TITLE

Provision of Long-Term Monitoring and Late Effects (LE) Services Following Adult Allogeneic Haematopoietic Stem Cell Transplant (HSCT): A Survey of UK NHS-Based Programmes.

RUNNING TITLE

Survey of UK Late Effects Service Provision

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CONFLICTS OF INTEREST

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ABSTRACT

Despite international guidelines, optimal delivery models of late effects (LE) services for HSCT patients are unclear from clinical, organisational and economic viewpoints. To scope current LE service delivery models within the UK-NHS, in 2014 we surveyed the 27 adult allogeneic HSCT centres using a 30 question online tool, achieving a 100% response rate.

Most LE services were led and delivered by senior physicians (>80% centres). Follow-up was usually provided in a dedicated allograft or LE clinic for the first year (>90% centres), but thereafter attrition meant only ~50% of patients were followed after 5 years. Most centres (69%) had an SOP for long-term monitoring but access to a LE Multi-Disciplinary Team was rare (19% centres). Access to medical specialities necessary for LE management was good, but specialist interest in long-term HSCT complications was uncommon. Some screening (endocrinopathy, cardiovascular) was near universal, but other areas were more limited (mammography, cervical smears). Funding of extra staff and investigations were the most commonly perceived barriers to implementation of LE services.

This survey shows variation in the long-term follow-up of allogeneic HSCT-survivors within the UK-NHS and further work is warranted to optimise effective, sustainable and affordable models of LE service delivery among this group.

INTRODUCTION

Since the first recorded allogeneic haematopoietic stem cell transplant (HSCT) using a donor other than an identical twin in 1968,[1] the worldwide annual number of patients undergoing this procedure has risen to more than 23,500.[2] Over the same period improvements in conditioning regimens[3] (e.g. reduced intensity conditioning [RIC]) and supportive care (e.g. management of infectious complications[4,5] and graft versus host disease [GVHD]),[6] as well as widening of indications to include non-malignant disorders (e.g. haemoglobinopathies)[7] and availability of alternative HSCT donor sources[8] have led to increasing numbers of long-term survivors (i.e. alive two years post-allogeneic HSCT).[9] However, with improved survival, even in the absence of disease relapse, normal life expectancy is not restored:[10] Survivors are susceptible to organ dysfunction[11,12] (aside from chronic GVHD) and subsequent malignancies[13] resulting in a significant morbidity burden[14] and premature mortality. In addition to physical sequelae, allogeneic HSCT survivors are at risk of psychological complications, including post-traumatic stress disorder,[15] which may have major impact on quality of life.[16]

The increased morbidity and non-relapse mortality exhibited by long-term allogeneic HSCT survivors led to recognition of the need for long-term follow-up and screening of this patient population to allow pre-emptive action to try and mitigate the increased risks. Accordingly, the Center for International Blood and Marrow Transplant Research (CIBMTR), European Group for Blood and Marrow Transplantation (EBMT) and American Society for Blood and Marrow Transplantation (ASBMT) produced consensus recommendations on the subject in 2006[17] (subsequently enshrined in JACIE [sixth edition] standard B7.6.8).[18] These were updated in 2011 with additional representation from the Asia-Pacific Blood and Marrow Transplantation Group (APBMT), Bone Marrow Transplant Society of Australia and New Zealand (BMTSANZ), East Mediterranean Blood and Marrow Transplantation Group (EMBMT) and Sociedade Brasileira de Transplante de Medula Ossea (SBTMO)to ensure their international applicability.[19] Owing to lack of prospective (randomised) controlled trials in this area these are based on retrospective studies, non-transplant data and expert consensus opinion, but nevertheless are considered to be the most comprehensive guidance available for management of this patient population.

However, there is little consensus on how the international guidelines are best applied and data is limited as to the extent of their implementation.[20,21] On behalf of the British Society of Blood and Marrow Transplantation (BSBMT), we therefore sought to establish how services for late post-transplant effects were delivered by UK adult allogeneic HSCT centres within the governmentally funded National Health Service (NHS). Although ultimately all NHS services are state funded, HSCT procedures are nationally commissioned while care from day 100 post-transplant is locally commissioned.[22]

MATERIALS & METHODS

Survey Development & Design

A 30 question web-based survey was developed following consultation with senior UK allogeneic HSCT physicians and nurses with an interest in LE services for allogeneic HSCT survivors and representatives of organisations concerned with allogeneic HSCT patient welfare (e.g. Anthony Nolan). Questions were designed around four themes; service organisation, access to other specialist services necessary for the management of LE, multi-disciplinary team (MDT) provision and patient engagement, service evaluation and improvement. Most questions required respondents to select one/several options from a range of possibilities although, where relevant, there was the ability to enter free text. The survey was piloted with members of the BSBMT-Clinical Trials Committee (CTC) prior to wider circulation.

For the purposes of this survey the National Cancer Institute definition of Late Effects was used: ‘A health problem that occurs months or years after a disease is diagnosed or after treatment has ended. Late effects may be caused by cancer or cancer treatment. They may include physical, mental, and social problems and second cancers'.[23] The definition was extended to patients with non-malignant diseases who had been treated with allogeneic transplantation, where LE may be caused by the disease or disease treatment. In several questions respondents were asked to provide the percentage of patients in whom a particular activity took place; this was intended to be a best estimate for surviving patients at that time point rather than an exact calculated figure.

Survey Administration

The survey was circulated via the BSBMT to programme directors of the 27 adult UK NHS allogeneic HSCT centres with an invitation for the most appropriate personnel to complete (medical or nursing). One generic reminder was sent to all centres after which individual approaches were made by the survey authors to non-responding centres. The survey was completed during 2014.

RESULTS

Centre Demographics

A 100%[a] response rate was achieved, with most surveys (85%) completed by allogeneic HSCT physicians (Table 1). All centres were engaged with the JACIE accreditation process; 82% were fully accredited (Table 1) having completed a median of two accreditation cycles. The lower age of allogeneic HSCT recipients ranged from 16-20 years (Table 1) with almost half of adult centres (46%) performing allogeneic HSCT in patients under 18 years of age (both the EBMT and UK legal definition of an adult).

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[a] Although all centres (27) submitted a response, some centres omitted to answer particular questions; results from these questions are reported as percentages of the responding centres with the number or responses used indicated by n=x.

LE Service Organisation

The LE service was most frequently organised and administered by medically qualified staff (88% centres) with the remainder being nurse led (Table 1). Most LE services were delivered in either a dedicated clinic (63%) or within the general allogeneic HSCT clinic (33%) with only one centre routinely reviewing patients in a general haematology clinic (Table 1). Figure 1a shows there was an attrition rate over time in the percentage of surviving post-allogeneic HSCT patients being followed up by the transplanting centre. Although 96% of centres followed up all patients from day 100 to 1 year, by 5 years post-allogeneic HSCT only 48% centres routinely reviewed all patients and 11% of centres were actively following up fewer than half their patients. In some centres part of this attrition was due to formal discharge of patients at 5 years post-allogeneic HSCT back to either their referring non-HSCT-performing haematology centre or primary care physician if they had received a RIC HSCT and were free of complications including GVHD. Other patients however were lost to follow up (e.g. moved away geographically from the transplanting centre).

A standard operating procedure (SOP) for long-term monitoring of LE (as indicated by JACIE [sixth edition] standard B7.6.8)[18] was available in 69% of responding allogeneic HSCT centres (n=26), with 39% of these centres having audited their adherence to the policy (Table 1). All SOPs included the physical assessment of patients but only 28% made any reference to psychological evaluation (Table 1). The use of a standard template to communicate treatment summaries and potential complications to other health care professionals (as recommended by the National Cancer Survivorship Initiative; example template available at http://www.ncsi.org.uk/wp-content/uploads/Treatment-Summary-Template1.doc) was undertaken in 41% of centres (Table 1).

Access to Specialist Services

Figure 1b illustrates the range of specialist services available to allogeneic HSCT centres (n=26) in the management of LE. All the medical specialities were accessible to >80% of responding centres.

Easiest access was reported to endocrinology, sexual health and respiratory services (96%, 93% and 93% centres respectively) while more limited, but still good, access was available for oral medicine and dentistry services (81% centres). Access to allied health specialities was more varied: Although most centres (89%) had access to a dietician, availability of physiotherapy, occupational therapy and psychology support was not universal with only 62%, 65% and 69% of centres being able to access these respectively.

In contrast to the overall good access to specialist services for allogeneic HSCT survivors, the number of centres reporting personnel in these specialities with an interest in the LE of allogeneic HSCT was low (Figure 1b). With the exception of key workers and clinical nurse specialists, the majority of whom had an interest in HSCT LE as might be expected (94% and 84% respectively), fewer than 50% of centres reported personnel with a specialist interest among any medical or allied health speciality. Greatest interest was seen in specialities likely to have the most contact with post-HSCT patients; endocrinology, dietetics, sexual health and respiratory medicine (46%, 39%, 39% and 35% respectively).

Respondents reported variable compliance with screening recommendations in the international guidelines:[19] Although routine rates of implementation of endocrine and cardiovascular screening were good (89% and 78% respectively), lower rates of cervical screening and mammography were reported (52% and 48% respectively) despite the existence of established National Breast[24] and Cervical Cancer[25] Screening Programmes within the UK for the general population (Table 1). Only 30% of centres found it easy to access these National Screening Programmes.

There was near universal implementation of revaccination post allogeneic HSCT (96% centres) although only 23% of centres undertook antibody testing in the majority of patients (>90%) to monitor vaccine efficacy (Table 1). Among the remainder of centres there was variation in post-vaccine antibody response monitoring; some never undertook such testing while others targeted it to patients with recurrent infections or those felt to have a particularly high infection risk (e.g. HLA mismatch, alternative stem cell donor source). Post-allogenic HSCT vaccination practice has been the subject of a separate more detailed BSBMT survey.[26]

MDT Provision

Only 19% of centres had access to a specific LE MDT (Table 1) and where available this was mostly (60% MDTs) limited to patients under 25 years (data not shown). Where LE MDTs were available membership varied: Although all included a senior haematologist and clinical nurse specialist there was less regular support from other speciality physicians (including paediatrics), psychologists and social workers.

Patient engagement, service evaluation and improvement

A patient support group whose target audience included long-term allogeneic HSCT survivors was available in 41% of centres (Table 1) variably led by nurses, social workers, psychologists or patients themselves. Where available most (73%) met at least every 3 months (data not shown). Given a central theme of JACIE standards relates to education, service evaluation and audit in order to bring about service improvement, centres were asked how often they engaged in such activities which included some aspect of LE monitoring or care. At least one formal educational event covering an aspect of LE management had been delivered by 67% of centres in the preceding three years, while a clinical audit or service evaluation had been performed by 59% of centres (n=26) over the same period. However, only 41% of centres had sought patient input regarding their satisfaction with LE and long-term follow-up arrangements over this time (Figure 1c).

During consultations with relevant stakeholders prior to development of this survey it became apparent there were a number of differences between the realities of the LE services provided by allogeneic HSCT centres and what they felt should be available. In order to ascertain the impediments to LE service delivery, centres rated potential barriers to implementation of an idealised service (suggested both by the survey authors and in the literature).[27] These are summarised in figure 1d, and the three highest rated obstacles all relate to finance/resource provision, with lack of funding for psychological support considered to be the greatest limitation.

DISCUSSION

To our knowledge, this is the first survey examining the practical provision of long-term follow-up and LE services for allogeneic HSCT patients across a national healthcare system. It provides a comprehensive view of how care is being delivered to this complex patient population. Despite national publically funded delivery of HSCT care, the survey demonstrates variability in almost every aspect of the service. Although some variation may reflect the historical, opportunistic way LE services have evolved in individual centres, other factors such as centre size, specialisation and geographical and referral base may be significant.

This survey highlighted some positives in that all centres had a LE service and most had a standard operating procedure outlining its processes. Additionally, most centres reported good local availability of a range of medical and some allied health specialities necessary for the management of LEs. Free text comments indicated many centres are engaged in active development of their LE service through the appointment of new personnel and by establishing separate clinics (in some cases combined with cGVHD management).

However, this survey also emphasised general weaknesses and limitations of LE services throughout the UK, including limited access to LE MDTs. Despite good provision of most other specialities necessary for the management of LE within tertiary NHS hospitals, most specialists delivering this care did not have a particular interest in post-allogeneic HSCT care. Although national screening programmes exist for both breast[24] and cervical cancer[25] detection, enrolling post-allogeneic HSCT patients in these outside of standard age-dictated times was problematic. Both these points highlight a need for better engagement and education of health care professionals outside of haematology.[21,28]

This survey also demonstrates a bias of LE services towards screening activities within the normal remit of transplant physicians and associated personnel: Assessment of endocrine and cardiovascular function was generally carried out well while in contrast, implementation of specialised services where transplant physicians have less control (e.g. mammography, cervical screening) was much poorer. In common with other post-HSCT populations,[29] there was limited access to specialist psychological services in this susceptible population.[15] Only 28% of LE SOPs had any reference to psychological function despite international guidelines and recommendations.[19]

The emphasis of many LE services on the management of medical symptoms may not always correlate with patient concerns: A recent audit of patient-reported symptoms in a nurse-led post-HSCT LE clinic indicated that the most prevalent problems were pain, sleep disturbance, fatigue and sexual function concerns,[30] none of which are easily attributable to a particular physiological system. The apparent misalignment of the LE service agenda[31] and patient concerns[32] is something that could be addressed by better engagement of patients through support groups and quality of life[33] or service satisfaction surveys.[34] Ultimately patient interests may be best served with a shift to predominantly nurse-led and delivered long-term follow-up LE services which is currently the exception rather than the norm. Perhaps as expected, all allogeneic HSCT centres identified lack of financial resources as the major constraint on the implementation of ideal services, particularly with regards to the delivery of psychological support.

As with any survey, it is necessary to exercise some caution with result interpretation as they inevitably reflect what a centre reports to be doing rather than what has been independently verified as taking place. Nevertheless, given the deficiencies in the LE service reported by almost all centres, it seems likely that the responses represent a consistent summary of service provision and operation. Although this survey documents variation in practice it does not provide information about how this affects patient outcome: In order to optimise long-term follow-up and LE service provision it is necessary to collect data on patient outcomes with the different models of care delivery.

In summary, this survey provides valuable feedback on the current delivery of LE service provision for post-allogeneic HSCT survivors within the UK, which is likely to be applicable to other healthcare systems internationally. It provides information of where international guidelines and recommendations[19] are being easily met and areas where services are deficient and require additional resource investment. Further research into which models of care provide the most clinically effective and cost-efficient means of service delivery is warranted.

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FIGURE LEGEND

Figure 1

A demonstrates the proportion of patients followed up by the transplanting centre at varying time points post-allogeneic HSCT.

B illustrates the percentage of allogeneic HSCT centres with access to specialist services involved in the long term follow up and LE care of patients who have undergone allogeneic HSCT. The percentage of centres with personnel delivering these specialist services with an interest in the complications of allogeneic HSCT are indicated by the blue bars.

C shows the percentage of allogeneic HSCT centres which have held educational events, clinical audit/service evaluation or patient questionnaire/satisfaction survey over the last 3 years and the number of such events undertaken.

D indicates the opinion of allogeneic HSCT centres as to the barriers to implementation of the 'ideal' late effects service. Respondents were asked to rate potential barriers on a numerical scale from 0-10 where 0 represents no barrier while 10 is a major barrier to implementation.