When ‘In Range’ Isn’t Enough:

The Importance of Quality of Life in Hypoparathyroidism

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Hypoparathyroidism is a rare endocrine condition caused by insufficient parathyroid hormone (PTH), leading to a range of physical, cognitive and emotional symptoms.[1] As it is uncommon, healthcare professionals may only encounter a handful of cases in their practice each year and management often falls on maintaining biochemical stability, particularly the regulation of serum calcium and phosphate levels in the blood.[1]

For many patients, a careful balance is required for conventional therapy, including oral calcium and active vitamin D, so that short-term symptom relief and long-term risk is managed appropriately.[1] Ongoing monitoring remains essential to prevent hospitalisation and acute complications.[2] However, even when the numbers are in range, clinical experience and evidence increasingly suggest that achieving biochemical stability alone does not always reflect patient wellbeing.[3]

In my role as an advanced nurse practitioner, I frequently encounter individuals whose biochemical measurements fall within recommended ranges, yet they continue to experience significant symptom burden. With previous studies showing over half of patients on treatment suffer from depression or sadness related to the condition, while four in five struggle with anxiety, the psychological burden of hypoparathyroidism is both significant and under-recognised.[3] Yet without consistent, structured ways of capturing this burden, these experiences are unlikely to be accurately identified, monitored or addressed in everyday practice.

The hidden burden

Symptoms reported by people living with hypoparathyroidism – from fatigue and muscle cramps, to brain fog and mood disturbance – are intrinsic features of the condition itself caused by the low or high levels of calcium that patients experience.[4]

Given these symptoms are wide-ranging and ‘non-specific’, there is a risk they might be considered unrelated to hypoparathyroidism and attributed to other external factors or separate conditions, overlooking the underlying burden of disease. Understanding their direct connection to hypoparathyroidism is critical to achieving a more accurate and holistic assessment of the patient experience.

When symptoms persist despite patients being told their biochemical results are stable, they may feel the impact of their hypoparathyroidism is being underestimated or “brushed over”. This lack of validation can add to their emotional load and ultimately erode trust in the care they’re receiving. In contrast, acknowledging how symptoms are affecting everyday life can change the tone and depth of conversations, opening the door to more meaningful management discussions. Embedding this approach into routine care not only requires clinical intent, but also practical tools that support meaningful dialogue around quality of life within NHS practice.

Understanding the value of patient-centred dialogue

Time pressures within the NHS remain a significant constraint, making it difficult to spend prolonged periods with patients. In this context, how consultations are structured and what information is prioritised becomes incredibly important. Creating space – for example, through open-ended questions – for patients to describe how they are coping in their daily life can provide valuable insights into disease impact that may not otherwise have been identified.

Where possible, continuity of care can further support meaningful dialogue. When patients see the same team consistently, trust builds, enabling discussions on topics that are harder to talk about, like fatigue that can make work unmanageable or anxiety stemming from uncertainty about how their body will behave. For individuals already experiencing low energy or cognitive burden, clear signposting to available support services can make a significant difference.

From listening to measurement

Listening forms the foundation of person-centred care, however, relying on informal conversations alone can be inconsistent for understanding a patient's quality of life. Without a structured approach, it becomes challenging to track progress over time, understand the impact of interventions, or identify unmet needs.

In practice, some clinicians may feel hesitant about using formal health-related quality of life (HRQOL) tools for a range of reasons. These might include time constraints, uncertainty about how to act on results, and sometimes a sense of helplessness if needs arise that services are not equipped to meet. While these concerns are valid, the presence of measurable patient-reported outcomes can help us determine whether care is genuinely improving patients' lived experience.[5]

In many other endocrine conditions, structured quality of life assessment is already well-established and embedded in routine practice. In hypoparathyroidism, a barrier is the perception that symptoms are not specific enough to measure meaningfully, but quality of life tools offer a way to capture symptom burden consistently over time, identify patterns that might not be obvious in clinic, and guide appropriate support, whether that involves psychological input, lifestyle advice, or adjustments in clinical follow-up.

The importance of consistent data collection

We have both generic quality of life tools and more condition-specific versions at our disposal. Generic health questionnaires offer useful insights and can help with broad comparisons across chronic diseases, but they may not fully reflect the symptom profile and lived experience associated with hypoparathyroidism. On the other hand, disease-specific tools – with several options available in hypoparathyroidism – capture symptom domains that are particularly relevant, supporting more meaningful assessment and interpretation of patient-reported data.[5]

Regardless of approach, consistency is critical. If every NHS Trust adopts a different approach, it becomes very difficult to bring results together, compare outcomes meaningfully, or share learnings across centres. If we can move towards the same method of collecting quality of life data in hypoparathyroidism, with alignment on a preferred disease-specific tool to use, it strengthens our ability to evaluate care and understand unmet needs at scale. It also supports wider initiatives that depend on shared outcomes, such as data registries and service evaluations.

Looking ahead

Measuring quality of life is not the end point, but it is a significant first step toward more person-centred care. It helps us identify unmet needs, validate what patients are experiencing, and create a clearer picture of whether clinical management is improving the quality of patients' lives.

In hypoparathyroidism, how we view the effect of medicine is changing. It's not just about how well a treatment works biochemically, but how people respond to the intervention in their everyday lives. We have an opportunity to move towards more consistent, empathetic care that reflects the real impact of the condition. To do so, we need a unified approach to measuring quality of life.

Consistent data can support service development and strengthen the case for more joined-up support, including psychological services where they are needed.[5] Data can also help us think strategically about how care is delivered – using pre-clinic questionnaires, patient portals, or in-clinic completion to minimise pressure on consultation time, while still capturing what is meaningful. These approaches allow us to gather patient-symptom level information in ways that are less burdensome for both patients and clinicians.

If we want to plant the seeds for long-term change, we need to start measuring the whole impact of hypoparathyroidism – and begin by making space for the question that patients often wish we asked first: "how have you been since we last spoke?".

This article has been supported and funded by Ascendis Pharma UK Limited. Seeds of Change is a disease awareness initiative developed and funded by Ascendis Pharma UK Limited and supported by Parathyroid UK and Society for Endocrinology.

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