

Mother's experiences of the transition to adult care

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Abstract

Purpose: Research has shown that the transition planning of young people with autism spectrum disorders from child to adult-directed services, to be both problematic and limited in function. Mothers of children with autism spectrum disorders have been shown to be at an increased risk from maternal mental health problems, and often taken on the role of care co-ordinator during the transition period. The current study sought to explore the experiences of transition of mothers' of young people with autism spectrum disorders in the United Kingdom (UK). *Method:* Interpretative phenomenological analysis was utilized in the analysis of six semi-structured interviews of mothers. *Findings:* Three superordinate themes were identified: Negative experiences, Resources to cope, facilitating self-preparation. All mothers had an adverse emotional response to transitioning their children from youth to adult services and all indicated a struggle with regards to their control over the process. In order to manage their negative feelings, some mothers adopted an activist attitude. Almost all mothers acknowledged the importance of support from other parents who had a child with an autism spectrum disorder. *Practical implications:* This study highlights the perceived lack of support and service provision for families with children with disabilities approaching adulthood. *Originality/Value:* This is the first study to identify the important role parent support groups may have in cultivating resilience during the transition from child to adult services.

Key words

Transition, Autism, Support, Mothers, Experiences

Introduction

One of the priorities identified in the statutory guidance Think Autism (Department of Health United Kingdom, 2014), is that young people with autism spectrum disorders and their families feel supported through major life changes, such as the transition from child to adult mental health services. This guidance formed part of the legislations in the UK of the Autism Act (Department of Health, 2009), and along with the Children and Families Act (Department of Health, 2014a) and the Care Act (Department of Health, 2014b) were designed to put the service user at the heart of the decision-making process. However, it has been argued that these legislations do not guarantee the availability of adult services for all legitimate cases (McConachie, Hoole & Le Couteur, 2011). As an increasing number of individuals with autism spectrum disorders are transitioning into the adult service world, it is crucial to gain an understanding of the experiences of this process from the family's perspective (Taylor & Seltzer, 2010).

Parents play a major role in the lifelong care of an adult child with autism spectrum disorders and these roles have been found to come with little choice, emotional demands and with personal restrictions (Spiers, 2014). Importantly, few disorders pose a greater threat to the psychosocial well being of family members than autism spectrum disorders (Seltzer, Krauss, Orsmond, & Vestal, 2000). For example, research has shown that parents of children with autism spectrum disorders are typically found to suffer from high levels of stress and increased symptoms of depression (Benson & Karlof, 2009), and increased levels of physical and mental health problems, compared to parents of children without autism spectrum disorders (Montes & Halterman, 2007). Mothers of children with developmental disabilities have been identified as being at particular risk from physical and emotional strain (Zablotsky, Kalb, Freedman, Vasa & Stuart, 2014), and caring for a child with autism has been shown to increase maternal mental health problems, even when controlling for the confounding

influence of other co morbid conditions (e.g., Totsika, Hastings, Emerson, Lancaster & Berridge, 2011).

While the complex nature of the behaviours characteristic of autism spectrum disorders may account in part for why so many parents of children report physical and mental duress, there have been other factors found to increase the risk of parents suffering from health problems. One such modulating factor is how much internal control (i.e. locus of control) a parent perceives they have over their own situation. For example, the increased depressive symptomology experienced by parents of children with autism spectrum disorders has been linked to the perception that events are outside of their control (Siman-Tov & Kaniel, 2011).

Mothers will often have to take on the role of an advocate for their child, interceding and fighting on behalf of their children. The more extreme the needs of their child, the more complex and demanding the advocate role will become (Todd & Jones, 2003). However, it has been suggested that through complex interactions with professionals, the mothers' role may move from being advocate to activist (Ryan & Cole, 2009; Seligman & Darling, 2017). For example, mothers have been found to play an active role in improving the system that cares for their children, such as raising awareness of their child's condition, or by supporting others in similar situations through setting up parent support groups. Therefore, activist mothers may be more likely to cope in an adaptive way when supporting the transition of their children from child to adult services.

Parent support groups have been shown to provide a useful social resource for parents, and their importance is illustrated by findings showing that these groups can influence more adaptive parental coping styles (Clifford & Minnes, 2013; Shu & Lung, 2005). Support groups may also grant parents the opportunity to learn from the shared

experiences of others enabling a normalising experience and relief of distress (Shilling, Morris, Thompson-Coon, Ukoumunne, Rogers & Logan, 2013), while acting as catalyst for activism (Ryan & Cole, 2009).

Given that mothers of transition-age adolescents with autism spectrum disorders have been identified as taking on both “care coordinator” and “life supporter” roles (Spiers, 2014), this paper aims to explore the experiences that mothers of children with autism spectrum disorders have had of the transition from child to adult support services. Insight into the impact of this transition on the service users, based on their personal accounts and reflections could help to influence policy and to deliver better services to those in need.

Method

Participants

Participants in the current study were recruited via National Autistic Society (NAS), Research Autism, and community support groups in London boroughs of the United Kingdom. Participants were therefore a self-selected sample and recruited nationally from a variety of geographical areas including the North West, London and the South East of England. The 6 participants were all mothers of a young adult with a diagnosis of autism spectrum disorders. Five of the children had comorbid intellectual disabilities, with three of them classified as severe (Table 1).

Table 1 around here

Procedure

A semi-structured interview schedule was developed with consideration given to previous studies focusing on the transition to adult services (Mitchell & Beresford, 2014). Factual questions including how long their child has had a diagnosis of autism spectrum disorders, and whether their child had any additional diagnoses, were asked initially in order to build a rapport and trust between the interviewer and interviewee, before moving on to potentially more difficult or sensitive areas.

The following core questions were then asked:

- 1) Could you give me a brief history of the transition process from when you first began considering it?
- 2) How did you feel during this process?
- 3) Can you describe any obstacles that you experienced during the stages of the transition?
- 4) Can you describe the support you had during the transition?

Ethical approval was granted from both the University of Hertfordshire and Research Autism. Participants were made fully aware of the aims and procedure of the investigation prior to providing written and verbal consent, including permission to record the interview. Data were collected in one-to-one semi-structured interviews conducted by the first author between June and September 2015. Interviews were conducted in a quiet location of the participants' choosing (usually own home) and lasted between 45 and 75 minutes.

Analysis

Interpretative phenomenological analysis (IPA; Smith, Flowers & Larkin, 2009) was chosen as the method of analysis to capture the holistic quality and rich texture of individual experience. It is a process of understanding the meanings a person applies to their experiences, and how they make sense of what is happening to them. Interpretative phenomenological analysis guidelines were followed throughout the investigation (Smith et al., 2009). Interviews were recorded and transcribed verbatim, these transcripts were then analysed in a systematic process that began with exploratory commentary (descriptive, linguistic and conceptual) of a transcript and mapping connections between these exploratory notes in order to create emergent themes. This initial coding represented a symbiotic process of description and interpretation. Connections between emergent themes were then explored through the processes of abstraction, subsumption, polarisation, contextualisation and function of language. These stages were repeated for each transcript in a case-by-case analysis and patterns were subsequently explored across all cases thus creating superordinate and component subordinate themes. Both data and investigator triangulation were adopted to confirm the appropriateness of coding, themes and interpretations at each stage of analysis. Themes were also discussed with autism professionals working regularly with families of children with autism spectrum disorders, to confirm adequacy.

Results

Three superordinate themes emerged from the accounts given by six mothers of young adults with autism spectrum disorders: Negative Experiences, Resources to Cope and Facilitating Self-Preparation.

Negative Experiences

All mothers had an adverse emotional response to transitioning their children from youth to adult services and all indicated a struggle with regards to their control over the process.

Negative experience was comprised of two subordinate themes: “the emotional impact of transition” and “perceived lack of control”.

The emotional impact of transition

The emotions associated with the experience of transition, for the four whom had already completed the process, included accounts of fear, frustration and anxiety:

It feels quite frightening, the danger of him being left with nothing, just like, falling off, with nothing to do, y'know, on the scrapheap at sixteen. (Lisa)

This mother’s use of the term “scrapheap” denotes the belief that society sees her son as useless and disposable. The perceived vulnerability of her son is also indicated by this mother’s concern that, aged sixteen, her son could be *falling off*, into nothingness, with no one to save him.

Two of the five mothers were unable to label their emotions regarding the transition, both of whom were, at that time, beginning the transition from school to higher education and residential placements. One mother (Lesley) described herself navigating the transition as *a bit blind*, which implied a certain level of anxiety, while the other mother found it difficult to describe how she felt:

Because we’ve been here so many times, it’s not easy, but, you know, you gotta do it. I dunno if it’s anxious...there isn’t a word that can say how you feel, it’s not nice but, it’s what you have to do. (Kayleigh)

The perceived lack of control.

The unpredictability of autistic manifestations and the challenges it brings can cause many parents to believe that circumstances are outside of their control. This was true for all accounts and was partly evidenced by their use of the word *lucky*:

This mother (Lisa) felt that the resources that she had available to her; such as her contact with other parents, her occupation within a charity for adults with learning disabilities, and the support and advice she had received from an National Autism Service, were there because of luck and not because of her own actions and preparations. Although not all participants felt that they had the resources to get their adult children the best support available, all of them indicated a sense that they were not in control of the outcome of transition or, indeed, of many circumstances within their lives. This may result in a feeling of uncertainty and unpredictability, which was true for one mother who was asked about her expectations of the oncoming transition:

I don't expect anything, it's like, "how long's a bit of string?" (Kayleigh)

This idiom connotes an impossibility to plan ahead, as if there was no possible prediction this mother could have made regarding the transition and therefore implying that events were entirely out of her control. The second mother who was yet to experience the transition (Lesley) also indicated towards a lack of control via expressing, throughout the interview, a reliance on the system and the professionals within it to guide her in the process of the transition, although her expectations never appeared to be met.

Resources to Cope

Taking care of one or more children with autism spectrum disorders can be physically and emotionally exhausting. Included within each account were indicators of the personal resources that were available to these mothers, which enabled them to cope with the proliferating stresses of transition.

Coping strategies.

Each account described unique efforts employed by these mothers in their attempts to combat the stress of transition as well as the general struggles of raising an autistic child. Two mothers (Kayleigh and Patricia) indicated an avoidance coping style by psychologically distancing themselves from potential problems:

I can't go too far in front; it does your head in, it really does. (Kayleigh)

This mother tends to manage her problems as and when they occur, demonstrating the unpredictability of autism and the all-encompassing effects of having a child on the spectrum.

In contrast to this, three mothers described a tendency towards more functional coping styles. Two of whom (Lisa and Janet) focussed on working through problems in a systematic manner, demonstrating a task-oriented approach:

I kind of think, all the time, we've got to try and get the right sort of things to be written on his record so that, at some point in the future, if we're not able to be there and they're having to advocate for him, it's all in writing that he's got these support needs. (Lisa)

Another mother employed a more positive coping style (Barbara) and changed her interpretation of problems, which was likely to reduce the emotional impact on her. She redefines the challenges that raising a child with an autism spectrum disorder brings and in doing so breaks down a potentially overwhelming combination of stressors into more manageable pieces.

Finally, one mother (Lesley) had delegated responsibility to a trusted organisation in order to guide her decision-making in the transition process. Through liaising with the National Autistic Society, this mother has lessened the burden on herself.

Resiliency-helplessness.

Resilience is the ability to rebound from a stressful situation as a stronger and more resourceful person. Two out of the six participants indicated traits of resiliency through: (a) describing a positive outlook; (b) considering the stressful situation within a broader context, and; (c) demonstrating a persistent yet pragmatic approach to challenges:

Sometimes, you just give up, you know, thinking, “no more, I can’t be bothered with these people,” but you have to be firm, just don’t give up, you can leave it for a little while and then you take it up again and you keep on (laughs). (Barbara)

This mother conveyed her persistency and determination in contacting social services. The two resilient mothers (Barbara and Janet) also demonstrated consideration of the stresses of transition within the context of other challenges associated with raising a child with an autism spectrum disorder. Both laughed frequently throughout the interview, which has been interpreted as indicative of a positive outlook.

The polar opposite of resiliency is helplessness, whereby giving into despair and accepting a negative fate. Three of the remaining four mothers (Lisa, Patricia and Lesley) indicated attitudes that lean towards the latter end of the resiliency-helplessness spectrum:

At the moment, we’re just, kind of, muddling through, if you know what I mean. (Lisa)

The use of the idiom *muddling through* suggests that this mother is almost managing to get the provisions that her son needs in adulthood but the process is awkward and sub-optimal. It implies a lack of motivation and absence of control in the transition process. All three mothers who indicated towards an attitude of helplessness described a similar powerlessness in their accounts.

One mother, however, appeared to lie somewhere in-between resiliency and helplessness (Kayleigh), as she described aspects of both in her account. This mother was yet to

experience the transition and tended to traverse a positive and negative outlook when talking about the future.

Facilitating Self-Preparation

This theme highlights considerations that influenced self-preparedness in these mothers: “the influence of an informed other” and a “cultivating activism-maintaining passivity” continuum.

The Influence of an informed other.

Four of the six participants interviewed spoke of individuals whom were knowledgeable on the subject of transition and helped them through the process. For two of these mothers (Barbara and Kayleigh), the acts of meeting these people were identified as key events, altering their perceptions and emotional experience of the transition:

I would say because I go to this [carers'] forum, these meetings, these coffee mornings, I got information from [parent carers], you know. (Barbara)

This mother was later asked what she believes the transition would have been like had she not met these parent/carers, to which she responds, “I wouldn’t have a clue. I wouldn’t have a clue what to do.” One other mother identified meeting an informed other person as a key event in her story, her informed other person was a teacher at her son’s school.

All mothers, bar one, nominate talking to other parents as a useful source of information and support prior to and during the transition:

Almost through the whole process I found it was really important to talk to other parents, y’know, try to get information from other parents. (Lisa)

When asked what advice she would give to other parents, one mother (Janet) replied, “I would advise them to talk to other parents locally for sure,” thus further endorsing the value of seeking an informed other person.

Cultivating activism versus maintaining passivity.

An activism- passivity continuum emerged from the accounts given by these participants.

Four mothers (Lisa, Janet, Barbara and Kayleigh) indicated that they were cultivating activist attitudes:

I want to do everything I can now to try and improve the system’s awareness and understanding of people like my son (...) and for professionals to be aware of people’s vulnerability, so that they don’t just take them at face value and say, “right, that’s it, you don’t qualify,” (Lisa)

This mother extended her fight to benefit those outside of her immediate family, seeking to raise awareness and understanding of individuals with autism spectrum disorders and in doing so is demonstrating activism. Another aspect of activism is providing support to others who are in similar situations and is included in the accounts of two mothers, one who operates a helpline for parents (Janet) and the other advises in parent support groups:

You still have to fight and you still have to keep on and I never give up, I always tell parents never to give up. (Barbara)

All “activist” mothers made frequent use of the word *fight* and other war-like synonyms, such as *battle* and *battlefield* to describe their experiences of acquiring support services. This fighting mentality indicates a developing activist attitude.

The two remaining mothers (Patricia and Lesley) gave accounts that portrayed a stance of passivism and acceptance, rather than a shift towards activism:

That meeting, which we weren't invited along to, we were told that we didn't need to be there. When school enquired, erm, they [social services] said that we didn't need to be there. (Lesley)

The two “passivist” mothers were more inclined to not challenge what they were told by social services and to accept or even make excuses for the lack of support from their local authorities.

Discussion

This was an exploration of the lived experiences that mothers of young people with autism spectrum disorders have had of the transition from child to adult services. All mothers described their experience of this transition as negative and felt they had a lack of control over the process. In order to manage their negative feelings, these mothers utilised the personal and social resources available to them, including the cultivation of an activist attitude. Almost all mothers acknowledged the importance of tangible support from other parents who had a child with an autism spectrum disorder.

Emerging as crucial to self-preparation were encounters with people who were more knowledgeable than them surrounding the process of transition. Interestingly, the mothers who demonstrated adaptive problem-focused coping and those who indicated resilience also had regular contact with other parents of children with autism spectrum disorders. The findings suggest that through their interaction with informed other people, these mothers adopted more positive coping strategies and bolstered their resiliency. Exchanging stories with other parents and engaging in social comparisons may have enabled these mothers to overcome feelings of isolation and helplessness, employ adaptive strategies for managing the

transition and to re-appraise their own difficulties in knowledge of the plight of others (Clifford & Minnes, 2013).

One way through which parents may access an informed other person is via parent support groups. Involvement in parent support groups has been linked with the development of a sense of collectivism leading to enhanced advocacy and activism in mothers of autism spectrum disorders (Ryan et al., 2009). Four out of the six mothers interviewed exhibited aspects of activism, partly demonstrated by their use of the word *fight* and other war-like synonyms when describing their strategies for acquiring support services. Mothers who indicate more resiliency are probably more inclined to push for the services that they feel would benefit their child, and when adversity strikes are more willing to persist with their demands (Bayat, 2007). In contrast to those high on the advocate-activism continuum, the two remaining mothers on the other end of this continuum adopted an unchallenging, passive stance towards social services and other professionals. We interpret this kind of passivity as a willingness to accept decisions of ‘experts’ rather than querying them, demanding explanations or putting up resistance. This passivity relates to their indications of helplessness and their inability to “fight” for affirmation of their child’s needs; feeling helpless and powerless, makes them more vulnerable to depression.

A major advantage of the interpretative phenomenological analysis methodology within the present investigation was the ability to provide rich descriptions of these mothers’ experiences paying attention to the uniqueness of their individual accounts. However, the small sample included in the study are unlikely to have covered all important personal experiences with relevant services and some caution is necessary in generalizing the results to a sample based outside the United Kingdom. In addition, the self-selective sampling method may have meant that mothers who experienced the transition as negative may have been more likely to volunteer. Crucially, fathers have tended to be overlooked in research to date, and

there is a clear need to understand their thoughts regarding their child's transition, particularly given that they are less likely to engage with parent support groups, and may identify more with a passive stance (Hartley & Schultz, 2015).

Conclusions for Practice

Recommendations for clinical and educational practice include promoting parent-carer support groups within the Child and Adolescent Mental Health Service and in both mainstream and specialist schools. In order, to help families to negotiate the transition better, and to strengthen their resilience mechanisms further, parents should be included as a major stakeholder in all aspects of decision making related to their child and to be made of all options available to them. They should also be provided with a clear list of the relevant adult services, including what each service can offer, and an appropriate delegated contact person for each. Many of the mothers acting successfully as an advocate for their child will often be motivated to help other parents from their own negative experiences. Professionals should therefore actively encourage these mothers for feedback in relation to improvements of their services, so these could be better tailored towards the particular needs of parents with children with autism spectrum disorders. Future research should further also examine the role that parent support groups play in both the development of positive coping strategies and the cultivation of the idea of 'advocacy' amongst parents with children with autism spectrum disorders. This could be particularly important for mothers and fathers who display signs of passivity and helplessness with the transition process. By investigating the advantages of joining a parent support groups, we could identify the important personal and social factors enabling parents to develop resiliency, cope successfully with the emotional challenges of this transition period and become effective advocates for their children's needs.

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