CASE REPORT

Inadvertently boarding a pirate ship: disease progression in a paediatric patient with relapsed metastatic Ewing sarcoma receiving treatment at a centre for alternative therapy in Mexico

Jessica H Cheng,¹ Leslie Y Chiang,² Dennis John Kuo³

¹School of Medicine, University of California, San Diego, La Jolla, California, USA

²Department of Pediatrics, University of California, San Diego, La Jolla, California, USA

³Department of Pediatric Hematology-Oncology, University of California, San Diego, San Diego, California, USA

Correspondence to

Dr Dennis John Kuo,
dekuo@ucsd.edu

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SUMMARY

Complementary and alternative medicine (CAM) therapies are commonly incorporated into the care of patients with paediatric cancer. Many modalities are safe and effective during cancer treatment and have proved beneficial for symptom relief and quality of life. However, situations where alternative therapy is provided without allopathic medical care supportive care resources can pose a safety risk to patients. This report describes the case of a 16-year-old Chinese girl with metastatic Ewing sarcoma who sought treatment with alternative treatment in Mexico. When her disease progressed with an ensuing significant loss of function, the centre personnel were unable to respond to her acute deterioration or provide necessary medical care. This resulted in her being stranded in a foreign country paralysed, isolated, and with large unanticipated financial expenditures.

travelled far from her home country to seek treatment with alternative therapies.

CASE PRESENTATION

A 16-year-old Chinese girl presented to a children's hospital in California with paralysis and loss of sensation in her lower extremities and urinary retention. The patient had been diagnosed with metastatic Ewing sarcoma of the right 7th rib in April 2014 in her home country. At that time she received standard of care treatment with chemotherapy, surgical resection, radiotherapy and adjuvant chemotherapy. Unfortunately, recurrent disease was discovered 2 months later. She received local radiotherapy and several additional courses of chemotherapy, but the cancer continued to spread with development of multiple metastatic lesions in the spine and ilium. Autologous stem cell transplant was discussed with the family; however, the salvage plan provided limited hope for cure with a high risk for toxicities. The parents understood that allopathic treatment options had become limited and wished to explore alternative therapies.

The family became interested in Gerson therapy, an alternative treatment regimen consisting of a strict diet, dietary supplements and enemas. The patient's primary oncologist discussed the risks and benefits of stopping treatment and pursuing alternative therapy, and was understanding of the family's wishes to pursue alternative therapies given her poor prognosis. The patient and her parents travelled to a wellness centre in Mexico for a 3-week course of Gerson therapy after stopping all allopathic treatments for 1 month, as required by the centre. The centre specified that patients needed to be ambulatory in order to be eligible for the treatment, but it did not specify what safeguards were in place should a patient's functional status change during the course of their stay. At the time of initiation of the alternative therapy, the patient had no functional deficits and was independent in all activities of daily living.

On arriving at the centre, the patient's parents needed to sign a waiver releasing the centre's founder and its personnel from medical liability should the treatment be ineffective or if treatment-related complications arise during treatment. Although the centre does not guarantee disease response or cure, the centre's website emphasised that Gerson therapy has enjoyed

BACKGROUND

The term complementary and alternative medicine (CAM) encompasses many diverse treatment modalities outside of allopathic medical care. In general, complementary medicine refers to treatments used alongside allopathic medical care, and alternative medicine refers to treatments used in lieu of allopathic medical care. These therapies include, but are not limited to, yoga, acupuncture, massage, biofeedback, meditation, chiropractic manipulation, qi gong, homeopathy, special diets, dietary supplements and naturopathic treatments. The CDC's 2012 National Health Interview Surveys show that among children aged 4–17 years in the USA, 11.6% have used any complementary health approach in the past year, with the use of CAM therapies by parents being the strongest predictor of use by children.¹ This percentage is higher among children with cancer, ranging from 6% to 91%, with the most common reasons reported for CAM use being to cure or fight the child's cancer, to provide symptomatic relief and to support ongoing standard medical care.²

Regardless of the type of therapy provided, care providers should have contingency plans in place in the event of acute medical emergencies. This becomes doubly important when patients seek care outside of their home country, where standards of care and insurance mechanisms may vary. This case report describes the experience of one patient who

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100 years of success in treating advanced diseases, with most patients with advanced cancers experiencing major reductions, if not complete disappearance of the tumours within 12–16 weeks. The waiver was in English, and the only languages spoken by the centre staff were English and Spanish. The patient and her parents were not fluent in either language, and a Chinese interpreter was not present when the waiver was signed.

The patient began a strict regimen of alternative therapies. She was given fruit-based and vegetable-based juices with added potassium and other dietary supplements, including niacin, acidol, CoQ10, selenium, digestive enzymes and probiotics eight times per day. She received coffee enemas two times per day, laetrile (ie, vitamin B17) injections 5 times/week and intramuscular injections of liver extracts twice per week. She soaked in a hot tub 3 times/week to induce hyperthermia to try to destroy cancer cells. She spent 45 min in a hyperbaric chamber 3 times/week. She received therapy with a Silver Pulser (a device that provides a small electrical current to purify the blood of cancer cells, microbes and toxins) and used a Bemer mat, which emits magnetic pulses, for 8 min twice per day.

The patient spent a total of 3 weeks at the treatment centre. Approximately 10 days into therapy, she began to develop weakness and numbness of the bilateral lower extremities. Over the next week and a half, her symptoms progressed until she was completely paralysed below the waist and had lost all sensation as well as bowel and bladder control. She developed severe pain in her back and neck which necessitated pain medications which were obtained from an outside facility, as the centre did not stock the pain medications. During her last few days at the centre, she started to have shortness of breath which again required a special outside order for supplemental oxygen. At one point the oxygen tank ran out overnight and a new tank could not be procured until the following day. During this time, she was also admitted overnight to a hospital in Mexico where she was found to be anaemic and received a blood transfusion. Given the lack of supportive services onsite and the need to send out for services that are routine in a typical hospital or clinic, her parents realised that the centre was unable to manage many of the potential complications of the advanced diseases treated.

The patient and her family had planned to return to their home country at the end of her treatment. However, given the serious and rapid decline in her clinical condition, the parents did not feel comfortable returning home at that time. The personnel at the centre recommended sending her to a local hospital in Mexico, which the family did not feel was appropriate. The family elected to cross the Mexican-American border and brought the patient to a children's hospital in California for evaluation and management.

TREATMENT

The patient was admitted to the Paediatric Intensive Care Unit (PICU) where an MRI demonstrated extensive metastases with compression fractures of the lumbar spine. A neurosurgery consultation felt that the extended period of nerve compression had likely caused irreversible damage that could not be alleviated by surgery. She was started on dexamethasone to attempt to decrease peri-tumorous oedema, but ultimately without recovery of function. Further complicating treatment options, since the family was not from the USA, they had no insurance coverage for care; thus all costs incurred would have been borne out-of-pocket. Radiation therapy would have been a consideration, but this would have been very costly, and at this late time

point would have had a low likelihood of success. Given the extent of the patient's disease, goals of care were discussed at length with the family. They understood that no curative options remained and that any further treatment in America would have been palliative at best and very expensive at least. They elected for non-invasive supportive care and made arrangements for medical transport back to their home country in Asia, which occurred 7 days after admission.

OUTCOME AND FOLLOW-UP

The patient and her family were transported back to their home country by International SOS, a company that provides medical and travel assistance to patients overseas. Once home, she was admitted to her home hospital where she was initiated on palliative chemotherapy and radiation therapy under the care of her primary oncologist. She passed away 5 weeks later.

From a financial perspective, the family paid over US\$24 000 at the alternative therapy centre in Mexico. This does not include the additional costs of pain medicines when the patient began to experience pain (~US\$700), blood transfusion and overnight admission at an outside hospital in Mexico (~US\$885) and ambulance transport to the Mexico-USA border (US\$300). There will also be significant expenses associated with the costs of a 7-day hospital stay (including two nights in intensive care) in the USA and medical transport to Asia.

The patient and her parents described their experience at the centre in Mexico to be frustrating, futile and ultimately harmful to the patient. There is a Chinese idiom (誤上賊船) which translates to 'inadvertently boarding a pirate ship'. It describes a situation where one unwittingly embarks on a journey that ends in one being trapped in misfortune. This encapsulated how this family felt about their experience at the wellness centre.

DISCUSSION

Complementary, integrative and alternative medical therapies can be attractive to patients who have exhausted conventional treatment options, and may be particularly attractive for patients diagnosed with an incurable terminal illness. Increasingly, CAM therapies are employed in conjunction with conventional medical treatments. Patients may use CAM as a means to have more control over and agency in their challenging situations.³ Many medical centres have integrative therapy programmes that combine allopathic and complementary medicine, with benefit to patients. Among patients with cancer, techniques such as mindfulness-based therapy and meditation have been shown to be effective in improving quality of life and managing emotional distress.^{4–8} In light of the promising results of various CAM interventions, more well-designed and high-quality studies should be continued to gauge their safety and efficacy.⁹

It is important to distinguish between complementary or integrative medicine and alternative medicine. Complementary and integrative medicine refers to therapeutic modalities used in conjunction with allopathic treatments. The term alternative medicine is used to describe therapies provided as a replacement for conventional allopathic medical therapy.¹⁰ However, when conventional allopathic treatment is deferred while alternative therapy is pursued, there is a risk that the patient will not have the benefits of disease or symptom control that conventional allopathic medical care would have provided.^{11–13} Among the therapies that our patient received, many have not been found to be efficacious in the medical literature, and some have been associated with significant risk of harm. Coffee enemas have not been demonstrated to detoxifying the body.¹⁴ Several cases of severe hyponatraemia (possibly from the Gerson method's

prescribed low-sodium, high-potassium diet) and fatal bacterial sepsis from improperly prepared bovine liver injections have been reported.¹⁵ Laetrile, a popular therapy among alternative therapy clinics, has not shown efficacy as a cancer treatment and is associated with the risk of cyanide toxicity.¹⁶

With interest in complementary and alternative therapies increasing, many patients with cancer have a legitimate desire to explore CAM therapy. Allopathic medical care providers should respect their patient's autonomy by providing them with up-to-date, evidence-based information about how CAM therapy may or may not be appropriate. CAM can play an important role in supportive care, especially with helping patients manage pain or mood symptoms. Patients should also be counselled in an unprejudiced way about the scientific literature of the risks, benefits and limitations of CAM.

When advising patients who are interested in alternative therapies, especially in the absence of allopathic medical support, it

is important to advise the patients about potential pitfalls and unforeseen complications. Patients seeking alternative therapies should be counselled to have a readily available allopathic medicine back-up plan to manage medical complications that may arise. Otherwise, these patients may also find themselves on the Chinese proverb's pirate ship.

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REFERENCES

- 1 NHIS—National Health Statistics Reports [Internet]. (cited 13 Sep 2016). http://www.cdc.gov/nchs/nhis/nhis_nhsr.htm
- 2 Bishop FL, Prescott P, Chan YK, *et al.* Prevalence of complementary medicine use in pediatric cancer: a systematic review. *Pediatrics* 2010;125:768–76.
- 3 Söllner W, Maislinger S, DeVries A, *et al.* Use of complementary and alternative medicine by cancer patients is not associated with perceived distress or poor compliance with standard treatment but with active coping behavior. *Cancer* 2000;89:873–80.
- 4 Rummans TA, Clark MM, Sloan JA, *et al.* Impacting quality of life for patients with advanced cancer with a structured multidisciplinary intervention: a randomized controlled trial. *J Clin Oncol* 2006;24:635–42.
- 5 Carlson LE, Ursuliak Z, Goodey E, *et al.* The effects of a mindfulness meditation-based stress reduction program on mood and symptoms of stress in cancer outpatients: 6-month follow-up. *Support Care Cancer* 2001;9:112–23.
- 6 Ott MJ, Norris RL, Bauer-Wu SM. Mindfulness meditation for oncology patients: a discussion and critical review. *Integr Cancer Ther* 2006;5:98–108.
- 7 Moadel AB, Shah C, Wylie-Rosett J, *et al.* Randomized controlled trial of yoga among a multiethnic sample of breast cancer patients: effects on quality of life. *J Clin Oncol* 2007;25:4387–95.
- 8 Carlson LE, Doll R, Stephen J, *et al.* Randomized controlled trial of mindfulness-based cancer recovery versus supportive expressive group therapy for distressed survivors of breast cancer. *J Clin Oncol* 2013;31:3119–26.
- 9 Bardia A, Barton DL, Prokop LJ, *et al.* Efficacy of complementary and alternative medicine therapies in relieving cancer pain: a systematic review. *J Clin Oncol* 2006;24:5457–64.
- 10 Adams M, Jewell AP. The use of complementary and alternative medicine by cancer patients. *Int Semin Surg Oncol* 2007;4:10.
- 11 Mistry R, Wademan B, Avery G, *et al.* A case of misdiagnosed squamous cell carcinoma due to alternative medical misadventure—time for tightening regulation? *N Z Med J* 2010;123:61–7.
- 12 Sheldon T. Netherlands to crack down on complementary medicine. *BMJ* 2004;328:485.
- 13 Coppes MJ, Anderson RA, Egeler RM, *et al.* Alternative therapies for the treatment of childhood cancer. *N Engl J Med* 1998;339:846–7.
- 14 Green S. A critique of the rationale for cancer treatment with coffee enemas and diet. *JAMA* 1992;268:3224–7.
- 15 Centers for Disease Control (CDC). *Campylobacter sepsis associated with "nutritional therapy"—California. MMWR Morb Mortal Wkly Rep* 1981;30:294–5.
- 16 Moertel CG, Fleming TR, Rubin J, *et al.* A clinical trial of amygdalin (Laetrile) in the treatment of human cancer. *N Engl J Med* 1982;306:201–6.

Learning points

- Complementary and alternative medicine (CAM) has become increasingly popular in modern-day medical treatment, especially among patients who have few allopathic options available to them. If patients are interested in pursuing CAM therapies, open and respectful discussions should be held with their physicians regarding the risks, benefits and alternatives.
- Informed consent is a critical prerequisite to any medical treatment, be it allopathic or CAM. This entails an understanding of the risks, benefits, alternatives, rights and contingency plans on the part of the patient and family and the assumption of fiduciary duty to the patient for the outcomes on the part of the provider.
- When administering CAM therapies, providers should have contingency plans with appropriate logistical preparations on hand in case complications or emergent situations arise.
- Special considerations should be taken into account when a patient travels outside of their home country to seek medical care. This includes financial costs incurred by lack of insurance, language barriers that preclude full understanding of information, documentation and proceedings, and the lack of legal protections that one would expect in one's home country.

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