

AN AUDIT OF THE PSYCHOLOGICAL BURDEN OF HLH: PSYCHOLOGICAL AND FUNCTIONAL STATUS ENQUIRY ESTABLISHING A TRAUMA INFORMED SERVICE

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Background

Haemophagocytic Lymphohistiocytosis (HLH) is a severe systemic hyperinflammatory state with high levels of morbidity and mortality of around 50%. Little is known about the burden of psychological trauma experienced by patients who survive HLH and there is no accepted standard for their ongoing psychological care.

Methods

We conducted a retrospective review of patients diagnosed with HLH between August 2021 and December 2023 who were managed in our central London HLH specialist unit at University College London Hospitals and followed up in our rheumatology-led HLH follow-up service. Data were extracted from the electronic patient record and analysed in Excel. We audited the rates and nature of psychology contact, their psychological symptoms and their return-to-work status.

Results

There were 39 patients that met the inclusion criteria. 21 (54%) had some contact with psychological services following diagnosis, 17 (44%) had no contact with psychological services of whom 5 (29%) specifically declined (Figure 1). One patient was referred but did not make contact thereafter (2%). Of those where the number of psychology sessions was recorded (n=17), the median number of sessions/contacts with a psychologist was 3 (range 1–30 sessions). Of the 21 patients who had psychology input, 18 had recorded details of psychological status, of these 12 (67%) had symptoms of anxiety, 5 (28%) had symptoms of depression and 4 (22%) of sleep disturbance, 1 had Post traumatic stress disorder (Figure 2). Regarding return-to-work status, of the 39 patients, 5 patients (13%) returned to their previous work/caring role, 10 (26%) specifically had not returned to work, 10 patients it was unclear (26%), and 14 not recorded (35%), (Figure 3).

Results

FIGURE 1. PROPORTION OF PATIENT RECEIVING POST-HLH PSYCHOLOGICAL CARE

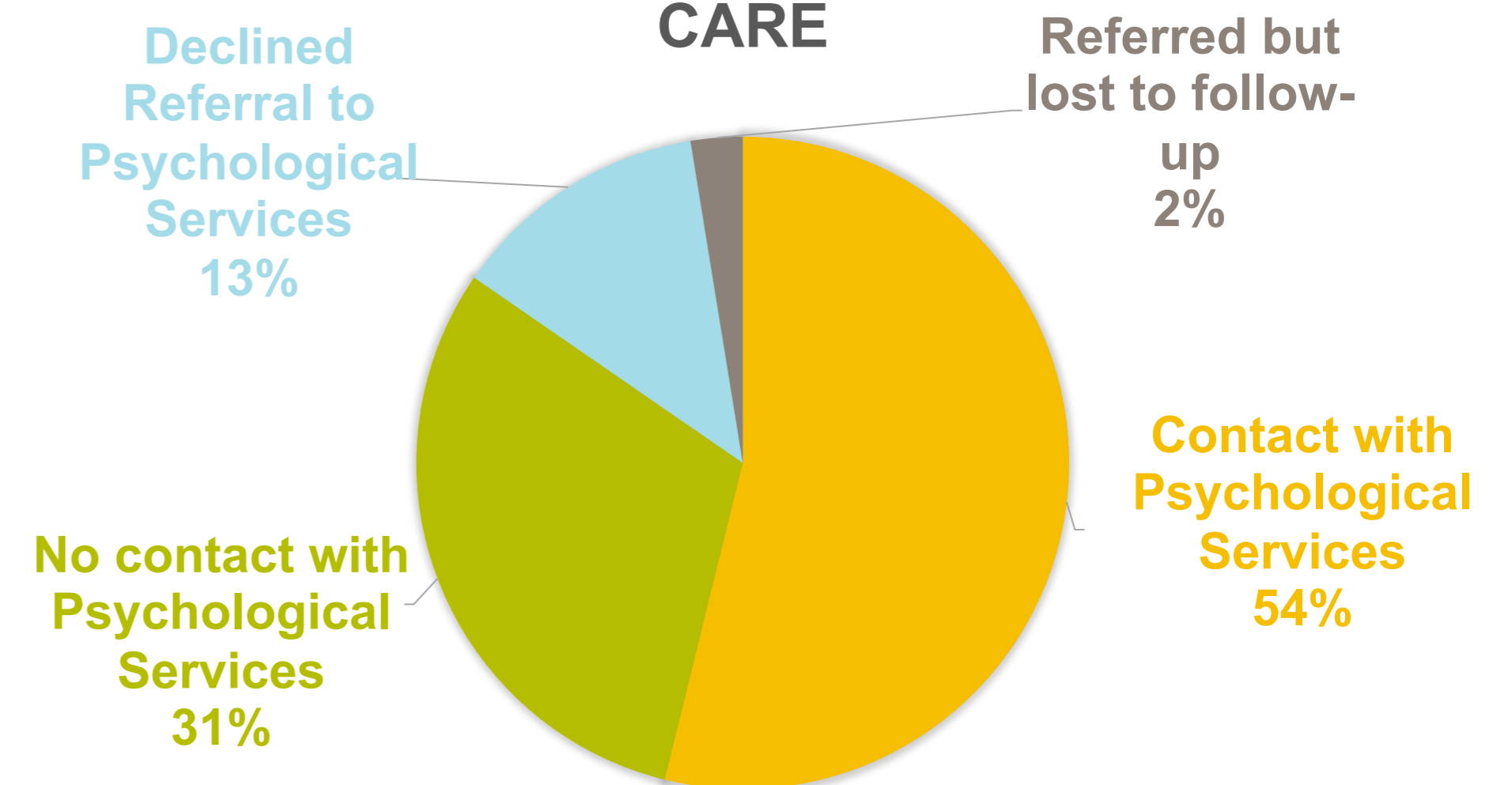


FIGURE 2. FREQUENCY OF REPORTED SYMPTOMS

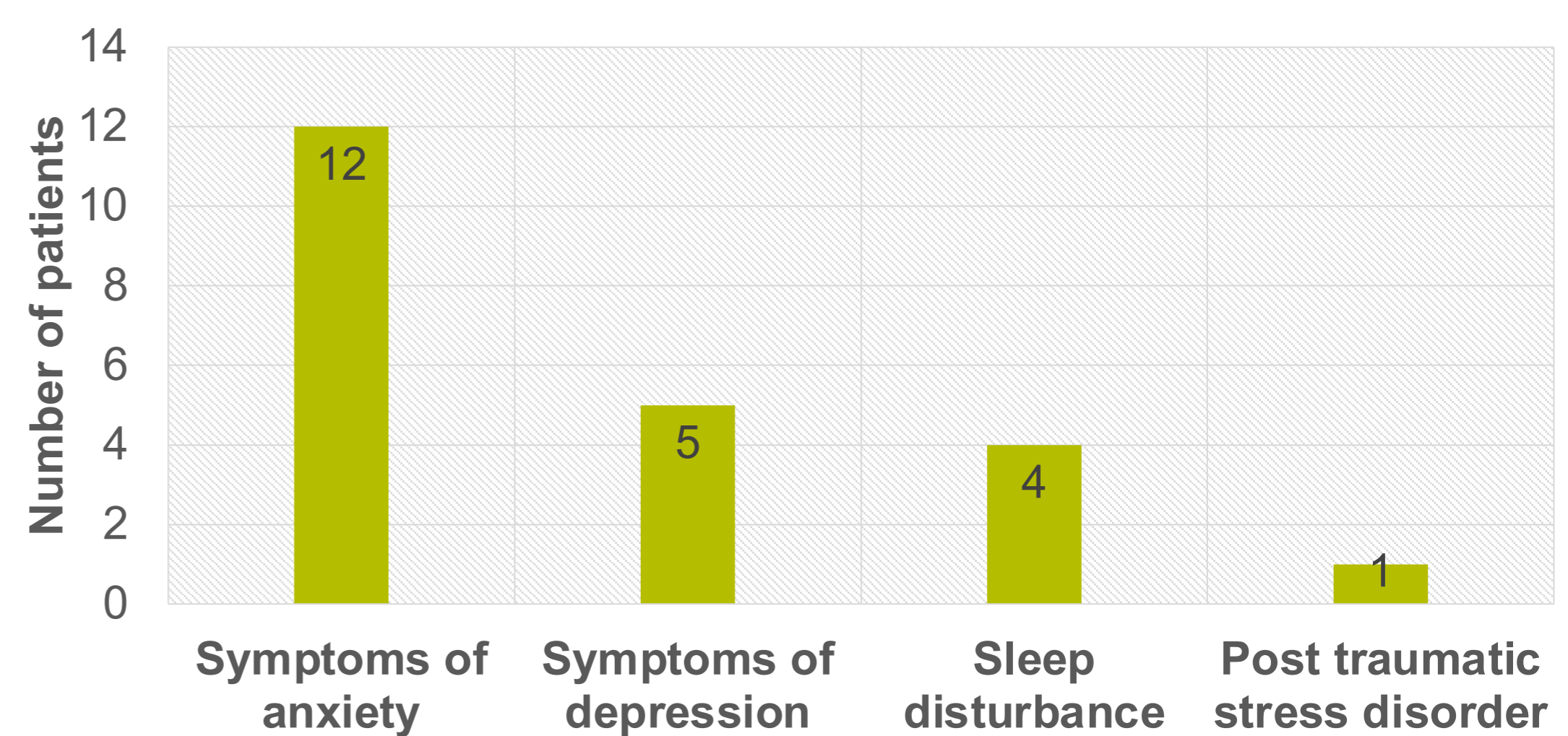
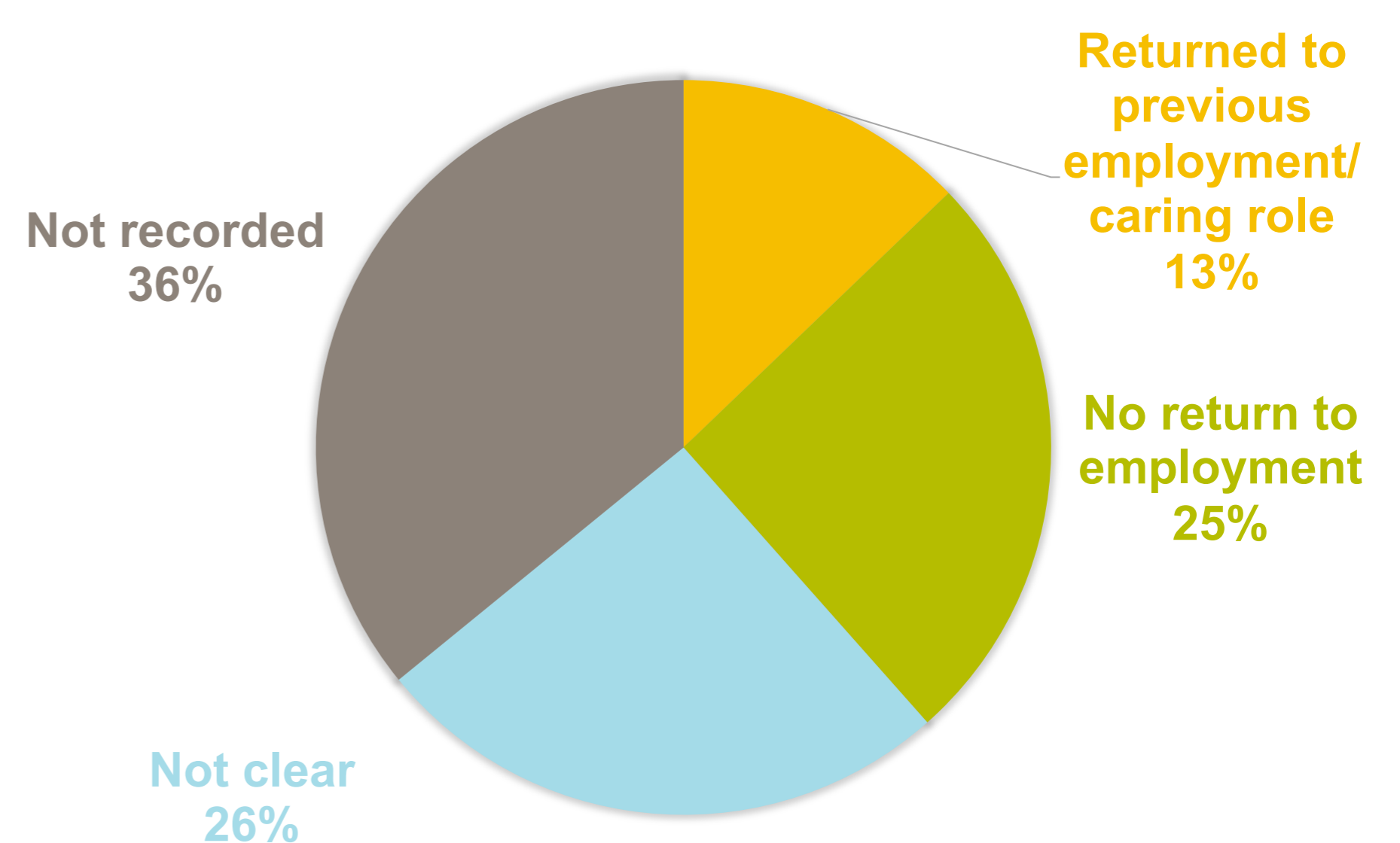


FIGURE 3. RETURN TO EMPLOYMENT'



Conclusions

Our data suggests a significant burden of psychological need amongst people who survive HLH and a significant impact on ability to resume previous work/caring roles. Further work is required to detail this need and provide appropriately resourced services.