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RESEARCH

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# Follow-up care experience of patients with invasive meningococcal disease and their family caregivers: a qualitative study

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## Abstract

**Background** Clinical guidelines recommend systematic follow-up of patients surviving invasive meningococcal disease (IMD) to assess sequelae. However, little is known about survivors and family caregivers' experiences of the follow-up care. Study sought to explore IMD survivors' and their family caregivers' experiences after hospitalization for IMD and to identify unmet needs.

**Methods** Semi-structured interviews were conducted with patients and family caregivers, identified through hospitals database. Interviews were audiotaped, transcribed and subject to a thematic analysis. NVivo software was used for data management and analysis.

**Results** Eight IMD survivors and 14 family caregivers were interviewed. Three themes were identified from the data: (1) perception of patient and family caregiver on follow-up after IMD and role of healthcare professionals; (2) access to care and support; (3) relationship with healthcare professionals. Although most were satisfied with follow-up care after IMD, suggestions for improving the healthcare pathway were made relating information on potential sequelae and follow-up care, coordination, and access to psychological support.

**Conclusions** This study confirms the need for more structured follow-up care for patients suffering from IMD and their families which is currently limited and focused on physical recovery. Optimal follow-up should aim to provide sufficient information, emotional support and logistical support for patient and family caregivers.

**Trial registration** Ethics Committee of University of Lyon, France (ref: 2022-06-23-002).

**Keywords** Meningococcal infections, Follow-up care, Patient experience, Family caregiver, Qualitative study

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## Background

Invasive meningococcal disease (IMD) causes significant morbidity and mortality worldwide. According to the World Health Organization (WHO), approximately 10% of people who contract IMD will die, while up to 20% may develop long-term sequelae such as physical, neurological, sensory, cognitive, or psychological issues [1]. IMD can also have a lasting effect on survivors' quality of life, even without any lingering complications [2–4]. It can also impact the families of those affected, leading to lower quality of life, and increasing parents' risk of developing psychological distress [5, 6].

In light of these potential long-term consequences, it's crucial that patients and their caregivers receive adequate care and support [7]. In 2020, the WHO launched a global action plan for defeating meningitis, emphasizing the importance of conducting research to enhance the support and care provided to families and survivors [7].

Although some countries, such as France [8] have implemented evidence-based guidelines for managing people who have experienced an IMD, post-discharge medical follow-up can sometimes be random and fail to meet the needs of patients and their families [9, 10]. According to a survey conducted in the United Kingdom, it was discovered that about half of the 194 participating parents expressed concerns that their child's requirements were not met [11]. The study identified several barriers, including difficulty to access medical follow-up, a lack of awareness of symptoms and potential sequelae, as well as poor communication between healthcare providers. These findings were echoed in another UK-based study, which interviewed 244 parents. Parents expressed a desire for improved communication regarding the treatment process and disease progression, as well as more frequent, specialized follow-up care [12]. However, it's important to notice that, to our knowledge, only two studies on this topic exist, both of which are over a decade old, indicating the need for updated data. Additionally, these two studies did not consider the perspectives of patients, whose experiences and needs may differ from those of family caregivers. Therefore, further in-depth research is necessary.

According to the WHO's plan, our study seeks to identify any gaps in post-IMD care as perceived by both patients and family caregivers. We aim to use this knowledge to inform the creation of future interventions. To do so, we will explore the experiences of individuals who have survived an IMD, as well as those of their family members, in terms of post-IMD follow-up. Through qualitative research, we can gain a profound understanding of the daily lives of patients and their family caregivers [13, 14]. This method reveals their perspectives and insights, highlighting areas where healthcare services could be improved [15, 16]. In light of the previous studies and the

relatively low incidence rate of IMD, we have opted for qualitative approach that places a premium on depth and quality over quantity. This approach allows us to deeply understand the experiences and perspectives of our participants, even with a limited number of participants.

## Materials and methods

The COREQ (consolidated criteria for reporting qualitative research) checklist guided the preparation of this manuscript (Supplementary Table S1).

### Study design

A pragmatic qualitative study using semi-structured interviews was implemented in 4 French intensive care units (ICUs) (two adults and two pediatrics ICUs) to address the research objective. Pragmatic qualitative research is not based on a specific theoretical perspective. It is more flexible and allows the study to be designed in way that is best suited the research question [17]. The aim of inquiry is to reach an in-depth understanding prioritizing description first [18]. Conducting qualitative research offers rich and compelling insights into the real worlds, experiences, and perspectives of the participants [19]. Semi-structured interviews are an effective way to collect open-ended data and are designed to garner subjective responses from the participants regarding their experiences, perspectives or phenomena they have experienced [20]. This type of interview allows the participant's world to be explored in greater depth, facilitating rapport and empathy because the conversations are simply guided by the interview guide rather than dictated in a linear way by questions and answers. In addition, it allows researchers to be flexible and adaptable by following the participant's story and exploring new, more in-depth avenues of research that had not been defined by the interview guide, while remaining within the framework of the research questions posed [21].

### Sample selection and recruitment

IMD cases were identified from a database of participating hospitals. Case managers at each hospital contacted eligible patients or their family caregivers by phone. If they agreed, they collected the consent forms and arranged appointments for interviews with the investigator (AB). The convenience and snowball methods were initially used to recruit participants, followed by the variation method to ensure that there was enough diversity in terms of gender, years of experience, and setting.

### Participants eligibility for interview

#### *Patients who suffered from IMD*

IMD patients were eligible for the interview if they: (1) were aged  $\geq 18$  years old at the time of the interview; (2) have no cognitive or psychological impairment that

might have prevented the participant from discussing during the interview; (3) had a sufficient level of understanding and spoke French.

#### **Family caregivers**

Family caregivers were eligible if they: (1) were close relatives (parents, legal guardians, spouse, or husband); (2) without cognitive or psychological impairment; (3) involved in the relative care; (4) had a sufficient level of understanding and spoke French.

#### **Data collection**

Data were collected from medical records and interviews. All the data were anonymised.

#### **From medical records**

Data extracted from medical records were age, gender, date of disease onset, clinical presentation, sequelae at hospital discharge, the wards to which patients has been admitted and follow-up consultations. Sequelae were defined as complications attributable to the meningococcal infection that were still present at hospital discharge and written in the medical record. Certain sequelae (such as hearing impairments, anxiety) may have been non-permanent. The objective of this data extraction was to describe follow-up modalities after IMD.

#### **From interviews**

Experts in care pathways analysis (FC, GM, CD, PB, AB) developed the interview guides (Supplementary Table S2) and a multidisciplinary team including experts on IMD care (GMO, KK, CS, LA and members of IMD patient associations) reviewed them. The investigator (AB) tested the interview guides with the first three participants. This allowed the rest of the team to validate the final versions based on their comments. The investigator (AB) conducted individual telephone or video interviews with all participants, recording them and taking detailed notes. Data collection continued until researchers found no new information to describe the research topic. Interviews were conducted at least 2 years after the IMD to ensure that patients and family caregivers had time to recover from the event.

#### **Data analysis**

A specialist transcriptionist (Genius, France) created verbatim transcripts based on the audio recordings. The three authors, AB, GM, and FC, who had received training in qualitative analysis, conducted the data analysis using an inductive approach and coding techniques (supplementary table S3). They followed the five-step methodology proposed by Braun and Clarke for thematic analysis [19].

1. *Familiarisation with the data*: The first step involved thoroughly understanding the data by repeatedly reading and reviewing it. This process allowed the authors to develop a deep understanding of the content (AB, GM, FC).
2. *Generation of initial codes*: Once familiar with the data, the authors started identifying and creating initial codes by converting raw data (verbatim transcripts) (AB, GM, FC).
3. *Identification of themes*: The authors then reorganised the data to identify themes by hierarchically categorising concepts into more general themes. These themes were further developed, refined, and connected through continuous comparison. A final level of analysis articulated these themes (according to relationships of continuity, causality, concomitance, coexistence or overlap) around the initial research questions to structure the analysis (AB, FC).
4. *Reviewing themes*: The resulting themes were discussed and refined (AB, GM, FC).
5. *Defining and naming themes*: Finally, finer coding was used to illustrate the themes with specific examples (AB).

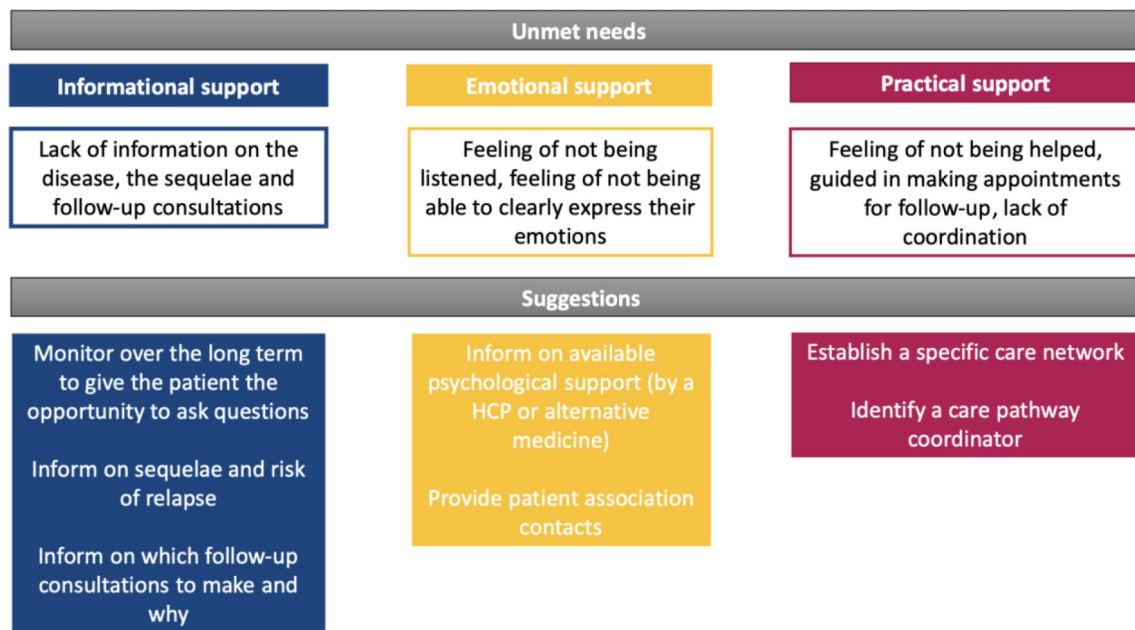
#### **Trustworthiness**

The criteria of credibility, confirmability, dependability, and transferability as proposed by Lincoln and Guba (1986) were used to enhance the trustworthiness of the study [15, 22].

The credibility of the researchers was strengthened in two ways. First, they ensured that the investigators possessed the required expertise and analytical abilities needed to perform their tasks [23]. Second, they organised routine update meetings with the main participants of the study to review the developing topics arising from the data analysis [24]. The confirmability was established through various triangulation methods such as using multiple data sources and researchers. The dependability was ensured by providing a comprehensive explanation of the study methodology and arranging frequent meetings among the lead coders and other team members to examine the results and address any potential coding discrepancies [25]. Lastly, to guarantee the transferability of the study, details about the participants and settings were included [26].

#### **Results**

A total of 56 IMD cases were screened between 2015 and 2020 and 19 accepted to participate. Based on the eligibility criteria for interview, 8 interviews were conducted with patients and 8 with family caregivers respectively ( $n=16$ ). A further 8 family caregivers were identified



**Fig. 1** Unmet needs identified by IMD patients, and their family caregivers and suggestions for change

**Table 1** Characteristics of patients interviewed ( $n = 8$ )

Variable	Number (%)
Gender	
Male	1 (12.5%)
Female	7 (87.5%)
Diagnosis	
Meningitis	3 (37.5%)
Meningitis + septicemia	2 (25%)
Purpura fulminans	3 (37.5%)
Time since the admission for IMD	
2-4y	6 (75%)
5-7y	2 (25%)
Sequelae <sup>a</sup>	
Yes	5 (62.5%)
No	3 (37.5%)
Sick leave <sup>b</sup>	
Yes	5 (62.5%)
No	0
Not applicable	3 (37.5%)
Age at time of the interview	
20-24y	3 (37.5%)
25-29y	2 (25%)
35-39y	3 (37.5%)

Y: year

<sup>a</sup> Sequelae were defined as complications attributable to the meningococcal infection that were still present at hospital discharge and written in the medical record

<sup>b</sup> According to participant's statements

**Table 2** Characteristics of family caregivers interviewed ( $n = 14$ )

Variable	Number (%)
Gender	
Male	3 (21.4%)
Female	11 (78.6%)
Family relationship	
Parent	12 (85.7%)
Cousin	1 (7.1%)
Spouse	1 (7.1%)
Age at time of the interview	
20-30y	1 (7.1%)
30-40y	6 (42.8%)
40-50y	2 (14.3%)
50-60y	4 (28.6%)
60-70y	1 (7.1%)
Temporary interruption of work <sup>a</sup>	
Yes	8 (57.1%)
No	2 (14.3%)
Not applicable	2 (14.3%)
Not reported	2 (14.3%)

<sup>a</sup> According to participant's statements, temporary work interruption to look after their children or spouse during and after hospitalization for IMD

during interviews with patients only, 6 of whom were interviewed (Fig. 1). A total of 14 family caregivers were interviewed. All participants were interviewed once with a total of 22 interviews. The median length of each interview was 93 [45–165] min.

#### Participant characteristics

Patients and family caregivers' characteristics are summarized in Tables 1 and 2 and detailed in supplementary file table S4-S5.

### Follow-up modalities post-IMD

In total, post-IMD follow-up data were collected from medical records and analysed for 16 patients (Table 3). Median duration of follow-up for patients with sequelae and without sequelae was 338.5 and 46 days respectively. Psychological support was offered by the hospital to 5 patients and 3 family caregivers (Table 4).

### Experience of patients and their family caregiver's post-discharge for IMD

Three main themes incorporating 6 categories were identified from the data (Table 5). Subcategories and quotes are detailed in supplementary file Table 6.

### Perception on follow-up after IMD and role of healthcare professionals

**Follow-up is satisfactory, although there are gaps** After the acute phase, the hospital arranged follow-up appointments to monitor the patient's recovery and assess possible sequelae. For most participants, this was seen as logical and necessary. Although some follow-ups lasted only a few days, participants generally found them appropriate for their level of sequelae. Those who did not experience sequelae themselves or whose children did not experience them believed that more follow-ups would have been offered if they had experienced any sequelae. Most of the time, no further follow-up appointment was perceived as 'positive.'

However, for participants, follow-up was perceived as insufficient, particularly in the long term. They expected to benefit from more appointments to ensure that they no longer suffered from sequelae and had fully recovered. They hoped that the hospital contacted them to arrange an appointment a few months after IMD. The patient P6 pointed out that follow-up appointment with the infectious disease specialist had taken place too early after discharge, with no sufficient time to recover and hence to ask questions on potential sequelae.

In both cases, patients and caregivers reported feeling relieved to stop follow-up appointments and return to normal life. Participants who required long-term follow-ups with multiple health professionals found it difficult to attend appointments for treating sequelae, leading to physical and mental exhaustion. They also expressed a strong desire to return to a social life.

**Perception of the role of healthcare professionals is heterogenous** Primary care healthcare professionals (HCPs) (such as general practitioners (GPs), physiotherapists, nurses) and secondary care HCPs (such as ears, nose and throat specialists, infectious disease specialists, nephrologists) played a role in follow-up care after IMD, according to the number and type of sequelae. For partici-

**Table 3** Follow-up characteristics of patients with IMD, France (n = 16)

	Patients without sequelae (n = 8)	Patients with sequelae (n = 8)
Length of follow-up (median)	46 [1-1496] days	338,5 [3-2591] days
Follow-up consultations within the 1 month after IMD (at least one)	71% (5/7)	75% (6/8)
Total number of follow-up consultations		
1 consultation	3	0
2 consultations	3	2
3 consultations	1	1
4 consultations	0	1
> 5 consultations	1	4
Neurological assessment (at least one) <sup>a</sup>	63% (5/8)	57% (4/7)
Hearing assessment (at least one) <sup>a</sup>	88% (7/8)	88% (7/8)
Cognitive assessment (at least one) <sup>a</sup>	0	0

IMD: Invasive Meningococcal Diseases

<sup>a</sup> According to French society of infectious diseases (SPILF) recommendations

**Table 4** Psychological support during and after IMD for patients and family caregivers, France

	Family caregivers (n = 14)	Patients (n = 16)
Psychological support within the hospital	3 (21%)	5 (31%)
During hospitalization	2 (14%)	5 (31%)
After hospitalization	1 (7%)	0
Psychological support without hospital	4 (29%)	6 (37%)

IMD: Invasive Meningococcal Diseases

**Table 5** Overview of themes and categories relating to patients' and family caregivers' experiences of follow-up after IMD

Main themes	Categories
Perception on follow-up after IMD and role of healthcare professionals	Follow-up is satisfactory, although there are gaps
	Perception of the role of healthcare professionals is heterogenous
Access to care and support	Difficulty navigating the healthcare system and access to care
	The importance of access to appropriate psychological support
Relationship with healthcare professionals	Communication is essential for patients and caregivers to understand and cope
	The humane posture of healthcare professionals is recognized to help the well-being of patients and their family caregivers.

pants P2, P3, P4, P5 and F13, GP played a supportive and accessible role. He or she was considered to be the first point of contact for any questions or concerns following discharge from hospital. The participants perceived their role as positive, particularly in terms of providing reassurance and consideration. Their availability made them feel like GP understood the seriousness of the disease.

However, for others (F14, F17 and F18), GP had limited role, if any, in follow-up. This was most often linked to the perception of GPs' perceived lack of knowledge on IMD and the sequelae, or the absence of consultation on the part of participants in the context of IMD.

In contrast, participants identified specialists (such as infectious disease specialists, ENT specialists, rehabilitation physicians) as those who know about the disease and its sequelae and have the skills to diagnose and treat them. Participants P6 and F17 considered specialists to be the most appropriate healthcare professionals to coordinate their care after hospital discharge.

#### **Access to care and support**

**Difficulties navigating within the healthcare system and to access to adequate care** For participants P6 and F18, navigating within the care system was difficult, especially when follow-up involved several healthcare professionals. Participants expressed the feeling of being “delivered to themselves”, especially for organizing follow-up appointments. This difficulty was major because they did not know which medical services to refer to or whom to contact if they had questions. Access to care was also difficult for several participants, particularly family caregivers who mentioned the logistical complexity of getting to appointments while managing other family members or work.

Participants P3, F20, and F21 who experienced fewer difficulties were aware of the healthcare system's organisation due to their own experience. They sometimes had a key contact who supported them with care organisation and provided a global view of the follow-up. This key contact was perceived very positively by the participants who benefited from it, giving them a sense of fluidity in care rather than just juxtaposed examinations by different specialists. These participants felt confident in the quality of care they received.

**Importance of access to appropriate psychological support** Patients and their families saw IMD as a meaningful event that evoked feelings of fear of death or witnessing a family member's death. Once back at home, they experienced emotions related to this event. In most cases, family and friends were supportive, providing emotional comfort and motivation to move forward. This support from the family group increased their confidence in dealing with IMD and its consequences.

Nevertheless, although patients and caregivers emphasised the key role played by their surroundings, they acknowledged the limits of the emotional support they could offer. They expressed difficulties in fully sharing their emotions, feelings of not being understood, and a desire to protect others from their own feelings. Patients

and family caregivers regretted that no psychological support had been proposed following the IMD. They described this as a ‘missing point’ or a ‘black head’ in the post-IMD discharge process.

Participants mentioned psychological support from a professional as a way to express their feelings and calm their fears with a neutral and unbiased person. However, this kind of support can take many forms. Participants P3, P7, F16 and F18 considered the meetings with other patients and parents as an opportunity to exchange on what they had lived through and how they felt, and to receive advice. The closeness to other survivors or family caregivers would make them feel ‘less alone’ and ‘understood’.

Participants emphasised the importance of timing psychological interventions. For patients, the need usually arises a few months after discharge, once their physical abilities have returned. For family caregivers, there was no consensus on an appropriate timing. Participants F19 and F20 thought that suggestions should be made either during hospitalisation or immediately afterward. Others (F12, F15 and F18) prioritised follow-up appointments for their children and highlighted the lack of time for psychological support during this period, as well as the need to give them time to resume a normal life.

#### **Relationship with healthcare professionals**

**Communication is essential for patients and family caregivers to understand and to cope** One of the principal reasons of dissatisfaction was the lack of information after acute phase. Participants reported feeling uninformed about possible sequelae following infection and the importance of follow-up appointments in recovering from IMD. This feeling was associated with the need for reassurance that there were indeed no consequences. The difficulty in identifying an appropriate professional to address these issues further contributed to this lack of information. Participants P6, F13, and F16 considered the systematic long-term follow-up as an opportunity to compensate for this lack. Parents specifically reflected a need for more information about the risk of IMD relapse, as well as advice on how to care for their child at home.

Participants explained that this need for information stemmed from a desire to understand the situation and prepare for what could happen in the future. This understanding allowed them to better cope with the situation and then move forward more effectively.

They thus emphasised the importance of clear and tailored communication. They highlighted the efforts made by healthcare professionals to simplify their discourse, making it easier to understand. This communication helped to alleviate their stress and anxiety.

### **The humane posture of healthcare professionals is recognized to help the well-being of patients and their family caregivers**

Participants complimented the professionals around them for their human qualities: empathy, active listening, and kindness. These qualities made them feel supported. Participants also really appreciated the availability of healthcare professionals, in particular GPs and physiotherapists. They felt reassured to have someone available to answer their questions.

Conversely, inappropriate posture by healthcare professionals reinforced participants' anxiety and the feeling that they had to deal with the situation on their own.

### **Discussion**

This study provides concrete evidence on how patients and their family caregivers perceive follow-up care following an IMD. They found it necessary to assess and manage sequelae, or to ensure that the patient does not suffer any sequelae following the serious event. The number of follow-up appointments was seen as being related to the presence of sequelae; this corresponds to findings from medical records indicating fewer consultations and shorter follow-ups for people who had none. These results are consistent with the literature, which shows that patients with sequelae consume more health services over the short and medium term, suggesting more complex and longer treatment pathway [27–31].

Participants experienced difficulties accessing care because they had to navigate through an unfamiliar and complex medical system. Their findings are consistent with those in the literature [11]. These difficulties were exacerbated when specialists' appointments were scheduled back-to-back, making it difficult for patients and family caregivers to understand the system, gather all the required information, and get an overview of the situation. The problem seems to be exacerbated by the lack of consensus on the roles of health professionals, especially GPs. This highlights the importance of defining these roles, as well as specifying how GPs and other health professionals can collaborate to ensure the continuity and coordination of care.

During the interview, there was a constant need for information. The patients and caregivers wanted to know 'the whole story' so that they could regain control over their lives and deal with the disease. This finding is consistent with those of Haines et al. and Sweeney et al. [12, 32]. As Bruchon-Schweitzer and Boujut point out, the search for information can serve as a coping strategy [33]. In response to difficult situations, people do not simply passively accept what happens; they take action. They view information as a tool that allows them to adapt and respond appropriately. This search for information, known as 'problem-focused coping,' protects against the negative effects of stressful emotions [33]. However,

the interviews showed that the content and quantity of information required can vary greatly, depending on the individual needs, literacy level and emotional state of the patient or caregiver. Healthcare providers communication should be based on professional awareness and understanding on how patients and their family caregivers understand and experience IMD to address their requirement without unnecessarily increasing their anxiety or insecurity [34, 35].

IMD was perceived as meaningful event by patients and family caregivers and psychological support was clearly identified as a key point to improve the healthcare pathway post-IMD. Even though the recommendations advise assessing the psychological consequences after hospital discharge, our findings showed that the psychological support was proposed by hospital to only a few of them, confirming the lack of systematic psychological support offer. This results support findings from others studies which reported the emotional burden associated with this event for both IMD survivors and their family [36–38] and the requirement to systematically offer psychological support after hospital discharge [39, 40]. Further research should determine the timing at which psychological support would be useful and could be proposed by medical team. This is an important point, as our interviews revealed that patients and family caregivers are initially mostly focusing on the physical aspects of recovery and freedom from disease. An offer of psychological support at the right time would improve patient and family caregiver adherence, as well as clear explanations of its benefits.

### **Clinical implications and perspectives**

Current follow-up care after the acute phase of IMD is variable and does not address patient's complex individual needs [10, 11]. The present study highlights the need for more structured care of patients and family caregivers following hospitalization on a long-term basis, including informational, emotional, and practical support (Fig. 1). Our results identify suggestions which can help inform guidelines to improve follow-up offered to IMD survivors and their caregivers after discharge.

To enrich our understanding, further research should focus on the experience of healthcare professionals involved in the post-acute care of patients with IMD. Studying their perceptions and attitudes would help us to understand gaps between the patient's expectations and the care provided.

### **Strength and limitations**

The greatest strength of this study is that it shows how individuals experienced the situation. This includes not just the patient's perspective, but also that of their families. These different perspectives have broadened our



understanding of the priorities for following up with patients and their families. However, there are limitations. Firstly, because of the small sample size and high proportion of female respondents, we must be cautious when generalising these results. Since there were too few participants, we could not conduct separate analyses on caregivers of children or adults, nor on dyads composed of children and their relatives. Secondly, due to practical considerations, only one researcher conducted the interviews, potentially introducing bias. Finally, despite having chosen to wait two or more years since diagnosis before interviewing patients and their families to allow them sufficient recovery time, the retrospective nature of the study presented difficulties in recalling details of their experiences. Therefore, further studies must include interviews with patients at different stages of the progression of their illness to corroborate and expand on these findings.

## Conclusion

This research examines the perspectives and expectations of patients and their family caregivers regarding post-IMD care. Results highlight the importance of enhancing the current, frequently fragmented strategy, which primarily concentrates on physical recovery but neglects to provide systematic mental health assistance. By integrating these findings, researchers can develop a more complete aftercare program. This program would provide adequate resources, including information, emotional support, and practical assistance, to both patients and their caregivers following an IMD.

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12879-024-09860-6>.

Supplementary Material 1

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## Author contributions

Conceptualization, A.B., C.D., P.B., G.M. and F.C.; methodology, A.B.; validation, C.D., P.B., G.M., L.A., K.K., G.M. and C.S.; investigation, A.B., L.A., K.K., G.M., C.S.; writing—original draft preparation, A.B. and F.C.; writing—review and editing, A.B., C.D., P.B., G.M.; F.C., L.A., K.K., G.M. and C.S. All authors have read and agreed to the published version of the manuscript.

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## Data availability

The data sets used in this study has been anonymised and are available from the corresponding author upon request.

## Declarations

### Ethics approval and consent to participate

The study protocol was approved by the Ethics Committee of University of Lyon, France (ref: 2022-06-23-002) on 7th September 2022. All participants received written and oral information about the study and gave written consent to participate.

### Consent for publication

Consent for publication was obtained as part of the informed consent for the study, although our study does not publish identifiable data of the participants.

### Competing interests

The authors declare no competing interests.

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