

PARKINSON'S

**Excellence
Network**



Better Bone Health Service Improvement Project

Executive summary

Background

There is an increased risk of both falls and osteoporosis in Parkinson's, each of which increase the chance of fractures. Proven treatments help to reduce fracture risks, but only around half of people with Parkinson's have their bone health assessed (2019 UK Parkinson's Audit). Although women are at higher absolute risk of osteoporosis and fracture than men, almost as many hip fractures each year are sustained by men with Parkinson's as by women with Parkinson's.

Aims of this project

A national project was developed by a multidisciplinary team with input from national experts in bone health and Parkinson's. The aim was to increase knowledge among Parkinson's healthcare professionals about how to assess bone health in Parkinson's, and to improve rates of assessing and treating bone health in specialist services (Elderly Care and Neurology).

Methods

In 2020 we invited NHS Parkinson's services to join a multicentre UK-wide improvement initiative. They were supported to pilot and implement a bespoke bone health algorithm, linked to guidance on investigation and management. Anonymised data were collected online. We used quality improvement methodology (Wells et al 2018) to identify and overcome barriers. Two rounds of piloting of the project allowed for iterative improvements, and this was followed by the full project. A baseline and post-project questionnaire were used to assess the effects of the project.

Results

1131 people with Parkinson's were assessed for bone health and fracture risk, by a total of 80 healthcare professionals from 44 specialist services.

At baseline, around 1 person in 6 was already on specific treatment for bone health, usually antiresorptive therapy, predominantly bisphosphonates. Many people had risk factors for future fractures (including falls in half of all cases, and previous fractures in 1 person in 5).

Around three quarters of cases needed an updated assessment of bone health, which consisted of fracture risk scoring with a Parkinson's focused algorithm. This resulted in bone density scans being requested in about one fifth of all cases, and new specific bone health treatment being started in 1 in 10 of all cases assessed.

A lower proportion of men than women required investigation and treatment of their bone health, in line with their lower absolute risks of fracture.

There were broadly similar average fracture risk scores between Elderly Care and Neurology service patients - Neurology cases had a longer diagnosis duration and a slightly younger average age. Patients assessed in Neurology were more likely to be newly started on anti-resorptive bone health medication, compared to Elderly Care patients.

The healthcare teams that participated indicated that they found the process very useful, and self-rating of the ability to assess bone health in clinical practice was improved.

Overall this project led to a 10% absolute increase in the proportion of patients managed with anti-resorptive treatment. This was a relative increase of around 67% from pre-project levels. An estimate of effectiveness suggests that the new treatments introduced to patients, in this project alone, would be expected to prevent around 3 vertebral fractures and 2 non-vertebral fractures (including the prevention of 1 hip fracture).

Conclusions

Important improvements in bone health assessment and treatment in people with Parkinson's are achievable in specialist services, with expected benefits to public and personal health from the avoidance of fractures.

Background

People with Parkinson's are more than twice as likely to have osteoporosis compared to unaffected individuals of the same age (Tornsey et al 2014) and twice as likely to sustain a fracture, likely resulting from the combination of increased fall risk and osteoporosis (Beydoun et al 2017). It is well known that women are at higher risk of osteoporosis than men. However, the annual number of hip fractures in men with Parkinson's has increased substantially and steadily in recent years, approaching the number sustained by women with Parkinson's. The hip fracture risk (compared to healthy age matched controls) is tripled for men with Parkinson's and doubled for women with Parkinson's (Walker et al 2013, Henderson et al 2019). Accordingly an assessment of bone health is at least as important in men with Parkinson's as it is in women with Parkinson's.

There are effective treatments to reduce fracture risk. With common anti-resorptive medications for osteoporosis, 1 vertebral fracture can be prevented by treating 33 patients; 1 non-vertebral fracture can be prevented by treating 50 patients; and 1 hip fracture can be prevented by treating 100 patients (National Institute of Clinical Excellence, 2008). Only around half of people with Parkinson's have any form of bone health assessment in their specialist clinic (2019 UK Parkinson's Audit).

Service Improvement

Methods to improve the assessment of bone health in people with Parkinson's were explored by a national working party formed by the Parkinson's Excellence Network in 2020. Barriers to delivery were examined and available tools explored to determine a standardised approach that could be adapted to local needs when necessary. Specialist Parkinson's clinics that had participated in the UK Parkinson's Audit were invited to join a multicentre UK-wide service improvement project. The aim was to develop an approach that could become a routine part of service delivery, where all people with Parkinson's had a streamlined assessment that addressed their bone health treatment needs.

Approach to assessing bone health

The fracture risk algorithm for Parkinson's (Henderson et al 2019) was identified as the core method of assessing and treating bone health in this project. This involves use of the FRAX risk assessment tool (Kanis et al 2008) but in selected cases the qFracture risk assessment tool can be applied (Hippisley-Cox and Copeland 2012). The method was tested and refined in two waves of pilot studies, then opened to all sites. Online meetings demonstrating the method allowed for questions and feedback, with further evolution of the approach. Multidisciplinary team involvement was encouraged, with involvement of medical, nurse specialist, physiotherapy and other disciplines, and people with Parkinson's, according to the structure of local services. A triage approach that quickly identified which cases needed, or did not need, a more detailed scoring of their bone health was developed.

Participant experience and confidence in bone health assessments

Participants were invited to complete a questionnaire at baseline and at the end of the project to capture their approach to managing bone health in Parkinson's. These questions were generally structured with answers on a Likert scale.

Results

Numbers of people involved

A total of 1,131 people with Parkinson's were assessed for bone health by a total of 80 healthcare professionals from 44 specialist services (listed in the appendix, being 28 Elderly Care services and 16 Neurology services). The patients assessed were on average 75.3 years old (SD 8.8 years), and 56.8% were male. The duration of the Parkinson's diagnosis was on average 5.8 years, with a range from 0 to 29 years; 57.7% were assessed within the first 5 years after diagnosis.

Risk factors and prevailing treatment in patients assessed

Out of the 1,131 cases assessed, 50.1% had a history of falls, 20.3% had a previous fragility fracture, and 16.9% had a history of vertebral fracture. 15.6% were already on treatment specific for bone health (oral or parenteral bisphosphonate 13.6%, denosumab 2.5%), and 44.1% were taking Vitamin D (with or without calcium).

Assessments: triage

73.3% of cases (829) were identified as being in need of more detailed assessment, while 26.7% (302) did not (because they had been assessed recently, were already on treatment, or had advanced disease or other health problems that made a bone health assessment inappropriate).

Assessments: bone health risk scores

Of the 826 cases where bone health risk was scored with a risk calculator, 95.1% used the FRAX score. The remainder used the QFracture score in almost all cases.

The median 10-year risk of **major osteoporotic fracture (MOF)** was 13.5% (IQ range 7.1 to 17%). This includes fractures of the humerus, spine, wrist and hip.

The median 10-year risk of **hip fracture** was 7.1% (IQ 2.5 to 8.4%).

The categorisation of risk by the NOGG (National Osteoporosis Guideline Group) assessment was:

- Red (suggesting that treatment should be considered) in 14.7%,
- Amber (suggesting consideration of bone density measurement) in 36.8%
- Green (suggesting lifestyle advice only) in 48.5%.

Investigation and treatment

A bone density (DXA) scan was requested in 19.5% of the total of 1,131 cases assessed in the project. As a proportion of the 826 cases that had a bone health risk score, 27.1% of cases had a DXA scan requested.

DXA scans were requested in:

- 17.4% of cases in the Red NOGG category
- 59.5% of cases in the Amber NOGG category
- 5.1% of cases in the Green NOGG category.

Specific bone health (anti-resorptive) treatments were started (or recommended to be started, if this was the local approach to prescribing) in 10.7% of all cases, consisting of:

- oral bisphosphonates (7.3%)
- parenteral bisphosphonates (2.9%)
- denosumab (0.8%).

The above treatments were given with newly started Vitamin D (with or without calcium) in 6.5% of cases. Treatment decisions were deferred until the result of the DXA scan in an additional 10% of cases; data about the treatment decisions for these cases were not available.

Relationship between risk fracture scores and treatment decisions

Fracture risks were high in patients that were started on specific (anti-resorptive) bone treatment, as follows:

- median risk of **major osteoporotic fracture** 25.0% (IQ 15.3 to 32.0%)
- median risk of **hip fracture** 14.5% (IQ 7.5 to 19.5%).

Fracture risks were lower in those started on Vitamin D without specific (anti-resorptive) bone treatment, as follows:

- median risk of **major osteoporotic fracture** 11.9% (IQ 7.4 to 15.0%)
- median risk of **hip fracture** 6.0% (IQ 2.6 to 7.6%).

8.4% of men and 26.2% of women were already on specific bone health treatment at the time of assessment. 13.1% of men and 27.7% of women were referred for DXA scanning. 5.1% of men and 18.0% of women were started on specific bone health treatment after their assessment. The median FRAX probabilities for men were 8.3% for **major osteoporotic fracture** and 3.5% for **hip fracture**, compared to those in women of 19.0% for **major osteoporotic fracture** and 7.8% for **hip fracture**.

For men referred for DXA scanning, the median FRAX probabilities were 12.0% for **major osteoporotic fracture** and 6.4% for **hip fracture**.

For women referred for DXA scanning, the median FRAX probabilities were 18.0% for **major osteoporotic fracture** and 7.3% for **hip fracture**.

Patients started on specific bone health treatment after assessment had a median **major osteoporotic fracture** risk of 13.0% in men (vs 30.0% in women) and median **hip fracture** risk of 8.4% in men (vs 16.0% in women).

Although rates of investigation and treatment were lower for men than for women, this was in line with their lower absolute fracture risk scores. There was an increase in the proportion that were prescribed anti-resorptive bone treatment of 61% for men (from 8.4% at baseline to 13.5% after the project) and 68% for women (from 26.2% at baseline to 44% after the project).

Service comparison: Elderly Care and Neurology

Cases assessed were slightly older in Elderly Care services (median age 77 years, compared to 74 years in Neurology), but the duration of diagnosis was shorter in Elderly Care at a median of 3 years, compared to 6 years for Neurology. The proportion with falls was similar between the specialties (Elderly Care 48.8%, Neurology 52.3%), as was the proportion with previous fragility fractures (Elderly Care 19.9%, Neurology 21.0%), while the proportion with evidence of vertebral fractures was slightly higher in Elderly Care at 18.1% compared to Neurology 15.0%). Bone health

assessments were relevant, and led to changes in management, in both service types. Neurology cases were more likely to be started on anti-resorptive bone health medication (12.4% of cases assessed) compared to Elderly Care (9.2% of cases assessed).

Participant self-rating

Questionnaires were completed by 106 participants at baseline and 35 at the end of the project, covering the full range of professions. Confidence in assessing bone health (0=not confident to 5=very confident) was 3.1 at baseline and 4.2 at the end of the project; the ability to include bone health assessment in routine practice (0=not able to 5=very able) was 3.4 at baseline and 4.1 at the end of the project; confidence in recommending bone health treatment (0=not confident to 5=very confident) was 2.9 at baseline and 3.5 at the end of the project.

Several participants highlighted the time required to complete bone health assessments; many opted to undertake a preparatory assessment from the case records, prior to clinic attendance. Access to DXA scans and processes for prescribing bone health medication both varied according to local practices, necessitating some adaptations to the protocol.

Limitations

The dataset balanced the desire for detail with the practicality of data collection within clinical services. Accordingly, we did not capture detail on certain aspects, such as doses of calcium and Vitamin D, or the reasons for these treatments being in place. We did not collect details of delay to DXA scanning, nor treatment decisions after DXA scan results became available, when this happened after the end of the project. This means that the figures for the percentage of cases starting bone health treatments as a result of the assessment in the project are likely to be an underestimate. Although we cannot attribute interventions specifically to the project (as investigations and treatment changes may have happened in routine clinical practice), the substantial increase in cases with active intervention, as well as feedback from clinical participants, suggests that the project was responsible for the significant majority of these interventions.

There was a high level of attention to dietary calcium intake, the importance of exercise, keeping alcohol moderate, and stopping cigarette smoking in the online tool, but the interpretation of the meaning of the questions on these topics was inconsistent, preventing further analysis.

We did not collect detail about any adjustment to the bone fracture risk estimates in the presence of falls, which may mean that we have slightly underestimated the values. However, this uprating due to falls is expected to be incorporated within the next revision of the NOGG guidance.

The completion rate for the post-project questionnaires was low at 32%, which limited its value in evaluating the participants' self-rated score regarding the impact of the project.

Summary and next steps

This was the first national service improvement project in Parkinson's, linked to the UK Parkinson's Audit. The project had a high level of engagement by clinical services, and involved over 1100 patients with Parkinson's. The treatments introduced to patients in this project alone have the potential to prevent around 3 vertebral fractures and 2 non-vertebral fractures (including the prevention of 1 hip fracture). Extension to larger numbers of centres and patients would be a fabulous example of preventive medicine. It is striking that the percentage of cases on anti-resorptive bone health treatment increased from around 16% at baseline to around 26% (an absolute increase of around 10%, and a relative increase of around 67%). Our overall aim is to substantially reduce fracture events in people with Parkinson's.

The project provides proof of concept for multicentre service improvement projects that could be adapted for other topics. In addition, an extension of the current project for additional services that have not yet participated should be possible with minor adjustments to the current project, for future rounds of service improvement.

Comparison of the figures in the 2019 UK Parkinson's Audit with those from the next audit cycle (due to report at the beginning of 2023) may further illustrate the impact of this 2021 service improvement project on bone health assessment in Parkinson's nationally.

Results of the project will be shared with specialist groups in several specialties, including the special interest groups of Elderly Care, Neurology, and physiotherapy, and via other communication channels. Information about bone health will be shared with patient groups via The Parkinson (Parkinson's UK's magazine) and other communication methods (Parkinson's UK website). Clinical services and patients will be guided towards methods of bone health assessment, to increase application in a larger number of services and patients. The bone health approach will be added to the resource directory of the Excellence Network (Parkinson's Excellence Network), and made available to all services across the UK.

Acknowledgments

This project was successful because of the high level of engagement by the clinical community for which we are extremely grateful, particularly considering the healthcare pressures due to COVID-19 that continued during the time of the project. The project was developed with extensive input from an expert multidisciplinary team including medical, specialist nursing, therapists, and people with Parkinson's. Particular thanks are due to Dr Veronica Lyell who gave invaluable expert advice on the topic which helped shape both the design and the interpretation of the results. This project would not have been possible without the financial and staff support kindly provided by Parkinson's UK. We are also grateful for helpful comments from Jill Griffin, Clinical Engagement Lead, Royal Osteoporosis Society.

Appendix A - members of the Advisory Group

- Donald Grosset - Senior Research Fellow and Professor of Neurology, Excellence Network Service Improvement Lead
- Anne-Louise Cunnington - Consultant Geriatrician, Audit Clinical Lead
- Veronica Lyell, Consultant Geriatrician, BONE-PARK algorithm co-author
- Rowan Wathes - Excellence Network Associate Director, Parkinson's UK
- Kim Davis - UK Parkinson's Audit Manager, Parkinson's UK
- Cathal Doyle - Head of Strategic Intelligence, Parkinson's UK
- Mary Ellmers - Service Improvement Manager Scotland, project QI lead, Parkinson's UK
- Jane Price - Parkinson's Nurse Specialist
- Hannah Martin - Parkinson's Nurse Specialist
- Louise Ebenezer - Parkinson's Nurse Specialist
- Laura Hartley - Specialist Occupational Therapist
- Danielle Pendry-Brazier - Specialist Physiotherapist
- Elaine Evans - Trustee for Wales, Parkinson's UK
- David Allan - Trustee for Scotland - Parkinson's UK

Appendix B - participating services

Elderly care services:

- Addenbrooke's and Brookfields Hospitals
- Barnsley Hospital
- Birmingham Heartlands Hospital
- Bristol Royal Infirmary
- Bronllys Hospital
- Charlestown Health Centre, Manchester
- Cornwall Partnership NHS Foundation Trust - Community hospitals
- Darent Valley Hospital
- Frimley Park Hospital
- Glasgow Royal Infirmary / Lightburn Hospitals
- Gloucestershire Royal Hospital
- Hairmyres Hospital
- Ipswich Hospital
- Jubilee Day Hospital
- Luton and Dunstable University Hospital
- Melville Day Unit, Freeman Hospital
- Musgrove Park Hospital
- Norfolk and Norwich University Hospital
- North Tees University Hospital
- Nottingham University Hospital
- Princess of Wales Hospital, Bridgend
- Queen Victoria Hospital, East Grinstead
- Rochdale Infirmary
- Rotherham General Hospital
- Royal United Hospital, Bath
- Stobhill Hospital
- Wirral University Hospital
- Ysbyty Glan Clwyd Hospital

Neurology services:

- Charing Cross Hospital
- Derriford Hospital
- Hillingdon Hospital
- Ipswich Hospital
- Newcastle Movement Disorder Service
- Northwick Park Hospital
- Queens Hospital, Romford
- Salford Royal Hospital
- St George's Hospital
- St Richard's Hospital, Chichester
- Surrey Downs Health and Care - Community Neuro Rehab team
- Tameside and Glossop Integrated Care NHS Foundation Trust - Community Neuro Rehab team
- University Hospital Coventry
- Whittington Hospital

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The Parkinson's Excellence Network is the driving force for improving Parkinson's care, connecting and equipping professionals to provide the services people affected by the condition want to see.

The tools, education and data it provides are crucial for better services and professional development.

The Network links key professionals and people affected by Parkinson's, bringing new opportunities to learn from each other and work together for change.

parkinsons.org.uk/excellencenetwork