

## Feasibility of a home care program in a pediatric hematology and oncology department. Results of the first year of activity at a single Institution

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**Background and Objectives.** Giannina Gaslini Children's Hospital (GGCH) is a tertiary care hospital with an average of 100 new cancer diagnoses made each year. In April 2000, following preliminary analysis of the potential benefits, and the results of a questionnaire filled in by the parents attending the out-patient clinic, a Home Care (HC) program was started.

**Design and Methods.** Children in stable, non-critical, clinical conditions requiring i.v. therapy, parenteral nutrition, transfusional support, blood examinations, and central venous catheter use training management, as well as terminally ill children needing palliative and support therapy were considered eligible for the program.

**Results.** After one year of activity, 45 children, aged 1 month-19 years (median 3 years), requiring i.v. therapy and blood tests in 32 cases, central venous catheter use training in 5, and palliative care in 8, were treated at home. The median duration of assistance for each child was 19 days (range 1-172). An average of 4 patients per week were assisted for a total of 1,364 days. A total of 881 accesses at home replaced 551 and 330 out-patient and in-patient days of hospitalization, respectively. The average cost per patient given home care (2,936 €, range 150-20,700) resulted to be significantly lower than the average cost per patient hospitalized to undergo the same procedures (9,785€, range 350-96,750).

**Interpretation and Conclusions.** The opportunity to reduce the frequency and duration of hospitalization represents an incalculable advantage for these children and their families. This report shows that home care is a feasible kind of assistance for children suffering from cancer, and reduces costs as well.

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Key words: home care, pediatric hematology and oncology.

Almost 1,500 new cases of childhood cancer are diagnosed every year in Italy and more than 70% of them are cured, yet over 20% eventually die despite modern therapy. The quality of life during cancer treatment is strongly affected by frequent and sometimes long periods of hospitalization during front-line therapy, treatment of possible relapse, because of toxicity after chemotherapy, or for the care of terminally ill patients.

Many of these complications do not require continuous medical supervision and may be cared for at home thus reducing discomfort due to hospitalization, and to some extent, also reducing costs to the National Health Service. In particular, during the terminal phase of the disease, the possibility of suffering and separation in a private environment allows patients and their families to avoid the interference of external and inopportune stimuli. Thus, the option of adequate Home Care (HC) may represent an important opportunity to ameliorate the quality of life of children suffering from cancer. Moreover, by reducing the frequency and duration of hospitalization, this kind of assistance allows for cost reduction<sup>1</sup> and greater availability of the hospital ward for patients requiring more critical care.

Herein, we report on the first year of activity of the HC program started at G. Gaslini Children's Hospital (GGCH), in order to evaluate the feasibility of this type of program in a pediatric setting.

### Design and Methods

The GGCH is a tertiary care hospital with an average of 100 new cancer diagnoses made each year. About 60% of them are from outside the Region, most of the patients reside more than 500 km away. Patients living in the metropolitan area or within the Region usually return home during the intervals

between chemotherapy cycles. Accommodation is usually offered to those from other regions and to at least one parent in a hospice near the hospital, or in flats run by volunteer associations.

In April 2000 after preliminary analysis of potential benefits, and the results of a questionnaire filled in by the parents attending the out-patient clinic, a HC program was started. To be eligible for the HC program, children had to live in the metropolitan Genova area and had to be in a stable, non-critical, clinical condition requiring at least one of the following procedures: i.v. antibiotic administration, antiviral or antifungal therapy, parenteral nutrition, blood tests, and/or central venous catheter (CVC) use training. Since performing transfusions is possible even in non-hospital environments in Italy, this procedure was not considered an exclusion criterion to undertake home care. The possibility of HC was also evaluated on the basis of the general condition and hematologic status when febrile episodes occurred in non-neutropenic patients. Neutropenic febrile children were not considered eligible for the HC program, but early discharge from the hospital followed by a HC program was taken into consideration as shown in Table 1.<sup>2-4</sup> Lastly, even terminally ill children needing palliative and support therapy were eligible for this program. The infusion of any type of antineoplastic chemotherapy, or the need for multispecialty examinations were considered non-eligibility criteria. Parents' knowledge and acceptance of the general management of the ill child at home was considered essential for inclusion in the program.

When a HC program was planned and accepted by the parents, the physician responsible for the patient planned the follow-up program together with the HC team. The physician in the HC team was responsible for defining dates and types of home access, and the date of subsequent hospital admission in order to continue treatment.

Between April and December 2000 the HC personnel included a visiting physician and a trained pediatric nurse, and were co-ordinated by a senior staff physician who was not involved in the assistance. As of January 2001 the staff is made up of two visiting physicians, two pediatric nurses, and a psychologist, co-ordinated by a senior physician. All the personnel are Hospital employees. The scheduled working time is 8 a.m. to 4 p.m. Monday to Friday. A physician on duty at the hospital is available on call during the other hours. Transfusional and laboratory support, together with all drugs and materials are supplied by the hospital. A car is available

**Table 1. Guidelines for possible early discharge of neutropenic febrile patients.**

- 
- age >1 year
  - absence of previous fungal infections
  - good clinical condition
  - at least 48 h without fever
  - negative cultures
  - expected hematologic recovery
  - Ht > 21% and platelet count > 25,000/mm<sup>3</sup>
  - PCR < 5 mg/dL
- 

thanks to a private donation and its maintenance is supported by a volunteer association.

## Results

In the first year of activity, 45 children (29 males, 16 females) were included in the HC program. Among them, 6 (13 %) resided in the region, while the remaining 39 (87%) were from other Regions and consequently cared for in the hospice or in flats run by volunteer associations. The median age at diagnosis and at inclusion in the program was 3 years (range 1 month-18 years) and 7 years (range 4 months- 20 years), respectively. All patients but one were children (<16 yr). The only patient above 16 years was taken care of in our center because he suffered from a pediatric cancer, i.e., Ewing's sarcoma. The underlying diagnoses are reported in Table 2.

The indication for HC was therapy and/or blood tests in 32 (71 %) children, training of parents in the use of CVC in 5 (11 %), while it was palliative and supportive therapy during the terminal phase of disease for the remaining 8 (18 %). Overall activity consisted of 530 blood withdrawals, 520 antibiotic, antiviral, antifungal or other i.v. therapy, 104 red blood cell or platelet transfusions, 100 pain therapy administrations, 55 training sessions of CVC use, 28 total parenteral nutrition, 27 re-hydrations, and 5 CVC medications. These procedures were administered over a total of 881 nurse and/or physician's visits, replacing 551 and 330 days of out-patient clinic and in-patient ward hospitalization, respectively.

HC programs were discontinued when the problem requiring HC was solved (35 patients – 78%), or because of the onset of fever in neutropenic children in 9 (20%) patients. In one case (2%) the program was interrupted because of low compliance by the family.

The median duration of the whole HC period for each child was 19 days (range 1-172) for a total of

**Table 2. Underlying diagnosis of the patients enrolled in the home care program.**

Diagnosis	N	%
Neuroblastoma	12	27
Acute lymphoblastic leukemia	10	23
Acute myeloid leukemia	5	11
Sarcoma	4	9
Central nervous system tumors	2	4
Myelodysplastic syndrome	2	4
Ewing's sarcoma	2	4
Other diseases*	8	18
Total	45	100

\*Include: non-Hodgkin's lymphoma, osteosarcoma, germinoma, chronic granulomatous disease, histiocytosis, Wilms' tumor, chronic myeloid leukemia, hemophilia.

1,364 HC days. A median of 4 patients per week (range 2-14) were followed by the HC program during the first year of activity.

To calculate the financial aspects of this project, the average cost per patient of one day of HC was calculated based on the price charged to the hospital for drugs, blood tests and transfusional support, plus the cost of the staff based on the amount of time spent with each patient. The cost of out-patient or in-patient hospitalization was calculated based on the hospital's health directorate estimates. The estimated cost for HC, out-patient clinic, and in-patient hospitalization was 150, 350, and 750 €, respectively. To measure the differences in cost for the National Health Service (NHS) between the HC program and standard hospital admission, we counted the single visits made to each patient by a physician and/or a nurse, and calculated how many out-patient and/or in-patient clinic days were avoided because of them.

Children needing i.v. treatment (antibiotics, antiviral agents, etc.) > 2 times per day, the terminally ill, and patients in a bad clinical condition were considered as those having avoided ward admission, whereas all other children were considered to have potentially required out-patient appointments.

A standard t-test was used to compare differences between the mean cost per patient of the HC program compared to standard hospitalization admission costs.

Table 3 reports the number of days of HC for each child entering the program, and the relative costs as compared to the number of days of out-patient or in-patient hospitalization avoided for each child. The average cost per patient assisted in the HC

program (2,936 €, range 150 - 20,700 €) proved to be significantly lower ( $p < 0.001$ ) than the average cost that would have been charged to the NHS in case of hospitalization to carry out the same procedures (9,785 €, range 350 - 96,750 €).

## Discussion

Over the last few years various experiments with pediatric HC have been set up in several countries in order to provide palliative care to terminal patients,<sup>5</sup> to treat infectious diseases,<sup>6-8</sup> or to administer chemotherapy.<sup>9</sup> Other Pediatric Hematology and Oncology centers have set up specific programs for both curative and palliative care.<sup>10-11</sup> In Italy, HC is increasingly being offered to adult patients suffering from several kinds of diseases. To our knowledge this is the first experience of a HC program in a Pediatric Hematology and Oncology Institution in Italy.

The financial advantages of this kind of assistance in terms of costs for the NHS are evident since the average cost per patient in HC resulted to be significantly lower ( $p < 0.001$ ) than the average cost that would have been paid per patient if hospitalized to undergo the same procedures.

This program was also very helpful in reducing both the discomfort of our patients and the need for space for hospitalization. Other important benefits must be stressed when taking the feasibility and utility of a HC program into consideration. In particular, the incalculable advantage of this kind of service is the *staying at home* itself. In fact, isolation from everyday life represents an important source of discomfort for children suffering from cancer and for their families, and the opportunity to reduce the frequency and duration of hospitalization allows us to ameliorate their quality of life.<sup>10,11</sup> Moreover, even parents may benefit from this program since it allows them to continue their daily life as much as possible, without having their habits contorted by continuous hospital admissions. Furthermore, HC enhances the parents' opportunities to maintain an active role in the child's care, avoiding the regression which often ensues when parental responsibility is delegated to the treating staff. Nonetheless, families admitted to HC programs must be chosen carefully. In our center parents are taught how to handle CVC and the general management of the child with cancer as well as his/her needs, and the choice to undertake HC must take into consideration the family's abilities. However, in our experience, all families but one showed good compliance to this

**Table 3. Comparison of the cost (EURO) of HC days per patients to the cost of hospitalization days (in-patient and/or out-patient).**

UPN	Sex	Age (years)	Diagnosis	HC days	Hospitalization Days		Total Cost (Euro)	
					Out patients	In patients	HC	Hospitalization
1	F	12	ALL post MUD-BMT	5	5	–	750	1750
2	M	7	NB	45	–	45	6750	33750
3	M	7	NB	18	–	18	2700	13500
4	F	7	NB	129	–	129	19350	96750
5	M	6	HLH post MUD-BMT	12	12	–	1800	4200
6	M	0.3	NB	6	6	–	900	2100
7	F	9	ES	19	19	–	2850	6650
8	M	8	ALL	18	18	–	2700	6300
9	M	12	CGC post Allo-BMT	20	14	6	3000	9400
10	M	11	STS	2	2	–	300	700
11	F	4	AML	3	–	3	450	2250
12	M	7	ALL	1	1	–	150	350
13	M	1	MB	36	36	–	5400	12600
14	F	4	NB	6	6	–	900	2100
15	M	9	ALL post MUD-BMT	116	92	24	17400	50200
16	M	4	MDS post Auto-BMT	14	–	14	2100	10500
17	M	1	BH	3	3	–	450	1050
18	M	6	MB	3	3	–	450	1050
19	M	2	WT	2	2	–	300	700
20	M	1	ALL post MUD-BMT	32	32	–	4800	11200
21	M	12	STS	13	13	–	1950	4550
22	M	0.9	ALL post MUD-BMT	32	8	24	4800	20800
23	M	9	HDL	2	–	2	300	1500
24	M	7	RMS	8	–	8	1200	6000
25	F	11	ALL post Allo-BMT	9	9	–	1350	3150
26	F	14	AML post Auto-BMT	14	14	–	2100	4900
27	M	5	ALL post Allo-BMT	27	27	–	4050	9450
28	F	14	CML post MUD-BMT	9	9	–	1350	3150
29	F	13	AML post MUD-BMT	138	93	45	20700	66300
30	M	2	ALL	5	5	–	750	1750
31	F	3	GCT	5	5	–	750	1750
32	F	1	MDS post Allo BMT	16	16	–	2400	5600
33	F	2	NB	6	6	–	900	2100
34	M	2	NB	3	3	–	450	1050
35	M	20	ES	12	–	12	1800	9000
36	M	3	NB	6	6	–	900	2100
37	F	8	OS	10	10	–	1500	3500
38	M	11	AML post Auto-BMT	26	26	–	3900	9100
39	F	8	NB	6	6	–	900	2100
40	M	1	ALL post MUD-BMT	17	17	–	2550	5950
41	M	3	NB	2	2	–	300	700
42	M	0.4	AML post Allo-BMT	11	11	–	1650	3850
43	F	4	NB	4	4	–	600	1400
44	F	5	NB	6	6	–	900	2100
45	M	3	SS	4	4	–	600	1400
Tot				881	551	330	132150	440350

ALL:acute lymphoblastic leukemia; NB:neuroblastoma; HBH:hemophagocytic histiocytosis; CGD:chronic granulomatous disease; ES:Ewing's sarcoma; BH:hemophilia; Wilms' tumor; MDS:myelodysplasia; HDL:Hodgkin's lymphoma; RMS:rhabdomyosarcoma; CML:chronic myeloid leukemia; OS:osteosarcoma; MB:medulloblastoma; SS:synovial sarcoma; STS:soft tissue sarcoma; GCT:germ cell tumor. The cost of one day of HC, outpatient and inpatient hospitalization was estimated at 150, 350 and 750 €, respectively.

service. Nonetheless, the risk of feeling abandoned or isolated should be carefully considered in some families that do not represent the ideal target for this kind of assistance due to their need for the continuous and reassuring presence of medical and nursing staff.

Another important element of this program is that the visiting physician and nurses belong to the same department where the child was diagnosed and treated, thus keeping a strong link with the whole staff, and reducing any potential feeling of being abandoned. In one year 8 children were assisted during the terminal phase of the disease. Staying at home during the terminal phase seems to have several advantages. Families requesting this kind of assistance can experience their suffering and separation in a private environment, avoiding interference by outside elements and respecting their individual needs.<sup>15-16</sup> This allows them to feel free to show their feelings as well as their own coping abilities, giving them the perception of better control. The number and type of procedures carried out at home depended on the staff involved in the program. Due to an increase in personnel, during the last 4 months our activity has involved a greater number of patients. By increasing the number of visiting nurses, following about 15-20 children per day will soon become a reality. We will also be able to start with chemotherapy administration at home, further reducing the number of children treated in hospital.

In conclusion, this preliminary report shows that the HC program is feasible, that the cost of medical assistance is reduced, and last but not least, it represents a valid alternative for children suffering from cancer by reducing their physical and psychological discomfort. Nonetheless, actual improvement in the quality of life needs to be confirmed by specific studies.

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*MM and GD contributed equally to this work and were primarily responsible for it, from conception to submitted manuscript: they should be considered as the principal authors. The remaining authors qualified for authorship according to the World Association of Medical Editors (WAME) criteria, and have taken specific responsibilities for the following part of the content: ML, GA, FS, TR, LM, LM, TD and RR, collection of clinical data, RH statistical analyses. Order of authorship. Authors are listed according to a criterion of decreasing individual contribution to the work, with the following exceptions: the*

*first two authors contributed equally to this article, while the last author had a major role as senior author in designing the study, interpreting the data and preparing the article.*

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#### *Disclosures*

*Conflict of interest: none.*

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#### References

1. Maltoni M, Nanni O, Naldoni M, Serra P, Amadori D. Evaluation of cost of home therapy for patients with terminal diseases. *Curr Opin Oncol* 1998; 10:302-9.
2. Talcott JA, Whalen A, Clark J, Rieker PP, Finberg R. Home antibiotic therapy for low risk cancer patients with fever and neutropenia: a pilot study of 30 patients based on a validated prediction rule. *J Clin Oncol* 1994; 12:107-14.
3. Mustafa MM, Aquino VM, Pappo A, Tkaczewski I, Buchanan GR. A pilot study of outpatient management of febrile neutropenic children with cancer at low risk of bacteremia. *J Pediatr* 1996; 128:847-9.
4. Aquino VM, Buchanan GR, Tkaczewski I, Mustafa MM. Safety of early hospital discharge of selected febrile children and adolescents with cancer with prolonged neutropenia. *Med Pediatr Oncol* 1997; 28:191-5.
5. Mulhern RK, Lauer ME, Hoffman RG. Death of a child at home or in the hospital: subsequent psychological adjustment of the family. *Pediatrics* 1983; 71:743-7.
6. Rehm SJ. Home intravenous antibiotherapy: a team approach. *Ann Intern Med* 1983; 99: 388-92.
7. Stiver JH. Self administration of i.v. antibiotics: an efficient cost-effective home care program. *Can Med Assoc J* 1982; 127:207-11.
8. Baptista RJ. Experience with 211 courses of home i.v. antimicrobial therapy. *Am J Hosp Pharm* 1989; 46:315-6.
9. Jabayose S. Home chemotherapy for children with cancer. *Cancer* 1992; 69:574-9.
10. Fernandez Navarro JM, Barahona Clemente A, Canete Nieto A, Orti Martinez P, Pozuelo Munoz B, Castel Sanchez V. Home hospitalization for children with cancer: one more step towards integral care in pediatric oncology. *An Esp Pediatr* 1998; 48:1-3.
11. Fernandez Navarro JM, Pozuelo Munoz B, Orti Martinez P, Lopez Ferrer L, Canete Nieto A, Verdeguer Miralles V, et al. Evaluation of a home care program for children with cancer. *An Esp Pediatr* 2000; 52:41-6.

12. Masera G, Spinetta JJ, Jankovic M, Ablin AR, D'Angio GJ, Van Dongen-Melman J, et al. Guidelines for assistance to terminally ill children with cancer: a report of the SIOP Working Committee on psychosocial issues in pediatric oncology. *Med Pediatr Oncol* 1999; 32:44-8.
13. Wolfe J, Klar N, Grier HE, Duncan J, Salem-Schatz S, Emanuel E, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA* 2000; 284:2469-75.
14. Martinson IM, Moldow DG, Armstrong GD, Henry WF, Nesbit ME, Kersey JH. Home care for children dying of cancer. *Res Nurs Health* 1986; 9:11-6.
15. Oakhill EJ, Cornish JM, Curnick S. Terminal care at home for children with cancer. *Br Med J* 1989; 298:937-40.
16. Wolfe J, Grier HE, Klar N, Levin SB, Ellenbogen JM, Salem-Schatz S, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000; 342:326-33.

## PEER REVIEW OUTCOMES

### *Manuscript processing*

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### *What is already known on this topic*

The volume of inpatient care in Western countries has decreased considerably over the last ten years. One of the factors contributing to this development has been the adoption of new medical technologies, among which is the prospect for outpatient treatment among patients traditionally treated as inpatients.

### *What this study adds*

The present study is the first to evaluate the home care program of children with cancer. The program is feasible and the costs for health care are reduced.

### *Potential implications for clinical practice*

There are potential cost savings for the health care sector if the outpatient treatment policy is implemented in pediatric hematology and oncology departments. Local circumstances and patients' and parents' preferences must be taken in great consideration when home care is offered.

*Giovanni Barosi, Associate Editor*