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The seen and unseen facets of Dravet syndrome across the disease trajectory: Insights from European ethnographic research

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ABSTRACT

Background: We investigated the lived experiences of individuals within the ecosystem of Dravet syndrome (DS) (patients, families, healthcare professionals, patient representatives) to gain a holistic understanding of the reality of caring for an individual with DS.

Methods and Results: Using ethnographic methodology, we interviewed and observed five families (seven parents) of children (aged 2–10 years) with DS, 21 healthcare professionals at five specialized epilepsy units, and 16 personnel working for patient organizations across France, Germany, Italy, Spain, and the UK, to explore aspects of daily life with DS. Observations from the study participants demonstrated that families are impacted by multiple factors within the DS ecosystem, in terms of position in society, daily life and environment, and family dynamics. Parents' informational, logistical, economic, and psychological needs differ over the course of the disease (first seizure, quest for diagnosis, diagnosis, reconfiguration, trial and error, stabilization, adjustments, adolescence, adulthood) in response to practical and emotional challenges. A framework was developed to define

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how parents cope and manage the information provided to them and the choices they must negotiate as the DS journey evolves. Four key territories of opportunity were identified.

Conclusions: Families of children with DS have complex and changing challenges related to different phases of their child's development and disease progression. Our findings may assist those working with families to identify key challenges and provide support specific to individual needs. Our findings could help clinicians adapt their communication, ultimately improving the quality of care provided and the quality of life of the different stakeholders.

1. Introduction

Dravet syndrome (DS) is a developmental and epileptic encephalopathy (DEE) that typically appears in the first year of life [1–3]. Affected infants develop prolonged seizures, often during febrile episodes, between the age of 5 and 8 months (mean 6 months). The first seizure is usually generalized and clonic, but the pattern evolves over time to include multiple seizure types, including clonic (generalized clonic, generalized tonic-clonic or alternating unilateral clonic), myoclonic, absence, focal (with or without focal to bilateral tonic-clonic spread) and, sometimes, tonic seizures. Seizures are often prolonged (>20 min in 25–49 % of patients) [4], occur during sleep, may progress to status epilepticus [1,5], and are treatment resistant [4]. Further, individuals with DS are affected by developmental and cognitive impairment [1,6]. DS is associated with a high mortality rate (15.84 deaths per 1000 person-years), mostly from sudden unexplained death in epilepsy (SUDEP) or status epilepticus [7].

DS is a rare condition, with an estimated prevalence of 1.2 to 6.5 per 100,000 people [8]. More than 80 % of patients carry a pathogenic variant in the *SCN1A* gene [9].

The natural history of DS places substantial psychological, physical, and financial burdens on the families and carers of affected children [10–14], as well as a significant impact on healthcare services [14,15]. A recent qualitative study [16] reported a high level of psychological trauma in parents/carers of children with DS (CwDS) and outlined a model of coping and adjustment. The specific domains of caregivers' lives that are affected, the tools to measure the impact of caregiving, and the factors that influence the impact on caregivers remain unknown [17]. Qualitative research is essential to address these issues, using a methodology that captures the experiences and impressions of all individuals involved in the care process.

Ethnography is a qualitative research method used to study and understand different cultures and social groups. It involves fieldwork wherein the researcher actively participates in and observes the group of interest in the setting of daily life [18] to identify shared patterns of behaviors, values, beliefs, and language [19,20]. Ethnography has not been previously used to study DEEs such as DS, and may provide insights that allow the development of solutions to improve the experiences of people living with the condition [21].

We designed an ethnographic study to investigate the entire ecosystem of DS care in Europe. Our goal was to uncover hidden insights and develop a deeper understanding of patients' and families' daily lives, based on the experiences faced by all participants in the DS ecosystem. We aimed to identify key facets and develop innovative concepts that may help, in the future, deliver concrete solutions to all stakeholders according to their specific needs. This article describes the methodology and results of this research.

2. Methods

The ethnographic research was conducted by anthropologists from InProcess, a strategic design agency, using a participatory design methodology [22]. The research was undertaken in five countries – France, Germany, Italy, Spain and the United Kingdom.

The first step was a macroanalysis of the potential factors influencing the DS ecosystem through a review of studies using the keyword 'Dravet syndrome' published in PubMed, openedition.org, Cairn, Google Scholar, and MDPI, conducted by an anthropologist. The review was refined to include articles addressing the human aspect of the disease, as opposed to the neurological aspect, and 37 relevant publications and resources were identified (Supplementary Table S1). Discussions were undertaken with local anthropologists to navigate cultural and societal differences among the five countries (social security systems, support services, administrative processes, etc.) and interviews were conducted with a pediatric neurologist and a neuropsychologist who treated the children of the families included in this study. Insights obtained from the literature review and interviews were used to develop an investigation plan.

A Steering Committee was convened, comprising two pediatric neurologists (NS and RN), the scientific director of the DS European Federation (LMA), a neuropediatric nurse (MD), a pediatric neuropsychologist (LD), and a patient representative (NB). The Steering Committee refined the investigational plan, including the criteria for participant selection (which included the demographic context, family context, and level of autonomy [physical and mental] of the CwDS; Supplementary Fig. S1), and the semi-structured interview questions adapted to each group of participants. Participants were selected to ensure that patients of all pediatric ages were included, i.e., early childhood (age < 4 years) when DS is the most severe in term of seizures, middle childhood (age 5–9 years) when the seizures are less prolonged and comorbidities need to be managed, and early adolescence and adolescence (age 10–17 years) to address the transition to adulthood. In addition, families were selected to ensure diversity, with each family representing at least one key aspect of the DS experience that we sought to explore. This approach allowed us to capture a broad range of coping mechanisms, strategies, and perceptions. The objective was to gain an in-depth understanding of the lived experiences of families of children with DS by including profiles that were emblematic of different realities. For instance, the daily life of a single-parent family with limited financial resources and an autonomous child with DS (in terms of social, motor, and cognitive functioning) may differ from that of a nuclear family with multiple children, financial stability, and a child with DS who is not autonomous from a motor perspective.

Semi-structured interviews were designed to collect information from families of CwDS, healthcare professionals [HCPs] who manage CwDS, and personnel working for DS patient organizations on the following topics (see Supplementary Table S2 for further details): the medical journey of CwDS; the perceptions of the healthcare ecosystem; daily life with DS; and expectations and vision of their future with DS. The interviews were conducted in local languages and consisted of open-ended questions followed by more probing questions to obtain additional information; the interviewer could adapt the questions depending on the participant's responses. The methods used to identify and recruit families, HCPs, and patient advocacy group members to participate in the research are outlined in the Supplementary methods.

Research with families of CwDS comprised in-depth semi-structured in-person interviews and 4–7 h of participatory observation (depending on caregivers' availability) at a venue involving the child's care (e.g., outpatient clinic, physiotherapy center) and at their home. Participating families were also asked to record video diaries on their smartphones, describing their lived daily experiences. Further details of the fieldwork are described in the Supplementary Methods.

Once the fieldwork was completed, the results were analyzed using a thematic approach [23]. The video recording and transcription app Grain were used to transcribe all interviews. Quotations were extracted from the transcripts by the anthropologist researchers and added to an Excel spreadsheet. There, the quotations were ordered thematically and tagged with relevant concepts (e.g., #dailystruggle, #equipment). Additional themes, such as motivation, development, and psychological help, were also identified. Thematic coding was validated collaboratively through debriefs between anthropologists. Cross-country discussion and iterative comparison ensured interpretive reliability, particularly regarding parental postures toward illness, consistent with qualitative and ethnographic standards. Based on the research by the anthropologists, the researchers and steering committee identified and refined four key territories of opportunity to create a world that is "Dravet ready" and developed three new concepts: (1) ecosystem of the family; (2) coping styles of parents/caregivers; and (3) emotional trajectory of life.

The study was conducted in accordance with the World Medical Association Declaration of Helsinki, and laws and institutional guidelines relevant to the countries in which the research was conducted. We obtained informed consent from all participants prior to initiation of the research. Data collection and storage were handled by InProcess in compliance with European data collection and privacy regulations and the French Commission Nationale de l'Informatique et des Libertés (CNIL). Information relevant to participants was anonymized prior to storage and all faces were blurred in the video footage. Data were encrypted and kept on a secure server. Only authorized researchers were able to access the data. Since completion of the analysis, the data are being kept in a secure archive (NetBackup) from which they will be automatically deleted after 5 years.

3. Results

In total, 20 family profiles from three countries were received and five families were selected and agreed to participate (seven parents). Five healthcare centers (21 HCPs) and five patient organizations (16 patient representatives) were contacted and all agreed to participate. A total of 44 people were interviewed (Table 1). The characteristics of the families are shown in Table 2. Patients' ages ranged from 2.5 to 10.5 years, and seizure frequency varied from once every 3 weeks to twice a year. Researchers spent 4–7 h in face-to-face sessions with each family.

3.1. *The DS ecosystem with parents as builders and orchestrators*

Fig. 1 describes the ecosystems of families of CwDS. The parents are at the center of this multi-component ecosystem that they have built by themselves by finding trusted stakeholders, and they act as orchestrators within the system. The distances between the parents/child and the stakeholders represent their proximity and importance to the family's daily life and interactions, based on the parents' description of the support they received from each stakeholder, which may evolve over time.

3.1.1. *Social identity*

Families experienced a new, challenging position in society with a substantial financial burden. One of the most impactful issues mentioned by parents was income, as one parent had to stop working to care for their CwDS, and there are significant financial burdens (cost of equipment and/or rehabilitation therapy). Another element was holidays, as most parents had experienced the cancelation of a holiday due to their CwDS having a severe seizure. This was exacerbated by associated financial loss or the increased cost of travel insurance.

One family described the financial burden:

> "*With our two salaries, we were comfortable, middle class. Now it's hard to make ends meet.*"

Table 1
Sources of data in the fieldwork.

Country	Families	Healthcare centers (no. interviewed)	Patient organizations (no. interviewed)
France	3 families – 1 parent per family interviewed	CHU de Toulouse, Toulouse (6) Nurse coordinator Pediatric neurologist Childcare assistant Psychologist for epilepsy service SMUR emergency physician Dietician	Alliance Syndrome de Dravet (3) Vice president Support to President Communications manager
Germany	–	Epilepsiezentrum Kleinwachau, Radeberg[a] (2) Psychosocial service provider Pediatric neurologist	Dravet-Syndrom e. V. (3) President (former pediatrician) Support to President Communications manager
Italy	1 family – both parents interviewed	Ospedale della Donna e del Bambino, Verona (6) EEG technician Pediatrician Pediatric neuropsychiatrist Dietician Psychologist Nurse	Gruppo Famiglie Dravet Associazone Onlus (4) President Secretary Platform project manager Social media manager
Spain	1 family – both parents interviewed	Sant Joan de Déu, Barcelona (6) Neurophysiologist Epilepsy nurse Social worker Adult neurologist (epilepsy unit) Neuropsychologist (epilepsy unit) Pediatric neurologist	ApoyoDravet (3) President Social worker Board member
UK	–	Great Ormond Street Hospital, London[a] (1) Pediatric neurologist	Dravet Syndrome UK (3) Director Medical advisory board member (retired nurse) Family support manager
Total number of people interviewed	**7**	**21**	**16**

EEG, electroencephalogram; SMUR, Structure mobile d'urgence et de reanimation.

[a] Remote contact only.

Parents also have had to learn to engage with the health, social care, and public assistance systems in new ways. They had to collect information about their child's level of handicap and complete forms (e.g., the MDPH file in France) for the handicap status to be recognized. This administrative process is particularly difficult for CwDS because the disease does not have an official definition in the healthcare system. Most parents became proficient in contacting local institutions, childcare/school systems, healthcare systems and HCPs, often encountering difficulties, ignorance, or rejection.

3.1.2. *Daily life and environment*

Families of CwDS experienced major changes to daily life that highlighted disparities both across and within countries, including physical distance from and funded access to specialist centers and support services. They learned to engage with their local environment in new ways relevant to their status as parents of a disabled child. It was difficult to access resources locally, including medical and allied health

Table 2
Characteristics of participating families involved in the fieldwork.

	Family 1	Family 2	Family 3	Family 4	Family 5
Country	France	France	France	Italy	Spain
Time spent with family, hours	7	4	4	7	5
Age of child with DS, years	2.5	9.5	5.5	4	10.5
Driving distance to medical facility	<1 h	<1 h	<1 h	≥1 h	<1 h
Family income	Low	Low	High	High	Low
Family structure	Nuclear family, 4 children	Single parent	Nuclear family, 2 children	Nuclear family, 1 child	Nuclear family, 2 children
Siblings	3 older	1 younger	1 younger	None	1 older
Autonomy of the child with DS					
Physical	Walking	Walking	Walking	Walking	Walking
Mental	Attending specialized school	Attending specialized school	Attending mainstream school	Attending mainstream kindergarten with special assistant	Attending mainstream school
Social	Talking is difficult	Talking is difficult	Talking	Talking is difficult	Talking is difficult

DS, Dravet syndrome.

facilities and services, leaving families feeling unsupported and abandoned. As a result, parents often created new social links with other parents of CwDS or with patient advocacy groups. One parent stated:

> "*I became president of the parents' association, because I was interested in the town and the school, and … I wanted my daughter to have … what she needed.*"

Patient advocacy groups were important for answering questions and providing advice and practical support with equipment and adjustments. None of the families had the support of a social worker. Similarly, psychologists were only accessed when families actively requested their involvement, which suggests a significant unmet mental health need.

3.1.3. *Family dynamics*

The families in our sample experienced having a CwDS as an impact that redefined the family unit, impacted the parents as a couple and as individuals, and affected parental mental health. Parents needed to change their expectations of what the future would be like, and many needed to adjust their working lives and their housing arrangements. For example, one family described the need for changes to be made to their dwelling:

> *"We had to fight with the building management to install an elevator in the building".*

Families with CwDS are at risk of social isolation, but do not want their family's life to revolve exclusively around DS. These families rely on close and extended family members (including grandparents) for emotional, practical, and sometimes financial support.

3.2. *Framework for parent coping styles*

We used dual-factor analysis to develop a quadrant map that could visualize the effects of simultaneous risk factors and protective factors on parental coping strategies. Based on the data collected, the quadrant map defined the extent to which the parent wanted to control the environment/situation for their CwDS and their considered level of expertise (Fig. 2). The four coping styles are the castaway, the gatekeeper, the personal assistant, and the maestro. Control varies from wanting complete control (of the environment, child's health, care provided by HCPs, amount of information available) to delegation (letting go of issues that cannot be controlled, giving power over the child's situation to others). The parents consider their level of expertise to vary from being an expert (in the child and their disease) to being a novice (does not always understand what is happening to the child and his/her way of expressing their disease). Coping is a dynamic process that evolves over the child's disease trajectory and circumstances. The framework illustrates how parents deal with the information and choices they make, and shows the various positions they may find themselves in at different times in the disease trajectory (Fig. 2).

The coping style framework is dynamic and parents may move through different sectors in response to their child's disease trajectory and evolving condition, the support provided to them, and their capacity to cope with the situation. For example, parents usually begin as castaways when they are unaware of the diagnosis or newly aware but lack knowledge of the implications. As parents find a trusted HCP and develop a greater trust in the medical guidance available, they could transition from a castaway to a maestro (via the gatekeeper and personal assistant). The maestro stage is reached when a parent has built a trusted ecosystem around their child and is willing to let others take care of some aspects of daily life. However, they do not remain in this stage permanently.

The levers that assisted in this transition included building an effective support system (e.g., by joining a relevant charitable association), requesting psychological help, reducing the focus on seizures, experiencing all the facets of DS, and developing a more holistic view

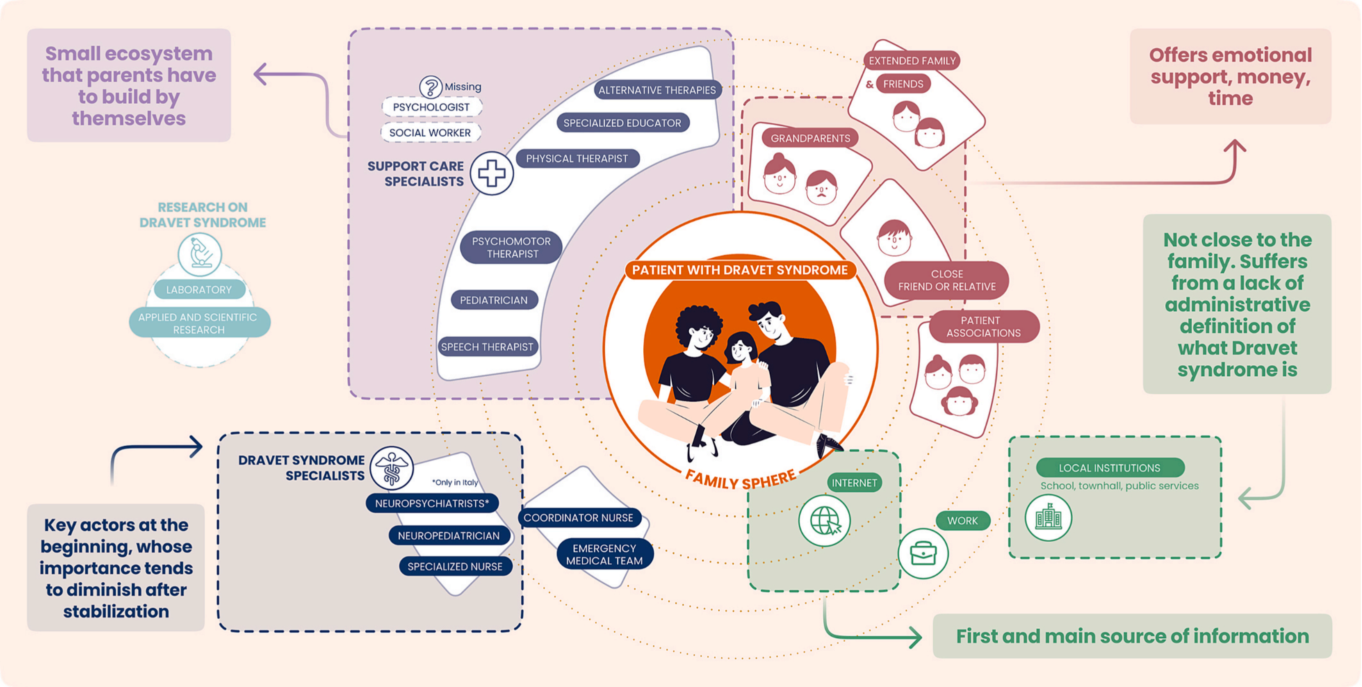


Fig. 1. Factors making up the ecosystems of the family with a child who has Dravet syndrome. The parents are at the center of this multi-component ecosystem and act as orchestrators. The distances between the parents/child and the stakeholders (shown as circles with dotted-lines) represent their proximity and importance to the family's daily life and interactions, which may evolve over time.

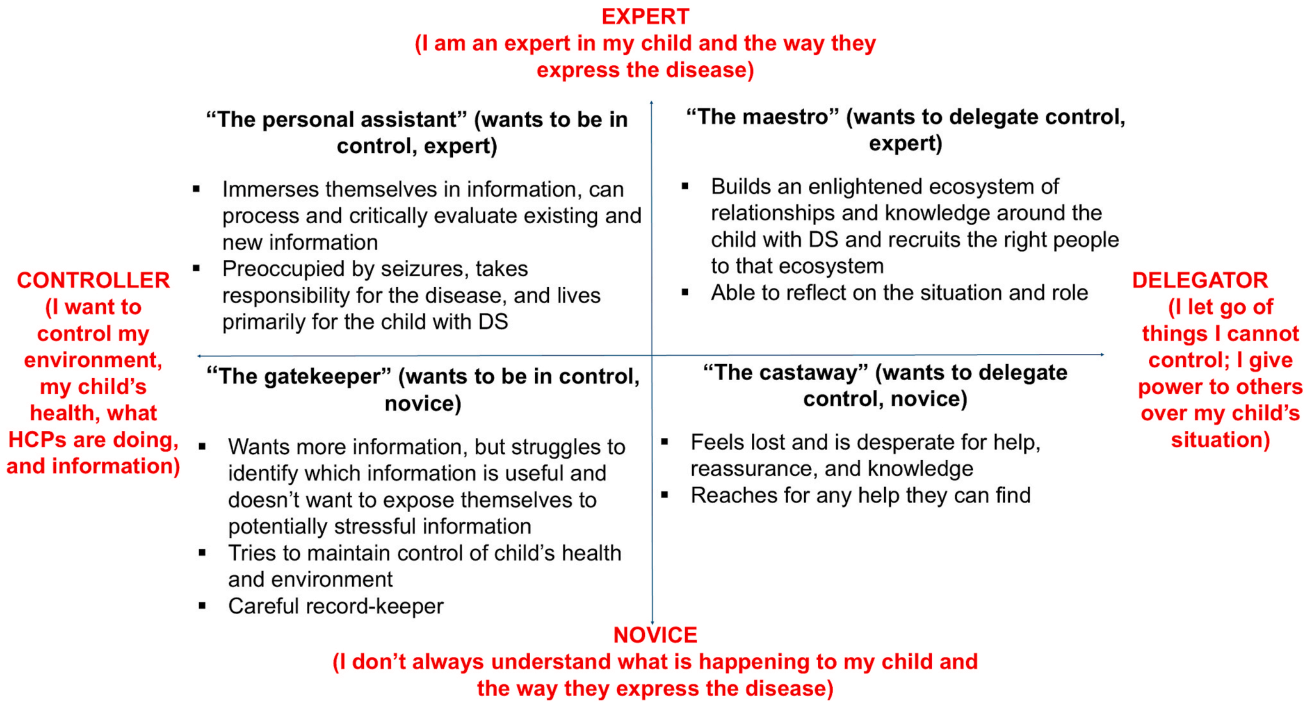
and acceptance of the disease.

3.3. *Emotional trajectory of life with DS*

We tried to model the emotional reactions of families living with DS and how they change over time (Fig. 3). The research highlighted specific issues and needs at different stages of the disease trajectory.

3.3.1. *First seizure*

The first seizure was identified as a traumatic event (Fig. 3); parents were fearful that their child was dying. Parents were asked by hospital staff to recount the details of this first seizure (e.g., nature of the



EXPERT
(I am an expert in my child and the way they express the disease)

"The personal assistant" (wants to be in control, expert)

- Immerses themselves in information, can process and critically evaluate existing and new information
- Preoccupied by seizures, takes responsibility for the disease, and lives primarily for the child with DS

"The maestro" (wants to delegate control, expert)

- Builds an enlightened ecosystem of relationships and knowledge around the child with DS and recruits the right people to that ecosystem
- Able to reflect on the situation and role

CONTROLLER
(I want to control my environment, my child's health, what HCPs are doing, and information)

DELEGATOR
(I let go of things I cannot control; I give power to others over my child's situation)

"The gatekeeper" (wants to be in control, novice)

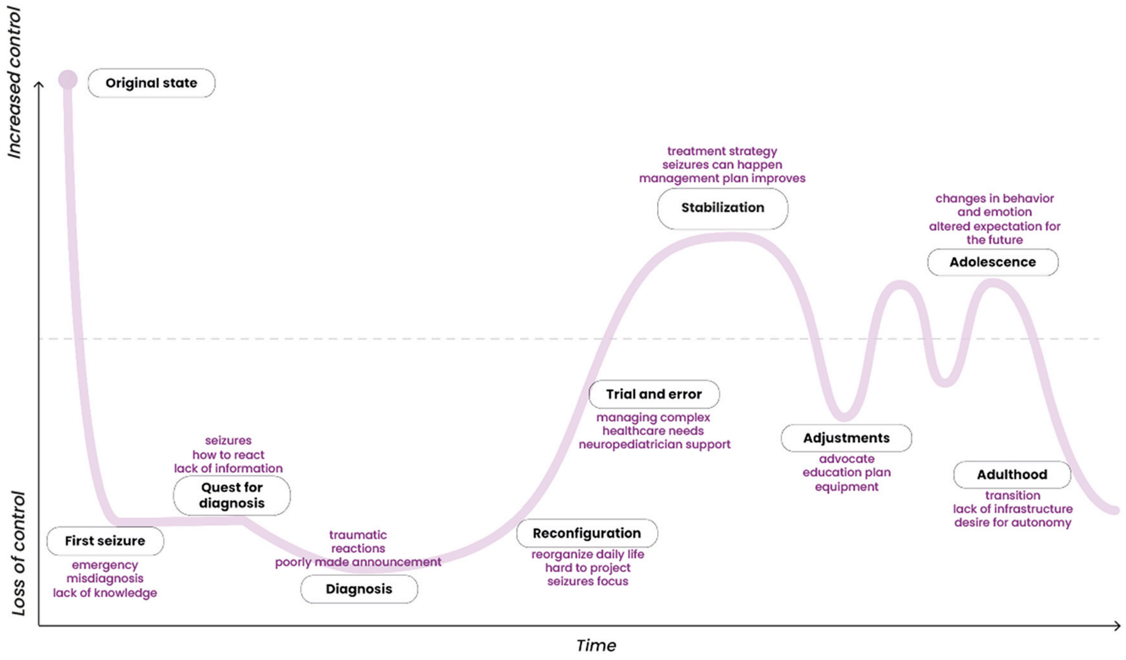
- Wants more information, but struggles to identify which information is useful and doesn't want to expose themselves to potentially stressful information
- Tries to maintain control of child's health and environment
- Careful record-keeper

"The castaway" (wants to delegate control, novice)

- Feels lost and is desperate for help, reassurance, and knowledge
- Reaches for any help they can find

NOVICE
(I don't always understand what is happening to my child and the way they express the disease)

Fig. 2. Coping styles of parents/caregivers of a child with Dravet syndrome (DS) using segmentation analysis. The four levels of expertise with the child's DS and delegation/control of their environment/situation are shown in red. HCP, healthcare professional. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)



Step	Patient/family needs
First seizure	Information about febrile infant seizures
Quest for diagnosis	Trustworthy information on the diagnostic process Information about how to react during and after seizures
Diagnosis	Information about DS that they can review later Counselling/psychological support Someone who can answer questions as they arise
Reconfiguration	To build relationships with their HCPs Psychological and practical support to navigate the changes to their life and their implications To build a supportive ecosystem around the child and the family
Trial and error	Trust in the healthcare team Support to deal with seizures and care for the child so that parents can care for themselves
Stabilization and restoration	Access to educational and rehabilitative resources Information about future disease trajectory and treatment options Less frequent interaction with HCPs DS association involvement
Adjustments	More frequent interaction with HCPs Practical support to navigate changes
Adolescence	Parental understanding of behavioral changes/need for autonomy Adjustment to changes in seizure type or frequency
Adulthood	Smooth transition from pediatric to adult healthcare (without loss of continuity) Social and legal infrastructure to support patient with DS to live as independently as they can

Fig. 3. Emotional trajectory of life with Dravet syndrome (DS) and the needs of families at each stage. HCP, healthcare professional.

movements, paralysis, and duration), yet may not have noted all of these details in the urgency of the situation. Parents returned home, shaken by the experience and may have felt that the hospital staff had downplayed the severity of the event if the seizure was dismissed as a typical febrile infant seizure. These traumatic early experiences for parents were not always taken into account by HCPs. Without proper acknowledgment of the trauma, parents often did not receive the psychological support they needed.

3.3.2. *Quest for diagnosis*

Parents and HCPs experienced the quest for diagnosis very differently (Fig. 3). HCPs often suspect the diagnosis and are aware of the likely impact on families before the diagnosis is confirmed. The healthcare team examined clinical features and carried out diagnostic tests (including electroencephalography) and DNA studies. The step-by-step approach is typical of many medical diagnostic pathways that include eliminating other potential causes before landing on the most likely or confirmed cause. The delay in receiving DNA test results varied between countries. The expertise of pediatric neurologists appeared to be important for a rapid diagnosis.

For parents, the quest for a diagnosis felt like it took a long time, as a result of the step-by-step process and delays in accessing expertise and test results. During this time, their child continued to have seizures, which were emotionally and physically difficult for the parents and required multiple visits to the emergency room, and sometimes admission to the intensive care unit (ICU). Parents were required to engage with the medical system, and to reorganize their family lives so that one parent could stay with the child who was recovering/undergoing tests. This was a period of great concern when parents felt powerless and frustrated by the lack of information about what was happening to their child, and were seeking out information online. During this phase, some caregivers had put their professional lives on hold.

Statements from parents highlighted the sense of helplessness during this period:

> *"It took more than a year before they managed to provide a treatment which stabilized her, and that was a difficult time because we felt helpless."*

3.3.3. Diagnosis

At diagnosis, HCPs observed that some parents already suspected their child had DS, based on their own internet research (Fig. 3). Other parents were not expecting a DS diagnosis and had more difficulty taking in the information. The emotional impact can be both positive (relief at finally having a diagnosis) and negative (learning that their child has an incurable condition). Different healthcare centers employed different strategies for informing parents of the diagnosis, with some inviting the psychologist from the team to attend the diagnosis meeting, and others scheduling a second meeting with the hospital social worker, psychologist, or specialized nurse. There was no protocol for best practice in delivering a DS diagnosis, and each healthcare center had its own practices and procedures.

A statement from a pediatric neurologist highlighted the different needs of parents that the healthcare team should accommodate:

> *"Having some information that we can give the families to take away, is very helpful. So we don't have to tell them everything and sometimes our nurse specialists can spend a bit more time with the families. …. Some of the parents just want to leave after hearing the diagnosis."*

At the diagnosis meeting(s), the healthcare team adapted the information to the needs and emotional state of the parents, but usually covered what epilepsy and DS were, the spectrum of the disease, different seizure types, and treatment strategies. Many parents needed psychological support to navigate these changes to their lives and the implications thereof.

A nurse coordinator explained how information should be delivered to parents at different times according to what they need:

> *"You also have to be able to address certain topics according to how people evolve. There are times when you realize that there's no point in telling parents certain things that they're not going to want to hear."*

A statement from one pediatric neurologist highlighted the need to address some of the difficult issues in DS in a sensitive way:

> *"My role is not to be a psychologist. My role is to support parents, and …. from time to time, my role is also to make them face certain realities, to tell them certain things that they don't want to hear, and to tell them in a gentle but firm way. Thereafter, the psychologist should provide follow-up support."*

Even if the healthcare team handled the situation well, the DS diagnosis remained a traumatic moment for caregivers, to the point that they did not recall all the information they were given. One parent's comments exemplified the magnitude of the DS diagnosis in their lives:

> *"We all remember September 11. Where we were, what we were doing. And for us, that trauma of the first seizure or the announcement of the diagnosis, it's the same."*

Parents were full of questions about what their child's future held, but the HCPs' usual response was "we don't know yet." A pediatric neurologist noted the sense of isolation and fear that parents face after a DS diagnosis:

> *"Families tell us that it is when they close the office door that the abyss begins. You can … explain very well, with a lot of empathy and sensitivity, but then the door of your office closes and these people go home. And that is where we fail."*

3.3.4. Reconfiguration

The diagnosis marked the beginning of a reconfiguration, during which parents grieved the fact that they did not have a healthy child and had to adjust their lives to the new reality (Fig. 3). One parent described it like this:

> *"We've been through mourning. You have an idea, when you are pregnant, that you are going to have a healthy child, and …. suddenly everything falls apart. Your daughter is not dead, but you have to … bury a daughter you thought you were going to have, to start a new life with a child who is sick."*

Parents started to build a support ecosystem with family members, and institutional, administrative, and healthcare support systems. During this period, some parents sought a second opinion and/or reached out to patient associations.

The diagnosis forced parents to redefine every aspect of their lives: their perception of the future, dreams and ambitions, family dynamics and parental roles. This reinvention was a journey that each parent took at their own pace and sometimes differed between the partners in a couple. The impact on the dynamics of the couple was exemplified in this comment from a parent:

> *"[T]wo things can happen with couples: either they separate because they are overwhelmed by the situation, or they get even closer together. In our case we came together."*

At this stage, parents wondered what the future would hold for them, what it would be like to have a CwDS, and what their child's life trajectory would be. With no clear answers, many parents struggled to prioritize, make decisions, and take action. During this phase, parents focused on the visible symptom of the disease: the seizures. Because these were unpredictable, parents reacted by trying to control every other aspect of their child's life, such as vital signs, activities and environment, and known triggers. They often controlled social activities or imposed very strict hygiene rules to reduce the risk of infection, and parents with older children considered home-schooling. This was exemplified in a comment from one mother:

> *"I tended to want to put her in a bubble. Fortunately, my husband didn't. … I really wanted to protect her, to get rid of all the germs, but at the same time I knew that he was right. This enabled me to change my point of view little by little."*

3.3.5. Trial and error

Parents and HCPs shared the common goal of reducing seizure frequency and duration. Despite the availability of treatment guidelines for DS [6], there is still an element of trial and error in treatment plans (Fig. 3). Caregivers were learning to observe the seizures, take notes, and record the seizures to provide HCPs with feedback on the nature of the seizures (type and duration) and potential triggers, as well as any adverse effects of medication. At this time, parents often found the information about treatment frightening, which can lead to an ambivalent relationship with treatment. This was exemplified in the following comment from one mother:

> *"So now we're really going to start drugging our 5-month-old baby? But then again, we don't have much choice. But it's very hard to accept. We've never not given the treatment voluntarily, but it's really hard."*

The process of trial and error was difficult for parents to understand. One pediatric neurologist described it like this:

> *"I spend a lot of time explaining to parents that if they have the impression that we practice medicine according to the principle of trial and error, then they are right."*

3.3.6. Stabilization

Once the frequency and intensity of the seizures were considered reasonable by the pediatric neurologist, the CwDS was considered to be in stabilization (Fig. 3). In this phase, the healthcare team saw the patient less often (e.g., once a year).

During this period, seizures still occurred but caregivers were aware of how to manage them, and could focus on their child's development. In addition, the family's daily life had become organized around the limitations of the child, and parents were more familiar with the need to suddenly change plans in response to a seizure. They had to face the constraints of their child's capabilities (e.g., not being able to attend a mainstream school). Most caregivers spent a lot of time searching for the right support care specialist/teacher aide, which was affected by the cost and distance of resources.

Rehabilitative therapies allowed parents to plan and set objectives for their child's future. An example statement exemplified the process of seeking out suitable therapies*:*

> *"I began to open to the possibility of rehabilitation, to what we could start putting in place. I started with music therapy. … I thought, why not, he loves making noise."*

A difficult reality for parents was facing the lack of inclusivity at local institutions, particularly educational institutions. There were regional disparities in access to local institutions, such as schools, specialized institutes and public services (social services, healthcare services [hospitals], transportation, etc.). Epilepsy centers may have refused the child based on his/her behavior or developmental delays, and specialist autism centers may have refused the child due to his/her epilepsy. Each parent had to advocate for their own situation as they faced the lack of inclusivity in society and the lack of knowledge around epilepsy. Nursery and/or school registration had to be anticipated and negotiated, and education professionals had to volunteer to be trained on epilepsy. In addition, related public services, such as school transportation and the cafeteria, may have refused to serve CwDS because their personnel were not trained in managing an epileptic seizure. These issues were evident in the comments from a mother:

> *"I had to fight with the childcare center because they wouldn't take my son. He was registered before his condition, but when I stated his needs, they said they didn't have the resources. I had to …. assert my rights. It was a long battle that took me almost a year."*

The stabilization phase was a time when caregivers started to focus on aspects of their child's function other than seizures, and question what was due to the disease or treatment, what was due to their child's personality, and how they could reorganize their family life accommodating their CwDS. One family described this period as follows:

> *"We are taking things slowly, at our own pace. For now we are enjoying the absence of seizures, sticking to our routines and cautiously taking small steps towards attainable goals, like a vacation ….. We were NOT in this state of mind this time last year."*

Families benefited from being involved in associations, exchanging tips, and talking about their child with other parents. One mother in France described the value of the patient association:

> *"All the questions we had around the crises, around the equipment… it's true that we got a lot closer to the parents through the association. That's a big, big, big help."*

During the stabilization phase, some parents felt the need to act and spread awareness, or even to look for solutions to feed their hope, for example, via alternative therapies with no evidence-based benefit.

3.3.7. Adjustments

Throughout the trajectory, adjustments were made in response to the natural history of the disease, the child's development, and the knowledge/needs of the caregivers (Fig. 3). Over time, parents often started to question the treatment strategy and asked for adjustments, particularly if there was an increase in seizure frequency and/or intensity, or if the child's condition stabilized and parents wanted to reduce medication. This illustrates how difficult it could be for parents to understand the importance of maintaining consistent treatment.

Treatment was not the only factor that required adjustment. Equipment and education may have also needed to be adapted as the child grew or if they evolved in an unanticipated way. Caregivers may have also wanted to change rehabilitative services as their child's status evolved. Many parents had to advocate for those adjustments by approaching the health or welfare system for new equipment, local institutions for educative plans, support care specialists for new development objectives, and the pediatric neurologist for a change in the treatment strategy.

3.3.8. Adolescence

None of the families included in our sample had an adolescent with DS; the findings presented here are based on interviews with HCPs and members of patient advocacy groups. It was noted that adolescence can be a major period of adjustment because seizures may return in different forms (e.g., during sleep) and that the CwDS is undergoing hormonal changes, becoming more self-conscious, and/or seeking autonomy (Fig. 3). Behavioral problems may worsen as the CwDS can develop new difficult-to-manage behaviors. A pediatric neurologist described the challenges of adolescence in this way:

> *"The patient becomes aware of his or her limitations, even if they are not severe. This awareness can cause frustration ….The disability also makes it more difficult for them to regulate their emotions and, together with their underlying pathology, they may present with more behavioral problems."*

Physical changes may also require the acquisition of equipment suited to adults. By the time most young CwDS reach adolescence, they will have severe intellectual impairments, and their support needs during adolescence, including around sexuality, mental health, and access to activities, will require specialized input from a wide range of professionals.

3.3.9. Adulthood

None of the families included in our sample had an adult CwDS; however, the HCPs and patient organization members interviewed mentioned that the transition to adulthood can be challenging and difficult for all parties to move through (Fig. 3). Patients transition to a new medical system, in which neurologists specialize in epilepsy but not in behavioral and/or developmental issues. Most healthcare systems do not have a protocol for ensuring continuity of care or easing the transition from pediatric to adult care. This can be a difficult change for caregivers and patients as they move to a new healthcare center, with personnel who were not familiar with their child's condition, needs, and challenges. Gaining access to psychological support for managing challenging behavior or mental health issues for the adult patient with DS may be especially difficult during this transition. Parents' expectations of whether their adult-child might remain at home or be cared for within a community residential facility are also major considerations.

Another challenge is the lack of adapted infrastructure for adults with DS. Parents are required to anticipate problems in advance and find or create the appropriate infrastructure that allows their adult-child to live independently but safely. When asked about adulthood and how they anticipated this step, parents may be very anxious and have difficulty projecting what this might mean for their family. Some parents feel guilty or regret not having done enough when their child was young to help them to be able to live autonomously as adults.

3.4. Territories for opportunity to support caregivers

The research identified four key territories of opportunity to create a world that is “Dravet ready”, in which the material and social environment enables patients with DS and their families to fully participate in daily life and to structure their future.

- Cushioning the shock of a DS diagnosis and building something new, so that parents are equipped from diagnosis and have the holistic support they need to manage their daily lives.
- Making reliable information and education more accessible for parents, by creating a synergy between all the trusted players locally, nationally, and internationally.
- Creation of a seizure-ready world, in which society is no longer scared by epilepsy, and people understand the disease, allowing parents to feel more supported, less stigmatized, and more confident about letting their child take on challenges.
- Being able to sustain a life journey with DS, so that parents and caregivers are supported throughout their lives (both within and outside the healthcare system) in a manner that is adapted to each individual’s specific needs.

3.5. Reflexivity statement

The anthropologists who conducted the field research had no previous exposure to CwDS or their families. They engaged in face-to-face contact with study participants, which may have been challenging. As such, we considered that their interactions with participants might have been influenced by their own professional backgrounds, experiences and prior assumptions, which may have also limited participants’ willingness to talk openly about their experiences. Based on the pre-study literature review, the researchers, steering committee and sponsor (Biocodex) expected families of a CwDS to be experiencing challenges, particularly in the early period after diagnosis, so we must consider how this may have shaped our approach to the participant interviews and to interpretation of the findings. While Biocodex attended the steering committee meetings, they did not participate in the field research, data analysis, or interpretation and reporting of the results.

4. Discussion

To our knowledge, this is the first study to use participatory methodology including parents, HCPs, and patient associations to gain insights into the wider ecosystem of DS. Previous studies into the impact of DS have used semi-structured interviews to gain qualitative information [10–12], but have not been so broad in scope.

Participatory methodology involves using multiple routes to understand the participants’ experiences, which allowed us to simultaneously identify not only what they say and do, but how they express their unspoken thoughts, feelings, and dreams [20]. We included families of CwDS who exhibited different characteristics to explore a variety of lived situations. The use of a small group of carefully selected participants allowed the fieldwork to go ‘deep’ instead of ‘wide’ and identified issues that were common to most families, as well as points of difference between families. The small sample size also allowed the researchers to spend considerable time with each stakeholder group; thus, allowing detailed information about the issues important to each group to be obtained. From this, we were able to conduct a thematic analysis to identify recurring information from families of CwDS in different countries, with different circumstances and caring for CwDS of different ages (2.5–10.5 years), thus confirming the validity of our findings.

A novel outcome of our research was the development of a framework of parent coping styles (Fig. 2). The style changed as parents moved through the different phases of their child’s development and disease progression. Another key finding of our study was the emotional adjustment of families caring for CwDS (Fig. 3). These results could assist those working with families to identify points of transition or change in the DS journey, tailor their advice, support the individual family’s needs, and build shared recognition and expectations between families and HCPs, patient organizations and local institutions.

Other researchers have investigated coping styles among parents of CwDS and applied a different framework. Nolan and colleagues described coping mechanisms as internal (e.g., personal research about DS, religious faith) and external (e.g., support from family/friends, patient organizations), noting that their needs for each type of mechanism changes over the course of the disease [24]. It is likely that these two mechanisms are interdependent. Research in children with epilepsy has shown that parents who seek more information are also more likely to seek out and obtain external support [25]. This is consistent with our model of coping whereby a parent’s coping style is predicated on changes in their knowledge and sense of control. Recently, Mercier and colleagues defined two stages of coping for parents of CwDS: initial coping and secondary coping [16]. Initial coping is characterized by trauma, a sense of being in ‘survival mode’, hypervigilance, guilt, and hopelessness (potentially analogous to the phase we described as castaway). Mercier and colleagues also noted that parents in the initial coping stage described themselves as being a medical professional parent and the only person who could provide their CwDS with care [16], feelings that we categorized as being characteristic of a gatekeeper or personal assistant coping strategy. Secondary coping is characterized by receiving and accepting support, reclaiming identity, acceptance and growth through the experience [16], analogous to the maestro coping strategy.

Our data confirm previous research highlighting the challenges faced by families of CwDS, including financial pressures [10,12,13,15,26–29], the time commitments of healthcare visits, and the impact of these visits and other aspects of care on their availability to work (mostly for mothers) [12,13,15,17,26,27,29–32]. Our data also reinforced previous findings on the effects of DS on caregivers’ psychological and emotional wellbeing, including fears for the future, stress, depression and anxiety [10–13,17,27,28,30–32], social isolation and stigma [10–13,16,27–29], and feeling inadequately supported by healthcare and social systems [16,32]. Our findings also demonstrated that the magnitude and impact of these challenges wax and wane over time as families move through the emotional trajectory of DS.

Having a CwDS puts pressure on relationships [12,28–31] and negatively impacts the lives of their siblings [10,13,15,31–33]. Many parents struggle to manage behavioral problems in their CwDS [11,27,29]. Sleep is often disturbed [12,13,17,27,30,31], contributing to parental fatigue [11–13,27].

Our research highlights the need for emotional and psychological support for parents and caregivers of CwDS, particularly during turning points in the patient journey, and confirms previous reports of stigma and social isolation among parents of children with rare neurodevelopmental disorders [11]. This need has been previously recognized in international surveys among parents of CwDS, who noted emotional support and respite care as key needs [34]. Our discussions with families highlighted two key barriers to accessing this type of support: (1) a lack of emphasis on the mental health/wellbeing of parents and caregivers (from the perspectives of both parents/caregivers and HCPs); and (2) economic and logistical barriers (whereby patients cannot afford or have no access to the support they need, or do not have time to engage in psychological sessions because of the time commitments associated with caring for a disabled child). The parents we interviewed reported difficulties in accessing educational support or practical help for mobility issues, a finding that has been reported previously [10,29,31]. These problems are often exacerbated by fragmented delivery of care [11].

Gaining deeper insight into these challenges is particularly important for a rare disease like DS, because parents of children with a rare disease often feel that their experience is unknown or misunderstood by HCPs [35]. Many of these parents need to become advocates for their children to obtain the services they need [35]. We anticipate that the holistic nature of the insights gained from the current study will facilitate the development of strategies and solutions to improve the lives of patients with DS and their families, while also recognizing the challenges faced by the patient organizations and HCPs who support these families. The success of our methodology also suggests that ethnography could be used to examine issues outside the direct DS ecosystem, such as those related to the wider healthcare setting.

A strength of our research is the innovative ethnographic approach that we used to obtain insight into the lived experience of 44 individuals from various settings, allowing a more precise understanding of the multidimensional reality of DS. Previous qualitative research in DS has focused on individual groups (e.g., parents/caregivers). To our knowledge, this is the first study to obtain an integrated analysis of the DS ecosystem, encompassing families, patient organizations, physicians, allied health professionals, and childcare specialists. In addition, most previous research has relied on interviews, whereas our ethnographic approach employed a mix of interviews and extended direct observation (4–7 h with each family). Like other DEEs, DS is a rare condition, which presents difficulties in enrolling an adequate number of participants. We used purposeful sampling [19] to recruit five families with various characteristics and, thereby, obtained a sample diverse enough to allow us to conduct a thematic analysis and identify commonalities. However, we recognize that the small number of participants ($n = 44$) who were interviewed is a limitation to our study. A further limitation is that none of the families who allowed direct observation of their lives had an adolescent or adult CwDS. This gap is partially addressed by our research among patient organization members (some of whom are parents of DS patients) and HCPs who provide support for older DS patients, but there remains a need for additional studies to obtain real-world data from families caring for such individuals, including how they cope with their child’s transition from adolescence to adulthood. Also, our research focused on HCPs who were DS specialists or encountered a reasonable number of CwDS during their usual clinical practice. It is difficult to identify HCPs who may have occasional *ad hoc* encounters with patients who have DS, such as general practitioners, and so we did not interview such individuals in our research. While we did not obtain the impressions of these HCPs, the scope of the fieldwork allowed us to collect data on how these ‘less experienced’ individuals are perceived by families and specialists. Moreover, our research did include a wide range of HCPs and not just those involved in epilepsy care, including an emergency physician, nutritionists, EEG technicians, a pediatrician and social worker.

5. Conclusions

To our knowledge, this is the first study to use ethnographic methodology to assess the ecosystem of DS from a range of affected individuals, including 44 participants who were family members, HCPs, or involved with patient organizations. This methodology is an innovative process that involves consideration of the real-life perspectives of stakeholders, information that is often absent in the data obtained from clinical studies. Using this methodology, we developed a holistic understanding of the DS ecosystem, and the next step in the process is to translate what we have learned into impactful and concrete solutions for HCPs, patients and their families in that ecosystem. These solutions will take into account the specific needs of the patient and their family in relation to their place on the disease trajectory and coping strategy quadrant and will likely include guidance for HCPs on how to recognize these positions and anticipate transitions. Our results demonstrate the usefulness of ethnographical methodology and suggest that it could be incorporated in future studies of DS and other DEEs that aim to assess stakeholder perspectives, and that the methodology may also be useful for examining issues outside the direct DS ecosystem.

Data availability.

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

CRediT authorship contribution statement

Liam Dorris: Writing – review & editing, Resources, Methodology. **Luis Miguel Aras:** Writing – review & editing, Resources, Methodology. **Marion Danse:** Writing – review & editing, Resources, Methodology. **Nadine Benzler:** Writing – review & editing, Resources, Methodology. **Caroline Hachon-Le Camus:** Writing – review & editing, Resources. **Francesca Darra:** Writing – review & editing, Resources. **Carmen Fons:** Writing – review & editing, Resources. **Robert Robinson:** Writing – review & editing, Resources. **Nils Holert:** Writing – review & editing, Resources. **Pauline Afonso:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Resources, Project administration, Conceptualization. **Perrine Hugon:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Project administration, Conceptualization. **Selva Gaberscek:** Writing – review & editing, Writing – original draft, Visualization, Validation, Investigation, Formal analysis, Conceptualization. **Letizia Nardi:** Writing – review & editing, Writing – original draft, Visualization, Validation, Investigation, Formal analysis, Conceptualization. **Nicola Specchio:** Writing – review & editing, Resources, Methodology. **Rima Nabbout:** Writing – review & editing, Resources, Methodology.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

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