



COVID-19 and effects on osteoporosis management: the patient perspective from a National Osteoporosis Foundation survey

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The novel coronavirus pandemic continues to have a profound impact on the global population, as well as the US population and healthcare system, as the number of reported COVID-19 cases in the USA continues to rise [1]. Early in the pandemic, hospitals and private health clinics cancelled non-emergency procedures and office visits, and many Americans postponed care as they sheltered in place to stop the spread of the virus. Concerns have caused delays in medical care for acute and chronic diseases [2]. Patients have been affected through limited provider access, hesitations to attend appointments, and treatment delays. The National Osteoporosis Foundation (NOF) sought to ascertain the impact on the management and care of osteoporosis and bone health by surveying patients and caregivers.

A Morbidity and Mortality Weekly Report by the Centers for Disease Control and Prevention (CDC) acknowledged that by the end of June 2020, an estimated 41% of adults in the

USA had delayed or avoided medical care including urgent or emergency care (12%) and routine care (32%) because of concerns or changes in healthcare delivery related to COVID-19 [3]. According to the CDC, the elderly and adults with underlying health issues and multiple comorbid conditions are at the greatest risk for infection with (and severe disease due to) COVID-19. This same group is at greatest risk for osteoporosis and osteoporosis-related fracture. These fractures, which amount to approximately two million annually in the USA, and which can be life-altering events, do not cease because there is a pandemic [4]. It is therefore imperative that patients suffering from osteoporosis and other bone health issues, as well as other chronic diseases, remain adherent with their treatment and have access to their healthcare providers during the COVID-19 public health emergency (PHE).

The COVID-19 PHE has impacted multiple aspects of osteoporosis care, some of which include reduced patient access from altered clinic schedules, screening/testing and treatment reductions, and challenges from implementation of telemedicine. Additionally, patients have been reluctant to schedule in-person visits when available, and there has been varied access to care across the country depending on the number of COVID-19 cases in each state and the restrictions put in place by local governments, including closure of businesses and having people shelter in place to reduce the spread of the virus.

The NOF aimed to understand the specific impact of the COVID-19 PHE on certain aspects of care, including assessment and management of osteoporosis and bone health from the patient and caregiver perspective, through a survey distributed to a sample of NOF's online support community of patients and caregivers.

There were approximately 14,000 recipients of the survey, which covered questions regarding the geographic location of respondents; from whom they received their bone health care; access to care during the PHE, such as availability of appointments and type of medical visits,

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information and satisfaction related to telemedicine experiences, and challenges related to starting or continuing treatment for osteoporosis; and access to testing. The survey was conducted between May 11 and 29, 2020, using the SurveyMonkey platform.

NOF received 348 responses to the survey, from 45 states, including major cities, smaller towns, and rural areas, as well as the District of Columbia and a smaller number of respondents from Puerto Rico, Canada, Iraq, Turkey, and the UK. The respondents were patients and caregivers with osteoporosis or bone health concerns.

Seventy-seven percent of respondents were 65 years of age or older with another 18% between the ages of 55 and 64. The majority of the survey participants (74%) had a diagnosis of osteoporosis, and 70% of all respondents were treated by a primary care physician or endocrinologist. Ninety-five percent of respondents lived in their own home (house or apartment) with another 4% residing in independent senior living communities.

The majority of patients were treated for osteoporosis/bone health by either primary care/internal medicine providers (~40%) or endocrinologists (30%) (Fig. 1). Forty percent of all respondents reported that their provider's office was open for osteoporosis care during the PHE (Fig. 2), but only 18% of those who had access to in-person medical appointments attended an in-person visit. Twenty-eight percent of all survey respondents either cancelled or rescheduled an appointment with their bone health provider. The reasons included concerns about vulnerability or exposure to COVID-19, a feeling that the scheduled appointment was not urgent and could be postponed, and a desire to avoid offices located on a hospital campus (Fig. 3). Other reasons were beyond the direct control of the patient and encompassed cancellation by the provider's office, conversion from an in-person to a telemedicine visit (most often initiated by the provider), and lack of availability of testing services such as dual-energy X-ray absorptiometry (DXA), for which the appointment had been scheduled. There were also concerns related to treatment, which centered on both fear of and delay in starting a new medication during the pandemic.

Thirty-six percent of patients participated in a telemedicine appointment between early March and the end of May 2020. Seventy-seven percent of patients who participated in telemedicine visits were satisfied with their appointments. They reported that the remote visits were convenient, easy, safe, and of good quality, which included being time efficient and allowing for "increased direct contact time" and "undivided attention" from their healthcare provider. For those respondents who were dissatisfied, complaints centered on technology issues, a need for services that require an in-person visit (physical examination, laboratory testing, etc.), and the sentiment that telehealth was not a satisfactory "proxy" for an in-person visit. The majority of responses from the "dissatisfied"

category simply had "no need for an appointment at the current time" and were not truly dissatisfied.

A smaller number of patients reported experiencing communication challenges with their healthcare provider (16%) or challenges in obtaining prescription osteoporosis medications (11%). Common communication challenges were slow/lack of response from the provider's office, scheduling difficulties, reduced office hours or office closures, and technical issues. Patients reported prescription challenges due to insurance or cost issues, inability to obtain refills from their providers, and a requirement for an in-person interaction (laboratory testing, pick-up at the pharmacy, injection or infusion at a healthcare provider's office or facility) which they felt was untenable due to risk or was not possible due to office closures or appointment postponement. Most frequently reported was a delay in administration of denosumab followed by a delay in zoledronate infusions. Twenty-two percent and 33% of patients either changed or cancelled appointments for bone health testing (DXA, laboratory testing) or were unlikely to obtain the tests requested by their provider, respectively.

Every year in the USA, millions suffer osteoporosis-related hip, spine, and other non-hip, nonvertebral fractures that can be life altering for individuals and costly to the nation, with \$57 billion spent in direct and indirect costs in 2018 [4]. Prior to the COVID-19 pandemic, approximately 60–80% of those who suffered an osteoporosis-related fracture in the USA were not getting diagnosed or treated, despite the availability of effective drug therapies that reduce the risk for repeat fractures by about 50% [5, 6]. There are significant concerns that the COVID-19 PHE has and will continue to widen this care gap through reduced access to needed evaluations, diagnosis, post-fracture care coordination, and osteoporosis treatment and therefore will result in even more serious and costly outcomes, especially in the over -65 vulnerable population where increased risks for both fracture and COVID-19 converge. As seen in the patient and caregiver survey, patients' access to their primary bone health provider was significantly limited during the first wave of the pandemic with only 40% reporting

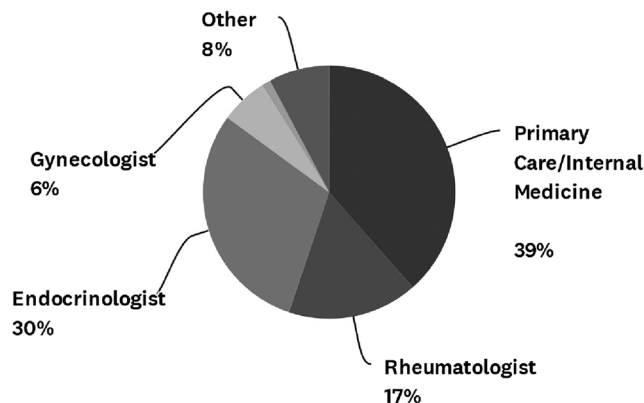
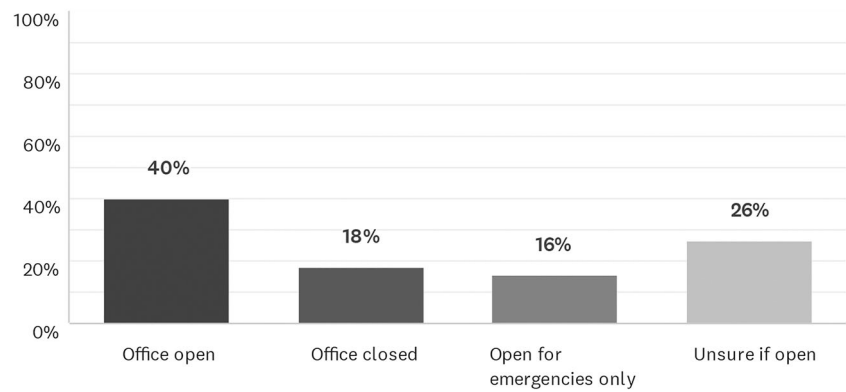


Fig. 1 Principal healthcare provider managing bone health. Other included oncologist, "osteoporosis specialist," and no provider

Fig. 2 Availability of in-person appointments with the primary bone health provider



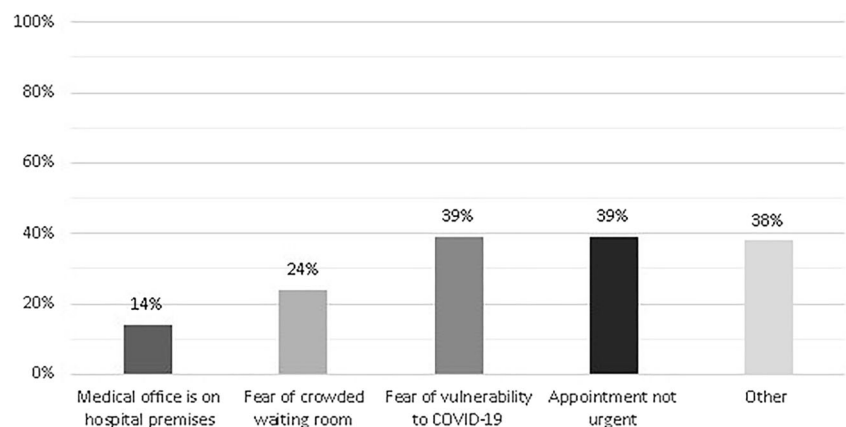
providers' offices being open for routine care and only a minority willing to be seen in person even when the option existed. The fear of starting and, hence, resultant delays in treatment initiation during the pandemic were also a problem. Reported challenges in obtaining medication prescriptions and delays in administration of injectable and infused osteoporosis medications also add to the concern for less than optimal care. Perhaps the most disturbing, however, were the lack of concern for fracture risk and respondents' perceptions that appointments for osteoporosis or bone healthcare were not necessary and could readily be postponed. Given the substantial clinical and economic burden of fractures, both on an individual and societal level, and the fact that the risk of subsequent fracture is highest in the first 1–2 years following a prevalent fracture [7, 8], lack of timely evaluation and treatment is particularly alarming for those who may have already sustained fractures.

NOF's public awareness, education, and advocacy efforts have focused on emphasizing the connection between osteoporosis and fracture/fracture risk as well as the potentially devastating consequences of fractures, a message which seems as important as ever in the midst of the current PHE. NOF has sought to keep patients, caregivers, and healthcare providers updated on new rules and regulations affecting osteoporosis care and treatment delivery. Through webinars

featuring clinical and policy experts, NOF has provided live and on demand information regarding policy and reimbursement changes resulting from the PHE.

As the PHE continues, it is imperative that we continue to monitor and respond to the continuing needs of patients and providers in managing chronic diseases such as osteoporosis. NOF conducted a webinar for healthcare providers that reviewed what new rules and legislation mean for clinicians caring for osteoporosis patients. With input from patients and providers and informed by data from the patient and caregiver survey, NOF responded to new measures and regulations by the Centers for Medicare and Medicaid Services (CMS) to focus on increasing the access points and modalities through which individuals could receive necessary healthcare, enabling patients to stay at home when possible and minimizing the burden on providers. These flexibilities were (and remain) particularly important for individuals with chronic conditions such as osteoporosis, who would otherwise have to risk a potentially serious COVID-19 exposure to be evaluated for or continue receiving their treatments. Furthermore, as CMS sought to clarify the definition of "homebound" for home health eligibility purposes to include instances of confirmed or suspected COVID-19 and circumstances where leaving the home would be contraindicated due

Fig. 3 Reasons for cancelling or changing an in-person appointment



to patient risk factors and the potential for contracting COVID-19, NOF urged CMS to enable streamlined provider certifications and care planning requirements. NOF requested that CMS identifies and implements policy refinements and flexibilities that would enable beneficiaries to receive their medications through a home health provider or other means without needing to be seen in healthcare settings or incurring the additional out-of-pocket cost burden associated with specialty drugs under Medicare Part D. This is particularly important for medications such as denosumab and romosozumab, which have a rapid offset of effect when discontinued and need to be given without treatment interruptions or delays to achieve the expected benefits of reduced fracture risk.

In addition to addressing access to treatment options, implementation of new care delivery mechanisms/modalities was necessary during the PHE. For many, the option of receiving care remotely through telemedicine has been readily accepted, and as noted in our survey findings, satisfaction with telemedicine visits has been high overall. A special Fracture Liaison Service (FLS) Bone Health TeleECHO (Extension for Community Healthcare Outcomes) session was held in April 2020 to discuss “Osteoporosis Care in the Time of COVID-19,” where providers discussed how to ensure that patients were receiving the appropriate treatments and care, along with reimbursements for telemedicine. Telemedicine is not a panacea; it has its challenges and shortcomings, a number of which were reported by healthcare providers in a similar survey, the results of which are detailed in a paper in this issue of the journal. As seen in our survey results, however, for many patients, it has offered critical access to the healthcare they need, particularly during this public health crisis.

As changes to the delivery of care and treatment are rapidly evolving, patients need to know that forgoing appointments and treatments are not the solution. Evolving and creative options to avoid the impact of delayed diagnosis and treatment of osteoporosis on fracture risk is important. It will be important to determine if telemedicine options can be expanded and retained for post-pandemic disease management. As new regulations are implemented regarding access to healthcare during the pandemic, it is worth considering which changes should remain post-pandemic to improve healthcare for patients with chronic diseases.

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Compliance with ethical standards

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