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The impact of arthritis on the educational and early work experiences of young people: a qualitative secondary analysis

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Abstract:

Introduction: Young people's transition into adulthood is intertwined with the worlds of education and work. Poor health in adolescence has been associated with poorer education and employment outcomes in adulthood. This paper explores the impact of arthritis on the educational and early work experiences of young people with arthritis.

Methods: We undertook a supplementary secondary analysis of a qualitative dataset comprising narrative and semi-structured interviews of 39 young people who had been diagnosed with arthritis in childhood, adolescence or young adulthood.

Results: Our findings illustrate how young people living with arthritis are faced with a range of added disruptions and challenges in their educational/vocational lives. There is an important element of resilience associated with the process of making a career choice and acting upon personal aspirations. Appropriate support and flexibility in the workplace/educational setting can enable successful outcomes, but disclosure is not a straightforward process for young people living with arthritis.

Conclusions: It is paramount that health providers consistently and effectively address self-advocacy skills with the young person, particularly during educational and vocational transitions. Alongside this, there is the need to further strengthen the health-school/work interface to ensure that young people living with chronic illness can meet their full potential in adulthood.

Keywords: adolescents, arthritis, education and employment, qualitative research, young adults

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Introduction

Young people's transition into adulthood is usually intertwined with the worlds of education and work. Vocational development is an integral component of adolescence, with several key educational transitions occurring during this stage of life [1], [2], [3]. In mid-adolescence, young people are expected to have early notions of a vocational future and will start to develop an educational trajectory. In late adolescence, the formation of interests will continue to evolve, and young people will continue to develop vocational capability and make further educational/vocational choices as they prepare to take on adult roles and responsibilities.

Education and employment are important social determinants of health for all young people [4]. Likewise, poor health in adolescence has been reported to be associated with poorer education and employment outcomes in adulthood [5], [6]. In the context of young people with long-term health conditions and/or disability, lower rates of mastering key vocational developmental milestones have been reported [7]. Furthermore, lower levels of vocational success are still being reported in spite of similar levels of social success in age-matched controls [8].

A review of the rheumatology literature reported that young adults with arthritis were less likely to be employed when compared to their healthy peers [9]. The different perspectives between young people and

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older adults with respect to vocational issues have also been highlighted [10]. The experience of developing chronic arthritis once one has established a career and/or found a vocation is very different to that of a young person prior to entry into the workforce for the first time. Only a few studies to date have used qualitative methods to report on the perspective of young people with arthritis: with some focussing on the young adult age range, between 16 and 31 years [11] and others focussing on younger adolescents, between 14 and 16 years [12]. This work has highlighted the importance of key areas of vocational readiness during adolescent and young adult development, including communication skills around disclosure [11], [12] and the potential of health professionals to equip young people with knowledge and skills to negotiate appropriate support in addition to providing opportunities within health care settings to practice related transferable skills [11]. In so doing, health professionals can potentially enhance young people's resilience, understood as a capacity for constructive adaptation to adversity which can be defined as both an outcome and a dynamic process [13] thereby potentially improving their health outcomes [14].

The aim of this study was to further explore the education and employment related aspects of the overall experiences of young people living with arthritis during early adolescence through to young adulthood, who had been sampled and recruited using different methods from those of previous qualitative studies specifically addressing education and employment issues in young people with arthritis [11], [12].

Methods

We employed qualitative secondary analysis methods [15] drawing on a dataset from a primary qualitative study carried out in 2011, which explored the experiences and information and support needs of young people living with arthritis, using narrative and semi-structured interviews. The primary study had an advisory panel consisting of academics, clinicians, nurse specialists, a representative from a national arthritis charity and four young people (two females and two males) with arthritis. This group met at the beginning of the project and were actively involved in discussions about the topic guide, sample size and constitution and also fed into the process of analysis by reading lay summaries of the data. Summarised findings of the full primary study are openly available online [16].

The study sample included 39 young people who had been diagnosed with arthritis in childhood, adolescence or young adulthood (Table 1). A purposive, maximum variation sampling strategy was employed [17]. Variation was sought across gender, age (both at time of interview and at time of diagnosis, thus including variation in terms of length of time living with the condition), geography and ethnicity of young people living with arthritis, including those with inflammatory arthritis and disability. Participants were recruited through GPs, rheumatology clinics, local and national support groups (including social media platforms), and through an advert in a UK-based arthritis magazine. Data analysis and data collection proceeded simultaneously and continued until 'data saturation' was reached to ensure that the widest practical range of experiences had been included. Ethical approval was obtained from a UK National Research Ethics Service Committee. Interviews were conducted throughout the UK in the participants' own home or elsewhere if they preferred, were video or audio recorded and typically lasted 1–2 h. Written consent was sought on the day of the interview. Participants were later sent a verbatim transcript of their interview to review. All participant names in the paper are pseudonyms.

Table 1: Characteristics of the study sample.

	n	%
Total study participants	39	100.0
Gender		
Female	29	74.4
Male	10	25.6
Employment/education situation		
In education	29	74.4
In employment	8	20.5
Not in education or employment	2	5.1
Age at interview		
10–14 years	8	20.5
15–19 years	11	28.2
20–24 years	12	30.8
25–29 years	8	20.5
Age at diagnosis		
<5 years	9	23.1

5–9 years	6	15.4
10–14 years	17	43.6
15–19 years	4	10.3
20–24 years	3	7.7
Time living with the condition		
<1 year	3	7.7
1–5 years	14	35.9
5–10 years	8	20.5
10–15 years	5	12.8
15–20 years	5	12.8
20–25 years	2	5.1
25–30 years	2	5.1

The secondary analysis reported in this paper aligned with Heaton's definition of supplementary analysis – that is, “a more in-depth investigation of an emergent issue or aspect of the data which was not considered or fully addressed in the primary study” [15]. In particular, we employed a thematic approach [18] to examine the impact of rheumatic disease on the educational and vocational domains of the lives of young people. NVivo 10 software (QSR International, Australia) was used to assist data management and coding. The secondary analysis was led by AF. JMCD, who was also involved in the primary study, provided an additional critical perspective and layer of rigour by independently analysing coding reports and comparing and discussing their interpretation of the data. The findings were then discussed and reviewed jointly by the authorship group to add a further layer of scrutiny, and debate and refine the emerging findings. Given that two of the authors were also involved in the primary study, we were confident that interpretations were consistent with the original findings.

Results

The impact of the unpredictability of arthritis symptoms and therapy on education and early work experiences

As with other chronic relapsing conditions, young people living with inflammatory arthritis are faced with the challenge of adjusting their lives to irregular periods when their condition becomes ‘active’, often described as ‘flares’, involving symptoms such as painful, swollen or stiff joints, increased tiredness and/or fever during the active phases of the condition. These will therefore involve a range of disruptions in young people's everyday life, which can often coexist with disruptions associated with medication side-effects as well as other difficulties such as regular hospital attendance for blood tests and treatment monitoring.

For young people, this also means that such disruptions will take place at a time where key developmental tasks and stages occur, including the educational and vocational aspects of their development. For example, experiencing extreme tiredness can add to the existing challenges for those in higher education, the impact of which can be further accentuated when young people with arthritis compare themselves with their peers without chronic conditions (Table 2, Quote 1).

Table 2: Illustrative quotations for Theme 1 – The impact of the unpredictability of arthritis symptoms and therapy on education and early work experiences.

Quote 1	<i>“comparing with friends, but also comparing with myself to when I was slightly younger a few years ago, I can quite often wake up maybe 8 or 9 o'clock for university and be really, really tired, during high activity periods, maybe at 3 or 4 o'clock. And I don't mean tired as in 'oh, you know, I need a break' [but] seriously tired, I need to go to sleep and, you know, if there was no kind of stimulus outside, so if someone talking to me, I would fall asleep. So it is a huge factor, I have to say, yeah”.</i> (Matt – Male, 21 years old, student, diagnosed at 21 years)
Quote 2	<i>“[this situation] is really complicated, but because of [my arthritis] and because of the medication, I get ill. And if I do get ill, it's really badly ill. And I possibly get ill more than somebody else normally would. It does have quite an effect on [my work]”.</i> (Holly – Female, 20-years-old, customer services, diagnosed at 18 years)
Quote 3	<i>“The more pressure I'm under ... especially at uni, the stress of essays or deadlines, [or] even at work now when I'm having a stressful day, yeah I definitely get a flare-up”.</i> (Amy – Female, 26 years old, recruitment consultant, diagnosed at 13 years)
Quote 4	<i>“because my knee hurts, I won't get to sleep as easy because it'll be too painful to get to sleep. Then when I start to go to sleep it'll start hurting because I'm lying there, and then once we tried putting a pillow underneath it and it got locked up over the pillow and I couldn't move. When I first had [this], like when I was 9 my Mum had to pick me out of bed”.</i> (Dave – Male, 12 years old, student, diagnosed at 8 years)

Quote 5 *"[when] they found out what I had, and then about a few months later I got onto my treatment, which I'm still on now, and that's helped massively. I've gone from just having, not even being able to tie up my tie in the mornings to being able to run about again. And I don't have to limp about anymore; I can walk about freely and just be normal like everyone else. So I think that, even though I have arthritis, I'm still a normal person and I can still participate in everything that people that don't have arthritis can". (Paul – Male, 14-years-old, student, diagnosed at 12 years)*

Likewise, side-effects and other complications associated with the medication can translate into spells of recurrent time off work, which can add to such disruptions for those in education and employment (Table 2, Quote 2).

And vice versa, the challenges and pressures associated with academic performance or work-related activities, can also translate in the worsening of some symptoms (Table 2, Quote 3).

Some commonly cited disruptions were less directly related to the participants' experiences of education and work but suggested an indirect impact on one's academic and/or professional performance. Participation in education and work are demanding on physical activity and energy levels, both of which are impacted by the presence of arthritis. Examples included the negative impact of pain on appropriate sleep (Table 2, Quote 4) as well as the positive impact of periods of disease remission (Table 2, Quote 5).

Despite such various disruptions, the participants' accounts also illustrate that experiencing recurrent pain can become an integral part of one's normal experience of, and relationship with, formal education and work. In addition, the cyclic nature of arthritis means that young people with inflammatory arthritis can engage in periods of 'normal' work and/or academic activities, particularly when the condition can be controlled with effective treatment and there is sustained adherence to medication.

Thus, with appropriate treatment and appropriate support and flexibility in the workplace or educational setting, there is room for successful educational and vocational outcomes. Crucially, however, the provision of appropriate support and flexibility requires acknowledgment by and understanding from educators, trainers and/or employers, as well as by colleagues and peers.

Negotiating disclosure, understanding, support and flexibility in school and the workplace

A necessary step towards accessing the aforementioned support is being able to disclose one's condition to supervisors and colleagues in the workplace or educational setting. However, negotiating disclosure was not a straightforward process.

Participants noted how difficult it was or had been for them to deal with their initial experiences of disclosure after being diagnosed, particularly when they were younger. Participants seemed to manage their disclosure based on how others may react to the communication of their illness (Table 3, Quote 6). Navigating the reactions of others to disease disclosure could impact the decision to disclose at various phases of career development. In early phases (e.g. in school settings) letting people around them know their diagnosis was experienced as 'a real big thing' by participants, who tended to try to keep it a secret and selectively tell the few key people that 'needed' to know. This initial reluctance to disclose was underpinned by a number of concerns, including fear of being judged or treated differently or that existing relationships with peers or partners might change as a result of letting them know they have arthritis.

Table 3: Illustrative quotations for Theme 2 – Negotiating disclosure, understanding, support and flexibility in school and the workplace.

Quote 6	<i>"In terms of friends and people on my course, I choose not to tell them because I, the fear of them treating me any differently because particularly, in like the, well, the academic arena with my degree. I don't want anybody to think that I've had any kind of special treatment or anything or I've got my degree by other means than the traditional methods [...] I don't really want people to talk to me in a way, whether it be in the seminars or about work generally, any differently. I want them to talk to me as if I was normal because I have, you know, mentally I am the same as anyone else. I just have a problem, you know, physically and that that doesn't impede my ability anyway". (Matt – Male, 21 years old, student, diagnosed at 21 years)</i>
Quote 7	<i>"I think [my concerns about telling others that I had arthritis] just gradually went away. Like, probably after college, like when I got to about 18 I think. By then, I just got used to telling people and no-one, no-one was bothered by it, so I think you just get used to telling people about it". (Sarah – Female, 24 years old, healthcare assistant, diagnosed at 4 years)</i>
Quote 8	<i>"Haven't been allowed to work since the start of December, they won't let me in with [a flared arthritis] at the moment. Because I had an appointment with a neurology consultant on Monday, he said there's no reason I shouldn't be allowed to work so I am going back to work on Monday on reduced hours but up until now, I haven't been able to work and it's been horrible". (Juliet – Female, 25 years old, quality team manager, diagnosed at 17 years)</i>

- Quote 9 *"If I had a sore joint, I'd mention it to a teacher and she'd send me to the reception area, which was where the medical bay was. And they'd say: [...] "We have to ring your mum because you can't obviously stay in school like that". They used to send me home all the time for the silliest reasons because they just didn't know what to do, or they didn't want to know what to do. [...] [The consultant] actually sent everything you could possibly send information-wise. And I just don't think they ... just probably put it away and weren't interested to be honest. I had so many problems with the school". (Kate – Female, 22 years old, not in education or employment, diagnosed at 5 years)*
- Quote 10 *"I've only been in the role for the last 10 months or so. So it's trying to explain, especially to like a manager, exactly why this [recurrent periods of illness] is happening and then of course they're sort of like, "Right so it's because of your knee?" It's like... "Yes it's the knee but it's the medication for the knee that means I'm getting ill a lot." [...] So it's hard, especially because people don't know about this, so it's hard to explain that your knee has led to this, which is quite difficult. [...] So it's then trying to explain it to your manager, who's obviously thinking from a work point of view, and because they've never heard of anything like this before, it's hard to get it across right without it making it sound ridiculous". (Holly – Female, 20 years old, customer services, diagnosed at 18 years)*

Such feelings and concerns were equally present when it came to the participants' experiences of education and work. However, young people's ability to manage disclosure seemed to improve with experience. Participants described becoming increasingly comfortable with disclosing their condition, particularly after some concerns and fears were not realised (Table 3, Quote 7).

Thus, however difficult, in retrospect participants tended to feel relieved to have been able to disclose their condition to others, particularly to their peers, and felt that the implications of this had been beneficial.

Whilst inconsistent disclosure can translate into lack of understanding and support from those around the young person – including peers as well as employers, supervisors and/or those in charge of management in the workplace or the educational setting – the reverse is not necessarily true. That is, disclosure does not automatically translate into better understanding and support from those around the young person, and there is still the need to increase understanding and awareness beyond the clinical domain (Table 3, Quote 8).

Even where there was an active effort from a senior health professional (e.g. a rheumatology consultant) to reach out, this did not necessarily translate into increased support and flexibility in the workplace or the educational setting (Table 3, Quote 9).

Similarly, getting managers to understand the variability of flare ups and periods of sick leave for different reasons was challenging. This could cause disruptions in one's work but also involve difficulties around handling and explaining the situation to colleagues and managers (Table 3, Quote 10).

Projecting the future: (re)appraising life's goals in the context of an uncertain prognosis

A key characteristic of arthritis diagnosed early in life is that it has an uncertain prognosis and thus the evolution of one's health status is uncertain going forward. Having to accommodate a condition with uncertain prognosis into the process of making sense of one's hopes and aspirations for adult life can become a major challenge. For example, the participants' experiences illustrate how young people may have to consider their aspirations in relation to 'what might be possible' given their condition. Or, depending on their age at onset and diagnosis, they may even have to reconsider whether they still can do what they already decided to do and perhaps even started to work towards.

Thus, it was not uncommon to find that some young people were particularly reluctant to consider their hopes and aspirations. Some participants explained how they had made or were making a deliberate and explicit effort to not think about their arthritis when it came to projecting their future, while others felt that the uncertain prognosis of their condition forced them to cling to a 'here and now' rationale (Table 4, Quote 11).

Table 4: Illustrative quotations for Theme 3 – Projecting the future: (re)appraising life's goals in the context of an uncertain prognosis.

- Quote 11 *"I tend not to think about the future because I don't know what I'm going to be like tomorrow, next week, in a year, in five years, etc. and I think if I think about the future and knowing that I'm going to have to deal with this for the rest of my life, I would get down so I live for now and I, and if there's something I want to do I do it now because I don't know whether I'm going to be capable of doing it in a year. And I just take each day as it comes". (Natalie – Female, 24 years old, student, diagnosed at 14 years)*

- Quote 12 *“I always think what am I going to be like in another 20 years. Am I going to be like round on a walking stick or needing a hip replacement or something? So there’s always like panics about the future I think, and when I was younger I never really worried about the future at all – and I think there was always the option as well that I’d grow out of arthritis, which obviously didn’t happen. So I think there’s definitely the stress as well of thinking, “Oh god if this is going to get any worse, am I going to have to take time off work?” and “What’s going to happen like say when I’m older?” so there’s always those worries. [...] When I was a teenager it was different, it was more you’re concerned about what other people thought. Whereas now I’ve started to think more about the future and sort of what’s going to happen if I don’t control this arthritis”.* (Sarah – Female, 24 years old, healthcare assistant, diagnosed at 4 years)
- Quote 13 *“Until I added arthritis into what I want to do as a career nothing seemed to be going right and now that I’ve added the two together and kind of starting accepting my arthritis, everything now seems to be just falling into place a little bit better. So now my focus is I’ve kind of got a good direction on where to go and it’s, yeah, I’m quite, I’m happy with that”.* (Jane – Female, 26 years old, student, diagnosed at 2 years)
- Quote 14 *“I would like to have a successful photography studio, you know as I think being the boss would help, because then I could pick when I work, I could employ others, but I’d still have a job that I could go to because I wouldn’t like to be at home, I’d just go crazy”.* (Emily – Female, 18 years old, student, diagnosed at 18 months)
- Quote 15 *“I was constantly told in school, you know, “You can’t do this, you’ve arthritis”.* You know I don’t think this subject is suited to you, you know, you’ve arthritis, but I’ve parred through that. I mean I passed my A-Levels and people got up to me going, “Oh I never thought you’d make it this far”. I’ve always been quite an academic person so to hear that was quite a shock. [...] I have arthritis, but it’s not the end of me [...] it’s not a nice thing to have, but it’s not the end of your life as it is”. (Olivia – Female, 19 years old, student, diagnosed at 13 years)
- Quote 16 *“I never really thought I could be still stuck to at home when I was 25, 26, 27, 29. And I think, because it took so long relatively for it to hit in its worse stage, it wasn’t really until it got to its worse that I really started to come to terms with what it was doing to me, and how it would affect the rest of my life. What I may or may not be able to do, because obviously you don’t know how far it is going to progress, how much worse it’s gonna get. You know, when I was 15 or 18, it was pretty bad but I didn’t know that in 10 years’ time it would be worse. [...] with every new treatment, with every, with this, with the joint replacements, thinking this time next year things will be better. And more often than not, this time next year they’ve been worse. Things are starting to improve with the joint replacements but they’ve almost had to get a little bit worse before they get better. And I don’t know, I mean when I was 18, 19, 16, if you’d said, “What do you want for the rest of your life?” Then I would have wanted it all, you know, travel, career, then you know in my thirties marriage, kids and whatever. And I think now, you know, you, I’d settle for just, just the marriage and the kids, you know, just somewhere nice to live, someone to love, someone who loves me and you know, a child hopefully”.* (Ruth – Female, 28 years old, not in education or employment, diagnosed at 5 years)

The ability to project one’s future in terms of hopes and aspirations is typically a major developmental task of young people as they prepare for and cope with transition into adulthood and, despite the additional uncertainty and challenges, the participants also explained how they gradually began to deal with it (Table 4, Quote 12).

At the point of considering their future, young people’s experiences reflected a range of reactions and approaches to dealing with this developmental task in the context of a diagnosis of arthritis.

For many, this meant that at some point they began to openly and explicitly engage in projecting their future as part of their normal development and transition into adulthood. Some participants also highlighted how being able to take their arthritis into consideration when planning for their future gave them a sense of balance in their lives (Table 4, Quote 13).

Others however described feelings of pressure and anxiety associated with the realisation that they had to choose a career based not just on preference but also on meeting their physical needs.

Similarly, other participants expressed their hope to be able achieve a professional status that ensured enough autonomy to provide the flexibility they require without having to depend on other people’s understanding and decisions (Table 4, Quote 14).

Another important aspect of trying to make sense of one’s hopes and aspirations for adult life in the context of living with a condition with an uncertain prognosis, involves dealing with the expectations of others. Resilience as conveyed by self-esteem and self-belief is associated with the process of making a career choice and pursuing a career pathway based on both suitability and personal aspirations, even in the context of inappropriately low expectations of others (Table 4, Quote 15). For others, the unpredictable course of arthritis led to the re-appraisal of their original goals and aspirations whilst never losing hope for the realisation of the re-appraised dreams of the future (Table 4, Quote 16).

Discussion

Our findings illustrate how young people living with arthritis are faced with a range of additional challenges and disruptions in their everyday life at a time when key developmental tasks and stages occur, including the educational and vocational aspects of their development.

Whilst some disruptions, such as lack of appropriate sleep, can have an indirect but important impact on young people's academic and/or professional performance [19], many aspects of the disease (such as pain, swollen/stiff joints or increased tiredness) will impact more directly on these areas of young people's lives. This is consistent with existing evidence associating different aspects of rheumatic disease in young people with future unemployment [20], [21], and arthritis-related symptoms such as fatigue with productivity loss and reduced job control [22]. Likewise, existing evidence in the area of young people with chronic pain also suggests an association between adolescents' pain experience and school impairment [23] which was found to be mediated by social functioning [24].

Our findings also show that the challenges and pressures associated with education or work-related activities can translate in the worsening of some symptoms. Thus, not only illustrating that a long-term relapsing condition (and treatments) can impact on young people's academic/professional lives [6], but also that such an impact is perceived to function in the opposite direction too, with education/work related pressures adding to those arising from life with arthritis per se.

Although young people with arthritis have to adjust their everyday lives to irregular periods of disease activity, our findings suggest that this becomes normalised and seen as an integral part of one's normal experience of, and relationship to, education and work. Furthermore, the unpredictable nature of arthritis also means that young people with arthritis can engage in periods of 'normal' work and/or academic activities, particularly when the condition can be controlled with effective treatment and there is sustained adherence to medication. Thus, with appropriate treatment as well as appropriate support and flexibility in the workplace or educational setting, there is room for successful educational and vocational outcomes.

As in previous work, disclosure was a key issue faced by young people in both the education and work settings [11], [12], [25]. However, as our findings illustrate, negotiating disclosure is not a straightforward process for young people living with chronic illness [25] with a range of concerns and expectations (such as anticipating that others might think that one is enjoying 'privileges' or 'special treatment' because of their condition) acting as barriers to disclosure. These findings are consistent with existing evidence from young people with a range of chronic illnesses, where non-disclosure has been found for reasons such as perceived fear of rejection, pity, and perceptions of being seen as vulnerable or different [26]. In addition, our findings suggest that such barriers to disclosure are more pronounced for younger adolescents, a difference that has also emerged in previous research [22] and which could be of particular relevance in light of recent evidence suggesting that young people with arthritis may be transitioning into employment at an earlier age than their peers without arthritis [10].

The data presented suggests that comfort with disclosure increases with regards to life and career phase. Young peoples' abilities to manage disclosure seem to improve with experience, particularly when initial concerns and fears are not realised, and they had developed the appropriate skills. Other factors not observed in this study such as having more seniority/job tenure could also provide the individual with a greater level of credibility, which in turn would make disclosure easier. However, disclosure is also an issue reported by adults who develop arthritis whilst employed [27], [28], [29], [30]. Prospective studies to further understand career trajectories of young people with arthritis will be of interest.

These findings however, suggest a number of potential avenues to improve existing interventions in this area [25]. Particularly in light of the finding that, in retrospect, participants tended to feel relieved to have been able to disclose their condition to others, particularly to their peers, and felt this had been beneficial. This is consistent with previous findings from adult focussed research on disability disclosure which was found to have the potential to enable an atmosphere of acceptance through employer's understanding of their need for accommodations and enhanced social integration [28], [29], [30]. Of note, in the UK, the rights under equality legislation [31] depend on the original disclosure of the health condition to the employer. For some young people, choosing not to disclose could be perceived as protective, enabling them to receive job offers and opportunities for career advancement and hence a coping strategy against perceived discrimination. It remains important however for the young person to be aware of the pros and cons of disclosure in the light of the equality legislation in the country they live in, as well as any positive discrimination initiatives such as the Disability Confident Employer scheme in the UK [32], as by choosing to not disclose they may also be missing out on opportunities.

Our findings also highlight one further nuance: disclosure is a necessary but not always sufficient step towards achieving an understanding and supportive environment in school or the workplace. Even where there was an active effort from the rheumatology health professionals to reach out, this did not necessarily translate

into increased support, flexibility or accommodations in the workplace or educational setting (e.g. Table 3, Quote 9).

A key characteristic of arthritis diagnosed early in life is that it has an uncertain prognosis. In this context, the process of making sense of one's hopes and aspirations for adult life can become a major challenge. Our findings suggest that young people with arthritis can become particularly reluctant to, or deliberately delay, consideration of their hopes and aspirations for adult life. Such a situation might not be too dissimilar from the experiences of young people in the general population who experience persistent career indecision, or difficulties in their vocational decision-making process, due to issues such as negative appraisal of individual worthiness, perceived career barriers or high levels of anxiety [33], [34].

However, unlike others, young people with arthritis will be faced with some additional challenges, such as: having to consider their aspirations in relation to 'what might be possible' and the need for re-appraisal of their aspirations given the evolution and unpredictability of their condition; depending on the onset age, perhaps having to consider a career change; and coping with feelings of pressure and anxiety associated with having to choose a career based not just on preference, but also on meeting their physical needs as their condition evolves. For some, this included the pressure of being able to achieve a professional status that ensured enough autonomy so as to secure any required accommodations without having to depend on other people's understanding and decisions. Alongside these issues, that young people felt that being able to take their arthritis into consideration when planning for their future gave them a sense of balance in their lives, suggest that there is an important impact on identity formation – an implication raised by previous research on young people with chronic illness [35], [36]. Sociological concepts of 'biographical disruption' in adults [37] describe how chronic conditions can force individuals to reappraise the meaning of their lives as highlighted in this study with reference to career aspirations. The potential for biographical disruption has been proposed to be exacerbated in adolescents [38] given that their identity is still developing. Thus, compared to adults, whose arthritis requires them to re-construct an already established vocational identity, the young people have the challenge of creating and consolidating a vocational identity in the context of a condition that may fluctuate, have uncertain outcomes and is typically represented as a disease of older adulthood [39].

Our findings support the idea that an important aspect of growing up with a chronic illness involves dealing with pre-conceived ideas and expectations about achievement from those around the young person. This is consistent with previous research on young people with rheumatic disease where low expectations of teachers, careers advisors and potential employers were reported to be perceived by young people [12], and an increased likelihood of employment was reported to be associated with increased independence and decreased perceived overprotection from parents/siblings/partners [40].

Implications for clinical practice

These findings suggest there is still the need to improve interagency working between health, education and workplaces and devise effective interventions to improve communication, understanding and awareness beyond the clinical domain (Table 5). In a study addressing current transitional care planning practice in European paediatric rheumatology centres, only two thirds specifically addressed education and a half addressed vocational readiness in adolescents and young adults with rheumatic disease [41]. Our findings will help to underpin the improvement and broadening of existing interventions and approaches used in the healthcare setting such as those rooted in the concepts of 'transferable skills' [42], [43] or 'vocational readiness' [44] which already address core skills and knowledge domains involved in disclosure, communication, and problem-solving among other key education and employment related aspects of adolescent and young adult development.

Table 5: Suggested strategies to strengthen the health-education/work interface.

Health care professionals	<ul style="list-style-type: none"> – Developmentally appropriate disease education including prognosis – Disclosure of condition – knowledge and skills – Knowledge of rights (e.g. equality legislation) and resources – informational resources and signposting for young people – Address expectations of others – Availability of clinic appointments out of school/work hours – Promotion of transferable skills (e.g. communication with professionals, negotiation, problem solving, information seeking, self-care)
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- Inclusion of educational/vocational issues in transition planning
- Professionals in education and workplace settings
- Enable inclusion in curricular and extracurricular activities at school/college/university [49]
 - Specific support at times of exams, assessment, transition
 - Strength-based careers counselling
 - Meaningful work experience
 - Knowledge of rights (e.g. equality legislation) and resources – informational resources and signposting for young people
 - Access to reliable disease information for education providers and employers
-

Strengths and limitations

The primary study was conducted in 2011 at a time of economic recession and significant youth unemployment [45]. However, recently published research continued to report the significant impact of rheumatic disease on education and vocation related decision-making from the perspective of the young person [46]. The results presented here are resonant with qualitative studies [44] and the subject/area continues to be highlighted by young people as in need of further research [47]. Some of the most disadvantaged young people with arthritis are those not currently in education, employment and training. Such young people may have been less willing to discuss an area of their lives in which they considered they had not succeeded. The original recruitment strategies involved non-traditional rheumatology settings thereby potentially reducing any selection bias towards specialist clinics where health professionals were more likely to have been trained in adolescent rheumatology.

Some research suggests that for young people with health conditions, experiences of support in educational and work settings can differ [48] but we were unable to explore such specific comparisons due to the primary study design and sampling strategy [16]. However, in the UK, where the study was conducted, the same equality legislation covers both education and employment settings and therefore rights to accommodation are similar in both settings. Likewise, information regarding educational attainment, or type of work was not collected as part of the primary study and therefore the potential influence of these aspects on the themes identified remains unclear but worthy of further study.

Conclusions

Young people living with arthritis are faced with a range of additional disruptions and challenges in their educational and/or vocational lives, which can in turn add to those arising directly from life with arthritis and its treatments. Appropriate support and flexibility in the workplace or educational setting, together with appropriate treatment and adherence to it, can enable successful educational and vocational outcomes. However, negotiating disclosure is not a straightforward process for young people living with arthritis, with a range of concerns and expectations acting as barriers to disclosure. Alongside this, it is equally important to consider that disclosure is a necessary but not always sufficient step towards achieving an understanding and supportive environment in school or the workplace. There is therefore the need to further strengthen the interagency working between health, education and workplaces particularly during education and vocational transitions, to ensure that young people living with chronic illness can meet their full potential in adulthood.

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