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Citation: Livermore, P., Gibson, F., Mulligan, K. ORCID: 0000-0002-6003-3029, Wedderburn, L. R., McCann, L. J. and Gray, S. (2021). Mapping the current psychology provision for children and young people with Juvenile Dermatomyositis. *Rheumatology Advances in Practice*,

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Mapping the current psychology provision for children and young people with Juvenile Dermatomyositis

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Funding Statement

PL 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. PL and LW 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. The Juvenile Dermatomyositis 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 declare no conflicts of interest

Abstract

Objectives

Juvenile Dermatomyositis is a rare, chronic autoimmune condition of childhood with known psychosocial implications. This study sought to establish current psychology support for children and young people across the United Kingdom with rheumatic conditions, with a specific focus on those with Juvenile Dermatomyositis.

Methods

Electronic surveys were distributed to the 15 centres that belong to the Juvenile Dermatomyositis Research Group in the United Kingdom, collecting responses from health care professionals in the fields of medicine, nursing and psychology.

Results

One hundred percent 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 more than 200 paediatric rheumatology patients. Of the remaining centres, hospital psychology provision varied considerably. When rating their service, only 3 (8%) out of 40 professionals scored their service as a 5, (where 1 is poor, 5 is excellent): there were wide discrepancies in these scores. Many challenges were discussed, including limited psychology provision, lack of time and difficulties of offering support across large geographical areas.

Conclusion

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

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.

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.

Key words

Juvenile Dermatology

Psychology provision

Paediatric Rheumatology

Nurse support

Psychosocial

Introduction

Juvenile Dermatomyositis (JDM) is a rare, chronic autoimmune condition of childhood typically diagnosed by identifiable skin rashes and symmetrical, proximal muscle weakness (1–3). Whilst 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). Whilst mortality is reported to have fallen, with rates between 2-8% 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).

It has been postulated that young people with juvenile rheumatic diseases may be more at risk of psychological concerns due to the characteristics of these conditions, including disability and chronicity (9). A recent study demonstrated over a 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 to healthy populations (12,13). More recently, young people with JDM described feelings of confusion, uncertainty and difference, when compared to 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 over 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 healthcare 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, anger)
- Better family functioning

- Reduced levels of disability and pain
- Reduced levels of distress around procedures

Historically however, 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 urgently needed (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.

Objectives

This study was initiated to examine psychology provision and psychosocial care for children with JDM across the United Kingdom (UK). Although it is well recognised that provision of psychosocial support is a core component of the roles of all members of a multidisciplinary team, this survey was 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 as anecdotally it is known 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 healthcare providers in each centre rate their psychosocial provision?

Setting

The Juvenile Dermatomyositis 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 Juvenile Dermatomyositis Research Group, with 15 of the then 17 tertiary paediatric rheumatology centres in England and Scotland being included at the time of this survey.

Ethics

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 healthcare professionals.

Methods

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 questions were relevant and specific, whilst being mindful of questionnaire fatigue in busy healthcare 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 may have more contact with patients outside of appointment times, may be more aware of these concerns. The surveys were divided into four sections: i) Applied Psychology Provision; ii) Role specific variance; iii) Challenges; iv) 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, S2 and S3.

Contact with each centre was with the JDCBS Principal Investigator (a paediatric Rheumatology Consultant) and paediatric Rheumatology Clinical Nurse Specialist. First contact via email 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 the author as Lead of the UK Paediatric Rheumatology Specialist Nurses Group, the psychologists were identified through communication from either the consultant or nurse. The survey was open for 6 weeks from the end of 2018, with two reminders sent in that time.

Analysis

Quantitative data reported, 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 summarised and presented.

Results

The results are anonymised to prevent site recognition. Anonymised quotes are used throughout to add explanation. Results are presented, beginning with response rate.

Response rate

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 who 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.

Site data

Table 1 presents the numbers of patients in the centres surveyed as reported by the paediatric Rheumatology consultants. In 13 (87%) centres they had over 200 paediatric Rheumatology patients and 7 (47%) had between 10-20 JDM patients.

(PLEASE ADD TABLE ONE HERE)

Research questions presented in turn for each professional group

As 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.

1. 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 summary of responses.

(PLEASE ADD TABLE TWO HERE)

Medical professionals

Medical professionals in 5 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).

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 specialities 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).

2. 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 summarises their responses.

(PLEASE ADD TABLE THREE HERE)

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?’ 9 (60%) said no, with one commenting: *“Not routinely, only if we think there might be issues needing psychology input”* (participant 11). Of the 6 (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?’ 8 (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?’ 9 (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 minutes once per month is set*

aside in this meeting to discuss possible referrals to psychology” (participant 8) and another commented that whilst 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.

3. Challenges as free-text comments

Each individual was asked what was the biggest challenge when providing psychosocial care. All challenges are summarised in Supplementary table S4.

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 prioritise 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 was also consistently mentioned. 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).*

4. 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 summarised in Table 4. As one psychologist did not respond at all to the survey and one nurse specialist and one clinical psychologist did not score their service, there is a total of 39 replies to this question.

(PLEASE ADD TABLE FOUR HERE)

Medical professionals

The majority, 7 (47%) of medical professionals scored their service a 4, 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 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 a 3. 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 and another”* (participant 8); *“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 out of the 11 psychologists completed this question, with 5 (50%) giving it a rating of 4 (with a median of 4). 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 firstly explored in-depth experiences of 15 children and young people’s psychosocial needs with JDM (3) and secondly, a larger UK wide study which captured the views of 123 children and young people regarding their psychosocial needs using validated surveys (currently in preparation for publication). This study presents the third phase; the perspectives from the healthcare 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), however, different to the responses of the medical professionals. A reason for this discrepancy may be that the psychology services provided were not formalised 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 4 or above. 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 a 4. 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 a 2, the nurse specialist scored it 3, and the psychologist in that centre scored it 5 (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 fully address psychosocial concerns, 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 healthcare boundaries and large geographical areas, not specific to the UK, with many patients with JDM in the United States 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 outside of the UK.

Whilst research has begun into psychological support, the views of siblings and parents also need further study, and this paper 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 may make this less representative, not only to centres outside of the UK health system, but also, smaller UK sites who may occasionally see children and young people with JDM. Services change rapidly with staff leaving and joining on an ever-rolling basis, so whilst one centre may be struggling this month, provision of care may 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

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

(2) Better joined up care, 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 organised regional/national/virtual groups would be helpful”* (participant 12).

(3) Integrating psychology provision into all paediatric Rheumatology teams to benefit all patients (regardless of age, race, gender, disease activity) and provide more dedicated time.

Conclusion

This survey established that 7 (47%) of the 15 centres in the UK at 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 advocate for more support and services and use this 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).

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Table 1 - Numbers of patients in centres surveyed: paediatric rheumatology patients in total and JDM patients

Approximately how many patients in your whole paediatric rheumatology service?	
Number of patients	Number (%) of centres
100-200	2 (13)
200+	13 (87%)
Approximately how many Juvenile Dermatomyositis patients in your centre?	
Number of patients	Number (%) of centres
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	Didn't	Total
Clinical Psychology provision		n (%)	n (%)	know	respond	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	10 (67)	1 (7)	4 (27)	-	15 (100)

	psychosocial needs, and if so, what are these?					
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)

Table 3. Role specific variance questions and responses

Research Question 2. Role specific variance		Yes n (%)	No n (%)	Don't know n (%)	Didn't respond n (%)	Total 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)

Table 4 – Rating of psychosocial provision of centre by healthcare professionals broken down by discipline

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

Supplementary Table S1 – Questionnaire for Medical professionals

Question number	Question asked	Answer options
1	Approximately how many patients in your whole paediatric rheumatology service?	0-100 100-200 200+
2	Approximately how many Juvenile Dermatomyositis patients in your centre?	0-10 10-20 20-30 30-50 50+
3	Do you have a named psychologist who provides clinical care to patients with rheumatic conditions?	Yes/No/Don't know Free text comment
4	If no, do you have access to Trust wide psychology in your hospital?	Yes/No/Don't know Free text comment

5	Do you know what percentage of JDM patients are currently seeing a psychologist or other similar professional, either in your hospital or locally?	Yes/No/Don't know Free text comment
6	Do you ask patients (and parents) routinely whether they are seeing a psychologist or other similar in clinic appointments?	Yes/No/Don't know Free text comment
7	What is your biggest challenge when providing psychosocial care?	Free text comment
8	Please rate in your opinion the psychosocial provision for your rheumatology patients provided by your centre?	1 (poor) -5 (excellent)

Supplementary Table S2 – Questionnaire for Nurse Specialists

Question number	Question asked	Answer options
1	Do you have a named psychologist who provides clinical care to patients with rheumatic conditions?	Yes/No/Don't know Free text comment
2	Do you think that some of your patients with JDM have unmet psychosocial needs, and if so, what are these?	Yes/No/Don't know Free text comment
3	Do you and your team routinely ask whether the young person is seeing a psychologist or other similar in appointments or on the phone?	Yes/No Free text comment
4	Do you think you have enough time / experience and/or support to manage any psychosocial concerns?	Yes/No/Don't know Free text comment
5	What is your biggest challenge when providing psychosocial care?	Free text comment
6	Please rate in your opinion the psychosocial provision for your rheumatology patients provided by your centre?	1 (poor) -5 (excellent)

Supplementary Table S3 – Questionnaire for Clinical Psychologists

Question number	Question asked	Answer options
1	Do you have dedicated funded rheumatology time?	Yes/No Free text comment
2	Do you have a waiting list for psychology input? And if so, how long is it?	Yes/No Free text comment
3	Do you attend any regular psychosocial meetings where children with JDM may be discussed?	Yes/No Free text comment
4	Do all newly diagnosed rheumatology patients routinely see a psychologist?	Yes/No/Don't know Free text comment

5	What is your biggest challenge when providing psychosocial care?	Free text comment
6	Please rate in your opinion the psychosocial provision for your rheumatology patients provided by your centre?	1 (poor) -5 (excellent)

Supplementary Table S4 – Biggest challenges responses, from each health care professional

Biggest challenge – medical professional replies	Biggest challenge – Nurse specialist replies	Biggest challenge – Clinical Psychologist replies
Lack of psychology, locally and within Trust. Dedicated psychology for rheumatology patients is vital but often unavailable/ unacceptable wait	Limited resources available	No answer
Time, local input	Undisturbed time slots with the family, interactions with the families become problem solving interactions	'Buy in' to biopsychosocial model. Being fully up to date on treatment plan.
More could be done with early intervention	Our psychology service is very limited, we need more psychology support. The waiting list is extremely long	DID NOT REPLY TO SENT SURVEY
Depends on individual patients and their requirements	Admission by family or young person that mental health is an issue that needs addressing	Not enough psychosocial resource in this area to meet need
Lack of psychologist on team. Long waiting times. Big case load means they [the clinical psychology service] do not prioritise 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	Not enough time nor experience, nor access to resources	No answer
Access to psychology in network clinics and as the medical professional trying to secure safe, effective, and	Wide age range for children, chronic nature of condition, not enough psych time and	Not being integrated into the medical team

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timely care for their patients, one can feel the frustration from arguing over health care boundaries when dealing with a child's mental health	long distances travelled by families	
Under-resourced clinical psychologist service which cannot meet demands	Time, resource. Once they see psychology they get a good service, the delay is the problem	Clinical psychologist is very part-time and cannot easily be present during team clinics
Lack of psychology in the team or named within the psychology department.	Not having a psychologist in JDM clinics	Time! And we have a very large catchment area since we are a Specialist Centre
Extremely limited in house psychology services	Knowing where we access support particularly as we are a regional service and patients want this care to be closer to home.	Logistics, I am part of a regional service, therefore providing equity of psychology across the service
Time and parental engagement	Time and space to see the young person	Resourcing it
Patients who live a long distance with poor local care or those that don't engage with psychology input	We offer psychology to all patients who need it as we have a dedicated clinical psychologist on our team	Not having dedicated time for rheumatology limits the screening / pre-emptive / early intervention work
Clinic space for psychologist	Time and consistent resources: we cover a large geographical area, some are unable to travel to access our service	Current wait for assessment, - would be ideal to have the time to be based in clinic more to routinely meet newly diagnosed families
Timely access	Engagement with services or consent to referrals	No answer
Until recently, lack of psychology, now better	No dedicated psychology time or specific psychologist identified	No answer
Not enough psychology time, waits to see our psychologists are getting longer	No answer	No answer