Queries for Author

Journal: BMJ Supportive & Palliative Care
Paper: bmjspcare-2015-001006
Title: Cancer and the family: assessment, communication and brief interventions—

The proof of your manuscript appears on the following page(s).

It is the responsibility of the corresponding author to check against the original manuscript and approve or amend these proofs.

Please read the proofs carefully, checking for accuracy, verifying the reference order and checking figures and tables. When reviewing your page proof please keep in mind that a professional copyeditor edited your manuscript to comply with the style requirements of the journal.

This is not an opportunity to alter, amend or revise your paper; it is intended to be for correction purposes only. The journal reserves the right to charge for excessive author alterations or for changes requested after the proofing stage has concluded.

During the preparation of your manuscript for publication, the questions listed below have arisen (the query number can also be found in the gutter close to the text it refers to). Please attend to these matters and return the answers to these questions when you return your corrections.

Please note, we will not be able to proceed with your article if these queries have not been addressed.

A second proof is not normally provided.

Note Reference	Note
N1	IMPORTANT: Corrections at this stage should be limited to those that are essential. Extensive corrections will delay the time to publication and may also have to be approved by the Editor. **Alterations cannot be made after the article has published online**.
N2	Author SURNAMES (family names) have been highlighted - please check that these are correct. Please check all names are spelt correctly, and that affiliations and correspondence details are accurate.
N3	Please check funding statement is accurate (and include grant numbers if applicable).
N4	Your article should display in PubMed within 1 week of Online First publication. If you have paid for Open Access, your article will be sent to PubMed Central upon issue publication.

Query Reference	Query
Q1	If your article is linked to a clinical trial please provide the trial registration number and the stage it relates to - Post-results, Pre-results or Results.
Q2	Please check and confirm the changes made in the article title.
Q3	Please provide the page range for reference [39].
Q4	Tables 1 and 2 have been changed to boxes 1 and 2 here and in text citation as they contain only list of questions. Please check and confirm the change.

Author query sheet

If you are happy with the proof as it stands, please email to confirm this. Minor changes that do not require a copy of the proof can be sent by email (please be as specific as possible).
Email: **production.spcare@bmj.com**

If you have any changes that cannot be described easily in an email, please mark them clearly on the proof using the annotation tools and email this by reply to the eProof email.

We will keep a copy of any correspondence from you related to the author proof for six months. After six months, correspondence will be deleted.

Please respond within 48 hours

Cancer and the family: assessment, communication and brief interventions—the development of an educational programme for healthcare professionals when a parent has cancer

Lucy Grant,[1] Amrit Sangha,[2] Sara Lister,[1] Theresa Wiseman[2]

[1]Department of Pastoral and Psychological Care, The Royal Marsden NHS Foundation Trust, London, UK
[2]Health Service Research, The Royal Marsden NHS Foundation Trust, London, UK

Correspondence to
Dr Lucy Grant, Pastoral and Psychological Care, The Royal Marsden NHS Foundation Trust, Fulham Road, London SW3 6JJ, UK; lucy.grant@rmh.nhs.uk

Received 8 September 2015
Revised 13 June 2016
Accepted 25 July 2016

To cite: Grant L, Sangha A, Lister S, *et al*. *BMJ Supportive & Palliative Care* Published Online First: [*please include* Day Month Year] doi:10.1136/bmjspcare-2015-001006

ABSTRACT

Objective This study developed and piloted an educational intervention to support healthcare professionals (HCPs) to provide supportive care for families when a parent has cancer.

Methods Programme development followed the Medical Research Council (MRC) framework, beginning with examination of theory and research, and consultation with experts. The programme content incorporated attachment theory, child development and family systems theory. It was piloted thrice with HCPs from a cancer centre. The evaluation involved a questionnaire, comprising open-ended questions, completed before and after the programme. Data from the questionnaire were analysed using framework analysis.

Results 31 HCPs from varying disciplines participated. The programme was evaluated positively by participants. Before the programme, participants had significant concerns about their professional competence, which included: managing their own emotions; a perceived sensitivity around raising child and family matters with patients and a lack of specialist experience, skills and knowledge. After completing the programme, participants reported greater understanding and knowledge, increased confidence to approach patients about family matters, greater skill to initiate conversations and explore family concerns and guiding parent–child communication according to the child's level of understanding, and an increased engagement and resilience for caring for parents with cancer.

Significance of the results Supporting HCPs to provide family-centred care is likely to reduce psychological difficulties in families where a parent has cancer. Further work is planned to disseminate the programme, evaluate the transfer of skills into practice, assess how HCPs manage the emotional demands of providing supportive care over time, and consider on-going professional support for HCPs.

INTRODUCTION

Families when a parent has cancer

In the UK, 10% of all new cancer cases occur in adults aged between 25 and 49 years.[1] Trends towards people having children later in life, combined with recent advancements in diagnostic and screening tools means the incidence of cancer in parents with young children will increase. Data on patients with dependent children do not exist in the UK, but ~4% of all children in Norway, aged 0–25 years, have or have had a parent diagnosed with cancer.[2] While in the USA, 18.3% of recently diagnosed cancer survivors and 14% of all survivors live with a minor child.[3] A Finnish cohort study followed up all children born in 1987; 3909 (6.6%) of the children had a parent with cancer.[4]

Families face many challenges associated with the nature of the illness and treatment.[5] Children contend with the disruption of family roles and routines, the temporary loss of the parent due to symptoms and treatment side effects and the threat of parental loss.[6] Family members are susceptible to distress and can experience clinical levels of stress, anxiety and depression,[7 8] which can lead to long-standing issues.[9] Poor family functioning and restricted communication are strongly associated with higher levels of psychological morbidity in families,[10] independent from disease characteristics.[11] Families that communicate illness-related information openly, express feelings directly and solve problems together show lower levels of depression and anxiety.[8]

Communication when a parent has cancer

Parents feel unsure about how to talk to children about cancer in a way the child will understand and identify a need for support in discussing these issues.[12 13] Children's understanding of illness follows developmental stages in line with the child's age, independent of other factors.[14 15] Communication around parental illness is commonly restrictive, parents believe children are too young to understand or focus on technical details;[13 16] however, it is possible if it is tailored to the child's level of understanding.[13 15 16]

Without guidance, parents may attempt to protect children by avoiding illness-related discussion or limit discussion to information giving rather than exploring the child's emotions about the parent's illness.[13] This is complicated by the way parents perceive the child's capacity to cope and the distress of disclosure on their children and on the patient themselves.[17] Studies show that parents misunderstand their child's reactions, are poor at recognising distress and underestimate the emotional difficulties experienced by their children,[18 16] highlighting a need for professional support.

The role of healthcare professionals

Patients report that healthcare professionals (HCPs) do not enquire about their children, and as a result, patients do not feel that they can raise the topic,[12 19] which leaves them feeling isolated with family-related challenges.[13 20]

Supporting patients' psychological needs can be a challenge for HCPs and, over time, some HCPs will experience emotional strain.[21] This is amplified when patients are younger and when there are more complex psychological and social concerns.[22] A way of coping with emotional strain is for HCPs to reduce investments by emotionally distancing themselves.[23]

An Australian study explored nurses' perceptions of the support given to patients with advanced cancer who had young children.[24] Providing support was viewed as important and central to their role, but the nurses had significant difficulties managing the emotional aspects. Caring for patients with young families brought up personal experiences of loss. Nurses also described a lack of education or psychological training, poor support and limited supervision, which compounded their feelings of uncertainty and distress.

Turner *et al*[25 26] developed and evaluated an educational programme for nurses working with parents with advanced cancer. The training was self-directed by participants using a distance learning manual but also included a 1-day communication skills training workshop. Nurses were highly accepting of the educational intervention and reported increased confidence in their ability to initiate discussion, provide support and information for patients.

Rationale for current study

In a recent cancer survivorship survey (UK Department of Health),[27] parents reported no practical or emotional support being offered by healthcare services in relation to the family and children. This lack of provision has previously been recognised in national cancer guidelines[28] and reviews[7 8 29] and provided the impetus to develop an education intervention to address this gap in services. It was hoped that by focusing on improving the quality of supportive care provided by HCPs, they can positively influence patient and family experience and potentially reduce psychological difficulties in children and families where a parent has cancer.

The aim of the pilot was twofold; first, to develop an educational programme suitable for a wide range of HCPs working across the illness trajectory to enhance the supportive care of patients and families when a parent has cancer; and second, to evaluate the implementation of the programme and begin to establish its efficacy.

METHODS

Development of the educational programme

Programme development followed the Medical Research Council framework[30] titled 'Cancer and the Family: Assessment, Communication and Brief Interventions'. Development of the 3-day educational programme involved examination of the theoretical and research evidence and consultation with experts in family therapy, child psychology and education.

The programme built on Turner's work[24–26] and drew on a range of seminal child development theories, including attachment theory,[31] Piaget's model of cognitive development[32] and developmental literature on children's conceptions of health, illness and bodily functions.[14 15] Theoretical concepts from family systems theory were included, with consideration given to how illness can disrupt the family life cycle and delay important individual and family developmental stages;[5 33] the influence of intergenerational patterns and behaviours on family functioning and relationships[34 35] and the strengths and qualities associated with resilient families.[36 37]

Learning methods

The delivery of the programme incorporated effective HCP communication skills training and learning methods.[38] Cognitive and experiential learning was promoted through case discussion, problem-solving exercises, role play based on clinical examples, and the use of digital versatile discs (DVDs) of real parents and children describing their experience of parental cancer.[39] To deepen learning, participants were encouraged to explore personal and professional experiences, their attitudes and beliefs about communication and providing supportive care to families.[40] Reflective practice was encouraged and modelled by facilitators to enhance participant's self-awareness and strategies for self-care.[41]

Pilot implementation

A total of three programmes were run with 31 participants. The range of senior HCPs included medics, clinical nurse specialists from various tumour groups, occupational therapists, ward-based nurses including sisters/senior staff nurses, radiographers, and clinical and health psychologists. The majority of participants were from a nursing background.

In total, 30 out of 31 participants were from a tertiary specialist cancer treatment centre with 1 external candidate.

The programmes took place away from the workplace to enhance participant engagement. Participant numbers were kept low with a maximum of 10 per group to ensure participants had sufficient opportunity to practice skills and to encourage experiential learning and group cohesion. Respondents had to have an active role in dealing with patients with dependent children to take part in the course.

The 3 programme days spanned 3 weeks to give participants time to read, reflect on the course material and practice clinical skills and bring back issues for discussion. The programmes were facilitated by a senior clinical psychologist with significant experience of working therapeutically with children and families and teaching professionals and a senior nurse educator.

Evaluation

The pilot was evaluated using semistructured questionnaires, consisting of open-ended questions, completed immediately before and after the programme. Free-text data were analysed using framework analysis.[42] Prior to the programme, the focus was on ascertaining participant's views and concerns about providing support to patients with young families (box 1). Following completion of the programme, the focus was on the participant's experience of the programme and their perceived impact of the course on their ability to provide supportive care when a parent has cancer (box 2).

Two researchers (LG and TW) independently conducted preliminary analysis on the data from the first pilot programme, to develop the framework. Following identification of potential themes, the researchers discussed and compared the themes and LG revised the framework. Emerging themes were used to form the following two axes of the framework: (1) professionals' concerns about providing supportive care when a parent has cancer (2) participants' experience and perceived impact of the programme on their practice. The framework was piloted for suitability and the final framework was used to analyse all data.

Box 1 Precourse open questions

1. Why would you like to attend the course and what do you hope to gain?
2. Do you have any concerns or anxieties about working with patients with dependent children on the topic of family support?
3. In brief, can you describe the work you currently do with patients and their families?

Box 2 Postcourse open questions

1. The things I have learnt from this course are;
2. This learning will influence my practice in the following ways;
3. I am feeling;
4. My concerns are;
5. The course could have been improved if: (was anything missing?);
6. I would recommend this course to the following colleagues.

Ethics

From 1 September 2011, changes to the Governance Arrangements for Research Ethics Committees (GAFREC) in the UK mean that it is no longer necessary to submit to the National Research Ethics Service for review of studies where the requirement is based solely on the use of National Health Services (NHS) staff as participants or the use of NHS premises. Consent was implied by returning completed questionnaires.

RESULTS

Professionals' concerns about providing supportive care when a parent has cancer

Data referring to participants' concerns were inserted into '*professional concerns about providing supportive care when a parent has cancer*' framework. The overarching concern reported was professional competence to provide support. Three subthemes emerged: managing difficult emotions; challenges associated with raising child and family matters; and a lack of experience, skill and knowledge to competently support parents with cancer.

Managing difficult emotions

Participants described concerns about their emotional capacity to deal with patients with young families and whether they could remain professional due to the emotional nature of the issues and identified a need for support in dealing with this.

> I worry about feeling out of my depth.
>
> I am worried about being able to stay professional because it is a very emotional area.
>
> I feel there is a potential to over empathise with this patient group.
>
> I find this issue generally challenging and benefit from support from my MDT colleagues.

Raising child and family matters

Participants worried about how to intervene on matters relating to family relationships, how to raise the topic of patients' children and family communication. They described a heightened sensitivity and were concerned not to upset or offend patients. They were aware that their care needed to be specialised and based on being able to competently form relationships with patients that would allow them to raise these issues.

> It's a sensitive issue to discuss with parents.
>
> I am aware that this is a difficult situation for families and for those involved and so I worry about saying the wrong thing.
>
> I am concerned about broaching the subject with a family who do not communicate openly.
>
> How can I develop a rapport with families so that matters of support can be discussed?

Experience, skill and knowledge

Participants described concerns about whether they had the personal and professional experience, as well as skills and knowledge to offer supportive care to younger patients and their children.

> Dealing with new patient cohorts who are generally younger and thereby have young families is quite challenging, as the psychosocial needs are very different to older population groups.
>
> I wonder whether or not having children of my own influence patients' view on my ability to help.
>
> I am uncertain about the level (amount) of information to give to children.

Participants' experience and perceived impact of the programme on their practice

Data referring to the evaluation of the programme were inserted into the framework; '*participants' experience and perceived impact of the programme on their practice*'. The five main themes were as follows: (1) greater understanding and knowledge, (2) increased confidence and skill, (3) increased engagement and emotional resilience towards providing family-centred care, (4) experience of the programme and (5) challenges transferring skills into practice.

Greater understanding and knowledge

Participants gained a more comprehensive and theoretical understanding of how parental illness impacts on children and families. They reported being more knowledgeable about how children process information, cope and emotionally respond to a parent with cancer according to the child's age and developmental stage. They were more aware of how open communication is beneficial within families and how restricted communication exacerbates distress experienced by family members and limits family coping.

> Understanding about how children of different ages and stages cope with a parent's illness.
>
> Picking up failed communication or where families lack communication and understanding how this can lead to further distress and compound issues and affect effective coping.
>
> A deeper understanding of the complex factors involved in working with parents and families.

Increased confidence and skill

Participants described more confidence to approach patients about family matters, they felt more skilful in their ability to initiate conversations and explore patients' family-related concerns.

Participants reported developing their ability to assess how families and children were coping and to identify signs when a child or family may be struggling. They felt they had greater confidence to guide parent–child communication about parental illness and treatment, tailored to the specific age of children and needs of the family. They also felt they could recommend resources, and know how and when to refer families for further support.

> Working with families in recognising their own individual needs and what they want in greater depth.
>
> More knowledgeable about how to assess and communicate with families.
>
> To listen carefully, advise less but facilitate discussion, explore emotions and feelings.
>
> I know how to communicate and tailor conversations to children's age and understanding of illness.
>
> How to support patient to break news to their children in a protected safe way.
>
> More confident giving advice, suggesting resources or services and in general talking to patients.

Increased engagement and emotional resilience

Participants described an enthusiasm to provide family-centred care when a parent has cancer. Some described becoming advocates for family-centred care within their teams. They reported feeling less anxious, experiencing fewer concerns and greater pragmatism around finding solutions and facing challenges.

They reported being more accepting and better able to manage their emotions when they were faced with parents and families who declined support or made decisions about communication that were different to their personal value systems. They were much more aware of the significance between their capacity to care and their emotional well-being and the need for their own self-care.

> Very privileged to work in this area and to support families who are going through one of the most significant life events they will find themselves having.
>
> I feel more knowledgeable and empowered to help others.
>
> I can teach others what I have learnt.
>
> I will feel more able to deal with emotional and challenging conversations.
>
> An acceptance and greater appreciation that not all families want support even when you feel they need it.
>
> How to look after myself better in order to effectively help patients

Experience of the programme

Participants valued the opportunity to reflect and share experiences in a multiprofessional group; the support system that was created within the group helped participants to normalise the challenges and difficult emotions associated with this area of care.

Participants valued the varied learning methods used, in particular DVDs of patients, children talking about their experiences of parents with cancer and role plays.

> Sharing experiences was extremely beneficial and allowed me to get most out of course.
>
> Simply fantastic! Enjoyed the course, even the role plays and group participation.
>
> Understanding in more detail the impact of illness on the family through the use of video, role play, discussion has helped to make it more meaningful.
>
> Great the course was multi-professional.

Challenges transferring skills into practice

While participants felt confident to engage in conversations with patients regarding their children, they described concerns about transferring their new knowledge and skills into practice and identified a need for support beyond the 3-day programme. They described concerns about forgetting skills and not implementing the new skills correctly.

Participants had concerns about losing the forum of the group and wanted more time for discussion. They valued the opportunity to reflect and anticipated challenges incorporating reflective practice into their role.

> Using knowledge appropriately into practice
>
> That I will lose momentum and not use what I've learnt.
>
> I would have liked that we had more time to learn from group members.
>
> I may not have enough time to have as many reflective moments as I might need.

DISCUSSION

Evaluation of this pilot supports previous research[21 23] and confirms that HCPs experience significant concerns over providing supportive care when a parent has cancer. They worry about providing competent specialised care and describe a significant level of anxiety professionally and personally. Participants described a lack of previous education, skill, knowledge and experience. This all highlights the need for tailored professional training and support, as HCPs may cope by disengaging from this aspect of patient's care and compound the lack of support experienced by patients.[11 12 19 26]

Following the programme, participants' reported an increased engagement to support families where a parent has cancer. They were more confident in their ability to initiate conversations, assess coping, judge how far to explore issues and intervene appropriately, especially in terms of facilitating parent–child communication. These outcomes may help to address the reported gap that HCPs were not initiating conversations about patient's children.[11 18] Participants particularly valued having a better understanding of how children tend to cope in response to parental illness according to developmental stage. This is important as parents struggle to explore children's emotional concerns and communicate in a way that is age appropriate.[12–15]

Participants described a deeper level of understanding and awareness of the individual needs of families when a parent has cancer and the protective role of communication within families.[7 9] They gained a more complex psychological understanding of patient and family members' experiences, behaviours, beliefs and emotional responses through the consideration of past events, contextual factors and systemic principles around family functioning and roles. It is hoped that this outcome may help HCPs to sustain and rationalise the need for family-centred care when a parent has cancer and maintain engagement, which may improve the quality of care and potentially reduce psychological difficulties in patients and children.

Experiential learning was identified as helpful, in particular participation within a multidisciplinary group, which gave an opportunity to share experiences and provide mutual support and encouraged reflective practice. Participants reported that this increased awareness of their own emotional needs and the relationship this has to their capacity to care for others. This insight may help HCPs to manage the emotional aspects of providing supportive care to parents with cancer, encouraging them to be more proactive in addressing their need for support.[21–23]

Although the findings of this pilot study are based on a self-selected sample, the content of the programme and the learning methods employed appears to have achieved positive learning outcomes and support Turner's research on addressing the training needs of HCPs, when supporting parents with cancer.[23 25]

Participants identified a need for support beyond the programme and described concerns about losing the reflective forum of the group and forgetting new skills and knowledge.

Further work is being carried out to disseminate the programme to other sites, evaluate the transfer of knowledge and skills into practice and assess how professionals continue to manage the emotional demands of providing family-centred support with the addition of supervision.

The programme is applicable to other areas of care where a family-centred approach is needed; for example, families caring for teenagers and young adults with cancer or other life-limiting illnesses such as HIV, multiple sclerosis (MS) and cystic fibrosis and may be adaptable pending further evaluation to other professional contexts, for instance, general practitioners and community HCPs.

CONCLUSION

The aim of the programme was to address the gap in education and support for HCPs. It is hoped that by focusing on improving the quality of supportive care that HCPs provide, they can positively influence patient and family experience. Providing support to families that encourages open communication, assesses family coping and considers children's needs may potentially reduce psychological difficulties in children and families where a parent has cancer. Findings from the pilot support previous research that an educational approach is acceptable and enhances HCPs' perception and confidence to provide supportive care.

Twitter Follow Theresa Wiseman at @gtwiseman

Acknowledgements The authors wish to thank the experts who were consulted on the development of the programme and the members of staff who participated. Research infrastructure was supported by the NIHR RM/ICR Biomedical Research Centre.

Contributors LG led the project, developed and delivered the programme, conducted analysis, devised the framework with TW, wrote the report and took overall responsibility for the manuscript. AS assisted with the report and drafting of the manuscript. SL supported the delivery of the programme and reviewed the manuscript. TW supervised the project and analysis, devised the framework and contributed to the analysis and drafting of the manuscript.

Funding Research was supported by The Royal Marsden Cancer Charity who were not involved in any part of the work.

Competing interests None declared.

Provenance and peer review Not commissioned; externally peer reviewed.

REFERENCES

1. Cancer Research UK. Cancer incidence by Age. 2014. http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/age#heading-Five (accessed Jun 2015).
2. Syse A, Aas GB, Loge JH. Children and young adults with parents with cancer: a population-based study. *Clin Epidemiol* 2012;1:41–52.
3. Weaver KE, Rowland JH, Alfano CM, *et al*. Parental cancer and the family: a population-based estimate of the number of US cancer survivors residing with their minor children. *Cancer* 2010;18:4395–401.
4. Niemela M, Paananen R, Hakko H, *et al*. The prevalence of children affected by parental cancer and their use of specialized psychiatric services: the 1987 Finnish Birth Cohort study. *Int J Cancer* 2012;9:2117–25.
5. Rolland J. *Families, illness, and disability. An integrative treatment model*. New York: Basic Books, 1994.
6. Welch AS, Wadsworth ME, Compas BE. Adjustment of children and adolescents to parental cancer. Parents' and children's perspectives. Parents' and children's perspectives. *Cancer* 1996;7:1409–18.
7. Osborn T. The psychosocial impact of parental cancer on children and adolescents: a systematic review. *Psychooncology* 2007;2:101–26.
8. Edwards B, Clarke V. The psychological impact of a cancer diagnosis on families: the influence of family functioning and patients' illness characteristics on depression and anxiety. *Psychooncology* 2004;13:562–76.
9. Wong M, Cavanaugh C, MacLeamy J, *et al*. Post traumatic growth and adverse long-term effects of parental cancer in children. *Fam Syst Health* 2009;1:2821–35.
10. Thastum M, Watson M, Kienbacher C, *et al*. Prevalence and predictors of emotional and behavioural functioning of children where a parent has cancer: a multi-national study. *Cancer* 2009;17:4030–9.
11. Kuhne F, Krattenmacher T, Bergelt C, *et al*. Parental palliative care: psychosocial adjustment and health related quality of life in adolescents participating in a German family counselling service. *BMC Palliative Care* 2012;11:21. doi:10.1186/1472-684X-11-21 [published Online First: 30 Oct 2012].
12. Barnes J, Kroll L, Burke O, *et al*. Qualitative interview study of communication between parents and children about maternal breast cancer. *BMJ* 2000;321:479–82.
13. Turner J, McGrath P. Children of mothers with advanced breast cancer: a review of needs and services. *Cancer Forum* 2004;3:191–5.
14. Koopman HM, Baars RM, Chaplin J, *et al*. Illness through the eyes of the child: the development of children understands of the causes of illness. *Patient Educ Couns* 2004;3:363–70.
15. Eiser C. Changes in understanding of illness as the child grows. *Arch Dis Child* 1985;5:489–92.
16. Forrest G, Plumb C, Ziebland S, *et al*. Breast cancer in the family—children's perceptions of their mother's cancer and its initial treatment: qualitative study. *BMJ* 2006;332:998–1003.
17. Semple CJ, McCance T. Parents' experience of cancer who have young children: a literature review. *Cancer Nurs* 2010;2:110–18.

18 Watson M, St James-Roberts I, Ashley S, *et al*. Factors associated with emotional and behavioural problems among school age children of breast cancer patients. *Br J Cancer* 2006;1:43–50.

19 Turner J, Clavarino A, Yates P, *et al*. Development of a resource for parents with advanced cancer: what do parents want? *Palliat Support Care* 2007;2:135–45.

20 Schmitt F, Manninen H, Santalahti P, *et al*. Children of parents with cancer: a collaborative project between a child psychiatry clinic and an adult oncology clinic. *Clin Child Psychol Psychiatry* 2007;3:421–36.

21 Leiter M, Maslach C. The impact of interpersonal environment on burnout and organizational commitment. *J Organ Behav* 1988;4:297–308.

22 Ramirez A, Addington-Hall J, Richards M. ABC of palliative care: the carers. *BMJ* 1998;316:208–77.

23 Maslach C, Jackson SE, Leiter MP, *et al*. *Maslach burnout inventory manual*. 3rd edn. Palo Alto, California: CPP, 1996.

24 Turner J, Clavarino A, Yates P, *et al*. Oncology nurses, perceptions of their supportive care for patients with advanced breast cancer: challenges and needs. *Psychooncology* 2007;2:149–57.

25 Turner J, Clavarino A, Yates P, *et al*. Enhancing the supportive care of parents with advanced cancer: development of a self-directed educational manual. *Eur J Cancer* 2008;12:1625–31.

26 Turner J, Clavarino A, Butow P, *et al*. Enhancing the capacity of oncology nurses to provide supportive care for parents with advanced cancer: evaluation of an educational intervention. *Eur J Cancer* 2009;10:1798–806.

27 Corner J, Wagland R. Quality of Life of Cancer Survivors in England: Analysis of Patients' Free Text Comments: Final Report. A National Cancer Survivorship PROMs Survey. University of Southampton and Department of Health, 2012. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213317/NCSS_PROMs_text_analysis_report_Final_Report_040213.pdf (accessed Jun 2015).

28 National Institute for Clinical Excellence. Improving Supportive and Palliative Care for Adults with Cancer, 2004. http://www.nice.org.uk/nicemedia/live/10893/28816/28816.pdf (accessed Jun 2015).

29 Niemelä M, Hakko H, Räsänen S. A systematic narrative review of the studies on structured child-centred interventions for families with a parent with cancer. *Psychooncology* 2010;5:451–61.

30 Craig P, Dieppe P, Macintyre S, *et al*. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ* 2008;337:a1655.

31 Bowlby J. Attachment. *Attachment and Loss*. Vol. 1. Loss. New York: Basic Books, 1969.

32 Piaget J. *The psychology of the child*. New York: Basic Books, 1972.

33 Carter B, McGoldrick M. *The expanded family lifecycle. Individual family and social perspectives*. 3rd edn. Pearson, 1998.

34 Goldenberg H, Goldenberg I. *Family therapy: an overview.* 8th edn. CENGAGE Learning Custom Publishing, 2012.

35 Byng-Hall J. *Rewriting family scripts: improvisation and systems change*. New York: Guilford Press, 1995.

36 Allison S, Stacey K, Dadds V, *et al*. What the family brings: gathering evidence for strengths based work. *J Family Therapy* 2003;3:263–84.

37 Patterson JM. Understanding family resilience. *J Clin Psychol* 2002;3:233–46.

38 Wilkinson S, Perry R, Blanchard K, *et al*. Effectiveness of a three-day communication skills course in changing nurses' communication skills with cancer/palliative care patients: a randomised controlled trial. *Palliat Med* 2008;4:365–75.

39 Chowns G. 'No—You Don't know how we feel!' (DVD) Collaborative Inquiry using video with children facing the life-threatening illness of a parent. In: *Handbook of action research*. Reason P, Bradbury H, eds. London: Sage, 2008. Q3

40 Argyris C, Schön D. *Organization learning: a theory of Action Perspective*. Addison Wesley Longman Publishing Co, 1978.

41 Schön DA. *The reflective practitioner: how professionals think in action*. 1 edn. Basic Books, 1984.

42 Ritchie J, Lewis J, eds. *Qualitative research practice: a guide for social science students and researchers*. London: Sage Publications, 2003.