

Young adults with cancer: parents' interactions with health care professionals

A. GRINYER, BA, PHD, *Institute for Health Research and the School of Independent Studies, Lancaster University, Lancaster, UK*

GRINYER A. (2003) *European Journal of Cancer Care* **13**, 000–000
Young adults with cancer: parents' interactions with health care professionals

This paper examines the relationship between medical professionals and parents of young adults who are being treated by them for cancer. This study aims to discover what practices and procedures make the cancer journey easier or more difficult to manage for parents in the medical setting. Many studies of carers focus on spouses, little attention has been paid to parents of young adults in this context. Self-selected parents who responded to an appeal for narratives about their adult son or daughter's cancer experience. A narrative correspondence method relying on contributions of a qualitative nature submitted in written form and analysed through the identification of emerging themes. Interactions with health professionals have a far-reaching effect on parents' experience. A clear understanding needs to be established at an early stage with agreement by all parties on how information and decision making should be shared. If parents feel excluded or uninformed about procedures, or believe that their son or daughter is receiving less than optimum care, this results in feelings of helplessness and frustration. While many of the issues identified in this paper might apply to relatives of cancer patients in other age groups, the effect of life stage during young adulthood exacerbates the complexities of the medical setting.

Keywords: cancer, young adults, life stage, parents, medical professionals, narrative correspondence method.

INTRODUCTION

We may not be able to make it alright for the parents of terminally ill young adults, but if it is not handled well we are certainly in danger of making it worse. (Health care professional working in a hospice for young adults)

This paper examines the relationship between the parents of young adults who have cancer and the health care professionals involved in the care of the young adults. The complexity of this tripartite partnership is made more problematic by uncertainties about the sharing of infor-

mation and decision making in the medical setting and presents a unique set of challenges for the health professionals. Through an analysis of narrative data contributed by the parents of young adults with cancer between the ages of 18–25, the paper explores how a son or daughter's age and life stage affect the relationship between parents and medical professionals.

The support of the family and friends of cancer patients was recognized as crucial in the Calman-Hine report (Department of Health 1995) and its importance emphasized 5 years later by the NHS Cancer Plan (Department of Health 2000). However, as Thomas & Morris (2002) acknowledge, there is a gap in the knowledge about carers who are not spouses. The family members in question in this paper are parents whose sons and daughters are young adults. This can create an anomalous situation that may be difficult for parents and health professionals to manage as young adulthood is a life stage when independence from

Correspondence address: Anne Grinyer, Institute for Health Research and the School of Independent Studies, Lancaster University, Lancaster LA1 4YT, UK (e-mail: a.grinyer@lancaster.ac.uk).

Accepted 28 August 2003

European Journal of Cancer Care, 2004, **13**, ••–••

family is actively sought. Indeed independence from the family may have been achieved – albeit briefly – and a return to dependency necessitated by illness may prove challenging to all concerned (Grinyer 2002a).

The negotiations required in managing the relationships between parents and health care professionals caring for an adult son or daughter may be fraught with confusion for a number of reasons. Young adults are legally entitled to be the recipients of medical information about their illness, diagnosis, prognosis and treatment regimes and have the right to make their own decisions about medical interventions. These young adults are also entitled to exclude their parents from the sharing of such information, but may have little useful experience upon which to draw in their attempts to manage either medical consultations or decision making independently. The parents, on the other hand, have no entitlement to access information or to be involved in decisions about treatments without the agreement of their son or daughter, despite the fact that they are likely to become the primary carers for their son or daughter. At this stage in their adult children's lives parents are expected to relinquish both control over and involvement in matters relating to their sons' and daughters' health and any resulting medical consultations (Brannen *et al.* 1994). This can be difficult enough under normal circumstances (Grinyer 2002a) but when the illness in question is cancer, and thus potentially life-threatening, the additional stress caused to parents can be immense. Coupled with this is the uncertainty of professionals responsible for the care of the young adult who may be unclear about procedures relating to the sharing of information and decision making.

The relationship between carers and health professionals has been the topic of research by Morris & Thomas (2001) who sought to understand the position of close friends and family members of cancer patients in the medical setting. Morris & Thomas address the problems of confidentiality and the sanctity of the doctor–patient relationship, and recognize that while health professionals have an obligation to maintain patient confidentiality, in practice this may not be clear-cut. Their findings suggest that many of the carers in their study managed to be present at most consultations, yet when the carer is a parent the lack of clarity may be exacerbated and very difficult for health care professionals to manage. Thus the ambiguous nature of the relationship between the parents of a young adult patient and the professionals involved in their care is inextricably linked in the following discussion.

Not only are there complex issues relating to confidentiality, even when there is a clear understanding relating

to the ownership of information, much distress can be caused if news about diagnosis and prognosis is not handled with sensitivity by health professionals. There is a growing literature on the breaking of bad news, much of which addresses not only the distress likely to be caused to the patient but also that experienced by the medical professional. Buckman (2003) acknowledges that the vast majority of oncologists will have to break bad news in a scenario that is emotionally charged and stressful for both patient and physician. He suggests a protocol to minimize the trauma, part of which entails the involvement of significant others. If there are people closely supporting the patient, he recommends that the patient should be asked who will act as the spokesperson for the family during the discussion. Although Buckman's discussion addresses the role of significant others, he does not relate this either to confidentiality or the varied roles those others may hold in relationship to the patient. This would seem to be crucial to the management of the consultation given the difference in dynamics between the role of spouse and that of parent to an adult son or daughter.

METHODOLOGY

The data drawn upon in this paper result from a research project funded by a charitable trust set up by Helen and Geoff, the parents of George who died from osteosarcoma at the age of 23. The data form part of a much larger data set of narrative material written by the parents of young adults with cancer and were submitted in response to an appeal from Helen distributed through health professionals and cancer-related organizations in the UK. However, responses were sent from countries including Germany and Australia, thus suggesting the issues are not geographically bounded.

This qualitative approach to data collection known as the 'narrative correspondence' method had been used successfully before by Thomas (1998; 1999a,b) – an original researcher in the project – and enables the research participant to be in greater control of many aspects of the process than other methods allow. Respondents were not asked to address any specific topic, but rather to 'tell their stories' in their own way, in their own words and at a time of their choosing. In total accounts from 28 families whose adult sons and daughters were diagnosed with cancer were contributed. Of these young people whose stories were told by their parents seven survived.

Of course undertaking research in such a painful and difficult area requires immense care and sensitivity and this was a constant cause for concern throughout the research process. Nadeau (1998) addresses the vulnerabil-

ity of bereaved respondents as an ethical issue. She made the assumption that respondents were most likely to be vulnerable in the earliest months after their loss. Thus she selected only those respondents who were 3 months or more past the death. However, the methodology used in this research means that the choice of whether or not to respond to the appeal and when to do so is left up to the participant to decide, thus minimizing the chance of the researcher being an unwelcome intruder on private grief at an inopportune time [A full description and discussion of the methodology and the ethical issues relating to the research can be found in Grinyer & Thomas (2001) and Grinyer (2002a). The methodology presented here draws upon a methodological description in Grinyer (2003)]. Once participants had responded, every attempt was made to be sensitive to their needs, thus they were consulted about and included in each stage of the research and publication process. Carverhill (2002) cites Gilbert's work in bereavement research and suggests that the story telling approach to grief research (in this case mostly written stories) helps to make meaning of our lives. This appeared to be the case in this study as though many parents spoke of the emotional cost of contributing to the research, most felt they had benefited from the process.

The narrative data, consisting as it did of a range of styles and approaches to story telling, presented a challenge when it came to the process of analysis. Nevertheless, the importance of rigour was recognized and a systematic data reduction, display and conclusion drawing method was used (Miles & Huberman 1994). This resulted in common themes being identified. The aim of the research was better to understand the particular life stage effects on both the young adults and their family when cancer is diagnosed in young people between the age of 18–25.

Each of the extracts from the narratives in this paper is attributed to the contributing parent. All participants were as a matter of course offered the anonymity that is assumed to be of fundamental importance by many codes of ethical practice (Grbich 1999; British Sociological Association 2002). However, before publication participants' preferences were verified and surprisingly the majority of parents (75%) wished they and their families to be known by their real names. Thus the resulting text is based on a mix of real names and pseudonyms according to the respondent's preference. This issue is discussed in detail in Grinyer (2002b).

While the majority of the data address issues related to life stage, there are some general observations on what the family did, or did not, find helpful in their dealings with the professionals caring for their son or daughter. While this was not an area that research participants were asked

to address specifically there was a significant amount of material within their narratives that reflected on this relationship. It is clear from the data that the attitudes and interaction between the parents and the health and other professionals involved in the care of a son or daughter, whose condition may be life-threatening, can transform the experience for better or for worse.

FINDINGS

Before turning to the analysis of the narrative data a brief summary of an interview George's father, Geoff, provides a contextual reference point.

Geoff emphasized his belief that George's age during his illness (19–23) directly affected relationships and interactions in the medical setting. Had he been the parent of a younger child Geoff believed he would have been referred to much more by the health care professionals and had a greater degree of input into the decisions relating to George's care. Had George been older it is likely he would have had a partner to accompany him or been on his own. A purely practical example of George's dependence on his parents is that Geoff was frequently called upon to drive George to consultations at hospitals many miles from their home. Yet despite such prosaic evidence of dependency the situation, once in the medical setting, becomes much less clear and constantly needs to be negotiated in the many encounters with a myriad of staff, often at a number of different sites.

Geoff's experiences with health care professionals appear to have been largely positive. He recounted incidents when those caring for George demonstrated sensitivity towards both George and the wider family, listened to their questions, answered them honestly and interacted with them as individuals and as a family unit. One of the most important and positive aspects of the family's relationship with the health professionals was, for Geoff, that a clear line of communication had been agreed. At an early consultation the surgeon, with George's consent, had said that he would give any medical information to George first and this would then be shared with his parents and George together. Although this meant the consultant having to go through everything twice, it was clearly of great help to the family and provided a model for future interactions – including those in other health care settings. Such clarity and transparency is of great significance when dealing with a potentially ambiguous situation when all concerned, including health care professionals, are uncertain about protocols regarding the sharing of information that could rightly be considered confidential. It seems that

it is of importance that a process, often tacit, needs to be made explicit under these circumstances.

The positive aspects of George's care also extended to the less formal interactions between George and the staff. Geoff recalled with amusement the incident when a young ward sister climbed into bed beside George, pulled the covers over them and they had their photo taken. Perhaps an unorthodox way in which to relate to a patient, but one that in this case provided a welcome moment of light relief and also at some level acknowledged George's identity as a young man rather than as a cancer patient.

However, there were also instances where health care professionals caused additional stress to both George and his father. Examples offered by Geoff include occasions when they were kept waiting for lengthy periods or when tests were cancelled without explanation. On one occasion news with potentially serious implications delivered with (apparently unwitting) insensitivity had a profoundly detrimental effect on both George and his family and resulted in George throwing his X-rays across the floor in anger and desperation.

In summary, Geoff felt that the relationship between the health care professionals and the parents of young adults with cancer was complex as the medical staff was called upon to identify a range of parent-child relationships. Young adults might be completely independent of their parents and able and willing to manage the situation on their own. Alternatively, they might be almost child-like in their dependency on their parents. Yet staff may be over worked and stressed and have little experience of work with this age group. Under such circumstances are they going to have the time, experience or sensitivity to make judgements about family dynamics?

An analysis of the narrative material from other parents begins by examining some of the experiences perceived as positive where health care professionals ameliorated the additional stresses related to life stage. Simon, a young Australian who was diagnosed in his home country, travelled to England soon after his diagnosis and died in a hospice in London. His mother, Helen V, acknowledges the role of the Australian palliative care doctor and his help in arranging for hospice care in London, a trip directly related to Simon's life stage in an attempt to see the world before his death. Here the implication is that Simon's parents were included in discussions about his welfare, and the difficulty of letting him go, both literally and metaphorically, was smoothed to some extent by support from the medical staff.

The role of the palliative care doctor is also mentioned by Gabrielle whose son Steve died from melanoma. Gabrielle describes her as 'lovely, direct and thorough' – again

suggesting a clear line of communication – and says that she visited a lot over the first few days in the hospice to 'get things under control'. While having to accept that they have no control over events themselves, parents need a belief that the professionals have a clear plan of action that is being implemented in a predictable and effective manner.

Gabrielle also shows that the environment in which Steve was cared for was crucial and recognizes the importance of her son being listened to, helping him come to terms with his loss of independence and impending death:

You don't find the hospice too bad . . . your own room and bathroom, 1-1 nursing. A lovely garden, friends, relatives and dogs visit daily. They are very kind and really understand. They spend a lot of time talking and listening to you, letting you cry, letting you laugh. They help you come to terms with your need for total dependence. They help you to admit that you are dying. (Gabrielle)

The loss of independence is of fundamental significance to young adults, and perhaps has a greater impact at this life stage than any other. Thus any input from health care professionals that helps the young adult come to terms with being thrown back to a dependent status – usually on their parents – is likely to benefit relationships in the family as a whole.

Geraldine, whose daughter Katy survived ovarian cancer comments on the benefits of sensitive interactions:

The staff . . . took time to explain procedures and gave us a contact telephone number to use in case of any later queries. On our first visit to Outpatients we had a long consultation, with everyone giving us the impression that they had plenty of time to explain the treatment and answer queries. They also involve the family and were pleased to explain things to me as well as Katy. This was quite a contrast to the (hospital) where Katy had seen the consultant alone and I had just been in the waiting room. Perhaps significantly, Katy came out from the first scan and asked me what the word 'malignant' meant. (Geraldine)

One of the most significant features of this quote is the contrast drawn by Geraldine between her experience of the hospital where she was not included in the discussions and the subsequent consultation at another hospital where she was included. As we have seen such practices may be made more problematic for both staff and family when it is unclear whether the consultation should respect the patient's entitlement to privacy as an adult, or

to acknowledge that while technically 'adult', patients in this age group may not have the experience to manage the consultation to best effect or to make informed decisions regarding treatment options. Where managed with skill the positive effects can be far-reaching – and correspondingly where there is a lack of clarity and confusion this can exacerbate an already distressing experience.

8 In terms of the sharing of the medical information (discussed in greater detail in Grinyer 2002a) there were clearly different approaches adopted between countries (e.g. Germany and England) and different institutions within the UK. Sue's experience of the English system reiterates Geraldine's observations in that where the sharing of information was honest and open between all parties. Sue says this was a helpful approach and contributed to a more positive experience. However, in Germany Sue and her husband not only had to struggle for Alex's right to be given accurate information but also had to have Alex's permission in writing to be allowed any information themselves and this was experienced as problematic and added to their distress.

9 Managing to remain connected to some sort of 'normality' is also of fundamental importance to young adults (Grinyer 2002a). Helen V mentions the significance of making contact with a junior doctor who had known Simon's sister at university. In addition, a student physiotherapist had taken the trouble to discuss with Simon what paperwork he should complete in order to defer his university exams. Such interactions, which recognized the lives both Simon and his family had outside their status as a patient and his family, were clearly of importance in improving morale – as Helen V says 'a connection to normal life'. At a stage where young adults are still negotiating other identities, recognition by health professionals of an identity that transcends that of 'patient' is of great significance to morale.

However, such connections to other identities are also experienced by parents as important. Barbara mentions a similar example and recognizes it as being helpful. After the diagnosis her son Jamie received of Hodgkin's disease – which he survived – Barbara called her general practitioner who was also a close family friend. She describes the 'familiar quiet tones' with which her friend and physician explained the nature of the illness and the process and treatments through which Jamie would go, thus establishing Barbara as not simply 'mother of the patient' but also friend and peer.

There are also aspects of the cancer journey that can prove challenging for families in very practical ways. For example, where do parents stay when their son or daughter is many miles from home and undergoing aggressive treat-

ment? Joyce specifically mentions how well the regional cancer hospital catered for families, having purpose-built accommodation and enabling her daughter Jill to have her family close by during her chemotherapy. Sue too, travelling from their home in Germany to be with her son Alex during his treatment in England, mentions her gratitude for such provision not only from the medical staff but also from the university where Alex was studying:

When Alex was in hospital in Birmingham, I was again both impressed and very thankful to the university for organising details such as what to do with his digs, etc. Full marks to the social worker, occupational therapist and hospital staff for giving us continued support in many ways . . . accommodation had been arranged for me in the nurses' home – another extremely welcome gesture that saved me no end of trouble. (Sue)

In London, Simon's mother who could not be there for his death (she and her husband were still on the journey from Australia to England when they heard that Simon had died) took comfort in the sensitivity with which the nurses had cared for Simon and helped the family to grieve. Again we see here recognition of the importance to Simon of his identity outside of his patient status and respect for this, even after his death, was a comfort to his parents:

They'd dressed him in his favourite black T-shirt and jeans. It was hard to get used to the dyed hair he'd had done just before he left. It was his last chance for a bit of teenage rebellion – black dye with purple highlights. (It sounds worse than it looked). The nurses said the purple came off on their hands. The hospice people helped us to arrange the funeral . . . The doctor who'd been on duty when Simon died talked to us about the last hours. He was so sensitive and kind. I noticed that he was concerned about Sara (Simon's sister), and offered to speak to her again, if she wished. (Helen V)

At this point we turn to examples of negative experiences many of which relate to parents being uncertain of what was happening and why or when. In contrast to Helen V's positive account offered above it is clear that there were also encounters with those caring for Simon that she found distressing:

The first day, he was scheduled to have an ultrasound, but for some reason it couldn't be done. The next day, he was asked to take part in a medical students' exam, which he agreed to, and then spent

an hour sitting in pain in a chair in the corridor. I don't think they ever called him in. The unreal situation continued, with none of us having any idea of what was going on . . .

When the ultrasound still hadn't happened after several days, I began to feel deeply frustrated with the whole situation. One of the nurses had mentioned that he might be discharged soon. So fearful and angry, I went to the nurses' station and demanded to see whoever was in charge . . . I . . . was told there were two consultant physicians on that ward. 'When could we speak to them?' 'Hard to say when they'll be around, one's away and the other's covering for him'.

I was consumed with frustration and fear, and decided that one thing I could do was to take advantage of our medical insurance and change his status from a public to a private patient. (Helen V)

Helen V continues by saying how private medical care was against her principles, but she felt she had no choice as the lack of any apparent progress or sense of urgency left her feeling helpless and that Simon was not getting the care she should have been. However, even after Simon's transfer to a private hospital the frustrations continued:

A kidney biopsy had been ordered, and for this we went back down the tunnel to the public hospital. We found the usual tumult there, and we slipped into that sense of helplessness you feel when you don't know what to expect, who will do the procedure, or when, or what is involved. Eventually it was done and Simon was wheeled out looking ghastly. Apparently the woman doctor had had several goes at getting tissue and it had been excruciating.

I was aflame with anger as he described the operation. I rushed off to the desk and demanded to know who'd done the procedure. As you'd expect when staff are bailed up by an irate family member, they were unresponsive. I think they told me a name. I stormed back to Simon's trolley planning complaints, letters, confrontations. (Helen V)

The word 'helplessness' is interesting here, fuelled by a lack of information and understandable anger at what was perceived to be a brutal procedure. Simon's mother needed to be active in her protection of his interests. Yet he made it clear that he had only been 'informing' her rather than complaining, and that he had no wish for her to 'make a fuss'. Here, although not articulated by her, it is possible to appreciate the anomalous position of a parent when an

adult child is ill. Helen V felt the need to intervene on her son's behalf and yet her 'right' to do so is debatable. Simon had not given his consent to her intervention, indeed it seemed he was actively against it, yet what parent when faced with apparent incompetence would not attempt to procure better treatment for a child – whether or not he or she is of adult status.

A similar scenario is described by Joyce whose daughter Jill died from osteosarcoma, she makes the following observation on Jill's treatment:

She had a horrific experience in the (hospital) when we went to visit her after the operation. She was rolling in agony. Her knuckles were white, with gripping on to the sheet. I put my arm around her and found her pillow and bed was soaking wet. The epidural had come out of her back, and she was not getting any pain relief. I reported this and was told they could not give her any painkillers, because they could not tell how much of the epidural she had actually received. So she had to suffer for a few hours more. We went through hell with her. (Joyce)

Again we see a parent who felt she had no choice but to report her daughter's distress. The following account from Luke whose son Martin survived testicular cancer demonstrates the extent of frustration encountered by disorganization. While he does not criticize the medical care, the administrative chaos appears to have made the ordeal even harder to manage and he felt compelled to intervene on his son's behalf:

The medics have all been super. I have no way of judging the treatment, but have to believe it is second to none . . . But they are just hopelessly disorganised. I know another week is not long to a medic, but to someone with a life threatening disease, it is OK if the medic is busy, but when the delay is caused through a failure of organisation it is a real downer . . . The thing is clearly not working right, although it was refreshing when a blushing nurse announced that she was sorry, Mr W was 45 minutes behind time . . . I know Martin is just one among millions who need them, but it really is very dispiriting . . . simple things like communication between two hospitals conspire to destroy his morale . . . Why on earth should it have to be his dad who makes sure than even the simplest task has been done, or even thought of? . . . It really is a disgrace; pitiful. (Luke)

Luke continues by saying how hard it was to hide his frustration from Martin and questions whether or not it

might be better to let him 'walk into disappointment or prepare him for possibilities'. Again such an example throws into relief the fact that parents cannot be expected to relinquish responsibility just because their son or daughter is legally an adult.

A strikingly similar situation is presented in Sue B's narrative relating to her son Paul's treatment for Hodgkin's disease. We can see that despite the fact that he is an adult, the perceived incompetence of the hospital cannot be ignored and she feels compelled to 'sort it out':

Today is two weeks on and Paul had heard nothing from the hospital. After several calls and no response . . . I rang this evening only to be shocked once more by the ill fortune and inefficiency which has struck again. I . . . explained Paul's situation to the sister on duty. She asked who his doctor was and when I told her – she said he'd left! She thought he'd probably left instructions in Paul's notes which hadn't been picked up! I couldn't believe my ears. She said the doctor on duty tonight was only standing (in) . . . I'm appalled, disgusted, shocked and desperate. Don't they know it's Paul's life they're leaving in a file and forgetting. (Sue B)

All these responses to the belief that the quality of care is falling short may be similar for any relative of a patient with a life-threatening illness. The difference in these cases is the parents' previous – and very recent – relationship to their child's health. While their son or daughter may now be technically an adult, standing by and allowing them to take control is not an option. Parents know that their son or daughter is unlikely to have the experience to know that their treatment could or should be better managed and it may be a short period because they would have accompanied them to an appointment at the doctor's and spoken on their behalf (Brannen *et al.* 1994).

DISCUSSION

Many of the issues raised in the narrative material above, could be experienced by any concerned relative or friend and cannot thus be considered specifically 'life stage' issues. However, all the encounters were also affected to some extent, whether consciously or not, by the adult status of the son or daughter being treated for life-threatening illness. It is clear in all these accounts, whether of positive or negative experiences, that parents are integral to the process through which their son or daughter is going. Even though the young people have adult status, it is unrealistic to expect parents to remain detached onlookers.

It seems that the best means by which to establish a productive relationship with health professionals is if an explicit agreement on the sharing of information and decision making can be formulated between the parents, their son or daughter and the medical and other professionals involved in the provision of care. In the case of George and his parents we can see that for the most part they negotiated successfully a positive relationship with the professionals involved in George's care yet, there were still occasions during which the interaction was experienced as problematic. George's father recognized that the health professionals must assess the relationship between the young adult and his or her parents on a family by family basis. However, this may not be easily achieved, as during this transition phase from dependency to independence the young adult may feel able to cope independently on one day, but be reduced to a childlike dependency on another. The fluidity of such unpredictable interaction and family dynamics may be difficult for all to negotiate. In addition, the volatility of family relationships under stress are likely to exacerbate those aspects of the parents' interactions with health professionals that would be found challenging for the relatives of a patient of any age. Thus when parents feel that their son or daughter is not receiving the best treatment, that there are unexplained delays, that they are not being listened to, that there is a lack of information or that there is perceived insensitivity, the effect is experienced as profoundly distressing. In many cases, as we have seen parents feel compelled to intervene with or without their son or daughter's knowledge or consent.

Yet we also have accounts of positive encounters, many of which relate to health professionals' ability and willingness to step out of their clearly defined roles and relate to the young adult and the parents on a different level. These instances demonstrate the significance of the parents, and in particular the young adults, believing that they are being treated as individuals – people whose status transcends that of being a patient or the family of a patient. It is perhaps more important at this transitional stage of life when other identities are not yet fully formed that the young adult does not feel that their only identity is that of patient. We have also seen that anything that makes the young adult feel better about themselves will impact upon the parents and make their burden easier to carry.

CONCLUSION

Young adults are in a transition stage in their lives that even without the potentially life changing effects of seri-

10 ous illness are undergoing sweeping changes (Brannen *et al.* 1994; Apter 2001; Grinyer 2002a). However, a cancer diagnosis throws an already turbulent phase into crisis. Having attempted to gain a degree of independence from adult jurisdiction they can find that not only are they 'answerable' to parents, in addition they are being told what to do and how to live by other adults as well – health professionals. Not only are parents having to let go of their young adult children at this life stage they are also having to relinquish control to a third party – health professionals, and the health professionals, caught between the young adults and their parents, have to negotiate a treacherous and unpredictable path between the two. However, if their approach is sensitive to these issues health care professionals can contribute a great deal to the support of both the young adults with cancer and their parents. They may be able to help the young adults realize that they need parental support even though this might not be acceptable to them under more 'normal' circumstances. Through developing a relationship of trust and collaboration with parents, health care professionals can also use the parents as a resource rather than them being perceived as a constraint.

So, to return to the quote at the start of this paper, it is certainly the case that the parents' experience can be made worse when the situation is not handled well by health care professionals. While good practice may not be able to make the situation 'alright', when approached with not only sensitivity and compassion, but also an understanding of the effect of life stage, health care professionals can have a profound and lasting impact on parents' ability to survive the ordeal of life-threatening illness in their young adult son or daughter.

REFERENCES

Apter T. (2001) *The Myth of Maturity: What Teenagers Need from Parents to Become Adults*. W.W. Norton and Co Inc., NY.

- Brannen J., Dodd K., Oakley A. & Storey P. (1994) *Young People, Health and Family Life*. Open University Press, Buckingham.
- British Sociological Association. (2002) *Proposed New Statement of Ethical Practice for the British Sociological Association*. 11
- Buckman R. (2003) *Conversations in Care*. Available at: http://www.conversationsincare.org/web_book/chapter05.html (accessed 20/2/03).
- Carverhill P.A. (2002) Qualitative research in thanatology. *Death Studies* 26, 195–207.
- Clark D. & Seymour J. (1999) *Reflections on Palliative Care*. Open University Press, Buckingham. 12
- Department of Health (1995) *A Policy Framework for Commissioning Cancer Services: A Report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales*. Department of Health, London.
- Grbich C. (1999) *Qualitative Research in Health*. Sage, London.
- Grinyer A. (2002a) *Cancer in Young Adults; through Parents' Eyes*. Open University Press, Buckingham.
- Grinyer A. (2002b) The anonymity of research participants: assumptions, ethics and practicalities. *Social Research Update*, 36. Spring edition. University of Surrey. 13
- Grinyer A. & Thomas C. (2001) Young adults with cancer: the effect on parents and families. *The International Journal of Palliative Nursing* 7, 162–170.
- Lynam J. (1995) Supporting one another: the nature of family work when a young adult has cancer. *Journal of Advanced Nursing* 22, 116–125. 14
- Miles M.B. & Huberman A.M. (1994) *Qualitative Data Analysis*. Sage, London.
- Morris S.M. & Thomas C. (2001) The carer's place in the cancer situation: where does the carer stand in the medical setting. *European Journal of Cancer Care* 10, 87–95.
- Nadeau J.W. (1998) *Families Making Sense of Death*. Sage, London.
- Thomas C. (1998) Parents and family: disabled women's stories about their childhood experiences. In: *Growing Up with Disability* (eds Robertson C. & Stalker K.), pp. 000–000. Jessica Kingsley, London. 15
- Thomas C. (1999a) *Female Forms: Experiencing and Understanding Disability*. Open University Press, Buckingham.
- Thomas C. (1999b) Narrative identity and the disabled self. In: *Disability Discourse* (eds Corker M. & French S.), pp. 000–000. Open University Press, Buckingham. 16
- Thomas C. & Morris S.M. (2002) Informal carers in cancer contexts. *European Journal of Cancer Care* 11, 178–182.

AUTHOR QUERY FORM

Journal: European Journal of Cancer Care

Article: 458

Dear Author,

During the preparation of your manuscript for publication, the questions listed below have arisen. Please attend to these matters and return this form with your proof.

Many thanks for your assistance.

Query References	Query	Remarks
1	Au: Please check if the short title running head is OK, if not, please provide one.	
2	Au: The summary headings – ‘Aim’, ‘Background’, ‘Sample’, ‘Method’, ‘Findings’, ‘Discussion’ – have been deleted as per the journal style. Please check if any appropriate change should be made.	
3	Department of Health 2000 has not been included in the list	
4	Au: the letter ‘a’ has been added to the year	
5	Au: the letter ‘a’ has been added to the year	
6	Grinyer 2003 is not to be found in the list.	
7	Au: The footnote in your manuscript has been inserted as bracketed text – OK?	
8	Au: the letter ‘a’ has been added to the year	
9	Au: the letter ‘a’ has been added to the year	
10	Au: the letter ‘a’ has been added to the year	
11	Au: Please provide the publisher and place of publication.	
12	Clark & Seymour 1999 has not been found in the text	
13	Au: Please provide the place of publication.	
14	Lynam 1995 has not been found in the text	
15	Au: Please provide the page range.	
16	Au: Please provide the page range.	

MARKED PROOF

Please correct and return this set

Please use the proof correction marks shown below for all alterations and corrections. If you wish to return your proof by fax you should ensure that all amendments are written clearly in dark ink and are made well within the page margins.

<i>Instruction to printer</i>	<i>Textual mark</i>	<i>Marginal mark</i>
Leave unchanged	... under matter to remain	Stet
Insert in text the matter indicated in the margin	⤴	New matter followed by ⤴
Delete	⤵ through matter to be deleted	⤵
Delete and close up	⤵ through matter to be deleted	⤵
Substitute character or substitute part of one or more word(s)	/ through letter or ⤵ through word	New letter or new word
Change to italics	— under matter to be changed	⤵
Change to capitals	≡ under matter to be changed	≡
Change to small capitals	= under matter to be changed	=
Change to bold type	⤵ under matter to be changed	⤵
Change to bold italic	≡ under matter to be changed	≡
Change to lower case	Encircle matter to be changed	⊖
Change italic to upright type	(As above)	⤵
Insert 'superior' character	/ through character or ⤴ where required	⤴ under character e.g. ⤴
Insert 'inferior' character	(As above)	⤵ over character e.g. ⤵
Insert full stop	(As above)	⊙
Insert comma	(As above)	,
Insert single quotation marks	(As above)	⤴ and/or ⤵
Insert double quotation marks	(As above)	⤴ and/or ⤵
Insert hyphen	(As above)	⊖
Start new paragraph	⤴	⤴
No new paragraph	⤵	⤵
Transpose	⤴	⤴
Close up	linking ⊂ letters	⊂
Insert space between letters	⤴ between letters affected	#
Insert space between words	⤴ between words affected	#
Reduce space between letters	⤴ between letters affected	⤴
Reduce space between words	⤴ between words affected	⤴