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Improving healthcare in pediatric oncology: development and testing of multiple indicators to evaluate a hub-and-spoke model

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ABSTRACT

Purpose: The hub-and-spoke is a new innovation model in healthcare that has been adopted in some countries to manage rare pathologies. We developed a set of indicators to assess current quality practices of the hub-and-spoke model adopted in the Interregional Pediatric Oncology Network in Northwest Italy and to promote patient, family, and professional healthcare empowerment.

Methods: Literature and evidence-based clinical guidelines were reviewed and multiprofessional team workshops were carried out to highlight some important issues on healthcare in pediatric oncology and to translate them into a set of multiple indicators. For each indicator, specific questions were formulated and tested through a series of questionnaires completed by 80 healthcare professionals and 50 pediatric patients and their parents.

Results: The results highlighted a positive perception of healthcare delivered by the hub-and-spoke model (M_{HP} = 156, M_{Pat} = 93, M_{Par} = 104). Based on the participants' suggestions, some quality improvements have been implemented.

Conclusions: This study represents the first attempt to examine this new model of pediatric oncology care through the active involvement of patients, families, and healthcare professionals. Suggestions for adopting a hub-and-spoke model in pediatric oncology in other regions and countries are also highlighted.

Keywords: Empowerment, Healthcare, Pediatric oncology

Introduction

At present, over 70% of children and adolescents with cancer are being treated successfully. This result is effected by adequate facilities and by various healthcare professionals working together to ensure early diagnoses and the best treatments available (1, 2). For some types of pediatric cancers, such as acute lymphoblastic leukemia, around 80%-85% of children can be cured through the use of risk-oriented chemotherapy protocols and supportive care (3, 4).

Care pathways in pediatric oncology require dedicated multidisciplinary teams, with experts from both pediatric and adult cancer backgrounds collaborating from the moment of the diagnosis to the survival phase. In order to facilitate care pathways and improve positive outcomes, new models of healthcare such as the adoption of service networks have to be considered by health systems. Oncology networks are integrated activity programs aimed at fulfilling a set of health needs by providing patients and parents with adequate and efficient quality of care.

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According to the European Society for Pediatric Oncology (SIOPE), the actions of oncology networks need to be delivered by well-trained multidisciplinary teams in specialized centers working with designated shared-care local centers in a so-called hub-and-spoke model. This model can help avoid a lack of homogeneity among the various centers by offering equal access to standard care (5). Hub-and-spoke models are already being set up in several European countries such as the United Kingdom, France, and Italy. The model provides a number of specialist centers (hubs), which are the primary fulcrum and are responsible for diagnoses, risk-stratified treatment decisions, and complex treatments, which are linked with local centers (spokes), which ensure families receive follow-up closer to their homes (6). To support the spread of effective infrastructure to deliver best-practice care, SIOPE has published a standards of care booklet covering various issues such as care access, healthcare professionals training, psychosocial support, and research. These standards also state that each European country strives to make continuous improvements to healthcare by adopting the hub-and-spoke model (7).

In Italy, the Italian Association of Pediatric Hematology and Oncology (AIEOP) aims at providing equal structural, medical, and assistance resources. The AIEOP was founded 40 years ago and now consists of 53 pediatric oncology centers dedicated to the study and treatment of pediatric cancer. However, despite the presence of AIEOP centers, there is still a lack of homogeneity in the quality of care throughout Italy. Optimal care is only provided by a few highly specialized hospitals in certain regions and this causes a certain degree of patient migration towards these centers, which means patients and their families have to leave their home towns in order to receive the best care. Therefore, to cope with patient migration and to be aligned with European standards, some Pediatric Oncology Regional Networks are trying to adopt the hub-and-spoke model in order to achieve greater uniformity in the provision of care.

Piedmont was the first region in Italy to adopt the hub-and-spoke model in the Pediatric Oncology Interregional Network Piedmont and Aosta Valley, the reorganization of which was approved in 2013 (8). The hub is in the Regina Margherita Children's Hospital in Turin and 9 spokes are located throughout Piedmont and the Aosta Valley. The spokes are further classified into 3 second-level units and 6 first-level units, which only offer essential facilities. See Table I for hub-and-spoke model healthcare professionals, structures, and functions.

In this model, patients aged 0 to 18 years are followed, but particular attention should be paid to adolescent patients, who are often at risk of being in a border area between pediatric and adult oncology. Adolescent diagnoses are often slower and adolescents' enrollment in clinical trials is complicated by leading them towards a lower possibility of cure (9, 10).

In order to recommend the application of the hub-and-spoke model to other Italian regions, an evaluation of the model adopted in Piedmont might prove useful. It is well-established that, once the process and the standards of care are defined, they need to be accompanied by a thorough quality assessment. Literature only provides a limited number of studies about the development of pediatric oncology care indicators, such as those delivered by the Pediatric Oncology Group of Ontario (11, 12). Thus, the goal of this study was to evaluate the healthcare provided by the hub-and-spoke model through questionnaires that were drawn up to glean points of view from healthcare professionals, pediatric patients, and parents. The feedback from the questionnaires is useful as it helps promote empowerment and the delivery of improvement actions that indirectly enhance general satisfaction, family-centered services, and adherence to treatment (13).

Methods

Development of the questionnaires

Various sources and methods were used to develop the questionnaires. First, a literature search was carried out using MEDLINE, PUBMED, the Cochrane Library, SCOPUS, and PsychINFO in order to identify any research on healthcare in pediatric oncology through the hub-and-spoke model. Workshops among multidisciplinary teams were then held to discuss some important issues on healthcare in pediatric oncology and about the care pathways delivered via the hub-and-spoke model. Subsequently, evidence-based clinical guidelines to evaluate the quality of care in the health system and hub-and-spoke model guidelines were followed (8). Finally, the concept of responsiveness of the World Health Report was taken into consideration in the development of the patients' and parents' questionnaires (13). Healthcare issues were translated into so-called indicators, which represent measurable elements of healthcare provided by the hub-and-spoke model. Specific questions were formulated for each indicator and then collected in self-report questionnaires for healthcare professionals, pediatric patients, and their parents (for responsiveness, indicators, and questions description, see Tables II and III).

The questionnaire for healthcare professionals

The questionnaire for healthcare professionals was divided into 9 indicators (accessibility, appropriateness, promptness, efficacy, patient-centered, security, government strategies for citizen empowerment, continuity of hospital/territory, and healthcare professional management). Each quality indicator had various questions, each one with a 5-point Likert scale from totally inappropriate/disagree (1) to totally appropriate/agree (5). Higher scores indicated a better perception of the healthcare delivered by the hub-and-spoke model (see Tab. II).

The questionnaire for patients and parents

The questionnaire for patients and their parents is the same and was divided into 7 quality indicators (autonomy, communication and confidentiality, dignity, timeliness, use of psychological and support services, confidence, and environmental comfort). Each quality indicator had various questions with 5-point Likert scales from totally inappropriate/disagree (1) to totally appropriate/agree (5). Higher scores indicated a better perception of the healthcare delivered by the hub-and-spoke model (see Tab. III).

TABLE I - Healthcare professionals' structures and functions of the hub-and-spoke model

Hub professionals and structures	Spoke professionals and structures
Daily and continuous hospitalization	Rooms in the pediatric department dedicated to daily and continuous hospitalization for oncology patients
Hematopoietic stem cell transplant unit	Pediatricians and nurses with oncology expertise
Oncology and transplantation day servic	Day service dedicated to oncology patients
Adequate space for adolescent patients	Psychologist
Psycho-oncology service	Trained medical and nursing staff for palliative care activities
Palliative care unit	
Microbiology laboratory (bacteriology, virology, mycology, parasitology)	
Cellular and molecular biology laboratory	
Pediatric surgery with expertise in pediatric oncology	
Anatomic pathology service with expertise in pediatric oncology	
Infectious service with expertise in pediatric oncology	
Pediatric intensive care	
Pediatric radiology	
Radiotherapy with pediatric expertise	
Therapeutic apheresis services with pediatric expertise	
Child neuropsychiatry and rehabilitation service	
Centralized pharmacy service	
Direct acceptance of patients (24-hour)	
Hospital school for all grades	
Social services	
Cultural mediation	
Volunteers	
Hub functions	**Spoke functions**
Diagnosis	Diagnosis definition
Staging	Mono-chemotherapy available in day hospital
Setting therapies according to national and international protocols	Ability to perform bone marrow aspiration, bone marrow biopsy, and lumbar puncture
Mono-chemotherapy available in ordinary daily or continuous hospital stays	Pre and postchemotherapy controls
Ability to perform bone marrow aspiration, bone marrow biopsy, and lumbar puncture	Controls during follow-up
Hematopoietic stem cell transplantation unit	Support therapy
Management of patients in therapy and off therapy	Rehabilitation
Support/therapy	Psychological care
Rehabilitation	Palliative care
Experience in dealing with adolescent patients	The functions of the level II spoke centers differ from level I spoke centers according to the possibility of providing more complex chemotherapy during continuous hospitalization
Psychological care	
Palliative/cure	
Hospital school for all grades	
Social care	
Cultural mediation care	
Educational care	

Study participants

The study was carried out among healthcare professionals and families treated in the hub-and-spoke model of the Piedmont Region, in northwest Italy. Inclusion criteria were healthcare professionals who had worked in the regional hub-and-spoke model for at least 3 years and Italian patients aged 8-18 years diagnosed with leukemia and their parents. We decided to include only patients with leukemia not only because it is the most common pediatric oncologic disease, but

TABLE II - Hub-and-spoke model quality indicators and items: healthcare professionals' questionnaire

Accessibility (n = 6)	**Appropriateness (n = 6)**	**Promptness (n = 5)**	**Efficacy (n = 4)**	**Patient-centered (n = 5)**	**Security (n = 2)**	**Government strategies for citizen empowerment (n = 3)**	**Continuity of hospital/territory (n = 4)**	**Personnel management (n = 4)**
Accessibility of the service in welcoming patients 0-18 years	Diagnostic pathways	Medical care	Effectiveness of the model to respond to the increased number of new diagnoses	Ability of the model to involve the patients in the care pathway	Adequacy of training for the health care professional team	Promotion of the activities of stem cell donation	Patients' home care	Organization in general
Organization and function of the structure	Improvement of the diagnostic pathways	Diagnosis and treatment process	Effectiveness in reducing complications related to treatment	Ability of the model to involve the family in the care pathway	Implementation of standard procedures to reduce clinical errors	Activities of healthcare professionals in providing adequate knowledge on disease	Effectiveness of palliative care network quality	Healthcare professional growth
Functionality of the patients' transfer in the hub-and-spoke	Treatment pathways	Psycho-oncologic care	Which complications?	Ability of the model to make the patient aware of the disease			Quality of palliative care	Healthcare professional communication
Communication with support services	Improvement of the treatment pathways	Activation and involvement of the support service (school, volunteers)	Effectiveness of the model in improving treatment care	Ability of the model to make the family aware of the disease		Pediatricians' prevention activities	Transition of the off therapy patients to adult care centers	Recognition by competent authorities of the healthcare activities
Possibility of follow-up at the spoke near the place of residence	Psycho-oncology service care	Multidisciplinary care (surgeons, radiotherapists)		Importance of patient awareness and the doctor-patient relationship				
Reduction of patients' extraregional migration	Transfer of the patient in the hub-and-spokes							

also because these patients receive most of their care from the services provided by the hub-and-spoke model. A member of the medical staff explained the hub-and-spoke model of the Regional Pediatric Oncology Network to each newly diagnosed patient and his or her family. The patient and his or her family also received written guidelines about the model. Data were collected on children with leukemia who underwent a second phase (consolidation) and third phase (reinduction) of treatment (AIEOP-BFM 2009) from June 2013 to January 2015. We were thus also able to collect data about patients and parents who had the opportunity to become familiar with the clinical and assistance pathways delivered by the hub-and-spoke model. Patients who were newly diagnosed and who had serious physical or mental pathologies such as terminal disease and psychosis, which might cause difficulty in the comprehension and completion of the questionnaire, were excluded from the study.

Survey

A researcher explained the aim of the study and the characteristics of the questionnaire to the healthcare professionals. Each healthcare professional was given a questionnaire to fill in; data confidentiality and anonymity were assured. The healthcare professionals were required to leave the questionnaire in an appropriate box left in a room of the day service. Each patient and his or her family was given the reasons for conducting the survey, encouraged to participate, and assured of anonymity and that data would be treated confidentially. The researcher offered help to participants who had difficulties in responding

TABLE III - Hub-and-spoke model quality indicators: patient and parent questionnaire based on responsiveness issues

Autonomy (n = 3)	Communication and confidentiality (n = 3)	Dignity (n = 1)	Timeliness (n = 2)	Use of psychological and support services (n = 4)	Confidence (n = 1)	Environmental comfort (n = 10)
Involvement in the treatment process	Clarity of the information received by the physician	Courtesy and respect by healthcare professional staff	Timeliness in receiving the treatment	Receiving correct information about the presence of psychologists	Perception of communication between healthcare professionals in the hub-and-spoke	Perception of cleanliness and hospitality (day hospital, day service, surgery, and transplant unit)
Opportunity to ask questions about other treatments	Availability of medical doctors		The facility of transition across the hub-and-spoke	Receiving correct information about the presence of school in hospital		Adequacy of the playroom for children
Freedom to choose the center in which to be treated	Confidentiality of information between doctor and patient			Receiving correct information about the presence of social services		Adequacy of the space for adolescent patients
				Receiving correct information about the presence of volunteers		

Health system responsiveness was given the formal definition of "the ability of the health system to meet the population's legitimate expectations regarding their interaction with the health system, apart from expectations for improvements in health or wealth." The population's legitimate expectations were defined in terms of international human rights norms and professional ethics.

TABLE IV - Healthcare professionals' mean values indicators, mean (range)

Accessibility	Appropriateness	Promptness	Efficacy	Security	Continuity hospital/ territory	Patient-centered	Government strategies for citizen empowerment	Personal management
25 (0-30)	28 (0-30)	23 (0-25)	15 (0-20)	8 (0-10)	16 (0-20)	19 (0-25)	13 (0-15)	15 (0-20)

to the questionnaire. Data obtained were then inserted and analyzed in terms of mean values in an Excel dataset.

Results

Questionnaires were completed by 80 healthcare professionals (physicians, nurses, and psycho-oncologists) (83% women; mean age 43.7 years) and by 50 patients (52% female; mean age 10.2 years) and their parents or guardians. The response rate obtained by this method was 80% for healthcare professionals and 83% for patients and parents. All the families live in Piedmont. The healthcare professionals' perception of the hub-and-spoke model was generally positive in terms of accessibility (mean 25, range 0-30), appropriateness (mean 28, range 0-30), promptness (mean 23, range 0-25), efficacy (mean 15, range 0-20), security (mean 8, range 0-10), continuity of hospital/territory (mean 16, range 0-20), patient-centeredness (mean 19, range 0-25), government strategies for citizen empowerment (mean 13, range 0-15), and healthcare professional management (mean 15, range 0-20) (see Tab. IV).

The patients' and their parents' opinions regarding the hub-and-spoke model was positive. Specifically, there was a positive perception in terms of (for patients and parents, respectively) autonomy (mean 13, mean 15, range 0-15), communication and confidentiality (mean 13, mean 15, range 0-15), dignity (mean 4, mean 4, range 0-5), timeliness (mean 9, mean 10, range 0-10), use of psychological and support services (mean 15, mean 16, range 0-20), confidence (mean 4, mean 4, range 0-5), and environmental comfort (mean 35, mean 37, range 0-50) (see Tab. V).

Discussion

The hub-and-spoke model is one of the most important cancer programs that has been formulated in recent years in the Piedmont and Aosta Valley regions. This model needed to be tested in terms of healthcare quality in order to provide further specific improvements. This was done by developing a valid set of indicators and by testing them via the use of questionnaires for healthcare professionals, patients, and parents. We were thus able to highlight the strengths and weaknesses of the hub-and-spoke model and to take corrective action where necessary. Our results show that healthcare professionals, patients, and parents were generally satisfied

TABLE V - Patients' and parents' mean values indicators, mean (range)

	Patient questionnaire	Parent questionnaire
Autonomy	13 (0-15)	15 (0-15)
Communication and confidentiality	13 (0-15)	15 (0-15)
Dignity	4 (0-5)	4 (0-5)
Timeliness	9 (0-10)	10 (0-10)
Use of psychological and support services	15 (0-20)	16 (0-20)
Confidence	4 (0-5)	4 (0-5)
Environmental comfort	35 (0-50)	37 (0-50)

with the healthcare offered by the hub-and-spoke model. However, there was a difference in the degree of satisfaction with some of the indicators examined.

While healthcare professionals expressed a high level of satisfaction with the appropriateness and promptness of the healthcare delivered by the hub-and-spoke model, their opinion was not as high in terms of accessibility and effectiveness. In general, there is a lower level of satisfaction concerning the quality of communication among professionals of the hub-and-spoke model and the model was considered by most participants as not being entirely adequate in reducing complications related to treatment. A possible explanation for these findings is that it is only in recent years that this has become one of the main priorities for pediatric oncologists in general, because in the past they concentrated their efforts on intensifying treatment for poor prognosis malignancies in an attempt to cure more children (14). A lower opinion was also reported about government strategies for the empowerment of citizens. This result highlighted the necessity to improve sensitization activities from doctors and pediatricians to the general population about the knowledge of cancer. There were also low professional perceptions of the continuity of hospital/territory (especially in terms of quality of the transition from a pediatric center to an adult center) as well as personnel management (specifically in terms of the value recognized by the authorities to time spent in working in the hub-and-spoke model). Specific corrective actions were conducted in order to remedy these shortcomings. A higher number of teamwork meetings (1 per month), joint research, exchange activities, and workshops were proposed to the multidisciplinary teams of the hub-and-spoke model in order to improve the capacity of the model to resolve any criticisms and difficulties not only for patient care, but also to improve professional communication and networking. These workshops also involve pediatricians, institutional officials, and other stakeholders in order to sensitize them to spread an awareness of the culture of the hub-and-spoke missions and their activities. Furthermore, greater attention was paid to the transition of the patients over 18 years old who have completed their medical treatment, by facilitating their transition to adult centers, monitoring their quality of life, and limiting feelings of isolation. Specific assistance and surveillance plans were drawn up and shared among the healthcare professionals of the hub-and-spoke model.

The parents reported an overall level of perception slightly better than the patients in all of the indicators investigated. Only the perception of environmental comfort seemed to be lacking for both, in particular regarding cleanliness and the hospitality of the day service rooms and of the dedicated rooms for adolescents. Following this observation, both the day service and the dedicated rooms were renewed and made available for the families. The adolescent patients were involved in the renovation and decoration of the rooms.

Further research about the validity of the application of our set of quality indicators might be useful for encouraging hub-and-spoke model adoption in other national and international health systems.

In Italy, AIEOP is promoting a nationwide application of the hub-and-spoke model and working on a draft of interregional restructuring based on the Piedmont model in order to optimize the healthcare system in general. This restructuring plan would provide a certain number of hub-and-spoke centers based on regional dimensions. This proposal will then be presented to the Italian Ministry of Health and then the hub-and-spoke model will be implemented by other Italian regions.

In this restructuring, AIEOP intends to take into account the issues surrounding adolescent patients' care and will seek common solutions with other associations and stakeholders. It is for these reasons that the Italian Society for Adolescents with Haemato-Oncology Diseases was founded in 2013 by AIEOP and the Italian Federation of Pediatric Oncology Parents, in cooperation with the Italian Association of Medical Oncology and the Italian Society of Haematology. The Italian Society for Adolescents with Haemato-Oncology Diseases is a comprehensive national program aimed at increasing adolescent access to the best quality of care. At regional levels, there are several adolescent care strategies such as the Youth Project of the Italian National Tumor Institute, which is aimed at optimizing clinical, supportive, and organizational aspects regarding adolescent care. Any future hub-and-spoke models have to be tailored for adolescent patients. First, they should allow adolescents to be enrolled into clinical trials, by facilitating shared-care follow-up close to home and by enabling them to continue their day-to-day activities. Furthermore, both the hub and the spokes in the model need to have age and psychosocially appropriate environments for this group of

cancer patients, surveillance programs, and specific activities supervised by a solid multidisciplinary team. As far as teams are concerned, one strong strategy to enhance adolescent care might be to include in the hub-and-spoke model new healthcare professionals such as oncologists and other healthcare professionals dedicated to adolescents and young adults with cancer with specific clinical, communicative, and relational tasks. The feasibility of this proposal is under evaluation (15).

Our method of collecting data from the opinions of healthcare professionals, patients, and parents has also led to a strengthening of the general empowerment process. While the possibility to reflect on their own experience has allowed children and adolescents to become an integral and active part of the healthcare path, subjective opinions through self-report questionnaires might have been influenced by personal disease characteristics. We therefore, as suggested by the literature, asked patients and parents for their opinions about their actual clinical care experiences. Working towards the provision of high-quality care for cancer in pediatric patients and for their parents should also lead to improvements in patient event-free survival and overall survival (16).

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