Medical journals and patients

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HELP – Health Education
Library for People
Why should editors care about patients?
"The cumulative risk for the development of protein-losing enteropathy was 13.4% (with confidence limits of 30% to 70%) among 30-day survivors, and 5-year survival decreased from 81% to 73% (p = 0.006). Hemodynamic studies done coincident with the diagnosis have shown increased systemic venous pressure, decreased cardiac index, increased pulmonary vascular resistance, and increased ventricular end-diastolic pressure."
Why should editors care about patients?

Traditionally, medical journals have had a focused readership, where doctors and scientists talk to other doctors and scientists.

Full of Jargon
Present complex findings and state of the art research
Why bother about patients who will not be able to understand in any case?
The purpose of medicine is to take care of patients
Our end-audience is patients
We need to care about them, whether we are editors, authors, or researchers!
You have to care about patients!

- The times are changing
- Patients have ever increasing clout
- Better informed
- More demanding
- The internet has made a world of a difference, and removed the barriers of the past
It is possible to translate medicalese!
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"One in ten early survivors of the operation run a risk of losing protein in their stools. This problem causes fewer patients to live beyond five years after surgery. These patients have raised pressure in their veins; their hearts pump weakly; their lung blood vessels resist flow of blood through them; and even when relaxed, their ventricles have a higher pressure - all these indicate poor heart activity."
The best example of how times have changed - Medline

In the past, medline searches were restricted to scientists and doctors.

Today, once the National Library of Medicine made Medline available free online, the vast majority of searches are done by patients!
Don’t underestimate the patient’s intelligence!

As Ogilvy said, “The customer isn’t a moron. She is your wife. “

Imagine the patient is your mother – or your son!

Highly motivated

Have lots of time

Are capable of understanding – if we allow them to!
Patients are a huge untapped healthcare resource!

We need to get patients actively involved in the health care system.

Need to make journal articles more “patient-friendly”, more readable and understandable.

Provide summaries and abstracts for patients.
Good for everyone

Using plain English helps to improve readability

Authors and editor will shun unnecessary jargon and treat the language with more respect

Greater readership and more clout!
Good medical journals have started doing this

- Good example – RBM Online
- New journal – just a few years old
- Innovative and original!
Abstracts of research articles are published in two categories:

- **Recently received**
  Not yet peer-reviewed and placed here for information only. These abstracts should not be quoted or discussed until the accepted unproofed versions of the articles to which they relate are placed on the web. Abstracts of papers not accepted will be removed.

- **Accepted**
  Peer-reviewed and accepted for publication after referees’ criticisms have been addressed by the authors and before full proofing. When printed in the journal, all Abstracts are removed from web.
Patients' & lay summaries

Ovary, follicles, oocyte, fertilization (in process)

**Cryopreservation as a tool to reduce multiple birth**
J Genis, D De Neubourg, P De Sutter, E Van Royen, K Mangelschots, M Veireynsens (23 Apr 2003)

**In-vitro maturation of human oocytes**
R-C Chian, W M Buckett, S L Tan (11 Jun 2003)

**Unsuccessful oocyte retrieval: technical artifact or genuine 'empty follicle syndrome'?**
M Bustillo (29 Sep 2003)

**Symposium: Cryopreservation and assisted human conception**
Developmental consequences of cryopreservation of mammalian oocytes and embryos
G D Smith, C A E Silva (23 Dec 2003)

**Symposium: Cryopreservation and assisted human conception**
An overview of oocyte cryopreservation
J Stachetti, J Cohen (11 Jun 2004)

**Biochemical and functional characterization of the human zona pellucida**
S Gehninger (15 May 2003)

**Preliminary experience of ovarian tissue cryopreservation procedure: alternatives, perspectives and feasibility**
I Demmeere, P Simon, Y Englert, A Debaere (7 May 2003)

**Physiological and endocrine approaches to study pre-fertilization gene in...**
Physiological and proteomic approaches to study pre-fertilization events in the human

Linda Lefèvre¹, Chris Barratt¹,², Claire V. Harper², Sarah J. Conner¹, Yfts M Resch¹, Emma Deeks¹,1, Fleur L. C. Moseley¹, Katherine L. Pixton¹, Ian Brewis¹, Steve J. Publicover¹

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The aim of this research is to study how a spermatozoon meets an egg. It is known from a number of studies that this process does not work properly and in such cases the people are infertile. Unfortunately, despite 20 years of research, little is known about why this process goes wrong. Several new techniques are being used to study this interaction. These techniques are now allowing researchers to examine in great detail how a spermatozoon gets activated by an egg. Once it is known how the systems works, hopefully it will be possible to find out why it fails.

Read the original abstract

Webpaper 2003/1000
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The general medical journal website

Articles
Online first
Current issue
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Topic collections
Theme issues

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Rapid responses
Q&A
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- GMC drops charge against paediatrician in Climbie case
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- Revised mental health bill fails to persuade patients or professionals

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Rapid D-dimer testing for DVT

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Bullying among doctors in training

Current issue

Other resources
BMJUSA
Other BMJ local editions
BMJ Careers
StudentBMJ
Netprints
Academic medicine campaign

Clinical Evidence
Best Treatments
bmjlearning
BMJ Journals
British National Formulary
BMJ Bookshop
Major market opportunity for the medical editor who is also an entrepreneur

Making medicine more understandable for the patient

Good example of this is the newsletter, “Pediatrics for Parents”
Isn’t this too much of a bother?

Actually, the smart medical journal editors do this routinely.

Send out press releases routinely, and hope that the article in your medical journal is featured in the New York Times!

Instead of wooing the press, you now need to woo the patient.
Welcome to CCNet - The Cochrane Collaboration's Consumer Network

This website is designed to tell you about the role of health consumers, patients and the general public in the work of the Cochrane Collaboration.

The Cochrane Collaboration
The Cochrane Collaboration is an international organisation that aims to help people make well-informed decisions about health by preparing, maintaining and ensuring the accessibility of systematic reviews of the effects of healthcare interventions.

For consumers
Would you like to know how you could get involved in the Cochrane Collaboration? This site aims to provide health care users with advice and practical assistance on how they can make their voice heard.

For Cochrane entities
Would you like to involve consumers in your entity? This site aims to provide advice and practical assistance in finding, recruiting and supporting health care users.
Consumer peer reviewing/consumer refereeing

Peer reviewing
Peer reviewing aims to ensure that Cochrane reviews and protocols are of the highest quality. Cochrane review groups send draft reviews and protocols, which are written descriptions of how the reviewer plans to carry out the review, to people with an interest in the subject, including consumers.

The authors of the review or protocol consider the suggestions they receive. Sometimes they will make changes. When the review is published it is open to public debate. Peer reviewers will be able to see how the review has changed during the editorial process and readers are welcome to comment.

Consumer peer reviewing
Consumers often serve as peer reviewers, and are usually called consumer referees or consumer peer reviewers. (This term is the subject of some debate.) When a consumer comments on a protocol or review they are bringing with them the perspective of a healthcare user. The questions they might ask include:

- Can I understand the language of the review and is it considerate to consumers?
- Do I know what the health problem is, and understand why the review is being done?
- Does it make sense for people with different backgrounds and from different parts of the world?
- Are the outcomes I and other consumers are concerned about being looked at?
- Has the reviewer considered potential harms as well as benefits?

The consumer referee therefore provides very valuable input into the design of a protocol and the editorial reviewing process.

Read about how to be a consumer peer reviewer:

A note about the term "peer reviewing"
Can consumers and doctors be considered to be peers (equals)?

Peer review is a refereeing process in which an article is reviewed by other experts in the area.

The concise Oxford dictionary defines "peer-group" as "a group of people of approximately the same age, status and/or interests".

In peer-reviewing research, all reviewers have an interest in the topic.

This is why consumers and health professionals can be considered "peers".
Consumer peer reviewing step-by-step

Getting started: Experienced consumer reviewers may develop their own approach to looking at protocols and reviews but if you are just getting started these tips may help.

Step 1: Gather your own ideas

To begin, you might try reading only the title of the protocol or review, and jot down your own ideas about the topic. You may prefer to flick through to get a general idea of the whole document first. Whichever method you prefer, notice what thoughts and questions you have. Try to think creatively.

Step 2: Thinking about the review

Read the report carefully and consider it in the light of your own experience and expertise. Notice how you react as you read through the report. Are there some sections that you particularly like or particularly don't like? Can you explain how and why you think this? Try to use your own experience, think about choice and ethics, think logically and look for clear communication.

Step 3: Ordering your thoughts

Look back at the notes you made in step 1. Are all the questions that arose from your initial thinking answered? Might you suggest changes in how the research is done or how it is reported?

Look at the notes you made in step 2. Would your suggestions allow the authors to keep those sections you liked and change the sections you did not like?

If you were given a checklist, try using it after you have had ideas of your own - this may help you see if there is anything else you could think about. You may like to read through the review or protocol again in light of the checklist. But reading the checklist...
Consumer referees – provide the end-user perspective

- Can I understand the language of the article?
- Do I know what the health problem is, and understand why the research is being done?
- Are the outcomes I and other consumers are concerned about being looked at?
- Has the author considered potential harms as well as benefits?
Medical librarians (cybrarians) now offer their services online and interpret medical journal articles for patients.

Translate "medicalese"

Charge money for this, which patients happily pay.
After the report

How Fontan survivors fare in the long run

GET EASY-TO-UNDERSTAND INFORMATION ON
LIFE AFTER A Fontan OPERATION - NOW!

The report on early and late outcome after the Fontan repair for complex congenital heart defects like Tricuspid Atresia, Pulmonary Atresia, HLHS and Single Ventricle conditions.

This is one of the Web's most widely visited sites devoted to the Fontan operation - thanks for your support

Dr. Mani's HEART DISEASE ONLINE

Heart Disease information EVEN your child can understand!

In the Fontan report, you get a taste of the uniquely readable explanations of complex heart conditions written by Dr. Mani Sivasubramanian, a specialist heart surgeon. Dr. Mani is Assistant Professor of Paediatric Cardiothoracic Surgery at the Institute of Child Health and Hospital for Sick Children, India, and has written extensively about birth defects of the heart. To read more of his articles on heart disease, you can visit those websites:

Heart Disease Online - http://www.HeartDiseaseOnline.com
CHD Awareness - http://www.CHDinfo.com/
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What a refreshing contrast!

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An opportunity

- Medical journals should have patients on their editorial board!
- Make journals more useful for patients
- Will need to look at the "big" picture
- Be proactive!
- After all, who could have imagined patients would be doing Medline searches a few years ago?
Why involve patients?

- Patients provide an outside, independent, unbiased view.
- Medical journals have become a community of inbred insiders – allowing entry to patients will help us remove our limitation and our blinkers.
- Ensure that issues which are important to patients are identified and prioritised.
- Ensure that research doesn't just measure outcomes that doctors consider important.
The internet has changed all the rules!

- Publishing is cheap
- Anyone can do it – no entry barriers
- Can cater to niche audiences
- No space limits
Ultimate goal

We can teach patients to understand and critique medical journal articles.

Can we teach medical journal authors and editors to treat patients with respect?
Putting Medline free on the Net highlights the principle that medical information should be freely available, not only to physicians, but to every citizen.

This is a democratic leveling of the playing field between doctors and their patients.
Today, smart patients may know more about the latest medical studies than their physician!

Physicians may feel threatened

However, this is a positive change!

The patient becomes a true partner in his treatment because he has had an active role in its choice.
We need to demystify medicine and get doctors off their pedestal!

Let’s put patients back at the center of the medical universe!