

## Original article

# Mapping the current psychology provision for children and young people with juvenile dermatomyositis

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## Abstract

**Objectives.** Juvenile Dermatomyositis (JDM) is a rare, chronic autoimmune condition of childhood, with known psychosocial implications. In this study, we sought to establish current psychological support for children and young people across the UK with rheumatic conditions, with a specific focus on those with JDM.

**Methods.** Electronic surveys were distributed to the 15 centres that belong to the JDM Research Group in the UK, collecting responses from health-care professionals in the fields of medicine, nursing and psychology.

**Results.** One hundred per cent of professionals from medicine and nursing replied from all 15 centres. Of these, 7 (47%) did not have a named psychologist as part of their rheumatology team, despite the majority [13 (87%)] having >200 paediatric rheumatology patients. Of the remaining centres, hospital psychology provision varied considerably. When rating their service, only 3 (8%) of 40 professionals scored their service as five (where one is poor and five is excellent); there were wide discrepancies in these scores. Many challenges were discussed, including limited psychology provision, lack of time and difficulties in offering support across large geographical areas.

**Conclusion.** Many of the challenges discussed are applicable to other centres worldwide. Suggestions have been proposed that might help to improve the situation for children and young people with rheumatic conditions, including JDM. Based on these findings, we suggest that rheumatology teams maximize use of these data to advocate and work toward more comprehensive psychology provision and support in their individual centres.

**Key words:** juvenile dermatomyositis, psychology provision, paediatric rheumatology, nurse support, psychosocial

## Introduction

JDM is a rare, chronic autoimmune condition of childhood, typically diagnosed by identifiable skin rashes and symmetrical, proximal muscle weakness [1–3]. Although advances with new treatment options are being made, there is still much we do not know about JDM, in

particular its exact pathogenesis, epidemiology and long-term outcomes [4]. Although mortality is reported to have fallen, with rates between 2 and 8% in recent reports [5–8], there are a significant number of young people with JDM who will continue to have active disease into adulthood [9, 10].

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Submitted 21 June 2021; accepted 16 August 2021

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### Key messages

- Psychological support and early interventions are needed for children with rheumatic conditions.
- Psychology support was limited in most centres surveyed and was determined by time and caseload.
- This study highlights the importance of integrating psychology into paediatric rheumatology teams to benefit patients.

It has been postulated that young people with juvenile rheumatic diseases might be more at risk of psychological concerns owing to the characteristics of these conditions, including disability and chronicity [9]. A recent study demonstrated that more than one-third of paediatric rheumatology patients surveyed (including those with JDM) had clinician-reported anxiety and depression, with a worryingly equally high number of self-diagnosed symptoms [11]. Further studies examining JDM as a distinct population have found significantly poorer quality of life when compared with healthy populations [12, 13]. More recently, young people with JDM described feelings of confusion, uncertainty and difference, when compared with their peers [3].

Psychological services for children and young people with chronic health conditions can help at every step of the patient journey: at diagnosis, during treatment and beyond [14]. According to the National Health Service (NHS) Long Term Plan, there are currently >20 000 psychological professionals working for NHS-funded services in England, which equates to only 1.7% of the NHS workforce [15]. National standards in the UK are now in place acknowledging that psychological services are not simply an adjunct to regular medical care, but represent an integral component of a health-care team for children and young people experiencing chronic health conditions [16, 17]. Of note, page 39 in *'Facing the Future: Standards for Children with Ongoing Health Needs'*, states that the commissioning and planning of paediatric services needs to:

'ensure children have timely access to a range of mental health and psychosocial services that are integrated with children's health services' [17].

There is an ever-increasing evidence base to support the clinical effectiveness of psychological interventions for a number of medical conditions and illnesses [18–21]. Psychological interventions and early support are known to result in the following: better medical outcomes (e.g. by increasing levels of adherence); better psychological functioning (e.g. anxiety, low mood, distress and anger); better family functioning; reduced levels of disability and pain; and reduced levels of distress around procedures.

Historically, children and young people's mental health services have experienced underinvestment, but now there is a clear recognition that increased investment in this area is needed urgently [22]. It is essential, therefore, to increase our understanding of the psychosocial support currently available for young people with

JDM at their major health-care centres and consider future recommendations if standards are not being met.

This study was initiated to examine psychology provision and psychosocial care for children with JDM across the UK. Although it is well recognized that provision of psychosocial support is a core component of the roles of all members of a multidisciplinary team, in this survey we were particularly interested in the availability of clinical psychology. It was important to establish what psychology support and psychosocial provision there is in every centre, and given that it is known anecdotally that not all centres have a paediatric rheumatology psychologist, to capture this comprehensively, the views of paediatric rheumatology consultants, nurse specialists and clinical psychologists (if available) together, were sought.

The following questions underpinned the study and frame the results:

1. What is the applied psychology provision for patients with JDM around the UK?
2. What role-specific factors impede or support good psychological/psychosocial care?
3. What are the biggest challenges when providing psychological/psychosocial care?
4. How do the health-care providers in each centre rate their psychosocial provision?

## Methods

The JDM Cohort Biomarker Study and Repository, UK and Ireland (JDCBS) provides the largest prospective registry and repository of linked biological and serological specimen collections of juvenile idiopathic inflammatory myopathies in Europe [23, 24]. Central to the success of this initiative is UK-wide collaboration and commitment to the study from centres belonging to the JDM Research Group, with 15 of the then 17 tertiary paediatric rheumatology centres in England and Scotland being included at the time of this survey.

The study complies with the 1975 Declaration of Helsinki, with full ethical approval obtained (ref. MREC 1/3/22) from the Northeast York Research Committee and approved by the Health Research Authority, which approved the use of this survey to health-care professionals.

The survey was tailored to each professional group: medical, nursing and psychology. This allowed for different questions within each section, asking about specific

roles, to ensure that questions were relevant and specific, while being mindful of questionnaire fatigue in busy health-care professionals. For example, when asking about site data, it was felt the medical professionals would more easily have the answer to this question. When seeking an opinion about unmet psychology needs, it was felt that the nurse specialists, who might have more contact with patients outside of appointment times, might be more aware of these concerns. The surveys were divided into four sections: applied psychology provision; role specific variance; challenges; and rating of service. Surveys provided options for collection of both quantitative and qualitative data. The questions were developed in conjunction with the research team, who brought clinical and academic expertise. Surveys were piloted with three individuals from each of the three target professional groups, with no changes made. Full surveys are presented in [Supplementary Tables S1–S3](#), available at *Rheumatology Advances in Practice* online.

Contact with each centre was with the JDCBS Principal Investigator (a paediatric rheumatology consultant) and paediatric rheumatology clinical nurse specialist. First contact via e-mail requested the details for the psychologist at their centre. Three centres were not able to identify a named psychologist who was either part of the paediatric rheumatology team or was a hospital psychologist with dedicated time allocated to rheumatology. Distribution of the survey was through a freely available Web-based survey tool, Opinio. The surveys were sent via e-mail to the rheumatology consultant, clinical nurse specialist and a clinical psychologist who works with the rheumatology team, where available. Each centre therefore received three profession-specific surveys if a clinical psychologist could be identified, and if not, only two. The consultants were known through the JDCBS network, and the clinical nurse specialists were known to P.L. as lead of the UK Paediatric Rheumatology Specialist Nurses Group. The psychologists were identified through communication from either the consultant or the nurse. The survey was open for 6 weeks from the end of 2018, with two reminders sent in that time.

### Analysis

Quantitative data reported are the numbers of patients in each centre, scoring of their overall psychosocial service provision and response to binary yes/no questions. These are presented using descriptive statistics. Qualitative data included free-text comments. These are summarized and presented.

### Results

The results are anonymized to prevent site recognition. Anonymized quotes are used throughout to add explanation.

All paediatric rheumatology consultants  $n = 15$  (100%) replied with no missing data fields. All 15 (100%) nurse

specialists replied with only two fields of missing data: one individual had not recorded their biggest challenge, and one, new to rheumatology, had not scored their service. Of the 12 sites that were sent a survey, 11 clinical psychologists replied (92%), with only one centre not responding at all to the survey. In total, there were three fields of missing data: two responders did not comment on their biggest challenges, and one did not rate their service.

[Table 1](#) presents the numbers of patients in the centres surveyed as reported by the paediatric rheumatology consultants. In 13 (87%) centres, they had >200 paediatric rheumatology patients, and 7 (47%) centres had between 10 and 20 JDM patients.

Given that the questions asked of each professional group were different, the data are presented in four sections, each addressing one of the initial research questions, further presented by profession.

Applied psychology provision (table of quantitative data, followed by free-text qualitative comments from each of the professional groups)

[Table 2](#) presents the questions asked for question 1 of each professional group, and a summary of responses.

#### Medical professionals

Medical professionals in five centres (33%) reported that they did not have a named psychologist as part of their rheumatology team, and one of these had no hospital psychology service, commenting: 'We used to, but they are closed to referrals now due to sickness, maternity leave etc. We are reliant on local services now' (participant 7). When not part of the team but available in the hospital, comments included: 'Very limited allocation. Very short staffed and last month announced that they will not be able to see any new referrals that are not inpatients. Totally unsatisfactory' (participant 14). Even when available as part of the team, there were still concerns raised: 'I think most services are directed towards crisis management and chronic pain, I think more could be done with early intervention' (participant 1).

**TABLE 1** Numbers of patients in centres surveyed: paediatric rheumatology patients in total and JDM patients

Number of patients	Number (%) of centres
Approximately how many patients in your whole paediatric rheumatology service?	
100–200	2 (13)
≥200	13 (87%)
Approximately how many JDM patients in your centre?	
0–10	4 (27)
10–20	7 (47)
20–30	2 (14)
30–50	1 (7)
≥50	1 (7)

**TABLE 2** Psychology provision questions and responses

Research question 1		Yes	No	Don't know	Didn't respond	Total
Clinical psychology provision		n (%)	n (%)	n (%)	n (%)	n (%)
Medical professionals	Do you have a named psychologist who provides clinical care to patients with rheumatic conditions?	10 (67)	5 (33)	–	–	15 (100)
	If no, do you have access to Trust-wide psychology in your hospital?	4 (80)	1 (20)	–	–	5 (100)
Nurse specialists	Do you have a named psychologist who provides clinical care to patients with rheumatic conditions?	7 (47)	8 (53)	–	–	15 (100)
	Do you think that some of your patients with JDM have unmet psychosocial needs, and if so, what are these?	10 (67)	1 (7)	4 (27)	–	15 (100)
Clinical psychologists	Do you have dedicated funded rheumatology time?	7 (64)	4 (29)	–	1 (8)	12 (100)
	Do you have a waiting list for psychology input?	9 (82)	2 (18)	–	1 (8)	12 (100)

*Nurse specialists*

Unmet needs were described as: 'Body image, disease management, compliance, fatigue, weight gain, lack of friends, falling behind with education' (participant 13); 'Overt skin changes & muscle weakness makes them feel different to peers and a burden on their family' (participant 1); and 'Lots of our patients have body image issues as well as issues around compliance and mental health concerns' (participant 2). An additional further comment: 'Body image, acceptance of their condition, physical impact of their condition ... patient with self-harm' (participant 3).

*Clinical psychologists*

The number and hours of psychology provision was limited for the majority of sites. One commented: 'We have a very small amount of resource spread across all the paediatric specialties with no designated funding, including rheumatology so we are only able to offer a very brief assessment and intervention service' (participant 1). Others said: 'No dedicated psychology time for Rheumatology' (participant 8); 'No funded service—there is an informal agreement to accept around 12 referrals/year' (participant 10); 'There is no dedicated service for Rheumatology in our Trust' (participant 3); and 'We have a very small amount of resource spread across all the paediatric specialties with no designated funding so we are only able to offer a very brief assessment and intervention service' (participant 1). Waiting lists ranged from 'very minimal' (participant 5) to 'approximately 6 months' (participant 10).

Role specific variance (table of quantitative data, followed by free-text qualitative comments from each of the professional groups)

Table 3 presents the questions asked for the second research question, examining role variance for each professional group, and summarizes their responses.

*Medical professionals*

When asked, 'Do you know what percentage of your patients are seeing someone for psychosocial support?', comments included: 'At a guess some will have had contact but no regular psychology' (participant 14) and 'Most of my JDM patients have seen or are seeing a psychologist' (participant 5). When asked, 'Do you routinely ask JDM patients or their families if they are seeing someone for psychosocial support?' nine (60%) said no, with one commenting: 'Not routinely, only if we think there might be issues needing psychology input' (participant 11). Of the six (40%) who said yes, one commented: 'I routinely ask adolescents (those aged 13–17) about psychological wellbeing and if this suggests difficulties I ask about other support via school or local doctor. I do not routinely ask the parents of younger children unless there is a concern' (participant 6).

*Nurse specialists*

When asked, 'Do you and your nursing team routinely ask patients and/or parents whether the young person is seeing a psychologist or other similar?', eight (53%) said 'No'. Three of these commented that they do not have the time. One reported: 'During the consultation this can be discussed or if concerns are raised, these will be addressed' (participant 9). When asked, 'Do you think you have enough time and/or experience and/or support to manage any psychosocial concerns?', nine (60%) said no. One commented: 'No, we do not have anywhere near enough time to do what we need to do' (participant 2), and another said: 'We do not have enough time' (participant 6).

*Clinical psychologists*

Comments to the question regarding attending team meetings included: 'Unable to attend monthly psychosocial meetings as my timetable no longer allows' (participant 10). More specifically, one of these participants commented: '10–20 min once per month is set aside in this meeting to discuss possible referrals to psychology'

TABLE 3 Role specific variance questions and responses

Research question 2		Yes	No	Don't know	Didn't respond	Total
Role specific variance		n (%)	n (%)	n (%)	n (%)	n (%)
Medical professionals	Do you know what percentage of JDM patients are currently seeing a psychologist or other similar professional, either in your hospital or locally?	7 (47)	8 (53)	–	–	15 (100)
	Do you ask patients (and parents) routinely whether they are seeing a psychologist or other similar in clinic appointments?	6 (40)	9 (60)	–	–	15 (100)
Nurse specialists	Do you and your team routinely ask whether the young person is seeing a psychologist or other similar in appointments or on the phone?	7 (47)	8 (53)	–	–	15 (100)
	Do you think you have enough time/experience and/or support to manage any psychosocial concerns?	6 (40)	9 (60)	–	–	15 (100)
Clinical psychologist	Do you attend any regular psychosocial meetings where children with JDM may be discussed?	7 (58)	4 (33)	–	1 (8)	12 (100)
	Do all newly diagnosed rheumatology patients routinely see a psychologist?	–	11 (92)	–	1 (8)	12 (100)

(participant 8), and another commented that although they did attend meetings, ‘the focus is patients with chronic pain’ (participant 1). All 11 participants replied to say that newly diagnosed patients do not routinely see a psychologist.

#### Challenges as free-text comments

Each individual was asked to state the biggest challenge when providing psychosocial care. All challenges are summarized in [Supplementary Table S4](#), available at *Rheumatology Advances in Practice* online.

#### Medical professionals

Lack of psychology provision, time and geographical boundaries were consistently discussed. Comments included: ‘Long waiting times. Big case load means they [the clinical psychology service] do not prioritize children with chronic diseases and are a reactive service. Regional politics also come into it and if they out of our city boundaries they are referred to another team’ (participant 10); ‘Dedicated psychology for rheumatology patients is vital but often comes with unavailable and unacceptable waits’ (participant 9); and ‘as the medical professional trying to secure safe, effective, and timely care for their patients, one can feel the frustration from arguing over health-care boundaries when dealing with a child’s mental health’ (participant 7).

#### Nurse specialists

Lack of time and lack of psychology provision were also mentioned consistently. Others talked about logistical issues: ‘We cover a large geographical area, some are unable to travel to access our service’ (participant 8); and ‘Knowing where we access the support particularly as we are a regional service and patients want this care to be closer to home’ (participant 3).

#### Clinical psychologists

Capacity was also mentioned: ‘We have a very large catchment area since we are a Specialist Centre’ (participant 11); ‘Not enough psychosocial resource in this area to meet need’ (participant 1); and ‘Clinical Psychologist is very part-time and cannot easily be present during team clinics’ (participant 7). Also, similar to the other professional groups, a recurring theme was lack of time: ‘Not having dedicated time for rheumatology limits the screening/pre-emptive/early intervention work that can be done’ (participant 8); and ‘Current wait for assessment’ (participant 2). Another commented, ‘The biggest challenge is not being integrated into the medical team’ (participant 3).

#### Rating of service (table of quantitative data, followed by free-text qualitative comments from each of the professional groups)

Each respondent rated their psychosocial provision of their centre; these results are summarized in [Table 4](#). Given that one psychologist did not respond at all to the survey and that one nurse specialist and one clinical psychologist did not score their service, there is a total of 39 replies to this question.

#### Medical professionals

The majority [seven (47%)] of medical professionals scored their service as four, adding comments such as: ‘Our service is doing its best, but limited by the quantity of psychology provision as a whole’ (participant 8); ‘Our doctors, nurses and physiotherapists provide psychosocial support as far as possible. When families see Clinical Psychology this is a very good service but the main problem is delay in accessing this’ (participant 6); and ‘We don’t ask enough about mental health in our

**TABLE 4** Rating of psychosocial provision of centre by health-care professionals broken down by discipline

	Poor	Somewhat poor	Neither poor nor excellent	Somewhat excellent	Excellent	Total
Rating	1	2	3	4	5	
Medical professional, <i>n</i> (%)	1 (7)	1 (7)	5 (33)	7 (47)	1 (7)	15 (100)
Nurse specialist, <i>n</i> (%)	0 (0)	2 (14)	7 (50)	4 (29)	1 (7)	14 (93)
Clinical psychologist, <i>n</i> (%)	1 (10)	1 (10)	2 (20)	5 (50)	1 (10)	10 (91)
Total, <i>n</i> (%)	2 (5)	4 (10)	14 (36)	16 (41)	3 (8)	39/41 (95)

Connective Tissue Disease patients, too much focus during clinic is on their physical issues' (participant 11).

#### *Nurse specialists*

Seven (50%) of the nurses scored their service as three. One of the nurses commented that: 'Our psychologist is excellent but part time. To have funding for full time hours would allow more accesses for families in a timely manner' (participant 8); and another: 'No rheumatology psychology support and even no [hospital] psychology support—we have campaigned for this over many years without success' (participant 3).

#### *Clinical psychologists*

Ten of the 11 psychologists completed this question, with five (50%) giving it a rating of four (with a median of four). One commented: 'We could be doing some more preventative work, at the time of diagnosis—education around adjustment and developmental challenges along the way—preparing parents for conversations about long-term conditions' (participant 5). Another said: 'The Rheumatology team have taken on many of the psychological concepts and put these to good use' (participant 2).

## Discussion

This research was part of a multi-phased study that first explored in-depth experiences of 15 children and young people's psychosocial needs with JDM [3] and, second, a larger UK-wide study that captured the views of 123 children and young people regarding their psychosocial needs using validated surveys (currently in preparation for publication). The present study presents the third phase: the perspectives from the health-care professionals. Evidence of need for psychological support for children who have a chronic illness and have experienced periods in hospital has been well described [25]. Similar to other child health specialities [26, 27], we sought to map current provision of the support available to children with rheumatic conditions.

Of the clinical psychologists who commented that they do not have any dedicated funded rheumatology time, this was consistent with responses from the nurses (when including the three sites where a named psychologist could not be identified), but different to the responses of the medical professionals. A reason for

this discrepancy might be that the psychology services provided were not formalized or funded. This concurs that 7 (47%) of the 15 centres surveyed do not have a named psychologist as part of the rheumatology team.

Each individual was asked to rate their hospital psychosocial provision to JDM patients as a whole. The scores were generally high, with, for example, 53% of the medical professionals scoring four or higher. Of note, there were only two centres where all three health-care professionals scored their service the same. In both of these centres, all individuals scored their service as four. Both of these centres had the most psychology offered to rheumatology, both with more than one individual being fully integrated into the rheumatology team. It is important to note here that asking health-care professionals to rate their service is a value judgement. For example, in one centre the medical consultant had rated their service as two, the nurse specialist scored it three, and the psychologist in that centre scored it as five (excellent). This shows the disparity of results from the health-care professionals and the subjective, personal and difficult nature of allocating a score to a service.

One of the findings throughout was lack of time to address psychosocial concerns fully, especially by the medical consultants and nurse specialists. This represents a fundamental issue with psychosocial care: there is clearly not parity of esteem given to biological and psychological care within consultations as advocated by the Long Term Plan [17]. Another concern frequently discussed was the lack of early intervention to prevent psychosocial concerns escalating and requiring more intensive crisis management.

The frustrations from the clinical psychologists were apparent. When answering about their biggest challenge, capacity, time and the limits imposed by not having funded rheumatology were mentioned. There are often informal agreements to accept a certain number of patients per year, leading one to question what happens if you are 13th in line for a psychologist who is only allowed to see a quota of 12 that year.

When asked about their biggest challenge, all three professional groups talked about JDM being a rare disease and patients living far away from treating sites. The issues imposed by working within health-care boundaries and large geographical areas are not specific to the UK, with many patients with JDM in the USA

also having issues when accessing care [28]. It is anticipated that many of the issues raised in this survey (lack of psychology support, rare disease with limited speciality knowledge, lack of time, and large geographical areas) are applicable to other countries in addition to the UK.

Although research has begun into psychological support, the views of siblings and parents also need further study, and the present study provides a sound base from which to explore the experiences of psychological support from patients and their families further.

### Limitations

This study has some limitations. Contacting only health-care providers in the larger centres in the UK might make this less representative, not only for centres outside the UK health system, but also for smaller UK sites that might occasionally see children and young people with JDM. Services change rapidly, with staff leaving and joining on an ever-rolling basis; therefore, while one centre might be struggling this month, provision of care might have improved by the next month. The survey also did not ask the wider team their views surrounding psychosocial provision, such as occupational therapists, physiotherapists and school teachers. These remain important issues to be explored further in the future.

### Recommendations for practice

First, more preventative work needs to be done early in the disease trajectory, as supported by the comments presented throughout this paper. This can be possible only with more designated psychology time.

Second, better joined-up care is needed, especially for those families who cannot travel to the larger centres. As one of the medical professionals commented: 'With small numbers of patients and wide range of ages, issues are different. More organized regional/national/virtual groups would be helpful' (participant 12).

Third, psychology provision should be integrated into all paediatric rheumatology teams to benefit all patients (regardless of age, race, gender or disease activity) and provide more dedicated time.

### Conclusion

This survey established that 7 (47%) of the 15 centres in the UK at the time of the survey did not have a psychologist as part of their paediatric rheumatology multi-professional team. The results from this survey can help centres to advocate for more support and services and use these data to illustrate the variations in practice. As one medical professional said: 'Hopefully the results from this survey can be used to help my deaf managers hear' (participant 7).

### Acknowledgements

P.L. and L.W. are supported by The Centre for Adolescent Rheumatology Versus Arthritis, which is

supported by Versus Arthritis (21593), Great Ormond Street Children's Charity and the NIHR Biomedical Research Centre at GOSH.

**Funding:** P.L. was funded by a National Institute for Health Research (NIHR)/Health Education England (HEE) Clinical Doctoral Research Fellowship (ICA-CDRF-2016-02-032) for this research project. The JDM Cohort Biomarker Study and Repository was supported by the Wellcome Trust UK (grant 085860), Arthritis Research UK, now Versus Arthritis (grants 14518, 20164, 21593), Action Medical Research UK (grant SP4252), the Myositis Support Group UK, the Henry Smith Charity, Great Ormond Street Children's Charity (grant V1268), Cure-JM and the NIHR UK. The views expressed are those of the authors, and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

**Disclosure statement:** The authors have declared no conflicts of interest.

### Data availability statement

All of the data underlying this article cannot be shared publicly due to offering the respondents anonymity in their responses for confidentiality reasons. The data will be shared on reasonable request to the corresponding author.

### Supplementary data

Supplementary data are available at *Rheumatology Advances in Practice* online.

### References

- Huber AM. Update on the clinical management of juvenile dermatomyositis. *Expert Rev Clin Immunol* 2018; 14:1021–8.
- Wu Q, Wedderburn LR, McCann LJ. Juvenile dermatomyositis: latest advances. *Best Pract Res Clin Rheumatol* 2017;31:535–57.
- Livermore P, Gray S, Mulligan K *et al.* Being on the juvenile dermatomyositis rollercoaster: a qualitative study. *Pediatr Rheumatol Online J* 2019;17:30.
- Feldman BM, Rider LG, Reed AM, Pachman LM. Juvenile dermatomyositis and other idiopathic inflammatory myopathies of childhood. *Lancet* 2008;371: 2201–12.
- Huber AM, Lang B, LeBlanc CM *et al.* Medium- and long-term functional outcomes in a multicenter cohort of children with juvenile dermatomyositis. *Arthritis Rheum* 2000;43:541–9.
- Martin N, Li CK, Wedderburn LR. Juvenile dermatomyositis: new insights and new treatment strategies. *Ther Adv Musculoskelet Dis* 2012;4:41–50.
- Sharma A, Gupta A, Rawat A, Suri D, Singh S. Long-term outcome in children with juvenile

- dermatomyositis: a single-center study from north India. *Int J Rheum Dis* 2020;23:392–6.
- 8 Okong'o LO, Esser M, Wilmshurst J, Scott C. Characteristics and outcome of children with juvenile dermatomyositis in Cape Town: a cross-sectional study. *Pediatr Rheumatol Online J* 2016;14:60.
  - 9 Ravelli A, Trail L, Ferrari C *et al.* Long-term outcome and prognostic factors of juvenile dermatomyositis: a multinational, multicenter study of 490 patients. *Arthritis Care Res* 2010;62:63–72.
  - 10 McCann LJ, Arnold K, Pilkington CA *et al.* Developing a provisional, international minimal dataset for Juvenile Dermatomyositis: for use in clinical practice to inform research. *Pediatr Rheumatol Online J* 2014;12:31.
  - 11 Fawole OA, Reed MV, Harris JG *et al.*; CARRA Investigators. Engaging patients and parents to improve mental health intervention for youth with rheumatological disease. *Pediatr Rheumatol Online J* 2021;19:19–4.
  - 12 Apaz MT, Saad-Magalhaes C, Pistorio A, *et al.*; Paediatric Rheumatology International Trials Organisation. Health-related quality of life of patients with juvenile dermatomyositis: results from the paediatric rheumatology international trials organisation multinational quality of life cohort study. *Arthritis Care Res* 2009;61:509–17.
  - 13 Kountz-Edwards S, Aoki C, Gannon C *et al.* The family impact of caring for a child with juvenile dermatomyositis. *Chronic Illn* 2017;13:262–74.
  - 14 Mercer A, O'Curry S, Donnan J *et al.* Delivering psychological services for children and young people with physical health needs and their families. *Child Fam Clin Psychol Rev* 2015;3:71–83.
  - 15 Psychological Professions Network. Implementing the NHS Long Term Plan: maximising the impact of the psychological professions. Psychological Professions Network, 2015; [https://www.nwppn.nhs.uk/attachments/article/2578/PPN\\_Long\\_Term\\_Plan\\_Online\\_Single\\_compressed.pdf](https://www.nwppn.nhs.uk/attachments/article/2578/PPN_Long_Term_Plan_Online_Single_compressed.pdf).
  - 16 Irwin LG, Johnson J. Interviewing young children: explicating our practices and dilemmas. *Qual Health Res* 2005;15:821–31.
  - 17 Royal College of Paediatrics and Child Health. Facing the future: standards for children with on-going health needs. London: RCPCH, 2018.
  - 18 Roberts MC, Steele RG. Handbook of paediatric psychology. New York: Guilford Press, 2018.
  - 19 Spirito A, Kazak AE. Effective and emerging treatments in pediatric psychology. New York: Oxford University Press, 2006.
  - 20 Gómez-Ramírez O, Gibbon M, Berard R *et al.* A recurring rollercoaster ride: a qualitative study of the emotional experiences of parents of children with juvenile idiopathic arthritis. *Pediatr Rheumatol Online J* 2016;14:13.
  - 21 Pai A, Drotar D, Zebracki K, Moore M, Youngstrom E. A meta-analysis of the effects of psychological interventions in pediatric oncology on outcomes of psychological distress and adjustment. *J Pediatr Psychol* 2006;31:978–88.
  - 22 Edwards M, Titman P. Promoting psychological well-being in children with acute and chronic illness. London: Jessica Kingsley Publishers, 2011.
  - 23 Martin N, Krol P, Smith S *et al.*; Juvenile Dermatomyositis Research Group. A national registry for juvenile dermatomyositis and other paediatric idiopathic inflammatory myopathies: 10 years' experience; the Juvenile Dermatomyositis National (UK and Ireland) Cohort Biomarker Study and Repository for Idiopathic Inflammatory Myopathies. *Rheumatology (Oxford)* 2011; 50:137–45.
  - 24 McCann LJ, Juggins AD, Maillard SM *et al.*; Juvenile Dermatomyositis Research Group. The Juvenile Dermatomyositis National Registry and Repository (UK and Ireland)—clinical characteristics of children recruited within the first 5 yr. *Rheumatology (Oxford)* 2006;45: 1255–60.
  - 25 Williams NA, Brik AB, Petkus JM, Clark H. Pediatric psychosocial care: historical context and a theoretically informed practice model. *Child Youth Serv Rev* 2019; 107:1–8.
  - 26 Knibb R, Halsey M, James P, du Toit G, Young J. Psychological services for food allergy: the unmet need for patients and families in the United Kingdom. *Clin Exp Allergy* 2019;49:1390–4.
  - 27 Seekles ML, Ormandy P, Coyne E. Mapping the UK renal psychosocial workforce: the first comprehensive workforce survey. *BMC Nephrol* 2019;20:100.
  - 28 Kwa MC, Silverberg JI, Ardalán K. Inpatient burden of juvenile dermatomyositis among children in the United States. *Pediatr Rheumatol Online J* 2018;16:70.