

## CASE REPORT

### MASTERING TASKS OF ADOLESCENCE: THE KEY TO OPTIMUM END -OF- LIFE CARE OF AN ADOLESCENT DYING OF CANCER.

*Suriati Mohamed Saini\* and Susan Mooi KoonTan.\**

\*Department of Psychiatry, Faculty of Medicine, UKM Medical Centre, Jalan Yaacob Latif, 56000, Cheras, Kuala Lumpur.

#### Abstract

**Objective:** This case report highlights the optimum end-of-life care of an adolescent dying of cancer. **Method:** We report our experience, as part of a multidisciplinary team in managing the cancers of a female student who died an untimely death at the age of 15. **Results:** Our role of motivating her for chemotherapy of her initial treatable carcinoma, became that of palliative care upon discovery of a second malignancy. We helped the patient “live life to the fullest” during her last days, she helped us realize that helping her master the tasks of adolescence was optimum “end-of-life care” as well. **Conclusion:** to help an ill adolescent die with dignity is to help her live whatever time she has left of her life. Allowing her to participate in decisions regarding her treatment and in other bio-psycho-social needs of that stage of life is crucial in helping her prepare for the end of life. *ASEAN Journal of Psychiatry, Vol.12(1), Jan – June 2011: XXX.*

**Keywords:** Adolescence, mastery of adolescent tasks, end-of-life care, death and dying.

#### Introduction

The Malaysia National Cancer Registry demonstrates that the Crude Incidence of paediatric malignancy aged from birth to 19 years for males and females were 18.0 and 14.0 per 100,000 populations, respectively [1]. For some young people this exciting period of individuation, increasing independence and freedom is profoundly altered and scarred by the unwelcome physical changes due to their cancer treatment.

The care of adolescent patients produce unique communication and management challenges because all aspects of their medical treatment are played out against a background of rapid physical, psychological, and social developmental changes [2].

The objectives of this case report are to highlight (i) the paradox that only by

helping the seriously ill adolescent master her tasks of adolescence optimally, can we help her accept and cope with the impact of serious illness and its potential physical and psychological disfiguring treatment, and (ii) that accurate, honest and sensitive communication between members of the multidisciplinary medical team together with understanding, loving and supportive family plays a pivotal role to achieve this outcome.

#### Case report

Z was a 15 year-old girl diagnosed to have ovarian carcinoma stage IV, of the juvenile metaplastic granulosa cell tumour type with liver and bone metastases. She had a total abdominal hysterectomy with bilateral salpingo-oophorectomy (TABHSO) and resection of involved areas of the gastrointestinal tract. She defaulted chemotherapy (Bleomycin, Etoposide, Cisplatin regime) after just 1

cycle done and was referred to child and adolescent psychiatry because she was lost her motivation to undergo treatment. This was because she could not tolerate the pain experienced during chemotherapy. The loss of her uterus after the TABHSO resulted in her perception that she had lost her femininity. Alopecia side effects of chemotherapy greatly affected her self-image. She had persistent depressed mood, anhedonia, poor appetite and death wishes. She believed all cancer patients would die. This was reinforced by dreams of her aunt who had died of cancer, wanting to 'take her away'. Premorbidly, she was a shy girl but active in sports and had won 3 gold medals in long jump whilst representing her district.

She was diagnosed to have Major Depressive Disorder and was started on Escitalopram 5mg daily. She learnt relaxation techniques to help with pain management such as breathing exercise, imagery and even enjoyed reading illustrated books which taught relaxation. She was happy to start chemotherapy after we had explained the process of treatment and likened it to her preparation for a sports competition but the goal of 'going through the pain' was to 'kill the bad cancer cells'. Local anaesthetic applied before blood taking and other invasive procedures relieved her fears of the recurrent pain. Discussions about the possible cosmetic use of a wig for alopecia put a smile on her face. Her mood improved and she was asking when the chemotherapy was going to start because she wanted to 'win the battle' against cancer.

The course of events changed drastically when she noticed a breast lump after one month in the ward, the histopathology showed infiltrative ductal carcinoma stage 111-BRCA2 hormonal negative. A multidisciplinary conference concurred that in view of the double malignancy, chances of response to active treatment of

both cancers would not be good. The primary team broke the bad news to Z and her family, taking care to discuss the options including palliative care and helping them understand the possible outcomes of each choice. Z did not speak but she understood all that was discussed. She still welcomed our visits and expressed interest in visiting the stadium where she won the gold medal. However, when the visit was actually planned and she realised she would need to go in a wheel chair because of her debilitating condition, she declined. She was still able to smile when treated to a box of chocolates, something the family did not usually indulge in. She decided to be discharged and three weeks after discharge the family called up to inform us that Z had breathed her last, lying on her sister's lap on the way back from seeing a traditional healer in Malacca. They thanked us for making Z's last days meaningful.

## Discussion

Adolescents have their own unique concept of death [3]. The Hungarian psychologist Mary Nagy described that children aged 9 and above can understand the concept that death is permanent, universal and inevitable[3]. Adolescents also are capable of understanding the physiological, psychological, and religious or spiritual aspects of death [4].

Adolescents face unique developmental challenges that require special consideration particularly when death from disease is likely. The primary challenges are (i) the achievement of biological and sexual maturation, (ii) the development of personal identity, (iii) the development of intimate sexual relationships with an appropriate peer, and (iv) establishment of independence and autonomy in the context of the socio-cultural environment [2].

The ultimate goal in discussing death with them is to optimize his/her comfort and alleviate any fears. Katz [5] has listed three inter-related principles for good end-of-life care (i) to enable the dying person to die with dignity, (ii) to retain the dying person in his/her familiar surroundings till death and (iii) good pain control and nursing care [6]. Depending on their religious belief and cultural practices, it is necessary to prepare them spiritually for the final everlasting place. This way he/she will be able to avoid bewilderment and the fear of an early death and leaving loved ones.

Decisions to continue or withdraw treatment can be facilitated when the patient's parents or next of kin and physician actively advocate the patient's best interests and communicates accurately, frequently and openly. In Z's case, the patient chose to go home and she died surrounded by her family in minimal discomfort.

In conclusion, accurate, honest and sensitive communication between member of the multidisciplinary team and the understanding, loving and supportive family are crucial to facilitate good quality of end-of-life care of a dying adolescent.

Paradoxically, quality end-of-life care of a dying adolescent is to help her master her tasks of adolescence optimally; as if she is

going to continue to live and grow up...for death is but part of life.

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**Corresponding author:** *Suriati Mohammed Saini, Lecturer, Department of Psychiatry, Universiti Kebangsaan Malaysia Medical Centre, Jalan Yaacob Latif, 56000, Cheras, Kuala Lumpur.*

**Email:** suriati@medic.ukm.my.

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