

1 **Title:** Variations in provision of psychological care to hematopoietic cell transplant recipients:
2 results of a national survey of UK Transplant Centers

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4 **Running title:** Variations in psychological care: a national survey

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15 Hematopoietic cell transplantation (HCT) is both a life-saving and life-threatening treatment
16 for which the associated psychological morbidity is high and associated with poor outcomes¹⁻
17 ⁴. However, studies are limited on how effectively transplant centers address psychological
18 care⁵. The Foundation for the Accreditation of Cellular Therapy and The Joint Accreditation
19 Committee for IST and EBMT (FACT-JACIE) require dedicated psychological staff to assist
20 in pre-transplant recipient evaluation and treatment, and post-transplant care⁶. However,
21 guidelines are limited regarding the optimal structure of psychological services^{7,8}. This national
22 survey explored UK transplant center (TC) psychological care practices. Our objectives were
23 to review psychological workforce and services, psychological screening, quality review
24 processes, participant perceptions on psychological care and current services, factors that
25 would improve services, and impact of center size on workforce and service ratings. The survey

26 also reviews transplant clinician practice in line with a four-tier model of psychological care
27 provision proposed by the National Institute for Health and Care Excellence (NICE), an
28 organization that develops evidence-based guidelines for healthcare in England⁹.

29

30 This survey was designed in liaison with clinicians and clinical psychologists with experience
31 in HCT. It was electronically distributed to three participants at each UK adult TC (n=24) that
32 performs allogeneic and autologous HCT: physician, clinical nurse specialist (CNS) and
33 specialist psychological practitioner who reviews HCT patients. The survey comprised 10-32
34 questions varying in number for each professional role (for example, only psychological
35 practitioners answered questions on workforce and services), and seven common questions on
36 perceptions of psychological care. Questions were mostly closed with options for comments.
37 Three open questions explored barriers to psychological care provision and ways to improve
38 it. Definitions were provided to avoid ambiguity (*see supplementary for questionnaire*).

39

40 The survey was approved by the Clinical Trials Committee of the British Society for Blood
41 and Marrow Transplantation and Cellular Therapy (BSBMTCT) (*CTCS-1902*). Participants
42 were recruited using purposive sampling. Psychological practitioners and CNSs were
43 identified via professional networks of practitioners known to have established roles in HCT.
44 Physicians identified were HCT programme directors. Invitations were distributed online via
45 the BSBMTCT. Participants were asked to identify a more suitable candidate to complete the
46 survey if they were not able to complete it themselves. Three reminders were sent to non-
47 responders, 3-4 weeks apart. In three TCs where psychological practitioners were not
48 recruited, collateral information was obtained from HCT clinicians to determine where the
49 psychological practitioner was based, and work time dedicated to HCT or Hematology. In
50 one center, the lead psychologist was contacted to verify this information. The remaining two

51 centers had no designated psychologist to contact. These three centers were otherwise
52 excluded from any data analysis on service structure.

53

54 The survey was piloted amongst nurses, physicians and clinical psychologists with experience
55 in HCT. The full survey was open from 30th October 2019 to 28th February 2020.

56

57 Data was collected in Excel version 16.45 and analyzed using descriptive statistics (frequencies
58 and medians). A content analysis of open text comments was performed. The Mann-Whitney
59 U statistical 2 tailed test was performed to determine center size effect on workforce capacity.

60

61 The TC response rate was 100% (24/24). Of 70 participants approached, 89% (n=62)
62 responded: 20 physicians, 21 CNSs and 21 psychological practitioners.

63

64 Results show that although psychological services are available in most centers, the time
65 available to HCT patients is highly variable. 33% TCs (n=8) have a hematology based
66 psychologist, with >0.5 work-time-equivalent dedicated to hemato-oncology including HCT.
67 Half these centers (n=4) have an HCT based psychologist. The remaining 67% TCs access a
68 psychological practitioner based outside hematology, with no dedicated time to HCT. TCs with
69 psychological practitioners based within hematology showed a trend towards being larger
70 centers with higher annual numbers of total transplants performed, although when compared
71 to remaining centers, a statistically significant difference in transplant numbers could not be
72 shown ($p=0.05$) (*supplementary Fig.S1*). Types of services provided to patients and staff are
73 also variable (*fig.1*). Only 52% (n=11) services use quality indicators to assess their service
74 (*supplementary Fig.S2*).

75

76 Of 23 TCs, 52% screen patients to some degree pre-transplant; and 52% post-transplant
77 (*supplementary Fig.S3*). In comparison, 90% participants feel that screening is needed. 85%
78 participants feel that pre-HCT psychosocial assessment could significantly improve the quality
79 of life of HCT recipients.

80

81 Regarding clinician practices, 76% of nurses and 30% of physicians rated themselves as
82 confident or very confident in identifying patients with psychological distress and referring
83 them appropriately.

84

85 Overall, physicians and nurses gave higher service quality ratings in centers where the
86 psychological practitioner is based within hematology: physicians' median ratings of
87 allogeneic services based within and outside hematology were 8/10 (n=7) and 3/10 (n=13)
88 respectively, where "10" is considered adequate to meet patients' needs (*supplementary Table*
89 *S1*). Similarly, psychological practitioners rated the availability of their services to HCT
90 recipients. This showed a trend towards higher ratings where services are more dedicated,
91 particularly pre-HCT (*supplementary Table S2*). 87% of all participants feel that the
92 psychological practitioner needs to be embedded within the HCT team to improve quality of
93 life and psychological outcomes (*supplementary Fig.S4*).

94

95 Apart from funding, the main factors identified to improve psychological care include:
96 Resources eg. staffing (n=32), HCT specific/trained psychologists (n=15), integrated medical
97 and psychological care (n=13) and better screening/assessment of patients (n=12)
98 (*supplementary Table S3*).

99

100 This is the first national survey of HCT psychological services within the UK. To our

101 knowledge, international studies on HCT psychological services are scarce. This survey's
102 strengths include the high TC and participant response rates and the involvement of both
103 psychological and medical practitioners, making findings highly representative of adult HCT
104 psychological care within the UK. It highlights considerations in meeting international quality
105 standards in HCT. There are some limitations. Firstly, as there is no pre-existing tool to
106 evaluate HCT psychological services, the survey tool is not validated. However, the tool aligns
107 with existing standards of care in HCT, and guidelines on cancer services. It was piloted
108 amongst HCT clinicians to ensure clarity and accuracy. Another limitation is that we use
109 subjective clinician ratings to assess effectiveness of services. We believe this is the best
110 measure given that standard service quality indicators are not widely used. Furthermore, our
111 findings aren't generalizable to pediatric HCT or to healthcare systems outside the UK.
112 Nevertheless, this study highlights the need for closer integration of medical and psychological
113 services to ensure equitable access to adequate care. In the US, the existence of mental health
114 services within TCs is influenced by center size and insurer coverage¹⁰. Access to available
115 services was not explored but two studies show that access to pre-HCT psychological
116 assessment in the US is limited^{11,12}. Policies ensuring better integration of services may help
117 improve access.

118

119 In summary, the availability of psychological care to HCT recipients throughout the UK is
120 markedly varied, and many healthcare providers consider it insufficient to meet patients' needs.
121 The variation in participants' service ratings, favoring TCs with more dedicated care, reflects
122 inequity in quality of care or access to psychological support. Most healthcare providers concur
123 that dedicated psychological care in HCT is needed to improve outcomes. We recommend
124 clearer guidelines and quality standards on the components of psychological care provision in
125 HCT to enable equitable and effective psychological services. A similar study should be

126 performed in pediatric centers, and international centers, taking into consideration varying
127 factors impacting access to care. Future studies should explore patient and clinician
128 perspectives on effectiveness of services.

129 Data Availability

130 The data that support the findings of this study are available from the corresponding author,
131 RN, upon reasonable request.

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170 **Fig. 1 Structure of psychological support services for patients and staff**

171 *a) Indicates the service that provides specialist psychological care to HCT patients. HCT patients with a non-cancer diagnosis are only*
 172 *provided for by 29% of these services and may therefore be referred to other psychology services b) Illustrates the types of services available to*
 173 *staff. This includes non-HCT staff where the practitioner is based outside the HCT service. Other factors may impact accessibility of these services*
 174 *c) Shows the types of services available to patients. This includes non-HCT patients where the practitioner is based outside the HCT service. Other*
 175 *factors may impact accessibility of these services. *Other services: Relaxation groups run by Occupational Therapy; Rehabilitation Group with*
 176 *focus on recovery and moving beyond treatment; Acceptance and Commitment Therapy. †NICE levels of psychological support: level 2 - healthcare*
 177 *professionals with basic psychological skills training; level 3 - psychological practitioners accredited in a particular therapeutic modality; level 4 -*
 178 *psychological practitioners accredited in a broad range of therapeutic modalities*

179 *Abbreviations: MDT=Multi-disciplinary team; CNS=Clinical nurse specialist; CBT=Cognitive-behavioral therapy*

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182

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187

188 **Data Availability**

189 The data that supports the study findings are available from the corresponding author, RN,

190 upon reasonable request.

191

192 **Contributions**

193 RN was responsible for the conception and design of the study, literature review, data

194 collection, data analysis and interpretation, drafting the manuscript and revision of the

195 manuscript. CA was responsible for the conception, design and supervision of the study, and

196 critical revision of the manuscript. JL (J Low), RD and AM were responsible for supervision

197 of the study and critical revision of the manuscript. MR contributed to the design of the

198 survey tool, data collection, data analysis and critical revision of the manuscript. HL

199 contributed to the design of the survey tool, data collection and critical revision of the

200 manuscript. JL (J Lee) contributed to data collection and critical revision of the manuscript.

201 All authors reviewed and approved the final version of the manuscript.

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