

BMJ Open Subjective experience of meningitis survivors: a transversal qualitative study using interpretative phenomenological analysis

Elisabetta Scanferla ^{1,2,3} Léonor Fasse,^{4,5} Philip Gorwood^{1,6}

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¹Clinique des maladies mentales et de l'encéphale (CMME), GHU Paris Psychiatrie et neurosciences, Hôpital Sainte-Anne, 1, rue Cabanis, Paris, France

²Université de Paris, ED 450, Paris, Île-de-France, France

³Université Paris Nanterre, EA 4403, CLIPSYD, Paris, France

⁴Université de Paris, LPPS, EA 4057, Paris, Île-de-France, France

⁵Département de Soins de Support, Gustave Roussy Institute, Villejuif, Île-de-France, France

⁶Université de Paris, Institut de Psychiatrie et Neurosciences de Paris (IPNP), INSERM, UMR 1266, Paris, France

Correspondence to

Mrs Elisabetta Scanferla; e.scanferla@ghu-paris.fr

ABSTRACT

Objectives (1) To capture the subjective experience of meningitis survivors during adolescence and adulthood and (2) To explore how they give meaning to this specific experience.

Design A qualitative study of in-depth interviews using interpretative phenomenological analysis.

Settings Participants recruited through an association of persons affected by meningitis and their relatives.

Participants Convenience sample of nine participants (seven women and two men) between the ages of 18 to 48 years (mean=28.3, SD=11.4), who personally experienced meningitis.

Results Eight major themes and three main meaning-making processes in relation to the participants' experiences of meningitis were identified: (1) the ability to rely on the testimony of others, (2) the impossibility of meaning-making and (3) the possibility of post-traumatic growth. We detailed here five major themes, which appear critical to answering the objective of the study.

Conclusions This study provides a unique insight into the first-hand experience of surviving meningitis. Findings highlighted factors characterising the disease experience, the psychological adjustment of meningitis survivors and their meaning-making processes. These findings are important for both research and clinical practice, demonstrating the importance of direct involvement of meningitis survivors in identifying key aspects of care, which include the critical role of relatives, and the importance of investigating the need for training among healthcare providers on how to diagnose meningitis.

INTRODUCTION

Meningitis is an infection of the envelopes surrounding the brain, the meninges, caused by several types of viruses, bacteria and fungi. Meningococcus (another name for the bacterium *Neisseria meningitidis*) is the major cause of acute bacterial meningitis. Over 1.2 million cases of bacterial meningitis are estimated to occur worldwide each year. The incidence and case-fatality rates for bacterial meningitis vary by region, country, pathogen and age group. Although infants are at increased risk of bacterial meningitis compared with older

Strengths and limitations of this study

- An empirical qualitative method (interpretative phenomenological analysis) was used to explore the first-hand experience of meningitis survivors.
- One of the first studies undertaken to explore the subjective experience of acute bacterial meningitis.
- The study results may be affected by the recruitment of participants through a patient association's website and by the retrospective study design (ie, reconstruction bias) due to the time period between the meningitis disease and participation in the study.
- Absence of a longitudinal design does not allow capturing of variations in the psychological adjustment of the study participants.

individuals, people of any age can develop bacterial meningitis. If left untreated, bacterial meningitis is fatal in up to 70% of cases.¹

Acute bacterial meningitis manifests as a combination of an infectious syndrome (eg, fever, severe headache, vomiting) and a meningeal syndrome (eg, neck stiffness, lethargy, disorders of consciousness up to a coma). Since these symptoms are not always specific, a timely diagnosis of meningitis is sometimes difficult to make. Even when the disease is diagnosed early and adequate treatment is started, 5% to 10% of patients die, typically within 24 to 48 hours after symptom onset. Additionally, bacterial meningitis causes brain damage, hearing loss or a learning disability in 10% to 20% of survivors.²

Although major physical sequelae of childhood meningitis have been studied extensively, this is not the case for the psychological adjustment of meningitis occurring during adolescence or young adulthood. By adjustment, we mean all the reactions deployed by an individual to face an event (ie, the experience of meningococcal disease), whether intentional or not. These responses may be normal or pathological (eg, reflecting

a dysfunction in a person's daily life),³ and may involve cognitive, emotional or behavioural domains. The way that adult survivors adjust and cope with this stressful event is barely explored.

A recent Delphi study⁴ was dedicated to the exploration and consensus about the burden of disease caused by serogroup B invasive meningococcal disease. The focus of this study, conducted by healthcare professionals, was on the characteristics of the sequelae and their multi-dimensional nature. The authors emphasised that the existing body of knowledge, which remains relatively poor regarding this topic, mainly relies on quality of life (QoL) aspects among survivors. While QoL is an overarching term that refers to the subjective appreciation of oneself regarding various aspects of one's life (eg, mental and physical health, spirituality, material and social well-being), this Delphi study indicated that the existing literature is dedicated to health-related QoL, that encompasses those aspects of overall quality of life that can be clearly shown to affect health, either physical or mental. We found that three studies were dedicated to reflections about, or description of, QoL in meningitis survivors during childhood.⁴⁻⁶ These studies concluded that meningitis survivors who experienced this disease during childhood presented poorer QoL when compared with non-affected individuals. Some of these studies⁴ stressed that QoL measures were not sufficiently rigorous to capture the complexity of the impact of this disease with highly heterogeneous QoL measurements, whether self-evaluations⁴⁻⁶ or hetero-evaluations.⁴

In addition, the vast majority of studies on the psychological adaptation of meningitis survivors are quantitative, assessing neurocognitive sequelae (eg, impact on IQ, memory/attention disorders) in patients who experienced bacterial meningitis during childhood or in infancy.⁷⁻⁹ Interestingly, Schmand *et al*¹⁰ investigated cognitive functioning and QoL in adult survivors 9 years after bacterial meningitis compared with control individuals, and showed that although all patients (n=28) had recovered by the time that they were discharged, some patients still showed cognitive slowness and low QoL 1 year after meningitis. However, at follow-up, cognitive functioning and QoL of patients and controls were similar.

In the scientific literature, a prevailing focus exists on both QoL and neurocognitive outcomes in childhood meningitis survivors. To our knowledge, only two quantitative studies have investigated psychological adjustment in meningitis survivors, beyond QoL. Khandaker *et al*¹¹ highlighted that exposure to meningitis in early life (0 to 18 months) was associated with neurocognitive, educational and psychological difficulties (eg, anxiety, depression and psychotic symptoms) during childhood and in early adolescence among apparently healthy survivors. Garralda *et al*¹² conducted a longitudinal study in children and parents after meningococcal disease. They demonstrated that admission to hospital with meningococcal disease was followed by an increase in psychological

symptoms (eg, emotional, conduct and hyperactivity symptoms), some being persistent and impairing, and by symptoms of post-traumatic stress, in a significant proportion of both children and parents. Besides these two quantitative studies, a qualitative study has also investigated psychological adjustments of young meningitis survivors. Wallace, Harcourt and Rumsey¹³ explored the impact of meningococcal septicaemia (which can result in severe scarring, amputation of digits and/or limbs and skin grafting) during adolescence, with an emphasis on adjustment to a permanently altered appearance following a life-threatening disease episode.

The above studies often relied on proxy questionnaires (ie, assessment of the children's symptoms through parent and/or teacher questionnaires^{11 12}). It is thus clear that the psychological adjustment of meningitis survivors during adolescence or adulthood remains barely studied. To our knowledge, no empirical study has investigated the subjective experience of meningitis in adults in terms of emotional reactions, feelings, memories and meaning-making processes in the mid-term and/or long-term. At a time when the focus is on the severity of sequelae, and on the cost they may imply (eg, disability, impact on working abilities, comorbidities, financial cost), information concerning the subjective experience of the patients may guide clinicians to consider personalised interventions. Besides sequelae, symptoms and survival rates, what do survivors precisely experience? Even if some exposed subjects do not have visible sequelae, they may experience emotional repercussions in the mid-term and long-term on their daily life, relationships with others or professional career. Additionally, the public, as well as general practitioners, need more information about the psychological sequelae of this disease. The objective of the present study is to capture the subjective experience of meningitis survivors during adulthood, offering a non-pathological perspective on psychological adjustment (ie, not only in terms of symptoms, debilitating condition or dysfunction) and giving an important insight on how these individuals experience this episode.

METHOD

Participants and recruitment

This study of adult patients with 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 relatives. A total of 20 participants, including nine individuals who personally experienced meningitis, were recruited through a patient association (*Association Petit Ange - Ensemble contre la meningitis*), thanks to a call for testimonies posted on the association's website. The participants were not necessarily members of the association. The inclusion criteria for the present study were: (1) Age ≥ 18 years at the time of the study; (2) A diagnosis of acute bacterial meningitis during childhood, adolescence or adulthood; (3) At least 6 months between the onset of

illness and the interview; and (4) Informed consent to participate to this study.

The exclusion criteria were: (1) Diagnosis of a psychiatric disorder that alters the perception of reality, as assessed by the researchers; (2) Severe cognitive impairment that hinders the participation to the study, as determined by the researchers; and (3) Not sufficient fluency in French to participate in the research interviews.

The recruitment was voluntary, and all participants expressed their non-opposition to participation in research, according to the French ethical board's recommendations for qualitative non-interventional research. The collection of information on ethnic origin and religious affiliation is not allowed according to the French legislation,¹⁴ so these aspects were therefore not assessed. This qualitative study, which uses the responses to a survey carried out by telephone from individuals who recovered from the illness more than 6 months ago, does not correspond to any of the three categories of study falling within the scope of research involving human subjects, according to Article L1121-1 of the French Public Health Code and therefore no ethical approval is required.

Procedure

Semi-structured interviews were conducted by telephone, as some study participants lived far from the investigation centre. 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 and physical state of the participant, as well as questions relating to the potential impact of the meningitis infection, as perceived by the participants. The interviews were conducted in October 2018 by four researchers familiar with qualitative interview methods and trained in qualitative approaches. The mean interview length was 60 min.

Analysis

Interviews were audio-recorded and fully transcribed; interpretative phenomenological analysis (IPA) was chosen to explore their content. This analysis method has been developed to understand the complex system of meanings attached to a unique, subjective and eminently intimate phenomenon.¹⁵ The experience of serious acute illness is made up of memories, impressions, sensations and fragments of speech from other people, and IPA gives access to the subjective construction that each participant was or was not able to make, which fits well with the advantages of the IPA method.¹⁵ IPA relies on a double hermeneutic wherein the researcher attempts to make sense of the way that the participant makes sense of his/her own subjective experience.^{15 16} In that sense, the researcher's reflexivity is reflected by this attempt, but also by the choice of the five major themes selected for this article and by the links that are proposed with other concepts or clinical fields familiar to the authors. Furthermore, with IPA, the researcher adheres closely to the participant's discourse and uses knowledge from the

literature to propose an in-depth analysis. The aim of IPA is not to develop general rules but to remain attentive to the subtleties of the experience, in all its complexity.

A standardised procedure ensured methodological rigour.¹⁵ First, every interview was read and the first author (ES) coded the main themes. Discourse themes (sufficiently characteristic topics, implying that the researcher could see a common function sense in them) were identified. The connections between the themes were then studied and the major themes were identified by ES; these themes are presented in the results section. Lastly, an interpretative account was produced that highlighted and analysed the experience through experiential themes and a meaning-making process, by illustrating the discourse. 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. Following the example of other IPA studies,¹⁷ the second author (LF) audited the documentation for the first five interviews as a validity check on the analytical process. This involved her repeating part of the analytical process described above, reading through the five interviews to identify themes, and checking whether her themes corresponded with those of the first author. In line with IPA methodology, the aim here was not to seek inter-rater reliability; rather, the intention was to provide an independent audit (as supervisor) at this stage of the analytical process to ensure that the interpretative account produced was credible, legitimised by a systematic and transparent analytical procedure.¹⁵ Throughout this study, we took great care to meet the scientific rigour criteria established by qualitative analysis.^{18 19}

RESULTS

Nine meningitis survivors were recruited, including seven women and two men. They were between 18 to 48 years old (mean =28.3, SD=11.4), and between 15 and 41 years old at the time of the meningitis diagnosis ($M=19.4$, $SD=10.9$). Four participants had acute bacterial meningitis as children. In average, 8.9 years had passed between the onset of illness and the interview ($SD=8.2$). We chose to include participants from various age groups both at the time of the interview and at the time of the onset of the illness in order to maximise the heterogeneity of the sample, as recommended by Smith *et al.*¹⁵

Concerning the bacterial agent causing the disease, five participants reported meningococcal and one reported pneumococcal disease; for three participants, the causative bacteria was not identified, although a meningitis diagnosis had been made by healthcare providers.

Eight major themes emerged, described as major ones, as shared by all the participants:

Table 1

Major themes	Subthemes
Meningitis disease (non-spontaneous theme)	Symptoms (fever, nausea/vomiting, neck pain, fatigue, lack of appetite, joint pain, overall pain, marbled skin, hypersensitivity to light, to touch...) Suffering (nature, intensity) Loss of body control Alternative diagnoses (influenza, gastroenteritis) Description of the disease (technical words, prevalence) Imputed causes (lack of luck, genetics)
Repercussions of the meningitis experience	Physical sequelae (partial paralysis, functional disability) Psychological impact (phobia, identity rearrangements, reshaping relationships with others, trauma, feelings of difference compared with others, insecurity, risky behaviour) Impact of meningitis on the life course (change of life trajectories)
Memory, memories	Vivid memories Blur of memories and inability to remember Memories of relatives
Knowledge/ignorance	About the disease (scientific background, technical vocabulary). Need for the patients to have the disease explained. Unpreparedness, lack of knowledge of health professionals/expertise Helplessness of familial caregivers (incomprehension of symptoms and/or lack of good reflexes; being overwhelmed by an exceptional situation)
Temporality	Sequencing (before/after, duration, length, urgency, very precise dates) Modification of the relation to time
Emotions	Intensity of emotions and emotionality Oscillation between negative and positive emotions Perception of other people's emotions
Relationships	Privileged conversation partners A complex link to others: between isolation and support
Healthcare and professionals	A rich and detailed description of the professional caregivers and services Experience of care routine Relationship and communication with healthcare providers

1. Meningitis disease (non-spontaneous theme).
2. Repercussions of the meningitis experience.
3. Memory, memories.
4. Knowledge/ignorance.
5. Temporality.
6. Emotions.
7. Relationships.
8. Healthcare and professionals.

Further analysis also revealed several subthemes included in these major themes (table 1).

Due to editorial restrictions by the journal, 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 (ie, the subjective experience of patients who experienced meningitis); and they were all spontaneously mentioned by the participants and do not correspond to the pre-established questions.

The original French extracts were translated into English, and all participant names were changed to pseudonyms. 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.

Repercussions of the meningitis experience

This first theme includes three subthemes: (1) physical sequelae; (2) psychological impact; and (3) impact of meningitis on one's life course.

Physical sequelae

Having experienced meningitis caused significant physical sequelae in most participants (eg, partial paralysis, heart problems, hearing and visual impairments, cognitive and mental functioning) and more globally, poor health. This disability interferes with functioning in social and personal realms and causes daily distress. Susanne's discourse (31 years old) illustrated this point:

I still have problems with my eyes; I have also lost hearing in my right ear (...) and it is true that since then, I have very, very fragile health.

Physical problems required many participants to engage in long periods of rehabilitation that are emotionally difficult to live through.

Juliette (23 years old):

After the period at the rehabilitation centre, I remained on morphine for more than a year because

I had constant headaches that did not pass (...) I stayed home for a year doing nothing, trying to figure out what I could do to compensate for a cardiac problem, while everyone was at work or at school. As a result, there was no social interaction; you are alone with yourself, thinking...It's awful.

Some testimonies focussed on cognitive impairments and a sense of permanent loss of prior abilities.

Marc (48 years old):

There are times at the end of the day when I can't move forward because my brain has been damaged. There are several images that my neurologist used to explain to me about how I work. He told me that my brain was a bit like a GPS: "When you ask it to go in a certain direction, to a place, it will go there, and if you change the route, it will recalculate [the route]. But your brain doesn't recalculate anymore".

Psychological impact

Most of the interviews revealed the psychological impact of meningitis and for most, an overall psychological fragility after experiencing the disease. Among the main impacts reported are phobia, insecurity, risky behaviours, social isolation, feelings of difference compared with others and feelings of not being understood.

Juliette (23 years old) described a phobia of certain medical procedures and the hospital environment as a consequence of her traumatic experience of hospitalisation and meningitis care.

I'm (...) afraid of blood tests now. I hate it (...) it's true that when I find myself in a hospital room, it makes me think about it again (...), blood tests, I have a real problem with them. I pass out every time (...). When I had my last surgery, that was the hardest thing (...) to inject me, it took an hour to get the catheter in (...). The image of my blue arms where they were trying to stick it in has stayed with me... It was horrible! It's been 5 years and I think it'll be a long time before I forget.

Marc (48 years old) stressed the difficulty of adjusting in his relationships with others and a sense of difference:

Everyone around me, both my colleagues and my wife, think that I'm a normal person... but no, I'm no longer a normal person, I can't do it anymore. People can't understand that. (...) it's not physical fatigue, it's mental fatigue.

Some other participants emphasised the traumatic nature of the experience on their life.

Louise (26 years old):

The problem is that this disease has put me down. There is no longer a dynamic person there, there is no one! (...) I'm still so stunned by what's happening around me! (...) I don't really know what I'm doing

right now. I don't know where I'm going; I don't know what to do.

Others insisted on the long-term severe consequences of meningitis:

Juliette (23 years old):

I lost a year because of this meningitis (...). Now I can't stand doing nothing for a day, it completely traumatised me. The year after meningitis was almost worse than the meningitis itself.

Furthermore, many testimonies referred to identity adjustments, as Sheila (43 years) explained:

I think that when you've been through this, you have to think differently.

Impact of meningitis on one's life course

A common thread among the interviews was the need to give meaning to the lived experience. Several elements emerged, such as a sense of pride in having managed to go through such an extreme experience, as well as a sense of post-traumatic growth. Mary gave an insightful example of this:

Overall, I think that having had this disease and these health difficulties gives me a very strong character. (...) I had something serious, and I did pretty well, so now I put things into perspective more easily.

The testimonies of some other participants highlighted the impact of meningitis on their life course, sometimes with radical changes in life trajectories.

Louise (26 years old):

If I hadn't had this meningitis, I would have become a restaurant manager (...), the culmination of all the skills I have been developing since I was 18 years old. Everything was going great, I was going to settle down, and it was the first time in my life that everything was going well. The meningitis ruined everything...

In general, the experience of the disease affected the majority of participants physically and/or psychologically to different degrees, and represented a turning point in their life trajectory: negative for some people and positive for others who were able to take a long-term perspective.

Memory, memories

This category includes three subthemes: (1) vivid memories; (2) blur of memories and an inability to remember; and (3) memories of relatives. All participants mentioned a kind of 'memory trajectory', that is a thread of memories whose content is linked to the meningitis disease. This trajectory was not linear and contained vivid memories of first symptoms while blackouts often characterised the experience of participants when their health deteriorated.

Vivid memories

Most participants remembered well the prodromal symptoms of the disease. Their descriptions were very bright

and intense, with meticulous accounts of their sensations and/or thoughts. For instance, Juliette (23 years) reported:

It was in August 2013, just after my high school diploma (...). It happened at the end of August and I had to go to a preparatory school at that time. I was reading my books in preparation (...). I was in the sun, it was fine, and suddenly, in the middle of my reading, my fingers began to tense on the book ...

Beyond the description of symptoms, participants remembered what they were doing, the general context, the weather and people around them at this specific time. Thus, almost 30 years ago, Sheila, 43 years, was able to recall her symptoms, the context of their occurrence (schooling ...) and even the interactions she had with her doctor.

At that time, I was in ninth grade (...), it was a Saturday (...), I remember that I had some vomiting before the doctor arrived. Then he arrived, he examined me. I was in pain, but it was not too uncomfortable, but when he took my blood pressure, it hurt very badly when the cuff was wrapped around my arm. The doctor said to me: "But you're a little cry-baby ...!". I told him, "No, I'm not a cry-baby, but you are hurting me a lot!"

This description could obviously be fuelled by a reconstruction phenomenon but what must be noticed is that for the participants, the sensations, the interactions, the context, were remarkably close and accessible in their memories.

Their picture of this experience related to an alternation of vivid elements and blackouts.

Blurry memories and inability to remember

If most participants clearly remembered the onset of their meningitis disease, some of them report, from the beginning, a loss of memory. Marc's, 18 years, discourse perfectly illustrated this point:

I do not remember anything. I lost my memory from the 25th of December to the 15th of January. And on January 15th, I woke up in the neurological intensive care unit (...). Many people (...) told me that I was lucky. But I do not know, I did not do anything. Basically, I fell asleep on the evening of the 25th and woke up on the 15th of January. What happened between the two dates I do not know.

Many people described a fluctuating memory, where after an initial period of precise elements related to their experience of illness, things were a lot blurrier. For example, Susanne, 31 years, recalls:

From there, I have blackouts, so I do not remember, except that I did not stand up and I drank a lot. (...) I was in a half sleep when I was in the emergency room and it's like I saw myself dying. I did not recognise

myself; I was sweating profusely and it seems that I even mentioned death. I thought it was my time.

From the testimonial of Suzanne, we can derive that she remained conscious and perceived some blurry feelings and thoughts, but had no control on them.

Moreover, for some people, these blackouts were inseparable from memory difficulties during the recovery phase from the disease. Thus, they perceived continuity between the episode of meningitis, marked by many fuzzy areas, and the current context, also marked by some vagueness, but more punctual. Florence, 32 years, explains:

I must admit that I remember things roughly, but in the aftermath of meningitis, I have memory problems. (...) I often forget things, which never used to happen to me before meningitis (...). I have forgotten some memories since then, or some details.

The vague nature of the memories does not seem to be related to the traumatic dimension of the disease experience. This dimension may exist in some participants, as mentioned earlier. But what arises here does not seem to correspond to a traumatic amnesia: the people were in a very serious medical condition, sometimes placed in induced coma in a reanimation unit, and the blackouts seem to have an organic cause rather than a psychological one. The laconism of the participants and their difficulties in precisely recalling this period does not appear as a defensive process, or as a non-processing of the information in their memory due to a disruptive event, as happens in traumatic amnesia.

Due to these memory difficulties, the continuity of existence was undermined. Hugo, 18 years, thus described:

When I woke up, I was asked: "Do you know where you are and what happened to you?". In fact, no, I was totally lost.

What could fill these gaps in memory, which threatened the sense of continuity for these people? This was where the patients' relatives played a major role.

Memories of relatives

The discourse of close relatives, especially family members, who were present during the diagnostic period and the hospitalisation, filled those holes and put words and pictures on what totally escaped the patients.

Lucie (19 years old):

I was apparently conscious, but I cannot remember anything until I woke up in the hospital. The rest is what my mother told me.

The words of family members gave meaning to this brutal experience, as well as the speech of the medical professionals. Marc, 48 years, integrated the gravity of his condition through the words of his doctor:

And even my neurologist told me that I had been incredibly lucky.

This 'luck' was accepted by Marc as a meaning making process that speaks about the seriousness of the disease and its potential lethal risk. Moreover, some metaphors, used by one of his doctors, allowed him to give meaning to his current difficulties:

As my neurologist told me: "There is a truck that has passed through your brain, and lots of pieces have broken."

The memories of relatives could also be used to restore some impulse after this very adverse event. Lucie, 19 years, thus reported that she focussed, with the help of her family, on positive memories that were transmitted to her by her relatives:

We can talk about it (the meningitis) but we talk about it in a funny way. We will try to remember the moments when we could laugh and relax (...). My parents took pictures (...) of me in a wheelchair, pictures of me leaving the hospital for the first time, when I was able to get out of my room.

Knowledge/ignorance

This theme includes three subthemes: (1) knowledge about the disease; (2) unpreparedness, lack of knowledge of health professionals; and (3) helplessness of familial caregivers.

Several participants stressed the importance of knowledge about meningitis: either regarding their need to learn about the disease and to take an active approach to it, or for many, to highlight the lack of knowledge of caregivers, the complexity of their care and the emotional impact on many relatives.

Knowledge about the disease

The question of knowledge about the disease is a key theme in most of the narratives. The interviewees reflected the need to develop knowledge about the disease, often totally unknown or partially unknown before experiencing it. Susanna, 31 years, insisted on this need:

I'd like to know how I got infected, or what I did to catch it.

Meeting this need involved the acquisition of a scientific background, and the ability to express it with technical vocabulary. Therefore, many of the participants wanted to acquire some form of expertise on the disease. For example, Sheila, 43 years, explained:

When you are in the middle of it, you look at everything (...). Then you see the other cases. You are told that it is rare (...) In addition, I had my son's medical file and my general practitioner got my (...) medical file. As a result, I was able to read what had happened to me because I had never seen that medical file.

Several participants expressed their desire to take an active position in their relationship with the disease, not only through the acquisition of knowledge about

meningitis, but also through the commitment to raise awareness of the disease. Hugo, 18 years, expressed his desire to act as an advocate:

(The disease) is a period that will always remain with me, it was a real stage time in my life, and that's why I want to talk about it through this organisation.

We may assume that taking an active position allowed participants to be in a position diametrically opposite to the passive position in which they found themselves during the meningitis experience while receiving care.

Unpreparedness, lack of knowledge of health professionals

In many cases, participants received alternative diagnoses (subtheme included in theme 'Meningitis disease', table 1), which indicates a lack of knowledge of the disease, accurate understanding of symptoms and/or a lack of good reflexes on the part of healthcare professionals. Indeed, in some cases they seemed overwhelmed by an exceptional situation. Several participants mentioned this point.

Juliette (23 years old):

It lasted 7 to 8 hours and when they (the healthcare providers) got to my room, there was panic on board ... it's not normal. They could have considered my symptoms. Neck pain, intolerance to light and sound, vomiting and fever, they could have done at least one lumbar puncture to remove the doubt.

Helplessness of familial caregivers

The experience of a lack of responsiveness on the part of healthcare professionals caused frustration and a sense of helplessness, particularly with participants' relatives. Juliette's words perfectly described the feeling of helplessness of the patient and her family, as well as the intensity of her mother's feelings of frustration:

Basically, it was "you can go away, I'm not interested!" [referring to the doctors' attitude]. My mother went crazy (...).

Temporality

This was a recurrent theme for most people interviewed, and included very detailed descriptions of the disease and its different stages: its first manifestations, the initial management of symptoms, hospital care, the critical phase, the attenuation of symptoms, discharge from hospital, and recovery time. References to the temporal dimension were ever-present and structured the narrative. More specifically, the stories presented a multitude of time markers. The repetition of logical connectors in sentences, multiplication of precise temporal landmarks (eg, before/after, first/then), events mainly reported in the past tense and detailing of the precise sequence of events (multiplication of references to very precise dates and times, and to duration and length).

Hugo, 18 years old, thus described the different stages of his experience of the disease in three sentences containing five precise dates and the mention of two durations in time expressed by just as precise figures. These sentences also contained two additional figures used to express the age of the interviewee before the illness and 2 weeks after discharge from hospital in relation to the celebration of his birthday. These dates and exact figures gave pace and structure to the narrative:

I was 17 years old. I was in a coma on the 31st of [January] and I woke up on February 7th. (...). I do a lot of running, and suddenly, it helped me to get back on my feet in 7 days. (...). So, they took me out on the 13th of February. It was partly at the request of my parents because I had to celebrate my 18th birthday on the 15th of February, 2 days later.

The same tendency to multiply time markers (13 time markers in 5 sentences) and an accurate description of the facts was evident in Juliette's, 23 years, story:

In fact, I did 4 days in intensive care, 2 or 3 weeks, (...) then 2 to 3 weeks in infectious diseases. (...). So after 3 weeks in infectious diseases, we started talking about the amputation of my leg. So (...) they left me 10 days until it was completely black, (...). I tried to move my leg every day, every day, and after 10 days, I was able to stand up for 2 seconds... After 3 weeks of infectious diseases, I went for 3 weeks to a rehabilitation centre.

We may suppose that structuring the time shows, on the one hand, the modification of the relationship to time of many participants, and on the other hand, their need to find milestones (ie, points of reference) for their experience of the disease. These time markers provide a reference point for events.

Emotions

This major theme integrates three subthemes: (1) intensity of emotions and emotionality; (2) oscillation between negative and positive emotions; and (3) perception of other people's emotions.

Intensity of emotions and emotionality

The main part of the interviews allowed perceiving quite intense negative emotions, which are related to the period itself of the meningitis disease, but still experienced at the moment of the interview, or which emerged later, such as misunderstanding, feeling of injustice, even revolt. The testimony of Louise, 26 years, is thus exemplary:

It's not normal what just happened to me. Sincerely, I do not deserve this (...). I have the right to cry, I have the right to be hurt because I'm starting to have a little more awareness of what's going on every day. It is not only that I am revolted, it is that I have ... I was going to say hatred, but I have no hatred. I hate what life has inflicted on me, and I do not want to move on.

This anger and this hatred, that she mentioned then denied, were related to Louise's perception that the meningitis has mowed down all her opportunities and career prospects.

The simple fact of thinking about this disease experience was moving. Sometimes, the participants did not specify the very nature of this feeling, but they felt overwhelmed by the story of their experience.

Juliette (23 years old):

Now, I can tell you about all this, but 2 years ago I was unable to talk about my meningitis without crying (...). But 2 years ago, I could not have talked to you about it. I would have been in tears, unable to speak about it.

Only one participant (Florence, 32 years) spontaneously mentioned a feeling of guilt, related to the separation from her little baby boy:

I had meningitis, and he... suddenly... he had a cut with his mom, he had a break in breastfeeding. So I feel a little guilty too.

Strikingly, fear or anguish were rarely reported as experienced during the disease period itself. Only Florence stated:

When my husband showed up (at the hospital), and when we both talked about the disease, we were both worried and we knew it was serious.

Thus, she perfectly recalled her experience in the hospital and this lucidity leaves room for concern and fear.

If feeling of fear or anxiety were reported in the interviews, it is rather anguish for the close ones.

Suzanne (31 years old):

It's true that for my daughter, I'm really scared that it can happen to her (the disease). And I'm very, very afraid to catch it again, actually. It's something that really frightens me.

Hugo, 18 years, mentioned a very similar concern, with worry for his family, coupled with a fear of falling ill again:

I worry a lot more for everyone because I think I can lose them overnight, as they almost lost me. (...) Me... I have only one fear, it is to lose them, and I also fear falling back in there (the disease) because I tell myself that if it happened once, why can't it happen again?

Oscillation between negative and positive emotions

Besides these negative emotions, the participants also reported some, although rarer, positive ones. Juliette, 23 years, thus highlighted her pride associated with her trajectory and more precisely all the progress she has made:

But there, I think about it and I'm almost proud of the course that I've completed since then.

Emma, 29years, expressed an important satisfaction with participating in this research and being active in a patient association:

I participate in this study because it is great to talk to people who can imagine what it really means, even if they have not experienced it themselves (the disease).

Finally, some participants could mention a feeling of happiness after what they had endured. Suzanne, 31 years, spoke of the happiness of being a mother:

I had the happiness of being a mom after what had happened to me in the past. It always hurts me, but my daughter gives me a lot of strength to see that there are still wonderful things to live for on this earth, and that life is too short...

These words are hopeful and show the participants' ability to elaborate on the inherent difficulties associated with their meningitis experiences, and also highlight some of the positive emotions that impacted on their daily lives.

Perception of other people's emotions

In addition, some individuals also evoked the emotional states of their loved ones. These descriptions were of course based on their family's posterior narrative, or on their current perception of their family members' feelings.

About his parents' emotional reaction, Hugo, 18years, said:

And then they were shocked that they had been so uninformed about this disease, to see that it can happen to anyone.

The participants did not precisely detail the very nature of these emotions. Based on their discourse, we can guess that it was basically astonishment mixed with worry, but once again it is not very precise. In the same line, for instance, Juliette, 23years, mentioned:

My mother was crazy. Luckily, my dad was not there at that time otherwise, I think that he would have gone mad.

Narrative account and profiles of meaning-making

The data analysis allowed us to group the major themes detailed above into three domains of experience and to identify three main profiles of meaning-making based on the study participants' meningitis experiences: (1) Reliance on the testimony of others; (2) The impossibility of meaning-making; and (3) The possibility of post-traumatic growth.

Reliance on the testimony of others

For some participants, the process of making sense of their disease experience was structured through their ability to rely on the testimonies of others. Sometimes it was their memories, other times participants used the

images and metaphors of others, including those used by professionals to communicate about the disease. These elements provided by others contribute to structuring time and the patient's own experience. This ensured that the experience was coherent and thus guaranteed continuity of the self. The experience of meningitis was largely marked by the experience of intensive care, often involving sedation. This caused a lack of memories, or blurry, sometimes distressing impressions, as a set of phenomena defined by Bury as 'holes' in the autobiographical memory ('Biographical disruption').²⁰ Indeed, as described above, some people were faced with discomfort in recounting their meningitis experience. For them, this was a major obstacle to building a coherent narrative of their disease experience. The ability to provide coherence to what was experienced seems to be an essential dimension when it comes to providing meaning and a guarantee of the continuity of the experience of self.

Sheila's descriptions of her experience of intensive care wholly demonstrated this experience of 'holes' in her autobiographical memory:

I had the impression that I had fallen asleep on Saturday afternoon and woken up only on Tuesday (...) When I woke up on Tuesday and saw myself in the hospital, I said to myself, "Oh, my God, what's going on?" (...).

In this perspective, the use of the memories of others helped to fill in these gaps. Therefore, the patient's reliance on this 'auxiliary memory' helps to create coherence to this experience.

It should also be noted that temporality seemed to be an essential dimension of the construction of the meaning of experience. This seemed to be articulated in two dimensions:

- ▶ The first concerns the relationship to time altered by the experience of the disease. As discussed above, many participants needed to find milestones, through the reference to time markers, to structure and give meaning to the traumatic experience they had faced.
- ▶ The second refers to the 'work of time' in this process. The ability to fill in the gaps and then find meaning seemed to be built over time. Indeed, temporality allowed one to review the meningitis experience, to give coherence to it, with the help of others, and for some people to turn it into something positive (please see *The post-traumatic growth* discussed below).

The impossibility of meaning-making

This profile of meaning-making is more of a profile of a lack of meaning. For some of the participants, the process of making sense was prevented and seemed impossible. Two dimensions appeared to emerge to explain this impossibility for some of the participants to find meaning in the experience. On the one hand, the patient's experience of non-sense and injustice and the consecutive withdrawal into his/her self; and on the other hand, negative emotions (anger and resentment) resulting from the

feeling of not receiving adequate answers (unpreparedness/lack of knowledge) or the necessary support from healthcare providers.

In the case where non-sense is still dominant in the patient's mind, he/she was sometimes unable to find coherence in his/her experience, as Marc's words illustrated:

I, in what I am going through, have the impression that it is getting worse and I have the impression that I am locking myself in, because others do not understand. I'm starting to isolate myself a bit because every time I say something, everyone tells me: "but no, it's going to be fine...". Other people may be fine, but not me.

The feeling of injustice, despair and refusal was even more accentuated for Louise, 26 years, who explained:

Everything is difficult. It's not me anymore, it's all ruined. I was an active person. I do not accept it. It's not fair at 26! We don't have to accept it. I don't know what I'm going to do with my life. My 26 years of effort to build myself are ruined.

Regarding Louise's experience, it should be noted that she was affected by meningitis less than a year before the interview, which could indicate that the process of making sense was still in a very initial phase and seemed troubled.

The possibility of post-traumatic growth

'Post-traumatic growth' is a term that refers to positive psychological changes resulting from the effort made to cope with adversity and any event that highly challenges the individual's resources.²¹ Among the significant positive changes resulting from the confrontation with meningitis, and having survived it, was the adoption of an altruistic and empathic perspective. We observed in the stories first and foremost that patients largely evoked a change in their view of the world, with a feeling of focusing on what really matters (eg, loved ones, children, personal values, increased focus on their health). Sheila's words were a striking example of a change in perspective on the world:

I think that when you've been through this, you have to think differently. If I hadn't lived through it and experienced it again with my son, I wouldn't see it that way.

Participants spoke of a transformation of worldview and outlook on life as well as a new capacity, acquired with the experience of the disease, to look at things with more subtlety and detachment. Susanne, 31 years, gave a striking testimony:

Before, I always had something planned. Now I enjoy life, and I enjoy it more than before (...). You don't see life the same way at all anymore.

Participants insisted on the need to focus on important personal values, their health and relationships with others

that were transformed by the meningitis experience. Juliette's narrative underlined this change of perspective:

I got along very, very badly with my father since I was a little girl (...), before we couldn't go a day without jumping on each other for any minor thing (...) Now, there is no problem. We know where we've gone and that there's no point arguing over trivial things when (...)

The desire to share the experience of the disease and its medical care is a subprofile of post-traumatic growth. This sharing was indeed conceived as a useful testimony, for oneself and for others. It consists of a desire to provide testimony of the experience of the disease and its treatment, with its limitations and failures, and to improve knowledge and management of the disease. Marc's testimony was a striking example of this specific dimension of the post-traumatic growth:

I'm here to help, if I can help with what I've been through. I'm open to it. (...) I'm open to all this stuff [meningitis awareness actions], because I'm lucky I got out of it (...) I would like to advance science and medicine on this subject.

In the end, it is possible to assume that each participant constructed a main profile of meaning-making or that several profiles of meaning-making might be identified in the same person, depending on their stage of the recovery journey in which she/he was in.

DISCUSSION

Our qualitative findings in meningitis survivors highlighted eight themes, shared by all the participants, among which five are presented in detail here. As mentioned above, considering that the participants in the study were from various age at the time of the onset, some of these themes apply in a diverse way to participants who experienced meningitis as children. For example, the unpreparedness and lack of knowledge of health professionals (theme: Knowledge/ignorance) are experienced differently depending on whether meningitis occurred in childhood or in adulthood.

Three main meaning-making processes in relation to the participants' experiences of meningitis emerged from their discourse. These processes emphasised the importance of others in the meaning making of illness, as well as the potential traumatic impact of the illness experience and the possibility of post-traumatic growth for some individuals. This study underlined various psychological consequences of meningitis disease.

This study underlined various psychological consequences of meningitis disease. Adults who experienced meningitis during childhood and adulthood reported long-term sequelae, including hearing loss, attention deficit or memory impairment. These results are in line with previous quantitative studies.²² Besides the cognitive sequelae, the participants also revealed an emotional

burden induced by the sequelae: undermining of their life project, painful feeling of diminishment, depression and anxiety. They often described a feeling of loneliness, a lack of medical education support and sometimes feeling that their relatives do not support them. As suggested by our results, the management of meningitis patients can be provided by different professionals: emergency doctors, infectious medicine specialists, intensive care professionals. These various treatment trajectories may induce fragmentation of care and explain why the meningitis survivors perceive a lack of answer to their difficulties in the mid-term and long-term. Patients had indeed many different medical staff interactions, and did not know who to talk to about their difficulties. As many guidelines emphasise the critical need of following and supporting cancer survivors in the long-term because of their potential fragility, survivors of acute illnesses such as meningitis could benefit from dedicated and systematic medical consultations in the months and years following their disease experience.

Our results also highlighted the tipping point that the meningitis experience represents in their life, and which the patients perceived as brutal and abrupt. It was related to the severity of the illness, with black holes and blurry memories during the acute phase taking a centre stage. The lives of the survivors were literally holed out, and they sometimes only recalled painful sensations. Some patients went through intensive care units (ICU) during the acute phase of their disorder, so the impact of this aspect of the course of their disorder should be analysed more specifically. Given the paucity of research on the experience of meningitis survivors, studies on survival in ICU could offer some insight. Kean *et al*²³, for example, associated difficulties in social recovery (ie, re-engagement with roles and activities following illness²⁴) reported by acute illness survivors, with ‘holed memory’. Social recovery is about re-engaging with life and one-self after a critical illness, and it is an aspect of the recovery process that remains relatively unexplored.²³

Some of the participants in our study mentioned difficulties in reshaping relationships with important persons in their lives after the meningitis experience. Fortunately, most study participants could rely on the account of relatives to fill these ‘holes’ and thus find a continuity in their existence between the before-illness and after-illness time periods. Once again, the role of sedation was underlined because the frequently reported coma causes memory holes and biographical disruptions for some participants.²⁰

The abrupt nature of the meningitis experience could also be enlightened by the concept of liminality. Van Gennep²⁵ defined liminality as “transition(s) from one state to another (that) is literally equivalent to giving up the old life and ‘turning over a leaf’”. Kean *et al*²³ added: “In essence, liminality explicates the experiences of ICU survivors’ transitions, including their inherent uncertainty and it is this aspect that is of interest to ICU survivorship”.

Our results empirically showed the presence of potential growth in some participants. As mentioned in a previous qualitative study¹³ of adolescent meningitis survivors, post-traumatic growth can occur in this population. Participants of the present study described a tightening of bonds, an improvement of relations with their loved ones or a growing altruism that could be manifested by a significant investment in the associative world. A certain ‘militancy’ could then be felt in some active members of patient associations: some participants insisting on the need to take into account the words of their relatives who had the intuition of the seriousness of their condition, and who had to fight against professionals whose knowledge of meningitis was perceived to be very limited.

Strengths and weaknesses of the study

This study has several limitations. The first is related to the representative nature of the sample. It consisted of participants who had volunteered to take part in the research and who were recruited through patient associations; the representativeness of our results can therefore be questioned to the extent that such associations may attract a certain group of participants. One way to mitigate this bias could be to elaborate a future study with a systematic recruitment in medical centres. A second limitation concerns the retrospective design of the research, which could have induced reconstruction bias, with variable time periods between the interview and the meningitis disease. A worthwhile direction for future research may be the construction of a mixed-method study, which explores the psychological adjustment of survivors shortly after the acute phase. A longitudinal design will also allow capturing variations in their adjustment. Despite these limitations, this research provides insight on the personal experience of meningitis survivors. Moreover, it offers information on their meaning-making processes, and above all, the critical role of relatives to restore the continuity of their existence. Although survivorship is mainly explored in the cancer context, our study is, to the best of our knowledge, the first attempt at using a validated methodology to explore the subjective experience of acute bacterial meningitis survivors.

Clinical implications

The biographical disruption that can be induced by loss of consciousness, quite common among the participants of our study, can indeed be alleviated or even overcome by the testimony of significant others. Relatives spontaneously shared this narrative (especially of the phase during which the patients were unconscious). Nevertheless, one of the characteristics of our sample was that participants were surrounded by family or friends, even if some complained of a lack of support later on. What about patients whose memory holes could not be filled by the accounts of their loved ones? An initiative was conducted for hospitalised patients in intensive care: the creation of an ICU diary in which, either relatives or professional caregivers, could write a few words retracing

the patient's journey while they were in a coma.²⁶ We may promote such initiatives when meningitis patients are sedated.

Importantly, study participants also highlighted the lack of training in the diagnosis, which they perceived to be due to lack of physician training. This need for healthcare professionals to develop a 'reflex-like' diagnosis of meningitis when faced with compatible symptoms merits further investigation, particularly with private general practitioners, who are the primary care physicians in the French healthcare system. Adherence to official guidelines for the medical management of acute bacterial meningitis is sometimes poor.²⁷ An audit concerning the management of long-term sequelae could be very interesting.

Patient and public involvement

The scientific team/board included two representatives of patients' associations. They were involved from the origin of the study and identified the potential psychological consequences of the disease experience. They also highlighted the interest and motivation of patients and relatives to participate in psychological research, and also participated in the discussions on which questions would be posed to the participants. These representatives were aware of any potential burden associated with this research and underlined on the contrary the benefits that participants could derive from the project. We plan to organise a conference for the association where the participants were recruited to disseminate the results of this study.

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ORCID iD

Elisabetta Scanferla <http://orcid.org/0000-0002-6985-6662>

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