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Pain Management in Children with Cancer: National Surveys of Practices and Perceptions in Morocco

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Abstract

AIM: The aim of the study was to improve the quality of pain management in Moroccan pediatric oncology units, the Moroccan Society of Paediatric Haematology/Oncology initiated a national quality improvement project in 2014 with the support of the Lalla Salma Foundation for Prevention and Treatment of Cancer.

METHODS: To assess the current situation of pain management in Moroccan pediatric oncology patients, two cross-sectional surveys were conducted, involving patient/parental proxies and health-care providers'.

RESULTS: The first survey concerned 108 care providers from five institutions. The second survey covered 155 children with cancer from the five Moroccan pediatric oncology units. Among them, 145 reported suffering from pain, which patients/families attributed to the underlying cancer (n = 85), to procedures and treatment (n = 46), or to both the cancer and procedures/treatment (n = 19). Procedural pain was mainly related to lumbar puncture and bone marrow aspirate. The majority of patients/parents reported that pain negatively impacted their emotional, physical, and social functioning. The majority of parents requested further information and communication about pain management.

CONCLUSION: Both health-care providers and families of children with cancer in Morocco report need for pain management improvement, including in institutional and educational practices. This current baseline data have informed the development of our ongoing project including continuing education, training, and practice policies development.

Introduction

Pain is a common, subjective, multi-dimensional experience, and a major health problem among pediatric patients with cancer, especially in children who experience fluctuations in pain intensity [1]. In developing countries, many children still have advanced stages and incurable disease. A meta-analysis reports that 64% of patients with advanced stage disease or metastatic cancer will experience pain [2]. Sources of children's pain are both diagnostic and therapeutic procedures, as well as disease related but pain is markedly undertreated [3]. Pain intensity is recognized as one of the most clinically relevant dimensions of pain experience, more than one-third of cancer patients with pain, rated their pain intensity as moderate or severe [2]. Many barriers impede implementing a cancer pain strategy, including lack of knowledge about cancer pain and its management as well as culturally based beliefs and myths about cancer pain. Those barriers can be divided into three areas: The lack of relevant training to healthcare workers, the poor accessibility of essential pain management drugs, and the lack of health policies in support of palliative care development [4].

Morocco is a North African country with a population of 35,406,797 people. It is considered a middle-income country and ranks 126th out of 177 countries in the Human Development Index. Morocco ranks among the top 15 countries in the world in terms

of pace and momentum of progress on the Human Development Index. Morocco's per capita GDP is $2·769, with $202 per person spent on healthcare. There are approximately six physicians and 7.8 nurses per 10,000 people. The mortality for children 5 years of age or under is 30 2/1000 and life expectancy at birth is 74.8 years [5]. There are five principal units of pediatric oncology; two of them are in Casablanca, one in Rabat, one in Marrakech, and one in Fes.

The incidence of cancer in patients under 15 years of age in Morocco is estimated to be 1000 new cases per year. Most pediatric cancer patients are managed by public hospitals. Thus, they are highly influenced by the Moroccan public health system, which is now considering cancer management a priority. Since 2009, a new large Moroccan non-governmental organization (Lalla Salma foundation for the Prevention and Treatment of Cancer) was directly implicated in cancer care by providing anticancer drugs to all government-run oncology units [6].

Pediatric oncology in Morocco has improved because of successful initiatives like twinning partnerships that pair medical institutions in high-income countries with some of our institutions [7]. These programs were led especially with the Saint Jude International Children's Research Hospital in Memphis, USA, and by Morocco's participation in the French-African Paediatric Oncology Group [7], [8]

In 2002, focus groups were conducted with pediatric oncology nurses and physicians, to identify issues in managing pain in children with cancer [3]. In 2004, a program of policy research called my child matters was launched by the Sanofi Humanitarian Sponsorship Department (Paris, France) and International Union against Cancer (UICC; Geneva, Switzerland) in collaboration with a consortium [7]. The aim of this program was to establish adapted guidelines for practice policies for managing children's cancer pain in Morocco, the improvement of awareness, diagnostic, and therapeutic tools. The approach was national, multidisciplinary, and sustainable. Pediatric oncologists, surgeons, anesthesiologists, nurses, and psychologists conducted the program. Their missions were to identify the needs, to organize workshops, to produce documents for parents and caregivers, and lobbying to ease state regulation of prescribing opioids. A first patient survey was carried out in 2006 as well as some workshops and training courses but the pain management program stopped in 2009.

At present, managing pain in children with cancer is one of the priorities of the health authorities and establishes one of the elements of the politics of improvement of the quality of care and quality of life. This project answers the objectives of the National Plan of Prevention and Cancer Control supported by the Lalla Salma Foundation, in partnership with the Ministry of Health, to encourage research. Among these objectives: The reduction of the morbidity and mortality rate, improvement of the quality of life of the patients and their parents, and the rational and relevant use of the existing resources. On the other hand, this project will establish the continuation of the My Child Matters program. The name of this project is "Paediatric Oncology without Pain" and the main objective is to improve the patient's quality of life by improving the pain management and its will be undertaken in four steps, of which this survey is the first one.

The purpose of this paper is to focus on the knowledge of the care providers and to examine parents' knowledge about and attitudes regarding pain management, use of pain relief strategies and satisfaction with the pain related to cancer management.

Patients and Methods

To assess the current situation of pain management in Moroccan pediatric oncology parent/patient and healthcare providers' surveys were conducted.

Care providers survey

a. Participants

Volunteer care providers: Physicians, nurses, other healthcare workers (psychologists, and nursing assistants/aides) working into the five pediatric oncology units in Morocco.

b. Survey instrument

The principal investigator and a working group developed the survey instrument. After defining the objectives, a bibliographic research was carried out to fix the concepts and the items to explore based on the critical reading of the published articles. The questions and items were adapted to our target population and focused on knowledge, communication, and attitudes in patients with cancer.

Before developing the final version of the questionnaire, it was pre-tested with ten care providers who were not part of our sample, to assess its clarity as well as the feasibility and the time required to complete it. Some inappropriate or too imprecise questions have been removed or changed.

The questionnaire includes 19 items and used, for the major multiple-choice questions, quantitative items regarding pain and its management. The 19 items focused on domains, which are deemed to be minimal but crucial competences. These include: General principles of pain management, assessment of pain, and opioids related issues. The form was in French; self-administrated and proceeded by sessions of raising awareness. The investigators were trained before.

c. Statistical analysis

All survey data were coded and entered into SPSS 16·0 Software. Qualitative variables were

expressed in headcount and percentage, quantitative variables in median. The Khi2 test was used to compare percentages; the significance level was set at 5%.

Patient survey

a. Participants

The participants included were patients with cancer aged between 6 and 18 years old or their parents if they were <6 years old or if they could not answer themselves the questions and who are followed into the five pediatric oncology units in Morocco. The unique exclusion criteria were parent's/ children refusal, participation in the survey was on a voluntary basis.

b. Survey instrument

The principal investigator and a working group developed the survey instrument. After defining the objectives, a bibliographic research was carried out to fix the concepts and the items to explore based on the critical reading of the published articles. The questions and items were adapted to our target population and encompassed patient demographics, communication regarding pain treatment and changes in quality of life. Before developing the final version of the questionnaire, it was pre-tested with ten patients/parents who were not part of our sample, to assess its clarity as well as the feasibility and the time required to complete it. Some inappropriate or too imprecise questions have been removed or changed.

The survey includes 20 multiple choices questions and used for the major questions quantitative items. The form was in French but also translated to dialectal Arabic. The investigators were trained before.

c. Statistical analysis

All survey data was coded and entered into SPSS 16.0 software. Qualitative variables were expressed in headcount and percentage, quantitative variables in median. The Khi2 test was used to compare percentages; the significance level was set at 5%.

Results

Health care providers survey

The care provider's survey was conducted in May 2014. One hundred and eight caregivers were assessed. They were 42 pediatric oncologists, 62 nurses, two nursing assistants/aides, and two psychologists. Regarding their estimation of pain intensity, they answered severe in 73% of cases, moderate in 38% of cases, and light in 2% of cases. In their opinion, pain is related into procedures in 74%, treatment in 76%, and the cancer itself in 78%. Ninety-nine (92%) of them evaluate the pain in children with cancer. For the pain evaluation, 76 (70%) used the verbal rating scale, 28 (26%) used the faces pain scale, and 16 (15%) used the numeric scale, no one used the hetero-evaluation scale.

Concerning the communication with patient/ parent about pain, they asked in 92% of cases the patient/family to report if the patient experienced pain. Ninety-nine (92%) of them were using morphine but in 49% of cases they did not look for the side effects and they did not inform the parents about it in 44% of cases. Thirty-two (31%) were aware that the length of morphine's prescription was extended to 28 days. Forty-one (39%) care providers did not consider premedication before invasive procedures. Thirty-three (31%) have protocols and policies of pain management, 12 (11%) documented pain management on the patient's chart. In the end, only 12 (11%) of caregivers were totally satisfied of pain management in their unit. Twenty-eight of them (26%) had already participated in continuous medical education for pain management and all of them requested training.

In bivariate analysis, there was no difference between the different centers in the distribution of different health workers especially physicians and nurses (p = 0·842). No difference was found when using pain management methods of measurement (the verbal rating scale, the faces pain scale, and the numeric scale), in the five sites with, respectively, p = 0.092, 0.031, and 0.092. Tables 1 and 2 summarize bivariate analysis of positive answers according to the site (Table 1) and to the type of health worker provider (Table 2).

Patient survey

The second survey was done in February 2015 and covered 155 children with cancer from the five Moroccan pediatric oncology units. There was no parent's/children refusal. Demographic characteristics and types of cancer are summarized in Table 3. Sixty-six

Table 1: Care workers affirmative answers according to the site

Survey inquiries	Casablanca 1 n=16 (100%)	Casablanca 2 n=25(100%)	Rabat n=31(100%)	Fès n=18(100%)	Marrakech n=18(100%)	p value
Pain related to cancer itself	4 (25)	16 (64)	27 (87)	15 (83)	15 (83)	<0.001
Pain evaluation	13 (81)	23 (92)	31 (100)	18 (100)	14 (78)	0.035
Communication about pain	16 (100)	21 (84)	30 (97)	15 (83)	17 (94)	0.181
Policies availability	3 (19)	6 (24)	17 (55)	6 (33)	1 (6)	0·017
Morphine prescription	15 (94)	22 (88)	14 (45)	18 (100)	15 (83)	0.233
Side effect research	5 (31)	7 (28)	21 (68)	11 (61)	9 (50)	0.043
Side effect information	4 (25)	4 (16)	8 (26)	9 (50)	13 (72)	<0.001
Premedication before invasive procedures	4 (25)	7 (28)	4 (13)	13 (72)	15 (83)	0.003
Parents presence during invasive procedures	11 (69)	17 (68)	8 (26)	12 (67)	14 (78)	<0.001
Pain management satisfaction	2 (12)	1 (4)	4 (13)	5 (28)	0 (0)	0.011

Table 2: Bivariate analysis of affirmative answers according to the type of health-care providers

Survey inquiries	Nurse n=62 (100%)	Physician n=42 (100%)	p value
Pain related to treatment	42 (68)	20 (48)	0.047
Communication about pain	57 (92)	38 (90)	0.481
Policies availability	17 (27)	16 (38)	0.087
Legal length of morphine prescription: 28 days	11 (18)	21 (50)	0.007
Side effect research	23 (37)	29 (69)	0.001
Side effect information	25 (40)	22 (53)	0.462
Premedication before invasive procedures	16 (26)	25 (60)	0.074
Parents presence during invasive procedures	39 (63)	19 (45)	0.028
Pain management satisfaction	7 (11)	4 (10)	0.364

(42%) of the patients/parents was not informed that they could experience pain during treatment. One hundred and forty-five suffered from pain (93%), 55 (35%) of them frequently. The pain was related to the disease in 85 (57%) patients, procedures in 46 (31%) patients, and to both in 19 (13%) patients. Pain was severe in 82 cases (55%), moderate in 60 (40%), and light in 8 (5%) cases. Eight was the median estimation of pain intensity. Even having pain, 24 (16%) did not inform the medical team about it. The majority of them, 107 (71%) reported to doctors about pain and the others related

Table 3: Patients characteristics

Characteristics	Number	%
Age (5 months–19 y)	Median: 6 y	
≤6 y	87	56
>6	69	44
Sex		
Female	71	46
Male	84	54
Sex ratio	1	2
Questionnaire		
Parents	102	66
Patients	44	28
Participation of both	9	6
Site		
Casablanca	43	28
Fès	36	23
Marrakech	29	19
Rabat	47	30
Cancer type		
Acute leukemia's	70	45
Solid tumors	62	40
Lymphomas	7	5
Others	16	10

to nurses or secretaries. Procedural pain was mainly related to lumbar puncture in 81 (54%), venous access in 56 (37%), and bone marrow aspirate in 33 (22%). Sixty-eight parents (49%) affirmed that their children have received medication to prevent procedural pain. The majority of patient/parents reported an impact on their emotional, physical, and social functioning (Table 4). After pain treatment, 131 patients (84%) were totally satisfied by pain management while 21 (14%) were not satisfied, three patients did not answer to this question. The majority of parents requested information and communication about pain management.

Table 4: Impact of pain on quality of life in children with cancer

Disposition	n	%
Sad	130	87
Irritable	140	93
Depressed	98	65
Disturbance of daily activities	137	91

Using the bivariate analysis, there was no influence of the gender in the entire items request. However, when analyzing children's and parent's answer's separately, there was a significant difference in the sadness and irritability as consequences of pain with, respectively, $p = 0{\cdot}018$ and $p < 0{\cdot}001$. Finally, Table 5 summarizes the bivariate analysis of positive patients' answers according to the different sites.

Discussion

Pain is defined as "an unpleasant sensorial and emotional experience linked to confirmed or possible tissue injury" this definition is done by The International Association for the Study of Pain [9]. Children with cancer are exposed to pain and anxiety; the pain is one of the major complaints in pediatric oncology consultation. It can be caused by cancer itself, procedures such vein or lumbar puncture, or surgery. These procedures linked to anxiety and emotional distress, they are stressful for both children and parents.

Recognition and assessment of pain in children can be difficult; the level of pain is often underestimated and neglected because of many factors [10].

In Morocco, this is the first survey done; it provides important information about the level of the care worker's knowledge of and attitudes to pain across Morocco. Those results are far from optimal. Regarding pain management training, a large proportion of responding caregivers (74%) had no prior pain management training; this may be related to the lack of attention given to pain education in Morocco in the past. The education in pain management for physicians is available only in postgraduate medical education, not in undergraduate medical programs; neither is it compulsory in undergraduate medical programs [4], but for the nurses, the pain education has not yet been emphasized and generalized across formal nursing education. There are a few local initiatives in pediatric oncology units but the total hours dedicated to this may not be sufficient to prepare nurses to deal with complicated clinical problems. Hence, one of the largest obstacles to the provision of good pain management is the lack of training for healthcare workers; one of the solutions is to develop pain experts and nurse educators to provide comprehensive pain education. On the other hand, managing pain in cancer patients should be a standard in the postgraduate training of family physicians, pediatricians, pediatric oncologists, and community nurses [11]. All of them are aware of the importance and the need for training and need to be informed but they are overwhelmed, and pain management is a small part of their everyday activities.

The analysis of the caregiver's responses concluded that there were significant differences in several items including the occurrence of cancer-related pain itself, pain assessment, side effects of morphine, and required information on these adverse effects. Furthermore, significantly differences responses were noted with premedication before invasive procedures,

Table 5: Bivariate analysis of positive patient's answer's according to the different sites

Survey questions	Casablanca n=43 (100%)	Rabat n=47 (100%)	Fès n=36 (100%)	Marrakech n=29 (100%)	p value
Have you been informed about pain?	11 (26)	27 (57)	20 (56)	8 (28)	<0.001
Have you experienced pain?	43 (100)	45 (96)	32 (89)	25 (86)	0·3
Did they ask you to report pain?	29 (67)	32 (68)	35 (97)	27 (93)	0.001
Have you ask to be treated for pain?	39 (91)	26 (55)	34 (94)	25 (86)	0.001
Did they use non-medical technique to avoid pain?	1 (2)	0 (0)	12 (33)	4 (14)	<0.001
Have you been present with your child during procedures?	5 (12)	46 (98)	35 (97)	27 (93)	<0.001
Did the child receive premedication before invasive procedures?	16 (37)	38 (81)	11 (36)	3 (10)	<0.001
Did the pain has been evaluated during the procedure?	34 (79)	1 (2)	29 (81)	2 (7)	<0·001
Did you feel sad because of pain?	38 (88)	40 (85)	23 (64)	27 (93)	0·029
Did you feel depressed because of pain?	36 (84)	18 (38)	23 (64)	17 (59)	<0·001

the presence of parents during these procedures, and the satisfaction of pain management.

These differences may be related to the heterogeneity of centers and the small number of participants in each center.

Pain in children is different from that witch experienced in adult [10], variations are also noted in children according age; young children cannot verbalize their pain experience [12]. Besides, parents can be affected by their children pain and increase children's anxiety [13], [14].

Good appreciation of pain level is crucial; it can guide the treatment approach; in fact, many times non-pharmacological measures can be sufficient to control pain. In fact, non-pharmacological approaches are more used especially for control procedural-related pain [15], [16].

Pain intensity is measured using several scales, including the visual analog scale (VAS), numeric rating scale, and verbal rating scale which is the most frequent in our context, but none of our care worker's used hetero-evaluation for patients without cognitive impairment. This is probably due to the lack of training. Those findings are similar to those found in nurses in Thailand. This indicates that the clinical reasoning about pain is complicated and may be heavily influenced by the patient's expression, conditions surrounding the pain experience and even personal pain experiences [17].

The assessment of pain in children needs use of several behavioral scales [12]. Numerical scales are not suitable for non-verbal infants, the good pain evaluation of pain in young children includes. The neonatal infant pain scale based on facial, expressing, crying, breathing, legs, and arms positions [18]. Other scales are used such as Face, Legs, Activity, Cry and Consolability (FLACC) based on FLACC evaluation [19].

For verbal children, many scales were developed, like the (VAS) corresponding to a medical draws a line of 10 cm, one side of line means no pain, the opposite site means intolerable pain, the child has to point on the scale corresponding his/her pain intensity. Another scale is often used, it is the revised face pain scale, and the child has just to show the face which represents his/her pain.

The pain can be managed and controlled by different ways. Non-pharmacological approaches can be employed for acute pain [12]. Many interventions are possible depending of age and patient capacity to cooperate, children can benefit from distracting activities, music, plays, interactive games, books, virtual reality, and hypnosis. [15] Non-pharmacological approaches can be combined with pharmacological treatment.

Many times, pain control warrants pharmacological treatment. Paracetamol is the most used for mild pain; it can be associated with ibuprofen or naproxen [20], [21]. For moderate and severe pain, opioids should be used for rapid pain relief [22], [23].

An important issue refers to the availability and the use of opioids in general and morphine in particular in different types of health-care facilities. Oral and injectable morphine are available in tertiary hospitals in Morocco but not in a continuous way, which is a big problem. In smaller health centers, the morphine is not available. Consequently, patients suffering from moderate to severe pain often need to be referred to the center of oncology making pain treatment difficult and costlier, especially for those living far from major cities [4]. Furthermore, there is no prohibition on prescribing morphine for home use, the doses are unlimited and the limitation on length of morphine prescription is 28 days [4]. Although not always adapted to pediatric cases, the use of morphine is strongly limited by the current restrictive and obsolete legislation which represents a major barrier to care [6]. Looking to our survey, morphine is largely used but not in the best way because almost half of our healthcare worker's neither looked for the side effects, nor neither informed the patients or their parents.

In the patients/parents survey, 42% of the patients were not informed that they could experience pain during cancer evolution: Diagnosis, procedures, treatment, or progression. Communication between patients and healthcare workers at diagnosis is crucial and requires an understanding of the patient's emotions and sensitivities and needs to be individualized [24], [25], [26]. This it is certainly the first step for improving pain management in children with cancer.

Ninety-three percent of our patient's/parents report that they suffered or still suffer from pain. This level is high if we compare it to other studies and the

same if we consider the experience of the GFAOP in sub-Saharan Africa. Maybe it is related to similar cultural and environmental factors [27]. The intensity of pain was higher than other surveys [28], maybe because pain is undertreated; the intensity of pain was cumulative. In resource-limited settings, pain has been found to be of moderate to severe intensity in 30–70% of cases [29]. In the majority of the studies, moderate to severe pain was registered in more than 50% of patients [29]. One of the topics that we must work on immediately is the medication before procedures; only 49% of patients had been medicated.

All parents like to make their child's treatment and procedures painless, they must be implicated; they should understand every step of treatment. The procedure-related pain must be prevented and controlled, the procedure must be well explained using schema or simulation, and the procedure should be performed if possible in presence of parents. The role of parents is crucial in helping children to cape with procedure, shifting attention away from procedure, so even the parents must be prepared according of their degree of anxiety [30], [31], [32]. According to parent's responses, 58 parents were informed about pain.

Because of all those deficiencies, a majority of patients/parents reported an important impact on their emotional, physical and social functioning. In fact, our finding illustrates that 90% of the children were irritable because of the pain, 84% of them were sad and 63% were depressed. Eighty-eight of the children report that the pain is at the origin of the disturbance of their daily activities.

Finally, and surprisingly, 84% of patient/parent declared to be totally satisfied about pain management. We thought that cultural factors such as endurance against pain still advocated by many African traditions might be the reason. Islam is the dominant religion in Morocco and observant Muslims believe that having an illness represents an opportunity to enhance the Muslim's degree or expiating personal sins. Islamic teachings encourage Muslims to seek treatment when they fall sick, as it is believed that Allah did not send down a sickness but rather a medication for it [33], [34]. Some of our patients thought that pain is inevitable and suffering is normal which is why some of them still do not report their pain.

In spring 2014, a 5-day training class was organized by the GFAOP in the frame of the African pediatric oncology school for African nurses, 19 from North Africa and 11 from sub-Saharan French speaking countries. The program included information about pain management and encouraged the implementation of the specific role of nurse training [35]. Such programs will certainly have a positive good impact on managing pain.

Topical anesthetics can be used to diminish the pain of phlebotomy, intravenous cannulation or lumbar puncture [14]. Corresponding to our survey, 49% of children received premedication before procedures, this percentage remains low given the good result obtained by non-pharmacological approach.

Non-pharmacological approaches seem to be successful and seem to represent a cost-effective alternative to pain management, which needs to be improved, and needs to be more used in resource-limited countries.

This survey is the first step of the project "Paediatric Oncology without Pain" which would be in four steps. The second step is to establish the systematic traceability of the evaluation of the pain as well as its intensity by writing guidelines and standardized protocols, which is ongoing. The third step is to disseminate the knowledge to all the partners, and the last step is to reevaluate the actions with a new survey.

This study has some limits especially the small number of patients representing the five children's cancer treatment centers in Morocco. The other limit is the use of a self-maid questionnaire that does not allow a reliable comparison with other studies. A new national prospective study will be undertaken this year with the main objective to assess pain management taking into account the measures realized and the training provided to nursing and medical staff all beyond the limits of this present study.

Conclusion

Pain and its management have been for a long time prisoners of myth, irrationality, ignorance, and cultural bias. Pediatric pain is underestimated and neglected. Limited resources, both human and financial, also explained the deficiencies. That is why insufficient pain management is a significant public health cancer in Morocco. Our study, the first large nationwide survey of care workers' pain knowledge and parent's/patients survey in Morocco, provides important information about knowledge deficits in pain management. All the protagonists are aware of the importance and the need for training. Non-pharmacological approaches must be included in strategy of pain control; it can be used alone or combined with pharmacological treatment. The program "paediatric oncology without pain" was designed to increase and disseminate pain education and knowledge in Morocco. Efforts must be done to develop our practice by optimizing recognition, assessment, and pain control.

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