

An Exploration Into Knowledge, Attitudes, and Beliefs Towards Risky Health Behaviours in a Paediatric Cystic Fibrosis Population

Rebecca Keyte , Helen Egan and Michail Mantzios 

Department of Psychology, School of Social Sciences, Birmingham City University, Birmingham, UK.

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ABSTRACT: Risky behaviours are prevalent within the cystic fibrosis (CF) population; however, there is a lack of research which has investigated risky behaviour engagement among adolescents with CF, with reasons for initiation currently being unknown, as no qualitative studies have been conducted. This research therefore examines knowledge, attitudes, and beliefs towards risky behaviours at an age commonly associated with initiation. Ten paediatric participants were recruited. Thematic analysis illustrated several psychological factors associated with risky behaviours. A desire for normalcy was evident, with this been associated with a desire to engage in normalised risky behaviours. Evidence of a life-orientated illness perspective was also prevalent, with participants believing that many individuals engage in risky behaviours for fun. Overall, there was a reported lack of knowledge on consequences of risky behaviours, with many participants not being informed of these by health care professionals (HCPs). This research provides insight into an area of CF paediatric care which could be improved on, with the provision of awareness regarding risky behaviours not being embedded within paediatric CF care. Consequently, this research demonstrates the need for interventions to be integrated into paediatric CF care for the prevention and reduction of risky behaviours.

KEYWORDS: cystic fibrosis, paediatric, risky health behaviours, qualitative research

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CORRESPONDING AUTHOR: Rebecca Keyte, Department of Psychology, School of Social Sciences, Birmingham City University, Curzon Building, 4 Cardigan Street, Birmingham B4 7BD, UK. Email: Rebecca.Keyte@bcu.ac.uk

Within the cystic fibrosis (CF) population, smoking, excessive alcohol consumption, and illicit drug use are prevalent, with the health consequences of engagement in such behaviours being far more detrimental for those with CF in comparison with the general population.^{1–3} These behaviours are classified as ‘risky behaviours’ which are any behaviours that expose an individual to harm or significant risk, which will therefore prevent them in reaching their potential.² Risky behaviour engagement can influence an individual’s treatment options. For instance, lung transplantation may become a necessity in individuals with severe lung disease whose FEV₁ falls below 30%;⁴ however, individuals who smoke will not be considered for lung transplantation.^{4–8} Therefore, smokers are decreasing their lung function, needing lung transplantation quicker than predicted, but failing the assessment due to their smoking behaviour (Minai & Budev, 2005).

Research within an adult CF population provided an exploration into experiences and beliefs around risky behaviours,⁹ indicating that many adults with CF desire normalcy,^{10,11} resulting in risky behaviour engagement forming part of their socialisation.¹² Some individuals with CF value their psychological health above their physical health, explaining how, despite awareness regarding the adverse health effects of risky behaviours, they still engage in such behaviours to restore normalcy against their illness identity, reducing the differences between themselves and their peers.^{8,13} Such individual perceptions hold a life-orientated illness perspective, with their engagement in such behaviours being for fun and enjoyment.¹⁴ This is found within multiple chronic diseases, with individuals

who hold a life-orientated illness perspective often focusing on their well-being, viewing their chronic disease as only part of their daily lives.¹⁴

Restoring normalcy against an illness identity due to negative emotions can be influenced by denial. A number of adults with CF do not acknowledge the CF-specific adverse health effects of a risky behaviour,⁹ with some believing their risky behaviour engagement is beneficial to their health. Such belief appears to be most prevalent among individuals who smoke marijuana, with individuals with CF reporting a respiratory improvement following engagement, focusing on short-term effects rather than long-term effects of usage,⁹ demonstrating an inaccurate perception of risk and susceptibility.^{15,16} The belief that a risky behaviour is beneficial demonstrates a degree of unrealistic optimism,¹⁶ which despite its psychological benefits¹⁷ can lead to biased health perceptions.¹⁸

Collaborations with health care professionals (HCPs) who work within CF paediatric care have illustrated that risky behaviour prevention is not currently strongly embedded within CF care,¹⁹ despite it being well acknowledged that it is easier to prevent initiation, as opposed to aiding cessation of an established behaviour. Due to risky behaviour initiation commonly occurring during adolescence, there is a need for evidence-based practice to be implemented within paediatric CF care, to address risky behaviours at a time when some individuals start to contemplate engagement. There is a lack of research focusing on risky behaviours within a paediatric CF population, especially in regard to qualitative studies; consequently, work is needed to highlight reasons as to why some adolescents with CF are



Table 1. Medical and demographic data collected for all paediatric participants.

PARTICIPANT NUMBER	SEX	AGE	LATEST LUNG FUNCTION RESULT	PREVIOUS RISKY BEHAVIOUR ENGAGEMENT REPORTED BY CONSULTANT
1	Male	14 years	/	No
2	Male	14 years	80%	No
3	Female	12 years	50%	No
4	Male	13 years	82%	No
5	Female	12 years	94%	No
6	Male	18 years	/	No
7	Female	12 years	28%	No
8	Female	13 years	85%	No
9	Male	16 years	65%	No
10	Female	12 years	/	No

motivated to initiate in risky behaviours. Awareness among HCPs of patient perceptions and influential factors in the initiation of risky behaviours within the CF population could be used, in part, to improve the quality of clinical care, reducing the occurrence of risky behaviours within the CF population.

The current research examined paediatric participants' knowledge, attitudes, and beliefs towards risky behaviours, at an age commonly associated with initiation using qualitative prospective interviews to take an interpretive perspective. Participants were free to discuss their own experiences, as well as highlight why they believe others engage in risky behaviours, with it being acknowledged that when individuals talk in third person, they are potentially demonstrating their beliefs without personalising the discussion. These collaborations with adolescents with CF will help to ensure that any interventions created are relevant to all individuals with CF, and particularly adolescents where it is assumed interventions will be most useful and preventive of initiation.

Method

Participants

Individuals with a diagnosis of CF (aged between 12 and 18 years) attending 2 different CF units in the Midlands, UK, were eligible to participate, regardless of whether or not they had experience of risky behaviour engagement. Individuals were excluded if they had a lack of capacity and if they were non-English speakers. Eligible participants were identified through discussions with the CF consultants and by consulting CF outpatient and inpatient lists (discussions with CF consultants were held in regard to age, capacity, language, and individuals being physically well enough to take part).

Data collection occurred over a pre-determined period of time (8 months) until data saturation occurred. All eligible

patients during that time scale were approached: at 1 research site, 9 paediatric patients (and guardians) were approached, with 3 refusing participation and 6 agreeing to take part; reasons for not participating were not recorded. Different procedures at the second research site lead to an inability to record figures for the number of participants who refused participation.

A total of 10 paediatric participants (males: 5, mean age of participants: 14 years) were recruited, with a median forced expiratory volume in 1 second (FEV₁), 69.1% predicted (see Table 1). One participant (male, age: 18 years), who was identified to be a 'non-risky' patient by HCPs, disclosed risky behaviour engagement.

Semi-structured prospective interview

The semi-structured prospective interviews investigated participants' awareness, knowledge, and beliefs towards risky behaviours, as opposed to focusing on participants' own engagement (see Appendix 1 for the interview schedule), as prospective interviews can be influenced by social desirability bias.²⁰ Consequently, the researcher gave participants the option to discuss their attitudes and beliefs towards risky behaviours in third person, asking participants why they think others, eg, friends, acquaintances, family members, and individuals within the general population (and others with CF), engage in such behaviours, potentially highlighting their initiation intentions without personalising the discussion. It was at the participant's discretion for them to personalise the discussion, and disclose their own risky behaviour engagement. Participants' awareness regarding the adverse health effects of risky behaviours was explored, investigating the current practices of CF HCPs, highlighting any attention participants gave to health warnings.

The interviews were conducted in a private room at the CF centre and lasted a maximum of 60 minutes (Mean: 26.88 minutes, SD: 7.14). The semi-structured interviews were conducted in the absence of participants' legal guardians, unless participants explicitly expressed a desire for them to be present. Five interviews were conducted where guardians were present for the duration of the interview; 1 interview was conducted where the guardian was present for the start of the interview but left before a discussion on risky behaviours commenced. Participants did not have to answer any questions they did not want to. All participation was voluntary and confidential, with participants being provided pseudonyms. Participants could withdraw from the research at any time.

Ethical approval

Ethical approval was obtained via an NRES Committee (REC reference: 14/EM/1183) and the R&D departments at each research site. To participate, the paediatric patient and the legal guardian had to provide written informed consent. The researcher explained the study to patients and guardians both verbally and in the form of a written information sheet, with both patients and guardians having the opportunity to ask any questions. The patient and guardian received different information sheets to aid their understanding of the research process and purpose. Patients and guardians had a maximum of 2 weeks to decide on participation, to help facilitate informed consent. If the legal guardian wanted their child to participate, they had to complete a consent form. If the patient wanted to participate, they either had to complete an assent form (used for patients aged 12-15 years) or a consent form (used for patients aged 16-17 years); the patient could only participate if consent had been obtained from both the patient (or assent) and their legal guardian.

Analysis

The recordings of the interviews were transcribed by the researcher using the Jefferson transcription coding (see Appendix 2 for a key and all quotes presented using Jefferson transcription coding) to focus on phonetic and paralinguistic features as well as spoken words, recording what was said and how it was said.²¹

The data were analysed by 1 researcher using thematic analysis following Braun and Clarke's²² model, as this is a flexible method. Thematic analysis was used as a contextualist method, positioned between the 2 poles of essentialism and constructionism, characterised by critical realism.²³ A contextualist method was used due to the reasons for engaging in risky behaviours being context-dependent;²⁴ therefore, thematic analysis acknowledged how participants made meaning of their experiences, alongside the impact the broader social context has on those meanings, indicating that meanings and

experiences are socially produced and reproduced rather than being inherent.²⁵ Thematic analysis provided a detailed inductive construction of the entire data set, providing valuable information to a currently under-researched area of health behaviours within CF.

Although only 1 researcher was responsible for analysing the data, the other 2 researchers acted as raters. This involved the 3 researchers working together to evaluate and revise the codes generated, with the validity of the codes being ensured when the researchers were in agreement regarding each code. In addition, the validity of the themes were confirmed when the 3 researchers agreed on the themes of the data and which codes should be represented within each theme. These collaborations helped to ensure the inter-rater reliability of the data generated.

To further ensure the validity of this research, the researcher used a reflexive diary, enabling the researcher to think in a critical and analytical way about the research during its progress.²⁶ In addition, triangulation was generated to ensure that results accurately reflect adolescents' attitudes and beliefs regarding risky behaviours, and to be certain that the findings are supported by evidence.²⁷ This research involved data triangulation as 2 institutes were used to recruit participants, providing the research with different sources of information.²⁸ In an aim to generate theory triangulation, the researchers presented this research at various national and international conferences and research meetings to use multiple perspectives to interpret the data.²⁷ The validity of findings was confirmed when professionals from different disciplines interpreted the information in the same way.²⁷

Results

Thematic analysis identified 4 themes within the data set providing an exploration into participants' attitudes and beliefs around some risky behaviours, illustrating how CF care regarding risky behaviour education could be enhanced.

The most challenging aspect of cystic fibrosis is getting up every morning to do your treatments'

This initial theme acknowledges that for a paediatric population, a risky behaviour that may be most prevalent is poor adherence or non-adherence. Participants' narratives demonstrate the time-consuming nature of CF treatment adherence, with this preventing individuals engaging in normal activities. Emily demonstrated the impact adherence has on her identity, explaining how her nebulised therapies prevent her from engaging in normal activities with her friends, which would provide herself with a sense of normalcy.

[Emily, 14 years]: You're trying to lead a normal life. Trying to go out after school how to deal with it, if you know what I mean; with the nebulisers, and stuff. I just want to be a normal person, like I just want to go outside.

Consequently, many participants openly discussed how non-adherence would have a positive impact on their life psychologically, with Sophie explaining how she would be more relaxed, not worrying about her CF treatments, and would be able to engage in normal activities.

[Sophie, 12 years]: I think I would be a bit more relaxed about things, and not having to worry as much [with non-adherence]. I'd probably just play out.

Such narratives suggest that these participants hold a life-orientated illness perspective where they desire a sense of normalcy. This desire for non-adherence could result in future poor or non-adherence when they become independent over their treatments, with this non-adherence potentially providing individuals with a normal identity in front of others. Although CF care does routinely monitor adherence and provide advice, the data suggests that awareness among HCPs regarding a patient's illness perspective and identity could be used to improve the quality of clinical care surrounding adherence.

Overall, the majority of participants viewed CF to be a challenge, predominantly due to their adherence efforts. Consequently, a number of participants talked about their need for support from others to aid with their adherence, with support also being needed for other aspects of their lives, such as providing them with awareness on the adverse health effects of other risky behaviours.

Don't keep cystic fibrosis to yourself

This theme focuses on the impact support from others can have on an adolescent with CF, specifically in influencing their attitudes and beliefs towards risky behaviours. From the data, it is suggested that when an adolescent has good awareness regarding the adverse health effects of risky behaviours, it works to prevent initiation, with such participants appearing to have accepted their illness identity, accepting they cannot engage in such behaviours. Many participants discussed the importance of families and friends in preventing their initiation; however, this support was not present for all, with some discussing how their family or friends have normalised such behaviours. Mandy explained how when she was offered a cigarette by her friends, she did contemplate smoking it to receive a normal identity in front of her friends; however, Mandy's awareness regarding the adverse health effects prevented her initiation.

[Mandy, 12 years]: I was out with my mates and they were all smoking, and someone gave me a fag. I held it in my hand. I was about to, but I just thought, no, I can't. I was trying to be cool. It made me feel so bad, not having this fag.

Nonetheless, with Mandy explaining how 'bad' it made her feel when she refused to smoke, it could impact her decision if she

was tempted to engage in a risky behaviour again, with adolescents valuing social acceptance. Although only 1 participant had had experience of risky behaviour engagement, the relationship between normalisation and initiation was apparent when participants spoke in third person.

Despite participants illustrating differences in their personal relationships, they discussed 2 different sources of support which should be present for all adolescents with CF. First, participants illustrated that schools often provide awareness on the adverse health effects of risky behaviours. Emily explained how she will never smoke due to her awareness on the adverse health effects, provided through her education at school.

[Emily, 14 years]: I would never do that [smoke]. I've done so many anti-smoking and anti-alcohol campaigns with school, and we learn about it in science. I'm like mega high on not to smoke.

Although this awareness is not CF-specific, it can still play a role in preventing initiation, due to the suggested relationship between awareness and abstinence.

In addition to schools, the varied levels of support received from family and friends highlight the importance of consistent clear support and advice from CF care, in encouraging adolescents to not engage in risky behaviours. Despite awareness on risky behaviours from HCPs appearing to have beneficial effects on adolescents, influencing their attitudes and beliefs towards risky behaviours, it became evident that this awareness is provided on an individualised basis. For instance, Tim believed that he had only been provided with awareness on the CF-specific adverse health effects of smoking as he instigated the conversation.

[Tim, 18 years]: I think it [smoking] has been brought up [by HCPs] before, but it's more me, kind of saying about it, asking about it. In hospitals they don't kind of talk about precautions of things, they're more talking about your treatments and stuff.

There was also evidence of participants not being provided any awareness on the adverse health effects of risky behaviours from HCPs, with this often causing participants to have poor awareness. Abi explained how her HCPs have never discussed alcohol consumption with her, with Abi not understanding what adverse health effects are associated with excessive alcohol consumption, and in particular how this behaviour can impact her CF.

[Abi, 12 years]: Researcher: Has anyone ever told you anything about drinking alcohol?

Participant: No. I don't get like, what's bad about it? I know it's like alcohol, but, like, what's there's something in it, or, I dunno.

Overall, this theme highlights the impact others can have on an adolescent's life. The role of others can be influential in preventing risky behaviour engagement, with the data suggesting that CF-specific awareness regarding risky behaviours

needs to be integrated into CF care, in an attempt to reduce the occurrence of such behaviours within the CF population, thus improving the quality of clinical care. Importantly, this theme identifies that on occasions, the role of others can work to encourage initiation through normalising risky behaviours; therefore, it is suggested that some adolescents with CF may engage in these behaviours in their future to possess a normal identity in public.

'I wish I did not have cystic fibrosis, that would be wicked'

This theme provides an understanding on how CF can impact an adolescent's identity. It illustrates how adolescents with CF react to this impact on their identity, focusing on how the engagement in risky behaviours can assist individuals with CF in possessing a normal identity, particularly when in front of others. Many participants demonstrated a strong belief that they are not defined by CF, believing they are more than an individual with CF. These participants highlighted that they know there are differences between themselves and their peers, due to CF, but it is clear that CF is not what defines these adolescents. Emily explains that she views herself to be the same as everyone else, as she is recognisable with her own identity, which does not include CF.

[Emily, 14 years]: I'm not like a small person in the corner, who's not recognisable. I'm quite a loud person [laughs] most of my friends would say that.

The fact that participants, such as Emily, do not see themselves fitting into the stereotype of what others might expect of someone with CF appears to be adaptive for their psychological well-being, with participants describing that they live a normal life with their peers.

However, a desire for normalcy was at times associated with a desire to engage in risky behaviours. Tim explained how he will drink alcohol due to him valuing the enjoyment provided through such engagement, suggesting that he possesses a life-orientated illness perspective, valuing his psychological health above his physical health.

[Tim, 18 years]: A lot of people associate drinking as a bad behaviour, but I don't. I just see that as a part of fun, life. Cause yes it can affect you, but not in the same with your lungs if you smoke, do you know what I mean?

Tim makes a distinction between risky behaviours, viewing alcohol consumption (including excessive alcohol consumption) to be less harmful than smoking, allowing his engagement to continue. This could be the result of unrealistic optimism, or could be as a consequence of Tim having a lack of awareness regarding the CF-specific adverse health effects of excessive alcohol consumption, demonstrating the need for

such awareness to be integrated into CF care, allowing patients to make a more informed choice regarding engagement.

Many other participants had not had experience of engaging in risky behaviours, with participants talking about their beliefs and attitudes rather than their experiences. Many participants did highlight the importance of having a normal identity and fitting in with their peers through talking in third person. Tony explained that he believes that some individuals with CF do smoke due to such behaviours being normalised within their environment. Tony had previously discussed how smoking is normalised by his parents; therefore, through talking in third person, Tony had potentially signalled how easy it would be for him to smoke.

[Tony, 13 years]: I'd say probably quite a few people, like teenagers an that, some adults might [smoke] with CF. Cause probably the area they've been brought up in, or some of the friends they have.

Many participants, like Tony, believed that engagement in risky behaviours is largely influenced by the behaviours of an individual's peers. Conformity to the group's identity is a way for CF adolescents to adopt the same identity as their peers, in an attempt to forget about the burden of CF, by enjoying themselves, demonstrating the need for HCPs to be aware of the impact identity can have on risky behaviour engagement.

The normalisation of a risky behaviour by an individual's social group does have the potential to be detrimental on the health of an adolescent with CF. However, many participants within the current research stated that they would not engage in such behaviours despite normalisation. Chris explained how smoking is normalised within his year group at school; however, he views this behaviour in a negative light, with Chris pointing out that he is aware that smoking is bad for his CF and would have dramatic adverse health effects.

[Chris, 14 years]: Most the people in my class do [smoke], it's ridiculous. I think they're really stupid.

Overall, it appeared that an influential factor affecting one's desire for initiation in a normalised risky behaviour is awareness regarding the CF-specific adverse health effects of that behaviour, and potentially the acceptance of one's CF, demonstrating that engagement is multi-factorial.

'A lot of people with cystic fibrosis do take it for granted and smoke and do stupid things'

This final theme provides an understanding on the role awareness has in working to prevent risky behaviour initiation among adolescents with CF, through acknowledging the CF-specific adverse health effects. This theme highlights that even when an adolescent has good awareness regarding the adverse health effects of risky behaviours, it does not always prevent such behaviours or prevent a desire for such behaviours.

Many participants discussed their awareness regarding the adverse health effects of risky behaviours, with such awareness often causing participants to view these behaviours in a negative light. Chris compared smoking with self-harm, recognising that smoking within CF can have fatal consequences, with Chris explaining that he would never smoke due to this awareness, despite it being normalised within his environment.

[Chris, 14 years]: Smoking, drinking, that kind of thing, they're stupid. It's basically like cutting yourself ain't it, it's killing yourself.

Some participants were aware that risky behaviours are 'more risky' to their health due to CF, in comparison with the general population.

[Tony, 13 years]: They're [smoking, drinking, drugs] risky for everyone really, but it's more risky for CF, cause that can make em more ill.

Tony was recognising that while the experimentation in normalised risky behaviours is risky for everyone, it is 'more risky' for the CF population; however, individuals would only be able to acknowledge this if they have been provided with good awareness regarding the true nature of their CF and the CF-specific adverse health effects of such behaviours. Although some participants had been provided awareness from HCPs, the data on occasions did identify flaws within such awareness. Participants such as Tony reported being informed about the adverse health effects of risky behaviours by HCPs; however, there were gaps within their knowledge.

[Tony, 13 years]: I've learnt, like [nurses name] told me about that [drug use] as well. We spoke about all, like smoking, drinking, an the drugs. But I can't remember, like, I know people inject themselves with it, an that can make their bloodstream, er, like, not healthy.

The data demonstrates the need for CF-specific awareness regarding risky behaviours to be integrated into CF care, with this awareness needing to be revisited on a regular basis, thus enhancing current practices.

Nonetheless, although awareness and abstinence appear to be related, CF care cannot just focus on increasing an adolescent's awareness, with it being noted that in some cases the discourse of participants suggests that awareness will not prevent their experimentation in a risky behaviour. Some participants provided reasons as to why others with CF may engage in risky behaviours despite their awareness, highlighting how psychological distress can motivate adolescents to engage in risky behaviours, with some participants explaining that if an adolescent's health is already bad, there is nothing to stop their engagement. This highlights the emotional burden of CF and the deteriorating nature that individuals are faced with. Many participants discussed a motivation to engage in risky behaviours in

third person; however, sometimes, they made no reference to CF, potentially demonstrating how they feel towards their CF and their future risky behaviour engagement, without confirming such assertion.

[Sophie, 12 years]: Sometimes, like, say they have a health issue, or something, an say they weren't in a very good state sort of thing, they may think, well I'm bad already, I might as well [smoke].

Overall, this theme identified the potential relationship between acceptance, awareness, and the engagement in health promoting behaviours among CF adolescents. However, as outlined within this theme, the factors that predict risky behaviours are manifold; therefore, an intervention to reduce the occurrence of risky behaviours cannot just focus on increasing an individual's awareness of such adverse health effects; instead, CF care also needs to consider one's identity provided through their interactions with their environment.

Discussion

The data provides an exploration into attitudes and beliefs regarding risky behaviours within a paediatric CF population. Participants had a range of different attitudes towards risky behaviours, suggesting a number of different reasons for why others engage in such behaviours. The data produced was prospective, which presented a deep understanding into participants' lives, examining individuals' attitudes and beliefs towards risky behaviours in real time. When paediatric participants were asked about what they regard as a risky behaviour, many identified non-adherence, demonstrating the emphasis CF care places on treatments' necessity.

Awareness was influential in encouraging individuals to engage in health promoting behaviours. When a participant did have good awareness regarding the adverse health effects of risky behaviours, they often acknowledged that these behaviours are more risky for them because of their CF, than they are for the general population. Nonetheless, with research in the adult population⁹ and previous literature indicating that the experimentation in risky behaviours is 'normal' during adolescence,² it is plausible that some paediatric participants may also be influenced to engage in these normalised behaviours. Some narratives could have been influenced by social desirability bias, potentially due to the differences in age between the participants and the researcher impacting on the power relationship within the research.^{29,30} Although adolescence is characterised as a time of experimentation with such behaviours, it is important to note that there is a 'line' or limit, which escalates normal to become extremely risky behaviours.^{2,31}

This research provides insight into the variety of reasons why CF adolescents may be motivated to initiate in risky behaviours regardless of their awareness. It is concluded that a desire for normalcy is seen to be important to many, with literature acknowledging that this desire for normalcy can be accompanied with the

engagement of normalised risky behaviours.^{10–12} Evidence of a life-orientated illness perspective is also prevalent, with some participants reporting that they believe individuals engage in risky behaviours for fun.¹⁴

Of awareness regarding risky behaviours, participants indicated that this can originate from a number of individuals. In general, there was a reported lack of knowledge concerning consequences of risky behaviours, with many participants not being informed about these behaviours within CF care, despite the apparent relationship between awareness and abstinence. The findings from this research therefore shed light into an area of CF paediatric care which could be improved on, providing practical insight into policy change for the prevention and reduction of risky behaviours within the CF population thus enhancing potential health benefits.

Risky behaviour awareness is not currently strongly embedded within paediatric CF care, with awareness being provided on an individualised basis.¹⁹ Most commonly, it was reported that when awareness is provided, HCPs provide verbal awareness on risky behaviours. Although it is positive that HCPs are addressing the issue of risky behaviours, the information that each adolescent receives may vary depending on the member of staff who provides that information, and may need standardising across all HCPs. To overcome inconsistencies in advice, and the problematic variation whereby different patients receive different amounts of information, research informed initiatives and guidance for clinicians is required regarding what risky behaviours are, what the CF-specific adverse health effects of risky behaviours are, and integrating preventive and on-going methods of care around quality of life into paediatric CF units.

The UK standards of care recommend that ‘smoking must be strongly discouraged in parents/carers from the time of diagnosis, as well as in all patients’³² (p. 17). Adolescents with CF who participated in this research demonstrated that paediatric patients are not always being made aware of this advice but also the wide range of risky behaviour engagement. It is therefore suggested that the UK standards of care should provide advice and counselling on a wider range of risky behaviours, with such awareness needing to be provided to all adolescents with CF on a proactive basis, regardless of their personal condition. Such advice needs to be revisited on several occasions, with participants often being able to recall that awareness was provided; however, they had gaps within their knowledge regarding why these behaviours are risky, which creates a concern of potential self-regulatory failure when faced with risky behaviour temptations.

Through the researchers’ reflections, it was indicated that different participants from the same CF centre did not have the same awareness regarding risky behaviours. Some participants reported not being informed by HCPs regarding risky behaviours, whereas other participants had been informed. This again potentially suggests that CF care approaches the issue of risky behaviours on an individualised basis. Alternatively, the differing awareness among participants from the same CF centre could

have been as a result of recall issues, again suggesting that awareness regarding risky behaviours needs to be revisited on several occasions, such as during annual review discussions. Collectively, findings suggest that policies are required for a more standardised method of providing information regarding risky behaviours within the paediatric CF population.

It is important to note that an intervention needs to go beyond awareness, with HCPs needing to be mindful regarding the influence psychological distress and avoidance of one’s CF can have on an adolescent’s engagement with risky behaviours.⁹ This research also highlights the effectiveness of well-being in deterring engagement with risky behaviours; this method requires further clinical and research consideration.

Study limitations

This research has some limitations worth acknowledging. During 5 interviews, guardians were present for the entire interview, with it being accepted that adolescents were unlikely to disclose experimentation with risky behaviours while their guardians were present.³³ Although this is a limitation, it is good practice when working with children and adolescents to allow their guardians to be present if participants express a desire for this; this is in line with NHS ethical guidelines. To overcome such limitations, future research could interview young people through online/social media platforms, thus increasing the autonomy of participants while still operating within ethical guidelines.

Even in the absence of guardians, a limitation of prospective interviews is the likelihood of social desirability bias. Despite the researcher’s effort to generate rapport, participants were unlikely to report current engagement in risky behaviours regardless of guardians being present, because participants most likely believed that these behaviours were ‘undesirable’.²⁰ That is why the research was not investigating engagement with risky behaviours, but instead focusing on one’s attitudes, beliefs, and awareness towards risky behaviours, with the researcher paying attention to the discourse of participants to identify accounts that had been influenced by social desirability bias.

Conclusions

Overall, this research provides an exploration into knowledge, attitudes, and beliefs towards risky behaviours among paediatric CF patients, at an age commonly associated with initiation. Through considering recent research with adults,⁹ and the current findings with paediatric data, it was concluded that future research should investigate how HCPs perceive the issue of risky behaviours within the CF population, in an attempt to gain insight into what interventions may work in practice. Research and clinical collaborations will create strong conclusions and recommendations on how to reduce the occurrence of risky behaviours within the CF population, with HCPs themselves identifying the provision of awareness regarding risky behaviours to embed within CF care.¹⁹

Author Contributions

RK - Conceptualization, recruitment, data collection, data analysis, writing - original draft, writing - review & editing. HE - Conceptualization, supervision, analysis, writing - review & editing. MM - Conceptualization, supervision, analysis, writing - review & editing.

Compliance With Ethical Standards

All procedures performed within this research which involved human participants were in accordance with the ethical standards of the institutional and/or national research committee (NHS NRES Committee East Midlands – Leicester; REC Reference: 14/EM/1183) and with the 1964 Helsinki declaration and its later amendments.

Informed Consent

Informed consent was obtained from all individual participants included in the study.

ORCID iDs

Rebecca Keyte  <https://orcid.org/0000-0002-5720-5184>

Michail Mantzios  <https://orcid.org/0000-0002-7476-3559>

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Appendix 1

Paediatric interview schedule

Ice Breakers Question's:

- Thank you for taking part
- What were your first thoughts when you were asked to take part in this research?
- Did you have any hesitations about agreeing to take part?
- So to begin with, can you describe what you do in a typical day?
 - Weekday/weekend difference
 - Spare time

Impact of cystic fibrosis on the patient's personal life:

- Could you tell me what it is like to live with cystic fibrosis
 - Discuss the challenges of living with cystic fibrosis
 - Has it always been this or were other aspects/things more difficult to cope with when you was younger?

- Do you tell others about your cystic fibrosis?
 - Who do you tell?
 - What do you tell them?
 - How do you find telling others about your cystic fibrosis?
 - Why don't you tell others about your cystic fibrosis?
- How do you find it sticking to your treatment regimen?
 - Does anyone help you stick to your regimen? (Who?)
 - Are there any aspects that are more difficult to stick to?
 - Has this changed over time?
 - Does it change depending on the situation/circumstances?
 - Are there any treatments you tend to 'miss out'?
 - Are there any treatments you wish you could 'miss out'?
 - How do you think it would make you feel if you did miss those treatments out?

Barriers to Adherence:

- What things make it difficult to stick to the regimen?

Areas for further elaboration may include:

- Not enough time in the day with school, etc
- The belief that the medical regimen is not benefitting them
- Are they self-prescribing according to their symptoms?
- Weekday/weekend difference
- Are there any situations where you are less likely to take your medication/complete your, eg, physiotherapy?

Areas for further elaboration may include:

- At school
- At a friend's house
- What makes it harder to complete your regimen in these situations?
- An area for further exploration may include the identity the medical regimen provides them with

Risky Health Behaviours:

- When I say 'risky behaviours', what does that make you think of?
- Do you think that some things are more risky for you because of your cystic fibrosis?
- What things would 'not be good' for your health?

Examples may include:

- Smoking
- Drugs
- Drinking alcohol

- Do you feel that these behaviours would have an impact on your cystic fibrosis?
- Have you ever been told that any of these behaviours would be bad for your cystic fibrosis?
 - Who has provided you with this awareness?
 - How does it make you feel towards these behaviours?
- Do you know anyone who takes part in these behaviours?
 - Who?
 - How does that make you feel?
- Have you/would you ever be motivated to try one of these behaviours?
 - What would motivate you?
 - What would stop you?
- Why do you think people do engage in these behaviours?
- Do you think any cystic fibrosis patients engage in risky behaviours?
 - Why do you think a cystic fibrosis patient would engage in these behaviours?
 - Why do you think a cystic fibrosis patient would not engage in these behaviours?

Family and Friends:

- If you did (eg, smoke), would you be open with family and friends about your (eg, smoking?) What do you think they would think about it? What would their reaction be?

'Other' may include

- Parents
- Siblings
- Partner

- Who do you go to with any concerns regarding your cystic fibrosis?

Examples may be:

- Consultants
- Family
- Friends
- Online forums
- Do you ever speak to any other cystic fibrosis patients?
 - Is this online?
 - Is this face to face?

Conclusion:

- What would you want to tell a younger patient with cystic fibrosis?
 - eg, about going to school with cystic fibrosis
 - eg, about telling others about their cystic fibrosis

- What would you tell a family who had just had a child with cystic fibrosis?
- Honestly if you were to have this discussion with another person (eg, someone who has cystic fibrosis), outside of this research, would this conversation be the same?
- Do you have anything else to add?

Appendix 2

Table 2. Key illustrating the codes used within this research from Jefferson transcription coding.

She wa::anted	Colons show degrees of elongation of the prior sound; the more colons the more elongation roughly one colon per syllable length.
(.)	A micropause, hearable but too short to measure.
Underlining	Emphasis; the extent of underlining within individual words locates emphasis, but also indicates how heavy it is.
#	Measures pauses in seconds, with one ‘#’ indicating 1 second.

[1]
 *[Emily, 14 years]: You're tr:rying to lead a (.) no:ormal life # tr:rying to (.) go out # after scho:ool [...] ho:ow to # dea:al with it # if you know what I mea:an ## with the nebuli:isers (.) an stuff ## I just want to be a no:ormal person # like I just want to go outsi:ide.

[2]
 *[Sophie, 12 years]: I think I would be a bit mo:ore # re:ela:axed (.) about thi:ings (.) and not ha:aving to worry as much [with non-adherence] [...] I'd probably just pla:ay out.

[3]
 *[Mandy, 12 years]: I was out with my ma:ates # a:and they were a:all smoking # and someone (.) gave me a fag # I held it in my hand # I was about to # but I just thought ### no # I ca:an't [...] I was trying to be # co:ool [...] it ma:ade me feel so ## ba:ad ## not having this fag.

[4]
 *[Emily, 14 years]: I would ne:ever do tha:at [smoke][...] I've done so:o many anti-smo:oking and anti-alcho:ol campaigns with scho:ool (.) an we learn about it in science:e (.) I'm like mega:a high on (.) not (.) to smo:oke.

[5]
 *[Tim, 18 years]: I think it [smoking] ha:as been brought up [by HCPs] befo:ore [...] but # it's mo:ore me # kind of # sa:aying (.) about it ## a:asking about it [...] in ho:ospitals they don't ki:ind of # ta:alk about precautions of things # they're mo:ore ta:alking about your treatments an stu:uff.

[6]
 *[Abi, 12 years]: Researcher: Has anyone ever told you # anything (.) about drinking alcohol.

Participant: No:o [...] I don't get like # wha:at's bad about it # I know it's like alcho:ol (.) but # like wha:at's # there's something in it (.) o:or ## I dunno:o.

[7]
 *[Emily, 14 years]: I'm not li:iike ## a sma:all person in the corner (.) who:o's ## not recognisable # I'm quite # a lo:oud person [laughs] most of my friends would sa:ay that.

[8]
 *[Tim, 18 years]: A lot of people associate dri:inking (.) as a # bad behaviour # but I don't # I just see that as a: a # part of fun # li:ife # cause yes it ca:an affect you # but not in the sa:ame # with your lu:ungs if you smo:oke # do you know what I mean.

[9]
 *[Tony, 13 years]: I'd say probably quite a fe:w people (.) like te:eenagers:s (.) an that # some adults:s might [smoke] with CF [...] cause probably the a:area they've been brought up in # o:or some of the friends they have.

[10]
 *[Chris, 14 years]: Most the people in my class do [smoke] # it's ridiculous [...] I think they're re:ally (.) stu:upid.

[11]
 *[Chris, 14 years]: Smo:oking (.) drinking # that kind of thing [...] they're stupid [...] it's basically like cutting yourself ain't it # it's killing yourself.

[12]
 *[Tony, 13 years]: They're [smoking, drinking, drugs] risky for eve:ryone (.) re:ally # but it's mo:ore risky for CF (.) cause that can make em mo:ore ill.

[13]
 *[Tony, 13 years]: I've lea:arnt (.) like # [nurses name] told me about that [drug use] as well # we spoke about a:all # like smo:oking (.) drinking # an the dru:ugs # but I ca:an't # remember # like ## I know people inject themse:elves with it # an that can make their bloodstrea:am # e:er:r # like # not hea:althy.

[14]
 *[Sophie, 12 years]: Someti:imes ## like (.) sa:ay # they have a ## health issue # o:or something # an sa:ay # they (.) we:eren't in a (.) very (.) good # state (.) sort of thing # they ma:ay think (.) well # I'm bad a:already # I mi:ight as well [smoke].