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Childhood abuse uncovered in a palliative care audit

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ABSTRACT

Objective: This article aims to highlight potentially high levels of childhood sexual abuse within Cancer and Palliative Care Service users.

Methods: During a routine audit, data was collated to quantify a perceived high level of disclosure of pre-existing psychological trauma within the palliative care caseload of a Macmillan Children and Families Therapist. Families comprised adults (generally parents or step-parents), one of whom was terminally ill or recently deceased who had direct responsibility for children and young people aged under 20 years old. Each family had at least two members using the service for advice, emotional support or counselling.

Results: A childhood sexual abuse rate of 33% for women and 10% for men was revealed. Of 59 families, 49% had one or more members who had experienced childhood sexual abuse. In addition a further 9% of adults had experienced severe physical and emotional abuse in childhood. Many families had faced multiple trauma.

Significance of results: Palliative care clinicians have access to detailed personal and family history during a highly vulnerable transition. While confidentiality is paramount it is essential to develop better data collection methods and raise the profile of childhood sexual abuse as a major contributing factor to morbidity. A whole family assessment is crucial to ensure child protection and emotional care for children facing the loss and subsequently bereaved of a parent or a carer. Clinicians must be able to offer a range of approaches which provide distressed patients with a history of childhood abuse some sense of emotional containment at the end of life, a challenge which cannot be overstated.

KEYWORDS: Sexual abuse, Children, Palliative care, Cancer, Family support

INTRODUCTION

The Macmillan Children and Families Support Service provides a psychosocial support, advice, and counseling service to partners and coparents, children, stepchildren, and young people facing the life-threatening and terminal phase and subsequent bereavement of patients referred to a Scottish National Health Service Palliative Care Service. Whenever possible, parents or carers are viewed as the most appropriate people to support their children during this traumatic transition. However, it is recognized that they are likely to need help with this process in the form of counseling and education about the impact of terminal illness and death on themselves and their children (Stokes et al., 1997).

It is generally acknowledged that work preparing families for parental death is demanding and uncertain. Judgments about timing and pacing involve weighing many complex factors (Chowns, 2005). The service carries the responsibility for overseeing specialist palliative care staff with this challenge and will often be directly providing most input. Clinical processes involve individually tailored support appropriate to the family group and each of its members. This may include life review and memorializing, preparation for saying goodbye, support and

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advocacy during the goodbye, advice and support with immediate responsibilities that follow a death, and bereavement support and counseling. In practice, the most extensive support is provided to families with the most complex problems, for example, coping with multiple loss or preexisting psychological trauma.

This study arose as a result of concerns regarding the numbers of families expressing unresolved issues regarding childhood sexual abuse, severe domestic abuse, and childhood and adult severe physical or emotional abuse. Issues of confidentiality make this work difficult to outline in detail. Levels of societal acceptance of alleged high numbers of affected adults make it difficult to discuss.

METHODS

Data were collated from notes during a routine audit for 2005–2006. I chose to report this year because the majority of individuals are now discharged and not actively seeking support at this time. Specific questioning regarding childhood abuse was not included in the assessment process; in all cases individuals chose to self-disclose during discussions about family history or current difficulties. This is likely to be due to the particular sense of vulnerability experienced when facing death or loss coupled with the very close relationships that can arise in a small specialist palliative care unit or in the safety of the family home.

Data that is sensitive and confidential in nature have been gathered retrospectively. This complicates the issue of raising questions regarding particular groups of patients while preserving anonymity, particularly for surviving family members. An example of this is women who have died of cervical cancer and who disclosed nonattendance for cervical smears because of the trauma of reliving childhood sexual abuse experiences.

Referrals come from any member of the specialist palliative care service, but generally from community, hospital, or hospice specialist palliative care professionals. Criteria simply state that families have dependent children and wish some advice and guidance regarding preparing and supporting those children with a parents' terminal diagnosis and/or bereavement needs.

Records are not held regarding families not told about the service or who refuse it. However, families causing concern to the specialist palliative care staff who decline help tend to be offered relevant booklets, and the majority will then contact the service at a later date of their own choosing, usually in the bereavement period.

During the time period, 71 families or single members of a family were accepted for support by the therapist and they were divided into 3 groups. The first group comprised 10 families who were facing the death of a grandparent to whom the children were particularly close but who did not actually live in the family home. There tended to be specific reasons why the family was struggling with the preparation of their children, for example, a history of parental life-threatening trauma that had led to the grandparents taking a key role in the care of both their adult child and their grandchildren during recovery or families with children with profound special needs who had received a high degree of practical and emotional support. However, in all these cases, the primary family unit would remain intact after the grandparent's death.

The second group comprised two families represented solely by a teenage member seeking counseling independently. In both families the surviving parents were unable themselves to accept help or to discuss the death of the deceased parent with their young adult children.

The third group is the sample under study and is comprised of 59 families with a terminally ill or deceased parent, stepparent, guardian, or coparent and a "well" parent, stepparent, family member guardian, or coparent who had direct responsibility for dependent children or young people aged up to 20 years in their home. This group of 59 families, 97 adults (57 women and 40 men) and 43 children and young people under 20 years old (39 aged 10–19 years) is the focus of study because more than one family member was seen by the service and each on more than two occasions. It should be noted that a further 62 children and young people were affected in these families who were not seen directly by the service during the period of the study, but advice regarding their needs was given to surviving parents in most cases. Twenty-six of these adults were patients (18 women and 8 men), but a further 18 deceased parents/stepparents, formerly patients, had been seen before the time period of the study and given information about their family circumstances.

Fifty-one (86%) families were referred before bereavement but, for six of these families, the sick parent either personally refused the service or was too ill to communicate. One well parent refused all contact even though the sick parent wished it. Those families seeking support after the death had usually had a rapid final trajectory with inadequate preparation time, serious infection and emergency hospitalization, or the patient had refused a referral.

Further detail of this sample of 59 families unsurprisingly presents a complex picture. Twenty-nine families (49%) were married or cohabiting couples with their own biological children. However two of these couples revealed that they had intended to divorce

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prior to the cancer diagnosis or recurrence and regarded themselves as "separated" but staying together for practical ease and with the hope of decreasing their children's distress.

Eighteen families (30%) were "reconstituted" either by remarriage or cohabitation, with the majority of children having acquired step- or half-siblings from the new arrangement.

Four families (7%) were separated or divorced with both parents living in their own homes as single people. Some had new partners who lived separately in their own homes.

Three families (5%) lived with a grandparent as coparent. These grandparents performed the roles of a parent, including collection from school, help with homework, making meals, and putting to bed. Three of the parents in these families were aged 18–22 years and had relied heavily on this grandparental support. Two of the families had gone to live with the grandparent to escape domestic abuse.

Four families (7%) had another family member as the children's carer. In two families, elder brothers had taken over the parenting role after the death of both parents (in one family the cause of death was cancer for both parents, some 5 years apart). An aunt and uncle had taken over after the death of both parents (18 months apart) in one family, and grandparents had been given custody of their grandchildren because of parental drug addiction.

One family (2%) comprised a widowed patient and her children.

RESULTS

Disclosures of Childhood Sexual Abuse

During discussions regarding personal history and current areas of concern or emotional difficulty, 23 adult members of the caseload disclosed that they and/or their partners (also members of the caseload) had been sexually abused as children. Nineteen concerned women (33% of females on the caseload) and four concerned men (10% of males on the caseload). Twenty-one of these disclosures were related to personal experience of childhood sexual abuse, two were disclosures that their partner had revealed to them. Eleven concerned patients and 12 concerned carers. Two disclosures came from men. Seventeen were first-time disclosures to a professional.

Eleven adults were abused by someone in their family, two by a "family friend", two at boarding school, one while in care, and seven were unwilling to state the abuser.

Five adults also disclosed childhood sexual abuse experienced by their now deceased partners. This involved three couples who had both been sexually abused as children.

In all cases emotional abuse was also described, including taunting, name calling, and threats of abandonment or death if the sexual abuse were to be disclosed. The majority further recalled incidents of physical abuse, including beatings and withholding of food.

Prior to this time period five patients (with bereaved family members on the caseload during the time period) had disclosed personal experience of childhood sexual abuse.

Two children disclosed sexual abuse during this year.

Taken as a whole, 29 (49%) families had one or both parents who had experienced sexual abuse in childhood and in one family every single member had done so.

Disclosures of Severe Physical and Emotional Abuse during Childhood

In a further group of 9 adults (2 women and 7 men), disclosures were made in a similar way about severe physical abuse in childhood. This was generally linked to mental cruelty and emotional neglect with beatings, food withholding, and rejection most frequently cited. Alcohol was most commonly given as the "reason" for this behavior. Four of these adults alluded to incidents of a more sexual nature but did not want to discuss them further. They have therefore remained in this group

Witnessing Domestic Abuse

Many adults could recall witnessing severe domestic violence during their childhood and feeling terror that their mothers may not survive. Two adults were removed (and separated from their siblings) to Children's Homes, apparently as a result of this violence and neglect, another two adults spent periods of time in foster care. One adult believed that he had indirectly been the cause of a younger sibling's death.

Disclosures of Domestic Abuse during Adulthood

Twenty-two women (38% of females on the caseload) described incidents of domestic abuse and sexual violence endured as adults, often, though not always, with previous partners. Eighteen of these adults also belonged to one of the two groups above. They all described several or repeated incidents of beatings from former partners or husbands, including being kicked in the stomach while heavily pregnant, cigarette burns to wrists and legs, and intimate partner

violence on more than one occasion. The four adults who described suffering solely adult abuse were reluctant to talk about their childhood, two stating it was something they usually avoided thinking about.

Other Disclosures of Abuse

During this time period one male patient disclosed having abused his children, who had been removed from the family home. He was unable to talk about his own life as he then became terminally ill.

Multiple Effects

Although the two groups of adults experiencing sexual abuse and physical abuse have been separated out, it is important to note the multiple traumas that many families face. Children disclosing sexual abuse did so of parents who had themselves disclosed childhood sexual abuse. Parents, sexually abused as children, were often married to others who had been sexually abused as children— though they had not necessarily shared this with each other. Adults may well have been parentally bereaved and had to deal with abuse.

Other Traumas

It is worth noting some other experiences perceived as very traumatic to these adults during their childhood. Six ill parents and 10 well parents had themselves been parentally bereaved as children. They all reported having been given little information and finding growing up very stressful as a result.

DISCUSSION

These data provide a picture of families who have experienced profound levels of trauma both as a group and individually. It has to be assumed that not all individuals who experienced childhood sexual abuse disclosed this, and, generally, retrospective disclosure of sexual abuse tends to be underreported (Fergusson et al., 2000; Hardt & Rutter, 2004). Studies requesting specific information and defining sexual abuse have tended to include questions about the exposure of sex organs or the threat of sex (Drossman et al., 1990) No such disclosures were made by the members of this caseload. In all cases, violent sex or rape was specified usually because flashbacks or intrusive thoughts were proving a source of additional distress to the individual concerned.

Accurate figures of childhood sexual abuse are understandably complex to ascertain, and variations in the definition of sexual abuse creates difficulties for data collection. Interpretation is complicated by the high degree of overlap between instances of sexual, physical, and emotional abuse and neglect. The prevalence of childhood sexual abuse in the United Kingdom may historically have been underestimated at 12% for females and 8% for males (Scottish Government, 2005).

Scottish Ministers have agreed to work with Community Health Partnerships and Managed Clinical Networks to develop better data collection methods and raise the profile of childhood sexual abuse as a major factor contributing to morbidity.

Arguments have been made that child abuse should be regarded as a public health epidemic with an incidence rate in the United States 10 times higher than cancer (Merrick & Browne, 1999) and, further, that it should be recognized as a "basic cause" of morbidity and mortality in adult life (Felitti et al., 1998). Palliative care and cancer services are, however, not mentioned among services likely to have higher numbers of adult survivors (The Scottish Government, 2005).

Felitti et al. (1998) examined the relationship of disease in adulthood to breadth of exposure to childhood emotional, physical, or sexual abuse and household dysfunction during childhood. A retrospective self-report questionnaire about the number of categories of adverse childhood experiences (including psychological, physical, or sexual abuse, violence against mother, living with substance abusers, mentally ill, suicidal, or ever imprisoned) was compared to measures of adult risk behavior, health status, and disease, which included cancer. The authors analyzed approximately 9,500 responses and found a graded relationship between the number of categories of childhood exposure to physical, psychological, and sexual abuse and each of the adult health risk behaviors and disease that were studied. The categories were strongly interrelated and adults with multiple childhood exposure were likely to have multiple health risks, showing a graded relationship with the presence of adult disease, including cancer. They found a strong graded relationship between breadth of exposure to abuse or household dysfunction during childhood and multiple risk factors for several of the leading causes of adult death.

Although it is recognized that women who recall childhood sexual abuse have an increased risk of a range of severe psychological problems, including anxiety disorders, major depressive disorder, posttraumatic stress disorder, social phobia, and substance dependence (Bifulco et al., 1991; Mullen et al., 1993; Hill et al., 2000; Molnar et al., 2001; Arnow, 2004), no such link is established with the onset of cancer in adulthood. However, hypotheses regarding links between behavioral and lifestyle factors, psychological stress, and impaired immune

function continue to be explored (Dalton et al., 2002) and Thomas et al., (2002) are confident enough to propose a model to test the impact of distress on the cancer patient prior to diagnosis.

Individual and cancer-specific risk factors likely to cause increased distress when one is dealing with a cancer diagnosis and treatment include being younger, having dependents under the age of 21, cumulative stressful life events, history of psychiatric problems, and poor marital or family functioning (National Breast Cancer Centre and National Cancer Control Initiative, 2003). The findings of this study reinforce the importance of a whole family approach with some consideration being given to family functioning as a group rather than simply identifying individuals at risk (Kissane et al., 2003). Parents who have been abused often have very clear ideas about members of their family who are not permitted to care for their children during the illness and this must be treated as a child protection issue by staff. The functioning of the surviving parent is recognized as the most significant predictor of a child's adjustment to the death of a parent (Worden, 1996), highlighting the responsibility of palliative care staff to identify those parents struggling with unresolved abuse history.

At the end of life patients often experience a decline in functional ability, such as performing personal care, which for some is intolerable. Dying can be seen as a process of facing the ultimate loss of self. This may involve confronting a multitude of smaller losses such as a sense of control, role, and sense of justice that psychological defenses may ward off for self–preservation purposes. However, at other times anxiety and panic may take over (Bolund, 1993). At such times the chaos of flashbacks of prior trauma can become overwhelming.

It is argued that emotional support from clinicians is reported by patients to be what they most want and find helpful and further that it is positively correlated with their psychological adjustment (Hunter et al., 2006). However, perceived quality of support from clinical staff may be more complex than a simple reflection of the level of support they are able to offer, but may depend also on patients' experience of childhood relationships and their capacity to accept support from staff (Salmon et al., 2007). Clinicians may find themselves withdrawing as a result of distancing or hostile cues or feelings of being unable to meet emotional demands, particularly in response to regressed childlike behavior (Tan et al., 2005). In addition they may well be unaware of a patient's abuse history (Salmon et al., 2006). The complexity of this is intensified at the end of life when feelings of responsibility toward the patient's sole opportunity to have a "good death" can be high. Thus the very group who most likely need emotional support may be the one least likely to be offered it or to be able to accept it.

There are no studies that evaluate the impact of psychotherapeutic interventions with terminally ill patients who have suffered childhood sexual abuse. However, a number of potential strategies may be considered. Recalling of abuse incidents, including disclosing, reviewing, and working through (Bass & Davis, 1988; Draucker & Martsolf, 2006), may be desired by those patients who have never before disclosed. Some may simply need to tell their story and have it truly witnessed before they die. For others, focusing on a "here and now" approach (Sanderson, 1990; Dale, 1993) may be more appropriate, such as concentrating on current significant relationships and important messages to be left for children. Others may simply opt for sedation to help contain flashbacks and control emotional pain combined with a safe holding environment.

Recommendations

Further research to identify the prevalence of childhood sexual abuse among cancer sufferers is called for, and the potential for and timing of routine screening of cancer patients needs to be considered.

A deeper understanding of the emotional and existential crises faced by patients and their partners who are survivors of abuse now facing death and bereavement is required to increase the confidence of those providing containment of internal processing. The impact on staff should not be underestimated, as holding paradox and conflicting emotion presents a considerable challenge.

REFERENCES

Arnow, B.A. (2004). Relationships between childhood maltreatment, adult health and psychiatric outcomes. *Journal of Clinical Psychiatry*, *65*(suppl 12), 10–15.

Bass, E. & Davis, L. (1988). *The Courage to Heal*. New York: Harper and Row.

Bifulco, A., Brown, G.W. & Adler, Z. (1991). Early sexual abuse and clinical depression in adult life. *British Journal of Psychiatry*, *159*, 115–122.

Bolund, C. (1993). Loss, mourning and growth in the process of dying. *Palliative Medicine*, *7*(Suppl 1), 17–25.

Chowns, G. (2005). Swampy ground: Brief interventions with families before bereavement. In *Brief Interventions with Bereaved Children*, Monroe, B. & Kraus, F. eds., pp. 125–139. Oxford: Oxford University Press.

Dale, P. (1993). *Guidebook for Counsellors*. Counselling adults who were abused as children. 531–532. Rugby: BAC.

Dalton, S.O., Boesen, E.H., Ross, L., et al. (2002). Mind and cancer: Do psychological factors cause cancer? *European Journal of Cancer*, *38*, 1313–1323.

Draucker, C.B. & Martsolf, D.S. (2006). *Counselling Survivors of Childhood Sexual Abuse*. London: Sage Publications.

Drossman, D.A., Leserman, J., Nachman, G., et al. (1990). Sexual and physical abuse in women with functional or organic gastrointestinal disorders. *Annals of Internal Medicine*, *113*, 828–833.

Felitti, V.J., Anda, R.F., Nordenberg, D., et al. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The adverse childhood experiences study. *American Journal of Preventive Medicine*, *14*, 245–258.

Fergusson, D.M., Horwood, L.J. & Woodward, L.J. (2000). The stability of childhood abuse reports. *Psychological Medicine*, *30*, 529–544.

Hardt, J. & Rutter, M. (2004). Validity of adult retrospective reports of adverse childhood experiences. *Journal of Child Psychology and Psychiatry*, *45*, 260–273.

Hill, J., Davis, R., Byatt, E., et al. (2000). Childhood sexual abuse affective symptoms. *Psychological Medicine*, *30*, 1283–1291.

Hunter, M.J., Davis, P.J. & Tunstall, J.R. (2006). The influence of attachment and emotional support in end-stage cancer. *Psycho-oncology*, *15*, 431–444.

Kissane, D.W., McKenzi, M., Forbes, A., et al. (2003). Psychosocial morbidity associated with patterns of family functioning in palliative care: Baseline data from the family focused grief therapy controlled trial. *Palliative Medicine*, *17*, 527–537.

Merrick, J. & Browne, K.D. (1999). Child abuse and neglect: A public health concern. *Public Health Review*, *27*, 279–293.

Molnar, B.E., Buka, S.L. & Kessler, R.C. (2001). Child sexual abuse and subsequent psychopathology. *American Journal of Public Health*, *91*, 753–760.

Mullen, P.E., Martin, J.L., Anderson, J.C., et al. (1993). Childhood sexual abuse and mental health in adult life. *British Journal of Psychiatry*, *163*, 721–732.

National Breast Cancer Centre and National Cancer Control Initiative. (2003). *Clinical Practice Guidelines for Psychosocial Care of Adults with Cancer*. Camperdown, UK: National Breast Cancer Centre.

Salmon, P., Hill, J., Krespi, R., et al. (2006). The role of child abuse and age in vulnerability to emotional problems after surgery for breast cancer. *European Journal of Cancer*, *42*, 2517–2523.

Salmon, P., Holcombe, C., Clark, L., et al. (2007). Relationships with clinical staff after a diagnosis of breast cancer are associated with patients' experience of care and abuse in childhood. *Journal of Psychosomatic Research*, *63*, 255–262.

Sanderson, C. (1990). *Counselling Adult Survivors of Child Sexual Abuse*. London: Jessica Kingsley Publishers.

The Scottish Government. (2005). *Survivors of Childhood Sexual Abuse: A Survivor Centred Strategic Approach Outline Strategy*. Edinburgh: Scottish Executive, Health Department.

Stokes, J., Wyer, S. & Crossley, D. (1997). The challenge of evaluating a child bereavement programme. *Palliative Medicine*, *11*, 179–190.

Tan, A., Zimmerman, C. & Rodin, G. (2005). Interpersonal processes in palliative care: An attachment perspective on the patient–clinician relationship. *Palliative Medicine*, *19*, 143–150.

Thomas, B.C., Pandey, M., Ramdas, K., et al. (2002). Psychological distress in cancer patients: Hypothesis of a distress model. *European Journal of Cancer Prevention*, *11*(12), 179–185.

Worden, W. (1996). *Children and Grief*. London: Guildford Press.