

Therapeutic journeys: the hopeful travails of stem cell tourists

Introduction

Medical tourism has become an increasingly prominent sector of contemporary healthcare. For those willing and able to pay, undertaking travel to receive treatments that are either unavailable or more expensive than where they live may be an attractive option. In recent years, the economy of medical tourism has burgeoned, exploiting the high optimism that surrounds new biomedical technologies (see, e.g. Gray and Poland, 2008; Bookman and Bookman, 2007; Connell, 2010, 2011; Whittaker, 2008; Whittaker, et al., 2010).

This article explores the dynamics of ‘hope’ in relation to one popular form of medical travel, so-called stem cell tourism. Stem cell treatments (SCTs) for various conditions are currently advertised on the Internet as being available at clinics and hospitals in many countries around the world (Ryan, et al., 2010; Petersen and Seear, 2011). Despite warnings by influential science bodies that SCTs are mostly clinically unproven and thus potentially harmful (e.g. ISSCR, 2008, 2012; Australian Stem Cell Centre, 2009), many people travel abroad to pursue these treatments (Ryan, et al., 2010). This is a field of science characterised by competing conceptions of truth and trustworthiness, with patients and their carers being left largely on their own in a mostly unregulated market to navigate treatment options. In science and policy debates on stem cell tourism, it is frequently argued or implied that those who undertake clinically unproven SCTs are unaware of the risks these treatments present to their health, and that patients therefore need to be better informed before making decisions before embarking on their journeys. This approach, we suggest, is simplistic in neglecting the dynamic, complex and constantly evolving contexts within which decisions about

treatments and assessments of risk and benefit are made. In particular, we argue, it overlooks the power of ‘hope’ pertaining to SCTs.

Drawing on ideas from the sociology of hope as applied to biomedicine (e.g. DelVecchio Good, 1995; DelVecchio Good, et al., 1995; Novas, 1996; Rose and Novas, 2005), we examine how hope is constituted and shapes actions in relation to SCTs. As we argue, with reference to the findings of our Australian study involving patients and carers who have travelled overseas for SCTs, ‘hope’ has ambiguous significance. On the one hand, for those who are ill or incapacitated, ‘hope’ provides a valued resource in offering a means to orient current actions to imagined future outcomes. On the other hand, those who embark on ‘hopeful’ treatment journeys are compelled to navigate between ‘regimes of truth’ and ‘regimes of hope’ (Moreira and Palladino, 2005) in relation to SCTs, with uncertain and potentially harmful consequences. We discuss the implications of this ambiguity in light of current responses to stem cell tourism. To begin, some comments about the context shaping the market of SCTs are in order.

The context of the SCT market

The recent growth in the international market of SCTs has been enabled by recent changes in the practices of healthcare associated with neo-liberal policies. These include the de-regulation of health and medical services; widespread belief in the societal and personal benefits to be derived from investment in biomedical science and treatments, particularly enhanced choice in healthcare decision-making (Clarke, et al., 2010: 174-180); and the emergence of new forms of citizenship (‘biological citizenship’) centred on the promises of biomedicine (Rose and Novas, 2005; Rose, 2007). Over the last decade or more, the health and medical tourism sector *in general* has come to constitute a thriving market that is supported by many governments and bio-industries (see Connell, 2010, 2011; Cortez, 2008, 2010; Cohen and Cohen, 2010; Kangas, 2002, 2007, 2010). The World

Health Organization has also promoted the benefits of health and medical tourism, as a means of advancing the national economies of developing countries (e.g. WHO, 2006; WHO, 2009). In recent years, the WHO has published a number of studies on medical tourism, which have explored the magnitude of the phenomenon, the potential economic benefits of the medical tourism industry for particular countries, and the implications of medical travel for healthcare services, including the demand for physicians (e.g. Chinai and Goswami, 2012; NaRanong and NaRanong, 2011).

A growing number of clinics and hospitals around the world currently advertise medical treatments—including those that are clinically unproven—for a range of conditions (e.g. Smith-Morris and Manderson, 2010; Sobo, 2009; Turner, 2007; Whittaker, 2008; Whittaker, et al., 2010). While it is difficult to assess the dimensions of the stem cell tourism sector specifically, it is believed that thousands of patients may undertake travel to other countries every year to receive SCTs (Song, 2010, 2011; Zarceznay and Caulfield, 2010). Among the factors that sustain the global economy of stem cell tourism is the market-driven pursuit of high-tech interventions in countries that are rapidly modernising such as India, Russia and China that enable medical entrepreneurs to flourish, with minimal or no regulatory oversight (Bharadwaj and Glasner, 2009; Chen, 2009; Cohen and Cohen, 2010; Glasner, 2009; Song, 2011).

While optimism surrounds many, if not most, biotechnologies, this would seem to be especially high with SCTs, given the strong ‘translational ethos’ that surrounds this field (Maienschein, et al., 2008: 48). Indeed, as Maienschein, et al. argue, stem cell research is ‘a poster child for translational research’ in that it embodies the dominant ethos that research *will* produce concrete outcomes (2008: 48). Scientists are required to promise specific results up front, in their research grant applications, and ‘must produce results sooner rather than later and more specifically targeted for particular ends rather than for general good’ (Maienschein, et al., 2008: 43). Public investors provide

much guidance in this respect. Governments in Australia, the US, the UK, and elsewhere have invested hundreds of millions of dollars in the expectation that the findings from stem cell research will be translated into marketable treatments in the not-too-distant future. The market for stem cells is already sizeable and rapidly growing—from \$US26 billion in 2011 to \$US119 billion in 2018 (Transparency Market Research, 2013)—if estimates are to be believed.

Widely promoted for their regenerative prospects, SCTs are seen to have considerable potential for treating the degenerative diseases and disabilities associated with rapidly aging populations. Breakthroughs in stem cell science are predicted to underpin the growth of regenerative medicine in the future (National Institutes of Health, 2001). Internationally, many clinical trials involving stem cells are underway—1,700 studies were recruiting in July 2013 (ClinicalTrials.gov, 2013). However, the majority of these trials are at the very early stages of translation (Trounson, et al., 2011), focused on safety with low intake numbers. Consequently, such trials are not readily accessible by those who would like to participate in a regulated study. As with nearly all other technology innovations, progress in the field is reliant on ‘market sentiment’ that affects investment decisions. The announcement in 2011 by US biotechnology company Geron that it would cease its embryonic stem cell research program ‘for business reasons’, including its US Food and Drug Administration Phase I clinical trial for Spinal Cord Injury, is a salutary lesson in this regard (see, e.g. Herper, 2011). In this context of high, yet unfulfilled expectations, many scientists, clinicians and policymakers fear that desperate patients may submit themselves to clinically unproven SCTs and suffer harm and financial exploitation.

These fears are not unfounded. Increasingly, SCTs for a wide range of conditions—including Spinal Cord Injury, Alzheimer’s Disease, Cerebral Palsy, Parkinson’s Disease and Muscular Dystrophy—are advertised via the Internet as being available at clinics and hospitals located in various countries

around the world (Petersen and Seear, 2011). The majority of the advertised SCTs, however, have not undergone clinical trials, with providers' offering little or no evidence of their clinical effectiveness and safety on their websites (Lau, et al., 2008; Petersen and Seear, 2011; Regenber, et al., 2009). On the other hand, there is ample evidence of the use of the rhetoric of hope in the content of providers' online advertising materials (see, e.g. Lau, et al., 2008; Levine, 2010; Murdoch and Scott, 2010; Petersen and Seear, 2011; Regenber, et al., 2009; Ryan, et al., 2010). Providers have employed an array of techniques to capitalize on the promise of SCTs, gaining leverage from the high optimism surrounding new and emerging technologies in general (Petersen and Seear, 2011: 330).

The significance of 'hope' in contemporary biomedicine

Stem cell science like other fields of bioscience relies heavily on the rhetoric of hope. As Brown (2005) observes, increasingly, from the late twentieth century, 'hope' has been symbolically mobilized by the bio-industries in advertising medical treatments and innovations such as cord blood banking. While 'hope' is conveyed and expressed somewhat differently in different national contexts, reflecting local and popular medical cultures and global cosmopolitan influences (DeVecchio Good, 1995), the rhetoric of hope pervades health and biomedical innovations and practices in many contemporary societies. One can find extensive evidence of this in various fields of healthcare, but perhaps most visibly in cancer treatment (see, e.g. Ehrenreich, 2009: 15-44), with a 'hopeful' or 'positive' outlook being seen as a source of resilience, a motivator of action, and a means for overcoming adversity and achieving recovery. In recent years, the benefits of 'instilling hope' or 'fostering hope' in patients have been widely promoted by healthcare professionals such as nurses (e.g. Cutliffe, 2009; Cutliffe and Herth, 2002; Elliott and Olver, 2007; Herth, 2008).

Novas (2006) and Rose and Novas (2005) have explored the significance of the discourse of hope *beyond* the clinic, in shaping citizens' efforts to influence the direction of science so as to hasten the process by which treatments are developed. They use the term 'political economy of hope'ⁱ to characterise the forms of activism in which citizens are engaged in seeking to achieve their goals (Rose and Novas, 2005: 452). As Rose and Novas argue, the Internet has become a key tool in enabling and sustaining the political economy of hope, by assisting self-education, fund raising, the sharing of patient experiences, access to various 'direct-to-consumer' resources, and connection with other actors, including the media, researchers, and politicians (Rose and Novas, 2005: 451-454). This dynamic aspect of 'hope' is clearly evident in the SCT field where patient organizations sometimes lobby for funding for stem cell research. However, as emphasised by our Australian study focusing on patients' experiences, to which we now turn, 'hope' is more ambiguous than tends to be assumed in the literature.

Methods

Our study, undertaken between late 2009 and June 2010, aimed to investigate the experiences of patients and carers (including those caring for minors) who had undertaken at least one course of SCT at an overseas clinic during the previous five years. Specifically, it sought to reveal the factors involved in the decisions of individuals to travel overseas to pursue SCTs not currently available in Australia, largely due to their experimental or clinically unproven status. We contacted respondents via the Australian Stem Cell Centreⁱⁱ (ASCC) and a number of patient groups. We also recruited participants via a snowballing sampling technique whereby respondents invited other participants and/or carers whom they knew had travelled overseas for treatments to take part in the study. The final sample comprised 16 individuals (7 patients and 9 carers of patients—see Table 1) who sought treatments for various conditions for either themselves or those for whom they cared: Motor

Neurone Disease, Multiple Sclerosis, Cerebral Palsy, blindness or vision loss, Spinal Cord Injury, and nerve damage. Semi-structured interviews were then undertaken.

Questions explored a wide range of issues, including sources of information about treatments and individuals who were consulted; factors affecting decisions to travel overseas for treatment; views on the benefits and disadvantages of receiving treatments abroad; experiences during the period of treatment; responses of friends, family members, and carers to the decision to travel abroad for treatment; post-treatment reflections; views on stem cell treatments offered abroad, and views on the kinds of support, resources and assistance needed by patients. We also allowed respondents the opportunity to raise issues not covered by the prepared questions. The treatments were reported to be undertaken between 2006 and 2010 and involved travel to India, China and Germany. Further, the number of separate treatments undertaken varied from one to three, with treatments involving stem cells that were either donated (allogeneic) or from the patient (autologous). (See Table 1) To preserve the participants' anonymity we have assigned pseudonyms with the exception of one participant who declined to be referred to using a pseudonym and is referred to as 'Anonymous' at their request. Key themes to emerge out of the study are explored below.

The findings

The power of 'hope'

The patients and carers whom we interviewed frequently articulated their decisions about or evaluations of treatments and/or travels, in terms of 'hope'. For example:

Improved eating and drinking. Gave me more confidence and hope. (Lynette, patient with Motor Neurone Disease)

We still hold high hopes that stem cell therapy could be the answer for something like, you

know, [child's name's] condition. (Owen, carer of child with blindness)

Further, in recounting their stories of hope, respondents often revealed a strong conception of self as an active agent with ultimate responsibility for their own health. Indeed, 'hope' had motivating significance—as revealed in following patient's comments:

I'm a happier person than I was before I went to India. I feel as though there is some sort of hope, that if I've had these few changes, then you never know what else can happen, and if more research is done using embryonic stem cells then maybe there's something more that's going to be happening in the future. I've got to keep on the Internet and keep learning about it and hopefully go back for more treatment, find out what else is happening over there. (Natalie, patient with Spinal Cord Injury)

However, the hopefulness expressed by these individuals differs from the hope that is generally described in clinical texts; namely belief in the therapeutic benefits to be derived from 'positive thinking'. None expected miraculous recovery following treatments; rather, they looked forward to and endeavoured to achieve small, yet significant improvements. As one respondent (Marion, a carer for a child with Cerebral Palsy) commented, 'I never thought it was going to be a miracle... and people who go with that thought in mind are going to be disappointed every time.' The outcomes that were hoped for, then, were modest by the standards of 'success' employed by some critics of these treatments.

As Novas argues, the hope attached to scientific progress would seem to be most pronounced in situations of desperation or 'near-hopelessness' (2006: 291). This was indeed the case with our respondents, who were offered limited or no treatment options and thus a future defined by resignation to their fate. A number of respondents referred to the 'hopelessness' presented to them by their Australian doctors. For example, '... there was never any hope given, it was stated very clearly, actually right from the first day of the accident that I was a paraplegic, complete paraplegic,

and that there would never be any hope at all of walking, or of any movement at all below my waist.’ (Natalie, Spinal Cord Injury) Like this respondent, others reported conditions for which there was little prospect of treatment and for which they had been given ‘no hope’. It was in this context of thwarted hopes that many individuals began to explore alternative treatment options.

Enacting hope

The patients and carers whom we interviewed, like others described in the sociological literature (e.g. Petryna, 2002; Novas, 2006; Rose and Novas, 2005), adopted an active relationship to expertise, using the Internet and various sources of information to inform themselves about their condition and available treatments. This active aspect of ‘hopefulness’, as Rose argues, ‘is not mere wishful thinking and anticipating’, but rather ‘it postulates a certain achievable and desirable future, which requires action in the present for its realization’ (2007: 148). For example:

... by that stage I was still walking, but I had lost the use of my left arm almost completely. So from that point on, in 2008, I started investigating, because there are no known causes and there are no cures for Motor Neurone Disease. So I thought oh, I better start to learn about it. So I really basically got on the Internet myself ... and started investigating possible ... alternative methods than mainstream ... (Carl, Motor Neurone Disease patient)

When I got out of hospital [after their accident], I was in hospital for about three and a half months, I got out fairly depressed, couldn’t believe I was going to spend the life sitting in this [wheel] chair, after having a fairly active life up until then, and also I was running around after three kids, not being able to do that anymore ... And, we were researching, practically from the day of my accident, researching any new therapies or any way that I can get assistance. We were looking into stem cell therapies. (Natalie, patient with Spinal Cord

Injury)

Such stories of self-education and research into alternative therapies and new treatments were very common. In most cases, the decision to embark on treatment was undertaken after a period of exploring various alternatives, discussion with friends, family, and other patients, and raising the funds required for travel and treatment. Information about SCTs typically was obtained via provider websites, blogs, the print media, patient support groups, and ‘word-of-mouth’ from people who had already travelled abroad to receive a SCT. In some cases, healthcare professionals in Australia were said to provide information. This often prompted further enquiries, in some instances involving direct communication with the clinics or hospitals advertising the treatments. (See below)

In some instances, respondents had spoken to their Australian doctors about SCTs beforehand, which was obviously an important factor in determining whether to proceed with a treatment for themselves or their children in the first place. In at least one case, however, a doctor’s indifference seemed to have been a spur to seeking treatment:

Look...the only [doctor] that I tried to talk to was the Spinal Injury Director at [an Australian hospital] and I was very disappointed with well, one he didn’t want to talk to me and then when he eventually did talk to me there was absolutely nothing gained, so I guess I felt I was probably disappointed to think at the time that I didn’t know where I could go for any information here in Australia so I thought well, ‘I’ll give it a shot.’ (Victor, patient with Spinal Cord Injury)

Choosing a destination

Online advertisements for SCTs lend the impression of virtually unlimited choice in regard to the countries offering treatments and, to some extent, the types of treatments that may be undertaken; for example, human embryonic-, fetal- or adult stem cell-based (see, e.g. Lau, et al., 2008; Petersen

and Seear, 2011). Like much medical tourism, stem cell tourism is often marketed as a ‘packaged’ holiday, comprising treatment along with ‘recreation’ (see, e.g. Connell, 2006). Sometimes, such clinics are established in exotic locations—offering sun, surf and sightseeing—in line with a long tradition of promoting places for both their recreational and therapeutic benefits (Connell, 2006: 1093-1094; Gesler, 1992). However, as Song notes in relation to SCTs in China, the association of tourism with ‘re-creation’ is problematic in relation to those who travel to undertake such treatments (2010: 386). As she observes, it misconstrues the purpose and significance of patient journeys that are likely to involve significant expense and hardship. While some in our study mentioned that they saw their visits as offering the prospect of some relaxation and sightseeing, for most, as with Song’s patients, their travels were guided by the specific objective of obtaining treatments that were otherwise unavailable to them (2010: 386).

Respondents’ comments suggest that various factors shaped their decisions about destinations for SCTs. These include trust in the provider and/or quality of the treatment, English proficiency, online statistical information on the success of treatments, and ‘value for money’. In some cases, national comparisons and stereotypes were evident in explanations for decisions about destinations, sometimes influencing assessments of their ‘trustworthiness’. Natalie mentioned that when deciding between China and India, the latter was thought to offer a less invasive treatment and that ‘a big difference’ was that ‘most people speak English’. Fluency in English was also mentioned as a justification for choosing treatment in Germany: ‘there’s plenty of people who speak English’ (Harry, carer of child with Cerebral Palsy).

Convenience and trust were also cited as factors influencing decisions. For one couple, Germany was convenient because they were living in London while their child was having physiotherapy treatment in Eastern Europe and ‘I didn’t know whether I could trust China’ but ‘with Germany you

expect really high regulation from the Government.’ Interestingly, since this interview was undertaken, Germany’s largest stem cell clinic, XCell-Centre in Dusseldorf has been closed down, reportedly after investigations that the clinic had been ‘preying on vulnerable patients’ and had ‘exploited a loophole in German law allowing it to charge for the experimental treatments’ (Mendick and Hall, 2011).

Others believed the treatment at their chosen destination was ‘far better value for money’.

The trips were expensive, costing between \$US10,000 and \$US60,000 per treatment, depending on the clinic, plus travel and additional costs for a carer. Consequently, for some individuals, fundraising was an essential preparatory step after the decision to travel. A number of the respondents reported holding successful fundraising drives, including community initiatives, such as performances, raffles and quiz nights, and sometimes contributions from family or partners, demonstrating a strong level of support for treatment decisions within some communities.

Pre-treatment visits to providers

In line with their active orientation to expertise, respondents often spoke with the doctors providing the SCT overseas *before* deciding to proceed with treatment. In a number of cases, this provided the necessary evidence that it was worth making the trip. Of course, we do not know about those who visit clinics or spoke to the providers and decide *not* to undertake treatments, so our sample is likely to present overly positive assessments of these visits. Patients and carers either phoned the Centre offering the treatment or undertook a preliminary trip to inspect the facilities, with some mentioning that they needed to find out for themselves more about the nature of the treatments on offer. For example, ‘We did do a trip before we went... a trip before the trip where we had the treatment; we went there and we visited the place and spoke to a doctor and asked various questions... I think going there and seeing the place was convincing, well, not convincing, but it was like, “Oh yeah,

this is a good place” ’ (Harry, carer of child with Cerebral Palsy).

In reflecting on their pre-treatment visits, respondents revealed the use of conceptions of risk that differed from expert definitions, with potential harm to health of these clinically unproven treatments tending to be less important than other factors such as potential financial loss. Consistent with the findings of previous research, personal experiences, and impressionistic information may influence individuals’ estimations of risk (see, e.g. Sanders, et al., 2007; Shaw, 2004). For example:

...we felt it was pretty sketchy before we headed over there, like even to the point of like being...arriving in Germany and then like, we were still sort of like well “I actually hope that this appointment really does exist”, and when we turn up they’re ready for us... However, when we did actually arrive at the hospital, it was a different story, they were pretty good, like it was a very nice hospital.... I’d have to say newer and better quality than the [Australian] Hospital.

(Thomas and Lisa, carers of child with Cerebral Palsy)

Visits often served to confirm that risks were minimal, that treatment was worth undertaking and/or that providers were ‘trustworthy’. After inspecting one clinic, one patient commented, ‘I don’t see it [the treatment] as a risk in terms of my health or anything’ (Rick, Spinal Cord Injury). One doctor in India was mentioned by several of our respondents (Natalie, Rick, Anonymous, Terri, Carl, Victor). This doctor seemed to have been especially trusted, having been described as having made themselves available to answer all questions. The same doctor was frequently praised for offering ‘realistic’ advice regarding the benefits of SCTs.

During these conversations with doctors, patients and carers were informed about the nature of the

treatment, and the prospects of improvement. According to a number of respondents, their doctor did not offer any promises, and indeed were circumspect in their claims. For example, in relation to the aforementioned Indian doctor, a patient commented:

I mean she was very frank... she's done some treatment with MND.... and whilst she didn't make any promises, you know, she was ready to try... (Terri, carer of patient with MND)

In their assessments of treatments, respondents often referred to others' experiences or subjective evaluations of providers or clinics. The reasoning of one carer is interesting in this regard:

the selling points [of the treatment] were we knew people who had personal experience and it seemed really low invasiveness, very safe and for us, it came down to the worst that could happen was nothing, really, the worse that could happen was we could spend our money and it could have been, we would have gotten no result.

(Lisa, a parent of a child with Cerebral Palsy)

The experience of the SCT

Given that respondents had often undertaken considerable research before embarking on their journeys, they exhibited surprisingly little knowledge about the sources of the cells used in their treatment, and seemed to rely mainly on what the providers had told them. As noted, a range of factors shaped individuals' assessments of the risk of SCTs, and it would appear that, in relation to the provenance of cells, individuals had invested trust in the provider to offer effective and safe treatments, or 'left things to chance'. In a number of cases, individuals claimed to be injected with cells from their own body; in other cases, where the cells used were not their own, individuals sometimes mentioned that they were aware of the sources of stem cells or the manner of their

handling prior to their treatment. For example,

I was told that I would have foetal stem cells from aborted babies.

(Lynette, patient with Motor Neurone Disease)

The stem cells aren't prepared or ready for the plane, 'cause the stem cells apparently are processed in one central laboratory, and then they're air freighted all over China to the various hospitals with the various amounts. They're processed particularly for each patient, what each patient's needs are....

(Kylie, patient with Multiple Sclerosis)

However, in these and other cases, individuals made no reference to the origin of the allogeneic (from a donor) cells used in treatment, how they were stored, whether cells were obtained after informed consent, and the ethnicity of the original cell donor. Nor did they raise significant concerns about transmission of potential infection and whether the cells had been fully screened. Whilst the method of delivering the treatment was not consistent for all patients, many participants reported that they had received the cells via intramuscular or intravenous injections, and frequently via lumbar puncture. In one case, cells were delivered directly into the patient's brain. (See Table 1) Cellular transplants are not without physical risks, with one study showing complications, including meningitis, among patients with Spinal Cord Injury following transplantation of fetal brain tissue at a clinic in China (Dobkin, et al., 2006). There have also been some recent reports of patients developing lesions and tumours (e.g. Amariglio, et al., 2009; Thirabanjasak, et al., 2010; Barclay, 2009; Nagy and Quaggin, 2010), and at least two reported deaths (Mendick and Hall, 2011; Pepper, 2012) following SCTs.

We acknowledge that those whom we interviewed may present atypical experiences of SCT. We only interviewed those who had completed at least one SCT and it is likely that, for a range of reasons, including the high level of personal commitment to and community financial investment in treatments, they were inclined to present a generally positive portrayal of their experiences. Further, many had received intensive physiotherapy along with their SCT, which may have resulted in some improvement in their condition, or at least assisted in providing a positive experience. However, it is noteworthy that *all* respondents reported benefits from an initial treatment. For some, improvements constituted a stabilisation of the patient's condition (Terri), and a minor improvement in physical function (e.g. 'more flexibility in their hands' (Anna), 'my swallowing improved' (Carl), 'we got tongue further in the mouth, better hand control, less spasticity across the middle trunk' (Harry)). However, in a few cases, there were more dramatic improvements. Rick, for example, commented that while he was in India he began to breathe independent of his ventilator for the first time in many years. And, Natalie reported that 'my nerve pain reduced by about 50 per cent, the excruciating pain that you're in 24 hours a day, reduced greatly, and that was just unbelievable.' Several respondents mentioned that the improvements they experienced were not verified by their Australian doctors, and indeed found their Australian doctors reluctant to investigate their claims upon their return. Such improvements can be a spur to subsequent treatments: for four patients, a second treatment, for two a third. (See Table 1) Patients had mixed views on the value of subsequent treatments, with some taking a 'wait and see' approach. Even in these cases, optimism is evident, with hopes that either the condition would improve or that a future new innovation may make a difference.

Discussion and conclusion

As the findings from our Australian study reveal, for those who are ill or incapacitated and their carers, 'having hope' is crucial to their self-identity as active agents who have at least some potential to control their future through current actions. However, this 'hope' does not equate with

faith in the not yet clinically proven regenerative powers of SCTs. As noted, our respondents were not expecting miracles from their treatments, but rather small, yet to them significant improvements. In one of the few studies of stem cell tourism involving fieldwork, Song uses the metaphor of pilgrimage to convey patients' sense of hope and transformation, and the promise of salvation in their efforts to cure that which conventional medicine had deemed incurable (2010: 387). We question the use of the metaphor of 'pilgrimage' to describe stem cell tourists' journeys, which, with its strong religious connotations, suggests uncritical faith in the benefits to be derived from SCTs (see, e.g. Turner, 1974). Nevertheless, the personal benefits that are derived from SCTs, even if not judged by biomedical standards to be clinically significant, need to be acknowledged if one is to properly understand the dynamics of the SCT market.

On the other hand, those who embark on these treatment journeys are compelled to navigate between 'regimes of truth' and 'regimes of hope' (Moreira and Palladino, 2005) in relation to SCTs, with uncertain and potentially harmful consequences. Such travel may entail various personal and community 'downsides' that are rendered invisible by the use of the term 'tourism'. As we explained, planning and undertaking trips to overseas clinics often entails considerable financial expense to the individual and their carers, and sometimes their communities, and the journey itself is likely to involve much time away from work, family and friends. While few of our respondents reported adverse outcomes from undertaking their treatment, potential long-term physical harm should not be discounted. As noted earlier, there have been several reports of adverse outcomes associated with SCT in recent years. Further, one should acknowledge the potential for patients and carers to be financially exploited by those seeking to capitalise on the promises of SCTs (see, e.g. Murdoch and Scott, 2010: 17). Finally, the question of who bears the costs in cases of fraud and adverse health outcomes—the individual, the provider, the 'donor' country or 'host' country—is unclear (Cohen and Cohen, 2010; McMahan and Thorsteinsdóttir, 2010; Shalev, 2010).

The ‘hopeful’ enactment of illness or incapacity then, we suggest, may have both ‘positive’ and ‘negative’ implications. This ambiguity of ‘hope’, however, has been overlooked in contemporary official discourses on hope, which, as noted, focus on the potential clinical benefits of ‘fostering hope’ in patients. The concern of many commentators, however, is that those pursuing SCTs do not suffer from a lack of hope, but rather are ‘overly hopeful’ and thus vulnerable to submitting themselves to clinically unproven treatments. In recent years, there have been a growing number of warnings about the dangers confronting ‘desperate’ patients pursuing promising but unproven treatments (see, e.g. BIONET, 2010; Lindvall and Hyun, 2009; Zarzeczny, et al., 2010). If regulation seeks to protect desperate yet hopeful patients then our findings suggest that the approach that has been adopted thus far, namely simply providing information to patients about the physical risks of undertaking unproven SCTs (e.g. ASCC, 2009; ISSCR, 2012) is a limited form of response. This approach is underpinned by a rational actor model that assumes that individuals will rationally ‘weigh up’ options in light of available information before deciding on the ‘optimal’ decision. It overlooks the context within which identity is formed and ‘hope’ assumes meaning.

Within the context of neoliberal healthcare, individuals are compelled to express their agency through exercising ‘freedom of choice’ in the market and through taking an active role in their own care, via processes of ‘responsibilisation’ (Burchell, 1996). In this sense, our ‘hopeful’ respondents are complying with the expectations attached to contemporary neoliberal, healthy citizenship. However, with factors such as subjective impressions and chance meetings playing a role in decisions about treatments, individuals who do not comply with the expectations of the citizen as a ‘rational’ actor are liable to be judged ‘irrational’ and ‘irresponsible’. In this respect, patients who pursue SCT find themselves at the heart of a central contradiction in the emerging global medical

market. Moreover, they find themselves denied rights to the regulatory safeguards provided by the state.

The rise of the Internet and advent of ‘direct-to-consumer’ advertising presents an especially acute challenge in this regard. Online ‘direct-to-consumer’ advertising reflects a change in conceptions of citizenship and responsibility for health. This form of advertising is not just a tool for facilitating individuals’ access to information about medical conditions and generating demand for particular treatments. It also produces consumers and their imaginary futures (e.g. Mamo, 2010: 180). It offers the prospect of transforming the self and achieving some degree of physical control through the consumption of certain products or services (2010: 176). ‘Direct-to-consumer’ advertising has radically transformed the relationship between lay citizens and experts. As our study highlighted, the local doctor may be but one of a number of actors, including overseas’ providers, whom individuals consult before deciding whether or not to embark on a SCT. While many medical authorities judge advertised SCTs as lacking credible evidence, and demand that treatments be subjected to the gold standard of the randomized double-blind clinical trial (e.g. ISCCR, 2012), many clinics either fail to produce such evidence or defend the efficacy of their treatments on other grounds.

While we are unable to offer a clear recommendation as to how ‘best’ to regulate SCTs, we suggest that an approach that is based on recognition of the complexity and ambiguity of ‘hope’ is most likely to be of value in assisting patients and carers who are contemplating travelling abroad for SCTs. For example, healthcare professionals who are approached for advice may be encouraged to understand what patients hope for and appreciate what the treatments may offer them without making assumptions about the expectations that patients have about those treatments. Further research into the ambiguities of hope regarding medical tourism, that eschews the assumption that

patients are unilaterally duped into treatment and unaware of or unconcerned about the risks, would do much to advance understanding of the dynamic context within which patients choose to travel overseas for treatments.

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Table 1 Summary of patient information

No	Pseudonym	Medical Condition	Country of Treatment	Year Treatment Received	Number of Treatments	Method of Delivery	Types of Stem Cell
1	Kylie	Multiple Sclerosis	China	2006 with second treatment date not specified	2	Intravenous injections and lumbar puncture	Allogeneic (not recorded)
2	Lynette	Motor Neurone Disease	China	2009	1	Lumbar puncture	Allogeneic (foetal)
3	Carl	Motor Neurone Disease	India	2009 (6 weeks) and 2010 (4 weeks)	2	Lumbar puncture	Allogeneic (embryonic)

No	Pseudonym	Medical Condition	Country of Treatment	Year Treatment Received	Number of Treatments	Method of Delivery	Types of Stem Cell
4	Terri (carer)	Motor Neurone Disease	India	2006	1	Intramuscular and lumbar puncture	Allogeneic (embryonic)
5	Anonymous	Severe nerve damage in leg	India	2009, 2 earlier dates (not specified)	3	Injection into leg and directly into nerve	Allogeneic (embryonic)
6	Rick	Spinal Cord Injury	India	2007	1	Intravenous and injections all over the body	Allogeneic (embryonic)
7	Natalie	Spinal Cord Injury	India	2007	3	Intramuscular and intravenous injections, lumbar puncture	Allogeneic (embryonic)
8	Victor	Spinal Cord Injury	India	2006 and 2007	2	Injections around the coccyx and lumbar puncture	Allogeneic (embryonic)
9	Anna (carer)	Cerebral Palsy	Germany	2010	1	Neuroendoscopic procedure (injection into the brain)	Autologous (bone marrow)
10	Marion (carer)						
11	Harry (carer)	Cerebral Palsy	Germany	Dates not specified	2	Lumbar puncture	Autologous (bone marrow)
12	Rebecca (carer)						
13	Thomas (carer)	Cerebral Palsy	Germany	Date not specified	1	Lumbar puncture	Autologous (bone marrow)
14	Lisa (carer)						
15	Owen	Blindness	China	2010	1	Lumbar	Allogeneic

No	Pseudonym	Medical Condition	Country of Treatment	Year Treatment Received	Number of Treatments	Method of Delivery	Types of Stem Cell
	(carer)					puncture	(cord blood)
16	Emily (carer)	Blindness	China	2008	1	Intravenous injections and lumbar puncture	Allogeneic (cord blood)

ⁱ This term was first used by DelVecchio Good (1990) in her study of disclosure in the oncology clinic.

ⁱⁱ Which, before it ceased operations in June 2011, kept a database of patients who have enquired about treatments.