



Osteoporosis Canada

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COPING

'A newsletter from COPN'

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Remember: You can live well with osteoporosis!

How does research improve osteoporosis care?

Research helps the medical profession and their patients in many ways. Through research, doctors gather the latest medical and technological information, they advance their knowledge, they solve problems and they make the best possible decisions with the information that they acquire. In short, research improves our knowledge about bone health which in turn provides better care for our bones.

For example, research on fragility fractures has led to the development of Osteoporosis Canada's 2010 Clinical Practice Guidelines for the Diagnosis and Management of Osteoporosis. These guidelines recommend that individuals who have had a fragility fracture (a broken bone from a minor event such as a trip, bump or a simple fall) should be routinely investigated and treated for any underlying osteoporosis. Despite these recommendations, however, most Canadian men and women who have had a fragility fracture are still not routinely investigated or treated for any possible underlying bone disease.

A different type of research on how individuals with a fragility fracture manage their bone health and navigate the health care system can help develop special programs to prevent such individuals from suffering future fractures. This type of research can also potentially reduce mortality (deaths) related to more disabling fractures such as hip fractures, as well as reduce health care costs. How does a fracture cost the health care system? Consider the cost of; surgery, admission to a hospital, admission to an extended care facility and/or nursing home, home care, medications, as well as long-term disability to name but a few.

One researcher who is trying to bridge the evidence-to-care gap in individuals with a fragility fracture is Dr. Joanna Sale, Associate Scientist at St. Michael's Hospital in Toronto. Dr. Sale recently conducted a research review on post-fracture programs to see how well it is progressing in closing this care gap. Results from her review showed that *despite the presence of these programs, investigation and treatment rates still remain sub-optimal* in fracture patients. One possible reason why these programs have

had only a modest effect on closing the care gap is that they are conducted from a health care provider or health care system perspective – the role of the patient who fractured is rarely considered. What is needed is patient-focused research.

What are examples of patient-focused research?

Dr. Sale has been leading a number of studies examining the perspective of patients who have had a fragility fracture. In one study, her team found that patients were unclear about many aspects of osteoporosis diagnosis, testing, and treatment despite being screened for bone health in an urban fracture clinic. In another study, the team examined patients' interpretations of their bone densitometry results and demonstrated that less than one-third of patients recalled a correct diagnosis of their test results.

The team has also looked at decision making around osteoporosis medication and found that approximately 50% of patients have a difficult time deciding whether or not to take osteoporosis medication when it is prescribed to them.

The definition of a “fragility fracture” or “low trauma fracture”, is a fracture that occurs when an individual falls by slipping or tripping or stumbling from a standing height. This may occur while standing or while walking or jogging. In one of her more recent studies, Dr. Sale suggests that individuals with a fragility fracture may actually reject the term “fragility”, or “low trauma” fracture because to them, their fall is often perceived as a sudden, dramatic and traumatic event that was unavoidable (which of course, most of them are not).

Here, we need to distinguish between what is physically traumatic and what is emotionally traumatic. A fall from a standing height is not considered to be of sufficient physical trauma to cause a fracture. In other words, it is not normal to fracture when falling from a standing height. Therefore, we call these fractures “fragility” fractures or “low trauma” fractures. However, because the outcome is often significantly traumatic to patients from an emotional perspective or from a pain perspective, they may refuse to accept the term “low trauma” fracture. This is one example of how medical terminology may be confusing to patients and may result in miscommunication between patients and the health care profession which in turn can result in sub-optimal post-fracture care.

Dr. Sale is currently conducting a research study funded by the Canadian Institutes of Health Research (CIHR) that is particularly relevant to COPN members. In this study, the research team is interviewing COPN members living in Ontario to examine their experiences following a fragility fracture. Participants are asked about their prior fracture(s), visits to health care providers for their bone health, actions regarding recommendations, and reasons for those actions. This study will provide information for programs in post-fracture osteoporosis care nationally as well as internationally so that these programs directly address the challenges and concerns of fracture patients. The overall goal of the research study is to reduce the burden of illness due to fracture by improving osteoporosis testing and treatment after a fracture has occurred.

What should I do if I am interested in participating in the current study?

The medical profession is doing the very best to help close the fracture care-gap in Canada. However, the medical profession cannot do this alone. It often needs the help of the patients. Those of you who are suffering or have suffered from osteoporotic fractures can help others avoid the same fate by participating in research studies such as this.

If you live in Ontario, have had one or more fractures that occurred after age 50 and were **not** taking any prescription medication for your bones (e.g. Actonel®, Fosavance®, Fosamax®, Evista®, etc.) at the time of your fracture(s), you may be eligible to participate in this very important research study. If you are an Ontario resident and are interested in participating or would like some more information about this study, please contact Cathy Cameron at 1-877-408-3076 or at cathy.cameron@rogers.com.

Save the Date – Wednesday, June 29, 2011, 1:00 p.m. to 2:30 p.m. ET

Join us and register for our upcoming virtual education forum on Medications and Osteoporosis titled *Osteoporosis Medications and You*. Open registration starts on May 27, 2011. The forum will be led by Dr. Rowena Ridout. Visit our website for more information www.osteoporosis.ca

Funny Bone – Great Truths from Adults: Families are like fudge -- mostly sweet, with a few nuts

Notices/references

i. Remember: It is important for you to eat a calcium rich diet (take calcium supplements, if necessary), get some appropriate exercise, take your vitamin D and if your doctor has prescribed a medication don't forget to take it as directed.

ii. COPING Weekly will come to you every second Friday. We hope you enjoy it and find the information useful. Remember to log on to www.osteoporosis.ca for up-to-date information.

iii. The material contained in this newsletter is provided for general information only. It should not be relied on to suggest a course of treatment for a particular individual or as

a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Should you have any healthcare-related questions or concerns, you should contact your physician. You should never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter.

iv. To have your name removed from the COPN mailing list please contact us at the email below.

You must provide the first and last name for which you registered in order to be removed from this list.

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