

Journeys of adjustment: the experiences of adolescents living with Juvenile Idiopathic Arthritis

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Abstract

Background: Juvenile Idiopathic Arthritis (JIA) is one of the most common diseases of childhood causing pain, swelling of joints and reduced mobility. Previous research has focused on the challenges and psychosocial impact of JIA, but there has been limited attention given to how young people adjust and adapt to living with a long-term condition such as JIA. The aim of this qualitative study was therefore to explore adolescents' experiences of living with JIA, with particular focus on the process of adjustment.

Methods: Ten adolescents (7 female, 3 male) aged 13 to 17 years with good treatment adherence, were recruited from an Adolescent Arthritis Clinic. In-depth interviews were conducted and data were analysed by 2 researchers independently, using Interpretative Phenomenological Analysis.

Results: These adolescents described the physical and psychosocial '*burden of living with JIA*' and the challenges faced by an underlying preoccupation '*to be a normal teenager*'. However, their accounts also revealed ways in which they regained agency and developed '*resilience through taking control*' over their lives. This resilience helped the adolescents re-establish a sense of wellbeing through an ongoing process of '*acceptance and self-growth*'.

Conclusions: Whilst much research has adopted a deficit-model which focuses on adjustment problems, the current study highlights the resourcefulness of young people in managing the challenges of living with a long-term condition. These experiences of successful adjustment can be used as the basis of positive, strengths based intervention approaches for adolescents with arthritis to enhance resilience and wellbeing.

Introduction

Juvenile Idiopathic Arthritis (JIA) is a heterogeneous group of inflammatory diseases in which pain, swelling and stiffness of the joints are the predominant features. It is one of the most common diseases of childhood affecting 95 to 130 children per 100 000 worldwide (Oen & Cheang, 1996). Control of the disease process has improved with advances in long term therapeutic regimes, new medications and physical therapy, but is often incomplete with flares of inflammation, residual biomechanical imbalance, joint deformity and resultant loss of physical function. Consequently, the impact of JIA on everyday activities, education, and functioning can be considerable (Haverman et al., 2012). Long term prognosis for adolescents with JIA is uncertain; continuing active inflammatory disease in adulthood has been reported in 30-50% of young people with JIA (Gare & Fasth, 2003).

Studies investigating psychological adjustment in youth with JIA have produced mixed results. A meta-analysis of 21 studies found youths with JIA experience increased adjustment problems and internalising symptoms (e.g. depression, anxiety, social withdrawal) compared to their healthy peers, but externalising symptoms (e.g. hyperactivity, oppositional behaviour, aggression) and self-concept were similar across groups (LeBovidge et al., 2003). Shaw et al., (2004) found health related quality of life was sub-optimal in adolescents with JIA and was predicted by pain, disease activity, and functional disability. However, deficits have not been found consistently, for example, Ding et al. (2008) reported that children and adolescents with JIA were not at significantly elevated risk of psychological difficulties compared to norms. Factors which may mediate the relationship between physical symptoms and psychological well-being include attitude towards JIA (LeBovidge et al., 2005) and social variables such as peer rejection and social behaviour (Sandstrom & Schanberg, 2004). Research consistently shows that

those with more parental and family support, and greater psychological resources within the family demonstrate better adjustment (Rapoff et al., 2003).

Whilst the majority of research has been quantitative, qualitative studies have provided greater insight into young people's experiences of living with JIA. A recent thematic synthesis of qualitative studies published between 1983 and 2011 (Tong et al., 2012) identified six major themes: aversion to being different; stigma and misunderstanding; suspension in uncertainty; managing treatment; desire for knowledge; and striving for normality. The two most recent studies in the above review (Eyckmans et al., 2011; Secor-Turner et al., 2011) both found that living with JIA presented challenges in multiple areas of young peoples' lives beyond managing health care itself, impacting on relationships, school, physical and individual domains. With the transition to adulthood, additional concerns about intimate relationships and the future became more predominant. This focus on the distress and difficulties caused by living with JIA is in line with the majority of research into the psychosocial aspects of JIA which has explored psychopathology and adjustment problems.

There has been relatively little attention given to the potential for positive growth and adaptation amongst adolescents with JIA. Within Tong et al.'s (2012) review, 'striving for normality' included coping strategies that young people employed to cope with the sense of being different, however there was still an underlying focus on overcoming problems as opposed to exploring positive adaptation. Recent understanding from positive psychology has highlighted the benefit of focussing on individual's strengths in terms of building self-esteem and facilitating positive well-being (Linley & Harrington, 2006; Wood et al., 2011). Exploring adolescents' stories of adjustment to JIA may provide new insights which could be used to support other adolescents and develop intervention programmes which focus on preventing psychological distress rather than dealing with its consequences. The aim of this phenomenological study was

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therefore to explore adolescents' experiences of living with JIA, with particular focus on the process of adjustment.

Methods

A qualitative approach using a phenomenological framework was used in which in-depth interviews were conducted with adolescents attending an adolescent arthritis clinic. Data were analysed using Interpretative Phenomenological Analysis (IPA) (Smith, 1996) which aims to access the 'insiders perspective' on their social world and to elucidate 'the subjective perceptual processes' involved when an individual tries to make sense of their experiences. It uses purposive sampling to provide a relatively homogenous sample and adopts an idiographic approach employing small samples in order to capture the richness of individual experience (Smith et al., 2009). The study was approved by both University and National Research Ethics Service Committees and written consent was obtained from all participants and their parents.

Participants

Ten participants were recruited from a regional service covering Thames Valley and neighbouring counties in the UK. Patients were considered for inclusion if they had a diagnosis of JIA, were receiving treatment, and were 12-17 years. In addition, we purposively sampled patients who the rheumatology team considered to be well-adjusted and have good treatment adherence. The sample consisted of three males and seven females (reflective of the 3:1 gender prevalence of JIA (Rapoff et al., 2003), aged between 13 and 17 years (mean=14.9), individual participants' characteristics are listed in Table 1.

Table 1: Participants' characteristics

<i>Pseudonym</i>	<i>Age (years)</i>	<i>Gender</i>	<i>School Year</i>	<i>Time since JIA diagnosis (years)</i>	<i>Other Medical Conditions</i>
Lily	13	Female	9	2	Diabetes
Jess	13	Female	9	1	Diabetes
Katie	14	Female	10	8	No
Amy	14	Female	9	12	No
Meg	15	Female	10	1	No
Jack	15	Male	11	2	No
Sophie	16	Female	12	8	Cataracts
Grace	16	Female	11	4	No
Tom	16	Male	12	5	Asthma
Sam	17	Male	13	5	No

Procedure

Eligible patients were approached by the paediatric rheumatology team and provided with information packs about the study. Potential participants were asked to return an opt-in slip if they were interested in joining the study; only one individual declined to participate. Semi-structured interviews were conducted by the same researcher (EF) and took place in participants' homes. The interview adopted a flexible approach in order to be responsive to the issues deemed important to the participant. However, each interview broadly explored the meaning and impact of living with JIA, feelings about JIA and experiences surrounding adaptation and treatment. The interview began with the question 'how does having JIA affect your daily life'. Interviews lasted between 40 and 70 minutes, were audio-taped and transcribed verbatim.

Data analysis

The analysis was conducted in accordance with IPA guidelines (Smith & Osborn, 2003). The initial analysis involved repeated readings of each transcript and the recording of observations and preliminary interpretations. The second stage involved the identification of emerging themes for each participant, coded with key words or phrases that reflected the meaning of individual accounts. A master list of themes was then constructed for one transcript reflecting an ordering of the themes illustrated with extracts. This master-theme list was used as the basis for analysing subsequent interviews, in which examples of the themes were recorded and any new themes identified. In order to ensure the themes remained grounded in the data, all transcripts were re-read to ensure cross-referencing of themes across participants. Finally, higher order ‘super-ordinate’ themes were identified which represented participants’ perceptions and experiences, both in terms of thematic prevalence (across participants) and thematic salience for individuals.

Several steps were taken to ensure the trustworthiness of the data and analysis. Two authors (EF and TC) analysed all transcripts independently; initially both authors read and analysed a single transcript and discussed emerging themes, developing the master-theme list used in subsequent analysis. Additionally, the cohesiveness and hierarchical structure of themes were discussed in group meetings at several stages of the analysis. The research team had a multidisciplinary background which informed both the research design and interpretative process: TC is a lecturer/researcher specialising in long-term conditions and qualitative research, both EF and KJ are clinical psychologists specialising in the management of children’s health conditions, and NW is a consultant rheumatologist. At the time of interviewing, EF was a trainee clinical psychologist in her early 20’s with previous experience of working with young people. Reflective notes were made after each interview and during the analytic process.

The data presented here specifically focuses on the meaning and impact of living with JIA and adolescents' feelings about the illness. The analysis is presented with reference to the recent methodological debate about 'quality' in published IPA studies (Smith, 2011); although most themes were prevalent across the majority of participants, particular attention was placed on areas of convergence and divergence amongst the sample.

Results

The majority of participants described a journey of adaptation that was often turbulent but led towards acceptance (see Figure 1). Participants narrated a range of physical and emotional difficulties following diagnosis with JIA along with continuing challenges, particularly centred around the underlying preoccupation to fit in with peers, both socially and behaviourally. However, their accounts revealed a range of strategies to regain a sense of agency and control over their lives. The journey towards acceptance therefore required ongoing work to integrate JIA into their developing identity.

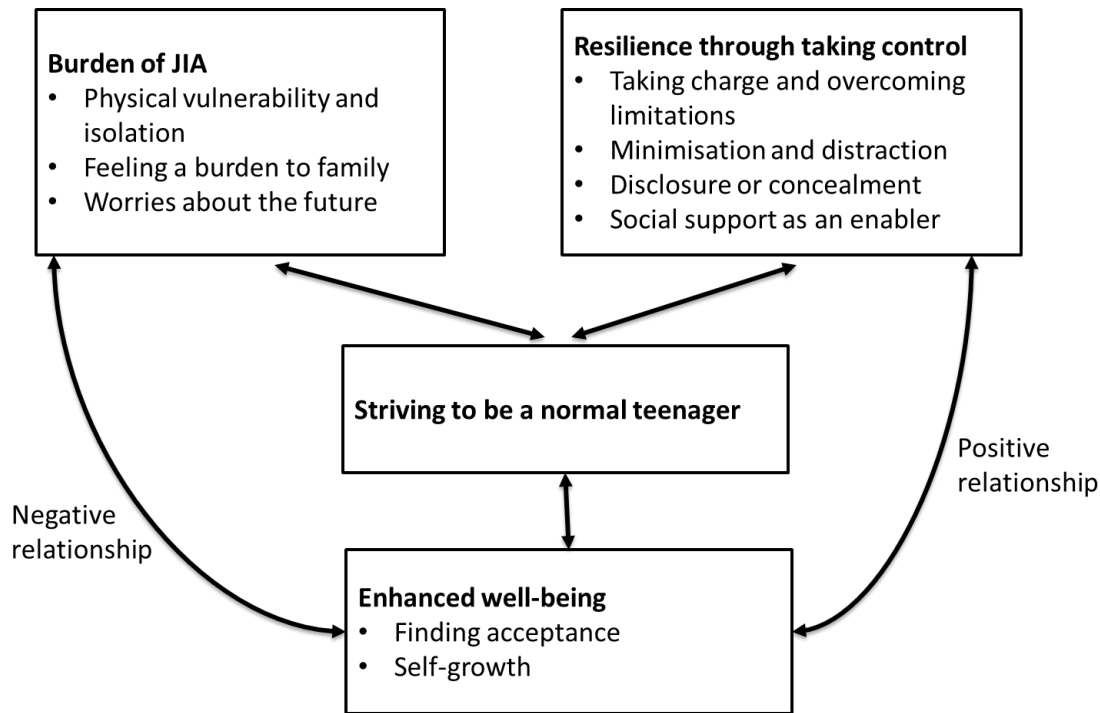


Figure 1: Summary of themes

Burden of JIA

Physical vulnerability and isolation

All adolescents discussed a wide range of physical difficulties including pain, fatigue, limited mobility and treatment side effects. These were particularly severe at disease onset and often accompanied by a sense of shock and disbelief:

“I know how bad it was and like not being able to move is the worst thing ever and you feel like you have turned 90 before you’re 14 or whatever and like I felt like I was completely crippled and it’s like turning a 100 or something because you just couldn’t do anything.” (Grace, 16, 4 yrs since diagnosis (YSD))

An association between symptoms of arthritis and aging was mentioned by several adolescents, both in relation to their own perceptions (above) and how their condition was perceived by others

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(*'here's the old Grandma'*, Lily). For Grace, the suddenness of this ageing process suggests an underlying fear that the crippling symptoms would be permanent and her youth irretrievably lost.

Many discussed the changing impact of JIA, with the initial focus on disease management and pain control, and fears about the future more prevalent as adaptation occurred. The shock of illness onset was difficult for young people to deal with over and above 'normal' adolescent concerns, with most describing anger, emotional venting, and frustration when initially diagnosed. Although physical limitations were reduced through medication, restrictions continued to highlight differences from peers and made participants feel vulnerable. A sense of isolation was thus experienced in both physical (missing out on shared activities) and psychological terms (feeling different from others). Particularly prevalent was the sense that others were incapable of fully understanding their lived experiences:

"Like my friends they might get a cold and they say "oh no I feel so ill" and it's like and then it's like they don't know what it's like to be me sometimes" (Katie, 13, 2 YSD)

The future and managing uncertainty

Health concerns were underpinned by the unpredictable nature of JIA and included worries about becoming more physically restricted over time, set against the hope that symptoms would cease in adulthood. Alongside this, the young people worried about the long-term prospects of requiring medication because of the lifestyle implications and side effects¹:

"It is stopping you drink, it's stopping me having kids, but currently it's not a big problem, but you know eventually I do think quite a bit, how long am I going to be on this,

¹ Most participants were taking Methotrexate- a disease-modifying anti-rheumatic drug which reduces the activity of the immune system.

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does this mean I'm going to be restricted to my alcohol limit until I'm 25?" (Sam, 17, 5 YSD).

Indeed, medication-related restrictions seemed at least as pertinent to older adolescents as concerns around physical symptoms worsening. Additionally, several adolescents voiced concerns that their career choices may be restricted as a consequence of their illness. Although most were able to move forward in their lives despite these concerns, for Jack, such uncertainties led to an inability to think about the future until his condition improved:

I: "so what has to happen for you to be able to think about the future?"

Jack: "Well for the arthritis to improve. Then I can go to the doctors and say yes it has improved, or if it hasn't then keep going. If they say keep going then I'll keep going.

Because if it gets better then I'll start thinking about the future, like if it comes back will I be able to cope."(15, 2 YSD)

Resilience through taking control

Despite these accounts of JIA as a long term burden, on the whole these adolescents were remarkably resilient to negative thoughts and feelings. Regaining a sense of control over one's body, and life more broadly, appeared to facilitate this resilience. Four strategies for (re)taking control emerged from participants' narratives.

Taking charge and overcoming limitations

This theme exemplified the battle to assume personal agency, and involved both physical and psychological mastery: "Physically I think that I can do anything if I put my mind to it, like it shouldn't hold me back" (Sophie). Often this involved a refusal to accept physical limitations or let arthritis interfere with normal activities; this was particularly evident in two adolescents who participated in high level sport prior to diagnosis. Despite continuing pain, Grace persevered with

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writing and sports to prove to herself and others that she was ‘fine as normal’, which enabled her to eventually regain her fitness and sporting ability:

“When I first got it I didn’t like know if I could ever do sport again and I used to get really upset about it but then it just kind of gave me the determination to prove everyone wrong” (Grace, 16, 4 YSD).

Tom did not return to play rugby at his previous level but he too described a strong determination to battle against physical limitations:

“I can play passing football and get my fitness back up and fight through the...

Interviewer: Did it feel like that, a fight?

Yeah it did yeah, sort of like playing a sport or going out for a walk just carrying on doing it, just fight through it sort of keep going which I did luckily.” (Tom, 16, 5 YSD)

Part of the process of ‘taking charge’ for these adolescents was facing up to the experience of pain and addressing pain-related fears and anxieties. As Jess explained:

“I figured like you don’t have it [pain] and you’re lucky, but if I have it I’m just going to get on with it, like you can’t, there’s nowhere it’s going to go, you just have to like overcome it and be brave.”(13, 1 YSD)

For Lily, prior experiences provide a benchmark of ‘real pain’ which enables Lily to adopt a positive ‘can do’ attitude which minimises the significance of current residual pain.

“You just sort of get on with it because before I was so much used to the pain like personally it’s not really that painful because I know what real pain feels like.”(13, 2 YSD)

Minimisation and distraction

One way in which the adolescents minimised the sense of differentiation from the norm was through downward comparison with those more disabled:

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“I’m very lucky it could be a lot worse, like other people have it like 10 times worse than I do and yes it interrupts sometimes but it doesn’t interrupt what I have to do every day like day after day, it’s not that bad.” (Katie, 14, 8 YSD)

This type of comparison gave the adolescents a sense of being fortunate with their own health and led to positive emotions such as gratitude. Avoiding rumination and focusing on the present were also seen as important strategies for avoiding negative feelings:

“When you’re by yourself you think about it a bit...but once it starts in my head I try and get it out and don’t think about it, live life while you can” (Tom, 16, 5 YSD)

Most adolescents described JIA as having minimal impact on their daily life and yet were aware that memories of illness were only just below the surface and could be triggered by casual comments or well intentioned questions revealing the fragility of this sense of normality:

“I hate that because now it’s in remission so it doesn’t really like, I just feel normal and I forget all about it so when someone brings it up it brings me back to those memories.” (Grace, 16, 4 YSD)

Disclosure or concealment

All participants discussed the balancing act of disclosure versus concealment of their condition. Whilst disclosure was a potential means of eliciting support from others and was associated with friendship and emotional closeness, concealment had a normalising function and was important to avoid being defined by one’s condition. Decisions about disclosure were an important means of maintaining control.

“It’s not something I would use as an icebreaker, I would have to get good friends with someone and then you know I could tell them, but you know I wouldn’t make it a huge deal, because to me it’s not anymore” (Meg, 15, 1 YSD)

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It was therefore a source of frustration when this sense of agency was lost when an explanation for pain, symptoms or absence was unavoidable. In these situations most adolescents chose to respond openly, however, Jack and Amy differed in their approach to disclosure. Whilst Jack maintained a strategy of concealment - *“if someone asks and I don't want them to know, then I just say I'm not telling you”* whereas Amy sometimes used disclosure to her benefit:

“I can always use the excuse if I'm late to my lesson, oh my, oh I've got arthritis, you know like, “Oh what a shame, it's ok, it's ok”, you know it's like, but that's naughty.”(14, 12 YSD)

These two contrasting approaches may reflect differing levels of acceptance of their condition. Amy was diagnosed with JIA at a young age, demonstrated ownership of her condition and had learnt to use JIA to her advantage. In contrast, Jack (diagnosed for only 2 years) felt unable to move forward until his condition had been resolved, suggesting limited acceptance of JIA.

Social support as an enabler

Consistent with a large body of research, social support was a strong and consistent theme, with familial and peer support perceived as an important coping resource, both emotionally and behaviourally:

“At times when I just felt like I'd had enough really, I would like, I don't want to do this anymore, I was just so fed up and then my mum comes in and helps me out and picks me up off the ground” (Jess, 13, 1 YSD).

In particular family and friends provided solidity, hope and reassurance, helping these young people to feel normal as well as alleviate some of the responsibilities associated with chronic disease:

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“None of my friends treated me differently, they were all the same, there was just Grace who was a little different” (Grace, 16, 4 YSD).

This theme was more evident for females than males, partly because of greater disclosure amongst peers for girls. Situational factors also played a part, for example Tom was at boarding school and had limited social support from his family. He had one “*best mate*” who “*knew quite a lot about it and was really helpful*”, but generally Tom described taking personal ownership of the condition and managing it alone – seemingly through necessity rather than choice.

The opportunity to talk to other young people with JIA was described as very helpful by those who had done so and desirable by those who had not. It reduced adolescents’ sense of isolation by meeting others who could fully understand their experience, particularly when the ‘other’ was of comparable age and gender.

“I met other people that had had Methotrexate and it felt like ‘wooo’ it was really nice but saying I guess that that really helped me I didn’t feel so alone.” (Amy, 14, 12 YSD)

Acceptance and self-growth

In spite of the substantial challenges faced by these teenagers and uncertainties over future health, all discussed the importance of positive attitude in coming to terms with their condition.

Acceptance required a combination of maturity and familiarity with the condition, with most participants discussing their resistance when initially diagnosed, particularly at a young age.

Acceptance was multifaceted incorporating elements of letting go and accepting limitations, as well as integration of the disease self as “*part of life*”. This integration included an element of resignation to having JIA:

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“it’s just something that I have grown-up with not something that takes over, it’s not something that rules my life it’s just something I have and not everyone does” (Meg, 15, 1 YSD)

Acceptance of the side effects of medication in order to gain long term improvements in symptoms emerged as a strong and consistent facet of acceptance in this group of adolescents and was associated with the development of greater cognitive maturity. Amy was most aware of a shift in her attitude to medication:

“Like now I’ve grown up I just feel a bit like I know, I think, I know it’s better for me that’s why I have the treatment and stuff so I don’t just decide to say no because I want to be a pain in the bum” (Amy, 14, 12 YSD)

Several participants also described a process of reappraisal and self-growth in which the challenges experienced as a result of having arthritis were character forming, helping them to become “a stronger person” or develop positive or distinctive traits. Grace describes how a change in perspective helped her to come to terms with her condition and regain the agency described earlier:

“I used to be so awfully negative and everyone used to complain at me for it...[JIA] made me realise that like if you’re positive things can go in your favour, like if you just sit there moping around, nothing gets done and you don’t enjoy yourself” (16, 4 YSD).

Sophie experienced weight gain through taking steroid medication which she attributed to her developing a “bubbly personality” and “confidence” as a way of coping:

“I used to be like to myself and quiet, but now I’m so like outgoing and I was voted funniest of the year, and it’s nice when people notice me and see how I’ve changed” (16, 8 YSD).

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The consequences of living with JIA were thus double edged – treatment was undoubtedly perceived as a burden with undesired consequences, and yet participants discussed their pride at developing the resources (often after considerable struggle) to manage such challenges. Closer friendships and greater awareness of the love and support of one’s family were also valued as positive outcomes arising from having JIA.

Striving to be a normal teenager

This final theme, central to all accounts, reflects the conflicts faced by these adolescents as they strive to take control over their lives and develop an identity which is separate from JIA while at the same time taking responsibility for their health and well-being. A common expression used by the adolescents was “*I want to be normal*” but there was variation in the meaning of ‘normal’. Older participants reported an added sense of responsibility and enforced awareness of the consequences of their actions which belied the spontaneity of their peers:

‘I want to be able to be a normal teenager, and go out and have.....like my first drink and stuff like that without having the guilt about my medication’ (Sophie, 16, 8 YSD).

For Sophie, there is tension between wanting to join her peers in experimentation and the recognition that this conflicts with medical advice and may have wider consequences for her condition: “*obviously I don’t want the stress of getting even worse, so I think it sort of makes you think twice about doing things like that*” (Sophie)

The tension was also felt keenly by Sam:

“I want to be like everyone else, I mean everyone is different but I want to do what everyone else is doing, I want to go blundering into everything like what everyone else is doing, but actually I’ve got to wait and check myself and wrap myself up like a Michelin man...”(17, 5 YSD).

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This metaphor of a heavily protected and constricted body seemingly symbolises the restrictions of JIA which contrasts sharply with the image of his ‘blundering’ peers. Sam feels that his opportunities for experimentation with drinking and sexual relations are less spontaneous than those of his peers and resents that the *‘fun is taken out it a little bit’*.

Younger participants primarily described wanting to be treated as ‘normal’ within the school context. Accommodations, such as being excused from PE, made them feel that their school was understanding but also highlighted that they were different from their peer group. Katie found it unsettling that she was not required to take exams which were stressed as important for her peers:

‘I missed my SATS it was really weird, they made a really big thing about how important they were before we started doing them and then they said I don’t have to do them’ (14, 8 YSD).

It is likely that such accommodations created discomfort by conflicting with control strategies such as minimisation and concealment which were important for maintaining well-being.

Discussion

The Department of Health has called for greater engagement of young people in the management of their illness (DOH, 2002) and our study specifically sought to understand adolescents’ own perspectives on managing one of the most common diseases of childhood. Consistent with previous qualitative research (Tong et al, 2012), adolescents graphically described the physical and socio-emotional difficulties of living with JIA, but also eloquently described their journeys of adjustment and the mechanisms through which they sought to establish control and normalise their experiences thereby facilitating resilience against negative thoughts and feelings. The

findings illustrate a complex process of adjustment which reflects developmental and social factors and incorporates both resistance and acceptance.

Some of the strategies used to establish agency were similar to those previously reported to help adolescents with JIA and other conditions cope with a sense of being different (Taylor et al., 2008; Tong et al., 2012), for example the importance of social support, mastering the body, and refusing to be limited due to pain. Other strategies such as minimising difficulties, focusing on the positives, and avoiding rumination are all methods of cognitive emotional regulation which enable the individual to develop a balance between their illness identity and broader self-concept (Garnefski et al., 2009; Woodgate, 1998). Interestingly in Tong's review, concealment of JIA was described as a coping strategy whereas in our study adolescents described more nuanced thoughts about when and to whom they would disclose that they had JIA. Voluntary disclosure often led to closer friendships as a result of sharing such personal information.

Whilst much research has adopted a 'deficit-model' which focuses on adjustment problems, the current study highlights the resourcefulness of young people in managing the challenges of living with a long-term condition. It has been suggested that illness during the developing years may lead to a stronger sense of coherence, based on Antonovsky's salutogenic model (Antonovsky, 1987; Moons & Norekvål, 2006). This posits that longer-term well-being is positively impacted by the development of generalised resistance resources in response to successful management of stressors. This is supported in the current study by adolescents' descriptions of how the challenges of JIA were transformed into positive experiences and identity development.

The concept of acceptance has not emerged as a theme from previous qualitative research into adolescents' experiences of living with JIA. However, acceptance is commonly viewed as an adaptive mechanism in the coping literature (Casier et al., 2008). In this study acceptance was

generally arrived at following a process of adjustment. This supports previous ethnographic research suggesting that acceptance is multifaceted, reflecting progression, resilience and resignation (Aujoulat et al., 2008). The idea of resignation emerges quite strongly in these accounts - whilst adolescents resign themselves to having JIA, they also have conflicting feelings of wanting to be 'normal'. Adolescents varied in the extent to which they experienced this conflict and linked their own process of adjustment to developing cognitive maturity. Whilst it is difficult to compare developmental trends for such a multifaceted concept, fears about the future and restrictions on experimentation appear to be more significant for older compared to younger adolescents (Secor-Taylor et al., 2011). So, as one facet of acceptance increases due to cognitive maturity, another facet may decrease. The relative impact of different facets of acceptance to overall well-being and the concept of resignation should be explored further in future research.

The potential methodological limitations of the study should be acknowledged. In accordance with the methodological approach, the sample was small and recruited from a single centre, although it covered a wide geographical area. Whilst homogenous samples are recommended for IPA, our sample had considerable variation in age, time since diagnosis, and comorbidities; however, we sought to draw on these variations in understanding the process of adjustment within the context of maturation and illness experience. As in most studies, there was a cultural bias towards white participants. There is a need to explore cultural differences in young people's experiences of chronic illness since there is a paucity of research in this area. The trustworthiness of the data and analysis (Stiles, 2003) was however enhanced through analyst triangulation whilst a multidisciplinary research team contributed to study design and analysis. Our study explored adolescents stories of adaptation to JIA based on a single interview at one point in time; in future work it would be desirable to explore experiences at key transitional

points - such as diagnosis and during flares – to provide appropriate support at these key, often challenging stages.

The findings have a number of implications for service provision. The need to place greater attention on the socio-emotional impact of illness echoes previous research (Barlow & Ellard, 2006; Barlow et al., 1999), particularly since a perceived lack of interest in these areas has been found to act as barrier to young people discussing wider problems (Beresford & Sloper, 2003). Managing perceptions of difference appears particularly crucial in empowering these young people to manage their condition within the everyday demands of teenage life and is supported by studies with other chronic conditions (Schur et al., 1999; Wells et al., 2012; Wilson et al., 2007). Peer support is a well-documented strategy for enhancing well-being in chronic illness (Gallant, 2003), and may encourage a response shift in evaluations of subjective well-being which reduce perceptions of difference and increase self-efficacy (Christian & D'Auria, 1997; Muldoon et al., 1998). Indeed, sharing experiences with others suffering from JIA were frequently mentioned by participants as both helpful and desirable, providing they were positive role models and gender/age congruent. Using the narratives of young people themselves can be a powerful and empowering medium to share experiences and minimise negative thoughts and feelings (Rich et al., 2000). The internet is an increasingly popular medium for both relating patient stories and providing self-management programmes to potentially large numbers of adolescents (Stinson et al., 2010).

In conclusion, this study provides a novel insight into the regulatory strategies used by adolescents as they learn to live with a long-term condition. Our findings suggest that in order to engage adolescents, interventions should focus on a variety of individual and social milestones rather than solely focusing on healthcare challenges (Secor-Turner et al., 2011; Shaw et al., 2004). Discussion of the concepts of acceptance and self-development should be incorporated

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into such programmes to promote resilience and well-being and move away from a deficit reduction approach to their illness.

Key messages

- JIA results in physical and psychosocial challenges that conflict with adolescents' desire to fit in with peers.
- Adolescents in our study responded to these challenges with strategies to re-establish control and agency over their body, drawing upon internal resources, cognitive-emotional regulation, restricted disclosure and social support.
- Given the importance of 'normalisation', sharing of experiences with other adolescents with JIA is recommended and could be facilitated through internet resources specifically geared to young people's needs.
- Acceptance was revealed as both multifaceted and changeable (rather than an end-point), influenced by developmental, individual and experiential factors.
- Service provision and intervention design should adopt a positive skills-based approach to support young people with JIA, using positive stories of adjustment to facilitate resilience and wellbeing.

References

- Antonovsky, A. (1987). *Unraveling the mystery of health. How people manage stress and stay well*. San Francisco: Jossey-Bass.
- Aujoulat, I., Marcolongo, R., Bonadiman, L., & Deccache, A. (2008). Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control. *Social Science and Medicine*, 66, 1228-1239.

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- Barlow, J., & Ellard, D. (2006). The psychosocial well-being of children with chronic disease, their parents and siblings: an overview of the research evidence base. *Child: Care, Health and Development*, 32(1), 19-31.
- Barlow, J., Shaw, K., & Harrison, K. (1999). Consulting the 'experts': children's and parent's perceptions of psycho-educational interventions in the context of juvenile chronic arthritis. *Health Education Research*, 14(5), 597-610.
- Beresford, B., & Sloper, P. (2003). Chronically ill adolescents' experiences of communication with doctors: A qualitative study. *Journal of Adolescent Health*, 33, 172-179.
- Casier, A., Goubert, L., Huse, D., Theunis, M., Franckx, H., Robberecht, E., . . . Crombez, G. (2008). The role of acceptance in psychological functioning in adolescents with cystic fibrosis: A preliminary study *Psychology & Health*, 23(5), 629-638.
- Christian, B., & D'Auria, J. (1997). The child's eye: Memories of growing up with cystic fibrosis. *Journal of Pediatric Nursing*, 12, 3-12.
- Ding, T., Hall, A., Jacobs, K., & David, J. (2008). Psychological functioning of children and adolescents with juvenile idiopathic arthritis is related to physical disability but not to disease status. *Rheumatology*, 47, 660-664.
- DOH. (2002). *The NHS Plan: A Plan for investment, a Plan for Reform*. HMSO, London.
- Eyckmans, L., Hilderson, D., Westhovens, R., Wouters, C., & Moons, P. (2011). What does it mean to grow up with juvenile idiopathic arthritis? A qualitative study on the perspectives of patients. *Clin Rheumatol*, 30(4), 459-465. doi: 10.1007/s10067-010-1444-0
- Gallant, M. (2003). The influence of social support on chronic illness self-management: a review and directions for research. *Health Education & Behaviour*, 30(2), 170-195.
- Gare, B., & Fasth, A. (2003). The outcome of juvenile idiopathic arthritis. *Current Paediatrics*, 13, 327-334.

Experiences of adolescents with JIA

- Garnefski, N., Koopman, H., Kraaij, V., & ten Cate, R. (2009). Brief report: Cognitive emotion regulation strategies and psychological adjustment in adolescents with a chronic disease. [doi: DOI: 10.1016/j.adolescence.2008.01.003]. *Journal of Adolescence*, 32(2), 449-454.
- Haverman, L., Grootenhuis, M., van den Berg, J., vanVeenendaal, M., Dolman, K., Swart, J., & al., e. (2012). Predictors of health-related quality of life in children and adolescents with juvenile idiopathic arthritis: results from a web-based survey. *Arthritis Care Res*, 64, 694–703.
- LeBovidge, J. S., Lavigne, J. V., Donenberg, G. R., & Miller, M. L. (2003). Psychological adjustment of children and adolescents with chronic arthritis: a meta-analytic review. *J Pediatr Psychol*, 28(1), 29-39.
- LeBovidge, J. S., Lavigne, J. V., & Miller, M. L. (2005). Adjustment to chronic arthritis of childhood: the roles of illness-related stress and attitude toward illness. *J Pediatr Psychol*, 30(3), 273-286. doi: 10.1093/jpepsy/jsi037
- Linley, P. A., & Harrington, S. (2006). Strengths Coaching: A potential-guided approach to coaching psychology. *International Coaching Psychology Review*, 1(1), 37-46.
- Moons, P., & Norekvål, T. M. (2006). Is sense of coherence a pathway for improving the quality of life of patients who grow up with chronic diseases? A hypothesis. [doi: DOI: 10.1016/j.ejcnurse.2005.10.009]. *European Journal of Cardiovascular Nursing*, 5(1), 16-20.
- Muldoon, M. F., Barger, S. D., Flory, J. D., & Manuck, S. B. (1998). What are quality of life measurements measuring? *BMJ*, 316(7130), 542-545.
- Oen, K., & Cheang, M. (1996). Epidemiology of chronic arthritis in childhood. *Seminars in Arthritis and Rheumatism*, 26(3), 575-591.

Experiences of adolescents with JIA

- Rapoff, M., McGrath, A., & Lindsley, C. (2003). Medical and psychosocial aspects of juvenile rheumatoid arthritis. In M. Roberts (Ed.), *Handbook of Pediatric Psychology* (3rd ed., pp. 119-140). New York: Guildford.
- Rich, M., Lamola, S., Gordon, J., & Chalfen, R. (2000). Video intervention/prevention assessment: a patient-centered methodology for understanding the adolescent illness experience. *The Journal of Adolescent Health, 27*(3), 155-165.
- Sandstrom, M. J., & Schanberg, L. E. (2004). Peer rejection, social behavior, and psychological adjustment in children with juvenile rheumatic disease. *J Pediatr Psychol, 29*(1), 29-34.
- Schur, H., Gamsu, D., & Barley, V. (1999). The young person's perspective on living and coping with diabetes. *Journal of Health Psychology, 4*(2), 223-236.
- Secor-Turner, M., Scal, P., Garwick, A., Horvath, K., & Wells, C. K. (2011). Living with juvenile arthritis: adolescents' challenges and experiences. *J Pediatr Health Care, 25*(5), 302-307. doi: 10.1016/j.pedhc.2010.06.004
- Shaw, K., Southwood, T., & McDonagh, J. (2004). User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. *Rheumatology, 43*, 770-778.
- Smith, J. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health, 11*, 261-271.
- Smith, J. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review, 5*(1), 9-27.
- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.
- Smith, J., & Osborn, M. (2003). *Interpretative Phenomenological Analysis Qualitative Health Psychology*. London: Sage.

Experiences of adolescents with JIA

- Stiles, W. (2003). Qualitative Research: Evaluating the Process and the Product. In S. Llewelyn & P. Kennedy (Eds.), *Handbook of Clinical Health Psychology*. Chichester: Wiley.
- Stinson J, McGrath P, Hodnett E, Feldman B, Duffy C, Huber A, Tucker L, Hetherington R, Tse S, Spiegel L, Campillo S, Gill N, White M. (2010). An Internet-based Self-management Program with Telephone Support for Adolescents with Arthritis: A Pilot Randomized Controlled Trial. *J Rheumatol*, 7(9),1944-1952.
- Taylor, R., Gibson, F., & Franck, L. (2008). The experience of living with a chronic illness during adolescence: a critical review of the literature. *Journal of Clinical Nursing*, 17, 3083-3091.
- Tong, A., Jones, J., Craig, J. C., & Singh-Grewal, D. (2012). Children's experiences of living with juvenile idiopathic arthritis: Thematic synthesis of qualitative studies. *Arthritis Care Res (Hoboken)*. doi: 10.1002/acr.21695
- Wells, F., Ritchie, D., & McPherson, A. (2012). 'It is life threatening but I don't mind'. A qualitative study using photo elicitation interviews to explore adolescents' experiences of renal replacement therapies. *Child: Care, Health and Development*, 39(4), 602-612.
- Wilson, C., Pistrang, N., Woodhouse, C., & Christie, D. (2007). The psychosocial impact of bladder exstrophy in adolescence. *Journal of Adolescent Health*, 41, 504-508.
- Wood, A. M., Linley, P. A., Maltby, J., Kashdan, T. B., & Hurling, R. (2011). Using personal and psychological strengths leads to increases in well-being over time A longitudinal study and the development of the strengths use questionnaire. *Personality and Individual Differences*, 50(1), 15-19. doi: 10.1016/j.paid.2010.08.004
- Woodgate, R. (1998). Adolescents' perspectives of chronic illness: "It's hard". *Journal of Pediatric Nursing*, 13(4), 210-223.