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A transversal qualitative study using interpretative phenomenological analysis.

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Abstract

Objectives: (1) To capture the subjective experience of close family ascendants of acute bacterial meningitis survivors; (2) To explore how they give meaning to this specific experience.

Design: A qualitative study of in-depth interviews using Interpretative Phenomenological Analysis. Primary outcome: to identify the main meaning-making processes of the participants' experience.

Settings: Participants were recruited through two associations of people affected by meningitis and their family ascendants.

Participants: Convenience sampling of eleven women whose children or grandchildren were between 0.2 and 20 years old at the time of their meningitis diagnosis (M= 4.06, SD= 7.3). On average, 9.39 (SD= 5.4) years had passed between the onset of illness and the interview.

Results: Six superordinate themes and two main meaning-making processes in relation to the participants' experience of meningitis were identified: (1) the sick child becoming a "hero" – ccomparison with other children; (2) engaged action/attitude: finding the "positive" of the traumatic experience and engaged action to improve the care system.

Conclusions: This study provides a unique insight into close family members' first-hand experience with acute bacterial meningitis. Findings highlighted factors characterising the disease experience, the psychological adjustment of meningitis survivors' families and their meaning-making processes. These findings are important for research and clinical practice, demonstrating for the multidimensional impact of the disease on family ascendants, their need for professional psychological support, and the importance of direct involvement of parents in identifying key aspects of care.

Keywords: Parents/Family ascendants; Subjective experience; Meningitis; survivors; Meaning-making process; Qualitative methods; Discourse.

Article Summary

Strengths and limitations of this study

- An empirical qualitative method (Interpretative Phenomenological Analysis) was used to explore the lived experience of parents and grandparents whose child or grandchild had suffered from and survived acute bacterial meningitis.
- One of the first studies undertaken to explore the experience of family ascendants' of this condition.
- The study results may be affected by the recruitment of participants through patient association websites and by the retrospective study design (i.e., reconstruction bias due to the time period between the meningitis episode and participation in the study).
- The participants were exclusively females (mothers or grandmother) and the study does not capture the experience of fathers (which is unfortunately quite common in studies dedicated to the parents of children with physical conditions).

INTRODUCTION

Paediatric acute bacterial meningitis is a life-threatening illness that results from bacterial infection of the meninges and leaves some survivors with significant sequelae. Meningococcus (another name for the bacterium *Neisseria meningitidis*) is one of the major cause of acute meningitis. Meningococcal infections have a high mortality rate, around 10 %, and a high epidemic potential [1].

Meningococcal meningitis usually occurs in early childhood (maximum incidence in children under five years of age) and in young adults (under twenty-five years. It combines an infectious syndrome (fever, severe headache, vomiting) and a meningeal syndrome (neck stiffness, lethargy, disorders of consciousness up to a coma). Even when the diagnosis and treatment were timely provided, the fatality rate still ranges from 5% - 10%, commonly within 24 -48 hours after the onset of symptoms [1]. Bacterial meningitis may result in brain damage, hearing loss, visual impairment, or a learning disability in 10% - 20% of survivors. A less common, but more severe (often fatal), form of meningococcal disease is meningococcal septicaemia (purpura fulminans), which is characterized by a haemorrhagic rash and rapid circulatory collapse [2].

Given the high mortality rate and the potentially severe sequelae induced by this condition, health authorities worldwide try to foster medical research in this domain and a relevant vaccine policy. With this perspective in mind, in some studies it was of high importance to better understand how parents view bacterial meningitis and its vaccination, in order to better capture potential barriers to vaccination. Thus, when tracking empirical studies dedicated to the familial experience of bacterial meningitis in children, we note that a certain number of articles are devoted to this perspective of vaccination. In Italy [3], the Netherlands [4] and in the UK [5], researchers highlighted that the public knowledge of meningitis and its related vaccinations is improved through correct health education and effective vaccine strategies that are implemented by policy-makers [3].

Besides the considerations regarding vaccination policy, the literature concerning family experiences of bacterial meningitis in children and adolescents is poor. To our knowledge, there are only three studies that specifically targeted the psychological adjustment of parents experiencing paediatric meningococcal meningitis. In 2005, Haines [6] conducted a qualitative study in interviewed parents based on a Heideggerian phenomenological qualitative approach, and highlighted, among other findings, a critical need for support and understanding, as well as a need for communication, information and publicity. Comparable results regarding the provision of information about the symptoms and possible sequelae of acute bacterial meningitis and regarding the need of better communication about the treatment process and the disease progression were also underlined by more recent research) [7]. This latter study also focused on the parents' desire for professional support after the child was discharged from the hospital. The psychological adjustment of parents after meningococcal disease was also quantitatively studied in the mid and term (3 and 12 months after discharge) [8]. The results indicated a risk for poor mental health among parents, with 13 of 54 mothers (24%) and six of 40 fathers (15%) scoring at high risk for posttraumatic stress disorder at 12 months. Additional studies not specific to acute bacterial meningitis, also pointed at the psychological vulnerability of parents and a great need for educational support of children who have survived meningitis and septicaemia [9]. One study [10] targeted ¨Post-intensive care syndrome (PICS) in patients and families after critical neurologic condition, which could include acute bacterial meningitis with neurological symptoms. This syndrome encompasses a variety of morbidities, including physical, cognitive, emotional, and psychological impairments following critical care. Taken together, these studies highlighted the psychological vulnerability of families after meningococcal disease and their need for communication and support. To the best of our knowledge, there is no French data on this question, despite the severe sequelae that could be induced by this disease [11]. Given the potential trauma induced by the disease and the hospitalization, it is important to gain insight on how the parents cope with this aversive event, especially how they give sense to this experience (with the possibility of a failure of this meaning-making process). Parents are the primary caregivers of these children, and the literature on dyadic coping in the context of illness underlined the intertwined nature of their psychological adjustment process [12]. As such, the family ascendants' adjustment has a direct impact on the psychological adjustment process of the children. Indeed, better mental health of the parent is associated with better mental and physical health of the children [13]. A better understanding of the parents' subjective experience would make it possible to offer more assistance to the parents and satisfactory care for the children. Indeed, we already underlined the paucity of the empirical literature regarding the long-term adjustment of meningitis survivors during adolescence or adulthood in a previous research. Not only did we do so in terms of presence or absence of symptoms but also in terms of emotional reactions, feelings, memories, and meaning-making process in the mid and/or long term [14].

The objective of the study is to capture the subjective experience of family ascendants confronted with acute bacterial meningitis, to highlight their meaning-making process in this adverse context, and to identify factors that could positively influence and develop the quality of care provided by healthcare professionals.

METHOD

Participants and recruitment

This study of close family members confronted with acute bacterial meningitis was part of a broader research project dedicated to the psychological adjustment and the subjective experience of people who have experienced meningitis, either as patients or as patients’ ascendants. A total of 20 participants, including eleven individuals whose children or grandchildren experienced meningitis, were recruited through two patients’ associations (*Association Petit Ange - Ensemble contre la meningitis* and *Epilepsie France*), thanks to a call for testimonies posted on the association’s website. The participants were not necessarily members of the association. The inclusion criteria were: (1) age ≥18 years at the time of the study; (2) being an ascendant of an individual who received a diagnosis of acute bacterial meningitis during childhood, adolescence, or adulthood; (3) a period of at least six months between the onset of illness of the descendant and the interview; and (4) informed consent to participate in this study.

The exclusion criteria were: (1) family ascendants who had lost their child due to acute bacterial meningitis, or bereaved parents (by other cause) were not included in the research because grief process could deeply affect the present results; (2) severe cognitive impairment that hinders participation in the study, as determined by the interviewers; (3) lack of a sufficient fluency in French to participate in the research interviews.

The recruitment was voluntary, and all participants expressed their agreement to participate in the research, according to the French ethical board's recommendations for qualitative non-interventional research. According to the French legislation, collection of information on ethnic origin and religious affiliation is not allowed [15], therefore these aspects were not assessed. In accordance to Article L1121-1 of the French Public Health Code [16], this qualitative study, which uses the responses to a survey carried out by telephone from relatives of individuals who recovered from the illness more than six months ago, does not correspond to any of the three categories of studies falling within the scope of research involving human subjects, and therefore no ethical approval was required.

Procedure

In-depth, semi-structured, qualitative interviews were conducted over the telephone. Although the interviewers followed an interview guide, the participants were encouraged to express themselves freely. This guide included questions relating to the history of the disease, the current emotional state of the participant, as well as questions relating to the potential impact of the meningitis infection for the family and siblings. The interviews were conducted in October 2018 by four researchers familiar with qualitative interview methods, and who were trained in qualitative approaches. The mean interview length was 60 minutes.

Analysis

Interviews were audio-recorded and entirely transcribed. Transcripts were subsequently anonymised by removing all identifying information. The original French extracts were translated into English. A bilingual French-English researcher verified that the translation of the verbatim to English was consistent with the meaning of the source texts in French. Interpretative Phenomenological Analysis (IPA) was chosen to explore the contents. For analysis key-elements, see Scanferla et al., (2020) [14]. Authors 1 and 3 (ES & LF) led the analysis following principles for IPA [15]. In brief, each interview was read by the first author multiple times to gain a holistic sense of the participant's account and discourse themes were identified by ES. The connections between the themes were then studied and the major themes were identified by the same author. Lastly, an interpretative account was produced that highlighted and analysed the experience through experiential themes and meaning-making processes. The meaning-making process is the means by which people try to make sense of their experiences, and the study of the processes of meaning-making describes what is happening in individuals and highlights the procedural dimension beyond symptoms and outcomes. It also helps to emphasise how meningitis can be experienced in different ways by different people through the analysis of convergences and divergences in the meaning-making processes. The third author (LF) audited the documentation for the first five interviews as a validity check on the analytic process. Great care was taken throughout the process to meet the scientific rigour criteria established by qualitative analysis [18].

RESULTS

In total, 11 women took part in the study, 10mothers and one grandmother. The children (child/grandchild) were 3–30 years old (Mean [*M*]= 13.45 Standard Deviation [*SD*]= 9.37) at the time of the interviews, and between 0,2 and 20 years old at the time of the meningitis diagnosis (*M*= 4.06, *SD*= 7.26). On average, 9.39 years had passed between the onset of illness and the parent's interview (*SD*= 5.46).

The participants' profile is described in Table 1.

Table 1: Participants' profile

	Participant	**Relationship to the survivor**	**Survivor sex**	**Survivor' age at time of the interview** (years)	**Survivor' age at diagnosis** (years)	**Infectious agent**	**Number & age of survivor's siblings** (years)
1	P2	Mother	F	7	0.33	Meningococcus B	1 (10)
2	P3	Mother	M	24	17	Meningococcus B	2 (26 and 22)
3	P5	Mother	F	8	0.08	Streptococcus B	2 (6.5 and 3)
4	P7	Mother	F	14	0.75	Pneumococcus	2 (8.5 and 6)
5	P10	Mother	M	26	4	*md*	2 (22 and17)
6	P11	Mother	F	14.5	0,33	Pneumococcus	1 (11)
7	P12	Mother	F	30	20	Meningococcus B	1 (27 and 24)
8	P13	Mother	F	12	2	Pneumococcus	2 (6 and 0,08)
9	P16	Grand-mother	M	3	0.02	Streptococcus B	2 (17 and 11)
10	P19	Mother	F	4,5	0.08	Streptococcus B	1 (4 ½ and2)
11	P20	Mother	F	5	0.08	Streptococcus B	1 (2)

md: missing data

Concerning the bacterial agent causing the disease of the child, 3 participants reported meningococcal, 3 reported pneumococcal, and 4 reported streptococcal bacterium. For one participant, the causative bacteria was not identified, although a meningitis diagnosis had been made by medical staff.

Six major themes emerged following the analysis superordinates:

1. Meningitis disease
2. Healthcare services and professionals
3. Knowledge / ignorance
4. Repercussions of the meningitis experience - "Life afterwards"
5. Sick child attitudes / behaviour
6. Siblings attitudes / behaviour

Further analysis also revealed several subthemes (Table 2).

Table 2: Major themes and subthemes

Major themes	**Subthemes**
Meningitis disease	**Symptoms** (description…). Perception of symptoms & their evolution **Diagnoses** (relevance, accuracy, time…) **Description of the disease** (technical words, prevalence…)
Healthcare services and professionals	**Experience of healthcare services and relationships with healthcare providers** (e.g. communication) **Need for psychological support** at the time of diagnosis, during hospital care and in the long term (e.g. rehabilitation)
Knowledge / ignorance	**About the disease** (scientific background, technical vocabulary ...). Need for the patients and their caregivers to explain the disease. Internet and association role (information) **Unpreparedness of health professionals / expertise** **Helplessness of familial caregivers** (e.g. incomprehension of symptoms and/or lack of good reflexes, feeling of being overwhelmed by an exceptional situation)
Repercussions of the meningitis experience - "life afterwards"	**Physical sequelae** (partial paralysis, functional disability ...). Relating and compensating **Psychological impacts and familial adjustment** in the short-term (coping with the possibility of death) and the long-term (physical sequelae, medical care, daily life, school) **Parents coping with the illness** (e.g. impact on the marital couple...)

	Impact of meningitis on the life course (financial and professional impact, change of life and professional trajectories, "giving up"…)
Sick child attitude / behaviour	At the onset of the illness During the hospitalization Long-term attitudes (personality): flexibility, adaptation, courage
Siblings attitude / behaviour	Coping with the illness and its long-term effects (psychological sequelae and adjustments)

Only 5 of the above themes were selected for inclusion in this publication. These five themes were all chosen because they were directly in line with our research question (i.e.. the family experience of the meningitis); and they were all spontaneously mentioned by the participants and did not correspond to the pre-established questions. A detailed analysis of the not-selected themes (i.e. meningitis disease) can be provided on demand.

1. Healthcare services and professionals

This theme includes 3 subthemes: (1) Experience of healthcare services and care routine; (2) Relationship with healthcare providers; (3) Need for psychotherapeutic support.

[illegible]

The overwhelming experience of an extreme situation, the interactions with healthcare professional and services were reported in by family ascendants. Feelings of dismay, refusal to accept their child's life is threatened and consecutive anger came over strongly in the interviews; for many, these emotional responses triggered a request for help.

Experience of healthcare services and the relationship with healthcare providers

The experience of care services as evoked by family members varied. Some of them emphasized the quality of care.

> *"I can't thank that paediatrician enough because he didn't know that it was meningitis yet, but he put a treatment in place (...), which saved us a few hours"*. (P13)

Others appreciated the attention they received at the hospital and stated that it helped them to reduce their stress and anxiety during the medical emergency situation.

"*We were very, very welcomed, they arranged a room for us at the hospital. It was a special room for the parents so we could sleep there the first night*". (P11)

Family ascendants praised both the technical and relational skills of healthcare providers.

However, within the narratives, there also appeared areas of dissatisfaction such as the long waiting time before receiving the diagnosis, the complexity of care received by their loved ones, and the hospital environment in general.

"After she got there, we waited for three or four hours without hearing from her. It was really a very, very long wait, no news, no nothing. (...). And then they put us in a very creepy office. It wasn't reassuring at all (…)". (P20)

It appears here that it is not so much the wait itself that is stressful, but rather the absence of communication with the healthcare providers and especially the absence of news concerning the state of the child. This leads us to approach the following sub-theme of communication.

Indeed, there were many occurrences which highlighted the difficulties in communication with health care professionals. The dialogue was perceived as difficult and generated frustration.

"The doctor came in and he got angry with me and told me I had to stop my show (...) he thought I was a crazy person who was there to bother them". (P10)

This mother perceived here a lack of consideration for her emotional distress, which is misjudged by the physician, according to her testimony. We found the perception of this lack of consideration in the testimony of another study participant who mentioned that professionals gave little credit to her opinion:

"In any case, the way they told us things weren't right at all... Insinuating that it was not justified to come and take her [to the hospital], when in the end the (positive) results proved it the next day". (P19)

Several mothers highlighted that the information they provided about their unwell child and their intuition of the seriousness of the situation was not considered. Therefore, they often felt discredited by the medical profession and expressed their frustration.

"I got angry (...), I told him that my daughter had had ear infections before, but that it hadn't put her in this state of drowsiness, with vomiting and a fever that wouldn't go down (...). I insisted, and he told me I was a hysterical mother". (P13)

Some family ascendants remembered making harsh comments to certain doctors whose attitude or behaviour were deemed to be disrespectful, inappropriate or dismissive.

"I told them, "We're not numbers" (…). *"There's even a doctor for whom I asked that he no longer treat my daughter. I even notified the hospital management, so he was replaced by another doctor."* (P2)

This mother placed herself as "guardian" of her child, in order to protect her son and to have him considered as an individual (and not as a "simple number").

Need for psychological support

The parents showed very intense emotions when confronting the different stages of illness. Their emotional response oscillated between uncertainty and frustration, to fear, anxiety and shock as a result of what they sometimes perceived as a "cold" and "hard" relationship with healthcare professionals. They stressed the need for psychological support to help them at the time of diagnosis and intensive care, especially when they felt overwhelmed.

"I had a very bad experience at the ICU because I found that the staff... well, I think they're people who see this every day and have to remain impassive before certain situations. But we, as parents, we need accompaniment, we need support, we need help, and that's not necessarily what we had". (P2)

This parent interestingly gave a contrasting description between the "distanced" functioning of ICU professionals, a function that she understands, and her own needs as a mother.

Moreover, family ascendants experienced difficult emotions in the long term as well during their children's rehabilitation period.

"They referred us to a psychologist. That's good in itself but it often happened in the hospital room with our daughter next door, so it wasn't necessarily the right time, we were very emotional. It was good to see a psychologist when our daughter was hospitalised, but we had very long medical visits for L., (...), but afterwards, we were abandoned to ourselves, we weren't supported at all." (P5)

Here, this mother indicated that the reference to a mental health professional was not always sufficient. The time and the clinical frame of psychological support were also critical and, despite this professional support, she felt abandoned.

For some, the help of professionals was essential in the process of alleviating their sense of guilt and making sense of the traumatic experience of accompanying a child who was experiencing meningitis.

"I started a behavioural and cognitive psychotherapy with a psychologist so that I could convince myself that it's not my fault that my daughter had purpura and was amputated." (P2).

Cognitive behavioural therapy and especially cognitive remediation are specific techniques used in cases of particularly distressful thoughts.

2. Knowledge/ Ignorance

This second theme includes 3 subthemes about: (1) the disease; (2) the unpreparedness of healthcare professionals / experts; (c) the familial caregivers' helplessness.

Unanimously, the interviewed parents focused on the importance of knowledge about acute bacterial meningitis including its symptoms and possible sequelae, as well as the treatment process and disease progression. The testimonials stressed the parents own need for understanding on the one hand, and on the other hand, the healthcare providers' knowledge about the disease, which they sometimes perceived as insufficient. The lack of communication, information and support for families was also highlighted.

About the disease

The main part of the interviews highlighted that knowledge about meningitis was key and many participants expressed the need to develop this knowledge, as most of the time the disease was totally or partially unknown before it affected their child.

"I didn't even know what it was. I didn't even know there were three forms of meningitis; I didn't even know what "purpura fulminans" was (...). I'd never even heard of it." (P2)

Meeting this need to better understand the disease involved the acquisition of a scientific background and the ability to express it with technical medical vocabulary. Therefore, many of the participants needed to acquire some form of expertise on the disease to learn the means and modalities of contamination. They widely stressed that the internet and patients' associations were a valuable source of knowledge.

"I've done a lot of research on the Internet, I've read testimonials and a lot of things. I contacted associations that receive amputees and do a lot of things for them. I talked on the phone with people from these associations who also reassured me a lot (...). I wanted to find out as much as possible. It helped me a lot to be able to manage the situation as well as possible". (P2)

Developing some forms of expertise on the disease and taking an active approach to it were reported as key aspects.

"I didn't realize how the infection is transmitted or the difference between viral and bacterial meningitis. But now I'm a meningitis expert...". (P5) *(...) I've done a lot of reading on the subject, and the first reflex you have when you have a medical team in front of you that gives you a flood of information without taking the time to use words that are accessible to everyone, you have to check it out (...).* (P5).

Having an active approach to learning about the disease probably compensated for the passive attitudes of healthcare professionals and the perceived lack of support that parents experienced during their child's care.

For some participants, their understanding of their child's potential situation contrasts with the expertise of the healthcare providers.

The perceived unpreparedness of health professionals / expertise

In several cases, the patients were given alternative diagnoses, suggesting an imprecise understanding of the symptoms and/or inadequate responses by healthcare professionals.

"When I was told that she had the germ of streptococcus, I consulted the Internet and saw that it could cause meningitis (...) The paediatrician told me: "Don't worry, (...) she was treated and you will never hear about it again... there's no chance of that happening", ... *a week later, hospital, emergency room, meningitis."* (P 20).

This mother underlined here some diagnostic wandering: despite words full of assertiveness advising her not to worry, what she dreaded effectively happened.

In other cases, healthcare providers seemed completely overwhelmed by the emergency context and did not fully perceive the seriousness of the symptoms.

"When I called [the emergency services] for the relapse and told them that she had been out of hospital for 15 days for meningitis and that she had all the symptoms again, they didn't want to send us someone (...) Then the doctor (..) told us that we were really not very recommendable parents and that we should only call for real emergencies instead of calling for a little girl who is crying because she has a little fever" (P19).

Helplessness of familial caregivers

The experience of a lack of responsiveness on the part of healthcare professionals caused frustration and feelings of helplessness in the patients' families.

"When they [the doctors] tell you that your child has a life expectancy of four years, when she reaches five years, you think that they may need to reconsider the diagnosis…". (P5)

The participants' narratives also emphasized the importance of public awareness of meningitis and the role that patient and carer associations play in this regard. Associations provide families emotional and psychological understanding and support, which significantly helped the family ascendants through the stressful events they were experiencing.

"I think it's a disease that isn't adequately known. When she was at the hospital, I was seeking answers to my questions and I searched on the Internet, and that's when I came across the website of [name of the association]. *Thanks to this website and the persons who foster it, we learn everything that can happen around meningitis. I tell myself that if people were better informed about the symptoms, more lives could be saved".* (P19)

Taken together, the testimonials highlighted the psychological vulnerability of families and their need for communication and support.

3. Repercussions of the meningitis experience - "life afterwards"

This major theme integrates 5 subthemes: (1) physical sequelae; (2) psychological impact; (3) parents coping with the illness (in the short and long term); (4) impact of meningitis on the life course; (5) meaning given to the extreme experiences they have gone through.

Physical sequelae of the child

Most of the interviews revealed the negative impact of meningitis on their family children and grandchildren health, and in particular the significant physical and cognitive sequelae associated with meningitis including partial paralysis, heart problems, hearing and visual impairments.

These impairments significantly limit the survivors' ability to function in an autonomous manner, and can cause daily distress and frustration for the whole family.

"(...). The definition is global psychomotor impairment, with a significant language deficit. Not long ago, it was absence of language. You have to understand that (her) brain doesn't work on its own (...). Today, she has the entire left hemisphere that is necrotic, she has frontal and lateral lesions on the cortex which is between the two hemispheres. So, it's all been damaged". (P5)

Some testimonies focused on the physical impairments and a sense of permanent loss of prior abilities of their child, which caused them to develop feelings of injustice.

"These are diseases that totally destroy the life. She was a little girl who was 9 1/2 months old, who was beginning to walk, who was very lively, and she was completely stopped in her stride. It's really an injustice". (P7)

Psychological impacts and familial adjustment

Besides the negative physical and cognitive impact of the disease on their relative, the participants also strongly insisted on the psychological impact of meningitis, and in particular the state of shock that they experienced at the period of the hospitalization.

"I was holding him in my arms, and I was looking for a way to comfort him. (...) I was just very, very anxious (...). I was completely shocked by his condition. I thought he was dying. In fact, I know he barely avoided death. I've always felt that my son was close to death" (P10).

The sight of the body of the diminished child, bearing the scars of the disease, was intolerable. Most of the participants described an impression of imminent death, which is terrifying. A grandmother mentioned this fear, which she states sometimes still comes to her.

"What's more, he was in great pain and that's really what shocked me the most. I've never seen anyone suffer like this, especially not a child. Three years later, I'm still shocked by it". (P16)

Some mothers stressed the traumatic nature of the experience of facing the danger of death of their child, especially during intensive care. The emotions described by most of the narratives are intense and vary between denial and deep anguish, some even evoking a state of stupor.

"When the doctor came to see us, she was still in a life-threatening prognosis. He told us that (...) there were three possible outcomes. Either she was not going to make it, or she was going to make it, but he was not able to say whether she will breathe on her own or not, or she was going to make it, but she will be very severely disabled" (...). For me, none of the options were possible". (P20)

Other testimonials illustrated the parents' aptitude to manage the exceptional situation and stay positive in front of their child during the hospitalization.

"Nevertheless, we had the chance (...) to keep hope alive. When we went to see her (...) in the intensive care unit, we talked to her, we sang songs to her. Even if we didn't know if she could hear us, we kept in mind that we had to stay positive". (P11)

However, most of the respondent commented on the long-term severe psychological consequences of the meningitis experience and sequelae. They described their global psychological vulnerability, and for some of them, depressive symptoms requiring treatments.

"I had nothing left to hold me. Everyone around me was happy, but I wasn't. I couldn't explain it, nothing had taste (...). I wanted to kill myself... but at the same time I told myself that those who remained would be too sad... so I didn't do it". (P12)

The description of depressive symptoms, including anhedonia and suicidal thoughts, were at times mixed with the perception of relief and happiness, often leading to a feeling of isolation.

The time necessary to regain personal and family balance also emerged as a common issue.

"After the first six months, I got the backlash. I tried to put up with everything, telling myself that I was strong. My daughter was strong, so I had to be strong. At one point, (...) I fell into a deep depression that lasted for two years. I was on medication, anxiolytics and antidepressants to get me out of this hellish spiral. I saw everything in black and I told myself that my daughter would never make it, that they would make fun of her and that life would be difficult for her. I locked myself in a negative bubble. Now I'm a little better, but there are always times when I think about the future, and I still have fears and anxieties about what might happen later on". (P2)

In these two testimonies, we can notice the lasting concern for their child, even when they progress to adulthood. This concern is permeated with anxious anticipation concerning the survivors' well-being.

Parents coping with the illness

Having to take care of a child who is often severely impaired is an ordeal for the parental couple. However, most of the interviewees highlighted that, despite occasional tensions, they managed to deal with this difficult situation.

"Concerning my couple, we have always remained very close together. My husband is always very, very present" (P11).

Along with the family, in many cases the partner is identified as a valuable source of mutual support in the moments of doubt. The family, as a whole, is described as an important source of support.

"Luckily, we have a big family that never gave up on us. They took turns coming to see us. Every day, we had someone to support us". (P13)

The quality of the relationship and communication of the two parents resulted in new forms of adjustment beyond the effects of the disease and brought new perspectives to family life.

> *"We complement each other (...). We talked about it* [the meningitis experience] *afterwards and we thought we'd done really well".* (P20)

The notions of complementarity and open communication appeared to be critical in coping with the disease and its multiple impacts.

Impact of meningitis on the life course

Caring for a child with a disability takes time, requires careful planning and often has a serious financial impact for the family, as underlined by the interviewed parents.

> *"I think it's all about her. For one thing, there are all her medical visits since she was four months old. There are 3 to 4 appointments a week, on top of work, you have to run around and it's still very heavy".* (P20)

Most of the time the disease and its consequences involved changes in the professional trajectories of the survivor's close family and in the whole family's way of life.

> *"At the time she was ill, I had planned to return to work (...) But I never went back to work, I didn't honour the contract. Then, for 6 years, I didn't work at all because (she) needed me, I was all the time with her, going back and forth for medical appointments. It was very complicated".* (P11)

These words showed that besides psychological impacts, caring for a child affected by acute bacterial meningitis also has a financial cost, even in a country like France where social assistance is present.

Finally, some participants underlined the positive impact of maintaining professional activities not only for financial reasons, but also as a way to facilitate a social life beyond the world of disability.

> *"This job allows me to get out of everything related to disability, nappies, housework. It makes me think of something else, and it makes me earn some money".* (P7)

Adjustments also concern material aspects such as the person's living and housing and the practical organisation of the child's care. They are necessary to allow the family to find a new form of everyday functioning.

> *"The house is being rearranged to create a room on the ground floor. Until now, she had been going upstairs, but we hope that when she has a room on the ground floor, it will be easier to find someone to relieve us so that we can leave from time to time".* (P7)

> *"If his behaviour is definitely related to meningitis, it is a real handicap for us in many ways, we can't go anywhere, it is really difficult. We try to show her many things so that she can continue to improve but taking her to a zoo or a park is a real challenge".* (P 20).

Thus, usual leisure activities for many children become extremely complex to organise: everyday life is often marked by renouncement.

The interaction with the health services administration regarding about the coverage of the family member's care is also a concern mentioned by family ascendants. They emphasized that the complexity of the administrative procedures and the constant need to prove legitimacy to their request constitute a considerable psychological burden in addition to the burden of caring for the meningitis survivors.

> *"I always say the biggest handicap is administration. (...) you have to keep fighting"* (P7).

The energy expended is considerable, and participants often use sports comparisons or fighting metaphors to describe their daily life.

> *"We always have to go running around, putting together files, emails... I think that is the worst. (...) When we had a renewal [of the disabled adult allowance file], and they stripped us of everything. We had to appeal. On top of that, they always take 6 months to respond... we spend our time fighting".* (P20)

4. Sick child attitude / behaviour

Several testimonials described the positive evolution of the children who have survived meningitis and stressed in particular the progress they have made and the skills that they have acquired, frequently reaching levels of results that go beyond what the healthcare professionals considered possible.

> *"When we see the MRIs, compared to the damage she has to her brain, the doctors don't understand that she can do what she does (...). For them, in relation to her lesions, she should be*

in a vegetative state, while she can eat by herself, she walks alone with her armchair, she sings, she loves to sing, she loves to play, music, early learning games, etc.”. (P13)

Some individuals also evoked the adaptability, flexibility, and courage of their loved ones.

“I think she's happy, but she has her ups and downs (...). She tries, she finds ways to do it (…). She has great strength of character and now she wants to do things even if it's hard for her”. (P11)

“And in the end, she has made up for her developmental delay (...). She has caught up with everything and even the attending doctor told me that she is amazing. She really is a great little girl” (P19).

Furthermore, many testimonies referred to the social abilities of the meningitis survivors and their capacity to enjoy a satisfactory quality of life despite the limits imposed by the severe handicaps they experience.

“She's very sociable, so she's a bit of a mascot everywhere she goes. As she is very charming, very attaching and very funny, she doesn't have too many problems adapting to a new environment”. (P5).

The child's ability to forge links with her/his peers and her/his “zest for life” are very often underlined.

Despite the disability and limitations brought on by the disease, the survivors' ability to bounce back and adjust is stressed with admiration by the participants. However, the experience of an event that suddenly and unexpectedly upsets the life of the whole family also required the siblings' capacity for psychological adjustment.

5. Siblings attitude / behaviour

The experience of acute meningitis disease and its sequelae is a stressful experience for the whole family, not only when a family member is admitted to Intensive Care Unit (ICU), but also in the mid- and long term. Within this study, parents focused on the siblings of the sick child, as they also experienced some form of impact or disruption as a result of their siblings’ illness.

A common thread among the interviewees was the parents' perception of the attitude and behaviour of siblings towards the meningitis survivors. Many participants could mention the supportive way in which the siblings coped with the disease, and their positive role in the recovery and life trajectories of their loved ones.

"I am convinced that it is thanks to her twin sister who has been a great stimulant for her. She has caught up with everything". (P19).

Likewise:

"I think his brother was really a driving force, even if it's not always obvious to him". (P5)

Particular emphasis is also placed on the siblings' ability to understand, help and protect their survivor sibling.

"He tells us: "You don't understand that she wants that! *We didn't understand fast enough, according to him, and he was interpreting".* (P5)

The brother here adopts the function of intermediary or more precisely as an interpreter between his sister and their parents, revealing a rare complicity.

"He's a child who's very protective of his sister. He doesn't hesitate to go and see the other children in the schoolyard if his sister is being teased". (P2)

The role of "guardian" that we evoked when speaking of parents can sometimes be taken by a brother or a sister of the sick child as well.

In addition, parents stressed that overall, the daily confrontation with disabilities enabled the siblings to develop a sense of openness and tolerance of other people's differences.

"*My daughters have a lot of empathy, whether with their* [disabled] *sister or with other children. It's true that they also have a different life. It is very enriching for them, because they know the difference, they learn the values of life, which not all children will necessarily have…".* (P7)

However, the testimonies of some other participants highlighted the psychological impact on siblings of the specific disease-related environment and the responsibility that they assumed.

Possible mentioned causes include the fact that the disabled child monopolised the parents' attention or that the place and role of everyone in the family may be affected.

> *"Our second* [daughter] *is everyone's elder sister. She says it all the time:* "By age, I am her little sister, but in my head I am her big sister...*".* (P13)

> *"Finally, he has developed obesity (...). He was deeply shocked and traumatised by his sister's amputation (...), he's aware that his sister is different from other children. He assigned himself the role of the big brother, which is:* "I'm here, I'll protect you, I'm here for you *(...), he took his role very seriously".* (P2)

The representation of this mother is clear: she sketched a linear causality between the amputation of her daughter, following meningitis, and the obesity of her son, whom she considered traumatised.

Despite the severity of the illness and the magnitude of its consequences for the survivors and the whole family, the narratives stressed that in the long term, one of the key elements of balance is the parents' ability to ensure a family life is "as normal as possible" for all siblings, where everyone (re)discovers his or her place.

Narrative account and profiles of meaning-making

The analysis of the above-mentioned themes allowed for the identification of the meaning-making processes deployed by the participants and which are reflected in their remarks. These two processes underpin the psychological adjustment to the meningitis and its consequences.

1. Comparison with other children- The sick child becoming a "hero"

In order to have reference points on the development of their child, some of whom are affected by serious sequelae, many parents compared the latter to other children in their family circle. This comparison often turned out to be a source of great distress, by noting how much the child is disabled and behind in their psychomotor development. For instance:

> *"I have a lot of children in my family, and I could see that for her there were some things that were wrong" (P5)*

> "*Thereafter, she evolved very slowly compared to children of her age*". (P11).

In some cases, the comparison did not come from the parents themselves, but came from a stranger.

> *"One day, our kid was 5 years old, she was in her stroller with a pacifier in her mouth, one couldn't see that she was disabled, and there was an old man who approached us saying: "look at my little grandson, he walks, he is not in a stroller and he does not have a pacifier, yet he is younger!* (P7).

This mother highlighted the perceived violence born from this comparison imposed by a stranger who knew nothing of her history.

Other parents insisted on the developmental similarities between their child, even when disabled, and other children of the same age:

> *"Otherwise, in terms of development, she is a child like any other (...). She makes a point of doing the same activities as other children" (P2).*

We found a similar statement in the testimony of a grandmother:

> "*[He] does everything like them (his siblings). He is a child who has his place among the siblings, there is no problem"* (P16).

Some parents expressed pride in having managed to cope with such an extreme experience, as an individual and as a couple.

> *"It [the meningitis experience] gave me that attitude because I wasn't like that before. It gave me a stronger temper to come with it. (...) It's ok to break down, you have to break down at some point, but the next day I am back on top, and I'm back on my feet.."*.. (P13)

Another mother evoked the support she found in her relationship with her partner.

> *"I see many couples (...) who split up because of their child's disability. However, we supported each other, we didn't argue, there were no conflicts related to that. No, we did well".* (P20)

However, above, the parents' pride was centred on their sick child. We found in their speech a highlighting of her/his exceptional character. As mentioned earlier, several participants expressed a sense of satisfaction about their child's trajectory. Some insisted on the fact that they initiated certain attitudes, instilling courage in their child.

"She's a little girl who's doing very well, we've done everything we could. She likes to be assisted, so we taught her that no, that wasn't life, she had to do it on her own". (P 19)

For some family ascendants, their loved one was in a way revealed in the disease, without the family having anything to do with it. The "hero figure" then becomes the one that best describes their child. "Hero", because the child is distinguished by her/his bravery, her/his exceptional abilities. So, this mother told us about her daughter:

"That's when I saw that my daughter was a fighter, because after waking up alone from a coma, she saw me and said "mama", at 4 1/2 months. She spoke. She woke up from a coma, looked me straight in the eye and said "mama"."(P2)

Faced with an extreme experience - the mother insisted that her daughter was close to death – the child's exceptional character was revealed in her verbal precocity. Furthermore, it is within the mother-daughter relationship that the extraordinary capacity of the child emerged. These exceptional capacities mentioned by family ascendants can thus be physical, as in the testimony mentioned above, or in the words of other parents:

"She has a phenomenal strength in her arms that she has developed due to the absence of her legs" (P13).

A physical force, therefore, but also a psychological one:

"(She) turns out to be a very combative little girl" (P5).

It appears that this revelation of the heroic character of their child allowed parents who perceived this extraordinary dimension, to find a positive meaning in this painful experience.

"*It is one of the most beautiful moments that I experienced in this terrible ordeal (...). At the beginning, the doctors didn't believe us (about the fact that their daughter was able to speak) and we rang them to show them. We even kept photos of those moments. For us, it was a magical moment because we realized that our daughter really wanted to live"* (P2).

We find here the characteristics of extraordinary events, which even look like a miracle for these parents: the fact that there are people who do not believe, who must therefore be convinced; the need for proofs, the fight that was carried out, and the ultimate meaning of this fight: the revelation of a will to live. This elaboration of the figure of the child as a hero thus made it possible to give a positive meaning to this painful experience and further, it may confirm the meaning and value of the child's life.

This mention about finding positive meaning through the distressful experience of meningitis leads to a second meaning-making process: engaging action to improve the healthcare system.

2. Finding the "positive" of the traumatic experience and engaging action to improve the healthcare system.

The discourse of the participants echoed a desire to take an active position in their relationship with the disease, not only through the acquisition of personal knowledge about meningitis, but also through the commitment to raise awareness of the disease in the general population. This commitment can also concern awareness-raising work about people with disabilities. For instance, this mother told us:

> *"I raise awareness among children and young people on the concept of disability. I go to schools or associations with a small booklet that I made, and I explain to children what disability is, to remove taboo words and so that they put words on the little friends who are dyslexic, or in a wheelchair, or mentally handicapped, etc."* (P7)

Believing that in France, individuals are not familiar enough with difference - here linked to a disability - this mother wanted to suggest to the youngest people to think about the inclusion of their disabled peers, so that they can have a life as normal as possible.

This engagement process, which allows for them to feel active instead of enduring the vagaries of life as a parent with a child with serious sequelae always starts from the intimate experience to try to improve things for the greatest number. Thus:

> *"We got a family house and we are in the process of renovating it to make a home to accommodate disabled people on vacation in the Alps (...). It was our dream for us, so we are doing it for others (P7)".*

Having been confronted with major difficulties relating to the accessibility for disabled people in many vacation homes, this family decided to take matters into their own hands and create this dedicated and accessible place. The form of altruism that this commitment constitutes can also be noted, which is why many, especially within the family, admire this commitment. Thus, the grandmother of a child who suffered from meningitis testified to her admiration for her daughter, the mother of this child.

> *"My daughter invests in everything, in everything, for her little son It's extraordinary"* (P16).

DISCUSSION

This study on the experiences of close family members of meningitis survivors highlighted six themes, shared by most of the participants, and two meaning-making processes that appeared through the analysis of the narratives. The qualitative findings stressed the parents' understanding about acute bacterial meningitis, their relationships with the care system and the healthcare providers; and they also highlighted the ignorance about this disease at the time of medical treatment, both their own and that of certain healthcare professionals. In contrast, they spoke of the knowledge that they had been able to acquire through patient associations. Much of their testimony dealt with the multidimensional repercussions of the disease on their sick child and for the whole family. The attitude and behaviour of the child affected by meningitis were largely described and often glorified. Finally, the reaction of the siblings was a matter of concern for many interviewed parents.

These qualitative results provide insight into the nature of the mid and long-term repercussions of the disease at an individual and familial level; they also offer an understanding of the distress induced by these impacts. Indeed, consistent with previous quantitative studies [8, 9], this research stressed the psychological burden associated with being the family of a child affected by acute bacterial meningitis. This burden is imbued with traumatic elements (confrontation with the possibility of the child's death, awareness of the possible sequelae), and is experienced daily by families who have to face medical, economic, and societal challenges. The present results also underline the expressed need for specific and professional support in this population. The interviewed parents insisted on their requirement for psychological support, not necessarily during the acute phase of the hospitalisation, when they were often stunned and preferred to be constantly at the bedside of the sick child, but rather at the hospital discharge and in the long-term, when they understood more clearly what their life would be like after this disease. A recent article showed that coping support interventions are effective for improving parents' anxiety and stress symptom burden related to acute paediatric hospitalisations [19]. Structured interventions could indeed be offered to parents of children affected by meningitis, during hospitalisation and at discharge.

However, the parents interviewed in this study not only experienced distressful challenges induced by the illness of their child but also, for some participants, trajectories of post-traumatic growth. Tedeschi and Calhoun [1998] [20] defines "Post-Traumatic Growth" as any positive personal changes that occur after experiencing a potentially traumatic event. The meaning-making processes analysed in this study indicated such a trajectory. The parents' pride in their child and the pride that some admit feeling about themselves because they are satisfied with the way they take care of their child and their family, echoes this growth process. A mixture of vulnerability and growth was underlined in a previous qualitative study [21], conducted among mothers whose school-aged children were born extremely prematurely; just as several participants of our research, these mothers celebrated their children's successes [21]. The celebration of the children's skills and their ability to overcome their disabilities become for certain participants the depiction of a hero trajectory ; that may be related to the dimension of "Post-traumatic Growth" such as "new possibilities" and "appreciation of life" [20].

Furthermore, the involvement of some parents in patient associations, even their participation in this study, may indicate the experience of "new possibilities" and "enhanced relationships". Highlighting this growth in some individuals should not lead to an "injunction to resilience" but to the observation that the close family members of meningitis survivors can adjust to this difficult experience and find meaning in it/

Strengths and weaknesses of the study

This study has several limitations. The first limitation concerns the nature of the recruitment and the representativeness of the sample. As participants volunteered to take part in the research, this may have resulted in self-selection bias. Therefore, findings may reflect the views of people more interested in taking an active approach to the disease through engagement with a patient association. Moreover, the sample consisted exclusively of adult females (ten mothers and one grandmother). Thus, this study might not be representative of the wider spectrum of close family members who faced the meningitis disease. Finally, the participants' close family members differed significantly in age at the time of the meningitis diagnosis, severity of their symptoms and sequelae. It is conceivable that their experiences would vary with these factors. In future studies, a more diverse sample, including male participants, recruited from a plurality of treatment facilities and setting contexts of care, would be preferred. This would allow for the examination of whether different experiences would be described and would provide a complete map of the meanings attached to subjective experiences and the generalisation of the study findings.

A second limitation concerns the retrospective nature of the interviews. This wide time period could have induced recall and reconstruction bias in material (e.g. negative aspects often tend to be better remembered than the positive one). A worthwhile direction for future research might be the exploration of the subjective experience of parents confronted with acute bacterial meningitis and the family members' psychological adjustment shortly after the acute phase. A longitudinal design would also allow for the capture of differences in their adjustment of variations in the psychological adjustment of the study participants.

Despite these limitations, this is the first study that uses a validated methodology to provide insights on the lived experience of families that have faced bacterial meningitis disease, and it highlights several meaning-making processes of this life-changing experience. It stresses, on the one hand, the interviewed parents' need for improved communication with the healthcare providers and on the other hand, the importance of an increased knowledge surrounding the disease, in particular with regard to the basic education of the public in general and the diagnostic competences of primary care providers in particular.

Clinical implications

The findings in this study highlighted two main dimensions that could be of clinical relevance. Firstly, it stressed that the disease-related environment, and more specifically, the experience of accompanying a child receiving intensive care and the related risk of death are stressful and may potentially result in some disruption or trauma for the whole family. Being regularly informed of the care provided to their child, taking an active part in it, and receiving attention by healthcare professional are mentioned as mitigating factors to help reduce stress and anxiety. Several authors have emphasized the positive impact of family open visitation and parental presence for the care of their child, especially in emergency care settings and intensive care units [22, 23]; the impacts include relieved anxiety and fear, as well as reduced psychological distress and post-intensive disorders, for both the family members and survivors [24, 25].

One specific aspect related to the family presence during ICU procedures is the siblings' visits. As in other contexts of severe diseases, sibling visitation is being increasingly endorsed as a positive development in patient care. This is relevant especially because it facilitates elaboration of the siblings' own perception of the situation and prepares post-discharge life, reduces fantasies, increases understanding and the sense of control over the situation, and increases bond enhancement and improves communication between families and care providers [23, 26, 27]. Thus, the implementation of experimental initiatives in the context of bacterial meningitis intensive care seems desirable. Collaboration between different healthcare providers (clinicians, nurses, psychologists) and parents in order to create the appropriate visitor conditions and organisation of staff is strongly supported by the literature [25, 28, 29]. Given the paucity of research on this issue, further studies on the psychological impact and implications of the siblings' presence in ICUs could offer some insight on how they cope with this averse event at the time of care and in the longer term. In this perspective, exploring the siblings' experience of the disease would provide a better understanding of the meaning-marking process and could identify potential pitfalls where there is a need for sustainable psychological assistance.

Finally, our findings stressed the need for continuing efforts to consider and monitor the emotional burden of the disease on the child's family ascendants, the psychological adjustment process and families' trajectories over time. In this regard, it would be valuable if family ascendants of acute meningitis survivors could benefit from systematic, and when necessary, professional consultations during and after their experience of the disease. The more appropriate forms and timing of this support, prognostic factors and outcome merit further investigation.

Conclusions

This study helped to capture the subjective experience and psychological adjustments of parents confronted with paediatric meningococcal meningitis. Two main meaning-making processes in relation to the participants' experiences of this adverse context emerged from their discourse. These processes emphasized the importance of information and support of families, the potentially traumatic impact of the illness experience, and the possibility of post-traumatic growth for some individuals, including the desires of parents to engage in improving the care system.

Providing family ascendants with accurate information about their child's conditions and treatments, as well as involving them in the care and medical decision-making could positively influence and develop the quality of care provided by healthcare professionals.

In the meantime, clinicians, caregivers, and other stakeholders of the healthcare system should be aware that information and the involvement of the family as an active partner in the care process are conditions for its effectiveness, from the onset of disease symptoms, their management in the emergency rooms and throughout the recovery journey.

PATIENT AND PUBLIC INVOLVEMENT

The scientific team/board included two representatives of patients' associations. They were involved from the origin of the study and identified the potential psychological consequences of the disease experience. They also highlighted the interest and motivation of patients and family members to participate in psychological research, and also participated in the discussions during which questions would be posed to the participants. These representatives were aware of the potential burdens associated with this research and underlined on the contrary the benefits that participants could derive from the project. A press conference took place on 18th September 2020 to disseminate the results of the study on meningitis survivors' experiences [14]. The present study exploring the subjective experience of close family members of the child with meningitis, corresponds to the second part of the results. In addition, we plan to organise a second conference for the association where the participants were recruited to disseminate our findings and their clinical implications.

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AUTHOR CONTRIBUTIONS

ES and LF conducted the review of the literature. ES was the main coder for the thematic analysis. LF was the second coder for the thematic analysis. ES and LF analysed the data and edited the manuscript. PG contributed to the construction of the research project and supervised the discussion of the results. All authors read and approved the final manuscript.

COMPETING INTERESTS

The authors declare that they have no competing interests regarding the publication of this article.

DATA AVAILABILITY STATEMENT

Data are available on reasonable request.

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		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1

Abstract

	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2

Introduction

Problem formulation	#3	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4
Purpose or research question	#4	Purpose of the study and specific objectives or questions	6

Methods

Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability.	6

		As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	8
Context	#7	Setting / site and salient contextual factors; rationale	6 & 7
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	6
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	7
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	7

Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	8
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	8
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	8
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	8 & 9
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	10 &11

Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	11 & more
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	28
Limitations	#19	Trustworthiness and limitations of findings	30
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	34
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	34

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A transversal qualitative study using interpretative phenomenological analysis.

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The familial experience of acute bacterial meningitis in children

A transversal qualitative study using interpretative phenomenological analysis.

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Abstract

Objectives: (1) To capture the subjective experience of close family ascendants of acute bacterial meningitis survivors; (2) To explore how they give meaning to this specific experience.

Design: A qualitative study of in-depth interviews using Interpretative Phenomenological Analysis. Primary outcome: to identify the main meaning-making processes of the participants' experience.

Settings: Participants were recruited through two associations of people affected by meningitis and their family ascendants.

Participants: Convenience sampling of eleven women whose children or grandchildren were between 0.2 and 20 years old at the time of their meningitis diagnosis (*M*= 4.06, *SD*= 7.3). On average, 9.39 (*SD*= 5.4) years had passed between the onset of illness and the interview.

Results: Six superordinate themes (Meningitis disease; Healthcare services and professionals; Knowledge / ignorance; Repercussions of the meningitis experience - "Life afterwards"; Sick child attitudes / behaviour; Siblings attitudes / behaviour) and two main meaning-making processes in relation to the participants' experience of meningitis were identified: (1) the sick child becoming a "hero" – ccomparison with other children; (2) engaged action/attitude: finding the "positive" of the traumatic experience and engaged action to improve the care system. These two processes underpin the psychological adjustment to meningitis and its consequences.

Conclusions: This study provides a unique insight into close family members' first-hand experience with acute bacterial meningitis. Findings highlighted factors characterising the disease experience, the psychological adjustment of meningitis survivors' families and their meaning-making processes. These findings are important for research and clinical practice, demonstrating for the multidimensional impact of the disease on family ascendants, their need for professional psychological support, and the importance of direct involvement of parents in identifying key aspects of care.

Keywords: Parents/Family ascendants; Subjective experience; Meningitis; survivors; Meaning-making process; Qualitative methods; Discourse.

Article Summary

Strengths and limitations of this study

- An empirical qualitative method (Interpretative Phenomenological Analysis) was used to explore the lived experience of parents and grandparents whose child or grandchild had suffered from and survived acute bacterial meningitis.
- One of the first studies undertaken to explore the experience of family ascendants of this condition.
- The study results may be affected by the recruitment of participants through patient association websites and by the retrospective study design (i.e., reconstruction bias due to the time period between the meningitis episode and participation in the study).
- The participants were exclusively females (mothers or grandmother) and the study does not capture the experience of fathers (which is unfortunately quite common in studies dedicated to the parents of children with physical conditions).

INTRODUCTION

Paediatric acute bacterial meningitis is a life-threatening illness that results from bacterial infection of the meninges and leaves some survivors with significant sequelae. Meningococcus (another name for the bacterium *Neisseria meningitidis*) is one of the major causes of acute meningitis. Meningococcal infections have a high mortality rate, around 10 %, and a high epidemic potential [1-3].

Meningococcal meningitis usually occurs in early childhood (maximum incidence in children under five years of age) and in young adults (under twenty-five years). It combines an infectious syndrome (fever, severe headache, vomiting) and a meningeal syndrome (neck stiffness, lethargy, disorders of consciousness up to a coma). Even when the diagnosis and treatment were timely provided, the fatality rate still ranges from 5% - 10%, commonly within 24-48 hours after the onset of symptoms [1]. Bacterial meningitis may result in brain damage, hearing loss, visual impairment, or a learning disability in 10% - 20% of survivors [4]. A less common, but more severe (often fatal), form of meningococcal disease is meningococcal septicaemia (purpura fulminans), which is characterized by a haemorrhagic rash and rapid circulatory collapse [5].

Given the high mortality rate and the potentially severe sequelae induced by this condition, health authorities worldwide try to foster medical research in this domain and a relevant vaccine policy [6]. If major physical sequelae of childhood meningitis have been extensively studied, this is not the case for the related familial experience. When tracking empirical studies dedicated to the familial experience of this disease, we note that some articles are devoted to the issue of vaccination and the identification of potential barriers to it [7-9]. In Italy [7], the Netherlands [8] and in the UK [9], researchers highlighted that the public knowledge of meningitis and its related vaccinations is improved through correct health education and effective vaccine strategies that are implemented by policy-makers [7].

Besides the considerations regarding vaccination policy, the literature concerning family experiences of bacterial meningitis in children and adolescents is poor. To our knowledge, there are only three studies that specifically targeted the psychological adjustment of parents experiencing paediatric meningococcal meningitis. In 2005, Haines [10] conducted a qualitative study in interviewed parents based on a Heideggerian phenomenological qualitative approach, and highlighted, among other findings, a critical need for support and understanding, as well as a need for communication, information and publicity. Comparable results regarding the provision of information about the symptoms and possible sequelae of acute bacterial meningitis and regarding the need of better communication about the treatment process and the disease progression were also underlined by more recent research [11]. This latter study also focused on the parents' desire for professional support after the child was discharged from the hospital. The psychological adjustment of parents after meningococcal disease was also quantitatively studied in the mid and long term (3 and 12 months after discharge) [12]. The results indicated a risk for poor mental health among parents, with 13 of 54 mothers (24%) and six of 40 fathers (15%) scoring at high risk for posttraumatic stress disorder at 12 months. Additional studies not specific to acute bacterial meningitis, also pointed at the psychological vulnerability of parents and a great need for educational support of children who have survived meningitis and septicaemia [13]. One study [14] targeted ¨Post-intensive care syndrome (PICS) in patients and families after critical neurologic condition, which could include acute bacterial meningitis with neurological symptoms. This syndrome encompasses a variety of morbidities, including physical, cognitive, emotional, and psychological impairments following critical care. Taken together, these studies highlighted the psychological vulnerability of families after meningococcal disease and their need for communication and support. To the best of our knowledge, there is no French data on this question, despite the severe sequelae that could be induced by this disease [15]. Given the potential trauma induced by the disease and the hospitalization, it is important to gain insight on how the parents cope with this aversive event, especially how they give sense to this experience (with the possibility of a failure of this meaning-making process). Parents are the primary caregivers of these children, and the literature on “dyadic coping” in the context of illness, concept that refers to the stress management process in the context of couple relationship, underlined the intertwined nature of their psychological adjustment process [16]. As such, the family ascendants' adjustment has a direct impact on the psychological adjustment process of the children. Indeed, better mental health of the parent is associated with better mental and physical health of the children [17]. A better understanding of the parents' subjective experience would make it possible to offer more assistance to the parents and satisfactory care for the children. Indeed, we already underlined the paucity of the empirical literature regarding the long-term adjustment of meningitis survivors during adolescence or adulthood in a previous research. Not only did we do so in terms of presence or absence of symptoms but also in terms of emotional reactions, feelings, memories, and meaning-making process in the mid and/or long term [18].

The objective of the study is to capture the subjective experience of family ascendants confronted with acute bacterial meningitis, to highlight their meaning-making process in this adverse context, and to identify factors that could positively influence and develop the quality of care provided by healthcare professionals.

METHOD

Participants

This study of close family members confronted with acute bacterial meningitis was part of a broader research project dedicated to the psychological adjustment and the subjective experience of people who have experienced meningitis, either as patients or as patients’ ascendants. A total of 20 participants, including eleven individuals whose children or grandchildren experienced meningitis, were recruited through two patients’ associations (*Association Petit Ange - Ensemble contre la meningitis* and *Epilepsie France*), thanks to a call for testimonies posted on the association's website (see Supplementary material). The participants were not necessarily members of the association. The inclusion criteria were: (1) age ≥18 years at the time of the study; (2) being an ascendant of an individual who received a diagnosis of acute bacterial meningitis during childhood, adolescence, or adulthood; (3) a period of at least six months between the onset of illness of the descendant and the interview; and (4) informed consent to participate in this study.

The exclusion criteria were: (1) family ascendants who had lost their child due to acute bacterial meningitis, or bereaved parents (by other cause) were not included in the research because grief process could deeply affect the present results; (2) severe cognitive impairment that hinders participation in the study, as determined by the interviewers; (3) lack of a sufficient fluency in French to participate in the research interviews.

Recruitment

The recruitment was voluntary, and all participants expressed their agreement to participate in the research, according to the French ethical board's recommendations for qualitative non-interventional research. According to the French legislation, collection of information on ethnic origin and religious affiliation is not allowed [19], therefore these aspects were not assessed.

Ethical approval

In accordance to Article L1121-1 of the French Public Health Code [20], this qualitative study, which uses the responses to a survey carried out by telephone from relatives of individuals who recovered from the illness more than six months ago, does not correspond to any of the three categories of studies falling within the scope of research involving human subjects, and therefore no ethical approval was required.

Procedure

In-depth, semi-structured, qualitative interviews were conducted over the telephone. Although the interviewers followed an interview guide, the participants were encouraged to express themselves freely. This guide included questions relating to the history of the disease, the current emotional state of the participant, as well as questions relating to the potential impact of the meningitis infection for the family and siblings. The interviews were conducted in October 2018 by four researchers familiar with qualitative interview methods, and who were trained in qualitative approaches. The mean interview length was 60 minutes.

Analysis

Interviews were audio-recorded and entirely transcribed. Transcripts were subsequently anonymised by removing all identifying information. The original French extracts were translated into English. A bilingual French-English researcher verified that the translation of the verbatim to English was consistent with the meaning of the source texts in French. Interpretative Phenomenological Analysis (IPA) was chosen to explore the contents. For analysis key-elements, see Scanferla et al., (2020) [18]. Authors 1 and 3 (ES & LF) led the analysis following principles for IPA [21]. In brief, each interview was read by the first author multiple times to gain a holistic sense of the participant's account and discourse themes were identified by ES. The connections between the themes were then studied and the major themes were identified by the same author. Lastly, an interpretative account was produced that highlighted and analysed the experience through experiential themes and meaning-making processes. The meaning-making process is the means by which people try to make sense of their experiences, and the study of the processes of meaning-making describes what is happening in individuals and highlights the procedural dimension beyond symptoms and outcomes. It also helps to emphasise how meningitis can be experienced in different ways by different people through the analysis of convergences and divergences in the meaning-making processes. The third author (LF) audited the documentation for the first five interviews as a validity check on the analytic process. Great care was taken throughout the process to meet the scientific rigour criteria established by qualitative analysis [22].

Patient and public involvement

The scientific team/board of the project included two representatives of patients' associations. They were involved from the origin of the study and identified the potential psychological consequences of the disease experience. They also highlighted the interest and motivation of patients and family members to participate in psychological research, and also participated in the discussions during which questions would be posed to the participants. These representatives were aware of the potential burdens associated with this research and underlined on the contrary the benefits that participants could derive from the project. A press conference took place on 18th September 2020 to disseminate the results of the study on meningitis survivors' experiences [18]. The present study exploring the subjective experience of close family members of the child with meningitis, corresponds to the second part of the results. In addition, we plan to organise a second conference for the association where the participants were recruited to disseminate our findings and their clinical implications.

RESULTS

In total, 11 women took part in the study, 10 mothers and one grandmother. The children (child/grandchild) were 3–30 years old (Mean [*M*]= 13.45 Standard Deviation [*SD*]= 9.37) at the time of the interviews, and between 0,2 and 20 years old at the time of the meningitis diagnosis (*M*= 4.06, *SD*= 7.26). On average, 9.39 years had passed between the onset of illness and the parent's interview (*SD*= 5.46).

The participants' profile is described in Table 1.

Table 1: Participants' profile

	Participant	Relationship to the survivor	Survivor sex	Survivor' age at diagnosis (years)	Infectious agent
1	P2	Mother	F	0.33	Meningococcus B
2	P3	Mother	M	17	Meningococcus B
3	P5	Mother	F	0.08	Streptococcus B
4	P7	Mother	F	0.75	Pneumococcus
5	P10	Mother	M	4	*md*
6	P11	Mother	F	0,33	Pneumococcus
7	P12	Mother	F	20	Meningococcus B
8	P13	Mother	F	2	Pneumococcus
9	P16	Grand-mother	M	0.02	Streptococcus B
10	P19	Mother	F	0.08	Streptococcus B
11	P20	Mother	F	0.08	Streptococcus B

md: missing data

Concerning the bacterial agent causing the disease of the child, 3 participants reported meningococcal, 3 reported pneumococcal, and 4 reported streptococcal bacterium. For one participant, the causative bacteria was not identified, although a meningitis diagnosis had been made by medical staff.

Six major themes emerged following the analysis superordinates:

1. Meningitis disease
2. Healthcare services and professionals
3. Knowledge / ignorance
4. Repercussions of the meningitis experience - "Life afterwards"
5. Sick child attitudes / behaviour
6. Siblings attitudes / behaviour

Further analysis also revealed several subthemes (Table 2).

Table 2: Major themes and subthemes

Major themes	Subthemes
Meningitis disease	**Symptoms** (description…). Perception of symptoms & their evolution **Diagnoses** (relevance, accuracy, time…) **Description of the disease** (technical words, prevalence…)
Healthcare services and professionals	**Experience of healthcare services and relationships with healthcare providers** (e.g. communication) **Need for psychological support** at the time of diagnosis, during hospital care and in the long term (e.g. rehabilitation)
Knowledge / ignorance	**About the disease** (scientific background, technical vocabulary ...). Need for the patients and their caregivers to explain the disease. Internet and association role (information) **Unpreparedness of health professionals / expertise** **Helplessness of familial caregivers** (e.g. incomprehension of symptoms and/or lack of good reflexes, feeling of being overwhelmed by an exceptional situation)
Repercussions of the meningitis experience - "life afterwards"	**Physical sequelae** (partial paralysis, functional disability ...). Relating and compensating **Psychological impacts and familial adjustment** in the short-term (coping with the possibility of death) and the long-term (physical sequelae, medical care, daily life, school) **Parents coping with the illness** (e.g. impact on the marital couple...) **Impact of meningitis on the life course** (financial and professional impact, change of life and professional trajectories, "giving up"…)
Sick child attitude / behaviour	At the onset of the illness During the hospitalization Long-term attitudes (personality): flexibility, adaptation, courage
Siblings attitude / behaviour	Coping with the illness and its long-term effects (psychological sequelae and adjustments)

Only five of the above themes were selected for inclusion in this publication. These five themes were all chosen because they were directly in line with our research question (i.e..the family experience of the meningitis); and they were all spontaneously mentioned by the participants and did not correspond to the pre-established questions. A detailed analysis of the not-selected themes (i.e. meningitis disease) can be provided on demand.

1. Healthcare services and professionals

This theme includes three subthemes: (1) Experience of healthcare services and care routine; (2) Relationship with healthcare providers; (3) Need for psychotherapeutic support.

[illegible]

The overwhelming experience of an extreme situation, the interactions with healthcare professional and services were reported in by family ascendants. Feelings of dismay, refusal to accept their child's life is threatened and consecutive anger came over strongly in the interviews; for many, these emotional responses triggered a request for help.

Experience of healthcare services and the relationship with healthcare providers

The experience of care services as evoked by family members varied. Some of them emphasized the quality of care.

"I can't thank that paediatrician enough because he didn't know that it was meningitis yet, but he put a treatment in place (...), which saved us a few hours". (P13)

Others appreciated the attention they received at the hospital and stated that it helped them to reduce their stress and anxiety during the medical emergency situation.

"*We were very, very welcomed, they arranged a room for us at the hospital. It was a special room for the parents so we could sleep there the first night*". (P11)

Family ascendants praised both the technical and relational skills of healthcare providers.

However, within the narratives, there also appeared areas of dissatisfaction such as the long waiting time before receiving the diagnosis, the complexity of care received by their loved ones, and the hospital environment in general.

> *"After she got there, we waited for three or four hours without hearing from her. It was really a very, very long wait, no news, no nothing. (...). And then they put us in a very creepy office. It wasn't reassuring at all* (…)". (P20)

It appears here that it is not so much the wait itself that is stressful, but rather the absence of communication with the healthcare providers and especially the absence of news concerning the state of the child. This leads us to approach the following sub-theme of communication.

Indeed, there were many occurrences which highlighted the difficulties in communication with health care professionals. The dialogue was perceived as difficult and generated frustration.

> *"The doctor came in and he got angry with me and told me I had to stop my show (...) he thought I was a crazy person who was there to bother them"*. (P10)

This mother perceived here a lack of consideration for her emotional distress, which is misjudged by the physician, according to her testimony. We found the perception of this lack of consideration in the testimony of another study participant who mentioned that professionals gave little credit to her opinion:

> *"In any case, the way they told us things weren't right at all... Insinuating that it was not justified to come and take her [to the hospital], when in the end the (positive) results proved it the next day".* (P19)

Several mothers highlighted that the information they provided about their unwell child and their intuition of the seriousness of the situation was not considered. Therefore, they often felt discredited by the medical professional and expressed their frustration.

> *"I got angry (...), I told him that my daughter had had ear infections before, but that it hadn't put her in this state of drowsiness, with vomiting and a fever that wouldn't go down (...). I insisted, and he told me I was a hysterical mother".* (P13)

Some family ascendants remembered making harsh comments to certain doctors whose attitude or behaviour were deemed to be disrespectful, inappropriate or dismissive.

> *"I told them,* "We're not numbers" (…). *"There's even a doctor for whom I asked that he no longer treat my daughter. I even notified the hospital management, so he was replaced by another doctor."* (P2)

This mother placed herself as "guardian" of her child, in order to protect her son and to have him considered as an individual (and not as a “simple number”).

Need for psychological support

The parents showed very intense emotions when confronting the different stages of illness. Their emotional response oscillated between uncertainty and frustration, to fear, anxiety and shock as a result of what they sometimes perceived as a “cold” and “hard” relationship with healthcare professionals. They stressed the need for psychological support to help them at the time of diagnosis and intensive care, especially when they felt overwhelmed.

> *"I had a very bad experience at the ICU because I found that the staff... well, I think they're people who see this every day and have to remain impassive before certain situations. But we, as parents, we need accompaniment, we need support, we need help, and that's not necessarily what we had”.* (P2)

This parent interestingly gave a contrasting description between the "distanced" functioning of ICU professionals, a function that she understands, and her own needs as a mother.

Moreover, family ascendants experienced difficult emotions in the long term as well during their children’s rehabilitation period.

> *“They referred us to a psychologist. That's good in itself but it often happened in the hospital room with our daughter next door, so it wasn't necessarily the right time, we were very emotional. It was good to see a psychologist when our daughter was hospitalised, but we had very long medical visits for L., (...), but afterwards, we were abandoned to ourselves, we weren't supported at all.”* (P5)

Here, this mother indicated that the reference to a mental health professional was not always sufficient. The time and the clinical frame of psychological support were also critical and, despite this professional support, she felt abandoned.

For some, the help of professionals was essential in the process of alleviating their sense of guilt and making sense of the traumatic experience of accompanying a child who was experiencing meningitis.

> *"I started a behavioural and cognitive psychotherapy with a psychologist so that I could convince myself that it's not my fault that my daughter had purpura and was amputated."* (P2).

Cognitive behavioural therapy and especially cognitive remediation are specific techniques used in cases of particularly distressful thoughts.

2. Knowledge/ Ignorance

This second theme includes three subthemes about: (1) the disease; (2) the unpreparedness of healthcare professionals / experts; (c) the familial caregivers' helplessness.

Unanimously, the interviewed parents focused on the importance of knowledge about acute bacterial meningitis including its symptoms and possible sequelae, as well as the treatment process and disease progression. The testimonials stressed the parents own need for understanding on the one hand, and on the other hand, the healthcare providers' knowledge about the disease, which they sometimes perceived as insufficient. The lack of communication, information and support for families was also highlighted.

About the disease

The main part of the interviews highlighted that knowledge about meningitis was key and many participants expressed the need to develop this knowledge, as most of the time the disease was totally or partially unknown before it affected their child.

> *"I didn't even know what it was. I didn't even know there were three forms of meningitis; I didn't even know what "purpura fulminans" was (...). I'd never even heard of it."* (P2)

Meeting this need to better understand the disease involved the acquisition of a scientific background and the ability to express it with technical medical vocabulary. Therefore, many of the participants needed to acquire some form of expertise on the disease to learn the means and modalities of infection. They widely stressed that the internet and patients' associations were a valuable source of knowledge.

> *"I've done a lot of research on the Internet, I've read testimonials and a lot of things. I contacted associations that receive amputees and do a lot of things for them. I talked on the phone with people from these associations who also reassured me a lot (…). I wanted to find out as much as possible. It helped me a lot to be able to manage the situation as well as possible*". (P2)

Developing some forms of expertise on the disease and taking an active approach to it were reported as key aspects.

> *"I didn't realize how the infection is transmitted or the difference between viral and bacterial meningitis. But now I'm a meningitis expert...".* (P5) *(...) I've done a lot of reading on the subject, and the first reflex you have when you have a medical team in front of you that gives you a flood of information without taking the time to use words that are accessible to everyone, you have to check it out (…).* (P5).

Having an active approach to learning about the disease probably compensated for the perceived passive attitudes of healthcare professionals and the perceived lack of support that parents experienced during their child's care.

For some participants, their understanding of their child's potential situation contrasts with the expertise of the healthcare providers.

The perceived unpreparedness of health professionals / expertise

In several cases, the patients were given alternative diagnoses, suggesting an imprecise understanding of the symptoms and/or inadequate responses by healthcare professionals.

> *"When I was told that she had the germ of streptococcus, I consulted the Internet and saw that it could cause meningitis (...) The paediatrician told me:* "Don't worry, (...) she was treated and you will never hear about it again... there's no chance of that happening", ... *a week later, hospital, emergency room, meningitis."* (P 20).

This mother underlined here some diagnostic wandering: despite words full of assertiveness advising her not to worry, what she dreaded effectively happened.

In other cases, healthcare providers seemed completely overwhelmed by the emergency context and did not fully perceive the seriousness of the symptoms.

> *"When I called [the emergency services] for the relapse and told them that she had been out of hospital for 15 days for meningitis and that she had all the symptoms again, they didn't want to send us someone (...) Then the doctor (..) told us that we were really not very recommendable parents and that we should only call for real emergencies instead of calling for a little girl who is crying because she has a little fever"* (P19).

Helplessness of familial caregivers

The experience of a lack of responsiveness on the part of healthcare professionals caused frustration and feelings of helplessness in the patients' families.

> *"When they [the doctors] tell you that your child has a life expectancy of four years, when she reaches five years, you think that they may need to reconsider the diagnosis…".* (P5)

The participants' narratives also emphasized the importance of public awareness of meningitis and the role that patient and carer associations play in this regard. Associations provide families emotional and psychological understanding and support, which significantly helped the family ascendants through the stressful events they were experiencing.

> *"I think it's a disease that isn't adequately known. When she was at the hospital, I was seeking answers to my questions and I searched on the Internet, and that's when I came across the website of* [name of the association]. *Thanks to this website and the persons who foster it, we learn everything that can happen around meningitis. I tell myself that if people were better informed about the symptoms, more lives could be saved".* (P19)

Taken together, the testimonials highlighted the psychological vulnerability of families and their need for communication and support.

3. Repercussions of the meningitis experience - "life afterwards"

This major theme integrates five subthemes: (1) physical sequelae; (2) psychological impact; (3) parents coping with the illness (in the short and long term); (4) impact of meningitis on the life course; (5) meaning given to the extreme experiences they have gone through.

Physical sequelae of the child

Most of the interviews revealed the negative impact of meningitis on their ~~family~~ children and grandchildren health, and in particular the significant physical and cognitive sequelae associated with meningitis including partial paralysis, heart problems, hearing and visual impairments.

These impairments significantly limited the survivors' ability to function in an autonomous manner, and caused daily distress and frustration for the whole family.

"(...). The definition is global psychomotor impairment, with a significant language deficit. Not long ago, it was absence of language. You have to understand that (her) brain doesn't work on its own (...). Today, she has the entire left hemisphere that is necrotic, she has frontal and lateral lesions on the cortex which is between the two hemispheres. So, it's all been damaged". (P5)

Some testimonies focused on the physical impairments and a sense of permanent loss of prior abilities of their child, which caused them to develop feelings of injustice.

"These are diseases that totally destroy the life. She was a little girl who was 9 1/2 months old, who was beginning to walk, who was very lively, and she was completely stopped in her stride. It's really an injustice". (P7)

Psychological impacts and familial adjustment

Besides the negative physical and cognitive impact of the disease on their relatives, the participants also strongly insisted on the psychological impact of meningitis, and in particular the state of shock that they experienced at the period of the hospitalization.

"I was holding him in my arms, and I was looking for a way to comfort him. (...) I was just very, very anxious (...). I was completely shocked by his condition. I thought he was dying. In fact, I know he barely avoided death. I've always felt that my son was close to death" (P10).

The sight of the body of the diminished child, bearing the scars of the disease, was intolerable. Most of the participants described an impression of imminent death, which is terrifying. A grandmother mentioned this fear, which she states sometimes still comes to her.

"What's more, he was in great pain and that's really what shocked me the most. I've never seen anyone suffer like this, especially not a child. Three years later, I'm still shocked by it". (P16)

Some mothers stressed the traumatic nature of the experience of facing the danger of death of their child, especially during intensive care. The emotions described by most of the narratives are intense and vary between denial and deep anguish, some even evoking a state of stupor.

"When the doctor came to see us, she was still in a life-threatening prognosis. He told us that (…) there were three possible outcomes. Either she was not going to make it, or she was going to make it, but he was not able to say whether she will breathe on her own or not, or she was going to make it, but she will be very severely disabled" (...). For me, none of the options were possible". (P20)

Other testimonials illustrated the parents' aptitude to manage the exceptional situation and stay positive in front of their child during the hospitalization.

"Nevertheless, we had the chance (…) to keep hope alive. When we went to see her (…) in the intensive care unit, we talked to her, we sang songs to her. Even if we didn't know if she could hear us, we kept in mind that we had to stay positive". (P11)

However, most of the respondent commented on the long-term severe psychological consequences of the meningitis experience and sequelae. They described their global psychological vulnerability, and for some of them, depressive symptoms requiring treatments.

"I had nothing left to hold me. Everyone around me was happy, but I wasn't. I couldn't explain it, nothing had taste (…). I wanted to kill myself… but at the same time I told myself that those who remained would be too sad... so I didn't do it". (P12)

The description of depressive symptoms, including anhedonia and suicidal thoughts, were at times mixed with the perception of relief and happiness, often leading to a feeling of isolation.

The time necessary to regain personal and family balance also emerged as a common issue.

"After the first six months, I got the backlash. I tried to put up with everything, telling myself that I was strong. My daughter was strong, so I had to be strong. At one point, (...) I fell into a deep depression that lasted for two years. I was on medication, anxiolytics and antidepressants to get me out of this hellish spiral. I saw everything in black and I told myself that my daughter would never make it, that they would make fun of her and that life would be difficult for her. I locked myself in a negative bubble. Now I'm a little better, but there are always times when I think about the future, and I still have fears and anxieties about what might happen later on". (P2)

In these two testimonies, we can notice the lasting concern for their child, even when they progress to adulthood. This concern is permeated with anxious anticipation concerning the survivors' well-being.

Parents coping with the illness

Having to take care of a child who is often severely impaired is an ordeal for the parental couple. However, most of the interviewees highlighted that, despite occasional tensions, they managed to deal with this difficult situation.

> *"Concerning my couple, we have always remained very close together. My husband is always very, very present"* (P11).

Along with the family, in many cases the partner is identified as a valuable source of mutual support in the moments of doubt. The family, as a whole, is described as an important source of support.

> *"Luckily, we have a big family that never gave up on us. They took turns coming to see us. Every day, we had someone to support us". (P13)*

The quality of the relationship and communication of the two parents resulted in new forms of adjustment beyond the effects of the disease and brought new perspectives to family life.

> *"We complement each other (...). We talked about it* [the meningitis experience] *afterwards and we thought we'd done really well".* (P20)

The notions of complementarity and open communication appeared to be critical in coping with the disease and its multiple impacts.

Impact of meningitis on the life course

Caring for a child with a disability takes time, requires careful planning and often has a serious financial impact for the family, as underlined by the interviewed parents.

> *"I think it's all about her. For one thing, there are all her medical visits since she was four months old. There are 3 to 4 appointments a week, on top of work, you have to run around and it's still very heavy".* (P20)

Most of the time the disease and its consequences involved changes in the professional trajectories of the survivor's close family and in the whole family's way of life.

"At the time she was ill, I had planned to return to work (...) But I never went back to work, I didn't honour the contract. Then, for 6 years, I didn't work at all because (she) needed me, I was all the time with her, going back and forth for medical appointments. It was very complicated". (P11)

These words showed that besides psychological impacts, caring for a child affected by acute bacterial meningitis also has a financial cost, even in a country like France where social assistance is present.

Finally, some participants underlined the positive impact of maintaining professional activities not only for financial reasons, but also as a way to facilitate a social life beyond the world of disability.

"This job allows me to get out of everything related to disability, nappies, housework. It makes me think of something else, and it makes me earn some money". (P7)

Adjustments also concern material aspects such as the person's living and housing and the practical organisation of the child's care. They are necessary to allow the family to find a new form of everyday functioning.

"The house is being rearranged to create a room on the ground floor. Until now, she had been going upstairs, but we hope that when she has a room on the ground floor, it will be easier to find someone to relieve us so that we can leave from time to time". (P7)

"If her behaviour is definitely related to meningitis, it is a real handicap for us in many ways, we can't go anywhere, it is really difficult. We try to show her many things so that she can continue to improve but taking her to a zoo or a park is a real challenge". (P 20).

Thus, usual leisure activities for many children become extremely complex to organise: everyday life is often marked by renouncement.

The interaction with the health services administration regarding about the coverage of the family member's care is also a concern mentioned by family ascendants. They emphasized that the complexity of the administrative procedures and the constant need to prove legitimacy to their request constitute a considerable psychological burden in addition to the burden of caring for the meningitis survivors.

"I always say the biggest handicap is administration. (...) you have to keep fighting" (P7).

The energy expended is considerable, and participants often use sports comparisons or fighting metaphors to describe their daily life.

"We always have to go running around, putting together files, emails... I think that is the worst. (...) When we had a renewal [of the disabled adult allowance file], and they stripped us of everything. We had to appeal. On top of that, they always take 6 months to respond... we spend our time fighting". (P20)

4. Sick child attitude / behaviour

Several testimonials described the positive evolution of the children who have survived meningitis and stressed in particular the progress they have made and the skills that they have acquired, frequently reaching levels of results that go beyond what the healthcare professionals considered possible.

"When we see the MRIs, compared to the damage she has to her brain, the doctors don't understand that she can do what she does (...). For them, in relation to her lesions, she should be in a vegetative state, while she can eat by herself, she walks alone with her armchair, she sings, she loves to sing, she loves to play, music, early learning games, etc.". (P13)

Some individuals also evoked the adaptability, flexibility, and courage of their loved ones.

"I think she's happy, but she has her ups and downs (...). She tries, she finds ways to do it (...). She has great strength of character and now she wants to do things even if it's hard for her". (P11)

"And in the end, she has made up for her developmental delay (...). She has caught up with everything and even the attending doctor told me that she is amazing. She really is a great little girl" (P19).

Furthermore, many testimonies referred to the social abilities of the meningitis survivors and their capacity to enjoy a satisfactory quality of life despite the limits imposed by the severe handicaps they experience.

"She's very sociable, so she's a bit of a mascot everywhere she goes. As she is very charming, very attaching and very funny, she doesn't have too many problems adapting to a new environment". (P5).

The child's ability to forge links with her/his peers and her/his "zest for life" are very often underlined.

Despite the disability and limitations brought on by the disease, the survivors' ability to bounce back and adjust is stressed with admiration by the participants. However, the experience of an event that suddenly and unexpectedly upsets the life of the whole family also required the siblings' capacity for psychological adjustment.

5. Siblings attitude / behaviour

The experience of acute meningitis disease and its sequelae is a stressful experience for the whole family, not only when a family member is admitted to Intensive Care Unit (ICU), but also in the mid- and long term. Within this study, parents focused on the siblings of the sick child, as they also experienced some form of impact or disruption as a result of their siblings' illness.

A common thread among the interviewees was the parents' perception of the attitude and behaviour of siblings towards the meningitis survivors. Many participants could mention the supportive way in which the siblings coped with the disease, and their positive role in the recovery and life trajectories of their loved ones.

"I am convinced that it is thanks to her twin sister who has been a great stimulant for her. She has caught up with everything". (P19).

Likewise:

“I think his brother was really a driving force, even if it's not always obvious to him”. (P5)

Particular emphasis is also placed on the siblings’ ability to understand, help and protect their survivor sibling.

“He tells us: “You don't understand that she wants that! *We didn't understand fast enough, according to him, and he was interpreting”.* (P5)

The brother here adopts the function of intermediary or more precisely as an interpreter between his sister and their parents, revealing a rare complicity.

"He's a child who's very protective of his sister. He doesn't hesitate to go and see the other children in the schoolyard if his sister is being teased”. (P2)

The role of "guardian" that we evoked when speaking of parents can sometimes be taken by a brother or a sister of the sick child as well.

In addition, parents stressed that overall, the daily confrontation with disabilities enabled the siblings to develop a sense of openness and tolerance of other people's differences.

“*My daughters have a lot of empathy, whether with their* [disabled] *sister or with other children. It's true that they also have a different life. It is very enriching for them*, *because they know the difference, they learn the values of life, which not all children will necessarily have…”.* (P7)

However, the testimonies of some other participants highlighted the psychological impact on siblings of the specific disease-related environment and the responsibility that they assumed. Possible mentioned causes include the fact that the disabled child monopolised the parents' attention or that the place and role of everyone in the family may be affected.

“Our second [daughter] *is everyone's elder sister. She says it all the time:* "By age, I am her little sister, but in my head I am her big sister...*".* (P13)

“Finally, he has developed obesity (...). He was deeply shocked and traumatised by his sister's amputation (...), he's aware that his sister is different from other children. He assigned himself the role of the big brother, which is: "I'm here, I'll protect you, I'm here for you *(...), he took his role very seriously”.* (P2)

The representation of this mother is clear: she sketched a linear causality between the amputation of her daughter, following meningitis, and the obesity of her son, whom she considered traumatised.

Despite the severity of the illness and the magnitude of its consequences for the survivors and the whole family, the narratives stressed that in the long term, one of the key elements of balance is the parents' ability to ensure a family life is "as normal as possible" for all siblings, where everyone (re)discovers his or her place.

Narrative account and profiles of meaning-making

The analysis of the above-mentioned themes allowed for the identification of the meaning-making processes deployed by the participants and which are reflected in their remarks. These two processes underpin the psychological adjustment to the meningitis and its consequences.

1. Comparison with other children- The sick child becoming a "hero"

In order to have reference points on the development of their child, some of whom are affected by serious sequelae, many parents compared the latter to other children in their family circle. This comparison often turned out to be a source of great distress, by noting how much the child is disabled and behind in their psychomotor development. For instance:

> *"I have a lot of children in my family, and I could see that for her there were some things that were wrong" (P5)*

> "*Thereafter, she evolved very slowly compared to children of her age*". (P11).

In some cases, the comparison did not come from the parents themselves, but came from a stranger.

"One day, our kid was 5 years old, she was in her stroller with a pacifier in her mouth, one couldn't see that she was disabled, and there was an old man who approached us saying: "look at

my little grandson, he walks, he is not in a stroller and he does not have a pacifier, yet he is younger! (P7).

This mother highlighted the perceived violence born from this comparison imposed by a stranger who knew nothing of her history.

Other parents insisted on the developmental similarities between their child, even when disabled, and other children of the same age:

> *"Otherwise, in terms of development, she is a child like any other (...). She makes a point of doing the same activities as other children" (P2).*

We found a similar statement in the testimony of a grandmother:

> "*[He] does everything like them (his siblings). He is a child who has his place among the siblings, there is no problem"* (P16).

Some parents expressed pride in having managed to cope with such an extreme experience, as an individual and as a couple.

> *"It [the meningitis experience] gave me that attitude because I wasn't like that before. It gave me a stronger temper to come with it. (...) It's ok to break down, you have to break down at some point, but the next day I am back on top, and I'm back on my feet.."..* (P13)

Another mother evoked the support she found in her relationship with her partner.

> *"I see many couples (...) who split up because of their child's disability. However, we supported each other, we didn't argue, there were no conflicts related to that. No, we did well".* (P20)

However, above, the parents' pride was centred on their sick child. We found in their speech a highlighting of her/his exceptional character. As mentioned earlier, several participants expressed a sense of satisfaction about their child's trajectory. Some insisted on the fact that they initiated certain attitudes, instilling courage in their child.

> *"She's a little girl who's doing very well, we've done everything we could. She likes to be assisted, so we taught her that no, that wasn't life, she had to do it on her own". (P 19)*

For some family ascendants, their loved one was in a way revealed in the disease, without the family having anything to do with it. The “hero figure” then becomes the one that best describes their child. “Hero”, because the child is distinguished by her/his bravery, her/his exceptional abilities. So, this mother told us about her daughter:

“That's when I saw that my daughter was a fighter, because after waking up alone from a coma, she saw me and said "mama", at 4 1/2 months. She spoke. She woke up from a coma, looked me straight in the eye and said "mama".”(P2)

Faced with an extreme experience - the mother insisted that her daughter was close to death – the child’s exceptional character was revealed in her verbal precocity. Furthermore, it is within the mother-daughter relationship that the extraordinary capacity of the child emerged.

These exceptional capacities mentioned by family ascendants can thus be physical, as in the testimony mentioned above, or in the words of other parents:

“She has a phenomenal strength in her arms that she has developed due to the absence of her legs” (P13).

A physical force, therefore, but also a psychological one:

“(She) turns out to be a very combative little girl” (P5).

It appears that this revelation of the heroic character of their child allowed parents who perceived this extraordinary dimension, to find a positive meaning in this painful experience.

“*It is one of the most beautiful moments that I experienced in this terrible ordeal (...). At the beginning, the doctors didn't believe us (about the fact that their daughter was able to speak) and we rang them to show them. We even kept photos of those moments. For us, it was a magical moment because we realized that our daughter really wanted to live”* (P2).

We find here the characteristics of extraordinary events, which even look like a miracle for these parents: the fact that there are people who do not believe, who must therefore be convinced; the need for proofs, the fight that was carried out, and the ultimate meaning of this fight: the revelation of a will to live. This elaboration of the figure of the child as a hero thus made it possible to give a positive meaning to this painful experience and further, it may confirm the meaning and value of the child's life.

This mention about finding positive meaning through the distressful experience of meningitis leads to a second meaning-making process: engaging action to improve the healthcare system.

2. Finding the “positive” of the traumatic experience and engaging action to improve the healthcare system.

The discourse of the participants echoed a desire to take an active position in their relationship with the disease, not only through the acquisition of personal knowledge about meningitis, but also through the commitment to raise awareness of the disease in the general population. This commitment can also concern awareness-raising work about people with disabilities. For instance, this mother told us:

> *“I raise awareness among children and young people on the concept of disability. I go to schools or associations with a small booklet that I made, and I explain to children what disability is, to remove taboo words and so that they put words on the little friends who are dyslexic, or in a wheelchair, or mentally handicapped, etc.” (P7)*

Believing that in France, individuals are not familiar enough with difference - here linked to a disability - this mother wanted to suggest to the youngest people to think about the inclusion of their disabled peers, so that they can have a life as normal as possible.

This engagement process, which allows for them to feel active instead of enduring the vagaries of life as a parent with a child with serious sequelae always starts from the intimate experience to try to improve things for the greatest number. Thus:

> *“We got a family house and we are in the process of renovating it to make a home to accommodate disabled people on vacation in the Alps (...). It was our dream for us, so we are doing it for others (P7)”.*

Having been confronted with major difficulties relating to the accessibility for disabled people in many vacation homes, this family decided to take matters into their own hands and create this dedicated and accessible place. The form of altruism that this commitment constitutes can also be noted, which is why many, especially within the family, admire this commitment. Thus, the grandmother of a child who suffered from meningitis testified to her admiration for her daughter, the mother of this child.

"My daughter invests in everything, in everything, for her little son It's extraordinary" (P16).

DISCUSSION

This study on the experiences of close family members of meningitis survivors highlighted six themes, shared by most of the participants, and two meaning-making processes that appeared through the analysis of the narratives. The qualitative findings stressed the parents' understanding about acute bacterial meningitis, their relationships with the care system and the healthcare providers; and they also highlighted the ignorance about this disease at the time of medical treatment, both their own and that of certain healthcare professionals. In contrast, they spoke of the knowledge that they had been able to acquire through patient associations. Much of their testimony dealt with the multidimensional repercussions of the disease on their sick child and for the whole family. The attitude and behaviour of the child affected by meningitis were largely described and often glorified. Finally, the reaction of the siblings was a matter of concern for many interviewed parents.

These qualitative results provide insight into the nature of the mid and long-term repercussions of the disease at an individual and familial level; they also offer an understanding of the distress induced by these impacts. Indeed, consistent with previous quantitative studies [12, 13], this research stressed the psychological burden associated with being the family of a child affected by acute bacterial meningitis. This burden is imbued with traumatic elements (confrontation with the possibility of the child's death, awareness of the possible sequelae), and is experienced daily by families who have to face medical, economic, and societal challenges. The present results also underline the expressed need for specific and professional support in this population. The interviewed parents insisted on their requirement for psychological support, not necessarily during the acute phase of the hospitalisation, when they were often stunned and preferred to be constantly at the bedside of the sick child, but rather at the hospital discharge and in the long-term, when they understood more clearly what their life would be like after this disease. A recent article showed that coping support interventions are effective for improving parents' anxiety and stress symptom burden related to acute paediatric hospitalisations [23]. Structured interventions could indeed be offered to parents of children affected by meningitis, during hospitalisation and at discharge.

However, the parents interviewed in this study not only experienced distressful challenges induced by the illness of their children but also, for some participants, trajectories of post-traumatic growth. Tedeschi and Calhoun [1998] [24] defines "Post-Traumatic Growth" as any positive personal changes that occur after experiencing a potentially traumatic event. The meaning-making processes analysed in this study indicated such a trajectory. The parents' pride in their child and the pride that some admit feeling about themselves because they are satisfied with the way they take care of their child and their family, echoes this growth process. A mixture of vulnerability and growth was underlined in a previous qualitative study, conducted among mothers whose school-aged children were born extremely prematurely; just as several participants of our research, these mothers celebrated their children's successes [25]. The celebration of the children's skills and their ability to overcome their disabilities become for certain participants the depiction of a hero trajectory; that may be related to the dimension of "Post-traumatic Growth" such as "new possibilities" and "appreciation of life" [24].

Furthermore, the involvement of some parents in patient associations, even their participation in this study, may indicate the experience of "new possibilities" and "enhanced relationships". Highlighting this growth in some individuals should not lead to an "injunction to resilience" but to the observation that the close family members of meningitis survivors can adjust to this difficult experience and find meaning in it/

Strengths and weaknesses of the study

This study has several limitations. The first limitation is related to the nature of the recruitment and the representativeness of the sample. As participants volunteered to take part in the research, this may have resulted in self-selection bias. Therefore, findings may reflect the views of people more interested in taking an active approach to the disease through engagement with a patient association. Moreover, the sample exclusively consisted of adult females (ten mothers and one grandmother). Thus, this study might not be representative of the wider spectrum of close family members who faced the meningitis disease. Finally, the participants' close family members differed significantly in age at the time of the meningitis diagnosis, severity of their symptoms and sequelae. It is conceivable that their experiences would vary with these factors. In future studies, a more diverse sample, including male participants, recruited from a plurality of treatment facilities and setting contexts of care, would be preferred. This would allow for the examination of whether different experiences would be described and would provide a complete map of the meanings attached to subjective experiences and the generalisation of the study findings.

A second limitation concerns the retrospective nature of the interviews. This wide time period could have induced recall and reconstruction bias in material (e.g. negative aspects often tend to be better remembered than the positive one). A worthwhile direction for future research might be the exploration of the subjective experience of parents confronted with acute bacterial meningitis and the family members' psychological adjustment shortly after the acute phase. A longitudinal design would also allow for the capture of differences in their adjustment of variations in the psychological adjustment of the study participants.

Despite these limitations, this is the first study that uses a validated methodology to provide insights on the lived experience of families that have faced bacterial meningitis disease, and it highlights several meaning-making processes of this life-changing experience. It stresses, on the one hand, the interviewed parents' need for improved communication with the healthcare providers and on the other hand, the importance of an increased knowledge surrounding the disease, in particular with regard to the basic education of the public in general and the diagnostic competences of primary care providers in particular.

Clinical implications

The findings in this study highlighted several dimensions that could be of clinical relevance, such as:

- The value of the intervention of experts in the field of infectious diseases in the Continuing Professional Development of physicians, which would improve not only their familiarity with meningitis and its treatment, but also their capacity to interact with carers in the most appropriate and efficient way [18].
- The disease-related environment, and more specifically, the experience of accompanying a child receiving intensive care and the related risk of death are stressful, and may potentially result in some disruption or trauma for the whole family.
- Being regularly informed of the care provided to their child, taking an active part in it, and receiving attention by healthcare professional, are mentioned as mitigating factors to help alleviate stress and anxiety. Several authors have emphasized the positive impact of family open visitation and parental presence for the care of their child, especially in emergency care settings and intensive care units, even in extremely difficult contexts, such as the one experienced with the Covid pandemic [26, 27, 28]; impacts include relieved anxiety and fear, as well as reduced psychological distress and post-intensive disorders, for both the family members and survivors [29, 30].The family presence during ICU procedures is the siblings' visits. As in other contexts

of severe diseases, sibling visitation is being increasingly endorsed as a positive development in patient care. This is relevant especially because it facilitates elaboration of the siblings' own perception of the situation and prepares post-discharge life, reduces fantasies, increases understanding and the sense of control over the situation, increases bond enhancement, and improves communication between families and care providers [27, 31, 32]. Thus, the implementation of experimental initiatives in the context of bacterial meningitis intensive care seems desirable. Collaboration between different healthcare providers (clinicians, nurses, psychologists) and parents in order to create the appropriate visitor conditions and organisation of staff is strongly supported by the literature [29, 33, 34]. Given the paucity of research on this issue, further studies on the psychological impact and implications of the siblings' presence in ICUs could offer some insights on how they cope with this adverse event at the time of care and in the longer term. In this perspective, exploring the siblings' experience of the disease would provide a better understanding of the meaning-making process and could help identify potential pitfalls where there is a need for sustainable psychological assistance. The need for continuing efforts to consider and monitor the emotional burden of the disease on the child's family ascendants, the psychological adjustment process and families' trajectories over time. In this regard, it would be valuable if family ascendants of acute meningitis survivors could benefit from systematic, and when necessary, professional consultations during and after their experience of the disease. The more appropriate forms and timing of this support, prognostic factors and outcome merit further investigation.

Conclusions

This study helped to capture the subjective experience and psychological adjustments of parents confronted with paediatric meningococcal meningitis. Two main meaning-making processes in relation to the participants' experiences of this adverse context emerged from their discourse. These processes emphasized the importance of information and support of families, the potentially traumatic impact of the illness experience, and the possibility of post-traumatic growth for some individuals, including the desires of parents to engage in improving the care system. Providing family ascendants with accurate information about their child's conditions and treatments, as well as involving them in the care and medical decision-making could positively influence and develop the quality of care provided by healthcare professionals.

In the meantime, clinicians, caregivers, and other stakeholders of the healthcare system should be aware that information and the involvement of the family as an active partner in the care process are conditions for its effectiveness, from the onset of disease symptoms, their management in the emergency rooms and throughout the recovery journey.

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AUTHOR CONTRIBUTIONS

ES and LF conducted the review of the literature. ES was the main coder for the thematic analysis. LF was the second coder for the thematic analysis. ES and LF analysed the data and edited the manuscript. PG contributed to the construction of the research project and supervised the discussion of the results. All authors read and approved the final manuscript.

COMPETING INTERESTS

The authors declare that they have no competing interests regarding the publication of this article.

DATA AVAILABILITY STATEMENT

Data are available on reasonable request.

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May 2021

Elisabetta Scanferla
Léonor Fasse
Philip Gorwood

Manuscript ID bmjopen-2020-047465 Article entitled

" The familial experience of acute bacterial meningitis in children. A transversal qualitative study using interpretative phenomenological analysis."

Call for testimonies

Meningitis survivors and families wanted for telephone interviews

“Petit Ange” is an association participating in a working group* aiming to describe the long-term effects of meningitis. For that purpose the association is looking for people with meningitis and/or their family members.
To date publications have described the medical consequences of meningitis. However, impact of the disease on people's daily life, relationships with family and others, and professional career are not sufficiently known nor taken into account.

To this end the working group is looking for meningitis survivors and their families to interview either by phone or face-to-face in Paris.

Would you be interested in taking part in a phone or face-to-face interview in Paris, run by “Edusanté” and lasting approximatively 45-60 min.?

A 50-euro compensation is given for the interview.

The content of these interviews will of course remain anonymous and the association “Petit Ange” will share with you the overall results of the study, should you choose so.

(*) - The working group consists of representatives from two associations, “Petit Ange” and “Méningite France”, a pediatrician, a psychiatrist, a sociologist, and an organization dedicated to patient education and support – “Edusanté”.
- The working group is independent and aims to improve knowledge about consequences of meningitis on the affected families. This research is funded by a pharmaceutical company, GSK.

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQRreporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1

Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Introduction			
Problem formulation	#3	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4
Purpose or research question	#4	Purpose of the study and specific objectives or questions	6
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability.	6

		As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	8
Context	#7	Setting / site and salient contextual factors; rationale	6 & 7
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	6
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	7
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	7

Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	8
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	8
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	8
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	8 & 9
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	10 &11

Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	11 & more
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	28
Limitations	#19	Trustworthiness and limitations of findings	30
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	34
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	34

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The familial experience of acute bacterial meningitis in children
A transversal qualitative study using interpretative phenomenological analysis.

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The familial experience of acute bacterial meningitis in children

A transversal qualitative study using interpretative phenomenological analysis.

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Abstract

Objectives: (1) To capture the subjective experience of close family ascendants of acute bacterial meningitis survivors; (2) To explore how they give meaning to this specific experience.

Design: A qualitative study of in-depth interviews using Interpretative Phenomenological Analysis. Primary outcome: to identify the main meaning-making processes of the participants' experience.

Settings: Participants were recruited through two associations of people affected by meningitis and their family ascendants.

Participants: Convenience sampling of eleven women whose children or grandchildren were between 0.2 and 20 years old at the time of their meningitis diagnosis (M= 4.06, SD= 7.3). On average, 9.39 (SD= 5.4) years had passed between the onset of illness and the interview.

Results: Six superordinate themes (Meningitis disease; Healthcare services and professionals; Knowledge / ignorance; Repercussions of the meningitis experience - "Life afterwards"; Sick child attitudes / behaviour; Siblings attitudes / behaviour) and two main meaning-making processes in relation to the participants' experience of meningitis were identified: (1) the sick child becoming a "hero" – ccomparison with other children; (2) engaged action/attitude: finding the "positive" of the traumatic experience and engaged action to improve the care system. These two processes underpin the psychological adjustment to meningitis and its consequences.

Conclusions: This study provides a unique insight into close family members' first-hand experience with acute bacterial meningitis. Findings highlighted factors characterising the disease experience, the psychological adjustment of meningitis survivors' families and their meaning-making processes. These findings are important for research and clinical practice, demonstrating for the multidimensional impact of the disease on family ascendants, their need for professional psychological support, and the importance of direct involvement of parents in identifying key aspects of care.

Keywords: Parents/Family ascendants; Subjective experience; Meningitis; survivors; Meaning-making process; Qualitative methods; Discourse.

Article Summary

Strengths and limitations of this study

- An empirical qualitative method (Interpretative Phenomenological Analysis) was used to explore the lived experience of parents and grandparents whose child or grandchild had suffered from and survived acute bacterial meningitis.
- One of the first studies undertaken to explore the experience of family ascendants of this condition.
- The study results may be affected by the recruitment of participants through patient association websites and by the retrospective study design (i.e., reconstruction bias due to the time period between the meningitis episode and participation in the study).
- The participants were exclusively females (mothers or grandmother) and the study does not capture the experience of fathers (which is unfortunately quite common in studies dedicated to the parents of children with physical conditions).

INTRODUCTION

Paediatric acute bacterial meningitis is a life-threatening illness that results from bacterial infection of the meninges and leaves some survivors with significant sequelae. Meningococcus (another name for the bacterium *Neisseria meningitidis*) is one of the major causes of acute meningitis. Meningococcal infections have a high mortality rate, around 10 %, and a high epidemic potential [1-3].

Meningococcal meningitis usually occurs in early childhood (maximum incidence in children under five years of age) and in young adults (under twenty-five years). It combines an infectious syndrome (fever, severe headache, vomiting) and a meningeal syndrome (neck stiffness, lethargy, disorders of consciousness up to a coma). Even when the diagnosis and treatment were timely provided, the fatality rate still ranges from 5% - 10%, commonly within 24-48 hours after the onset of symptoms [1]. Bacterial meningitis may result in brain damage, hearing loss, visual impairment, or a learning disability in 10% - 20% of survivors [4]. A less common, but more severe (often fatal), form of meningococcal disease is meningococcal septicaemia (purpura fulminans), which is characterized by a haemorrhagic rash and rapid circulatory collapse [5].

Given the high mortality rate and the potentially severe sequelae induced by this condition, health authorities worldwide try to foster medical research in this domain and a relevant vaccine policy [6]. If major physical sequelae of childhood meningitis have been extensively studied, this is not the case for the related familial experience. When tracking empirical studies dedicated to the familial experience of this disease, we note that some articles are devoted to the issue of vaccination and the identification of potential barriers to it [7-9]. In Italy [7], the Netherlands [8] and in the UK [9], researchers highlighted that the public knowledge of meningitis and its related vaccinations is improved through correct health education and effective vaccine strategies that are implemented by policy-makers [7].

Besides the considerations regarding vaccination policy, the literature concerning family experiences of bacterial meningitis in children and adolescents is poor. To our knowledge, there are only three studies that specifically targeted the psychological adjustment of parents experiencing paediatric meningococcal meningitis. In 2005, Haines [10] conducted a qualitative study in interviewed parents based on a Heideggerian phenomenological qualitative approach, and highlighted, among other findings, a critical need for support and understanding, as well as a need for communication, information and publicity. Comparable results regarding the provision of information about the symptoms and possible sequelae of acute bacterial meningitis and regarding the need of better communication about the treatment process and the disease progression were also underlined by more recent research [11]. This latter study also focused on the parents' desire for professional support after the child was discharged from the hospital. The psychological adjustment of parents after meningococcal disease was also quantitatively studied in the mid and long term (3 and 12 months after discharge) [12]. The results indicated a risk for poor mental health among parents, with 13 of 54 mothers (24%) and six of 40 fathers (15%) scoring at high risk for posttraumatic stress disorder at 12 months. Additional studies not specific to acute bacterial meningitis, also pointed at the psychological vulnerability of parents and a great need for educational support of children who have survived meningitis and septicaemia [13]. One study [14] targeted ¨Post-intensive care syndrome (PICS) in patients and families after critical neurologic condition, which could include acute bacterial meningitis with neurological symptoms. This syndrome encompasses a variety of morbidities, including physical, cognitive, emotional, and psychological impairments following critical care. Taken together, these studies highlighted the psychological vulnerability of families after meningococcal disease and their need for communication and support. To the best of our knowledge, there is no French data on this question, despite the severe sequelae that could be induced by this disease [15]. Given the potential trauma induced by the disease and the hospitalization, it is important to gain insight on how the parents cope with this aversive event, especially how they give sense to this experience (with the possibility of a failure of this meaning-making process). Parents are the primary caregivers of these children, and the literature on “dyadic coping” in the context of illness, concept that refers to the stress management process in the context of couple relationship, underlined the intertwined nature of their psychological adjustment process [16]. As such, the family ascendants' adjustment has a direct impact on the psychological adjustment process of the children. Indeed, better mental health of the parent is associated with better mental and physical health of the children [17]. A better understanding of the parents' subjective experience would make it possible to offer more assistance to the parents and satisfactory care for the children. Indeed, we already underlined the paucity of the empirical literature regarding the long-term adjustment of meningitis survivors during adolescence or adulthood in a previous research. Not only did we do so in terms of presence or absence of symptoms but also in terms of emotional reactions, feelings, memories, and meaning-making process in the mid and/or long term [18].

The objective of the study is to capture the subjective experience of family ascendants confronted with acute bacterial meningitis, to highlight their meaning-making process in this adverse context, and to identify factors that could positively influence and develop the quality of care provided by healthcare professionals.

METHOD

Participants

This study of close family members confronted with acute bacterial meningitis was part of a broader research project dedicated to the psychological adjustment and the subjective experience of people who have experienced meningitis, either as patients or as patients’ ascendants. A total of 20 participants, including eleven individuals whose children or grandchildren experienced meningitis, were recruited through two patients’ associations (*Association Petit Ange - Ensemble contre la meningitis* and *Epilepsie France*), thanks to a call for testimonies posted on the association's website (see Supplementary material). The participants were not necessarily members of the association. The inclusion criteria were: (1) age ≥18 years at the time of the study; (2) being an ascendant of an individual who received a diagnosis of acute bacterial meningitis during childhood, adolescence, or adulthood; (3) a period of at least six months between the onset of illness of the descendant and the interview; and (4) informed consent to participate in this study.

The exclusion criteria were: (1) family ascendants who had lost their child due to acute bacterial meningitis, or bereaved parents (by other cause) were not included in the research because grief process could deeply affect the present results; (2) severe cognitive impairment that hinders participation in the study, as determined by the interviewers; (3) lack of a sufficient fluency in French to participate in the research interviews.

Recruitment

The recruitment was voluntary, and all participants expressed their agreement to participate in the research, according to the French ethical board's recommendations for qualitative non-interventional research. According to the French legislation, collection of information on ethnic origin and religious affiliation is not allowed [19], therefore these aspects were not assessed.

Ethical approval

In accordance to Article L1121-1 of the French Public Health Code [20], this qualitative study, which uses the responses to a survey carried out by telephone from relatives of individuals who recovered from the illness more than six months ago, does not correspond to any of the three categories of studies falling within the scope of research involving human subjects, and therefore no ethical approval was required.

Procedure

In-depth, semi-structured, qualitative interviews were conducted over the telephone. Although the interviewers followed an interview guide, the participants were encouraged to express themselves freely. This guide included questions relating to the history of the disease, the current emotional state of the participant, as well as questions relating to the potential impact of the meningitis infection for the family and siblings. The interviews were conducted in October 2018 by four researchers familiar with qualitative interview methods, and who were trained in qualitative approaches. The mean interview length was 60 minutes.

Analysis

Interviews were audio-recorded and entirely transcribed. Transcripts were subsequently anonymised by removing all identifying information. The original French extracts were translated into English. A bilingual French-English researcher verified that the translation of the verbatim to English was consistent with the meaning of the source texts in French. Interpretative Phenomenological Analysis (IPA) was chosen to explore the contents. For analysis key-elements, see Scanferla et al., (2020) [18]. Authors 1 and 3 (ES & LF) led the analysis following principles for IPA [21]. In brief, each interview was read by the first author multiple times to gain a holistic sense of the participant's account and discourse themes were identified by ES. The connections between the themes were then studied and the major themes were identified by the same author. Lastly, an interpretative account was produced that highlighted and analysed the experience through experiential themes and meaning-making processes. The meaning-making process is the means by which people try to make sense of their experiences, and the study of the processes of meaning-making describes what is happening in individuals and highlights the procedural dimension beyond symptoms and outcomes. It also helps to emphasise how meningitis can be experienced in different ways by different people through the analysis of convergences and divergences in the meaning-making processes. The third author (LF) audited the documentation for the first five interviews as a validity check on the analytic process. Great care was taken throughout the process to meet the scientific rigour criteria established by qualitative analysis [22].

Patient and public involvement

The scientific team/board of the project included two representatives of patients' associations. They were involved from the origin of the study and identified the potential psychological consequences of the disease experience. They also highlighted the interest and motivation of patients and family members to participate in psychological research, and also participated in the discussions during which questions would be posed to the participants. These representatives were aware of the potential burdens associated with this research and underlined on the contrary the benefits that participants could derive from the project. A press conference took place on 18th September 2020 to disseminate the results of the study on meningitis survivors' experiences [18]. The present study exploring the subjective experience of close family members of the child with meningitis, corresponds to the second part of the results. In addition, we plan to organise a second conference for the association where the participants were recruited to disseminate our findings and their clinical implications.

RESULTS

In total, 11 women took part in the study, 10 mothers and one grandmother. The children (child/grandchild) were 3–30 years old (Mean [*M*]= 13.45 Standard Deviation [*SD*]= 9.37) at the time of the interviews, and between 0,2 and 20 years old at the time of the meningitis diagnosis (*M*= 4.06, *SD*= 7.26). On average, 9.39 years had passed between the onset of illness and the parent's interview (*SD*= 5.46).

The participants' profile is described in Table 1.

Table 1: Participants' profile

	Participant	Relationship to the survivor	Survivor sex	Survivor' age at diagnosis (years)	Infectious agent
1	P2	Mother	F	0.33	Meningococcus B
2	P3	Mother	M	17	Meningococcus B
3	P5	Mother	F	0.08	Streptococcus B
4	P7	Mother	F	0.75	Pneumococcus
5	P10	Mother	M	4	*md*
6	P11	Mother	F	0,33	Pneumococcus
7	P12	Mother	F	20	Meningococcus B
8	P13	Mother	F	2	Pneumococcus
9	P16	Grand-mother	M	0.02	Streptococcus B
10	P19	Mother	F	0.08	Streptococcus B
11	P20	Mother	F	0.08	Streptococcus B

md: missing data

Concerning the bacterial agent causing the disease of the child, 3 participants reported meningococcal, 3 reported pneumococcal, and 4 reported streptococcal bacterium. For one participant, the causative bacteria was not identified, although a meningitis diagnosis had been made by medical staff.

Six major themes emerged following the analysis superordinates:

1. Meningitis disease
2. Healthcare services and professionals
3. Knowledge / ignorance
4. Repercussions of the meningitis experience - "Life afterwards"
5. Sick child attitudes / behaviour
6. Siblings attitudes / behaviour

Further analysis also revealed several subthemes (Table 2).

Table 2: Major themes and subthemes

Major themes	Subthemes
Meningitis disease	**Symptoms** (description…). Perception of symptoms & their evolution **Diagnoses** (relevance, accuracy, time…) **Description of the disease** (technical words, prevalence…)
Healthcare services and professionals	**Experience of healthcare services and relationships with healthcare providers** (e.g. communication) **Need for psychological support** at the time of diagnosis, during hospital care and in the long term (e.g. rehabilitation)
Knowledge / ignorance	**About the disease** (scientific background, technical vocabulary ...). Need for the patients and their caregivers to explain the disease. Internet and association role (information) **Unpreparedness of health professionals / expertise** **Helplessness of familial caregivers** (e.g. incomprehension of symptoms and/or lack of good reflexes, feeling of being overwhelmed by an exceptional situation)
Repercussions of the meningitis experience - "life afterwards"	**Physical sequelae** (partial paralysis, functional disability ...). Relating and compensating **Psychological impacts and familial adjustment** in the short-term (coping with the possibility of death) and the long-term (physical sequelae, medical care, daily life, school) **Parents coping with the illness** (e.g. impact on the marital couple...) **Impact of meningitis on the life course** (financial and professional impact, change of life and professional trajectories, “giving up”…)
Sick child attitude / behaviour	At the onset of the illness During the hospitalization Long-term attitudes (personality): flexibility, adaptation, courage
Siblings attitude / behaviour	Coping with the illness and its long-term effects (psychological sequelae and adjustments)

Only five of the above themes were selected for inclusion in this publication. These five themes were all chosen because they were directly in line with our research question (i.e. the family experience of the meningitis); and they were all spontaneously mentioned by the participants and did not correspond to the pre-established questions. A detailed analysis of the "meningitis disease" (not-selected theme), its physical sequelae (partial paralysis, functional disability…) and psychological impact (phobia, identity rearrangements, trauma, insecurity, risky behaviors...) [18], can be provided on demand.

1. Healthcare services and professionals

This theme includes three subthemes: (1) Experience of healthcare services and care routine; (2) Relationship with healthcare providers; (3) Need for psychotherapeutic support.

[redacted]

The overwhelming experience of an extreme situation, the interactions with healthcare professional and services were reported in by family ascendants. Feelings of dismay, refusal to accept their child's life is threatened and consecutive anger came over strongly in the interviews; for many, these emotional responses triggered a request for help.

Experience of healthcare services and the relationship with healthcare providers

The experience of care services as evoked by family members varied. Some of them emphasized the quality of care.

"*I can't thank that paediatrician enough because he didn't know that it was meningitis yet, but he put a treatment in place (...), which saved us a few hours*". (P13)

Others appreciated the attention they received at the hospital and stated that it helped them to reduce their stress and anxiety during the medical emergency situation.

"*We were very, very welcomed, they arranged a room for us at the hospital. It was a special room for the parents so we could sleep there the first night*". (P11)

Family ascendants praised both the technical and relational skills of healthcare providers.

However, within the narratives, there also appeared areas of dissatisfaction such as the long waiting time before receiving the diagnosis, the complexity of care received by their loved ones, and the hospital environment in general.

> *"After she got there, we waited for three or four hours without hearing from her. It was really a very, very long wait, no news, no nothing. (...). And then they put us in a very creepy office. It wasn't reassuring at all* (…)". (P20)

It appears here that it is not so much the wait itself that is stressful, but rather the absence of communication with the healthcare providers and especially the absence of news concerning the state of the child. This leads us to approach the following sub-theme of communication.

Indeed, there were many occurrences which highlighted the difficulties in communication with health care professionals. The dialogue was perceived as difficult and generated frustration.

> *"The doctor came in and he got angry with me and told me I had to stop my show (...) he thought I was a crazy person who was there to bother them"*. (P10)

This mother perceived here a lack of consideration for her emotional distress, which is misjudged by the physician, according to her testimony. We found the perception of this lack of consideration in the testimony of another study participant who mentioned that professionals gave little credit to her opinion:

> *"In any case, the way they told us things weren't right at all... Insinuating that it was not justified to come and take her [to the hospital], when in the end the (positive) results proved it the next day"*. (P19)

Several mothers highlighted that the information they provided about their unwell child and their intuition of the seriousness of the situation was not considered. Therefore, they often felt discredited by the medical professional and expressed their frustration.

> *"I got angry (...), I told him that my daughter had had ear infections before, but that it hadn't put her in this state of drowsiness, with vomiting and a fever that wouldn't go down (...). I insisted, and he told me I was a hysterical mother"*. (P13)

Some family ascendants remembered making harsh comments to certain doctors whose attitude or behaviour were deemed to be disrespectful, inappropriate or dismissive.

> *"I told them,* "We're not numbers" (…). *"There's even a doctor for whom I asked that he no longer treat my daughter. I even notified the hospital management, so he was replaced by another doctor."* (P2)

This mother placed herself as "guardian" of her child, in order to protect her son and to have him considered as an individual (and not as a “simple number”).

Need for psychological support

The parents showed very intense emotions when confronting the different stages of illness. Their emotional response oscillated between uncertainty and frustration, to fear, anxiety and shock as a result of what they sometimes perceived as a “cold” and “hard” relationship with healthcare professionals. They stressed the need for psychological support to help them at the time of diagnosis and intensive care, especially when they felt overwhelmed.

"I had a very bad experience at the ICU because I found that the staff... well, I think they're people who see this every day and have to remain impassive before certain situations. But we, as parents, we need accompaniment, we need support, we need help, and that's not necessarily what we had”. (P2)

This parent interestingly gave a contrasting description between the "distanced" functioning of ICU professionals, a function that she understands, and her own needs as a mother.

Moreover, family ascendants experienced difficult emotions in the long term as well during their children’s rehabilitation period.

“They referred us to a psychologist. That's good in itself but it often happened in the hospital room with our daughter next door, so it wasn't necessarily the right time, we were very emotional. It was good to see a psychologist when our daughter was hospitalised, but we had very long medical visits for L., (...), but afterwards, we were abandoned to ourselves, we weren't supported at all.” (P5)

Here, this mother indicated that the reference to a mental health professional was not always sufficient. The time and the clinical frame of psychological support were also critical and, despite this professional support, she felt abandoned.

For some, the help of professionals was essential in the process of alleviating their sense of guilt and making sense of the traumatic experience of accompanying a child who was experiencing meningitis.

> *"I started a behavioural and cognitive psychotherapy with a psychologist so that I could convince myself that it's not my fault that my daughter had purpura and was amputated."* (P2).

Cognitive behavioural therapy and especially cognitive remediation are specific techniques used in cases of particularly distressful thoughts.

2. Knowledge/ Ignorance

This second theme includes three subthemes about: (1) the disease; (2) the unpreparedness of healthcare professionals / experts; (c) the familial caregivers' helplessness.

Unanimously, the interviewed parents focused on the importance of knowledge about acute bacterial meningitis including its symptoms and possible sequelae, as well as the treatment process and disease progression. The testimonials stressed the parents own need for understanding on the one hand, and on the other hand, the healthcare providers' knowledge about the disease, which they sometimes perceived as insufficient. The lack of communication, information and support for families was also highlighted.

About the disease

The main part of the interviews highlighted that knowledge about meningitis was key and many participants expressed the need to develop this knowledge, as most of the time the disease was totally or partially unknown before it affected their child.

> *"I didn't even know what it was. I didn't even know there were three forms of meningitis; I didn't even know what* "*purpura fulminans*" *was (...). I'd never even heard of it."* (P2)

Meeting this need to better understand the disease involved the acquisition of a scientific background and the ability to express it with technical medical vocabulary. Therefore, many of the participants needed to acquire some form of expertise on the disease to learn the means and modalities of infection. They widely stressed that the internet and patients' associations were a valuable source of knowledge.

> *"I've done a lot of research on the Internet, I've read testimonials and a lot of things. I contacted associations that receive amputees and do a lot of things for them. I talked on the phone with people from these associations who also reassured me a lot (...). I wanted to find out as much as possible. It helped me a lot to be able to manage the situation as well as possible*". (P2)

Developing some forms of expertise on the disease and taking an active approach to it were reported as key aspects.

> *"I didn't realize how the infection is transmitted or the difference between viral and bacterial meningitis. But now I'm a meningitis expert...".* (P5) *(...) I've done a lot of reading on the subject, and the first reflex you have when you have a medical team in front of you that gives you a flood of information without taking the time to use words that are accessible to everyone, you have to check it out (...).* (P5).

Having an active approach to learning about the disease probably compensated for the perceived passive attitudes of healthcare professionals and the perceived lack of support that parents experienced during their child's care.

For some participants, their understanding of their child's potential situation contrasts with the expertise of the healthcare providers.

The perceived unpreparedness of health professionals / expertise

In several cases, the patients were given alternative diagnoses, suggesting an imprecise understanding of the symptoms and/or inadequate responses by healthcare professionals.

> *"When I was told that she had the germ of streptococcus, I consulted the Internet and saw that it could cause meningitis (...) The paediatrician told me:* "Don't worry, (...) she was treated and you will never hear about it again... there's no chance of that happening", ... *a week later, hospital, emergency room, meningitis."* (P 20).

This mother underlined here some diagnostic wandering: despite words full of assertiveness advising her not to worry, what she dreaded effectively happened.

In other cases, healthcare providers seemed completely overwhelmed by the emergency context and did not fully perceive the seriousness of the symptoms.

> *"When I called [the emergency services] for the relapse and told them that she had been out of hospital for 15 days for meningitis and that she had all the symptoms again, they didn't want*

to send us someone (...) Then the doctor (..) told us that we were really not very recommendable parents and that we should only call for real emergencies instead of calling for a little girl who is crying because she has a little fever" (P19).

Helplessness of familial caregivers

The experience of a lack of responsiveness on the part of healthcare professionals caused frustration and feelings of helplessness in the patients' families. They also stress that some diagnoses are shocking, and that physicians should be cautious in the way they phrase them as their diagnosis might be contradicted by the favourable evolution of the disease.

"When they [the doctors] tell you that your child has a life expectancy of four years, when she reaches five years, you think that they may need to reconsider the diagnosis…". (P5)

The participants' narratives also emphasized the importance of public awareness of meningitis and the role that patient and carer associations play in this regard. Associations provide families emotional and psychological understanding and support, which significantly helped the family ascendants through the stressful events they were experiencing.

"I think it's a disease that isn't adequately known. When she was at the hospital, I was seeking answers to my questions and I searched on the Internet, and that's when I came across the website of [name of the association]. *Thanks to this website and the persons who foster it, we learn everything that can happen around meningitis. I tell myself that if people were better informed about the symptoms, more lives could be saved".* (P19)

Taken together, the testimonials highlighted the psychological vulnerability of families and their need for communication and support.

3. Repercussions of the meningitis experience - "life afterwards"

This major theme integrates five subthemes: (1) physical sequelae; (2) psychological impact; (3) parents coping with the illness (in the short and long term); (4) impact of meningitis on the life course; (5) meaning given to the extreme experiences they have gone through.

Physical sequelae of the child

Most of the interviews revealed the negative impact of meningitis on their children and grandchildren health, and in particular the significant physical and cognitive sequelae associated with meningitis including partial paralysis, heart problems, hearing and visual impairments.

These impairments significantly limited the survivors' ability to function in an autonomous manner, and caused daily distress and frustration for the whole family.

> *"(...). The definition is global psychomotor impairment, with a significant language deficit. Not long ago, it was absence of language. You have to understand that (her) brain doesn't work on its own (...). Today, she has the entire left hemisphere that is necrotic, she has frontal and lateral lesions on the cortex which is between the two hemispheres. So, it's all been damaged".* (P5)

Some testimonies focused on the physical impairments and a sense of permanent loss of prior abilities of their child, which caused them to develop feelings of injustice.

> *"These are diseases that totally destroy the life. She was a little girl who was 9 1/2 months old, who was beginning to walk, who was very lively, and she was completely stopped in her stride. It's really an injustice".* (P7)

Psychological impacts and familial adjustment

Besides the negative physical and cognitive impact of the disease on their relatives, the participants also strongly insisted on the psychological impact of meningitis, and in particular the state of shock that they experienced at the period of the hospitalization.

> *"I was holding him in my arms, and I was looking for a way to comfort him. (...) I was just very, very anxious (...). I was completely shocked by his condition. I thought he was dying. In fact, I know he barely avoided death. I've always felt that my son was close to death"* (P10).

The sight of the body of the diminished child, bearing the scars of the disease, was intolerable. Most of the participants described an impression of imminent death, which is terrifying. A grandmother mentioned this fear, which she states sometimes still comes to her.

> *"What's more, he was in great pain and that's really what shocked me the most. I've never seen anyone suffer like this, especially not a child. Three years later, I'm still shocked by it".* (P16)

Some mothers stressed the traumatic nature of the experience of facing the danger of death of their child, especially during intensive care. The emotions described by most of the narratives are intense and vary between denial and deep anguish, some even evoking a state of stupor.

"When the doctor came to see us, she was still in a life-threatening prognosis. He told us that (...) there were three possible outcomes. Either she was not going to make it, or she was going to make it, but he was not able to say whether she will breathe on her own or not, or she was going to make it, but she will be very severely disabled" (...). For me, none of the options were possible". (P20)

Other testimonials illustrated the parents' aptitude to manage the exceptional situation and stay positive in front of their child during the hospitalization.

"Nevertheless, we had the chance (...) to keep hope alive. When we went to see her (...) in the intensive care unit, we talked to her, we sang songs to her. Even if we didn't know if she could hear us, we kept in mind that we had to stay positive". (P11)

However, most of the respondent commented on the long-term severe psychological consequences of the meningitis experience and sequelae. They described their global psychological vulnerability, and for some of them, depressive symptoms requiring treatments.

"I had nothing left to hold me. Everyone around me was happy, but I wasn't. I couldn't explain it, nothing had taste (...). I wanted to kill myself... but at the same time I told myself that those who remained would be too sad... so I didn't do it". (P12)

The description of depressive symptoms, including anhedonia and suicidal thoughts, were at times mixed with the perception of relief and happiness, often leading to a feeling of isolation.

The time necessary to regain personal and family balance also emerged as a common issue.

"After the first six months, I got the backlash. I tried to put up with everything, telling myself that I was strong. My daughter was strong, so I had to be strong. At one point, (...) I fell into a deep depression that lasted for two years. I was on medication, anxiolytics and antidepressants to get me out of this hellish spiral. I saw everything in black and I told myself that my daughter would never make it, that they would make fun of her and that life would be difficult for her. I locked myself in a negative bubble. Now I'm a little better, but there are always times when I think about the future, and I still have fears and anxieties about what might happen later on". (P2)

In these two testimonies, we can notice the lasting concern for their child, even when they progress to adulthood. This concern is permeated with anxious anticipation concerning the survivors' well-being.

Parents coping with the illness

Having to take care of a child who is often severely impaired is an ordeal for the parental couple. However, most of the interviewees highlighted that, despite occasional tensions, they managed to deal with this difficult situation.

"Concerning my couple, we have always remained very close together. My husband is always very, very present" (P11).

Along with the family, in many cases the partner is identified as a valuable source of mutual support in the moments of doubt. The family, as a whole, is described as an important source of support.

"Luckily, we have a big family that never gave up on us. They took turns coming to see us. Every day, we had someone to support us". (P13)

The quality of the relationship and communication of the two parents resulted in new forms of adjustment beyond the effects of the disease and brought new perspectives to family life.

"We complement each other (...). We talked about it [the meningitis experience] *afterwards and we thought we'd done really well".* (P20)

The notions of complementarity and open communication appeared to be critical in coping with the disease and its multiple impacts.

Impact of meningitis on the life course

Caring for a child with a disability takes time, requires careful planning and often has a serious financial impact for the family, as underlined by the interviewed parents.

"I think it's all about her. For one thing, there are all her medical visits since she was four months old. There are 3 to 4 appointments a week, on top of work, you have to run around and it's still very heavy". (P20)

Most of the time the disease and its consequences involved changes in the professional trajectories of the survivor's close family and in the whole family's way of life.

"At the time she was ill, I had planned to return to work (...) But I never went back to work, I didn't honour the contract. Then, for 6 years, I didn't work at all because (she) needed me, I was all the time with her, going back and forth for medical appointments. It was very complicated". (P11)

These words showed that besides psychological impacts, caring for a child affected by acute bacterial meningitis also has a financial cost, even in a country like France where social assistance is present.

Finally, some participants underlined the positive impact of maintaining professional activities not only for financial reasons, but also as a way to facilitate a social life beyond the world of disability.

"This job allows me to get out of everything related to disability, nappies, housework. It makes me think of something else, and it makes me earn some money". (P7)

Adjustments also concern material aspects such as the person's living and housing and the practical organisation of the child's care. They are necessary to allow the family to find a new form of everyday functioning.

"The house is being rearranged to create a room on the ground floor. Until now, she had been going upstairs, but we hope that when she has a room on the ground floor, it will be easier to find someone to relieve us so that we can leave from time to time". (P7)

"If her behaviour is definitely related to meningitis, it is a real handicap for us in many ways, we can't go anywhere, it is really difficult. We try to show her many things so that she can continue to improve but taking her to a zoo or a park is a real challenge". (P 20).

Thus, usual leisure activities for many children become extremely complex to organise: everyday life is often marked by renouncement.

The interaction with the health services administration regarding about the coverage of the family member's care is also a concern mentioned by family ascendants. They emphasized that the complexity of the administrative procedures and the constant need to prove legitimacy to their request constitute a considerable psychological burden in addition to the burden of caring for the meningitis survivors.

"I always say the biggest handicap is administration. (...) you have to keep fighting" (P7).

The energy expended is considerable, and participants often use sports comparisons or fighting metaphors to describe their daily life.

"We always have to go running around, putting together files, emails... I think that is the worst. (...) When we had a renewal [of the disabled adult allowance file], and they stripped us of everything. We had to appeal. On top of that, they always take 6 months to respond... we spend our time fighting". (P20)

4. Sick child attitude / behaviour

Several testimonials described the positive evolution of the children who have survived meningitis and stressed in particular the progress they have made and the skills that they have acquired, frequently reaching levels of results that go beyond what the healthcare professionals considered possible.

"When we see the MRIs, compared to the damage she has to her brain, the doctors don't understand that she can do what she does (...). For them, in relation to her lesions, she should be in a vegetative state, while she can eat by herself, she walks alone with her armchair, she sings, she loves to sing, she loves to play, music, early learning games, etc.". (P13)

Some individuals also evoked the adaptability, flexibility, and courage of their loved ones.

"I think she's happy, but she has her ups and downs (...). She tries, she finds ways to do it (...). She has great strength of character and now she wants to do things even if it's hard for her". (P11)

"And in the end, she has made up for her developmental delay (...). She has caught up with everything and even the attending doctor told me that she is amazing. She really is a great little girl" (P19).

Furthermore, many testimonies referred to the social abilities of the meningitis survivors and their capacity to enjoy a satisfactory quality of life despite the limits imposed by the severe handicaps they experience.

"She's very sociable, so she's a bit of a mascot everywhere she goes. As she is very charming, very attaching and very funny, she doesn't have too many problems adapting to a new environment". (P5).

The child's ability to forge links with her/his peers and her/his "zest for life" are very often underlined.

Despite the disability and limitations brought on by the disease, the survivors' ability to bounce back and adjust is stressed with admiration by the participants. However, the experience of an event that suddenly and unexpectedly upsets the life of the whole family also required the siblings' capacity for psychological adjustment.

5. Siblings attitude / behaviour

The experience of acute meningitis disease and its sequelae is a stressful experience for the whole family, not only when a family member is admitted to Intensive Care Unit (ICU), but also in the mid- and long term. Within this study, parents focused on the siblings of the sick child, as they also experienced some form of impact or disruption as a result of their siblings' illness.

A common thread among the interviewees was the parents' perception of the attitude and behaviour of siblings towards the meningitis survivors. Many participants could mention the supportive way in which the siblings coped with the disease, and their positive role in the recovery and life trajectories of their loved ones.

"I am convinced that it is thanks to her twin sister who has been a great stimulant for her. She has caught up with everything". (P19).

Likewise:

"I think his brother was really a driving force, even if it's not always obvious to him". (P5)

Particular emphasis is also placed on the siblings' ability to understand, help and protect their survivor sibling.

"He tells us: "You don't understand that she wants that! *We didn't understand fast enough, according to him, and he was interpreting".* (P5)

The brother here adopts the function of intermediary or more precisely as an interpreter between his sister and their parents, revealing a rare complicity.

"He's a child who's very protective of his sister. He doesn't hesitate to go and see the other children in the schoolyard if his sister is being teased". (P2)

The role of "guardian" that we evoked when speaking of parents can sometimes be taken by a brother or a sister of the sick child as well.

In addition, parents stressed that overall, the daily confrontation with disabilities enabled the siblings to develop a sense of openness and tolerance of other people's differences.

"*My daughters have a lot of empathy, whether with their* [disabled] *sister or with other children. It's true that they also have a different life. It is very enriching for them, because they know the difference, they learn the values of life, which not all children will necessarily have…".* (P7)

However, the testimonies of some other participants highlighted the psychological impact on siblings of the specific disease-related environment and the responsibility that they assumed. Possible mentioned causes include the fact that the disabled child monopolised the parents' attention or that the place and role of everyone in the family may be affected.

"Our second [daughter] *is everyone's elder sister. She says it all the time:* "By age, I am her little sister, but in my head I am her big sister…*"*. (P13)

"Finally, he has developed obesity (…). He was deeply shocked and traumatised by his sister's amputation (…), he's aware that his sister is different from other children. He assigned himself the role of the big brother, which is: "I'm here, I'll protect you, I'm here for you *(…), he took his role very seriously".* (P2)

The representation of this mother is clear: she sketched a linear causality between the amputation of her daughter, following meningitis, and the obesity of her son, whom she considered traumatised.

Despite the severity of the illness and the magnitude of its consequences for the survivors and the whole family, the narratives stressed that in the long term, one of the key elements of balance is the parents' ability to ensure a family life is "as normal as possible" for all siblings, where everyone (re)discovers his or her place.

Narrative account and profiles of meaning-making

The analysis of the above-mentioned themes allowed for the identification of the meaning-making processes deployed by the participants and which are reflected in their remarks. These two processes underpin the psychological adjustment to the meningitis and its consequences.

1. Comparison with other children- The sick child becoming a "hero"

In order to have reference points on the development of their child, some of whom are affected by serious sequelae, many parents compared the latter to other children in their family circle. This comparison often turned out to be a source of great distress, by noting how much the child is disabled and behind in their psychomotor development. For instance:

> *"I have a lot of children in my family, and I could see that for her there were some things that were wrong" (P5)*

> "*Thereafter, she evolved very slowly compared to children of her age*". (P11).

In some cases, the comparison did not come from the parents themselves, but came from a stranger.

> *"One day, our kid was 5 years old, she was in her stroller with a pacifier in her mouth, one couldn't see that she was disabled, and there was an old man who approached us saying: "look at my little grandson, he walks, he is not in a stroller and he does not have a pacifier, yet he is younger!* (P7).

This mother highlighted the perceived violence born from this comparison imposed by a stranger who knew nothing of her history.

Other parents insisted on the developmental similarities between their child, even when disabled, and other children of the same age:

> *"Otherwise, in terms of development, she is a child like any other (...). She makes a point of doing the same activities as other children" (P2).*

We found a similar statement in the testimony of a grandmother:

"*[He] does everything like them (his siblings). He is a child who has his place among the siblings, there is no problem"* (P16).

Some parents expressed pride in having managed to cope with such an extreme experience, as an individual and as a couple.

> *"It [the meningitis experience] gave me that attitude because I wasn't like that before. It gave me a stronger temper to come with it. (...) It's ok to break down, you have to break down at some point, but the next day I am back on top, and I'm back on my feet..".*. (P13)

Another mother evoked the support she found in her relationship with her partner.

"I see many couples (...) who split up because of their child's disability. However, we supported each other, we didn't argue, there were no conflicts related to that. No, we did well". (P20)

However, above, the parents' pride was centred on their sick child. We found in their speech a highlighting of her/his exceptional character. As mentioned earlier, several participants expressed a sense of satisfaction about their child's trajectory. Some insisted on the fact that they initiated certain attitudes, instilling courage in their child.

"She's a little girl who's doing very well, we've done everything we could. She likes to be assisted, so we taught her that no, that wasn't life, she had to do it on her own". (P 19)

For some family ascendants, their loved one was in a way revealed in the disease, without the family having anything to do with it. The "hero figure" then becomes the one that best describes their child. “Hero”, because the child is distinguished by her/his bravery, her/his exceptional abilities. So, this mother told us about her daughter:

> *“That's when I saw that my daughter was a fighter, because after waking up alone from a coma, she saw me and said "mama", at 4 1/2 months. She spoke. She woke up from a coma, looked me straight in the eye and said "mama".”*(P2)

Faced with an extreme experience - the mother insisted that her daughter was close to death – the child’s exceptional character was revealed in her verbal precocity. Furthermore, it is within the mother-daughter relationship that the extraordinary capacity of the child emerged.

These exceptional capacities mentioned by family ascendants can thus be physical, as in the testimony mentioned above, or in the words of other parents:

> *“She has a phenomenal strength in her arms that she has developed due to the absence of her legs”* (P13).

A physical force, therefore, but also a psychological one:

> *“(She) turns out to be a very combative little girl*” (P5).

It appears that this revelation of the heroic character of their child allowed parents who perceived this extraordinary dimension, to find a positive meaning in this painful experience.

> “*It is one of the most beautiful moments that I experienced in this terrible ordeal (...). At the beginning, the doctors didn't believe us (about the fact that their daughter was able to speak) and we rang them to show them. We even kept photos of those moments. For us, it was a magical moment because we realized that our daughter really wanted to live”* (P2).

We find here the characteristics of extraordinary events, which even look like a miracle for these parents: the fact that there are people who do not believe, who must therefore be convinced; the need for proofs, the fight that was carried out, and the ultimate meaning of this fight: the revelation of a will to live. This elaboration of the figure of the child as a hero thus made it possible to give a positive meaning to this painful experience and further, it may confirm the meaning and value of the child's life.

This mention about finding positive meaning through the distressful experience of meningitis leads to a second meaning-making process: engaging action to improve the healthcare system.

2. Finding the "positive" of the traumatic experience and engaging action to improve the healthcare system.

The discourse of the participants echoed a desire to take an active position in their relationship with the disease, not only through the acquisition of personal knowledge about meningitis, but also through the commitment to raise awareness of the disease in the general population. This commitment can also concern awareness-raising work about people with disabilities. For instance, this mother told us:

"I raise awareness among children and young people on the concept of disability. I go to schools or associations with a small booklet that I made, and I explain to children what disability is, to remove taboo words and so that they put words on the little friends who are dyslexic, or in a wheelchair, or mentally handicapped, etc." (P7)

Believing that in France, individuals are not familiar enough with difference - here linked to a disability - this mother wanted to suggest to the youngest people to think about the inclusion of their disabled peers, so that they can have a life as normal as possible.

This engagement process, which allows for them to feel active instead of enduring the vagaries of life as a parent with a child with serious sequelae always starts from the intimate experience to try to improve things for the greatest number. Thus:

"We got a family house and we are in the process of renovating it to make a home to accommodate disabled people on vacation in the Alps (...). It was our dream for us, so we are doing it for others (P7)".

Having been confronted with major difficulties relating to the accessibility for disabled people in many vacation homes, this family decided to take matters into their own hands and create this dedicated and accessible place. The form of altruism that this commitment constitutes can also be noted, which is why many, especially within the family, admire this commitment. Thus, the grandmother of a child who suffered from meningitis testified to her admiration for her daughter, the mother of this child.

"My daughter invests in everything, in everything, for her little son It's extraordinary" (P16).

DISCUSSION

This study on the experiences of close family members of meningitis survivors highlighted six themes, shared by most of the participants, and two meaning-making processes that appeared through the analysis of the narratives. The qualitative findings stressed the parents' understanding about acute bacterial meningitis, their relationships with the care system and the healthcare providers; and they also highlighted the ignorance about this disease at the time of medical treatment, both their own and that of certain healthcare professionals. In contrast, they spoke of the knowledge that they had been able to acquire through patient associations. Much of their testimony dealt with the multidimensional repercussions of the disease on their sick child and for the whole family. The attitude and behaviour of the child affected by meningitis were largely described and often glorified. Finally, the reaction of the siblings was a matter of concern for many interviewed parents.

These qualitative results provide insight into the nature of the mid and long-term repercussions of the disease at an individual and familial level; they also offer an understanding of the distress induced by these impacts. Indeed, consistent with previous quantitative studies [12, 13], this research stressed the psychological burden associated with being the family of a child affected by acute bacterial meningitis. This burden is imbued with traumatic elements (confrontation with the possibility of the child's death, awareness of the possible sequelae), and is experienced daily by families who have to face medical, economic, and societal challenges. The present results also underline the expressed need for specific and professional support in this population. The interviewed parents insisted on their requirement for psychological support, not necessarily during the acute phase of the hospitalisation, when they were often stunned and preferred to be constantly at the bedside of the sick child, but rather at the hospital discharge and in the long-term, when they understood more clearly what their life would be like after this disease. A recent article showed that coping support interventions are effective for improving parents' anxiety and stress symptom burden related to acute paediatric hospitalisations [23]. Structured interventions could indeed be offered to parents of children affected by meningitis, during hospitalisation and at discharge.

However, the parents interviewed in this study not only experienced distressful challenges induced by the illness of their children but also, for some participants, trajectories of post-traumatic growth. Tedeschi and Calhoun [1998] [24] defines "Post-Traumatic Growth" as any positive personal changes that occur after experiencing a potentially traumatic event. The meaning-making processes analysed in this study indicated such a trajectory. The parents' pride in their child and the pride that some admit feeling about themselves because they are satisfied with the way they take care of their child and their family, echoes this growth process. A mixture of vulnerability and growth was underlined in a previous qualitative study, conducted among mothers whose school-aged children were born extremely prematurely; just as several participants of our research, these mothers celebrated their children's successes [25]. The celebration of the children's skills and their ability to overcome their disabilities become for certain participants the depiction of a hero trajectory; that may be related to the dimension of "Post-traumatic Growth" such as "new possibilities" and "appreciation of life" [24].

Furthermore, the involvement of some parents in patient associations, even their participation in this study, may indicate the experience of "new possibilities" and "enhanced relationships". Highlighting this growth in some individuals should not lead to an "injunction to resilience" but to the observation that the close family members of meningitis survivors can adjust to this difficult experience and find meaning in it.

Strengths and weaknesses of the study

This study has several limitations. The first limitation is related to the nature of the recruitment and the representativeness of the sample. As participants volunteered to take part in the research, this may have resulted in self-selection bias. Therefore, findings may reflect the views of people more interested in taking an active approach to the disease through engagement with a patient association. Moreover, the sample exclusively consisted of adult females (ten mothers and one grandmother).Thus, this study might not be representative of the wider spectrum of close family members who faced the meningitis disease. In future studies, a more diverse sample, including male participants, recruited from a plurality of treatment facilities and setting contexts of care, would be preferred and provide a complete map of the meanings attached to subjective experiences and the generalisation of the study findings. This would allow for the examination of whether different experiences would be described and would provide a complete map of the meanings attached to subjective experiences and the generalisation of the study findings.

A second limitation concerns the retrospective nature of the interviews. This wide time period could have induced recall and reconstruction bias in material (e.g. negative aspects often tend to be better remembered than the positive one). A worthwhile direction for future research might be the exploration of the subjective experience of parents confronted with acute bacterial meningitis and the family members' psychological adjustment shortly after the acute phase. A longitudinal design would also allow for the capture of differences in their adjustment of variations in the psychological adjustment of the study participants.

Despite these limitations, this is the first study that uses a validated methodology to provide insights on the lived experience of families that have faced bacterial meningitis disease, and it highlights several meaning-making processes of this life-changing experience. It stresses, on the one hand, the interviewed parents' need for improved communication with the healthcare providers and on the other hand, the importance of an increased knowledge surrounding the disease, in particular with regard to the basic education of the public in general and the diagnostic competences of primary care providers in particular.

Clinical implications

The findings in this study highlighted several dimensions that could be of clinical relevance, such as:

- The value of the intervention of experts in the field of infectious diseases in the Continuing Professional Development of physicians, which would improve not only their familiarity with meningitis and its treatment, but also their capacity to interact with carers in the most appropriate and efficient way [18].
- The mis-match between family members and healthcare professionals during the onset and course of the meningitis, as well as its management in health care facilities that should be given attention. A promising avenue for improvement, both from a research perspective and from a clinical standpoint, is the integration of expert patients into care procedures and into the training curriculum of healthcare professionals.
- The disease-related environment, and more specifically, the experience of accompanying a child receiving intensive care and the related risk of death are stressful, and may potentially result in some disruption or trauma for the whole family. Being regularly informed of the care provided to their child, taking an active part in it, and receiving attention by healthcare professional, are mentioned as mitigating factors to help alleviate stress and anxiety. Several authors have emphasized the positive impact of family open visitation and parental presence for the care of their child, especially in emergency care settings and intensive care units[26, 27, 28]; impacts include relieved anxiety and fear, as well as reduced psychological distress and post-intensive disorders, for both the family members and survivors [29, 30]. While this open visitation is more and more widespread in France, sometimes this is not made possible, due to a lack of human resources (professional to support families) and of available premises. One specific aspect

related to the family presence during ICU procedures is the siblings' visits. As in other contexts of severe diseases, sibling visitation is being increasingly endorsed as a positive development in patient care. This is relevant especially because it facilitates elaboration of the siblings' own perception of the situation and prepares post-discharge life, reduces fantasies, increases understanding and the sense of control over the situation, increases bond enhancement and improves communication between families and care providers [27, 31, 32]. Thus, the implementation of experimental initiatives in the context of bacterial meningitis intensive care seems desirable. Collaboration between different healthcare providers (clinicians, nurses, psychologists) and parents in order to create the appropriate visitor conditions and organisation of staff is strongly supported by the literature [29, 33, 34]. Given the paucity of research on this issue, further studies on the psychological impact and implications of the siblings' presence in ICUs could offer some insights on how they cope with this adverse event at the time of care and in the longer term. In this perspective, exploring the siblings' experience of the disease would provide a better understanding of the meaning-making process and could help identify potential pitfalls where there is a need for sustainable psychological assistance.

- The need for continuing efforts to consider and monitor the emotional burden of the disease on the child's family ascendants, the psychological adjustment process and families' trajectories over time. In this regard, it would be valuable if family ascendants of acute meningitis survivors could benefit from systematic, and when necessary, professional consultations during and after their experience of the disease. The more appropriate forms and timing of this support, prognostic factors and outcome merit further investigation.

Conclusions

This study helped to capture the subjective experience and psychological adjustments of parents confronted with paediatric meningococcal meningitis. Two main meaning-making processes in relation to the participants' experiences of this adverse context emerged from their discourse. These processes emphasized the importance of information and support of families, the potentially traumatic impact of the illness experience, and the possibility of post-traumatic growth for some individuals, including the desires of parents to engage in improving the care system. Providing family ascendants with accurate information about their child's conditions and treatments, as well as involving them in the care and medical decision-making could positively influence and develop the quality of care provided by healthcare professionals.

In the meantime, clinicians, caregivers, and other stakeholders of the healthcare system should be aware that information and the involvement of the family as an active partner in the care process are conditions for its effectiveness, from the onset of disease symptoms, their management in the emergency rooms and throughout the recovery journey.

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AUTHOR CONTRIBUTIONS

ES and LF conducted the review of the literature. ES was the main coder for the thematic analysis. LF was the second coder for the thematic analysis. ES and LF analysed the data and edited the manuscript. PG contributed to the construction of the research project and supervised the discussion of the results. All authors read and approved the final manuscript.

COMPETING INTERESTS

The authors declare that they have no competing interests regarding the publication of this article.

DATA AVAILABILITY STATEMENT

Data are available on reasonable request.

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May 2021

Elisabetta Scanferla
Léonor Fasse
Philip Gorwood

Manuscript ID bmjopen-2020-047465 Article entitled

" The familial experience of acute bacterial meningitis in children. A transversal qualitative study using interpretative phenomenological analysis."

Call for testimonies

Meningitis survivors and families wanted for telephone interviews

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“Petit Ange” is an association participating in a working group* aiming to describe the long-term effects of meningitis. For that purpose the association is looking for people with meningitis and/or their family members.
To date publications have described the medical consequences of meningitis. However, impact of the disease on people's daily life, relationships with family and others, and professional career are not sufficiently known nor taken into account.

To this end the working group is looking for meningitis survivors and their families to interview either by phone or face-to-face in Paris.

Would you be interested in taking part in a phone or face-to-face interview in Paris, run by “Edusanté” and lasting approximatively 45-60 min.?

A 50-euro compensation is given for the interview.

The content of these interviews will of course remain anonymous and the association “Petit Ange” will share with you the overall results of the study, should you choose so.

(*) - The working group consists of representatives from two associations, “Petit Ange” and “Méningite France”, a pediatrician, a psychiatrist, a sociologist, and an organization dedicated to patient education and support – “Edusanté”.
- The working group is independent and aims to improve knowledge about consequences of meningitis on the affected families. This research is funded by a pharmaceutical company, GSK.

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQRreporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1

Abstract

	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2

Introduction

Problem formulation	#3	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4
Purpose or research question	#4	Purpose of the study and specific objectives or questions	6

Methods

Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability.	6

		As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	[#6](#)	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	8
Context	[#7](#)	Setting / site and salient contextual factors; rationale	6 & 7
Sampling strategy	[#8](#)	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	6
Ethical issues pertaining to human subjects	[#9](#)	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	7
Data collection methods	[#10](#)	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	7

Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	8
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	8
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	8
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	8 & 9
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	10 &11

Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	11 & more
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	28
Limitations	#19	Trustworthiness and limitations of findings	30
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	34
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	34

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