

Annual report 2015

Pediatric Advanced Home Care
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Introduction on the unit

Pediatric Advanced Home Care Unit was established in 2012. The unit was initially run in collaboration with the municipalities of Helsinki, Espoo and Vantaa. Since its launch, the unit has expanded and now provides services to all residents within the HUCH catchment area: Helsinki, Espoo, Vantaa, Kauniainen, Kerava and Kirkkonummi.

The purpose of setting up the unit was to reorganize home care for children with special needs, which had previously fallen under the remit of individual local authorities that found the provision of such services extremely challenging. The home care rings were created by various service providers, with no concentrated overall management of care. Today, the Pediatric Advanced Home Care Unit is in charge of all pediatric home care provision for children with specialized needs within the HUCH catchment area, including patients in need of tracheostomy management or ventilator treatment, or who have a severe form of epilepsy. Their treatment at home has to be arranged through care rings mainly consisting of practical nurses. All nurses are employed by HUS and managed by the nurse manager of the Pediatric Advanced Home Care Unit. In practice, pediatric advanced home care patients with a long-term illness are those who would have to remain in hospital care were it not for the home care ring service.

Besides home care for children with long-term illnesses, the Pediatric Advanced Home Care Unit provides home care in the case of acute illnesses and children requiring short-term care at home. Acute hospital at home care is provided by nurses in collaboration with doctors. In practice, this involves home visits of 30 minutes to 2 hours in duration, as frequently as the diagnoses and care needs require.

The Pediatric Advanced Home Care Unit employs one pediatric consultant, one nurse manager, one deputy nurse manager, six registered nurses (acute hospital at home), 32 practical nurses and a department secretary. In addition, the unit works closely with social services, nutritionists and rehabilitation instructors.

As a new format, hospital at home was fairly poorly understood among other pediatric units at first. To break down this barrier, our consultant and nurses have regularly visited departmental and doctors' meetings, in order to introduce the unit and its role. This has clearly improved cooperation between the home care unit and other pediatric units.

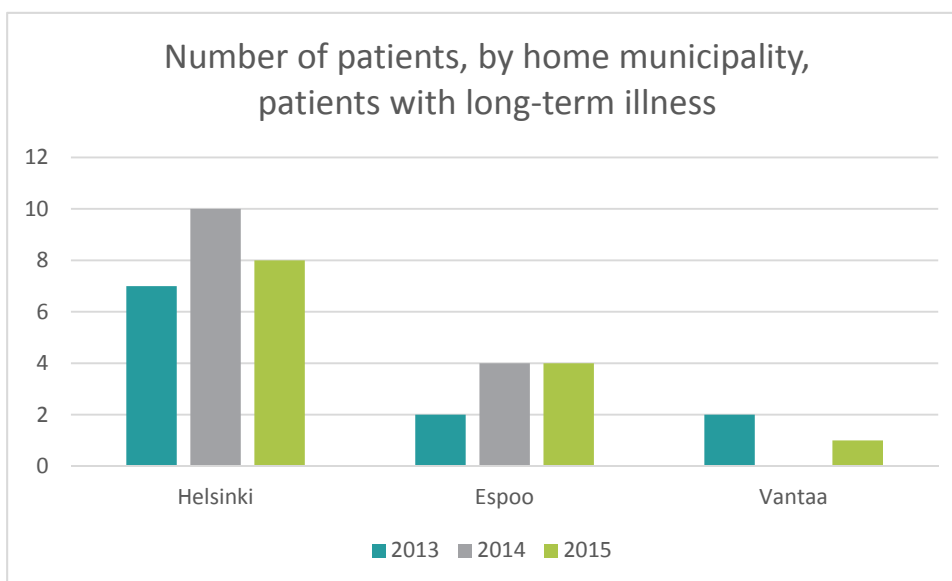
Pediatric advanced home care

HUS was previously unable to provide centralized specialized care at home for children. The pediatric cancer ward K10 has run its own home care unit, with resources dedicated to treating children with cancer at home. The Pediatric Advanced Home Care Unit was established in 2012, with the aim of provide safe, high-standard care for children at home. This is a new format in HUCH and was first piloted in Helsinki, Espoo and Vantaa. An assessment of the pilot was carried out 2014; based on the pilot's findings, it was decided that other HUCH catchment area municipalities – Kauniainen, Kerava and Kirkkonummi – should also join the unit. All patients of the Pediatric Advanced Home Care Unit are outpatients. Hospital at home is voluntary for the family in question. The patient and family must be suitable for hospital at home care in all respects and the arrangement must be safe for everyone concerned.

Care rings for children with specialized needs

The Pediatric Advanced Home Care Unit provides care for children with specialized needs due to a long-term illness, who would otherwise have to be hospitalized. Initially, the care was arranged around the needs of six patients with long-term illnesses. By 2013, the number of patients had increased to 11, by 2014 to 14 and in 2015 there were 13 patients. Each patient is cared for by a care ring consisting of practical nurses who work in the patient's home. Each ring comprises 1–5 nurses, depending on the nature of the care provided. The most common reason for employing a home care ring for a pediatric patient in 2015 was tracheostomy (7 patients). Other reasons for assigning a home care ring included ventilator/oxygen concentrator treatment (4 patients, for one of whom a respiratory paralysis decision has been issued) and a severe form of epilepsy (2 patients).

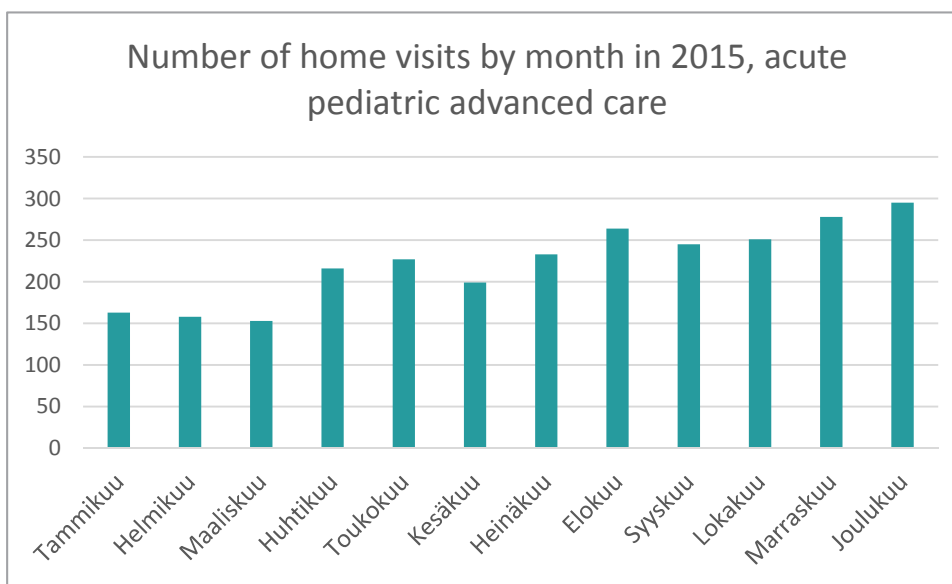
The children in Pediatric Advanced Home Care are treated under a consultant based on the diagnosis. Many patients have multiple health issues and are therefore under the supervision of several consultants. The Pediatric Advanced Home Care Unit's consultant coordinates the treatment and manages the compatibility of different treatments. When necessary, the consultant has made home visits to children suffering from a long-term illness. Regular visits are made in order to exchange tracheal cannulas and for the flushing of infusion ports, among other reasons. Home visits are also made to treat acute problems in patients with a long-term illness, such as infections.



Acute pediatric advanced home care

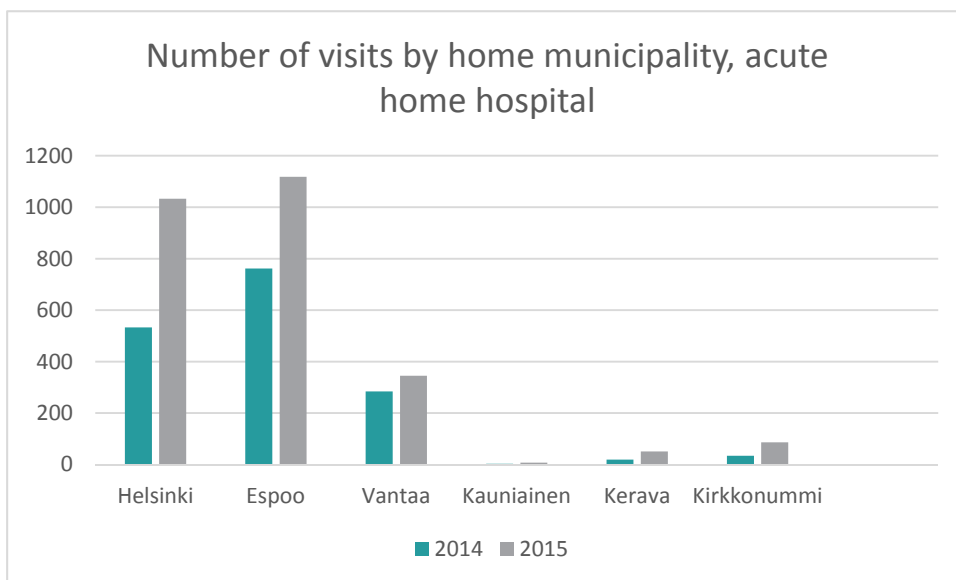
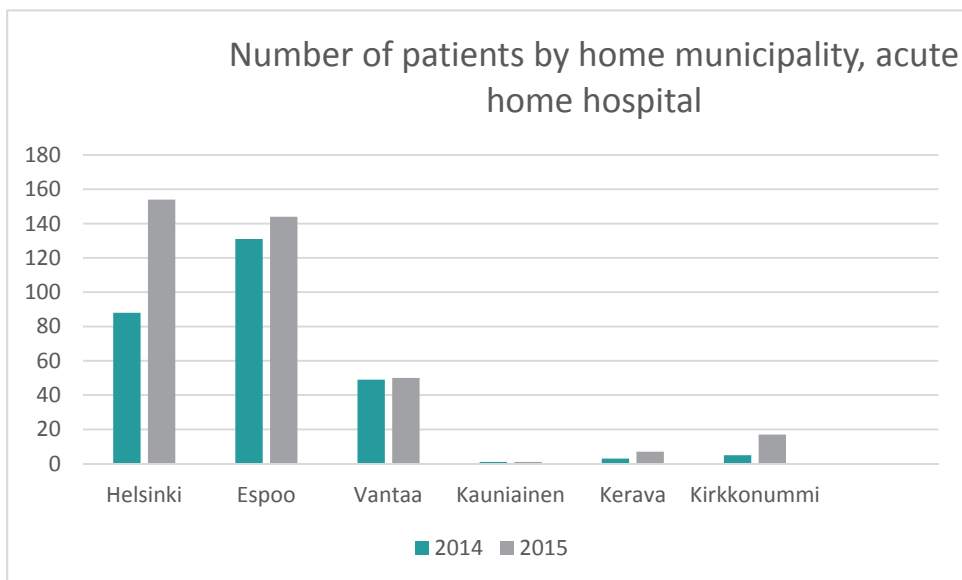
Acute pediatric advanced home care is intended for patients with acute illnesses, or those requiring short-term care contact. Such patients include children requiring intravenous antibiotics due to an acute infection. This group also includes children with long-term illnesses, such as cancer patients, whose care plan involves intravenous medication, taking lab samples or intravenous nutrition at home. Home visits for acute pediatric advanced home care are mainly carried out by registered nurses. If necessary, a Pediatric Advanced Home Care Unit consultant will also make a home visit.

At the beginning of 2015, acute pediatric advanced home care had one car in use for one nurse on duty at a time. The operating hours were from 7am until 10 pm every day. In April 2015, acute pediatric advanced home care acquired a second vehicle, allowing two nurses to be on duty at a time. One of the nurses initially worked during normal office hours only. Towards the end of the year, the operations were expanded so that for the most of the week there are always two nurses on duty.



In 2014, telephone consultation was still available between 10pm and 7am, giving the families of acute home care patients and care rings for patients with long-term illnesses the opportunity to consult a registered nurse during the night. Home visits were not made during the night and no new patients were admitted. In the spring of 2015, the decision was made to discontinue the night-time telephone back-up service.

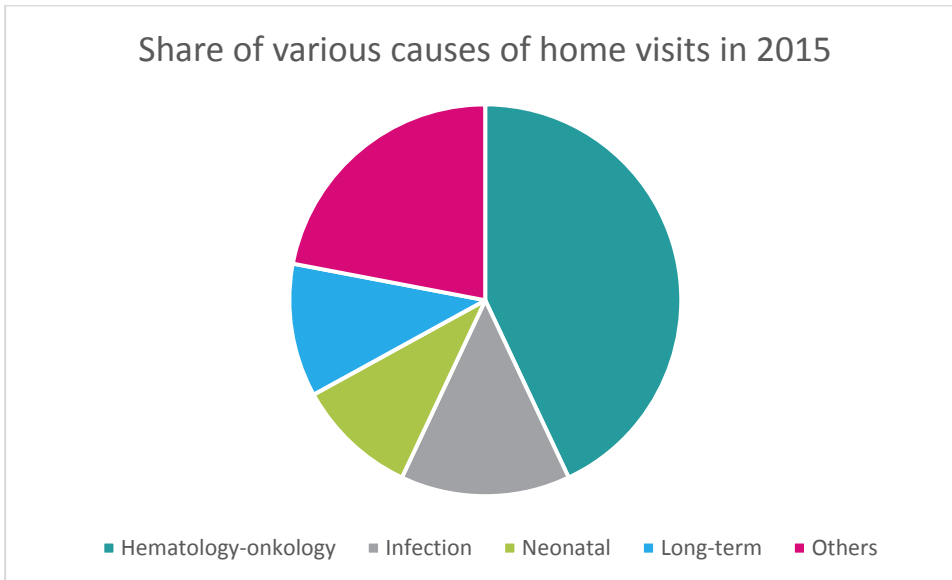
In 2015, the number of home visits for acute pediatric advanced home care made by registered nurses was 2,662, an average of 7.3 visits/day (2014 1653, 4.5/day) involving 373 patients (2014 281). The average number of patients per day was 6.8. One visit per day (for 2/3 patients) is made as a rule, with a maximum of 3 visits per day. The target is that home visits do not exceed 2 hours. Over 80% of the care periods are 1–4 days in duration.



In 2015, the reasons for acute home care visits were as follows: hematology-oncology 43% (2014: 12%), infection 14% (29%), neonatal problems (mainly infections and hyperbilirubinemia) 10% (17%). In addition, a number of patients were visited by the acute home care team who have been given a single, long-term diagnosis and are regularly visited by the pediatric advanced home care team. Visits to these patients accounted for approximately 11% (20%) of all home visits.

The increase in the number of visits and the proportion of hematology-oncology patients reflect the changes that have taken place in acute home hospital care during 2015.

Share of various causes of home visits in 2015



Most patients in acute pediatric home hospital care were referred by the Children's Hospital or the pediatric wards of Jorvi Hospital. In addition, emergency care units referred a small number of patients for home hospital care. Fewer than 10% of the patients were referred by the pediatric surgery or neonatal units.

Patient safety and quality of care

In 2015, the acute home hospital team developed a series of check-lists in support of the work of different patient groups, to be used as part of a patient's care and monitoring at home. These lists ensure sufficient communication of information between the nurse and doctor. The aim is to double check all medication dosages whenever the nursing rosters allow. The long-term patient care rings have paid attention to improving medication safety through measures such as providing guidelines for structured practices for checking drug combinations and dosages as well as care equipment. There are also written guidelines for emergency situations. The nurses attend CPR training at the Children's Hospital and the unit has organized its own CPR training during training days.

At times, the resources allocated for acute home hospital care have been stretched. In 2015, patients had to be turned away from acute home hospital care on 110 occasions (37 in 2014). These figures are probably even higher in reality.

There have only been a few isolated cases (fewer than 10 patients per year) for whom it has been necessary to refer a patient in acute home hospital care back to the hospital due to the deterioration of their health. This suggests that the selection of patients for home hospital has been successful.

In spring 2015, it was decided that telephone stand-by consultation by a registered nurse should be discontinued. This has somewhat increased the need for guidance and the risk of potential miscommunication when families are given different phone numbers for day and night-time consultation. It has also had a clearly negative impact, particularly on the care of terminal patients.

New in 2015

Ward K10's Pediatric home care provision was transferred to the Pediatric Advanced Home Care Unit

In spring 2015, home care operations at the Children's Cancer Ward K10 were discontinued there and transferred to the Pediatric Advanced Home Care Unit. At the same time, a second car was acquired for the acute home care team and was initially in service from 7 am till 3 pm on weekdays, with two nurses on duty. Following these changes, the number of home visits has increased and in diagnoses the emphasis is clearly now on hematology-oncology. The use rate of the second vehicle used by the acute home care team was increased in the autumn of 2015: it is now in service Mon–Fri from 7am till 10pm and Sat from 7am till 3pm.

Since the home care for Children's Cancer Ward K10 was transferred to the Pediatric Advanced Home Care Unit, responsibility for home-based terminal care has also been moved there. This also concerns child patients with illnesses other than cancer, who require palliative/terminal care. During terminal care, the home hospital team works closely with the doctor and ward in charge, on the basis of the diagnosis. In 2015, there were four patients in terminal care.

The preconditions and readiness for administering blood products at home have been developed due to the increase in the number of hematology patients in 2015. Nurses have completed the necessary courses and skills demonstrations. Furthermore, written guidelines have been drawn up on the administering of blood products in a home hospital setting, as well as instructions on possible hypersensitivity reactions. Administration of blood products at home will be fully introduced during 2016.

A practical nurse was added to the acute pediatric home care team

In autumn 2015, a practical nurse was added to the acute home care team in support of the team's registered nurses. At the same time, a third car was acquired for the team's use. This is expected to bring savings through lower taxi costs. The addition of a practical nurse has freed up capacity among the registered nurses for home visits, since the practical nurse can take over some of the other nurses' duties. The practical nurses are existing employees of the unit, who were transferred to new duties from the home hospital care rings of patients with long-term illnesses. Initially, two nurses were inducted in the new position. They mainly work during office hours. In future, the duties of the practical nurses will involve guidance and support for families with newborn babies in various situations (phototherapy for hyperbilirubinemia, eating problems, growth monitoring, discharge after a lengthy hospital period), and wound care and terminal care where appropriate, for example when a registered nurse's training is not required in care work. The practical nurse on the acute home hospital team also makes visits to patients with long-term illnesses in order to check and, if necessary, train home care ring nurses in recording procedures and the administering of medication.

Meetings with parents

In autumn 2015, meetings were begun for the parents of children with long-term illnesses. The purpose of this was to provide parents with a platform for meeting each other and freely sharing their experiences. All such meetings are attended by a team member from the advanced home care unit, who gives advice and ensures that parents have access to accurate medical information.

Challenges

The substantial increase in the number of hematological-oncological patients altered the profile of acute home hospital operations in 2015. The number of laboratory samples taken has increased, even though the home hospital team only plays a small role in the overall care plan of these patients. This issue has been raised for discussion with Children's Cancer Ward K10. In the future, responsibility for the monitoring of certain patients and, for example, the administering of blood products between rounds of chemotherapy, will transfer to the Pediatric Advanced Home Care Unit.

As the capacity of the acute home hospital team is expanded, the number of patients and home visits will increase. There seems to be a greater need for home hospital care on the wards than the unit is currently able to provide. The aim is to assign all coordination work to a single nurse on duty during office hours, which would free up the care team's time for actual care work while the coordinator manages communications with parents and other hospital units. The coordinator would also plan the day's schedule and the order of home visits. This would allow more time for each home visit, since those making such visits are free of administrative duties. The acute home hospital team does not currently have access to a coordinating nurse of this kind.

Lack of a data communication connection has markedly impeded home hospital operations and there has been no fundamental improvement in the situation. This means that home care rings for patients with long-term illnesses are unable to create electronic records and nurses do not always have access to the medical histories of patients. For this reason, nurses may not always be up-to-date with the most recent prescriptions, for example. The acute home care team's work is also impeded by the fact that home visits cannot be recorded in real time during visits.

Summary

According to international recommendations, children should be admitted to hospital wards only in cases where sufficient care cannot be provided at home or as an out-patient. It is in the best interests of both child and family to seek a situation in which the number of hospital stays and their length is kept to a minimum so long as this is safe with regard to the overall situation. Thanks to pediatric advanced home care, there is less need for admitting child patients into hospital wards. Home visits also enable a reduction in the number of out-patient control visits.

The Pediatric Advanced Home Care Unit looks after patients with long-term illnesses, children with specialized needs (with the help of the home care ring), as well as child patients with short-term care needs. The unit was launched fairly recently and is undergoing intensive development work. Its operations have been expanded gradually, as the need for more home hospital care has become apparent. More patients are currently eligible for home hospital care than the unit has resources to cover.

The Pediatric Advanced Home Care Unit provides high-level and safe doctor-led care in the child's own home. Families have welcomed the option of having their children treated at home. In the future, the role of advanced home care in pediatric terminal care will be increased in collaboration with the wards in charge of the patients' care. In time, expansion of pediatric advanced home care practices into other HUS municipalities may also be an option.



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