

Post discharge care needs for patients with treated Primary CNS Lymphoma – a baseline single centre retrospective study

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INTRODUCTION

Primary central nervous system lymphoma (PCNSL) is a rare lymphoma localised to the brain, leptomeninges or eyes. It's a subtype of diffuse large B-cell lymphoma accounting for 1% of non-Hodgkin's lymphoma.¹

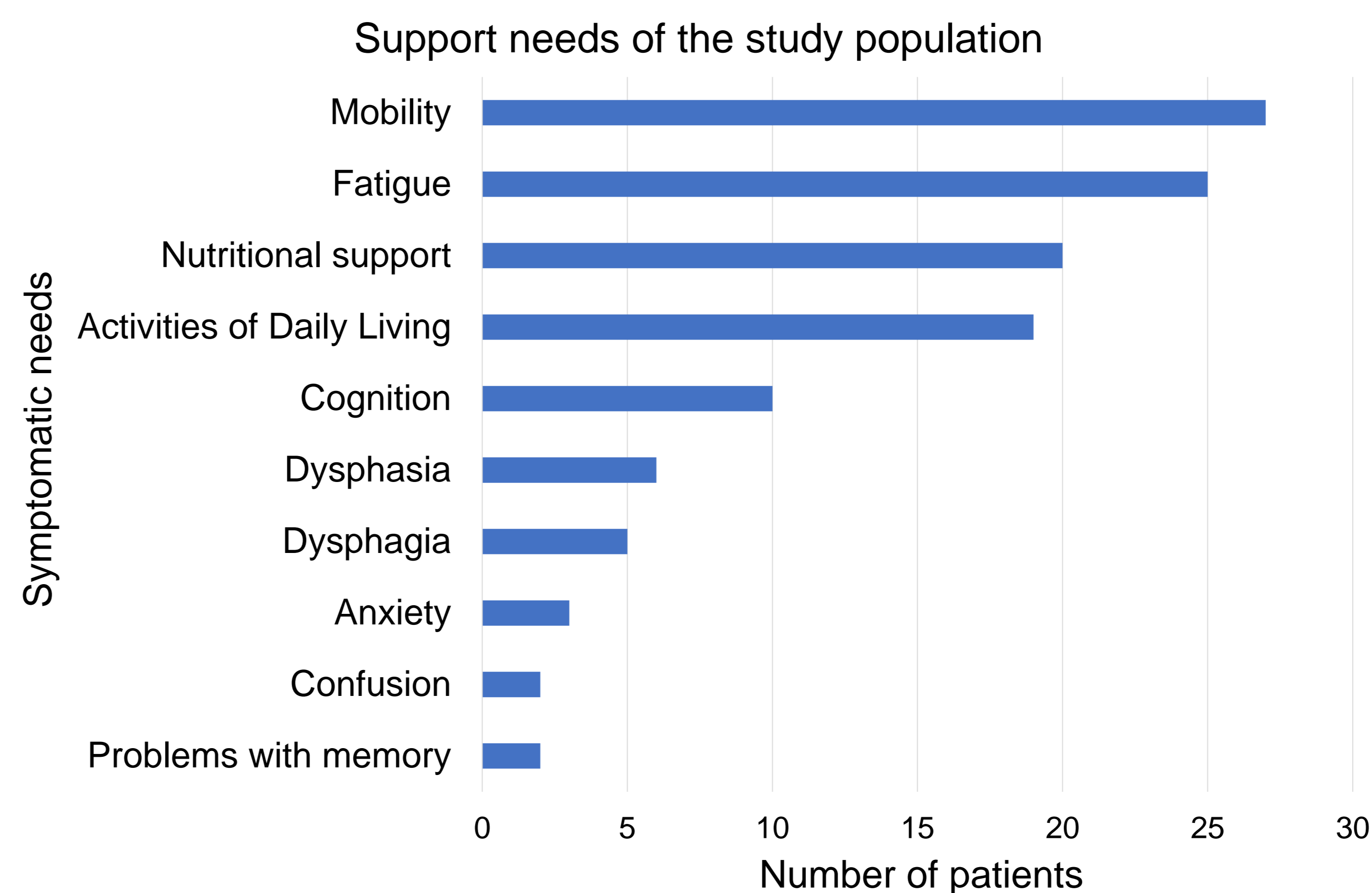
It presents with a range of non-specific symptoms such as seizure and hemianopia which can be confused with other diseases of the older population hence it takes longer to reach a diagnosis.²

Currently modern multi-agent induction chemotherapy with MATRix (high dose methotrexate, cytarabine with thiotepa and rituximab) followed by whole-brain radiotherapy or stem cell transplantation consolidation is the mainstay treatment.^{3,4}

It has significantly improved survival rates and created, in parallel, a survivor population with unmet and poorly defined treatment and disease-related care needs.

RESULTS

The audit identified 62 patients from the initial search, and 42 met the inclusion criteria. The patient population was made up of 20 males and 22 females with the age ranging from 36-91. In terms of survival, 26 patients were alive as of 01/04/2019 when this study was completed.



As shown in figure 1, poor mobility was the most common support need - present in 80% of patients – followed by fatigue in 60%, poor nutrition in 48%, inability to perform activities of daily living in 43% and cognitive problems in 24% of patients.

Figure 1: 10 of the most common support needs of patients in the study population, n=42

AIM

In view of the lack of research in patient experience and support needs of PCNSL patients, we decided to perform a retrospective analysis. We aimed to identify the supportive care needs, available services in Greater Manchester and any unmet needs of these patients following treatment at a single tertiary care centre.

Over 73% of the study population were referred to community support services shown in figure 2 and specialist allied health professionals were directly involved in the care of 15 patients due to the complexity of their rehab needs. We also found that in most patients, their needs were met as an inpatient however following discharge due to reasons such as weak documentation of symptomatic needs, lack of referral or shortage of services in their area needs were unmet.

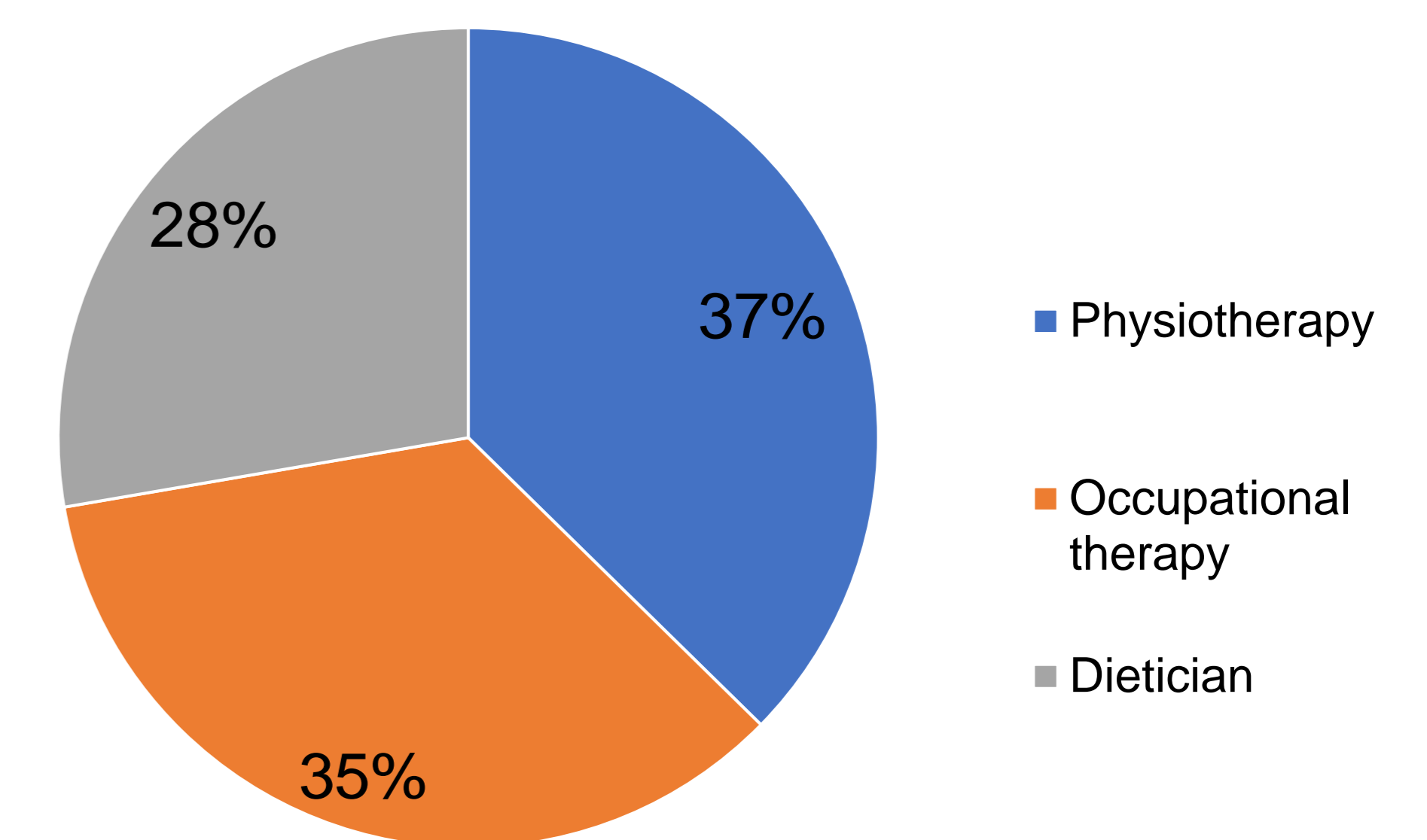


Figure 2: The most common referral for community support services

METHOD

Newly diagnosed PCNSL patients consecutively treated at The Christie NHS Foundation Trust between January 2012 - December 2018 were identified from hospital records. The following inclusion criteria was used:

- Received at least one cycle of multi-agent chemotherapy or whole-brain radiotherapy
- A minimum of 3 months survival from the start of treatment

Symptom severity was graded using the common terminology criteria for adverse events grading system version 4.03. Referrals for supportive care in the community following treatment completion and unmet care needs were identified and recorded.

CONCLUSIONS

A high proportion of treated PCNSL patients have ongoing care needs following discharge from the hospital, but this information is incompletely and inconsistently documented in the patient record. We are developing a patient-reported outcomes measures tool to identify common care needs for referral and follow-up. This tool will be prospectively audited and gaps in service provision across Greater Manchester identified for future service development.

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