

Introduction

The aims of this module are to enable readers to explore the complexities of cancer survivorship and to facilitate greater understanding of related issues such as management of the consequences of treatment, supported self-management and the role of rehabilitation. Throughout the module, readers will develop an understanding of survivorship at a conceptual level, before applying this to cancer care. Application of the evidence base will be encouraged, in addition to a process of reflection on the reader's own practice.

This module should take approximately 3 – 4 hours to complete, comprising the learning activities and time for reading, thinking and reflection.

Learning objectives

The activities and content of this module are built around the following learning objectives:

- To gain an understanding of the need to develop new models of care for those people living with and beyond cancer, in the context of government policy and the current financial climate within healthcare using England as an exemplar.
- To understand the importance of rehabilitation in maximising quality of life for people living with and beyond cancer
- To gain increased awareness of the experience of surviving cancer
- To feel more confident in recognising survivorship issues in patients, and begin developing the skills to address them
- To gain experience of formulating survivorship care plans pertinent to your own area of work
- To develop an insight into the core principals of solution-focused care, chronic disease management and self-management and how these can be applied to people living with and beyond cancer.

Background

As the UK population ages, the incidence of cancer is increasing and with recent improvements in detection and treatment, people are living longer (Department of Health [DH], 2007). It is estimated that there are currently around 2 million people in the UK living with and beyond a cancer diagnosis, some of whom are newly diagnosed and others who are living with the consequences of the disease and its treatment (Devane, 2009). As people live longer with and beyond cancer, its management is becoming more akin to that of a chronic disease (Little, 2004). The role of the healthcare professional in cancer care needs to reflect this change, with a focus on rehabilitative techniques aimed at educating people to manage their symptoms, monitor for recurrence and learn to cope with the fear of the possibility of the disease returning (Forbes & While, 2009).

Recent government directives have stressed the importance of identifying and addressing the needs of people who are living longer with and beyond cancer (DH, 2007; DH, 2008; DH, 2010). The National Cancer Survivorship Initiative was born out of the recognition that current services do not meet the needs of this group of people. With these recommendations aimed at

modernising cancer-care, acknowledging the current economic climate, healthcare professionals are provided with an opportunity to develop new and more cost-effective models of care (Dow Meneses et al, 2007).

Many people treated for cancer report that support from healthcare professionals tends to tail off sharply as treatment ends (Armes et al, 2009). The challenge is for healthcare professionals to work effectively as a multi-professional team, utilising the skill-mix already available and to be able to recognise the needs of their patients as they enter this challenging phase of transition from cancer patient to cancer survivor (Aranda et al, 2005; Hewitt & Ganz, 2006). The National Cancer Survivorship Initiative (NCSI) vision document (DH, 2010) identifies a need to change the approach to care and support for people living with and beyond cancer, clarified in 5 recommendations:

- A cultural shift in the approach to care and support for people affected by cancer – to a greater focus on recovery, health and well-being after cancer treatment
- A shift towards assessment, information provision and personalised care planning
- A shift towards support for self-management
- A shift from a single model of clinical follow-up
- A shift to an emphasis on measuring experience and outcomes for people surviving cancer.

(DH, 2010, p.7).

Defining cancer survivorship

The experience of surviving cancer is complex but can be summarised as “a process beginning at diagnosis and involving uncertainty. It is a life-changing experience with a duality of positive and negative aspects, and is unique to the individual but has some universality” (Doyle 2008, p. 499). Over the years many definitions of cancer survivorship have been proffered from the numerical (for example, being alive 5 years after diagnosis) to the more experience-orientated which includes the experiences of family members (Feuerstein, 2007). However, the important consideration remains the individual’s perception of themselves, which may not always fit with the ideas of healthcare professionals (Victorson et al, 2006). The Cancer Reform Strategy (DH, 2007) used the inclusive definition of all those living with and beyond cancer to enable the NCSI (DH, 2010) to explore and address the needs of this increasingly diverse population. The Cancer Reform Strategy also acknowledges that those healthcare professionals charged with meeting these needs would also be equally diverse and in possession of varying skill sets. The process of living with and beyond a cancer diagnosis is unlikely to be linear and may involve more than one phase as an acute patient (Grinyer, 2009). Mullan (1985) in his seminal paper “Seasons of Survival” describes the evolving process of surviving cancer as beginning on diagnosis and involving acute, extended and permanent phases. The state in which survivors live has been portrayed as “liminality” from the Roman word *limen*; a place between two spaces (Little et al, 2000, p.502). Deimling et al (2005) suggest surviving cancer is a lifelong journey.

Activity 1 (allow 60 minutes)

Task 1: Explore the literature and the ways in which cancer survivorship is described or defined, both from the healthcare professional’s perspective and the patient’s perspective. Consider a way in which you would feel comfortable initiating a discussion on survivorship with one of your patients.

Allow 30 minutes

Task 2: Are the government directives on cancer survivorship being taken forward in your workplace? What steps could be taken to influence service delivery and practice?

Allow 30 minutes

Resources required to complete this activity

Useful websites

Macmillan Cancer Support
www.macmillan.org.uk

National Cancer Survivorship Initiative
www.ncsi.org.uk

Livestrong – Lance Armstrong Foundation
www.livestrong.org

healthtalkonline
www.healthtalkonline.org

Background reading

Aranda S, Schofield P, Weih L, Yates P, Milne D, Faulkner R & Voudouris N (2005) Mapping the Quality of Life and Unmet Needs of Urban Women with Metastatic Breast Cancer. *European Journal of Cancer Care*. 14: 211-222.

Armes J, Crowe M, Colbourne L, Morgan H, Murrells T, Oakley C, Palmer N, Ream E, Young A & Richardson A, (2009) Patients' Supportive Care Needs Beyond the End of Cancer treatment: A Prospective, Longitudinal Survey. *Journal of Clinical Oncology*. 27(36): 6172-6179.

Armstrong L (2001) *It's not About the Bike: My Journey Back to Life*. Yellow Jersey Press, London.

Deimling GT, Sterns S, Bowman KF & Kahana B. (2005) The Health of Older-Adult, Long-Term Cancer Survivors. *Cancer Nursing*. 28(6): 415-424.

Department of Health (2007) *Cancer Reform Strategy*. Her Majesty's Stationery Office. London.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081006 [Accessed 9th April 2010]

Department of Health (2008) *High Quality Care for All – NHS Next Stage Review Final Report*. Department of Health, London.

Department of Health/Macmillan Cancer Support (2010) *National Cancer Survivorship Initiative Vision*
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111230 [Accessed 9th April 2010]

Devane C (2009) The Entire Journey. *Cancer Survivorship*. *Nursing Times*. 105 1-16.

Dow Meneses K, McNeess P, Loerzal VW, Su X, Zhang Y & Hassey LA (2007) Transition from Treatment to Survivorship: Effects of a Psychoeducational Intervention on Quality of Life in Breast Cancer survivors. *Oncology Nursing Forum*. 34(5): 1007-1016.

Doyle N (2008) Cancer Survivorship: Evolutionary Concept Analysis. *Journal of Advanced Nursing*. 62: 499-509. <http://www3.interscience.wiley.com/cgi-bin/fulltext/119403837/PDFSTART> [Accessed 9th April 2010]

Forbes A & While A (2009) The Nursing Contribution to Chronic Disease Management: A Discussion Paper. *International Journal of Nursing Studies*. 46: 120-131.

Feuerstein M (2007) Defining Cancer Survivorship. *Journal of Cancer Survivorship*. 1: 5-7.

Grinyer A (2009) Life after Cancer in Adolescence and Young Adulthood: The Experience of Survivorship. Routledge, Abingdon.

Hewitt M & Ganz P (2006) From Cancer Patient to Cancer Survivor: Lost in Transition. The National Academies Press, Washington.

Koocher GP, O'Malley JE (1981) The Damoclese Syndrome. Psychosocial Consequences of Surviving Childhood Cancer. McGraw-Hill, New York.

Little M, Sayers EJ, Paul K & Jordans CFC (2000) On Surviving Cancer. *Journal of the Royal Society of Medicine*. 93(10): 510-3.

Mullan F (1985) Seasons of Survival: Reflections of a Physician with Cancer. *The New England Journal of Medicine*. 313(25): 270-273.

Picardie R (1998) Before I Say Goodbye. Penguin, London.

Victorson D, Cella D, Wagner L, Kramer L & Smith ML (2007) Measuring Quality of Life in Cancer Survivors. Chapter 6 in Feuerstein M (2007) (ed.) *Handbook of Cancer Survivorship*. Springer, Bethesda.

Thinking Point:

- Using the cancer survivorship literature, consider the survivorship issues relevant to patients within your particular healthcare setting
- Consider patients' expectations of you, as a healthcare professional, in terms of their survivorship
- What role do you think you can play in the survivorship phase for your patients?

Rehabilitation and self-management

Rehabilitation in cancer care has been defined as a means to “improve quality of life, so that lives are as comfortable, productive and independent as possible” and has become recognised as an integral part of cancer treatment (Rankin & Gracey, 2008). This definition draws strong parallels with the DH’s definition of cancer survivorship – that is, in its focus on re-building the lives of people with cancer, and maximising quality of life. Much of the philosophies of cancer rehabilitation and that of cancer survivorship fit very well together.

Rehabilitation can be said to begin prior to a cancer diagnosis (Rankin & Gracey, 2008) for example with the educational process of information-giving. Rehabilitation continues throughout the entire cancer journey, with a shift in focus as patients enter different phases of the disease process and treatments (Dietz, 1981). Cancer rehabilitation must be delivered with an individualised approach, and it is fundamental that it is driven by a commitment to client-centred practice (National Institute of Clinical Effectiveness [NICE], 2004). Likewise, the client-centred approach is pivotal in meeting the particular challenges of cancer survivorship, and there is a call for the development of individualised, client-centred survivorship care planning as a means of establishing and effectively addressing the needs of survivors of cancer (DH, 2010).

Carlowe (2009) challenges healthcare professionals to move beyond thinking that they can address the needs of survivors merely by sign-posting them on to other services at the end of treatment, or by information-giving. Moreover, survivorship interventions should be focused on teaching patients an entire new set of living skills (Carlowe, 2009), centred on the concept of “supported self-management” (DH, 2010). Once again, these ideas concur strongly with core rehabilitation philosophies, aiming at working collaboratively with patients, educating them and encouraging them to take an active approach to their care (NICE, 2004; Sumsion, 2006). Positive outcomes in the management of chronic or long-term conditions are best achieved by putting the patient at the core of care, promoting empowerment, “patient choice, shared-decision-making and the psychosocial aspects of care delivery” (Forbes & While, 2009), p. 121). Expanding on the notion that chronic disease management should be patient-focused (rather than service-focused), Forbes and While suggest the following model of practice:

- Patient involvement (including self-care behaviours such as monitoring own symptoms and managing medication)
- Vertical integration of care, which acknowledges that different levels of disease require different levels of care
- Care system integration, to make more effective use of diverse healthcare services and providers.

(Forbes & While, 2009).

Central to the concept of self-management is the idea that wellness or recovery is at its heart (DH, 2010; Lorig & Holman, 2003) rather than a focus on the condition itself. This echoes government-produced guidance for healthcare professionals on the importance of their commitment to interventions that promote health and well-being (Prime Minister’s Commission on the Future of Nursing and Midwifery in England, 2010). Denmark-Wahnfried et al (2005) suggest using a patient’s transition to survivorship as an opportunity to promote healthy behaviours, not only in the patient themselves, but also within their social sphere of influence. The concept of health literacy, an individual’s understanding and interpretation of the information given to them, has been explored by Nutbeam (2008) and if capitalised upon, could be put to good use in this setting.

Lorig and Holman (2003) acknowledge that in order to encourage patients to make the shift in focus towards recovery, healthcare professionals may need to utilise techniques that facilitate behavioural change and/or emotional adaptation for this to occur. Just as our patients need to become more “up-skilled” in taking greater responsibility for their long-term care, we need a highly-skilled healthcare workforce in order to facilitate this (Prime Minister’s Commission on the Future of Nursing and Midwifery in England, 2010). Self-management has much in common with solution-focused models of care, which place an emphasis on the patient as the expert in their own care, with a focus on their strengths and how they can and do cope with illness (Bray 2007). In this way, solution-focused approaches are highly applicable to the management of chronic health problems (Bray, 2007).

Lorig and Holman (2003) go on to identify 5 elements that are key to the process of self-management in cancer survivorship. These comprise of:

- basic problem-solving skills
- decision-making
- the ability to find and utilise resources
- the forming of collaborative partnerships between patients and healthcare providers
- taking action.

(Lorig & Holman, 2003, p.2-3).

The National Cancer Survivorship Initiative makes an important assertion that patients require support from healthcare professionals in order to self-manage (DH, 2010) but empowering patients to be able to undertake this cannot be achieved through “paternalistic” methods of delivery (Carlowe, 2009). Carlowe (2009) recommends that support groups or educational courses should be facilitated by patients themselves, rather than health professionals - they are the experts on their condition, after all. “Consumer-led” services may be the best way in which to meet the needs of survivors, as such modes of practice can lend a perspective beyond that of the healthcare professional (Sumsion, 2006).

Supported self-management has a very important part to play in the development of more efficient and cost-effective follow-up procedures (DH, 2007). The Cancer Reform Strategy places a new emphasis on reducing reliance on routine follow-up; instead there should be a move to link patients into local support services and primary care (DH, 2007). In addition to considering cost-effectiveness, bringing people back to clinic again and again can serve as a powerful emotional reminder about the diagnosis (Grinyer, 2009).

In returning to Rankin and Gracey’s (2008) definition of rehabilitation, one of the key facets of cancer survivorship is to focus on assisting individuals back into “productive” living. With the knowledge that more and more people are surviving cancer, a growing proportion of these people will be of working age (Macmillan Cancer Support, 2008). It has been identified that cancer patients of working age rarely receive advice on returning to work (Macmillan Cancer Support, 2008). If healthcare professionals are to work in a truly “holistic” manner, enabling patients to return to work must become part of routine practice and care-planning.

The activity of work can be very important for many people, positively influencing self-esteem, sense of identity and in solidifying social roles (Cook & Lukersmith, 2010). It can even be seen as an important marker of recovery itself (Verbeek & Spelten, 2007), and for many, it can represent a positive strategy for coping with the stresses of living with cancer (DH, 2007). Healthcare professionals have been called upon to address work-related issues with survivors of cancer, as early as possible during the course of the illness (Macmillan Cancer Support,

2008). The key factors preventing integration back into the workforce have been identified as physiological (such as the effects of cancer-related fatigue), emotional (such as diminished confidence) and practical (for example, needing to take time off work for treatment) (DH, 2010). The government recognises the current need to develop more integrated services between the domains of healthcare, social care and employers to enable effective transition back to work (DH, 2010).

Activity 2: (allow 60 minutes)

Task 1: Consider the following case studies and identify the salient survivorship issues for both:

Matthew is a 40 year old man with a diagnosis of sarcoma of his right leg. Having previously undergone several excisions of his tumour, Matthew has undergone an above-knee amputation, one week ago. Other than his cancer diagnosis (from which he has no distant metastases), he is fit and well, and is engaging well in rehabilitation on the ward; he is already largely independent in all activities of daily living. Matthew lives alone and has one daughter (aged 12 years) living nearby. He is keen to return to his roles of father and building site labourer in the near future.

Enid is a 76 year old woman with a diagnosis of breast cancer, with widespread metastases to bones and lung. She has been told that her condition is palliative and is for no further active treatment. She has accepted her diagnosis and prognosis and considers herself to be fairly well at the current time. She lives with her husband, for whom she is main carer. She admits she is feeling low in mood and feels isolated at home.

Allow 30 minutes

Task 2: What services or specialists might you want to refer on to, to assist Matthew and Enid? What kind of follow-up would you recommend for them?

Allow 30 minutes

Thinking Point:

- How do you consider you could encourage your patients to self-manage? What would be the salient points for educating them to do this successfully?
- Whose expertise, within your own multi-professional team, would you draw on to assist in the survivorship care-planning of Matthew and Enid?
- What community agencies are you aware of in your local area that can support people living with and beyond cancer? (consider both cancer specific and non-cancer specific services)
- What might the barriers be in assisting your patients to get back into the workforce?

Resources required to complete this activity

Useful websites

The LIVESTRONG Care Plan
www.livestrongcareplan.org

Background reading

Armes J, Crowe M, Colbourne L, Morgan H, Murrells T, Oakley C, Palmer N, Ream E, Young A & Richardson A, (2009) Patients' Supportive Care Needs Beyond the End of Cancer treatment: A Prospective, Longitudinal Survey. *Journal of Clinical Oncology*. 27(36): 6172-6179.

Bloom JR, Kang SH, Petersen DM & Stewart SL (2007) Quality of Life in Long-Term Cancer Survivors. Chapter 4 in Feuerstein M (ed.) (2007) *Handbook of Cancer Survivorship*. Springer, Bethesda.

Bray D (2007) Brief Solution-Focused Practice: a tailor-Made Psychological Approach for Palliative Care. *European Journal of Palliative Care*. 14(4): 141-143.

Carlowe J (2009) Self-Management for Survivors. *Nursing Times*. 105(12): 8-9.

Cook C & Lukersmith S (2010) Work Rehabilitation. Chapter 27 in Curtin M, Molineux M, Supyk-Mellson J (2010) (eds.) *Occupational Therapy and Physical Dysfunction: Enabling Occupation*, (6th ed.). Churchill Livingstone, Edinburgh.

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http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111230 [Accessed 9th April 2010]

Department of Health/Macmillan Cancer Support (2009). Vocational Rehabilitation Strategy paper: A Proposed Model of Vocational Rehabilitation in Cancer. National Cancer Survivorship Work and Finance Workstream, London.

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http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081006 [Accessed 9th April 2010]

Denmark-Wahnfried W, Aziz NM, Rowland JH & Pinto BM (2005) Riding the Crest of the Teachable Moment: Promoting Long Term Health after a Diagnosis of Cancer. *Journal of Clinical Oncology*. 23: 5814-5830.

Dietz JH (1981) *Rehabilitation in Oncology*. John Wiley, New York.

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Forbes A & While A (2009) The Nursing Contribution to Chronic Disease Management: A Discussion Paper. *International Journal of Nursing Studies*. 46: 120-131.

Lorig KR & Holman HR (2003) Self-Management Education: History, Definition, Outcomes and Mechanisms. *Annals of Behavioural Medicine*. 26(1): 1-7.

National Institute for Clinical Effectiveness (2004) Improving Supportive and Palliative Care for Adults with Cancer. NICE, London.

Nutbeam D (2008) The Evolving Concept of Health Literacy. *Social Science and Medicine*. 67: 2072-2078.

Prime Minister's Commission on the Future of Nursing and Midwifery in England (2010) *Front-line Care: The Future of Nursing and Midwifery in England 2010*, London: Prime Minister's Commission on the Future of Nursing and Midwifery in England.

Rankin J & Gracey J (2008) Rehabilitation in Oncology and Palliative Care, in *Rehabilitation in Cancer Care*. Rankin J, Robb K, Murtagh N, Cooper J, Lewis S (eds.) (2008) Wiley-Blackwell, Chichester.

Sumsion T (2006) Overview of Client-Centred Practice. chapter 1 in Sumsion, T (ed.) (2006) *Client-Centred Practice in Occupational Therapy: A guide to Implementation*. (2nd edition) Churchill Livingstone, Philadelphia.

Macmillan Cancer Support (2008) *Returning to Work: Cancer and Vocational Rehabilitation*. Macmillan Cancer Support, London.

Verbeek J & Spelten E (2007) Work, Chapter 21 in Feuerstein M (ed.) (2007) *Handbook of Cancer Survivorship*. Springer, Bethesda.

Consequences of treatment

As people live longer with and beyond cancer, it is likely that the numbers of people presenting with the consequences of treatment will rise. Until fairly recently, much of the focus of addressing consequences of cancer treatment has been tailored towards the paediatric cancer population; it is now recognised that a much broader scope is necessary, as many of these effects can occur throughout the course of people's lives (Aziz, 2007). Management of these effects is still an emerging field of cancer practice, and remains an area of somewhat "uncharted territory" (Aziz, 2007, p.66).

Consequences of treatment can include a vast and diverse range of symptoms and effects, such as chronic pain, lymphoedema, cancer-related fatigue and depressive illness, (DH, 2007; Baines, 2009; Grinyer, 2009; DH/Macmillan Cancer Support, 2010). Some of these effects can last for years after treatment has finished (Grinyer, 2009). Some can onset fairly rapidly during or after treatment (for example, cancer-related fatigue), whilst others can develop years after the completion of treatment (such as lymphoedema) (Baines, 2009). Some consequences of treatment will require the input of generalist health professionals, and self-management interventions will be applicable (as per the NICE recommended model of rehabilitation, assessment and support, 2004), whilst others will require highly specialist interventions from

expert healthcare professionals (for example psycho-sexual difficulties) (NICE, 2004; White, 2008).

It has been said that healthcare professionals must address the “aftermath” of cancer treatment and take “responsibility...for its management [as] we proudly produce survivors of disease” (Little, 2004, p. 202).

Activity 3 (allow 1 hour)

Task 1: Identify a patient with whom you are currently working. What might the consequences of treatment be for him/her? How would you go about addressing these?

Allow 30 minutes

Task 2: How would you prepare a patient for the possible onset of future (and possibly long-term) consequences of their treatment? What might be the pitfalls of pre-preparing patients about future complications of treatment?

Allow 30 minutes

Thinking Point:

Consider Little’s (2004) assertion that healthcare professionals must take some responsibility for the adverse consequences of cancer treatment. Do you agree with his view?

Resources required to complete this activity

Background reading

Andrykowski MA, Lykins E, Floyd A (2008) Psychological Health in Cancer Survivors. *Seminars in Oncology Nursing*. 24(3): 193-201.

Aziz NM (2007) Late Effects of Cancer Treatments, in Ganz PA (ed) (2007) *Cancer Survivorship: Today and Tomorrow*. Springer, New York.

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Discussion Board

The discussion board is a forum in which you can exchange ideas with other participants. This activity relates to the work you will have completed in earlier tasks and provides an opportunity for you to explore the difference in perspectives between the participants.

Discussion Board

When will it take place

For a 3 month period from date of publication of this article.

Which discussion thread

Survivorship in cancer care

What is expected of you as a participant

This module has explored survivorship in cancer care. By sharing your experience and questions regarding this practice we can build on the current body of knowledge.

Summary of this module

Through participation in this module, you should have gained a clearer understanding of the complex concept of cancer survivorship and an overview of the relevant literature, including government directives. You will have had an opportunity to reflect on your own clinical practice and to apply some of the principles of cancer survivorship to case studies.

On completion of this module you will have had the opportunity to:

- Explore the concept of cancer survivorship and its place within the current healthcare agenda
- Explore the shared, core philosophies of cancer survivorship and rehabilitation
- Gain an insight into the experience of cancer survivorship and explore the myriad of consequences of cancer treatment
- Apply some of the theory of cancer survivorship to case studies, and some of your own, real-life cases

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