

ABSTRACT

Despite recent growth in Palliative Care education and research, there remains a paucity of attention paid to the voice of young patients, especially those in transition from adolescence to adulthood, living with and dying from advanced illness. The purpose of this project was to use one patient's story (through the gift of his uncensored journal) to better understand the perspective of youth living with and dying from advanced illness, ultimately improving the care provided. Insight gained through the patient's own narrative and interviews with his family, friends, and health professionals was used to create a play, which painted a "verbatim" portrait of the experience of one youth living with and dying from cancer.

Interviews were conducted with 25 family members and health professionals purposively sampled to reflect their relationships and knowledge of the patient. Semi-structured interview questions were based on the methodology of phenomenology and narrative analysis of the journal. This allowed the interviewer to focus on standard questions considered pertinent to the development of the play, but primarily provided an opportunity for the interviewee to tell his/her story.

This poster highlights the steps in bringing Ed's story to life. It offers reflection on the process and lessons learned from the perspective of the medical student, as interviewer.

INTERVIEWS

In total, 25 family, friends, and health professionals involved in Ed's care were invited to participate in interviews: 11 family members (parents, sister, aunts, cousins and friends) and 14 health professionals (nursing, oncology, surgery, physiotherapy, radiation oncology, anaesthesiology, occupational therapy, spiritual care, and palliative care) were purposively sampled to encompass a broad range of perspectives on the issues facing Ed at end-of-life. Interviews were audio-taped, transcribed, and analyzed for themes, noting similarities and differences expressed.

Health professionals were interviewed in offices or hospital meeting rooms, while family were interviewed both in hospital or private homes. The environment definitely affected the tone of the interview. When an interview was held in the home, items such as photo albums, and other mementos were used to illustrate points, while those conducted in hospital took on a more formal tone.

Interviews ranged from < 30 min (ostomy care nurse, anesthesiologist) to > 2.5 hours (primarily Ed's family and friends).

REFLECTION ON INTERVIEW QUESTIONS

Please tell me a bit about yourself and your relationship with Ed/Please tell me about Ed?

- Health professionals identified their roles in detail and then spoke about Ed, his illness and used consistent words in describing him. Family and friends simply stated their relationship to Ed and then proceeded to tell stories.

How did your experience with Ed affect you personally/as a health professional?

- This question revealed remarkable consistencies between family and caregiver interviews suggesting the experience of caring for Ed created some profound changes in their lives. For some, it forced them to re-examine how they practiced their profession, the radiation oncologist coming to terms with the healing and destructive potential of his treatment, and the physiotherapist not focusing on rehabilitation but comfort and protection. Family expressed similar perspectives, including looking to Ed's experience for strength to make challenging decisions, and modeling their behaviours to others, reflective of Ed's compassion.

Is there anything about Ed and your experience with him that you would like to share?

- Especially in a pediatric setting, the importance of a youth who possessed the maturity to be his own decision maker, was recognized.
- That Ed maintained his sense of humor and pursued his interests and hobbies while in hospital was noted as allowing one to express one's true "authentic self".
- His never ending hope "Remember Mom, there is only one fight, to the death"

INTRODUCING ED

Ed is a trickster, a skater, a gamer, a brother, son and friend.



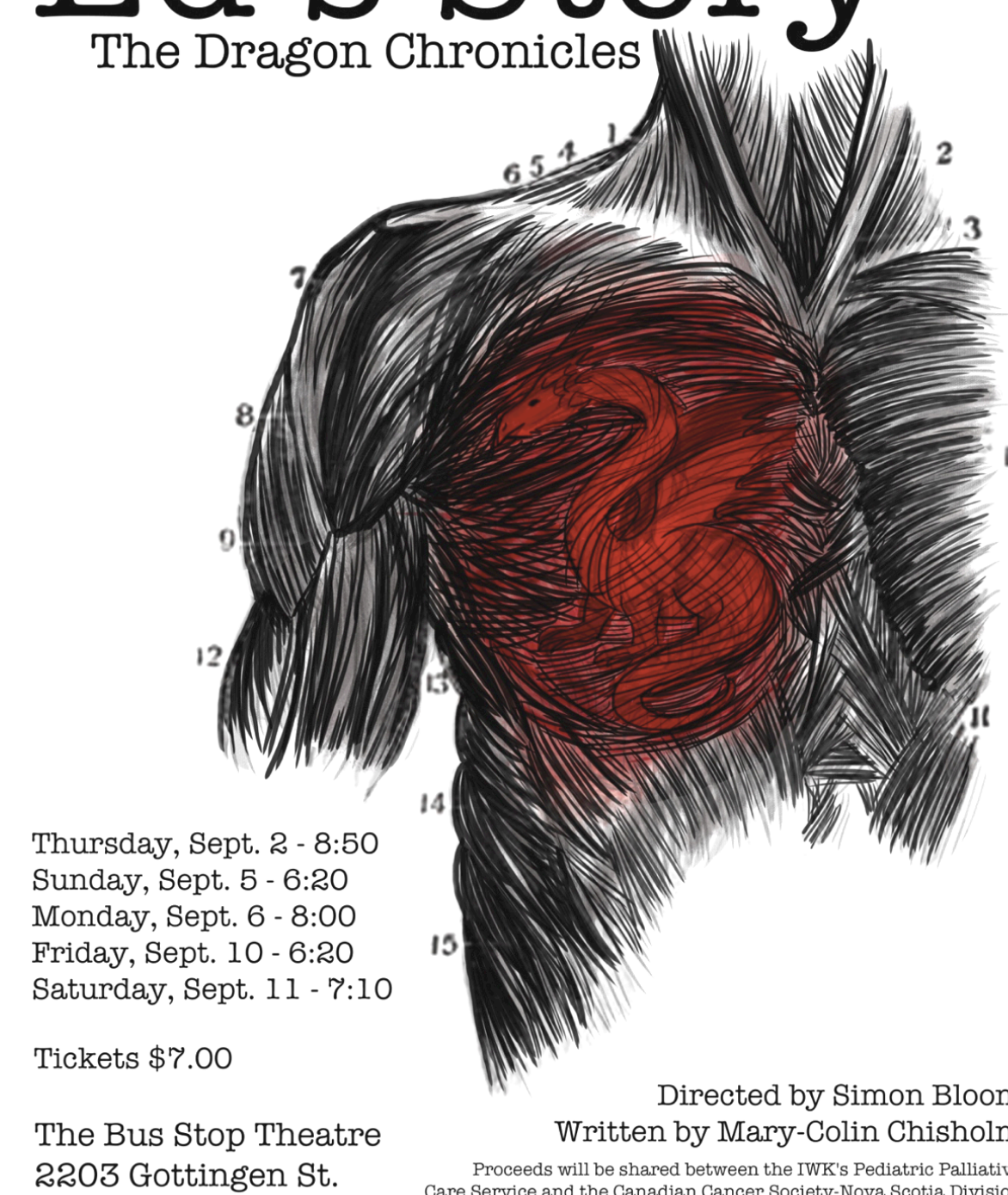
The kid who moons the whole school on a dare and always sticks up for the underdog.

Edward Kenneth Snair June 18, 1987 – May 27, 2004

At the age of 7, Ed accompanied his friend to Camp Good Time, a summer camp for children with cancer. Little did Ed know that he too would face his own battle with cancer

Ed was 15 years old when diagnosed with bone cancer and died 15 months later.

Ed's Story



Thursday, Sept. 2 - 8:50
Sunday, Sept. 5 - 6:20
Monday, Sept. 6 - 8:00
Friday, Sept. 10 - 6:20
Saturday, Sept. 11 - 7:10

Tickets \$7.00
Directed by Simon Bloom
Written by Mary-Colin Chisholm
The Bus Stop Theatre
2203 Gottingen St.
Produced with the support of Dalhousie University's Palliative Care Program
Cure Services and the Canadian Cancer Society Nova Scotia Chapter



ED'S JOURNAL

The journal was a Christmas gift from Ed's mother. Ed "spoke" to his journal everyday. Indeed, it was his confidante, the one "person" to whom he could honestly express his ideas, joys and fears. It offered him a place for artwork and creativity and a medium for reflection. The journal truly took on a life of its own.

... I'm glad I started using a journal. It's helped me a lot just getting my thoughts out and all.

Ed's journal was analyzed for themes that helped to determine the direction and content of interviews with family and caregivers. Themes identified include independence, burden, blame, escape, routine, spirituality and despair. Some of the major themes are highlighted below, illustrated by Ed's narrative:

Hope *I pray every night for some strength and the strength to get through this. My hopes are still up and all that. I've never really lost hope. Not gonna. Not gonna let this beat me.*

Pain *I think the tumor is growing REALLY fast or the swelling has gotten worse. I just can't get comfortable... My dressings have to be changed daily. I might need sedation again tomorrow. If I'm in a lot of pain - then I'll make them stop.*

Humor *If there are any arguments over who gets what - then a fight to the death will be used to determine - so hand to hand, no weapons, must take place at Bayers Road bowling alley.*

Relationships *Last time I was sick it was easy. I had Nichole. I really thought we were gonna be together forever. This time I don't have that comfort to see me at the end. I'd like to get involved again but I think I'll wait in case something happens. Not gonna put anybody else through this.*

Responsibility *Sure, I love hanging out with her and just chillin' but I don't want her to see me like this either... Both are really extreme ends of it but I want her to have fun when she's here. (referring to his 13 yo sister)*

Pride *Too stubborn. Didn't wanna admit I needed help. Look at where that's got me.*

Self awareness *I told her (Mom) to "Shut up or get out". Can't believe I did it. Really didn't handle it well... I don't ever remember back talking like that. Didn't know I had it in me. Guess I do have some spine. Wrong time to use it.*

CLINICAL PEARLS FOR THE STUDENT DOCTOR

Recognizing the need to develop good history and assessment skills, these interviews provided excellent education. While interviewing healthcare staff, especially faculty, I was aware of my language and tone, to appear "professional and competent". I found I was both listening/interviewing and trying to learn from their answers, gathering any "clinical pearls" prior to my own patient work. Staff were precise and succinct in their responses, gestures indicating the end of responses and transitions were more readily observed.

With the family interviews, each person had a unique way of expressing his/her stories, and it was my challenge to discover how best to encourage that. I had the luxury of virtually unlimited time. For some, it was to simply restate the question. For others, I needed to offer long pauses of silence and observe subtle hand or facial gestures indicating they were ready to move on. I also began observing incongruity between a person's verbal communication and their affect – the one subtle cue that would inform me that there was much more to explore.

During each interview, I was aware of my own limitations. Many stated these interviews provided the first opportunity to discuss Ed's story since his death and, as such, had the potential to unleash emotions that may never have had resolution. One can not deny the therapeutic potential of "giving permission" to explore these emotions, but I was also aware that I had neither the mandate, nor most importantly, the skill to guide persons through this experience. Palliative care staff did follow up with each person interviewed and counselling was made available to all. In reflection, I acknowledge that in future clinical encounters, I must be prepared professionally to deal with the sequelae of my actions.

Following the play, audience members expressed how pleased they were with a holistic approach that respected patient autonomy and that Ed was truly "not just a disease but a whole person." Discussion then followed concerning how both patients and professionals can work towards ensuring a "patient centered approach" to healthcare. Personally this challenges me as a learner to manage the patient's and my time efficiently by prioritizing the urgent issues, while at the same time demonstrating a commitment to follow up and discuss other issues that may deserve more time and in depth consideration.

Acknowledgements

- Ed for the generosity of his spirit and leaving the legacy of his journal
- Ed's family, friends and healthcare team who shared their thoughts which have now become the play
- Dr. Shauna Flaveller for her in-depth analysis of Ed's Journal
- Pat Randel and Grace MacConnell for expert analysis of the interview transcripts
- The actors: Iain Soder, Paul d' Alessandro, Ona Archibald and Schoel Strang (who also works as Administrative Assistant for the IWK's Pediatric Palliative Care Service) for their sensitive and compassionate portrayal of Ed's Story.
- Mary-Colin Chisholm for her extraordinary work in synthesizing mountains of information into a seamless portrait that maintained the dignity of Ed's experience.
- Simon Bloom for his skill in directing this complex play, ensuring humor is visible even through one's tears.
- The 25 interviews were supported by Dalhousie University's Medical Education Research and Development Fund and the Norah Stephens Oncology Scholar Award-Cancer Care Nova Scotia, awarded to M. Natarajan.
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