

The Informal Caregiver: A Qualitative Assessment of Needs and Requirements

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Abstract

Background: The centralisation of many medical services to hospitals in larger centres, as well as the cost consciousness of patients and medical insurers alike, has led to an increased necessity to travel nationally to seek medical treatment. This phenomenon is observed in New Zealand and world-wide. This is not unlike international medical tourism but research into the needs and requirements of the informal caregiver, accompanying the patient, has been neglected.

Methods: Informal caregivers (IC), accompanying a patient for 2 or more days to receive medical treatment were recruited from private and public medical service providers in Dunedin, New Zealand. A semi-structured interview producing in-depth information to profile the visitor demographics and to explore the nature of their visit and their experiences was constructed. The qualitative material was screened for similarities and contradictions and analysed taking the situation of the support person and the environment into account.

Results: Five participants were ICs of patients in private treatment; one participant accompanied a patient to a publicly funded treatment. ICs stayed for 2 days to 5 weeks. In the private sector no assistance was offered to help with basic requirements such as travel and accommodation although this was funded and therefore arranged for in the public sector. All IC critically missed interaction with other IC and most were interested in local attractions.

Conclusions: This research shows that service provision for medical tourists at least in the private health care sector is solely focussed on the patient while the basic needs and requirements of the IC are neglected. This leads to social isolation and creates a barrier to travel. This fact offers an opportunity for local tourism operators to engage with health care providers to gain access to this niche market and aid the recovery process of the patient by allowing the IC to concentrate on the support that is expected.

Keywords: Medical tourism; Informal caregiving; Recovery; New Zealand

Introduction

Medical tourism is usually defined as “to travel with the express purpose of obtaining health services abroad” [1]. Services typically sought by these health travelers include elective procedures as well as complex specialized surgeries such as joint replacement, cardiac surgery, dental surgery, and cosmetic surgeries. The avoidance of waiting times is the leading factor for medical tourism from the UK, whereas in the US, the main reason is cheaper prices abroad. This definition might sufficiently describe the well-studied international health traveller however, a subsector of medical tourism, namely domestic medical tourism, developed out of necessity almost in parallel to the international market and the motivation of the traveller to seek healthcare away from home is only partly overlapping with the international traveller [2,3]. A clear definition of domestic medical tourism however is not available.

World-wide and also in New Zealand, shortages of doctors, health care funding issues, urbanisation and other problems have led to the centralisation of many services to hospitals in larger centres. The advancement of medical knowledge has led to the necessity to sub

specialise to keep abreast with the field and is leading to ever more costly and high-tech medicine that cannot be offered in smaller centres [4]. During the 1990's the New Zealand government introduced market forces to public hospitals leading to the outsourcing of services and treatments, allowing publicly funded hospitals the purchase of services from commercially operated providers [5,6]. The resulting rationalisation and therefore the centralisation of medical services led to the reduction or even closure of many rural services [7]. The centralised medical services are offered through five lower level tertiary care hospitals in the country, namely in Auckland, Hamilton, Wellington, Christchurch and Dunedin (Hospital Service Plan 1996-1999) and only three high level tertiary care hospitals, in Auckland, Wellington and Christchurch. This has led to difficulties accessing local medical care, creating the need to travel. Therefore, depending on the specialty of treatment or procedure required the patient has to travel domestically or even Trans-Tasman (PET scans). These procedures are publicly funded and require travel to receive treatment; the bare essentials are also funded: travel and accommodation; the travel arrangements include a support person. The government is charged with the task to ensure operational efficiency and cost-minimisation, whilst maintaining equitable access and quality of health services. Nevertheless, as a consequence, rural communities are struggling to maintain viable health care services and face significant disadvantages compared with urban regions [8]. While

some patients travel to seek private medical care in order to bypass waiting times and to increase flexibility of the arrangements and therefore do so voluntarily, other patients seeking public healthcare are also forced to travel to access specialist medical care.

This centralisation of medical services has several profound follow-on effects on the patients themselves but also the immediate environment. There is very limited literature on domestic medical tourism as such. Reviewing this literature, it is obvious that the scientific focus is mainly on the patient with regards to the quality of health care, risks, and the economic advantages and disadvantages for both the patient and the provider [9,10]. In this context, cancer care has been most extensively studied with some negative outcomes being demonstrated. Studies in the U.K. demonstrated lower uptake of treatment in correlation to travel distance [11-13] while in New Zealand, even poorer survival was seen for some cancers [14]. Other studies highlighted deficiencies in health care quality (adherence to guidelines, pre-treatment care, etc.) depending on the distance to the next specialist centre [15]. Furthermore, for domestic medical tourism, it has been recognised that patients who live far away from specialised services experience time, financial, and personal barriers to care. Impacts include direct costs for transport, accommodation and food, cost of time away from work, child care cost, etc. [16-18].

In order to ease this burden, at least in New Zealand, travel and accommodation for the patient and a support person are subsidised. Other less measurable barriers include lost productivity, finding substitutes for home and business activities, unfamiliarity with new surroundings, and isolation from family support [17,18].

Internationally operating medical tourism companies have acknowledged the needs and requirements of the informal caregiver at least in part and their services offer packages including travel arrangements, hotel reservations and holiday excursions [19]. It has furthermore been recognised that in the overall scheme of medical tourism, the informal caregiver does play a crucial role but again, the forerunner is the globally operating medical tourism industry (personal communication with Dr E Watson, Director, www.medtral.com). It is remarkable however, how little scientific attention has been given to the wellbeing of the informal caregiver. The role of the IC as a “knowledge broker, companion and navigator” has recently been well described by Casey et al. [20] however it is less well documented that ICs experience many of the same disadvantages and stresses as the patients and it can be postulated that it is their wellbeing that contributes significantly to the patients’ convalescence. Quality of life issues have been illustrated for ICs caring for disease specific patient groups (mainly cancer and Alzheimer’s disease) but not in more general terms, disregarding the supported patients illness and not in relation to travelling, domestically or internationally [21-23]. Mediators of international medical tourism stress the importance of the support for informal caregivers (Medical Tourism Association 2009) and in the non-academic literature (www.Bernamea.com) there is a brief outline of the existing family facilities of the hotel industry and the opportunity to participate in tourism activities [24] but research is lacking in detail concerning the informal caregivers needs and requirements [25].

The aim of this study on domestic medical tourism was to turn the focus from the patient to the important position of the informal caregiver and to profile their basic and emotional needs and requirements and access to relaxation and distraction during the stay. In turn, the IC can benefit the patient in terms of mitigating the implications of travelling to access medical care.

Materials and Methods

This study was approved by the University of Otago Human Ethic Committee. With prior permission of the participants, the interviews were digitally recorded and later transcribed. All but one interview took place in the private and public hospital environment in Dunedin, New Zealand; the remaining interview was conducted at the IC’s motel accommodation.

Recruitment

Suitable patients were identified through administrators at the time of arrangement of their visit to private and public medical facilities and invited to participate in this research per letter if they intended to travel with a IC. Participants of this research project were IC of in-patients at the private or public hospital. IC was eligible if they resided usually outside Dunedin and planned to stay for a minimum of two nights.

Interviews

As the aim of this research was to gain an understanding of the IC, their basic needs and requirements and behaviour towards leisure or tourism activities, an interpretive approach was deemed to be appropriate [26], an approach which enables the social context to be included in the study was required [27]. A semi-structured interview producing in-depth information to profile the visitor demographics and to explore the nature of their visit and their experiences in Dunedin was constructed. This allowed a two-way conversation with probing questions applied when appropriate, gaining a maximum of information from each individual IC.

Analysis

The researcher interpreted the acquired qualitative material from the interview notes and digital transcripts. The material was screened for similarities in its meanings; the interpretation process identified key themes, similarities and also contradicting ideas. It was important to include the contradicting ideas to gain a better understanding, as these also contribute to the acceptance of different motivations to travel and to seek healthcare away from home. The wider context of the situation for the IC as such (i.e. accompanying a relative to receive treatment) and the environment in which the interview took place were taken into consideration as these also influenced the responses of participants. To validate the findings, quotes of the interviewees were included in the research findings.

Results

A series of six in-depth interviews (by HS) was undertaken in the public and or private medical facility. Five participants were ICs of patients in private treatment (Participants A-D, F); one participant accompanied a patient to a publicly funded treatment (Participant E). No participants of this study travelled internationally to obtain medical treatment in Dunedin. Five of the six interviewees were female. Places of residence were Invercargill (1), Christchurch (3), Tauranga (1) and Hamilton (1), all in New Zealand. The age of the participants ranged from the mid-30s to mid-60s. All patients attended for prearranged elective procedures. Further characteristics of their visit are given in Table 1.

Participant	Hospital	Relationship to patient	Composition of travelling party	Mode of travel	Duration of visit
A	Private Hospital	Husband	2 children and mother in law	Car	2 weeks
B	Private Hospital	Mother	2 grandchildren and son in law	Car	2 weeks
C	Private Hospital	Mother	No further travelling companion	Air	1 week
D	Private Hospital	Wife	No further travelling companion	Car	2 days
E	Public Hospital	Husband	No further travelling companion	Air	5 weeks
F	Private Hospital	Wife	Mother	Car	2 days

Table 1: Characteristics of Study Participants

Objective 1-Basic and emotional needs of the IC

The first objective aimed to understand the basic (e.g., accommodation, food) and emotional (e.g., support, relaxation) needs of the IC in relation to their visit. All ICs required rented accommodation while the patient was undergoing treatment. Arrangements for Participant E were made by the public service provider. The stay was subsidised by the Ministry of Health, and the patient/IC was required to contribute a daily surcharge. ICs of patients in private care were asked to arrange accommodation by themselves, with only limited information available from the clinics involved (some flyers or verbal recommendations). No subsidies were available. These participants utilised mainly the internet for information on accommodation.

The length of stay varied greatly and was dependent on the type and length of treatment the accompanied patient was receiving. In this study, the length of stay varied from day surgery with recovery for two nights in nearby accommodation (Participant D), to five weeks of outpatient treatment with stay in a local motel (Participant E). IC staying longer than a week were more inclined to book accommodation with cooking facilities opposed to those staying a week or less, who are happy to go out for meals or consider various food outlets and take outs.

Although, as per Ethics Committee advice, the researcher was not allowed to address the condition of the accompanied patient, it was obvious that this was a matter of major concern for the IC. Focussing on the interview was hindered by issues surrounding the patient. This can be interpreted as need to communicate with others as expressed by Participant D: "For me personally it would be great to have somebody here with me, just to chat for a while."

Confirming the positive influence of company was Participant E who was able to communicate with volunteer staff of the public hospital and furthermore had contact with fellow ICs during the day in the waiting room. It was obvious to the interviewer that this participant was significantly more focussed on the interview questions than other participants. The treatment of his partner was not talked about in detail, and only mentioned where the treatment influenced the leisure time of Participant E: "My wife gets a little tired after

treatments and she needs a bit of a lie down for about an hour or so, and so I just do my own things and jump on the computer and send messages and stuff."

Participant E further emphasised the positive impact of contact to other people. He stated that the unit at the public hospital is staffed with (untrained) volunteers who are prepared to provide emotional support on a personal basis otherwise the ICs support each other while in the waiting areas: "We tend to chat to other IC's in the waiting room. Spending weeks here you tend to talk a lot to strangers and you get to know them a bit." (Participant E)

In contrast, the private sector is clearly focussed on the patient and the IC is only "remotely" looked after (access to coffee making facilities and toast in the family room, toys for children, books and magazines). However, this was not seen as a significant issue for the IC. Emotional, ministerial support is available and could be accessed through the chapel.

Issues of transport were not of significance to any of the ICs. Participants did use their own cars, in the case of participant C, the daughter's car to travel around Dunedin. Participant E did not have access to a car, but did not state any concerns or problems with the use of public transport. Daily errands were done either by bus or on foot. However the possibility to hire a rental car was considered at a later stage of the treatment, especially for weekends when there was no treatment. Accommodation arrangements were either in walking distance to the city centre (Participant E) or to the private medical facilities.

Objective 2 – Leisure and tourism activities

The research further explored if IC have any interest or need in undertaking any leisure or tourism activities while the accompanied patient is receiving treatment. Furthermore of interest was if the patient and IC planned to expand their visit to Dunedin beyond the treatment or to return to Dunedin as a holiday destination.

All but one IC stated that they were undertaking some activities while the patient is in hospital. Participant C did not show any interest in activities outside the hospital. "I came from H. to look after my daughter and that is what I am doing here. I am happy to sit at her bedside and read a book. I am not here to go out and about."

A barrier to engage in tourism activities was seen in the sense of responsibility to the accompanied patient. Participant F stated: "I do not want to leave the hospital just in case something goes wrong...as long as it is close by and I can be back in time."

In contrast, Participant A was determined to engage in some activities, mainly to keep the two children busy and distracted: "We cannot stay all day [in the hospital] we have to entertain the kids, otherwise they would drive us mad, and M (the patient) needs time to rest anyway." (Participant A). This statement was supported by Participant B, who travelled with his mother in law, Participant A: "... the kids need to keep a certain routine, and see it a bit like a holiday" (Participant B).

There seems to be a certain consensus amongst the ICs that only a limited time should be spent at the hospital and that is important for the IC to engage in other activities firstly to give the patient time to rest and secondly to entertain/distract themselves. All participants excluding Participant C said that they will or already have explored Dunedin, mainly its galleries and museums. However, it was clear that no IC came to Dunedin with the primary intention to explore its sights

and attractions; these are more seen as time filler. Only Participant B had informed himself before the visit to Dunedin. During the interpretation of the interviews it became clear that the destination Dunedin was not the motivator to receive treatment in Dunedin. In the case of Participant E the only motivator to travel from Tauranga to Dunedin was to receive public treatment. Due to the centralisation of specialist services this specific treatment is not offered anywhere else in New Zealand. The remaining participants confirmed that access to a private health service provider is mainly to bypass the public waiting lists and increase flexibility of the arrangements. This was confirmed by Participant A: "M (the patient) would qualify for an operation in public, but she needs to wait a long time... the other thing is that we need to organise the children around it... there is always the possibility that the operation is cancelled on very short notice. P (IC) needs to take time off work (2 weeks) so we need a set date..." (Participant A). In these cases the private provider chosen was the closest provider to their current residence.

Obviously, the nature of the medical procedure determines the length of stay and this in turn seems to be the major factor influencing the IC to engage in leisure activities. Participant E and his wife, who were staying in Dunedin for the whole duration of the five-week treatment, tried to establish a daily routine around the treatment, but more so tried to maintain as much of their daily schedule as possible. This included daily walks and the exploration of the inner city during the week and the wider area during the weekends. All these activities were meant to establish some kind of normality for Participant E and his wife. That the length of the stay influenced the extent of leisure activities was further confirmed in the cases of Participant A and B who stayed in Dunedin just under two weeks. These ICs engaged in a variety of leisure and tourism activities. IC who stay longer in Dunedin were more inclined to engage in activities either including the patient (Participants E) but also without the patient (Participants A, B and D). However, the activities are not limited to the classic tourism activities or experiences but more so centre around the IC's hobbies or interests, confirmed by Participants D and E plans of exploring the arts and crafts scene in Dunedin. Participant D stated that she would like to get in touch with locals who also do crafts (e.g. Embroidery Guild).

Discussion

Domestic medical tourism in New Zealand is a relatively new phenomenon and a consequence of long waiting times in the public system, centralisation of specialist services and limited access to private health care providers. The academic literature focusses mainly on the international medical traveller, risk and benefits that are associated with the health provision abroad, mainly in third world countries [28-31]. Domestic medical tourism only partly fulfils these definitions and has not been studied in greater detail. For public patients at least, the motivation to travel is different to those seeking medical treatment abroad and therefore, findings cannot be generalised [3]. It is known from other studies however that the need to travel to receive medical care is associated with a number of disadvantages and barriers [11-13,16-18]. In an attempt to ease some of these barriers, most patients do not travel on their own but in the company of an Informal Caregiver (IC). The need to include an IC in the travel arrangements has already been realised in the international market however, and while research into the role of the IC is abundant [20-23,32], Casey et al. in their publication on the role of IC in international medical tourism state that there is a noticeable lack of attention to the role of the IC who accompany the patient. To our

knowledge, this is the first study of its kind attempting to profile the IC and their specific needs and requirements in domestic medical tourism. Furthermore, this is being done disregarding of the underlying illness of the patient and through direct interviewing of the IC in contrast to gaining second hand knowledge through Patient Coordinators [20].

In-depth interviews of ICs as part of this pilot study demonstrated that basic and emotional needs of the IC are only partially addressed by the service providers and in contrast to the international market this is more evident with private service providers compared to the public service. Patients and ICs are required to search for accommodation and transport themselves. Most significantly, this leads to an isolation of the IC. Most IC, while not travelling with the primary intention to engage in tourism activities, in an attempt to allow the patient to rest and recover or to establish a daily routine and distraction are open to explore their surroundings. This gives the travel destination, in our case Dunedin, opportunity to engage in this niche market.

In the public system, the government is trying to ease some of the disadvantages that patients and their IC face by offering subsidised accommodation and travel assistance, which in general includes the IC. Administrative assistance is also offered. Therefore, the basic needs are being taken care of which is in stark contrast to the private system where help in this regard is only limited. Financial assistance is not offered. Interestingly, and in contrast to other findings [9,18] patients and their IC did not see this as a disadvantage and as most of our patients/ICs were not 'forced' to travel, any financial or administrative assistance with travel arrangements was not expected. However, despite the fact that in the public sector financial travel assistance is provided, it can be assumed that costs related to the travel remain to be covered by the patient and the IC. In our study, costs were not seen as a barrier to seeking public health care away from home; however our public sample was limited. This is in contrast to findings cited by a paper prepared for the Canterbury DHB [10].

Most critically, the individualisation of travel arrangements was leading to an obvious isolation of the IC. The emotional benefit to be able to communicate with other IC or untrained volunteer staff was clearly emphasised by Participant E and became further obvious by the ability to concentrate on the interview rather than the need to use the time with the interviewer to discuss the accompanied patients diagnosis and treatment. Emotional support in the private sector was offered through the chapel but this study did not assess if these services were taken up. The importance of the well-being of the IC and their emotional balance has been recognised by globally operating health tourism providers but is also often demonstrated in other studies referring to barriers to seek centralised medical care. Goins identified five categories of barriers to health care and amongst those social isolation was seen as significant [18]. In a study from New Zealand, Hopley et al. did not identify social isolation and the lack of family support or the unfamiliarity with the environment as a factor [9]. While the role of the caregiver to provide physical and emotional care is being recognized, the emotional needs of the IC are far less researched, especially in the context of travel [23]. In the first instance, untrained volunteer staff or even the possibility to meet other IC seems to be sufficient however, a study by Veitch [17] suggested that specific staff members within centralised facilities should be assigned to smooth the care path and minimise barriers for patients from rural and remote areas. The responsibilities of these personnel seem to go

beyond emotional assistance and can more be seen as health administrators.

The aim to seek private medical care in our sample was clearly the increased flexibility to arrange procedures according to their schedule to minimise the work, family and business related impact and to bypass the waiting time in the public sector. In this regard, the domestic medical tourist overlaps with international medical travellers (Type 3, Table 2).

	Type 1	Type 2	Type 3	Type 4
Int. Medical Tourist				
			Domestic Medical Tourist	
	Well - Wanting to enhance health	- Voluntary medical procedure	Not well access to treatment at home	-No insurance at Sent by provider or voluntary travel
Location	+++	++	+	+
Quality of Health Care	+++	++	++	++
Price	+++	++	(+++) ²	++
P/T ¹	Spa, Resort	Plastic surgery	Specialised treatment	Dental service Elective surgery
Impact on economy at Destination	+++	++	++	+
+ (less important/relevant), ++ (relatively important), +++ (Extremely important/relevant), ¹ Example of Procedure or Treatment, ² Subsidised in public patients				

Table 2: Types of Medical Tourists

According to Connell, ‘medical tourism has grown dramatically ... primarily because of ... often long waiting lists...’ [33]. Due to the increased provisions of medical services globally, the international medical traveller has the choice where he/she wants to undergo treatment. The decision is based on various factors: costs, destination image and quality (Table 2). Lovering points out that for the international medical traveller, the attractiveness of the destination is the main contributing factor to the consumer’s/patients’ choice of place of treatment (Type 1) [34]. Although our study shows that this is only true to a lesser degree for domestic medical tourism (Type 3/4), all but one IC stated that they were undertaking some activities while the patient is in hospital. The motivation to do so ranged from the necessity to maintain a certain routine for accompanying children (Participant A/B) to the acknowledgement that the patient needs rest (Participant A/B). Only one participant saw her role purely in the support of the patient and was not interested to leave the bedside. One participant (Participant B) had made the effort to obtain information about the destination. The need for activities ranged from family entertainment to access to the local arts and crafts scene. Obviously, the chance of a destination to portray itself to the visitor should not be forgotten. Participant E confirmed: “Once we have our camper ready and we do a South Island tour, we might return to Dunedin.”It can be postulated that while currently, the closest private health care provider is selected for elective procedures; in the near future private patients might abandon the local market and chose a more attractive, cost

comparable destination abroad leading to a blurred border between international and domestic medical tourism.

In conclusion, our study has clearly shown a significant gap in the academic literature concerning the individual needs and requirements of the informal caregiver in the context of domestic medical tourism. The informal caregiver plays a crucial role in the recovery process of the patient. To a certain extent, this has already been recognised by international operators but research into the needs and requirements of the IC has been neglected in the international literature. The IC is often left alone as the service, significantly so in the private sector, is focussed primarily on health delivery/revenue generation and the patient. This leads to critical social isolation of the IC and an additional barrier created by the need to travel. It can be assumed that the IC could fulfil its role to a much higher degree if assistance and information is provided. In addition to this, most IC seek distraction and depending on the required length of stay attempt to maintain a certain routine by embracing the environment offered by the destination. This is not unlike the international medical tourist trying to combine procedure with pleasure [33,34]. On a different note, this creates a unique opportunity for the national destination to engage with local health care providers and to access a critical niche market. The IC needs to be informed about the possibilities the destination offers but furthermore, to allow the IC to concentrate on patient support, administrative support needs to be put in place providing assistance to sort out basic needs for the IC. As indicated in the literature, this could help significantly to mitigate the critical implications of travelling long distances to treatment centres to receive medical care.

Authors’ Contribution

HS conceived, designed and carried out the research, analysed the data and drafted the manuscript. This work forms part of her Postgraduate Diploma in Tourism at the Department of Tourism, School of Business, University of Otago, New Zealand. JH supervised the project, participated in its design and helped to draft the manuscript. MS participated in the design of the study, recruitment and its translational relevance for clinical practice and aided in the drafting of the manuscript. All authors read and approved the final manuscript.

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