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Negotiating Place Through Material Culture

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Article abstract

In this article the author reflects on the objects brought into his father’s hospice room in the last eight weeks of his life. Objects and their placement were continually renegotiated as he moved through various stages of his disease — greater and lesser pain, appetite, freedom of movement, and lucidity, and shifting timeframes for his imminent passing. The author’s father had no direct control over the presence or absence of objects, and little control over their placement, so that the room became a site of polite contestation among the various parties helping him in his final days.

“THE VERY ENVIRONMENT MILITATES AGAINST DENIAL”

Negotiating Place Through Material Culture

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On Monday, the tenth of September 2001, three days after his regular checkup with his family doctor, Bernard Brodie awoke at 5:30 in the morning with a stomach pain, only to find blood in his urine. He called his companion Gladys, a retired nurse who was out of town visiting her daughter’s family, and she recommended he go to the emergency room. Expecting to hear of a kidney stone, he was instead told that it was probably renal cancer in his right kidney, which meant a simple nephrectomy (removal of a kidney) followed by a return to normal. Three days later a biopsy confirmed that it was indeed renal cancer. At the end of the month, an oncologist informed him that the initial prognosis was perhaps a little optimistic: if the cancer had metastasised, which was likely, he was in trouble. Renal cancer does not respond well to treatment, with little benefit from radiation and none at all from chemotherapy. It was thought likely to have metastasised because renal cancer, being asymptomatic, is more often than not diagnosed indirectly by its secondary tumours: blood in the urine is the only directly attributable warning sign, which typically appears at an advanced stage. Some additional lesions were suspected in the lymph nodes surrounding the kidney and, on the first of November, during the radical nephrectomy which had been postponed a week, that suspicion was also confirmed. When the surgeon described the amount of removed tumour, kidney, and surrounding tissue to Gladys and his daughter Elanor, he held his arms, in Elanor’s words, as if he were holding a ten pound baby. Although he had removed the lymph nodes immediately surrounding the kidney, the doctor described seeing the renal fascia (the sheath of tissue that surrounds the kidney) peppered with lesions. However, with no confirmed lesions elsewhere, it was believed to be only in the first stages of metastasis.

In the weeks that followed, Bernard noticed a numbness and loss of fine motor skills in his left side, particularly in his arm. Upon asking the oncologist about this he was told it was probably minor tissue damage to the nerves, having spent the four and a half hours of the operation lying on his left side with his arm tied behind his back. The numbness continued, and a subsequent dizziness and loss of equilibrium was attributed to the same tissue damage. On the eighteenth of November, the loss of sensation was so great that he again went to the emergency room, where he tripped and fell in the waiting room, hitting his head on a table. A CAT scan and an MRI discovered four lesions in his brain, two on each side. A pressure was building which gave "stroke-like" symptoms. He was immediately prescribed, among others, *Decadron* (dexamethasone), a synthetic steroid used in instances of brain metastasis as an anti-inflammatory. After meeting with the radio-oncologist in early December, a course of treatment was chosen: daily sessions of general "washing" radiation of the brain to eliminate microscopic traces of cancer in the brain, followed by stereotactic radiation, whereby two separate streams of radiation are directed so that at their confluence is a high dose of concentrated radiation. The stereotactic radiation had been mentioned as a possible treatment prior to the meeting with the oncologist, and Bernard was told that it was the same "miracle" treatment that George Harrison had been receiving. It was small consolation when Harrison died on the first of December, only days before the consultation. The treatment was to begin sometime in mid-January. Meanwhile, his daily doses of *Decadron* were increasing, eventually hitting as high as 100 mg, as blood tests revealed he had yet to hit the therapeutic level.

On the eighteenth of December, having fallen unconscious in the upstairs bathroom of Gladys' house, Bernard was taken to hospital, where it was decided to begin immediately a three-week course of washing radiation. He was discharged from hospital on the fourth of January, with an appointment set for the fifteenth for his stereotactic treatment. On the morning of the fifteenth, a pre-treatment CAT scan revealed three things: that the lesions had not shrunk from the washing radiation and had in fact grown; that one of them had changed from having a smooth edge to having tendrils of cells breaking from it; and that there was now a fifth lesion. The radio-oncologist believed that the treatment would be of no effect and would probably in fact kill him on the table. Bernard was deemed to be in the palliative stage, and was sent home. After three days of round-the-clock care from Gladys and her nursing friends and colleagues at her house, a vacancy opened up at a local hospice, into which he moved on the eighteenth of January.

An Autoethnographic Approach

Recent contributions to the practice of ethnography (Ellis and Bochner 1996; Emoff and Henderson 2002; Goodall 2000) have expressed reservations about traditional ethnographic writing. Whereas the very real achievements made by anthropologists, ethnologists, and folklorists cannot be denied, the ethnographer's voice, when disembodied, is granted an authority of interpretation which cuts off the possibility of debate, reinterpretation, contestation, or simple dissent. As Goodall puts it, "the episodes in the story reveal an omniscient narrator who is armed with preconceived questions and theoretical framing, and who proceeds to create knowledge by coding and analyzing data" (2000: 121). Newer ethnographies, then, aim at being open-ended, as providing a description that is conversant with theoretical approaches yet expressly the perspective of only one of the many who make up the ethnographic moment. As Emoff and Henderson note, "writing then becomes, in part, less the mastery of a form of knowledge and more a collection of excerpts, outtakes from a continuous conversation about what happens on the edges of multiple forms of knowledge" (2002: 3).

The prototypical ethnographer's reason for being an informed outsider at a particular place at a particular time is to conduct the research for the ethnography itself. But this paper is, for the most part, an autoethnographic account of time spent in my father's hospice room. Despite the foregone conclusion of it being a dedicated space for the death of a loved one, the room was nevertheless perceived differently by different, or differently interested, parties. With competing visions of the ideal comfortable space coming from a variety of persons of greater or lesser centrality in my father's life, the inclusion and exclusion of particular objects and the relative placement thereof made the hospice room a contested space, if only tacitly so. For reasons both interpersonal and patriarchal (not simply systemically but, as I was to find out, explicitly and systematically, to a degree that even went beyond my expectations), I had a position of centrality to the events, acting as both agent and arbiter of my father's wishes, in addition to my literal role of executor. My role of ethnographer was contingent on my required presence: I took it up for both practical reasons[1] and, in retrospect, as a form of catharsis, as a way of objectifying the experience by theoretical framing in order to distance myself from it. In writing this, I was aiming at providing a report of this time that did not privilege my perspective as the authoritative voice. Compounding matters, as his condition went through various stages, my father himself perceived the room differently, allowing for both a synchronic and diachronic description of the space. My approach has been to favour description over analysis, ethnography over ethnology, providing cues for how one could locate this within the discipline.

This paper began ostensibly as an inventory of the objects brought into my father's hospice room. Although he was aware of the idea for the paper from the first week of his stay, much of the inventorying was done somewhat clandestinely. One inventory was made on a latter visit to the hospice during my initial stay in Ottawa, on the fifteenth of February, when he was at the height of what was thought to be a temporary recovery, and another was made while unpacking the boxes brought back from his room after his death on the fifth of March. Neither was complete, and neither accounted in detail for his clothes or his food. As a consequence, lacunae in data have been reconstructed from memory, both my own and in consultation with my wife. Furthermore, the rationale behind the inclusion (or omission) of some of the objects, apart from those for which I either solicited an opinion or explanation at the time or was personally responsible, can at best be a reconstruction, albeit an informed one.

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[1] This article was originally written as part of coursework for Dr. Gerald Pocius's "Material Culture" (FOLK 6400), at Memorial University, Winter 2002. As is described below, my father's palliative time took me away from St. John's for the better part of nine weeks during this semester: as it was unclear how long I would be away, by previous arrangement I was permitted to continue my coursework despite my absence. Thanks are due to the participants of that course and to Dr. Pocius for subsequent suggestions. My thanks also to Lynnette Butt for her help in contextualising some of the issues arising from Bernard's treatment. Lastly, I wish to offer my sincerest thanks to Jodi McDavid, who has been instrumental in her assistance at all phases of this paper's writing and at other times, as shall be made evident to the reader.

Beginnings

Bernard was a hospice resident for forty-six days, from the eighteenth of January to the fifth of March, 2002. The major part of his stay was spent in room four, at the south-east corner of the building. For the first three days he had been placed in room nine but, given the number of people who were going to be in regular attendance — myself, Elanor, Gladys, and, within a few days, his elder brother Jim and sister-in-law Vicki — he was moved to room four, which was originally a double room from which one of the beds had been taken, leaving more room for chairs and visitors. Although there are at least one, and more commonly two, nurses on call for the nine beds of the residence, and although there is a phalanx of volunteers scheduled to talk to the residents, prepare their meals, and assist the nurses, friends and family are encouraged to take an active role in the resident's care.

The room, like the rooms of most institutions (Adams 1994; Kenyon 1999; McGahan 1987), comes equipped with the bare requisites for the purpose that it serves: in this case, a hospital bed, two wall-mounted fluorescent lights and two call-buttons (one for each of the original two beds in the room), a tray table, an electric-powered recliner, two chairs for visitors, two bedside tables, a bedside lamp, a floor lamp, and a privacy screen. Built-in to the room is a wardrobe and a desk with two sets of drawers, over top of which is a set of shelves with a recessed fluorescent light illuminating the desktop (Figure 1). A painting, a decorative Wedgwood plate, and a candleholder complete the inventory of objects that were already in the room upon my father's admission. Although some of the patients are on oxygen, the hospice is not a full medical facility, and as a result the rooms are not filled with the normal medical instruments and machines one would find in a regular hospital room. The room is painted a cool blue, not an institutional white.

As soon as Bernard was admitted, however, additional things were brought into the room. Some were available from the storage room of the hospice; most were from outside. Some he requested specifically; some were our idea. Some were purchased specially; most were already owned and in use. Some objects were necessities, some were niceties, some were entertainment, and some were wishful thinking. As my father's disease and symptoms went through various stages, the objects he "needed" — whether from his perspective or from someone else's — changed, and each was the subject of some form of negotiation. This process is similar to Hockey's study of an English senior's residence, wherein she writes: "to an extent [by bringing in possessions from a previous home], domestic home was thereby re-created, on an individual basis, within the context of the residential home" (1999: 111).

The First Few Days

When one is moved into a palliative-care hospice, the presumption is that one will not be leaving under one's own power, and that continued treatment at home is not a viable option.[2] The three days at Gladys' house subsequent to the aborted stereotactic radiation required that Bernard have injections at least every four hours and more often every two, and that he be attached to two intravenous lines. The prolonged pressure in his brain and the washing radiation had left him violently nauseated: he had not been able to eat for the best part of a month. Since the onset of his disease he had lost fifty pounds, albeit ten pounds of that was tumour and kidney. The idea that I rush back to Ottawa was on the assumption that he would not have many days left.

The objects brought into his room for the first few days were, therefore, of two types: either they were to serve an immediate practical purpose (clothing and toiletries), or they were meant to be a few comfortable touches to make his deathbed less antiseptic. Included in the former were clothing and toiletries. He also had a quilt that had been made for him by Victoria's Quilts, a volunteer organisation that makes and donates quilts for cancer patients. Gladys was the principal organiser of one of the local chapters, and it was no surprise that her group quickly rallied in producing a quilt for Bernard. One of the most important objects was his "kidney dish," a stainless steel, kidney-shaped surgical dish that he still had from his stay at the Civic Hospital for his radiation treatment, which he always kept within arm's reach in case he was overcome with nausea. Although he was not eating (or rather, not

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[2] The hospice movement, "in stark contrast to the curative hegemony in biomedical discourse that encourages intrepid and heroic measures to save the life of the patient" (Brown 2003: 835), arose in the United Kingdom with the rise of specialised centres for palliative care. In its North American manifestation, however, palliative care tends to take place in the home. My father's hospice is an example of only a recent trend in North America and Canada to a British-style system. For more on the history of hospice and the ramifications of domestic dying on the home, see Brown (2004).

keeping anything down), Gladys and I, who were keeping more or less constant vigil, still needed to eat. Plastic containers for fresh fruit, a sharp knife, and some soft drinks were brought in. (My sister, Elanor, was present for much of this time: however, she was in the second semester of her public relations programme at Algonquin College, and it was my father's express wish that her coursework not be interrupted by his illness. Her time, therefore, was limited to evenings and weekends.)

As for the more comfortable touches, Gladys had brought in an assortment of photographs: a formal portrait of all five of her grandchildren; one of her youngest grandchild on Bernard's shoulders; two of Bernard and Gladys on recent holidays, one from Fort Lauderdale and one from Cape Spear (Newfoundland); and one of the pair of them, Jim and Vicki, Elanor, and myself taken when I was visiting Ottawa in December. To these were added some drawings and get-well cards by her grandchildren.

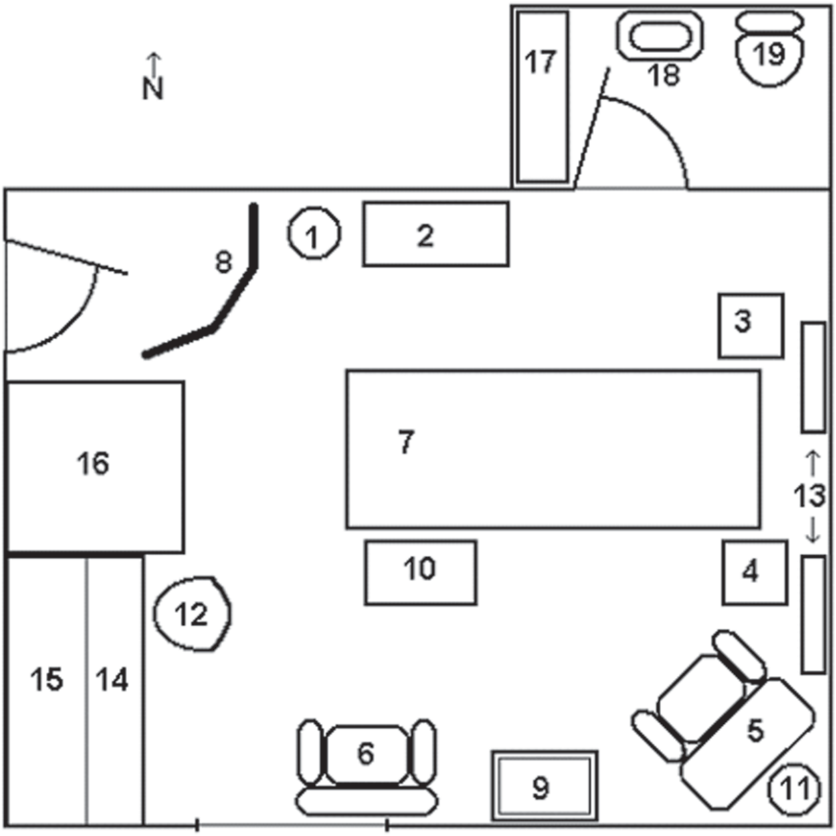
Elanor brought in two wall posters, one an Anne Geddes print of a baby in repose on a bed of pink roses, and one of a school of dolphins titled "Corps de Marines." These were not put up until Bernard had been moved to room four. The dolphin print was put on the wall to the left of the window, while the Anne Geddes print was placed on the right door of the wardrobe, directly in front of the bed. It was to stay up for the duration of his stay although, once he was lucid, he confessed to Gladys and me that he hated it. The Anne Geddes pictures of babies whimsically placed in terracotta pots reminded him of his postwar childhood and how as a child he interpreted the news of the discovery of Nazi "baby farms": the association tainted all Geddes prints for him. However, since it had been brought with the best of intentions, he kept it up. Furthermore, when Gladys was out of earshot, he confessed to hating the grandchildren's drawings as well — not for their associations but simply for their lack of symmetry and their raggedness — but he did not wish to offend Gladys either. They too were on the wardrobe door, to the left.

The posters and the drawings introduce the central dilemma — the interpretation of wants and the projection of desires by one person come into conflict with the actual wants and desires of another. Elanor makes the assumption that images of babies and dolphins can not help but be a comfort: Bernard makes the assumption that their removal would cause great distress to his well-intentioned daughter. The objects therefore remain in the room as a symbol of a mutual lack of communication, or negotiated space left non-negotiated. The constant influx of flowers, which Bernard also hated, was nevertheless left on display until they were sufficiently dying that manners would allow for their removal. There was no such latitude with the non-ephemera.

There is a further dimension illustrated by the posters and drawings. In most other studies of the relationship between people and the objects they choose to surround themselves with, the presence of an object may be said to be a consequence of a deliberate action, as can its placement. In this situation, for the first few days, Bernard had no control over the presence or placement of the objects within the room. By the time he was able to assert some control, the objects had become part of the sense of place, if not for him then for others, which he could not bring himself to disturb. Furthermore, once he had this control, it was only over the placement of objects, which was still limited by his reduced mobility. Since he could not leave the room, let alone the hospice, he was not in a position to bring in or remove objects. Anything that was brought in, therefore, came at the discretion of someone else, whether it was as a gift or as something we thought he would want, or as the execution of his request.

Erving Goffman's dramaturgic analysis (1959) introduces the concept of "fronts," wherein the area displayed to the general public is presented in such a way as to give an impression about the manner in which the operations behind the scenes are performed: a soothing anteroom at a psychiatrist's office indicates the restorative properties of the therapy; a spotless bakery counter inspires confidence in the hygienic practices in the back. The reality of the hidden operations is largely irrelevant. The generic serenity of the hospice room as provided by hospice management, and the specific serenity of the room as decorated by family, both belie the agonistic throes of the palliative patient, the raging against the dying of the light. Vicariously for us, and eventually directly for Bernard, the room became an opportunity to present some aspect of his personality that implied stoicism in the face of impending mortality. It was also, in a manner of speaking, a pre-emptive spontaneous shrine: as Holly Everett has put it in her work on roadside crosses, "the memorials become representative not only of the mystery of death, but of the deceased themselves, encompassing aspects of both lived experience and abstract thought" (2002: 80).

Figure 1. Layout of Room Four, February 15th, 2002



Furnishings in room as of
January 18th, 2002 (clockwise from door):
1) Floor lamp
2) Tray table
3) Bedside table
4) Bedside table (with telephone and lamp)
5) Electric-powered recliner
6) Armchair
7) Hospital bed
8) Privacy screen

Additional furnishings brought in
from elsewhere within the hospice
9) Television cart and television
10) TV tray table

Additional furnishings brought
from Prescott
11) Halogen lamp
12) Wicker chair

Fixtures
13) Wall-mounted fluorescent lights
14) Desk unit
15) Over-desk shelving unit
16) Side by side two-door wardrobe
17) Bathroom shelving
18) Sink
19) Toilet

Although he had lived in Ottawa for over thirty years, worked in Ottawa, had a companion who lived in Ottawa, had a daughter still living in Ottawa, and was seeking treatment and ultimately given palliative care in Ottawa, in September of 2000 Bernard had moved to Prescott, Ontario, a town on the St. Lawrence at the other end of the recently completed Highway 416, about an hour's drive away. Many of his more functional possessions, like his clothing and toiletries, were at Gladys' house, considering that prior to his illness he stayed there more nights in a week than he would stay in Prescott. Since he had taken ill, and certainly since his surgery when he was advised to stop driving, Gladys' house had been more or less his fulltime home. When I had visited in November and December, I had stayed at Gladys' along with Bernard and my aunt and uncle. When I visited in January, it was decided that I would stay at the house in Prescott, partly to get out from under Gladys' feet, but mostly to begin the process of winding up his estate: contacting realtors, meeting with the other executors, and preparing for the duties that would fall to me as principal heir. In essence, I was to be his proxy until the time when I was officially to assume other responsibilities. This meant, however, that the contents of his home were now available to him, and to others acting in his interest.

A brief list was drawn up. Elanor suggested I bring Mrs. Rabbit, a stuffed animal from his childhood. Gladys thought photographs of Elanor and I were appropriate, to which I added pictures of his mother and father, and a childhood picture of him with his mother and brother. I decided to bring some books: Jerome K. Jerome's *Three Men in A Boat*, Boswell's *Life of Johnson*, Stephen Fry's *Paperweight*, and Kenneth Grahame's *The Wind in the Willows*, which were some of his favourites. As I was unable to find his copy of *The Wind in the Willows* (he later told me that it was in my apartment in St. John's, which he had visited in the summer of 2001,[3] but I was unable to find it upon my return), Elanor brought in hers. Bernard also specifically requested the Boswell a few days later.

Books were considered integral for the room, as most people considered Bernard to be a voracious reader. After his death many of the people to whom we wanted to give a token of gratitude specifically

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[3] This trip, ten days at the end of July and the beginning of August, was a strained time, as Bernard's behaviour was unusually irritable and distracted, behaviour which, only in retrospect, was directly attributable to his condition.

requested books, and during his time at the hospice he had me bring in books to be given as gifts for six different people. He was loaned or given a further five books during his time at the hospice. However, for most of his stay he was unable to concentrate on reading anything more than a paragraph or two. The books in the room were more in keeping with totems than practical objects.

Settling In, Settling Affairs: Bernard's Requests

Bernard did not remember the first few days, and was chronically exhausted, but he did start making requests almost as soon as he was admitted. Of pressing concern to Bernard was tying up loose ends (or nailing them down, which we could never identify as a mixed metaphor or not). According to the little notebook I began keeping, he wanted answers to the questions of (a) what will become of the house, (b) what will become of the computer, (c) what will become of the car, (d) what will become of the big screen television, (e) will the fourth quarter GST and income tax instalments be paid prior to the January 31st deadline, (f) will the books he had been loaned be returned to the rightful owners, and related issues. To answer them, he needed his planners, which contained all his phone numbers, some pens and paper, and all the related files (including his home improvement file, his car file, his computer file, the manual for the television, etc.), brought in from either Gladys' house (where some had been kept), or the house in Prescott. The fact that he was not able to read, write legibly or intelligibly, or make himself understood on the telephone did not deter him.

By the time he entered the hospice, Bernard had been on high levels of *Decadron* for two months. One of the immediate side effects of *Decadron* is a frenetic hyperactivity. Garrulous at the best of times, Bernard was prone to chronic "motor-mouth," as his palliative doctor phrased it, as if a censor had been turned off in his head, allowing no thought to remain unexpressed. (I have been informed that this may also have been one of the many behavioural side effects resulting from the tumours themselves, although it may have been exacerbated by the *Decadron*.) Much of the data for this paper, for example, was not so much solicited as absorbed from his constant stream-of-consciousness monologue. I heard his opinion of the Anne Geddes print and the Nazi baby farms at least fifteen times. In conjunction with his pre-existing propensity for worrying and planning, the moment I came through the door and rudimentary pleasantries were exchanged, we were immediately on the topic of the house, the car, who wanted to come visit, and so on. There was a tension between his inability to do much of anything for himself, the false sense of energy bestowed by the *Decadron*, and the unknown variable of the time left. This variability was always an uncertainty, for within a week of his admittance the worst of his symptoms had been controlled and his passing looked less imminent.

Entertainment

Since the Damoclean sword had a sturdier thread than first imagined, the next hurdle was trying to keep his mind stimulated without his normal diversions of reading and puttering about. His cassette player had been brought from Gladys', but the rules of the hospice required that all electronic equipment be enjoyed with headphones only. Bernard still had radiation burns on the top of his head and the back of his neck, so both the conventional over-the-head and the newer slung-across-the-neck headphones would irritate his skin. He wanted a pair of ear-bud headphones that pop into the ear, but instead I bought him a pair of ear-buds that hook around each ear with a soft rubber grip. Given his twitching and thrashing about, I thought this was the right choice, although he complained about them nevertheless.

His thrashing introduced another dilemma: he either had to have the cassette player on the bed with him or on the hospital tray table. When it was on the bed, he was constantly rolling on to it: when it was on the table the headphones were fully extended, and he either pulled them out of his ears or pulled the player off the table. No real solution was to be had until, after discussions with the staff, they allowed him to listen without headphones provided his door was closed and the volume was moderate.

The headphone problem was also encountered when he acquired a television from the storage room of the hospice. Bernard had had a television set in his house since he was five years old, and it had always been his principal form of relaxation, even when he would read and watch television at the same time. Although the television made available was a recent model with a remote control and good picture quality, there was no cable in the rooms, and the poor reception, the poor selection, and the need for headphones did not mix well with the *Decadron*-addled mind. Gladys at first brought in her video tape player, but could not find the remote control for it. Limited to the stop and play buttons on the machine itself, Bernard quickly found the process tiresome, and continually asked Gladys to try harder to find the remote. I brought in his player with the attendant remote from Prescott. With one additional trip to the store to purchase both a headphone jack splitter, so that he and Gladys could watch shows together, and a six-prong adapter, to handle all the electronics, some peace was restored. Having the means to play both audio and videotapes, we brought in the tapes themselves.

One thing he was constantly requesting from Prescott was his weights: small dumbbells that he could use in bed to help rebuild the muscle tone he had lost in the three months since his surgery. On occasion he would use a lamp, a footstool, or a heavy book to do some repetitions, since we had not been forthcoming with the weights. However, most of his medications were administered in the form of a subcutaneous injection, usually at least one needle every two hours. To facilitate this, a "shunt" had been placed on each arm, which was to a subcutaneous injection what a permanent IV line is to intravenous medication. The vigorous upper-body exercise would pull and tear at the subcutaneous shunts. Only when the nurses pointed this out to him (when we did, he did not seem to hear) did he stop.

Challenging the System

It seems that, for Bernard, the opportunity to exercise choice was what was most crucial. The array of books, audiotapes, videotapes, and, later, food and clothing, belied the institutional nature of the hospice. Surprisingly, Bernard took much pride in how easily he thought himself able to adjust to institutional life, having spent a significant part of his childhood away at boarding school and then at the residential colleges of Oxford in the early 1960s. Unlike the life histories he imagined for the other residents (most of whom were a generation ahead of him), he had not moved from his familial home to his marriage home, never being subject to the routines and limited choices of a distant administration.

It never quite occurred to him that he challenged almost every in-house policy. In addition to the headphone rule, it is a rule that while the patient is in bed, even when there is a responsible adult in the room but especially when alone, the guardrails at the side of the bed are to be in the upright position lest he fall out. Similarly, patients are encouraged to use the bed urinals exclusively, and if they want to use the toilet they are to be accompanied by a responsible adult and the door is not to be closed with them on the other side. Bernard fought these, but he did it politely, and therefore did not perceive himself as a difficult patient. Furthermore, his adjustment could not have been possible without his ever-present retinue of retainers, despite what he may have thought. These retainers used their discretion when it came to bringing items in to make him more comfortable. Much passed without judgment: books, videos, and so forth. But certain objects required more consideration. To bring or not bring in an item often depended on criteria that we did not wish to discuss directly with Bernard.

A good example would be the discussion concerning his computer. At one point he was making hints that he wanted it brought in. One consideration against this was, admittedly, a selfish one, given that it got in the way of the requests of a dying man: a lot of effort would be involved in disconnecting it, transporting it from Prescott, and reconnecting it. Without an Internet connection,[4] its primary function for him as a communication tool would be pointless. Further, it would deprive the house in Prescott of a computer, on which I was theoretically trying to keep up with coursework. Related to all these was the lack of will on our part to go through this trouble, only to undo the process an indeterminate time later: in a way, we (projecting my own reasons onto the group) were trying to stave off future resentment.

But the final reason, and ultimately the one that would make or break these decisions, was to avoid a situation wherein he (and we) would have to face the very real degeneration he was going through and had yet to overcome. In November, soon after he was diagnosed with the metastasis, he had tried to read and reply to his e-mail from my sister's apartment. The lack of fine motor skills manifested in his bad typing (typing, that is, far worse than it had been prior to his illness)

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[4] There was actually no impediment stopping him from hooking up to the Internet through a phone line that a long enough extension cord that could reach from the phone jack (behind his bed) to the desk could not handle. However, he was unable to grasp the concept that, although all incoming calls came through a switchboard, outgoing calls could be made directly from the room, provided one connected to an outside line first. This inability was not a sign that he had deteriorated any: rather, it was evidence of a preexisting inability to grasp anything even remotely technical whatsoever.

induced an anxiety attack. The same thing happened in December in my presence when reading his e-mail from his house in Prescott. Although Bernard's current medications were beginning to curb these symptoms, they had not quite improved to the point of recovery. To introduce into his current environment, over which he had acquired a certain mastery, an item from his past with which he could not cope to the same degree might cause an emotional setback. He had been using computers at work for over twenty years, so to discover an inability to use it would be similar to discovering that he could not operate a telephone. (He actually had been unable to use the telephone for the first few days, but he more or less regained this skill with the receding symptoms.) There was a fine balance to be struck between not having him in a state of denial and not having him constantly confront his mortality.

Playing Host: Food and Clothing

With the stabilising of his symptoms and the end of his chronic nausea came a renewed interest in food. The hospice allowed for personal food items to be kept in the room, and items requiring refrigeration to be stored in the kitchen, provided they were labelled and dated. Pre-prepared meals were also available, as well as basic staples (cereals, breads, juices), which could be served by the volunteers. As the routine usually had Gladys coming to the hospice in the late afternoon and staying until Bernard was asleep, she would bring in a dinner to share with him. The kitchen was equipped with a microwave and a stove, and a full complement of utensils, plates, and glasses. Much of the food and food items in the room, therefore, were for snacking and entertaining.

One notable exception to this was Bernard's alcohol. For the previous months he had been prohibited from drinking so as not to cause ill effects with the medications. Once he was deemed palliative, however, the possible consequences of interaction were overshadowed by his unavoidable impending death. The revelation that potentially fatal behaviour no longer had to be avoided was a mental obstacle which took a long time for Bernard to negotiate. He was somewhat mortified to hear that no effort would be made to assist him were he to have a cardiac arrest, save to ease his suffering, neither would he be treated for any further metastasis of his cancer. Fearing that it would spread to his testicles, he bitterly opined about the health care system if they were to do nothing. Only when I employed the indelicate metaphor of, "When your brakes have failed and you're rolling downhill, you don't fix the air conditioning," did he seem to grasp the finality of being declared palliative. The prohibition on alcohol was thus lifted, and he began having wine (which he at first found too harsh on his system but was able to take once his symptoms were more stable) and rum. Although he had previously been a rum and cola drinker, the cola seemed to cause reflux and hiccupping,[5] so he made the switch to rum and ginger ale.

Alcohol was also present in his capacity as "host," a role he played in his recuperative moments with as much urgency and pageantry (if not ability) as he did when he was at his own home. A twelve-ounce bottle of Chivas Regal had also been given to him as a present, but not being a whiskey drinker he left it for guests, specifically his lawyer. He felt uncomfortable, however, serving the whiskey in the plain water glasses from the hospice's kitchen. On several occasions he had asked for some glasses to be brought in from his home in Prescott, specifically two Waterford crystal "ladies' tumblers." When the Chivas was nearing empty, he further requested we bring in his two Waterford crystal decanters, one full of scotch and one full of rye. Although we had decided that he was able to handle glass, I had thought it best not to accede to these requests, given that (a) these were both more heavy and more delicate than the glasses and bottles he was currently using, (b) because they were expensive, they were heirlooms, and they had already been divided amongst his children, and if he were to break them he would be greatly distressed, and (c) no one in their right mind would take offence at being served whiskey in a regular glass when they are seated in the presence of, and being served by, a dying man. However, once I had left Ottawa to return to St. John's on the eighteenth of

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[5] Another of the side effects of the swelling in his head was chronic hiccupping. In his first week Bernard would suffer bouts that would last for several hours. At first, it was unsure whether they were a direct result of the swelling or whether they were caused by irritations to the diaphragm caused by the presence of additional cancerous lesions. After a hiccup, he would have difficulty starting to breathe again, which was feared to be a problem with his autonomous nervous system. A new drug, *Nozanan*, was prescribed to replace his antinauseant, which also took away his hiccups. However, because they are not only resultant from but also a cause of pressure in the brain, they were to be avoided at all costs, and their return was always taken as a bad sign.

February, someone else (James or Vicki, who were still staying in Prescott) brought in the tumblers and the decanters.

Such was another example of striking a balance between his wishes and his best interests. James would rather deny his baby brother nothing: I would rather avoid situations that would force him to confront his changed circumstances. I tended to be the least willing to allow my father denial, while at the same time not enabling opportunities for his optimism to be deflated. A hard reality was the relationship between Bernard's diet and his disease. He had assumed, as most people would, that a healthy caloric intake would provide the energy for his body to resist the cancer's growth. As a result, when his appetite would wane, he would be concerned. His doctor explained that, while not eating would make him tired and weak, eating would paradoxically provide energy to the cancer, not to the body.

Bernard's clothing was also a source of contention. In the first few days he would wear underwear and, occasionally, a golf shirt, although most of the time he was so hot and uncomfortable that he preferred to wear nothing at all. Soon, however, when his symptoms were more stable, he wanted to be a little more modest, so he took to wearing shorts as well. He struggled at first with his regular shorts, and a few elastic-waist pairs were bought for him, but he soon changed back. When my wife came for a visit, Bernard — in his host capacity — wanted to greet her wearing long pants. In all instances his clothing had been brought from Gladys' (and, since she did his laundry, returned there as well), and they were all selections from his vacation wardrobe. Whatever his clothing choice, it had to meet the criteria of both easy accessibility to and a loose fit around his upper arms to accommodate his subcutaneous shunts. A sleeve that could be easily pushed up or a robe that could be easily opened wide enough to slip out an arm was critical.

Another consideration was footwear. At first, his feet were cold, and he wore socks. But socks did not give him a good grip on the linoleum tile floor when he was able to get out of bed. I brought a pair of rubber-soled socks from Prescott, but they were too small. Soon, with increased mobility, his circulation got better, his feet were warmer, and he went either barefoot or, when he did get out of bed, wore his Birkenstock sandals. When he started using the wheelchair to go further and further afield, he always wore the Birkenstocks, as he did not so much wheel himself around as scuttle, propelling the chair as Fred Flintstone would. When swelling and water retention began (another side effect of the *Decadron*), Bernard at first tried controlling it with tight socks, but the poor grip and the loss of sensation caused him to fall on one occasion. He went back to the Birkenstocks with the straps set at their loosest setting, until they grew too tight. Since much of the swelling could be contained simply by prolonged periods of elevating his legs, Bernard resigned himself to more bed rest, and the issue of footwear ceased to be problematic.

Wishful Thinking

At the end of the second week, the first weekend in February, my wife Jodi came up from St. John's. Bernard had been looking forward to this as, given her position in his eyes as the family matriarch-in-waiting, it would be the opportunity to settle more arrangements. A "family meeting" was convened, with far too much ceremony, whereby we were meant to decide on the dispersal of the house contents. Although everything was in theory a fifty-fifty split between my sister and myself, how that worked out in practice was an unknown, and another (at the time, the final) loose end. The urgency with which the meeting was called, we were to find out later, was due to his concern that he would soon start demonstrating Alzheimer-like symptoms. The damage to his brain, he feared, would be a gradual descent into a vegetative state. He wanted everything settled and everyone home, so none would have to see him as he had seen my maternal grandfather in his last few months.

This had all been left unsaid until my wife intuited this fear and, when he and she were alone on her last day, approached him about it. That afternoon, he in turn asked his doctor about his future. She assured him that mental incapacity was not in the cards: he had actually already experienced the worst. When he was first admitted to the hospice he was in fact only days away from dying: the chronic exhaustion, the nausea, and the pain would reappear when he moved away from the apogee of this recovery period and again experienced a descent. Any mental degeneration would be more in keeping with the fatigued's inability to concentrate.

This news, an unexpectedly positive answer to a question he had feared asking, gave Bernard fresh hope. With his medications so finely balanced, the more debilitating of his symptoms were going away: his appetite was not only restored but practically voracious; he was waking at six in the morning and going until ten at night; he was in no pain; and he was more or less fully mobile (although he was using the wheelchair most of the time and, when walking, continued to use his cane). If he continued to look this healthy, he was in danger of being asked to leave the hospice until he grew worse again, or so the doctor told him.

This came as either a promise or a warning, depending on one's perspective. Going back to Prescott was not an option, as he would be an hour from his doctor and, just as important, from Gladys. The cutbacks in funding to hospitals in Ontario had led to such a low standard in care (too few nurses with too many responsibilities and a lack of autonomy for the individual hospitals) that a return to hospital was not an option to be entertained. Barring admittance to a nursing home or renting a fully furnished apartment in Ottawa at a time of high rents and low vacancies, the only available destination would have been Gladys's. But her home was not set up for a person who cannot climb stairs, and, as a breast cancer survivor and an arthritis sufferer, she was not physically able to personally give the level of care that he needed. It was for these reasons that he moved from Gladys' to the hospice in the first place, and, despite what he thought, he was not yet in a condition to be without around-the-clock nursing care.

But the thought of resuming some semblance of a normal life was too large a carrot to dangle in front of Bernard without getting a reaction. When he was meeting in early December with the oncologists who were plotting out his course of treatments, he had asked for a time frame, and was told anywhere from a few months to a year or two. He took his reinvigoration as a sign that the radiation had worked,[6] and that he should start thinking in terms of months and years again instead of days.

A Man of Action

This called for radical changes, starting with his room. No longer was it to be the final stop of a dying man, or a great hall for a paterfamilias: it was now a launching pad for a return to the real world. It needed to be organised to his liking, by me, under his supervision. All the

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[6] Bernard had been told that radiation still continues to work on the system well after the course of treatments has ended: in fact, although radiation may work up to two weeks after treatment has stopped, by this point it had been well over a month since the cessation of the general radiation treatment.

photographs, which had previously taken up the two middle shelves of the shelf unit above the desk, were consolidated onto the top middle shelf. Heretofore both the videocassettes and the books had been stacked on top of one another on either the bottom shelf of the TV/VCR stand or on top of the VCR itself: these were moved to the shelf below the picture shelf. All the plants that could find a better home, whether in the garbage or in another room of the hospice, were removed from the desktop: the hospital tray table was moved against the wall between the door and the bathroom door, and any new plants could be set there. The candleholder and Wedgwood plate provided by the hospice were both hidden from view behind the books. Papers, files, mailing labels, notepads, spare pens, all were put into the left-hand drawer for easy access. Business cards were brought from Prescott, the address and phone number crossed out and the phone number of the hospice written on them.

If he was going to stay at the hospice for the foreseeable future, a more functional environment was required. Much later we were told that yet another side effect of *Decadron* is light sensitivity and a difficulty adjusting to changes in brightness (although this could also have been more a consequence of the tumours than the medication). Until then the room was, in Bernard's words, "always so goddamn dark," so a halogen floor light was brought in from Prescott to make it easier both to read and to entertain. The furniture needed to function both as an office and a living room: he needed furniture he could manoeuvre himself unaided from his wheelchair. He asked that one of the hospice's heavy armchairs be removed, and that his wicker armchair, which he could move with one hand, be brought in from Prescott. (One hope for the chair was that, when the warmer months of summer came, he could wheel down the hallways of the hospice to the outside, bringing the wicker chair on his lap, and sit smoking his pipe.) Lastly, a small TV-tray table had been found in the storage room of the hospice, which he could easily move around and which, unlike the hospital tray table, was suitable for someone sitting in a chair, not in bed. Thus two ad hoc areas were created which were apart from his bed. To watch television, he could position his wheelchair directly in front of the TV/VCR stand, with the TV-tray table at his side (see figure 1, with the wheelchair located to the right of item 10). To entertain guests, the TV-tray and wheelchair could switch positions, forming a conversation pit (with seats 6 and 12, figure 1).

The concern that Bernard had for the objects around him may at first seem strange, given that one often associates the decoration and dominion over domestic space with women (Pocius 1991: 94). However, he had been separated for thirteen years prior to entering the hospice, and, having moved twice since, had decorated three houses. Moreover, his father had been divorced for the last twenty-five years of his life, and had decorated his own house according to his own wishes, having designed and built the house himself twenty years previous. Additionally, Bernard's father had owned and operated a store in Wolverhampton that prided itself on being able to suggest and supply the furnishings for an entire house. Finally, Bernard's Uncle Colin had been a bachelor and was a major influence on his young life, including inculcating notions of "gentleman's space." To this was added Bernard's own aesthetic based on expediency and perpendicularity. The room had been allowed to stand as others would have it as long as he was a passive presence. Once his prognosis turned, and he found he would be staying, he exercised control. As Scheiberg says in her discussion about the decoration of work spaces, "if a person feels positively about his or her job and expects to be there for a length of time, the process of personalisation is usually carried out" (1990: 336). While the "positive feeling" at hospice is about the non-imminence of one's own death and not job satisfaction, the same holds true.

Having procured a "properly" organised room over which he had some control, thoughts turned to the future. I had typed his long-overdue Christmas letter for him, made sixty copies, and provided him with his personal address list printed onto mailing labels, envelopes, and stamps. He now wanted, however, to have personal correspondence with people, and he wanted to do some creative writing. He was thinking about the possibility of another reprint of his privately printed book. There was even a plan to get back to work: a friend and fellow human resources consultant was at work on developing a sexual harassment policy for the entire Canadian government. Bernard had recently written the policies for several government departments, and these could easily be plundered for the Canada-wide policy. The question of the computer therefore arose again, but this time it was for business and not entertainment. Although the Prescott computer was too ungainly for his desktop, perhaps an old laptop could be found.

One morning in Prescott I received a three-page fax from Bernard with a long to-do list. Among the items was his most recent flash: his old but perfectly serviceable Smith Corona typewriter was in the basement. Could I clean it up, see if it worked, see if one could get replacement ribbons for it, and bring it in? It worked, and it looked like the ribbon inside it would last for another month or so, so I brought it in, stopping at Business Depot to see if they had spare ribbons in stock. Having demonstrated to Bernard that it was in working order, he asked about the ribbons. I told him that Business Depot did not carry them, but one could order them if need arose. Did I order any? The ribbon would probably last at least a month. What about after that? I shrugged in a manner that tried to evince "If you are lucky enough to outlast the ribbon, then we can worry about ordering new ones," but the subtlety was lost. That evening I returned to Business Depot and ordered spare ribbons. (They were available for pickup on the second of March, the day after he slipped into what was later interpreted as a coma. The ribbon was still working when I did the final inventory.)

Much discussion took place concerning the fate of his cellular phone. I had been using it as a local contact number for people wishing to schedule appointments (the number was not long distance for people calling from Ottawa, unlike the Prescott number), and to stay in touch during the hour-long drives to and from Prescott. But upon my planned for departure, and with James' assurance that he did not wish to use it, Bernard wanted it for his room. He would then be able both to receive calls without having them go through the switchboard and to make long distance calls without charging them to a calling card. However, the battery had been failing lately and not always accepting a full charge. With the obvious solution of leaving it plugged in at all times and using it as one would a regular phone completely eluding him, the hunt was on for a new battery — a difficult prospect for a phone two years obsolete. It was not until after my departure that a new one was found, after much hunting.

Deconstruction

With his condition seemingly stable, our presence was not seen as necessary. He wanted us to get back to our "regular lives." For me, this meant returning to coursework and salvaging what I could of the semester. For my aunt, this meant making her annual trip to England to visit her mother. (Jim would stay, with nothing to do back home and no wife to do the nothing with.) Airline tickets were purchased, and I was booked for the eighteenth of February, and Vicki for the second of March. We were both to return in April to see what use we could be then.

As I was leaving Ottawa, his doctor was initiating an experiment. The swelling in his feet was just one of the side effects of the *Decadron*. It was obvious that his medication could sustain him for the immediate future, and that his condition was such that he could be mistaken for a person in moderately good health. Was this apparent robustness actually a result of the radiation having worked, or was it simply the high doses of *Decadron*? If Bernard reacted well to a lower dose, it would mean that there was improvement, and he might get to leave. If he did not, it meant that his condition was either stable or had worsened, and he would stay.

Bernard consented to the experiment. He had already been making what he considered preparations for life beyond the institution. He had switched to oral medications for some of his prescriptions, with the idea that he could stay at Gladys' for at least an overnight visit and, simply by setting an alarm clock, self-administer his four in the morning pill. He had begun to keep a journal with such categories as "health overall," "bowels," and "food intake." The morning I left, one of the administrators, without running it past his doctor first, had approached him with the suggestion that, if all went well, he could leave. His commitment to the experiment and to his preparations intensified.

His *Decadron* dose was decreased, and the symptoms flared back. He took it as a personal failure, as if there were something else he could have done. The experiment, no matter the outcome, was a success, in that it secured an answer. He was not recovering. On the second of March, Gladys called me at my home in St. John's and advised that I should get back to Ottawa as soon as I could, with the implication of a few days. My wife and I left St. John's by car that evening, and arrived at midnight on the fourth.

Bernard died on Tuesday, the fifth of March, at 6:30 in the morning. Gladys, Elanor, James, Jodi, and I were all present. The doctor was called, as there was no doctor present to officially pronounce death. The funeral home was called, in the hope that they would arrive before nine o'clock, and our attention quickly turned towards tidying up the room. Although there is no requirement by the hospice to do so, it was felt that the sooner we returned the room to its unoccupied state the better. James went out to a local grocery store to grab some boxes. All the food went into the kitchen for general consumption. The two posters (which Elanor assured us she did not want returned) and the drawings from the grandchildren (which Gladys did not want to keep) were thrown away. Clothes were placed in suitcases and duffel bags. People were asked whether there was anything in particular they wanted from the room, but it was decided to go through that process later. Gladys started collecting some of the items, but when James returned most everything else was boxed and put in the car for Prescott. Spare medicines and treatments — Alka-Seltzer, Maalox, Imodium – were donated to the hospice, as was the halogen lamp from Prescott. All of this was done with the body still in the room, and the process was interrupted with the occasional paroxysm of grief. Once the doctor arrived and had pronounced, everything we were taking with us was put into the cars, and Elanor, James, and Gladys went to Gladys' house. Jodi and I did the finishing touches on the room, and stayed until the funeral home arrived at eight-thirty to take away the body, whereupon we too went to Gladys'.

Tentative Conclusions

It is difficult to draw conclusions from a simple inventorying of Bernard's room. There are differences between this and most other occasions for decorating space, whether it is institutional or not. Non-institutional implies some form of proprietorship and therefore both permanence and liberty. The sheer effort required to rearrange pre-existing objects or bring in new ones normally precludes one from personalising a short-term temporary space like a hotel room. Residents of certain institutional spaces, like students in university residences or prisoners not serving a life sentence, place a finite term on the stay, but that term is of sufficient duration to make personalising viable. Still other spaces — monasteries, retirement homes, death row — may imply that their residents are there for an indeterminate stay, normally meaning the rest of their life, but this indeterminate period is still expected to last beyond the immediately foreseeable future.

With the hospice, time is uncertain. When one is admitted it is presumed that death is imminent. There had been over a hundred people through this hospice's doors since it opened in February of 2001 to the time of Bernard's death, and only one had left because he had recuperated. It is specifically a place to facilitate the transition from life into death. It is, functionally, liminal, and as such it is ritualistically liminal. When that liminality is assured, and the person is making a transition, the space is constructed by those around him or her. In instances like this, when the imminence of death has gone and the liminality is obscured, it reverts back to personal space. It needs to be made domestic, not sacred. However, the function the room serves is never totally obscured, no matter how domestic the space is made. As Bernard put it, "the very environment militates against denial." Interestingly, the greater his denial — which, to be fair, coincided with the raising of his hopes by his doctor and attendants — the more greatly he modified his environment.[7]

Secondly, unlike residents of most spaces, Bernard was physically unable to be an agent in the acquisition of objects for the room: he had to rely on others to acquire them for him. Furthermore, there were residues from when he was not able even to voice an opinion. The only analogue for this is the personal space of infants and young children: even when they are able to have a voice, they can not exercise it independently. But infants and young children can realistically think to a time when they can exercise control: the infirm do so only hopefully.

Finally, the objects themselves were not so much "life review" (Kirshenblatt-Gimblett 1989) as they were suggestions. His family and friends, with the choices they made, were providing the objects which, when taken together, might form some sort of life review, as if we were suggesting that it was a time for contemplation and resignation. On the other hand, Bernard was looking forward, not back, to either the organisational logistics of settling his estate or, in the later stages, the anticipated time when he would resume his life. His objects of choice were either to suggest the day-to-day (food, clothing, toiletries) and non-personal (books, movies), or to suggest his continued and ongoing role as host (decanters, speciality foods), patriarch (files and items related to estate management), and productive member of society (computer, business cards).

All three concluding themes — sacred / profane, independence / dependence, and contemplative / proactive — reflect a tension inherent

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[7] For a thorough discussion on the denial of death and its use within palliative and hospice literature, see Zimmermann (2004).

in both our original construction of the personal space and any subsequent attempt to interpret it. Much like language, any hermeneutic of personal space can be only a movement towards a more and more likely probability of meaning.

Looking Back

It has now been a few years since the time spent at hospice and my original efforts to commit those events to paper. To frame that time as a moment of "contestation" is to do a disservice to the participants. There was never conflict about the overall rationale for *why* we needed to do what we were doing, *why* we needed to make the decisions we made. There was unity of purpose, but disunity in execution. Each brought to the situation different traditions, different experiences with death, different relationships to Bernard, different faith perspectives, different medical belief practices, and so on. When a negotiation arose, each would position him or herself at the periphery or at the confluence of the decision process, as each saw fit. No taxonomy of appropriate influence could be assumed from one negotiation to the next, and, whereas each decision could be surprising, decisions in which Bernard was more directly involved could have truly unexpected results as a result of his slow deterioration. The consequences of these decisions have in the meantime mostly come to fruition: some have proved negligible, some have healed, some have only begun to fester.

As his world dissolved and his emotions crumbled, he was drawn more and more to a sense of England as his true home, a sentiment he would have actively rejected a year previous. This was betrayed in such moments as his insistence on the word "emigrated" over "immigrated" when he and I sat down to write his obituary: the obituary that he hoped to have printed in the Wolverhampton paper was, in his eyes, normative, while Ottawa's papers were incidental. He broke with his long-expressed plans to have his ashes scattered in Ottawa and instead wished to have them placed in the family plot in England.

But his home had been filled with the contents of his own ancestors' houses, shipped long ago from across the ocean, and kept as much out of a familial obligation as out of desire. These objects act as mementos (in the Kirshenblatt-Gimblett sense of a reminder of an absent person), where once they were the material companions of his forebears (1989: 330-331). But there are elements of sympathetic magic to the inheritance of objects: Bernard ordered his home in much the same way as his father and uncle before him, and placed within that order objects handed down. It is magic, both the homeopathic magic of taste and the contagious magic of an object's lineage, that makes us replicate and bring with us the past in order to invoke the possibilities of the past (Frazer 1999). For Bernard, it was a past that was profoundly English, informed in Edwardian sensibilities and postwar humility, to which he seemed resolutely drawn in his final days. So too was the effort with his hospice room, each invoking a comfortable place through the arrangement of and the inclusion of particular objects, but there were too many magicians.

And so it is with the objects I have inherited, as I in turn try to balance a sense of order, self, and history. With time, the ardour of the sense of obligation that made me keep many of these objects has cooled, half through reason and time, half through resentment and time. I contest with myself, between responsibility to my self and responsibility to the self others, long dead, have created for me.

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