Miles Little is an Australian surgeon, poet, and philosopher whose published work spans diverse topics in surgery, medicine, philosophy, and bioethics. In 1974 he co-authored a survey that included an analysis of interviews conducted with amputees. This was his first foray into qualitative research. Twenty years later he established a research centre at the University of Sydney that initiated a programme of qualitative research in cancer medicine. For twenty years after that, the centre acted as a hub for research that applied qualitative methods from the social sciences to study the experiences of people who endure illness and onerous treatments and to reveal their evaluations of what medicine does to and for them. This essay explains why Little turned to qualitative research instead of pursuing two other research paradigms that were better established in the 1990s, namely, evidence-based medicine and quality-of-life research. It also notes a development in qualitative research methods that Little’s legacy helps to explain, one which can augment the symbolic power of socially marginalized individuals and groups. With reference to a current controversy in surgery, I argue that Little’s survey of amputees models a laudable response to criticism, and in this respect, it is still relevant today.
Survey of Amputees

The survey of amputees portrays disparity between lay and professional perspectives. The surgeons’ technical preoccupations with “a sound and functional stump” (794) are met by complaints from a cohort of patients who are struggling to come to terms with a technoscientific identity (“amputee”) (Clarke et al. 2003) that marks them as disabled in a social context that would today be characterized in terms of its ableism (Campbell 2009) and its deficiency in providing support that is due to them as a human right (United Nations 2006; Harpur 2012). The authors find that “These social failings are matched by major medical failures,” chiefly ongoing pain, lack of ongoing support after discharge from hospital, and lack of improvement in quality of life (794). The authors conclude that clinicians must compensate for the failure of Australian society by maintaining a relationship with those whose bodies they have mutilated.

The focus on social relationships is unsurprising given that one of the authors is a social worker. This is also a hallmark of qualitative research, however, and several other discursive characteristics of this paradigm are also evident in the report. The authors state they “have examined the social impact of amputation … from a medical point of view” (793). By acknowledging other, non-medical perspectives, the text creates the possibility of a dialogue between different perspectives or at least a consideration of their differences and the possibility of bridging them. It also relieves the authors of a need to cultivate the appearance of objectivity that typically characterizes reports of medical research. In fact, their subjectivity is explicitly inscribed: they expected a hostile reception from the research participants, but this expectation was confounded as the amputees welcomed a reprieve from their loneliness and an opportunity to have their say (793).

Concerning values, the report construes the medical perspective as having particular rather than universal standards (“By medical standards this is a reasonably good result,” 794) and it highlights radically different evaluations of the outcomes of amputation that stem from lay and professional perspectives. It also includes a terse observation about the researchers’ own epistemic advantage: “Medical practitioners tend to judge the results of any method of treatment according to criteria they establish themselves” (793).

The features of the text highlighted above would later be elaborated in the methodological literature using philosophical abstractions like “epistemological pluralism,” “heteroglossia,” “rejection of objectivity and universality,” and “reflexivity.” The concluding paragraphs, which contain four instances of “must” and one of “should,” indicate that the authors do not hesitate to reach normative conclusions based on their empirical findings. The final sentence describes remedial action that the clinic has taken in response to the amputees’ criticism.

The Turn to Qualitative Research

This survey of amputees foreshadows a programme of research that Little pursued more than twenty years later at the research centre he established at the University of Sydney, the Centre for Values, Ethics and the Law in Medicine (VELiM), which later became Sydney Health Ethics. With initial support from the then Department of Surgery, Little turned his attention to cancer medicine in a qualitative study investigating outcomes of treatments for colorectal cancer. In retrospect, similarities with the survey of amputees are evident. A series of publications portrays a cohort of patients who are struggling to fit back into their social context after illness and treatment, but in this setting the enduring effects of their ordeal are typically invisible to others. In the absence of an established discourse that would allow them to communicate this predicament, their social relationships become strained (Little et al. 1998). As a discourse is gradually generated, it endows them with a new technoscientific identity, that of “cancer survivor” (Little et al. 2001). This identity has been received ambivalently, as it symbolizes a person’s enduring difference—one that blocks their return to the normality they previously enjoyed (Little, Paul, et al. 2002b).

1 Notably, it is the experience of the interviewer/social worker that forms the basis of this reflexivity.

2 I was closely involved in this programme of research from its inception, as indicated by my co-authorship of several publications cited in this essay.
Little was not the only researcher turning to qualitative methods to pursue research into health and illness at Sydney University in the 1990s, but he certainly created space for the application of these methods in clinical medicine and, most pertinently, in bioethics. The initial study of colorectal cancer was followed by a series of other qualitative studies that were funded by grants secured under the leadership of Professor Ian Kerridge who succeeded Little as director of VELiM in 2003. These studies extended the scope of the Centre’s research programme to survivors of bone marrow transplantation, ovarian cancer, multiple myeloma, and to adolescents and young adults diagnosed with cancer. Each study provided opportunities for new researchers, some of whom completed higher research degrees (e.g., Stephens 2012; Lewis 2012). Many went on to forge academic careers elsewhere in Australia and abroad.

Both Little and Kerridge combined their work as leading Australian bioethicists with qualitative empirical research, and for about twenty years the Centre was a hub within the Faculty of Medicine for research and scholarship in social sciences and the humanities, attracting scholars, local and international, from diverse disciplinary backgrounds. The predominance of social science methods differentiated it from other centres of academic bioethics where, typically, the discourse and methods of normative ethics are applied under the leadership of professional philosophers. This was the enduring influence of Little’s turn to qualitative research. In 2004, academics associated with the Centre were involved in creating the *Journal of Bioethical Inquiry* to provide an outlet for research and scholarship in bioethics with an interdisciplinary orientation (Anderson and Jordens 2004)—an orientation that reflected the ethos of the centre that Little established.

Qualitative research has provided Little with a means to study the perspectives and experiences of those who endure illness and onerous treatments and particularly their evaluations of what medicine does to and for them. The seminal 1997 study of colorectal cancer was structured as an encounter between three different discourse communities (Little, Jordens, and Sayers 2003) with different values and different ways of meaning—differences that complicate communication and co-operative action. The encounter was mediated by the research team who elicited narratives of personal experience from articulate representatives of each discourse community and, in conversations within the team, sought to make useful inferences, generate insights, and share them with a wider audience in ways that protected the confidentiality of participants. This design provided a model for many future studies.

What follows is a brief attempt to place Little’s turn to qualitative research in its historical context and explain it with reference to two contemporaneous research paradigms.

**Two Paths Not Taken**

Two years before the publication of Little’s (1974) survey of amputees, a Scottish epidemiologist authored an influential report (Cochrane 1972) that would, in time, lead to his anointment as the founding figure of evidence-based medicine (EBM). A quarter of a century later, this movement was gaining global ascendence and not least at the University of Sydney, just as Little was establishing his research centre there. It is tempting to see Little’s turn to qualitative research as a counter-cultural move, but this is to risk missing an important similarity between Little and Cochrane (and the movement that anointed Cochrane as its founder).

In the early 1970s, medicine was subject to sustained social criticism and probing economic critiques that called into question the enormous social investment in medical institutions and the diminishing marginal returns they were yielding in post-industrial societies. Cochrane’s (1972) rallying call for “effectiveness and efficiency” was a response to such criticism and it paved the way for a research culture that would temper the claims that medicine made about its social value. In effect, Cochrane was responding to criticism of health systems in the same spirit that Little was responding to the complaints of amputees about surgical treatment: with a degree of humility uncharacteristic of their shared profession, followed by remedial action. Both Little and Cochrane...
can be understood as internal critics and reformers of medicine and “modest witnesses” (Haraway 1997) to clinical medicine’s contribution to human health. The hubris that is sometimes associated with the EBM movement (Little 2003; Smith 2004)—and indeed the antipathy commonly shown by its adherents to qualitative research—disguises the fact that, from the standpoint of postmodern feminism at least, the two are fellow-travellers among the shifting values of post-modernity (Lyotard c. 1984).

Despite the similarity between Little and Cochrane, Little remained critical of EBM (Little 2003) and cast his methodological lot with qualitative research. To explain this move more fully, it helps to reflect on what is taken to be the signal and what is treated as noise in empirical research.

EBM famously elevated the double-blind, placebo-controlled, randomized clinical trial as the means sine qua non for medicine to adduce empirical evidence of the value of its treatments over and above the inherent resilience and self-healing powers of the human body (which Cochrane had witnessed as a doctor in prisoner-of-war camps) and everything medicine lumps into the junk category of placebo effects (Sullivan 1993). Thus, the effectiveness that EBM takes as its signal excludes as noise the symbolic power of the patient (the effect of “mind over matter” that intrigued Freud and other neurologists) and the ability of others to amplify this power through care and attention. Little, as a scholar of the humanities, focuses on the powers of discourse and communication. He therefore required a means of turning that into a signal to study its effects in the world of medicine. EBM, therefore, could not provide the methodological means for him to maintain this focus.

As well as bracketing symbolic power as noise, EBM typically treats inferences from experience as a source of error. This points to another wellspring of EBM in the early 1970s: research into the heuristics people use to make judgments in the face of uncertainty and which give rise to systematic errors or what epidemiologists call “biases” (Tversky and Kahnemann 1974). For Little, the “commendatory, prescriptive talk of everyday life” (Findlay 1970: 3) can be a source of truth as well as error. For the epistemological pluralist, truth can issue from narratives of personal experience as well as from unbiased measurements produced by clinical epidemiologists.

The link with error also explains why Little did not pursue quality of life (QoL) research. This choice needs explaining because by the time Little had established his research programme in the late 1990s, QoL research was the dominant means of investigating subjective evaluations of treatment outcomes, and it was much better established in medical research than qualitative research. So why did Little opt for qualitative research instead?

In the year that Little launched his research programme, a probing review of the field of QoL research (Allison, Locker, and Feine 1997) asked “What do repeated subjective measures of QoL measure?” The review gives three answers:

1. They measure changes in quality of life (“alpha change”).
2. They register changes in the internal standards by which people gauge the magnitude of such changes (“beta change”).
3. They register the subjective effects of a wide range of responses to major life events, such as sudden disablement, that are characterized by people’s ability to make sense of the experience (i.e., to make meanings) that allow them to adapt in the aftermath (“gamma change”).

The authors go on to describe how QoL research has devised methods that aim to control for beta- and gamma-change. In other words, it treats them as noise as it seeks to isolate the signal of alpha change. Qualitative research, by contrast, treats beta- and gamma-change as an important signal. As I suggest below, for example, beta-change might be understood as a portal into post-traumatic growth and gamma-change might be used to explain the importance of forms of discourse, such as storytelling and conversation, in both investigating and giving effect to symbolic power, and the ways in which social relationships can amplify—or indeed, reduce and even negate—this power.

---

4 This is typically precipitated by an extreme experience. If someone has an extremely painful experience, for example, the responses they give before and after the experience on a conventional pain scale of 1 (no pain) to 10 (the worst pain imaginable) are likely to be incommensurable.
Paths Ahead

Since Little established his research programme in the mid-1990s, qualitative research has become widely accepted as a legitimate option for researchers in medicine and public health. The social science cat is out of the methodological bag, so to speak, and has taken up residence in the medical faculty. The place of qualitative research in bioethics is more contested as discourse and debate about “empirical bioethics” continues (e.g., Ives, Dunn, and Cribb 2017). Also, over the past few decades, successive Australian governments have reduced funding to public universities, and as these universities tighten their belts, researchers are seeking safety at the core of their disciplines. We can therefore expect more intensive use of philosophical methods in Australian bioethics, such as thought experiments and conceptual analyses, and fewer interdisciplinary, empirical adventures. Furthermore, the COVID-19 pandemic has recently afforded opportunities for managerialism to tighten its hold within Australian universities (Sims 2020), and in a relentless series of restructuring exercises at the University of Sydney, the centre that Little established in the mid-1990s has been disestablished. What this means for bioethics in Australia remains to be seen. In the meantime, and to conclude, I will highlight one notable development in the use of qualitative research methods that Little’s legacy helps to explain.

In the 1990s, another group of ex-patients confronted the medical profession with complaints of disappointment and medical failure through an advocacy organization called the Intersex Society of North America (ISNA). According to a leading advocate, “most clinicians ignored or dismissed these attempts to communicate” (Chase 1999, 452). Relations between ISNA and the medical profession improved as critics inside and outside the profession, including bioethicists, gave the complaints due attention. ISNA eventually folded with a Pyrrhic victory, however: while it was able to influence new standards of care adopted by the medical profession, it was unable to ensure their implementation in practice (Intersex Society of North America 2021).

Tensions between intersex advocates and the medical profession thereby endure for reasons that echo the findings of Little’s (1974) survey. A recent qualitative study (Hart and Shakespeare-Finch 2021) characterizes intersex experience primarily in terms of enduring trauma due to inter alia mutilating surgery that is unwarranted by evidence of long-term improvement in the QoL of those whose bodies it seeks to normalize. The study also reveals the signals that qualitative research is calibrated to detect: this trauma is counterposed by post-traumatic growth that is an expression of the patient’s own symbolic power and the capacity of others to amplify it though peer support and community. If medical care is failing patients and changing in theory only, the findings regarding trauma and alternative sources of support are unsurprising. The study’s methods illustrate a notable development, however: the “reflexivity statement” identifies the author as an intersex woman, so the study is an example of erstwhile research “subjects” becoming researchers.

Members of socially marginalized groups usually figure in qualitative research as anonymized “wounded storytellers” (Frank 1995). Stories do not carry much weight in the language games that govern the activity of health institutions, however (Jordens 2002, 201–203). This is an issue that Little’s research programme sought to address by involving cancer survivors as collaborators in research (e.g., Little, Jordens, et al. 2002a). Members of marginalized populations are now using qualitative research to enter these language games on three levels: as storytellers, as consumers of expert medical knowledge (Fox and Ward 2006), and as knowledge producers who understand and use their symbolic power on all three levels to pursue their ethical and political goals. In the case of intersex, these goals include displacing a technoscientific identity imposed on patients by the medical profession since the 1950s—that of children whose disordered sex needs to be fixed (Karkazis 2008)—and replacing this technoscientific identity with a social identity of the group’s own making: that of “intersex.”

Conclusion

The survey of amputees (Little, Petritsi-Jones, and Kerr 1974) models a way that medicine can and should relate to those who are disappointed by medical failure and who criticize medicine and advocate for changes in practice where they are not forthcoming. Medical professionals should listen to criticism with an attitude of humility, undertake remedial action as “modest
witnesses” to what medicine can achieve, and maintain supportive relationships with survivors and the communities they form. Political criticism of medicine stimulates changes in medical practices (Jordens 2019, 119), and the capacity of a discourse community to sustain critique of itself and other discourse communities is what makes it an ethical community (Little, Jordens, and Sayers 2003). On that note, bioethicists should ask whether their efforts in relation to intersex are also a failure. But that is a question for another day (Carpenter and Jordens 2022).

Acknowledgements This essay is, in part, a response to a thought-provoking presentation by Professor Stacy Carter at the University of Sydney on 13 May 2021.

References

Allison, P.J., D. Locker, and J.S. Feine. 1997. Quality of life: A dynamic construct. Social Science and Medicine 45(2): 221–230.

Anderson, L., and C. Jordens. 2004. Where do we stand? Journal of Bioethical Inquiry 1(1): 3.

Campbell, F.K. 2009. Contours of ableism: The production of disability and abledness. Basingstoke: Palgrave Macmillan.

Carpenter, M., and C.F.C. Jordens. 2022. When bioethics fails: Intersex, epistemic injustice and advocacy. In: Interdisciplinary and global perspectives on intersex, edited by M. Walker. London: Palgrave pp 107–124. https://doi.org/10.1007/978-3-030-91475-2_7.

Chase, C. 1999. Rethinking treatment for ambiguous genitalia. Pediatric Nursing 25(4): 451–454.

Clarke, A.E., J.K. Shim, L. Mamo, Fosket J.R., and J.R. Fishman. 2003. Biomedicalization: Technoscientific transformations of health, illness, and U.S. biomedicine. American Sociological Review 68(2): 161–194.

Cochrane, A.L. 1972. Effectiveness and efficiency: Random reflections on health services. London: The Nuffield Provincial Hospitals Trust.

Findlay, J.N. 1970. Axiological ethics. London: Macmillan.

Fox, N., and K. Ward. 2006. Health identities: From expert patient to resisting consumer. Health: An Interdisciplinary Journal 10(4): 461–479.

Frank, A. 1995. The wounded storyteller: Body, illness and ethics. Chicago: The University of Chicago Press.

Haraway, D.J. 1997. Modest_Witness@Second_Millennium. Femaleulam®_Meets_Oncomouse™: Feminism and technoscience. New York & London: Routledge.

Harpur, P. 2012. Embracing the new disability rights paradigm: The importance of the Convention on the Rights of Persons with Disabilities. Disability & Society 27(1): 1–14.

Hart, B., and J. Shakespeare-Finch. 2021. Intersex lived experience: Trauma and posttraumatic growth in narratives. Psychology & Sexuality. https://doi.org/10.1080/19419889.2021.1938189.

Intersex Society of North America. 2021. Our mission. interACT: Advocates for Intersex Youth. https://isna.org/. Accessed June 20, 2021.

Ives, J.C.S., M. Dunn, and A. Cribb, eds. 2017. Empirical bioethics: Theoretical and practical perspectives. Cambridge: Cambridge University Press.

Jordens, C. 2019. After dominance: The elastic politics of medicine. In Medical professionals: Conflicts and quandaries in medical practice, edited by K. Montgomery and W. Lipworth, 107–124. New York and Oxford: Routledge.

———. 2002. Reading spoken stories for values: A discursive study of cancer survivors and their professional carers. PhD dissertation, The University of Sydney.

Karkazis, K. 2008. Fixing sex: Intersex, medical authority and lived experience. Durham and London: Duke University Press.

Lewis, P. 2012. Growing up with cancer: A qualitative study of the impact of cancer on the experience of growing up. PhD dissertation, The University of Sydney.

Little, J.M. 2003. “Better than numbers …” A gentle critique of evidence-based medicine. ANZ Journal of Surgery 73(4): 177–182.

———. 2021. Panegyric. Celebration of service of prof miles little and a/Prof Chris Jordens. The University of Sydney, May 13.

Little, J.M., D. Petritsi-Jones, and C. Kerr. 1974. Vascular amputees: A study in disappointment. Lancet 1(7861): 793–795.

Little, M., C.F. Jordens, K. Paul, K. Montgomery, and B. Philipson. 1998. Liminality: A major category of the experience of cancer illness. Social Science & Medicine 47(10): 1485–1494.

Little, M., C. F. Jordens, K. Paul, et al. 2002a. Discourse in different voices: Reconciling N = 1 and N = many. Social Science & Medicine 55(7): 1079–1087.

Little, M., C. Jordens, K. Paul, and E.-J. Sayers. 2001. Surviving survival: Life after cancer. Sydney: CHOICE Books.

Little, M., C.F.C. Jordens, and E.J. Sayers. 2003. Discourse communities and the discourse of experience. Health: An Interdisciplinary Journal 7(1): 73–86.

Little, M., K. Paul, C. F. Jordens, and E. J. Sayers. 2002b. Survivorship and discourses of identity. Psycho-Oncology 11(2): 170–178.

Lyotard, J.-F. c. 1984. The postmodern condition: A report on knowledge. Manchester: Manchester University Press.

Sims, M. 2020. Bullshit towers: Neoliberalism and managerialism in universities in Australia. Oxford: Peter Lang.

Smith, J. 2004. From optimism to hubris. BMJ 329(28 October).

Stephens, M. 2012. Living on: A qualitative study of the experience of living with multiple myeloma. PhD dissertation, The University of Sydney.

Sullivan, M.D. 1993. Placebo controls and epistemic control in orthodox medicine. Journal of Medicine and Philosophy 18(2): 213–231.

Tversky, A., and D. Kahnemann. 1974. Judgment under uncertainty: Heuristics and biases. Science 185(4157): 1124–1131.

United Nations. 2006. United Nations Convention on the Rights of Persons with Disabilities. New York: United Nations.

Publisher’s note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.