From referral to discharge: Young people and parents' experience of a systemic paediatric psychology service.

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Abbreviations: UCLH - University College London Hospital, YP- Young People, NHS - National Health Service, TA - Thematic Analysis

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Author Contributions

All authors drafted and revised the manuscript, and approved the final manuscript as submitted.

Deborah Christie, Susie Colville and Isabella Girling conceptualized and designed the study.

Susie Colville and Mimi Borelli collected the data.

Isabella Girling, Susie Colville, Nicola Bowman and Deborah Christie carried out the analyses and interpretation of data.

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Abstract:

Objectives: The paediatric and adolescent clinical psychology service at UCLH provides age-appropriate services to young people under the care of a hospital consultant up to nineteen years old. This short report describes how young people and parents experience what we provide as a systemic paediatric psychology team.

Method: A semi structured questionnaire was designed to gather service user perspectives on the systemic clinical psychology service. The questionnaire included open and closed questions to generate qualitative and quantitative data about the different stages of the treatment process.

Results: 44/79 families discharged in the previous year were contacted by phone. The majority of young people and parents were happy being called to discuss the referral before being offered an appointment and liked the way in which the psychologist worked with the family. The majority of young people and parents reported their situation had improved as a result of the work offered by the psychology team. Negative aspects of the experience reflected the realities of service driven constraints including having to travel a long distance for the appointment, lack of rooms and having to be discharged at 19 years of age.

Conclusions: Service user feedback is imperative to providing a high standard of care. This study highlighted positive experiences of a systemic service and indicated areas for future improvement that we are attempting to address

Introduction

Over recent years, government and commissioners have become increasingly interested in the demonstration of effective clinical services by focussing on clinical outcomes and service user feedback to guide service improvement and policy (Wolpert, Fugard, Deighton, & Görzig, 2012). The national wellbeing agenda aims to establish effective ways of evaluating both economic welfare and the emotional well-being of service users (Law, 2012).

As well as enhancing the emotional well-being of service users, the economic benefits of paediatric psychology services are of interest to government and commissioners (Law, 2012). There is evidence to suggest that YP who are referred to psychological services have fewer subsequent medical encounters than those who are not (Finney, Riley, & Cataldo, 1991; Graves & Hastrup, 1981). A good model for the utility of psychological interventions is in interventions shown to increase adherence to treatment regimens and improve outcomes for adolescents with Type 1 Diabetes (Christie & Martin, 2012). Improved metabolic control can reduce the acute and long-term complications leading to reduced demands of the health service in the future. Meta-analyses and reviews of adherence intervention studies with children with a range of chronic illnesses have found that multi-component and behavioural interventions can improve adherence and health outcomes both at treatment completion and as late as nine months follow-up (Kahana, Drotar, & Frazier, 2008; Lemanek, Kamps, & Chung, 2001) and fewer chronically ill children may require readmission to hospital following discharge if they are referred to paediatric psychology during their in-patient stay (Martin, Wolliscroft, Borland, Melville, & Ghosal, 2013).

Many service evaluations use parental report to measure clinical effectiveness and satisfaction with services (Charlop, Parrish, Fenton, & Cataldo, 1987; Krahn, Eisert, & Fifield, 1990; Ritter et al., 2001). A meta-analysis of twelve psychological interventions aiming to reduce distress and help psychological adjustment in children with cancer and their parents/caregivers reported statistically significant levels of stress reduction and adjustment in parents, but not in children (Pai, Drotar, Zebracki, Moore, & Youngstrom, 2006). There

has been an increasing emphasis on services actively involving children and YP in the commissioning, development and evaluation of services. Exploring what is important to YP enables them to be actively involved in service provision and ensure that services are relevant, accessible and meet their needs. Measuring patient experience empowers patients and ensure services are patient focused, (NHS Institute for Innovation, 2010; Department of Health, 2010).

The paediatric and adolescent clinical psychology service at University College London Hospital (UCLH) provides age-appropriate services to young people (YP) under the care of a hospital consultant up to 19 years old. Specialist inpatient, day care and outpatient support is available to help YP and families manage issues raised by their illness and its treatment, and build emotional well-being. The psychology team is embedded in the paediatric and adolescent service with referrals often received following conversations with the multidisciplinary team. Families can also self-refer using an online referral form. Referrals come from a large number of medical specialties including weight management, oncology, chronic fatigue and pain disorders, urology, endocrinology and diabetes.

Over the last 15 years a range of systemic practices (Vetere & Dallos, 2003; Johnstone & Dallos, 2006; Fredman, Anderson, & Stott, 2010) have been integrated into a service delivery model that offers an initial consultation and a treatment plan based on a shared formulation with the family and YP offering a combination of individual, family and parental work. Regular reviews with the family and the wider medical system ensure that the intervention being offered is appropriate, useful and is contributing to positive change.

Referrals are discussed in a team meeting, consisting of qualified clinical psychologists as well as psychologists in training and assistant psychologists. Thought is given to who is asking for help, whether it be the family or medical professionals, as well as what the different perceptions of psychology may be (Reder & Fredman, 1996). Referrers tell families they will be contacted by telephone before they are offered an appointment. In order to try and begin well we call and try to speak to at least one parent and the young person (13 and older) on the telephone to help us understand their situation, expectations and clarify whether an initial meeting is really wanted. This telephone conversation may also help us decide who we should invite to the first meeting. This might be the family or might also include the paediatrician and/or other members of the system where the family have indicated they have

questions that we cannot answer as psychologists. For young people who don't like talking on the phone we will email them questions about the referral. When we are unable to reach a family we will write and ask them to get in touch to discuss the referral if they want to go ahead. At the first appointment a clinical psychologist will work with a reflecting team. The team are there to help the interviewer and family create a shared understanding of the situation and make a plan (Friedman, 1995). The plan identifies who will offer sessions, how many they will offer and an agreed goal that the child, YP and family wish to work towards. At discharge the psychologist managing the case rates the clinical outcome as improved, no change or worse. Service users perspectives have not been systematically included in the collection of outcome and satisfaction data. This study was designed to gain an understanding of young people and parent's experience of the journey from referral to discharge.

Participants
79 YP and families were discharged between April 2011 and March 2012.
The median age at time of discharge was 17 (5-21). 70% of the 79 families were white British. 51% were female. After attending an outpatient initial consultation, 9 families decided they did not want further treatment. The remaining 70 were offered a median number of 8 appointments (range 1- 42). In addition to the individual or family therapy offered 17 YP also attended a therapy group, and four were offered a cognitive assessment.

45 families were successfully contacted by telephone over a six month period. All but one of the 45 families agreed to take part in the study. 28 of the 44 telephone interviews (64%) were carried out with both the YP and their parent/carer. 11 (25%) were completed with the parent/carer only. Reasons for this include: the YP was aged 12 or under ($n=7$; 16%), the YP could not be contacted ($n=2$; 5%), or the YP declined to take part ($n=2$; 5%). In one family both parents completed the interview. 5 interviews (11%) were completed with the YP only. All respondents consented to their comments being reported as part of the audit.
There was no difference in the demographic profile of the contacted sample from the total sample of 79.

Development of the interview
 A semi structured questionnaire was designed with open and closed questions to generate qualitative and quantitative data about the different stages of treatment. Participants were asked to rate responses on a scale of $1 - 10$ to provide quantitative scores on their experience of:
- Being contacted by telephone prior to meeting.

- The initial consultation and what they found particularly helpful/unhelpful.

- The sessions offered and whether there was anything they found particularly helpful/unhelpful.

- Days and timings of appointments and whether these were convenient.

- Surroundings in which the appointments took place.

- Families who attended 'reviews/network meetings' run by the psychology team which involved inviting the wider multi-disciplinary team were asked what they found particularly helpful/unhelpful about these meetings.

- How it was decided that the sessions should come to an end and experiences of endings.

- How things are now.

- Overall satisfaction with the service including what they would have liked to be different and whether they would recommend the psychology service to other YP and their families.

The draft questionnaire was reviewed by the psychology team and practice interviews were completed (using case examples) to identify redundant or repetitive questions. The final interview comprised 18 items.

Procedure

Families were contacted by telephone by a medical student (MB) between July 2012 and November 2012.

Qualitative analysis

Qualitative data was entered onto nVivo version 9.0 and analysed using Thematic Analysis (TA) by NB/IG. TA involves identifying patterns within qualitative information in order to discover emerging themes. This method can report experiences and the reality of participants (realist method); it can examine the ways in which experiences are the effects of a range of discourses operating within society ('constructionist') (Braun & Clarke, 2006), and finally can acknowledge the ways individuals make meaning of their experience ('contextualist' method (Braun & Clarke, 2006). TA can be utilised both to reflect reality and to unravel the surface of 'reality' (Braun & Clarke, 2006). TA was used in this case as a constructionist and contextualist method. We were seeking to extract what patients' experiences of care are and how important certain aspects are, which may or may not reflect reality.

The data was read in detail several times by an Assistant Psychologist (NB) to code key-words, phrases and associations in order to identify emerging themes. Subsequent readings acknowledged themes which described connected or closely associated issues. Once themes were established a sub-sample of data was read and coded by another Assistant Psychologist (IG) to ensure the themes were clearly grounded in the data. Exemplary quotations were used to achieve trustworthiness. A table of themes and analogous quotations was produced and themes were counter-coded by the Consultant Clinical Psychologist (DC). Themes were grouped into super-ordinate themes that shared commonality and organized to create a coherent thematic account. Exemplary quotations were chosen for their richness and how representative they were of the data. Some were chosen because they were deemed poignant or significant.

Results

YP are referred to as their gender followed by their age, for example *Male, 13*. Parents are referred to as Parent and their reference number, for example *Parent, 12*.

Initial Telephone conversation

36/44 (82%) of families remembered the initial telephone conversation and described it as an opportunity to explore their hopes and expectations of the service. Clients explained that it was useful to share their ideas, and clarify their thoughts about why they were coming. They described the call as being '*about me*' and sharing further information in a helpful way to build up reassurance before the meeting which made coming *'less intimidating'*.

> *"I found it all really helpful - after a referral we knew why we wanted to be referred and sometimes expectations and result are different - to put our views across and clarify what we wanted out of the sessions was helpful" [Parent, 4]*

> *"Yeah it was helpful - erm well basically they explained what is going to happen, who will be there, who was doing what and what the meetings were about" [Female, 17]*

The Initial Consultation

Both YP and parents rated the initial consultation as helpful (7.75/10, 8.75/10). They both felt that it addressed issues that were important to them (9/10) and said that they felt respected (10/10).

YP described the initial meeting as an opportunity to share the plan for next steps. The clear, '*methodical*' structure of the initial meeting and the detailed plan were very helpful.

> "*It was quite decisive about what was going to happen which was helpful. I felt secure afterwards that I was in the hands of people who knew what they were doing and who had a plan, which felt good because she was telling me what we're going to do in the future.*"*[Female, 16]*

YP and their parents described therapists as communicating with the young person in '*an age-appropriate manner*', as well as engaging the whole family.

> "*It was personal and they were interested and willing to help… the fact that [therapist] did not find our situation strange was VERY helpful her attitude was great - we were not a problem …somebody to listen*"*[Parent, 15]*

Therapists '*understanding*' the challenges and offering '*ideas*' and '*coping strategies*' was helpful.

> "*What we could and could not achieve, they did not promise miracles, she asked what we wanted and we would take on board the ideas with her health so it was very useful*"*[Female, 18]*

> "*Understanding of the issue and trying to see how it could help [YP] with coping to lead as natural and positive a life as possible… [therapist] was great in coming up with new ideas.*"*[Parent, 9]*

Clients commented on how helpful it had been to have the '*whole family*' present to share the '*issues*'. The '*collaborative approach*' was appreciated by families and was described as a '*way of opening up ways communication*' between family members.

> "*We have had brilliant help from all involved they wanted to see [YP]'s younger brother and my husband - when I was included there was a collaborative approach that I appreciated*" *[Parent, 28]*

Experience of work offered

32/33 YP and 38/39 parents were happy with the way the psychologist worked with them.

'Talking with clients' emerged as a superordinate theme for YP and parents with three subthemes. A description of each subtheme and quotes are listed below.

1.1 Being listened to

YP and their parents described their experience of the session as being '*listened to*'. They explained how they liked time in between questions to think and felt that the therapist would '*listen no matter what.*' YP commented on not feeling judged in sessions which enabled them to speak openly '*without criticism.*' The parents described the therapist being '*neutral*' and '*impartial*' as helpful. It was very important to YP that they were not patronised or spoken about as though they were not present. Not feeling patronised encouraged YP to be '*more open*'.

> *"Loved [therapist] and loved [therapist] - they were really helpful and understanding - one of the most beneficial things I have done. They did not judge her and were impartial and neutral. [Therapist] would listen to her and repeat back what she said in a way that made more sense… really listened very well and understood in a way that no-one else did."[Parent, 40]*

1.2 Rapport

YP discussed the importance of having a good rapport with the therapist enabling YP to ask questions and feel comfortable. The 'therapeutic alliance' was equally important for the YP and their parents.

> *"[Therapist] and [YP] had a really good rapport which gave me a lot of confidence in [therapist]. As a parent you are relieved your child has someone to talk to."[Parent, 34]*

It was helpful for YP to have the opportunity to talk alone with the therapist but to also have to option to invite important others such as doctors, teacher or family members to the sessions.

> *"Well the first time I went with my sister and she was very accommodating even though I had brought someone along."[Female, 17]*

1.3 Getting new ideas

YP commented on the helpfulness of gaining ideas, information and support through the sessions. YP described how *'breaking the problem down'* and *'learning'* something from the session was helpful. Talking through *'strategies'* and *'managing situations'* was also helpful, however it was important for YP to gain '*advice*' that they could '*apply in real life*' as well as gaining a new or different perspective.

> *"They told me strategies and ways to help myself if I felt angry and upset and how to deal with it and respond to it."[Male, 17]*

Endings and Outcomes

30/33 (91%) of young people and 29/37 parents (78%) felt that the decision to end therapy was mutually agreed between therapist and the family

> *"Basically it got to the point where he was ready."[Parent 27]*

> *"I think it was because of both of us. It was a mutual decision to come to an end. And I had a final review session with [therapist] to chat and she thought it was good too" [Female, 13]*

YP noticed improvements from the sessions and thought they were no longer needed. YP and parents commented that they had *'got things sorted'* to a point where the sessions had come to a natural end and were '*no longer beneficial.*' Many YP commented on improvements at school and in family life.

> *"I finished and achieved what I wanted to achieve but I was sad to go. I liked coming and expressing my feelings but I was pleased to finish. Right the way through with {therapist} was really good." [Female, 14]*

28/33 (85%) young people and 33/34 parents (97%) said that as a result of the work with the psychology team things were very improved or improved.

Timings of appointments

The majority of the feedback suggested that the timings were convenient, reasonable and mutually agreed. Many parents and YP appreciated flexibility with appointment times although appointments during school and work times were a challenge for some.

Environment

The majority of YP explained that it was '*calm, peaceful and quite comfortable.*' Having a private space to talk '*away from others*' with '*no one to disrupt*' was important.

Some described the room as a '*bit small and cramped.*' Families also commented on difficulties with room availability, explaining that sometimes it was difficult for the therapist to find a room and that '*more organisation*' prior to sessions was needed.

Overall Satisfaction

32/33 (97%) of YP and 35/36 (97%) of parents said they would recommend the service. They described the work as '*helpful and effective*', described '*positive results*', that it encouraged them to think from different perspectives and that they learnt a lot from the sessions. Parents commented on '*big improvements*' and the '*positive effect*' it had had on their child as well as the family.

YP said the reason they would recommend the service is because it is offers someone '*that will listen.*' They described the importance of '*being able to talk to someone on a level*' which they said was different to the way they are treated by other professionals in the hospital. They enjoyed being given '*choice*' as opposed to '*nagging*'.

> *"Big change and effects to the rest of your life. Talking to someone was good. She was friendly…I was comfortable to express how I was feeling. I think it is still important… some questions she asked I thought I have not thought about it from that angle, links it well and it makes you think from a different perspective." [Female, 17]*

YP and parents valued the experience of professionals normalising their concerns or worries but also providing strategies and ideas to support them to '*cope*'. Parents found the sessions '*valuable*' and that a '*third party*' to '*hear your story*' without '*judgement*' was very much appreciated.

> *"It helped [YP] cope and take control. He had taught himself negative mechanisms of dealing with the situation - but he had to be shown that they were negative mechanisms and he took this on board."[Parent, 27]*

YP and parents found it helpful to have the whole family involved in the process of therapy. They commented how a medical condition can have an effect on family life and it was important to have a space to understand each other's perspectives.

"Because I think it was really important for the whole family to work it out - e.g. Diabetes…It's amazing the impact it can have on the whole family. He would forget his insulin etc. and wanted to make sure he had something, he was very good at manipulating things, once he started going to sessions that all stopped and he realised how hard it was for me and mum through sessions and how it affected him and I think this has prepared him now for university. I think all that is through the work with you guys. He was a party animal, I think he has realised he does not want to mess it up and this is such a different approach to his approach in Birmingham."[Parent, 13]

Unhelpful aspects of the work

Some families raised that the distance they had to travel in order to get to the clinic made it difficult to attend. Some YP commented on the challenges of managing appointments around school and work. Offering support only up to the age of 19 was a significant restriction for some.

"Because of age otherwise I would still be going (they even kept me on a bit longer)." *[Female, 19]*

Some YP said the therapist went over the same themes or topics at each session and a small number of YP felt the therapists were '*talking down*' to them. Some felt uncomfortable sharing their concerns in front of other family members in the initial appointment. One person commented on how the approach did not fit for their family as having too many professionals in the room was '*scary for younger children.*'

Discussion

We describe the experiences and realities for families referred to a systemic paediatric psychology service. Whilst taking time to think about the referral and call the family on the phone can slow down the time taken to offer an appointment we work like this in order to 'begin well' and increase engagement with families before they come to the first meeting. Since introducing this approach 12 years ago less than 10% of families cancel or fail to attend their first appointment. Families described the initial telephone contact as positive, offering a chance to explain their situation, discuss their expectations and build reassurance before the initial meeting. This fits with a key service intention to create a positive engagement with families before they attend their first meeting (Reder & Fredman, 1996). Another key

intention of the service is to offer a systemic approach which involves the young person and their family in the process of the therapy (Vetere & Dallos, 2003; Johnstone & Dallos, 2006; Fredman et al., 2010).The initial meeting creates a plan for future sessions with clear goals for the therapist, young person and family to work on. YP and parents commented on how helpful it was to have a family approach to their care. Therapists were experienced as having a willingness to help and listen. Miller, Duncan, & Hubble, (2008) describe the positive effect of a positive therapeutic alliance on clinical outcomes. 97% of YP were happy with the way in which the psychologist worked throughout the sessions, felt '*completely respected*' and identified the '*connection*' between the therapist and client as helpful. 91% of YP felt the work ended at an appropriate time and that it was a mutual decision between the YP and their therapist. Fewer parents (78%) felt the therapy ended at the right time. 85% of YP felt their situation had improved and 97% would recommend the service to other YP.

The team are aware that the environment is a challenge with rooms often on the small side for larger family or network meetings and general issues about room availability which can impact on the therapist's ability to be flexible around appointment times. This has been fed back to hospital management.

Other areas that we are addressing as a team include trying to develop methods to collect outcome data in real time in order to be more responsive to YP and families who are not happy with the service. Therapists need to review the impact of repetition of material as well as finding ways to check that YP experience their communication style as being at an appropriate level. We are also developing a number of business plans that will enable us to extend the service past 19 years of age in some specialities. This has already been successfully achieved in the cancer service. A final challenge is how to improve access for families who have to travel a significant distance to attend appointments; this may include the use of evolving technologies such as Skype and Face Time.

The focus for healthcare should be to deliver cost-effective clinical outcomes and improve patient experience. Quantitative measures may be relevant to demonstrating such effectiveness, however should not be the only approach to hear what people want from services. Giving service users the opportunity to explain their experiences in the service, outside of a format with specific predefined questions, adds depth and attempts to understand what services users expect from a service. This more challenging approach to data collection provides the opportunity to hear both positive and negative accounts in a way that may reach out to service providers. Reaching out in a humanitarian way as opposed to presenting

objective numerical figures alone will begin to connect patients with caregivers, engaging both in the quest to improve patient experience, service delivery and provide world-class care (Merlino & Raman, 2013).

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