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When children “start to live their last days”: Two dying trajectories for children with hematological conditions

*You can't put yourself even for a second in someone else's shoes.
Mariana (Staff Clinician at the Hematology Unit)*

Introduction

In this last chapter I am mainly concerned with those instances in which children are experiencing their end of life, family members are witnessing their children's dying processes, and health professionals have to handle, on the one hand, the delicate situation of children experiencing the agony phase and, on the other hand, the relationship with parents and other family members who will need support from them. Therefore, what I will do in this closing chapter is to think about the co-experience of children's end-of-life processes in this particular clinical setting. The main question of this chapter is: How do children, families, and several health professionals deal with the end of children's lives? This question is framed within the larger context of my dissertation in which I show the social, medical and inter-personal process that starts before a child is diagnosed with an hematological condition and in the majority of the cases generates a vary degree of outcomes categorized as “X years of survival without illness.” In few cases though the outcomes are children, and everyone involved with them, experiencing their end of life. Still although numerically speaking there are few children dying at the Children's Hospital because of the impossibility of overcoming their diseases, qualitatively speaking the possibility of becoming a dying child is always latent and threatening children, families, and multiple health professionals. Here we will see how children, family members and several professionals deal with

the end of children's lives; some for the first time and others as a constant presence in their lives.

Vignette 1

One day while I was conducting fieldwork with the hematologists I followed one of the hematologists and one of the residents in their daily routines and we went to see Laura.¹ She had an ALL (acute lymphoblastic leukemia) type B that was diagnosed when she was nine-years old less than a year ago; Laura is in the PICU [Pediatric Intensive Care Unit] since three days ago. According to the Intensivists she is "bleeding all over; she has an acute renal failure... she is dying." One of the Intensivists talked with the mother and told her an awful prognosis, "she may die soon," he said. We find Laura's mother and her sister seating outside the PICU. Laura, the hematologist, is the one talking. She tells the mother and sister that she is very sorry of what is happening; she adds that they as a family and the hematologists did everything they could. The mother agreed and she says she knows everyone did everything they could. Laura says goodbye to the mother and sister and just two meters after we left them Laura starts to cry. Laura said that both her and the patient have the same name (Laura Emilia) and so from the very first time they met they made jokes about it and she built a good bond with her. So now seeing her dying was sad for Laura. (The mother will say after that she realized she was crying and she will thank to the hematologists for the good and honest relationship they had with her daughter.)

Medicalized end-of-life

¹ All names are pseudonyms. (This footnote should go the first time I mention a name).

Glaser and Strauss (1965) were the first to highlight the socio-economic and political changes in the medicalization and hospitalization of dying processes in the US and how these processes showed certain duration, shape, and implicit expectations; they revealed a dying trajectory. What they found back in the 1960s in the US was a generalized progression in the ways the end of life was handled in clinical sites and particular forms of medicalized dying trajectories (loosely generalizable to other places like Argentina –where the state and the right to access to public free health is always a contested field). From that time many studies have shown how end-of-life processes are constantly changing and how they are perceived, understood, and experienced differently throughout the globe (Lock 2002, Bluebond-Langner 1996, Scheper-Hughes 1992, Kaufman 2005). We are dealing here with one of the most powerful modern biomedical enterprises, what Baumann (1992) describes as the “modern strategy” which dismantles mortality by overcoming the unsolvable issue of death into many particular problems of health and illness, which are “soluble in theory.” Yet what actually happen when they cannot be solved? And how particular are these processes when looking at the end of children’s lives in the Argentine context?

The end of children’s lives are intense moments that may last hours, days, or even weeks if the child experiences her end of life either at an isolated room at one of the wards or at the PICU plugged into multiple tubes and stabilized with drugs. What is key to understand here is how three processes are co-happening: 1) children are living their end-of-life, 2) parents, siblings, and other family members are witnessing children’s end-of-life, and 3) different health professionals are not only doing what they can to influence this particular “dying trajectory” (Glaser and Strauss 1965) but also witnessing children’s end-of-life from their own professional and personal

perspectives, and 4) other children are witnessing these children die. Still the key element here is that in many cases it is almost impossible to foresee the end of children's lives; the usual definition of "terminal illness" (less than six months of life) does not work with children. Therefore, how much "awareness of dying" are children capable of experiencing, and can children be prepared to their own death, or is there a 'mutual pretense' as Glaser and Strauss (1965) found between children, families, and professionals when everyone pretend they do not know what they know? How do parents manage to witness the end their children's lives? These are bodies being mutually affected when a child is experiencing her agony phase. Then, what are children, parents, other family members, and different health professionals doing in those situations and how the end of children's lives affects them all? How do children do their end of life?

Vignette 2

One day I was conducting fieldwork with the hematology team at the usual mid-morning patients' review at their office, they were discussing the most critical patients of the day. Their main concern that day was Laura. One of the staff clinician said, "Laura is in multi-organic failure." Another hematologist stated, "I called the PICU [Pediatric Intensive Care Unit] and John, one of the Intensivists, told me 'she is worst than yesterday, in fact, she is not worst than yesterday, she is way worst than yesterday.'" And then she added, "he is very cold", she remembered that when Julia died John told her mother, "your daughter has died, don't cry, don't cry, you are going to be fine, and you also have to do a lot of paper work." They also recalled that another Intensivist came and told him that he should not do that and then she tried to ease the mother's pain and they both cried together. They were talking about this

when the secretary of the Hematology Unit opened the door saying "They called you from the PICU for Laura." Everyone stopped what they were doing and many pronounced simultaneously "Did she die?" Another hematologist said, "If she died we have to go and talk with the mother." One of the medical resident immediately left the room for about ten minutes, the patients' review continued, and then she came back and said "They [Intensivists] are not going to send the basic [blood count], they are going to send nothing, she has a BP [blood pressure] of 25, and they say if we want we can go and talk with the parents."

Laura's body was sustained with drugs, the Intensivists were delaying her death to let her father arrive and say goodbye to her. Laura's main doctors were the hematologists; they were the ones that gave her chemotherapy treatment, at that time she was going through the 'maintenance phase' with lower doses of chemotherapy. Four days before I saw Laura and her mother in one of the clinical check-ups. She looked tired and pale. When the staff clinician at the Hematology Unit checked her she instantly realized that Laura was not good: she had an oral mucositis, she had also vomited the previous night. Chemotherapy was suspended and they decided to start with antibiotics right away and to hospitalize her in the first isolated room they could find at the hospital (it was in the midst of the winter and the hospital was packed with children with bronchiolitis). One of the hematologists tried to find a bed for her without success all morning and afternoon. Laura was supposed to come for a check-up the day before but someone wrote the day wrong and the mother was going to bring her the following day. The hematologists had to call and ask her to bring Laura that day (they knew she was not good when the mother told them she could not eat for two days because of the mucositis). By 3pm Laura had a septic shock at the "Day Hospital" within the Onco-Hematology Unit where children receive chemotherapy

and blood transfusions. At that time there was a seventeen-year old boy receiving chemotherapy that saw how nurses and residents started to expand Laura with fluids, gave her oxygen, and had to transfer her to the PICU.² He witnessed something that could potentially occur to him. One of the hematologists told me that it happened once at the "Day Hospital" that one child got a crisis, and then as a domino effect another child got a crisis, and another, an another. And when they were able to stabilize one, another was getting a crisis. She said, "when they see what is happening to the other children, it's like, it affects their mood and they get worse."

(Often) Long illness processes

As we have seen throughout the previous chapters children with hematological conditions experience a long illness process. Since diagnosis they endure a lengthy treatment punctuated by the different phases of the chemotherapy, and they seldom have to go through radiotherapy and/or transplants as well.

By the time treatment is in fact not working and the illness advances unstoppable children, families, and the hematologists have gone through countless meetings, check-ups, and hospitalizations; children have experienced hundred of pricks for blood being taken, dozen of lumbar punctures and less than dozen bone marrow examinations, among many other procedures. Throughout these months, and often years, children, families and several professionals have built a relationship. Which most likely will influence the way children, families and professionals are able to handle the end of each particular child's life.

In the majority of the cases of children dying at the hospital they have been under treatment for more than six months. Though in few cases children died just at the

² When a patient has a massive septic shock the first step health professionals take is to 'expand', which is to introduce IV fluids into the body so the blood volume is expanded plus giving oxygen. This is done because there is generalized crisis, a 'systemic inflammatory response syndrome.'

beginning of treatment. In one occasion I observed a thirteen-year old girl with down syndrome who came with her middle-class family from a small city in the province of Buenos Aires. She was sent to the Children's Hospital after a routine lab results showed abnormal white blood cells count (children with down syndrome have a higher risk of developing hematological conditions –in particular leukemia). Only seven days passed since the day she was diagnosed and started treatment and the day she died. I just heard that she died in the midst of a hectic morning, and it seems it did not impact so much to the Hematologists given their unfamiliarity with the girl. But this is not usually the case. In general, children will be medicalized, hospitalized, and utterly exhausted by the time they start to experience the end of life.

Vignette 3

Following with Laura's "dying trajectory", the day she died we went to the PICU and I wrote on my notes:

Laura has a breathing of 28, she is supported with drugs to let her father arrive to the hospital to say goodbye to her, according to the hematologists she is 'technically dead', she has her nails black, 'she is not here anymore' one hematologist told me. I went with three hematologists to the PICU and they get into the therapy where Laura (among 11 other children) is plugged to tubes and machines, I stay outside observing from a distance. During this time there is a constant and hectic movement of nurses, residents and staff going and coming and there is this intense noise of all the PICU's machines working together. The hematologists spent like 10 or 15 minutes with Laura's mother and sister close to her bed.

One of the hematologists, the old one, seem to be talking more to the mother and sister, the other two were in silence. One of the hematologists gives caresses to

Laura’s mother on her back. For a moment (5’?) they all stay in silence. Then I see how the hematologists say goodbye to the mother and sister and one also to Laura.

They all leave the bed and come to the medical station where I am.

Mary [staff clinician]: This moment is terrible, and it makes worst the coldness of the PICU...

Rafael: Why do you think this moment is terrible?

Mary: You can’t put yourself even for a second in someone else’s shoes, because as a mother if you put yourself on this mother’s shoes you can’t go on...

Two basic processes

While conducting fieldwork at the Communicable Diseases Unit, where children are often hospitalized for months given their ups and downs with the long chemotherapy treatment and its effects on their immune systems, I was able to observe many children experiencing their end of life.³ What I have found is that there are two basic dying trajectories occurring at the institution. Either children deteriorate fast, experience a septic shock or other major crisis at the ward, and are transferred to the PICU where they may eventually die. Or, they can be under certain control; their symptoms and overall quality of life can be managed by the ward staff and may eventually die at the ward. These two occurrences create a huge difference in terms of children’s dying trajectories and the ripple effects on families and professionals. At the ward their families, friends and the familiar faces of different health professionals may surround them and both children and parents may have a bigger chance to interact and have some “control” over the situation. **For example, XXXXX**. Whereas at the PICU both children and parents will be subject to all sorts of technical and

³ I was not able to go to children’s houses and observe children dying outside the hospital (which happens but less often) so I am only referring to instances that happened under the close clinical gaze of the health professionals within the Children’s Hospital.

bureaucratic regulations and often will have to follow strict procedures set by the PICU staff. In fact, in almost all the cases children will be sedated even if they were conscious and able to respond.⁴ (So here we will find less doing for children and less possibilities for families to interact with their children.)

In the following sections I will discuss these two processes and I will do it having in mind that they are almost like ideal-types or models (some examples will illustrate these models and some will not fit so much). In these two models the first will focus more on children's dying experience and the second on professionals' perspectives and management of children's end of life.

"Inward" Processes: Dying at the Ward

Dying at the ward gives the possibility, not always present, of increasing the "awareness of dying" to the children and everyone involved with them. Depending on their age and how alert they may be, children may know that they are going to die. Accompanying and witnessing the end of a child's life is a complicated process. Not everyone is on the same page. Parents may always keep expectations and hope for recovery; some may resist the inevitable, some may avoid thinking about it, and some may accept that their children are dying. Children may try to protect their parents and may need to hear that they will be fine. The head of the medical residents at the Communicable Diseases Unit told me that

In the case of children that experience a dying process in which one can accompany them, it's like, what happened with this child Pedro, his mother was all the time, like the child wanted something, and the mother was asking "What do you want? Do you want to pee? Do you want to pee?" And I would tell her "Just

⁴ In fact, it would be a nightmarish experience to be conscious on a place where lights and loud noises are constantly present 24/7. So what happens is that children are sedated even if they could be alert and communicative.

let it be." And the mother would again ask, "Do you want to drink water? Because you will be dehydrated." We told her we took fluids away so she was worried about it⁵. So I told her, "Analía, stay calm, he will be OK and he will decide what he wants, and we want him to decide what he wants."

This attempt to let children decide, or at least try to let children have a say (as much as they are able given their constrained options) on their own dying trajectories is in direct opposition with the situation at the PICU. The head of the medical residents also told me that she often advises mothers "tell her that everything is fine, tell her to stay calm. That she will be OK and you will be OK too." And she does that because

...Children in general they don't want to go when they see there's something [that may worry their parents]. So the day when parents tell their children "go, stay calm, rest, you will be fine" the child dies. It happens like that.

Of course, these possibilities of "inward processes" do not always occur nor the conditions are always present for them to occur. What we see here is how people create (or attempt to create) meaning of children's last trajectories. Health professionals struggle to give meaning to those experiences that... the failure of medical professional... not trained to let people die...

I call them as "inward processes" to highlight the progression of children "getting toward the inside" without the external manipulation and regulations present at the PICU. Still, we do not actually know what happens within children's (or any dying person's) mind. Needless to say, I am also referring to them as "inward" oriented

⁵ During the agony phase doctors will slowly reduce the amount of solids and liquids to help children go through the last days. In those cases the body is shutting down and having too much fluids or solids will create more stress on the body. Parents usually understand it but given the symbolic associations with foods there are constant debates and negotiations between parents and professionals. In some cases professionals will allow parents to give a little bit of liquid but often no solids in the last days. For an overview discussion see Buiting et al. 2007.

processes in contrast to what happens at the PICU, but they may produce different outcomes in all the different actors. Indeed, we may only find small gestures, like Luis who was nine years old and had cancer, and the night before he died he hugged and smiled to his parents although he was not moving his arms for months because of pain. In many cases, children may try to protect their parents and think, "I don't want to let my parents down. They've done everything for me." (Bluebond-Langer et al. 2010: 331). It can also be that health professionals need to believe that children are doing something, whereas at the PICU they do nothing. In fact, another medical residents told me that when Pedro died:

...He asked his cousins to come, he said goodbye to them, he talked to them, he asked his favorite food, he did everything, and then he died... Until he saw that his parents, uncles, all his family were united... and it always happen, until the child does not see the person he wants to see before leaving he doesn't die...

What is important to highlight is that, in contrast with the homogenous experience of dying at the PICU, when children die at the different wards (those that have isolated rooms since children with hematological conditions cannot be hospitalized in a general room) there are a wide gradation of dying trajectories children may experience. The notion of "inward" in this context has a double function; it contrasts with the more "outwardly" oriented PICU and it reminds us of the dissolution process that is occurring in front of everyone's eyes. However, we should not assume that every single child would go through a getting-inside process. From what I observed and listened, and from what others told me, in many cases children would go through a mixed process of absorption in which they seem to be "disconnected" and moments

in which they are alert talking and communicating with their parents, families, and health professionals.

"Outward" Processes: Dying at the PICU

When any patient (adult or children) is sent to an intensive care unit it is because the patient is experiencing an acute life-threatening situation. Within the PICU children are being constantly monitorized, filled with dozen of drugs, and their organs and basic body functions closely measured. Multiple monitors and pumps are connected to the body and in almost all the cases children are kept sedated and unconscious.

Furthermore, parents can only see their children for very short periods of time. So the whole situation is less conducive for social interactions and accompanying children's dying processes. The head of the medical residents highlighted to me in an interview

...It's like these children that are sent to the PICU don't go through a process in which they realize that something is going on and there's a change. Besides, to me it's horrible, so when a child that is in a terrible situation, when we transfer him to therapy [PICU] and he died there, to me it's the worst scenario...

All the intensive care units have an aggressive therapeutic approach and that is what saves lives. But then, when they help to overcome the urgency, the situation changes for children with hematological conditions who often have experienced a very long deteriorated process. Because they may not overcome the acute moment and go back to a "normal" life, they will eventually die at the PICU⁶. Indeed, one medical resident gave me the example of taking a plane, when children are sent to the

⁶ One of the medical residents that were rotating at the Communicable Diseases Unit while I conducted fieldwork told me that when she rotated at the PICU there was a case of a two-year old girl with a myeloproliferative disease (an hematological disease of the bone marrow) who was under mechanical ventilation and with continuous internal bleeding, with low platelet count, and with countless transfusion. The bioethics committee decided to take the breathing support and other measures and everyone was expecting her to die. But one day she started to get better, they took the respirator and did a tracheotomy and she got better and was taken out of the PICU when everyone expected her to die.

PICU "is like they are taken away from one place and put them into another, it's like you don't have a process of ... transportation." Another medical resident put it this way, "...those who go to Therapy [PICU], well, you don't see them, and it's like a sudden, horrible thing, they die in a manner... it's like they are taken away..."

This idea that children when transferred to the PICU are taken away made me think on the big differences between dying at the PICU or at the ward. At the PICU children are sent because they have to be sent, it is a major crisis that cannot be controlled by residents and staff at the wards. So children are quickly transferred to the PICU with the aim of overcoming the crisis and with the hope they will go back to the ward to be with their parents and families. But often that is not the case and children may experience their end of life at the PICU. This is a high-tech and crowded place filled with machines, mechanic ventilators, and all sorts of monitors, tubes, and constant noises. Children are almost always intubated and monitored 24/7. In the majority of the cases children will die unconscious. The notion of "outward" here merely described the functioning of the PICU with its set of rules and regulations that control every aspect child's dying process. Children's body (and consciousness) is oriented to an outside that regulates every bodily basic function. Like in the case of Laura's death, her mother and sister were only able to see her for some few minutes; the father could see her because Laura's was stabilized with drugs to delay her death. But they were saying goodbye to an unconscious Laura surrounded by eleven more unconscious children plugged to machines, tubes, pumps, etc.; and two dozen of professionals between nurses, Intensivists, and medical residents running from one place to another. In the following section I will focus on the professionals' perspectives on the last days of children's lives.

"Semiology of the scene": the agony phase

Once I was talking with Alberto, one of the doctors at the Palliative Care Team, about the kinds of processes that are triggered when a child is going through the agony phase. My questions were focused more on the types of mutual affectations that were occurring between the child, her family and the several health professionals assisting them. He then narrated a cinematographic description of the last days of Pedro (the same child the head of the medical resident was referring before). He went to assist Pedro and the medical resident that was on duty that night when Pedro was supposed to die. Here we will see what he called as the "semiology of the scene", the wider picture of a ward that is temporally revolutionized by experiencing the agony of one child, which according to him, is better seen when looked upon with a holistic and wide approach.

So when you have a patient, in this state of sepsis the way to approach it, even a R1 [first-year Resident] that started last week knows it, is in a global manner. You have to expand it, give oxygen, no one would say why, may be someone would not know why is doing it, but if that patient is septic you have to give oxygen, even if at the beginning it was a urinary infection, and you may ask what oxygen has to do with it. But the whole body is suffering, right? This is a systemic approach to something that initially was focalized. So when I arrived to the ward [to assist Pedro], we came with Mónica [from the Palliative Care team], I started to pay attention to things that I haven't noticed before, something that can may be called as, we doctors are very habituated to produce a semiology of the patients, this could be called as the semiology of the scene. So I was observing the patient, his family, how was the doctor treating the patient, how was the doctor in charge of the treating doctor, how were the doctors that don't have anything to do with

the patient, how were the nurse, how were the mother or the father, how were the uncles that were outside, I would even say how were the other parents that know this mother. The analogy would be, if a patient in the communicable diseases unit has pneumonia for the system of this unit this is a focal problem, but when patients start to live their last days, my sensation is like if it was a systemic inflammatory response syndrome that threatens the whole ward. It threatens to everyone, the resident in charge, the others that are not in charge, so you start to see a lot of reactions; you see the one who is scared, the one that says, "How can I help you?" You see the resident that says, "I am going to look for the MRI results" and disappear.

So I asked Albert how he approached this scene and he said:

My sensation was that the only way to approach it in its totality, or as globally as I could, was trying to take into the account all these characteristics of the scene.

Why? Because I believe, and here I am going to something more concrete, a sort of reflection, all the doctor not matter how much we presume about our most open view we always end up looking at a part, for many different reasons, so my question was: how much efficacy are you losing when you are narrowing down your view? How much efficacy the treatment loses when we don't approach the global scene?

Alberto's question, in other words, is similar to the question I aimed to develop at the beginning of the chapter: how does the end of children's lives is dealt by children and those closely involved with them? According to what different professionals and parents told me this seems like a vortex in which some try to help, others try to escape, other parents try not to bother and stay locked inside their rooms, everyone is more silent, it is hard to know exactly what to do. Alberto points to the fact that very

often medical residents in charge of the night shift are overwhelmed. In this particular case, when Pedro was dying, the second-year medical resident was totally overwhelmed; she called her mother and her psychoanalyst many times during that afternoon. Alberto went back again in the late afternoon to talk with her and with Pedro's family, and both Peter and his family and the resident were calmer. This is not something that is taught in medical school, how to accompany the dying process has to be learnt while experienced, and it can affect not only the medical resident in charge but also everyone that is in contact with that child. In the middle of that moment, when Alberto was talking with the resident in charge, according to Alberto an "oncologists' sub-scene" happened:

Oncologists came yelling, "How come you didn't hang the sedation if he is going to die in five minutes?" The patient died five days later. Oncologists crying, oncologists yelling, and yelling, and one minute later they are all gone. Eight oncologists entered to the patient's room to see the patient and give the condolence, and five minutes later, not even, one minute later there were no oncologists at the ward. And they yelled how we didn't give the sedation that was being prepared by the nurses.

Children and families need some time for preparing for the child's death but no one knows when death will come. In fact, what happened with Pedro's death is that he did not die that day but five days later. And the medical resident who was overwhelmed when Pedro started his agony phase was the same that was on duty the last night when Pedro died. And she said "he waited for me," and Alberto told me "but he didn't wait just for waiting, he waited for the best version of her."

Let them go?

One thing that also appeared on my observations and interviews was the notion of parents at one point during the agony phase needing to give permission to their children to die. One doctor at the Neuro-Surgery Unit once complained that one child's agony was prolonged because his parents "didn't let him go." But, can we imagine what it would be like doing that? On the other hand, one mother of a four-year boy told me, "Why he has to suffer so much? Why he can't go and rest?"

What I am trying to show here is a glimpse of this complex and intense continuum between "acceptance" and "negation." Even in those cases in which children, parents, and other family members will all accept the inevitable death each dying trajectory will be influenced by the particular setting of the hospital and the connections children, families and professionals will be able to create. Still, this does not mean that facing the end of children's lives is easy. After we heard that Laura died I was with one of the hematologists getting out of the Hematology Unit and she told me "I have to go and guzzle the energy from the other children of the other units to feel better." And I wondered that day, and again now, what does it mean her need to absorb the energy of the other children to feel better after the death of one of her patients?

As we have seen in Chapter 6, children experience pain and suffering throughout the long treatment and during the agony phase as well. Alberto, the doctor from the Palliative Care team summarized what happened with Pedro's death:

It was good that Pedro died, that he could die, as many times happened, when his parents let him, neither before nor after.

And then he points directly to the fact about how children's death affects all

... I thin everyone that feels bad about the death of a child they are not feeling bad about it, they are without realizing absorbing the bounces of that death. There are

myriad of possibilities of identifying with the elements that conform the death. Some identify with the child's suffering; others don't even register the child and identify with the mother; of course, this happens in more unconscious levels because there is always the child dying there...

Often, medical residents, the ones that are closer to children and families in the everyday of the hospital are unable to anticipate how parents will react to their children's death. One of the residents at the Communicable Diseases Unit told me:

Very strange things happen, for instance, the mother of Alex came to give thanks to all of us for our efforts and everything we did for Alex, for her, and her husband. She told me they learnt a lot from Alex, especially the way she lived her end of life. Everything she told me is still striking me, I cannot understand it, but at the same time, from the first moment we realized that Alex's mother was different, that Alex's parents lived the whole process in a different way. Alex's mother told us that her daughter was very smart. It seems they had everything more internalized than other parents; they all had a different inner maturity, and Alex as well. On the contrary, with the father of Denise it was the opposite. It seemed they had it all assumed and processed but when Denise died he behaved like crazy, he destroyed all the room, he broke the window and cut his hand.

Evidently, there are multiple reactions to children's death. For instance, Laura's mother told the hematologists, in particular, to Laura (the hematologist that had a good bond with her daughter) that she thank her and the rest of the team for everything the did and for the good connection they had. She also thanked them because they always explained to Laura everything and they also warned the mother

that there was a chance that treatment may not work. She asked them to keep trying to cure all the children. She was fine because she knew that both the family and the hematologists did everything they could but it was not enough.

Conclusions: Multiplicity, Simultaneously and the Co-Experience of the End of Children's Lives

In this paper I have described two different processes in relation to how children and others experience the end of children's lives at the Children's Hospital, one that I portrayed as more "inward" and another more "outward" oriented. In both cases the kinds of connections and mutual affectations and the ways children, family members, and professionals are able to interact and to process children's end of life are strikingly different. When children have had a long illness trajectory, and a long treatment, a multiplicity of actors are simultaneously experiencing the end of children's lives. This co-experience has to be understood in its complexity since children, families and professionals will have a different experience if the end of children's lives occurs at the PICU or at the wards of the Children's Hospital.

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