Impact of Treatments on the Family of Breast, Prostate, Colon and Lung Cancer Patients

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Abstract

Objective: Many patients describe travel to cancer treatment as inconvenient and a practical hardship and it may be perceived or experienced as a barrier to treatment. We investigated which impact cancer treatments has on the family of the patients, especially for the most frequent cancer type prostate, breast, colon and lung cancer.

The aim was to identify groups of patients with an increased burden for the family.

Method: All patients coming in February 2012 for chemotherapy to one of the four centres of the hospital or to the unique private practice were asked to answer a survey. The questionnaire covered items as gender, date of birth, living place, kind of cancer, kind of treatment and questions covering different aspects of the travel: how the patient travelled to the centre, how long the travel lasted, which kind of support was necessary to travel and who provided this support, whether the accompanying person had to absent herself from her workplace, whether the patient lives alone or not and how many journeys to health care providers the patients had in the last month were included in the analysis

Results: 298 patients answered to all required questions (73%). 186 came accompanied, a vast majority by a member of the family and one out of four of the accompanying person had to leave the workplace. Help at home is almost exclusively provided by family members. Patients have several journeys to health care providers per month.

Conclusions: The type of cancer has an impact on the support needed and must added to the previously published factors as age, gender and distance. The journey to the cancer treatment is not the unique journey to health care providers the patients have and increase the burden for the patient and the family.

Keywords: cancer, social support, burden of travel

1. Introduction

Many patients describe travel to cancer treatment as inconvenient and a practical hardship and it may be perceived or experienced as a barrier to treatment (Payne S. et al. 2009). The need to travel for treatment cause many practical, emotional and financial problems for patients and burden them with additional worry concerning family and work commitments (Butow P. et al. 2012). Recent publications highlighted as well travel-related burden for cancer patients (Zucca A. et al, 2011) and financial and social impacts for support persons of cancer survivors (Carey M. et al. 2012) as impact of age and distance on the willingness of cancer patients to travel more or further away for a slightly more efficient therapy (Groux P. et al. 2014a) and the impact of gender, age and travel time impact on the need for social support of patients to have access to cancer treatment (Groux P. et al. 2014b).

The Swiss health system is based on principles of free demand and supply as well as regulated competition (Busato A & Künzi B. 2008) with a fee-for-service system for the reimbursement. As travel costs are not reimbursed they can increase the financial burden for patients living in remote areas. Valais is a Swiss alpine

canton at the southern border of the country and consists in a main valley and the valleys of several feeder rivers. The population of the upper part of the valley speaks German, the population in the middle and the lower part of the valley speaks French. All cancer treatments are offered in places in the main valley. A former study emphasized transport issues as a major obstacle to cancer treatment (Anchisi S, & Anchisi A. (2008).

We investigated which impact cancer treatments of patients who came in February 2012 has on the family of the patients, especially for the most frequent cancer type prostate, breast, colon and lung cancer.

Approval for the study was obtained from the medical-ethical commission of the canton of Valais.

2. Methods

All patients coming in February 2012 for consultation or ambulatory treatment to one of the four centres of the H ôpital du Valais or to the unique private practice in the region were proposed to answer a survey. Patients were asked to fill out the questionnaire at least once per centre. If a patient came up in two different centres he was asked to answer in both centres. The questionnaire covered items as gender, date of birth, living place, kind of cancer, kind of treatment and questions covering different aspects of the travel: how the patient travelled to the centre, how long the travel lasted and which kind of support was necessary to travel and who provided this support. Details of the questionnaire have been published separately (Groux P. et al. 2014b).

The present analysis focussed on the role of the family in giving support to have access to the treatment and is a sub-analysis of previously published results (6). The questions (a) whether the accompanying person had to absent herself from her workplace, (b) whether the patient lives alone or not and (c) how many journeys to health care providers the patients had in the last month were included in the analysis. To quantify the number of journeys the patients could choose between (1) daily, (2) 2 to 4 times a week (3) once a week, (4) twice a month and (5) once a month.

The data were summarized and analyzed using Microsoft Excel and EpiData Analysis (Epidata Association, Odense, Denmark). Crude odd ratios were calculated from a 2x2 table. The odds ratio (OR), its standard error and 95% confidence interval are calculated according to Kirkwood and Sterne (Kirkwood B. & Sterne J. 2003).

3. Results

629 questionnaires were handed out from which 619 were collected. 408 different patients participated to the survey and 298 different patients answered all requested questions for this publication (73% of all participating patients). 7 patients answered twice to the questionnaire but in different sites (2% of the patients).

186 patients came accompanied. 183 answered by whom they were accompanied (98%) and 181 answered whether the accompanying person hat to leave her workplace (97%). 115 times the accompanying person was the spouse or life partner (62%), 33 times a child (18%), 5 times a parent (3%) and ten times another family member (5%). In total family members account for 88% of the escort. 44 patients declared the accompanying person had to leave her workplace (24%), 137 declared the person had not to leave her workplace (74%). 5 patients didn't answer (3%),

153 patients had somebody taking care at home during their journey, all answered who this person was. 99 times the person was the spouse or life partner (65%), 19 times a child (12%), 12 times a parent (8%), 11 times another family member (7%). In total family members account for 92% of this kind of support.

56 patients declared to leave alone (19%), 237 declared not to leave alone (80%) and 5 patients didn't answer to this question (2%).

274 patients answered to the question, how many journeys to health care providers they had. 20 patients answered daily (7%), 29 two to four times a week (16%), 70 once a week (23%), 78 twice a month (26%), 57 once a month (19%) and 24 didn't answer to the question (8%).

Men are statistically significantly more accompanied by their spouse or life partner than women with an OR of 2.3 (95% CI 1.1 - 4.7) and men had also statistically significantly more help at home provided by the spouse or life partner with an OR of 2.7 (95% CI 1.2 - 5.9). Gender has no impact on whether the patients lived alone or not or how many journeys to health care providers they had.

The importance of the family to accompany the patient increases with age. Starting at 77% for patients below 50 it increases to 83% and 89% for patients between 50 and 59 respectively between 60 and 69 and ends to 94% for patients 70 and above. The difference between the patients below 50 and those 70 and above is statistically significant with an OR of 4.3 (95% CI 1.0 - 18.0). If parents count for 23% in patients below 50, they weren't mentioned by patients 50 and above. On the other hand, children accompany their parent above 50: 5 in patients between 50 and 59 (13%), 9 in patients between 60 to 69 (15%) and 19 in patients 70 and above (30%). Whether

the accompanying person had to leave her workplace is influenced by age with a statistically significant difference between patients 70 years old or more and patients younger than 70 years with an OR of 2.8 (95% CI 1.2-6.6).

The help at home is also mainly provided by the spouses/life partners, parents and children, with changing proportions depending of the age of the patients: 39% spouse/life partner, 30% parents and 3% children for patients below 50 years, 66%/5%/16% for patients between 50 and 59, 81%/0%/8% for patients between 60 and 69 and 64%/0%/25% for patients 70 and above. Spouse and life partners provide the help at home for patients above 50 with a statistically significant difference to patients below 50 compared to other persons providing this kind of support with an OR of 3.9 (95% CI 1.7 - 8.7). The number of journeys to health care providers is not impacted by age.

Distance impacts only who accompanies the patient to the treatment with a statistically significant difference between patients living closer than 15 minutes to the oncology ward and those living further away with an OR of 3.9 (95% CI 1.0 - 15.2) to be accompanied by friends or neighbours.

Whether a patient lives alone or not, impacts on who is giving support to the patients, but not on the percentage of being accompanied or not. Patients not living alone are accompanied in 94% of the answers by a family member, patients living alone in 61% of the cases. Help at home is provided in 97% of the answer by a family member, if the patient doesn't live alone, in 60% of the answers if the patient lives alone. Both differences are statistically significant with an OR of 9.4 (95% CI 3.4 - 26.4) and 21.3 (95% CI 5.6 - 81.3). No influence of this parameter on the number of journeys to health care providers or whether the accompanying person had to leave her workplace has been observed.

We didn't observe any difference between the two language regions regarding by whom support was given, whether this person had to leave her workplace or the number of journeys to health care providers.

Cancer type influences the support patients need. Figure 1 summarizes the support given to prostate, breast, colon and lung cancer patients. With 56 years on average breast cancer patients are younger than lung cancer patients (65 years), colon cancer (66 years) and prostate cancer patients (70 years).



Figure 1. The kind of support claimed by cancer type

Lung cancer patients call more for an accompanying person than prostate, breast and colon cancer patients, the difference is nevertheless not statistically significant. The need for help at home is statistically significant as well

for lung cancer patients as for breast cancer patients compared to colon and prostate cancer patients with an OR of 3.9 (95% CI 1.5 - 10.0) and 2.8 (95% CI 1.4 - 5.6). The differences for external help are not statistically significant.

Journeys to health care providers are summarized in figure 2 and differ by cancer type. Lung cancer patients travel more frequently than other cancer patients. The difference between is statistically significant whether patients travel at least once per week or less than once per week with an OR of 2.9 (95% CI 1.2 - 7.4).



Figure 2. Number of journeys to health care providers during the last month by cancer type

4. Discussion

Cancer patients need the support of their family to get access to a cancer treatment. The vast majority of the persons accompanying a cancer patient to the treatment are family members, almost exclusively them for patients not living alone. The spouses/life partners contribute mainly to this form of support, followed by parents and children, dependent of the age of the patient. We observed a gender specific difference with men being statistically significant more accompanied by their spouse or life partner than women. Almost one accompanying person out of four (44/186) has to leave her workplace to accompany the patient, except for elderly patients (70 and above), which is probably due to the age of the spouse/life partner who is frequently also retired.

Age impacts on the need for help at home during the journey with a decreasing need with age. The vast majority of the persons providing this help at home are family members, almost exclusively for patients not living alone.

A majority of patients living alone are accompanied by a family member as well but the contribution of friends and neighbours is statistically significantly higher. The help at home is as well mostly provided by a family member but the contribution of friends and neighbours is also statistically significantly higher. Patients living alone seem to have access to help to palliate a lack of support by their family.

Cancer patients probably require support also for other journeys to health care providers, we asked therefore for the total number of journeys during the last month. We observed a broad disparity from daily journeys to one journey per month, which is the patients journey to his cancer treatment.

The cancer type impacts on the need for support. Prostate cancer patients are with an average age of 70 years the oldest group in our study population. Two third are accompanied to the cancer treatment, which is in line with former results we published showing that escort increases with age. They need less help at home, which is also in line with our former results showing that need for help at home decreases with age and men calling less for help

at home. They also tend to have less journeys to health care providers. We assume that the general condition of the prostate cancer patients in our study population was better that the condition of other patients.

Lung cancer patients need more support than other patients. As the majority of these patients have a metastatic disease, we assume that their bad condition makes this intensive support necessary. Breast and colon cancer patients show a broad variety of patterns of support. Our sample is too small to analyse the reasons, particularly as we don't know whether the disease of the single patients is advanced or not.

The study methodology has several limitations, particularly the voluntariness to participate to the survey and to answer to the specific questions of interest for this investigation. Socioeconomic factors as education level, income class, immigration background or size of the household were not collected, bias is therefore possible. For example, the decline of percentage of patients requiring help at home with growing distance could be biased by other factors, e.g. the type of cancer. The answers are probably influenced by further factors which were not included in the questionnaire. as *e.g.* the performance status or the advancement of the disease. We renounced to a multivariate model as our questionnaire didn't contain all these relevant factors, accepting the limitation of a univariate logistic regression. The survey was done during winter where snow causes additional difficulties to travel.

5. Conclusion

We investigated which impact cancer treatments of patients has on the family of the patients, especially for the most frequent cancer types prostate, breast, colon and lung cancer. Families play an active role to allow access to cancer treatment, for persons living in a multi-person household they provide almost all the support. Patients living alone get also support from friends and neighbours. The type of cancer has an impact on the support needed and must be added to the previously published factors as age, gender and distance. The journey to the cancer treatment is not the unique journey to health care providers the patients have. These additional journeys increase the burden for the patient and the family and have also to be taken in consideration.

Cancer treatments are highly specialised and mostly done in a multidisciplinary approach with a major trend to centralisation of the services in specialised centres covering all disciplines. This centralisation has a direct impact on the patient and his family. The greater the distance, the more patients travel accompanied. We have also demonstrated that one person out of four accompanying a patient have to leave her workplace. These factors have to been taken in consideration in planning cancer care services and are a plea for an organisation of care according to the model of chronic care. Involving the primary caregivers (doctors and nurses) in providing decentralized care which do not require highly costly devices, specialized infrastructures or competencies would be of primary importance to relieve the burden of these therapies not only of the journeys.

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Disclosure

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