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Implications of social isolation during cancer treatment. The implications of residence away from home during cancer treatment on patients' experiences: a comparative study

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Abstract

With the centralisation and specialisation of cancer services, patients may have to travel considerable distances and stay away from their homes during treatment. This paper describes a comparative study that sought to identify the effects on patients of receiving chemotherapy and/or radiotherapy away from their homes, families and social support networks. Eighty four cancer patients treated in Southampton (42 from Guernsey and 42 from Southampton) agreed to participate in a structured interview and a standardised measure of social support. There were few differences in terms of satisfaction with services between Guernsey patients who stayed away from home during treatment and Southampton patients who lived at home. Counter-intuitively, Guernsey patients perceived themselves to have better social support. © 2001 Elsevier Science Ltd. All rights reserved.

Keywords: Cancer; Social support; Distance

Introduction

Island communities may be faced with dilemmas regarding the level and location of provision of specialist medical services for their populations. The island of Guernsey, one of the British Channel Islands lies 48 km from the French coast of Normandy about 120 km south of the British mainland. Guernsey has a total land area of approximately 60 sqkm and a resident population of around 60,000. It has never formed part of the British National Health Service (NHS), and primary care services are provided on a 'fee for service' basis by private family practitioners, whilst secondary care is provided under contract by the independent 'Medical Specialist Group' (Jeffs, 1999). In response to technolo-

gical advances in cancer treatment, and the organisational changes foreshadowed in the Calman Hine Report (1995), the Board of Health established a 'Cancer Strategy Steering Group' to recommend on further development of cancer services for Guernsey residents during the first decades of the present century. Given the potentially high financial and social costs of treatment 'off island', the Cancer Strategy Steering Group felt it essential to attempt to gain deeper insights into the likely psycho-social effects of being referred away for cancer treatment. The lack of relevant published material on this important aspect of overall cancer care led to the commissioning of this present study.

Literature review

A previous literature review identified only 11 relevant studies, four of which were conducted in Britain (Payne

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et al., 2000). Junor et al. (1992) and the National Cancer Alliance (1996) highlight the difficulties associated with getting to treatment, and advocate nearby hotel provision and improved parking facilities. Cosford et al. (1997) argue that whatever these difficulties may be they do not affect radiotherapy uptake and the National Cancer Alliance's (1996) study illustrates patients' acceptance of the associated hardships. These three studies do not criticise the centralisation of cancer services, although they make suggestions for service improvements. The fourth British paper (Benghiat, 1992) argues that centralisation is unnecessary given good quality local provision of cancer treatment, citing shorter travel times and distance to the local hospital to support this view.

Three other studies indicate a perceived or actual influence of distance and travel to treatment upon the treatment outcome or compliance greater than suggested in the British work. In the USA, cancer patients from ethnic minority groups (Hispanics and Blacks) saw transportation difficulties as barriers to taking up treatment (Guidry et al., 1997), while both Desoubeaux et al. (1997) in France and Goodwin et al. (1993) in a Canadian study suggest distance and/or lack of access to transport might contribute to survival chances or the prescription of treatment, respectively. Research by Hinds and Moyer (1997) support much of the British work in suggesting inconveniences and difficulties for patients associated with travel to treatments, but indicated that patients still attended treatments.

The above literature on cancer and travel predominantly deals with cancer patients attending out-patient appointments and treatment, where travel refers to travelling to treatment centres for each therapy session. Reductions in social support from friends and family available in the home environment may be of greater concern to those patients who are separated from these social support networks for some length of time because they are having treatment some distance away from their home.

Only three studies were identified which dealt with temporary separation from the home environment of family and friends and their relevance to British health-care contexts were limited. One argues for the need for cancer care closer to home for Canadian Inuits (Martin et al., 1995), another addresses effects of cancer on new immigrants in Israel (Baider et al., 1996) and a third considers the effects of travelling to treatment for rural women with breast cancer in Australia (Davis et al., 1998).

These three studies deal with cancer patients who are from minority groups, and have extremes of distances to travel to treatment, or are away from family support, and only deal with aspects of the topic in question. However, one study suggests that giving women their cancer diagnosis and treatment nearer home saves money and increases satisfaction (Martin et al., 1995). This suggests that treatment far away from home is more

expensive and less satisfying for patients, but issues of quantifying satisfaction and comparing new services with different older ones, makes the picture less clear.

Overall the literature is contradictory but there is evidence that long distance travel to obtain cancer treatment appears to be inconvenient for patients and may impact on compliance with treatment. It is likely that there is a complex interaction between the nature and distances travelled, and the physical or psychological status of the patient. For example, those patients treated by chemotherapy which itself may induce nausea, which may be compounded by car-sickness during a long and bumpy ride. Therefore, the consequences of treatment may reduce the tolerance of patients for journeys, which may otherwise be considered acceptable.

Social support and cancer

Social support has been defined as information leading individuals to believe they are cared for and loved, esteemed and valued, and belong to a network of communication and mutual obligation (Cobb, 1976). A number of different types of social support have been identified including informational, tangible, emotional, affirmatory support and social affiliation. A previous literature review of social support and breast cancer concluded that social support is important for psychological adjustment and survival for breast cancer patients (Carlsson and Hamrin, 1994). Frequently psychological need constitutes the largest number of self-identified needs for both patient and their home care-giver, above physical, financial, informational and household needs (e.g. Hileman and Lackey, 1990). The opportunity to confide in others appears to be an important component and function of social support, although research indicates gender difference in the number of available confidantes, with more female patients appearing to utilise multiple confidantes (Harrison et al., 1995).

There is an assumption that the 'family' functions as the primary source of social support and can be viewed as a stable entity. However, changing demographic patterns, with increasing numbers of divorced and separated people, greater numbers of elderly people, and geographical mobility in the working population, challenge commonly held notions of the family. The importance of the family to the majority of cancer patients can be demonstrated through links between family disturbance and psychological maladjustment, for the family may play a role in exacerbating the stress of cancer as well as easing the burden. Rodrigue et al. (1994) found that family disturbance, and perceived quantity and quality of social support, distinguished between good and poor adjustment, for example, and were most likely to predict psychological distress.

However, this study was unable to determine any direction of causality in the relationship between family dysfunction and maladjustment, hence the authors conclude that the relationship is probably reciprocal. Different families are likely to respond and cope in different ways when a member has cancer and within the family different members' may have differing perceptions. Kissane et al. (1994), for example, defined five types of families when a member had cancer, along with the characteristics of cohesion, conflict and expressiveness. Patients' perceptions of family functioning were often different to those of spouses and offspring.

In conclusion there is a paucity of research on the implications of receiving cancer treatment while residing away from home. The evidence that travel distance and difficulty increases psychological distress, and reduces compliance with treatment and take up of treatment is largely inconclusive. However, travel to cancer treatment is described as inconvenient and a practical hardship for many patients. It may also be perceived or experienced as, a barrier to treatment for some.

Perceived social support generally functions as a positive coping resource, but different individuals/sources may provide different types of support. It can tentatively be concluded that there are likely to be psychosocial, physical and practical implications for patients receiving treatment for cancer while residing away from their homes. These may be different for patients travelling to their treatment and those residing away from their home during treatment, but little research has been discovered which investigates this issue.

This study therefore sought to identify differences in perceived social support and perceptions of health care between those cancer patients who:

- (a) remained at home and travelled daily to the treatment centre, or
- (b) underwent treatment at a centre too far from home for daily travel.

Design

A cross-sectional interview study was conducted which compared cancer patients living in Guernsey with those living in and nearby Southampton. Both groups received either radiotherapy and/or chemotherapy treatments at the Regional Cancer Centre in Southampton.

Context

Approximately 80 patients per year are referred by the States of Guernsey for cancer treatment at Southampton. Patients are entitled to apply for financial support to meet the cost of flights to Southampton. If they require in-patient treatment they can be admitted to

appropriate oncology wards at the Royal South Hants Hospital, otherwise they were accommodated at Netley Castle Convalescent Home prior to January 1999, or the Abbey Unit after this date.

Participants

Two groups of cancer patients were invited to participate in the study. Those from Guernsey who stayed away from home and a comparison group who lived in daily travelling distance in the Southampton and surrounding area. Guernsey patients were proportionally similar but not individually matched with Southampton patients on the following variables: age (in 5 year bands), gender and type of cancer.

Inclusion criteria for participation included:

- receiving radiotherapy or chemotherapy;
- over 18 years of age;
- able to understand written and spoken English.

Exclusion criteria for participation included:

- failure to understand written and spoken English;
- having medical investigations but not treatment;
- too ill to complete data collection;
- refusal to participate in the study.

Between September, 1998 and August, 1999, 84 patients were recruited. Forty-two patients were from Guernsey (20 men, 22 women) and 42 from the Southampton area (15 men, 27 women). During the study period, 97 Guernsey cancer patients were referred to Southampton. Forty of these failed to meet one or more of the eligibility criteria. Of the 15 who were eligible but did not participate:

- 5 refused consent,
- 8 had been accepted for, but had not commenced treatment at the conclusion of the study period,
- 2 died prior to completing treatment.

These 15 patients not recruited into the study comprised 10 men and 5 women with a mean age of 58.1 years. They were not statistically different from the 42 participating patients in terms of age (t : -1.550 , p : 0.125 , $d.f.$: 82). The 42 patients from Guernsey who participated in the study represent 73.7% of those eligible. Fig. 1 summarises the recruitment process of Guernsey patients.

The mean ages were: Guernsey 62.2 years (range 25–91) and Southampton 57.1 years (range 19–84) which was not statistically significantly different (t -test: -1.550 , p : 0.125 , $d.f.$: 82). Gender differences in the samples were not statistically significantly different (chi-square 1.224 , p : 0.268 , $d.f.$: 1). In terms of employment status, 19 Guernsey patients and 16 Southampton patients were employed (chi-square: 0.441 , p : 0.507 ,

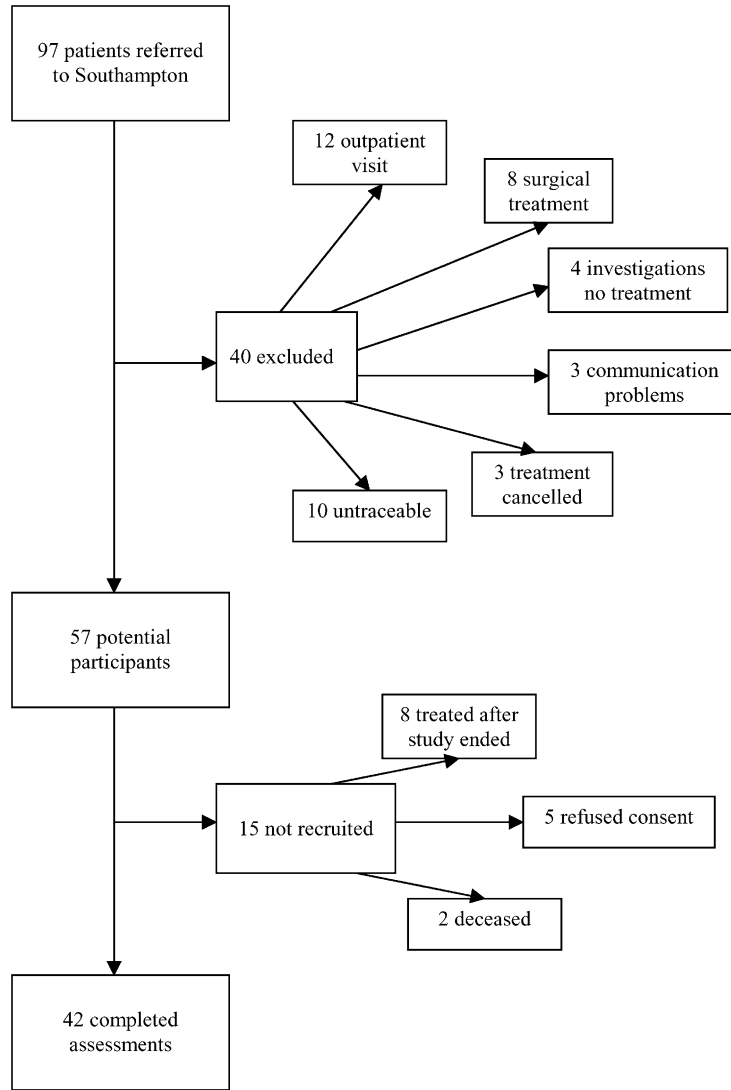


Fig. 1. Recruitment of Guernsey patients.

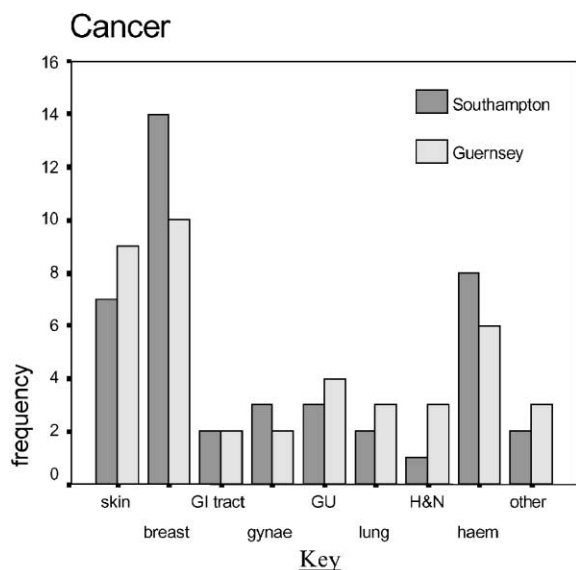
d.f.: 1). The groups were proportionally similar in terms of the types of cancer diagnosed as shown in Fig. 2. However, more Southampton patients received chemotherapy (25 versus 5) in comparison with the Guernsey patients who largely received radiotherapy (33 versus 15) (chi-square: 22.776, p : 0.001, d.f.: 2), while 6 patients received both.

Measures

Structured interview

A structured interview schedule was developed based on previous research with cancer patients (Jarrett and

Payne, 2000). An interview has the advantage of being responsive to participants' own agendas, in addition to those of the researcher (Payne, 1999). The interview was designed to elicit patients' experiences of treatment and was comprised of 26 items and a 20 item rating scale. The first seven questions were concerned with determining socio-demographic and relevant clinical background whilst the next 5 questions focused on social circumstances associated with attending for treatment. Questions 13–21 addressed experiences of travel to treatment and social contact. The final 5 questions asked respondents to evaluate the services provided. The interview schedule used both closed response and open response formats. It was pilot tested on 3 patients for face validity and patient acceptability prior to use,



GI tract = gastrointestinal tract cancer
Gynae = gynaecological cancer
GU = genito-urinary cancer
Haem = haematological cancer

H&N = head and neck

Fig. 2. Differences in cancer diagnosis between groups.

minor modifications were made to remove ambiguous or irrelevant items.

MOS social support survey

The MOS social support survey (Sherbourne and Stewart, 1991) was used to elicit data on social network and perceived social support. This is a 19 item standardised measure where patients are asked to rate each statement on a 5 point scale from 'none of the time' to 'all of the time'. It is comprised of four subscales assessing: tangible support, emotional/informational support, affectionate support and positive social interaction. A single item measured structural support. It was selected since it was both quick to administer and acceptable to patients. This measure has demonstrated good reliability and validity (Sherbourne and Stewart, 1991).

Procedure

Most but not all patients from Guernsey were identified via their application for financial assistance for travel. Screening lists of patients attending the Regional Cancer Centre identified the comparison

group. Patients were invited to participate in the study when they attended the Regional Cancer Centre for treatment. Both groups of patients received written and oral information about the study from the research assistant. If they agreed to participate, they were offered either an appointment for a audio-tape recorded face-to-face interview or a telephone interview when they returned home. Face-to-face interviews were held in a private room during a scheduled treatment visit so that additional hospital attendance was not required. The research assistant, following informed consent, administered the structured interview and the MOS social support survey. Data collection took between 20–30 min.

Data analysis

Data comprised responses to closed and open questions. Where all possible data were coded numerically and entered in SPSS for Windows. Open responses were examined and grouped into themes and excerpts from interviews transcribed to illustrate emerging issues. Excerpts of interview text have been included to illustrate themes discussed in the paper. These quotes were selected on the basis of two criteria. First, they illustrate the issue being discussed and second, an attempt was made to utilise a spread of participants rather than rely on a few individuals. After the excerpt from an interview, the participant is identified with an interview number, in brackets, as from Southampton (S) or Guernsey (G), their gender and age. Socio-demographic variables were coded as nominal data. Numerical data from the two samples were compared using chi-square, *t*-tests and Mann Whitney *U* tests as appropriate.

Results

The results will be reported in two main sections; those relating to patients psychosocial experiences of treatment, and secondly their perceived social support.

Perception of treatment experience

The research design meant that the main difference between these groups was that most Southampton patients could stay at home during their treatment whilst most Guernsey patients stayed at special accommodation (as shown in Fig. 3). This accommodation was also used by patients from Jersey and the Isle of Wight. Guernsey patients who were living away from home during treatment were significantly more likely to report dissatisfaction with their accommodation than Southampton patients (*U*: 202, *p*: 16).

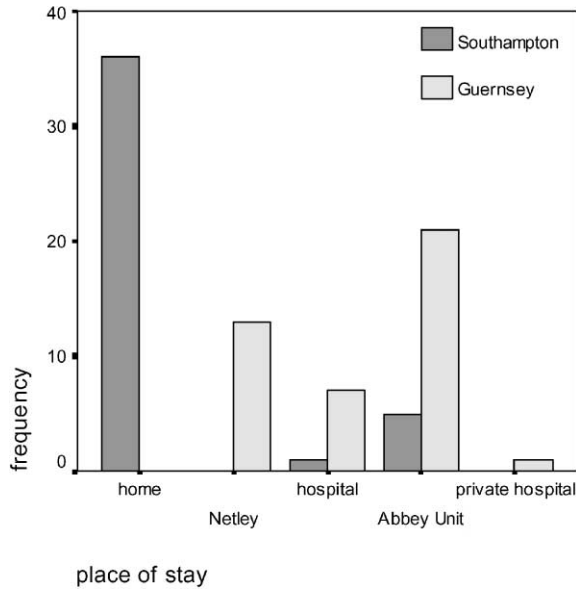


Fig. 3. Differences between groups in place of residence during treatment.

However, patients also noted positive aspects related to their accommodation, including the helpful contribution of staff which was mentioned by 23 Guernsey patients.

The staff here are superb, in so far as they are very experienced in dealing with people that are suffering with cancer. They are very supportive. They just keep the atmosphere here buoyant. (G21 male, 50 years)

Guernsey patients had positive views of the care they received at Netley Castle and the Abbey Unit. In particular they appeared to be liberated from day-to-day domestic duties and concerns about travelling arrangements.

They supply everything. You are well looked after. I mean you are brought backwards and forwards, if you wish. Luckily you know it is all laid on for you really. (G26 male, 59 years)

Southampton patients were more likely to report a consistent home life despite the upheaval of receiving treatment:

It is a better sense of normality. (S4 female, 32 years)

The freedom of course not having to stay in bed and look through a window and have nothing else to do but read. I am an outdoor person. (S29 male, 76 years)

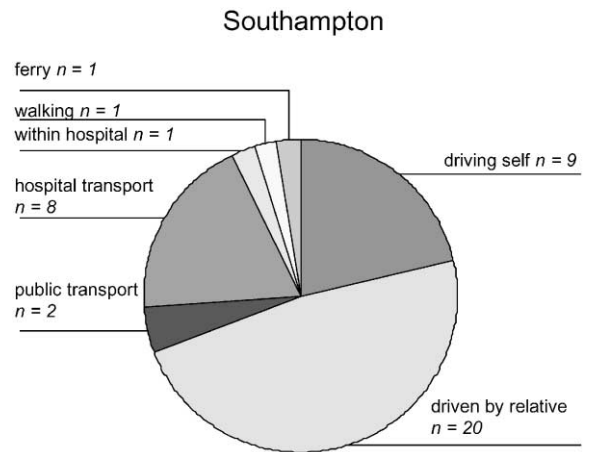


Fig. 4. Mode of transport to daily treatment for Southampton patients.

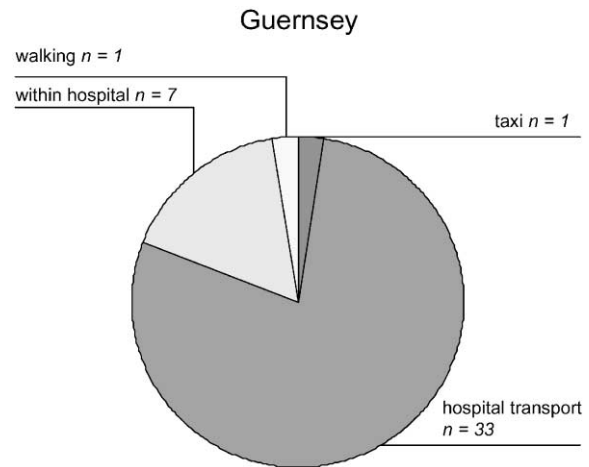


Fig. 5. Mode of transport to daily treatment of Guernsey patients.

I suppose because you are in your own environment and you have got your family around you. (S16 female, 64 years)

Mode of transport to treatment

Figs. 4 and 5 show that the majority of the Southampton patients drove themselves ($n = 9$) or were driven to their treatment sessions by a relative or friend ($n = 20$), whereas the majority of the Guernsey patients relied on hospital transport ($n = 33$). The interview responses suggest that Southampton patients often valued the greater independence resulting from using their own transport.

I think the fact that I do not have to rely on someone around for me because as I never really know how long I am going to be, I do not like inconveniencing other people. (S4 female, 32 years)

I do not have to wait around for hospital services or buses I do not have to pay for taxis or anything, it is just convenient for my daughter to bring me. (S16 female, 64 years)

Distance travelled to treatment

Figs. 6 and 7 show that most patients in both groups did not have far to travel (in miles or in time) to their treatment sessions from their place of residence during treatment. A key difference between the groups concerned Guernsey patients travel experiences on and off the island, which included adverse experiences of flights. This also affected those from the associated smaller Channel islands as well as in the following example from a resident of Alderney.

Gale force winds diverted the plane from Alderney. Therefore had to stay on Guernsey for a night and was sick. (G13 female, 42 years)

Social contact

As the Southampton patients stayed at home, 33 (78%) were in direct daily contact with their families. In

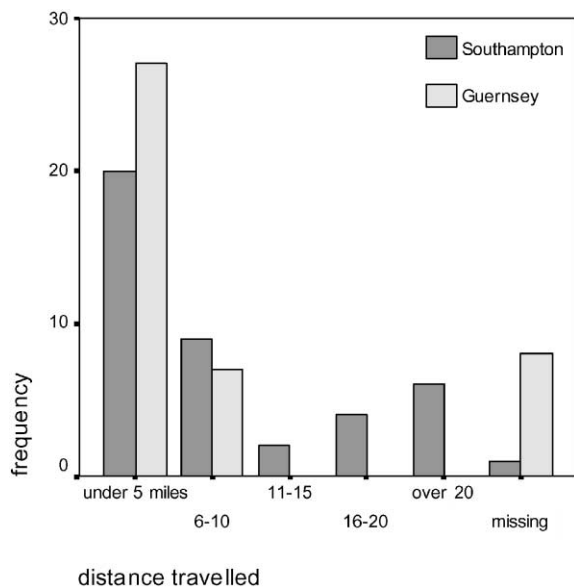


Fig. 6. Differences in distance travelled from place of residence during treatment.

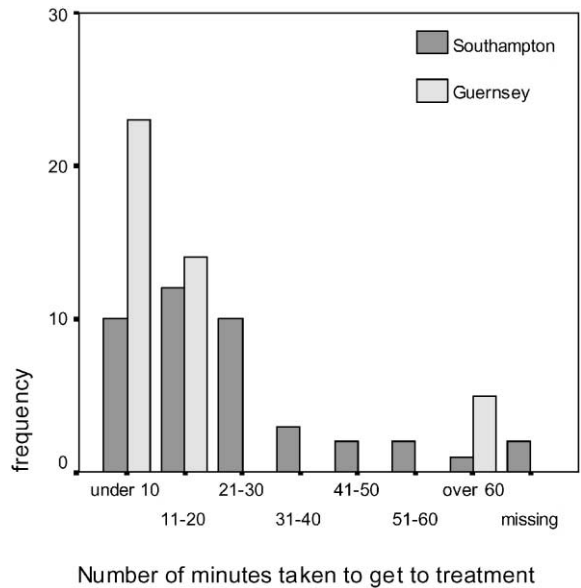


Fig. 7. Differences in time taken to travel to daily treatment.

comparison, only 11 (26%) Guernsey patients had direct daily contact, with a further 13 (31%) having weekly contact. Four patients from Guernsey and 5 patients from Southampton normally lived alone which was not statistically different (chi-square: 0.124, *p*: 0.724, d.f.: 1). Having dependants at home was a concern for some Guernsey patients, but not reported as a problem for Southampton patients.

Having a child in his teens...worrying how it is affecting him. (G21 male 50 years)

My husband has had to go into a nursing home because he is 80 and has Parkinson's. (G30 female 74 years)

Perceptions of social support

Overall all patients felt well supported by their family and friends but, contrary to what might have been expected, Southampton patients were significantly more likely to report problems with supportive (*U*: 459.5 *p*: 0.044) and intimate relationships (*U*: 500 *p*: 0.032) during the interview. However, on the MOS social support survey, there were no significant differences between the groups in terms of scores (see Table 1). Guernsey patients reported having more close friends and relatives than those in Southampton (a mean of 15 compared to 8). This is perhaps reflective of a more close-knit community.

Table 1
Results of the MOS social support survey

	<i>U</i> ^a	Probability
Tangible support	824	0.708
Emotional/informational support	831.5	0.646
Affectionate support	859.5	0.816
Positive social interaction	686.5	0.70
Overall score	791.5	0.414
Number of close friends and family	790.5	0.412

^a Mann–Whitney *U* test

Patients in both groups reported that meeting staff (Guernsey = 11, Southampton = 7,) and other patients (Guernsey = 21, Southampton = 11,) were positive consequences of having treatment. Those patients staying in Netley Castle or the Abbey Unit, met other patients who were not only receiving treatment for cancer but also understood the effects of coming from a small island community. The camaraderie and support which evolved between the islanders was something which was perceived to alleviate some of the anxiety of the treatment experience.

Obviously down here it is like one big family really because you're all in the same boat, um you are all on the same wavelength, if you know what I mean. So um yeah there is that the age difference as well obviously the older people there are more likely to do their own thing but younger people... I met somebody from Guernsey who come over on Monday, last Monday, I mean she is... We get on like a house on fire it is great you know we talk and whatever, and have a laugh.. The two of us went out for a walk this morning... Getting away from this environment, just getting away for a bit. (G4 male 48 years)

I find because we are all here and we are all receiving the same treatment there is a camaraderie and jokes between Guernsey and Jersey because we are sort of old time rivals and there is lots of joking and um even though we are all ill and um having treatment there is lots of laughter and like I say we are all suffering from the same thing and you just sort of know it is there is quite a closeness actually it is amazing. (G28 female 60 years)

You meet friends people here, or even people down the hospital that you have never met before, and you can relate your problems with each other knowing that you are both probably suffering from the same the same problem, it may not be in the same area of the body, but you know you are both cancer patients, if you like. And to me that has been a great experience. It has opened my eyes, if you like, to

cancer itself and the treatment of cancer. (G31 male, 64 years)

However, being in the company of other cancer patients was also regarded as stressful as it exposed patients to witnessing illness and distressing symptoms in others with the realisation that they might experience a similar fate. The following two Guernsey patients expressed these types of reservations.

When you are around suffering people it is depressing. (G25 male, 76 years)

You see people worse than yourself and you think, "Oh my golly" you know, "Why am I here? They are so much worse than me". (G28 female, 60 years)

In addition, they still experienced separation from their families, which was perceived to be stressful.

I am not there to baby sit, and to cuddle my husband, and walk the dogs, and look after my husband as he likes to be looked after. (G28 female, 60 years)

Only that we are split up as a family, we are a very close family, so you know, it is a long time to be away from home. (G31 male, 64 years)

Overall, the qualitative and statistical comparisons revealed no significant differences in psychological pressures and concerns between the two groups. Despite the relative isolation of the Guernsey patients from their normal friends and families during treatment, they gained social support from fellow patients, staff and used indirect (e.g. telephone) means to maintain contact with their island community.

Discussion

In principle, cancer patients should have equity of access to the most appropriate treatment regardless of where they live (Calman Hine, 1995). The key difference between the Guernsey and Southampton patients was the need for those from Guernsey to stay away from home during treatment. The results of this study highlight the positive and negative aspects of having cancer treatment while staying away from home, which has implications for other isolated communities. Overall there were few differences in the self-reported experiences of patients normally residing in Guernsey compared to those living in Southampton. Guernsey patients were more likely to make negative comments regarding their accommodation in Southampton but most reported it to be an advantage to have greater contact with other patients and supportive staff. The benefits of meeting other patients were important in sharing and comparing experiences and to lighten the mood through shared humour. The helpfulness of social comparison

processes in facilitating coping with cancer treatment has been previously noted (Costain Schou and Hewison, 1999) and even in those dying of cancer (Payne et al., 1996). The good quality of care and accommodation facilities contributed in part to alleviating some of the stress of being away from the home environment. This was also perceived to be a source of reassurance to their families who felt that their loved one was being cared for. There was some anecdotal evidence that the accommodation suited the needs of older patients but was experienced as more restrictive and therefore less acceptable to younger patients.

According to Cooper and Watson (1991, p. 104) 'social relationships promote health by moderating or buffering the potentially deleterious health effects of psychosocial stress.' For the Southampton sample, staying at home was associated with maintaining normality and contact with friends and relatives. In comparison, Guernsey patients found being away from home meant separation from loved ones and the additional worry of how the experience was affecting their families. Those with dependants (children or elderly relatives) were concerned about the potential disruption to the family. Paradoxically the Guernsey patients reported experiencing greater support and feelings of intimacy with their loved ones than those from Southampton. There may be two possible explanations for this unexpected result. Firstly there was some evidence that Guernsey patients were drawn from a more socially enmeshed society where people tend to live in more dense social networks. There is evidence that individuals with more interactions and larger social networks tend to have lower psychological morbidity rates than individuals who are loners (Burton and Watson, 1998). Secondly the disruption of leaving the island might have elicited more explicit expression of social support. There is an important distinction between social support 'provided' and that which is 'perceived' to be helpful (Krishnasamy, 1996).

The focus of the current study is limited, in that the information was self-reported, involved a small, non-random sample and patients from Guernsey who were unable or unwilling to travel for cancer treatment were not included. The long-term outcome of the patients was not measured, and it should be acknowledged that those with advanced disease or requiring palliative treatment are likely to have additional needs, which were not addressed in this study. The Guernsey and Southampton samples were overall well matched except in relation to treatment, with more Guernsey patients being treated by radiotherapy.

This study provides evidence that the majority of patients coped well with having to stay away from home during cancer treatment. However, patients with dependants had concerns about the disruption to family life and their need to ensure care either for children or

elderly adults. Adults, especially women, are increasingly likely to spend some time in middle or old age, caring for family members (Clark and Seymour, 1999). There should be some recognition that for these people, who are both patients and carers, additional support may be required. Our research concentrated on the perspectives of patients but future research might investigate the impact on families and carers of such separation.

This increased understanding of the psycho-social impact of receiving cancer treatment 'far from home' has proved valuable to the Guernsey Cancer Strategy Steering Group when deciding on the future developments of cancer services for Guernsey residents, and especially when purchasing more specialised services from NHS or private health facilities 'off island'. It is hoped that this information will also be useful to other Island Health Authorities, and to those responsible for ensuring the provision of health services for residents in other remote locations.

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