

Patient with dementia and basal cell carcinoma

Laura Fung MD CCFP Rita K. McCracken MD CCFP

Mrs Birch (not her real name) was a strong, cherished 95-year-old woman with severe dementia. She grew up in Vancouver and White Rock in British Columbia. As a child she played at the beach on sunny days; as an adult, she spent every day outdoors in her garden. Her fair skin, untouched by sunscreen, was sun damaged and covered with lesions consistent with actinic keratosis. Otherwise, Mrs Birch's physical health was quite remarkable, especially in stark contrast to her advanced cognitive disease. Her family had cared well for her at home until her Alzheimer disease became very severe.¹ I (R.K.M) took over her primary care 2 years into her 7-year nursing home stay; by then she made only occasional intelligible verbal expressions, sometimes appeared to recognize close family members, was incontinent, had contractures in all 4 limbs, and needed her meals spoon-fed by an attentive companion. Her previously expressed desire for comfort care and a nonresuscitative code status was well understood by her family, by me, and by the staff at the care facility. Given her advanced Alzheimer disease and what I had been taught about reasonable prognosis,² I told her family members when I first met them that we could expect her to pass away in the next 18 to 24 months and that we would do everything we could to keep her comfortable.

Treatment course

In August 2010, I noted an ulcerated lesion on Mrs Birch's right temple. Over the next 30 months, the lesion grew from 1 to 3 cm and then became slightly raised. I discussed this lesion (as well as a few others on different body parts) with her family and at her annual multidisciplinary patient care conference. Her family members maintained their desire to avoid unnecessary treatments and trips outside the facility. Accordingly, we kept the lesions clean, but otherwise did nothing.

By May 2013, the lesion on her face had grown to the size of half a golf ball. A large bandage kept it covered, as nurses were concerned with its appearance (it was friable, occasionally bleeding, and eventually malodorous). Because dressing changes were time-consuming, they were usually done before I arrived for my weekly rounds, so I only rarely looked at the lesion. I did review nursing notes and check in with the family regularly. We still made no change to our conservative treatment plan.

In late July, Palliative Wound Care was consulted by a facility nursing team member who was concerned with the possibility of a massive "terminal bleed" from the lesion. After this unexpected consultation, I examined the lesion and became more concerned by how much

it had grown between May and July; it had increased to the size of half a softball. Subsequently, I second-guessed my ability to care for this patient and called a radiation oncologist and a plastic surgeon. With the aid of a photo I sent, the surgeon and oncologist identified the lesion as a giant basal cell carcinoma (BCC). Both specialists remarked that they had rarely seen one that big. The tumour measured 12×12×7 cm and was encroaching on her right eye. Over the telephone, both specialists recommended an urgent course of radiation, perhaps a surgical resection, and were eager to see Mrs Birch in person. I met with her family members and let them know that I supported the idea of radiation. They were a bit confused about this change in course of treatment, especially because she still did not appear to be bothered by the lesion. However, they trusted my judgment, and Mrs Birch was transported via ambulance for several specialists' appointments (as well as for a computed tomography scan, which revealed no sign of metastases).

In September, Mrs Birch completed a brief course (5 sessions) of palliative radiotherapy in an effort to decrease the bulk of the tumour for easier wound care and comfort. By early October, the tumour appeared to have decreased in size by 20%. However, her right eye was now clouded over, and I suspected she was having pain from a large radiation burn that was visible on the right side of her face.

The plastic surgeon suggested aggressive resective surgery; however, when the issues regarding risk of death, complications, and suffering were explained by the surgeon and reiterated by me, her family decided not to proceed. The palliative radiation therapy had only marginally decreased the bulk of the tumour and it caused what appeared to be a painful burn. In fact, the treatment might have resulted in more discomfort for the patient than the tumour would have produced had it been left alone.³

In November, the lesion began to grow again, fungating along the periphery. Within weeks, Mrs Birch developed a cough with crackles on auscultation. Her family members' decision was clear: they did not want unneeded intervention. Together, we opted for hydro-morphone for dyspnea and decided not to use antibiotics for the possible pneumonia. Days later, Mrs Birch died peacefully.⁴

Discussion

As I reviewed this case with peers and trainees, we identified 2 of the main decision points that affected the

outcome for Mrs Birch. First, the treatment for BCC is well understood,⁵⁻⁷ and if I had followed routine interventions early on, I might have spared this woman and her family having to deal with the giant tumour later. However, both rapid growth and metastases of BCC are exceedingly rare: incidence rates range from 1% and 0.0028% to 0.55%, respectively.⁸ Given the clinical context of Mrs Birch's end-stage dementia before the rapid tumour growth, I had thought it was reasonable to manage the lesion conservatively, aiming to maximize comfort, avoiding even the potential pain and itching from a topical treatment.^{9,10} I think I would likely make the same decision about not treating again for small lesions in someone with such considerable advancement of a cognitive disease.

Second, despite her family members being clear about their decision that Mrs Birch receive comfort care only, when faced with the dramatically large tumour, I advocated for the treatment plan laid out by my intervention-oriented colleagues in radiation oncology and plastic surgery. But when I saw the resulting radiation burn, I once again began doubting my decision making: Had I done the right thing? Had I prolonged the dying process because seeing something big and ugly made me act differently? Was the tumour worse than the dementia was? Why had I called specialist colleagues and not someone in palliative care or someone else who worked in the nursing home setting and had more experience than I did?

Conclusion

My experience with Mrs Birch and her rare giant BCC speaks to the very real and common dilemmas of treatment at the end of life and the fine balance between prolonging survival and supporting a dignified death. I learned much from Mrs Birch and her family, and I hope that in the future I will have the clinical courage to listen to family and patient wishes, watch such a lesion grow,

and allow nature to take its course, rather than following an interventional model of care.



Dr Fung is a practising physician in Toronto, Ont. **Dr McCracken** is a family physician in Vancouver, BC, and a doctoral candidate in the Department of Family Practice at the University of British Columbia in Vancouver.

Contributors

Dr Fung contributed to the conception of this article, performed a literature review, wrote the first several drafts of the paper, and provided comments on all other drafts. **Dr McCracken** provided clinical care to the patient described in this article, managed interactions and permissions with the patient's family, and wrote the first-person version of this paper.

Competing interests

None declared

Correspondence

Dr Rita K. McCracken; e-mail rita.mccracken@ubc.ca

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