

Beyond the scarlet door: Exploring palliative care in terminal illness

Sharon Tay

Fourth Year Medical Student
Wellington School of Medicine
University of Otago

Sarah is a fourth year medical student at Auckland University with a prior BSc and outside interests in practically everything including: music, art, humanitarian issues, philosophy and cultures/languages. She's also been involved in medical research, with hyperreflexia being the main research interest. The hyperemesis gravidarum article was written for a General Practice learning needs paper.

*The true story of an unforgettable patient, Mr S.B.,
to whom I owe the privilege of peering into his amazing journey.*

*Dedicated to the memory of my maternal great grandmother (1903–1992)
whose courage in the face of terminal cancer I will never forget.*

Disclaimer: The names of all persons in this narrative have been changed in order to maintain the confidentiality of the patient and his carers.

*"For death begins with life's first breath, and life begins at touch of death" –
John Oxenham*

I. First Impressions: The Scarlet Door

Scarlet: an unforgettable bright red, symbolic of living blood. We faced the scarlet door with anticipation and uncertainty, three curious medical students on our first palliative care home visit. An earlier attempt to meet our patient had failed for he had been acutely hospitalised, so I was eager to venture beyond the scarlet door:

The door opened to reveal a slightly thin, white-haired gentleman who greeted us with warm handshakes. We were ushered to an upstairs living room and then a hushed silence fell upon us. I marvelled at the remarkable interior design of his home: sliding glass doors, sleek metallic sculptures, warm illumination and bold colours contrasting with cool, dark tones. As we sat against a stunning hilltop view of the Wellington harbour by night, our patient revealed his story.

II. Joe Architect: His Story

Born in Wellington in 1952, Joe Architect, a 55-year-old European New

Zealander, left college to carve his niche as an architect and builder. Following two failed marriages, he met his partner Shirley two years ago while he was battling colon cancer. They have since lived together. Joe's next-of-kin are an elderly mother and his eldest son from his first marriage who is now 23.

Joe was diagnosed with colon cancer in late October 2003. Previously well and active, he had developed symptoms of altered bowel habit, bloody stools and significant weight loss. Following surgery in November 2003 to remove a tumour from his sigmoid colon, he underwent six months of adjuvant chemotherapy. Despite having received a good prognosis, Joe suffered his first relapse in May 2005 with metastases to his paraaortic lymph nodes; he received chemotherapy and surgery with subsequent remission. By July 2006, the cancer recurred in his paraaortic lymph nodes with liver metastases. Within six months his disease progressed rapidly beyond hope of eradication and he suffered from significant breakthrough pain, nausea, episodic vomiting and jaundice due to obstruction of his stomach and bile duct by an enlarging epigastric tumour. The disease that was slowly consuming his body also took a psychological toll on Joe: he developed nocturnal hallucinations and spiralled into depression.

By January 2007 Joe was grappling with his treatment options. The side-effects of chemotherapy made him feel very ill and he did not wish to continue. Repeated biliary stenting had only lasted a month each time with recurrence of obstruction. Therefore with support from his GP and partner, Joe requested his oncologist to cease all curative treatment seeking instead palliative radiotherapy and medications for symptomatic relief. Joe's current medications are antibiotics (ciprofloxacin, clexane, omeprazole) for prophylaxis of infection; cyclizine for nausea; morphine via a syringe-driver for pain; bisacodyl and laxsol to relieve constipation; clonazepam for insomnia; and nortriptyline for depression.

III. Living with Terminal Illness: Joe's Perspective

Joe's journey through his illness has been an emotional rollercoaster ride. Upon his initial diagnosis, he experienced intense psychological shock for he was "too young to die of cancer." After his initial surgery in 2003, he was optimistic about his "85% chance of survival." However, his hopes diminished with each relapse. Faced with recurrent metastases, Joe began to channel his frustration into lifestyle changes like aggressive exercise and diet modification, with his zeal to "battle his cancer" manifesting as denial of disease progression. He continued to strive towards his hopes and dreams, throwing himself into his work and renovating Shirley's home into an architectural masterpiece. However, as he grappled with the reality of his deteriorating condition Joe sank into depression. The spectrum of emotions in his grieving process finally culminated as acceptance by early

2007 when he began to consider a palliative approach to his care. This significant development has enabled him to begin carrying out plans for "the rest of his life." Nonetheless Joe still vacillates between various stages of grief, triggered primarily by his concerns for the future.

Progressive terminal cancer has also taken a physical toll on Joe, manifest as intractable nausea and vomiting, cholestatic itch, worsening breakthrough pain exacerbating insomnia and fatigue, and the side effects of his increasing analgesic requirements. His weight has declined drastically as the very sight or smell of food causes nausea. In addition he is also prone to infections due to his immunosuppression. Joe's main physical concerns at this time are adequate relief of his pain and nausea to ensure dignity, as well as comfort and quality of life for his last days with Shirley and his loved ones.

Living with terminal cancer also poses psychosocial concerns for Joe. Despite having accepted that he is dying, Joe appears to be facing tremendous existential pain. During the interview he broke down several times and wept in silence, uncertain of how much time remained for him to achieve his unfulfilled hopes and dreams, as well as anxiety and sorrow at the thought of saying goodbye to his loved ones.

Joe denied being spiritual, deriving support primarily from loved ones, particularly his partner and son, as well as his friends.

IV. The Impact of Terminal Illness on Loved Ones

Shirley shared some of her experiences living with Joe as he grappled with his terminal illness. As his partner of two years, she had initially faced disapproval from well-intentioned friends when she fell in love with Joe regardless of his uncertain prospects as he actively battled cancer at the time. She is now his constant companion and source of emotional support.

Shirley acknowledged the pain and frustration of witnessing Joe suffering physically. She also described the struggle in keeping up with Joe's unpredictable mood swings, especially since she often cannot adapt her mood quickly enough to buffer his. When Joe opted for palliative care Shirley was disappointed that he had given up the fight against cancer but supported him nonetheless. She has coped very well with his terminal illness, despite its physical and social toll on herself: she has given up her job indefinitely to spend with Joe his remaining days, accompany him to medical consultations and live in the hospice during his admission. Their quality of life and future plans are entirely dependent on changes in Joe's condition.

Joe's family and friends have yet to accept his terminal illness. He has faced pressure from them to continue curative treatment or seek alternative and complementary therapies. Joe's primary social concern is the well being of his loved ones, making financial arrangements for after his death and organising his mother's living arrangements. Regular meetings are held to update the family about Joe's condition and plans for the future.

V. Role of Health Professionals

Joe expressed great satisfaction with the care he received from his multidisciplinary team. Joe has received hospital care from both Surgery and Oncology, in close coordination with his GP. Following his decision for palliative care, Joe's transition towards hospice care has decreased his reliance on his GP.

At present, ongoing management is coordinated by a Palliative Care Coordinator (PCC) from Mary Potter Hospice. A specialist nurse who conducts fortnightly home visits monitors Joe's health and medications including pain management, diet plans and acute admissions. In so doing, the PCC serves as a source of continued external support and ensures liaison between all health professionals involved.

In grappling with recurring thoughts of death and dying, Joe expressed a strong desire for "a peaceful death that will not be unpleasant or messy," rather than burdening his carers. Aside from prescribing medications to relieve insomnia and depressive symptoms, Joe's psychiatrist has played

a vital role in dealing with Joe's overwhelming anxiety and existential pain by empowering Joe to address his anxiety and actively plan how to live his remaining days.

Joe continues to live at home with Shirley. However, he intends to move into the hospice should his condition deteriorate suddenly in order to "avoid inconveniencing his family." He desires to preserve pleasant memories for Shirley of times shared in their beautiful home.

VI. Ethics of Palliative Care

Shirley is grateful to health professionals for including her in consultations, since the decisions made would impact significantly on both Joe and herself. The couple feel that excellent communication and rapport with the healthcare team is central to ensuring the best quality of care. Joe's autonomy has been respected in his medical decisions, which was facilitated by strong advocacy from healthcare professionals; informed consent through clear explanations of disease and illness progression; and integration of professional knowledge and opinions on appropriate management through a multidisciplinary approach.

In Joe's situation, the ethical issue of significance is the critical decision to accept the transition into palliative care. In other words, when should curative treatment cease? The question is raised whether it is justifiable to continue with curative treatment given his poor prognosis. Evidently, the opinions of healthcare professionals, carers, family and social contacts may vary distinctly from that of the patient. In any circumstance, Joe's perspective is undoubtedly critical and emphasis should be placed on ensuring his well being by respecting his autonomy as much as possible. From a public healthcare perspective, resource allocation issues for patients would also need to be justified, however; this does not appear to be a significant issue in Joe's care.

Upon careful consideration of Joe's transition from curative treatment to palliative care, ethical frameworks must be applied to weigh the benefits and disadvantages of both options. The ethical tenets of beneficence, non-maleficence, justice, autonomy, dignity and truth-telling may come into conflict with each other; thus need to be balanced in light of Joe's unique context. Factors supporting Joe's decision for palliative care include respecting his right to make personal decisions concerning his life's end (autonomy); maintenance of dignity through ensuring a comfortable, peaceful death by relieving his symptoms (beneficence); and avoiding the unpleasant side-effects of curative treatment such as vomiting (non-maleficence). At this stage, these factors appear to best fulfil Joe's desires and outweigh the disadvantages of terminating curative treatment, which include the loss of hope of remission (beneficence), and the inevitable outcome that Joe is likely to die from cancer (non-maleficence).

As such, Joe's decision for palliative care appears to be ethically justified, and it is vital that his decision continues to receive full support from his partner and healthcare team, as well as gradual acceptance by his loved ones.

VII. Personal Reflections: Beyond the Scarlet Door

My meeting with Joe and Shirley in their home has been a novel and enlightening experience. I was impressed by the scope and quality of professional care and support that Joe and Shirley have received in living with his terminal illness. Moreover, taking into consideration the ethical issues involved, it was heartening to acknowledge that Joe's well being and autonomy have been highly prioritised. Joe has been able to take an active role in decisions about his dying and the management of his care, and this has helped him regain a degree of control and 'normalcy' in living with his terminal illness.

I have a finer appreciation of Joe's struggle to accept his terminal illness and transition into palliative care. It is apparent that his emotional and psychological struggles are likely to persist in the remaining days of his life, even as his body succumbs to physical disease, highlighting the crucial