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A capacity-building project for the establishment of a hematopoietic stem cell transplant (HSCT) center at the Hiwa Cancer Hospital (HCH), Sulaymaniyah, Iraqi Kurdistan: A look inside professional barriers and gender issues

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Summary. A capacity-building project has been developed by an Italian team in the Region of Iraqi Kurdistan since 2015, to establish a hematopoietic stem cell transplantation (HSCT) center at the Hiwa Cancer Hospital, in the city of Sulaymaniyah. The Italian Agency for Development Cooperation (AICS) supported the project. This approach was successful thanks to the voluntary collaboration of many experts in the fields of adult and pediatric hemato-oncology, transfusion medicine, apheresis, infectious diseases, nursing, cell manipulation, molecular biology and biophysics coming from many Italian institutions. A first autologous transplant was successfully done in June 2016. Afterwards, many other autologous transplants were done in different diseases, and 3 months later a first β-thalassemia patient was allografted from her HLA-identical sister, opening the way to transplantation for malignant disorders as acute leukemia. To date, the team has conducted 29 autologous and 7 allogeneic transplants, remaining the only one in the region to perform this procedure. The project is now evolving into an extensive hematology and pediatric onco-hematology clinical and laboratory reassessment. Besides technical and medical aspects, we investigate here the main obstacles encountered with the local professionals, due to language barrier (rare) or to a different tradition or lifestyle, the most critical being direct patient care, nursing rotation, use of proper clothes and uniforms, admission rules and staff interactions. Some issues about the patients' perspective are also raised. The capacity building approach with on-site training is apparently more effective than traditional methods, and current limitations for immigration policies further encourage this approach.

Key words: Kurdistan, transplantation, capacity-building, gender.

Un progetto di capacity building per la costituzione di un centro per il trapianto di cellule staminali ematopoietiche all'Hiwa Cancer Hospital, Sulaymaniyah, Kurdistan iracheno. Uno sguardo all'interno delle barriere professionali e dei problemi di genere

Riassunto. Un team italiano ha sviluppato un progetto di capacity building nel Kurdistan iracheno fin dal 2015, per creare un centro per il trapianto di cellule staminali ematopoietiche presso l'Hiwa Cancer Hospital, a Sulaymaniyah. Il progetto è stato sostenuto dall'Agenzia Italiana per la Cooperazione allo Sviluppo. Questo approccio è stato un successo grazie alla collaborazione volontaria di molte persone esperte nei campi dell'emato-oncologia pediatrica e per gli adulti, della medicina trasfusionale, dell'aferesi, delle malattie infettive, nel nursing, nella manipolazione cellulare, della biologia molecolare e della biofisica, provenienti da molte istituzioni italiane. Nel giugno del 2016 è stato eseguito con successo un primo intervento di trapianto autologo. Successivamente sono stati eseguiti molti altri trapianti autologhi per diverse patologie. Tre mesi dopo una paziente con beta-talassemia è stata sottoposta a allotrapianto dalla sorella con HLA identico, aprendo la strada ai trapianti per disturbi maligni come la leucemia acuta. Finora, il team ha eseguito 29 trapianti autologhi e 7 allogenici, ed è rimasto l'unico, nella regione, a eseguire questa procedura. Il progetto si sta ora evolvendo con una estesa rivalutazione clinica e di laboratorio in ematologia e oncoematologia pediatrica. Oltre agli aspetti tecnici e medici, qui analizziamo i principali ostacoli incontrati con professioniste e professionisti del posto, dovute a (rare) barriere linguistiche oppure a tradizioni e stili di vita diversi: gli ostacoli più critici sono stati l'assistenza diretta delle/dei pazienti, la rotazione del personale infermieristico, l'uso di vestiti e uniformi appropriati, le regole per il ricovero e le interazioni tra i membri dello staff. Sono emerse anche problematiche relative alle prospettive delle persone ricoverate. L'approccio del capacity building con training sul posto sembra essere più efficace dei metodi tradizionali, e le attuali limitazioni nelle politiche dell'immigrazione incoraggiano ulteriormente tale approccio.

Parole chiave: Kurdistan, trapianto, capacity-building, genere.

Introduction

A capacity-building project, developed by an Italian team in the critical Region of Iraqi Kurdistan since the year 2015, had the aim to establish a hematopoietic stem cell transplantation (HSCT) center in a specialized oncology institution, the Hiwa Cancer Hospital, in the city of Sulaymaniyah. The project was successful, and in the last six months a new project was also launched aimed at improving the standard of care of adult and pediatric acute leukemia. We will describe the different phases of the HSCT project, from the initial steps to fund raising, from the establishment of an on-site Italian team to the dramatic incidental fire that destroyed the center, from its reconstruction to the first autologous transplant and clinical standardization of transplant procedures. We will also discuss some dif-

ficulties encountered during the project affecting daily work and relationships with the local staff and with patients, in part due to tradition or religion, and in part to political issues. These aspects include some gender-specific issues, that may often constitute a major obstacle to the development of a modern specialized activity

HSCT, either autologous or allogeneic, is an effective treatment for many acquired hematologic disorders[1] as acute leukemias and malignant lymphomas, and for some inherited conditions as β-thalassemia major and sickle-cell disease[2]. These inherited disorders are critically frequent in some geographical areas: β-thalassemia in the Mediterranean basin and Middle East countries, sickle cell disease in the sub-Saharian area. Unfortunately, due to economic and/or political constraints, not all these countries and geographical areas have enough resources and expertise to establish a HSCT program. On a global basis, over 70.000 procedures are currently performed every year in more than 70 countries[3]. In countries where the HSCT technology is not available, a considerable number of patients is forced to emigrate when a transplant is needed, with heavy social and economic problems for their families and governments.

Iraqi Kurdistan (Figure 1) is an 8 million population region north of Iraq that gained autonomous status in 1970 following an agreement with the Iraqi government. The region has considerable oil and mineral resources. However, due to the current conflict with the Islamic State, with more than a million Syrian and Iraqi refugees seeking shelter in the Kurdish territory, and also due to the fall of oil prices, in 2012 the country entered a deep economic crisis that also involved the health system. The capital is Erbil, official languages are Kurdish, Arabic and Turkoman. Religion is Islam, with a predominance of the Sunni current, but Christianity and Yazidism are well represented minorities. Gross domestic product per capita was 7,000 USD in 2015, but this estimate is far from being reliable. Though considered to be a democracy, with 3 main parties sitting in the parliament, Iraqi Kurdistan is dominated by a limited number of families holding the resources of the country as well as political power.

The Italian Ministry of Foreign Affairs, through the Italian Agency for Development Cooperation (AICS), is regularly supporting the Kurdish population also with health and social projects. Several NGOs are currently present in the country, doing excellent work in specific areas in particular with refugees from Syria and Iraq, and with war victims.

History of the project

In 2015, a delegation of the University Cooperation Institute (ICU) came back from Iraqi Kurdistan after a fruitful visit to the Hiwa Cancer Hospital (HCH), city of Sulaymaniyah, south of the Kurdistan Region (Figure 1). This is reported as the first oncology center in Kurdistan and second in the whole Iraq. Most importantly, the HCH was equipped with a brand new, positive pressure, HEPA filtered air, sterile unit, which had been previously donated by the Tuscany Region on a cooperation project, but had never been started, for a number of technical and organizational reasons. Despite this, a huge number of children with thalassemia major where regularly sent to India, Turkey or Jordan to receive a transplant from their HLA-identical sibling donors, with heavy social and economic problems for their families and the government. To be more precise, in 2015 the government assigned a budget of approximately 6 million dollars/year for 3 consecutive years to the thalassemia transplants program abroad (India and Turkey).

Ignazio Majolino, on behalf of ICU, visited the HCH for the first time in August 2015. During this exploratory mission aimed at assessing the feasibility of a transplantation project at the HCH, an appropriate grid, already successfully employed in other circumstances, was applied to verify the adequacy of the hospital itself and of all the necessary services involved in HSCT. At the end of the visit, the feasibility of the project was confirmed. The second step was designing the project. A capacity building project was submitted by ICU following a call by the Italian Ministry for Foreign Affairs – General Direction for Development Cooperation, and it was approved and funded in December 2015.

Capacity building is the process by which individuals, organizations, institutions and societies develop abilities to perform functions, solve problems and set and achieve objectives[4]. Specifically, in the project we developed at the HCH, this methodology addressed the implementation of a sustainable HSCT program through the collaboration with experts in the field of adult and pediatric hemato-oncology, transfusion medicine, apheresis, infectious diseases, nursing, cell manipulation, molecular biology and biophysics coming from different Italian institutions. All of them were volunteers. A steering team planned the intervention, but unfortunately, at the end of 2015 an incidental fire developed on the top of the HSCT building with involvement of the transplant center itself. Despite all the efforts and following the intervention of the Italian diplomacy in Iraq, the restoration works started in April 2016, and were finished in July. Meanwhile, the Italian team landed in Sulaymaniyah, and decided to start the training program, with an intensive course of lectures and seminars to local personnel, the implementation of the coaching method for nurses and doctors, and the editing and approval of the most important HSCT protocols following some of the indications of the Joint Accreditation Committee ISCT EBMT (JACIE) standards[5]. All the activities were planned in agreement with the HCH direction, and local personnel was fully involved, keeping in

Figure 1. Iraqi Kurdistan is a 8 million population autonomous region north of Iraq. The capital is Erbil, but our intervention was based in Sylaymaniya, the southern province, at the Hiwa Cancer Hospital, the main onco-hematology institution in that area.

Figure 2. The first patient undergoing autologous transplantation with an Italian staff nurse. Disposable gowns were initially worn by the patients in the transplant room.

Figure 3. The first thalassemia patient undergoing allogeneic transplantation is a 4-year-old girl who did very well and is now free of disease 10 months after the transplant.

mind that all the necessary knowledge had to be transferred within the 10-month duration of the project. The lack of a priority scale, the absence of teamwork as well as of appropriate methodology for problem-solving, decision-sharing and quality management were identified as the main obstacles, and appropriate efforts were applied to remove them. A tendency not to establish a transparent and effective responsibility tree was another factor, but following repeated attempts, a responsibility tree was designed and finally accepted. An extensive re-evaluation of the hospital critical areas was performed with special attention to microbiology, HLA typing and hematology lab, apheresis unit, pharmacy and cell manipulation. A written infection control policy was developed, and a separate area of the hospital was identified that enabled the temporary start of an autologous transplant activity[6], until the final completion of the restoration works. The process of stem cell mobilization, collection, counting, and cryopreservation was rapidly set up[7], and the clinical transplant program officially started.

In fact, a first autologous transplant was successfully done in June 2016 in a 40 y-old man with multiple myeloma (Figure 2). Afterwards, many other autologous transplants were performed also in patients with Hodgkin lymphoma, non-Hodgkin lymphoma and acute myeloid leukemia. Meanwhile, the pediatric team (Attilio Rovelli, Marta Verna) that was in charge of the allogeneic transplant program in children, brought to transplantation a first 4-year-old girl with β-thalassemia major, who received the bone marrow from her HLA-identical, 14-year-old sister (Figure 3). The transplant was successful, and opened the way to subsequent allogeneic transplants, not only in thalassemic children, but also in adult patients with acute leukemia[8,9]. Up to now, the team has performed a total of 29 autologous and 7 allogeneic transplants; the latter were almost exclusively children with thalassemia. A first retrospective evaluation of the stem cell collection, manipulation and reinfusion has been recently accomplished and is now submitted for publication[10]. With this initial experience the HCH transplant team was admitted as full member in the European Blood and Marrow Transplant Group, the institution that leads HSCT programs, manages a registry and promotes clinical research (https://www.ebmt.org/Contents/Pages/Default.aspx).

At the beginning of 2017 the project funding managed by ICU was ended, but all participants agreed that it was necessary to prolong our coaching activity for transplants at the HCH and to extend cooperation to the field of adult and pediatric hematology, so AVSI (International Voluntary Service Association) successfully

Figure 4. A staff nurse with typical hijab in the new transplant center.

Figure 5. The Kurdish-Italian team in the surgery room during a bone marrow harvest procedure.

applied for a new project (Valentino Conter, Scientific Director) which was approved and funded allowing the prolongation of our cooperative effort at the HCH.

Nursing job and its barriers

We will now describe the main obstacles encountered with the local professionals, not always easy to understand and to cope with, due to language barrier (rare) or to a different tradition or lifestyle.

Nursing was introduced in Iraq in 1933 and according to the Iraqi Ministry of Health, there are currently no more than 40,000 Iraqi nurses, 75% of them men[11]. Over the last five years, women have been increasingly willing to work in this sector. However, the transplant nursing team at the HCH currently includes 22 staff nurses and 3 nurses with special duties (infection control, pre-transplant unit and outpatient clinic), led by a Head Nurse. In the transplant center nurses are mainly women (92%), with an average age of 23 years (Figure 3).

Figure 6. The Italian team at the Hiwa Cancer Hospital during the visit of the Italian Ambassador in Baghdad, Dr Marco Carnelos (center) with the Scientific Advisor of the project, Prof Ignazio Majolino (with bow tie) receiving an award from the local Thalassemia Society.

In the planning phase of the project, we noticed the absence of policies and documents regulating nursing activity. This was in line with the general reports on nurses in Kurdistan. Health authorities are concerned about nurse training, absence of defined nursing competencies, roles and responsibilities. This results in lack of care and inefficient use of nurses in clinical care[12]. Job description and nursing care plans were identified as possible solutions to these gaps[12]. A committee including several hospital authorities and staff representatives was established and approved a final document. However, working alongside Kurdish professionals, the Italian nursing team immediately identified some critical aspects, mostly related to gender issues.

1. Direct patient care. Patients in the transplant unit have a high risk of severe infections, due to neutropenia and immunosuppression induced by the conditioning regimen[13] so they should maintain good personal hygiene, especially perineal, to minimize the loss of skin integrity and risk of infections. A routine inspection of the critical skin sites (i.e. perineum, intravascular access sites) is recommended[13]. Moreover, the daily skin inspection should be performed after transplantation to identify graft-versus-host disease, together with regular lubrication of the skin. Even if strong evidence supports direct care of the patients, Kurdish nurses prove reluctant to perform personal hygiene and close inspections of the patients. These activities involve touching the patient's body, which is considered to be "strange", especially in case of a gender difference. Kurdish nurses are not used or educated to do this in any clinical setting. As in other low or middle resource countries, hospitalized people are cared for by family caregivers, who almost permanently live with them in the hospital on a 24/7 basis.

Caregivers provide intimate care, like personal hygiene and clothes change. The first draft of the Nurse Job Description (*Skills and Competencies* section) included duties that should have been embedded in the profession itself, but the need to specify them was perceived:

"Provide patient hygiene and personal care; Collect culture swabs (all kinds of swabs)" (HSCT Nursing Staff Job Description, 2016).

The document mentioned *"all kinds of swabs"*, referring to the rectal ones, particularly important in patients after transplantation because of the high risk of colonization by multi-resistant bacteria[14]. Nurses were deeply embarrassed by direct contact with people of different sex and even of the same one because of the intimacy implied by these activities. They strongly disagreed with these supposed duties (with no consideration for scientific evidence and rationale) and with the document itself. They refused to perform patient hygiene and personal care. The HCH general director, the Kurdish transplant unit Head Nurse and the Italian team discussed all the issues extensively, but the nurses remained oppositional and finally threatened to quit. The document was modified and currently states that nurses have to:

"Maintain hygienic and safe working environment in agreement with the healthcare procedures and patient personal hygiene (..)": *"to maintain"* instead of *"to provide"* as in the previous draft: this means that nurses obtained to have less direct involvement in the process.

"Manage pressure lesions": this includes skin care, with an intimate and direct contact (HSCT Nursing Staff Job Description, 2017).

All the HSCT Unit nurses now sign their own Job Description, as a confirmation of agreement.

2. Nursing rotation, gender implications. Nursing and medical activity in HSCT unit was based on a 12-hour or 24-hour rotation, including night shifts. At the beginning, with few patients admitted in the Unit, this schedule seemed to be functional, responding to the local personnel's needs. Over time, clinical activity in the unit increased, requiring professionals to devote more energy and attention. There was a high risk of errors and low performance because of lack of sleep and fatigue. As Italian team, we were not able to change doctors' rotation due to the low number of employees, but we worked with the nursing staff to make shifts shorter and to guarantee safer care. Therefore we set an 8-hour schedule, based on three shifts. This was a big issue for the nursing staff, especially for women: most of the nurses do not own a personal car and reach the hospital by bus or even taxi. In fact, as a result of a conformist view, it is considered "strange" for a woman to go around by herself during the night, maybe taking a taxi or public transport. The afternoon shift ending at 8 pm forced them to be in that situation, feeling uncomfortable and under judgment. However, the director of the HCH and the Italian team offered a proposal, as mediation for short shifts, with women sharing a car that took them to the hospital and back home for the afternoon and night, and most importantly, with transportation costs fully borne by the hospital. The reason why men did not support the rotation changes was deeply different. In fact, as mentioned above, Kurdistan has a financial crisis compromising perceived salary levels. Professionals employed in government institutions (as HCH) earn one third of what would be due. Nurses often have more than one job, to earn a decent salary. Male nurses were worried about the fact that the new rotation made it too difficult to combine two jobs, and, thus, earn more money. This shows that men are socially and culturally considered the ones in charge of earning enough money to support their families, while women contribute to their family life more with a domestic and maternal role. The introduction of the new rotation caused the resignation of 8 nurses out of 20, who did not want to share the new working hours. Needless to say, female nurses always share their night shift with other women as it is considered unethical to work overnight with a man.

3. Admission, clothes and uniforms. As the HSCT setting is particularly risky for infections and transmission through people attending the Unit (like staff and caregivers), isolation rules for transplant Unit were applied, to protect patients and improve their clinical outcomes. Kurdish personnel were used to routinely providing disposable gowns to patients (Figure 2). That was uncomfortable especially for women. We recommended that female patients buy and wear men's pajamas to be more comfortable for hospital life and care activities (i.e. daily clinical examinations, CVC management). After some reluctance, most accepted and found the 2-piece pajamas covered them better than a long dress.

Clothing became an issue for nurses as well. Nursing Job Description states:

"(…) a clothing uniform is provided. This should be obeyed". (BMT Nursing Staff Job Description, 2017)

Some female nurses were used to long jumpers or scarves to further cover their shoulders and lower arms but these had been forbidden because of infection control. In fact, during some procedures, these accessories contaminated devices and sterile fields, making the procedure risky for patients. We also managed the use of the hijab (Figure 4), the headscarf worn by many women, both for religious beliefs (as said in the Coran) and for cultural reasons. In Sulaymanya the influence of religion is quite moderate and it is not easy to find someone wearing full covering clothes. However, the hijab is common among Kurdish women. The ones who wear it believe in its meaning and we did not want or had the right to forbid the hijab in the Unit. We explained to the

women (both staff and patients) the infection risks associated with the hijab. We recommended that patients have a stock of clean hijabs in their hospital room and to wash them very often. We also asked nurses and patients to tie their hijabs so that the scarves would not lay on the shoulders or on the central venous catether dressing. This issue is completely solved: we had great collaboration from the staff and patients, who showed partnership, understanding and trust (Figure 5).

4. Staff relations and interactions. Looking at the transplant unit's staff, there is a high prevalence of women but the top positions are covered almost equally by the two genders. For example, the Head Nurse is a man, leading three female nurses with special responsibilities; the person in charge of the apheresis program is a woman and the director of the HLA lab (human leukocyte antigen) is a man. However, the fact that the most powerful and influential position within the clinical transplant unit (director of the HSCT program) is covered by a woman has some consequence for the program itself, with personal envies and oppositional behaviors leading to a low number of patients' referrals, as compared to what was expected. Considering other positions than the top ones, women are respected and well considered both by male colleagues and patients. According to nursing discipline, this could be due to the fact that it is historically a female dominated profession. However, female nurses still need to develop stronger self-confidence and professional independence. In the nursing team, men show more technical skills; they are more enterprising and resourceful, trying to be the ones performing difficult procedures as may be the lumbar puncture, bone marrow aspiration, stiches removal. This attitude allowed men to deliver a higher number of procedures, becoming more experienced. Conversely, even if it was clear that women had good abilities and knowledge, they were scared and hesitant to do things by themselves and they always needed to be at least two, even for simple procedures, as may be device dressing, to share responsibility and obtain support. We tried hard to empower female nurses, and that is why three women were given special duties. However, the work is still in progress.

Interestingly, a gender issue appeared during the Ramadan period, occurring twice a year. During this time, all the women in their menstrual period are allowed to suspend their fasting. The fact that male colleagues could have seen female nurses eating, was considered shameful by the latter: for one thing, they were not respecting a religious dogma and, for another, the men would know about their period. This is a simple and explicit demonstration of the disparity between the two genders in daily life, not related to the work field. Moreover, they are still not used to easily talk about their gender-related issues, which they view as intimate, indiscreet and not to be shared.

Medical doctors

There is much less about medical doctors and other graduate professionals. This is due in part to the fact that this professional area is much less influenced by religion and cultural traditions, due to better education, higher social class, frequent journeys abroad and better compliance with western style. However, in their community physical examination during consultation practice, as well as during the daily clinical round, is only occasional. This is obviously more pronounced between one gender and the other. The reported reason is that lab or image investigations are considered to be more accurate. At the beginning, when we were managing the consultation clinic in common with the Kurdish colleagues, the patients' physical examination was always considered a remote option, not a routine practice, and it was always up to the Italian professionals to do it or not. With time, and with experience accumulating in favor of routine physical examination, the Kurdish professionals now more often ask a patient to expose the abdomen or the chest for examination, though most often this is a very partial exposure, especially between different genders, and the information obtained is often minimal or even misleading.

Opposite to this is our feeling that "handling" the patients' body during physical examination or nurse maneuvers retain some special meaning, glamour or sorcery, and often patients show great gratitude and gratification for that. This is not surprising, and it is also part of the experience we gained in our context, especially in some rural areas of southern Italy.

The medical staff has significant problems in management. The lack of a priority scale, the absence of team work, the need for a problem-solving method and quality management where identified from the beginning as the main targets for our intervention. Professional education is adequate in technical terms, but this culture is often based on "the word of the master" more than on literature research and reading. The powerful instrument of Hinari, a WHO site that gives open access to thousands of scientific journals and books in medium-low income countries is seldom if ever employed. They rely on authority, the men's being always more influential than the women's.

The patients' perspective

It is more difficult to explore the patients' perspective, mainly due to communication issues, the great majority of patients being of low social class, possibly coming from rural areas, and speaking only Kurdish or Arabic. The interaction between volunteers and patients is most often mediated by local personnel. Though access to the

public medical care system is theoretically free of charge and there are no differences between genders, still a suspicion arises that some difference exists, at least in terms of referral.

We have recently analyzed the initial experience at the HCH[10]. Of the 27 patients given an autologous transplant between June 2016 and May 2017, 19 were male, and only 8 were female. Usually the rate is close to 1:1, in this case it is 2.3:1. It is impossible to conclude that there is a problem in the referral of women, and the next patients will give us an opportunity to clarify this aspect.

Conclusion

We show here the results of an Italian effort aimed at establishing a leading center for hematology and stem cell transplantation in the autonomous Region of Iraqi Kurdistan (Figure 6). As soon as the autologous transplant program was developed and finally established, also the allogeneic transplant program was started, and overall the program is now counting almost 40 transplants including 7 thalassemia patients. This activity is in progress and a new project is being developed, targeted at the diagnosis and treatment of pediatric leukemia.

To complete this new center in the Iraqi Kurdistan, the specific capacity-building methodology was adopted. At present, we have no evidence that on-site training is more effective than the traditional methodology, and what are the situations where it would be more appropriate. With all the current limitations for immigration policies, in the future more projects based on on-site capacity building will probably be developed, and more data will be available.

At the HCH, as Kurdish-Italian steering team, we had a unique opportunity to explore the professional, as well as the cultural context, and to direct personnel training and manage the laboratory and clinical protocols from the beginning of the activity. We conclude that excellent results can be obtained, even in difficult contexts, when a correct strategy – namely the capacity building method - is applied from the beginning of the program.

Concerning gender issues, the social, cultural and religious structure of the country gives rise to specific problems that make nursing, medical care and probably access to care more difficult than in western contexts. We are striving to cope with these different situations and look forward to support from the gender scientific community for suggestions and guidelines.

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