

Attending pediatric acutely ill patients at home: families' socioeconomic characterization, expectations, and experience

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Abstract

Purpose

To have a thorough understanding of an acute pediatric homecare program, it is essential to analyze all factors related to the matter: medical, social, economic, and families' experience. No studies have been found describing profusely this topic in such a complex program like ours (considering diseases and treatments offered). With this study, we will obtain a fine population characterization and families' needs understanding. This will contribute to a better knowledge of our program and the detection of its possible deficiencies.

Methods

This is a prospective quantitative and qualitative study. 372/532 families are asked to answer two independent questionnaires (preadmission and postadmission), aimed to: understand their socioeconomic characteristics; assess families' expectations and experience; and identify factors influencing the homecare preference. Results are presented in frequencies and comparisons (Fisher's exact test).

Results

Families have an adequate social network; workload is less than expected and most families would repeat the experience despite it; expectations regarding caregiver's well-being at home were better than the actual situation, as some experienced anxiety or fear; and rating is better in homecare compared with inpatient care.

Conclusions

Despite limitations (participants' voluntariness to respond the surveys and lack of inpatient hospitalization's socioeconomic data to compare with homecare), this study offers the possibility of improving our service portfolio, focusing on vulnerable families' access to the program and caregiver's risk of burnout.

What Is Known:

- Pediatric homecare is an effective alternative to conventional hospitalization.
- Pediatric acute homecare programs are not frequent.
- Families' satisfaction with homecare programs is already cited in prior work.

What is new:

- Families' socioeconomic characterization and caregivers' experience about acute homecare is essential to get a better understanding of a program like this.
- Families attending to acute homecare have an adequate social network and high educational level.
- Most families would repeat the experience despite workload.
- Although short-term admissions, caregivers can suffer burnout.

1. Introduction

Home hospitalization is a well-known, safe, and effective alternative to conventional hospitalization in eligible patients, as it is described profusely in literature [1–3]. Homecare enables patients to be in their own environment, accompanied and taken care by their relatives. It offers significant benefits compared with inpatient hospitalization, like decreased iatrogenic complications and readmission rate, or improved patient and caregiver satisfaction [4]. Experience in this field goes back to 1947, where the first adults' home hospitalization unit was designed, in Guido Montefiore Hospital (New York). The main objectives of this program were to relieve hospital congestion and humanize hospitals [5]. After this experience, homecare has grown rapidly in last decades, due to high healthcare costs and few available beds in hospitals [6].

Focusing on the pediatrics' field, homecare experiences are mostly centered in chronic and palliative patients [7–10]. Hospital Sant Joan de Déu (SJD) in Barcelona is one of the first hospitals that implemented, in 2019, a home hospitalization program specifically addressed to acutely ill and chronic exacerbated patients in Spain. The main objective of the program is to offer homecare for children with acute diseases, maintaining quality and safety compared to hospital care, but in a more comfortable and pleasant habitat for patients and families. As important as supported pathologies are the families admitted to the program. In this context, being able to characterize the families admitted to acute homecare and evaluate their expectations and experiences is essential to better understand their needs. Although families' characterization and satisfaction in pediatric homecare has been well studied in chronic and palliative patients [11–13]; being acute pediatric homecare recent, there are few articles centered in the experience of those [14–18]. No studies have been found that provide extensive social information about such a complex acute pediatric home-hospitalization program like ours (considering the variety of pathologies and treatments offered). Aspects as families' characterization, expectations towards acute homecare, or possible modulating factors when deciding to enter the program are not reported yet.

Such a study is challenging, as differences between pediatric chronic/palliative patients and acutely ill patients result in a totally different environment: (1) chronic patients' caregivers are well trained on the child's care [19], while acutely ill patients are normally healthy children, who do not have such prepared caregivers; (2) acutely ill patients' caregivers need to be skilled in nursing techniques in a short time; and (3) the doctor-patient/family bond is not that solid compared with chronic patients.

To overcome the limitations of previous research on the topic, we propose this study, which aims are: (1) to describe the social characteristics of families admitted to acute home-hospitalization; (2) to assess families' expectations towards acute homecare; (3) to investigate possible factors that can influence the decision of preferring the home-hospitalization modality; and (4) to evaluate families' satisfaction with the program. As a result, we will obtain a fine population characterization and families' needs understanding. This will contribute to a better knowledge of our program and its possible deficiencies.

2. Methods

2.1 “SJD a Casa” Program

SJD a Casa, that stands for SJD at home, is the program's name that attends children that, otherwise, would be admitted in hospital. In our case, most of the patients specifically need pediatric follow-up (not only nurse care). Diseases treated at home are: respiratory illnesses in requirement of oxygen therapy; infections in need of parenteral antibiotic treatment; and other pathologies that may demand pediatric follow-up, as dehydrations, onset of nephrotic syndrome, or renal failure (requiring intravenous hydration).

This program is composed by 2 pediatricians and 4 nurses, in addition to administrative and technological support. Patients' follow-up includes face-to-face visits and tele-homecare. The maximum capacity of the service is 12 patients. Most of the children are visited daily, while some of them require in-person visits two or three times a week. Attention is given 7 days a week from 8 am to 18 pm (pediatrician and nurse care during workdays, and nurse care on non-working days). Families have 24-hour telephone contact and are admitted to the Emergency Department if evaluation is needed from 18 pm to 8 am.

Patients can be referred to SJD a Casa from Inpatient Ward, Outpatient Department, or Emergency Department, although the most frequent referral department is Inpatient Ward. Before being transferred to homecare, a specialized nurse from the home-hospitalization program, meets the patient and family to explain the main characteristics of the program, evaluate admission criteria, and empower the caregiver in the recognition of warning signs and home treatments' administration (intravenous antibiotics, oxygen therapy, continuous liquid infusion, wound care, etc.). After that, patient and family will be transferred to home.

2.2 Participants

Test participants are patients' caregivers attending SJD a Casa Program from 10/13/2020 to 12/15/2021. Patients admitted directly from Emergency Department or Outpatient Department are excluded. Participants are asked to answer two independent questionnaires, being the inclusion voluntary and anonymous for each of them. The study was proposed to 532 families, of which 372 (69,92%) answered either one of the surveys or both.

2.3 Ethical considerations

Conflict of interests: none declared.

Informed consent was obtained from all individual participants included in the study.

All procedures performed in studies involving human participants were in accordance with the ethical standards of the Hospital Sant Joan de Déu research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

2.4 Experimental design

In the first phase, an anonymous questionnaire in paper format was delivered to the patient's caregiver in hospital, previously of being admitted to hospital-at-home. The survey was answered after the nurse had provided the caregivers all basic information on the program and they had received the care training. This questionnaire is aimed to: (1) evaluate the reasons why families choose acute home-hospitalization, (2) explore expectations regarding home-hospitalization (focusing on the child's and the caregiver's well-being); and (3) analyze possible factors that could influence the choice of homecare rather than in-hospital care (child's anxiety and increased economic burden in hospital). See the preadmission survey in Online Resource 1.

In the second phase, another anonymous questionnaire was sent by e-mail (Google Survey) to the patient's caregiver, right after the patient's discharge. This survey is aimed to: (1) evaluate the families' socioeconomic characteristics, (2) explore current admission experience (child's and caregiver's well-being, economic burden, and convenience of hospital-at-home), (3) compare the attention received during home-hospitalization with the conventional hospitalization's attention; and (4) analyze possible factors that could influence the choice of homecare (previous admissions to hospital and traumatic experiences prior to current admission). See the postadmission survey in Online Resource 2.

Some of the questions are the same in the two surveys, for the aim is to evaluate whether the expectations and reality are consistent or whether the caregiver's fears or beliefs may distortion expectations. Note that, being both questionnaires voluntary, some subjects may answer either one or both surveys.

2.5 Statistical analysis

Data were collected in an internal database. The results from each question were calculated in absolute frequencies. Fisher's exact test was used to compare preadmission results with postadmission results and home-hospitalization with inpatient hospitalization. In all stages, we used the software R [20].

3. Results

Results are described in tables 1-9.

4. Discussion

4.1 Comparison with Previous work

As already cited previously, there are few papers that focus on the pediatric acute homecare understanding and the families' characterization. The following provides the information described in previous work.

Sartain et al. report a qualitative study aimed to compare 40 families' experiences of homecare and hospital care. The project is based on a nursing acute homecare program and the trial includes children with only three types of symptoms: pyrexia (viral infection, tonsillitis), breathing difficulties (asthma, chest infection, croup), and diarrhea. The paper provides information on the parent's and the patient's view by interviews. User's satisfaction, effects on family, financial costs, and relationship with professionals are studied. Main results are increased reassurance and confidence to parents in the specific case of acute nursing needs (no pediatric need in any case)¹⁴.

Bryant et al. do a systematic review focused on inpatient versus outpatient parenteral antibiotic treatments at home, including efficacy, safety, satisfaction, and cost. Principal findings related to satisfaction are increased opportunity to keep up with school or work, greater privacy and comfort, improved quality of sleep and appetite and increased time to spend with family¹⁵.

Cabrera et al. refer to a program similar to ours, that includes pediatric and nurse care and treats a great variety of pathologies. This study provides much information on pathologies and treatments received at home, and few information on perceived safety, satisfaction, and preference over conventional hospitalization. Nevertheless, it does not include the specific questions asked to caregivers, nor precise results. Greater comfort, privacy, ease of familial organization and perception of earlier recovery are the main aspects to consider in this paper¹⁶.

Young et al. have reported a full qualitative study addressed to children with subacute needs, based on interviews to 16 families. However, their program is based on tele-homecare (vital signs monitors, two-way videoconferencing connecting home and hospital, and community-based-homecare nurses – not hospital nurses, nor pediatricians). Principal findings suggest that care at home during the subacute care phase can be as good as in hospital, that families prefer to be at home, and that tele-homecare facilitated the transition home¹⁷.

Previous work on our program, SJD a Casa, is already reported, the aim being the pilot test evaluation to determine the program's implementation in the hospital's portfolio. Although the results were excellent (a level of care scored overall Excellent and a desire to repeat the experience if needed in all the families)¹⁸, the study has its limitations: restricted survey and small sample.

Note that none of these studies is like ours because: (1) the aim is not the families' characterization; or (2) although it reports a full families' description, the program's characteristics are different, according to pathologies treated and homecare staff.

4.2 Actual work

Social characterization of families has permitted to identify a predominant profile of caregiver: Spanish parent, with college instruction, satisfactory household economy, and adequate family and social network. Although these results may constitute a bias because of the experiment design (participants' voluntariness to respond the surveys), it is interesting to remark that caregivers in our program must get involved in nursing techniques, some of them quite challenging, with short time of empowerment. Thus, patients with fewer family resources may encounter difficulties entering the program.

Focusing on the reasons to choose acute hospital-at-home, economic burden being admitted in hospital does not constitute a motivation in most of the cases. Nevertheless, more than a half of participants admit family's economic burden in hospital is higher than usual. Therefore, we may conclude that household economy can influence on the decision. Other expected modulating factors when selecting homecare (such child's anxiety, having had a previous hospital admission or having experienced some traumatic event in a hospital) are infrequent and do not seem to interfere with the homecare choice.

It is valuable to focus on the caregiver's experience view. Although regarding workload families affirm to have had less work than initially expected; when analyzing the caregiver's well-being, results are worse than expected in the preadmission survey. This is remarkable, as it may suggest symptoms of fear, tiredness and anxiety being at home. It is also noticeable that, despite 18 families answered the workload was more than expected, only 5 would not repeat homecare because of it. One may think that families' desire for the patient to stay at home along with the feelings of fear or anxiety could lead eventually to caregiver's burnout.

Moreover, this study corroborates satisfactory results referring to the acute hospital-at-home experience, as already described in literature¹⁵¹⁶¹⁸¹⁴. Rating is better in hospital-at-home in comparison with conventional hospitalization, being these results also consistent with previous work¹⁵¹⁷¹⁴. We can assume it may be due to a closer relationship between caregiver and health staff and because of the comfort being at home.

This paper offers a general vision on the socioeconomic situation of families admitted in an acute pediatric hospital-at-home program, and on the actual caregivers' and child's experiences. It would be of interest to center further studies in specific social aspects as single-parent families or immigrant parents and introduce the health staff's view towards acute homecare.

Limitations in this study are: (1) the previously mentioned bias because of the experiment design and (2) the lack of inpatient hospitalization's socioeconomic information to compare properly with homecare.

Conclusions

Despite limitations, this trial is of service to have a thorough understanding of the acute pediatric hospital-at-home, which is essential to have an exemplary program. It offers the possibility of improving the service portfolio, as it is noticeable it is mandatory to focus on the vulnerable families' access to the program and the caregiver's well-being and risk of burnout. In fact, our health staff has already been working on actual changes in the SJD a Casa program, the main proposal being the elaboration of a brief survey aimed to detect signs of caregivers' burnout.

Abbreviations

SJD: Hospital Sant Joan de Déu

Declarations

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Author contributions: Astrid Batlle, Sandra López, Isabel Moya and José Carlos Fernández contributed to the study conception, design, material preparation and data collection. Analysis was performed by Santiago Thió-Henestrosa. The first draft of the manuscript was written by Astrid Batlle and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Ethics approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the Hospital Sant Joan de Déu research committee (07.23.2020/ C.I. PIC-184-20) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Consent to participate: Informed consent was obtained from all individual participants included in the study.

Consent to publish: Informed consent to publish is not required in this study, as the manuscript does not include identifiable personal data.

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Tables

Table 1. Families' socioeconomic characteristics.

	Mean;sd or n;%
Parent 1 age (n=209)	38.7;6.2
Parent 2 age (n=196)	38.7;6.11
Parent 1 origin (n=217)	
Africa	4;1.84%
America	36;16.59%;
Asia	6;2.76%
Europe	11;5.07%
Spain	160;73.73%
Parent 2 origin (n=203)	
Africa	4;1.97%
America	30;14.78%;
Asia	5;2.46%
Europe	15;7.39%
Spain	149;73.40%
Parents' highest education (n=214)	
Elementary school	8;3.74%
High school	54;25.23%
College education	152;71.03%
Familial economical characteristics	
Receiving economical support (n=218)	74;33.94%
Someone in family unemployed (n=214)	51;23.83%
Friends and family support if needed (n=217)	153;70.51%
Home characteristics	
Patient has his /her own room (n=215)	134;62.33%
Shared house with other families (n=215)	3;1.40%
House well-equipped to accommodate hospitalization (n=217)	213;98.16%
Patients' characteristics	
Chronic condition (n=215)	25;11.63%

Disability degree (n=218)	10;4.59%
Level of dependence (n=214)	11;5.14%
Work reduction (n=213)	22;10.33%

Table 2. Reasons to choose acute homecare and possible influencing factors.

	n;%
Reasons to choose acute home-hospitalization (n=372)	
Child and family comfort	249;66.94%
Balancing work and family life	93;25%
Child's health	75;20.16%
Economic burden in hospital	6;1.61%
Other ^a	18;4.84%
Influencing factors when choosing acute homecare	
Being admitted in hospital previously (n=217)	119;54.84%
Patient's anxiety during examination in hospital (n=351)	131;37.32%
Increased economic burden during conventional hospitalization (n=354)	243;68.64%
Previous traumatic event in hospital ^b (n=217)	37;17.05%

^aOther answers are: "pediatric recommendation", "because of COVID19".

^bTraumatic events include medical misdiagnosis, lack of empathy, and obstetric violence.

Table 3. Expected and final experience during homecare.

HEMECARE: CAREGIVER'S WELL-BEING			
	Expected experience (n=372) n;%	Actual experience (n=218) n;%	Fisher's exact test (p value)
Difficulties contacting healthcare team			
Yes	12;3.26%	2;0.92%	0.094
No	356;96.74%	216;99.08%	
Difficulties administering medication^a			
Yes	2;0.55	14;6.45%	<0.001
No	363;99.45%	203;93.55%	
Workload			
More ^b	57;16.19%	18;8.8%	0.091
Usual	236;67.05%	147;68.06%	
Less	59;16.76%	50; 23.15%	
Feelings at home			
Better	314;88.95%	171;79.17%	0.004
Equal	36;10.2%	40;18.52%	
Worse	3;0.85%	5;2.31%	
HEMECARE: CAREGIVER'S WELL-BEING			
Sleeping			
Better	262;67.24%	169;77.52%	0.449
Equal	88;24.79%	48;22.02%	
Worse	5;1.41%	1;0.46%	
Eating			
Better	236;67.24%	163;75.02%	0.091
Equal	109;31.05%	53;24.42%	
Worse	6;1.71%	1;0.46%	

Playing			
Better	298;86.88%	197;91.63%	0.105
Equal	41;11.95%	18;8.37%	
Worse	4;1.17%	0;0%	
Hygiene			
Better	213;60.34%	160;73.73%	0.001
Equal	134;37.96%	57;26.27%	
Worse	6;1.7%	0;0%	

^aIn the preadmission questionnaire, asked about problems during administration, parents declare fear doing it wrong. In postadmission questionnaire, 1/14 patients who had a problem when administering medication expressed it was not solved rapidly enough.

^bIn the postadmission questionnaire, only 5/18 caregivers would not repeat the acute homecare experience because of workload.

Table 4. Open-ended question about caregiver's feelings at home, some of the answers (n=40).

<p>Expressing fear/restlessness:</p> <p>"I was afraid my boy could get worse, and I didn't know what to do."</p> <p>"I have felt a bit restless and nervous because of lack of confidence, as I knew I didn't have a nurse 24 hours a day (...)."</p>
<p>Other feelings:</p> <p>"I've felt happier because I've been accompanied by my family and the health team, which has helped professionally and humanly."</p> <p>"I feel tired, but happy to see my child getting better."</p> <p>"What really helped was not having to entertain a 1-year-old girl in a hospital bed. She seemed quieter in her own environment. The medication administration produced me some anxiety at the beginning, but having seen this in hospital, after a while everything went smoothly (...). I also was very grateful with the hospital's training (...)."</p>

Table 5. Caregiver's opinion about the reasons why the child felt better at home and about the recovery.

Homecare: Why the child felt better at home	n;%
Because they were accompanied by their families and in their own environment	177;84.69%
Because the child had improved when transferred to homecare	16;7.66%
Both	8;3.83%
Other answers ^a	8;3.83%
Homecare recovery: Speed	
The same or faster than in hospital	175;81.02%
Slower than in hospital	41;18.98%

^aOther reasons were: “Because it is very difficult for her to eat (in hospital)”; “Because there’s no space in a hospital room to move, it’s really uncomfortable”; “She has everything at home: her bed, her bath, her hammock”; “He could rest at home, especially at night”.

Table 6. Comparing home-hospitalization and conventional hospitalization regarding information and care.

INFORMATION	Excellent n;%	Very good n;%	Good n;%	Regular n;%	Bad n;%	Very bad n;%	Fisher's exact test (p value)
Home-hospitalization (n=217)	179;82.49%	32;14.75%	4;1.84%	2;0.92%	0;0%	0;0%	0.014
Conventional hospitalization (n=218)	152;69.72%	49;22.48%	11;5.05%	5;2.29%	0;0%	1;0.46%	
CARE							
Home-hospitalization (n=216)	184;85.19%	28;12.96%	2;0.93%	2;0.93%	0;0%	0;0%	0.004
Conventional hospitalization (n=216)	157;72.69%	46;21.3%	10;4.63%	2;0.93%	1;0.46%	0;0%	

Table 7. Comparing home-hospitalization and conventional hospitalization regarding economic burden.

	n;%
Comparing economic burden in hospital and in homecare (n=205)	
Higher in hospital	124;60.49%
The same as in hospital	74;36.1%
Higher in homecare	7;3.41%
Extra spending because of home-hospitalization (n=218)	
Yes	33;15.14%
No	185;84.86%

Table 8. Home-hospitalization convenience.

	Mean;sd or n;%
Rating SJD a Casa (n = 217)	9.47;0.822
Repeating homecare if needed (n=215)	
Yes	211;98.14%
No	4;1.86%

Table 9. Improvements' suggestions (n=44).

Related to the telemonitoring dispositive:

“Wireless monitoring dispositive.”

“Being able to have the monitoring software in my phone, rather than having a tablet.”

Related to the healthcare team’s organization:

“To better specify visiting hours and medication scheduling, which must be difficult with so many children admitted to homecare.”

“To include transportation to hospital when the patient needs to be checked there.”

“Being myself mother and primary care physician, I think primary care should be contacted before discharge in case of chronic or complex patients.”

“To answer the phone quickly.”

Related to medical devices to administer medication:

“The nebulizer is too noisy”.

“The nebulizer is too slow”.

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