

SUMMARY OF SURVEY RESULTS AS PUBLISHED IN THE BRITISH JOURNAL OF NURSINGⁱ

1. **Background:** Instigating a patient support group for patients with pernicious anaemia (PA) revealed dissatisfaction with its current diagnosis and treatment.
2. The authors investigated the clinical features, patient experience of diagnosis and treatment of PA in the UK.
3. **Methods:**
4.
 - a. Between August 2010 and November 2012, 1184 individuals completed the questionnaire. After eliminating those who filled in the questionnaire on behalf of a friend or family member, and non-UK respondents, 889 completed questionnaires remained.
 - b. The questionnaire was either completed online or by completing a paper version.
 - c. The ages of respondents at the time of diagnosis of PA varied from less than 10 years (4 individuals) to greater than 80 years (12 individuals). The most frequent age at diagnosis was 41–50 years (228 individuals).
5. **SYMPTOMS:**
 - General:** Most of the individuals (99%) reported a range of general symptoms, predominantly tiredness (96%) but also (in decreasing order of frequency) 'waking up tired' (87%), dry skin (58%), brittle nails with (47%) or without (37%) ridging, flushes or fever (43%), glossitis (34%), hair loss or greying (30%), weight loss (21%) and jaundice (6%). The remaining 1% reported no symptoms and their B12 deficiency will have been an incidental finding.
 - Neurological:** Most individuals (98%) also reported a range of neurological symptoms including memory loss (78%), poor concentration (75%), clumsiness (66%), pins and needles (66%), poor sleep (64%), confusion (62%), dizziness (59%), headaches (52%), nominal aphasia (word-finding difficulties) (50%), 'shoulder bumps' (frequently bumping into things as a result of balance problems) (48%), unable to stand with eyes closed (34%), Grierson syndrome (33%) and vertigo (33%). Cardio-respiratory symptoms were reported by 86% of individuals, comprising shortness of breath (73%) and palpitations (56%).
 - Gastrointestinal:** Gastrointestinal problems were commonly reported (82%). These included diarrhoea (58%), indigestion (42%), diarrhoea following constipation (40%), stomach cramps (39%), loss of appetite (27%) and loss of taste (26%).
 - Emotional:** Emotional symptoms were also commonly reported (86%), including irritability (75%), impatience (64%), mood swings (58%) and suicidal thoughts (22%). Finally, 21% reported urinary tract infection.

6. Length of time to diagnosis

One-third of patients experienced symptoms for up to 1 year before diagnosis, 22% had to wait 2 years, 19% for 5 years and 4% for 10 years for an accurate diagnosis. 14% of individuals experienced symptoms for **more** than 10 years before arriving at their diagnosis.

7. Patient satisfaction with current treatment:

Patients were asked if they were satisfied with their treatment - 64% said 'No', 28% said 'Yes' and the remaining 8% did not provide an answer.

Patients were asked to choose a word that would best describe their medical care - the results were: Poor (20%), Inadequate (18%), Good (10%), Poor (10%), Undecided (9%), Reasonable (8%), Adequate (8%), Very Good (7%), Excellent (3%) and Unreasonable (2%). The remaining respondents did not answer the question.

8. Results:

- a. Nearly two-thirds of respondents were dissatisfied with current treatment
- b. 10% used a non-licensed form of B12 to supplement their prescribed injections.
- c. Respondents were asked which word best described how they rated their medical care. The results were: Very Poor (20%), Inadequate (18%), Good (10%), Poor (10%), Undecided (9%), Reasonable (8%), Adequate (8%), Very Good (7%), Excellent (3%) and Unreasonable (2%). The remaining respondents did not answer the question.

9. Conclusion:

This large survey shows that a thorough review needs to be conducted into how PA is diagnosed and treated in particular and how vitamin B₁₂ Deficiency is diagnosed and treated in general.

End of Summary

ⁱ Patient journeys: diagnosis and treatment of pernicious anaemia; Martyn Hooper, Peter Hudson, Fiona Porter and Andrew McCaddon; British Journal of Nursing, 2014, Vol. 23, No 7