The Importance of Reliable Information Sources for Prospective Medical Travellers

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Abstract

More people are travelling overseas for health or wellness reasons; however, there is limited understanding of the background of those travelling and how information is sourced for decision-making. Those travelling for treatment are likely to be unaware of all of the risks. Reliable information sources are scattered and not easy to find. Interviews were conducted with 51 Australians contemplating or who had travelled for stem cell treatment. Information sources people used were identified, and an analysis was undertaken of how this influenced their decision. The data highlight that health travellers are likely to search extensively using a wide range of sources including information on clinics' websites, Facebook, blogs, friends and family. Interviewees highlight that often decisions are made based on unreliable sources. The implications are that without quality, reliable information health travellers are at risk of suffering adverse outcomes and spending significant funds without any improvement in their condition.

Keywords medical travel, health information, information needs, information sources

1   Introduction

Increasingly people are travelling overseas for health or wellness for a range of treatment types (Lunt, Smith et al. 2011) yet little is known about this industry (Hanefeld, Smith et al. 2014). Many websites of clinics intensely market their services providing information on treatments, outcomes and patient testimonials. The industry promotes travel to locations with cheaper health services, no waiting lists and procedures often not available in consumers' home countries. The services offered vary from cosmetic surgery and dental work to vitro fertilisation (IVF), stem cell treatment and major surgery (Lunt et al., 2011). Travelling for any form of health related treatment may involve risks; however, these increase with treatments that are unproven or are approved only for certain applications, such as stem cell treatments.

Credible, quality information is critical for anyone making decisions regarding their health ((Nguyen, Burstein et al. 2015). Those seeking treatment overseas access information from a wide range of sources; not surprisingly, the Internet is widely used by those searching for information. There is however a lack of reliable information available for people travelling to clinics (Hanefeld, Smith et al. 2014), particularly those travelling for treatments such as stem cell treatment (Lunt, Smith et al. 2011, Munsie 2015). Reliable evidence on the safety and efficacy of treatments is often absent. Further, information can be contradictory and unbalanced, designed to sell the treatment on offer (Lunt and Carrera 2011). The lack of an adequate means for verifying the efficacy and safety of treatments results in people having to rely on testimonials, promissory statements, and partial information oriented to persuasion.

This research in progress paper reports on the first stage of research examining how we might, via a web based system, provide more reliable information for health travellers given the importance information and information sources have on travellers' decision making. The second stage will involve the development of a prototype portal designed to provide tailored, reliable information for people seeking to travel overseas for treatment.

2   Travelling for treatment

'Medical tourism' is commonly used to describe people who travel overseas for some health or wellness purpose, frequently involving medical treatment. However, while some people may also engage in some recreational activity around their treatment, many do not. Further, some may travel for reasons other than medical treatment; for example, 'wellness tourism', 'spa tourism'. We therefore refer to those travelling for health reasons as 'health travellers', which includes a diverse array of health and medical related travel.

A recent OECD report on travel medicine says ".. our broad review outlines key health policy considerations, and draws attention to significant gaps in the research evidence. The central conclusion from this review is that there is a lack of systematic data concerning health services trade, both overall and at a disaggregated level in terms of individual modes of delivery, and of specific countries." (Han and Flaherty 2015) (p.2). Given this identified paucity of information relating to travelling overseas for treatment it is no wonder potential patients struggle to find reliable, quality information to support their decision-making.

The OECD report (Lunt, Smith et al. 2011), reinforces that there are risks involved in any medical treatment. Overseas travellers face some health risks (Dan 2015, Epelboin, Robert et al. 2015, Vila 2015). However, these risks, particularly around health can be magnified when travelling overseas for treatment. These risks include post-operative infections, surgical complications and the chance of returning home with dangerous, including anti-biotic resistant, pathogens (Lunt, Smith et al. 2011). In addition, there are risks with air travel particularly after surgery (Lunt, Smith et al. 2011) (Han and Flaherty 2015) and post-operative treatment on returning home (Crooks, Kingsbury et al. 2010, Snyder, Adams et al. 2014).

2.1   Legal framework

The legal framework under which treatments are provided can present a risk. Currently there are no international regulations governing overseas clinics; many clinics are unregulated (Lunt, Smith et al. 2011). Legal redress post treatment can be problematic (Crooks, Cohen et al. 2015). Many overseas clinics people choose for treatment are illegal and offer unproven treatments (Crooks, Cohen et al. 2015); the treatment outcomes advertised may not be realistic with no protections if something goes wrong.

2.2   Information and risks

Health travellers draw on a variety of sources when making travel decisions. The Internet is a common source of health information (Fox and Jones 2009, McKemmish, Manaszewicz et al. 2009). The OECD report notes that there are questions around how Internet based information is understood by health travellers and the influence of such information on decision making (Lunt, Smith et al. 2011).

Lunt and Carrera (Lunt and Carrera 2011) identified portals, media sites, and consumer and commercially orientated sites as sources of information for health travellers. Websites of clinics are a major information source. In one study the authors found the focus on clinics' websites was on the health facilities and medical services offered. Little information was found on, for example, the costs, post-discharge arrangements and online tools for enquiries (Moghavvemi, Ormond et al. 2017). In reviewing 50 commercial websites offering treatments, the researchers concluded that the sites were primarily focused on sales. Potential risks were either not discussed or minimised, surgery was portrayed as routine and consultations were undertaken via email (Lunt and Carrera 2011).

Hohm and Snyder (Hohm and Snyder 2015) examined marketing approaches by Indian clinics and providers they identified that promotions strongly focused on the safety of the offered treatments. One study of testimonials posted on the websites of different Indian and Canadian clinics found that risks were not mentioned or if they were it was claimed the facilitation company would manage them (Penney, Snyder et al. 2011). Unless patients fully understand the risks their decision making will be impacted (Hohm & Snyder, 2015).

Conflicting health information is common, given the complex nature of health, and can result in people being suspicious of the information they find, rendering decision making more difficult (Covello and Peters 2002, Wu and Ahn 2010, Lunt, Smith et al. 2011). For example, Wu & Ahn, (2010) found that although research participants understood the health information they viewed on tanning was contradictory, participants sought to reduce the contradictions and maintained their earlier beliefs.

There are many other sources of information health travellers draw on such as informal networks (Hanefeld, Lunt et al. 2015), societies and support groups, and the media (Snyder, Adams et al. 2014). Networks (clinicians, previous patients, friends/family) may be the most important information source (Yeoh, Othman et al. 2013, Hanefeld, Lunt et al. 2015). There are also websites which consolidate reviews of popular medical tourism destinations (see (Intuition 2017))).

3   Research methods

There is a dearth of empirical research relating to health travellers. Hanefeld et al., (Hanefeld, Smith et al. 2014) note that most in-depth interviews are conducted with only a few people. Health travellers are highly diverse with different patterns of travel, motivations, destination countries and needs. The knowledge gaps include where travellers source information from, how decisions are made such as where to travel to and the treatment types and the characteristics of those travelling or choosing not to travel (Crooks, Kingsbury et al. 2010, Hanefeld, Smith et al. 2014, Petersen, Munsie et al. 2017).

It should be noted that our research focused on only those travelling for stem cell treatment and may not necessarily be generalised to those seeking other treatments. People travelling for stem cell treatment are often desperate, with life threatening illnesses or for whom conventional treatment options are limited or non-existent e.g. multiple sclerosis, cerebral palsy, spinal cord injury. Hence, their pre-treatment experiences may not be representative of other health travellers. Although we cannot generalise to the wider population, the experiences of those considering travelling for stem cell treatment do provide insight into why people consider travelling for health reasons and the potential issues they face. Patients with conditions such as these tend to confront broadly similar challenges confronting others with chronic conditions in regards to the day-to-day management of symptoms, gaining social acceptance and some degree of control, and accessing appropriate, timely information (Petersen, Munsie et al. 2017). People pursuing stem cell treatments are investing in hope, with many believing that the stem cell treatment promises made will hold true for them (Munsie 2015).

In-depth semi-structured interviews were conducted with 27 patients and 24 carers (parents and a partner). (One interview was conducted jointly with the patient and their carer; two with carer-parents.) University ethics approval was obtained prior to the interviews and the participants signed consent forms. Approximately half (N = 24) had travelled overseas for stem cell treatment (known as travellers). The remainder (N = 27) had considered travelling but at the time of their interview were still undecided about travelling (non-travellers). The interviews were conducted over the telephone and were between an hour and an hour and a half in length. They covered a wide range of topics, which included

interviewee demographics, reasons for treatment, information sources and treatment outcomes where applicable.

Participants were identified through various sources, including a dedicated project website which included details of the project and its aims and a contact page, and patient groups, which advertised the project through newsletters and patient forums.

3.1 Data analysis

A thematic analysis was conducted with high-level topics identified. These included type of information, sources of information, decision-making, location of treatment, nature of treatment, treatment outcome and costs. Draft data codes for each topic were agreed on by the researchers drawn from four of the interview scripts of travellers and non-travellers. These were further refined as the remaining interviews were coded and analysed.

A key word search of all the transcripts was conducted using NVivo system, and further refined. A count was made of the top ten words of 6+ characters used by the interviewees when explaining their information search experiences. A search of the literature identified more words. These words were used to map an understanding of the information needs of health travellers.

4   Results

Those interviewed came from a range of backgrounds and ages suffering from different conditions. It should be noted that whilst most non-travellers were interested in travelling most had not yet made a decision, some had decided against it, one traveller did travel then elected not to go through with treatment.

Twenty-two different conditions were noted. The most common among both travellers and non-travellers were multiple sclerosis (MS) (10), spinal injuries (7), cerebral palsy (4) and autism (4). Six people travelled for treatment for spinal injuries or spinal problems, four for MS, four for cerebral palsy, two for autism, another for kidney disease, Parkinson's disease, issues with sight and motor neuron disease. It should be noted that for the conditions stem cell treatment people sought and travelled overseas for as yet there are no results from trials as to the efficacy of stem cell treatment with the exception of some treatments for sight (Munsie 2015).

The countries travellers travelled to or non-travellers were considering included: Germany (9), China (12), Mexico (5), US (7) and Australia (7).

Participants were asked about the outcome of their treatment and what improvements, if any they had seen. Treatment outcomes varied, these are detailed in Table 1. Note one person intended to travel and then changed their mind.

Outcome	Female	Male
No improvement	1	5
Small improvement (small movements, eye contact, feeling in toes)	2	6
Modest improvement (move/ walk more)	2	2
Excellent improvement	2	

Table 1. Treatment outcomes

Table 1 illustrates that nearly 60% of those who had travelled for stem cell treatment saw either no improvement or small or modest improvement. These results highlight that despite the authoritative information available on what conditions may be successfully treated with stem cells (Munsie 2015), people make their decisions to travel based on other information.

4.1 Risks

Travelling for stem cell treatment involves some risks. A significant risk is that the condition they sought treatment for is unproven (Munsie 2015) therefore treatment may be unsuccessful. Cost could be seen as a risk given there are significant treatment costs whether or not treatment was successful. Treatment costs (excluding travel, accommodation, living costs) reported by the interviewees varied from $AUD9,000 to $AUD150,000. The average paid by travellers for treatment was $AUD55,000.

Non-travellers were much more likely to talk about and recognise risks and identify more risks compared with travellers. Seven non-travellers considered the risks to be high compared whereas only one traveller thought the risks were high.

Our participants were not naïve. Many recognised there were biophysical risks but were desperate for help and were often swayed by other factors to pursue treatment. Most people asked the clinic they were seeking treatment from about risks; nine reported that the clinic assured them there were 'no risks'. Some mentioned that day-to-day life was a risk. Factors swaying decision making included the reassurance of the clinics, positive outcomes reported by people they made contact with, distrust of what they were told by local medical people or they saw no alternative. Nine people thought it was worth taking the risk if the treatment worked.

A small number reported problems in the hospitals where the treatment was undertaken including very basic facilities, poor quality care, poor hygiene in the hospital, pain or problems with the procedure and, in one case, the need to wait until specific equipment was flown in from somewhere else. In some cases the hospital or treatment facilities were said to be not of the same standard presented on the clinics' websites.

Next we discuss the sources of information health travellers drew upon through the decision making process.

4.2   Internet based information sources

The Internet was the first place all participants turned to when looking for information. Consistent with the literature (McKemmish, Manaszewicz et al. 2009) interviewees were overwhelmed with information when they searched. Often the information was conflicting, making decision making more difficult. We found 119 references to accessing information from websites and 102 references to using the Internet for information searches more generally.

4.2.1 Websites

Consistent with the literature (Moghavvemi, Ormond et al. 2017), clinics' websites were an important information source particularly with respect to the range of conditions they claimed could be treated with stem cells. As mentioned, earlier research found that such websites are primarily designed to sell treatments (Crooks, Kingsbury et al. 2010). Our interviewees highlighted that the clinics' websites were just selling treatments, were not providing information about risks, did not substantiate claims as to the efficacy of treatments and, in one case, were soliciting business before their clinic was open. All but one traveller and seventeen non-travellers looked at the website of clinics. Our participants highlight that the information provided on these sites influenced their decision making. Ten said that the websites they viewed promoted positive treatment outcomes. Testimonials of treatment claims and videos were read or viewed by twenty of the participants.

One traveller and five non-travellers were sceptical of what they read or found the information conflicting. Others had a more positive reaction to the stories and testimonials.

There are also many other websites which discuss stem cell treatment and eleven interviewees reported seeing positive outcomes described on these. The outcome of clinical trials was important for many participants; twelve people were influenced, that is made positive comments about what they had read of stem cell trials discussed on various websites.

4.2.2 Blogs, forums, Facebook and YouTube

Facebook and blogs were an important source of information for many participants. The word 'Facebook' was mentioned 64 times by interviewees. Many found Facebook pages and blogs promoting or providing information on, stem cell treatment. Some Facebook pages and blogs were ostensibly set up by interested groups, others by clinics themselves. Ten of the participants made contact with people they found through Facebook or a blog site. Most of the sites were promoting positive outcomes from stem cell treatment. One person explained that they had made a decision to travel to Panama for treatment based purely on positive comments posted on a Facebook page. One person is part of a forum and claimed there were 12 doctors involved. Forum participants could ask questions and so this participant trusted the forum as a source of information.

Five participants spoke about YouTube clips they had watched. People were influenced by these clips and what they saw, in particular they believed those making the claims were authoritative.

4.3   Direct personal contacts

Often the participants were unwilling to believe that the stem cell treatment they were seeking was unproven. It was a common theme that people did not entirely trust the information provided by their specialist/doctor because, for example, they thought the doctor had a closed mind, was dismissive or not willing to consider alternative treatments, or did not listen to the evidence the patient provided, or was 'not up to date'. Thirteen participants specifically mentioned that the government or medical authorities did not support stem cell treatment because there was no money in it for them, because it cost too much or were not willing to fund trials. One person changed their neurologist because their first specialist would not consider stem cell treatment for them. In two cases, a clinician supported the participant's decision to travel for treatment.

All those who travelled had direct contact with the clinics either via the telephone or via email. Many indicated they were impressed with the information they received directly and how well their questions were answered. It was clear from the interviews that the clinics marketed their treatments very well when dealing directly with potential clients; it is likely this influenced participants' decision making. However, participants also said the clinics were very persistent, very quick to return phone calls and followed up with further calls if the person did not initially respond positively.

Other information sources mentioned included societies such as those supporting parents with autistic children and those with MS. Apart from friends and family others who encouraged participants to travel included physiotherapists, acupuncturists, chiropractors, naturopaths and in one case a carpet cleaner.

5   Discussion

Travelling overseas for medical treatment is risky, and being well informed helps mitigate those risks. The risks are costs where Australian travellers travelling for stem cell treatment paid on average $55,000. For many, the treatment did not work or they saw only marginal improvements. Travelling in itself is risky when one is unwell; several of our interviewees needed help to travel. There is also of course, the risk of an adverse outcome with no legal redress or returning home with a serious infection.

Those who travelled for a stem cell treatment, however, were prepared to play down the risks. They sought advice from the treating clinics about risks and in many cases accepted the clinic's assurance that the risks were low. Participants who did not travel were more concerned about risks, and sought additional information. They were also less prepared to accept the advice of the treating clinic that the risks were small.

Previous research highlights that if someone finds information that conflicts with what they believe to be true they are suspicious about it, and this can impacts on their decision making (Wu and Ahn 2010). Our analysis also found such relationship with more than 30% of those who had travelled unwilling to believe what they had been told by specialists, doctors or other authoritative sources, preferring to believe that the treatment they sought would work. Since this is quite a significant number – there is a need to ensure the credible information is presented in a very persuasive way. For example, there can be some ways of linking a bundle relevant information in a logical and persuasive form, , which would allow the user to follow on her/his queries further without necessarily initiating a new search. Providing information in a variety of forms and style, eg text, short videos, personal stories, forums, etc, has demonstrated to improve the level of satisfaction with (McKemmish, et al. 2009) and trust in the health information online (Leimeister, et al. 2005)

Participants obtained information from a wide range of sources, many of which (the websites of clinics, Facebook, blogs and forums) would generally be regarded as unreliable by scientists and health authorities, yet it is clear some people made the decision to travel based on these. That said, however, our participants want better quality information. Almost 20% of interviewees mentioned that they would like to have information provided by a trustworthy source such as the government. They want a source they can trust or is endorsed by a Government agency. Given that most of those who travelled were distrustful of information from sources such as their doctor or specialist, an alternative information source people see as neutral is needed.

The results highlight that those who investigated travelling for treatment, but then did not go ahead immediately, were more cautious about the information they viewed.

Figure 1 summarises the key issues drawn from the literature and the research data analysis and highlights the need for a new approach to web based health information provision.
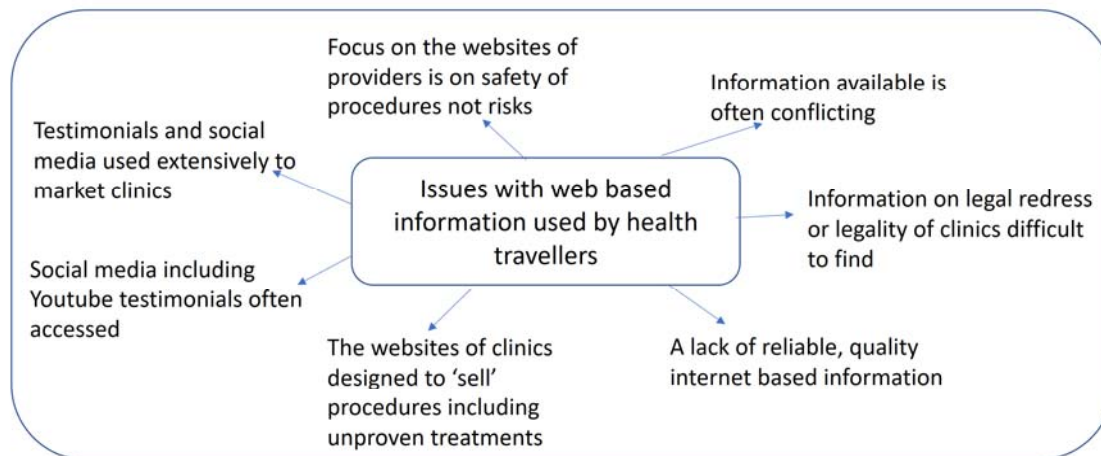
Figure 1: Issues with web based health information for travellers

This can be used as a road map for designing an online resource to better cater for health travellers information needs.

6   Conclusion

While this study focused on patients contemplating stem cell treatment and their experiences may not reflect those of other categories of patient, the study does emphasise the need for quality information for people who are considering travelling overseas particularly for what could be regarded as controversial treatments such as stem cell treatment. In Australia at least, there are no government or health related organisations responsible for providing reliable information to those travelling overseas for a treatment or enhancement (e.g. cosmetic, dental). This is an issue as our study highlights the wide range of sources people draw on when making decisions whether or not to undertake travel for treatment. Given there are recognised risks for people travelling overseas for treatment it is important to understand what information sources people are using. This is important, particularly as less formal sources such as Facebook and blogs and the websites of clinics aiming to 'sell' treatments often provide unreliable information yet these are impacting on decision-making. While this group of health travellers (who have acute conditions) may not be representative of other health travellers, the findings indicate that, without quality, reliable information, health travellers are at risk of suffering adverse outcomes and spending significant funds without any improvement in their condition. Our research raises the question of what can be done to ensure reliable information is available for those contemplating travelling overseas for any type of treatment and what systems might be provided to better support them.

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