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**Healthcare professionals’ perceptions of risky health behaviours: a qualitative evaluation of preventative measures for populations with cystic fibrosis**

**Objectives:**

Previous qualitative data highlight why individuals with Cystic Fibrosis (CF) may be motivated to initiate in risky behaviours (smoking, excessive alcohol consumption, illicit drug use). To inform interventions aimed to reduce the occurrence of risky behaviours, we investigated how CF health care professionals (HCPs) perceive the issue of risky behaviours, providing insight into what interventions could work in practice.

**Methods:**

This research had two phases of data collection. In phase one, nine CF Specialist Nurses participated in a semi-structured interview via telephone. In phase two, HCPs who work within a CF multi-disciplinary team (MDT) participated in a dissemination meeting.

**Results:**

CF HCPs identified that although risky behaviours were a major concern within the CF population, education regarding the adverse health effects of such behaviours is not embedded within practice, the issue of risky behaviours is addressed on an individualised basis. HCPs suggested that they would welcome interventions, and that such interventions firstly need to raise HCPs awareness and knowledge regarding risky behaviours before focusing upon patients.

**Discussion:**

Within this research, HCPs provided practical insight into the need for policy change for the prevention and reduction of risky behaviours by informing current advice and practice.

Key Words: Cystic Fibrosis, Risky Health Behaviours, Qualitative Research, Dissemination Meeting

**Introduction**

 Smoking, excessive alcohol consumption and illicit drug use are prevalent within Cystic Fibrosis (CF) populations resulting in poorer health outcomes for patients regardless of adherence efforts1, and removing the possibility of future lung transplantation. The initiation and common occurrence of risky behaviours during adolescence2 and transitioning from paediatric to adult care are fundamental and timely to the discussion of abstinence and prevention of risky behaviours, which in the UK occurs between the ages of 16-18 years3-5

The move to adult care precipitates a change from a model of care-from-others to a more independent model of self-care and signifies a shift in responsibility for regulating health behaviours from clinicians and family to the individual and this is when risky behaviours within the CF population become more prevalent6.

Qualitative research within the adult and paediatric CF populations demonstrated how risky behaviours of young adults with CF replicate those of healthy young adults, and initiation and continuation occurs even when there are high levels of parental or caregiver engagement and support 2,7.

During adolescence identity formation becomes increasingly important, and for young adults with CF, perceptions of oneself as being ‘typical’ and not being defined by CF are associated with ‘normal’ activities which include risky behaviours. Engagement in common risky behaviours is one way of emphasising normalcy and provides a distancing from any notion of an illness identity.

 While research indicates the importance of CF-specific awareness regarding risky behaviours, and the potential of integration to CF-care2,7, there is little information around whether and how much information is provided. The researchers therefore emphasised the importance of investigating CF HCPs perceptions around the issue of risky behaviours, and to gain a greater understanding of what is needed for interventions to be practically applicable in a clinical setting with this specific patient group. Findings will inform current practice and advice provided, and highlight where policy and practice change could be made to improve the prevention and reduction of risky behaviours within the CF population.

**Method**

This research contained two phases of data collection exploring how information regarding risky behaviours is provided to patients with CF.

***Phase 1: HCPs’ views on risky behaviours and current interventions used in practice***

*Design*

The researcher conducted semi-structured telephone interviews with CF Specialist Nurses exploring how they perceive the issue of risky behaviours within the CF population and the strategies implemented to address this. Telephone interviews allowed for recruitment over a wider geographical range than face-to-face interviews would have allowed8. Telephone interviews may also have facilitated more open discussions, particularly around sensitive issues such as perceptions of flaws or inadequacies in service provision.

*Data Collection*

Data collection continued until data saturation occurred. Nine CF Specialist Nurses were recruited each from a different UK CF unit (three paediatric Nurses, five adult Nurses, one adult and paediatric Nurse; range of experience 11 months - 23 years, mean = 14 years), and pseudonyms were used to ensure confidentiality. CF Specialist Nurses were chosen as they are most likely to be engaged in delivering interventions around risky behaviours9-11. Evidence shows that CF patients have a closer relationship with Nurses and disclose more information to them than other members of the MDT. Nurses are therefore well placed to offer valuable insights into the issue of risky behaviours and to deliver effective interventions.

The interviews aimed to progress previous findings focusing upon risky behaviours within the CF population2,7 by investigating CF Specialist Nurses’ awareness about risky behaviours within the CF population, and how Nurses currently address this issue. Ethical approval was obtained by the Business, Law and Social Sciences Ethics Committee at Birmingham City University (application number 068/16), with Nurses providing written informed consent via email prior to the telephone interview being conducted.

***Phase 2: Dissemination of research findings to CF Multi-Disciplinary Teams around the issue of risky behaviours within the CF population***

*Design*

The researcher disseminated the research findings from the previous qualitative studies2,7 and the qualitative interviews with CF specialists including a focus on Nurses’ perceptions towards risky behaviours. The aim of the previous qualitative studies were to implement an intervention into CF care to reduce the occurrence of risky behaviours, with Henriksen et al12 acknowledging the importance of collaborating with HCPs to implement an intervention into practice. Findings were presented to HCPs who work within CF MDTs utilising a PowerPoint presentation in workshops, with such findings being evidence of the creation of knowledge and knowledge distillation to HCPs as acknowledged by Henriksen et al12. Once the researcher had disseminated the findings12, the researcher encouraged HCPs to discuss the research using a plan14. HCPs were asked to discuss the research, providing the opportunity to critique the findings and to make suggestions for how the research could be used to enhance and develop pragmatic and effective interventions. The questions asked were open ended, allowing HCPs to provide an in-depth insight into their beliefs regarding the need for a new intervention, as well as what intervention they believe would work in practice. The dissemination plan was semi-structured, allowing HCPs to discuss topics that had not been predetermined by the researcher. HCPs’ discussions were audio recorded. Collaborative dissemination demonstrates good practice and complies with NHS Institute for Innovation and Improvement13, and The Foundation of Nursing Studies14 guidelines ensuring the new knowledge this research generated was added to the field of CF15.

*Data Collection*

HCPs who work within the CF MDTs (adult and paediatric teams) at two different hospitals were recruited to participate in a dissemination meeting. Both hospitals were research sites when recruiting adult and paediatric participants2,7, illustrating their invested interest in informing practice regarding risky behaviour awareness. Three dissemination meetings were conducted. Ethical approval was obtained by the Business, Law and Social Sciences Ethics Committee at Birmingham City University (application number 069/16), with the CF units providing verbal consent to participate in a dissemination meeting prior to the meeting being arranged.

 ***Analysis applied to phase 1 and 2***

The recordings of the interviews were transcribed by the researcher. The data was analysed using thematic analysis following Braun and Clarke's model16 as this is a flexible method. Thematic analysis was used as a contexualist method, positioned between the two poles of essentialism and constructionism, characterised by critical realism17. A contextualist method was used as the reasons for engaging in risky behaviours are context-dependent18, thematic analysis considered how individuals made meaning of their experiences, alongside the impact the broader social context has upon those meanings; acknowledging that meanings and experiences are socially produced and reproduced rather than being inherent19.

Within both phases of data collection 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. To conduct thematic analysis within each phase of data collection, the researcher firstly became familiar with the data, paying attention to any patterns that occurred. Data familiarisation occurred firstly during data collection and transcription of the data (with the same researcher conducting and transcribing all interviews), where the researcher actively processed the data. In addition, data familiarisation occurred as a consequence of the researcher reading through the transcripts several times.

 Once the researcher was familiar with the data, the researcher coded each transcript line by line. Whilst only one researcher was responsible for coding the data, the other two researchers acted as raters. This involved the three researchers working together to evaluate and revise the codes generated, with the validity of the codes being ensured when the researchers were in agreements regarding each code.

Once the researchers were satisfied with the generated codes, the researcher generated the themes of the data. To create the themes, the researcher categorised the codes into meaningful groups of codes, with the themes identifying major patterns that emerged from the codes. Again, the validity of the themes were confirmed when the three 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.

**Results**

 The overarching message from both phases of data collection was that there is a need for greater knowledge around health risk behaviours, and for more robust and effective measures to help reduce the occurrence of risky behaviours within the CF population. From the interview study with CF Specialist Nurses, three themes were constructed from the data set. The first highlights the changing nature of CF care and the increased prevalence of risky behaviours. The second focuses on the importance of good knowledge and understanding of the factors and circumstances in patients’ lives which may influence engagement with risky behaviours. Finally, the third theme focuses on the benefits and limitations of current interventions in practice; the need for development of more efficacious interventions and what these might include was emphasised by participants. Two themes from analysis of the dissemination meetings data were identified, these focused upon the problematic notion within CF care that education and awareness around risky health behaviours is provided by others, in school for example, and the need for further training for HCPs around risky health behaviours.

Both phases of data collection provide an opportunity for the implementation of research informed practice within the CF population.

***Phase 1: HCPs’ views on risky behaviours and current interventions used in practice***

This first phase of data collection aimed to gain an in-depth understanding of the awareness and perceptions of CF specialist Nurses on risky health behaviours, and to explore their experience and views on current interventions and potential future interventions.

*Cystic Fibrosis Care is a changing environment*

Many CF Nurses highlighted that with life expectancy increasing, and many individuals with CF entering adolescence and adulthood being relatively well, CF care now needs to address risky behaviours, which is becoming a major concern. Several participants said that this is not currently part of standardised care and believed that it should be integrated into current delivery: "For us, that's [risky behaviour engagement] obviously a real concern with treatments, and their health and everything else. It's only just becoming an issue in more recent years" [Michelle, 4 years, paediatric nurse].

The urgency for addressing this issue was emphasised by a number of participants, particularly given the changing demography and improved health status of adolescent CF patients: "With our patients living longer, their lives aren't particularly easier, because they're getting more and more CF related issues. I would say it's made the job more complex" [Debbie, 23 years, Adult Nurse]. The need for improved interventions was clearly expressed by all participants and for this to happen there were a number of factors to consider, including training needs as outlined in the second theme.

*Cystic Fibrosis Specialist Nurses’ knowledge regarding a patient’s life*

 This second theme provides insight into CF Specialist Nurses’ knowledge regarding their patients’ lives, and their awareness concerning what influences patients’ decisions regarding health behaviours. For the issue of risky behaviours to be actively addressed, many Nurses, including Michelle, explained that they require more education to be able to provide awareness: "I want to be a bit more knowledgeable, because it [risky behaviours] will affect them so much, if we don't get to the bottom of it" [Michelle, 4 years, paediatric nurse].

Literature reports that some HCPs know less about illegal substances than their patient’s do20; however it should be expected that when HCPs know a patient engages in risky behaviours, awareness is provided, nonetheless Jayne explains that this is not always the case: "We do have a few patients who we know dabble in a few things they shouldn’t, but there’s nothing, we don’t give any information, we don’t have, er, leaflets here from an infectious control point of view, we don’t keep a stand or anything" [Jayne, 11 months, adult nurse]. This demonstrates the need to implement standardised interventions within the CF population both on a reactive and proactive basis and for these to be revised regularly to incorporate and reflect changes in risky behaviours. For example, Alice discusses changes in smoking behaviours and the perceived concomitant increase in other risky behaviours: “One of the respiratory consultants was commenting on the fact, in another sixty years they won't have anything to do because the amount of cigarette smoking is dropping, teenagers now are more likely to take a pill than to smoke" [Alice, 21 years, adult nurse].

This point was also emphasised by Michelle, who was very clear in expressing her lack of knowledge around risky behaviours, and the clear need for greater professional education and training: "Intervention needs to be support for us. What to look out for, and how to address it. There is so much that can happen, probably half of it we're unaware of. What kinds of risky behaviours they could engage in, I wouldn't even have a clue about [laughs]" [Michelle, 4 years, paediatric nurse]. In this theme, participants clearly identified that they lacked sufficient knowledge and awareness around risky behaviours, particularly new behaviours and how these might specifically affect CF. This point is further elaborated in the next theme where participants discuss how interventions may be improved and developed.

*Interventions which Cystic Fibrosis Specialist Nurses believe would work in reality to encourage health promoting behaviours*

This final theme provides suggestions into what interventions Nurses believe need to be implemented to reduce the occurrence of risky behaviours, as well as how current interventions need to be progressed. Proactive interventions do currently exist, with Nurses discussing the use of the “ready, steady go” questionnaires5, which are part of a transition programme aimed at helping adolescents gain the knowledge and skills to manage their condition. Paediatric patients receive this questionnaire three times prior to transition, assisting the adult medical team in developing an individual treatment plan. Within this questionnaire there are two questions relating to risky behaviours:

1. “I understand the risks of alcohol, drugs and smoking to my health”
2. “I know where and how I can access information about my sexual health”

Answers are given by ticking a “yes” or “no” box. Additional options exist, such as ticking a box “I would like some extra advice / help with this”; and there is the opportunity for individuals to write comments.

Kirstie and Dawn, who are Nurses from different CF units, report using the ready, steady, go intervention5 as a platform to instigate discussions regarding risky behaviours with patients: "We use it [ready, steady, go] as a forum to discussing the issues [risky behaviours], which is brilliant cause actually having something, a piece of paper in front of you, you don't have to have that embarrassing, eye balling conversation [laughs], which young people hate" [Kirstie, 22 years, paediatric nurse].

Whilst it is positive that these units are addressing risky behaviours, Kirstie and Dawn shared a concern that this intervention may be a “tick box exercise” for some, without having the necessary "conversation" regarding the adverse health effects of risky behaviours with their patients. Both Kirstie and Dawn commented that this is likely especially when their patients state that they are aware of the risks. Additionally patients do not always disclose full information to their clinicians, and knowledge of awareness of the risks is not always sufficient to prevent engagement in damaging behaviours. Furthermore, the ready, steady, go paperwork has an accompanying set of paperwork to be used at the adult unit after transition (Hello paperwork); however, Kirstie disclosed that the adult unit at her hospital do not use this, indicating the lack of standardisation across CF units.

 Kirstie and Dawn also discussed the verbal information they provide patients with, as well as using the ready, steady, go intervention, in an attempt to prevent initiation: "When they get to thirteen, part of that consultation [annual review] will include, not a vast amount, but we will refer to drugs and alcohol, and the way those can affect Cystic Fibrosis" [Dawn, 20 years, adult and paediatric nurse]. Again, whilst it is positive that these units address the issue of risky behaviours, the use of verbal information has its limitations, with Nurses acknowledging that verbal information is dependent on the individual clinician and on the relationship with the patient.

 There was evidence within two different CF units of patients being provided with supplementary written information on risky behaviours, however many Nurses did identify that whilst the use of written information is good, there is a need to use technology as this is the way that adolescents and young adults commonly communicate, both online and through various mobile apps21. Many Nurses stressed the importance of fostering such communication style in order to reach their patients: "Online is so key, every teenager I meet is surgically attached to their phone, it's such an easy way to provide information, cause that's what they want to look at, they don't want to be talked at, they want to find this information, so whether you could put it on things like facebook, twitter, CF apps. I think the only way you're going to grab their attention is in the media form they're used to" [Alice, 21 years, adult nurse]. Patients would not just favour the use of technology; it would also be less time demanding for HCPs, with many Nurses explaining that they do not have time for in-depth conversations regarding risky behaviours with "non-risky" patients. The use of technology would also be advantageous in targeting the "hard to reach" patient group, who Nurses know are engaging in risky behaviours, however they rarely attend clinic appointments.

Overall, this theme identifies that many Nurses do acknowledge the need for new interventions to be implemented into CF care regarding risky behaviours. Firstly, Nurses believe that staff training is required: "I think it would be useful for people more knowledgeable than me, about what the current trendy things are. It's tough enough to keep up to date on all the things that are changing, without having to read up on the latest ecstasy, designer drug is [laughs]" [Alice, 21 years, adult nurse]. Such training would allow Nurses to provide awareness to all patients regarding risky behaviours on a proactive basis, through both verbal information and supplementary written information. Nurses believe that technology based interventions would be most successful, due to it fostering the communication style of adolescents and young adults.

These interviews indicate that whilst the majority of CF Specialist Nurses acknowledge that risky behaviours are becoming a major concern within the CF population, not all CF units address this issue. These findings, as well as those from previous research2,7 provide the opportunity for the implementation of research informed practice to address the issue of risky behaviours. This phase of data collection investigated how Nurses perceive the issue of risky behaviours within the CF population, and what interventions they would like implemented. The researchers therefore identified the importance of speaking to and collaborating with other HCPs, in order for this research to have a "real world" impact in the practice of health care2,7.

***Phase 2: Dissemination of research findings to CF Multi-Disciplinary Teams around the issue of risky behaviours within the CF population***

 This second phase of data collection allowed the researchers to disseminate their findings to MDTs of CF HCPs, allowing HCPs to critique the findings and offer suggestions regarding interventions which could work in practice. All HCPs within the dissemination meetings agreed that risky behaviours are a growing concern. In agreement with CF Specialist Nurses, many HCPs stated that the provision of awareness regarding the adverse health effects of risky behaviours is not embedded within practice, with the topic being approached on an individualised basis: "I know when I used to do Asthma clinic, I always used to ask about smoking, and I don't do it within CF clinic" [Paediatric Nurse].

 In response to the evidence presented that some adults with CF were unaware of the adverse health effects of risky behaviours until they experienced such effects themselves2, HCPs suggested that patients already received education on this from agencies outside their hospital care. A common belief was that adolescent CF patients receive awareness regarding risky behaviours from school: "They get educated at school. They get quite a lot of information about these things at school, which, the drug information for instance at school is more up to date than what I know" [Paediatric Consultant]. Whilst education regarding risky behaviours is often provided within schools, the quality and effectiveness of this education differs greatly across providers with some large gaps in provision. HCPs may then have overestimated the quality of school-based awareness, and understated the need to have this awareness implemented into CF care.

In addition, as acknowledged by some HCPs, because school-based interventions are not CF-specific they may not resonate with CF patients. Predominantly, school-based interventions focus upon the elevated risk of cancer associated with risky behaviours, with HCPs highlighting that cancer can occur in individuals at an age which is above the life expectancy for CF: "At school they're not going to be focused on that [CF risks] are they, they're going to be focusing on the cancer risk. There's a difference, CF patients thinking life expectancy wise, cancer risk, it doesn't matter" [Dietician]. The need for CF-specific awareness was highlighted by adults with CF2, with some participants who had engaged in risky behaviours stating that if they had have been informed of the impact such behaviours can specifically have upon CF, it may have prevented their initiation.

 In addition to school-based interventions, some HCPs believed that sufficient risky behaviour awareness is provided through the NHS, targeted at adolescents, provided online: "You would hope that somewhere, in the NHS there must be some teeniebop information on sex, drugs and rock and roll I would have thought" [Adult Consultant]. Whilst NHS choices22 provides information online regarding risky behaviours, as with the education provided through schools, this information is not CF-specific. In terms of CF-specific awareness, there is limited awareness provided online. The CF Trust does provide a warning that drinking alcohol or taking illegal drugs can be very dangerous in CF within their “Festival Planning Guide”23, however they do not explain what these adverse health effects are, and the information is badged very specifically at ‘festival goers’ rather than aimed at all areas of life. (e.g. University, work, relaxation).

 After being presented with data from individuals with CF stressing the need to be provided with CF-specific awareness regarding risky behaviours2,7, HCPs acknowledged the need for an intervention to be implemented. Many HCPs stated that initially an intervention needs to target HCPs, in order to raise their awareness regarding risky behaviours, as discussed by CF Specialist Nurses. Many HCPs suggested that, apart from smoking, they do not have a clear understanding of how risky behaviours impact specifically on CF: "Alcohol, it's, you know, drinking to excess is a bad idea, is it worse because you've got CF?" [Paediatric Consultant]. Many HCPs emphasised the need for staff training to raise their awareness regarding what behaviours are prevalent within the general population, how they could identify such behaviours within their patients, as well as awareness regarding the CF-specific effects of risky behaviours. HCPs stressed that without sufficient training they do not feel confident in dealing with information that patients disclose, often not being aware when confidentiality should be broken, thus discouraging discussion: "Sometimes it's not knowing what to do with that information as well when you get it, cause then you've got the awkward do I tell the parents, or not? It depends what it is, is it safeguarding, isn't it safeguarding? [Laughs]" [Physiotherapist].

 HCPs believed that following staff training they would be able to provide sufficient awareness to patients, potentially incorporating this information into annual reviews. As stressed by CF Specialist Nurses, HCPs agreed that this awareness could be partly delivered via technology, with technology providing adolescents the opportunity to access CF-specific information regarding risky behaviours in a confidential manner. HCPs were keen to emphasise however that more should be done than just providing awareness, with it being well established that knowledge it not always enough to prevent initiation or aid cessation of risky behaviours.

**Discussion**

Overall, this research provides practical insight into the need for policy change for the prevention and reduction of risky behaviours within CF populations. It is essential to promote awareness regarding the CF-specific adverse health effects of risky behaviours as an element of standardised prevention across CF care. Additionally, the dissemination meetings highlighted to CF HCPs an opportunity for further professional development, which could have positive effects upon prevention and treatment of risky behaviours.

Both phases of the current research suggested that services address risky behaviours in different ways. Despite the widespread acceptance that risky behaviours are a major concern within the CF population, as emphasised within previous research2,7, HCPs outlined that they approach risky behaviours on an individualised basis. Accordingly, while literature suggests that risky behaviours are easier to prevent than terminate (once initiated), current interventions are predominately focusing on aiding the cessation of an initiated behaviour, which suggests missed opportunities to enhance care and services24.

HCPs suggested that these missed opportunities are partly due to HCPs limited awareness of risky behaviours and feeling uncertain about how to instigate conversations with patients regarding such behaviours. HCPs and CF Specialist Nurses identified the need to have some form of staff training to raise their awareness, allowing them to correctly and confidently provide awareness to all patients on a proactive basis. Proactive awareness is rarely incorporated within CF care, particularly with patients who are not identified as being ‘at-risk’ and this suggests the urgent need for the development of evidence-based practices and policies to enhance the ability to prevent initiation.

Some CF Nurses discussed that recently their CF unit had started addressing caring around risky behaviours; however, they identified some flaws in the units’ newly adapted interventions. The majority of units provided verbal information, with Nurses acknowledging that the verbal information a patient receives is influenced by the HCP who provides that information, with this varying depending upon many factors, such as the clinic environment and time constraints. Furthermore, literature indicates that patients within the general population forget up to half of the verbal information received within five minutes, and recall only 20% of the information25. Consequently, Nurses identified the need to accompany verbal information with written information, either via leaflets or technology.

Many HCPs emphasised that technology, and more specifically, the role of smart-phone apps was vital in raising patients’ awareness regarding risky behaviours. Smart-phone apps have been implemented into CF care to encourage treatment adherence26, and the potential incorporation to already existing treatment and prevention apps appears cost-effective and easy to implement. Work could be done to integrate education regarding risky behaviours into these apps through working with experts who can provide CF-specific awareness regarding the adverse health effects of risky behaviours. As highlighted by HCPs, education provided to patients would need to be continually reviewed due to new risky behaviours which emerge on a regular basis, such as new drugs formerly known as legal highs.

Furthermore, HCPs identified that interventions need to go beyond providing awareness. Based upon previous research with adult and paediatric CF patients, an intervention could screen for psychological distress and avoidance of CF as influential factors affecting risky behaviour initiation2,7. Identified patients should then be provided with additional support to cope with these aspects of their lives, which may reduce the occurrence of risky behaviours. This support could involve the use of patient advisory groups, and online mentoring, which have been set up within the USA to allow CF patients to communicate and encourage positive health behaviours amongst one another27.

***Conclusion***

 Overall, this research highlights the need for awareness of risky behaviours, and the corresponding CF-specific adverse health effects. Importantly, HCPs suggest that interventions are needed for both HCPs and patients, with professional training around risky behaviours; both in terms of why patients may engage in such behaviours, along with clear information on the CF-specific adverse health effects these behaviours can have upon CF patients. HCPs then believe that interventions need to focus upon patients. Based on previous work it is recommended that an intervention should firstly screen for psychological distress and avoidance of CF as influential factors affecting risky behaviour initiation2,7. In addition to this, as discussed by HCPs, an intervention should inform all patients regarding the adverse health effects of risky behaviours regardless of their personal condition. HCPs and the researchers of the present research are now proposing a collaboration between them, and an open call to patients and other HCPs to engage with designing the suggested intervention, ensuring that any intervention created will be welcomed into practice, providing the potential of impact at national and international clinics by disseminating appropriate standardised practices.

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