

Impacts of Hypoparathyroidism on Patient Work Productivity and Out-of-Pocket Costs

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BACKGROUND

Hypoparathyroidism (HP) is a rare endocrine disorder characterized by absent or inappropriately low levels of circulating parathyroid hormone (PTH).^{1,2} Patients with HP on standard of care and/or short-acting PTH therapy report debilitating physical and cognitive symptoms, which may be indicative of a reduced quality of life (QOL).³⁻⁵ Scant data are available on the economic burden of illness experienced by patients with this condition.

OBJECTIVE

- To examine the impacts of HP on patient work productivity and out-of-pocket costs

METHODS

- Using a patient-centered, qualitative study design, semi-structured individual interviews were conducted by telephone with 42 adult patients with post-surgical or idiopathic HP
- Inclusion criteria:
 - At least 18 years old
 - Ability to read, write and speak English
 - A diagnosis of HP of either at least 6 months (post-surgical), or 12 months (auto-immune or idiopathic)
 - Stable (defined as infrequent severe hypo- or hypercalcemia with high-normal to elevated urine calcium excretion $\geq 200/250$ mg for adults on thiazides or $\geq 225/275$ mg not on thiazides) on standard-of-care (oral calcium and vitamin D supplements) and/or PTH replacement therapy for at least 3 months
- Exclusion criteria:
 - HP due to CASR mutation or pseudo-hypoparathyroidism
 - Having concomitant condition that may affect calcium or phosphate metabolism
 - Impaired renal dysfunction (Chronic Kidney Disease Stage 4 or 5 [eGFR ≤ 30 ml/min/1.73 m²])
 - Cognitive impairment or other medical condition, including psychiatric disorders, that would impact one's ability to participate
- Interviews were conducted with a semi-structured interview guide, which was developed based on a literature review and preliminary discussions with clinical experts
- Transcripts were coded utilizing qualitative analysis software and analyzed for content by theme using an adapted grounded theory approach common to qualitative research

RESULTS

Participant Sample Description

- The majority of participants were female (n=35, 83%)
- The primary etiology of reported hypoparathyroidism was post-surgical (n=36, 86%)
- Participants reported having an average of 5.0 (range 0-20) comorbidities in addition to HP
- 71% (n=30) rated the difficulty of managing their HP as somewhat, a lot or extremely difficult
- 31% (n=13) of participants were working full-time, and 19% (n=8) were working part-time; 26% (n=11) were retired

Impacts of HP on Work Productivity

- One-third of the study sample (n=14, 33%) reported that they were no longer able to work due to their HP symptoms
- Among those currently employed (n=21), 86% (n=18) reported that their HP symptoms interfered with their work productivity, including:
 - Interference with cognitive functioning/ability to perform cognitive tasks (n=12, 57%)
 - Absenteeism (n=8, 38%)
 - Interference with physical functioning (n=7, 33%)
- Nearly 30% reported being limited in the type of occupation they could do (n=6, 29%)
- Nearly one quarter reported needing to reduce the number of hours they work (n=5, 24%)

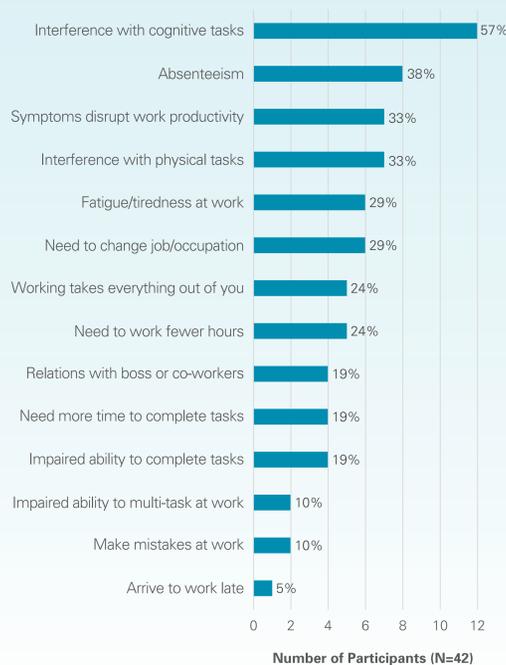
Out-of-Pocket Costs of HP

- 81% of participants (n=34) reported incurring out-of-pocket expenses associated with HP, including:
 - Medications and supplements (n=28, 67%)
 - Medical visits (n=17, 40%)
 - Travel costs to see specialists (n=11, 26%)
- In addition to out-of-pocket costs, 45% of study participants (n=19) reported as a financial impact the loss of income due to taking unpaid time off, needing to reduce the number of hours worked, or no longer being able to work
- 12% of participants (n=5) further reported experiencing difficulty accessing health insurance plans with affordable premiums that covered their treatment needs

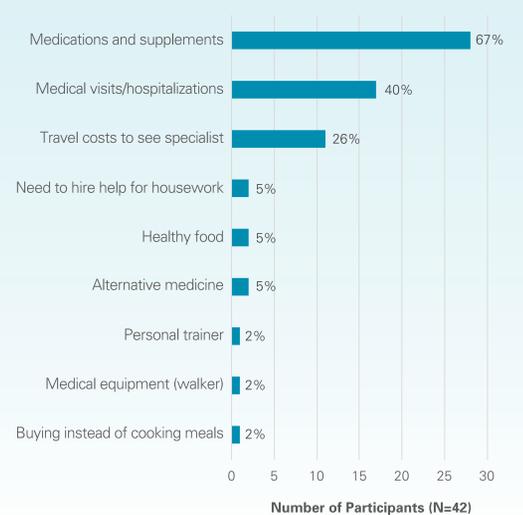
Demographic and Health Characteristics	Total (N=42)
Gender, n (%)	
Female	35 (83)
Age	
Mean (median, range)	53 (56, 26-76)
Marital status, n (%)	
Married/partnered	27 (64)
Race/ethnicity, n (%)	
White/Caucasian	40 (95)
Household Income, n (%)	
>US \$50,000	21 (50)
Decline to answer	11 (26)
Work status, n (%)	
Work full-time or part-time for pay	21 (50)
Retired	11 (26)
Source of hypoparathyroidism, n (%)	
Post-surgical	36 (86)
Idiopathic	6 (14)
Duration of diagnosis (years)	
Mean (median, range)	14 (9, 0.6-49)
Self-reported other medical conditions, n (%) ^a	
Hypothyroidism	30 (71)
Osteoarthritis	16 (38)
Depression	12 (29)
Chronic back pain	10 (24)
Reflux disease	9 (21)
Thyroid cancer	8 (19)
Medications and supplements currently used to treat HP, n (%) ^a	
Calcium supplements	40 (95)
Vitamin D supplements	41 (98)
PTH replacement therapy (PTH [1-84])	22 (52)
Hydrochlorothiazide (HCTZ)	7 (17)
Magnesium supplements	24 (57)
Potassium supplements	7 (17)

^aParticipants could choose more than one response.

Impacts of Hypoparathyroidism on Work Productivity Among Currently Employed



Out-of-Pocket Costs Associated With Hypoparathyroidism



LIMITATIONS

- The patients who responded to recruitment outreach were primarily female with post-surgical HP. However, the proportions in this study are similar to those reported in other studies.^{6,7}

RESULTS

Selected Quotes About Impacts of HP on Work Productivity

"We own a business and I do all the accounting and numbers, and all of that, and I just have days where I just—my brain just doesn't work."

Interference With Cognitive Tasks

"Missing work because you're not feeling well, there's a hit right there."

Absenteeism

"With the tingling in my hands, I just stop for a while and . . . go back to work when my hands aren't so numb."

Symptoms Disrupt Work Productivity

"I have to pass instruments to the dentist. If I'm having tremors in my hand . . . sometimes I do drop things."

Interference With Physical Tasks

Selected Quotes About Out-of-Pocket Costs Associated With HP

"Medication's a huge financial cost, which is—most of it's out of pocket. The calcium supplements aren't covered by insurance."

Medications and Supplements

"Every time you end up in the ER, that's another \$2,000."

Medical Visits/Hospitalizations

"It costs me \$1,500 every three months just to go see a doctor in another state, and that isn't covered by insurance."

Travel Costs to See Specialist

CONCLUSIONS

- Findings from this qualitative study suggest that the severity of symptoms experienced by many patients with HP may substantially impact their work productivity and generate multiple out-of-pocket costs
- Further research is needed to quantitatively assess the economic burden of illness associated with HP

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This study was sponsored by Ascendis Pharma Bone Diseases A/S.

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