Professor Nick Glasgow, Ms Helen Leonard will address our theme of 'Facilitating Knowledge Exchange and Transfer' in order to improve patient health outcomes and the quality of healthcare provided by our health and community services. I shall now make a few remarks on this topic from a patient perspective.

Paper:

Knowledge Exchange and Transfer: A Patient's Perspective

For a health professional, the experience of a family member being diagnosed with a serious illness and undertaking the patient journey quickly brings to mind how important adequate knowledge exchange and transfer is for patients! In some situations, such as the example provided here concerning breast cancer, the patient needs to quickly make decisions about their treatment alternatives and this may have long term consequences in terms of survival and in terms of health related quality of life.

The first decision breast cancer patients need to make is whether to have a lumpectomy or a mastectomy. A biopsy result will usually guide this decision (in addition to mammogram and ultrasound imaging) and the clinician will generally discuss these results with the patient to help explain what they mean. However, many patients want to read these reports themselves and to understand more fully what they mean. However, here one soon detects some barriers concerning knowledge exchange and transfer.

Some Barriers: Knowledge Exchange and Transfer

- Understanding the language and jargon of biopsy reports (cancer type, stage, tumour grade, hormone receptor status, nodal status). Some reports (NBCC, 2003) make a good attempt at briefly explaining these concepts but this report adds 'you can ask your doctor to explain what the report means, and any words you don't understand'. This raises the additional issue of the clinician's communication skills.
- The speed with which the patient needs to make a decision (usually a week or two).
- The currency of information provided in the information sheets and booklets provided, on web sites (e.g. 2001 – 2005) and in practice guidelines. Consistency in the interpretation of the various guidelines as they are translated into practice is also an issue. There is an inevitable gap between evidence and its implementation in practice (Glasziou, 2002) so we need to find better ways to bridge this gap.
- Understanding of the pros and cons of the alternative interventions (e.g. web forum complaints concern the limited nature of this discussion).
- Weighting the relevant pieces of information to guide this decision (e.g. biopsy status, family history).
- Finding critical pieces of information relevant to decision making (e.g. recurrence rates for the same or other breast for lobular cancer were not easy to ascertain)
- Obtaining information concerning reconstruction in the case of mastectomy (e.g. ABC Health Report 18/2/2008).

Many of the broader issues remain critical throughout one's treatment for cancer (and indeed for many other health conditions) but another very critical element for the patient is:

- Knowing the right questions to ask

To give an example a patient opted for lumpectomy, despite a family history (both siblings and mother), as the initial biopsy results were indicative of a small, non aggressive tumour, (Stage 1, Tumour Score 1/9, No Signs Nodal Involvement, Hormone Positive) and as lumpectomy treatment would be in line with current guidelines. It was not an easy decision particularly as the patient was unclear as to how much she should weight family history.

However, in making this decision there were three questions the patient did not ask which may have been very pertinent:

- How often do women who have lumpectomies proceed to further surgery including mastectomy on medical grounds? (@33%-40%; Koshy, Buckingham et al, 2005)
- How accurate are initial biopsy findings in relation to the follow up biopsy once the lump is removed? (as above)
- Is there some other form of assessment that could be undertaken to further clarify matters (e.g. MRI– to further assess spread and to identify whether the tumour is multicentric).

Although *A Guide for Women with Early Breast Cancer* (NBCC, 2003) provides an excellent list of questions for patients to ask their clinician these particular issues were not generally addressed in the information material provided.

Of course the patient did not realize the importance of asking these questions until after she received a second biopsy report which was discrepant to the first report (Stage 2 vs. Stage 1; Tumour Score 8/9 vs. 1/9 – Grade 3 vs. 1; Size 4cm vs. 2cm, Nodal Involvement (2) vs. No Nodal Involvement; Unicentric - but with satellite deposits). Consideration of the second biopsy report following the lumpectomy indicated the necessity of a follow up mastectomy. Although access to this information may/may not have changed the patient's initial decision making, it would have been useful for the patient to consider these questions prior to making such decisions.

Decision Making Tools

As can be seen in this example the patient is required to assess a range of new information within a very short time frame in order to make informed decisions about treatment alternatives. It is noted that online decision making tools are available for use by clinicians in assisting with decisions concerning adjuvant therapy for cancer (e.g. Adjuvant! Online). Such tools can be used to inform patients of the likely outcomes of different types of adjuvant treatment (hormone and chemotherapy).

Currency can also be an issue with such tools (e.g. 2005 vs. 2008) although they can be very useful in quickly providing probabilities of mortality and relapse following surgery for different types of hormone treatment and chemotherapy. They have the advantage of bringing together all the different information required to assist patients and clinicians in making decisions (age, co morbidities, stage, tumour size, node status, hormone receptor status).

Such tools are usually examined by the patient and clinician together. Not all patients may wish to examine such data but for those that do it can be of considerable interest and can be useful in guiding and understanding the treatment options and one's prognosis. It might be that some aspects of such tools could be used to develop a similar tool to educate and assist patients (with clinical support) with regard to their initial surgical decisions concerning lumpectomy or mastectomy.

Conclusion

An example concerning breast cancer is provided to illustrate how information provided to patients needs to better address the questions that patients' ask and also questions that the patients' should ask! There must be more effort to explain the medical jargon, and a more adequate coverage of issues pertinent to patient decision making particularly when speed is of the essence.

Research indicates that uptake of information by patients is often poor (Lavelle-Jones et al, 1993), and is influenced by such factors as intelligence and education. More effort could be made to provide plain English summaries or explanations to patients in the information material and test reports provided.

The information provided needs to be updated for currency on a regular basis – by 5 years much material is becoming out of date. Hard bound patient booklets such as *A Guide for Women with Early Breast Cancer* (NBCC, 2003) provide very useful information but over time will become increasingly out of date. Consideration could be given to other printing styles – for example loose leaf bindings where new material can be inserted to replace outdated material on a regular basis. A section on the relevant websites (e.g. NBOCC) could also provide links to information updates for sections within such publications where evidence and practice has changed.

With regard to the particular example of surgical intervention for breast cancer provided in this paper the development of a further online tool to assist patients' with initial surgical decisions for breast cancer could also be considered. Further information concerning breast reconstruction should be made available to patients prior to surgery.

The National Breast and Ovarian Cancer Centre provide much useful material to patients on their website and this includes a recent publication which focuses on a range of psychosocial issues (*Cancer - How Are You Travelling?*; NBCC, 2007). The recently formed Cancer Voices Australia organization provides advocacy to improve services and care all people affected by cancer in Australia. Recently Cancer Australia has also put to tender a research project concerning the assessment of patient's experiences, perceptions and satisfaction with their cancer treatment. Such research, information and advocacy activities are important as these will help to further identify critical issues in treatment from the patient perspective and in turn will hopefully lead to an improvement in care processes.

References

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