What initiatives are ongoing to help patients gain access to healthcare data in journals?

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Patients’ access to healthcare data

• Why is it important?
• What data?
• Barriers to access
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• Conclusion
Why is patient access important?

- More-engaged patients have lower costs and better health outcomes
- Improves quality
- Improves patient satisfaction

“Getting access to personal health information is the start of engaging patients to be full partners in their care” Lygeia Ricciardi, director of the Office of Consumer eHealth (National Coordinator for Health Information Technology)

...[When patients] participate more actively in the process of medical care, we can create a new healthcare system with higher quality services, better outcomes, lower costs, fewer medical mistakes, and happier, healthier patients. We must make this the new gold standard of healthcare quality and the ultimate goal of all our improvement efforts:

Not better hospitals.
Not better physician practices.
Not more sophisticated electronic medical systems.
Happier, healthier patients.

—Charles Safran
What data?

- Personal medical health records
  - Access to personal medical data allows patients to manage their own health
  - The aim is to move patients and doctors into a relationship of “shared accountability”
- Healthcare data published in journals
  - Access to published healthcare data allows patients to stay on top of chronic conditions
Barriers to access

- Awareness
- Jargon/understanding
- Paywalls
- Technology (mobile apps, enhanced articles etc.)
Initiatives

• *patientACCESS*
• *patientINFORM*
• Access to Research
• Open access journals
• Journal-specific initiatives
patientACCESS

• Provides patients and their caregivers with low-cost access to peer-reviewed research articles

• patientACCESS is a collaborative project with selected publishers such as Wiley, the Professional/Scholarly Publishing (PSP) Division of the Association of American Publishers, the International Association of Scientific, Technical & Medical Publishers (STM), and the Copyright Clearance Center (CCC).

• Articles in included journals can be obtained by patients via RightsLink (there is a fee of $3.5 + taxes levied by CCC). Articles are then emailed to the requestor.
patientINFORM

• Publishers who participate in patientINFORM help patients gain access to research in two ways:
  – By allowing participating health organizations that create research summaries, news reports etc. to place special links on their sites to the associated research articles in participating journals. These links provide users with free access to the articles.
  – By providing patients and their caregivers with free or reduced-price access to relevant articles through their own web sites.
PROVIDING ACCESS TO THE TOP MEDICAL JOURNALS...
patientINFORM
ACCESS + INTERPRETATION = UNDERSTANDING + EMPOWERMENT

American Heart Association
Learn and Live

LUPUS
Foundation of America, Inc.

American Cancer Society

IDENTIFIED BY TRUSTED HEALTH ORGANIZATIONS...

American Diabetes Association
Cure • Care • Commitment

National Breast Cancer Coalition

National Organization for Rare Disorders

ARThritis FOUNDATION
Take Control. We Can Help
Access to Research

• Gives free, walk-in access to a wide range of academic articles and research in participating public libraries across the UK

• > 8,400 journals included in the service (Jan 2014). As more publishers continue to join the initiative, even more content will become freely available.
Participating publishers

ALPSP
Bloomsbury Publishing
Cambridge University Press
De Gruyter Open (formerly Versita)
Dove Press
eCancer
Edinburgh University Press
Elsevier
Emerald
IOP Publishing
Manchester University Press

Nature Publishing Group
Oxford University Press
Portland Press
Royal Society Journals
SAGE Publications
Science Reviews 2000 Ltd
Springer
Taylor & Francis
Wiley
Wolters Kluwer Health
Open access journals

• Universally available online without any barriers to access
• Increased access, readership, usage and impact
• Peer review
• Indexing
• Immediate publication
• Users are free to read, download, copy, distribute, print, search, or link to the full texts of these articles for any (non-commercial) purpose
• Authors retain copyright
• Supported by publication fees
Some open access journals

- Patient Preference and Adherence
- Patient Related Outcome Measures
- Drug, Healthcare and Patient Safety
- Patient Intelligence
- Pragmatic and Observational Research
- Smart Homecare Technology and TeleHealth
Journal-specific initiatives

- Enhanced papers (videos, podcasts)
- Lay summaries
- BMJ
- JAMA
Journal-specific initiatives

- Enhanced papers (video abstracts, podcasts)
Talk medicine from BMJ
Podcasts from The BMJ and specialist journals

Lorimer Moseley on the brain and mind in chronic pain

BMJ talk medicine – Lorimer Moseley on the brain and mind in chronic pain
BMJ talk medicine – FIFA, the World Cup, and the disappearing alcohol ban
BMJ talk medicine – Apophyseal injury in children and adolescents
BMJ talk medicine – Excess weight gain in the first 18 months and later childhood weight and arterial wall thickness
BMJ talk medicine – Characterisation of faecal protease activity in irritable bowel syndrome with diarrhoea
BMJ talk medicine – In this issue: June 2014
BMJ talk medicine – Drugs for weight loss
Editors' Summary

Background. Trauma - a serious injury to the body caused by violence or an accident - is a major global health problem. Every year, injuries caused by traffic collisions, falls, blisters, and other traumatic events kill more than 5 million people (9% of annual global deaths). Indeed, for people between the ages of 5 and 44 years, injuries are among the top three causes of death in many countries. Trauma sometimes kills people through physical damage to the brain and other internal organs, but hemorrhage (serious uncontrolled bleeding) is responsible for 50% of trauma-related deaths. Consequently, early trauma care focuses on minimizing hemorrhage (for example, by using compression to stop bleeding) and on restoring blood circulation after blood loss (health-care professionals refer to this as resuscitation). Red blood cell (RBC) transfusion is often used for the management of patients with trauma who are bleeding; other resuscitation products include isotonic saline and solutions of human blood proteins.

Why Was This Study Done? Although RBC transfusion can save the lives of patients with trauma who are bleeding, there is considerable uncertainty regarding the balance of risks and benefits associated with this procedure. RBC transfusion, which is an expensive intervention, is associated with several potential adverse effects, including allergic reactions and infections. Moreover, blood supplies are limited, and the risks from transfusion are high in low- and middle-income countries, where most trauma-related deaths occur. In this study, which is a secondary analysis of data from a trial (CRASH-2) that evaluated the effect of tranexamic acid (which stops excessive bleeding) in patients with trauma, the researchers test the hypothesis that RBC transfusion may have a beneficial effect among patients at high risk of death following trauma but a harmful effect among those at low risk of death.

What Did the Researchers Do and Find? The CRASH-2 trial included 26,157 patients with trauma and major bleeding treated in 274 hospitals in 40 countries. In their risk-stratified analysis, the researchers investigated the effect of RBC transfusion on CRASH-2 participants with a predicted risk of death (estimated using a validated model that included clinical variables such as heart rate and blood pressure) on admission to hospital of less than 6%, 6% to 20%, 21% to 50%, or more than 50%. That is, the researchers compared death rates among patients in each stratum of predicted risk of death who received a RBC transfusion with death rates among patients who did not receive a transfusion. Half the patients received at least one transfusion. Transfusion was associated with an increase in all-cause mortality at 28 days after trauma among patients with a predicted risk of death of less than 6% or of 6% to 20%, but with a decrease in all-cause mortality among patients with a predicted risk of death of more than 50%. In absolute figures, compared to no transfusion, RBC transfusion was associated with 5.1 more deaths per 100 patients in the patient group with the lowest predicted risk of death but with 11.9 fewer deaths per 100 patients in the group with the highest predicted risk of death.

What Do These Findings Mean? These findings show that RBC transfusion is associated with an increase in all-cause deaths among patients with trauma and major bleeding with a low predicted risk of death, but with a reduction in all-cause deaths among patients with a high predicted risk of death. In other words, these findings suggest that the effect of RBC transfusion on all-cause mortality may vary according to whether a patient with trauma has a high or low predicted risk of death. However, the patients in the CRASH-2 trial were not randomly assigned to receive a RBC transfusion. It is not possible to conclude that receiving a RBC transfusion actually increased the death rate among patients with a low predicted risk of death. It might be that the patients with this level of predicted risk of death who received a transfusion shared similar unknown characteristics (confounders) that were actually responsible for their increased death rate. Thus, to provide better guidance for clinicians caring for patients with trauma and hemorrhage, the hypothesis that RBC transfusion could be harmful among patients with trauma with a low predicted risk of death should be prospectively evaluated in a randomised controlled trial.

Additional Information. Please access these websites via the online version of this summary at http://dx.doi.org/10.1371/journal.pmed.1001664.

- This study is further discussed in a PLOS Medicine Perspective by Dr. Bunch.
- The World Health Organization provides information on Injuries and on Violence and Injury prevention (in several languages).
- The US Centers for Disease Control and Prevention has information on injury and violence prevention and control.
- The National Trauma Institute, a US-based nonprofit organization, provides information about hemorrhage after trauma and personal stories about surviving trauma.
- The UK National Health Service Choices website provides information about blood transfusion, including a personal story about transfusion after a severe road accident.
- The US National Heart, Lung, and Blood Institute also provides detailed information about blood transfusions.
- MedicinePlus provides links to further resources on injuries, bleeding, and blood transfusion (in English and Spanish).
- More information is available about CRASH-2 (in several languages).
Journal-specific initiatives

• BMJ – *Promoting patient partnership*
  – Embedded patient peer review of research papers where patient input is helpful
  – Publish papers that advance the science, implementation and assessment of the impact of patient partnership, shared decision making and patient-centred care
  – Request authors to obtain input from patients and document their contribution
  – Publish patient co-authored “state-of-the-art” reviews
  – Educational articles also peer reviewed by patients
  – Invite expert patients on the Editorial Board
  – Recruit a Patient Editor
  – Encourage patients to participate in internal decision making committees
  – Provide input into lay versions of papers published in the “overdiagnosis” series (Consumer Reports, in partnership with Choosing Wisely initiative)
Author Interviews — Translations

Summaries of important research published in JAMA Network journals, described by authors in their own words and translated into several languages.

Conclusion

• Push towards patients involvement and engagement in healthcare
• More initiatives are being launched to facilitate patients’ access to healthcare data
• If you’re publishing articles that are relevant to patients as well as experts, it’s important that these are published in journals that allow free access or that participate in one of these initiatives
Discuss?

Thank you

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