

Nursing measures to support the needs of haematological cancer survivors, post treatment:

A literature review

## **Abstract**

**Background:** Haematological cancers are the fifth most common cancer in the United Kingdom. Patients with haematological cancer are surviving longer due to prompt diagnosis and increasingly effective treatments, comprising of no-intensive treatment regimens, supportive care or palliative care for slow growing cancers. Where cancers are fast growing, intensive treatment is used, inclusive of high dose chemotherapy, radiotherapy, targeted therapies, and stem cell transplants. Support needs continue after treatment since survivors of intensive haematological cancer treatment experience a reduced life expectancy with greater morbidity, when compared to an age-adjusted population. They can also experience late effects of the primary disease or its treatment (physical/mental/social health problems or secondary cancers) months to years after diagnosis or treatment.

**Aims:** To review the support needs of patients after intensive treatment for haematological cancer, in order to establish nursing measures for supporting them.

**Methods:** Literature review and thematic analysis of 6 primary research papers. A search in CINAHL Complete, MEDLINE Complete and PSYCH Info databases yielded 313 results, that were refined to the final 6 papers used for the review through the application of inclusion and exclusion criteria, then systematic appraisal using Critical Skills Appraisal Programme (CASP) checklists. Research papers (n=6) scoring 9 or above against the relevant CASP tool were included in the review. Data were thematically analysed.

**Findings:** Three themes were identified: a sense of abandonment; education about late effects and becoming a survivor.

**Conclusion:** Understanding an individual's support needs after intensive treatment for haematological cancer enables nurses to offer sensitive individualised care to patients. A tailor-made survivorship plan, led by a specialist nurse, helps to meet the ongoing holistic needs of haematological cancer patients.

**Key phrases:**

Patients who survive intensive treatment for haematological cancer experience feelings of abandonment after treatment is complete.

Patients express unmet needs around becoming a survivor and around the provision of information/educational support.

The development of a tailor-made survivor/rehabilitation plan, as advocated in the NCSI plan, can support patients to meet their expressed needs as they transition to becoming a survivor.

A specialist nurse can be a consistent point of contact for patients, as well as a role model to develop best communications practice in junior nursing staff.

**Key words:** Support needs after treatment. Haematological cancer. Cancer survivor. Education. Abandonment.

## **Introduction**

Advances in cancer treatment have resulted in a growing population of those who are alive and in remission from their cancer (cancer survivors) following treatment (Bower and Waxman, 2015). The increase in survival rate relates to early diagnosis and improvements in the types of treatment that are available (Jefford et al., 2008).

Haematological malignancies are blood borne cancers beginning in the blood-forming tissues, that can range from slow developing and chronic, to fast growing and acute diseases. Haematological cancers account for an estimated 230,000 cases of cancer, making it the fifth most common form of cancer in the United Kingdom (UK), (Haematological Malignancy Research Network, 2014, cited by Bloodwise, 2014). Depending on the type of cancer and its growth rate, as well as the physical health of the patient at presentation, treatment options vary. Individuals with slow growing cancers are likely to be actively monitored, with non-intensive chemotherapy treatment initiated in the presence of changes (Bloodwise, 2016). Where disease is advanced at presentation and diagnosis, or in the case of disease progression, individuals may receive supportive or palliative care, in order to manage the physical symptoms and provide emotional support (Bloodwise, 2016).

The most common haematological cancers are fast growing leukaemias, lymphomas and multiple myelomas, all of which require intensive treatment regimens, inclusive of high dose chemotherapy, radiotherapy, targeted therapies, and stem cell transplants (Carey et al.,

2012). Autologous (using the patient's own stem cells) and allogeneic (using donor stem cells) haematopoietic stem cell transplantations (HSCTs) are curative procedures for patients with haematological diseases and immune deficiencies. In 2016, over 40,000 HSCTs were performed across 49 countries, with 40% of these being allogeneic and 60% autologous transplants (Passweg et al., 2018). 5 year survival is reported to be 50%, with the increasing success of stem cell transplantation linked to the increasing incidence of long term effects of treatment (Kenyon et al., 2018).

Survivors of intensive haematological cancer treatment can experience physical and psychological side-effects for many years after treatment. Overall, they experience a reduced life expectancy with greater morbidity, when compared to an age-adjusted population (Kenyon et al., 2018). Late effects are considered to be health problems (physical/mental/social problems or secondary cancers) occurring months/years after diagnosis or treatment, caused by the primary disease, or its treatment (see table 1).

Survivors with late effects report more unmet needs for care and have significantly greater use of health services compared with survivors without late effects.

Graft versus host disease

Infection

Fatigue

Respiratory disease

Cardiovascular disease

Psychological morbidity

Psychosocial difficulties including social reintegration and intimate relationships

Fertility concerns

Concerns regarding education and employment

Second malignancy

Table 1: Possible late effects of haematological cancer treatment (Kenyon et al, 2018).

Experiencing late effects renders the survivorship period difficult. This literature review seeks to analyse the experiences of those who have survived haematological cancer and its treatment, with respect to their support needs, in order to explore how nurses can meet their needs, after treatment has finished.

### **Methods and Search Strategy**

The search used keywords, precisely focused to the question (see table 2). Contextually synonymous keywords and Boolean logic were used to extend the breadth of available literature. Search results were returned in CINAHL Complete, MEDLINE Complete and PSYCH Info.

were 'Nurs\* or Support\* or Car\*' AND 'Cancer or Neoplasms or Haematology or Oncology or

Malignancy' AND 'Post Treatment or Dischar\*'

Table 2. Search terms.

There were 313 results returned after applying a date limiter of 2010. Papers were individually assessed for eligibility, using the inclusion and exclusion criteria in table 3. Ultimately, 6 original papers, clearly focused on the question, were systematically analysed and scored, using Critical Skills Appraisal Programme checklists, serving to strengthen the validity, reliability and transparency of the research process (Critical Skills Appraisal Programme, 2018). All of the final 6 papers (table 4) scored 9 or above, so were considered to be appropriate for inclusion in the literature review.

<p>Inclusion criteria:</p> <ul style="list-style-type: none"> <li>Research with adult patients</li> <li>Peer-reviewed primary research papers</li> <li>Papers written in the English language</li> <li>International papers where transferable/generalisable to UK practice</li> </ul>	<p>Exclusion criteria:</p> <ul style="list-style-type: none"> <li>Papers published before 2010</li> <li>Papers without a haematological cancer focus</li> <li>Papers focusing on end of life care</li> <li>Papers focused on caregivers</li> <li>Papers not focused on survivor needs or nursing input</li> <li>Papers focusing on a paediatric population</li> </ul>
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Table 3. Inclusion and exclusion criteria.

Author(s).	Date.	Sample characteristics	Design	Data Collection
Parry et al.	2010	51 adult survivors of leukaemia and lymphoma treatment (28 women and 23 men, aged 20-82 years)	Qualitative	<p>Individual interviews:</p> <p>Phase 1 – 22 patients recruited from a community-based cancer support organisation</p> <p>Phase 2 – 29 adult survivors of leukaemia and lymphoma, purposively sampled from a cancer registry database</p>
Molassiotis et al.	2011	193 patients with multiple myeloma and 93 of their partners	Quantitative	<p>Patients completed a Supportive Care Needs scale, the Hospital Anxiety and Depression Scale (HADS) and the EORTC QOL scale with its Myeloma module</p>

				Partners completed the partners version of the Supportive Care Needs scale and HADS
Gates at al.	2012	30 5 year+ survivors of Hodgkin's Lymphoma, with a referral to a late effects clinic; and 30 healthy controls matched for age and gender	Quantitative	Phase 1, quasi-experimental pilot study; based on the General Health Index and the Health Promoting Lifestyle Profile II.  Repeat questionnaires after interventions
Langbecker et al.	2015	136 nurses caring for patients with haematological cancer	Qualitative:  Thematic analysis	2 prospective cross-sectional surveys – open free text
Matheson et al.	2016	10 Hodgkin's Lymphoma survivors (4 men and 6 women, aged 21-39 years) across 3 cancer centres, recruited as part of a larger study of	Qualitative:  Grounded Theory	Semi-structured interviews: at 2 and 9 months post-treatment completion



		28 survivors		
Monterosso et al.	2017	17 survivors who had received lymphoma treatment between 6 and 30 months previously.	Qualitative: Thematic analysis	2 focus groups, exploring informational, psychological, emotional, social, practical and physical needs, following treatment

Table 4: study characteristics

Data from each paper was plotted, enabling a process of thematic analysis to occur, whereby the researcher became familiar with the data, searching for themes and writing up the results.

### **Findings**

Three discrete themes were revealed: a sense of abandonment, becoming a survivor and education about late effects.

#### **A sense of abandonment.**

A sense of abandonment, was prevalent throughout the research analysed. Participants in a qualitative study of 51 survivors of leukaemia and lymphoma reported feelings of abandonment in 45% (n=23) of cases, during the initial period of finishing treatment. The survivors felt abandoned by the medical system, likening their feelings to the 'trauma of a divorce', feeling lost and confused as to where to turn next (Parry et al., 2011).

Matheson et al. (2016) interviewed 10 survivors of Hodgkin's Lymphoma, using a grounded theory approach to explore patients' experiences during the first year after treatment. The participants felt as though a 'safety blanket' of having medical professionals to support them when needed along with routine tests, had been removed, resulting in increased feelings of vulnerability and fear of their cancer returning.

Monterosso et al. (2017) undertook focus group interviews with lymphoma survivors, to elicit their post-treatment experiences and preferences for follow-up. One male participant stated that whilst his medical needs had been met by the end of treatment, he did not feel understood holistically. Many participants felt a sense of loss around communication with healthcare professionals, but also with other patients receiving treatment at the same time. Losing the relationships formed during treatment, as well as the security of knowing that they were being looked after by an expert team, left many of them wondering what their sense of purpose was.

Loss of relationships was not a universal feature. Molassiotis et al's. (2011) quantitative survey of 132 survivors and 93 partners, highlighted that 48.5% (n=64) of survivors had a positive gain in their appreciation of relationships with close family and friends. Similarly, 43.2% (n=40) partners appreciated relationships more. Whilst these positive aspects lessened the sense of abandonment to a degree, commonly expressed concern around 'living with the possibility of relapse', reinforced the feeling of abandonment from the safety net of the medical system.

Whilst the sense of abandonment relates predominantly to relationships with health care professionals, it can also be a feature of dynamics between family and friends. Appreciation of close relationships with family and friends can reduce the sense of abandonment experienced.

### **Becoming a survivor.**

The theme 'becoming a survivor', reveals that many patients feel a sense of fear throughout this transition period. Matheson et al. (2016) found that male patients in particular, struggled with the initial phase of becoming a survivor, where they had to accept temporary dependence on support from others, conflicting the perceived role of a male. Although many struggled with this period, survivors who sought help from cancer organisations and/or used alternative therapies, such as meditation and spiritual support, found the transition period easier, due to regaining a small sense of control.

Of 51 leukaemia and lymphoma survivors interviewed, 60% (n=31) believed that a lack of targeted services for haematological cancer survivors hindered the transition, particularly regarding support for financial and social needs, resulting in feelings of isolation and depression (Parry et al., 2011). Many survivors wanted to move away from the 'cancer label', however moving from the structure of hospital treatment, to 'normal' life, was narrated as difficult (Monterosso et al., 2017). One participant highlighted that when the obvious side effects of chemotherapy had vanished, the support from their social circle quickly moved on.

Delayed onset of depression and anxiety was noted within the research reviewed.

Unexpected emotions in the initial months of becoming a survivor were apparent in 21% (n=11) of participants in Parry et al's. (2011) study. Molassiotis et al. (2011) used the Hospital Anxiety and Depression Scale (HADS) to assess the levels of anxiety and depression for survivors. They found that the survivors with unmet psychological support needs were living with the fear of relapse, thus had a significantly higher level of anxiety compared to those whose needs had been met. This experience reflected the stress of the transition period (to becoming a survivor) and learning to live with the side effects caused by haematological cancer treatments.

The theme of 'becoming a survivor' relates to the transition period between undergoing treatment and finishing treatment/being discharged. It features struggles around being dependent on others, especially for male patients, in the initial phase after completing

treatment. This can result in anxiety and depression for some patients. Accessing cancer support services and/or alternative therapies may support the transition to becoming a survivor by affording patients some control over their situation.

### **Education and late effects.**

'Education about late effects' featured in each of the 6 studies reviewed, with survivors stating that they would have benefited from better education about long term and late effects (such as pain and fatigue) caused by their treatments, prior to completion of treatment and discharge. Monterosso et al. (2017) revealed that patients were so focused on getting through their treatment, they had not given the time to process the effects of after treatment and beyond. The participants then described difficulty accessing information from healthcare professionals about late effects, once the acute phase was over.

Whilst survivors often did not know who to seek help from once their treatment had finished, they also found that the health care team sometimes appeared unprepared or unable to help with specific physical after effects or other survivorship issues (Parry et al., 2011). This was especially evident in the younger population of survivors (aged 20-39), felt that information from health professionals was lacking or vague, especially regarding their return to work, alcohol consumption and the use or need for contraception (Matheson et al., 2016). Whilst the information needs of a younger population may be different, the

frustrations of the participants reinforce the need to provide appropriate education about late effects of treatment.

Oncology nurses highlight the barriers that they face in being able to provide specialised information about survivorship care (Langbecker et al., 2016). A qualitative study which sought the views of 136 nurses providing care to haematological cancer patients revealed that they place higher priority on treating the active cancer than on survivorship, so that time and resources to allow detailed discussions about survivorship planning are limited. The data also revealed that many nurses felt inadequately educated to have discussions about survivorship planning. They felt they survivorship planning and information should be coordinated by a specialist nurse, in collaboration with physicians and allied health professionals, to overcome their fear of sharing misleading information (Langbecker et al., 2016).

Specialist nurses have been found to have a positive impact when educating haematological cancer survivors in a late effects clinic (Gates et al., 2012). The study evaluated the impact of a survivorship care intervention with patients, focusing on the development of a tailored made survivorship plan, led by an Advanced Practice Nurse (APN). The APN was a single point of contact for patients to share concerns and seek information about late effects. Areas covered included physical activity, healthy eating, smoking status, alcohol consumption, self-examination, sun protection, sexual health, fertility and mental health. The APN was valued as a consistent and expert source of information and support. Health

education interventions from the APN empowered patients in the study to make healthy lifestyle changes.

Patients in this literature review expressed a wish for more education about late effects of treatment (i.e. pain and fatigue), and survivorship planning (i.e. return to work, alcohol consumption and contraceptive advice). Both patients and nurses reinforced the strong focus on getting through the treatment and whilst information may available about late effects in the treatment phase, patient's thoughts focus on the present, not on their future as a survivor. Once treatment is complete and they are discharged, patients find it difficult to access information. Nurses acknowledged the need for focused education, however expressed a fear of sharing misleading information, so support a specialist nurse role for this purpose, working in collaboration with the multi-professional team supporting patients with cancer. Patients have expressed benefit of an APN supporting them, where this role exists.

### **Discussion and implications for practice**

This literature review highlights three clear challenges for haematological cancer survivors. A sense of abandonment, becoming a survivor, and education and late effects, all have the potential to impact on physical and psychosocial wellbeing. The impacts of the challenges are typically influenced by the degree to which patient's needs are met, therefore understanding the themes supports nurses to develop practice, in order to meet needs and thus facilitate a positive transition to survivorship.

The focus on unmet needs is strongest in the theme of education and late effects. Great emphasis is placed on the lack of access to reliable and person-centred advice, from the perspective of both survivors and oncology nurses alike. Long term and/or late to present side effects of the treatment for haematological cancer (i.e. fatigue, issues regarding fertility, pain and depression), can have detrimental effects on survivor's ability to live their lives (Bellizzi et al., 2012). Access to reliable, specialist support is considered key to managing these impacts. The reality is that patients are naturally highly focused on the active treatment and cure of cancer (Monterosso et al., 2017). This literature review revealed that oncology nurses also place higher priority on the active treatment of cancer, whilst discussing survivorship plans post discharge takes low priority.

Oncology nurses' perception of prioritising curing the cancer could stem from the historical biomedical approach to treat the cancer as a primary intention, not accounting for any holistic needs the survivor may have (Hewitt and Ganz, 2006). A biomedical approach can create barriers to effective holistic treatment taking place, with the patient often having a lack of control and opinion regarding the care that they receive (Naidoo and Wills, 2016). The Nursing and Midwifery Council (2018) set out nurses' responsibility to prioritise care effectively, to ensure the highest standard of care for their patients. Whilst the serious nature of a haematological malignancy focuses attention on the treatment plan to cure the disease, it is vital that nurses utilise their knowledge to support each individual in a holistic way, anticipating care needs for the future, such as survivorship planning. This is an imperative outlined in the National Cancer Survivorship Initiative plan (Department of Health et al., 2013), which focuses on taking action to improve survivorship outcomes,



reinforcing the use of information, advice and support, to facilitate self-management, health and well-being, choice and control. This links clearly to the themes, reinforcing the importance of effective communication to identify patient's support needs for the future as they transition to survivorship, and the importance of relevant, focused health education around late effects of treatment.

One reason why haematological cancer survivors' educational needs remain unmet may be the time constraints that operate within the health system and National Health Service. It is widely reported that nurses are placed under immense pressure in clinical environments due to inappropriate staffing levels, compromising the level of humanised and safe care that can be delivered, resulting in unmet patient needs (National Institute for Health and Care Excellence, 2014; Nursing and Midwifery Council, 2014). Nursing staff in this literature review reported having insufficient time to implement survivorship plans. They also expressed concern about being inadequately educated to provide and discuss the information that patients wanted to know.

Many survivors want information about personal and sensitive topics, such as fertility, employment and financial worries (Langbecker et al., 2016). As a society, British people find it difficult to discuss personal information, in the context of health-related subjects, sexual relationships, religion and death (Park et al., 2012). Many people hesitate to disclose their issues or thoughts, for fear of being embarrassed or placing burden on another individual (Curtice et al., 2016). Many survivors experience feelings of depression, anxiety and low

esteem following their treatment, due to changes in their body image and struggles with coping with the long-term side effects (Parry et al., 2011; Molassiotis et al., 2011). Alongside a lack of education in how to manage these conditions, social attitudes towards mental health act as a barrier for health professionals to provide help (Clement et al., 2015). Social stigmas associated with mental health treatment, combined with self-stigmas of accepting that help is needed, have a negative effect on the level of support that can be given, with many people who feel stigmatised reducing their social contact to avoid social prejudice (Bathje and Pryor, 2011). Nurses need to use their understanding of patients' needs to initiate discussions around sensitive areas. The 'Making Every Contact Count' (MECC) brief intervention framework serves to support the development of a therapeutic relationship between nurses and patients, enabling health promotion through goal setting, based on brief, meaningful conversations with patients (Nelson et al., 2013; Health Education England, 2018). In the context of haematological cancer survivors MECC can enable nurses to provide support and education for the transition to survivorship and for the late effects of treatment.

Kenyon et al (2018) propose that the increasing number of haematological cancer survivors presenting with unpredictable and complicated and late effects demands rigorous, regular, life-long assessment. A higher focus on long term surveillance would increase the opportunities for nurses to engage in health promotion around late/long-term effects and survivorship issues. Survivorship care brings together a wide range of health professionals, including physicians, nurses, psychologists, social workers and occupational therapists. Effective communication is essential to ensure that everybody knows what survivorship

plans are in place and what information has been discussed. The Cancer Rehabilitation Pathway (Macmillan Cancer Support, 2013) and associated service improvement tools for cancer rehabilitation (Macmillan Cancer Support, 2018) seek to enable a coordinated approach to recovery, rehabilitation and survivorship after cancer treatment.

Organising a survivorship service for patients who have undergone cancer treatment was found to be of great benefit (Gates et al., 2012). Patients valued the opportunity to have a tailor-made survivorship plan, providing an opportunity for personal needs to be discussed. A single point of contact within the multidisciplinary team, for survivors to reach out to, following discharge after the acute phase of treatment, ensures continuity of care and consistency of information. Nurses are ideally placed to adopt this role. In the UK, practice development is informed by the National Cancer Survivorship Initiative plan, focused on delivery of a recovery package (holistic needs assessment; treatment summary; cancer care review; health and wellbeing event) for all patients who have had cancer treatment (Hughes et al., 2014). The plan supports a drive for increased education for nurses around communication skills and the delivery of sensitive information, based on the patient's need. Confidence is a key factor in initiating sensitive discussions. A mentorship model could help with confidence by using experienced oncology nurses as role models, demonstrating effective communication skills for junior nurses, alongside role play scenarios enabling communications practice in a safe environment.

## **Conclusions**

Three themes have been revealed with respect to the experiences of survivors of haematological cancer, after treatment has been completed. These are sense of abandonment, becoming a survivor and education about late effects. The impact of the challenges posed to patients are largely influenced by the extent that their needs are met. Nurses can help to meet patients' needs by having an understanding of the late and long-term side effects of treatment for haematological cancer. The use of effective communication skills to develop a therapeutic relationship, through brief interventions such as MECC, can support nurses to understand each patient's needs. The development of tailor-made survivor/rehabilitation plan, as advocated in the NCSI plan, can support patients to meet their expressed needs as they transition to being a survivor. This may reduce the feelings of being abandoned and of not having sufficient educational support from health care professionals. A specialist nurse role is key, as a consistent contact for patients within the multi-professional team supporting haematological cancer survivors. The specialist nurse is also key in role modelling communication skills to junior nurses, in order that they can develop their own confidence in initiating sensitive discussions with patients, in order to best understand them and meet their needs. All of these actions will serve to enhance the patient experience.

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### **CPD questions**

- Reflect on a patient you have cared for with haematological cancer and consider the impact the treatment on their life
- Consider what communication skills can be used to support and empower patients who have survived haematological cancer and who may be at risk of late effects of their cancer treatment
- Consider how a tailor-made survivorship/rehabilitation plan can support haematological cancer patients as they transition to becoming a survivor
- Reflect on how you can use your understanding of the themes in this article (a sense of abandonment; education about late effects and becoming a survivor) to enhance the care of haematological cancer survivors