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Osteoporosis: the patient's perspective

C. Severgnini

National Osteoporosis Society, Bath, UK

Abstract

Osteoporosis and fragility fractures are a significant health problem. In the UK, 3 million people are estimated to have osteoporosis, and there are approximately 300 000 fragility fractures every year. One in two women and one in five men over the age of 50 years will break a bone, which robs these people of their independence, mobility and quality of life. The National Osteoporosis Society (NOS) is the only UK-wide charity dedicated to improving the diagnosis, prevention and treatment of osteoporosis and fragility fractures. It ensures that support and information are available for everyone who has been diagnosed with osteoporosis, those who have had a fracture, and those who are worried about themselves or their loved ones. The NOS also provides a wide range of services that are designed to help people learn how to prevent osteoporosis, or to manage living with the disease and fractures, and it supports health professionals in providing better care for their patients.

Keywords: fragility fracture, National Osteoporosis Society, osteoporosis, patient perspective, support.

Introduction

Osteoporosis is a common long-term condition that affects an estimated 3 million men and women in the UK (NOS 2013a). The bones of people with osteoporosis become fragile as the result of an imbalance in the normal processes of bone formation and resorption, which work together to maintain bone strength. The disease is defined medically as a “progressive systemic skeletal disease characterized by low bone mass and microarchitectural deterioration of bone tissue, with a consequential increase in bone fragility and susceptibility to fracture” (WHO 1994, p. 3), or as “a skeletal disorder characterized by compromised bone strength predisposing to an increased risk of fracture” (NIH 2000, p. 5).

Osteoporosis itself is painless, but the disease leads to an increased risk of “fragility fractures” (NICE 2012). This kind of low-trauma injury is often defined as “a fracture resulting from a fall from standing height or less” (WHO 1994, p. 23), although some, particularly those of the spine, can occur as a result of something as simple as coughing. With potentially devastating

consequences for the individuals who suffer from these injuries, and putting a substantial burden on health and social care resources, the 300 000 fragility fractures that occur every year in the UK (NICE 2012) pose a significant public health problem.

The National Osteoporosis Society (NOS) actively pursues greater prioritization of osteoporosis and fragility fractures in both nationwide health policy and local National Health Service (NHS) decision-making. It also offers invaluable information and support to anyone affected by the disease, as well as the health professionals who care for them.

Osteoporosis and fractures: what these mean to those who are affected

Osteoporosis and related fractures can have profound and far-reaching consequences. Fragility fractures of the wrist, rib, hip and spine are most common (NICE 2012). The effects of these injuries rob people of their independence, mobility and quality of life, and can lead to people becoming housebound, socially isolated and depressed. As a result, a significant number of people with osteoporosis live in fear of falling

Correspondence: Ms Claire Severgnini, Chief Executive, National Osteoporosis Society, Camerton, Bath BA2 0PJ, UK (e-mail: c.severgnini@nos.org.uk).

and suffering further fractures. Without early diagnosis and preventive action, osteoporosis puts people onto a pathway of multiple, disabling fragility fractures. Many suffer dramatic changes in body shape, leading to a range of problems that include loss of self-esteem and difficulty in finding clothes that fit.

Vertebral compression fractures differ from other common fragility fractures in that these are not usually a consequence of a fall, and may occur following routine activities of daily living (ADLs) such as bending or lifting. These fractures result in changes in vertebral shape that cause shortening of the trunk, loss of height and curvature of the spine. Consequently, people with vertebral fractures can be affected by: acute and chronic pain; changes in posture that result in pressure on the nerves, ligament strain and muscle spasm; and changes in body shape such as a protruding stomach. Shortening of the trunk sometimes leads to problems with ADLs such as breathing, continence and mobility (NICE 2012). Forty per cent of people who are diagnosed with a vertebral fracture will experience constant pain, and a majority will find ADLs difficult (Scane *et al.* 1994).

A hip fracture is all too often the final destination of a 30-year journey through multiple fragility fractures that has been fuelled by decreasing bone strength and warning signs being ignored. The consequences of a hip fracture are devastating. Cooper (1997) reported that, 12 months after a fracture, 40% of patients were unable to walk independently, 80% were still unable to do basic tasks like driving or shopping, and 60% were still having problems with other ADLs. Older people are often more concerned about a potential loss of independence than dying following a hip fracture (NHFD 2013), and 80% of women would rather die than go into a care home (Salkeld *et al.* 2000). Fifty per cent of people suffering a hip fracture will be permanently disabled (Osnes *et al.* 2004), and 30% will die within a year (BOA 2007).

Risk factors for osteoporosis and fragility fractures

By being aware of the major factors contributing to osteoporosis and an increased risk of fracture, physiotherapists can effectively participate in all aspects of prevention and management.

The “gold standard” for diagnosing osteoporosis is the measurement of bone mineral density

(BMD) using dual-energy X-ray absorptiometry. The patient’s BMD is then compared with that of a young adult of the same sex. The results are expressed by a T-score, which describes standard deviations relative to the young adult normal. Osteoporosis would be diagnosed in anyone with a T-score of ≤ -2.5 (WHO 1994).

However, bone density is only one of a number of indicators of the potential for fracture. The two major risk factors are being female and older age (WHO 1994). In addition, there are a number of other well-established risk factors which have been used to develop online fracture risk assessment tools, including: the WHO risk assessment tool, FRAX (WHO 2013); and the UK-developed QFracture risk calculator (ClinRisk 2012). These bring together established risk factors for fracture in order to calculate an individual’s 10-year probability of a major osteoporotic fracture (e.g. of the spine, hip, forearm or proximal humerus) and hip fracture. Both tools were recommended by the National Institute for Health and Clinical Excellence (NICE) in a recent clinical guideline (NICE 2012).

According to NICE (2012), the most important risk factors for fragility fracture are:

- *Age.* The incidence of fragility fractures increases as individuals get older, and peaks occurs between the ages of 60 and 75 years, with vertebral and hip fractures occurring most frequently in those over 70 and 80, respectively.
- *Gender.* Fragility fractures are twice as common in women as in men.
- *Low BMD.* The risk of fracture increases progressively with reductions in BMD.
- *Prior fragility fracture.* Good evidence exists to support investigations of patients with a low-trauma fracture, particularly those of the wrist, spine, humerus and hip. Those who have sustained one recent fracture are at increased risk of sustaining another, irrespective of the site of the injury, and these can often indicate the beginning of a cascade of fractures that will culminate in a hip fracture, with all its implications (Kanis *et al.* 2004). For individuals who sustain a new incident fracture, the risk of a further one increases five-fold in the first year, during which nearly a quarter of the re-fractures occur.
- *Parental history of hip fracture.* A maternal and paternal history of hip fracture is the most reliable indicator of a genetic risk of fragility fracture.

- *Low body mass index (BMI)*. A BMI of $\leq 19 \text{ kg/m}^2$ is associated with an increase in the risk of hip fracture (and probably other fractures) in both women and men.
- *Hormones*. Premature menopause (i.e. in women under the age of 45 years) – whether natural, or induced by surgery, chemotherapy, radiotherapy or endocrine therapy – increases risk. Risk is elevated in men who have had an orchidectomy or androgen deprivation therapy.
- *Medical conditions associated with bone loss*. These include rheumatoid arthritis, inflammatory bowel disease (e.g. Crohn's disease), malabsorption (e.g. coeliac disease), cystic fibrosis, hyperthyroidism, hyperparathyroidism, vitamin D insufficiency, immobilization (e.g. resulting from a cerebrovascular accident or Parkinson's disease), chronic obstructive pulmonary disease, diabetes mellitus type 1, and chronic renal and hepatic disease.
- *Drug treatments associated with bone loss*. These include oral corticosteroids, aromatase inhibitors (i.e. breast and ovarian cancer treatments), androgen deprivation therapy (i.e. prostate cancer treatments), some anti-epileptic medications and glitazones.
- *Lifestyle factors*. Both smoking and an alcohol intake of ≥ 3 units per day increase the risk of fracture.
- *Falls*. In individuals with compromised bone strength, non-vertebral fragility fractures usually result from a fall, and therefore, the risk factors for falls should be routinely considered in older patients.

Management of osteoporosis and fragility fractures

As the clinical consequence of osteoporosis, fragility fractures have a serious impact on people's lives, and therefore, it is essential to understand how to implement successful strategies to reduce the risk of these injuries occurring. Both effective drug treatments, which have been proven to reduce fracture risk (NICE 2012), and a range of lifestyle approaches have a part to play, and an understanding of the evidence behind current interventions and what expert guidance is recommending will help to shape effective clinical practice.

Weight-bearing exercise has been identified as a major contributor to the achievement and maintenance of a healthy peak bone mass.

Appropriate exercise has also been extremely effective in older, frailer populations, in which it has the following aims:

- falls reduction;
- prevention of further fractures;
- balance/coordination;
- improvements in muscle strength, flexibility, aerobic capacity and posture;
- gait re-education;
- psychological well-being and increased confidence; and
- reduction and control of pain.

Those issuing official advice about clinical osteoporosis, such as the National Osteoporosis Guideline Group (NOGG), have been reluctant to make recommendations about global or population strategies involving lifestyle modifications to reduce fracture risk. This is partly because there is insufficient evidence for direct causal links, but just as importantly, because "the uptake and compliance of such strategies have not been adequately assessed, so the value and the feasibility of population programmes in osteoporosis prevention or treatment cannot be evaluated" (NOGG 2013, p. 5).

Nevertheless, the NOS continues to include "preventive" messages in its publications, as recommended by its clinical and scientific advisers. The Society has also been persuaded to do this by the feedback it gets from its members and callers to its helpline. These individuals are hungry for lifestyle advice, and seem to want to take action and gain control over their bone health if this is at all possible.

Current evidence, all of which usefully ties in with the prevention of many other medical conditions, supports the following lifestyle choices:

- eating a well-balanced, calcium-rich diet
- maintaining a healthy weight and taking particular care to consume an adequate amount of protein in old age;
- having sensible exposure to sunlight in order to get adequate vitamin D;
- not smoking;
- keeping alcohol intake within recommended limits;
- increasing weight-bearing exercise to maintain bone strength; and
- keeping active in later life, and including muscle-strengthening and balance exercises to reduce the risk of falls.

Having control over the above factors, as well as a reluctance to take unnecessary drugs, can

make lifestyle changes a priority for patients. There is still a lack of evidence about which types of exercise are most useful to keep bones strong, and those with a high fracture risk may struggle to find fitness regimes that are likely to improve bone density without increasing this risk still further. Discussing this uncertainty with patients, directing them to the available literature and publications (e.g. NOS 2012), and appropriate referral to physiotherapy may all be valuable.

With older patients, this approach needs to broaden to an understanding that some changes (e.g. exercising to keep fit and active, or getting enough vitamin D) may also help to prevent falls, and thus, reduce the risk of a fracture occurring. Fear of falling may be a disincentive to increase exercise levels in itself, and making suggestions about suitable exercise programmes or a referral to specialized fall prevention services may be appropriate. Patients need explanations about how fall prevention fits in with drug treatments as part of an overall approach to fracture prevention.

Pain management is a major part of the therapeutic intervention in this group. These patients are often referred for physiotherapy following painful vertebral compression fractures. Therefore, pain management becomes a priority before the patient can be introduced to any exercise programme.

Preventing future fractures

Studies have shown that 23% of re-fractures occur within a year of the first one, and 54% within 5 years (van Geel *et al.* 2009). Therefore, interventions to reduce the risk of future fractures must be timely.

Coordinator-led fracture liaison services (FLSs) have been shown to be clinically successful and cost-effective. These ensure that the bone health of new fracture patients is considered, and that they are offered appropriate interventions, such as bone-protecting treatment and fall-prevention measures. However, FLSs are currently only available in a minority of locations across the UK.

In the absence of robust NHS services to identify people at risk, the NOS launched its Stop at One campaign in October 2013. This seeks to raise awareness in the general public of the link between broken bones and osteoporosis. Anyone over the age of 50 years who has broken a bone is encouraged to seek more information about bone health at the campaign's website

(www.stopatone.org), as well as to speak to their general practitioner. The website also includes resources to support the campaign, such as posters suitable for healthcare settings.

By asking falls and fracture patients whether they have talked to someone about osteoporosis, physiotherapists can also play a helpful role in closing this care gap.

Ways in which the National Osteoporosis Society can support you and your patients

Established in 1986, the NOS is a well-respected national charity with approximately 25 000 members and over 50 employees. It is the only UK-wide charity that is dedicated to improving the prevention, diagnosis and treatment of osteoporosis (NOS 2013b).

The NOS is supported through the generous donations of individuals and charitable trusts, but receives no government funding. The vision of the charity is a future without fragility fractures. To realize its aim, the NOS has set out a series of goals that must be achieved if it is to have a positive impact upon people with osteoporosis and fragility fractures. These wide-ranging programmes aim to improve understanding, raise awareness, influence services, and provide information and support.

The charity provides a range of information and support for both the public and health professionals, including:

- a confidential helpline staffed by specialist osteoporosis nurses who have been providing information and support to callers for over 20 years, the majority of whom seek osteoporosis information for themselves or those caring for them (Enquirers generally want information about: the impact of the condition; aspects of diagnosis and risk; drug treatments; lifestyle changes for bone health and to prevent fracture; or help with pain and problems caused by fractures – particularly vertebral ones. The helpline is open to callers who are health professionals.);
- a network of support groups with a programme of activities, events and medical updates across the UK;
- an e-bulletin, i.e. a regular e-mail for health professionals that keeps them up-to-date with the latest news and issues in the field;
- resources for clinical settings, including information leaflets and posters that are available to order or download from the website;

- clinical guidance reflecting best practice that is available to download from the website;
- Osteoporosis Resources for Primary Care, a comprehensive online resource for health professionals working in primary care (www.osteoporosis-resources.org.uk);
- training and professional development, including the Osteoporosis Conference, a bone densitometry course, and study days for specialists and generalists; and
- the UK Allied Health Professional Network, which provides peer support and professional development for specialist allied health professionals working in the field.

For further information about all of the resources and services described above, contact NOS (tel: 0845 130 3076; e-mail: info@nos.org.uk), or visit the website (www.nos.org.uk).

Conclusions

The number of people with osteoporosis and fragility fractures continues to grow dramatically in the UK because of the ageing population, lifestyle choices and patchy access to FLSs. Without urgent action, hip fracture rates are set to rise by 57% over the next 25 years (AUK & NOS 2012). In addition to the impact that this will have on people, the cost to the NHS will spiral from the current figure of £2.3 billion to over £6 billion in 2036 (AUK & NOS 2012), with UK hip fracture rates already being among the highest in Europe (NOS 2013c).

We need to take steps now to improve the prevention, diagnosis, treatment and care of people with osteoporosis and fragility fractures. The NOS will continue to raise awareness, campaign for the right services, educate and support health professionals, and most importantly, ensure that the people who are affected by osteoporosis and their loved ones get the care and support that they need.

Physiotherapists have an important role to play in managing falls and the consequences of fractures (e.g. pain and immobility). They are among a wide range of health professionals who come into everyday contact with individuals who might have undiagnosed osteoporosis. By understanding the risk factors, we can all make the most of every opportunity to consider bone health and prevent further fractures.

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Claire Severgnini is the Chief Executive of the National Osteoporosis Society.