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Medication adherence after pediatric allogeneic stem cell transplantation: Barriers and facilitators

Delphine Hoegy[a,b,c,f,*], Nathalie Bleyzac[a,b,d,1], Chrystèle Rochet[a], Humbert De Freminville[c], Cécile Rénard[a], Kamila Kébaili[a], Yves Bertrand[a,e], Claude Dussart[b,c], Audrey Janoly-Dumenil[b,c,f]

[a] Institute of Pediatric Hematology and Oncology, Lyon, France
[b] Lyon Public Hospices, Lyon, France
[c] EA4129, Systemic Health Pathway Laboratory, Lyon, France
[d] EMR 3738, Therapeutic Optimization in Oncology and Hematology/Oncology, Lyon, France
[e] University of Lyon I, Villeurbanne, France
[f] Pharmacy, Centre Hospital Group, Lyon, France

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ABSTRACT

Purpose: Immunosuppressive therapy following pediatric hematopoietic stem cell transplantation is essential for the patient's prognosis, as the antibioprophylaxis and the isolation measures. But medication adherence is suboptimal for children and adolescents, from 52 to 73% in literature. The aim of this study is to provide an understanding of medication adherence after pediatric allogeneic stem cell transplantation (SCT), by identifying facilitators and barriers.

Method: Semi-structured interviews were conducted by a pharmacist with caregivers and healthcare providers in a pediatric centre. Four topics were discussed: transplantation, post-transplantation therapies, caregivers' experience and the healthcare system. Interviews were audiotaped, transcribed and analysed by inductive approach.

Findings: Semi-structured interviews with 15 caregivers and 21 healthcare providers identified factors of medication adherence and hygiene measures. The long-term nature of therapy and difficult transitions of care were identified as major barriers. Recognizing the benefits of medication and parental involvement are facilitators. Furthermore, caregivers expressed the need to take into consideration the family entity. They would like also to receive earlier information from healthcare providers before hospital discharge. Those needs were not always identified by healthcare providers.

Conclusion: This analysis revealed barriers and facilitators to the medication adherence and to the care. It demonstrated similarities and differences between caregivers and healthcare providers' perceptions and has thereby initiated an improvement process of the healthcare system. As part of this process, medical and paramedical healthcare providers at this French pediatric centre are currently working on a support program for post-alloSCT hospital-home transition.

1. Introduction

Pediatric allogeneic hematopoietic stem cell transplantation (alloSCT) is followed by immunosuppressive therapy accompanied by prophylactic antibiotic therapy and hygiene recommendations. This post-alloSCT therapy is essential for the patient's prognosis (Locatelli et al., 2000). However, post-alloSCT pediatric medication adherence is suboptimal, ranging from 52 to 73% (McGrady et al., 2014, Phipps and DeCuir-Whalley, 1990).

The 5 determinants of medication adherence are: factors related to the patient, the disease, the therapy, the system of care, and socio-economic factors (World Health Organisation, 2003). All those factors help to understand health-related behaviours as medication adherence (Brown et al., 2016, Unni and Farris, 2011).

With the aim of understanding medication adherence and recommending adapted actions, individuals' perceptions have to be taken into consideration. In fact, individuals' perceptions are the basis of their reasoning and emotions and therefore influence the construction,

* Corresponding author. Pharmacy, Hôpital Edouard Herriot, 5 place d'Arsonval, 69003 Lyon, France.
E-mail address: delphine.hoegy@chu-lyon.fr (D. Hoegy).
[1] Poison Control Centre, Lyon Public Hospices, Lyon, France.

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adoption as well as changes in their health-related behaviours (Leventhal et al., 1995; Nascimento-Schulze et al., 1995). This psychosocial concept can explain health-related lifestyles and behaviours such as medication adherence (Bergman, 1998).

The qualitative approach is interesting to explore the perceptions of the population studied without any *a priori*. It also allowed identifying factors of medication adherence, barriers and facilitators.

In pediatrics, the role of the caregiver, who is usually the parent or legal guardian, is central to the patient's care and their adherence to medication. This is why it is essential to explore parents' perceptions, especially for young patients (Baudrant et al., 2007). It also seems worthwhile to explore healthcare providers' (HPs) perceptions because this is an important step in improving the system of care. It provides knowledge of the similarities and differences in perception between HPs and caregivers (Fiks et al., 2011, Street and Haidet, 2011).

To our knowledge, caregivers and HPs' perceptions of the disease and its therapy during the pediatric post-alloSCT period have never been explored. The aim of the study was to provide an understanding of medication adherence after pediatric allogeneic stem cell transplantation (SCT), by identifying facilitators and barriers.

2. Methods

The research took place in a hospital specialised in pediatric onco-hematology. Semi-structured interviews were conducted by a pharmacist (DH), dedicated to this research and with prior training in methodology.

2.1. Participants

The inclusion criteria for caregivers were: being a caregiver (parent or legal guardian), > 18 years old, of a patient in the post-alloSCT period who was receiving immunosuppressive treatment. The exclusion criteria were: having a level of understanding of French incompatible with a semi-structured interview, being a caregiver of a young adult (> 18 years old) and/or having an early post-therapy complication when asked to participate in the interview (primary graft failure as incomplete chimerism, or early relapse of the malignant disease).

The inclusion criteria for HPs were: being a medical or paramedical HP in the study centre and being involved in the direct care of alloSCT patients.

2.2. Study design

Prior to inclusion, two guides were drawn up by two pharmacists (DH & AJD) for the interviews with caregivers (Fig. 1) and HPs (Fig. 2). They were based on determinants of medication adherence (World Health Organisation, 2003). They were validated by a multidisciplinary team (pharmacists, haematologists, oncologists, psychiatrists and nurses) and by a test interview. The four themes that were discussed were: alloSCT, post-transplantation therapies, caregivers' experience and the healthcare system.

The caregivers were asked to participate in the interview after approval by the physician in charge of care: before coming to the hospital, by telephone if the patient was monitored by monthly follow-up visits (FV) or at a day hospital visit (DHV). The interviews were conducted during a DHV or FV.

The HPs were invited to participate in the interview during their working hours. The interviews were conducted at the hospital.

For both groups, participants were included until no new data were collected (data code saturation) in the investigator's (DH) opinion (Hennink et al., 2017).

All the interviews were realised in private and were audiotaped.

2.3. Data analysis

The audiotapes were manually transcribed without rephrasing and in the same format while the interviews were being conducted. The study material was then analysed manually by inductive approach according to Thomas (2006). Three steps were realised by each analyst. First the raw text was read; second the analysts created categories by identify specific text segments. Then the analyst reduced and organized the categories. Both analysts (DH & AJD) then pooled their analyses by resolving differences in opinion by consensus; there were no inter-coding calcul.

2.4. Ethical considerations

Before starting, this study was presented and approved by the Lyon Hospices Civils ethics committee in March 2015. It was also registered at the French Data Protection Authority in February 2015.

3. Results

3.1. Participants

Caregivers: Fifteen interviews with caregivers were conducted from April to September 2015. Their sociodemographic characteristics were presented in Table 1. The majority of participants were mothers (12) approximately 36 years old (22–43). The patients were five years of age (0.5–17.0) with two siblings (1–4). The patients had different types of graft: 8 file, 5 related, and 2 cords. Six patients were present during the interview: they were four and an half years old (1.5–7). The number of medications prescribed on discharge from hospital was on average 8 (4–13). The average period between alloSCT and the interview was 99 days (57–177), and between hospital discharge and the interview was 54 days (8–151). The average interview length was 15 min (7–39).

Healthcare Providers: Twenty-one interviews with HPs were conducted from September to December 2015. HPs were 11 nurses, three child minders, two residents and five doctors. Their sociodemographic characteristics were presented in Table 2. Ten worked in the transplant department, five in the day hospital, and six divided their activities between the two services. The average experience of the HPs (excluding residents) in the centre was more than six years (1.5- > 10 years). The average interview length was 11 min (6–21).

3.2. Caregivers and healthcare providers' perceptions

3.2.1. Allogeneic stem cell transplantation

Parents had an ambivalent opinion of transplantation: relief and re-birth. *Transplantation is the way out from everything. It means finally putting the disease aside, giving everyone a chance* (Caregiver 1). Parents hoped for recovery. *What you see is recovery* (Caregiver 13). However, transplantation was very stressful and demanding for them, especially the conditioning, complications and the isolation due to extended hospitalization.

In the HPs' opinion, parents were ambivalent about transplantation: it is a re-birth. *It is the treatment that will heal their child for good, the miracle treatment!* (Nurses 2). But it was also very distressing and demanding, from pre-transplantation to post-transplantation, including the isolation due to the long hospitalization. For the HPs, before any explanation parents saw transplantation in a different light from the reality. *Many of them think it is an operation.* (Doctor 3).

3.2.2. Post-transplantation therapies

Parents expressed the benefits of post-transplantation medications. However, they expressed being “sick and tired”, especially due to the long treatment period, the bad taste of cyclosporine syrup, the large quantity of medications, the strict administration times and the difficulty manipulating medications. *It was really complicated … you have to*

KEY THEMES	QUESTIONS
AlloSCT	- In your opinion, what is allogeneic stem cell transplantation? - How did you cope with this transplantation?
Current post-transplantation treatment	- Since returning home, which treatment has your child been taking? - What do you think of this treatment? - How does taking the treatment go on a daily basis?
Facilitators of treatment adherence	- What encourages you to give your child these treatments?
Barriers to treatment adherence	- What prevents you from giving your child these treatments?
Healthcare system	- Do you think the organisation related to your child's transplantation is appropriate? - How have things been going with the healthcare teams since discharge? With doctors and nurses?
Summary	- Is there anything else you would like to tell me? - Rephrasing what was said

Fig. 1. Guide for conducting interviews with caregivers.

KEY THEMES	QUESTIONS
AlloSCT	- In your opinion, what do parents think allogeneic stem cell transplantation means?
Caregivers' experience	- How do they cope with this transplantation?
Current post-transplantation treatment	- In your opinion what do parents think of post-transplantation treatments? - How has treatment been going on a daily basis at home?
Facilitators of treatment adherence	- In your opinion, what encourages parents to give their child these treatments?
Barriers to treatment adherence	- On the contrary, what difficulties do they encounter? - What might prevent them from giving their child these treatments?
Healthcare system	- What do you think the parents feel about the care and communication with the teams (medical and nursing)? And regarding the information received?
Improving care	- What do you think can be improved to increase treatment adherence, to facilitate adherence?
Summary	- Is there anything else you would like to tell me? - Rephrasing (brief summary of the interview)

Fig. 2. Guide for conducting interviews with healthcare providers.

Table 1
Sociodemographic characteristics of caregivers.

n	Patient's gender	SCT indication	Length of time since SCT/Hospital discharge (d)	Number of medication at home	Interviewed caregiver	Interview duration (min)
1	M	m	78/48	12	mother	13
2	F	nm	180/133	10	mother	39
3	M	nm	96/66	10	mother	18
4	F	m	57/8	11	mother	27
5	M	m	69/17	10	mother	13
6	F	m	75/38	8	mother	8
7	F	m	177/151	7	mother	10
8	F	nm	105/50	6	father	11
9	M	nm	144/112	6	mother	10
10	F	m	138/30	10	mother	7
11	F	nm	57/47	8	Mother& father	12
12	M	m	80/20	13	mother	13
13	F	m	66/9	5	mother	25
14	F	nm	78/28	7	father	8
15	F	nm	82/47	4	mother	8

Abbreviations: m: malignant, non-m: non-malignant, SCT: stem cell transplantation, DHV: daily hospital visit, CV: consultation visit.

Table 2
Sociodemographic characteristics of paramedical and medical healthcare providers.

Profession	n	Age (years old)	Interview duration (min)
child minder	3	44.3 (25–54)	12.5 (11–14)
doctor	5	40.6 (31–56)	9 (6–11)
nurse	11	37.5 (25–49)	12.7 (6.5–21)
resident	2	24; 27	8; 9

dilute, then do the rule of 3." (Caregiver 5) On the contrary, according to the parents, parent-child joint management, the habit of taking medications and comparing past experiences facilitated taking medications. *After all they've been through, as I tell them (her transplanted girls), it's (therapies after transplantation) nothing at all in comparison.* (Caregiver 7) The nasogastric tube and "threatening" strategies were also facilitating. In addition, parents mentioned the duration of treatments and hygiene recommendations as determinants of family isolation.

However, like the hygiene recommendations, medications were demanding, restrictive and even distressing for parents. Parents were "sick and tired" and could not wait to return to a "normal" life. *Being able to say to yourself: At least we're home, which is good, even though we have those treatments to take, at least we're home.* (Caregiver 10). As the caregivers, the nasogastric tube, "threatening" or encouragement strategies, organisation and the habit of medications were reported as facilitating adherence from HPs. *It's like preparing breakfast in the morning, they prepare their syringe.*" (Nurse 7) Unlike the caregivers, the HPs considered the duration of treatment as a facilitator: according to them, it is short, unlike the duration of post-SOT treatment. For the HPs, caregivers were aware of the benefits of medications. In addition, HPs mentioned the child's age as a determinant of adherence, and the adolescent period as a critical period.

3.2.3. The caregivers' experience: the family, siblings and the family circle

For the parents, their child's disease and allograft were disrupting for the family and siblings. Organisational and psychological adaptation and support from the close family circle was necessary, especially on discharge from the hospital: family ties became stronger. However, there was ambivalence about parents sharing their experience. *What reassured us is that when we arrived we were able to talk to other parents (…) It's already difficult to deal with your own child's situation, but having to listen to other people's story as well …* (Caregiver 8).

In the HPs opinion, parents "do well" when their children "do well". Parental involvement was an investment for medication adherence, especially on discharge from the hospital when, according to the HPs, parents felt isolated again. Post-alloSCT, parents became "parents-carers". *In a way it's as if they become little nurses.* (Nurse 7) In addition, parent-child conflicts and the attitude of parents towards HPs influenced medication adherence. *If the parents tell you: Oh, you hassle us about medications, how can a child take his medications?*" (Nurse 10).

3.2.4. The healthcare system

The parents talked about their satisfaction and being grateful: the support and presence of the team were appreciated. *We felt good, like a little family.* (Caregiver 2) In addition, the information provided reassurance and helped to prepare, but it was also difficult to hear. The time when information was provided was called into question. *Some things concerning the possible after-effects should be explained a bit earlier, such as sterility.* (Caregiver 5) And for parents, there was a lack of coordination of intra and inter-hospital communication of information.

According to the HPs, the supervision and presence of the teams as well as the information they provided reassure parents, helped them to understand the care and guided them with regards to taking medications. A strong bond between HPs and parents was created which, according to HPs, made the hospital-home transition distressing and difficult. *In a way, because we know them so well, parents have a hard time leaving the nest, the transplantation department nest!* (Nurse 11) In addition, HPs talked about the difficulty for parents to make the transition from the regular hospital to the transplantation hospital. For them, better intra- and inter-hospital coordination was needed. In general, the transmission of information should be systematized and at the same time adapted to the individual needs of each family. *It is very different from one family to another: some understand very easily and it is more difficult for others!*" (Nurse 10).

3.3. Barriers and facilitators of medication adherence

The analysis of semi-structured interviews permitted the identification of facilitators and barriers of post-alloSCT medication adherence according to caregivers and healthcare providers.

In terms of the facilitators of medication adherence, for caregivers and HPs these included: the acknowledgement of post-alloSCT medications as necessary, the importance of including medications in a daily family routine, the support of parents on the subject of taking medications, as well as the information provided by HPs (Table 3).

On the contrary, the barriers to medication adherence according to caregivers and HPs were: the difficulties manipulating medications, difficult transitions between hospitals and on discharge from the transplantation department, as well as the lack of coordination between HPs concerning the information provided (Table 4).

Table 3
Facilitators of post-alloSCT medication adherence according to caregivers and/or healthcare providers.

FACILITATORS of medication adherence		
CAREGIVERS	COMMON to caregivers and healthcare providers	HEALTHCARE PROVIDERS
- Child-parent joint management - Sharing experiences with other parents - Support from the family and family circle	- Acknowledgement that the medications are necessary - Integration into daily life (habit/routine) - Nasogastric tube that enables medication administration - Experiences (failure of previous therapies) - Organisation (preparation for the day, telephone reminders) - Communication with the child (explanations) - Support and assistance by parents and HPs - Practical informations (manipulating medications)	- Comparison with other more care (solid organ transplantations) - Caregivers' understanding the care - Proactive role of the parent

4. Discussion

To our knowledge, this study is the first one that concerns perceptions after pediatric alloSCT, notably in terms of the therapy. It is also original in that it focuses both on caregivers and HPs' opinions. By virtue of the diversity of parents met (age of the patient, reason for the transplant, origin of the graft, family social context), it provides a good target population representativeness.

4.1. Allogeneic stem cell transplantation

Parents and HPs' expressed that alloSCT has opposing facets, as is the case for post-autoSCT parents according to Oppenheim et al. (2002). In fact, it generated fear (of the conditioning and complications) as well as the hope of recovery. Pradère J. et al. (2008) explained parents' stress and fear after an alloSCT for sickle cell disease: recovery was not yet established because the psychological healing process was longer than the biomedical process; therefore, the disease could intervene at any time. One might wondered whether this fear was heightened in our study in which parents were interviewed shortly after transplantation. However, Vrijmoet et al. (2010) still identified this emotion several years after SCT allograft.

4.2. Post-transplantation therapies

Two major facilitators of medication adherence identified by the caregivers and HPs in our study were reported before in pediatric haematology and post-solid organ transplantation (SOT): including medication taking in the daily family routine (Santer et al., 2014) and the acknowledgement that treatments are necessary (Landier et al., 2011).

In terms of the barriers to adherence, for parents and HPs, being "sick and tired" of the medications was related to the duration of treatment, considered long on return home. According to the HPs, this was related to the parents impatience to return to a "normal life", an impatience also noted in the literature for adolescents on maintenance therapy for acute leukaemia (AL) (Malbasa et al., 2007). In fact, Malbasa et al. (2007) referred to the AL maintenance therapy phase as an unsuitable phase for medication adherence as it was an ambiguous period between disease and recovery. This AL maintenance therapy phase could be compared with the post-alloSCT period: the child is doing well, is no longer hospitalized in the isolated transplantation department but must nevertheless, take medications in a strict manner (administration times), and follow hygiene recommendations.

In addition to being "sick and tired" of post-alloSCT medications, the difficulty of isolation was widely expressed by parents and HPs concerning both hospitalization and the post-alloSCT period. The isolation of hospitalization was described in the literature from parents' standpoint during auto-SCT (Oppenheim et al., 2002) and from that of children and adolescents during allo-SCT (Manookian et al., 2014). Isolation during the post-alloSCT period was described for the first time in our study. This physical and psychological isolation could be explained, notably by the desire for a "normal life" that parents of children with chronic diseases also feel (Santer et al., 2014).

The literature concerning adolescents identified one barrier as parent-adolescent joint management wherein the responsibilities of both parties are ambiguous making it impossible to clearly identify who is responsible for treatment administration (Tebbi et al., 1986; Heyduck et al., 2015). However, in our study, which only concerned few adolescents, parents described parent-child joint management as a facilitator. The HPs did not mention this but rather the differences according to age and the critical adolescent period.

4.3. The family, siblings and the family circle

The strengthening of family ties was predominant in our study. Pradère et al. (2008) described intra-family donation as a determinant for the "reinforcement of blood ties", and Wu et al. (2005) as a factor

Table 4
Barriers to post-alloSCT medication adherence according to caregivers and/or healthcare providers.

BARRIERS to medication adherence		
CAREGIVERS	COMMON to caregivers and healthcare providers	HEALTHCARE PROVIDERS
- Multiplicity of medical interlocutors - Hospital-home geographic distance - Lack of information (role of medications) - Late information (later than desired) - Information that is not very precise	- Number of medications and the daily doses - Treatment duration - Unpleasant taste (cyclosporin syrup) - Nausea/vomiting - Strict administration times - Difficulty manipulating medications - Not well planned transitions (between hospitals and hospital-home) - Communication that is not well coordinated (intra and inter-hospital)	- Desire for a "normal life" - Adolescence - Family context (monoparental) - Parent-caregiver role not desired by the parent - Parent-healthcare provider disagreement - Conflicts between parents and children - A difficult "parent-carer" role - No systematic information - No sufficiently individualized information - Lots of information in a short space of time - Difficulty to plan ahead (theory different from reality)

that upset siblings and reshuffled family relations. However, in our study, of the 5 children who received a graft from an intra-family donor, the source of the graft was not emphasized by the parents as a determinant for reinforcing ties.

In the study by Manookian et al. (2014) the support of family and siblings was expressed by the patients, and similarly, it was widely mentioned by the parents in our study. In the same vein, parental involvement, notably in medication administration, was widely described by HPs as a facilitator of adherence. The post-SOT literature (Lochridge et al., 2013; Masuda et al., 2010; Berquist et al., 2008), in hematology (Malbasa et al., 2007), and cancerology (Kondryn et al., 2011) also mentioned this.

Similarly, parents widely expressed the disturbance in the family and among the siblings caused by alloSCT during hospitalization and during the post-transplantation period. The pediatric post-alloSCT literature also identified this disturbance (Wu et al., 2005, Wilkins and Woodgate, 2007). For Wilkins and Woodgate (2007), siblings even talked about "a disrupted family life".

According to parents, faced with this disruption, psychological and organisational adaptation occurs in great part, thanked to the family circle. Wu et al. (2005) also mentioned required family resources; whether this meant socio-economic support or sharing with other caregivers. The HPs in our study did not express this. From the unique standpoint of the parents, family, sibling and family circle support was a true facilitator of medication adherence, and even for post-alloSCT care.

Oppenheim et al. (2002) discussed the difficult role of the parent in relation to the sick child, siblings, spouses and also HPs. The parents in our study did not express this directly. However, they mentioned many difficulties related to the transplantation and the post-transplantation period and the manipulation of medications. Similarly, the HPs in our study mentioned the difficult "parent-carer" role of caregivers during the post-alloSCT period. Therefore, they recommended notably, intensifying and preparing the training for medication manipulation for hospital discharge.

4.4. The healthcare system

Like the family circle, HPs were a resource for parents. In fact, the caregivers in our study went as far as speaking of "family" when they talked about their relationship with HPs. Wu et al. also mentioned HPs in "family resources" (Wu et al., 2005). The literature in pediatric haematology/oncology described the strong emotional ties between HPs, the patients and the parents and the resource that the support of HPs represented (Corsano et al., 2013).

Similarly, parents having a positive attitude towards HPs were described as a true facilitator of adherence to care, and this was mentioned in the literature in terms of a parent-HP partnership (Ford et al., 2011).

In addition, the information provided by HPs was reassuring and enabled psychological preparation, as is the case for Manookian et al. (2014). Forinder (2004) demonstrated that the information provided and the questions that parents asked help them to "feel less terrified". According to the parents and HPs in our study, the information provided was more than an essential facilitator of adherence to care; it was also an adaptation strategy (Forinder, 2004). However, the methods of communicating this information could be improved according to parents and HPs who mentioned a lack of coordination in the information provided.

HPs mentioned "the nest effect" of the transplantation unit as a reason why caregivers feel that the transition of care was difficult on hospital discharge. Similarly, Forinder (2004) mentioned the dependence of parents on the "healthcare system" on return home post-SCT. To contribute to the autonomy of families, the HPs in our study recommended notably anticipating the information provided before hospital discharge.

4.5. Barriers and facilitators of medication adherence

Barriers and facilitators of medication adherence identified concerned "post-transplantation therapies" as discussed in the specific paragraph, "the family, siblings and the family circle", and "the healthcare system". Many facilitators and barriers were similar between caregivers and HPs and some others were enunciated only by caregivers and HPs. Important barriers were about:

- Nature of the information given: not precise and not sufficient for caregivers, not systematic and not enough individualized for HPs
- Temporality of the information given: too late for caregivers, too much in short time-lapse for HPs

So to enhance adherence, the nature and temporality of information given need to be optimized. Also improving coordination between HPs (expressed by HPs and parents) and considering the whole family entity (expressed only by parents) are essential. Regarding medication adherence for other patients than pediatric post-alloSCT, Osterberg et al. (2005) reported the necessity of good interactions between patient, provider (including HPs and caregiver), and the healthcare system to give possibility and ability to the patient to follow the treatment.

4.6. Limitations

As in all qualitative studies, this study contains a subjectivity bias in the data collected. Due to his function as a healthcare provider, the interviewer may have biased the position of the participant who might have wanted to "please" by responding in a way that puts the hospital in a good light. Nevertheless, the person who conducted the interview was not known by the participants up to that point as he is not involved in the direct care of patients.

Another limitation is not having added an analysis by software in addition to the manual method. The available software programs were not used because they were complex, not adapted to our analyses and/or they were only manual analysis aids (Tong et al., 2007).

The patient's perceptions were not collected, and this is a limitation of this study. However the median age of patients receiving allo-SCT in this centre was around 7 years old. If they were interviewed, the methodology would be completely different (Guérin and Thibaut, 2008). Six patients were present during their caregiver's interview; it could influence the caregiver's expression. However, it was not possible to do it in another way.

Finally, the caregivers who were interviewed were those whose children were "doing well" at the time of the interview (cf. inclusion/exclusion criteria). The question of whether the satisfaction and acknowledgement of caregivers are related to this could be asked, because it is known that the psycho-emotional status of parents is related to the health status of their child (Wu et al., 2005).

5. Conclusion

This original study has identified barriers and facilitators of adherence to care. It has also demonstrated similarities and differences in perceptions between caregivers and HPs and has thereby initiated a process of improvement of the healthcare system. Considering and acknowledging family, sibling and family circle support is essential to post-alloSCT care as is coordination between HPs. Those complementary improvements will enhance adherence to care.

As part of the process of improving practices that prompted this study, medical and paramedical HPs at this French pediatric centre are currently working on a support program for post-alloSCT hospital-home transition. This transition program considers facilitators and barriers identified by the present study. For instance, caregiver's education about medication manipulation is now systematically anticipated, and only key information is provided in a short time-lapse. So the nature

and temporality of information provided post-hospital discharge is being optimized. Working together on this program, HPs are so exercising their coordination. Considering and acknowledging the whole family entity (and not only the parents) will be a crucial point to be integrated to the transition program.

Conflict of interest

The authors declare no conflict of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejon.2018.11.006.

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