

RESEARCH ARTICLE

The importance of the Therapeutic Relationship when Providing Information to Parents of Children with Long-Term Disabilities: The Views and Experiences of UK Paediatric Therapists.

Abstract

The purpose of this study was to understand the views and experiences of paediatric therapists working in the UK regarding the importance of the therapeutic relationship when providing information for parents of children with long-term disabilities. The aim was to develop new perspectives, to encourage dialogue and reflection for change and to identify practical suggestions for health-professionals when developing therapeutic relationships. Employing an interpretive phenomenological methodology, semi-structured, in depth interviews were carried out with seven health-professionals from a single NHS trust in the UK (Children's physiotherapists, Occupational therapists and Speech therapists). Resultant data were analysed using a systematic process of thematic content analysis. One main theme 'The Importance of the Therapeutic Relationship: balancing a positive relationship with professional responsibility' is presented and discussed. The findings of this study suggest paediatric therapists recognise that fostering a positive therapeutic relationship is vital to facilitate parental engagement with the information they

provide. Despite this it was felt that efforts to maintain a positive relationship needed to be carefully balanced with discharging professional responsibility to the child. A preliminary model 'The Therapeutic Relationship Continuum' is presented, aiming to help health-professionals self-assess and reflect on the dynamic interface between the therapeutic relationship and information provision.

Key Words Therapeutic relationship; information provision, Family Centred Care, Allied health professional, child health.

Background

Over the past two decades there have been substantial developments in UK (United Kingdom) government legislation regarding the provision of health and social care to children with long-term disabilities (e.g. The Children's Act (Great Britain Parliament, 2004); The Children's Plan (DfES 2007)). This has culminated in the publication of the Children and Families Act (Great Britain Parliament, 2014), which recognises the importance of the needs and wishes of children and their families, placing them as central partners in the design and delivery of services.

This concept of person/family centred care is underpinned by both national and international policy; written into the NHS (National Health Service) constitution (DoH, 2015), the NHS Five Year Forward Review (NHS England, 2014) and the World Health Organisation's 'Health 2020' framework (WHO, 2012). It is also made explicit within the newly revised Health and Care Professions Council's 'Professional standards of conduct performance and ethics' (HCPC, 2016).

It is the responsibility of health-professionals to both engage and empower parents to embrace their role as collaborators and decision-makers in the provision of care for their child (Adler et al. 2015; Kruijsen-Terpstra et al. 2016). Furthermore, it is widely recognised that this can be facilitated by thoughtful provision of information which is both appropriate and timely (Corlett and Twycross, 2006; Edwards, Davies and Edwards, 2009; Aarthun and Akerjordet, 2014; Adler et al. 2015).

The process of information provision can be fraught with difficulties, given the often complex family circumstances (Nuutila and Salanterä, 2006; Reid et al. 2011), requiring health-professionals to be sensitive to parents' ability to understand information and to make use of it. The value of establishing a good working rapport, trust and advocacy has frequently been reported as a vital prerequisite for effective information exchange (Whiting, 2012; Tipping, Scholes and Cox, 2010; Nuutila and Salanterä, 2006; Rahi et al 2004). This concept can be described as the therapeutic relationship, which is commonly defined as;

‘...the feelings and attitudes that a therapist and client have towards one another and how these are expressed’ (Norcross, 2010; p113).

A strong and positive therapeutic relationship has also been found to have benefits reaching beyond improved transfer of information. A meta-analysis of the literature reported that a positive therapeutic relationship was a key determinant of treatment outcomes (Martin, Garske and Davies, 2000) and in some instances, was more strongly correlated with treatment outcome than choice of treatment (Green, 2009).

Health-professional awareness of the importance of the therapeutic relationship with parents, and more importantly how it informs their clinical practice (including providing information) is unclear. There appears to be a paucity of primary research related to this topic, with much of the evidence base related to the relationship between health professional and patient (described below). Whilst there are undoubtedly important parallels, it is recognised that in child healthcare settings the relationship dynamic is more complex, involving both the child or young person and their parents (Green, 2009).

In one study by Langbecker, Janda and Yates (2013), a concept mapping strategy was used to investigate health professionals' opinions regarding information provision to patients. They reported that health professionals did recognise the need to maintain continuity and to develop a strong therapeutic relationship, which allowed patients to be more open with their enquiries. Interestingly this is not supported in other studies. Tipping Scholes and Cox (2010) reported that the health-professionals in their study did not always recognise the need to establish a good therapeutic relationship with patients and Piggott et al (2003) found that, whilst health-professionals reported valuing a trusting relationship, they appeared unaware of the need to prioritise developing the therapeutic relationship with patients over providing new information or instruction.

This conflict is described in a study by Caladine (2013), who looked at physiotherapists' constructs of their role in patient education and reported a tension between participants' views on the therapeutic relationship. Whilst a collaborative (equal power) relationship was reported to be the preferred model of patient

education, the author felt that there remained a strong element of an expected compliance (paternalistic relationship), where the therapist held the power and the patient was the passive recipient of information.

It is suggested that the persistence of paternalism could be related to the health professional's focus on discharging their professional responsibility to the patient (Green, 2009; Aarthun and Akerjordet, 2014). This reluctance to forego clinical aim in favour of establishing a sound therapeutic relationship is described by Hanna and Rodger (2002) who reported that health professionals have difficulty adjusting their approach to consider other demands or roles that were not directly related to their practice.

There appears to be a gap in the literature related to health professionals' views on the value of the health professional – parent therapeutic relationship, particularly in the context of providing information. This has informed the rationale for completing this study, which addresses the question, 'What are the views and experiences of paediatric therapists regarding the importance of the therapeutic relationship when providing information to parents of children with long term disabilities?' The aim of the study was to develop new perspectives and to encourage dialogue and reflection for change. Moreover, to identify practical suggestions for health-professionals to more successfully establish and foster a positive therapeutic relationship.

This paper reports one aspect of a broader study investigating paediatric health professionals' experiences of providing information to parents, which identified three overall themes (1. Parent Readiness for Information; 2. Health Professional as

Information Manager; 3. The Importance of the Therapeutic Relationship: balancing a positive relationship with professional responsibility). Themes 1 and 2 are reported in another article (Reeder and Morris, 2016), which has a specific focus on health professionals as parent educators. This paper brings focus on the discrete and important area of therapeutic relationships.

Methods

This study was guided by an interpretive phenomenological methodology. This is a qualitative approach, used to understand a phenomenon through the lived experiences of individuals (Kumar, 2012). Moving beyond description, interpretive phenomenology focuses on participants' interpretations of the meaning of their experiences. The rationale for adopting this approach is based on the Heideggerian philosophical assumption that humans are embedded in their world and as such, a researcher cannot (and should not) deny or ignore participants' a priori understandings of and engagements with the phenomena under investigation (Reiners, 2012). The study did not aim to prove or disprove a hypothesis; rather it sought to inform a deeper understanding of how paediatric therapists perceive the therapeutic relationship and how this influences the process of information provision.

Data were collected using semi-structured interviews of a purposive, convenience sample of seven paediatric therapists working in a Children and Young Person's Therapy Service (two physiotherapists, two occupational therapists and three speech and language therapists). Given the homogeneity of the participants, the literature suggests that a sample size of seven would be adequate to achieve sampling sufficiency (Nicholls, 2009).

Participants were eligible to participate in the study if they were currently employed by the hosting organisation and working with families of children with long term disabilities. The definition of long term disability was taken from Part 2, Chapter 1, section 6 of the Equality Act 2010 (Great Britain Parliament, 2010), which states a person (or child) has a disability if they have a physical or mental impairment which has a significant and long-term adverse effect on that person's ability to carry out normal day to day activities.

Interviews were initiated by asking participants to reflect upon their experiences of developing a therapeutic relationship with parents and how this had influenced their approach to information provision. Subsequent questioning was iteratively guided by the responses of the participants (i.e. when it went well, when it did not go well and what might have influenced this) in order to encourage a more complete account of their experience (Englander, 2012).

It is necessary to state that the interviews were conducted by a researcher who was also working in the same team as the participants; therefore, it was considered important to formally address potential coercion and power issues. This was achieved by employing indirect recruitment strategies, by providing a detailed participant information sheet, with opportunity to discuss participation, making it clear that participation in the study was voluntary. Each participant also provided informed consent. Additional measures were also taken as part of a process of reflexivity (discussed below).

Ethical approval was granted by both the sponsoring higher education institution and the Caldecott Guardian of the healthcare organisation. NHS REC approval was not required as the research was conducted with participants in their capacity of employees of the healthcare organisation.

Analysis

All interviews were digitally recorded before being transcribed verbatim and then analysed using thematic content analysis as described by Braun and Clarke (2006).

This is a rigorous, systematic process involving a number of defined stages.

(Familiarisation with the data; Generating initial codes; Searching for themes; Reviewing themes; Defining/naming themes)

During each of these stages, and throughout the research process, the researcher's positionality as an 'insider researcher' was acknowledged and brought to the fore. It has been suggested that, in order to uphold scientific quality, it is vital for an insider researcher to maintain transparency, truthfulness and discernment about his role in collecting and interpreting participant experiences (McDermid et al, 2013). This was addressed by maintaining a research diary, which was a process of self-examination and reflexivity (Tuesner et al 2016), whereby the researchers 'active' role as an insider researcher was both recognised and embraced. This practice itself was an active, iterative process, embedded within each stage of the research (Guillemin and Gillam, 2004). Maintaining a research diary in such a way supported the researcher to recognise and challenge how his pre-existing knowledge and understandings may have influenced his approach to conducting interviews and interpreting data (Kumar, 2012). Furthermore, it has challenged him to reflect and consider how his dual role

as researcher/clinician might have influenced the participants and their responses (Etherington, 2004; Tuesner, 2016).

Scientific rigor and trustworthiness were further addressed using strategies suggested in the literature (Nichols, 2009; Shenton, 2004). This included maintaining transparency by keeping an audit trail of the data analysis alongside the reflexive diary; with regular discussion and debriefings held with the research supervisor to enhance the credibility of the findings.

Analysis generated a number of initial themes, which were reviewed and refined to produce three main themes. The third theme 'The Importance of the Therapeutic Relationship: balancing a positive relationship with professional responsibility' is presented and discussed below.

Results

Findings are presented with direct quotations taken from the interview transcripts with an identifier which represents the participant's profession (e.g. OT1 – Occupational Therapist; PT1 – Physiotherapist; S1 –Speech and Language Therapist). Any additional explanations offered by the researcher are enclosed in squared brackets.

Main Theme

The Importance of the Therapeutic Relationship: balancing a positive relationship with professional responsibility.

This theme describes participants' experiences of their therapeutic relationship with parents of children with long term disabilities and how this has influenced how they might approach provision of information to parents. It highlights the perceived tension between maintaining both a positive relationship with parents and professional responsibility to the child.

Participants highlighted that fostering a positive, trusting relationship with parents helped to promote readiness for and engagement with information and services...

...right at the beginning...our role is also about helping them [parents] begin their journey and building a therapeutic relationship... (OT2)

...recognising this as an important part of the process of information provision.

...I think if you have a trusting relationship you are much more open to hear what somebody is trying to say..." (S1)

Some participants described potential difficulties maintaining the therapeutic relationship if parents perceived they were being challenged...

...it's much easier (to give information) when you get into therapy, because then you kind of get a really strong relationship with them...or no relationship at all sometimes...if you challenge too much then...well you know, I've got parents that say they don't want to see me again, because I have gone in too fast...but then I have judged it wrong haven't I? (S2)

Whilst others talked of the challenges arising from a sense of not connecting...

...there are some people that you just don't connect with...very few...but there are just some families that you just don't seem to have that connection with and then the information just doesn't flow... (PT1)

...and highlighted how important that relationship is to parents.

...the biggest complaint from parents is therapists who don't listen or who don't have the customer service skills... (OT1)

Some participants reported that they would be cautious when giving difficult/upsetting information to parents as this could undermine their working relationship.

...I think it is important to have that relationship kind of well established...hopefully before they ask those sorts of questions, because if you haven't got their trust...I don't think they would appreciate that information as much... (PT2)

In one instance, a participant highlighted the possible destructive effect of giving negative or difficult information.

...One thing that holds with me is that you don't want to take away hope...there is some research out there with evidence to suggest that vocabulary levels at 4 will dictate outcomes at GCSE [General Certificate of Secondary Education – public examinations for pupils aged 16]...but that seems like a fairly destructive message to give at 4, when they are only just thinking about putting their child into school...I mean, I just think I might increase suicide rates or something... (S2)

Others suggested that they would prioritise giving the difficult information if they felt that it was necessary.

...I have said to families in the past, 'I know you don't want to hear this but I am going to say this to you because I need to tell you this...this is my role, to give you this information'...and I have had parents threaten me with legal action, I have had parents threaten me physically, I've been threatened verbally, I've been sworn at. But, you know that's part of the (job)... (OT1)

Some participants felt that the efforts made to maintain a positive relationship needed careful monitoring, and reported a risk of not fulfilling professional responsibilities or in some instances that their role as an advocate may turn into collusion with parents.

...but at the same time...that can very easily lead to kind of collusion, so you know if the parent really doesn't want to know something and...we are thinking well if I push that issue, that parent is going to back off and then we

are going to have no involvement with them, but actually not pushing that issue is going to be detrimental to that child, then it becomes really difficult...

(S1)

It was recognised that giving difficult/upsetting information and then managing the consequences of that information was a very challenging aspect of the therapist's role.

...someone was saying [in a supervision session] that they had to say something very hard to a family and they didn't know how to do it...and how hard that had been... (S3)

Whilst the consensus was that this was a part of the therapists' role, it was felt that there was very little training given to therapists for giving difficult information or counselling parents...

...with that whole counselling thing, it is an area that we are not taught and it would be really helpful, especially as we are dealing with children with these much longer term disabilities... (S1)

...and any that had been given was considered very useful.

...we were really fortunate that we had some counselling training, counselling skills training...so the therapists who dealt with feeding difficulties, or giving more bad news kind of stuff, we went through a series of workshopy kind of lecture things at a higher education institution... (S2)

The challenge of balancing a positive therapeutic relationship with professional responsibility is now discussed in the context of existing literature.

Discussion

Instituting a positive working rapport, trust and advocacy has been found to be a key component for effective information exchange (Whiting, 2013; Tipping, Scholes and Cox, 2010; Nuutila and Salanterä, 2006; Rahi et al 2004). Participants in this study appeared very aware of this, highlighting the importance of fostering a positive, trusting relationship with parents. This finding adds support to the work of Langbecker, Janda and Yates (2013), who also suggested that health professionals were aware of the benefits of a strong therapeutic relationship. This does remain in conflict with the findings of other studies (Tipping, Scholes and Cox, 2010; Piggott et al. 2003), which have suggested that health professionals are not always cognisant of such benefits. It is not clear why participants in this study seem to be more aware of the significance of the parent – health professional relationship; however, it is possible that the relatively recent focus on person/family centred care (driven by central government policy) could have pushed this relationship into sharper focus.

This understanding, and the awareness of problems reported when a relationship breaks down, introduces a certain level of pressure to maintain the therapeutic relationship. This is of particular importance for parents of children with a long-term disability, where the therapeutic relationship with health professionals could potentially be in place for many years. Participants were acutely conscious of this

and described some of the dilemmas they faced, particularly related to providing 'difficult' information or information which parents were not ready for.

An interesting finding was the lack of agreement or certainty about the practice of withholding potentially difficult information. Most participants felt that by giving this type of information they risked undermining the therapeutic relationship, leading to disengagement or, in more extreme cases, to parents losing hope for the future.

This finding is in line with those of Langbecker, Janda and Yates (2013) who looked at the perceptions of health professionals regarding information giving and reported that health professionals might withhold, what they considered to be, harmful information from patients, even though they recognised that this 'protective behaviour' was a highly contentious practice. Interestingly, whilst the intention of withholding difficult information would be to preserve the therapeutic relationship, it has been suggested that this practice can actually contribute to feelings of discord for the health professional, negatively affecting their relationship and interactions with patients and their families (Vivian, 2006).

Participants acknowledged that by placing such importance on maintaining the therapeutic relationship there was a danger of what one participant described as 'collusion' with parents. It is important to highlight that in this context, collusion seems to represent going along with a parent's perception of the needs of their child, even if that does not represent the views held by the health professional. It is understandable therefore that it was felt this practice could be detrimental to the child's management. Conversely participants felt that if difficult issues were routinely

addressed, or parent's perceptions were challenged, there was a risk of relationship breakdown and disengagement.

These findings have informed the development of a preliminary model, representing the dynamic interplay between the maintaining therapeutic relationship and discharging professional responsibility. It is proposed that this model can be presented as a continuum, with 'Focus too high on discharging professional responsibility', risking relationship breakdown and disengagement with services at one end and 'Focus too high on maintaining the therapeutic relationship', risking health professional/parent collusion at the other. Here it is illustrated as a 'Therapeutic Relationship Continuum' (see figure 1). This model is not intended to present a dichotomised vision of the 'right' or 'wrong' way to interact with parents, rather it is to suggest that a dynamic interface might exist between the therapeutic relationship and the provision of information.

Whilst the participants in this study appeared very aware of the tension between maintaining a sound therapeutic relationship and discharging their professional responsibility, it was clear that they still struggled to maintain what they perceived to be an acceptable balance (i.e. their position on the continuum).

Implications for Practice/Further Research:

It is recommended that paediatric health professionals should explore opportunities to improve their awareness of the complexities associated with providing information (including giving difficult information) to parents of children with a long-term disability. This could involve accessing formal training or setting up support networks within

teams. It is suggested that by employing the 'Therapeutic Relationship Continuum' model in such contexts, it might help to initiate discussion and promote reflection about this complex topic.

Further research investigating the legitimacy of the proposed preliminary model 'Therapeutic Relationship Continuum' would be recommended; with particular focus on what represents an acceptable balance between maintaining a positive relationship with parents and discharging professional responsibility.

Further investigation into parental perceptions of the therapeutic relationship would be welcomed. This would serve to strengthen, or potentially challenge the findings of this study.

Limitations

It is important to again highlight that the interviews and subsequent analysis of data was carried out by a single 'insider' researcher. Several strategies, described in detail above were employed to maintain and uphold scientific quality; however, it is acknowledged that the researcher's extant knowledge, understanding about the topic of investigation may still have influenced the findings of the study.

It is also acknowledged that the participants in the study were a small, self-selecting group of health professionals from a single healthcare organisation. Whilst this does raise the issue that the sample may not be truly representative of the population being investigated, the homogeneity of the participants and their responses suggest that findings may still resonate with the broader target population. It is

acknowledged that the small sample size does risk undermining the legitimacy of the proposed model and as such, in its current form, it can only be considered a preliminary model.

To improve the richness of data in this study, it may have been useful to have employed group interviews or focus groups, as well as individual interviews. This would have introduced the opportunity for point/counter point discussion and resolution, improving the credibility of the findings.

Conclusions

The findings of this study suggest that paediatric therapists do recognise the importance of the therapeutic relationship and how this interfaces with information provision and engagement with services. Furthermore, it has been recognised that providing difficult/upsetting information, or providing information that parents are not ready for risks undermining the relationship. It is proposed that the dynamic between maintaining a positive therapeutic relationship and discharging professional responsibility might be represented as a 'Therapeutic Relationship Continuum'. With further investigation, this model may be utilised by health professionals as a tool to promote more reflective awareness of this complex phenomenon.

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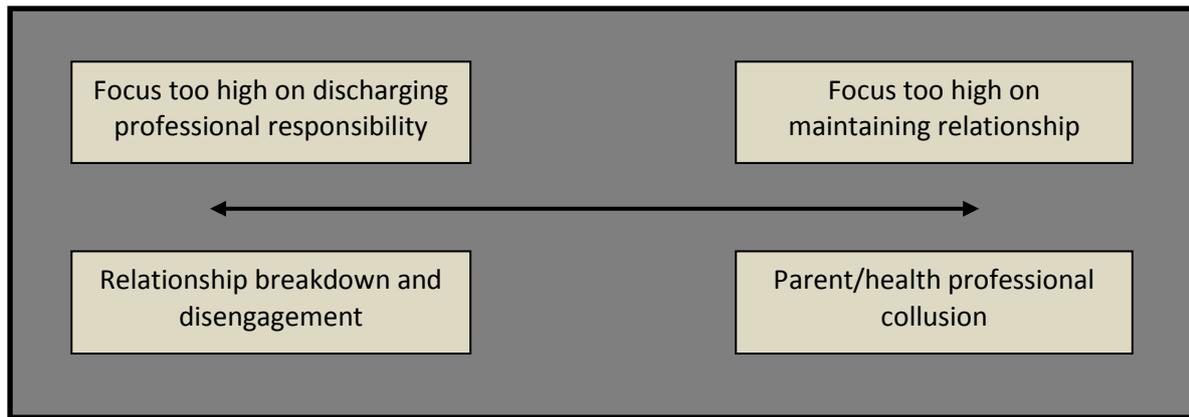


Figure 1: The Therapeutic Relationship Continuum'.