Findings from interviews with patients of the 3DFD service

A research report based on interviews with patients of the 3DFD programme.

October 2011
Introduction

This document is a research report based on interviews with patients of the 3DFD programme. It aims to explore and evaluate patient experience of the programme and to provide some guidance for the programme’s future.

About 3DFD

3DFD is a programme designed to tackle to growing challenge of complex diabetes in Southwark, an area in which it is disproportionately prevalent.

The programme recognises the many challenges faced by those with the problem and the broad range of skills, not just clinical, that must be employed in order to enable patients to live a full and active life and to effectively manage their condition.

The programme is currently being trialed using a small team in a single hospital.

In doing so it takes a holistic look at the patient and aims to cater for a wide range of needs including addressing the financial, social and psychological needs of the patient.

About this report:

This piece of research was aimed to gain a deeper understanding how patients experience the service and to capture their thoughts on how it can be improved in future. It is intended that the insights generated from this research be used to inform future service improvement activity.

thinkpublic approached this task by carrying out one-to-one interviews with 3DFD patients. These interviewed followed a semi-structured format. This meant that the lead interview had a set of topics to cover but patients were allowed to shape the course of discussion, depending on their interests and experiences. Five patients were referred to thinkpublic by the 3DFD team, four of whom were interviewed in person at King’s College Hospital and one of which was contacted by telephone but had no response.

Both the participants and the professionals mentioned specifically have been anonymised. Participants were told before the interviews began that the names of professionals that they used would be annonymised in this report.

Each interview covered the following topics:

- Initial involvement with the 3DFD project.
- Experience throughout journey through the service.
- Staff attitude and communication.
- Perceptions of difference between 3DFD and other approaches.
- Perceptions of qualitative differences made by 3DFD to patients lives.
- Diabetes challenges not being addressed by 3DFD.
- Experiences of care prior to 3DFD.
- Areas in which 3DFD could be improved.
- Broader opportunities for the improvement of people’s lives with complex diabetes.

This report summarises the key points to emerge from interviews with patients. In particular, it focuses on how patients have experienced the 3DFD and identifies the key characteristics which underpin the service. The report also aims to identify areas for improvement. This aspect of the report is covered in less detail, however, due to the patients’ strongly positive experiences of, and relationship with, the 3DFD service.

Patients’ routes to 3DFD

All of the patients interviewed were offered access to the 3DFD service after being identified by a health professional as having serious difficulties managing their diabetes.

The reasons patients indentified for the difficulties they experienced varied. Two patients (ST-002 and ST-005) identified an aversion to needles as the main source of difficulty, as it made it hard for them to inject the insulin required to manage their conditions. Two patients (ST-003 and ST-0006) identified depression and stress as a the key factor preventing them managing their condition.

Even where patients did not specifically identify themselves as having psychological difficulties, it was evident from our conversations that these played a role in the difficulties they experienced. For example, patient STE-002 described how his diabetes was affecting his mental well-being, reducing his interest in getting out of the house and causing him to ‘ponder’ too much.

All of the patients expressed some kind of reluctance to become involved in the programme initially, though they retrospectively put this reluctance down to their condition they would not have necessarily expressed this to professionals at the time. For example STE-003 said:

“The state I was in was so bad that yeah, you know when people are talking but you don’t really see what you can benefit from it....”

In STE-006’s case, reaching a point of breakdown seems to relate to her acceptance of the help that 3DFD provides:

“I missed an appointment because I was going through depression and stress and stuff and I basically had an appointment with the renal clinic and broke down and said I had too much to deal with and I’m not coping and Dr X said they had a service called 3DFD helping people with diabetes having someone to talk to... and when I’d spoken to people before it did help me... to try and do it now.”

She goes on to describe the appeal of the project being that it was directed at her specific condition:

“The fact that it was 3DFD - 3 dimensions for diabetes... I thought this is specifically for me, my health and other stuff surrounding my health...”
Initial experiences:
Initial experiences of the services provided by 3DFD were mixed, patient STE-002 said:

“I was expecting miraculous stuff, but I was told it had to come from me! I thought what you mean its got to come from me!”

Though this comment is not necessarily negative he was tone was of disappointment rather than of pleasure. Similarly, patient STE-003’s initial reaction to the psychology was dismissive:

“at first I was like... tch...”

It appears that while 3DFD is effective at getting through to patients, this is a difficult time at which opening up to a stranger is a significant barrier. Patient STE-005 described the process of opening up:

“Well it felt ok, I had to get it off my chest, talking about it is hard, but talking about it to someone was Ok I guess, gradually I got use to it... remembering the pain I went through in and out of hospital injections and stuff like that....It opened up everything, what emotions I’ve been having, how stressful and painful and stuff..."

Though described as a difficult process, all the patients interviewed described extremely positive effects in the long term.

Patients’ experiences of support from 3DFD:
All of the patients we interviewed spoke extremely positively about their experiences of 3DFD and the difference the service had made to their lives. Patient STE-002 was typical in saying he feels much happier and in full control of his food intake and health monitoring, as a result of the service he has received. His current outlook contrasted sharply with how he previously described his life, when he was underweight, in denial about his condition and had ‘so many crazy ideas’.

Patients identified a number of positive characteristics about the service. Often, patients contrasted these characteristics with their past experiences of healthcare services. The core positive aspects of the service as described by patients are were:

Optional and flexible nature of the service.
Patients described positively how they were invited, rather than compelled, to take part in the 3DFD project. Patients experienced this as someone caring for them and taking a chance on them. Two of the patients described the very act of choosing to attend the service as an important step in helping them manage their condition. For example, patient STE-002 described his decision as ‘putting silly ideas to one side’, in order to make progress. Patient STE003 said:

“At first to be honest... I didn’t wanna let anyone know my business... but it wasn’t like they was pushy , it was like in your own time, you don’t have to... and I started talking and saying how I feel and its just that kind of encouragement... Some people might think its rubbish, but you’ll never know unless you try.”

Self-directed nature of support.
Closely associated with patients’ free choice to attend the service was the way the service made patients feel they had the power within themselves to make positive changes to their lives. For some patients, this approach was unexpected. As quoted previously, patient STE-002, described his surprise at being told change had to ‘come from me’. Another patient, STE-003, described how the service gave people the time and choice to make up their own mind, with the reassurance of knowing the service was there for her.

Despite this initial surprise, all patients spoke favorably of this approach. For example, patient STE-005 welcomed being supported to discuss the stress and pain he was experiencing as a result of his condition. Now, he used the memory of the pain he experienced as a way of motivating himself to manage his condition and thus avoid painful hospital visits.

Similarly, patient STE-003 greatly valued being introduced to stress and anxiety management techniques by the 3DFD service. Despite initial reservations, the patient described how she uses these techniques to review stressful situations and decided whether or not something is a ‘helpful worry’. The impact of this technique was powerfully demonstrated by the patient describing her anxiety over whether her ability to have children has been affected by how she has previously managed her diabetes as an ‘unhelpful worry’ until she has resolved her other problems related to her health. Another patient, STE-002, described in positive terms being supported by Dr X to identify and build upon his existing strengths. From discussions with Dr X he was able to understand how the visualisation techniques he used in martial arts could be used to help him overcome his aversion to needles.

Useful content:
When called upon, the programme did provide specific tools and techniques that proved very valuable to patients. These included the use of diagrams:

“One of the main things that helped me were the diagrams... they were very visual and I was able to relate to them very well... it was the way X demonstrated them... I could see the pattern, I knew it already... I was thinking I’m superhuman, this was a fantasy... in reality by trying to achieve that you’re exercising failure... so I realise the state I’m in... and I’ve got to get over there... not going to the bottom, but above and lets say 30% and then 70 or 80% kind of area... not trying to go for the extra 20. So it was mainly the diagrams and demos that gave me the gravitas... and also with my needle phobia”

Other techniques that were praised were the use of relaxation CDs or DVDs and structured approaches to managing anxiety and depression.
Caring attitude of staff.

All patients greatly valued the attitude of 3DFD staff. One patient, STE-002 described the relationship between himself and a member of the 3DFD team in comparison to a previous experience of a doctor:

“In some aspects it was like having a chat with a friend, it didn’t feel clinical... There was one other situation which happened some years ago and I went to see a doctor and he was very aggressive and wasn’t expecting that at all, and... I think he was struck off the list... he was very confrontational didn’t answer questions, you don’t feel at ease... coming here, you see nice people they are approachable and sometimes you break protocol and you talk about things you shouldn’t, very approachable and nice....”

The friendly and approachable nature of the 3DFD, in this case appears so different to other types of care, that it is perceived as ‘breaking protocol’.

Patient STE-006 described one member of staff as always smiling, kind and ‘not sarcastic’. This was often contrasted to less favorable past experiences of healthcare services. For example, patient STE-003 said she felt 3DFD staff were always there for her, unlike her GP’s surgery, where short visits made that difficult. The softer skills of staff were recognised and appreciated greatly by patients, including STE-006 who said:

“When I first met her she smiled and she was just always smiling.... she never looked at me like ‘I feel sorry for you’, she’s just normal person... she’s got a soft voice as well.... and she smiles as well....”

Patients also reported feeling that more time was being invested in them:

“When I’m with doctor X, they overrun the time, sometimes 20 minutes, sometimes half and hour... before 3DFD it was mechanical interventions... we’re gonna put some stats... this one’s much more friendly and human and approachable.” -STE-002

Persistence:

From reviewing the interviews, it appears that the perceptions of the normal doctor patient relationship are hard to break, patient STE-002 explains the transition to trusting the 3DFD team:

“Hang on, this person is being nice to me... why am I fighting them?” ... [laughs] so and also because I was willing to try things out... to see how it will help me...”

The persistence of the 3DFD team was highly praised. Two patients recognised that because of their fragile psychological state they could be unreliable and difficult to communicate with; they appreciated that 3DFD understood this and persisted with friendly communication. For examples STE-003 said:

“It was regular sessions... actually... every 2 weeks... they gave me that week to see what I could do for myself... if I went they had the patience they had the time to go through and stay try once more and if that don’t work we can we can work with next solution... I found that handy... if there were times when I say... I can’t be bothered... they’d say ‘don’t give up’... you know... they make me see the bigger side of things... if I do this.. I was like ‘yeah’...” 03

Similarly, patient STE-002 described the benefit of regular updates.

“They called me and said ‘Yes!’ you get updates and its great. I just like it, I don’t go out that much and you get this call and they suggest this and that and I think that’s quite nice you know. “You’re making progress, and those kind of things. It makes it much more approachable. Almost like a friend.”

Reliability:

3DFD was described by all patients as being extremely reliable. This reliability connected to their ability to open up to and trust the service and to their feelings of being cared for:

“3DF, they were always there, no matter what. The difference they made... the service they provided different to anyone else, you almost felt welcome... there’s this sort of love or something, I don’t know... It’s something that made you feel you’re comfortable... and coming from me, I don’t want to talk about my [personal] business, but somehow, they made me relaxed... person and more opened, you know, I can sit down and say.. or someone else I know, I can say ‘never give up, there’s a lot more...” -STE-003

The reliability of the service was also highlighted by STE-006:

“She sticks to her word. I never have to ask her twice. Very supportive.... When she says she’s going to do something she always does it, almost immediately... if she’s trying to find out about my hypo... within like an hour she’ll phone me and say she’s spoken to this person and that it might be a good idea if I do it like this and err...and she just remembers me really.”

Professionalism and communication.

Patients positively described a number of characteristics associated with professionalism. Staff were praised for their commitment and not giving up on patients. For example, patient STE-006 was impressed by the fact that Dr X, despite only meeting her three times, actively monitored her case and regularly sent letters on her behalf. This professionalism was felt to extend across the team, with members of the team sharing knowledge and working together on behalf of the patient. This professionalism and effectiveness communication appeared to have a deep impact on patient’s ability to be transfer between doctors:

“I hate having to change doctors... it was a struggle accepting... but just the fact she’s supported me in what I needed doing.... she’s written letters to my employers...
and sorted out my appointments with regards to my eyes... I would have had to wait to September, she got it done straight away. When she first sent the letter I didn’t think she would have done it and she did, and she’d obviously been reading my notes and taking an interest in what was happening to me... because when she wrote everything it seemed as if I’d been sitting with her... so she’d been taking an interest in my health"

The same patient went on to say:

“When I get a doctor the consultant never got back to me. But this year, it seems when I call for help she always calls me back in 24 hours or the same day. My appointments are more regular, they keep up to date, my consultants seem to know... I don’t feel weird about seeing different consultants, they seem to know so I don’t have to repeat myself, they know what’s going on with me and I feel comfortable they’re all making the right choices... they are all working as team and their communication’s much better...it was terrible before. Communication with me communication with my GP... every appointment I get I get cc’d into the email with my doctors as well... I can hand it into work... there’s more communication with my doctors, the GP and my consultants, and now medication’s not getting confused, as to what I should be taking and yeah...”

Though the other patients we spoke to were not as specific about the effect of improved communication on their attitude to the hospital professionals, there was agreement that the communication and professionalism were core to the success of the service.

Structured problem-solving.

All patients, to a greater or lesser extent, described how 3DFD had helped them to address the multiple problems they were experiencing in a structured fashion. This approach was described most clearly by patient STE-006, who told us how for every session she would agree with 3DFD staff a list of topics to discuss. She described how the 3DFD service had helped her understand that her health was the most important thing. She was then supported to “deal with things one by one” in respect of her health, before going on to address debt problems and how to budget effectively.

This statement from patient STE-006 explains how the structured support has helped her to cope with the complexity of her challenges:

“Because of the pain. I think back to that and I can’t. I can’t go back to being like that. So [psychologist] X dealt with it one at a time... and she asked me what was the most important thing and it was health, so first we dealt with that and she introduced me to the diabetes nurse and the dietician. And we worked out ways to control my condition and things like that, sort of under control and I felt more in control of that... and then we went to my next stress which was debts, and they put me in touch with X, and X and X gave me the details of the people I should write to and basically opened all my letters which was ... facing what I’ve got... it was hard but once I did it... those were my foremost worries. I’ve spoken to them and now I’ve got agreements as to how much I can pay.”

Results:

Patients describe numerous positive results as a result of their interaction with the 3DFD programme. Two of the patients report feeling like a different person: STE-006 described how much affect the programme has had with a relatively short interaction time:

“It’s Weird, its five months ago I’m not the same person and that’s just from coming here one a week for an hour to talk to X... and she gets so much done in that hour... just listening to me yabbler on.”

STE-002 describes in more detail the physical and mental benefits of the programme:

“I feel much better now... my legs, my quads there, were almost skin and bones... so all of that’s come back... so there’s been a lot of improvement in my physical health and I’ve also taken full control of my food intake and control and monitoring and regulating and trying to eat as much and as little... so I feel very positive and argghghgh...I’m a new monster!”

Improvements in confidence were described numerous times by the participants, STE-003 said:

“I’m more confident... knowing there’s always someone there who understanding how I feel at that time.” and STE-005 said “I just really get on with it, I’m not scared any more, I don’t get myself into trouble anymore... there isn’t much fear anymore of going in and out...”

The increased confidence seems to affect many of the aspect of patients life, making the more able to cope with the situation overall.

STE-006 said:

“Now if I’m feeling low, I feel more confident to test my sugar level and what to do with it...and if its low what to do with it... I feel more confident to face up to things other than what I was doing 9 months ago... which was leaving it behind and it comes up again, I’m more able to face up to things and try to sort them out as soon as possible. I feel more confident to ask for help... instead of thinking “I don’t want to bother these people.”

Patients reported enormous changes in their lives that they attributed directly to their involvement with 3DFD. Patient STE-003 said:

“Without it, maybe I’d still be the same... I might not have had my kids with me... to be honest I thought that was the road I was going down... I was putting danger to myself and putting danger to my children.”

She went on to describe how her life is now much more fulfilling.

Similarly, patient STE-005 described a shift from a downward momentum to a much more positive outlook:

“I know my sugar levels would not have been controlled... I would not have been confident to go and see a diabetic
For example, described a situation where he was told they received, the topic of improvement did prompt support for service expansion, 

Although patients were very happy with the service, some patients expressed an interest in increasing in development relating to the management of his condition. This patient also recommended that the service places on reassurance and humour when patient, STE-006, who said the 3DFD team should work with people can benefit from it. Patient STE-003, for example, described being alerted to the success of the programme when a friend noticed a change in her well-being: “I introduced a friend, and when I explained, you know what, she said ‘I always see you and you look sad and down, but now it’s like you’ve got this glow and you’re more happier.’ Without you knowing, people can see from your outside, the difference from when you are low and when you’re at a stable stage. It’s like, OK, these people do really work.”

From the evidence provided in these interviews it is clear that the 3DFD programme is having profound effects on its patients. Its approach of tackling not just the medical symptoms but also the broader challenges has been widely praised by patients and described as having a life-changing effect on their ability to manage their condition.

How could the 3DFD service be improved?

Patients were extremely positive about the 3DFD service and struggled to identify substantive improvement suggestions. One patient, STE-003, said she had no thoughts as to how the service could be improved as she felt ‘3DFD had covered all areas’:

“I haven’t come across any faults with them. They covered all areas, there’s not even an area for me to say they could improve on this, they could improve on that.”

When prompted to suggest how the service could be improved, a strong message was conveyed of the desire to bring the 3DFD service to other areas so that more people can benefit from it. Patient STE-003, for example, said the Government should expand and bring the service to other areas. This view was shared by patient STE-006, who said the 3DFD team should work with other teams and services to bring their approach to more people.

Closely related to support for service expansion, some patients expressed an interest in increasing in the level of service provided by 3DFD. One patient, STE-006, expressed an interest in having more face-to-face contact with a consultant. Another, STE-002, expressed an interest in the service providing patients with more information and regular updates on medical developments relating to the management of his condition. This patient also recommended that the service could be improved by expanding the emphasis the service places on reassurance and humour when supporting patients.

Although patients were very happy with the service they received, the topic of improvement did prompt examples of less satisfactory service. Patient ST-002, for example, described a situation where he was told the tests he would undergo would be non-invasive and even ‘pleasurable’, only to find out they involved being injected with needles. In this case, the patient felt the Doctor should have been more honest about what was involved. Another patient, STE-006, identified the issue of poor customer service at the diabetes reception. She felt the member of staff was rarely at his desk, meaning she had to go to another reception point to be served. In the overall context of the service they receive, it seemed patients recognised these deficiencies as relatively unimportant.

Recommendations for improvement:

From the evidence provided by these interviews 3DFD appears to be a prodigiously successful service. Its impact on the four patients interviewed is described throughout this document. The interviews only give a small amount of information about 3DFD can be improved but reveal a great about the National Health Service more broadly.

Expansion

A clear recommendation from the patients was that they would like to see the programme be expanded. Subject to cost-benefit analysis, the authors would like to echo this recommendation.

Maintaining the levels of care and reliability

This qualitative evidence seems to suggest that there is a stark difference between levels of care on the 3DFD programme and in the rest of the Health Service. Being part of a pilot projects can often result in participants putting additional energy in to the project. In 3DFD the high levels of care and reliability are describe as a core element of its success. There is a risk then that if the project scales and the levels of care and reliability go down in line with the rest of the Health Service then the project will be significantly less effective. We recommend that the project team identify precisely the factors which impact the high levels of care being provided by 3DFD and that they work to ensure that these are scalable or replicable in other environments.

Potential improvement of initial contact

The patients that we interviewed were all successfully on the programme. It is possible, given the descriptions of the difficulty and lack of confidence experienced by many at the beginning of their journeys through 3DFD, that other patients, who are in real need of the programme do not get on to it. Though this report does not provide evidence that this is the case, the descriptions of this stage in the journey reveal the fragility of patients’ thinking at this time. We recommend that the 3DFD team explore this initial, and crucial, stage of the process very careful to ensure that those who need the programme most find it accessible.
Investigate the relationship between reliability and attitude to care:

This report suggests a correlation between patients attitude to their care and the reliability of the staff that they interact with. Patients described how they really felt they were being cared for when staff were consistently reliable in their actions and communication.