



Response—A Commentary on Miles Little et al. 1998. Liminality: A major category of the experience of cancer illness. *Social Science & Medicine* 47(10): 1485-1494

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Abstract This paper by Miles Little and colleagues identified the state they described as “liminal” within the trajectory of cancer survivorship. Since that time the concept of liminality has provided a powerful model to explore some of the difficulties experienced by people with severe and chronic illness. In this commentary I consider the expanding application of liminality not just to a widening range of medical conditions but to the consequences of therapeutic interventions as well and how this expansion has enriched and challenged its use as a conceptual tool.

Keywords Liminality · Chronic illness · Embodiment · LVAD · Transplant

The work by Miles Little and his collaborators on cancer survivorship in the 1990s was at the leading edge of health sciences’ growing interest in the patient experience of acute and chronic illness. Earlier, Bury’s (1982) model of illness as biographical disruption had provided a framework for understanding how illness disturbs normal life, not simply through the experience of unpleasant and debilitating symptoms but because of the impact those symptoms have on a person’s ability to engage with their

world. Illness disrupts the structures and meaning of an individual normal life and as a result interrupts its expected trajectory—the path I see myself taking, that is biographically unique and at the same time given its shape by cultural expectations about the kind of lives people like me should have.

The idea of biographical disruption suggests something significant but temporary. A personal biography may be shaken but it doesn’t stay like that; the individual either returns to the life they had before or accommodates to the new biographical normal. But thinking of illness as a transient disruption of one story before another takes over fails to capture the experiences of those patients who don’t return to whatever they considered to be normal life but continue to exist in the space that Kleinman described as the “frightening no man’s land” of chronic illness (1988, 181). In this ground-breaking paper Miles Little and his colleagues adopted the terminology of liminality to describe the reported experience of long(er) term cancer survivors. As “the state into which the survivor of serious illness, or the person with chronic illness, enters,” liminality reflects their participants’ sense of inhabiting a “neither sick nor healthy” space, constrained by new limits of various kinds and unable to communicate their experience adequately to those who have not themselves undergone it.

More than the identification of liminality per se, Little et al.’s key insight was that it is not just a temporary disruption (1489). They identified two stages in the journey into enduring liminality:

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an immediate, acute phase, followed by “sustained liminality which may last for the rest of the patient’s life” (1490). Crucially, their research showed that this can continue irrespective of the actual clinical outcome. The experience of serious illness cannot be un-experienced. People are changed by it, so that even when someone is considered by others to be a cancer survivor rather than a patient, they themselves may not feel they have returned to pre-cancer life (Balmer, Griffiths, and Dunn 2015; Trusson, Pilnick, and Roy 2016; Rees 2017).

It is not just the symptomology or the diagnosis of cancer that produces the sense of being stuck on the margins of normal life. Cancer is socially recognized as a serious and life-threatening condition; therapeutic interventions are demanding and create symptoms and vulnerabilities that require a physical withdrawal from everyday life, while the hormonal treatment of some cancers can disturb sex, gender, and family roles (Navon and Morag 2004; Gray et al. 2005); there are long periods when nobody knows whether the treatment has been successful; and patients must live with the long-term possibility of disease recurrence. Several authors have since argued for a taxonomy of differentiated liminal states extending beyond the acute and sustained liminality discussed by Little et al. Crouch and McKenzie (2006), for example, suggest there is a third phase beginning five years or more post-diagnosis (i.e. in long-term survivorship) that “transcends” sustained liminality and enables survivors to become more like “ordinary people” (495). Survivorship itself is now often constructed as an integral part of a “cancer process or trajectory, moving through phases or transition points” (Blows et al. 2012, 2156).

Cancer has tended to draw most research attention because it has several features that make it an archetype of the pathway to illness liminality, as well as being common and therefore easy to study (Blows et al. 2012). More recently the idea of liminality has been applied to the experience of illness and treatment in other conditions. Not all illness follows the same trajectory or disrupts normal lives in quite the same way, and as a result of this work our conceptualization of liminality has necessarily been enriched and challenged. In the rest of this paper I look at one aspect: when it is the biomedical intervention, rather than the illness itself, that generates liminality.

Therapeutic Liminality

Implicit in the original paper but not discussed in detail is that to some extent, and depending on the condition, the impact of the pathology can be distinguished from the impact of treatment. Little et al.’s interviewees spoke of their “cancer patientness” being formed as much by the practical mechanics of dealing with a stoma, for example, or losing control over their daily schedule to comply with the timing of hospital appointments, as by the disease itself. It seems that as therapeutic interventions become more sophisticated and effective, and often more invasive, they become powerful generators of liminality in their own right. Kaufman et al. (2011) described as “ironic” those medical technologies that rescue people from imminent death but in doing so set them onto a slower, and often more fraught, trajectory of dying. In a growing number of situations medical interventions not only maintain patients in the more or less tolerable liminality of more or less compromised health but also actively create distinctive “between states” of their own.

Liminal Lives: LVAD

Several authors (Overgaard, Kjeldgaard, and Egerod 2011; Guidry-Grimes and Sederstrom 2015; Barg et al. 2017; Standing et al. 2017) have reported on the experience of liminality in the lives of people fitted with left ventricular assist devices or LVADs. These are mechanical pumps, usually implanted, that support patients in severe heart failure by compensating for the reduced cardiac function. They can be used either as a temporary bridge to transplant (BTT) or, where transplantation is not suitable, as so-called destination therapy with the goal of providing a better quality of life for the patient until their eventual death. And the evidence is clear that LVADs do make many aspects of life better for their wearers but equally clear that this comes at a significant price. In addition to the risk of standard clinical complications such as infection and stroke, an LVAD creates a state of extreme dependency on the machinery (and indirectly on caregivers) that many patients find alienating and hard to bear.

The everyday realities of life with an LVAD hold people in a transitional state in more than one way. In addition to the subjective sense of being stuck in the no man's land common to all chronic illness, patients who are using LVADs as destination therapy are even more starkly suspended between a state of compromised health and death, while for those whose LVADs are a temporary solution to the crisis of heart failure, the natural flow of their lives becomes a “stagnating present” (Toombs 1990, 237) on the transplant waiting list.

The LVAD is a device that creates a distinctive form of physical liminality as well. Many LVAD wearers describe themselves as a fusion of human and machine; they speak of the uncanniness of “being plugged into the wall” and their acute awareness that “[m]achines fail ... Anything manmade is gonna fail” (Barg et al. 2017, 8). Meanwhile, the clinical team may be aware of the practical difficulties facing their patients after they leave hospital but generally fail to realize that life with an LVAD profoundly changes “the ways that patients think of themselves as persons or the meaning of their machine-dependent existence” (9) and that this has major unnoticed implications for the quality of patients' lives.

Yet just as with the journey through the successive phases in cancer survivorship, the liminality of LVAD life is not static. Describing a patient waiting for a donor heart to become available, Standing et al. (2017) observe that his “conception of life with the device changed ... [T]his was a new and different normality, but it was one that he accepted, at least for the foreseeable future” (145). They suggest that at this point of acceptance of a new normality, life with the LVAD is no longer really liminal. But they also recognize the precarity of this equilibrium, noting that “any normality that VAD recipients may achieve is unstable ... the liminality experienced by VAD recipients may be best conceived not as a state in itself, but rather the loss of a fixed state.”

Liminal Lives: Transplant

Interventions such as LVADs, dialysis, extracorporeal respiratory support and so on successfully prolong and often improve the quality of life but also produce distinctively abnormal forms of existence. In conditions where hearts, kidneys, livers, lungs, and

pancreases are irretrievably failing, organ transplantation may be presented as a cure for the disease and a way out of chronic illness back to normal life. One of Standing et al.'s LVAD patients looks ahead to this with envy, saying “You see people post-transplant who just seem to be really completely back to where they were ... ” (2017, 145).

Yet in reality, organ transplantation is another biomedical intervention that in saving lives also generates its own version of chronic not-quite-health. While the attention of health scientists has focused on the undoubted clinical success of transplantation, and meanwhile bioethical interest has been directed almost exclusively towards the (admittedly gripping) moral dilemmas of organ acquisition and allocation, there has been a curious lack of interest in the lived experience of post-transplant life and its consequences for ethical healthcare. This indifference may be the unintended result of public health messaging about organ donation. Campaigns to motivate potential donors (have to) emphasize the transformative potential of organs for transplant recipients, but in doing so necessarily talk up the restoration of recipients to health and to normal life, downplaying more complex narratives. The actual ambiguity of post-transplant survivorship only becomes clearly visible in social media and online support groups where transplant recipients can openly discuss all aspects of their lives outside the clinical context. In these conversations the sense of liminality is more evident and shows that the liminality of post-transplant life can be rather different from that of either cancer survivorship or life with an LVAD.

In their phenomenological investigation of six kidney transplant recipients Bogue Kerr et al. (2018) observed the now-familiar experience of “living in between” both life and death and health and illness. What was different for most of these patients was that they had already experienced a liminal life on dialysis prior to transplant, and they now described it as an ongoing feature of their lives post-transplant as well. But this was not, or not simply, because the transplant has failed to cure their original disease. Bogue Kerr et al. point instead to other factors, notably the regime of immunosuppression that transplant patients must take, usually for the rest of their lives, in order to prevent the donated organ being rejected by their own immune systems. Immunosuppression keeps the organ intact and the recipient alive, but the powerful

drugs have side effects that in the short term can make recipients feel actively unwell (with nausea, insomnia, headaches, and other maladies), while in the longer term they can lead to significant health problems of their own, including kidney damage and cancer. As one transplant recipient put it, “Feeling like shit is the price of staying alive.”¹ Immunosuppression also increases a recipient’s general vulnerability to infection, and despite integrating extra precautions against exposure into their daily routines this often leads to intermittent periods of illness. In other words, it is often the immunosuppressive medication rather than the transplanted organ that creates the conditions for liminality. The motif of transplantation as “the gift of life” glosses over the reality that the life it offers is both precarious and radically unlike life before transplant. Crowley-Matoka observes this realization striking kidney recipients when they find that their “new normal” life is not as they imagined, or were encouraged to imagine, when they were on the waiting list. “I thought I would be healthy again, and normal, but really I’m just a different kind of patient now” (2005, 821).

Liminality, Miles, But Not As We Know It

In its original anthropological sense, liminality is a ritualization of the end of one identity and the onset of a new one, a socially recognized passage with clearly defined entry and exit points (Turner 1969; van Gennep 1960). Little et al. are careful to acknowledge that their use of the word is different, and in the social sciences of health the meaning of liminality continues to evolve. As research explores an expanding range of conditions in granular detail, some authors suggest there is a need for more differentiated terminology. Bogue Kerr et al. (2018) for example introduce the notion of the *transliminal self* to capture the lived experience of transplant recipients. They use the term *transliminal* both to echo the language of transplantation and to highlight that the liminal experience contributes to the formation of an identity that “never completely emerges from its rites of passage and is never completely healed” (568). In an account of her own kidney failure and transplant, Richards

(2012) describes life on dialysis in classically liminal terms as being in “a waiting room between succumbing to a fatal disease and receiving therapy that might save my life” (173). She does not think that liminality can be anything other than temporary and wants to distinguish the pre-transplant state from her post-transplant experience by introducing a new term, *littorality*. Littoral zones are those areas on the shore that are neither purely sea nor purely land but emerge out of the constantly shifting relationship between the two. Richards defines the experiential littoral state as dynamic, at any one time holding the potential for both the transience of liminality and an enduring existence “as a zone in itself” (13).

This proliferation of nomenclature is a response to the entirely predictable diversity of ways that people experience the in-betweenness of chronic and disabling illness. But I suggest that rather than devise new names for every nuance, it may be more useful to remember that liminality is not a diagnostic category but something that is felt. Little et al. were prompted to turn to the concept of liminality in the first place by “the central fact of embodiment” in their participants’ accounts (1485): the aspects of their stories that reflected what being a cancer survivor feels like. Although the analytic lenses of discourse and narrative have yielded valuable theoretical insights, there is a danger in the discursive perspective of losing touch with the embodied materiality of illness. The body is the means through which subjects have a presence in and engage with the world; whatever a sick person experiences can be traced back to their body and the personal sense they, and those around them, try to make of it when things go wrong.

However theoretically rich and useful we find the idea of the liminal state, it should not be forgotten that the common thread running through the experience of liminality is distress. Being cut off by illness from what patients consider to be their proper life is traumatic, and as liminality persists so does its trauma. Nevertheless, and without denying this painful reality, the recent and more subtle accounts begin to raise the possibility of re-imagining liminality in ways beneficial to those living it. In their original paper Little et al. make the intriguing suggestion that the liminality of chronic illness is a historically recent phenomenon and that in the past, being ill

¹ Personal observation.

was so regularly encountered that it was socially incorporated into the normal run of life. With effective, scientifically based medicine having changed our expectations of both health and therapeutic interventions, illness that persists and that medicine fails to make better has become much more of an anomaly. When existentially disruptive illness presents as an affront to a well-ordered life rather than a shared human experience, the liminality that follows can never be anything other than alienating.

Yet the increasing number of life-sustaining but non-curative biomedical tools, as well as the ability to diagnose a range of conditions presymptomatically, suggest that for more and more people “normality” will involve long stretches in which they live somewhere between health and illness. In this context it is interesting that some writers have cautiously (given that we are, after all, talking about serious illness) suggested reframing liminality less as a state of social alienation and more as a breathing space in which identities can shift and re-form. Ironically, this brings us closer to the original anthropological meaning of liminality as a site of metamorphosis before entry into a new existence.

Clearly, reframing liminality as a transformative opportunity would be misleading and offensive if it were interpreted to mean that patients just need to bring a better attitude to serious or long-term illness. The key point, as Little et al. showed, is that liminality is intrinsically relational. It emerges in the clash between a person’s lived reality and the expectations, their own and others’, of how their life should go. Without downplaying the physical and mental impact of illness or the distress of liminality, the pressures exerted by social norms (of behaviour, practices, and roles) are significant contributors; patients may be more troubled by the expectations of those around them that they ought to be back to their former lives, than by the practical reality that they are not. Modifying social expectations to accommodate different kinds of chronic illness as a normal part of life would not be straightforward but could alleviate some of the alienation of chronic illness. It would also help to endorse life in liminality as meaningful in its own right.

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