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Daily Symptomology Tracking in Pernicious Anaemia: The Impact of Vitamin B^{12} Treatment

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Pernicious Anaemia (PA) is a common, multifactorial disease caused by malabsorption of vitamin B^{12} (B^{12}) due to a lack of intrinsic factor (IF) because of autoimmune damage to the IF-producing parietal cells lining the stomach[(1)]. PA remains largely neglected by the research/clinical communities, leading to high rates of mis/underdiagnosis[(2)] and an inadequate 'one-size-fits-all' treatment protocol. The current maintenance therapy of 1 mg intramuscular B^{12} injections every 2–3 months[(3)] is inadequate for 60% of PA patients, advocating for more frequent B^{12} injections. If untreated, megaloblastic anaemia and neurological damage ensue[(4)].

We hypothesise that a personalised approach to PA treatment will improve the quality of life and prevent severe irreversible neurological complications among PA patients. Our aim is to undertake the first large-scale real-time study of symptom range, severity and response to treatment across multiple B^{12} treatment cycles.

An initial online survey was developed and distributed to PAS members (www.surveymonkey.com/r/YV6M25Y) to collect data on diagnosis, treatment, family history and comorbidities. Individuals who completed the survey were given the opportunity to participate in Phase 1 of the subsequent daily symptom profile survey. Qualtrics was used to create a simple online tool to collect daily data on participants' symptoms, severity (1–10 scale, mild = 1, moderate = 5, severe = 10), and treatment regimen. Descriptive statistics were used to report the range, severity, and response of symptoms to B^{12} treatment for a preliminary pilot sample.

Between April-September 2022, 1182 respondents completed the initial PAS survey. Of these, 50% (n = 417) reported receiving treatment within the recommended guidelines; 55% (n = 684) expressed dissatisfaction with their current treatment regimen. Eight participants participated in the pilot study for a median of 58 days, during which they received B^{12} treatment on average 10/58 days and were symptomatic 46/58 days. The most common symptoms and their mean severity were: tiredness (80%, 5.28 [SD1.97]), tinnitus (43%, 4.71 [SD2.09]), and myalgia (33%, 5.17 [SD1.59]). Two participants data are presented in detail to illustrate the large variability in treatment and symptom severity in PA: Participant 1 received 3 intramuscular injections over 62 days and was symptomatic 98% of the time, reporting tinnitus (100%, 7.38 [SD1.43]), poor concentration (51%, 5.35 [SD1.43]) and aphasia (51%, 5.43 [SD1.56]). Participant 2 received 15 injections over 62 days and was symptomatic for 43% of the time, reporting tiredness (36%, 3.44 [SD0.83]), aphasia (24%, 3.83 [SD0.69]) and dizziness (24%, 1.83 [SD0.69]).

This pilot data provides real-time insight into the large inter-individual variability in the range, severity, and response of PA symptoms across multiple treatment cycles. Most patients report a significant reduction in symptoms using an "individualised" treatment approach, suggesting that a "one-size-fits-all" approach to treating PA is ineffective. Data collection is ongoing with the recruitment of 200 participants with PA to Phase 2 of the study.

References

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