
Adolescents with Cystic Fibrosis Expressing their Possible Selves through Photovoice: A Longitudinal Interpretative Phenomenological Analysis to Prepare a Peer Support Intervention for Healthcare Transition

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Cover Page Footnote

We thank the adolescents who agreed to participate in the study and were involved in sharing their experiences and imagining new possibilities together. We thank the healthcare teams who contributed to the recruitment of study participants. We thank the Association Gregory Lemarchal for financially supporting the project.

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RESEARCH

Adolescents with Cystic Fibrosis Expressing their Possible Selves through Photovoice: A Longitudinal Interpretative Phenomenological Analysis to Prepare a Peer Support Intervention for Healthcare Transition

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ABSTRACT

While the transition from pediatric to adult care has become a field of study and practice focused on preparing the adolescent to “become an adult with a chronic condition”, we are conducting participatory research to develop, implement, and evaluate a peer-support intervention aimed at supporting transition from pediatric to adult care for adolescents living with cystic fibrosis within two hospital centers in France. In preparation for this intervention, we would like to better understand *how* peer support *could* support identity self-determination of the adolescents. We conducted a longitudinal qualitative research using *photovoice* technique. For one year, 8 French adolescents (15–18 years old) with cystic fibrosis were interviewed 3 times (every 6 months) and, based on a photo representing what “becoming an adult” meant to them and that they had taken, they explained their experience of transitioning to adulthood. Data were analyzed using the interpretative phenomenological analysis approach. The evolution of adolescents’ capacities to integrate disease into their identity and imagine possible selves that are not determined by the disease varies depending on a range of exploratory processes and self-event connections that we mapped to produce a dynamic framework of “illness identity” development. Rejecting master narratives of illness identity, adolescents seek to develop a self-determined gaze, mobilizing cultural and social mediation in particular. In this sense, peer support intervention could support the adolescent’s agentivity.

Keywords: Patient experience, Peer support, Longitudinal interpretative phenomenological analysis, Photovoice, Healthcare transition

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1. Introduction

Over nearly 40 years, transition from pediatric to adult care for adolescents living with a chronic condition has become an indispensable field of study and practice in public health.^{1,2} While educational practices associated with healthcare transition engage adolescents in their identity development by acting as a social information source on what “becoming an adult with a chronic condition” means,³ the identity dimension of healthcare transition needs to be further documented.⁴ Indeed, research in psychology highlighted that living and growing up with a chronic condition threatens the identity development of adolescents. Self-narrative and the exploration of possible selves may be reduced to the role of a “sick person”,^{5,6} limiting the necessary processes of exploration for identity construction and adolescent development.⁷

The phenomena of limited self-determined identity among adolescents living with a chronic condition are now widely documented.^{8,9} However, we currently lack knowledge about the effect of educational interventions on the identity development of adolescents living with a chronic condition, particularly in the context of healthcare transitions. That is why we align our approach with a liberation psychology approach¹⁰ and health intervention research¹¹ aiming to generate knowledge with the ambition of social transformation.

In this perspective, with the University Hospitals of Lyon and Grenoble (France), we are currently conducting participatory research aiming to design, implement, and evaluate a peer support intervention for adolescents living with cystic fibrosis during transition from pediatric to adult care aimed to facilitate psychosocial development. Cystic fibrosis is a severe inherited genetic, with respiratory impairment at the core of prognosis and treatment, that requires regular follow-up at a specialized cystic fibrosis center. On the one hand, we know that adolescents living with cystic fibrosis who have difficulty detaching themselves from their identity as ‘being sick’ experience more discomfort and/or encounter more medical complications.¹² However, studies on intervention programs to facilitate identity development are limited. As highlighted by Harrigan et al.,¹³ the literature currently only allows us to conclude that there is a need to raise clinicians’ awareness about the importance of identity development in adolescents living with cystic fibrosis, while the production of knowledge through interventional and longitudinal studies is recommended. On the other hand, we know that adolescents with cystic fibrosis seek more

experience-sharing opportunities with peers, to learn to live and grow with the disease.¹⁴ Indeed, peer support is relevant as a mutual support among individuals who have similar difficult life experiences.¹⁵ While studies have shown the promise of peer support in improving knowledge and attitudes, reducing risk behaviors, and enhancing self-management behaviors,¹⁶ no study has explored the processes and effects of peer support in healthcare transition among adolescents living with cystic fibrosis, and no study has explored the links between identity development and peer support among adolescents with a chronic condition.

Therefore, we led a preparatory study of the intervention on adolescents’ needs to better understand *how* peer support *could* promote their identity development during transition from pediatric to adult care. Indeed, participatory processes can hardly be effective in bringing about changes if they do not rely on a deep understanding of the stakeholders’ perspectives.¹⁷ Our approach was rooted in developing interventions based on the target population,¹⁸ aiming to draw on the viewpoints and practices of intervention beneficiaries or those representative of them. Our research question was “*how peer support could support identity self-determination of adolescents with cystic fibrosis*”? The objectives of the study were to explore how adolescents learn to self-determine in expressing their narrative identity, to understand the mechanisms of change and stability at play, and to identify the potentialities of action of a peer support intervention.

2. Materials and methods

2.1. Type of study

We conducted a longitudinal qualitative research (LQR). LQR aims to study how and why experiences change over time.¹⁹ It is a specific qualitative method emerging in the healthcare field, with the major premise that human experiences are rarely composed of concrete events limited in time; rather, they evolve and change over time.²⁰ LQR is particularly suitable for studying transition processes.²¹ The choice of LQR is also motivated by the fact that research on adolescents with chronic condition identity development mainly adopts a quantitative approach (focused on objectifying trajectories), a cross-sectional approach (addressing adolescence less as a process than as a state), and a fundamental approach (without considering the interventional dimension). In our study, we placed adolescents in a situation of self-inquiry based

on lived experience (cognitions, emotions, sensations, etc.) with a view to addressing problems identified during the process and preparing for the intervention under development. Adolescents took part in three in-depth semi-structured interviews over the course of a year.

2.2. Paradigm & framework

Our approach was phenomenological in the sense that it aimed to understand how the experiences lived by adolescents shaped their perception of the world, how they imagined the future, and how they made sense of it. We subscribed to the theoretical and methodological framework of Interpretative Phenomenological Analysis (IPA).²² We were particularly interested in exploring who the adolescents *will be* and not just who *they are*, focusing on the possible selves defined as representations of individuals' ideas of what they might become, hope, or fear to become.²³ This situated our study within Sartre's phenomenology, which considers the human condition in terms of freedom of existence and the necessity to make choices in a constant state of becoming.²⁴

2.3. Participants

The participants in our study were adolescents aged from 15 to 17 years living with cystic fibrosis, receiving care at the University Hospitals of Grenoble and Lyon (research project partners and experimentation sites for the future peer support intervention). In accordance with the methodological principles of IPA, we applied purposive homogeneous sampling to select adolescents involved in the transition process to adulthood, while obtaining a diversity of perspectives related to this process: diversity in age (from 15 to 17 years at the start of the study), diversity in gender (female and male), diversity in location of care (Grenoble and Lyon), diversity in location of residence (urban and rural), and diversity in healthcare transition situation (transfer to adult care during the study and no transfer yet). We selected adolescents from the age of 15 to explore the mechanisms of change and projection into adulthood before reaching legal majority.

Participant recruitment was conducted by physicians from two study partner centers who contacted their patients who met the inclusion criteria to inquire about their willingness to participate in the study, after explaining it to them and providing them with an information letter outlining the objectives and participation procedures. The researchers (MM and AVL)

then contacted the adolescents to obtain their second consent and schedule an interview appointment.

Considering the longitudinal design of the study, as well as its phenomenological and idiographic approach, a significant amount of data can be gathered from a small sample (fewer than 10 participants).²⁵ We relied on the principles outlined by Malterud²⁶ to estimate the sample size in qualitative research guided by the concept of “information power” (the more information the sample holds relevant for the study, fewer participants are needed). Thus, considering the methodological approach used (IPA and longitudinal), the homogeneity of the sample, the in-depth narrative interview technique (see Section 2.4 below), and the relatively focused research question, we opted for a small sample to study each case in depth. Eight adolescents participated in the study. Twenty-four interviews were conducted (three for each adolescent). The average age at the first interview was 16.1 years. Five girls and 3 boys participated in the study. Five adolescents were cared for in Lyon and 3 were cared for in Grenoble (see Table 1). The average duration of the interviews was nearly 46 minutes, consistent with the timing of IPA interviews with adolescents.

2.4. Data collection

Individual semi-structured interviews were conducted. The Photovoice technique was used. Photovoice involves using photography as a narrative tool during the research interview. The participant produces the photo and explains what they wanted to express, thus allowing access to their symbolic universe without suggestion.²⁷ Photovoice proves to be an invaluable aid in describing concepts or experiences that are difficult to express in words, in structuring the subject's thoughts and narrative, in offering new perspectives and viewpoints,²⁸ and in working towards processes of transformation.²⁹

In our study, adolescents were asked to take a photo representing what “becoming an adult” meant to them before each interview. At the beginning of the interview, the adolescent described and explained what the photo represented. An interview guide (Box 1) was then used to conduct the interview to cover different domains of the transition experience to adulthood (self-concept, self-image, learning autonomy, transition to adult care, etc.). During each interview, the way in which a peer support intervention could support (or not) the experiences recounted was also explored with the adolescent.

Table 1. Demographic data for participants.

Pseudonym (Gender)	Age at the first interview	Hospital	Date Interview 1 (Duration)	Date Interview 2 (Duration)	Date Interview 3 (Duration)
Sarah (F)	17	Grenoble	04/05/22 (40')	10/05/22 (1h15')	04/05/23 (1h49')
Clarisse (F)	17	Grenoble	04/19/22 (28')	10/25/22 (29')	05/17/23 (44')
Maude (F)	16	Grenoble	06/28/22 (1h10')	12/07/22 (1h17')	05/24/23 (1h14')
Nathan (M)	16	Lyon	07/05/22 (34')	02/03/23 (28')	07/10/23 (35')
Emilie (F)	16	Lyon	07/12/22 (48')	01/04/23 (35')	07/18/23 (53')
Vincent (M)	16	Lyon	08/30/22 (51')	01/25/23 (1h02')	07/07/23 (36')
Nathalie (F)	15	Lyon	10/19/22 (29')	03/08/23 (38')	08/02/23 (33')
Yannick (M)	16	Lyon	10/19/22 (23')	03/01/23 (26')	07/10/23 (30')

2.5. Procedure

Adolescents took part in three in-depth semi-structured interviews over the course of one year (M0 – M6 – M12). This one year was chosen because it allows for the observation of a significant evolution cycle and the understanding of life transitions during adolescent development. Due to the repeated nature of the interviews, they were conducted via videoconference, as studies have shown that this promotes adolescent adherence to the study by reducing the costs associated with participating in the interviews (time, travel, etc.), increasing accessibility, and meeting the quality criteria for qualitative research interviews.^{30,31}

The interviews were recorded via a tape recorder and transcribed verbatim.

2.6. Analysis framework

Data were analyzed according to the principles of longitudinal interpretative phenomenological analysis (LIPA). Still an emerging approach,³² LIPA is grounded in the principles of IPA, which aims to understand how individuals live and make sense of their experiences, considering the dynamic nature of the phenomenon under study and each person's potential to change without being determined by defined roles.³³

LIPA involves an idiographic approach to analysis in order to account for the complexity of the evolution

processes of each case. Each adolescent's pathway was analyzed and interpreted individually. Then, all intra-case analyses were reviewed to establish inter-case coherence and identify shared mechanisms of change or stability. We have sought to illustrate how different experiences appearing at each moment dynamically contribute to the overall process of identity transition to adulthood.²⁵ Verbatims were analyzed by two researchers (MM and AVL) according to the framework analysis developed by Smith et al.,²² which involves analyzing each case individually and constructing personal experiential themes before developing group experiential themes across cases.

2.7. Ethics and quality control

The study was approved by the Ethics Committee of Research from University of Paris, on November 9th, 2021 (IRB number: 00012021-95). Adolescents and parents were informed and provided written consent. Data anonymity was guaranteed.

We controlled the quality of our research process by referring to the Standards for Reporting Qualitative Research,³⁴ as well as the criteria defined by Smith et al.²² specifically for IPA.

3. Results

This section will present the key components of the mechanisms of change in narrative identity during transition to adulthood derived from the analysis of the case studies, with illustrative examples. The main

Box 1: Interview Guide

Could you describe and explain what the photo you took represents?
 How do you see yourself in the future?
 How would you define yourself?
 How do you think others perceive you?
 How are you getting to know yourself better?
 How do you see yourself managing your care in the months and years ahead?
 What do you think will change when you go into adult care?
 How would you feel about sharing your experiences on a regular basis with a young adult with cystic fibrosis?

results of the analysis are grouped in Table 2, whose structure is borrowed from Shaw et al.³⁵ We developed 4 main Personal Experiential Themes (PETS), considering the transition to adulthood as a process of learning and seeking possible selves: “Initiating transition through a quest”; “Learning to define oneself”; “Learning to take care of oneself”; and “Being supported in one’s learning by peer support”.

We drew on Smith’s approach³⁶ to present our results in a way that respects IPA’s idiographic approach. In each sub-section, one adolescent, Maude¹, is introduced first in order to help the reader establish continuity and to report the dynamic process of development as complex and unique. The analysis is complemented by findings from other cases that may highlight points of convergence, divergence, opposition, nuance, etc.

3.1. Initiating transition with a quest

The exploration of possible selves through photovoice revealed the notion of “quest” in the adolescents’ discourse, which developed throughout the 3 interviews. This quest acts as a framework for interpreting the current and past experiences of adolescents and their projection into the future. When envisioning the future, Maude emphasized her desire to “be herself” and develop an authentic relationship with herself.

“It’s something I’ve thought about for quite some time this summer. I’ve spent a lot of time wondering: ‘Am I really acting in a way that is true to who I am? Am I acting the way that I want to? Am I actually allowing myself to be me?’” (Maude, interview 3)

According to Maude, this existential quest was rooted in her relationship with death and the fleeting nature

of life, which leaves no time for not being oneself. This reflection on death was made more prominent by the experience of illness.

“What gives meaning to life, its preciousness, is the fact that it can end. Someone who is close to death, for example, a seriously ill person with cancer, will go through deep introspection and think: ‘I don’t have time to be unhappy, I owe it to myself to be happy.’ So, it’s the realization that it will end that allows us to be happy. And of course, one must have experienced sadness to appreciate happiness; otherwise, it doesn’t hold much value.” (Maude, interview 2)

Sarah also mentioned the passing of time. However, her experience was not analytical, and she did not make a direct connection with illness. Instead, she evoked the realm of sensation, which she expressed as a realization of the passage of time she experienced while attending a concert.

“I felt like I was doing something grown-up by going to a concert. It’s really the day that made me think: ‘This is it. Mom and Dad soon won’t be around anymore (. . .) During the concert, it really hit me. . . In fact, I sort of retraced the thread of my life. I thought to myself: ‘Remember when you used to say: ‘When I turn 18. . . but that’s four years away.’ Well, today is that day, so wow, time flies. Because back then, it seemed like an eternity, but it’s gone now, and it’s gone by super fast. In fact, I feel like I didn’t live through my teenage years, because everything went by so quickly that I don’t remember anything (. . .) It’s really

¹ All names mentioned in this article are pseudonyms.

Table 2. Personal experiential themes (PETS) generated in the analysis.

PETS	Sub-themes	Experiential Statements	Participants Contributing to this Theme
Initiating transition through a quest	Creating a quest	<ul style="list-style-type: none"> • Becoming oneself • Being free • Helping others 	<ul style="list-style-type: none"> • Maude, Nathan • Sarah, Clarisse • Emilie
	Remaining unchanged	<ul style="list-style-type: none"> • Remaining an adolescent • No problems to solve 	<ul style="list-style-type: none"> • Yannick, Nathalie, Vincent • Yannick, Nathalie
Learning to define oneself	Self-concept	<ul style="list-style-type: none"> • Giving meaning to the «sick status» • Elasticity of the self 	<ul style="list-style-type: none"> • Maude, Vincent • Sarah, Clarisse, Nathan • Nathalie, Yannick, Emilie
	Relationships with peers	<ul style="list-style-type: none"> • No mention of illness • Wish for change • Satisfying relationships 	<ul style="list-style-type: none"> • Maude, Clarisse, Sarah • Nathan, Emilie, Yannick • Sarah, Clarisse
	How change is perceived	<ul style="list-style-type: none"> • New life configuration • New material • Sensation • Imitation 	<ul style="list-style-type: none"> • Maude, Emilie • Sarah, Clarisse • Maude, Sarah, Emilie • Maude
	Meta-cognition	<ul style="list-style-type: none"> • Self-observation 	<ul style="list-style-type: none"> • Maude
Learning to take care of oneself	Attitude towards illness	<ul style="list-style-type: none"> • Under construction • Negative • Neutral • Physiological warning signs 	<ul style="list-style-type: none"> • Maude, Vincent • Nathalie • Nathan, Yannick, Emilie, Clarisse • Clarisse, Nathan Nathalie
	Learning triggers	<ul style="list-style-type: none"> • Perceived support 	<ul style="list-style-type: none"> • Maude, Nathalie
Being supported in one's learning by peer support	Perception of need	<ul style="list-style-type: none"> • Wish to find role models • Not rooted in own experience • No added value 	<ul style="list-style-type: none"> • Maude, Vincent • Sarah, Clarisse, Emilie, Nathan, Yannick • Clarisse, Nathalie

a kind of realization that here we are, I'm entering my adult life, and that before I know it, I'll blink and tomorrow, I'll be 40." (Sarah, interview 3)

In order to live life to the fullest despite time passing quickly, Sarah was in search of freedom. When she talked about the future, friendships, romantic relationships, or what motivates her daily, she mentioned an unconditional pursuit of freedom. Her first photo depicted a mountainous landscape: a place where she had gone on a trip with her friends and experienced a sense of freedom.

"At that time, what I felt was a real sense of freedom, thinking to myself: 'Well, I'm still in high school, but actually, I can do a lot of things that I couldn't necessarily do before, and I can enjoy life in a different way'." (Sarah, interview 1)

However, other adolescents discussed the experience of stability or of the desire not to change throughout the 3 interviews, as they were aware, according to them, of the privileged nature of the adolescent status compared with that of adults.

"The older you get, the more you have to deal with financial problems and things like that. You need to get a job to earn a living, to have a house or an apartment. When you're an adolescent, you don't worry about all of that." (Vincent, interview 1)

The experience of change was therefore not something that happened automatically but took shape in an existential quest that initiated the adolescent into a process of identity transition linked to the transition to adulthood.

3.2. Learning to define oneself

The adolescents expressed the need to understand what it means to "be sick", involving identity and questions of meaning. Firstly, they rejected being reduced to a sick status and did not identify with social discourses about illness that emphasized their vulnerability or courage.

"I don't like being seen as a model of resilience, as someone fighting against a disease when, in fact, I just take

medications, go to physiotherapy, and wash my hands. In concrete terms, there's not much to it." (Maude, interview 3)

"I think what annoys me the most is my family worrying about my health, but they couldn't care less about everything else. But, guys, I'm not dying, I'm never going to die from this, at least not for now. So, stop calling me, I don't want you to." (Sarah, interview 3)

Secondly, Nathan thus introduced the distinction between social life (where the illness is rarely present) and life away from the gaze of others (where the illness regularly emerges). He described the space away from social life where the illness makes existence more difficult as the "back stage."

"In fact, the illness doesn't change anything in my life, but inevitably, back stage, there are small changes, you see. (...) The back stage is taking medication, the fact that I'll sleep less, that I'll have to be more available for the hospital, that I'll have to think about the repercussions, for example, when I go out, especially when I'm with my friends, I have to think that if I go out, I need to take salt, etc., so I don't get dehydrated, etc., etc. Yeah, that's it, before I do anything, I have to think about a lot more things. That's the back stage reality." (Nathan, interview 3)

The experience of a non-social self that would accept the constraints and difficulties associated with the illness thus emerged in the identity development of adolescents. This distinction between life *under the gaze of others* and life *away from the gaze of others* was a phenomenon of preservation of possible selves. Not showing the signs of illness to the social body protected oneself from the (self-)assignment to the role of a sick person and established an equal footing of identity possibilities with peers. This phenomenon was accompanied by an experience of invisibility of self-care practices.

However, the study started a few months after the arrival of a new treatment (Elexacaftor-lumacaftor-ivacaftor triple therapy), which significantly reduces the symptoms of cystic fibrosis, making them less prominent even in the "back stage". Maude and Yannick explained that they did not *feel* sick, which led her to question the legitimacy of their status as "chronic patients."

"I have a relatively normal life, so sometimes I feel like I'm not legitimate in being considered to be sick because I'm not that affected." (Maude, interview 3)

"I consider myself a regular person. I just have cystic fibrosis but I don't feel that it handicaps me in life or... in fact, I feel just like other kids, well, like other people my age. And otherwise, yes, I'm a fairly regular person." (Yannick, interview 3)

Adolescents were thus led to learn *cognitively* what it means to "be ill", as the register of sensations can no longer be relied on to experience the illness. Social and/or cultural mediation were then employed by adolescents to acquire knowledge about what it means to "be ill with cystic fibrosis." As seen earlier, in the third quote, Maude mentioned a book that tells the story of a sick child, which resonated with her own experience. Other adolescents also mentioned movies or TV shows as cultural references that facilitated self-awareness and reflection on their lived experience.

"I watch a lot of medical TV shows. Currently, I watch 9-1-1. It's always about health problems. I love watching that kind of show. Every time, there are sort of little morals in each episode, and every time it makes me take a step back and think about certain situations that they handle in a certain way. It opens my eyes a little more each time." (Sarah, interview 1)

Sarah also discussed her relationship with a friend who lives with type 1 diabetes, which made her reflect on her own health situation through a mechanism of social comparison. These mediations allowed adolescents to better define their health situation, which is essential for making sense of treatment adherence, by compensating for a low sensory experience of the illness through narration constructed by mechanisms of observation, identification, and comparison. The results thus reveal that the phenomenon of identity self-determination was motivated by a refusal to submit to the gaze of others when it reduces the adolescent to their illness. Adolescents then engaged in a process of creating their own perception of themselves, supported by mechanisms such as self-observation, and cultural or social mediation. The phenomenon of identity self-determination was not only reflected in the search for alternatives to *being sick* but also in the search for possible selves that

were not assigned to the illness. Adolescents actively sought to understand “*what it means to be ill when the daily sensations of being ill are not present?*”, thereby excluding the attribute “ill” from the sensory and physical register to which it is generally associated.

3.3. Learning to take care of oneself

Among the challenges faced while growing up, adolescents mentioned autonomy, particularly regarding managing illness and treatments. The start of the process of becoming more autonomous was triggered by a realization that made it necessary for the adolescent to take control of their health. In Maude’s case, it was a discussion with her boyfriend.

“I recently changed the way I receive my test results. In the past, they were sent to my parent’s email address. So, every time, my dad would say, ‘Oh, there’s a new document.’ It was my boyfriend who pointed it out to me, saying, ‘It’s your health, so you’re the one responsible.’ So, I changed the email address so that I receive the emails from the doctor and look at the results myself.” (Maude, interview 2).

This realization could also have been triggered by a period of non-adherence to treatment and of experimentation with limits, which acted as a testing process aimed at making sense of the recommended adherence, according to the adolescents’ discourse.

“I actually felt like even if I didn’t take my medications, I was doing fine. So, I stopped taking them. But at some point, I wasn’t doing well anymore. And that’s when I realized, ‘Well damn, maybe I need to get a grip on myself.’” (Sarah, interview 1)

The functional autonomy required to manage the disease was nonetheless dependent on the attitude toward the disease. When the disease caused crises, the adolescent was reminded of their health situation in a sensory way, which led to feelings of weariness. Nathalie recalled phases of strong symptoms that were emotionally difficult, as they reminded her of the fact that having a life like other adolescents who do not live with cystic fibrosis was impossible for her.

“At the moment, I’m sick, I’m back on antibiotics, so there you go. . . But it annoys

*me. First, yes, it annoys me when I’m sick because it’s getting worse. But also. . . because it annoys me. Sometimes, **having cystic fibrosis is tough.**” (Nathalie, interview 2)*

*“Last week, after my stomachache, it got on my nerves a bit, but oh well. . . It’s not a big deal. I thought to myself that actually, with Kaftrio® (editor’s note: the new therapy), I had regained a normal life. But now, it **made me realize that I won’t have a normal life.**” (Nathalie, interview 3)*

From Nathalie’s account, we can observe that experiencing the symptoms of the disease provoked anger in her (“*it annoys me*”), caused her to have a negative attitude towards cystic fibrosis (“*having cystic fibrosis is tough*”), and triggered the realization of an existence conditioned by the disease (“*it made me realize that I won’t have a normal life*”). While adolescents constructed their identity around the idea of a “*normal life*,” “*like others*”, facilitated by the reduction in symptoms made possible by the new treatment, the physical sensation of being sick triggered an awareness of “*reality*”, understood here as the reality of chronic illness, which can sometimes be forgotten about in daily life. The ability to make sense of what it means to “*have cystic fibrosis*”, described earlier, thus contributed to the development of an attitude towards cystic fibrosis that influences self-care practices.

3.4. Being supported in one’s learning by a peer support intervention

At the end of each interview, we explored with the adolescents how a peer support intervention could support (or not) the experiences they recounted during the interview. It was specified that peer support, within the framework of this project, consisted of an intervention in which young adults could be available to talk with them and support them in their transition into adult life.

The possibility of observing and exchanging with a role model emerged as a facilitator of change. This role model was perceived as relevant as long as they share common experiences with the adolescent not only in healthcare (transitioning to adult care) but also in life outside the hospital (similar study path, shared experiences, etc.). Maude briefly mentioned it, emphasizing the academic characteristics of the

young adult with whom to converse, in connection with her own changing study aspirations.

“It’s a good idea because we can feel a bit lost and having some role models could help us feel more confident. Especially if there’s a patient studying political science, it could be nice to have a talk.” (Maude, interview 1)

However, the relevance of a peer support intervention did not spontaneously emerge in the discourse of adolescents. This was related to the phenomenon of “distance” from the event of transitioning to adult care (in time, in perception) and the difficulty in picturing the actual differences between pediatrics and adult care before experiencing the change firsthand. It was noted that the peer mentoring program is interesting “for other adolescents” but “not for oneself”, highlighting a positive perception of the initiative, but as one that does not necessarily seem relevant to their own lived experiences.

“I know that for others, for example, talking to someone can reassure them, whereas, for me, I can’t be reassured because I know that in any case, it will pass.” (Emilie, interview 3)

“I think it’s a good thing. In my case, I feel zero stress when I go to the hospital. For me, honestly. . . whether there’s someone to talk to or not, I don’t know, it would feel the same to me. For someone who feels more stressed than me, I think it would be really good.” (Nathan, interview 1)

Therefore, the results highlighted that peer support must be grounded in the experiences of adolescents so that they can make sense of the intervention and be inclined to participate in it. Adolescents were in search of answers in their close sphere about the experiences they were going through, which were related to growing up with an illness in a broad sense, and not only to the change in care services.

4. Discussion

In preparation for a peer support intervention aimed at facilitating healthcare transition for adolescents living with cystic fibrosis, which will be implemented in two French hospitals, we explored *how*

this peer support program *could* support adolescents’ self-determination capacities in their identity development (Fig. 1).

The results helped to better understand the mechanisms of self-determination involved in the development of narrative identity in adolescents living with cystic fibrosis, whose centrality of illness in the identity is a risk factor,¹² and for which a recent literature review has highlighted the need for in-depth understanding.¹³ Firstly, adolescents explicitly reject master narratives about cystic fibrosis, defined as culturally shared narratives,³⁷ and engage in practices of agency aimed at conceiving a narrative about the disease that belongs to them, that they control, and that they can shape. The concept of “gaze” emerged as a central core of narrative identity in adolescents’ discourse, considering the fluctuation of an identity always under the scrutiny of others who produce a misguided discourse about the experience of the disease. Furthermore, the experience of illness is distinguished in its social aspect (*under the gaze of others*) and its intimate aspect (*away from the gaze of others*). One adolescent also mentioned the term “back stage” to describe life away from the gaze of others, which includes a series of constraints related to managing the illness in a way that remains invisible to the social body. This term implicitly introduced the notion of “front stage” from Goffman³⁸ according to which social interactions are governed by the attribution of roles, which are generally to the disadvantage of people living with a chronic health condition.³⁹ In addition to research on the socio-cultural processes of illness identity,⁴⁰ our study highlighted that distress is triggered by the inability or impossibility to develop one’s self-perception and to imagine alternatives to the social assignment to the sick role.

While adolescents refused to be reduced to the role of sick individuals, their coping strategies did not solely consist of conceiving alternative selves to the sick self: they also sought to understand what “being ill” means. Our results showed that the emergence of a new therapy (Elexacaftor-Tezacaftor-Ivacaftor triple therapy), which has significantly reduced cystic fibrosis symptoms and whose psychosocial implications are not yet known,⁴¹ changed the process of identification with the illness. While the humanities and social sciences primarily focus on the phenomena of “exo-experience” as a capacity for self-determination and emancipation from social assignments,⁴² involving embodying someone else or another social role for a determined period of time, our study highlighted the phenomenon of “infra-experience” to regulate the dissonance between cognitions and

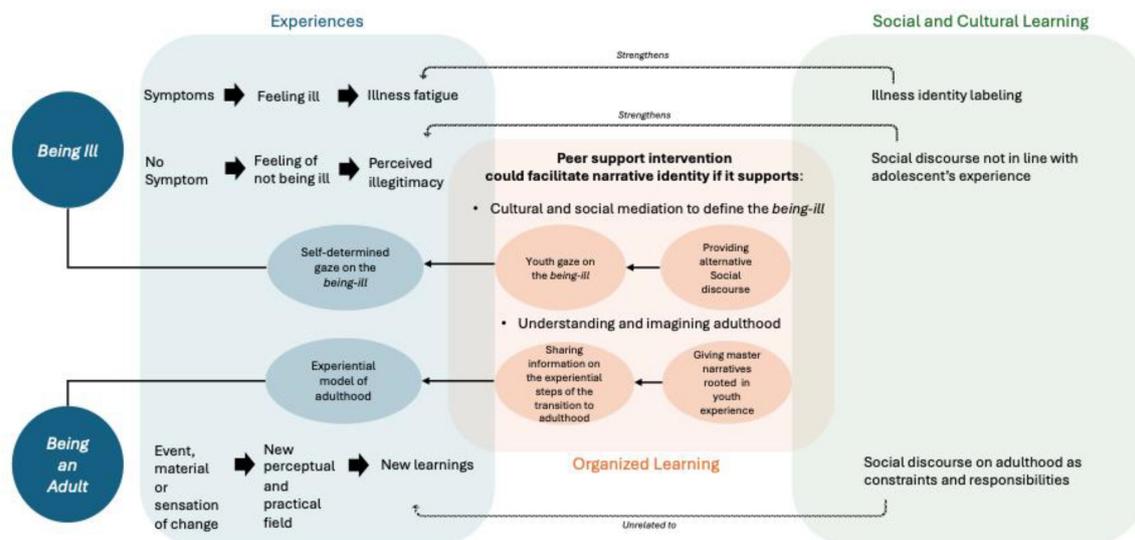


Fig. 1. Schematic representation of the study results showing how a peer support intervention could enable the support of adolescents' self-determination capacities in their narrative identity.

physical sensations. Infra-experience would consist of embodying or understanding one's health condition from one's own perception, defining one's authentic identity from within without resorting to socially predefined categories. These infra-experiences were all the more necessary as the master narratives about cystic fibrosis (being brave, being vulnerable, etc.) were distant from the daily experience of the illness.

Our findings also highlighted the socio-cultural dimension of narrative identity development in adolescents living with cystic fibrosis. Our qualitative exploration of the processes of constructing meaning about illness and oneself has shown that adolescents utilized cultural mediation (books, movies, TV shows...) and/or social mediation (discussions with peers affected by other chronic illnesses) to acquire knowledge about their existential condition as young people living with a chronic condition and as future adults. This is a currently major scientific perspective in the study of human development, emphasizing that people's thinking and action capacities are developed in interaction with materials and signs in the environment,⁴³ which still receives little attention in the study of healthcare transition. In this sense, the peer support intervention meets an educational need and an empowerment need for creating a social discourse by the adolescents living with cystic fibrosis about the transition process to adulthood. Peer support indeed strengthens the social identity of beneficiaries⁴⁴ and could avoid the pitfall of reinforcing illness identity by producing a discourse more anchored in concrete situations and empirical learning of change than

that of professionals. Therefore, our results pointed the intervention project toward the recognition and evaluation of adolescents' social identity, as a process mobilized by peer support through social learning⁴⁵ that allows for rebalancing the hegemony of master narratives developed by non-concerned individuals.

Finally, from a methodological standpoint, the longitudinal approach allowed for understanding adolescents in their evolving dynamics and thus to avoid freezing them into fixed identity statuses that do not sufficiently reflect the reality of identity development, which is non-linear, creative, and context-dependent.⁴⁶ Indeed, the results showed that adolescents changed social roles within their peer groups, modified their social and emotional practices, or gained new perspectives on themselves over the course of a year. The approach is aligned with the foundations of IPA developed based on work on individual transition processes³⁶ and the new perspectives offered by LIPA, which aims to produce knowledge about mechanisms of change as an experience of meaning-making embedded in a defined temporality and context.⁴⁷ Furthermore, we anchored this knowledge production in a methodology of the possible, concerned with reflecting on the conditions of access to and mastery of what is not determined,⁴⁸ utilizing qualitative research insofar as it can prioritize "possibility" over "probability".⁴⁹ In this sense, we have considered the transition in how it can transform the individual from an agentic perspective. While the qualitative study of the possible selves and illness identity remains rare, our findings

weigh in favor of its development in light of its ability to support the narratives of those concerned from an agentic, dynamic, and non-stigmatizing perspective. In psychology and social sciences, the call to direct research towards the future not to “illuminate what is, but to create what will become”⁵⁰ is finding increasing resonance within the research community, and prospective methods aiming to study the future are growing in number within the discipline. LIPA would thus not be characterized solely by its focus on changes and temporality but also by the creation of an “existential” possible and the means to achieve it.

However, our study has several limitations. Firstly, we observed that the participating adolescents had heterogeneous capacities and/or motivations to develop a self-narrative but the data do not allow us to analyze these differences. Secondly, we did not explore, within the scope of this study, the transition mechanisms implemented in healthcare settings or the conduct of consultations during this period. Finally, our study is exploratory and oriented toward an interventionist perspective in a local context. Complementary studies are still needed to better understand the development of self-determination capacities in the identity development of adolescents living with cystic fibrosis. The impact of the new treatment on self-perceptions and perceptions of the illness could, in particular, be studied. Additionally, observations or studies of clinician-patient interactions in real-world settings could be conducted to better understand the social and cultural processes of co-construction of the roles related to illness. Finally, mixed-methods studies combining effect measures with interviews on the understanding of the peer support intervention process in adolescents living with cystic fibrosis would help advance knowledge production and consider the transferability of the results.

5. Conclusions and perspectives

Our study on the identity self-determination needs of adolescents living with cystic fibrosis was the first part of an intervention participatory research. Our study showed that adolescents reject the master narratives about cystic fibrosis and seek, through infra-experiences, to make sense of what it means to ‘be sick’ during the transition to adulthood. Therefore, peer support could contribute to the psychosocial development of adolescents with cystic fibrosis if it facilitates the construction and sharing of a social discourse on *being sick* or *being an adult with cystic fibrosis*, produced by and for young people.

In the continuation of this preparatory study of the intervention, the peer support program will be co-constructed by a working group composed of adolescents and young adults with cystic fibrosis, parents, healthcare providers, and researchers. Next, the pilot intervention will be implemented and evaluated in the two French hospital centers initiating the project. Based on the results of our study, outcome measures related to the ability to define oneself as a young person living with cystic fibrosis and as a future adult will be added.

Declaration of interest statement

None.

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