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Review

Enhancing the supportive care of parents with advanced cancer: Development of a self-directed educational manual

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ABSTRACT

Diagnosing and treating young patients with cancer can be stressful for health professionals; however, when the prognosis is poor and the patient has dependent children, even experienced clinicians can feel distressed and helpless. Parents with advanced cancer commonly express anxiety about the impact of the disease on their children, yet health professionals often feel unable to respond constructively because of lack of training, or concern that discussion about such difficult issues will compound parental distress. In response to this problem, an educational manual has been devised to assist oncology staff to better understand the emotional impact of parental advanced cancer, encompassing information about specific reactions of children, including strategies to help children and families cope. This paper describes the development and content of the resource which provides clinically relevant information and evidence-based recommendations to guide supportive care. The manual differs from the more traditional didactic resources in that it examines the very personal impact for professionals working with parents with advanced disease, encouraging reflection and engages the reader in clinical exercises which encourage active learning and application of knowledge into authentic clinical contexts. Although the manual is designed primarily for nurses, it is clear that much of the information is relevant for all health professionals involved in the care of parents with advanced cancer.

1. Background

A diagnosis of advanced cancer affects the whole family,[1] severe or overwhelming anxiety being documented in 32% of families newly referred to a palliative care service.[2] Severe family anxiety is twice as common if the patient with cancer is aged younger than 45 years.[3] Few parents receive information or support about ways of helping their children cope, and this compounds distress,[4] leading to the avoidance of discussion about difficult issues.[5] Children with a parent with

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cancer tend not to seek support from siblings or friends,[6] and do not commonly access support from school counsellors,[7] so it is not surprising that 27% of children with a parent with terminal cancer have above average depression scores, compared with 15% of a community sample.[8]

An intervention is currently underway to provide increased supportive care for parents with advanced cancer, delivered by oncology nurses. Support from oncology nurses is highly acceptable to patients[9]; however, nurses recognise the need for focused education to be able to extend their usual supportive care roles.[10] This paper describes the development and content of the educational manual developed as part of this project. Although developed primarily for use by oncology nurses, the material is relevant for all health professionals involved in the care of parents with life-threatening illness.

2. Development of educational manual

The manual is designed to be self-directed, the style and content of the manual reflecting important educational principles: involving the learner actively; providing learning related to understanding and solving real clinical problems and opportunities to reflect on practice.[11] Reflection on practice involves the analysis of nursing practice, fostering an understanding of the nurse's work and the development of 'critically thoughtful processes essential for providing nursing care in complex environments'.[12] Many of the difficulties encountered by oncology nurses in their clinical work are not amenable to 'off-the-shelf solutions', so nurses and patients potentially benefit from the review of events, interventions and outcomes.[13]

2.1. *Stage 1 – review of literature*

A literature review was undertaken on key issues: the impact of advanced cancer on parents and children; strategies to promote adjustment; communication with patients with cancer, and staff stress and burnout. Resilience research was also reviewed. This field examines children's outcomes in response to adversity such as poverty, violence or parental mental illness. In the absence of an extensive literature about interventions to assist children coping with a parent with advanced cancer, it was considered that basic concepts in the resilience literature may be applicable.

Scope of the content was ratified by the project group. Four members are nurses with experience in education and clinical service delivery, the background of the other two being Social Work and Consultation-Liaison Psychiatry.

2.2. *Stage 2 – Focus Groups*

Focus groups with oncology nurses revealed that information alone would be insufficient to meet their educational needs. Critical issues were the lack of professional confidence in initiating discussion about children's coping, and apprehension about exacerbating family distress. Nurses were keenly aware of the burden of caring, eager to learn more about coping with the emotional demands of their work and wanted guidance from experienced role models about responding in difficult clinical situations.[10]

2.3. *Stage 3 – expert review*

An expert panel comprising six nurses with a national profile in nursing education and service delivery reviewed the manual, documenting their opinions about the relevance, style and content of each section of the manual, noting if any important topics were missing. Return of manuals with reviewer annotations allowed for revisions. There was an overwhelming endorsement of the need for such educational materials, with only minor revisions being suggested.

2.4. *Stage 4 – final version*

The final version of the educational manual incorporates feedback as above and from the focus groups. The manual is presented in three Modules. The first two are designed to enhance knowledge and confidence about responding to parents with advanced cancer, incorporating 6 clinical problem-solving exercises and 28 self-reflective exercises. Module 3 provides a structured, practical approach to communication with parents with advanced cancer. The educational manual was developed as a personal resource for nurses to retain in their possession, so their reflections in the exercises remain private, and they can revise and refresh their learning as necessary. Formal evaluation of the effectiveness of the training includes self-report measures and scripted videotaped interviews, results of which will be reported elsewhere.

3. Module 1

3.1. *Emotional dimensions of advanced cancer*

It is essential to review concepts such as grief, loss and hope and appreciate that as disease progresses, existential issues assume increased importance,[14] influencing treatment decisions and adjustment. However, often health professionals feel uncomfortable about raising these issues. Caring for a patient coping with advanced disease inevitably elicits personal responses in the carer, and a reflective exercise encourages consideration of the ways this could affect clinical care, see Table 1.

Anxiety and depression are more common as disease progresses, intimately related to disease burden and side-effects of treatment. It is important not to 'over-understand' depression as inevitable, and recognise that both pharmacological and non-pharmacological interventions are often highly effective. Health professionals are encouraged to develop a referral network of professionals with expertise in the treatment of anxiety and depression.

3.2. *Issues arising for staff*

Advances in treatments mean improvements in survival and quality of life, but technical aspects of service delivery can be stressful for professionals who are required to deliver increasingly complex treatments.[15] Caring for patients of similar age or background is stressful,[16] as is providing emotional support for patients and their families,[17] particularly when patients are angry, depressed or withdrawn.[18] Understanding concepts such as displacement can be helpful in ameliorating

Table 1 – Reflective exercise – Module 1

- Think about a patient you have seen who was anxious because of past experiences with cancer. What was the nature of their anxiety and fear?
- How did you respond, for example, reassurance; give information; listen?
- Reassurance can be tricky! Sometimes we feel we have done a good job because we reassured the patient. This may be so. And if the patient is more settled, our job is easier. But conversely by reassuring the patient, it is possible to give a message that you do not want to hear about their inner fears and distress. Sometimes, the reassurance is more for us than the patient. This is because most health professionals like to fix things, and we find it difficult if we cannot do this.
- Are there times when you are especially quick to offer reassurance? In what ways do you think this might relate to how the patient is making you feel?

the frustration engendered when, for example, a patient complains about all manners of apparently trivial problems. Recognition that the person has unconsciously displaced his/her fear about prognosis or anxiety about family concerns onto other matters can help staff to respond rather than becoming defensive. Responding to patients can also rekindle grief about our own personal losses, yet traditionally these feelings are downplayed, with the potential to cause avoidance of the patient, thus affecting clinical care. It is useful to reflect on ways in which the past experiences of loss can resonate with clinical issues.[19]

Although multidisciplinary teams have been demonstrated to have benefits in terms of patient care and outcome, systems and team issues may also be a source of stress for health professionals especially if they feel that their contribution is not valued.[20] Consideration of the specific issues within the team and the interaction of these with personality style and professional expectations may promote coping, assisted by the awareness of the need to identify points of personal vulnerability, and consider strategies for coping when caring for patients with serious illness.[21]

3.3. *Communication with patients*

Good communication should underpin all clinical encounters, and it is important to review basic components including good eye contact; clarification of the patient's concerns; responding to cues that are suggestive of emotional distress; asking questions about the patient's feelings; enquiring about the situation at home; making supportive comments; and handling interruptions well.[22] For nurses in particular there may be a tension between the need to complete designated tasks ('doing something') and the less active, more facilitative approach of supportive care. However, listening and being emotionally present with the patient are interventions of worth to the patient, just as surely as insertion of an intravenous line or changing a dressing.

'Blocking' refers to behaviours which inhibit the patient's expression of emotional concerns or distress. Health professionals commonly 'block' patient expressions of concern by offering reassurance before the main problems have been identified; explaining distress as 'normal'; attending to only the physical aspects of the patient's care; switching the topic; and 'jollying the patient along'.[23] A problem-solving exercise draws attention to 'blocking' in a clinical setting, see Table 2.

3.4. *Communication skills training*

Communication skills training leads to improvement across multiple domains including listening, asking more open questions and expressing empathy.[24,25] A day-long communication skills training workshop supplements learning in the educational manual. The workshop is based on role-plays with the opportunity to practice and receive feedback, in order to improve professional confidence and skills. Knowing that others have also experienced difficulties, discussing challenging clinical problems can be powerful in reducing feelings of isolation and stress. The format and structure of the workshop, including nurses' perspectives, will be reported elsewhere.

4. Module 2

4.1. *Needs of the children of parents with cancer*

Up to 20% of children with a parent with early cancer have high self-reported anxiety.[26] Children with a parent with terminal cancer have lower self-esteem and deficits in social competence,[27] and have also been reported to have signifi-

Table 2 – Clinical problem-solving exercise, Module 1

You are working in the oncology outpatient department of a large metropolitan hospital. One of the oncologists, Dr Simpson, has an appointment to see Maria, an attractive 34-year-old woman with advanced breast cancer. Her most recent scans are not available and you are asked to check on the results. You know that she has been increasingly symptomatic, and are not surprised to find that the scans show disease progression despite aggressive chemotherapy. This is especially upsetting, as you know that she has three young children. When Dr Simpson tells Maria the results, she looks shocked and says 'What happens now?' Dr Simpson responds by giving Maria a detailed information about several clinical trials for which she may be eligible.

- What do you think Maria is really communicating with her question 'What happens now?'
- What feelings do you think this consultation is causing for Dr Simpson?
- Can you think of any different responses that Dr Simpson could have made?
- What could you do in this situation to open discussion and allow Maria to openly discuss her concerns?

cantly more behaviour problems than other children.[28] Stress levels of children with a parent with advanced cancer are even higher than levels following parental death.[29]

A major factor affecting the adjustment of children is their developmental stage,[30] and an awareness of key stages is vital for health professionals in their supportive role.

4.1.1. *Younger children*

Up to about 8 years of age children are egocentric, and believe in magic. They have an authoritarian sense of morality and interpret bad events as punishment, rather than being due to chance. Pervasive issues for young children are the fear of being abandoned, and guilt about their own perceived contribution to parental illness,[31] as they cannot reconcile that illness 'can just happen', instead assuming it is because of something they have said or done. Young children reveal their concerns by behavioural disturbance rather than directly,[32] so parents need to be aware of non-verbal expressions of distress. Conversely, the child who is quietly terrified may be 'extra good', this serving to take parental attention away from their unexpressed needs. Hence children in this age group need reassurance:

- that the cancer is not their fault,
- that their behaviour will not influence the outcome (that is, not telling them to 'be good' so that the parent can be well),
- that they will always be safe and cared for.

4.1.2. *Middle childhood*

From about 8 to 12 years, it is important for children to feel accepted by others, and being different for any reason can be distressing. Insensitive comments of other children, are not uncommon, and can be especially wounding. Capacity for abstract thought is limited, and play and physical activity remain the important ways of discharging tension. Being brave is valued, and children may struggle with their distress, made worse if the extended family members exhort the child to 'be big and brave'. Children in this age group need

- information at an appropriate level,
- opportunities to engage in peer relationships,
- activities such as sport which are likely to be affirming,
- the opportunity to talk about the comments of other children, and how this makes them feel.

4.1.3. *Adolescents*

Adolescents are particularly vulnerable when a parent is seriously ill, and any background tension is likely to be exacerbated. Cognitive maturity and capacity to think in abstract terms may fluctuate; however, physiological maturity may mean that parents have unrealistic expectations about emotional maturity and responses. Adolescents struggle to adopt the changes in role and care-giving necessary when a parent has cancer,[33] and just under a third express dissatisfaction with the amount of information they are given about parental cancer, its timing or the way it is given.[34] Adolescent daughters may be especially vulnerable,[35] and the perception of high domestic responsibilities increases anxiety.[36] Inability to discuss the illness with the affected parent, spending less time involved with friends, sport and leisure activities and problems with schoolwork also lead to anxiety.[37] Adolescents need

- acknowledgement and discussion of changed roles,
- negotiation rather than imposition of domestic tasks,
- social relationships,
- access to information,
- opportunities to talk openly about the cancer with their parents.

Adolescents need specific information about, and preparation for parental death[38] (see Table 3).

4.2. *Issues for parents with advanced cancer*

The emotional impact of a diagnosis of advanced cancer is compounded by disease burden and side-effects of treatment, so it is perhaps not surprising that ill parents are often unaware of their children's distress, rating them as asymptomatic when children themselves report high levels of psychological symptoms.[39] Parents may avoid sharing their feelings and concerns in order to protect one another.[40] When parents do talk with their children it tends to be to offer information, rather than checking on the child's emotions or understanding.[41] Hence, health professionals have a crucial role in acknowledging the tension that parents feel between wanting to protect their children, balanced against their children's need for open communication. The health professional may well need to take the initiative in exploring specific concerns, offering support and providing information.

Table 3 – Clinical problem-solving exercise, Module 2

James is 5 years of age, and his brother Fergus is 13 years of age. They have an 8-year-old sister Kate. Their father Malcolm is 42 years of age, and has cerebral metastases from melanoma. He has angry outbursts at times, and on 2 occasions has had a grand mal seizure, witnessed by the boys. Their mother Prue is determined to do the best for the children, and everyone says how strong she is. Fergus asks his mother if his Dad is going to be OK, to which Prue replies 'Of course, sweetie. Everything will be fine.'

- What is Fergus communicating to his mother? What message is Prue giving to Fergus? Is there another way she could respond to him?
- When Malcolm attends for an outpatient appointment, you note that James is extremely defiant and rude, and has destroyed some magazines in the waiting room. Prue shouts at him. What issues is James struggling with? What might help him?
- Prue says 'Thank heavens for Kate- she is being a perfect angel. I don't know how I could cope without her.' What issues are likely to be relevant for Kate?

4.3. *Interventions to promote adjustment of children*

4.3.1. *Cancer-specific interventions*

The fundamental components underpinning interventions are the need for good communication,[30] and provision of information which is appropriate to the developmental stage of the child.[42] Failure to facilitate honest communication and age-appropriate understanding can lead to misunderstanding and isolation of children.[43] It is important for children to be able to express fear about the outcome of treatment, and concerns about the well parent, and anger about the changes in family life.[44] Children benefit from plenty of interactions with the well parent[45]; however, the well parent may be so consumed with their role as a carer that they overlook this unless supported to reflect on their child's needs.

4.3.2. *Resilience*

Resilience is the capacity of the individual to cope with adversity rather than being crushed by it. Protecting children from adversity does *not* imbue them with resilience. Rather, the provision of a supportive environment, in which the child is assisted to negotiate the hurdle, is critical.[46] Parents need to hear that it is much less about their illness, and more about how it is dealt with which will determine the outcome for their children. Opportunities for 'pleasurable success' are likely to give children enhanced optimism and confidence, these spilling over into other areas of their life.[46] Consideration of the characteristics of resilient children and adolescents provides insights about the potential ways of helping children cope with the difficulty of parental illness (see Table 4).

4.3.3. *Responding to parental death*

Even pre-verbal children can tell from the distress of adults around them that something terrible has happened, so withholding information is not protective, and prevents the child from receiving appropriate support.[53] Unfortunately, most studies of bereaved children have focused on the gross measures of adjustment such as mental illness; however, bereaved children have been found in one study to have high levels of somatic symptoms, and lower levels of self-worth and self-efficacy than non-bereaved children.[54]

For adolescents, having support from family and friends helps with coping,[55] and good communication with the surviving parent is associated with lower levels of anxiety and depression.[56] Being able to ask questions about the dead parent appears to be protective.[57] A sense of connection with the deceased parent has been found to be an important part of coping for children, and 81% of children in one study felt that their parent was watching over them.[58] Hence, the parent who is supported and informed may feel empowered to act in ways which facilitate adjustment, despite the temptation to minimise discussion about the dead parent in order to avoid confronting the pain of loss.

5. Module 3

This Module provides prompts and suggestions which could be used in response to specific challenges, such as parents who express anger, guilt about their illness or even minimise its significance for the family. The emphasis in these examples is on being supportive and acknowledging parental distress, rather than the more instinctive reassurance commonly offered by health professionals (see Table 5).

6. Discussion

Even with practical suggestions and guidance, responding to young patients and those with young children is stressful for nurses.[59] When placed in difficult situations, nurses give information which is not requested by patients in order to maintain control over the clinical encounter, and to prevent them having to engage in emotionally loaded discussions.[60] Whilst protective for the nurse, this limits attention to the patient's needs. This is of concern, given the evidence about the benefits of support and expression of feelings in promoting adjustment of patients with cancer.[61]

Few oncology textbooks encourage health professionals to consider the complexities of supportive care, and the need to approach this from multiple perspectives. Strong features of this educational resource are the promotion of self-reflection, clinical problem-solving exercises encouraging the application of knowledge into a realistic context and the use of specific examples and prompts to assist in challenging communications. Reflection on practice is a strong theme, and this manual is designed to provide a 'safe' opportunity to reflect, aiming to balance the potential feelings of vulnerability against the benefit of enhanced personal awareness, insights and capacity to develop new approaches to these difficult communications. Reflection in clinical practice can lead to confidence to try something new, to 'move beyond their usual boundaries, and take courageous actions',[62] surely of great worth when caring for parents with advanced cancer.

Table 4 – Module 2. Characteristics of resilient children

- They feel a strong sense of connectedness to at least one adult who demonstrates unconditional positive regard[47]
- They have a strong sense of being seen, confirmed and respected for who they are[48]
- They have the opportunity to discuss problems at home and are encouraged to face up to difficulties in a constructive way[47]
- Their parents express concern for their well-being[49]
- They have chores and tasks which they carry out for the good of the family and feel that they are contributing
- They believe that they can control at least some aspects of their lives and what happens to them, rather than seeing themselves as being powerless[47]
- They have a capacity to recognise what is beyond their control, for example, due to bad luck[50]
- They have a perceived area of self-competence valued by themselves or society, such as artistic or athletic achievements[51]
- They have fewer delinquent peer group associations[52]

Table 5 – Module 3. Communication strategies

- **Regret:** Listen rather than rush to reassure: 'As parents we would do anything to protect our children, and it is terribly painful when we look at what we have done, and wish that we had done things differently.' Or: 'I guess none of us knows how we would cope in a particular situation. What I do know is that you care deeply about your children, and your courage in being prepared to think about these difficult things will be a big factor in helping the family get through it'
- **Fear or guilt:** Offer encouragement and some optimism: 'It's hard to believe, but children do handle even things like this. What is really important to remember is that it is not the cancer that is important so much as the way you handle it. And we know quite a bit about how to help children handle it.' Followed with 'A lot of people have asked children of all ages about how they cope, and what helps them. It may not be the answer you expect, but over and over it has been found that children actually cope better if they can talk about even very difficult things.'
- **Anger:** The anger is about the cancer, injustice and grief, not a personal attack. The person is communicating: 'I'm alone, I'm struggling. No-one else knows my pain, and no-one can help.' Let the person talk; listen; allow silence; do not feel responsible for 'fixing' the person's pain or be defensive: 'I couldn't begin to imagine just how difficult this must be' or 'This is just so hard.'
- **Reassuring children who ask about death:** Parents are often tempted to offer reassurance to their children, despite the clinical reality. Encourage the parent to reflect on the child's feelings: 'I guess for him to ask that (if you are going to die) he must have been doing a bit of thinking about difficult things' and 'I wonder if he could be scared about what the future might hold.'
- **Avoidance and denial about prognosis:** Gentle encouragement to consider all possibilities: 'It is true that people in your situation have been known to have dramatic recoveries, and of course new treatments become available all the time. We all hope that things will work out for you. But I guess it's also important to think about what would need to happen for the family if things didn't work out as we all hope.'

Conflict of interest statement

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