

SOCIAL IMPLICATIONS FACED BY BONE SARCOMA PATIENTS' FAMILIES

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SUMMARY

The orthopaedic oncology group provides medical and psychosocial care to patients, both in hospital and outpatient facilities, with musculoskeletal tumors. With this research we aimed to know the socioeconomical profile of the patients/ families, as well as the changes occurred after such diagnosis is received. The sample was constituted of 25 families of patients with osteosarcoma on lower limbs. The study was conducted between September and October 2005 by means of forms containing open and closed questions, using the collective subject speech for qualitative analysis. The study had a prospective, descriptive design with quanti-qualitative

approach. Among the respondents, 68% were females including 44% of mothers; 76% worked, and 28% of these had formal jobs. 60% had a family income amounting 2-5 minimum wages. After diagnosis, 92% faced increased expenses; 80% reported challenges with the chemotherapy; 56% mention transportation as the major factor affecting compliance to treatment. 100% feel desperate when they first know they have cancer. Cancer causes changes in family members' roles. There is always the fear of recurrence, which ultimately lead the family to fear death, thus requiring a joint effort with a multidisciplinary team.

Keywords: Family; Bone neoplasia; Patient care team

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INTRODUCTION

Certain diseases cause impacts for patients and their families due to the stigma they carry, leaving weak families, negatively impacting emotional and social relationships.

Illness causes crises and moments of disorganization for patients and their families, because this is the first relationship group to which the individual is connected, and, most of the times, family members are the closest people with which a patient lives. Many changes occur in the lives of a patient and his/ her family, making them face restraints, frustration, and loss. These changes will be established by the kind of the disease⁽¹⁾.

When a patient is diagnosed with cancer, families are involved, there is a feeling of loss, anxiety and depression. That is why family bonds are important in helping patients to face the disease.

The IOT's orthopaedic oncology group intends to provide medical and psycho-social care to patients, both hospitalized and on an outpatient basis, living with primary or metastatic musculoskeletal tumors. The team is composed of Orthopaedic Doctors, Pediatricians and Oncologists, as well as Social Workers and Physiotherapist.

The medical care in this group can consist of chemotherapeutic and radiotherapeutic treatment, rehabilitation, drug or surgical therapy. In the latter, amputation may be indicated, and, when this occurs, the patient will use a tailored prosthesis manufactured in our orthopaedic workshop or acquired from other orthopaedic services in the community.

At the IOT HCFMUSP's orthopaedic oncology group patients living with bone tumor receive care, with no age limits and coming from locations throughout Brazil. When a patient is admitted to the group, a multidisciplinary team prepares a specific treatment plan for each patient, where a number of aspects are assessed and elaborated in order to enable patient's compliance aiming a better effectiveness of the treatment proposed by the team.

According to Camargo⁽²⁾ "Osteosarcoma is the most common primary malign tumor on bone tissues. It is characterized by

sarcomatous stroma, with direct formation of osteoid and bone tissue by neoplastic cells. Its most common location is the long bones' metaphysis, notably the distal femur and the proximal tibia, occurring between the ages of 10 and 30. It is a fast-growing tumor, which can evolve within weeks, with pain and progressive local growth".

Literature outlines that 'early diagnosis of primary bone tumors is critical, especially in malignant cases, where local control as well as therapy approach are required for increasing patients' survival rate. In the last 15 years, a great change was seen on the treatment of such neoplasias, which led to a substantial 5-year survival increase, which, in the past, reached almost 10% and today is around 50-60%. Another important aspect is that over half of the patients are submitted to conservative surgeries, sparing functional limbs, significantly improving patients' quality of life"⁽³⁾.

Upon the reality exposed during treatment, the job of social workers serves as a way to intervene on the social context in which the patient and his/her family live, aiming to provide alternatives to certain social issues faced by them, providing reassurance and compliance to the treatment proposed by the healthcare team.

Therefore, a research was conducted aiming to know patients and their families' socioeconomical profile as well as the changes occurred in these families after receiving a diagnosis of cancer: changes in the work environment, how their social relationships are left, how the family organizes itself to provide support to the patient, which network to rely on, and, finally, what difficulties the family is facing for the patient to be able to comply with the treatment.

CASE SERIES AND METHODS

The research was conducted between September and October 2005 with families of patients admitted to the orthopaedic oncology group at IOT – HCFMUSP, living with osteosarcoma on the lower limbs, confirmed by biopsy at least six months earlier.

We found, through week-basis statistics at the Medical Files Service – SAME – that in May 2005, 30 patients received care in one week

Study conducted at the Orthopaedics and Traumatology Institute, Hospital das Clínicas, University of São Paulo – Medical School (IOT-HCFMUSP).

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on an outpatient basis. The sample was determined as 4 families a week, totaling 25 families within the period of the study. The patients came accompanied by their families, and were invited to take part of the research after signing a Free and Informed Consent Term, and then they were able to respond the interview forms with open and closed questions, using a tape recorder. This was a prospective and descriptive study, with the research tool being divided into: personal data, socioeconomical layer, socioeconomical status before and after diagnosis, leisure, rehabilitation, and family.

For the quantitative analysis, the "Collective Subject Speech" methodology, as developed by Fernando Lefèvre, which starts from "the conjecture that collective awareness may be seen as a set of speeches about a given topic, the Collective Subject Speech intends to give light to the set of semantic peculiarities of the social mindset... in brief, it is a way or resource designed to allow a free speech" (6).

This speech is based on withdrawing, from each testimonial, key expressions that are the peculiarities of a similar thought, the core ideas that are the expressions that provide a brief report of the testimonial under analysis, building a single speech: the Collective Subject Speech, reported using the "I" pronoun, intending to manifest the collective mindset, on a logical and consistent way, with the expressions of a population addressing a given topic.

RESULTS

We noticed that 84% of the patients receiving this diagnosis were between 10 and 30 years old; these are teenagers or young adults in a productive phase of life, confirming what literature reports. Usually, in this phase, a great expectation is observed from the patient and his/ her family about school development, jobs, the beginning of a career, with all these expectations being frustrated when they are diagnosed with the disease, requiring a reorganization of the daily routine and a re-evaluation of the plans for the future.

Among the family members interviewed, 68% were females, 44% patients' mothers, being noticed, during interviews, a prevalence of women as the care provider, reinforcing women's image as the responsible person for taking care of the home and the people living there. (Figure 1)

64% of the families were catholic, 16% belonged to gospel religions, and the remaining had other religions. During families' reports, we noticed that all of them mentioned God and were somewhat stuck to any religion in times of trouble, raising religiousness and mysticism levels because of the need of protection in moments of weakness. (Figure 2)

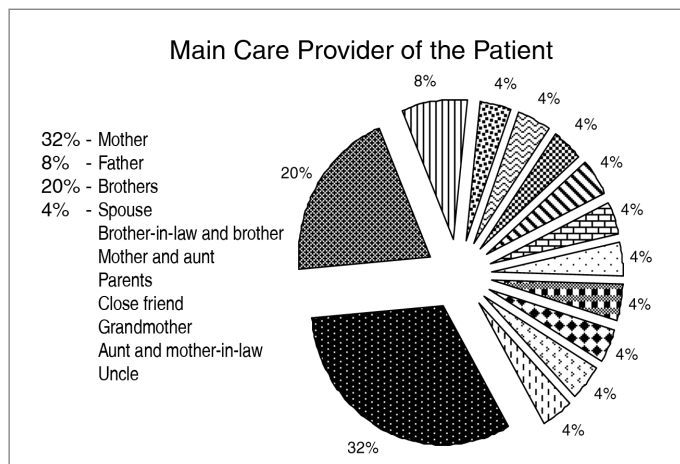


Figure 1 – Distribution of family members as main care provider of the patient.

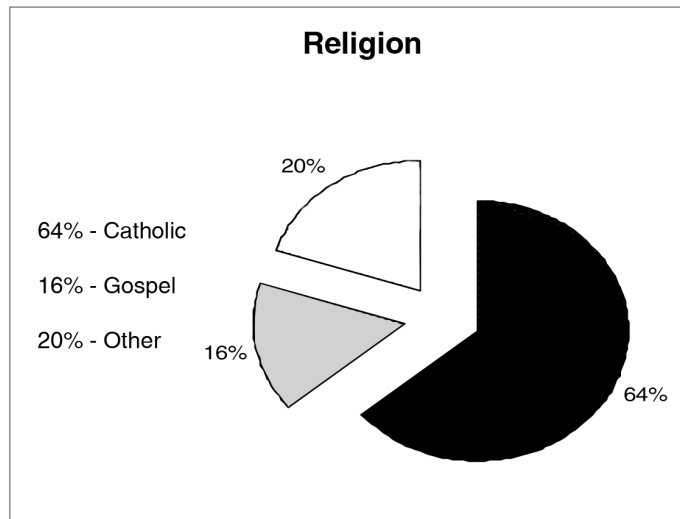


Figure 2 – Respondents' religion

Of the 25 respondents, 68% had come from other states, 52% were living in São Paulo, 48% had incomplete high-school education level, and 60% reported an income of 2-5 minimum wages. (Figure 3)

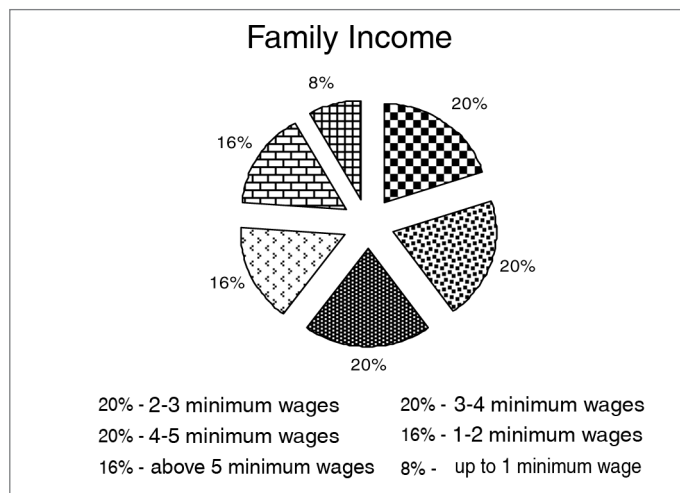


Figure 3 – Respondents' family income

By correlating all these data, we found that most of the families belong to socioeconomical classes C and D, with relatively low purchase power, yet these families used all possible resources to face crisis moments resulting from the disease, reorganizing themselves in order to face the situation and showing a sympathy attitude among the family members.

A social worker's role is to guide the family pointing out the need of reorganizing themselves as to provide care to the patient, not placing an excessive burden on a single member. Care must be distributed among all family members, including the patient himself/herself, making him/her feel responsible and participative in the rehabilitation process and in the decisions made about treatment. 68% of the respondents were the owners of their houses comprising between two and four rooms, and 92% reported that, after the diagnosis, there was an increased expense thus reducing family income. (Figure 4)

These data evidence that even when patients receive healthcare from SUS – Single Health System, family expenses increase, once this disease requires a long-term treatment, several kinds of tests, requiring money and time availability from the family for the several hospitalizations and discharges and with other needs resulting from the new routine imposed by the disease.

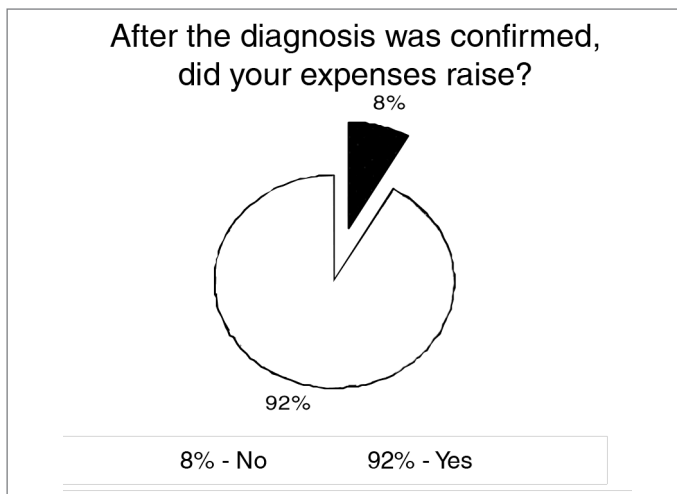


Figure 4 – Increased expenses after receiving the diagnosis. Challenges faced along treatment.

Concerning the challenges found along the treatment, 28% of the respondents reported having trouble with the side effects of the medication; 24% reported having had trouble to get to the hospital and with the side effects of the medication; other 20% reported having trouble to get to the hospital, with the side effects of the medication and to comply with the rehabilitation program; 12% reported no difficulties; 8% reported trouble only with getting to the hospital; 4% reported having trouble with the side effects of the medication and to comply with the rehabilitation program, and; other 4% found difficulties with the side effects of the medication, with complying with the rehabilitation program and others. (Table 1)

Challenges faced along treatment	Amount	%
No challenges	3	12%
Side effects of the medication	7	28%
Get to hospital, side effects of the chemotherapy, compliance with rehabilitation treatment (transportation)	5	20%
Get to hospital	2	8%
Side effects of the medication, compliance with rehabilitation (transportation), other	1	4%
Get to hospital, compliance with rehabilitation (transportation)	1	4%
Get to hospital, side effects of the medication	6	24%
	25	100%

Table 1 – Main challenges faced along treatment

When the patients were questioned about the challenges to get the patient to the orthopaedic oncology group, 56% reported this problem; of these, 43% reported shortage of financial resources and transportation; 29% reported unavailability of transportation; 21% transportation and others; 7% for other reasons. By assessing these data, we found that the greatest challenge for receiving healthcare is transportation, as shown by Figure 5. 100% of the

respondents reported that, after receiving the diagnostic, they felt desperate and feared by the diagnostic of the disease. I was desperate, I couldn't believe in the diagnosis, it was very sad, everybody got out of control, we couldn't think. It was not easy at all, there are times when we disrespect God, but then we calm down. I didn't show anything, but it was hard.⁽³⁾

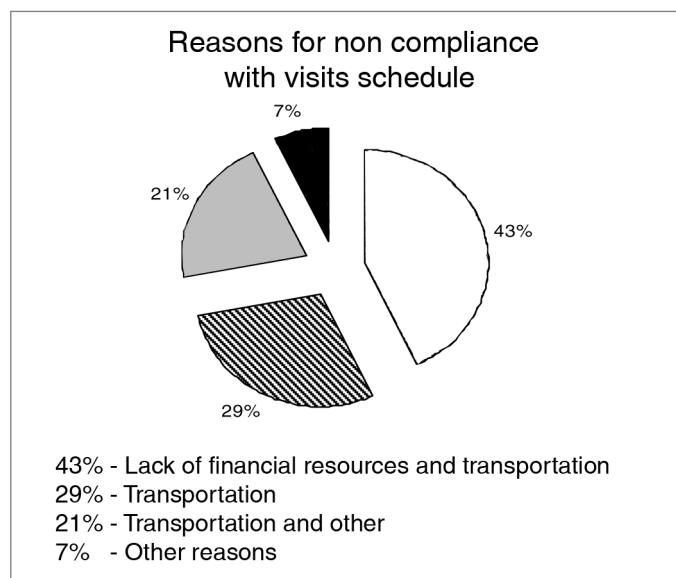


Figure 5 – Causes of non-compliance with the treatment

In that moment, the family is shocked. Silva^{a(4)} "reports this shock as a numbness in which the patient and/or family, from that moment on, cannot correctly perceive what is going on around them, as if reality was too hard that it must be denied. It is like saying: 'no, this is not happening, it's not true' because it is a cruel and hard to accept reality".

Usually, people think that the family will provide support to the patient, presupposing that the patient is the one in despair. However, sometimes the family seems to be more desperate than the patient. According to a systemic view, this behavior is totally justifiable, once a family is an intercommunication system.

"... I couldn't believe it, I was desperate... I couldn't believe this diagnostic was true... the family got desperate, it was very hard". (Family member testimonial)

Silva^{b(4)} report that the way in which the information is communicated may cause a very strong impact on the patient, on the family, or even on his/ her support network. This crisis may be accompanied by despair, anger, fear, intolerance, among other emotions, when patients and their families get aware of the potential of death this disease may cause. That fear causes psychological and social changes both on the patient and on his/ her family. This disease required long-term follow-up, with exhaustive visits to hospital, with chemotherapy interventions, causing a negative impact to the family from a physical standpoint, because it is tiring, as well as from the emotional perspective. With the side effects of chemotherapy, physical changes are noticed such as: weight loss, alopecia, constant vomiting, sensitiveness to smells, evidencing the fear of death. Despite of all side effects resulting from chemotherapy, patients and families make their best efforts to comply with treatment, following the routine prescribed by the doctor, once chemotherapy is likewise a distress and a synonym of hope and life.

"The challenge was the side effects of chemotherapy. He felt very sick, lost much weight, vomited, couldn't eat properly, his mouth

was hurt, lost his hair, couldn't smell anything, coughed, fainted, fall in depression. I thought he was going to die."⁽³⁾.

The reaction to disease may be present in other family members, such as, for example, in a son reacting to his father's disease becoming more responsible, or a husband that starts taking care of the routines of the house in the absence of a wife. These speeches may indicate roles readjustment within family routines. "... Thank God, my husband is very understanding, I would be lost without his struggle against my son's illness; he was a real partner... he arrived early, he took care, he cooked for him. I've never left my son alone in none of his hospitalizations". (Family member testimonial)

Another reaction exhibited on family members' testimonials, was the concern about other people's look fearing that the disease could be contagious. We saw the challenges for these patients and families upon a new reality imposed by the disease, when they experience the stigma that the word tumor carries, with its connotation of terrible incurable disease ultimately leading to a long-suffering death. Families and patients must deal with society's prejudice due to physical and emotional restraints this disease imposes.

"... after amputation, she barely leaves the house, she only goes to school, because she says that everybody looks at her wondering what her problem is. Sometimes, people ask if it was an accident, and she tells right away what happened so that people stop talking about it". (Family member testimonial)

Another characteristic on the respondents' testimonials is that the disease made the family to be more close, which is a positive aspect resulting from this situation, with, upon a serious disease, family members are sympathetic to the condition of one of its members, many times reorganizing themselves, for example, even concerning dwelling, which, sometimes does not provide enough comfort for people who have special needs resulting from the disease.

"... this ultimately made us closer to each other, when the family noticed we could lose her, then our family got even closer... when we see a member of our family ill, on the slack rope, who we don't know will survive, then we give life its real value". (Family member testimonial)

Some families reported that the best way to get help from a medical team would be the access to information concerning the disease and treatment access, healthcare, guidance on the dos and don'ts. It was evident that families want technical data, for being reassured, and, with these data in hands, they could be able to take part on decisions and plan their reorganization. We can infer that the family wants to know the truth, even when it is undesired and so painful.

"I expect getting further information about the treatment. We get stronger"⁽³⁾.

The faith in God or the attendance of the family members in ceremonies or religious acts help them dealing with the stress resulting from a disease in one of its members. Some relatives reported facing the problem with God's help; others reported that with the disease, they were back stuck to religion.

Another characteristic noticed on 100% of the respondents was the families' report about the trust they have on assistant doctors and on the professor of the orthopaedic oncology group, evidencing that they recognize and totally trust them.

Families report that they do not value other non-medical professions, as if the compliance to these occupations and therapeutic indications provided secondary gains. According to Belkiss⁽⁵⁾ "the disease situation can trigger attitudes and

expectations in some people, where the patient takes the imaginary form of an object on the hands of the 'cure owner', i.e., the doctor".

"... to be honest, he has done just a few physiotherapy sessions. Because of the challenges to get here, he dropped out". (Family member testimonial)

Bone tumor treatment leaves several sequels to the patient and his/ her family. By the reports, we could notice that, even after cured, the patients cannot live a supposedly "normal" life, because of surgical sequels, amputation with the use of prostheses, endoprostheses. The disease may cause delays on the educational schedule, social contact loss, trouble with returning to labor activities, fear of recurrence, bringing, as a result, a number of social and emotional problems.

Family members also reported challenges to conciliate their jobs and daily lives with treatment follow-up.

In this sense, family's attendance in a support group is important, and, according to Burd⁽⁶⁾, these groups help families to give new meanings to complaints and hard feelings, which can reflect on important changes in the way they live with an ill member, with others and among each other.

CONCLUSION

In this research, we noticed that most of the patients on the sample are on the age group of 10-30 years, i.e., in their productive years. Each family exhibits specific peculiarities, where a system of required actions, procedures, skills and technical knowledge is used for providing specific care for social interventions on complicating factors imposing difficulties to a patient's treatment. We found that when the family receives the diagnosis is the time when they most need reassurance, listening. Thus, the healthcare professional must confidently play a reassuring role, enabling the family and patient to express their distress. It also evidenced the importance of the healthcare professional being true, telling them what the real situation is to the family and patient, using these data to reassure them, leading to cooperation and a better acceptance of treatment, and to participate on the decisions to be taken.

Concerning the role of the Social Worker, we noticed the importance of checking who is the ill person in the family, if he/ she is the only provider of the family, what is his/ her support network, or whether the patient is the provider or not, what is his/ her role in the family. The healthcare professional is responsible for investigating the routine of the family, identifying their real needs upon the vulnerability this disease imposes, and socializing these data with the healthcare team. In social workers' interventions, it is advisable to provide information about patients' rights and duties, hospital routine, internal and external referrals, making arrangements for providing medical treatment supplementation.

We also noticed the fear of recurrence leading to death, showing that healthcare professionals must explain about the disease's real prognosis. It is relevant to encourage patients and families to view this disease and its treatment as less threatening, being recommendable the indication of the families to pathology forums, patients' associations, and support groups built by people who had a cancer experience.

In some testimonials, the families reported that after they received the diagnosis, they stuck more together, evidencing that, after the impact of the news, they reorganized to deal with the disease.

Another factor observed was that some families expect that, after treatment, the patient will have a "normal" life, which not necessarily happens, requiring explanation by healthcare professionals about

the prognosis, not only in the sense of learning how to deal with restraints, but also to know its real potential. It is important to highlight that, in moments of crisis or upon a potential death of one of its members, families stick to religion and God to relief the stress generated by the disease.

Upon the reality lived by patients of the orthopaedic oncology group, a joint work becomes necessary, in a reciprocal relationship among the professionals of the team, making each professional

to overcome his/ her limits, and enabling contributions from other disciplines.

Therefore, a more careful view on the patient is necessary, following him/her upon a global basis, as an individual that must be included in a context of a family and social network. Thus, the family must be an ally of the social worker along the treatment, because family acts as a support within a patient's relationships, constituting a powerful source of care and protection.

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