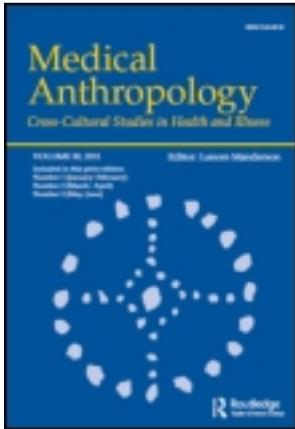


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### Elusive Genes: Nuclear Test Veterans' Experiences of Genetic Citizenship and Biomedical Refusal

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# Elusive Genes: Nuclear Test Veterans' Experiences of Genetic Citizenship and Biomedical Refusal

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Anthropological studies of genetic citizenship have focused on illnesses with medically explained etiologies. Such studies tend to trace patients' agency and resistance as they encounter genetic knowledge. By contrast, we explore how genetic knowledge is configured by those suffering from contested illnesses. Through interviews, we examine the claims for health care made by British and New Zealand veterans who in the 1950s took part in nuclear testing in the Pacific. We illustrate how genetic citizenship can be crafted largely without mainstream medical support or state legitimation, showing that participants understood genetics through personal, relational, and affective experiences. These experiences were utilized to build illness narratives in part because they were the best resources available. Veterans also trusted these discourses because they captured experiential knowledge and revealed personal and familial suffering in ways that biomedicine could not.

**Keywords** *contested illnesses, genetic citizenship, genetics, knowledge, nuclear radiation*

"The genetic effect is a big worry," Terrance admitted during his interview. A New Zealand naval veteran aged in his late seventies, Terrence had just described witnessing three nuclear bomb explosions mushroom above the Pacific Ocean half a decade before: "Our grandkids, my grandkids are alright, but what about their kids, you know? It's a scary thing." Terrence was not alone in being preoccupied by his descendants' genetic health. Like many nuclear test veterans in New Zealand and Britain, Terrance spent time in private family spheres, in veteran gatherings, and in engagements with medical and state officials, detailing his desire for genetic knowledge, health care, and financial support for the suffering that he blamed on the British bomb-testing program. Humphrey, an 81-year-old New Zealand veteran, expressed both resignation and despair over the government's response to test veterans' concerns. "They can't do much for us [test veterans] now, I think we're history," he stated. "But I'm really annoyed that the [government] should be doing something for my family and my grandchildren. And if they

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get on it early enough they might be able to sort it. Why wait for them to develop these illnesses that . . . they will suffer [from] for the rest of their lives? And that hurts me.”

The sense of hereditary damage and biological vulnerability expressed by nuclear test veterans such as Terrance and Humphrey reflects a recent cultural shift that increasingly prioritizes the role of genetics in shaping illnesses, medical knowledge, and even kinship ties. Today biomedicine appears to bring genetic risk within the realms of human prediction, control, and action (Goodman 2007:1; Heath, Rapp, and Taussig 2004). For some scholars, this signals ‘the rise of the gene’ in both bioscience and public cultural domains (e.g., Lippman 1992) and emerging forms of genetic citizenship (Heath et al. 2004).

In this article we join a body of expanding scholarship that problematizes the seductiveness of stories that tell of the gene’s ascent (e.g., Finkler 2003; Gibbon 2008; Lock 2009; Rapp 1998). We explore a case study in which genetic knowledge has not gained medical or political legitimacy, despite the persistent efforts of nuclear test veterans and their advocates. This case study cuts against the grain of most studies of genetics in anthropology, which have focused on genetic disorders that have some degree of biomedical legitimacy. By contrast, we focus on medical conditions that mainstream biomedicine contends cannot be explained genetically. Utilizing the insights offered by studies of contested illnesses (e.g., Brown 2007), we examine how genetic citizenship is constituted when it is without mainstream medical support or state legitimation. For test veterans and their families, scientific configurations of genetic vulnerability were subsumed within personal, relational, and affective illness narratives. This is partly because, in the absence of solid medical proof and political validation, they are the only resources available to understand and assert genetic vulnerability; these narratives speak less of agency and resistance, and more of making do. Yet such illness narratives located outside the medical domain are also utilized because they are ‘experience near’ and a trusted resource in test veteran communities. They also powerfully expose personal and familial suffering in ways that scientific discourses do not. We thus argue that medical anthropology should attend to the ways in which emerging forms of genetic citizenship can craft uncertainty, expose the limits of scientific knowledge, and constrain action, just as they can enable new collectivities and agency.

We base this article on research carried out by Catherine Trundle from 2009–2012, which includes more than 60 interviews with male test veterans, aged in their seventies and eighties, who were members of nuclear test veteran associations in New Zealand and the United Kingdom. These interviews also commonly included test veterans’ family members, or were conducted with deceased test veterans’ children or widows.<sup>1</sup> In centering our analysis on test veterans’ interviews, we take a narrative approach. Narratives of the self make sense of the flux of everyday experiences, structuring them into stories of meaningful life trajectories. Chronic illnesses require particular narrative identity work because they disrupt corporalities, subjectivities, expectations and hopes, and the flow of life events (Hydén 1997; Kleinman 1988). For test veterans, illness narratives must weave together stories of chronic illness and damaged kin with wider historical and political forces in order to make sense of networks of suffering, find cause and blame, and imagine biopolitical endpoints (Trundle 2011b).

## GENETIC CITIZENSHIP AND GENETIC REFUSAL

In crafting illness narratives, test veterans and their families sought to claim forms of biological citizenship. Anthropologists use the term “citizenship” to refer to the wide-ranging obligations, rights,

sacrifices, duties, and forms of care that are envisaged to circulate between citizens, society, and the state (Trnka, Dureau, and Park 2013). Medical anthropologists have sought to document the ways in which citizenship projects are increasingly configured along biological, therapeutic, and pharmaceutical lines (Ecks 2006; Nguyen et al. 2007; Petryna 2002). While they illustrate how the protection and pursuit of health has become a central component of modern forms of governmentality (Foucault 1978), they also uncover the uneven distribution of biological citizenship, as those on the margins of society and outside crucial social networks struggle to gain biological entitlements, care, and resources (Biehl 2007; Fullwiley 2004; Petryna 2002). Correspondingly, test veterans' claims reveal what occurs when biological citizenship intersects with genetics and contested illnesses, demonstrating how forms of social inclusion and exclusion become embodied through the effects of particular political realities. In an age when illnesses are increasingly understood in relation to genetic codes and predispositions, many claims for illness recognition, treatment, and prevention express emergent forms of 'genetic citizenship' (Heath et al. 2004). Genetic citizenship "connects discussions of rights, recognitions, and responsibilities to intimate, fundamental concerns about heritable identities, differential embodiment, and an ethics of care" (Heath et al. 2004:157).

Anthropologists studying genetics and genetic citizenship have often worked to "dethrone" the gene as a determinant of health and illness, outlining the range of social, cultural, and technological factors that complicate illness experiences and outcomes (Lippman 1992; Lock et al. 2006; Lock 2009; Montoya 2011; Petryna 2002; Raspberry and Skinner 2007; Whitmarsh 2008). Anthropologists have explored how social groups engage with emerging genetic knowledge, charting patients' agency and resistance, and the competing explanatory frames that emerge from, for example, family relations, histories of racism, economic insecurity, gender dynamics, and religious beliefs (Lock 2008; Lock et al. 2007; Rapp 1999). The genetic conditions examined in these studies are established hereditary illnesses, contained within family lineages or the result of chance mutations within specific genes, where emotions of blame and guilt are muted or enacted largely within the family sphere.<sup>2</sup> By contrast, test veterans claim that their illnesses are genetically transmitted, but of a recent environmental and social origin. Attributed to radiation exposure, their illnesses thus link damaged bodies directly to the moral culpability of the State.

A body of research that does explore competing medical claims and conflicts is that focused on contested illnesses, such as chronic fatigue syndrome, multiple chemical sensitivities, and fibromyalgia (e.g., Phillips 2010; Ware 1992). Yet genetic citizenship has not been anthropologically theorized in relation to the insights proffered by this literature. Military personnel have claimed a number of contested illnesses, such as Gulf War syndrome (Brown 2007), Agent Orange dioxin exposure in the Vietnam War (Scott 1988), and posttraumatic stress disorder (Young 1997). Although biomedical evidence is elusive, patients of such conditions commonly experience chronic and debilitating symptoms, and that medical experts often delegitimized, trivialized, and challenged their illness narratives (Ware 1992). In this vein, we ask: What are the effects of such biomedical refusals on test veterans' claims, and what openings do these refusals create for alternative genetic explanations?

## BACKGROUND

From 1952–1958, the British Ministry of Defense operated a program of atmospheric nuclear testing, deploying forces to detonate 12 bombs in remote Australia (Maralinga) and on the island

of Monte Bello. A further nine tests, most in the megaton range and codenamed 'Operation Grapple,' were detonated above Christmas and Malden Islands in the central Pacific. The Royal New Zealand Navy deployed two frigates, HMNZS Rotoiti and HMNZS Pukaki, to the Pacific tests to conduct weather sampling. In total, 551 New Zealand, and around 22,000 British, 14,000 Australian, and 150 Fijian armed forces personnel, served at the testing sites (Muirhead et al. 2003:iii; Pearce et al. 1990:4). Then under British jurisdiction, these islands are now part of the Republic of Kiribati (Arnold and Smith 2006; Crawford 1989).

Several decades later, test veterans began expressing concern about their potential exposure to radiation during service. In both Britain and New Zealand, veterans formed associations; forged links with scientists, lawyers, politicians, and journalists who were interested in their claims; and began lobbying for increased entitlements, health care, medical research, and compensation. The formation of such 'biosocialities' (Rabinow 1992) are common within contested illness groups, as advocates draw on varied coalitions of scientists, health advocates, private corporations, and political actors (Heath et al. 2004) who collectively work to 'empower' sufferers and craft economies of hope (e.g., Biehl 2007).

In response to increasing pressure, the British Ministry of Defence (MoD) and New Zealand Defence Force have both asserted that personnel were only exposed to minute and harmless levels of radiation (Moonie 2002). Even so, both governments have made some concessions in providing health care and financial support. New Zealand test veterans have been able to claim war disablement pensions for a range of cancers in connection to Operation Grapple, and British veterans suffering from leukemia within 25 years of the tests were also eligible to make pension claims.

Yet many test veterans argue that a much wider range of illnesses should be included, and they have fought to gain medical entitlements for their descendants. Most recently, in 2009, around 1000 British, New Zealand, and Fijian veterans filed a claim against the MoD in the British High Court in order to receive compensation for their ill health (Trundle 2011a). They recently narrowly lost this case before the UK Supreme Court.

## SCIENTIFIC OPENINGS AND CLOSURES

In interviews, veterans and their wives described in detail their descendants' ill health. For example, the daughter of British veteran Robin had 30 operations to correct a disfigured arm, fingers, and breasts, and New Zealand veteran Andrew's grandson underwent ten operations for his hair-lip. Some reported their children suffering from cancers such as leukemia, ovarian cancer, and skin cancer; several daughters highlighted their fertility problems. Down syndrome, autism, and heart problems were also present in accounts of grandchildren's health and linked to nuclear testing.

Nuclear test veterans and their widows recalled their desire to gain a sure scientific grasp of their genetic damage. Yet science can only provide test veterans with uncertain knowledge. Contested illnesses linked to environmental causes such as low dose radiation or chemical exposure test the efficacy of science and medicine, because the causal pathways between toxins and health outcomes are complex and little understood; they are not adequately revealed by clinical and epidemiological models and techniques, which struggle to map low dose exposure and response relationships (Brown, Kroll-Smith, and Gunter 2000). Nor can such models track environmental

illnesses at a genetic or hereditary level with precision. Studies of contested illness thus uncover the limits of scientific knowledge paradigms and ask what patients do in the face of this.

Mainstream epidemiological studies have not unequivocally linked radiation exposure to human hereditary effects (e.g., Kiuru et al. 2003). The largest studies of Hiroshima survivors and their offspring indicate negligible risk of congenital conditions (e.g., Kodaira et al. 2010). Some scientists, however, challenge the validity of these results, criticizing the studies' underlying assumptions, control group selection, and even suggest the influence of political forces (e.g., Sawada 2007). Some smaller epidemiological studies indicate that UK test veterans' children and grandchildren suffer worse health than control groups (Busby and de Messieres 2007; Rabbit-Roff 2009), with increased rates of spina bifida, cancer, and dermatological, musculoskeletal, and gastrointestinal conditions. Rates of stillborn births and miscarriages were also reported to be higher than normal. Government radiation bodies in New Zealand, Australia, and the United Kingdom have rejected these findings, criticizing the studies' un-randomized sample selection, lack of peer review, or weak statistical validity.

Experimental studies within radiobiology have, however, asserted that radiation can create hereditary effects in plants and animals (Vogel 1992). As the United Nations Scientific Committee on the Effects of Atomic Radiation argued in an official report, "Humans are unlikely to be an exception in this regard" (2001:1). They concluded that radiation may cause a small increased risk of hereditary diseases. While there is increasing recognition that even low doses of radiation can have adverse health effects, the scientific community has failed to reach a clear consensus on hereditary effects, and the methods for detecting health outcomes are still emergent (Brenner et al. 2003; United Nations Scientific Committee on the Effects of Atomic Radiation 1993). This leaves test veterans with only controversial scientific knowledge on which they might rely when determining the genetic damage that they and their descendants face.

Seeking genetic evidence for their ill health, the New Zealand Nuclear Test Veterans Association commissioned an independent university-based clinical study in the mid-2000s. This multi-colored Fluorescent In-Situ Hybridization (mFISH) study measured the chromosomal aberrations (translocations) present within blood samples of 49 exposed veterans, and compared them to those in the blood samples from a control group. The study found that the nuclear test veterans had three times the chromosomal translocation compared with the controls (Wahab et al. 2008). The study did not attempt to extrapolate the health risks of such translocations for veterans and their offspring, but did state that a high rogue cell count could be linked to immunodeficiency. The New Zealand government initially rejected these findings, despite their publication in a peer-reviewed international journal, and a year later it sought a review through its Advisory Group on Veterans' Health. The Advisory Group, composed of health professionals and university-based researchers, concluded that:

The Massey University mFISH study results do provide evidence that the nuclear test veterans were exposed to ionising radiation. It is not possible to determine the extent of exposure from these studies. . . . The clinical consequences of this, if any, are not known. . . . There is no reason to believe that these changes would have a transgenerational effect and have adverse health consequences for the children and grandchildren of the veterans. The Advisory Group found no evidence in the literature that children of nuclear veterans were at increased risk of inherited disorders. (Campbell 2010)

Following from this recommendation, the New Zealand government still does not recognize any hereditary effects on test veterans' offspring, illustrating how genetic knowledge needs to be

operationalized within spheres of power for it to be an effective resource for genetic citizenship. As a consequence of this lack of recognition and action, many test veterans believe that these government-sponsored scientific bodies are biased and influenced by political pressures.

The trajectory of participants' experiences over the years in seeking recognition for genetic damage is typical of contested illnesses more generally. Contested diagnosis commonly emerges in lay sufferer groups, as individuals and groups recognize reoccurring symptoms across social networks, gather their own "community epidemiology," and demand action to alleviate suffering (Brown 2007:7). Governments are often slow to respond, regarding lay explanations and anecdotal evidence as unpersuasive, creating a polarizing, cynical, and adversarial relationship between parties (Shriver, White, and Kebede 1998:459). In such circumstances, patients develop alternative strategies as they lose faith in institutionalized science, relying selectively on some scientific models, producing their own medical studies, or trusting their own experience and beliefs over experts' explanations (Brown 2007).

Not surprisingly then, despite the mixed recommendations of the Advisory Group's conclusions, and the State's negative response, many test veterans remain certain in their belief that radiation has compromised their own health and that of their descendants. Now backed by the colorful mFISH images of their painted abnormal chromosomes, they believe that they have passed on 'bad blood' to their children, as new genetic imagery and older kinship idioms overlap. A New Zealand test veteran, Henry, explained how the mFISH study had become one important means by which to understand illness experiences, as well as the seductiveness of genetic imaginaries and the currencies of hope that the gene provides to emerging biosocialities:

That's our biggest problem, especially now with . . . [the mFISH] findings, with this chromosome damage, and apparently that could go on for generations, that's the worrying part. I would like to think that . . . I've got three grandchildren, I would like to see them tested, DNA tested for this chromosome, if there's damage.

## BIOMEDICAL REFUSAL

Biomedicine is not a cohesive monolith. The fragile hope that the mFISH study offered test veterans contrasted with their daily interactions within the wider sphere of state health care. While advisory boards help to establish policy governing veterans' entitlements, doctors and medical specialists are the gatekeepers who determine access to such entitlements, including veterans', widows', and children's war pensions and benefits. In doctors' consultation rooms, participants received uncertain, oblique diagnoses. Many test veterans reported that doctors refused to equivocally link their illnesses and those of their children to radiation exposure and nuclear testing. Henry explained, "You go to these specialists and doctors, [and they say] 'Oh maybe, could be,' but no one will come out and say yes, and that seemed to be one of our major problems." Another New Zealand veteran Paul put it simply: "Nobody will put anything in writing."

Test veterans recalled how doctors sometimes responded with heightened interest and concern when veterans mentioned the nuclear tests and asked if it could cause congenital illnesses and miscarriages. One New Zealand veteran, Angus, recalled that, "When we were expecting our first child we told the gynecologist that I was a nuclear vet and she was a bit worried."

However, this concern did not translate into any clear medical assertions of risk. A British widow, Patricia, described how her doctor implicitly explained her troubles in conceiving a child with her test veteran husband:

The doctor said . . . to me, “Mrs. Wilson, with another partner you would be okay,” but he said, “the chemistry just isn’t right between you and Mr. Wilson.” . . . and I never thought to question the doctor then. I mean, [when] we were brought up, the doctor was an authoritarian figure and you believed him, and you did as he said. . . . So I never questioned [him], what do you mean “the chemistry is not right?” . . . And eventually I was told not to try [conceiving] any more.

Many veterans thus registered concern from medical actors, but these moments rarely moved beyond subtle affective interchanges, senses of unease that were never discussed directly or translated into medicalized language or action. In consultations with doctors, veterans and their wives thus acquired fleeting but palpable expressions of risk and were left alone with new or heightened senses of biological vulnerability that they found difficult to explain or act upon.

Sometimes test veterans themselves rejected any implications of genetic damage, even when tentative openings were offered within the medical domain. New Zealand veteran Charles recalled how a fellow test veteran’s wife could not conceive a child. The gynecologist said to her,

“There’s no reason in the world you can’t be productive and produce children. There’s not a thing wrong with you. Get your husband in here.” He was very quiet, modest sort of a bloke and he said, “No, I’m not going to be examined. No, I don’t want to be examined.” And she puts that down to [the fact that] we had radiation poisoning from Operation Grapple. But he died really young.

Robin, for instance, recounted how he had initially dismissed his doctors’ questions regarding the link between congenital illness and radiation: “[The doctor] said, ‘Your wife tells me . . . that that you’ve got a deformed child.’ I said, ‘Yes.’ He said, ‘Did you not think it was anything to do with being out there [at Christmas Island]?’ I said, ‘No . . . we were perfectly safe.’” Robin reflected on the trust that he had once placed in his Army superiors’ assurances. Connecting illnesses to radiation exposure in the medical realm was thus a fragile process that could be thwarted by not only doctors’ uncertainty, but by veterans themselves; military cultures of obedience or distrust in the medical gaze could easily foreclose avenues to genetic knowledge.

In many accounts of genetic citizenship, the domains of biomedicine, commercial industry, and government are presented as intersecting forces that variously utilize, develop, and enable genetic technologies (Heath et al. 2004; Rabinow 1992). Genetic techniques have already achieved degrees of certitude regarding the etiology and existence of the illnesses that they chart (e.g., Gammeltoft 2008) even if the predictions they offer are uncertain and unstable. Biosocial collectives form by culturally refashioning bioscientific knowledge and resources for their own ends (Gibbon and Novas 2008). Consequently, the practices of genetic refusal that scholars explore tend to be at the level of the patient and/or family rather than science. Genetic risks emerge first from the biosciences, and are variously transformed, rejected, forgotten, misunderstood, and incorporated by the layperson. For nuclear test veterans, the inverse occurs. Genetic refusal arises at the level of the State and biomedicine. The veterans themselves demand knowledge of their chromosomes and forge genetic identities without the State’s help and in conflict with official policy and legitimized scientific conclusions.

## RISKY GENES BEYOND THE MEDICAL DOMAIN

In the absence of any legitimized science to inform their perceptions of faulty genes, nuclear test veterans and their families mapped social and personal knowledge onto chromosomal damage. This helped to build up a profile of radiation-induced bodily harm. Nuclear test veterans and their wives employed personal and family histories to understand reproductive difficulties. Without genetic or even reproductive tests, they instead relied on “experience-near” perceptions of somatic frailty (Rapp 1998:53). Patricia calculated the harm caused to her family by radiation based on expectations of her own body: “My son’s from my first marriage, and I had no trouble with the pregnancy at all.” After marrying her second husband, a test veteran, however, she failed to carry a child to full-term. Her previously able body provided all the evidence she required, from which she determined that the faulty ‘chemistry’ her doctor described was in fact her husband’s irradiated sperm.

Other widows asserted personal understandings of probability that did not rely on external statistical or scientific validation. For example Matilda, the daughter of a British test veteran, recalled how, “I just thought the probability of three [unhealthy] children to [Mum], to one mother, I just think it seems a bit [strange].” Her mother Elsie further connected Matilda’s fertility problems, and grandsons’ autism and leukemia to Operation Grapple by making the point that her own siblings’ children were all healthy. Here intimately known healthy familial networks provided the proof Elsie required to locate abnormality beyond the wider family sphere and outside the realm of chance (cf. Lock 2008). Illness narratives thus utilized the logic of revelation, and centered on the gradual process of weaving together key pieces of personal evidence, leading ultimately to a certainty of proof.

When test veterans formed associations from the 1980s, they created social spaces within which they could exchange personal stories. Here they accumulated experiential knowledge from their peers to build “collective histories of social risk” (Rapp 1995:185). A New Zealand test veteran, Tom, commented that, “When they formed the Association we sort of discovered people that were really ill, and the results [on] children.” Correspondingly, Henry recalled one of the first New Zealand Test Veteran meetings: “There were kids that had been deformed, born deformed, and miscarriages, and all that sort of thing. And everyone that went to that conference had a horror story to tell about their family. So it was quite frightening really.” Robin recalled speaking with a widow at a test veteran gathering:

[I asked after her children] “Are they both all right?” And she said . . . “Why, have you [had problems]?” I said, “I’ve got a little girl who’s badly deformed.” And she said, “Uh, well, that’s funny. . . . We had one of those too. . . . But she was very ill.” So I thought there’s something funny here.

Robin went on to recite an almost encyclopedic list of the illnesses and conditions that afflicted veterans and their families:

[Another] lady . . . she’s got twin boys, and their bodies keep making too much calcium. . . . [Another lady] she’s had seven children, five of them are abnormal, one died of leukemia, two have got problems with their eyes. . . . One of my colleagues . . . I was at the meeting one night, and his daughter was there, and her. . . . I think the right leg, was black and blue, all the way up and down. Like um, like a summer pudding! . . . and I said, “What’s wrong with your leg?” She said, “Well, I was born like this.” She had been affected as well. And her problem, really, is similar to [my daughter]. . . .

[Another lady], she's got retarded children. Her husband died from a, I think it was a brain tumor, in his thirties!

In the absence of any medically and politically accepted evidence of hereditary harm, in interviews test veterans recounted as many examples of illness that they could remember. As in many contested illness claims, “(a)ccounts of individual illness struggles and suffering confer social power, as these narratives and images make illness claims tangible” (Vanderlinden 2011:45). Lacking epidemiological statistics, participants provided the weight of numbers to validate their claims in a more personalized and immediate manner, forging a “community epidemiology” (Brown 2007:7; see also Petryna 2002).

Olive, a widow prominently involved in a British nuclear test veteran group, described her role in supporting all veterans with ‘affected children.’ She recalled a social gathering where she heard a test veteran, Jack, describe how his daughter had been born with no organs on her left side, and how she in turn had given birth to a deformed child: “I went and put my arms around him and I said, ‘Jack, I am Olive, and I have just heard that awful story you have told, course we have all got awful stories. . . .’ I said, ‘Don’t worry Jack, I am here now, Ted will sort it out, we will all help you.’” Leaders in test veteran groups thus ensured that the ill health of members’ descendants came to be understood as proof that fitted within a collective story of suffering. Their trajectory of their illness narratives thus sought to chart the shift from isolated, naïve individuals, to a cohesive, empowered, and supportive community. Gaining contact with the wider test veteran community was cast as a process of gaining knowledge and a will to fight. Using the tropes of truth, freedom, and strength, their narratives operated to morally legitimize their biosocial network.

## THE AFFECTIVE AND MORAL DIMENSIONS OF GENETIC CITIZENSHIP

In participants’ narratives, the damaged gene figured in emotive, morally charged domains of experience. Significantly, a range of affective experiences enabled and expressed a deeply relational notion of genetics. In this way, genetic damage was embedded within the fabric of inter-subjective exchanges, entangled with notions of luck, blame, betrayal, and innocence. Veterans’ personal understandings of military risk fused with a sense of biological danger only as their life histories progressed. Test veterans reflexively contrasted their current understandings with a previous ignorance. New Zealand test veteran Donald described how, like many young men sent to Christmas Island, he had felt invincible and adventurous: “I think being teenagers we’re all sort of gung-ho and bullet proof, and everything’s a new thing.” Furthermore, many participants regarded nuclear weaponry at the time of testing as a new technology with great potential to ensure peace. Its somatic risks were framed in contrast to the far greater and tragic human losses of two world wars. Donald explained, “This [was] the new age and [nuclear bombs] stopped . . . finished a country going to war, you know, from that point of view. And I lived in an area where a lot of the people never came back [from World War Two]—brothers and sons never came back.” Personal risks were thus at the time of service overridden by the greater social good or masked by the hubris of youth.

Many participants contrasted their youthful ignorance with emerging scientific discoveries about the genetic effects of radiation, which they learned were discussed confidentially within

government spheres in the 1950s. British veteran Hugh described an archived telegram sent during the British Testing program, which many test veterans had recently read:

They knew, the government of the day knew what they were doing. . . . The head of the . . . [UK] Medical Research Council . . . wrote to the Prime Minister [Anthony Eden and] sent them a report as to what would happen with these nuclear tests. And he said that we would have genetic problems and . . . [the] Prime Minister at the time, he just wrote and said, “A pity, but we cannot help it.”

Many test veterans associated their exposure to bodily harm with betrayal, with a government that had calculated military costs in ways that disregarded the worth of their lives. Robin applied to the MoD for a war disablement pension for his own illnesses and for his daughter’s disfigurements. He recalled with anger that his application was rejected, and recounted the explanation given in the letter he received:

[It read] “There’s no evidence to support this claim, it is up to the appellant to prove that they’ve been affected.” But . . . how could I prove that my semen has affected my wife, and my daughter? How am I supposed to do that? Fifty years I’ve been at it. So what they’re doing is putting the onus back on the appellant.

Robin and many other test veterans felt that the State had left them alone with their faulty genes, unsupported in accumulating the evidence necessary to make a medical case for support. Few MoD records had been collected of the radiation levels at the nuclear tests, many MoD documents remained confidential and inaccessible, and the MoD offered the servicemen little medical monitoring on their return home. Claims of genetic citizenship entailed demanding from the State acts of responsibility, care, and protection that were enabled and evidenced through the material realm of state documentation. Such bureaucratic processes make certain illnesses and claims for social inclusion both possible and legitimate, and others not (Trundle 2011a; see also Petryna 2002:111–112).

This reveals the conflicting expectations of proof at play in many contested illness conflicts (Richter, Laster, and Soskolne 2005). The state expected test veterans to personally bear the burden of proof when making claims, while test veterans demanded from the State a precautionary and proactive approach. In many cases of contested illnesses and public health more widely, powerful actors such as governments or corporations control the flow of information upon which claims for support depend (cf. Briggs 2011; Vanderlinden 2011). In bearing the burden of proof while having little access to information, sufferers face an uphill struggle in gaining support. Test veterans thus understood the quest for genetic knowledge through the emotive lens of abandonment, and in relation to the ideals of an elusive military covenant: the unique gifts of sacrifice that military service required needed to be repaid by the State through preferential and proactive health care, medical monitoring, and a benevolent approach toward illness claims (Trundle 2012a, 2012b). Genetic citizenship claims were, at their core, assertions of exchange and reciprocity, upon which both the State and soldiers depended.

Conversely, in everyday language damaged genes were at times equated with luck. Some test veterans who did not suffer ill health, and who reported that their offspring were unaffected, explained this in terms of fortune and misfortune. As Ben explained, “I don’t know why I didn’t or my family didn’t [get sick], just dead lucky I suppose . . . some families have been really badly hit and others not.” Notions of chance were tempered and underwritten by the persuasive

language of science. Many test veterans discussed the settling particles of radioactive fallout on the land, the ocean, their equipment, and their ships. They described tiny, invisible “alpha and beta radioisotopes” undetected by the gamma radiation monitoring carried out at the tests. These were harmless on the skin, but if “ingested and inhaled” could lodge in their bodies for decades. Near impossible to medically detect once internal to the body, there they could emit tiny but dangerous levels of radiation that could cause malignant cell growth. Luck or misfortune determined whether the servicemen ingested dangerous particles. Dealing with a highly complex and almost undetectable etiological process, they utilized narratives of luck to retrospectively make sense of a process that would likely never yield transparent knowledge (cf. Lock et al. 2006). Luck is here ultimately used to expose the limits of scientific evidence. Ideas of luck further served to create a language of exception. Those who identified themselves as lucky measured their health against the more pervasive narratives of illness and distress within their groups; misfortune was cast as the norm, and luck rendered the healthy body anomalous.

This was not always the case. Some participants reflected on how other test veterans utilized notions of luck as it intersected with a sense of duty in order to deny genetic vulnerability. As already demonstrated, genetic refusal could come from within their own ranks. Adam, a New Zealand veteran, recalled,

When I . . . went down to the first [Test Veteran] reunion . . . I told [a test veteran friend James] I’d pick him up and take him. He said, “no, no, no, I’m not going . . . the way I look at it . . . I was on that ship when it [went to Christmas Island] and that was just luck of the draw. I was doing my duty.” And I said, “Yeah, but, you know . . . what about your grandkids, that’s what you’ve got to think of.” “No, no, no, I took the luck of the draw,” he said. . . . When I came back he said, “Good conference?” and I said, “Yep.” And he never asked me another question, he didn’t want to know what happened. . . . Bloody suffered in the long run, in the end. He could of got something out of it [a war pension]. . . . One of his grandkids suffered too!

James considered it the veteran’s sacrifice to stoically bear the burdens of misfortune associated with a serviceman’s duty to preserve the State, rather than the State’s duty to respond to the vicissitudes of service with an attentive ethic of care. Collective illness narratives therefore sometimes struggled to forge coherence, and biological citizenship claims were at times multiple and competing.

Ideas of genetic citizenship also fused with notions of blame and guilt. Several participants expressed a deep sense of guilt that their damaged genes, semen, and bodies had caused their wives, children, and grandchildren to suffer. These admissions were often gendered. Veterans presented themselves as damaged in their abilities to biologically provide as husbands and fathers, and portrayed women and children using the idiom of innocence. Charles explained that “The thing that really bugs me about . . . Operation Grapple was the women and children. The innocent ones had nothing to do with it and they’re the ones who are suffering.”

Sometimes these emotions were intersubjectively negotiated across generational lines. Andrew and his wife Willa painfully recalled a rupture within their family caused by the perceived biological effects of Operation Grapple:

Andrew: My two daughters won’t talk to me because my eldest daughter blames me for my grandson’s disability, that’s the hair-lip, up until when I was speaking to her he’d had ten operations.

Willa: Yes, they think it was [Andrew's] fault because he was exposed to radiation, but he didn't know that.

Andrew: It hurts me that they've taken that attitude, that I caused their deformities in their children, which is wrong and we all know it's wrong, but I'm having trouble.

The causes of such family rifts may have been wider than the explanations given in interviews, but the biological effects of Operation Grapple served as the explanatory frame for understanding fragile family ties. Illness narratives of guilt and blame worked to lay bare the social and personal costs of radiation. For another family, a father's guilt was also mediated by his daughter's beliefs, but with different results:

Sam: I know that our daughter has never been able to have children.

Catherine Trundle: And she hasn't attributed it...?

Sam: No she wouldn't [...]

Sam's wife: We used to say to her it's probably something with Dad being up at the bombs, but no, she wouldn't, she didn't want to blame that.

Within perceptions of genetic harm, notions of guilt and blame were mapped onto wider familial histories and intimate ties, becoming the means by which emotions of love, care, anger, suffering, and resentment could be voiced. Genetic vulnerability ties individuals into webs of obligation, care, and conflict, as actors anticipate their biological legacies within kinship lines of present and future descendants (Novas and Rose 2000:507). For test veterans, experiences of kinship were crucial moral forces that countered medical and government denials.

## CONCLUSIONS

Studies of genetic subjectivity and citizenship have focused on illnesses that have gained degrees of biomedical and social recognition. Agency is expressed by active patient citizens, who claim and transform treatment regimes, technologies, and policies to manage risk and live well. Genetic predictions are offered, even if they are only probabilistic and unsure, and decisions are there to be made. Many studies trace the ways that patients rely on 'informal knowledge' to make such decisions which undercut or overwrite biomedical and genetic scripts. Yet this category of knowledge relies on its distinction from scientific knowledge and implies that such 'formal knowledge' exists and is readily available (e.g., Lock et al. 2006:280).

By contrast, unrecognized and contested genetic illnesses cannot rely on established and emerging scientific explanations. Patients must work to prove the very existence or causes of their illness, of which the State, biomedicine, and commercial forces often remain skeptical, and may even have vested interests in denying (Brown et al. 2000). This illustrates that claims for genetic citizenship always occur within structures of power, in which state, biomedical, and corporate interests intersect to offer or deny fundamental resources for recognition and legitimation. Participant narratives that focus on the social, personal, and affective dimensions of genetic damage are not always expressions of lay agency, resistance, and choice. They may be relied on because they are the only solid truths available; they fill the evidential gap that biomedical refusal creates.

Biomedical explanations and social, personal, and affective perceptions are not mutually exclusive categories or experiences. If science does one day provide the nuclear test veterans and their families with certain genetic proof of radiation harm across the generations, their genetic subjectivities will still be woven through with multiple modes of understandings. These relational, personal, and affective dimensions of genetic knowledge are lived as ‘experience near’ and have come to be a trusted currency among test veteran groups. They are one of the means by which their shared solidarity and collective identity are forged. Test veterans’ genetic subjectivities are therefore strategies that craft meaning out of a range of available and sometimes scarce resources: family histories, personal experiences, information sharing between veterans, and public narratives, which are grafted onto the results of contested genetic research and uncertain openings offered within doctors’ consultations. These elements are pieced together over time until an illness profile is created, augmented by new information as it becomes available. Here the gene remains an uncertain but seductively hopeful figure of proof. For test veterans, the gene does not compete with other explanatory frames, but relies on the weight of wider stories to have moral and affective purchase within their claims of suffering.

These relational and affective narratives of genetic damage are also powerful because they allow the social costs and personal burdens of somatic harm to become visible. As Das (1995) and Schuck (1987) illustrated in cases of contested environmental illness lawsuits, victims seeking redress often attempt to go beyond providing scientific evidence of cause and effect. They work to publically articulate the extent of their suffering to those responsible; this is a vital aspect of gaining legitimacy and finding closure. For test veterans, the gene was an entity that revealed the painful existential and relational realities of illnesses just as it offered evidence of physical damage.

Biological citizenship is a process that can constrain agency just as it can enable new forms of action and personhood. By focusing on the frustrations that people face when developing genetic subjectivities, “it turns down the volume on individual volition, beckoning us to also attend to the structural situations over which individuals have very little control, but within which they regularly operate and compose their lives” (Rapp 1999:229). Genetic technologies create as many gaps and uncertainties in biological knowledge as they do opportunities to understand illness processes.

As Petryna (2002) revealed, biomedicine can offer different and competing levels of certainty and uncertainty, proof and denial. Correspondingly, for test veterans, divergent aspects of biomedicine created distinct and contradictory possibilities for imagining and asserting genetic identities. Equally, veterans themselves both claimed and denied illnesses and genetic subjectivities at various stages of their life histories, and could not always agree on the level of harm to which they had been exposed. We must thus stay attentive to the dynamic nature of genetic narratives as they unfold within uncertain political terrains and along transforming life trajectories.

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## NOTES

1. Interviews lasted between one and three hours and were conducted in participants' homes across New Zealand and the United Kingdom. The questions posed were semistructured and open ended, encouraging participants to reflect on their experiences of nuclear testing, their subsequent health, their explanations for the causes of illness, and their engagements with scientific and government bodies. All participants' names in this article are pseudonyms to ensure confidentiality. Catherine Trundle also conducted participant observation in test veteran groups and gatherings, archival research in both countries, analysis of official and archival documents, court observation in the United Kingdom, and interviews with scientists, lawyers, and veterans' advocates in New Zealand and the United Kingdom. British and New Zealand veteran participants are linked by their engagement in a transnational test veteran forum, regular correspondence, and shared involvement in litigation.

2. These include hereditary illnesses such as Huntington's disease or conditions linked to chance genetic aberrations such as Down Syndrome (e.g., Rapp 1995:78; Raspberry and Skinner 2007:377–379).

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