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**Peer-based social support for young-people with Juvenile Arthritis: views of young people, parents/carers and healthcare professionals within the UK.**

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**Abstract**

**Purpose:** A deeper understanding was sought of what peer-based social support means to young people with juvenile arthritis within the UK and ways in which it could be best provided.

**Design and methods:** A secondary analysis of underused, descriptively rich data relating to peer-based support contributed by young people with juvenile arthritis, their parents/carers and healthcare professionals from a qualitative study (seeking their views on a potential self-management mobile-app) was carried out using methods suggested by Interpretive Phenomenological Analysis.

**Results:** Peer-based support can provide a new kind of 'normality' for young people with juvenile arthritis, including greater understanding, relief, reassurance, shared learning and increased self-efficacy. However, the risk of stigma through this shared identity suggests a need to offer various forms of access including using new electronic media.

**Conclusion and implications:** The evidence suggests that although desired, the potential social cost of identifying with peers living with juvenile arthritis is influenced by the way such support is provided, which in turn impacts on how readily it will be accessed. This suggests the need to provide various means of accessing peer-based contact, including electronic media, to ensure that young people with juvenile arthritis benefit. Therefore, when promoting and supporting peer-based social support, as far as possible, professionals need to individualise ways in which such support can be accessed because there is no 'one size fits all' approach.

**Key Words:** peer- based social support; young people; juvenile arthritis; support groups; online social support.

## **Introduction**

Juvenile Arthritis (JA) is a common cause of chronic joint inflammation in childhood with the potential to create permanent disabilities (Ravelli & Martini, 2007). It can slow physical development and involve pain, stiffness and limited mobility which restricts young people's social and family life, reduces their independence (Moorthy, Peterson, Hassett, & Lehman, 2010), and often persists into adulthood (Selvaag, Aulie, Lilleby, & Flatø, 2014). The effects of such a reduction in independence becomes particularly evident as young people diagnosed with JA approach adolescence.

When seeking ways to improve young people's management of JA by researching their preferred content for a mobile self-management app (Anon., 2018), the importance of peer-based social support became apparent. The term 'young person' used here, includes early adolescence (10–13 years), mid adolescence (14–16 years) and late adolescence (17–19 years) in line with Foster et al (2016). As the original objectives of this prior research meant that it was only possible to report briefly on the detailed references made by participants to young

people's need for peer-based social support, it was felt that this issue deserved further exploration.

It was, therefore, decided to carry out a secondary analysis of this rich, but underused data collected within the primary study, to gain greater awareness of what peer-based social support means to young people with JA. Such a reanalysis was considered appropriate given the assertion by Hinds, Vogel and Clarke-Steffen (1997) that it can generate new knowledge as well as support existing theories.

Participants' references to a need for peer-based contact provided a subset of the larger section: 'Social Support (emotional and practical)' reported within the primary study, which was felt to warrant further investigation.

Sharing life experiences with similar others provides support through a sense of connectedness, improving confidence and the ability to form and maintain friendships (Gartland, Bond, Olsson, Buzwell, & Sawyer, 2011; Westmaas & Silver, 2006). Such support becomes particularly important during adolescence when peers often become attachment figures (Mikulincer & Shaver, 2009). This can be a challenging period for those diagnosed with JA given the restrictive nature of chronic illness (Békési et al., 2011; Masten, 2001). However, fostering relationships between those diagnosed with similar conditions can help reduce some negative experiences. Peer support has been found to promote coping strategies which help reduce the gap between the perceived stressor and the ability to respond appropriately (Cutrona & Russell, 1990; Lazarus, 1966; Lazarus & Folkman, 1984). Indeed, promoting companionship, conversations and shared activities has been found to be better than providing conventional stress-reducing interventions (Lahey & Orehek, 2011; Lahey, Vander-Molen, Fles, & Andrews, 2015).

Positive, reciprocal friendships can assist in developing resilient outcomes (Bolger & Patterson, 2003) which enables young people to successfully maintain expected development despite being diagnosed with a chronic illness (Egeland, Carlson, & Sroufe, 1993). This is

particularly important for young-people with juvenile arthritis. For example, Hart et al (2015) found that in addition to family members, empathetic friends with a chronic health condition were important confidants and advisors when young people with JA had to make important decisions about biologic treatments. Such peers were valued above healthy peers given their increased empathy and understanding, knowledge of the health service regimens and the reciprocal nature of shared experiences. These shared experiences with such 'trusted others' enabled the young people with JA to still retain a sense of being 'normal'. Hart et al. (2015) concluded that it was important for healthcare professionals to be aware of the direct impact that peer and other 'trusted' relationships could have on treatment decisions, to effectively meet the needs of young-people with JA.

The benefits of peer support reported by Hart et al (2015) and others cited above also emerged from participants' contributions within our original study. However, it became apparent that to fully appreciate the extent to which it can be effective there is a need to also appreciate how such support is provided in order to justify promoting this as integral to their care.

The purpose of this paper, therefore, is to report on a secondary analysis of participants' requirements for peer-based social support (expressed previously, but not fully explored, in relation to what should be included in a self-management mobile-app) to allow us to begin addressing this important issue.

## **Objectives**

To gain a deeper understanding of what peer-based social support means to young people with juvenile arthritis and ways in which it could be best provided.

## **Methods**

### **Design**

Reassessment of information relating to peer-based social support offered by 24 participants was guided by Hinds, Vogel and Clarke-Steffen's (1997) suggestions of how secondary analysis should be conducted. We were confident that the semi-structured interviews and focus groups

used within the primary study provided enough appropriate additional data for secondary analysis to complement and extend the original findings.

A literature search relating specifically to peer-based social support was carried out to complement the electronic scoping exercise conducted for the original study and guided by the Cocharne Handbook (Higgins & Green, 2011). Ethical consent previously obtained from the National Health Service Research Authority for the original research was sufficient for this secondary analysis given that greater insight was being sought into an element (social support requirements) identified within the first study.

### **Participants**

Interviews had been carried out with eight young people (diagnosed with JA) and eight parents/carers recruited from the data base of a rheumatology clinic of a large teaching hospital in the north of England, and two focus groups conducted with eight healthcare professionals (including consultant rheumatologists, nurses, a psychologist, a pharmacist and a youth worker). Inclusion/exclusion criteria included: being between 10-18 years and having received a diagnosis of JA or being a parent or an individual responsible for the daily care of such a young person (parent/carer), or being a professional responsible for treating young people with JA. All participants had to be able to speak and read English. Interviews and focus groups including parents/carers and professionals provided rich sources of data (Leech, 2002; McLafferty, 2004) supporting and contextualizing the young people's views.

**Table 1. Participants – Young people with juvenile arthritis, parents/carers and healthcare professionals.**

Young-People (N = 8)	Pseudonym	Annie	Harr	Tess	Lily	Mel	Louis	Tom	Amy
	Sex	F	M	F	F	F	F	M	F
	Age yrs.	17	14	13	11	14	10	15	15
	Yrs. since diagnosis	12	13	11	0.5	3	9.5	4	12
Parents/Carers (N = 8)	Pseudonym	Gill	Tina	Liam	Beth	Jack	Claire	Nettie	Becky
	Sex	F	F	M	F	M	F	F	F
Healthcare Professionals (N=8)	Pseudonym	HCP 1	HCP 2	HCP 3	HCP 4	HCP 5	HCP 6	HCP 7	HCP 8

### Procedure

Participants had been given verbal and written information including age appropriate information sheets, topic guides and consent/assent forms. Consent forms had been signed by participants over 16 years. Younger participants had signed assent forms and their parents/carers had signed consent forms on their behalf.

Contributions specifically relating to peer support in transcripts originally gathered by means of semi-structured interviews with young-people and their parents/carers and focus groups comprised of healthcare professionals (Anon., 2018) were, therefore, re-analysed by the first author. Interviews and focus groups had lasted between thirty-five and sixty minutes and were digitally recorded and transcribed by the first author.

### Data analysis

In line with the requirements of Hinds, Vogel and Clarke-Steffen (1997) participants' comments relating to an issue (peer-based support) emerging from analysis within the primary study were reanalysed. An attempt was made to achieve the necessary balance between sensitivity and

distance as having been involved in collecting the original data, the first author conducted the reanalysis but using new analytical methods. These were based on interpretive phenomenological analysis (IPA) (Smith, Flowers, & Larkin, 2009) as, according to Pietkiewicz and Smith (2014), not only does this approach seek to gain an understanding of participants' experiences but also acknowledges the role the researcher's interpretation plays in expressing findings.

To capture different perceptions of how peer-based social support was envisaged, participants' comments relating to peer support were considered individually and then collectively. Given the first researcher's role in gathering and analysing the data during the primary study, it was not possible to comply with the need within IPA to bracket out preconceptions (Smith, et al., 2009). However, an attempt was made to acknowledge and use the first researcher's past experiences sensitively to reflect on what appeared to emerge from the new analysis. Also, as pointed out by Smith, et al. (2009) the ability of the researcher to interpret the data through a 'lens' of existing psychological theory helps develop insight which participants may not even be aware of.

In line with requirements of IPA the analytical process undertaken involved familiarisation with the data through having conducted interviews, listening to the audio tapes and reading through transcripts a number of times whilst making notes on what main points seemed to be being made and how they had been expressed. After gaining an overall sense of what was being conveyed in the transcript extracts for each participant, notes were made on individual scripts, identifying points where a theme appeared to be emerging. A list was then drawn up clustering these different points under tentative headings in terms of their shared relationships. Connections were sought between these emerging themes such that they could be clustered again to form sub-themes. When no further themes were evident, sub-themes were considered again and those relating to shared concepts were seen to form major themes. Initial

analysis was carried out by the first author and once completed, evidence of the whole process was interrogated independently by the second author to try to ensure credibility.

This process offers an audit trail and can be seen to fulfil the definition of good qualitative research identified by Yardley (2000) and cited by Pietkiewicz and Smith (2014) as it provides a context and demonstrates rigour and commitment with the potential to impact on practice.

## Results

After ascribing pseudonyms to ensure anonymity and analysing the transcript extracts the following six major themes emerged:

**Table 2. Major themes and sub-themes emerging from the views of young people, parents/carers and healthcare professionals on peer-based contact for young people with juvenile arthritis.**

Theme	Major theme	Sub-themes
1	A new kind of normality	<ul style="list-style-type: none"> <li>• Reduced feelings of isolation</li> <li>• Shared similarities</li> <li>• Identification based on shared experience of condition rather than physical effects</li> <li>• Impact of young person's age</li> </ul>
2	Understanding	<ul style="list-style-type: none"> <li>• Feeling understood</li> <li>• Acceptance</li> </ul>
3	Relief and Reassurance	<ul style="list-style-type: none"> <li>• Relief</li> <li>• Reassurance</li> </ul>
4	Shared learning	<ul style="list-style-type: none"> <li>• Learning from each other</li> <li>• Increased self-efficacy through helping others</li> </ul>
5	Ambivalence towards peer contact	<ul style="list-style-type: none"> <li>• Peer contact not always desired</li> <li>• Potential price paid for belonging</li> </ul>
6	No one-size fits all – varied access to peer support required	<ul style="list-style-type: none"> <li>• Not all forms of peer contact provision acceptable</li> <li>• Varied types of access to peer support required</li> </ul>

Peer support appears to offer young people with JA a new kind of 'normality' (THEME 1) with reduced isolation through recognised similarities based on shared experiences rather than the physical effects of JA. Young people felt better understood (THEME 2) and accepted by peers

which offered relief and reassurance (THEME 3). The shared learning between peers (THEME 4) helped to increase self-efficacy through greater knowledge of how to manage the condition and act as role models. However, young people may experience some ambivalence in terms of the potential social costs of this shared identity (THEME 5) and the ways in which peer support was accessed as no one agency suited everyone (THEME 6).

### **Theme 1. A new kind of normality**

Peer contact was seen to create a new kind of 'normality' including experiences not appreciated by those who do not have such a condition, which reduces feelings of isolation and becomes more important when approaching adolescence. Young people with JA may never regain the same kind of 'normality' experienced prior to the onset of their condition. For example, Gill explained that when healthcare professionals encourage her daughter to '...have a normal life, she tries to lead a normal life but the stuff she does has an impact on her arthritis then or the next day.'

Healthcare professionals pointed out just how much having JA can leave young people feeling isolated. Only two of the young people interviewed had met others diagnosed with juvenile arthritis, and that was only very briefly. Annie explained that, '*I didn't really know anybody at all that had arthritis. I have had it thirteen, thirteen years next month and, I have not met a single person [with JA].*' The impact of such isolation was evident when during her interview, Gill described how she wished that her daughter could, '*...meet somebody who has the same condition, where they do not leave Annie on the bench and then come back to her when she is alright.*' Tess also explained how important it would be, '*...just knowing somebody else that has got it,*' and HCP3 suggested that young people with JA needed a, "*social network that they could opt into, with parental consent.*"

Peer contact was seen to offer a sense of shared similarities where it was possible to '*...have somebody who knows exactly what they can and can't do, you know it has got to be of benefit. Just somebody else who knows what you are going through,*' (Gill-parent/carer). Annie,

explained how important it was that she could have, *'...a really close friend that I could go to and actually understands where I'm coming from.'*

A particularly surprising finding was the extent to which the desire to meet others who had experience of JA was greater than any physical differences between them, even when these were obviously apparent. For example, it could be thought that young adolescents with no visible signs of having JA may be reticent to identify with peers whose condition was so debilitating that they had to use a wheelchair. However, although no one would guess from Tess's appearance that she had JA she expressed her delight, at having met someone with a similar diagnosis: *'There was actually somebody there who was in a wheelchair and I thought oh, I am not the only one! It was so good.'* Also, Amy pointed out how meeting someone with JA was important because they shared the same emotional experiences therefore, *'... someone feeling like you would be better, because somebody knows.'*

The need for peer-based social support appears to become increasingly important as young people approach adolescence. For example, Claire explained how her daughter, *'...when she was younger, she never questioned it, she just got on with it. But, then as she has got a bit older she is saying, "how come I have got it, nobody else has got it at school". So... it could be nice if she could have somebody there who she could just say well, yes I have got it.'*

The importance of peer-based social support was seen to be particularly important when young people with JA faced the transition from paediatric to adult based care. Liam (parent/carer) suggested that contact with others with JA, *'...may be something that could help the whole transitional unit. Because this is something that we have been discussing with other parents, actually and it does seem that the jump to adult is a really big one.'*

## **Theme 2. Understanding**

HCP1 mentioned the need for patients to discuss the depression which is often experienced by those with rheumatic conditions but pointed out how it is, "Quite difficult for even teenagers to do this." However, contact with other young people with JA particularly seems to offer an

opportunity for such disclosure through providing a sense of shared understanding and acceptance. For example, Annie pointed out that, '*...my family can't understand as they have obviously not got it ...people like the doctor [say], "Well it is not going to hurt," but you don't know because you have not got arthritis and you don't understand,*' and Mel explained that, '*... the doctor can tell you about like the bases of the condition and stuff but they can't really tell you how it is different for everyone.*' Peers can understand experiences in clinic which professionals may not always appreciate. For example, Tess described her response to being seen by the multidisciplinary team as, '*...they are all saying that it won't be really that scary but I can hardly talk to the doctors as it is!*' Also, when referring to health professionals, Lily explained that '*...you know that they are really trying to help you but it makes you frustrated especially because they are not going through what you are.*'

Similar peers can appreciate the frustrations for those with JA created by the way others without JA respond to their condition. For example, Mel said, '*Other people, who just have not got the condition and do not know what it is like... question you.*' Others with JA understand better the variable nature of the condition which could mean appearing perfectly able-bodied at certain times yet on other occasions not being able to walk without aid. Mel offered the example of the reaction of peers at school when she had to resume using crutches, '*...because, you haven't been on crutches for ages and then it is, "Oh why were you off?"*' Also, Claire reported that often teachers did not understand her daughter's condition as, '*...when she is at school they will say oh she can play out now because it is warm. They don't seem to be able to understand that even if it is or if it isn't it does not make any difference, her arms and her legs are still hurting aren't they?*' In contrast, a shared understanding by similar peers offered a sense of acceptance into, '*A kind of, community, where, you can kind of help each other and support each other.*' (Mel).

### **Theme 3. Relief and Reassurance**

It became evident that contact with similar peers provided a sense of relief and opportunity to express frustrations. Annie stated that, *'...if I could actually speak to someone that has got the same thing as me, it will be like "Well I know what you are going through," and it would be a relief off my shoulders,'* and Jack pointed out that this would help his daughter as, *'...I guess that a lot of the discourse is around levels of frustration or the treatments or whether they have been met. These are really important things that people need to be able to express.'* Contact between peers also offered young people, *'...some privacy to talk amongst themselves. You know, without your parents looking on.'* (Becky-parent/carer).

Contact with similar peers was also seen to offer reassurance, alleviate concerns and raise spirits. Lily explained how she felt that her condition, *'...is never going to go and, it would be nice to know if other people were experiencing that too.'* Tina thought that such contact for her son would help to, *'...alleviate worries'* and Annie felt that talking to others could help reassure them as, *'...they need to know, like, it is ok, it is not my fault that I have arthritis, other people have it. You know, like I wasn't chose to have it, it just happens.'* Beth thought that contact with similar peers would help her daughter as, *'...you can talk to others and have individual conversations and try and raise each other's spirits sort of thing,'* as, *'they are all going through it, they will understand and be quite supportive.'*

### **Theme 4. Shared learning**

Peer contact was thought to offer the opportunity for new ways of learning together. HCP8 described how working with groups of young people with other conditions offered the opportunity to see, *"...how they deal with it which is really beneficial to them. So, I can see how having some way of being in contact with other people who have the same condition can be really helpful."* Amy suggested that meeting similar others meant that, *'...you could sort of talk about things that you are going through with people like yourself because they have got it as well and how they are dealing with it,'* and Mel pointed out that, *'...you can ask someone who*

*has had something like this before, so that it is like, how should I deal with such and such?’*

Tess explained that the first thing she did when diagnosed with JA was to look up information, *‘...about other people’s coping strategies ... and, then I tried the different strategies myself.’*

Hearing of peers’ experiences was helpful for young people with JA when facing new forms of treatment. For example, Harry reported that talking to a girl who was already receiving the treatment that he was to shortly undergo was helpful and Beth expressed concern that her daughter may need steroids, *‘...so it would be nice to be able to talk to other children and find out if it is ‘Oh, yes you will definitely be pain free at the end of the twelve weeks.’*

The process of such shared learning appeared to help to increase confidence and self-efficacy in young people with juvenile arthritis. For example, Jack (parent/carer) pointed out how dialogue between peers involves *‘...thinking together about things and coming to new conclusions and new ideas,’* and Annie explained how it enables young people to give as well as receive help, *‘...I can tell them, I know, I have been through it and this is what I know.... I would not feel exactly privileged but I would feel quite surprised that people had come to me and said like, Annie I am hurting and scared and obviously I would know what they were going through and they would know what I was going through.’*

### **Theme 5. Ambivalence towards peer contact**

Despite the desire for peer contact expressed by participants a few comments suggested that this may not always be desired by all young people with JA. For example, although interested to see how others may cope, Tom explained emphatically that, *‘...I prefer to do things by myself..... I am more kind of self-contained.’*

It appeared that there may be a risk of inappropriate responses when seeking support from others with JA as Liam (parent/carer) asked, *‘...what if they made you feel uncomfortable?’* Also, Becky (parent/carer) was concerned that, *‘...if you are feeling really down and the other person just says, “Oh it is easy you just....” You know that makes you feel even worse.’* Even though Jack (parent/carer) felt that, *‘...there needs to be the opportunity there for people to be*

*able to say what they want,' he feared 'an awful lot of negativity like of experience.'* However, Mel maintained that, *'... you can say something like, "no that is fine; your experience is as good as their experience." You should all just work through it together sort of thing.'*

It also became clear that associating with similar other peers may mean having to openly acknowledge the condition and risk being labelled. For example, Nettie turned to Tom saying, *'You don't like to be labelled as someone with arthritis, someone with a disability,'* and Tom nodded vigorously in agreement.

### **Theme 6. No one-size fits all – varied access to peer support required**

It became apparent that how peer support was provided influenced the extent to which it was desired and accessed. Clinics are ideal places to facilitate contact between young people with JA and/or offer details of organisations providing such contact but have heavy, competing priorities. For example, Jack (parent/carer) explained, *'...there seems to be a kind of limit to what can be done and time and that sort of thing.'* Nevertheless, some clinics attempt to facilitate such contact, as Gill described how recently the nurse at her daughter's clinic, *'...has been trying to get them so that she could speak to Gemma [a girl of similar age with JA].'*

HCP7 described the different support organisations which they recommended to patients but it appeared that these were not always seen as desirable. For example, Nettie (parent/carer) was concerned that given the variable nature of JA once in contact with others with the same condition, those with well controlled symptoms may fear that they too may become as disabled as others who were not responding well to treatment. She explained that, *'Everybody's slightly different with their symptoms ...It can be in a more active phase and you might think that, "oh, I don't want that".'* Claire also explained *'I have looked at support groups and stuff but I am a bit wary with them really....those who go to those particular groups are the really bad ones [severely affected], ....I did not want to take her and there be loads of really bad kids and her be thinking well is this going to happen to me. And, that is why I have never gone.'* Amy also admitted that even though she would like to meet others with JA this would not be through a

support group as, *'We are a bit antisocial really,'* and Becky (parent/carer) said such groups are, *'...not our cup of tea.'*

However, some participants saw support groups as a good way to access peer support. For example, Tess described positive experiences of attending a 'fun day' and Liam (parent/carer) also described such a day and how, *'...there were certain things that they did not think through but ninety percent of the time it was good.'* However, Beth (parent/carer) pointed out that it was not always easy to travel to the different support group venues, *'I know there are attempts to get kids together across the UK but they are not always from the same area, are they?'*

Nevertheless, Becky (parent/carer) stated that her family used Facebook to make contact with other parents of children with JA and HCP6 explained that young people *'..are used to that kind of forum.'* This suggests that electronic devices could be used to inform about support groups and contact similar others to gain valuable peer-based support.

## **Discussion**

Peer support appears to offer young people with JA a new kind of 'normality' where they experience greater understanding, relief, reassurance and participation in shared learning with increased self-efficacy. However, they may also experience some ambivalence in terms of the potential costs of this shared identity and ways in which it may be accessed.

The findings that contact with peers diagnosed with JA offered a new kind of 'normality' including participation in shared learning and increased self-efficacy, confirms studies cited previously. For example, Hart et al. (2015) found that similar peers help to create a sense of being 'normal', Gartland, Lyndal, Olsson, Buzwell, & Sawyer (2011) suggest that contact with peers offers a sense of connectedness and Tong, Jones, Craig, and Singh-Grewal (2012) report that peer support improved self-image through helping young people to feel 'normal'.

References made by participants in our study to how contact with similar peers offers reassurance and suggest new ways of coping support points made by Lakey & Orehek (2011),

Lakey et al. (2015) and Cutrona and Russell (1990). Also, their suggestions that sharing experiences helps in building reciprocal relationships with similar others was also reported by Hart et al. (2015). Providing as well as accessing help also offers young people with JA the opportunity to become the 'role models' advocated by Thomas, McLeod, Jones, and Abbott, (2015) and can promote self-efficacy in ways suggested by Bandura (1977). Improved self-efficacy is essential to the ability to be able to self-manage a chronic condition such as JA. Shared learning through reciprocal role-models can help young people with JA to make more informed decisions and promote the successful self-management seen by Foster et al (2016) as necessary for them to become ultimately responsible for their own health and well-being as adults.

#### **Ambivalence to peer-based contact.**

The ambivalence towards peer contact expressed by some participants due to potential negative responses from others diagnosed with JA was also reported by Hart et al. (2015). Also, the risk of being 'labelled' through belonging to a group at risk of restricted lifestyle and visible disability expressed by one young person and parent/carer mirrors concerns reported by Masten (2001), Békési et al. (2011) and Tong et al. (2012). Sallfors and Hallberg (2009) suggest that a diagnosis of chronic arthritis may expose young people to stigma, stereotyping and negative social attitudes and Thomas et al. (2015) suggest that attempts to hide the effects of a chronic condition can increase feelings of isolation with the constant fear of 'being found out.'

Interestingly, it is possible that comments offered from participants within our study regarding positive and negative aspects of peer-based support can be interpreted in terms of the paradox identified by Thomas et al. (2015). They suggest that whilst some of those diagnosed with a chronic condition may suffer through having internalised negative stereotyping, others who do not identify with similar others ignore negative reactions, while a third group have the confidence to reject being stigmatised through identifying strongly with

similar others. It is possible that in our study, Tom had internalised social stereotypes of disability as, although insisting that he was 'self-contained,' his concern that identifying with others with JA risked being 'labelled' suggests he feared the opinion of others. Other participants appear to reflect Thomas et al's. (2015) third group as they were keen to identify with others diagnosed with JA. For example, Mel anticipated some potential negative responses but, insisted that identification with similar others would enable overall positive support. This could offer the opportunity to engage in a common cause and provide reciprocity which helps in resisting stigma and increases self-esteem and self-efficacy (Thomas, et al., 2015).

### **Use of organisations providing group peer based support.**

A novel finding within our study was that the way support was offered could influence the motivation to contact others with JA. Sallfors and Hallberg (2009) suggest that joining a support group can not only help empower young people but also provides the opportunity to work towards changing negative social attitudes towards chronic illness as advocated by Scambler (2009).

Examples were given by healthcare professionals in our study of attempts within paediatric rheumatology clinics to facilitate contact between peers with juvenile arthritis. Despite this being difficult, given the variable nature of the different conditions and developmental milestones of young patients, information including 'useful websites' is offered. Staff increasingly utilise social media and are developing initiatives for young people with JA to meet up, particularly as part of preparing for transition to adult-based care. Nevertheless, as Nick (parent/carer) pointed out, the time available to provide social support in clinics is limited.

Some participants in our study valued the opportunity to be made aware of relevant voluntary support groups; however, others were reticent to access such support due to negative perceptions of voluntary organisations and, given the variable nature of JA, their potential to include young people who were not responding well to treatment.

**No 'one size fits all' - increased use, and value of, electronic devices to facilitate peer based support**

Given the different perceptions of participants in our study it appears that although peer support is desired, the extent to which it is accessed will be determined by how it is provided and this needs to be in a variety of ways. Electronic media could offer a useful medium. For example in the UK, Stones (2017) recommends new online initiatives from closed Facebook groups such as, 'Arthur's Place,' (<http://arthursplace.co.uk/>) for young adults with arthritis, and Your Rheum (<http://yourrheum.org>), for young adolescents with juvenile arthritis.

Participants within our study suggested a chat room as a means of contacting others with JA, however, Eysenbach et.al. (2004) cautioned that whilst such chat rooms can create virtual communities they may not be as supportive as face to face support groups. Nevertheless, Funnell (2009) states that chat rooms provide the opportunity for peers to express their feelings and improve health behaviour and Ammerlaan et al. (2014) found face to face and online support to be equally effective. Thomas et al. (2015) and Taft et al. (2016) point out how the internet can offer individual and group contact with similar others and reduce feelings of stigma created by having a chronic condition. Stinson et al. (2016) demonstrated the successful use of the internet in supporting young people with JA particularly at stages of transition from paediatric to adult based care and into post-secondary education.

Nevertheless, it is important to note the point made by Hamine, Gerth-Guyette, Faulx, Green, & Ginsburg, (2015) that reliance on using electronic devices also has the potential to exclude those who do not have access to technology and often are those most in need of support. Moreover, participants within our study recognized the potential safeguarding issues including difficulties in monitoring chat rooms reported by Eysenbach et.al. (2004). Further studies are needed to investigate ways of safeguarding access to chat rooms as well as evaluating the value of peer group contact through electronic media.

**Unexpected findings**

An intriguing issue emerging from the re-analysis of the transcripts within our study relates to Tess who displayed no visible signs of JA yet was delighted to recognise a fellow peer with this condition despite this young person's need to use a wheelchair. Such a reaction seems to run counter to current understanding of the wheelchair as symbolising the least desired and most disabling nature of chronic conditions and, thus, poses most risk of stigma and labelling. Tess's reaction may be interpreted as rejecting common assumptions of stereotyping and representing the third type of young people's reaction to stigma found by Thomas et al.(2015) mentioned above. It suggests a need for future investigation into the views of young people towards visible signs of disability.

The negativity expressed towards support groups by some participants in our study suggests a need for future work on how such perceptions arise and ways in which they can be reduced. Interestingly, the fear expressed by some participants that peer contact through support groups may risk exposure to others more adversely affected by the condition contrasts with what the first author experienced when running a support group for young people with JA. A father of a son with significant involvement (needing to use a wheelchair) requested that his son was not introduced to other young people who looked 'less disabled' as, his son found it depressing and could not understand why they shared the same condition yet were not as disabled. Such issues demonstrate the complexity support groups face when using peers as role models due to the variability of JA.

**Strengths and shortcomings**

It must be acknowledged that findings within this study relate to a UK based population. Further studies including participants from other countries could help assess the extent to which the need for such peer-based social support transcends cultural influence. Also, there are other obvious limitations to the findings reported here given that they are based on reanalysis of the

issue of peer-based support which emerged when seeking views about the content of a self-management mobile-app for JA. Nevertheless, Hinds et al. (1997) stress how tentative conceptualisations can be formed from reanalysis of findings which had not been possible to explore explicitly when reporting the primary study. It was felt that the process adopted here followed their requirements that objectives and area of investigation were integral to the primary study, the original methods used to generate data were amenable to a secondary analysis and results complemented the original findings.

Using IPA to re-analyse participants' references to peer-based support offered a rigorous method of analysis which produced some enlightening information. However, we are aware of the tentative nature of any findings from such a small sample from a single site despite it being in line with the aims within IPA to gather depth, rather than breadth of detail. Also, given that existing transcripts were reanalysed meant that other requirements of IPA such as bracketing preconceptions could not be followed as carefully as required. Future studies into this area could consider member checking through contacting participants and ways of triangulating data.

Nevertheless, using IPA to reanalyse the transcripts meant that the researcher's perspective also is acknowledged. An attempt was made to sensitively acknowledge the first researcher's past experiences of having JA, involvement in supporting young people with JA and their families and working with healthcare professionals, which allowed meaningful insight into participants' comments about peer-based social support.

These findings may offer an example of how adopting a qualitative approach can reap far more benefits (depths) than originally intended. The use of interviews and focus groups gave participants an opportunity to express frustrations and concerns. The outcome indicated that it was important that once the original task was completed, some further work must be done to explore the detailed, rich, data that could not be included in the primary study report and

address the concerns about the need for young people with JA to talk to similar others expressed by participants.

### **Recommendations and conclusions**

#### Implications for Practice and Recommendations for Further Research

With a growing recognition in society of the importance of peer-based social support for young people in their daily life, both pediatric nurses and other healthcare professionals can be guided by this new evidence as they support those living with juvenile arthritis. As this study demonstrates, peer-based, social support becomes particularly important for young people with juvenile arthritis as it can offer a new kind of normality, understanding, relief and reassurance, and shared learning. However, when promoting and supporting peer-based social support, as far as possible, professionals need to individualise the approaches suggested because there is no 'one size fits all' approach.

Shortcomings within this reanalysis means that findings may at best only sensitise us to the need for peer support, its potential benefits and how it can best be provided. However, the information offered can provide a useful basis from which to conduct future investigations.

#### Conclusions

Reanalysis of interviews with young people with JA and their parents/carers suggests that contact with peers with a similar diagnosis offers young people with JA a new kind of 'normality' where they experience greater understanding, relief, reassurance and participation in shared learning with increased self-efficacy. However, whilst confirming such findings reported in previous studies, this secondary analysis also offers novel insight into how, although desired, the potential social cost of identifying with peers diagnosed with juvenile arthritis is influenced by the way such support is provided, and impacts on how readily it will be accessed. This suggests the need to provide various means of contacting peers, including electronic media, to ensure that young people with JA can fully reap the benefits of peer-based social support.

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