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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 and two main meaning-making processes in relation to the participants' experience of meningitis were identified: (1) the sick child becoming a "hero" – comparison 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].

1
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3 Besides the considerations regarding vaccination policy, the literature concerning family
4 experiences of bacterial meningitis in children and adolescents is poor. To our knowledge, there
5 are only three studies that specifically targeted the psychological adjustment of parents
6 experiencing paediatric meningococcal meningitis. In 2005, Haines [6] conducted a qualitative
7 study in interviewed parents based on a Heideggerian phenomenological qualitative approach, and
8 highlighted, among other findings, a critical need for support and understanding, as well as a need
9 for communication, information and publicity. Comparable results regarding the provision of
10 information about the symptoms and possible sequelae of acute bacterial meningitis and regarding
11 the need of better communication about the treatment process and the disease progression were
12 also underlined by more recent research) [7]. This latter study also focused on the parents' desire
13 for professional support after the child was discharged from the hospital. The psychological
14 adjustment of parents after meningococcal disease was also quantitatively studied in the mid and
15 term (3 and 12 months after discharge) [8]. The results indicated a risk for poor mental health
16 among parents, with 13 of 54 mothers (24%) and six of 40 fathers (15%) scoring at high risk for
17 posttraumatic stress disorder at 12 months. Additional studies not specific to acute bacterial
18 meningitis, also pointed at the psychological vulnerability of parents and a great need for
19 educational support of children who have survived meningitis and septicaemia [9]. One study [10]
20 targeted "Post-intensive care syndrome (PICS) in patients and families after critical neurologic
21 condition, which could include acute bacterial meningitis with neurological symptoms. This
22 syndrome encompasses a variety of morbidities, including physical, cognitive, emotional, and
23 psychological impairments following critical care. Taken together, these studies highlighted the
24 psychological vulnerability of families after meningococcal disease and their need for
25 communication and support. To the best of our knowledge, there is no French data on this question,
26 despite the severe sequelae that could be induced by this disease [11]. Given the potential trauma
27 induced by the disease and the hospitalization, it is important to gain insight on how the parents
28 cope with this aversive event, especially how they give sense to this experience (with the
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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

1
2 inclusion criteria were: (1) age ≥ 18 years at the time of the study; (2) being an ascendant of an
3 individual who received a diagnosis of acute bacterial meningitis during childhood, adolescence,
4 or adulthood; (3) a period of at least six months between the onset of illness of the descendant and
5 the interview; and (4) informed consent to participate in this study.
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12 The exclusion criteria were: (1) family ascendants who had lost their child due to acute bacterial
13 meningitis, or bereaved parents (by other cause) were not included in the research because grief
14 process could deeply affect the present results; (2) severe cognitive impairment that hinders
15 participation in the study, as determined by the interviewers; (3) lack of a sufficient fluency in
16 French to participate in the research interviews.
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25 The recruitment was voluntary, and all participants expressed their agreement to participate in the
26 research, according to the French ethical board's recommendations for qualitative non-
27 interventional research. According to the French legislation, collection of information on ethnic
28 origin and religious affiliation is not allowed [15], therefore these aspects were not assessed. In
29 accordance to Article L1121-1 of the French Public Health Code [16], this qualitative study, which
30 uses the responses to a survey carried out by telephone from relatives of individuals who recovered
31 from the illness more than six months ago, does not correspond to any of the three categories of
32 studies falling within the scope of research involving human subjects, and therefore no ethical
33 approval was required.
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48 **Procedure**

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51 In-depth, semi-structured, qualitative interviews were conducted over the telephone. Although the
52 interviewers followed an interview guide, the participants were encouraged to express themselves
53 freely. This guide included questions relating to the history of the disease, the current emotional
54 state of the participant, as well as questions relating to the potential impact of the meningitis
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1
2 infection for the family and siblings. The interviews were conducted in October 2018 by four
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4 researchers familiar with qualitative interview methods, and who were trained in qualitative
5
6 approaches. The mean interview length was 60 minutes.
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10 **Analysis**

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12 Interviews were audio-recorded and entirely transcribed. Transcripts were subsequently
13
14 anonymised by removing all identifying information. The original French extracts were translated
15
16 into English. A bilingual French-English researcher verified that the translation of the verbatim to
17
18 English was consistent with the meaning of the source texts in French. Interpretative
19
20 Phenomenological Analysis (IPA) was chosen to explore the contents. For analysis key-elements,
21
22 see Scanferla et al., (2020) [14]. Authors 1 and 3 (ES & LF) led the analysis following principles
23
24 for IPA [15]. In brief, each interview was read by the first author multiple times to gain a holistic
25
26 sense of the participant's account and discourse themes were identified by ES. The connections
27
28 between the themes were then studied and the major themes were identified by the same author.
29
30 Lastly, an interpretative account was produced that highlighted and analysed the experience
31
32 through experiential themes and meaning-making processes. The meaning-making process is the
33
34 means by which people try to make sense of their experiences, and the study of the processes of
35
36 meaning-making describes what is happening in individuals and highlights the procedural
37
38 dimension beyond symptoms and outcomes. It also helps to emphasise how meningitis can be
39
40 experienced in different ways by different people through the analysis of convergences and
41
42 divergences in the meaning-making processes. The third author (LF) audited the documentation
43
44 for the first five interviews as a validity check on the analytic process. Great care was taken
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46 throughout the process to meet the scientific rigour criteria established by qualitative analysis [18].
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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 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	<i>md</i>	2 (22 and 17)
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 and 2)
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.

~~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.~~

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)

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3 Others appreciated the attention they received at the hospital and stated that it helped them to
4
5 reduce their stress and anxiety during the medical emergency situation.
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8 *“We were very, very welcomed, they arranged a room for us at the hospital. It was a special*
9 *room for the parents so we could sleep there the first night”*. (P11)
10

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12 Family ascendants praised both the technical and relational skills of healthcare providers.
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15 However, within the narratives, there also appeared areas of dissatisfaction such as the long
16
17 waiting time before receiving the diagnosis, the complexity of care received by their loved ones,
18
19 and the hospital environment in general.
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23 *“After she got there, we waited for three or four hours without hearing from her. It was*
24 *really a very, very long wait, no news, no nothing. (...). And then they put us in a very creepy office.*
25 *It wasn't reassuring at all (...)*”. (P20)
26

27
28 It appears here that it is not so much the wait itself that is stressful, but rather the absence of
29
30 communication with the healthcare providers and especially the absence of news concerning the
31
32 state of the child. This leads us to approach the following sub-theme of communication.
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35 Indeed, there were many occurrences which highlighted the difficulties in communication
36
37 with health care professionals. The dialogue was perceived as difficult and generated frustration.
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40 *“The doctor came in and he got angry with me and told me I had to stop my show (...) he*
41 *thought I was a crazy person who was there to bother them”*. (P10)
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44 This mother perceived here a lack of consideration for her emotional distress, which is misjudged
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46 by the physician, according to her testimony. We found the perception of this lack of consideration
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48 in the testimony of another study participant who mentioned that professionals gave little credit to
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50 her opinion:
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54 *“In any case, the way they told us things weren't right at all... Insinuating that it was not*
55 *justified to come and take her [to the hospital], when in the end the (positive) results proved it the*
56 *next day”*. (P19)
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3 Several mothers highlighted that the information they provided about their unwell child
4 and their intuition of the seriousness of the situation was not considered. Therefore, they often felt
5 discredited by the medical profession and expressed their frustration.
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10 *“I got angry (...), I told him that my daughter had had ear infections before, but that it*
11 *hadn't put her in this state of drowsiness, with vomiting and a fever that wouldn't go down (...). I*
12 *insisted, and he told me I was a hysterical mother”*. (P13)
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16 Some family ascendants remembered making harsh comments to certain doctors whose
17 attitude or behaviour were deemed to be disrespectful, inappropriate or dismissive.
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21 *“I told them, “We're not numbers” (...). “There's even a doctor for whom I asked that he*
22 *no longer treat my daughter. I even notified the hospital management, so he was replaced by*
23 *another doctor.”* (P2)
24

25 This mother placed herself as "guardian" of her child, in order to protect her son and to have him
26 considered as an individual (and not as a “simple number”).
27

28 29 30 *Need for psychological support*

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33 The parents showed very intense emotions when confronting the different stages of illness.
34 Their emotional response oscillated between uncertainty and frustration, to fear, anxiety and shock
35 as a result of what they sometimes perceived as a “cold” and “hard” relationship with healthcare
36 professionals. They stressed the need for psychological support to help them at the time of
37 diagnosis and intensive care, especially when they felt overwhelmed.
38
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41
42 *“I had a very bad experience at the ICU because I found that the staff... well, I think they're*
43 *people who see this every day and have to remain impassive before certain situations. But we, as*
44 *parents, we need accompaniment, we need support, we need help, and that's not necessarily what*
45 *we had”*. (P2)
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51 This parent interestingly gave a contrasting description between the "distanced"
52 functioning of ICU professionals, a function that she understands, and her own needs as a mother.
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56 Moreover, family ascendants experienced difficult emotions in the long term as well during
57 their children's rehabilitation period.
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“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

1
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3 The main part of the interviews highlighted that knowledge about meningitis was key and
4 many participants expressed the need to develop this knowledge, as most of the time the disease
5 was totally or partially unknown before it affected their child.
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10 *"I didn't even know what it was. I didn't even know there were three forms of meningitis; I*
11 *didn't even know what "purpura fulminans" was (...). I'd never even heard of it."* (P2)
12

13
14 Meeting this need to better understand the disease involved the acquisition of a scientific
15 background and the ability to express it with technical medical vocabulary. Therefore, many of the
16 participants needed to acquire some form of expertise on the disease to learn the means and
17 modalities of contamination. They widely stressed that the internet and patients' associations were
18 a valuable source of knowledge.
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26 *"I've done a lot of research on the Internet, I've read testimonials and a lot of things. I*
27 *contacted associations that receive amputees and do a lot of things for them. I talked on the phone*
28 *with people from these associations who also reassured me a lot (...). I wanted to find out as much*
29 *as possible. It helped me a lot to be able to manage the situation as well as possible"*. (P2)
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35 Developing some forms of expertise on the disease and taking an active approach to it were
36 reported as key aspects.
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40 *"I didn't realize how the infection is transmitted or the difference between viral and*
41 *bacterial meningitis. But now I'm a meningitis expert..."*. (P5) (...) *I've done a lot of reading on*
42 *the subject, and the first reflex you have when you have a medical team in front of you that gives*
43 *you a flood of information without taking the time to use words that are accessible to everyone,*
44 *you have to check it out (...).* (P5).
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48 Having an active approach to learning about the disease probably compensated for the
49 passive attitudes of healthcare professionals and the perceived lack of support that parents
50 experienced during their child's care.
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54 For some participants, their understanding of their child's potential situation contrasts with the
55 expertise of the healthcare providers.
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59 *The perceived unpreparedness of health professionals / expertise*
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3 In several cases, the patients were given alternative diagnoses, suggesting an imprecise
4 understanding of the symptoms and/or inadequate responses by healthcare professionals.
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6

7
8 *“When I was told that she had the germ of streptococcus, I consulted the Internet and saw*
9 *that it could cause meningitis (...) The paediatrician told me: "Don't worry, (...) she was treated*
10 *and you will never hear about it again... there's no chance of that happening”, ... a week later,*
11 *hospital, emergency room, meningitis.” (P 20).*
12

13
14 This mother underlined here some diagnostic wandering: despite words full of assertiveness
15 advising her not to worry, what she dreaded effectively happened.
16
17

18
19 In other cases, healthcare providers seemed completely overwhelmed by the emergency
20 context and did not fully perceive the seriousness of the symptoms.
21
22

23
24 *“When I called [the emergency services] for the relapse and told them that she had been*
25 *out of hospital for 15 days for meningitis and that she had all the symptoms again, they didn't want*
26 *to send us someone (...) Then the doctor (..) told us that we were really not very recommendable*
27 *parents and that we should only call for real emergencies instead of calling for a little girl who is*
28 *crying because she has a little fever” (P19).*
29
30

31 *Helplessness of familial caregivers*

32
33

34 The experience of a lack of responsiveness on the part of healthcare professionals caused
35 frustration and feelings of helplessness in the patients' families.
36
37

38
39 *“When they [the doctors] tell you that your child has a life expectancy of four years, when*
40 *she reaches five years, you think that they may need to reconsider the diagnosis... ”. (P5)*
41
42

43
44 The participants' narratives also emphasized the importance of public awareness of
45 meningitis and the role that patient and carer associations play in this regard. Associations provide
46 families emotional and psychological understanding and support, which significantly helped the
47 family ascendants through the stressful events they were experiencing.
48
49
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51

52
53 *“I think it's a disease that isn't adequately known. When she was at the hospital, I was*
54 *seeking answers to my questions and I searched on the Internet, and that's when I came across the*
55 *website of [name of the association]. Thanks to this website and the persons who foster it, we learn*
56 *everything that can happen around meningitis. I tell myself that if people were better informed*
57 *about the symptoms, more lives could be saved”.* (P19)
58
59
60

1
2
3 Taken together, the testimonials highlighted the psychological vulnerability of families and
4 their need for communication and support.
5
6
7
8

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

10
11
12 This major theme integrates 5 subthemes: (1) physical sequelae; (2) psychological impact; (3)
13 parents coping with the illness (in the short and long term); (4) impact of meningitis on the life
14 course; (5) meaning given to the extreme experiences they have gone through.
15
16
17
18

19 *Physical sequelae of the child*

20
21
22 Most of the interviews revealed the negative impact of meningitis on their family children and
23 grandchildren health, and in particular the significant physical and cognitive sequelae associated
24 with meningitis including partial paralysis, heart problems, hearing and visual impairments.
25
26
27
28

29
30 These impairments significantly limit the survivors' ability to function in an autonomous
31 manner, and can cause daily distress and frustration for the whole family.
32
33
34

35 *"(...). The definition is global psychomotor impairment, with a significant language deficit.*
36 *Not long ago, it was absence of language. You have to understand that (her) brain doesn't work*
37 *on its own (...). Today, she has the entire left hemisphere that is necrotic, she has frontal and*
38 *lateral lesions on the cortex which is between the two hemispheres. So, it's all been damaged".*
39 (P5)
40
41
42
43

44 Some testimonies focused on the physical impairments and a sense of permanent loss of
45 prior abilities of their child, which caused them to develop feelings of injustice.
46
47
48

49 *"These are diseases that totally destroy the life. She was a little girl who was 9 1/2 months*
50 *old, who was beginning to walk, who was very lively, and she was completely stopped in her stride.*
51 *It's really an injustice". (P7)*
52
53

54 *Psychological impacts and familial adjustment*

55
56
57
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1
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3 Besides the negative physical and cognitive impact of the disease on their relative, the
4 participants also strongly insisted on the psychological impact of meningitis, and in particular the
5 state of shock that they experienced at the period of the hospitalization.
6
7
8
9

10 *"I was holding him in my arms, and I was looking for a way to comfort him. (...) I was just*
11 *very, very anxious (...). I was completely shocked by his condition. I thought he was dying. In fact,*
12 *I know he barely avoided death. I've always felt that my son was close to death"* (P10).
13
14

15 The sight of the body of the diminished child, bearing the scars of the disease, was intolerable.
16 Most of the participants described an impression of imminent death, which is terrifying. A
17 grandmother mentioned this fear, which she states sometimes still comes to her.
18
19
20
21
22

23 *"What's more, he was in great pain and that's really what shocked me the most. I've never*
24 *seen anyone suffer like this, especially not a child. Three years later, I'm still shocked by it"*. (P16)
25

26 Some mothers stressed the traumatic nature of the experience of facing the danger of death
27 of their child, especially during intensive care. The emotions described by most of the narratives
28 are intense and vary between denial and deep anguish, some even evoking a state of stupor.
29
30
31
32

33 *"When the doctor came to see us, she was still in a life-threatening prognosis. He told us*
34 *that (...) there were three possible outcomes. Either she was not going to make it, or she was going*
35 *to make it, but he was not able to say whether she will breathe on her own or not, or she was going*
36 *to make it, but she will be very severely disabled" (...). For me, none of the options were possible"*.
37 (P20)
38

39 Other testimonials illustrated the parents' aptitude to manage the exceptional situation and
40 stay positive in front of their child during the hospitalization.
41
42
43
44

45 *"Nevertheless, we had the chance (...) to keep hope alive. When we went to see her (...) in*
46 *the intensive care unit, we talked to her, we sang songs to her. Even if we didn't know if she could*
47 *hear us, we kept in mind that we had to stay positive"*. (P11)
48

49 However, most of the respondent commented on the long-term severe psychological
50 consequences of the meningitis experience and sequelae. They described their global
51 psychological vulnerability, and for some of them, depressive symptoms requiring treatments.
52
53
54

55 *"I had nothing left to hold me. Everyone around me was happy, but I wasn't. I couldn't*
56 *explain it, nothing had taste (...). I wanted to kill myself... but at the same time I told myself that*
57 *those who remained would be too sad... so I didn't do it"*. (P12)
58
59
60

1
2
3 The description of depressive symptoms, including anhedonia and suicidal thoughts, were
4
5 at times mixed with the perception of relief and happiness, often leading to a feeling of isolation.
6

7
8 The time necessary to regain personal and family balance also emerged as a common issue.
9

10
11 *“After the first six months, I got the backlash. I tried to put up with everything, telling*
12 *myself that I was strong. My daughter was strong, so I had to be strong. At one point, (...) I fell*
13 *into a deep depression that lasted for two years. I was on medication, anxiolytics and*
14 *antidepressants to get me out of this hellish spiral. I saw everything in black and I told myself that*
15 *my daughter would never make it, that they would make fun of her and that life would be difficult*
16 *for her. I locked myself in a negative bubble. Now I'm a little better, but there are always times*
17 *when I think about the future, and I still have fears and anxieties about what might happen later*
18 *on”.* (P2)
19

20
21 In these two testimonies, we can notice the lasting concern for their child, even when they
22
23 progress to adulthood. This concern is permeated with anxious anticipation concerning the
24
25 survivors' well-being.
26

27 28 *Parents coping with the illness* 29

30
31 Having to take care of a child who is often severely impaired is an ordeal for the parental
32
33 couple. However, most of the interviewees highlighted that, despite occasional tensions, they
34
35 managed to deal with this difficult situation.
36
37

38
39 *“Concerning my couple, we have always remained very close together. My husband is*
40 *always very, very present”* (P11).
41

42
43 Along with the family, in many cases the partner is identified as a valuable source of mutual
44
45 support in the moments of doubt. The family, as a whole, is described as an important source of
46
47 support.
48

49
50
51 *“Luckily, we have a big family that never gave up on us. They took turns coming to see us.*
52 *Every day, we had someone to support us”.* (P13)
53

54
55 The quality of the relationship and communication of the two parents resulted in new forms
56
57 of adjustment beyond the effects of the disease and brought new perspectives to family life.
58
59
60

1
2
3 *“We complement each other (...). We talked about it [the meningitis experience] afterwards*
4 *and we thought we'd done really well”*. (P20)

5 The notions of complementarity and open communication appeared to be critical in coping with
6 the disease and its multiple impacts.
7

8
9
10 *Impact of meningitis on the life course*

11
12
13 Caring for a child with a disability takes time, requires careful planning and often has a
14 serious financial impact for the family, as underlined by the interviewed parents.
15

16
17
18 *“I think it's all about her. For one thing, there are all her medical visits since she was four*
19 *months old. There are 3 to 4 appointments a week, on top of work, you have to run around and it's*
20 *still very heavy”*. (P20)

21
22 Most of the time the disease and its consequences involved changes in the professional
23 trajectories of the survivor's close family and in the whole family's way of life.
24

25
26
27 *“At the time she was ill, I had planned to return to work (...) But I never went back to work,*
28 *I didn't honour the contract. Then, for 6 years, I didn't work at all because (she) needed me, I was*
29 *all the time with her, going back and forth for medical appointments. It was very complicated”*.
30 (P11)
31

32
33
34 These words showed that besides psychological impacts, caring for a child affected by
35 acute bacterial meningitis also has a financial cost, even in a country like France where social
36 assistance is present.
37

38
39
40 Finally, some participants underlined the positive impact of maintaining professional
41 activities not only for financial reasons, but also as a way to facilitate a social life beyond the world
42 of disability.
43

44
45
46 *“This job allows me to get out of everything related to disability, nappies, housework. It*
47 *makes me think of something else, and it makes me earn some money”*. (P7)
48

49
50
51 Adjustments also concern material aspects such as the person's living and housing and the
52 practical organisation of the child's care. They are necessary to allow the family to find a new
53 form of everyday functioning.
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“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

1
2
3 *in a vegetative state, while she can eat by herself, she walks alone with her armchair, she sings,*
4 *she loves to sing, she loves to play, music, early learning games, etc.”. (P13)*
5

6 Some individuals also evoked the adaptability, flexibility, and courage of their loved ones.
7

8
9
10 *“I think she's happy, but she has her ups and downs (...). She tries, she finds ways to do it*
11 *(...). She has great strength of character and now she wants to do things even if it's hard for her”.*
12 *(P11)*
13

14 *“And in the end, she has made up for her developmental delay (...). She has caught up with*
15 *everything and even the attending doctor told me that she is amazing. She really is a great little*
16 *girl” (P19).*
17

18
19 Furthermore, many testimonies referred to the social abilities of the meningitis survivors
20 and their capacity to enjoy a satisfactory quality of life despite the limits imposed by the severe
21 handicaps they experience.
22

23
24
25
26 *“She's very sociable, so she's a bit of a mascot everywhere she goes. As she is very*
27 *charming, very attaching and very funny, she doesn't have too many problems adapting to a new*
28 *environment”.* (P5).
29

30
31 The child's ability to forge links with her/his peers and her/his “zest for life” are very often
32 underlined.
33

34
35
36 Despite the disability and limitations brought on by the disease, the survivors' ability to
37 bounce back and adjust is stressed with admiration by the participants. However, the experience
38 of an event that suddenly and unexpectedly upsets the life of the whole family also required the
39 siblings' capacity for psychological adjustment.
40
41
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45

46 47 48 **5. Siblings attitude / behaviour** 49

50
51 The experience of acute meningitis disease and its sequelae is a stressful experience for the
52 whole family, not only when a family member is admitted to Intensive Care Unit (ICU), but also
53 in the mid- and long term. Within this study, parents focused on the siblings of the sick child, as
54 they also experienced some form of impact or disruption as a result of their siblings' illness.
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2
3 A common thread among the interviewees was the parents' perception of the attitude and
4
5 behaviour of siblings towards the meningitis survivors. Many participants could mention the
6
7 supportive way in which the siblings coped with the disease, and their positive role in the recovery
8
9 and life trajectories of their loved ones.
10

11
12 *"I am convinced that it is thanks to her twin sister who has been a great stimulant for her.*
13 *She has caught up with everything". (P19).*
14

15 Likewise:

16
17
18 *"I think his brother was really a driving force, even if it's not always obvious to him". (P5)*
19

20
21 Particular emphasis is also placed on the siblings' ability to understand, help and protect
22
23 their survivor sibling.
24

25
26
27 *"He tells us: "You don't understand that she wants that! We didn't understand fast enough,*
28 *according to him, and he was interpreting". (P5)*
29

30 The brother here adopts the function of intermediary or more precisely as an interpreter between
31
32 his sister and their parents, revealing a rare complicity.
33

34
35
36 *"He's a child who's very protective of his sister. He doesn't hesitate to go and see the other*
37 *children in the schoolyard if his sister is being teased". (P2)*
38

39 The role of "guardian" that we evoked when speaking of parents can sometimes be taken by a
40
41 brother or a sister of the sick child as well.
42
43
44

45 In addition, parents stressed that overall, the daily confrontation with disabilities enabled
46
47 the siblings to develop a sense of openness and tolerance of other people's differences.
48
49
50

51
52 *"My daughters have a lot of empathy, whether with their [disabled] sister or with other*
53 *children. It's true that they also have a different life. It is very enriching for them, because they*
54 *know the difference, they learn the values of life, which not all children will necessarily have...".*
55 *(P7)*
56

57 However, the testimonies of some other participants highlighted the psychological impact
58
59 on siblings of the specific disease-related environment and the responsibility that they assumed.
60

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:

1
2
3 *“I have a lot of children in my family, and I could see that for her there were some things*
4 *that were wrong” (P5)*
5

6
7 *“Thereafter, she evolved very slowly compared to children of her age”.* (P11).
8
9

10 In some cases, the comparison did not come from the parents themselves, but came from a
11 stranger.
12

13
14
15 *“One day, our kid was 5 years old, she was in her stroller with a pacifier in her mouth, one*
16 *couldn't see that she was disabled, and there was an old man who approached us saying: “look at*
17 *my little grandson, he walks, he is not in a stroller and he does not have a pacifier, yet he is*
18 *younger! (P7).*
19

20 This mother highlighted the perceived violence born from this comparison imposed by a stranger
21 who knew nothing of her history.
22

23
24
25 Other parents insisted on the developmental similarities between their child, even when disabled,
26 and other children of the same age:
27

28
29
30
31 *“Otherwise, in terms of development, she is a child like any other (...). She makes a point*
32 *of doing the same activities as other children” (P2).*
33

34 We found a similar statement in the testimony of a grandmother:
35

36 *“[He] does everything like them (his siblings). He is a child who has his place among the*
37 *siblings, there is no problem” (P16).*
38

39
40
41 Some parents expressed pride in having managed to cope with such an extreme experience, as an
42 individual and as a couple.
43

44
45 *“It [the meningitis experience] gave me that attitude because I wasn't like that before. It gave*
46 *me a stronger temper to come with it. (...) It's ok to break down, you have to break down at*
47 *some point, but the next day I am back on top, and I'm back on my feet..”.* (P13)
48
49

50 Another mother evoked the support she found in her relationship with her partner.
51

52
53 *“I see many couples (...) who split up because of their child's disability. However, we*
54 *supported each other, we didn't argue, there were no conflicts related to that. No, we did well”.*
55 *(P20)*
56
57
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1
2
3 However, above, the parents' pride was centred on their sick child. We found in their speech a
4 highlighting of her/his exceptional character. As mentioned earlier, several participants expressed
5 a sense of satisfaction about their child's trajectory. Some insisted on the fact that they initiated
6 certain attitudes, instilling courage in their child.
7
8
9
10

11
12 *"She's a little girl who's doing very well, we've done everything we could. She likes to be*
13 *assisted, so we taught her that no, that wasn't life, she had to do it on her own". (P 19)*
14
15

16
17 For some family ascendants, their loved one was in a way revealed in the disease, without
18 the family having anything to do with it. The "hero figure" then becomes the one that best describes
19 their child. "Hero", because the child is distinguished by her/his bravery, her/his exceptional
20 abilities. So, this mother told us about her daughter:
21
22
23
24

25
26 *"That's when I saw that my daughter was a fighter, because after waking up alone from*
27 *a coma, she saw me and said "mama", at 4 1/2 months. She spoke. She woke up from a coma,*
28 *looked me straight in the eye and said "mama"."(P2)*
29
30

31 Faced with an extreme experience - the mother insisted that her daughter was close to
32 death – the child's exceptional character was revealed in her verbal precocity. Furthermore, it is
33 within the mother-daughter relationship that the extraordinary capacity of the child emerged.
34 These exceptional capacities mentioned by family ascendants can thus be physical, as in the
35 testimony mentioned above, or in the words of other parents:
36
37
38
39

40 *"She has a phenomenal strength in her arms that she has developed due to the absence*
41 *of her legs" (P13).*
42
43

44 A physical force, therefore, but also a psychological one:
45
46

47 *"(She) turns out to be a very combative little girl" (P5).*
48
49

50 It appears that this revelation of the heroic character of their child allowed parents who
51 perceived this extraordinary dimension, to find a positive meaning in this painful experience.
52
53
54

55 *"It is one of the most beautiful moments that I experienced in this terrible ordeal (...). At*
56 *the beginning, the doctors didn't believe us (about the fact that their daughter was able to speak)*
57 *and we rang them to show them. We even kept photos of those moments. For us, it was a magical*
58 *moment because we realized that our daughter really wanted to live" (P2).*
59
60

1
2
3 We find here the characteristics of extraordinary events, which even look like a miracle
4
5 for these parents: the fact that there are people who do not believe, who must therefore be
6
7 convinced; the need for proofs, the fight that was carried out, and the ultimate meaning of this
8
9 fight: the revelation of a will to live. This elaboration of the figure of the child as a hero thus made
10
11 it possible to give a positive meaning to this painful experience and further, it may confirm the
12
13 meaning and value of the child's life.
14

15
16 This mention about finding positive meaning through the distressful experience of meningitis leads
17
18 to a second meaning-making process: engaging action to improve the healthcare system.
19

20
21
22
23 2. Finding the “positive” of the traumatic experience and engaging action to improve the
24
25 healthcare system.
26

27
28 The discourse of the participants echoed a desire to take an active position in their relationship
29
30 with the disease, not only through the acquisition of personal knowledge about meningitis, but also
31
32 through the commitment to raise awareness of the disease in the general population. This
33
34 commitment can also concern awareness-raising work about people with disabilities. For instance,
35
36 this mother told us:
37
38

39
40 *“I raise awareness among children and young people on the concept of disability. I go to*
41
42 *schools or associations with a small booklet that I made, and I explain to children what disability*
43
44 *is, to remove taboo words and so that they put words on the little friends who are dyslexic, or in a*
45
46 *wheelchair, or mentally handicapped, etc.” (P7)*
47

48
49 Believing that in France, individuals are not familiar enough with difference - here linked to a
50
51 disability - this mother wanted to suggest to the youngest people to think about the inclusion of
52
53 their disabled peers, so that they can have a life as normal as possible.
54

55
56 This engagement process, which allows for them to feel active instead of enduring the vagaries
57
58 of life as a parent with a child with serious sequelae always starts from the intimate experience to
59
60 try to improve things for the greatest number. Thus:

1
2
3 *“We got a family house and we are in the process of renovating it to make a home to*
4 *accommodate disabled people on vacation in the Alps (...). It was our dream for us, so we are*
5 *doing it for others (P7)”.*

6 Having been confronted with major difficulties relating to the accessibility for disabled
7
8 people in many vacation homes, this family decided to take matters into their own hands and create
9
10 this dedicated and accessible place. The form of altruism that this commitment constitutes can also
11
12 be noted, which is why many, especially within the family, admire this commitment. Thus, the
13
14 grandmother of a child who suffered from meningitis testified to her admiration for her daughter,
15
16 the mother of this child.
17
18

19
20
21 *“My daughter invests in everything, in everything, for her little son It’s extraordinary”*
22 *(P16).*

23 24 25 26 27 **DISCUSSION**

28
29
30 This study on the experiences of close family members of meningitis survivors highlighted
31
32 six themes, shared by most of the participants, and two meaning-making processes that appeared
33
34 through the analysis of the narratives. The qualitative findings stressed the parents’ understanding
35
36 about acute bacterial meningitis, their relationships with the care system and the healthcare
37
38 providers; and they also highlighted the ignorance about this disease at the time of medical
39
40 treatment, both their own and that of certain healthcare professionals. In contrast, they spoke of
41
42 the knowledge that they had been able to acquire through patient associations. Much of their
43
44 testimony dealt with the multidimensional repercussions of the disease on their sick child and for
45
46 the whole family. The attitude and behaviour of the child affected by meningitis were largely
47
48 described and often glorified. Finally, the reaction of the siblings was a matter of concern for many
49
50 interviewed parents.
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56 These qualitative results provide insight into the nature of the mid and long-term
57
58 repercussions of the disease at an individual and familial level; they also offer an understanding of
59
60

1
2
3 the distress induced by these impacts. Indeed, consistent with previous quantitative studies [8, 9],
4
5 this research stressed the psychological burden associated with being the family of a child affected
6
7 by acute bacterial meningitis. This burden is imbued with traumatic elements (confrontation with
8
9 the possibility of the child's death, awareness of the possible sequelae), and is experienced daily
10
11 by families who have to face medical, economic, and societal challenges. The present results also
12
13 underline the expressed need for specific and professional support in this population. The
14
15 interviewed parents insisted on their requirement for psychological support, not necessarily during
16
17 the acute phase of the hospitalisation, when they were often stunned and preferred to be constantly
18
19 at the bedside of the sick child, but rather at the hospital discharge and in the long-term, when they
20
21 understood more clearly what their life would be like after this disease. A recent article showed
22
23 that coping support interventions are effective for improving parents' anxiety and stress symptom
24
25 burden related to acute paediatric hospitalisations [19]. Structured interventions could indeed be
26
27 offered to parents of children affected by meningitis, during hospitalisation and at discharge.
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34 However, the parents interviewed in this study not only experienced distressful challenges
35
36 induced by the illness of their child but also, for some participants, trajectories of post-traumatic
37
38 growth. Tedeschi and Calhoun [1998] [20] defines "Post-Traumatic Growth" as any positive
39
40 personal changes that occur after experiencing a potentially traumatic event. The meaning-making
41
42 processes analysed in this study indicated such a trajectory. The parents' pride in their child and
43
44 the pride that some admit feeling about themselves because they are satisfied with the way they
45
46 take care of their child and their family, echoes this growth process. A mixture of vulnerability
47
48 and growth was underlined in a previous qualitative study [21], conducted among mothers whose
49
50 school-aged children were born extremely prematurely; just as several participants of our research,
51
52 these mothers celebrated their children's successes [21]. The celebration of the children's skills
53
54 and their ability to overcome their disabilities become for certain participants the depiction of a
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3 hero trajectory ; that may be related to the dimension of “Post-traumatic Growth” such as “new
4
5 possibilities” and “appreciation of life” [20].
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8 Furthermore, the involvement of some parents in patient associations, even their
9
10 participation in this study, may indicate the experience of “new possibilities” and “enhanced
11
12 relationships”. Highlighting this growth in some individuals should not lead to an “injunction to
13
14 resilience” but to the observation that the close family members of meningitis survivors can adjust
15
16 to this difficult experience and find meaning in it/
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20 **Strengths and weaknesses of the study**

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23 This study has several limitations. The first limitation concerns the nature of the recruitment and
24
25 the representativeness of the sample. As participants volunteered to take part in the research, this
26
27 may have resulted in self-selection bias. Therefore, findings may reflect the views of people more
28
29 interested in taking an active approach to the disease through engagement with a patient
30
31 association. Moreover, the sample consisted exclusively of adult females (ten mothers and one
32
33 grandmother). Thus, this study might not be representative of the wider spectrum of close family
34
35 members who faced the meningitis disease. Finally, the participants’ close family members
36
37 differed significantly in age at the time of the meningitis diagnosis, severity of their symptoms and
38
39 sequelae. It is conceivable that their experiences would vary with these factors. In future studies,
40
41 a more diverse sample, including male participants, recruited from a plurality of treatment facilities
42
43 and setting contexts of care, would be preferred. This would allow for the examination of whether
44
45 different experiences would be described and would provide a complete map of the meanings
46
47 attached to subjective experiences and the generalisation of the study findings.
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53 A second limitation concerns the retrospective nature of the interviews. This wide time
54
55 period could have induced recall and reconstruction bias in material (e.g. negative aspects often
56
57 tend to be better remembered than the positive one). A worthwhile direction for future research
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2
3 might be the exploration of the subjective experience of parents confronted with acute bacterial
4 meningitis and the family members' psychological adjustment shortly after the acute phase. A
5 longitudinal design would also allow for the capture of differences in their adjustment of variations
6
7 in the psychological adjustment of the study participants.
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12 Despite these limitations, this is the first study that uses a validated methodology to provide
13 insights on the lived experience of families that have faced bacterial meningitis disease, and it
14 highlights several meaning-making processes of this life-changing experience. It stresses, on the
15 one hand, the interviewed parents' need for improved communication with the healthcare
16 providers and on the other hand, the importance of an increased knowledge surrounding the
17 disease, in particular with regard to the basic education of the public in general and the diagnostic
18 competences of primary care providers in particular.
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29 **Clinical implications**

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32 The findings in this study highlighted two main dimensions that could be of clinical
33 relevance. Firstly, it stressed that the disease-related environment, and more specifically, the
34 experience of accompanying a child receiving intensive care and the related risk of death are
35 stressful and may potentially result in some disruption or trauma for the whole family. Being
36 regularly informed of the care provided to their child, taking an active part in it, and receiving
37 attention by healthcare professional are mentioned as mitigating factors to help reduce stress and
38 anxiety. Several authors have emphasized the positive impact of family open visitation and
39 parental presence for the care of their child, especially in emergency care settings and intensive
40 care units [22, 23]; the impacts include relieved anxiety and fear, as well as reduced psychological
41 distress and post-intensive disorders, for both the family members and survivors [24, 25].
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55 One specific aspect related to the family presence during ICU procedures is the siblings'
56 visits. As in other contexts of severe diseases, sibling visitation is being increasingly endorsed as
57 a positive development in patient care. This is relevant especially because it facilitates elaboration
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1
2 of the siblings' own perception of the situation and prepares post-discharge life, reduces fantasies,
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4 increases understanding and the sense of control over the situation, and increases bond
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6 enhancement and improves communication between families and care providers [23, 26, 27].
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8 Thus, the implementation of experimental initiatives in the context of bacterial meningitis
9
10 intensive care seems desirable. Collaboration between different healthcare providers (clinicians,
11
12 nurses, psychologists) and parents in order to create the appropriate visitor conditions and
13
14 organisation of staff is strongly supported by the literature [25, 28, 29]. Given the paucity of
15
16 research on this issue, further studies on the psychological impact and implications of the siblings'
17
18 presence in ICUs could offer some insight on how they cope with this aversive event at the time of
19
20 care and in the longer term. In this perspective, exploring the siblings' experience of the disease
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22 would provide a better understanding of the meaning-marking process and could identify potential
23
24 pitfalls where there is a need for sustainable psychological assistance.
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30 Finally, our findings stressed the need for continuing efforts to consider and monitor the
31
32 emotional burden of the disease on the child's family ascendants, the psychological adjustment
33
34 process and families' trajectories over time. In this regard, it would be valuable if family
35
36 ascendants of acute meningitis survivors could benefit from systematic, and when necessary,
37
38 professional consultations during and after their experience of the disease. The more appropriate
39
40 forms and timing of this support, prognostic factors and outcome merit further investigation.
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44 **Conclusions**

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47 This study helped to capture the subjective experience and psychological adjustments of
48
49 parents confronted with paediatric meningococcal meningitis. Two main meaning-making
50
51 processes in relation to the participants' experiences of this adverse context emerged from their
52
53 discourse. These processes emphasized the importance of information and support of families, the
54
55 potentially traumatic impact of the illness experience, and the possibility of post-traumatic growth
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57 for some individuals, including the desires of parents to engage in improving the care system.
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3 Providing family ascendants with accurate information about their child's conditions and
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5 treatments, as well as involving them in the care and medical decision-making could positively
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7 influence and develop the quality of care provided by healthcare professionals.
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11 In the meantime, clinicians, caregivers, and other stakeholders of the healthcare system should be
12
13 aware that information and the involvement of the family as an active partner in the care process
14
15 are conditions for its effectiveness, from the onset of disease symptoms, their management in the
16
17 emergency rooms and throughout the recovery journey.
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20 **PATIENT AND PUBLIC INVOLVEMENT**

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23 The scientific team/board included two representatives of patients' associations. They
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25 were involved from the origin of the study and identified the potential psychological consequences
26
27 of the disease experience. They also highlighted the interest and motivation of patients and family
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29 members to participate in psychological research, and also participated in the discussions during
30
31 which questions would be posed to the participants. These representatives were aware of the
32
33 potential burdens associated with this research and underlined on the contrary the benefits that
34
35 participants could derive from the project. A press conference took place on 18th September 2020
36
37 to disseminate the results of the study on meningitis survivors' experiences [14]. The present study
38
39 exploring the subjective experience of close family members of the child with meningitis,
40
41 corresponds to the second part of the results. In addition, we plan to organise a second conference
42
43 for the association where the participants were recruited to disseminate our findings and their
44
45 clinical implications.
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51
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56
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58
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60

1
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4
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6
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8

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17

18 19 **AUTHOR CONTRIBUTIONS**

20 ES and LF conducted the review of the literature. ES was the main coder for the thematic
21 analysis. LF was the second coder for the thematic analysis. ES and LF analysed the data and
22 edited the manuscript. PG contributed to the construction of the research project and supervised
23 the discussion of the results. All authors read and approved the final manuscript.
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30 31 **COMPETING INTERESTS**

32 The authors declare that they have no competing interests regarding the publication of this
33 article.
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38 39 **DATA AVAILABILITY STATEMENT**

40 Data are available on reasonable request.
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47 48 **REFERENCES**

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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 SRQR reporting 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.

		Page
	Reporting Item	Number
Title	<p>#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</p>	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

Introduction

[#3](#) Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement

[#4](#) Purpose of the study and specific objectives or question

Methods

[#5](#) Qualitative approach and research paradigm

Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, 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.

As appropriate the rationale for several items might be discussed together.

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1	Data collection	#11	Description of instruments (e.g. interview guides,	8
2			questionnaires) and devices (e.g. audio recorders)	
3	instruments and		used for data collection; if / how the instruments(s)	
4			changed over the course of the study	
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11	Units of study	#12	Number and relevant characteristics of participants,	7
12			documents, or events included in the study; level of	
13			participation (could be reported in results)	
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19	Data processing	#13	Methods for processing data prior to and during	8
20			analysis, including transcription, data entry, data	
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31	Data analysis	#14	Process by which inferences, themes, etc. were	8
32			identified and developed, including the researchers	
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34			paradigm or approach; rationale	
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41	Techniques to enhance	#15	Techniques to enhance trustworthiness and credibility	8 & 9
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48	Results/findings			
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51	Syntheses and	#16	Main findings (e.g. interpretations, inferences, and	10 & 11
52	interpretation		themes); might include development of a theory or	
53			model, or integration with prior research or theory	
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1	Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts,	11 &
2			photographs) to substantiate analytic findings	more
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10	Intergration with prior	#18	Short summary of main findings; explanation of how	28
11	work, implications,		findings and conclusions connect to, support, elaborate	
12	transferability and		on, or challenge conclusions of earlier scholarship;	
13	contribution(s) to the field		discussion of scope of application / generalizability;	
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30	Conflicts of interest	#20	Potential sources of influence of perceived influence on	34
31			study conduct and conclusions; how these were	
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38	Funding	#21	Sources of funding and other support; role of funders in	34
39			data collection, interpretation and reporting	
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 44 American Medical Colleges. This checklist was completed on 21. January 2020 using
 45 <https://www.goodreports.org/>, a tool made by the [EQUATOR Network](#) in collaboration with
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BMJ Open

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

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Primary Subject Heading:	Neurology
Secondary Subject Heading:	Infectious diseases, Intensive care, Global health, Mental health, Qualitative research
Keywords:	Infectious disease/HIV < NEUROLOGY, PSYCHIATRY, QUALITATIVE RESEARCH, INTENSIVE & CRITICAL CARE

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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" – comparison 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.

1
2
3 Keywords: Parents/Family ascendants; Subjective experience; Meningitis; survivors; Meaning-
4 making process; Qualitative methods; Discourse.
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10 **Article Summary**

11 **Strengths and limitations of this study**

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15 ○ An empirical qualitative method (Interpretative Phenomenological Analysis) was used to
16 explore the lived experience of parents and grandparents whose child or grandchild had suffered
17 from and survived acute bacterial meningitis.
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- 20
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22 ○ One of the first studies undertaken to explore the experience of family ascendants of this
23 condition.
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- 26
27 ○ The study results may be affected by the recruitment of participants through patient association
28 websites and by the retrospective study design (i.e., reconstruction bias due to the time period
29 between the meningitis episode and participation in the study).
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- 32
33 ○ The participants were exclusively females (mothers or grandmother) and the study does not
34 capture the experience of fathers (which is unfortunately quite common in studies dedicated to
35 the parents of children with physical conditions).
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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 septicemia [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

1
2
3 association's website (see Supplementary material). The participants were not necessarily members
4
5 of the association. The inclusion criteria were: (1) age ≥ 18 years at the time of the study; (2) being
6
7 an ascendant of an individual who received a diagnosis of acute bacterial meningitis during
8
9 childhood, adolescence, or adulthood; (3) a period of at least six months between the onset of
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11 illness of the descendant and the interview; and (4) informed consent to participate in this study.
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15 The exclusion criteria were: (1) family ascendants who had lost their child due to acute bacterial
16
17 meningitis, or bereaved parents (by other cause) were not included in the research because grief
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19 process could deeply affect the present results; (2) severe cognitive impairment that hinders
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21 participation in the study, as determined by the interviewers; (3) lack of a sufficient fluency in
22
23 French to participate in the research interviews.
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26 27 **Recruitment**

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30 The recruitment was voluntary, and all participants expressed their agreement to participate in the
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32 research, according to the French ethical board's recommendations for qualitative non-
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34 interventional research. According to the French legislation, collection of information on ethnic
35
36 origin and religious affiliation is not allowed [19], therefore these aspects were not assessed.
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40 41 **Ethical approval**

42
43 In accordance to Article L1121-1 of the French Public Health Code [20], this qualitative study,
44
45 which uses the responses to a survey carried out by telephone from relatives of individuals who
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47 recovered from the illness more than six months ago, does not correspond to any of the three
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49 categories of studies falling within the scope of research involving human subjects, and therefore
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51 no ethical approval was required.
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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

1
2
3 divergences in the meaning-making processes. The third author (LF) audited the documentation
4
5 for the first five interviews as a validity check on the analytic process. Great care was taken
6
7 throughout the process to meet the scientific rigour criteria established by qualitative analysis [22].
8
9

10 11 **Patient and public involvement**

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14 The scientific team/board of the project included two representatives of patients' associations.
15
16 They were involved from the origin of the study and identified the potential psychological
17
18 consequences of the disease experience. They also highlighted the interest and motivation of
19
20 patients and family members to participate in psychological research, and also participated in the
21
22 discussions during which questions would be posed to the participants. These representatives were
23
24 aware of the potential burdens associated with this research and underlined on the contrary the
25
26 benefits that participants could derive from the project. A press conference took place on
27
28 18th September 2020 to disseminate the results of the study on meningitis survivors' experiences
29
30 [18]. The present study exploring the subjective experience of close family members of the child
31
32 with meningitis, corresponds to the second part of the results. In addition, we plan to organise a
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34 second conference for the association where the participants were recruited to disseminate our
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36 findings and their clinical implications.
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43 **RESULTS**

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46 In total, 11 women took part in the study, 10 mothers and one grandmother. The children
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48 (child/grandchild) were 3–30 years old (Mean [M]= 13.45 Standard Deviation [SD]= 9.37) at the
49
50 time of the interviews, and between 0,2 and 20 years old at the time of the meningitis diagnosis
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52 (M = 4.06, SD = 7.26). On average, 9.39 years had passed between the onset of illness and the
53
54 parent's interview (SD = 5.46).
55
56
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58
59 The participants' profile is described in Table 1.
60

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

1
2 did not correspond to the pre-established questions. A detailed analysis of the not-selected themes
3
4 (i.e. meningitis disease) can be provided on demand.
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9 **1. Healthcare services and professionals**

10 This theme includes three subthemes: (1) Experience of healthcare services and care routine;
11
12 (2) Relationship with healthcare providers; (3) Need for psychotherapeutic support.
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15 ~~The overwhelming experience of an extreme situation, the interactions with healthcare~~
16 ~~professional and services were reported in by family ascendants. Feelings of dismay, refusal to~~
17 ~~accept their child's life is threatened and consecutive anger came over strongly in the interviews;~~
18 ~~for many, these emotional responses triggered a request for help.~~
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26 *Experience of healthcare services and the relationship with healthcare providers*

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29 The experience of care services as evoked by family members varied. Some of them
30 emphasized the quality of care.
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34 *“I can't thank that paediatrician enough because he didn't know that it was meningitis yet,*
35 *but he put a treatment in place (...), which saved us a few hours”.* (P13)
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39 Others appreciated the attention they received at the hospital and stated that it helped them to
40 reduce their stress and anxiety during the medical emergency situation.
41
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43
44 *“We were very, very welcomed, they arranged a room for us at the hospital. It was a special*
45 *room for the parents so we could sleep there the first night”.* (P11)
46
47

48 Family ascendants praised both the technical and relational skills of healthcare providers.
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51 However, within the narratives, there also appeared areas of dissatisfaction such as the long
52 waiting time before receiving the diagnosis, the complexity of care received by their loved ones,
53 and the hospital environment in general.
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3 *“After she got there, we waited for three or four hours without hearing from her. It was*
4 *really a very, very long wait, no news, no nothing. (...). And then they put us in a very creepy office.*
5 *It wasn't reassuring at all (...).” (P20)*
6

7 It appears here that it is not so much the wait itself that is stressful, but rather the absence of
8
9 communication with the healthcare providers and especially the absence of news concerning the
10
11 state of the child. This leads us to approach the following sub-theme of communication.
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13

14 Indeed, there were many occurrences which highlighted the difficulties in communication
15
16 with health care professionals. The dialogue was perceived as difficult and generated frustration.
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19 *“The doctor came in and he got angry with me and told me I had to stop my show (...) he*
20 *thought I was a crazy person who was there to bother them”.* (P10)
21
22

23
24 This mother perceived here a lack of consideration for her emotional distress, which is misjudged
25
26 by the physician, according to her testimony. We found the perception of this lack of consideration
27
28 in the testimony of another study participant who mentioned that professionals gave little credit to
29
30 her opinion:
31
32

33 *“In any case, the way they told us things weren't right at all... Insinuating that it was not*
34 *justified to come and take her [to the hospital], when in the end the (positive) results proved it the*
35 *next day”.* (P19)
36
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38 Several mothers highlighted that the information they provided about their unwell child
39
40 and their intuition of the seriousness of the situation was not considered. Therefore, they often felt
41
42 discredited by the medical professional and expressed their frustration.
43
44

45 *“I got angry (...), I told him that my daughter had had ear infections before, but that it*
46 *hadn't put her in this state of drowsiness, with vomiting and a fever that wouldn't go down (...). I*
47 *insisted, and he told me I was a hysterical mother”.* (P13)
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51 Some family ascendants remembered making harsh comments to certain doctors whose
52
53 attitude or behaviour were deemed to be disrespectful, inappropriate or dismissive.
54
55

56 *“I told them, "We're not numbers” (...). “There's even a doctor for whom I asked that he*
57 *no longer treat my daughter. I even notified the hospital management, so he was replaced by*
58 *another doctor.”* (P2)
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3 This mother placed herself as "guardian" of her child, in order to protect her son and to have him
4 considered as an individual (and not as a "simple number").
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8 *Need for psychological support*
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10 The parents showed very intense emotions when confronting the different stages of illness.
11
12 Their emotional response oscillated between uncertainty and frustration, to fear, anxiety and shock
13 as a result of what they sometimes perceived as a "cold" and "hard" relationship with healthcare
14 professionals. They stressed the need for psychological support to help them at the time of
15 diagnosis and intensive care, especially when they felt overwhelmed.
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23 *"I had a very bad experience at the ICU because I found that the staff... well, I think they're*
24 *people who see this every day and have to remain impassive before certain situations. But we, as*
25 *parents, we need accompaniment, we need support, we need help, and that's not necessarily what*
26 *we had". (P2)*
27

28
29 This parent interestingly gave a contrasting description between the "distanced"
30 functioning of ICU professionals, a function that she understands, and her own needs as a mother.
31
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34 Moreover, family ascendants experienced difficult emotions in the long term as well during
35 their children's rehabilitation period.
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40 *"They referred us to a psychologist. That's good in itself but it often happened in the*
41 *hospital room with our daughter next door, so it wasn't necessarily the right time, we were very*
42 *emotional. It was good to see a psychologist when our daughter was hospitalised, but we had very*
43 *long medical visits for L., (...), but afterwards, we were abandoned to ourselves, we weren't*
44 *supported at all."* (P5)
45
46

47 Here, this mother indicated that the reference to a mental health professional was not
48 always sufficient. The time and the clinical frame of psychological support were also critical and,
49 despite this professional support, she felt abandoned.
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52 For some, the help of professionals was essential in the process of alleviating their sense
53 of guilt and making sense of the traumatic experience of accompanying a child who was
54 experiencing meningitis.
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3 *“I started a behavioural and cognitive psychotherapy with a psychologist so that I could*
4 *convince myself that it's not my fault that my daughter had purpura and was amputated.” (P2).*
5
6

7 Cognitive behavioural therapy and especially cognitive remediation are specific techniques
8
9 used in cases of particularly distressful thoughts.
10
11

12 13 **2. Knowledge/ Ignorance** 14 15

16 This second theme includes three subthemes about: (1) the disease; (2) the unpreparedness
17
18 of healthcare professionals / experts; (c) the familial caregivers' helplessness.
19
20

21 Unanimously, the interviewed parents focused on the importance of knowledge about acute
22
23 bacterial meningitis including its symptoms and possible sequelae, as well as the treatment process
24
25 and disease progression. The testimonials stressed the parents own need for understanding on the
26
27 one hand, and on the other hand, the healthcare providers' knowledge about the disease, which
28
29 they sometimes perceived as insufficient. The lack of communication, information and support for
30
31 families was also highlighted.
32
33
34

35 36 *About the disease* 37 38

39 The main part of the interviews highlighted that knowledge about meningitis was key and
40
41 many participants expressed the need to develop this knowledge, as most of the time the disease
42
43 was totally or partially unknown before it affected their child.
44
45

46 *“I didn't even know what it was. I didn't even know there were three forms of meningitis; I*
47 *didn't even know what “purpura fulminans” was (...). I'd never even heard of it.” (P2)*
48
49

50 Meeting this need to better understand the disease involved the acquisition of a scientific
51
52 background and the ability to express it with technical medical vocabulary. Therefore, many of the
53
54 participants needed to acquire some form of expertise on the disease to learn the means and
55
56 modalities of infection. They widely stressed that the internet and patients' associations were a
57
58 valuable source of knowledge.
59
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1
2
3 *"I've done a lot of research on the Internet, I've read testimonials and a lot of things. I*
4 *contacted associations that receive amputees and do a lot of things for them. I talked on the phone*
5 *with people from these associations who also reassured me a lot (...). I wanted to find out as much*
6 *as possible. It helped me a lot to be able to manage the situation as well as possible". (P2)*
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11 Developing some forms of expertise on the disease and taking an active approach to it were
12
13 reported as key aspects.
14
15

16 *"I didn't realize how the infection is transmitted or the difference between viral and*
17 *bacterial meningitis. But now I'm a meningitis expert...". (P5) (...) I've done a lot of reading on*
18 *the subject, and the first reflex you have when you have a medical team in front of you that gives*
19 *you a flood of information without taking the time to use words that are accessible to everyone,*
20 *you have to check it out (...). (P5).*
21
22

23
24 Having an active approach to learning about the disease probably compensated for the
25
26 perceived passive attitudes of healthcare professionals and the perceived lack of support that
27
28 parents experienced during their child's care.
29

30 For some participants, their understanding of their child's potential situation contrasts with the
31
32 expertise of the healthcare providers.
33
34

35 *The perceived unpreparedness of health professionals / expertise*

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39 In several cases, the patients were given alternative diagnoses, suggesting an imprecise
40
41 understanding of the symptoms and/or inadequate responses by healthcare professionals.
42
43

44 *"When I was told that she had the germ of streptococcus, I consulted the Internet and saw*
45 *that it could cause meningitis (...) The paediatrician told me: "Don't worry, (...) she was treated*
46 *and you will never hear about it again... there's no chance of that happening", ... a week later,*
47 *hospital, emergency room, meningitis." (P 20).*
48
49

50 This mother underlined here some diagnostic wandering: despite words full of assertiveness
51
52 advising her not to worry, what she dreaded effectively happened.
53
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55 In other cases, healthcare providers seemed completely overwhelmed by the emergency
56
57 context and did not fully perceive the seriousness of the symptoms.
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“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

1
2 Most of the interviews revealed the negative impact of meningitis on their family-children and
3
4 grandchildren health, and in particular the significant physical and cognitive sequelae associated
5
6 with meningitis including partial paralysis, heart problems, hearing and visual impairments.
7
8

9
10 These impairments significantly limited the survivors' ability to function in an autonomous
11
12 manner, and caused daily distress and frustration for the whole family.
13
14

15 *"(...). The definition is global psychomotor impairment, with a significant language deficit.*
16 *Not long ago, it was absence of language. You have to understand that (her) brain doesn't work*
17 *on its own (...). Today, she has the entire left hemisphere that is necrotic, she has frontal and*
18 *lateral lesions on the cortex which is between the two hemispheres. So, it's all been damaged".*
19 (P5)
20
21
22
23

24 Some testimonies focused on the physical impairments and a sense of permanent loss of
25
26 prior abilities of their child, which caused them to develop feelings of injustice.
27
28

29 *"These are diseases that totally destroy the life. She was a little girl who was 9 1/2 months*
30 *old, who was beginning to walk, who was very lively, and she was completely stopped in her stride.*
31 *It's really an injustice".* (P7)
32
33

34 *Psychological impacts and familial adjustment*

35

36 Besides the negative physical and cognitive impact of the disease on their relatives, the
37
38 participants also strongly insisted on the psychological impact of meningitis, and in particular the
39
40 state of shock that they experienced at the period of the hospitalization.
41
42
43

44 *"I was holding him in my arms, and I was looking for a way to comfort him. (...) I was just*
45 *very, very anxious (...). I was completely shocked by his condition. I thought he was dying. In fact,*
46 *I know he barely avoided death. I've always felt that my son was close to death"* (P10).
47
48

49 The sight of the body of the diminished child, bearing the scars of the disease, was intolerable.
50
51 Most of the participants described an impression of imminent death, which is terrifying. A
52
53 grandmother mentioned this fear, which she states sometimes still comes to her.
54
55

56 *"What's more, he was in great pain and that's really what shocked me the most. I've never*
57 *seen anyone suffer like this, especially not a child. Three years later, I'm still shocked by it".* (P16)
58
59
60

1
2
3 Some mothers stressed the traumatic nature of the experience of facing the danger of death
4
5 of their child, especially during intensive care. The emotions described by most of the narratives
6
7 are intense and vary between denial and deep anguish, some even evoking a state of stupor.
8
9

10
11 *“When the doctor came to see us, she was still in a life-threatening prognosis. He told us*
12 *that (...) there were three possible outcomes. Either she was not going to make it, or she was going*
13 *to make it, but he was not able to say whether she will breathe on her own or not, or she was going*
14 *to make it, but she will be very severely disabled” (...). For me, none of the options were possible”.*
15 (P20)

16
17 Other testimonials illustrated the parents’ aptitude to manage the exceptional situation and
18
19 stay positive in front of their child during the hospitalization.
20

21
22 *“Nevertheless, we had the chance (...) to keep hope alive. When we went to see her (...) in*
23 *the intensive care unit, we talked to her, we sang songs to her. Even if we didn't know if she could*
24 *hear us, we kept in mind that we had to stay positive”.* (P11)
25

26
27 However, most of the respondent commented on the long-term severe psychological
28
29 consequences of the meningitis experience and sequelae. They described their global
30
31 psychological vulnerability, and for some of them, depressive symptoms requiring treatments.

32
33 *“I had nothing left to hold me. Everyone around me was happy, but I wasn't. I couldn't*
34 *explain it, nothing had taste (...). I wanted to kill myself... but at the same time I told myself that*
35 *those who remained would be too sad... so I didn't do it”.* (P12)
36
37

38
39 The description of depressive symptoms, including anhedonia and suicidal thoughts, were
40
41 at times mixed with the perception of relief and happiness, often leading to a feeling of isolation.
42

43
44 The time necessary to regain personal and family balance also emerged as a common issue.

45
46 *“After the first six months, I got the backlash. I tried to put up with everything, telling*
47 *myself that I was strong. My daughter was strong, so I had to be strong. At one point, (...) I fell*
48 *into a deep depression that lasted for two years. I was on medication, anxiolytics and*
49 *antidepressants to get me out of this hellish spiral. I saw everything in black and I told myself that*
50 *my daughter would never make it, that they would make fun of her and that life would be difficult*
51 *for her. I locked myself in a negative bubble. Now I'm a little better, but there are always times*
52 *when I think about the future, and I still have fears and anxieties about what might happen later*
53 *on”.* (P2)
54
55
56
57
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1
2
3 In these two testimonies, we can notice the lasting concern for their child, even when they
4 progress to adulthood. This concern is permeated with anxious anticipation concerning the
5 survivors' well-being.
6
7
8

9 10 *Parents coping with the illness*

11
12 Having to take care of a child who is often severely impaired is an ordeal for the parental
13 couple. However, most of the interviewees highlighted that, despite occasional tensions, they
14 managed to deal with this difficult situation.
15
16
17
18

19
20 *“Concerning my couple, we have always remained very close together. My husband is*
21 *always very, very present”* (P11).
22

23
24 Along with the family, in many cases the partner is identified as a valuable source of mutual
25 support in the moments of doubt. The family, as a whole, is described as an important source of
26 support.
27
28
29

30
31
32 *“Luckily, we have a big family that never gave up on us. They took turns coming to see us.*
33 *Every day, we had someone to support us”*. (P13)
34

35
36 The quality of the relationship and communication of the two parents resulted in new forms
37 of adjustment beyond the effects of the disease and brought new perspectives to family life.
38
39

40
41 *“We complement each other (...). We talked about it [the meningitis experience] afterwards*
42 *and we thought we'd done really well”*. (P20)
43

44 The notions of complementarity and open communication appeared to be critical in coping with
45 the disease and its multiple impacts.
46
47

48 49 *Impact of meningitis on the life course*

50
51
52 Caring for a child with a disability takes time, requires careful planning and often has a
53 serious financial impact for the family, as underlined by the interviewed parents.
54
55

56
57 *“I think it's all about her. For one thing, there are all her medical visits since she was four*
58 *months old. There are 3 to 4 appointments a week, on top of work, you have to run around and it's*
59 *still very heavy”*. (P20)
60

1
2
3 Most of the time the disease and its consequences involved changes in the professional
4 trajectories of the survivor's close family and in the whole family's way of life.
5
6

7
8 *"At the time she was ill, I had planned to return to work (...) But I never went back to work,*
9 *I didn't honour the contract. Then, for 6 years, I didn't work at all because (she) needed me, I was*
10 *all the time with her, going back and forth for medical appointments. It was very complicated".*
11 (P11)
12

13
14 These words showed that besides psychological impacts, caring for a child affected by
15 acute bacterial meningitis also has a financial cost, even in a country like France where social
16 assistance is present.
17
18

19
20 Finally, some participants underlined the positive impact of maintaining professional
21 activities not only for financial reasons, but also as a way to facilitate a social life beyond the world
22 of disability.
23
24

25
26 *"This job allows me to get out of everything related to disability, nappies, housework. It*
27 *makes me think of something else, and it makes me earn some money".* (P7)
28
29

30
31 Adjustments also concern material aspects such as the person's living and housing and the
32 practical organisation of the child's care. They are necessary to allow the family to find a new
33 form of everyday functioning.
34
35

36
37 *"The house is being rearranged to create a room on the ground floor. Until now, she had*
38 *been going upstairs, but we hope that when she has a room on the ground floor, it will be easier*
39 *to find someone to relieve us so that we can leave from time to time".* (P7)
40
41

42
43 *"If her behaviour is definitely related to meningitis, it is a real handicap for us in many*
44 *ways, we can't go anywhere, it is really difficult. We try to show her many things so that she can*
45 *continue to improve but taking her to a zoo or a park is a real challenge".* (P 20).
46

47
48 Thus, usual leisure activities for many children become extremely complex to organise: everyday
49 life is often marked by renouncement.
50
51

52
53 The interaction with the health services administration regarding about the coverage of the
54 family member's care is also a concern mentioned by family ascendants. They emphasized that the
55
56

1
2
3 complexity of the administrative procedures and the constant need to prove legitimacy to their
4
5 request constitute a considerable psychological burden in addition to the burden of caring for the
6
7 meningitis survivors.
8
9

10 *“I always say the biggest handicap is administration. (...) you have to keep fighting”* (P7).
11

12
13 The energy expended is considerable, and participants often use sports comparisons or
14
15 fighting metaphors to describe their daily life.
16
17

18 *“We always have to go running around, putting together files, emails... I think that is the*
19 *worst. (...) When we had a renewal [of the disabled adult allowance file], and they stripped us of*
20 *everything. We had to appeal. On top of that, they always take 6 months to respond... we spend*
21 *our time fighting”*. (P20)
22
23

24 **4. Sick child attitude / behaviour**

25
26
27

28 Several testimonials described the positive evolution of the children who have survived
29
30 meningitis and stressed in particular the progress they have made and the skills that they have
31
32 acquired, frequently reaching levels of results that go beyond what the healthcare professionals
33
34 considered possible.
35
36
37

38 *“When we see the MRIs, compared to the damage she has to her brain, the doctors don't*
39 *understand that she can do what she does (...). For them, in relation to her lesions, she should be*
40 *in a vegetative state, while she can eat by herself, she walks alone with her armchair, she sings,*
41 *she loves to sing, she loves to play, music, early learning games, etc.”*. (P13)
42
43

44 Some individuals also evoked the adaptability, flexibility, and courage of their loved ones.
45
46
47

48 *“I think she's happy, but she has her ups and downs (...). She tries, she finds ways to do it*
49 *(...). She has great strength of character and now she wants to do things even if it's hard for her”*.
50 (P11)
51

52 *“And in the end, she has made up for her developmental delay (...). She has caught up with*
53 *everything and even the attending doctor told me that she is amazing. She really is a great little*
54 *girl”* (P19).
55
56
57
58
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1
2
3 Furthermore, many testimonies referred to the social abilities of the meningitis survivors
4 and their capacity to enjoy a satisfactory quality of life despite the limits imposed by the severe
5
6 handicaps they experience.
7
8

9
10 *"She's very sociable, so she's a bit of a mascot everywhere she goes. As she is very*
11 *charming, very attaching and very funny, she doesn't have too many problems adapting to a new*
12 *environment". (P5).*
13

14
15 The child's ability to forge links with her/his peers and her/his "zest for life" are very often
16
17 underlined.
18

19
20 Despite the disability and limitations brought on by the disease, the survivors' ability to
21
22 bounce back and adjust is stressed with admiration by the participants. However, the experience
23
24 of an event that suddenly and unexpectedly upsets the life of the whole family also required the
25
26 siblings' capacity for psychological adjustment.
27
28

31 **5. Siblings attitude / behaviour**

32
33

34
35 The experience of acute meningitis disease and its sequelae is a stressful experience for the
36
37 whole family, not only when a family member is admitted to Intensive Care Unit (ICU), but also
38
39 in the mid- and long term. Within this study, parents focused on the siblings of the sick child, as
40
41 they also experienced some form of impact or disruption as a result of their siblings' illness.
42
43

44
45 A common thread among the interviewees was the parents' perception of the attitude and
46
47 behaviour of siblings towards the meningitis survivors. Many participants could mention the
48
49 supportive way in which the siblings coped with the disease, and their positive role in the recovery
50
51 and life trajectories of their loved ones.
52
53

54
55 *"I am convinced that it is thanks to her twin sister who has been a great stimulant for her.*
56 *She has caught up with everything". (P19).*
57

58 Likewise:
59
60

1
2
3 *"I think his brother was really a driving force, even if it's not always obvious to him". (P5)*
4
5

6 Particular emphasis is also placed on the siblings' ability to understand, help and protect
7
8 their survivor sibling.
9

10
11 *"He tells us: "You don't understand that she wants that! We didn't understand fast enough,*
12 *according to him, and he was interpreting". (P5)*
13
14

15 The brother here adopts the function of intermediary or more precisely as an interpreter between
16
17 his sister and their parents, revealing a rare complicity.
18
19

20
21 *"He's a child who's very protective of his sister. He doesn't hesitate to go and see the other*
22 *children in the schoolyard if his sister is being teased". (P2)*
23

24 The role of "guardian" that we evoked when speaking of parents can sometimes be taken by a
25
26 brother or a sister of the sick child as well.
27
28

29
30 In addition, parents stressed that overall, the daily confrontation with disabilities enabled
31
32 the siblings to develop a sense of openness and tolerance of other people's differences.
33
34

35
36
37 *"My daughters have a lot of empathy, whether with their [disabled] sister or with other*
38 *children. It's true that they also have a different life. It is very enriching for them, because they*
39 *know the difference, they learn the values of life, which not all children will necessarily have...".*
40 *(P7)*
41

42 However, the testimonies of some other participants highlighted the psychological impact
43
44 on siblings of the specific disease-related environment and the responsibility that they assumed.
45
46 Possible mentioned causes include the fact that the disabled child monopolised the parents'
47
48 attention or that the place and role of everyone in the family may be affected.
49
50

51 *"Our second [daughter] is everyone's elder sister. She says it all the time: "By age, I am*
52 *her little sister, but in my head I am her big sister...". (P13)*
53
54

55 *"Finally, he has developed obesity (...). He was deeply shocked and traumatised by his*
56 *sister's amputation (...), he's aware that his sister is different from other children. He assigned*
57 *himself the role of the big brother, which is: "I'm here, I'll protect you, I'm here for you (...), he*
58 *took his role very seriously". (P2)*
59
60

1
2
3 The representation of this mother is clear: she sketched a linear causality between the amputation
4 of her daughter, following meningitis, and the obesity of her son, whom she considered
5 traumatised.
6
7
8
9

10 Despite the severity of the illness and the magnitude of its consequences for the survivors
11 and the whole family, the narratives stressed that in the long term, one of the key elements of
12 balance is the parents' ability to ensure a family life is "as normal as possible" for all siblings,
13 where everyone (re)discovers his or her place.
14
15
16
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20

21 **Narrative account and profiles of meaning-making**

22

23
24 The analysis of the above-mentioned themes allowed for the identification of the meaning-making
25 processes deployed by the participants and which are reflected in their remarks. These two
26 processes underpin the psychological adjustment to the meningitis and its consequences.
27
28
29
30

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

32

33
34 In order to have reference points on the development of their child, some of whom are
35 affected by serious sequelae, many parents compared the latter to other children in their family
36 circle. This comparison often turned out to be a source of great distress, by noting how much the
37 child is disabled and behind in their psychomotor development. For instance:
38
39
40
41
42

43
44 *"I have a lot of children in my family, and I could see that for her there were some things*
45 *that were wrong" (P5)*
46
47

48
49 *"Thereafter, she evolved very slowly compared to children of her age". (P11).*
50
51

52 In some cases, the comparison did not come from the parents themselves, but came from a
53 stranger.
54
55

56
57 *"One day, our kid was 5 years old, she was in her stroller with a pacifier in her mouth, one*
58 *couldn't see that she was disabled, and there was an old man who approached us saying: "look at*
59
60

1
2
3 *my little grandson, he walks, he is not in a stroller and he does not have a pacifier, yet he is*
4 *younger! (P7).*

5 This mother highlighted the perceived violence born from this comparison imposed by a stranger
6
7 who knew nothing of her history.
8

9
10 Other parents insisted on the developmental similarities between their child, even when disabled,
11
12 and other children of the same age:
13

14
15
16 *“Otherwise, in terms of development, she is a child like any other (...). She makes a point*
17 *of doing the same activities as other children” (P2).*
18

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

20
21 *“[He] does everything like them (his siblings). He is a child who has his place among the*
22 *siblings, there is no problem” (P16).*
23

24
25 Some parents expressed pride in having managed to cope with such an extreme experience, as an
26
27 individual and as a couple.
28

29
30 *“It [the meningitis experience] gave me that attitude because I wasn't like that before. It gave*
31 *me a stronger temper to come with it. (...) It's ok to break down, you have to break down at*
32 *some point, but the next day I am back on top, and I'm back on my feet..” (P13)*
33

34
35 Another mother evoked the support she found in her relationship with her partner.
36

37
38 *“I see many couples (...) who split up because of their child's disability. However, we*
39 *supported each other, we didn't argue, there were no conflicts related to that. No, we did well”.*
40 *(P20)*
41

42
43 However, above, the parents' pride was centred on their sick child. We found in their speech a
44
45 highlighting of her/his exceptional character. As mentioned earlier, several participants expressed
46
47 a sense of satisfaction about their child's trajectory. Some insisted on the fact that they initiated
48
49 certain attitudes, instilling courage in their child.
50
51

52
53 *“She's a little girl who's doing very well, we've done everything we could. She likes to be*
54 *assisted, so we taught her that no, that wasn't life, she had to do it on her own” (P 19)*
55
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2
3 For some family ascendants, their loved one was in a way revealed in the disease, without
4 the family having anything to do with it. The “hero figure” then becomes the one that best describes
5 their child. “Hero”, because the child is distinguished by her/his bravery, her/his exceptional
6 abilities. So, this mother told us about her daughter:
7
8
9
10

11
12 *“That's when I saw that my daughter was a fighter, because after waking up alone from*
13 *a coma, she saw me and said "mama", at 4 1/2 months. She spoke. She woke up from a coma,*
14 *looked me straight in the eye and said "mama".”(P2)*
15

16
17 Faced with an extreme experience - the mother insisted that her daughter was close to
18 death – the child’s exceptional character was revealed in her verbal precocity. Furthermore, it is
19 within the mother-daughter relationship that the extraordinary capacity of the child emerged.
20 These exceptional capacities mentioned by family ascendants can thus be physical, as in the
21 testimony mentioned above, or in the words of other parents:
22
23
24

25
26 *“She has a phenomenal strength in her arms that she has developed due to the absence*
27 *of her legs” (P13).*
28

29
30 A physical force, therefore, but also a psychological one:

31
32 *“(She) turns out to be a very combative little girl” (P5).*
33
34
35

36
37 It appears that this revelation of the heroic character of their child allowed parents who
38 perceived this extraordinary dimension, to find a positive meaning in this painful experience.
39
40

41
42 *“It is one of the most beautiful moments that I experienced in this terrible ordeal (...). At*
43 *the beginning, the doctors didn't believe us (about the fact that their daughter was able to speak)*
44 *and we rang them to show them. We even kept photos of those moments. For us, it was a magical*
45 *moment because we realized that our daughter really wanted to live” (P2).*
46

47
48 We find here the characteristics of extraordinary events, which even look like a miracle
49 for these parents: the fact that there are people who do not believe, who must therefore be
50 convinced; the need for proofs, the fight that was carried out, and the ultimate meaning of this
51 fight: the revelation of a will to live. This elaboration of the figure of the child as a hero thus made
52 it possible to give a positive meaning to this painful experience and further, it may confirm the
53 meaning and value of the child's life.
54
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1
2 This mention about finding positive meaning through the distressful experience of meningitis leads
3
4
5 to a second meaning-making process: engaging action to improve the healthcare system.
6
7

8
9 2. Finding the “positive” of the traumatic experience and engaging action to improve the
10
11 healthcare system.
12
13

14 The discourse of the participants echoed a desire to take an active position in their relationship
15
16 with the disease, not only through the acquisition of personal knowledge about meningitis, but also
17
18 through the commitment to raise awareness of the disease in the general population. This
19
20 commitment can also concern awareness-raising work about people with disabilities. For instance,
21
22 this mother told us:
23
24
25

26 *“I raise awareness among children and young people on the concept of disability. I go to*
27 *schools or associations with a small booklet that I made, and I explain to children what disability*
28 *is, to remove taboo words and so that they put words on the little friends who are dyslexic, or in a*
29 *wheelchair, or mentally handicapped, etc.” (P7)*
30
31
32

33 Believing that in France, individuals are not familiar enough with difference - here linked to a
34
35 disability - this mother wanted to suggest to the youngest people to think about the inclusion of
36
37 their disabled peers, so that they can have a life as normal as possible.
38
39
40

41 This engagement process, which allows for them to feel active instead of enduring the vagaries
42
43 of life as a parent with a child with serious sequelae always starts from the intimate experience to
44
45 try to improve things for the greatest number. Thus:
46
47
48

49 *“We got a family house and we are in the process of renovating it to make a home to*
50 *accommodate disabled people on vacation in the Alps (...). It was our dream for us, so we are*
51 *doing it for others (P7)”.*
52
53

54 Having been confronted with major difficulties relating to the accessibility for disabled
55
56 people in many vacation homes, this family decided to take matters into their own hands and create
57
58 this dedicated and accessible place. The form of altruism that this commitment constitutes can also
59
60 be noted, which is why many, especially within the family, admire this commitment. Thus, the

1
2 grandmother of a child who suffered from meningitis testified to her admiration for her daughter,
3
4 the mother of this child.
5
6

7
8 *“My daughter invests in everything, in everything, for her little son It’s extraordinary”*
9 (P16).
10

11 12 13 **DISCUSSION**

14
15
16 This study on the experiences of close family members of meningitis survivors highlighted
17 six themes, shared by most of the participants, and two meaning-making processes that appeared
18 through the analysis of the narratives. The qualitative findings stressed the parents’ understanding
19 about acute bacterial meningitis, their relationships with the care system and the healthcare
20 providers; and they also highlighted the ignorance about this disease at the time of medical
21 treatment, both their own and that of certain healthcare professionals. In contrast, they spoke of
22 the knowledge that they had been able to acquire through patient associations. Much of their
23 testimony dealt with the multidimensional repercussions of the disease on their sick child and for
24 the whole family. The attitude and behaviour of the child affected by meningitis were largely
25 described and often glorified. Finally, the reaction of the siblings was a matter of concern for many
26 interviewed parents.
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43 These qualitative results provide insight into the nature of the mid and long-term
44 repercussions of the disease at an individual and familial level; they also offer an understanding of
45 the distress induced by these impacts. Indeed, consistent with previous quantitative studies [12,
46 13], this research stressed the psychological burden associated with being the family of a child
47 affected by acute bacterial meningitis. This burden is imbued with traumatic elements
48 (confrontation with the possibility of the child's death, awareness of the possible sequelae), and is
49 experienced daily by families who have to face medical, economic, and societal challenges. The
50 present results also underline the expressed need for specific and professional support in this
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2
3 population. The interviewed parents insisted on their requirement for psychological support, not
4
5 necessarily during the acute phase of the hospitalisation, when they were often stunned and
6
7 preferred to be constantly at the bedside of the sick child, but rather at the hospital discharge and
8
9 in the long-term, when they understood more clearly what their life would be like after this disease.
10
11 A recent article showed that coping support interventions are effective for improving parents'
12
13 anxiety and stress symptom burden related to acute paediatric hospitalisations [23]. Structured
14
15 interventions could indeed be offered to parents of children affected by meningitis, during
16
17 hospitalisation and at discharge.
18
19

20
21 However, the parents interviewed in this study not only experienced distressful challenges
22
23 induced by the illness of their children but also, for some participants, trajectories of post-traumatic
24
25 growth. Tedeschi and Calhoun [1998] [24] defines "Post-Traumatic Growth" as any positive
26
27 personal changes that occur after experiencing a potentially traumatic event. The meaning-making
28
29 processes analysed in this study indicated such a trajectory. The parents' pride in their child and
30
31 the pride that some admit feeling about themselves because they are satisfied with the way they
32
33 take care of their child and their family, echoes this growth process. A mixture of vulnerability
34
35 and growth was underlined in a previous qualitative study, conducted among mothers whose
36
37 school-aged children were born extremely prematurely; just as several participants of our research,
38
39 these mothers celebrated their children's successes [25]. The celebration of the children's skills
40
41 and their ability to overcome their disabilities become for certain participants the depiction of a
42
43 hero trajectory; that may be related to the dimension of "Post-traumatic Growth" such as "new
44
45 possibilities" and "appreciation of life" [24].
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52 Furthermore, the involvement of some parents in patient associations, even their
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54 participation in this study, may indicate the experience of "new possibilities" and "enhanced
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56 relationships". Highlighting this growth in some individuals should not lead to an "injunction to
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3 resilience” but to the observation that the close family members of meningitis survivors can adjust
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5 to this difficult experience and find meaning in it/
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8 **Strengths and weaknesses of the study**

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11 This study has several limitations. The first limitation is related to the nature of the recruitment
12
13 and the representativeness of the sample. As participants volunteered to take part in the research,
14
15 this may have resulted in self-selection bias. Therefore, findings may reflect the views of people
16
17 more interested in taking an active approach to the disease through engagement with a patient
18
19 association. Moreover, the sample exclusively consisted of adult females (ten mothers and one
20
21 grandmother). Thus, this study might not be representative of the wider spectrum of close family
22
23 members who faced the meningitis disease. Finally, the participants’ close family members
24
25 differed significantly in age at the time of the meningitis diagnosis, severity of their symptoms and
26
27 sequelae. It is conceivable that their experiences would vary with these factors. In future studies,
28
29 a more diverse sample, including male participants, recruited from a plurality of treatment facilities
30
31 and setting contexts of care, would be preferred. This would allow for the examination of whether
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33 different experiences would be described and would provide a complete map of the meanings
34
35 attached to subjective experiences and the generalisation of the study findings.
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42 A second limitation concerns the retrospective nature of the interviews. This wide time
43
44 period could have induced recall and reconstruction bias in material (e.g. negative aspects often
45
46 tend to be better remembered than the positive one). A worthwhile direction for future research
47
48 might be the exploration of the subjective experience of parents confronted with acute bacterial
49
50 meningitis and the family members’ psychological adjustment shortly after the acute phase. A
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52 longitudinal design would also allow for the capture of differences in their adjustment of variations
53
54 in the psychological adjustment of the study participants.
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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

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

51 **Conclusions**

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54 This study helped to capture the subjective experience and psychological adjustments of
55 parents confronted with paediatric meningococcal meningitis. Two main meaning-making
56 processes in relation to the participants' experiences of this adverse context emerged from their
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3 discourse. These processes emphasized the importance of information and support of families, the
4
5 potentially traumatic impact of the illness experience, and the possibility of post-traumatic growth
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7 for some individuals, including the desires of parents to engage in improving the care system.
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9 Providing family ascendants with accurate information about their child's conditions and
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11 treatments, as well as involving them in the care and medical decision-making could positively
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13 influence and develop the quality of care provided by healthcare professionals.
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17 In the meantime, clinicians, caregivers, and other stakeholders of the healthcare system should be
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19 aware that information and the involvement of the family as an active partner in the care process
20
21 are conditions for its effectiveness, from the onset of disease symptoms, their management in the
22
23 emergency rooms and throughout the recovery journey.
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41
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43
44 paediatrician; Myriam Winance, sociologist).
45
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58 59 **AUTHOR CONTRIBUTIONS**

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2
3 ES and LF conducted the review of the literature. ES was the main coder for the thematic
4 analysis. LF was the second coder for the thematic analysis. ES and LF analysed the data and
5 edited the manuscript. PG contributed to the construction of the research project and supervised
6 the discussion of the results. All authors read and approved the final manuscript.
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11 12 **COMPETING INTERESTS**

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14
15 The authors declare that they have no competing interests regarding the publication of this
16 article.
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18 19 **DATA AVAILABILITY STATEMENT**

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21 Data are available on reasonable request.
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27 28 **REFERENCES**

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For peer review only

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 SRQR reporting 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.

		Page
	Reporting Item	Number
Title	<p>#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</p>	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

Introduction

[#3](#) Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement

[#4](#) Purpose of the study and specific objectives or question

Methods

[#5](#) Qualitative approach and research paradigm

Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, 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.

As appropriate the rationale for several items might be discussed together.

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1	Data collection	#11	Description of instruments (e.g. interview guides,	8
2			questionnaires) and devices (e.g. audio recorders)	
3	instruments and		used for data collection; if / how the instruments(s)	
4			changed over the course of the study	
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11	Units of study	#12	Number and relevant characteristics of participants,	7
12			documents, or events included in the study; level of	
13			participation (could be reported in results)	
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19	Data processing	#13	Methods for processing data prior to and during	8
20			analysis, including transcription, data entry, data	
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31	Data analysis	#14	Process by which inferences, themes, etc. were	8
32			identified and developed, including the researchers	
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41	Techniques to enhance	#15	Techniques to enhance trustworthiness and credibility	8 & 9
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48	Results/findings			
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51	Syntheses and	#16	Main findings (e.g. interpretations, inferences, and	10 & 11
52	interpretation		themes); might include development of a theory or	
53			model, or integration with prior research or theory	
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1	Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts,	11 &
2			photographs) to substantiate analytic findings	more
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10	Intergration with prior	#18	Short summary of main findings; explanation of how	28
11	work, implications,		findings and conclusions connect to, support, elaborate	
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24	Limitations	#19	Trustworthiness and limitations of findings	30
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30	Conflicts of interest	#20	Potential sources of influence of perceived influence on	34
31			study conduct and conclusions; how these were	
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38	Funding	#21	Sources of funding and other support; role of funders in	34
39			data collection, interpretation and reporting	
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 44 American Medical Colleges. This checklist was completed on 21. January 2020 using
 45 <https://www.goodreports.org/>, a tool made by the [EQUATOR Network](#) in collaboration with
 46 [Penelope.ai](#)
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BMJ Open

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

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Primary Subject Heading:	Neurology
Secondary Subject Heading:	Infectious diseases, Intensive care, Global health, Mental health, Qualitative research
Keywords:	Infectious disease/HIV < NEUROLOGY, PSYCHIATRY, QUALITATIVE RESEARCH, INTENSIVE & CRITICAL CARE

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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" – comparison 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.

1
2
3 Keywords: Parents/Family ascendants; Subjective experience; Meningitis; survivors; Meaning-
4
5 making process; Qualitative methods; Discourse.
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10 **Article Summary**

11 **Strengths and limitations of this study**

- 12
13 ○ An empirical qualitative method (Interpretative Phenomenological Analysis) was used to
14
15 explore the lived experience of parents and grandparents whose child or grandchild had suffered
16
17 from and survived acute bacterial meningitis.
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- 20
21 ○ One of the first studies undertaken to explore the experience of family ascendants of this
22
23 condition.
24
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- 26
27 ○ The study results may be affected by the recruitment of participants through patient association
28
29 websites and by the retrospective study design (i.e., reconstruction bias due to the time period
30
31 between the meningitis episode and participation in the study).
32
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- 34
35 ○ The participants were exclusively females (mothers or grandmother) and the study does not
36
37 capture the experience of fathers (which is unfortunately quite common in studies dedicated to
38
39 the parents of children with physical conditions).
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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

1
2
3 association's website (see Supplementary material). The participants were not necessarily
4
5 members of the association. The inclusion criteria were: (1) age ≥ 18 years at the time of the study;
6
7 (2) being an ascendant of an individual who received a diagnosis of acute bacterial meningitis
8
9 during childhood, adolescence, or adulthood; (3) a period of at least six months between the onset
10
11 of illness of the descendant and the interview; and (4) informed consent to participate in this study.
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13

14
15 The exclusion criteria were: (1) family ascendants who had lost their child due to acute bacterial
16
17 meningitis, or bereaved parents (by other cause) were not included in the research because grief
18
19 process could deeply affect the present results; (2) severe cognitive impairment that hinders
20
21 participation in the study, as determined by the interviewers; (3) lack of a sufficient fluency in
22
23 French to participate in the research interviews.
24
25

26 27 **Recruitment**

28
29
30 The recruitment was voluntary, and all participants expressed their agreement to participate in the
31
32 research, according to the French ethical board's recommendations for qualitative non-
33
34 interventional research. According to the French legislation, collection of information on ethnic
35
36 origin and religious affiliation is not allowed [19], therefore these aspects were not assessed.
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39

40 41 **Ethical approval**

42
43
44 In accordance to Article L1121-1 of the French Public Health Code [20], this qualitative study,
45
46 which uses the responses to a survey carried out by telephone from relatives of individuals who
47
48 recovered from the illness more than six months ago, does not correspond to any of the three
49
50 categories of studies falling within the scope of research involving human subjects, and therefore
51
52 no ethical approval was required.
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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

1
2
3 for the first five interviews as a validity check on the analytic process. Great care was taken
4
5 throughout the process to meet the scientific rigour criteria established by qualitative analysis [22].
6
7

8 **Patient and public involvement**

9
10 The scientific team/board of the project included two representatives of patients' associations.
11
12 They were involved from the origin of the study and identified the potential psychological
13
14 consequences of the disease experience. They also highlighted the interest and motivation of
15
16 patients and family members to participate in psychological research, and also participated in the
17
18 discussions during which questions would be posed to the participants. These representatives were
19
20 aware of the potential burdens associated with this research and underlined on the contrary the
21
22 benefits that participants could derive from the project. A press conference took place on
23
24 18th September 2020 to disseminate the results of the study on meningitis survivors' experiences
25
26 [18]. The present study exploring the subjective experience of close family members of the child
27
28 with meningitis, corresponds to the second part of the results. In addition, we plan to organise a
29
30 second conference for the association where the participants were recruited to disseminate our
31
32 findings and their clinical implications.
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42 **RESULTS**

43
44 In total, 11 women took part in the study, 10 mothers and one grandmother. The children
45
46 (child/grandchild) were 3–30 years old (Mean [M]= 13.45 Standard Deviation [SD]= 9.37) at the
47
48 time of the interviews, and between 0,2 and 20 years old at the time of the meningitis diagnosis
49
50 (M = 4.06, SD = 7.26). On average, 9.39 years had passed between the onset of illness and the
51
52 parent's interview (SD = 5.46).
53
54
55
56

57 The participants' profile is described in Table 1.
58
59
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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	<i>md</i>
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	<p>Symptoms (description...). Perception of symptoms & their evolution</p> <p>Diagnoses (relevance, accuracy, time...)</p> <p>Description of the disease (technical words, prevalence...)</p>
Healthcare services and professionals	<p>Experience of healthcare services and relationships with healthcare providers (e.g. communication)</p> <p>Need for psychological support at the time of diagnosis, during hospital care and in the long term (e.g. rehabilitation)</p>
Knowledge / ignorance	<p>About the disease (scientific background, technical vocabulary ...). Need for the patients and their caregivers to explain the disease. Internet and association role (information)</p> <p>Unpreparedness of health professionals / expertise</p> <p>Helplessness of familial caregivers (e.g. incomprehension of symptoms and/or lack of good reflexes, feeling of being overwhelmed by an exceptional situation)</p>
Repercussions of the meningitis experience - "life afterwards"	<p>Physical sequelae (partial paralysis, functional disability ...). Relating and compensating</p> <p>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)</p> <p>Parents coping with the illness (e.g. impact on the marital couple...)</p> <p>Impact of meningitis on the life course (financial and professional impact, change of life and professional trajectories, "giving up" ...)</p>
Sick child attitude / behaviour	<p>At the onset of the illness</p> <p>During the hospitalization</p> <p>Long-term attitudes (personality): flexibility, adaptation, courage</p>
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

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2
3 *“After she got there, we waited for three or four hours without hearing from her. It was*
4 *really a very, very long wait, no news, no nothing. (...). And then they put us in a very creepy office.*
5 *It wasn't reassuring at all (...).” (P20)*
6

7 It appears here that it is not so much the wait itself that is stressful, but rather the absence of
8 communication with the healthcare providers and especially the absence of news concerning the
9 state of the child. This leads us to approach the following sub-theme of communication.
10
11

12 Indeed, there were many occurrences which highlighted the difficulties in communication
13 with health care professionals. The dialogue was perceived as difficult and generated frustration.
14

15 *“The doctor came in and he got angry with me and told me I had to stop my show (...) he*
16 *thought I was a crazy person who was there to bother them”.* (P10)
17
18

19 This mother perceived here a lack of consideration for her emotional distress, which is misjudged
20 by the physician, according to her testimony. We found the perception of this lack of consideration
21 in the testimony of another study participant who mentioned that professionals gave little credit to
22 her opinion:
23
24

25 *“In any case, the way they told us things weren't right at all... Insinuating that it was not*
26 *justified to come and take her [to the hospital], when in the end the (positive) results proved it the*
27 *next day”.* (P19)
28

29 Several mothers highlighted that the information they provided about their unwell child
30 and their intuition of the seriousness of the situation was not considered. Therefore, they often felt
31 discredited by the medical professional and expressed their frustration.
32
33

34 *“I got angry (...), I told him that my daughter had had ear infections before, but that it*
35 *hadn't put her in this state of drowsiness, with vomiting and a fever that wouldn't go down (...). I*
36 *insisted, and he told me I was a hysterical mother”.* (P13)
37
38

39 Some family ascendants remembered making harsh comments to certain doctors whose
40 attitude or behaviour were deemed to be disrespectful, inappropriate or dismissive.
41
42

43 *“I told them, "We're not numbers” (...). “There's even a doctor for whom I asked that he*
44 *no longer treat my daughter. I even notified the hospital management, so he was replaced by*
45 *another doctor.”* (P2)
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3 This mother placed herself as "guardian" of her child, in order to protect her son and to have him
4 considered as an individual (and not as a "simple number").
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6

7
8 *Need for psychological support*
9

10 The parents showed very intense emotions when confronting the different stages of illness.
11
12 Their emotional response oscillated between uncertainty and frustration, to fear, anxiety and shock
13 as a result of what they sometimes perceived as a "cold" and "hard" relationship with healthcare
14 professionals. They stressed the need for psychological support to help them at the time of
15 diagnosis and intensive care, especially when they felt overwhelmed.
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23 *"I had a very bad experience at the ICU because I found that the staff... well, I think they're*
24 *people who see this every day and have to remain impassive before certain situations. But we, as*
25 *parents, we need accompaniment, we need support, we need help, and that's not necessarily what*
26 *we had". (P2)*
27

28
29 This parent interestingly gave a contrasting description between the "distanced"
30 functioning of ICU professionals, a function that she understands, and her own needs as a mother.
31
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34 Moreover, family ascendants experienced difficult emotions in the long term as well during
35 their children's rehabilitation period.
36
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39
40 *"They referred us to a psychologist. That's good in itself but it often happened in the*
41 *hospital room with our daughter next door, so it wasn't necessarily the right time, we were very*
42 *emotional. It was good to see a psychologist when our daughter was hospitalised, but we had very*
43 *long medical visits for L., (...), but afterwards, we were abandoned to ourselves, we weren't*
44 *supported at all."* (P5)
45
46

47 Here, this mother indicated that the reference to a mental health professional was not
48 always sufficient. The time and the clinical frame of psychological support were also critical and,
49 despite this professional support, she felt abandoned.
50
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52 For some, the help of professionals was essential in the process of alleviating their sense
53 of guilt and making sense of the traumatic experience of accompanying a child who was
54 experiencing meningitis.
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1
2
3 *“I started a behavioural and cognitive psychotherapy with a psychologist so that I could*
4 *convince myself that it's not my fault that my daughter had purpura and was amputated.” (P2).*
5
6

7 Cognitive behavioural therapy and especially cognitive remediation are specific techniques
8
9 used in cases of particularly distressful thoughts.
10
11

12 13 **2. Knowledge/ Ignorance** 14 15

16 This second theme includes three subthemes about: (1) the disease; (2) the unpreparedness
17
18 of healthcare professionals / experts; (c) the familial caregivers' helplessness.
19
20

21 Unanimously, the interviewed parents focused on the importance of knowledge about acute
22
23 bacterial meningitis including its symptoms and possible sequelae, as well as the treatment process
24
25 and disease progression. The testimonials stressed the parents own need for understanding on the
26
27 one hand, and on the other hand, the healthcare providers' knowledge about the disease, which
28
29 they sometimes perceived as insufficient. The lack of communication, information and support for
30
31 families was also highlighted.
32
33
34

35 36 *About the disease* 37 38

39 The main part of the interviews highlighted that knowledge about meningitis was key and
40
41 many participants expressed the need to develop this knowledge, as most of the time the disease
42
43 was totally or partially unknown before it affected their child.
44
45

46 *“I didn't even know what it was. I didn't even know there were three forms of meningitis; I*
47 *didn't even know what “purpura fulminans” was (...). I'd never even heard of it.” (P2)*
48
49

50 Meeting this need to better understand the disease involved the acquisition of a scientific
51
52 background and the ability to express it with technical medical vocabulary. Therefore, many of the
53
54 participants needed to acquire some form of expertise on the disease to learn the means and
55
56 modalities of infection. They widely stressed that the internet and patients' associations were a
57
58 valuable source of knowledge.
59
60

1
2
3 *"I've done a lot of research on the Internet, I've read testimonials and a lot of things. I*
4 *contacted associations that receive amputees and do a lot of things for them. I talked on the phone*
5 *with people from these associations who also reassured me a lot (...). I wanted to find out as much*
6 *as possible. It helped me a lot to be able to manage the situation as well as possible". (P2)*
7

8
9 Developing some forms of expertise on the disease and taking an active approach to it were
10 reported as key aspects.
11

12
13
14 *"I didn't realize how the infection is transmitted or the difference between viral and*
15 *bacterial meningitis. But now I'm a meningitis expert...". (P5) (...)* *I've done a lot of reading on*
16 *the subject, and the first reflex you have when you have a medical team in front of you that gives*
17 *you a flood of information without taking the time to use words that are accessible to everyone,*
18 *you have to check it out (...). (P5).*
19

20
21 Having an active approach to learning about the disease probably compensated for the
22 perceived passive attitudes of healthcare professionals and the perceived lack of support that
23 parents experienced during their child's care.
24

25
26 For some participants, their understanding of their child's potential situation contrasts with the
27 expertise of the healthcare providers.
28

29 *The perceived unpreparedness of health professionals / expertise*

30
31 In several cases, the patients were given alternative diagnoses, suggesting an imprecise
32 understanding of the symptoms and/or inadequate responses by healthcare professionals.
33

34
35
36 *"When I was told that she had the germ of streptococcus, I consulted the Internet and saw*
37 *that it could cause meningitis (...) The paediatrician told me: "Don't worry, (...) she was treated*
38 *and you will never hear about it again... there's no chance of that happening", ... a week later,*
39 *hospital, emergency room, meningitis." (P 20).*
40

41
42 This mother underlined here some diagnostic wandering: despite words full of assertiveness
43 advising her not to worry, what she dreaded effectively happened.
44

45
46 In other cases, healthcare providers seemed completely overwhelmed by the emergency
47 context and did not fully perceive the seriousness of the symptoms.
48

49
50
51 *"When I called [the emergency services] for the relapse and told them that she had been*
52 *out of hospital for 15 days for meningitis and that she had all the symptoms again, they didn't want*
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3 *to send us someone (...) Then the doctor (..) told us that we were really not very recommendable*
4 *parents and that we should only call for real emergencies instead of calling for a little girl who is*
5 *crying because she has a little fever” (P19).*
6
7

8 *Helplessness of familial caregivers*

9

10 The experience of a lack of responsiveness on the part of healthcare professionals caused
11 frustration and feelings of helplessness in the patients’ families. They also stress that some
12 diagnoses are shocking, and that physicians should be cautious in the way they phrase them as
13
14 diagnoses are shocking, and that physicians should be cautious in the way they phrase them as
15
16 their diagnosis might be contradicted by the favourable evolution of the disease.
17
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19
20 *“When they [the doctors] tell you that your child has a life expectancy of four years, when*
21 *she reaches five years, you think that they may need to reconsider the diagnosis... ”. (P5)*
22
23

24
25 The participants’ narratives also emphasized the importance of public awareness of
26 meningitis and the role that patient and carer associations play in this regard. Associations provide
27 families emotional and psychological understanding and support, which significantly helped the
28
29 families emotional and psychological understanding and support, which significantly helped the
30
31 family ascendants through the stressful events they were experiencing.
32
33

34
35 *“I think it's a disease that isn't adequately known. When she was at the hospital, I was*
36 *seeking answers to my questions and I searched on the Internet, and that's when I came across the*
37 *website of [name of the association]. Thanks to this website and the persons who foster it, we learn*
38 *everything that can happen around meningitis. I tell myself that if people were better informed*
39 *about the symptoms, more lives could be saved”.* (P19)
40

41 Taken together, the testimonials highlighted the psychological vulnerability of families and
42 their need for communication and support.
43
44
45
46
47

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

49

50
51 This major theme integrates five subthemes: (1) physical sequelae; (2) psychological impact;
52
53 (3) parents coping with the illness (in the short and long term); (4) impact of meningitis on the life
54
55 course; (5) meaning given to the extreme experiences they have gone through.
56
57
58
59
60

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)

1
2
3 Some mothers stressed the traumatic nature of the experience of facing the danger of death
4
5 of their child, especially during intensive care. The emotions described by most of the narratives
6
7 are intense and vary between denial and deep anguish, some even evoking a state of stupor.
8
9

10 *“When the doctor came to see us, she was still in a life-threatening prognosis. He told us*
11 *that (...) there were three possible outcomes. Either she was not going to make it, or she was going*
12 *to make it, but he was not able to say whether she will breathe on her own or not, or she was going*
13 *to make it, but she will be very severely disabled” (...). For me, none of the options were possible”.*
14 (P20)
15

16 Other testimonials illustrated the parents’ aptitude to manage the exceptional situation and
17
18 stay positive in front of their child during the hospitalization.
19
20

21 *“Nevertheless, we had the chance (...) to keep hope alive. When we went to see her (...) in*
22 *the intensive care unit, we talked to her, we sang songs to her. Even if we didn't know if she could*
23 *hear us, we kept in mind that we had to stay positive”.* (P11)
24
25

26 However, most of the respondent commented on the long-term severe psychological
27
28 consequences of the meningitis experience and sequelae. They described their global
29
30 psychological vulnerability, and for some of them, depressive symptoms requiring treatments.
31

32 *“I had nothing left to hold me. Everyone around me was happy, but I wasn't. I couldn't*
33 *explain it, nothing had taste (...). I wanted to kill myself... but at the same time I told myself that*
34 *those who remained would be too sad... so I didn't do it”.* (P12)
35
36

37
38 The description of depressive symptoms, including anhedonia and suicidal thoughts, were
39
40 at times mixed with the perception of relief and happiness, often leading to a feeling of isolation.
41
42

43 The time necessary to regain personal and family balance also emerged as a common issue.
44

45 *“After the first six months, I got the backlash. I tried to put up with everything, telling*
46 *myself that I was strong. My daughter was strong, so I had to be strong. At one point, (...) I fell*
47 *into a deep depression that lasted for two years. I was on medication, anxiolytics and*
48 *antidepressants to get me out of this hellish spiral. I saw everything in black and I told myself that*
49 *my daughter would never make it, that they would make fun of her and that life would be difficult*
50 *for her. I locked myself in a negative bubble. Now I'm a little better, but there are always times*
51 *when I think about the future, and I still have fears and anxieties about what might happen later*
52 *on”.* (P2)
53
54
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1
2
3 In these two testimonies, we can notice the lasting concern for their child, even when they
4 progress to adulthood. This concern is permeated with anxious anticipation concerning the
5 survivors' well-being.
6
7
8

9 10 *Parents coping with the illness*

11
12 Having to take care of a child who is often severely impaired is an ordeal for the parental
13 couple. However, most of the interviewees highlighted that, despite occasional tensions, they
14 managed to deal with this difficult situation.
15
16
17
18

19
20 *“Concerning my couple, we have always remained very close together. My husband is*
21 *always very, very present”* (P11).
22

23
24 Along with the family, in many cases the partner is identified as a valuable source of mutual
25 support in the moments of doubt. The family, as a whole, is described as an important source of
26 support.
27
28
29

30
31
32 *“Luckily, we have a big family that never gave up on us. They took turns coming to see us.*
33 *Every day, we had someone to support us”*. (P13)
34

35
36 The quality of the relationship and communication of the two parents resulted in new forms
37 of adjustment beyond the effects of the disease and brought new perspectives to family life.
38
39

40
41 *“We complement each other (...). We talked about it [the meningitis experience] afterwards*
42 *and we thought we'd done really well”*. (P20)
43

44 The notions of complementarity and open communication appeared to be critical in coping with
45 the disease and its multiple impacts.
46
47

48 49 *Impact of meningitis on the life course*

50
51
52 Caring for a child with a disability takes time, requires careful planning and often has a
53 serious financial impact for the family, as underlined by the interviewed parents.
54
55

56
57 *“I think it's all about her. For one thing, there are all her medical visits since she was four*
58 *months old. There are 3 to 4 appointments a week, on top of work, you have to run around and it's*
59 *still very heavy”*. (P20)
60

1
2
3 Most of the time the disease and its consequences involved changes in the professional
4 trajectories of the survivor's close family and in the whole family's way of life.
5
6

7
8 *"At the time she was ill, I had planned to return to work (...) But I never went back to work,*
9 *I didn't honour the contract. Then, for 6 years, I didn't work at all because (she) needed me, I was*
10 *all the time with her, going back and forth for medical appointments. It was very complicated".*
11 (P11)
12

13
14 These words showed that besides psychological impacts, caring for a child affected by
15 acute bacterial meningitis also has a financial cost, even in a country like France where social
16 assistance is present.
17
18

19
20 Finally, some participants underlined the positive impact of maintaining professional
21 activities not only for financial reasons, but also as a way to facilitate a social life beyond the world
22 of disability.
23
24

25
26 *"This job allows me to get out of everything related to disability, nappies, housework. It*
27 *makes me think of something else, and it makes me earn some money".* (P7)
28
29

30
31 Adjustments also concern material aspects such as the person's living and housing and the
32 practical organisation of the child's care. They are necessary to allow the family to find a new
33 form of everyday functioning.
34
35

36
37 *"The house is being rearranged to create a room on the ground floor. Until now, she had*
38 *been going upstairs, but we hope that when she has a room on the ground floor, it will be easier*
39 *to find someone to relieve us so that we can leave from time to time".* (P7)
40
41

42
43 *"If her behaviour is definitely related to meningitis, it is a real handicap for us in many*
44 *ways, we can't go anywhere, it is really difficult. We try to show her many things so that she can*
45 *continue to improve but taking her to a zoo or a park is a real challenge".* (P 20).
46

47
48 Thus, usual leisure activities for many children become extremely complex to organise: everyday
49 life is often marked by renouncement.
50
51

52
53 The interaction with the health services administration regarding about the coverage of the
54 family member's care is also a concern mentioned by family ascendants. They emphasized that the
55
56

1
2
3 complexity of the administrative procedures and the constant need to prove legitimacy to their
4
5 request constitute a considerable psychological burden in addition to the burden of caring for the
6
7 meningitis survivors.
8
9

10 *“I always say the biggest handicap is administration. (...) you have to keep fighting”* (P7).
11

12 The energy expended is considerable, and participants often use sports comparisons or
13
14 fighting metaphors to describe their daily life.
15
16

17
18 *“We always have to go running around, putting together files, emails... I think that is the
19
20 worst. (...) When we had a renewal [of the disabled adult allowance file], and they stripped us of
21
22 everything. We had to appeal. On top of that, they always take 6 months to respond... we spend
23
24 our time fighting”*. (P20)
25

26 **4. Sick child attitude / behaviour**

27

28 Several testimonials described the positive evolution of the children who have survived
29
30 meningitis and stressed in particular the progress they have made and the skills that they have
31
32 acquired, frequently reaching levels of results that go beyond what the healthcare professionals
33
34 considered possible.
35
36

37
38 *“When we see the MRIs, compared to the damage she has to her brain, the doctors don't
39
40 understand that she can do what she does (...). For them, in relation to her lesions, she should be
41
42 in a vegetative state, while she can eat by herself, she walks alone with her armchair, she sings,
43
44 she loves to sing, she loves to play, music, early learning games, etc.”*. (P13)
45

46 Some individuals also evoked the adaptability, flexibility, and courage of their loved ones.
47

48 *“I think she's happy, but she has her ups and downs (...). She tries, she finds ways to do it
49
50 (...). She has great strength of character and now she wants to do things even if it's hard for her”*.
51
52 (P11)

53 *“And in the end, she has made up for her developmental delay (...). She has caught up with
54
55 everything and even the attending doctor told me that she is amazing. She really is a great little
56
57 girl”* (P19).
58
59
60

1
2
3 Furthermore, many testimonies referred to the social abilities of the meningitis survivors
4 and their capacity to enjoy a satisfactory quality of life despite the limits imposed by the severe
5
6 handicaps they experience.
7
8

9
10 *"She's very sociable, so she's a bit of a mascot everywhere she goes. As she is very*
11 *charming, very attaching and very funny, she doesn't have too many problems adapting to a new*
12 *environment". (P5).*
13

14
15 The child's ability to forge links with her/his peers and her/his "zest for life" are very often
16
17 underlined.
18

19
20 Despite the disability and limitations brought on by the disease, the survivors' ability to
21
22 bounce back and adjust is stressed with admiration by the participants. However, the experience
23
24 of an event that suddenly and unexpectedly upsets the life of the whole family also required the
25
26 siblings' capacity for psychological adjustment.
27
28

29 30 31 **5. Siblings attitude / behaviour** 32 33

34
35 The experience of acute meningitis disease and its sequelae is a stressful experience for the
36
37 whole family, not only when a family member is admitted to Intensive Care Unit (ICU), but also
38
39 in the mid- and long term. Within this study, parents focused on the siblings of the sick child, as
40
41 they also experienced some form of impact or disruption as a result of their siblings' illness.
42
43

44
45 A common thread among the interviewees was the parents' perception of the attitude and
46
47 behaviour of siblings towards the meningitis survivors. Many participants could mention the
48
49 supportive way in which the siblings coped with the disease, and their positive role in the recovery
50
51 and life trajectories of their loved ones.
52
53

54
55 *"I am convinced that it is thanks to her twin sister who has been a great stimulant for her.*
56 *She has caught up with everything". (P19).*
57

58 Likewise:
59
60

1
2
3 *"I think his brother was really a driving force, even if it's not always obvious to him". (P5)*
4
5

6 Particular emphasis is also placed on the siblings' ability to understand, help and protect
7
8 their survivor sibling.
9

10
11 *"He tells us: "You don't understand that she wants that! We didn't understand fast enough,*
12 *according to him, and he was interpreting". (P5)*
13
14

15 The brother here adopts the function of intermediary or more precisely as an interpreter between
16
17 his sister and their parents, revealing a rare complicity.
18
19

20
21 *"He's a child who's very protective of his sister. He doesn't hesitate to go and see the other*
22 *children in the schoolyard if his sister is being teased". (P2)*
23
24

25 The role of "guardian" that we evoked when speaking of parents can sometimes be taken by a
26
27 brother or a sister of the sick child as well.
28
29

30 In addition, parents stressed that overall, the daily confrontation with disabilities enabled
31
32 the siblings to develop a sense of openness and tolerance of other people's differences.
33
34

35
36 *"My daughters have a lot of empathy, whether with their [disabled] sister or with other*
37 *children. It's true that they also have a different life. It is very enriching for them, because they*
38 *know the difference, they learn the values of life, which not all children will necessarily have...".*
39 *(P7)*
40

41 However, the testimonies of some other participants highlighted the psychological impact
42
43 on siblings of the specific disease-related environment and the responsibility that they assumed.
44
45 Possible mentioned causes include the fact that the disabled child monopolised the parents'
46
47 attention or that the place and role of everyone in the family may be affected.
48
49

50 *"Our second [daughter] is everyone's elder sister. She says it all the time: "By age, I am*
51 *her little sister, but in my head I am her big sister...". (P13)*
52
53

54
55 *"Finally, he has developed obesity (...). He was deeply shocked and traumatised by his*
56 *sister's amputation (...), he's aware that his sister is different from other children. He assigned*
57 *himself the role of the big brother, which is: "I'm here, I'll protect you, I'm here for you (...), he*
58 *took his role very seriously". (P2)*
59
60

1
2
3 The representation of this mother is clear: she sketched a linear causality between the amputation
4 of her daughter, following meningitis, and the obesity of her son, whom she considered
5 traumatised.
6
7
8
9

10 Despite the severity of the illness and the magnitude of its consequences for the survivors
11 and the whole family, the narratives stressed that in the long term, one of the key elements of
12 balance is the parents' ability to ensure a family life is "as normal as possible" for all siblings,
13 where everyone (re)discovers his or her place.
14
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21 **Narrative account and profiles of meaning-making**

22

23
24 The analysis of the above-mentioned themes allowed for the identification of the meaning-making
25 processes deployed by the participants and which are reflected in their remarks. These two
26 processes underpin the psychological adjustment to the meningitis and its consequences.
27
28
29
30

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

32

33
34 In order to have reference points on the development of their child, some of whom are
35 affected by serious sequelae, many parents compared the latter to other children in their family
36 circle. This comparison often turned out to be a source of great distress, by noting how much the
37 child is disabled and behind in their psychomotor development. For instance:
38
39
40
41
42
43

44 *"I have a lot of children in my family, and I could see that for her there were some things*
45 *that were wrong" (P5)*
46
47

48
49 *"Thereafter, she evolved very slowly compared to children of her age". (P11).*
50
51

52 In some cases, the comparison did not come from the parents themselves, but came from a stranger.
53
54

55 *"One day, our kid was 5 years old, she was in her stroller with a pacifier in her mouth, one*
56 *couldn't see that she was disabled, and there was an old man who approached us saying: "look at*
57 *my little grandson, he walks, he is not in a stroller and he does not have a pacifier, yet he is*
58 *younger! (P7).*
59
60

1
2 This mother highlighted the perceived violence born from this comparison imposed by a stranger
3 who knew nothing of her history.
4
5

6
7 Other parents insisted on the developmental similarities between their child, even when disabled,
8 and other children of the same age:
9
10

11
12
13 *“Otherwise, in terms of development, she is a child like any other (...). She makes a point*
14 *of doing the same activities as other children” (P2).*
15

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

17
18 *“[He] does everything like them (his siblings). He is a child who has his place among the*
19 *siblings, there is no problem” (P16).*
20

21
22 Some parents expressed pride in having managed to cope with such an extreme experience, as an
23 individual and as a couple.
24

25
26
27 *“It [the meningitis experience] gave me that attitude because I wasn't like that before. It gave*
28 *me a stronger temper to come with it. (...) It's ok to break down, you have to break down at*
29 *some point, but the next day I am back on top, and I'm back on my feet..”.. (P13)*
30

31
32 Another mother evoked the support she found in her relationship with her partner.
33

34
35 *“I see many couples (...) who split up because of their child's disability. However, we*
36 *supported each other, we didn't argue, there were no conflicts related to that. No, we did well”.*
37 *(P20)*
38

39
40 However, above, the parents' pride was centred on their sick child. We found in their speech a
41 highlighting of her/his exceptional character. As mentioned earlier, several participants expressed
42 a sense of satisfaction about their child's trajectory. Some insisted on the fact that they initiated
43 certain attitudes, instilling courage in their child.
44
45
46
47
48

49
50 *“She's a little girl who's doing very well, we've done everything we could. She likes to be*
51 *assisted, so we taught her that no, that wasn't life, she had to do it on her own”.* (P 19)
52
53

54
55 For some family ascendants, their loved one was in a way revealed in the disease, without
56 the family having anything to do with it. The “hero figure” then becomes the one that best describes
57
58
59
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1
2
3 their child. “Hero”, because the child is distinguished by her/his bravery, her/his exceptional
4
5 abilities. So, this mother told us about her daughter:

6
7 *“That's when I saw that my daughter was a fighter, because after waking up alone from*
8 *a coma, she saw me and said "mama", at 4 1/2 months. She spoke. She woke up from a coma,*
9 *looked me straight in the eye and said "mama".”(P2)*
10

11
12 Faced with an extreme experience - the mother insisted that her daughter was close to
13 death – the child’s exceptional character was revealed in her verbal precocity. Furthermore, it is
14 within the mother-daughter relationship that the extraordinary capacity of the child emerged.
15
16 These exceptional capacities mentioned by family ascendants can thus be physical, as in the
17 testimony mentioned above, or in the words of other parents:

18
19 *“She has a phenomenal strength in her arms that she has developed due to the absence*
20 *of her legs” (P13).*
21

22
23 A physical force, therefore, but also a psychological one:

24
25 *“(She) turns out to be a very combative little girl” (P5).*
26
27

28
29
30
31 It appears that this revelation of the heroic character of their child allowed parents who
32 perceived this extraordinary dimension, to find a positive meaning in this painful experience.

33
34 *“It is one of the most beautiful moments that I experienced in this terrible ordeal (...). At*
35 *the beginning, the doctors didn't believe us (about the fact that their daughter was able to speak)*
36 *and we rang them to show them. We even kept photos of those moments. For us, it was a magical*
37 *moment because we realized that our daughter really wanted to live” (P2).*
38
39

40
41
42 We find here the characteristics of extraordinary events, which even look like a miracle
43 for these parents: the fact that there are people who do not believe, who must therefore be
44 convinced; the need for proofs, the fight that was carried out, and the ultimate meaning of this
45 fight: the revelation of a will to live. This elaboration of the figure of the child as a hero thus made
46
47 it possible to give a positive meaning to this painful experience and further, it may confirm the
48 meaning and value of the child's life.
49

50
51
52 This mention about finding positive meaning through the distressful experience of meningitis leads
53
54 to a second meaning-making process: engaging action to improve the healthcare system.
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1
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3
4 2. Finding the “positive” of the traumatic experience and engaging action to improve the
5
6 healthcare system.
7
8

9 The discourse of the participants echoed a desire to take an active position in their relationship
10 with the disease, not only through the acquisition of personal knowledge about meningitis, but also
11 through the commitment to raise awareness of the disease in the general population. This
12
13 commitment can also concern awareness-raising work about people with disabilities. For instance,
14
15 this mother told us:
16
17
18
19

20
21 *“I raise awareness among children and young people on the concept of disability. I go to*
22 *schools or associations with a small booklet that I made, and I explain to children what disability*
23 *is, to remove taboo words and so that they put words on the little friends who are dyslexic, or in a*
24 *wheelchair, or mentally handicapped, etc.” (P7)*
25
26

27
28 Believing that in France, individuals are not familiar enough with difference - here linked to a
29 disability - this mother wanted to suggest to the youngest people to think about the inclusion of
30 their disabled peers, so that they can have a life as normal as possible.
31
32
33
34

35
36 This engagement process, which allows for them to feel active instead of enduring the vagaries
37 of life as a parent with a child with serious sequelae always starts from the intimate experience to
38 try to improve things for the greatest number. Thus:
39
40
41
42

43 *“We got a family house and we are in the process of renovating it to make a home to*
44 *accommodate disabled people on vacation in the Alps (...). It was our dream for us, so we are*
45 *doing it for others (P7)”.*
46
47

48 Having been confronted with major difficulties relating to the accessibility for disabled
49 people in many vacation homes, this family decided to take matters into their own hands and create
50 this dedicated and accessible place. The form of altruism that this commitment constitutes can also
51 be noted, which is why many, especially within the family, admire this commitment. Thus, the
52 grandmother of a child who suffered from meningitis testified to her admiration for her daughter,
53 the mother of this child.
54
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2
3 *“My daughter invests in everything, in everything, for her little son It’s extraordinary”*
4 (P16).
5
6
7

8 **DISCUSSION**

10
11 This study on the experiences of close family members of meningitis survivors highlighted
12 six themes, shared by most of the participants, and two meaning-making processes that appeared
13 through the analysis of the narratives. The qualitative findings stressed the parents’ understanding
14 about acute bacterial meningitis, their relationships with the care system and the healthcare
15 providers; and they also highlighted the ignorance about this disease at the time of medical
16 treatment, both their own and that of certain healthcare professionals. In contrast, they spoke of
17 the knowledge that they had been able to acquire through patient associations. Much of their
18 testimony dealt with the multidimensional repercussions of the disease on their sick child and for
19 the whole family. The attitude and behaviour of the child affected by meningitis were largely
20 described and often glorified. Finally, the reaction of the siblings was a matter of concern for many
21 interviewed parents.
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37 These qualitative results provide insight into the nature of the mid and long-term
38 repercussions of the disease at an individual and familial level; they also offer an understanding of
39 the distress induced by these impacts. Indeed, consistent with previous quantitative studies [12,
40 13], this research stressed the psychological burden associated with being the family of a child
41 affected by acute bacterial meningitis. This burden is imbued with traumatic elements
42 (confrontation with the possibility of the child's death, awareness of the possible sequelae), and is
43 experienced daily by families who have to face medical, economic, and societal challenges. The
44 present results also underline the expressed need for specific and professional support in this
45 population. The interviewed parents insisted on their requirement for psychological support, not
46 necessarily during the acute phase of the hospitalisation, when they were often stunned and
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1
2 preferred to be constantly at the bedside of the sick child, but rather at the hospital discharge and
3
4 in the long-term, when they understood more clearly what their life would be like after this disease.
5
6 A recent article showed that coping support interventions are effective for improving parents'
7
8 anxiety and stress symptom burden related to acute paediatric hospitalisations [23]. Structured
9
10 interventions could indeed be offered to parents of children affected by meningitis, during
11
12 hospitalisation and at discharge.
13
14
15

16
17 However, the parents interviewed in this study not only experienced distressful challenges
18
19 induced by the illness of their children but also, for some participants, trajectories of post-traumatic
20
21 growth. Tedeschi and Calhoun [1998] [24] defines "Post-Traumatic Growth" as any positive
22
23 personal changes that occur after experiencing a potentially traumatic event. The meaning-making
24
25 processes analysed in this study indicated such a trajectory. The parents' pride in their child and
26
27 the pride that some admit feeling about themselves because they are satisfied with the way they
28
29 take care of their child and their family, echoes this growth process. A mixture of vulnerability
30
31 and growth was underlined in a previous qualitative study, conducted among mothers whose
32
33 school-aged children were born extremely prematurely; just as several participants of our research,
34
35 these mothers celebrated their children's successes [25]. The celebration of the children's skills
36
37 and their ability to overcome their disabilities become for certain participants the depiction of a
38
39 hero trajectory; that may be related to the dimension of "Post-traumatic Growth" such as "new
40
41 possibilities" and "appreciation of life" [24].
42
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47
48 Furthermore, the involvement of some parents in patient associations, even their
49
50 participation in this study, may indicate the experience of "new possibilities" and "enhanced
51
52 relationships". Highlighting this growth in some individuals should not lead to an "injunction to
53
54 resilience" but to the observation that the close family members of meningitis survivors can adjust
55
56 to this difficult experience and find meaning in it.
57
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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

1
2 disease, in particular with regard to the basic education of the public in general and the diagnostic
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4 competences of primary care providers in particular.
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7 8 **Clinical implications** 9

10 The findings in this study highlighted several dimensions that could be of clinical
11
12 relevance, such as:

- 13
14 - The value of the intervention of experts in the field of infectious diseases in the Continuing
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16 Professional Development of physicians, which would improve not only their familiarity with
17
18 meningitis and its treatment, but also their capacity to interact with carers in the most
19
20 appropriate and efficient way [18].
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- 23
24 - The mis-match between family members and healthcare professionals during the onset and
25
26 course of the meningitis, as well as its management in health care facilities that should be given
27
28 attention. A promising avenue for improvement, both from a research perspective and from a
29
30 clinical standpoint, is the integration of expert patients into care procedures and into the training
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32 curriculum of healthcare professionals.
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- 35
36 - The disease-related environment, and more specifically, the experience of accompanying a
37
38 child receiving intensive care and the related risk of death are stressful, and may potentially
39
40 result in some disruption or trauma for the whole family. Being regularly informed of the care
41
42 provided to their child, taking an active part in it, and receiving attention by healthcare
43
44 professional, are mentioned as mitigating factors to help alleviate stress and anxiety. Several
45
46 authors have emphasized the positive impact of family open visitation and parental presence
47
48 for the care of their child, especially in emergency care settings and intensive care units[26, 27,
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50 28]; impacts include relieved anxiety and fear, as well as reduced psychological distress and
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52 post-intensive disorders, for both the family members and survivors [29, 30]. While this open
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54 visitation is more and more widespread in France, sometimes this is not made possible, due to a lack of
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56 human resources (professional to support families) and of available premises. One specific aspect
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1
2 related to the family presence during ICU procedures is the siblings' visits. As in other contexts
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4 of severe diseases, sibling visitation is being increasingly endorsed as a positive development
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6 in patient care. This is relevant especially because it facilitates elaboration of the siblings' own
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8 perception of the situation and prepares post-discharge life, reduces fantasies, increases
9
10 understanding and the sense of control over the situation, increases bond enhancement and
11
12 improves communication between families and care providers [27, 31, 32]. Thus, the
13
14 implementation of experimental initiatives in the context of bacterial meningitis intensive care
15
16 seems desirable. Collaboration between different healthcare providers (clinicians, nurses,
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18 psychologists) and parents in order to create the appropriate visitor conditions and organisation
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20 of staff is strongly supported by the literature [29, 33, 34]. Given the paucity of research on this
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22 issue, further studies on the psychological impact and implications of the siblings' presence in
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24 ICUs could offer some insights on how they cope with this adverse event at the time of care
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26 and in the longer term. In this perspective, exploring the siblings' experience of the disease
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28 would provide a better understanding of the meaning-making process and could help identify
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30 potential pitfalls where there is a need for sustainable psychological assistance.
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- 36
37 - The need for continuing efforts to consider and monitor the emotional burden of the disease on
38
39 the child's family ascendants, the psychological adjustment process and families' trajectories
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41 over time. In this regard, it would be valuable if family ascendants of acute meningitis survivors
42
43 could benefit from systematic, and when necessary, professional consultations during and after
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45 their experience of the disease. The more appropriate forms and timing of this support,
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47 prognostic factors and outcome merit further investigation.
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52 53 **Conclusions**

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56 This study helped to capture the subjective experience and psychological adjustments of
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58 parents confronted with paediatric meningococcal meningitis. Two main meaning-making
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2
3 processes in relation to the participants' experiences of this adverse context emerged from their
4
5 discourse. These processes emphasized the importance of information and support of families, the
6
7 potentially traumatic impact of the illness experience, and the possibility of post-traumatic growth
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9 for some individuals, including the desires of parents to engage in improving the care system.
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11 Providing family ascendants with accurate information about their child's conditions and
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13 treatments, as well as involving them in the care and medical decision-making could positively
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15 influence and develop the quality of care provided by healthcare professionals.
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19 In the meantime, clinicians, caregivers, and other stakeholders of the healthcare system should be
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21 aware that information and the involvement of the family as an active partner in the care process
22
23 are conditions for its effectiveness, from the onset of disease symptoms, their management in the
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25 emergency rooms and throughout the recovery journey.
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42
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44
45 paediatrician; Myriam Winance, sociologist).
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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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For peer review only

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 SRQR reporting 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.

		Page
	Reporting Item	Number
Title	<p>#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</p>	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

Introduction

[#3](#) Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement

[#4](#) Purpose of the study and specific objectives or question

Methods

[#5](#) Qualitative approach and research paradigm

Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, 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.

As appropriate the rationale for several items might be discussed together.

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45	Data collection methods	#10	7
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1	Data collection	#11	Description of instruments (e.g. interview guides,	8
2			questionnaires) and devices (e.g. audio recorders)	
3	instruments and		used for data collection; if / how the instruments(s)	
4			changed over the course of the study	
5	technologies			
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11	Units of study	#12	Number and relevant characteristics of participants,	7
12			documents, or events included in the study; level of	
13			participation (could be reported in results)	
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19	Data processing	#13	Methods for processing data prior to and during	8
20			analysis, including transcription, data entry, data	
21			management and security, verification of data integrity,	
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23			excerpts	
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31	Data analysis	#14	Process by which inferences, themes, etc. were	8
32			identified and developed, including the researchers	
33			involved in data analysis; usually references a specific	
34			paradigm or approach; rationale	
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41	Techniques to enhance	#15	Techniques to enhance trustworthiness and credibility	8 & 9
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43			triangulation); rationale	
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48	Results/findings			
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51	Syntheses and	#16	Main findings (e.g. interpretations, inferences, and	10 & 11
52	interpretation		themes); might include development of a theory or	
53			model, or integration with prior research or theory	
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1	Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts,	11 &
2			photographs) to substantiate analytic findings	more
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6	Discussion			
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10	Intergration with prior	#18	Short summary of main findings; explanation of how	28
11	work, implications,		findings and conclusions connect to, support, elaborate	
12			on, or challenge conclusions of earlier scholarship;	
13	transferability and		discussion of scope of application / generalizability;	
14			identification of unique contributions(s) to scholarship	
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24	Limitations	#19	Trustworthiness and limitations of findings	30
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30	Conflicts of interest	#20	Potential sources of influence of perceived influence on	34
31			study conduct and conclusions; how these were	
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38	Funding	#21	Sources of funding and other support; role of funders in	34
39			data collection, interpretation and reporting	
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 44 American Medical Colleges. This checklist was completed on 21. January 2020 using
 45 <https://www.goodreports.org/>, a tool made by the [EQUATOR Network](#) in collaboration with
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