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ADHERENCE TO INFECTION PREVENTION AND CONTROL GUIDELINES: A VIGNETTE-BASED STUDY OF DECISION-MAKING AND RISK-TAKING IN YOUNG ADULTS WITH CYSTIC FIBROSIS.

Running title: ADHERENCE TO INFECTION PREVENTION AND CONTROL GUIDELINES

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Abstract

Background

Balancing cystic fibrosis (CF) care with demands of normal life is associated with decreased adherence to infection prevention and control (IPC) guidelines.

Methods

Adults with CF, aged 18-25 years, were invited to participate via UK CF Trust social media platforms. An online survey evaluated participants' decision-making in nine clinician-rated vignettes and assessed the perceived influence of infection-related information sources.

Results

Participants (n=87, mean 21.4 years [SD=2.45]; 75% female) were less likely to engage in the high-risk scenarios, although demonstrated greater awareness of cross-infection than environmental risks. Associations between risk-perception and willingness to participate in five vignette-based hypothetical activities were significant ($p<0.05$). Thematic analysis emphasised influences of past experience and a need to achieve good quality of life. Knowledge gaps were evident.

Conclusions

People with CF make decisions that discriminate between risk-levels but are not always based on robust knowledge. They also show some inclination towards engaging in risky behaviours.

Keywords: cystic fibrosis, adherence, infection prevention and control, decision-making, cross-infection.

1. Background

Infection prevention and control (IPC) guidelines recommend that people with CF avoid meeting one another and engaging in activities associated with increased infection risk[1-4]. Whilst non-adherence to CF treatments is well-reported and linked to negative health outcomes[5-9], adherence to IPC recommendations is less well-understood. Patient rates of avoiding contact with other people with CF are reported to be low (21%-27%), particularly in young adults[10,11]. Similarly, in a sample of UK adults (n=94), 35% reported mixing with others whilst in hospital, despite almost 64% having been informed of cross-infection risk[12]. Patients may doubt the potential infection risk and prioritise the benefits over the costs of meeting someone with CF[10,12].

In our previous qualitative work[13], eight young adults with CF were shown infection-related social vignettes and asked to discuss their decision-making about associated risks. They struggled to balance reducing risk with engagement in everyday life activities, selecting high-risk behaviours almost 60% of the time. Substantial knowledge gaps and misconceptions about the nature of risk were evident. This study develops these themes in a larger young adult sample for quantitative analyses, retaining qualitative properties that explore perceptions of, and reasoning about, environmental infection risks.

2. Methods

The School of Medicine Research Ethics Committee, University of Leeds, granted ethical approval on 01/12/2014 (SoMREC, Ref; SoMREC/14/011).

2.1. Participants

UK patients with CF (aged 18-25 years inclusive) were recruited via UK CF Trust social media platforms (January-February 2015) and were asked to consider participating in an online survey. Completion conveyed explicit consent.

2.2. Measures and Methods

The survey recorded participants' self-reported demographics (age, gender, height, and FEV_1%) and their decisions about courses of action in four vignettes adapted from our qualitative study[13]. These were based on current IPC guidelines[1] and approved by a Consultant Microbiologist with extensive knowledge of CF, to ensure validity. Each vignette outlined a social situation that required participants to choose between declining to participate in a potentially enjoyable activity and risking infection acquisition. IPC guidelines are binary in their recommendations (i.e., to avoid an activity or not), but each scenario within the study was assigned a rating of 'slightly increased, 'increased', or 'significantly increased' risk to indicate comparative risk. Risk in each vignette was presented iteratively, with each stage requiring a decision to participate or not; later elements involved the highest potential risk.

Participants indicated their decision to engage in the vignette activity by answering 'Yes', 'No', or 'Maybe' for each, and were subsequently required to rate the perceived risk of each scenario (low, medium, high, no risk, or uncertain), as well as explaining their decision-making qualitatively. Finally, they were asked to rate seven possible sources of IPC information in terms of perceived influence on their knowledge of infection risk (ten-point scale). Links to support and information (UK CF Trust Helpline and web-links) were provided.

Descriptive statistics were produced for each question and a Fisher's exact test examined the relationship between perception of scenario risk and decision-making. Thematic analyses explored participants' comments. The vignettes, clinician-rated risk-level

and associated infection(s), together with a summary of participant decisions, is shown in Table 1.

<INSERT TABLE 1>

3. Results

3.1. Demographics

The survey was completed by 132 respondents; however, 35 fell outside the specified age range and ten were not UK residents, resulting in 87 valid responses (female n=65; mean age 21.4 years [SD=2.48]; mean BMI 21.49 [SD=3.25]; median FEV_1% 60-79%).

3.2. Vignettes

Responses to each vignette are summarised in Table 1. Knowledge of pathogens varied: almost all respondents stated awareness of MRSA (97-98%) and Pseudomonas aeruginosa (PsA) (99%), but over one-third claimed to be unaware of Burkholderia cepacia complex (Bcc).

3.3. Perceived risks

Participants' perceptions of risks associated with each activity are shown in Table 2, and the association between decision-making, perceived risk and clinician rating of risk illustrated in Figure 1 (available as supplementary material online). Judgement of risk was broadly aligned with clinician-rated risk, particularly in the scenario that involved meeting another person with CF. Only a small number of respondents chose to participate despite rating the activity as 'medium/high' risk.

Whilst the number declining to participate correspondingly increased with clinician-rated risk, the same pattern was evident in all vignettes: perception of risk aligned with willingness to participate. This was tested with Fisher's Exact Test. For the analysis, risk perception was collapsed into 'No/Low Risk' and 'Medium/High Risk', whilst response was collapsed into 'No' and 'Maybe/Yes' (i.e. indicating active consideration of participation). Responses of 'I don't know' and 'I don't know what [pathogen] is' were removed. No participants rated the risk of one scenario as 'no/low risk'. For the remaining eight, the results show a statistically significant relationship between perceived risk and willingness to participate in five scenarios.

<INSERT TABLE 2>

3.4. Ratings of sources of information

Participants considered their CF team to be the most influential source of infection-control information; the highest-rated sources were 'your doctor and team' (mean = 8.4), 'written information from team' (mean = 7.7), and 'CF Trust/National charity' (mean = 6.7). Family and other (non-CF Trust) online sources were considered only moderately influential, whilst friends and other people with CF had minimal reported influence (mean rating <5).

3.5. Thematic analyses

Analyses of participants' reasoning behind their decision-making revealed seven main themes. As these responses were optional, the analysis does not include all participants: 20 provided no qualitative responses and only 14 responded to all qualitative questions. Analysis involved generating initial codes by examining each vignette individually and manually grouping the responses. The dataset was then examined as a whole, with codes grouped into emerging themes.

Theme 1: Infection risk as priority. These responses considered health risk above all other influences, often indicating little consideration of additional factors. Most (n=58, 67%) cited infection risk as the key motive for decision-making in at least one scenario, and often demonstrated clear knowledge of infections and their transmission (e.g., *"Pseudomonas can be contracted from the warm, circulating water"* [Vignette 3b]). Others (n=4, 5%) recognised that, whilst infection risk was the key factor in their decision, this was at some personal cost (e.g., "[meeting] *is a risk to both of our health so no. That doesn't mean it is easy to say no or not feel upset because of this."* [Vignette 4a]).

Theme 2: Prioritising Quality of Life (QoL). Participants providing these responses (n=32, 37%) largely neglected to consider infection, citing enjoyment and fun as primary motives for taking risks. Some explicitly stated (n=8, 9%) their desire not to allow their condition to interfere with QoL (e.g., *"I love this kind of environment and don't want CF to completely rule my life"* [Vignette 2b]).

Theme 3: No perceived risk. Some participants expressed a belief that the activity posed no risk, which was particularly apparent in the 'horse-riding' (2a) (n=13, 15%) and 'swimming' (3a) (n=6, 7%) vignettes. This belief was also evident when participants were asked about meeting another CF patient who had, or had recently eradicated, an infection. A significant minority (n=13, 15%) implied that having the infection themselves removed any risk, suggesting important gaps in knowledge (e.g., *"I have two siblings with CF. It's no different to me spending time with them"* [Vignette 4a]).

Theme 4: Decision-making and compromise. This theme included evidence of strategising (i.e. compromise, or considering alternative actions) and emphasised the importance of achieving balance between CF and other desirable or necessary activities, which many participants acknowledged. Some were explicit about the use of strategies that they believed minimised risk and permitted participation (e.g., *"I would weigh out the*

importance of the visit [and] whether I could wear a mask, gloves and an apron" [Vignette 1a]). Throughout all vignettes, almost half of the respondents (n=41, 47%) stipulated conditions under which they would participate, or considered active alternatives that would allow them to maintain a comfortable balance (e.g., *"It's not worth the risk. I can always ring or text them. They'd understand"* [Vignette 1a]).

Theme 5: Influence of past experiences. Responses indicated that past experiences could both encourage risk-taking (e.g., opting to engage in an activity as it had never previously resulted in illness) (n=10, 11%) or discourage it (n=12, 14%), if participants associated the activity with a past infection (e.g., *"Oh God!* [it] took me most of my life to shift [Pseudomonas]*"* [Vignette 4b]).

Theme 6: Social factors. This comprised three sub-categories: (i) family/friends as a priority, (ii) peer-influences, and (iii) prioritising health for others. These social influences, particularly perceived obligation to family and friends, sometimes took precedence over perceived infection risk (n=7, 8%) (e.g. *"*My close family and friends would visit me. It *wouldn't be fair if I didn't visit them"* [Vignette 1a]). Maintaining peer relationships was also important, predominantly in the holiday vignette. Some (n=12, 14%) rationalised participation with a desire not to be left out of activities, or cited other peer influences (e.g., *"Having a social life is a priority. Living in a bubble is not helpful"* [Vignette 3a]). Some (n=4, 5%) indicated a desire to reduce risk-taking for the sake of others, such as their family.

Theme 7: Lack of interest in the activity. Some respondents (n=7, 8%) expressed no interest in certain activities and risk was therefore irrelevant to decision-making.

4. Discussion

This study utilised a mixed-methods approach to explore decision-making and risk-taking behaviours in young adults with CF. In contrast to existing data[10,12], participants were

largely unwilling to engage in activities that posed significantly increased risk; however, most opted to engage in behaviours that posed some risk (e.g., >50% opted to use a Jacuzzi or hot tub). Such decisions may partially reflect 'optimism-bias' rather than lack of knowledge per se[10], where individuals perceived that their chances of experiencing adverse effects were smaller than others'[14]. Participants broadly demonstrated accurate risk-appraisal and most decisions were concurrent with their judgement, though as decisions were indicated before rating perceived risk it is possible that the decisions influenced the subsequent rating rather than vice versa.

Consistent with existing evidence[12], significant knowledge gaps were observed, particularly surrounding environmental risk. Some participants believed that previous pathogen acquisition prevented further cross-infection, unaware that different strains exist[15]. The significant proportion unaware of Bcc is of particular concern given association with decreased survivorship[16].

Several important themes emerged, including social influences, a desire to maintain QoL, and risk beliefs: factors known equally to impact medication adherence[17]. Some participants prioritised social activities over CF needs although, whilst peers may collude with their prevention of feeling 'left out'[17], at times they provided the motivation to avoid risky behaviour[18].

Respondents utilised perceived 'risk-reduction' strategies to permit participation. This is well-described[19,20] and underpinned by cognitive dissonance theory[21], which explains why individuals faced with making risky choices that create emotional discomfort will attempt to reduce this by citing evidence that justifies the risk-taking decision (e.g., the prevalent rationale to participate in 'horse-riding' and 'swimming' was "exercise benefit").

Conclusions drawn from a small number of participants who opt into studies are almost always limited because of sample-bias; however, our demographic data conferred

good representativeness of UK Registry data on patients aged 18-25 years (n=2,030 in 2014)[22]. Although transition to adult care usually takes place when patients are 14-18 years old[23], we did not account for some respondents perhaps still receiving paediatric care. Thematic analysis would have been affected by the small number of respondents answering all qualitative questions (n=14) but these were intentionally made optional to encourage completion. Only one low-risk scenario was included, potentially underestimating participant willingness to engage in lower risk situations.

Despite these limitations, misconceptions about, and willingness to engage in, risky behaviour expressed in our sample are of real concern given these are highly likely to be a conservative estimate of prevalence in the CF population. Knowledge gaps existed yet tackling these alone does not seem sufficient. Intervention also requires honest conversations between patients and team if harmful misconceptions about infection risk are to be avoided. IPC information may be inconsistent across centres[24]; therefore, an important next step would be to standardise this and establish common resources for dissemination during transition to adult services, which expect people with CF to demonstrate increasingly autonomous healthcare behaviour[25].

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Table 1.

Clinician-rated risk level of vignettes and associated infection(s) in order of risk level, and participants' decision whether to participate in each activity (n(%))

Risk Level [a]	Vignette Content	Associated Infection(s)	**Decision** Yes	Maybe	No
1	3a. Use a public swimming pool	PsA	67 (77%)	8 (9%)	12 (14%)
2	2a. Go horse-riding	Aspergillus	62 (71%)	10 (12%)	15 (17%)
2	1a. Visit hospital - someone on the ward has MRSA	MRSA	18 (21%)	19 (22%) [b]	47 (54%)
3	1b. Visit hospital - the person you are seeing has MRSA	MRSA	2 (2%)	10 (12%) [c]	73 (84%)
3	2b. Clean the stables and feed the horses	Aspergillus	36 (42%)	11 (12%)	40 (46%)
3	3b. Use a Jacuzzi/hot tub	PsA	44 (50%)	11 (13%)	32 (37%)
3	4b. Meet someone with CF - and they have Pseudomonas (PsA)	PsA, Bcc	9 (10%)	10 (12%) [d]	67 (77%)
3	4a. Meet someone with CF	PsA, Bcc	7 (8%)	19 (22%)	61 (70%)
3	4c. Meet someone with CF - and they had cepacia (Bcc) 6 months ago	PsA, Bcc	3 (3%)	4 (5%) [e]	50 (57%)

[a] Risk level was categorised by a Consultant Microbiologist as follows: 1 = Slightly increased risk; 2 = Increased risk; 3 = Significantly increased risk; [b] 3(3%) indicated no awareness of MRSA; [c] 2 (2%) indicated no awareness of MRSA; [d] 1 1(%) indicated no awareness of Pseudomonas (PsA) ; [e] 30 (35%) indicated no awareness of cepacia (Bcc)

Table 2.

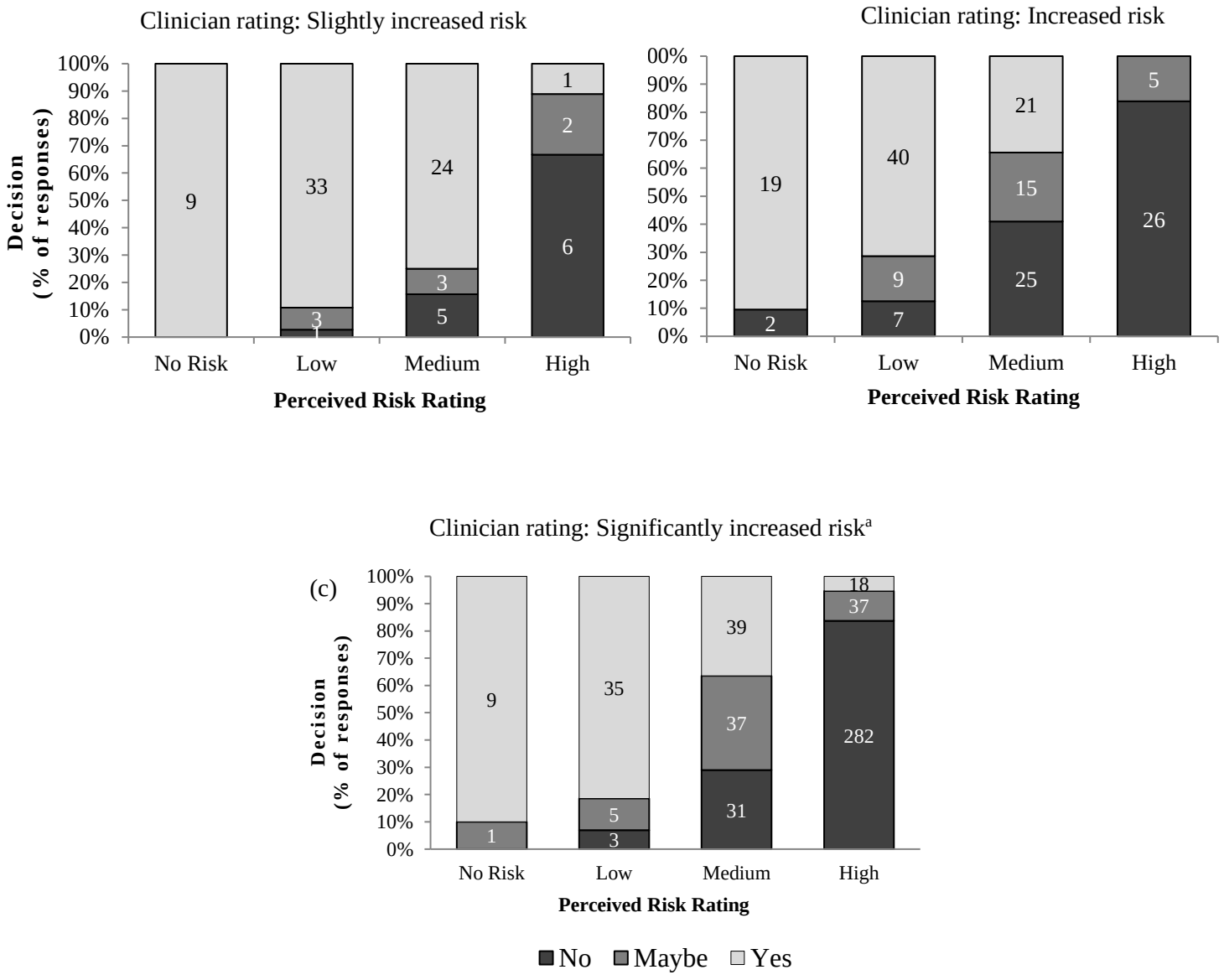
Participant perception of risk presented by each activity (n(%)), and Results of Fisher's exact tests examining the relationship between participant perception of risk (No/Low risk vs. Medium/High risk) and response to each scenario ('Maybe/Yes' vs. 'No')

Clinician-Rated Risk	Vignette content	No risk	Low risk	Medium risk	High risk	Don't know	Exact Sig. (2-tailed)
1	3a. Use a public swimming pool	9 (10%)	37 (43%)	32 (37%)	9 (10%)	0	p = 0.001*
2	2a. Go horse-riding	20 (23%)	46 (53%)	16 (18%)	3 (4%)	2 (2%)	p = 0.002*
2	1a. Visit hospital - someone on the ward has MRSA	1 (1%)	10 (12%)	45 (52%)	28 (32%)	3 (3%)	p = 0.055
3	1b. Visit hospital - the person you are seeing has MRSA	0	1 (1%)	9 (10%)	73 (84%)	4 (5%)	p = 0.145
3	2b. Clean the stables and feed the horses	5 (8%)	16 (18%)	36 (41%)	30 (33%)	0	p = < 0.001*
3	3b. Use a Jacuzzi/hot tub	4 (5%)	21 (24%)	23 (26%)	39 (45%)	0	p = <0.001*
3	4a. Meet someone with CF	0	3 (3%)	27 (31%)	57 (66%)	0	p = 0.212
3	4b. Meet someone with CF – and they have Pseudomonas (PsA)	1 (1%)	2 (2%)	8 (9%)	73 (84%)	3 (4%)	p = 0.011*
3	4c. Meet someone with CF – and they had cepacia (Bcc) 6 months ago	0	0	4 (4%)	65 (75%)	18 (21%)	[a]

* Significant at $p < 0.05$ level

[a] Fisher's Exact Test not computed as no participants rated this scenario as 'No/Low Risk

Figure 1. Percentage of participants willing to engage in an activity based on their perception of its presenting risk, organised by clinician rating of risk.



[a] The figure of 282 in the third graph is accurate and reflects the fact that almost all of the participants that accurately perceived the high risk scenarios as posing the highest risk indicated that they would not participate.