University students' support to an NGO that helps children with cancer: Lessons learned in thirteen academic projects

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In this article we discuss thirteen academic projects undertaken by undergraduate and graduate students on the behalf of *Casa Assistencial Amor e Esperança-CAAE* (Home Care Love and Hope), a Brazilian NGO that helps poor families with children with cancer and other non-communicable diseases. Our intent is to share with the Action Research community our findings in an experience that involves co-operation between university students and an NGO that operates on behalf of children and their families. We present our findings by means of a systemic analysis.

Key words: Action Research cycles, systemic analysis, cancer patient support, collaboration between university and NGOs

Apoyo de estudiantes universitarios a una ONG que ayuda a niños con cáncer: Lecciones aprendidas en trece proyectos académicos

En este artículo discutimos trece proyectos académicos realizados por estudiantes de grado y posgrado, en beneficio de la Casa Assistencial Amor e Esperança-CAAE (Casa Asistencial Amor y Esperanza), una ONG brasilera que ayuda familias pobres con niños con cáncer y otras enfermedades no trasmisibles. Nuestra intención es compartir, con la comunidad de investigación acción, nuestros hallazgos en una experiencia que involucra la cooperación entre estudiantes universitarios y una ONG,

que actúa a favor de los niños y de sus familias. Presentamos nuestros hallazgos por medio de un análisis sistémico.

Palabras clave: ciclos de investigación acción, análisis sistémico, apoyo a los pacientes con cáncer, colaboración entre universidad y ONG´s

1. Introduction

In this article we discuss the lessons learned from a partnership between CAAE and the first author in projects undertaken between 2012 and 2015. During this time, the first author worked as professor of graduate courses from University of Sao Paulo (USP), following a project-based learning teaching strategy. During this period, his students accomplished thirteen projects on behalf of CAAE.

In 2015, the first author left the University of Sao Paulo to become a professor at the Federal University of Sao Paulo Campus Osasco (Unifesp-Osasco). He continued the partnership with CAAE at Unifesp-Osasco, using the project-based learning approach. His undergraduate students have accomplished two projects so far.

We begin by giving an overview of CAAE: explaining the origins and evolution of the institution and describing the work it does. Later we briefly describe the context of the graduate courses taught at USP and the undergraduate courses taught at Unifesp-Osasco. Next, we describe the partnership and projects accomplished. Finally, we discuss the lessons learned during the experience.

2. Background

Casa Assistencial Amor e Esperança (CAAE) is an institution created in 1990 by two sisters, Telma Dinelli and Roseli Dinelli. The story of its creation is quite touching. In their childhood, the sisters dreamed of working on behalf of people in need. They grew up and kept that dream. As the years passed, Telma married and had a daughter. In the late 1980s, her daughter developed health problems and the family went for medical advice. The doctors sus-

pected that she was developing leukemia. The two sisters worked together to find the best treatment for Roseli's daughter, visiting cancer hospitals and coming into contact with children with cancer from very poor families. These families had come to Sao Paulo from distant states all over the country, searching for free medical treatment.

In Brazil, the Ministry of Health has a system called *Sistema Único de Saúde-SUS* (Unified Health System). The goal of SUS is to provide free access to medical treatment for all Brazilians. SUS provides free medical support to 200 million people, offering help from single outpatient care to complex organ transplants. Unfortunately, the system does not work very well, especially for cancer patients.

There are few specialised public hospitals in Brazil that are able to treat cancer patients. The best of these hospitals are located in Sao Paulo State. People who live in distant states are told by their doctors to go to Sao Paulo and apply for treatment in public hospitals that belong to SUS. However, when they arrive in Sao Paulo, they find themselves in a problematic situation: the treatment can take months or even years, and, most of the families do not have sufficient money to rent a place to live in Sao Paulo or to buy food and medicine. Many such families decide not proceed with the treatment, returning to their original state. Others insist on the treatment, despite all odds. Some of them become homeless, living in public parks and facing much violence. Telma and Roseli were shocked by the stories that some families told them.

Fortunately for Telma's daughter her prognosis was positive: she did not have cancer. But Telma and Roseli decided that they should do something in order to help the children and the families that were suffering. They decided to create an NGO that would provide a safe place for the poor families who come to Sao Paulo searching for treatment for their children.

At that time, Roseli was a landlord of a small house. She asked her tenant to leave, and offered the house to shelter the families. CAAE began its activities on March, 15, 1990.

2.1 CAAE evolution

Over time, CAAE has evolved. In 1996, the CAAE representatives, with the help of several individual donors from the community and the Rotary Memorial Club of Latin America, were able to acquire with great effort, a better house, more appropriate to the NGO's activities. Nowadays CAAE provides not only a free and safe place to the families to stay, but also healthy food, medicines, dental care, transportation to and from the hospitals, psychological support and recreational activities for the children and their parents. CAAE provides a house where children can interact with other children in similar circumstances. The environment is cozy, and the rooms are full of colour.

The house was conceived to be a place where the children and their families could relax and obtain support to continue the treatment. The house has five dorms, one office, one room for psychological care, two small playgrounds, a laundry, dining hall, food pantry, small store (a bazaar that sells used clothes) and bathrooms. There is no luxury here: it is simply a modest house located in a poor Sao Paulo neighbourhood, called "Vila Miriam."

The mothers of the patients run the daily activities of the house. They cook, clean the house, and wash the clothes. Some of them also work in the store, helping the NGO to raise part of the resources they need.

It very is costly to maintain such a place: about five thousand dollars per month. On average, CAAE lodges 30 people per month (fifteen children with their mothers). While some families stay for only a short time, others stay for years. It all depends on the kind of treatment the children are receiving.

Nowadays the CAAE management team has 10 people (Telma and Roseli's families and friends). The majority of institution resources come from individual donors. CAAE also regularly promotes fundraising events.

In 2011, the first author met Telma's son, Rodrigo, an MBA student from the University of Sao Paulo enrolled in a Project Simulation course taught by the first author. Before explaining how the partnership developed, we will first describe the context of the graduate and undergraduate courses in which the project later played a major role.

2.2 The Project Simulation course: The graduate course context

From 2012 to 2014, the first author taught in two very similar MBA pro-grammes at the University of Sao Paulo. The first, called *Curso de Especialização em Gestão de Projetos-CEGP* (Project Management Specialization Course) was designed to provide management concepts to professionals working in engineering, and in administration in general. The second, *Curso de Especialização em Gestão de Projetos de Tecnologia da Informação-CEGP TI* (Information Technology Project Management Specialisation Course) was aimed at professionals who work in the information technology field. The MBA programmes were very similar: core project management courses were given in both programmes. There were few courses specific to each programme. Project Simulation was offered in both MBA programmes as the final course, following a project-based learning approach.

During the MBA programmes, the students learn the basics of project management: project planning, project execution and control, risk manage-ment, communications management, project finance and so on. In the Project Simulation course, the students are challenged to work in teams performing real projects on the behalf of NGOs that help people in vulnerable conditions (elders, orphans, victims of violence and so on).

The main objective of the course was to provide the students with hands-on experience in project management. The students were working profes-sionals, with employment experience of at least five years. Many of them were working in large corporations and had a well-established work net-works. Their ages ranged from 28 to 45 years, and many of them had practi-cal experience in project management field.

In this course we worked in partnership with several NGOs and public in-stitutions; thereafter, these NGOs became permanent course partners. The course dynamics work in the following way: the course partners present their needs to the students. The needs are diverse: some partners need equipment: computers, sofas, refrigerators and so on; others need clothes, food, toys, children's books. Sometimes the partners need help in order to repair their facilities (painting walls, replacing windows, repairing floors, and so on). Sometimes they need help to develop websites, databases and managerial systems. We call these needs *project themes*. The students work in groups (an

average of five members) and select one project theme from one NGO. In each class we had an average of 30 students; therefore on average six academic projects were accomplished in each course.

The students have roles and responsibilities. They have freedom to define their roles based on the project characteristics. For example, in a project that involved fundraising activities, a group might have one student acting as project manager, another student managing fundraising, other student in charge of project acquisitions, another one managing donations from companies, and one student responsible for communication with the stakeholders.

2.3 The project management course: The undergraduate course context

As described previously, by the middle of 2014 the first author left the University of Sao Paulo (USP) and began to work as a professor at Unifesp-Osasco, where he was in charge of teaching an undergraduate course entitled Project Management. Unlike the USP course, the students in this course had not had any experience in the project management field. In this course, the professor was supposed to teach them the basic concepts of project management.

Obviously, there is a big difference between the profile of graduate students and that of the undergraduates. The undergraduate students are quite young, ranging in age from 17 to 22 years. Many of them have neither work experience nor practical experience in project management. However, in spite of the differences in student backgrounds, the professor decided to follow a teaching strategy similar to the one he had used previously, in graduate programmes of USP.

The course was also structured following a project-based learning framework. Therefore the students also worked in small teams in order to accomplish real-world projects. The same NGOs that had worked with us in USP courses were invited to work with in Unifesp-Osasco. Casa Assistencial Amor e Esperança (CAAE) was one of the NGOs.

3. Theoretical framework

We follow Action Research as our research method. Although some authors point out that there is not yet a broadly established definition to Action Research (Altrichter, Kemmis, McTaggart, & Zuber-Skerritt, 2002), it seems there is a consensus of what the main characteristics of Action Research are.

According to Huang (2010, p. 93):

> Action research is an orientation to knowledge creation that arises in a context of practice and requires researchers to work with practitioners. Unlike conventional social science, its purpose is not primarily or solely to understand social arrangements, but also to effect desired change as path to generating knowledge and empowering stakeholders.

In addition, Thiollent (2005, p. 91) stresses the importance of the involvement of the all participants in Action Research activities in solving problems, sharing knowledge and learning during the process. Vickers (2005) ponders that by doing so, the Action Researchers may contribute to the improvement of human conditions. Aligned with Vickers, Bradbury (2015) also stresses the commitment that Action Researchers should have in minimising suffering and injustice, thus creating a positive impact on society.

Other researchers list the core features of Action Research as follows (Brydon-Miller, Greenwood, & Maguire, 2003): commitment to democratic social change, the integration to theory and practice, the relationships for learning and action.

Engel (2000) emphasises that Action Research involves cycles of action and reflection, and that Action Researchers should constantly reflect upon the impacts of their interventions. A typical Action Research cycle develops through four steps (Burns, 2007): planning, acting, observing and reflecting.

During our courses, we carefully plan the interventions the students make; the students carry on the intervention (under our guidance); we observe the consequences of such interventions and reflect on what we learned in the cycle. What we learn guides us to improve the process in the following cycles.

In our Action Research work, we (professors and university students) were committed to an institution that helps poor families who have children with cancer. The collaborative work involved two universities, both graduate

and undergraduate students, the NGO representatives, and the families. The students' projects helped to minimise the financial stress that the NGO was facing, providing them part of the resources they needed. Taking care of cancer patients is not an easy task. Researchers (McGrath, 2001; Payne, Smith, & Dean, 1999) report that a family caregiver suffers a considerable amount of tension and anguish while taking care of the patients. According to other researchers (Chesney, Chesler, & Abrigo, 1990, p. 1) cancer has been labelled "a family disease" because it invades not only the patient's life, but the lives of all those close to him or her. Adding to psychological problems, parents of children with cancer can also face financial problems, since the costs involved in the treatment often exceed their resources (Grahn, 1996). That was the scenario of our study. The families were very poor, having almost no resources to use to treat their children.

Parents of children with cancer usually seek the social support of their relatives and friends, along with that of members of specialised medical and community agencies (Chesler, 1984; Chesney, Chesler, & Abrigo, 1990). Research discusses the role of this social support to children and adolescents with cancer (Woodgate, 1999; Ritchie, 2001). Physicians, nurses, health care professionals, parents, schools and peers play an important role in providing support to the patients (Suzuki & Kato, 2003). Ribeiro (2012, p. 12) points out:

> NGO participation is particularly critical in those countries where no public funds through the government are available for medications or social support for the families of children with cancer. Typically, these NGOs provide shelter, food, and transportation for patients and families, and they purchase medications and other services.

NGOs can play an important supportive role. NGOs can help to create an environment that helps children to interact with others in similar conditions, therefore allowing them to make friends and enjoy social activities. Researchers (Enskär, Carlsson, Golsäter, Hamrin, & Kreuger, 1997, p. 25) stress:

> The health care personnel also need to involve the parents as well as create possibilities for the children to maintain friends, activities, and school. Finally the health care personnel need to supply equipment and pastimes suitable for children.

The NGO actions can be understood in a broader context. They can also contribute to the improvement the patients' quality of life. Hinds (1990, p. 290) points out other factors that impact the children's quality of life:

> Nurses can be most ware of the quality of life for these pediatric oncology patients by ascertaining their desires (present and future), recognising any existing gaps, and assisting these children and adolescents in taking reasonable approaches for diminishing the size of those gaps.

CAAE has helped to improve the children's quality of life by understanding their needs and providing, whenever was possible, the necessary support. However, the amount of available resources they have to do so is limited. The partnership between CAAE and the university is a creative way of obtaining the necessary support. In fact, it is a win-win relationship.

Moreover, partnership with NGOs and public institutions can create several educational opportunities to the students. Vernon and Ward (1999, p. 36) point out that many in higher education are recognising the power of partnerships between campuses and communities.

But how do we make this partnership work in a practical way?

One good way is to make the students and the community partners work together in well-structured projects, following a project-based learning approach (Eyler, 2002; Lee, Blackwell, Drake, & Moran, 2014). According to Savery (2015, p. 10):

> Within the project-based learning approach, learners are usually provided with specifications for a desired learn end product (build a rocket, design a website, etc.) and the learning process is more oriented to following the correct procedures.

During our Action Research, the students developed several projects on behalf of CAAE, each project bringing systemic consequences. Action researchers (Flood, 2010; Coghlan, 2002) are interested in studying the systemic impacts of their actions. Some researchers calls systemic Action Research (SAR) an approach that combines system thinking concepts with Action Research (Vasstrøm, Christensen, Sriskandarajah, & Lieblein, 2008; Burns, 2007; Ison, 2010; Burns, 2014). Vasstrøm et al. (2008, p. 104) argue that:

> "the systemic perspective that makes meaning of the complex entirety of the situation, helps to construct the inquiry process, and emphasises the critical reflection on the affects of change in relation to the boundaries of the situation."

Our Action Research has this systemic perspective. Each project we developed was a systemic intervention that brought several results, including improvement in CAAE's ability to attend to its patients, the enhancement of the patients' environment, the honing of the students' project management skills, and the increase in knowledge sharing between all involved.

In the next section we describe our findings by means of a detailed systemic analysis, which allows us to understand the research outcomes.

4. Methods

We performed Action Research cycles within each course and between courses. In this section we detail our method.

Action research cycles activities for each course

In each course, we perform Action Research cycle every two weeks. We follow the traditional Action Research steps: planning, developing actions, observing and collecting results and reflecting (Figure 1). In so doing, we try to assure continuous improvement of on-going courses.

For each course, we plan the course two weeks before the course begins. During this period, the professor interacts with CAAE, asking its to define its needs for the project themes. During the first fortnight, the students interact intensively with CAAE, visiting its facilities and understanding the projects' requirements. We observe the students' actions and results. We also ask the students to create a project blog, making it easier for us to collect project data. At the end of the fortnight, the professor sets up a project status report meeting. Each team presents to the others the actions taken during the period and the management plans created. During the meeting there is intense knowledge sharing; the students share their findings and the professor gives guidance about the projects.

Figure 1:   Ensuring continuous improvement for each course, in two weeks' Action Research cycles
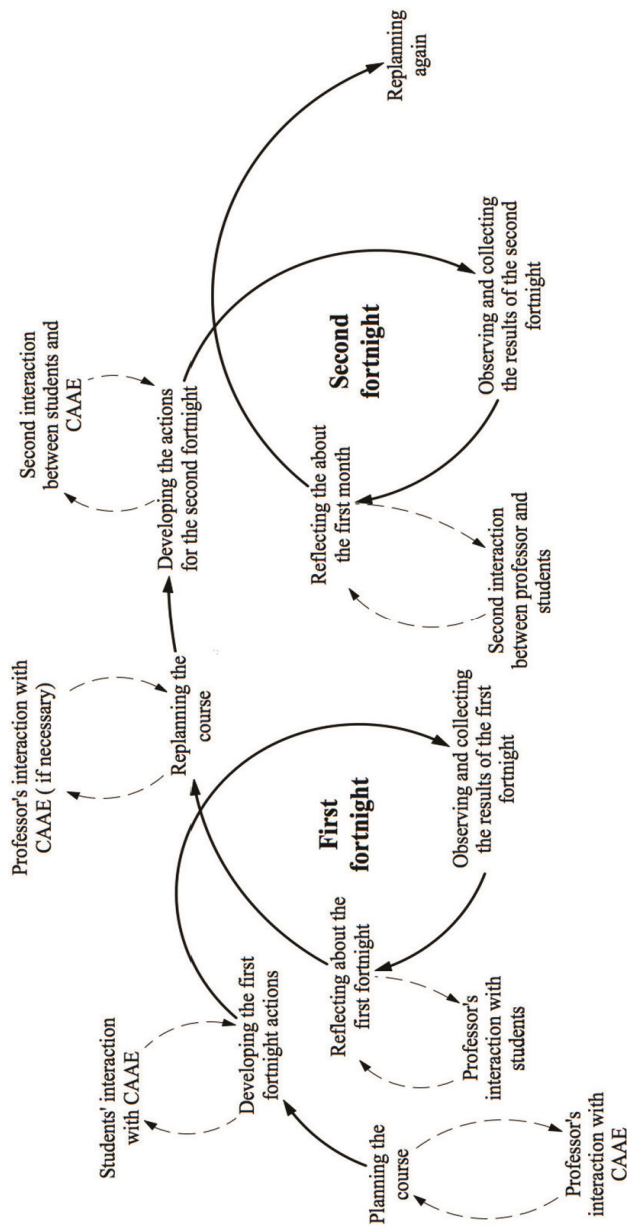
Based on these reflections, there is sometimes a need to re-plan the course activities for the next fortnight. We try, during each course, to adapt the course content to the students' needs. Sometimes, during the re-planning, we need to interact with CAAE, in order to obtain insights into what has happened during the period.

The course moves on to the second fortnight and the Action Research cycle repeats itself. This looping enables us to perform course adjustments during the course development.

At the end of the course, we invite CAAE (and other NGOs we are working with) to the final status report presentation. In this meeting the students present each project's results and the lessons learned, during which there is an intense knowledge sharing between all participants.

Action research cycles activities for the sequence of courses

At the end of each course we reflect on what we have learned during the entire period (Figure 2). Whenever we feel that our findings may be of interest to other researchers, we make an effort to publish them in peer-reviewed journals. We also take actions to share our findings with our community partners, either by promoting workshops with them or publishing subjects of interest to the community partners on our course website. Recently the professor participated in radio and television programs where the project results and findings are discussed.

Based on what we have learned in previous courses, we plan the next one. We develop the course, observe the results achieved and reflect again. We can thus evaluate the efficacy of our educational approach, see what has worked and what has not. We replace the old processes with improved ones, assuring continuous improvement of the course method and the Action Research activities.

Figure 2:   **The Action Research cycles led to continuous course improvement**
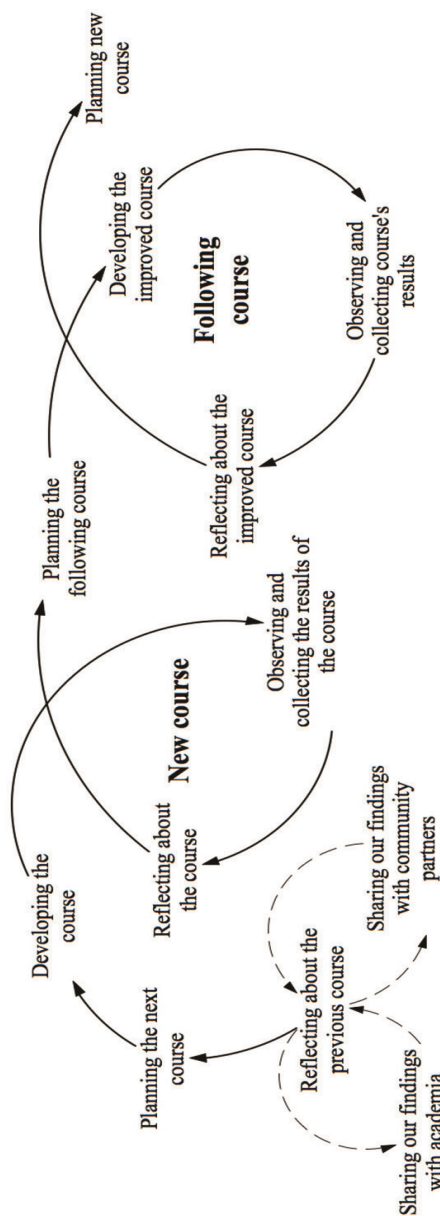
5. Results

In this section, we briefly describe the projects accomplished by our students in the last four years. As stated earlier, in 2011, one of our students, Rodrigo, told the professor about the work of CAAE. He suggested that CAAE could join the group of NGOs, becoming a new course partner. In 2012, our partnership with CAAE began. Table 1 brings the results from projects developed from 2012 to 2015. The 13 projects ranged from appliance acquisition to facilities reform. In gross numbers, we can estimate that the projects brought something between 7,500 to 15,000 dollars to CAAE.

Table 1:   Project achievements

Year/ Quarter	Project achievements	Student's fundraising strategies
2012, 1Q	Acquisition of air conditioner, refrigerator and microwave	Fundraising party and donations campaign.
2012, 2Q	Acquisition of hangers, mannequins and organizing boxes to CAAE's bazaar.	Raffles.
2012, 3Q	Acquisition of an acrylic lobby logo panel	Donations from small companies
2012, 4Q	Acquisition of sofas	Raffles.
2012, 4Q	Acquisition of classroom projector, notebook and a network of five computers	Donations from an international school
2013, 1Q	Acquisition of a TV	Raffles
2013, 1Q	Acquisition of a refrigerator	Raffles
2013, 2Q	Website development	There were no fundraising activities involved.
2013, 2Q	Acquisition of wood fired pizza oven and sink	Fundraising party and raffles.
2013, 3Q	Fixing the walls and buying plastic chairs and tables	Raffles
2014, 1Q	Painting the house	Donations from small companies and raffles
2014, 2Q	Baby stroller acquisition	Selling candies.
2015, 1Q	Acquisition of 100 children's' books	Donations and raffles

6. Discussion

We will discuss our Action Research in systemic perspective, analysing the multiple consequences of our actions (Figure 3). With the discussion we aimed to examine the results into a broader context, sharpening Action Research perspective.

6.1 Systemic analysis

Over the years, the number of successful projects has increased. This has led to an increase in material donations. Some of donations (such as the computer network) have increased the communication between patients and their families, which in turn has helped strengthen family bonds, thus reducing the stress of the patients and contributing to an increase in the patients' quality of life. Other material donations (such as sofas, TV, books) have increased the patients' comfort, further contributing to the increase in the quality of life of the patients. Some projects have led to the enhancement of CAAE facilities (such as the small repairs, painting, and acquisition of a refrigerator) , which has improved the quality of service provided by CAAE to the patients. Some projects (such as the bazaar's improvement, the pizza oven acquisition and the website) have improved the ability of CAAE to obtain resources by themselves, selling clothes and pizza. The website also helps to solicit donations. Therefore it leads to increase in the amount of resources saved. These savings increase CAAE's capacity to attend to its patients, which leads to an increasing in the number of children they are able to support. The sum of all these effects ultimately brings benefits not only to the patients, to their families, and to CAAE, but to the whole society. We name this dynamic as "Bringing benefits to society" (Figure 3).

The benefits generated have motivated the professor to take even further actions in order to publicise the projects' results, the project-based learning techniques used and our Action Research approach. He does so in three different ways, aiming at different audiences. The first audience is academia. He and his research group are publishing articles that discuss their findings, hoping that by doing so, other professors will become incentivized to undertake similar work. The second audience are the NGOs he has worked with.

Figure 3:   The systemic effects of our Action Research

He has presented small workshops in order to share the experience among the participants. The third audience is the broader community, whom he has reached through radio and television interviews. Those combined actions increase the amount of knowledge shared. Sharing knowledge impacts the course quality: as the years pass, the students receive access to a better course support material, with more peer-reviewed articles describing different aspects of the research. The radio and television interviews are also used as complementary course material. We name this dynamics "Sharing experiences" (Figure 3).

The increase of the number of successful projects has impacted the number of students interested in taking our course. Course alumni have passed the word to students from different departments within the university, sparking interest in the course and developing its reputation as a high-quality course. This in turn has led to an increase in the number of students enrolling. With more students, we are able to develop more projects. We name this dynamic "Bringing more Students".

As the number of successful project increases, the number of lessons learned also grows. We have learned more and more about the use of project-based learning techniques and Action Research, which contributes to course improvements. Along the years the course quality increases, what contributes in making the students more motivated to work on project activities. We named this feedback loop as "Continuous improvement". Observe in Figure 3 that continuous improvement dynamics reinforces the dynamics explained previously.

Finally we can say that the resources saved by CAAE have increased their interest in participating as a client in subsequent courses. The CAAE participation enriches the diversity of project themes offered to our students, contributing to the enhancement of the course quality. We name this feedback loop "CAAE commitment".

We consider that in Action Research like this, involving NGO, students and universities, it is important to bring the voices of the other participants (CAAE's representatives, patient's family members and students) into the discussion. In so doing, we are able to capture insights that could complement our systemic analysis.

6.2 The voices of the participants

We interviewed the Telma (the CAAE representative), Flavio (the student who was the project manager of one of our projects) and Juliana (the mother of one of our patients). Telma told us:

> The projects brought by the professor, and accomplished by graduate students from UNIFESP and undergraduate students from (USP), are essential for the maintenance and improvements of CAAE. The projects invigorate us, the CAAE directory board. The partnership helps us to improve the assistance we give to people in need. The resources we save with the projects' help us to do more and better, improving the quality of the assistance that we can offer to our patients.
>
> The projects also gave the students new perspective; they became more conscious of their importance as citizens; and the projects made them able to contribute to the improvement of the conditions of the less fortunate people. The projects made them aware of the importance of their role, as future leaders of social change.

Flavio shared with us his thoughts:

> The professor had an excellent idea in choosing to work in charitable projects. Many of our classmates work on information technology projects. When the professor presented us the idea of developing the project on behalf of charitable organisations, it motivated the students, because it was new experience from many of us. We had the opportunity to put into practice all the theory that we have learned during the MBA program. Working with real client improved the team's motivation: we wanted to go beyond the project's requirements! The seeds of doing good were planted in each and every student.

Juliana, who currently lives in the CAAE facilities, said:

> We depend on the CAAE, but CAAE also depends on the University. This is truly a chain of goodness that gives support to all involved.

Analysing the voices of our partners, we saw that our Action Research may be bringing an interesting and unforeseen result: a change in the mental models of all involved. Telma, who was involved in all of the projects, stressed the transformation in the students' mindset, becoming more con-

scious citizens. Fabio's comments are aligned with that. Juliana emphasised the systemic aspect of our intervention, bringing benefits to all involved.

7. Conclusions

We can say that within our Action Research we achieved significant impacts that led to social changes in the lives of the cancer patients and their families. Our students and CAAE representatives also felt the social impacts. We believe we integrated theory and practice in a practical way: that there was a clear relationship between action and learning.

With a systemic analysis we were able to make explicit the ripple effects of our actions. We could see that, as we were undertaking systemic interventions, all our actions and consequences were interconnected.

The students' projects brought educational benefits to them by enabling them to put into practice project management concepts in real-world projects. This action also empowered CAAE, improving its capacity to obtain resources by themselves and improving the quality of the service they provide to the children and their families.

It has been a unique educational experience for all involved. We hope this article will encourage those at other universities to engage in similar projects that can benefit both students and the larger community.

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