Understanding the Experience of Children Aged Between Five and Thirteen Years Old and Their Parents Undergoing Long-Term Treatment for Juvenile Dermatomyositis

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Megan Jeffries

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Abstract

This thesis examines the emotional and practical challenges faced by children with juvenile dermatomyositis and their parents during treatment. It also explores the challenges experienced on the journey to diagnosis. Juvenile dermatomyositis (JDM) is a rare chronic childhood autoimmune disease with the average age of onset of 7 years old with a girl-to-boy ratio of 3:1 (Pachman et al., 2021). The international annual incidence of juvenile dermatomyositis is 1.7-3 per million, as reported by Concannon (2021). The existing literature demonstrates a robust focus on biomedical interventions for juvenile dermatomyositis; however, empirical investigations into the experiences of children and their parents remain scarce. This study primarily utilises parental perspectives to highlight the systemic challenges that may influence the treatment experience of children with juvenile dermatomyositis. Purposive sampling was used to recruit participants to complete an anonymous survey, resulting in sixteen survey participants. Of those sixteen survey participants, five agreed to an interview. The results were analysed using reflexive thematic analysis and descriptive statistics. The main findings were the need for advocation during the journey to diagnosis and throughout treatment, treatment experience, and parent knowledge. There was a common thread of emotional resilience required for constant advocation, mental labour for treatment logistics, and the need for independent research due to lack of information given around prognosis and treatment options. The research revealed a significant lack of mental health services offered for the child or the family, highlighting the need for psychosocial support for both children and their families due to the ripple effect that treatment experience has. Future research could benefit from prioritising the voices of the children and gaining access to a larger, more diverse sample pool.

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Table of contents

List of Tables and Figures

List of Abbreviations/Terms

Childhood Myositis Assessment Scale 548 (CMAS)

Critical realism (CR).

Dermatomyositis (DM)

Facebook (FB)

General Practitioners (GPs)

Idiopathic inflammatory myopathy (IIM)

Interstitial lung disease (ILD)

Intravenous immunoglobulin (IVIG)

Juvenile Dermatomyositis (JDM)

Myositis Specific Autoantibodies (MSA)

Magnetic Resonance Imaging (MRI)

Patient-reported outcomes system (PROMIS)

Paediatric rheumatic diseases (PRDs)

Rare Diseases (RDs)

Serum glutamic oxaloacetic transaminase (SGOT)

Serum glutamate pyruvate transaminase (SGPT)

Ultraviolet (UV)

Chapter 1 - Introduction

This chapter will introduce Juvenile dermatomyositis (JDM) and discuss the prevalence and incidence of JDM in New Zealand, Australia, and the United Kingdom. Next, the chapter will cover the definition and diagnosis, followed by the current treatment model and the rationale for the present study, including the research questions.

Background

Juvenile dermatomyositis (JDM) is a rare chronic childhood autoimmune disease affecting approximately one in three million children (Concannon, 2021). A girl-to-boy ratio is reported to be between 3:1 (Enders et al., 2017). Although rare, JDM is the most common idiopathic inflammatory myopathy within paediatric rheumatic diseases (PRD), accounting for 85% of all cases (Concannon, 2021). It has an average age of onset of seven years; however, one-quarter of children present before the age of five years (Martin et al., 2012).

The manifestations of JDM and adult dermatomyositis vary significantly, although it is important to maintain awareness of both if a child does not enter remission before adulthood. Adult dermatomyositis (DM) is more common than JDM, with approximately sixty to seventy per million, and affects twice as many women as it does men (Schlecht, 2020). Adult DM has a higher likelihood of malignancy and interstitial lung disease (ILD) than JDM and a higher risk of patients developing depression and anxiety (Christopher-Stine, 2025).

Prevalence and Incidence of JDM in New Zealand, Australia, and the United Kingdom

Due to the rarity of the disease, the etiology of JDM remains poorly understood. Recent research exploring viral infections as a potential cause suggested there are genetic susceptibility and environmental factors, such as pollution or infection, that could be playing a role (Rhim, 2022). Poorly understood epidemiology may result from diverse outpatient management, inconsistent diagnostic criteria, and a variable clinical course that delays diagnosis, (Dourmishev, 2009).

The prevalence of JDM in Australia (New South Wales Government, 2024) and the United Kingdom is similar to that of New Zealand (Concannon, 2021), and global prevalence is estimated at two to four cases per million (Martin, 2011). While there are no significant ethnic variations in overall diagnosis rates, Māori and Pacific Island children with JDM are less likely to obtain clinical remission and have a weaker clinical response to treatment (Concannon, 2021). Additionally, Māori and Pacific Island children are also more likely to experience a chronic disease course instead of a monocyclic one (Concannon, 2021). Complications such as calcinosis, lung disease, and cutaneous vasculopathy are also more likely to occur among Māori and Pacific Island children (Concannon, 2021).

It is important to note that there are shortages of specialist training and staff to diagnose and treat JDM. Cox (2017) revealed that there is a global shortfall in the paediatric rheumatology workforce of 68% based on minimum requirements and a shortfall of 225% based on ideal ratios. Consequently, in Australia and New Zealand, Cox (2017) suggests we fail to provide patients with paediatric rheumatic diseases adequate access to multi-disciplinary team care considered standard in comparable developed health economies.

Often, hospitals are under-resourced due to staffing shortages, increased patient volume, and a lack of funding, which can influence the quality of patient care.

Symptoms

Juvenile dermatomyositis (JDM) is a rare type of autoimmune disease in children that causes skin irritation (dermato) and muscle inflammation (myositis). In autoimmune diseases such as JDM, the body's immune system, which is a collection of specific cells that protect the body against infections, turns on itself and attacks its cells, mistaking them for antigens (Rabadam, 2024). This attack on the body's cells causes muscle inflammation, which can be confirmed through Magnetic Resonance Imaging (MRI) or can be detected with a muscle biopsy. The key clinical features of JDM include a heliotropic rash around the eyelids and proximal muscle weakness that affects the thighs, hips, shoulders, and arms (Sag et al., 2021; Wu et al., 2020).

The main symptoms include skin rashes and dermatological (skin) manifestations, which occur in around 85%-100% of children with JDM (Wu et al., 2020). The myositis component of JDM consists of insidious, progressive proximal myopathy where the muscles continue to weaken without intervention. Weakness typically occurs in the shoulders, hips, thighs, and arms, making it difficult for the child to do activities such as standing up from a seated position (Wu et al., 2020). This becomes especially impactful if seated on the floor in classrooms, daycare, or home as it makes it challenging for the child to participate in daily tasks. The skin involvement is mostly evident in rashes with the main one being the heliotropic rash around the eyes (Wu et al., 2020). Calcinosis, the formation of calcium deposits beneath the skin, is a distinguishing feature of JDM however, the etiology is poorly understood. Gottron papules, which can present as dry, swollen, and thick skin, can manifest

on the knuckles, elbows, and knee areas (Sag et al., 2021). In rare cases, JDM can involve the oesophagus, which can lead to progressive respiratory paralysis, so care must be taken to assess the patient's swallowing ability, as this can quickly turn into a medical emergency (Rhim, 2022).

Additional common symptoms include fever, myalgias, arthralgias, abdominal pain, and melena due to gastrointestinal (GI) involvement (vasculopathy) (Sag et al., 2021). Disease activity can be monitored through elevated serum muscle enzymes (Sag et al., 2021), particularly creatinine kinase (CK), aspartate aminotransferase (AST), lactate dehydrogenase (LDH), and aldolase levels, which are enzymes released into the bloodstream that indicate muscle or tissue damage.

Sun exposure can also have an impact on children with JDM, exacerbating their rashes and increasing the likelihood of the rash spreading to other areas of the body (Pachman, 2021). Due to the risk of worsening the disease from prolonged and intense exposure to the sun, it is recommended to use high-grade SPF 50 sunscreen, wear protective clothing that reduces skin exposure, and always wear a hat outdoors (Pachman, 2021). Recently, more specific guidelines and criteria for improvement have provided further clues surrounding JDM pathophysiology. These guidelines widen the scope of potential medical therapies (Pachman, 2021).

Diagnosis

Gaining a diagnosis for JDM is challenging, with the symptoms often being mistaken for ‘growing pains’ and other myopathies, such as Idiopathic Inflammatory Myopathy (IIM) (Papadopoulou, 2023). General practitioners frequently adopt a ‘wait and see’ approach before initiating further diagnostic investigations. In New Zealand, the public healthcare

system provides children with access to free emergency care and either free or heavily subsidised healthcare through their general practitioner. Australia and the United Kingdom have similar healthcare systems that support accessible healthcare for children. In contrast, countries like the United States of America, unfortunately, do not, leaving families facing significant challenges, for example, having to purchase expensive medications to treat their children, making care and treatment inaccessible to many, especially those in lower socio-economic areas and developing countries. This is reflected in the literature showing developing countries with a higher mortality rate for rare diseases (Wedderburn, 2009). Research indicates that early aggressive front-line treatment increases positive outcomes and the likelihood of remission (Wedderburn, 2009). Delayed diagnosis has shown to be a contributing factor to further complications such as calcinosis, other ongoing skin diseases, and a higher possibility of osteoporosis if carried over into adulthood (Wedderburn, 2009).

There is no specific blood test or singular diagnostic test to diagnose JDM. Instead, multiple sources of diagnostic tests and clinical assessments are required to confirm a diagnosis. Furthermore, children are often required to visit multiple specialists before receiving a diagnosis. A paediatric rheumatologist is commonly the specialist to make the diagnosis due to the minimal knowledge of such a rare disease in the general healthcare system (Kountz-Edwards et al., 2017). Consequently, this puts further strain on an already stretched healthcare system.

Blood tests are performed to help diagnose and monitor the disease, which usually shows increased levels of one or more muscle-related enzymes, including CPK, aldolase, serum glutamic oxaloacetic transaminase (SGOT), serum glutamate pyruvate transaminase (SGPT), and LDH (Pachman, 2021). Additionally, a thorough physical

examination of the body is essential to determine how the body is functioning. This includes surveying the surface of the skin to identify any JDM-related rashes, notably a heliotropic rash around the eyelids and reddening of the knuckles, elbows, or knees. Physicians will also check for signs of arthritis in the joints and joint flexibility. Skin involvement is a significant marker of the disease and can signify the level and possible severity of disease activity. MRIs are commonly utilised to detect inflammation of the muscles, which confirms a suspected diagnosis. Following this, if further confirmation is required, a muscle biopsy may be used. Biopsy results typically reveal signs of inflammation within the muscle tissue, damaged muscle fibres, perivascular inflammation, and abnormal blood vessel changes, all of which are characteristics of JDM (Nguyen, 2020).

The diagnostic criteria outlined by Bohan and Peter (1975) are to meet four out of five of the following shown in Table 1.

Table 1

Diagnostic Criteria for Juvenile Dermatomyositis

Symptom	**Diagnostic test**	**Treatment**
Proximal muscle weakness	Childhood myositis assessment scale (CMAS)	Physiotherapy
Elevated muscle enzymes	Blood test	Medications
EMG	Electromyography	
Muscle biopsy	Invasive sampling	
Skin manifestations	Visual confirmation	Medications

JDM is a subgroup of idiopathic inflammatory myopathies (IIM), which are a heterogeneous group of rare muscular autoimmune diseases, characterised by skeletal

muscle inflammation. Although individuals with IIM can experience significant diagnostic delays of up to six years, a study by Namsrai (2022) across IIM and its subtypes has shown that the average diagnostic timeframe for JDM is six and a half months. This is in line with the participants in this study who received a diagnosis between six and twelve months. However, due to the insidious nature of the disease, it has likely started setting in well before the first symptoms are noticed. Additionally, JDM can involve other major organs such as the heart, lungs, and the gastrointestinal tract, there is a significant increase of risk if treatment is delayed (Feldman et al., 2008).

A recurring theme among patients who acquire a diagnosis of a rare disease is that doctors put the symptoms down to the most common causes in the first instance and tell them to 'wait it out.' Furthermore, due to doctors' authoritarianism style, which creates a power dynamic, patients or their caregivers can lack the confidence to advocate for further diagnostic testing, often adopting the passive and compliant patient in the first instance (Tirraoro, 2014). Pushing for more answers requires a fair amount of advocacy on the part of the patient or the patient's parent. The degree of detail given by the parent regarding the background and other possible related symptoms all strengthens a case for further investigation. Without this advocation, patients' diagnosis can be delayed for up to a year or longer until the symptoms become unmanageable. A study by Namsrai (2022) on the diagnostic delay of multiple sclerosis (MS) showed that diagnostic delay had a significant impact on quality of life. The study also highlighted the importance of understanding the experience of individuals on their journey to diagnosis. Research into individuals' experiences with MS revealed that diagnostic delays can cause significant uncertainty and a worsening of symptoms, leaving patients and their families in a state of prolonged ambiguity (Namsrai, 2022). This prolonged state of ambiguity can cause increased states of stress and

anxiety and a lack of understanding from workplaces and schools. Not having an official diagnosis can also increase the barriers to accessing additional government support for loss of income, extra travel, and time off school.

Disease phases/prognosis

There is currently no known cure for JDM, consequently, the goal of medical treatment is to control disease activity, prevent mortality, and reduce long-term disability and other complications (Sag et al., 2021). Since the introduction of corticosteroids as a first-line treatment in the 1970s, the mortality rate has decreased from 30% to under 5%. Notably, no major treatment changes have developed since the 1970s, with steroids still being the primary treatment. Before the routine use of corticosteroids and other immunosuppressive therapies such as methotrexate as the standard of care treatment for Juvenile idiopathic inflammatory myopathy (IIMs), more than one-third of children with JDM died. However, the mortality rate has significantly decreased with recent reviews described by Huber (2014) reporting mortality rates of less than 2%. Despite this progress, mortality rates remain high in developing countries due to challenges of accessing healthcare for low socioeconomic families (Wijayawardhana, 2024).

The prognosis historically was in a rule of thirds: one-third of patients would suffer mortality; one-third of patients would experience a polyphasic chronic disease course; and one-third of patients would experience a monophasic course of the disease before entering permanent remission (Rhim, 2022; Sag et al., 2021). Gao (2020) stipulates that JDMs disease course is heterogenic, with three distinctive disease courses being identified:

- Monocyclic course: permanent remission within 2-3 years (25-37%)
- Polycyclic course: periods of remission followed by relapse (11-27%)

- Chronic, continuous course: persistent disease for longer than 2-3 years (44- 52%)

Due to there being little understanding of JDM, it is difficult to provide a prognosis to individuals who have recently received a diagnosis. However, it has been shown that JDM, when characterised by a chronic or polyphasic course, is a strong indicator of a negative prognosis (Concannon, 2021). Furthermore, chronic issues are more likely to present with calcinosis and other skin conditions. These complications are more common in minority groups such as Māori, Pacific Island, Black, and Indigenous African children (Concannon, 2021). Lung disease, which is a rare but possible further complication to patients diagnosed with JDM, is more likely among Japanese children (Concannon, 2021).

Historically, defining remission in JDM has been vague and challenging. However, a Besançon (2017) study provided a clearer definition of complete remission by using the PRINTO criteria. The PRINTO criteria include a childhood myositis assessment score (CMAS) score of 548 alongside the complete absence of skin involvement. Additionally, there has also been promising research in identifying myositis-specific autoantibodies (MSA) with 95% specificity. Notably, despite their high specificity, MSAs only have 20% sensitivity in the diagnosis of JDM, thus limiting their global use so far (Namsrai, 2022).

Given the wide age range of JDM patients, a patient-reported outcomes system (PROMIS) has been developed to help strengthen young children's voices during diagnosis and treatment (Gao, 2022). The PROMIS application uses animation to engage children in a way that is accessible to them, helping them articulate what they are feeling and communicate those feelings with health professionals (Gao, 2022). However, this is mainly used in research, not in a standard clinical setting.

Current Treatment Model for JDM

Since the 1970s, significant advances have been made in the diagnosis, management, and treatment of childhood IIM. Despite this, little is known about the epidemiology and possible cures, which represent a considerable economic, medical, and social burden (Martin, 2011). Evidence has shown that early and aggressive treatment of the disease improves patient outcomes, whereas delayed diagnosis can increase the likelihood of disease complications such as calcinosis and daily functioning (Martin, 2011). There is a risk that the disease could continue into adulthood, but there is a lack of research on long-term health outcomes for childhood IIMs (Martin, 2011).

For JDM, the aim is medical remission, achieved through a two-pronged approach: first, high-dose intravenous corticosteroids to suppress the immune system and disease activity rapidly, and then, a tailored regime of immunosuppressant therapy to maintain dormancy (Kim, 2009). Effective treatment for JDM requires a multidisciplinary approach with patients, including occupational therapy, physical therapy, infusions, daily/frequent medications, and frequent blood tests to monitor disease activity. Depending on the severity of the disease, some patients may also require mobility aids such as wheelchairs or other supportive equipment for daily functioning (Cox, 2016; Sag et al., 2021).

The Single Hub and Access point for Paediatric Rheumatology in Europe (SHARE) is an initiative to optimise treatment regimens for children with rheumatic diseases. SHARE recently published best practice guidelines for the investigation and treatment of JDM, which were derived from a validated systematic literature review and consensus meetings with experienced paediatric rheumatologists. Based on these recommendations, a flow chart (appendix A) was established for the treatment of JDM (Kuemmerle-Deschner, 2017).

There have been significant advances in the quality of care for paediatric patients due to the introduction of multidisciplinary teams (MDT) which have been established worldwide (Cox, 2016). However, due to a multitude of reasons, such as socioeconomic status and geographic status, MDTs are not always easily accessible.

Veldkamp (2024) stipulates there is currently limited evidence to support the best treatment protocol for individual patients with JDM, largely due to a lack of validated tools to predict treatment response. Conversely, Enders (2017) states that there is a general consensus among clinicians on a treatment model, as shown in Appendix A, which practitioners currently follow. However, providing patients with a reliable prognosis remains challenging, particularly due to the rarity of the JDM and the limited clinical experience physicians have with this disease (Kountz-Edwards et al., 2017). Treatment schedules often depend heavily on the physicians' experience with rheumatic disease as there is an absence of sufficient randomised controlled trials in JDM.

While developed healthcare economies such as the United Kingdom and the United States of America have documented workforce standards for paediatric rheumatology, this is not yet the case in countries such as New Zealand and Australia. Additionally, there is a significant gap between child and adult healthcare services, which the child will eventually need to navigate and transition through. Research has shown, however, that adolescents are seldom examined as a distinct group (Tsitsani, 2023), resulting in insufficient data generation to guide future developments for paediatric support. Challenges such as reduced school attendance, disrupted developmental milestones, and the transition to adult services should be central to treatment planning (Tsitsani, 2023). Yet, healthcare systems are usually rigid, requiring the child and family to adapt to the system rather than the system adapting to

meet their needs (Tsitsani, 2023). A summary of the main interventions used in the treatment for JDM, depending on the child's symptom presentation, are provided in Table 2.

Table 2

Symptoms, interventions, and medications for Juvenile Dermatomyositis

Symptom	**Intervention**	**Medication**
Proximal muscle weakness	Physiotherapy	Corticosteroids Methotrexate Hydroxychloroquine (brand name Plaquenil) Intravenous Immunoglobulin (IVIG) Mycophenolate Mofetil (Cellcept) high-dose intravenous corticosteroids (Prednisone) Cyclosporine (brand names Neoral or Sandimmune)
Elevated muscle enzymes		Methotrexate
Skin disease	Shield from the sun	high-dose intravenous corticosteroids (Prednisone) Hydroxychloroquine (brand name Plaquenil) Mycophenolate Mofetil (Cellcept) Cyclosporine (brand names Neoral or Sandimmune)
Gottron papules		high-dose intravenous corticosteroids (Prednisone) Hydroxychloroquine (brand name Plaquenil) Mycophenolate Mofetil (Cellcept) Cyclosporine (brand names Neoral or Sandimmune)

Symptom	Intervention	Medication
Calcinosis	Surgery if significant enough	Intravenous Immunoglobulin (IVIG)

Since the 1970s, first-line treatment has been high-dose corticosteroid therapy 1-2mh/kg. Following this, depending on how the disease reacts to the administration of the corticosteroids, intravenous methylprednisolone (10-30/mg/kg) alongside methotrexate (0.4-1mg/kg) can be added. Maillard (2005) asserted that early aggressive treatment of the disease may reduce further complications such as calcinosis and lung disease and increase the likelihood of achieving early remission. For patients who do not respond adequately to the first-line treatment, additional immunosuppressive therapies can be implemented, such as cyclosporine, azathioprine, cyclophosphamide, and intravenous immunoglobulin (IVIG). Hydroxychloroquine is used for individuals with significant skin involvement. Physiotherapy is introduced early in treatment as soon as the patient can tolerate it, as research has demonstrated that despite earlier beliefs, there are no detrimental effects to starting physiotherapy while the disease is still active (Maillard, 2005). The most effective intervention would be the education of general medical staff to improve recognition of rheumatic disease and reduce delays in diagnosis (Cox, 2017). There are significant side-effects of the treatment model which are summarised in Table 3.

Table 3

Side-effects of corticosteroids

Biomedical	Psychosocial
Build-up of fluid	Mood swings
High blood pressure	Behavioural issues

Upset stomach	Confusion
Weight gain predominantly in the stomach and face	Delirium
Rounded face termed ’moon face’	Low self-esteem
Increased risk of infection	Depression

Personal Reflections

I will briefly outline my experience of parenting a child with JDM and getting a diagnosis in Aotearoa, New Zealand, as there is very little literature. My story and my daughter have inspired this research.

My story

It took approximately four visits to our GP and consistent advocation alongside a strongly worded email to gain a diagnosis for my daughter. After listening to my mother's intuition that was telling me that something was not right with my daughter, I took her to the GP to run a full set of bloods. Her blood results showed that she was highly sensitive to gluten. We all thought we had solved the mystery and put her on a gluten-free diet and monitored her symptoms. Three months later, she developed Raynaud's disease, which is a whitening of the extremities (mainly fingers and toes) due to a restriction of blood vessels as a response to cold or stress (Marczyk et al., 2024). Shortly after, she developed proximal weakness of her muscles, mainly in her thighs and arms. I took her back to the GP, who put her pain down to growing pains. After giving it some more time, my daughter started crying and being in intense pain after short walks around the mall. I took her back to the doctor, who could not pinpoint any cause as she presented well at the doctors with no soreness to the touch and no other visible symptoms.

After being sent away again and given more time, I started to investigate what it could be and spoke with other parents. I came up with a theory that it could be that she had one leg longer than the other, or she could have flat feet, which was causing her pain when walking. Once I thought about this idea, it dawned on me that the GP had not performed a thorough physical examination of my daughter despite her presenting multiple times complaining about sore legs. I sent my doctor's practice a polite but firm email stating that I was not happy with the care received for my daughter and that it was not right that she was in this much pain after going for short walks and that he needed to perform a thorough physical examination of her and run further blood tests. Once I sent that email, we were seen within a few days. The doctor gave her a thorough physical examination and gave us a form for further blood tests. Three days later, we received a phone call advising us that she had elevated blood enzymes that could be signifying inflammation in her muscles. The doctor had spent his personal time after hours on a Friday night researching what this could mean. After adding up her symptoms and her results, he hypothesised that she could have myositis. We were immediately referred to a paediatrician, who saw us once and, after listening to our story, confirmed the suspicion of Juvenile dermatomyositis and referred us to rheumatology. My daughter was six years old at the time of diagnosis. This story highlights the necessity for advocation and the strength of storytelling to help doctors and specialists put together puzzle pieces to form a diagnosis.

Due to the rareness of JDM, it is challenging to form a prognosis, which left me with no way to tell how my child will cope with treatment, what the overall disease progression might look like, or which path it will follow. There is no firm treatment plan in place; instead, treatment is fluid from start to finish and changeable at any given moment. These are big

concepts to grapple with as a newly diagnosed child of JDM and a parent. Treatment experiences for us have been a range of negative to positives for several reasons. We nearly always had positive interactions with most nurses while they tried to compensate for the state of the public healthcare system. Conversely, we had some negative experiences due to not being listened to; one of these is outlined in the findings under advocation. My daughter's veins were difficult to locate, and while she handled needle insertion well, it took the nurses up to five times to get a line in her veins. We requested that an ultrasound machine be used for her cannulas as that way they got the line in first time every time and reduced the trauma my daughter experienced by a simple yet resource heavy alteration to the normal protocol. We were extremely patient and often waited up to five hours for the cannula to be put in before starting an eight-hour infusion, as only an anaesthetist could use the ultrasound machine when inserting cannulas. Compounding this resource demand was the fact that there were only two ultrasound machines available for use that needed to be shared around the wards. From start to finish, the procedure took approximately five to ten minutes and was done the first time, every time. Conversely, if an ultrasound machine was not used, it took three different staff members attempting three separate times to locate a vein before calling a senior doctor to try and access already sore and tired veins. While we appreciate the hospital trying to accommodate my daughter's needs, this highlights how a simple resource such as having an adequate number of ultrasound machines to service a hospital could have a significant impact on children's treatment experience. Our local children's hospital is being renovated, which is a four-year-long process. This means that space is restricted further, and we were often moved two or three times a day around the hospital to go where they had staff or room due to the infusions taking up to thirteen hours a day. Our experience highlighted the pressure and restrictions the hospital staff have to

work within each day with a rising tension between quality of care and what is practically possible. Staff shortage was a significant factor both in rheumatology and the hospital as a whole.

The hospital where we received our treatment had a very small team consisting of one paediatric doctor specialising in rheumatology and two rheumatology nurses who were both part-time. Due to this, it could cause delays when we were waiting for blood test results to dictate whether we could continue weaning off steroids. This is due to the on-call registrars not having the required knowledge of patient history and JDM to make the call without cross-checking with the specialist. It would mean we would have to wait for them if they were on annual leave as there was no adequate cover.

There is little support offered in the way of information, support systems, or how to access alternative support such as counselling services or cultural support. Children and their parents are presented with complex medical requirements that demand multiple aspects of specialist care. I received no guidance around supporting my daughter's emotional, spiritual, or mental well-being. We were not offered counselling sessions or given information on signs or symptoms of depression or anxiety to look out for, as my daughter underwent invasive and persistent treatment for her symptoms. I advocated for psychological support for my daughter, but we are still on the waiting list to see a psychologist, however, we were offered sessions with a mental health nurse. We had sessions with her once a month while we were in the hospital for infusions. These sessions were vital as they gave my daughter much-needed communication where she could be honest and speak with someone outside of her support network which I felt was important as it meant she did not have to ‘perform’. However, due to my daughter presenting so well

in sessions, we were soon discharged. This is despite having informed them that my daughter was experiencing violent outbursts resulting in self-harm. We were reassured that we were doing everything right and doing very well coping, as such, other children needed the service more. I have also not been offered any psychological support for myself, meaning finding a community of support and information has been key for me.

Rationale for the present study

The rationale for surveying and talking to the parents is that while children have their perspectives on how the experience made them feel, there are many aspects that they will not be aware of, such as the difficulties in advocating for a diagnosis, the logistics and cost associated with treatment, managing the flow of information, attending appointments in an acceptable time frame and navigating the politics of the health care system. For this reason, the primary participants in this research are the parents. The secondary reason is due to the rarity of JDM, few robust studies adequately cover the experience of children's journey to diagnosis, treatment, and long-term outcomes. However, it was important to gain the child's perspective and children were encouraged to answer one question in the survey.

Current research predominantly employs quantitative methods to assess treatment outcomes with a significant emphasis on developing prognostic tools for newly diagnosed individuals. Whilst this is valuable research, there is a gap in the literature focusing on the experience of children and their parents going through the journey of diagnosis, the aggressive first-line treatment, and the long and unknown treatment path for an incurable disease. I could locate one 2020 doctoral thesis based in the United Kingdom called '*Understanding the lived experience and psychosocial needs of children and young people with Juvenile Dermatomyositis'* (Livermore, 2020), and a handful of articles on parenting

experiences including one 2017 article called '*The family impact of caring for a child with juvenile dermatomyositis*' (Kountz-Edwards, 2017) and '*Perspectives and experiences of parents of children with juvenile dermatomyositis: a semi-structured interview study* (Kelly et al., 2025). These publications noted the scarcity of qualitative research available on the experience of children with JDM. Additionally, they all summarised that early mental health support and screening for psychosocial concerns such as anxiety or depression with the child or, ideally, the entire family would be beneficial.

There are many gaps in the literature surrounding JDM, such as long-term outcomes, early markers for prognosis, and the effect long-term treatment has on the child and their support system. There has also been very little phenomenological research on the experience of children undergoing treatment in the public healthcare system for JDM and their parents (Cole, 2013). Understanding the treatment experience of children and their parents is crucial for the advancement of treatment and is essential for improving patient care to ensure that their medical and psychological needs are met. By conducting this study, I am hoping to add to the current research to provide a better understanding of those experiences to better inform health professionals in the industry of how these experiences can be better supported.

The primary aim of this research was to explore the unique experiences of parents of children with Juvenile dermatomyositis (JDM) undergoing treatment through the public healthcare system. This research aims to explore the systematic challenges experienced in the healthcare system that can have a significant impact on the child and their treatment experience and inspire systematic change.

Research questions

This research is aimed at answering the following questions:

1. What are the lived experiences of children undergoing long-term treatment for Juvenile dermatomyositis (JDM) and their parents within the public healthcare system?
2. What are the main barriers to gaining a confirmed diagnosis?
3. What challenges do children and families face when they do not have enough wraparound support for their chronic illnesses?

The objectives of this research are to:

1. Understand the subjective experiences of children and their parents undergoing long-term treatment for Juvenile dermatomyositis in the public healthcare system.
2. Identify areas where extra support is required.
3. Focus on areas of holistic support: what is offered surrounding the hard front-line treatments, long-term treatments such as mental health support, comfort during treatments, and basic human needs being met such as food offered and better communication.

Chapter 2 - Literature Review

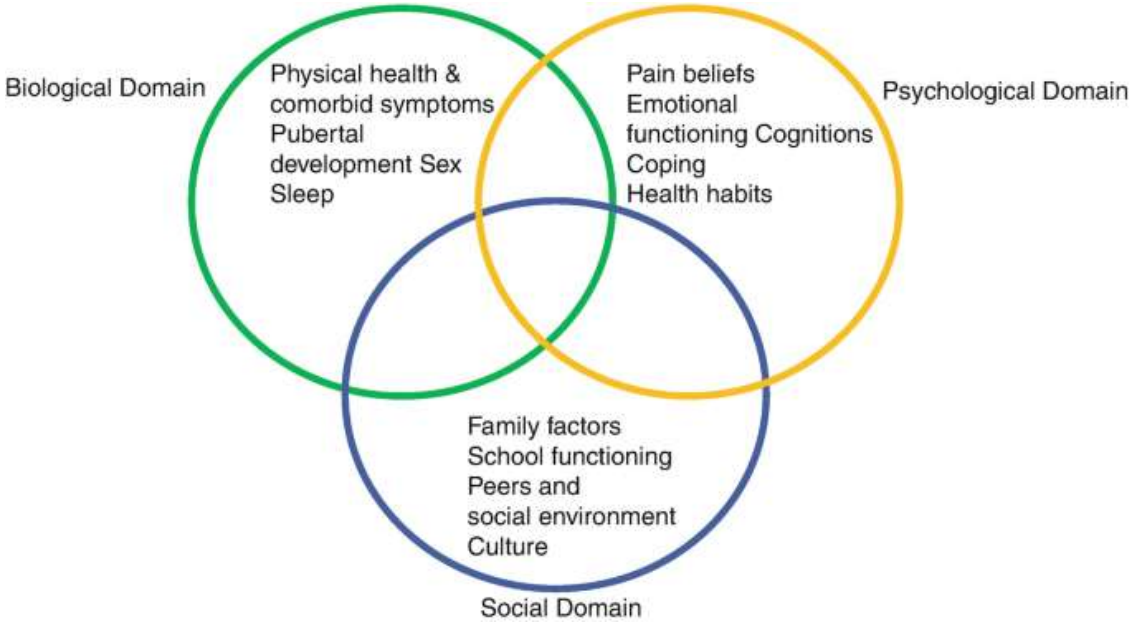
This chapter is organised into four main sections. Firstly, the need for a biopsychosocial model of care is explored. Next, the chapter reviews research that supports this approach, focussing on the quality of life and the impact of diagnostic delays. Thirdly, the experience of treatment is examined. Early and intensive treatment is recommended to halt the disease progression before the symptoms become unmanageable. Unfortunately, due to the rarity and insidious nature of the disease, symptoms can set in long before a diagnosis is obtained.

Biopsychosocial model of care

While a biopsychosocial model specific to JDM currently does not exist, the model shown in Figure 1 for the paediatric chronic pain framework (Essner et al., 2020) effectively illustrates the key areas to consider in understanding and treating JDM. Chronic pain is part of the experience of JDM, so this model fits JDM well in the absence of its own. Also, as the children in this study were between ages five and seven years, it is important to consider both the child and family. The primary caregiver typically spends large amounts of time and emotions supporting the child, and there may be differing levels of distress and financial and other burdens (Essner et al., 2020).

Figure 1

Biopsychosocial model of care for paediatric pain



Note: Recreated by author based on Biopsychosocial Approaches to Pediatric Chronic Pain Management (Essner et al., 2020).

While there is no psychosocial model of care for JDM specifically, when treating children with rare chronic diseases in paediatric care, it is recommended that the 'best interest standard' in paediatric chronic disease framework is followed. The best interest standard is a child-centred and family-oriented framework that prioritizes the child's well-being (HarnEnz et al., 2023). This best standard encompasses some of the biopsychosocial model's principals, such as focusing on the child and their support system, not the disease and treatment alone. Parents are assigned as the surrogate decision-makers in following the best interests of their child rather than their preferences or biases, taking into consideration the child's medical condition and overall well-being (HarnEnz et al., 2023). A holistic model

of care that includes families and primary caregivers, ensuring all are supported at all stages of the disease, is ultimately required for the best outcomes for all. In a research article on the family impacts of JDM treatment, parents shared that they would prefer an integrated care model that includes a social worker (Kountz-Edwards et al., 2017). In Aotearoa, New Zealand, a similar model using te whare tapa whā (Durie, 1985) is ideally used in health settings to ensure holistic care and is endorsed by the Ministry of Health (Purdy, 2020).

Biological domain

The biological domain for JDM encompasses physical health, comorbid symptoms, pubertal developmental sex, and sleep. The main challenges for JDM are the developmental stages as young children will go through major development milestones physically, emotionally, and psychologically. Additionally, children with chronic illness may not develop in line with their healthy counterparts due to delayed neurocognitive development, disruptions in education, and social isolation in addition to medical treatments and their potential to impact physical development (Turkel, 2007). It is important to consider these developmental milestones when treating the children. Dosages change due to weight gain, and dosage changes with treatments such as IVIG mean longer infusion times. Additionally, sleep patterns can be affected as treatment schedules can start early in the morning and can sometimes run late into the night. Bouncing back after treatment into daily life at home and school can be largely affected by the age of the child and where they are developmentally.

Models using biopsychosocial models for pain have highlighted in the biological area that the age and gender of the child can be important to consider (Essner et al., 2020). For example, older female children have been found to have worse self-reported pain post-operatively or in situations of chronic pain (Rabbitts et al., 2020). However, research

remains inconclusive as to whether older youth can cope better with pain or that there are no gender differences (Caes et al., 2024). Age plays an important role in cognitive and psychosocial development and is important to consider which is why I chose children between ages five to thirteen years for this study. Genetics play an important role in JDM, plus any other pre-existing medical conditions as well as inflammatory and endocrine responses (Rabbitts et al., 2020).

Psychological domain

The psychological domain encompasses pain beliefs, emotional functioning cognitions, coping, and health habits. Temperament has also been shown to have the potential to moderate pain experiences and interventions aimed at pain reduction (Caes et al., 2024). Individual responses to stress, trauma, and other psychological stressors vary significantly from individual to individual and also through developmental milestones (Falvo, 2014). Children can experience fear of their illness and medical procedures, consequently, children are also at risk of developing maladaptive behaviours that increase the risk of impaired physical functioning, fatigue, obesity, psychological distress, and a poor quality of life (Rohan, 2020).

Anxiety and depression have closely been tied to chronic pain in paediatric samples (Rabbitts et al., 2020). Some of this can be explained by fear and catastrophic thinking, such as pain catastrophizing, pain-related fear, and pain vigilance. This is explored further in a Donnelly (2020) study that reveals that parental catastrophizing and protective behaviour directly influence children's protective mechanisms and stress response. Children develop protective factors such as pain-coping efficacy and pain acceptance as well as optimism that have all been shown to impact how a child and their family cope with chronic pain (Caes et

al., 2024; Rabbitts et al., 2020). Behavioural factors point to sleep and level of disability to be important in predicting coping with chronic pain. Due to a lack of mental health resources and funding, particularly in New Zealand, Aotearoa, providing a complete wrap-around service encompassing psychological support to children experiencing rare and chronic illness is challenging. Additionally, the healthcare system tends to prioritise the biomedical aspect over the psychological as it presents as the most pertinent; however, if left unattended, psychological health can manifest pathologies such as depression or anxiety as a post-trauma response (Rabbitts et al., 2020).

Social domain

The social domain encompasses family factors, school functioning, social environment, and culture. These areas significantly impact various pain-related psychological constructs, such as pain anxiety, catastrophizing, flexibility, and sensitivity, as well as depression. Parental reactions to pain and overall family functioning also play crucial roles (Rabbitts et al., 2020). There is further research in other spaces, such as supporting a child with cancer, that points to the important role of parents in outcomes for the child but also the importance of supporting parents (e.g. Nielsen et al., 2024). The term used to describe parents helping their children through chronic illness is ‘coping assistance’ (Hildenbrand, 2011). Hildrenbrand (2011) also reported that children experiencing cancer treatment reported stressors associated with disruptions in their daily routines, which created feelings of isolation and a sense of missing out on school and family life.

Culture significantly shapes family functioning in the context of chronic pain, impacting family structure, the distribution of caregiving roles, and the integration of how cultural needs are being met through treatment. In New Zealand, there is a resurgence of

integrating Kaupapa Māori methodology into treatment to ensure that cultural needs are being met, which is positive; however, in practice, experiences of Māori in health settings are often not positive (Manuel, 2024).

Family culture also significantly affects treatment experience, and cultural beliefs about medicine can influence treatment adherence (Shah, 2021). Much of the research about families focuses on mothers or assumes a nuclear family which ignores fathers' perspectives or families that are blended (Nielsen et al., 2024). Additionally, there is a lack of research focusing on single parents who are often left to balance work, other children and the child's medical needs on their own (Rafferty, 2017). These single parents report that the sense of being overwhelmed can often interfere with their ability to advocate (Rafferty, 2017). The family's individual and collective coping mechanisms and belief systems around coping can have significant impact on how the child processes treatment experience (Carrol, 2020). For example, if the family encourages open expression of emotions and talking about challenges as a family which can encourage the child with JDM to freely express themselves in a psychologically safe environment. Adversely, if the family adopt a stoic culture of withholding emotions and not talking about feelings or repressing them with alcohol, this can create an environment where the child does not feel safe expressing their feelings which can put them at risk of developing mental health issues. Additionally, the impact on the family may be similar to or even greater than that experienced by the patient (Shah, 2021). This can be due to siblings and parents lives also being impacted by extra time off work or school, not being available to attend social functions or host at home due to the child with JDM being immunocompromised. Family dynamics also influence the treatment experience of children with JDM (Carrol, 2020). Families who are close with extended family available to provide extra support greatly ease the burden of caregiving. Whereas families

living rurally or who do not have a great support network to provide additional assistance can experience added stress and anxiety due to being unable to share the responsibilities of the caregiving role.

The developmental stages of families are also important in shaping the experience of children with JDM. The age of the child when they start experiencing symptoms and the age of their siblings and even their parents all influence how they each process the treatment experience. The emotional, psychological, and physical needs of a three- or five-year-old are significantly different from those of a young teenager (Borg-Laufs, 2013). The ages of their siblings and whether they have any siblings also influence how much time their parents can dedicate to their specific needs while not neglecting the needs of their other children or themselves.

Quality of Life for children and families living with JDM

There are many demands put on families who are managing chronic and serious long-term illness. Ideally, for the best outcomes, parents and children should be supported in all domains, as highlighted in the previous section. However, research in areas such as child cancer and rare childhood illnesses points to challenges around communication and insufficient wrap-around support for parents (Hemmati et al., 2022). Research has consistently found that parents feel there are gaps in information and emotional and psychosocial support for parents of children with cancer (Thomas et al., 2023). Gill et al. (2020) identified that support for parents of children with life-limiting illnesses should focus on communication (including choice and information) and practical and psychological support in both emotional and physical areas. However, there remains a lack of support in these areas creating additional burden and distress. More concernedly, interventions aimed

at one area for parent support often do not translate into significant improvements (Gill et al., 2020). This may suggest that more holistic support is needed rather than just focusing on one domain.

Quality of life and role of the parents

Parents facing a child's chronic illness diagnosis are required to dramatically restructure their roles. They are required to simultaneously maintain their parental roles while assuming critical medical responsibilities, including injections, oral medication, and adherence to a strict treatment regime. Additionally, parents assume the role of coordinator of family logistics while they navigate treatment schedules (Rafferty, 2016) around family obligations. Parents also become experts on their child's condition, often having to advocate for them in different healthcare settings, including diagnosis and treatment, coordinating between multiple specialists, and ensuring no mistakes are made due to poor paperwork or communication. This totals in an immense increase of mental labour that parents take on when they receive a diagnosis for their child; this increase comes without warning, and parents are often left to navigate this journey alone.

Research has indicated that parents of children with chronic illness can be negatively affected, experiencing greater levels of stress and are susceptible to increased levels of anxiety (Kountz-Edwards, et al 2017). Tsitsani (2023) also noted that the quality of life for parents can be severely impacted by disruptions to their professional lives and social connections, alongside the lack of personal time and space required to maintain physical and mental well-being. Parents also need to prioritise and juggle appointments between their child with JDM and the needs of their other children. Additionally, parents can experience intense feelings of guilt over spending time with their JDM child over their other

children. Siblings can also experience feelings of neglect and abandonment when their sibling is receiving more attention than they are. It is important that siblings receive the support that they need and the education required to understand what is happening and what it means for the child with the diagnosis and the rest of the family (Knecht, 2015). The developmental stages of other siblings also need to be considered with families undergoing long-term treatment for chronic illnesses. A younger child will have less cognitive understanding and more physical, emotional, and psychological needs, whereas an older child or teenager will have more cognitive understanding and less physical needs but possibly equal or greater psychological needs (Knecht, 2015).

The role of parents serves as a vehicle of essential knowledge in rare health conditions as they can influence how children perceive their health and process their condition (Carrol, 2020). If the parent remains calm and in control of their responses to diagnosis, treatment updates, and the treatment schedule, it creates a solid grounding for the child to manage their responses. If the parent responds in a way that inspires fear and uncertainty in the child, this will be reflected in how the child processes what is happening to them (Carrol, 202). For example, if the parent catastrophises and indulges in extreme worry, then it is highly likely that the child will too. However, if the parent remains calm and pragmatic, the child will highly likely remain calm as a result. While there has been very little research that focuses solely on the parent experience of JDM, there are studies on similar chronic conditions that show that parents are adversely affected by the status of their child's disease, which in turn affects family functioning (Kountz-Edwards et al., 2017).

Despite the many potential negative effects of JDM, some parents have reported that their worldview has shifted, and they have developed more empathy and compassion

(Kountz-Edwards et al., 2017). Björk (2009) noted that knowledge is power for the parents, and researching to educate themselves as much as they can about JDM can help to reduce their anxiety. This has been emphasised through the literature on living with a chronic illness, that although physicians and health professionals can guide the individual's care and treatment, it is ultimately the responsibility of the patients, along with their families (Kountz-Edwards et al., 2017). Subsequently, the daily responsibilities and management of the disease fall into the hands of the patient and their families, which can cause a significant burden as they re-prioritize their lives to suit their new normal (Kountz-Edwards et al., 2017).

Quality of life for the child

The quality of life for a child with JDM and their family can vary greatly depending on how the disease presents. Some children can have heavy muscle involvement with little skin involvement, while others may have heavy skin involvement. The skin involvement can be on exposed parts of the body, making it highly visible, and can be itchy and uncomfortable, with sores developing in intimate areas. Gottron papules can develop which are very red and obvious lumps on the knuckles, elbows, and knees (Kumar, 2017). Children with heavy muscle involvement can lack the strength to sit on the floor and stand back up again or open a car door. Quality of life across all areas can be affected by bullying in school due to the visual nature of JDM to daily functioning and loss of independence.

JDM can also present as an invisible illness; children can appear fairly normal and mask their symptoms well. Children often hide their symptoms so they can partake in normal daily living both at home and at school as much as possible. The danger in this is that triggers such as too much sun or physical activity can trigger a sudden and rapid decline in

their symptoms and health. In a study on children living with congenital adrenal hyperplasia (CAH), the children reported challenges with managing their illness at school, by taking time away from class to take medications, handling staff and peer perceptions, and coping with stigma (Carrol, 2020). Additionally, children reported that they felt that their chronic illness affected their academic performance and that their absences from school affected their social relationships (Carrol, 2020). School staff, including school nurses, often lack the knowledge and training to be able to adequately attend to children with chronic illnesses (Carrol, 2020). Consequently, schools often express concerns over risk and liability over caring for children with chronic illnesses, often erring on the side of caution and prohibiting them from taking part in certain activities due to fear (Carrol, 2020). An understanding of chronic illness and continued social support are integral to a child's quality of life (Carrol, 2020).

Age is important to take into consideration, younger children tended to present with a sunny disposition than their older counterparts who present with a much more self-critical perception (Carrol, 2020). Younger children have the advantage of maintaining a sense of naivety due to not having the developed cognition to completely comprehend the extent of what living with a chronic illness entails.

Family impacts

As Kountz-Edwards et al (2017) noted in their research, families of children with JDM experience increased challenges with daily family functioning, communication, and an increase in family conflicts. Additionally, the child's siblings and extended family can also be affected by the child's chronic illness (Kountz-Edwards et al., 2017). The effects can range from heightened emotional states, including increased anxiety or worry, or disrupted daily

life due to multiple appointments being juggled with other responsibilities. Due to the rigorous treatment regimens of JDM, family functioning can be significantly impacted (Kountz-Edwards et al., 2017). Early and intensive treatment is recommended to halt the progress of the disease before the symptoms become unmanageable (Martin, 2011). Unfortunately, due to the rarity and insidious nature of the disease, symptoms can set in long before a diagnosis is obtained. The fear of the unknown and the battle for diagnosis can have a strenuous effect on the rest of the family unit while the child with JDM gradually declines, resulting in unmet needs and tense family dynamics (Tsitsani, 2023).

Barriers to Diagnosis and Treatment

Systematic barriers in the healthcare system can influence treatment experience

It is well known that healthcare systems in most countries are stretched for resources; however, rheumatology, in particular, has a severe lack of resources and funding (Cox, 2017). Some hospitals are reported to have only one small rheumatology team, and they can often be part-time workers. Additionally, if the rheumatology team is not available there are no teams who can make major treatment decisions without consulting the rheumatology team first. Instead, whatever is occurring is put on hold until someone from the rheumatology team is reached. Subsequently, this can sometimes cause treatment delays, especially if it falls on a Friday afternoon, and the family is required to wait until the following Monday to receive answers.

According to the National Health Service (NHS) UK, to provide comprehensive care, there needs to be one paediatric rheumatologist, two specialist nurses, one physiotherapist, and one occupational therapist per 200,000 children (Cox, 2017). In Australia and New Zealand, that would require a minimum of 14 full-time paediatric rheumatologists with

multi-disciplinary support teams to provide clinical care to our population (Cox, 2017). New Zealand and Australia face a critical shortage of paediatric rheumatology specialists, with only one training site in New Zealand and two in Australia (Cox, 2017). Consequently, this issue will be difficult to overcome until more training facilities are created. Cox (2017) also reported that Australia has the most significant delay of symptom onset to diagnosis of JIA; this could be due to the lack of specialists in the rheumatology field. In a recent study, Cox (2017) found that more than 40% of children across Australia and New Zealand do not have easy access to multidisciplinary team care, which is essential in the care of patients with JDM. This could be due to a combination of factors, one of which is rural living and the other a lack of specialists available. Teutsch (2023) stipulated that those children living in rural areas of Australia experienced significantly more barriers to healthcare access than children from major cities.

Hospitals can often be short-staffed, relying on whoever they can find to cover. The staff that are covering can often not be qualified to do more than monitor vital signs and ensure basic needs are met. A Cox (2017) study stipulates that provisions must be in place to ensure that the paediatric rheumatology teams work within connected networks to ensure that adequate cover can be obtained if and when required. Furthermore, tight disease control has led to an increase in the use of early and aggressive immunosuppressive therapy and biological drugs, which can only be prescribed by paediatric rheumatologists (Cox, 2017). This places additional pressure on an already stretched healthcare system that, as mentioned earlier, is already understaffed. Due to the chronic nature of rheumatic diseases, individuals living with one can become a long-term burden on the healthcare system, their families, and their communities (Cox, 2017). Lack of practical resources can also have an impact on patient care. Wards can struggle with not having enough beds, pillows, or cups in

the shared patient kitchen. Nurses can share thermometers between wards along with more technical equipment such as ultrasound machines that are used to access tricky veins.

Health promotion and advocacy

Advocacy plays a significant role in the journey to diagnosis and treatment for rare diseases. It is often left to the patient or their caregiver to advocate for a multitude of services ranging from further diagnostic testing when answers are not provided, adequate treatment and follow-up appointments, and alternative treatment services. The degree to which a parent needs to advocate on behalf of their child spans across three main areas: school, community, and medical (Rafferty, 2016).

Parents are required to advocate for their child and their needs in the education system. Advocating is required for additional services or support in the classroom, gaining access to additional resources to facilitate at-home learning, and sometimes making the call to pause or eliminate their schooling during treatment (Rafferty, 2016). Advocating for staff understanding and flexibility for school hours can be challenging especially if the child is presenting '*normal*'. While there is scarce research in this area for JDM, Rabba et al. (2024) found that mothers experienced emotional exhaustion from the need for constant advocation to gain support and understanding from schools for their children with autism. They were made to feel like they were the problem. Rabba et al. (2024) also found that parents' confidence in advocacy grew over time as they started to feel comfortable speaking up.

Parents are often tasked with the responsibility to advocate for fair and adequate treatment in a medical setting. This entails entering into power struggles with doctors and specialists (Rafferty, 2016). There is a significant gap in the research concerning parents'

roles as advocates for their children in healthcare settings (Rafferty, 2016). When parents perceive inadequate care from their medical team, they often find themselves having to advocate on behalf of their children (Rafferty, 2016). This tension between wanting the best for their child and respecting the opinion or actions of the medical team can create uneasy situations that both parties carefully navigate while hopefully keeping the best interest of the child in mind. Rafferty (2016) reported that parents had a sense or authority due to knowing their child best even though they relied on medical professionals for healthcare. Furthermore, conflicts were exacerbated when medical professionals did not respect the parents' expertise on their child and their treatment choices (Rafferty, 2020). These conflicts create a significant amount of added stress on the already stressed parent and can often leave them with feelings of exhaustion and powerlessness (Rafferty, 2016).

Parents have reported advocacy as being challenging and emotionally draining (Rafferty, 2016). Subsequently, parents join social networks that foster social relationships and networking with other parents in similar situations. A study by Sonsteng-Person (2023) revealed that parents developed spaces of hope through advocacy. Sonsteng-Person (2023) also reported the challenges parents faced in a system that did not consider them experts and often felt unheard. Feeling a part of a community can increase feelings of belonging and decrease feelings of isolation that being the parent of a child with a rare chronic condition can bring. Social media sites such as Facebook can provide social networking and support for parents including providing extensive experiential knowledge and validation of their struggles (Rafferty, 2016). These groups can also morph into activist groups as parents discuss and share ideas of how to access the most up-to-date treatment for their children and any alternative treatments that exist that they have not been informed of. Through this process, parents may find out that services in one area are offered but not in others, so

parents would form groups to lobby and advocate for fundamental systematic change to make treatment more accessible for a wider range of people.

Socioeconomic disparities produce significant barriers to the early diagnosis of JDM. This can be due to the cost of repeatedly going back to the doctors in search of more answers: the cost of an appointment, the cost of transport to and from the clinic, time off work or school, and how that affects family members. There is also a strong correlation between socioeconomic status and disease outcome, as described in a study by Abramson et al. (2017), which showed poorer disease outcomes for minority groups. Minority groups were more likely to have a lower socio-economic status as well as poorer disease outcomes with lower scores on muscle weakness, physical function, and quality of life as well as being more likely to develop calcinosis (Abramson et al., 2017).

Patient awareness of JDM

As Miller (2023) highlights, there is a call for greater awareness and understanding of adulthood auto-immune diseases such as lupus, multiple sclerosis (MS), dermatomyositis, and Crohn's disease. However, there is scarce research calling for more awareness regarding childhood autoimmune diseases. Dermatomyositis (DM), which is the adult version of JDM presents quite differently to Juvenile dermatomyositis (JDM), the childhood disease. JDM can persist into adulthood, and if this happens, additional side effects can develop with further risks, such as the risk of interstitial lung disease, amyopathic disease, and malignancy (Patil, 2023). Subsequently, constant monitoring of the disease is imperative while it is still active and, if the child is getting close to adult age, a plan to integrate them into adult care needs to be incorporated into their treatment plan. Developmental

milestones also need to be considered as the child moves from childhood into adulthood, so consistent access to mental health support is beneficial.

The majority of the general population will not have heard of JDM unless they have had a personal tie with it through a loved one or someone they know. When searching online for JDM, it can become intimidating, with the information presented alongside visuals of the lumps caused by calcinosis and Gottron papules. Patients and their parents can easily become frightened with little understanding of the disease and no early available prognosis and concrete treatment plan. The sudden nature and severity of the onset of symptoms of JDM make it one of the most shocking diseases to experience. Patients report feelings of shock and confusion when witnessing the sudden decline in physical function (Gómez-Ramírez et al., 2016).

Healthcare Awareness of JDM

Rare diseases (RD) in paediatrics are characterised by clinical heterogeneity and are chronic (Tsitsani, 2023). Treatment demands a multidisciplinary approach where parents act as the conduit between different specialists. Due to the rare occurrence of JDM, it is not a well-known disease, even within the healthcare community. Most doctors and nurses outside of the specialist team have very limited knowledge of the cause or treatment of JDM. Due to a lack of specialists in the rheumatology profession, patients can often be treated by non-rheumatology doctors. These doctors may not be aware of all the available management modalities to offer the patient, resulting in suboptimal care (Cox, 2017).

There seems to be a gap between healthcare professionals' understanding of JDM and the real-life experiences of individual patients. In search for answers, parents turn to social media support groups and charity organisations such as CureJM. Conducting

independent research can quickly become overwhelming as information can be received out of context. However, some physicians may be reluctant to provide complete information and may dismiss parental concerns regarding potential complications. This tension created from managing parents' expectations can be translated into feelings of not being listened to or taken seriously. Björk (2009) found that when parents had meaningful discourse with hospital staff, they felt heard and supported, and when they did not feel listened to, they felt they lacked support and understanding.

Summary

The literature highlights that there is a need for further research into the treatment experiences of children with JDM. Furthermore, it is necessary to identify strategies to assist in facilitating the early diagnosis and treatment plan for adolescents to ensure the best outcome. Currently, there are no standardised treatment protocols following the first-line treatment leading to feelings of fear and uncertainty in patients and their families. Treatment is based largely on the physician's experiential knowledge and the funding of the hospital that dictates the number of staff and priorities. There is a shortage of rheumatology specialists, which compounds the aforementioned challenges. Families require additional support through the journey to diagnosis, treatment, and remission. As highlighted by Cox (2017), to ensure that children living in New Zealand, Australia, and the United Kingdom receive internationally recognised standards of care, increased allocation in clinical services, specifically rheumatic diseases, is required.

Chapter 3 – Methodology

In the following chapter, I will discuss the philosophical assumptions underpinning my research and the qualitative approach I used to interpret it. I will outline the methodology of the data collection, including study design, survey, and interview styles. Following this, I will outline the process of Thematic analysis and why it is appropriate for my research. Next, I will outline the ethical considerations, cultural awareness, and the implications of including children in my research. Finally, I will touch on the reflexivity included in my research process.

Epistemology

This research is interested in how children and their parents experienced treatment which is underpinned with critical realism (CR). Critical realism acknowledges that an objective reality exists, such as JDM as a diagnosable condition, however, the individual experiences of JDM are unique, and individuals construct their meaning through their personal experience (Peter & Park, 2018). The unique meaning individuals construct from their experiences is what differentiates them, and even with a shared diagnosis, each participant's experience of the disease remains unique.

I chose reflexive thematic analysis as this is a flexible framework that allows me to explore the parents' experiences from both the survey and interviews (Braun & Clarke, 2006). Through this process, I interpreted participant responses, making sense of how they understood their experience. I maintained a sense of transparency for how my interpretation and the method of analysis were used to engage and develop together (Braun & Clarke, 2006). I achieved this by keeping records of the development of my analysis,

sharing my mind mapping file with my supervisor, and reflecting on the way themes developed through the research.

Therefore, my approach was interested in the experiences of children and their parents: their experiences of attending treatments and follow-up appointments and their experiences of facilitating multidisciplinary specialist appointments. This research is not just interested in the *what* but in the *how*.

- How did the long treatment days make the child and their parent feel?
- How did the healthcare system cater to their feelings and needs?
- How does the parent feel when the healthcare system won't believe that there is something wrong with their child?
- What are the ripple effects that affect family, social, and school life?

Study Design

As JDM is such a rare condition with scarce qualitative research available, it was important to me to get both depth and breadth of information. This was the primary motivation for utilising a mixed-method study design, using an anonymous online survey followed by a semi-structured interview. To better understand the perspectives of children and parents facing long-term JDM treatment, this research used a survey focused on treatment experiences, with opportunities for parents to share their own stories and insights through open-ended responses. While the qualitative aspects of the survey granted the research relative depth and coverage of the JDM treatment experiences, the research required further detail that could not be covered in a survey due to the sensitive information I was seeking. Consequently, I also offered semi-structured interviews to all survey participants. Semi-structured interviews are powerful tools that enable researchers to access

in-depth accounts from interviewees while also maintaining the focus of the study (Ruslin, 2022). The purpose of the interviews was to provide experiential data that would complement and expand upon the survey findings. Utilising qualitative methods through a mixed-methods approach and two-phase research created a rich and complex data set not achievable with a quantitative method alone (Reay, 2019). This mixed-method survey design facilitated the capture of a broad range of individuals' meaning-making experiences and perspectives while undergoing long-term treatment for JDM (Braun et al., 2021).

Survey Design

The strength of an anonymous survey is that it facilitated the recruitment of a diverse, international sample pool, which encouraged participants to share their experiences without fear of identifying their place of treatment (Braun et al., 2021). The survey was created initially in Word and then put into Qualtrics. The survey included the information sheet and the survey questions (A copy of the information sheet can be found in Appendix B and a copy of the survey can be found in Appendix F.)

The first part of the survey was used to gain demographic information such as the children's age and gender, country of residence, whether the mother or the father answered the questionnaire, and the length of time since diagnosis. The rest of the survey asked about treatment experiences. The survey started with the journey to diagnosis, facilitators and barriers to having a positive experience during treatment, and interactions with healthcare providers, and finishing with an optional question for the child asking the child to describe what it is like having JDM and if there was anything that would make treatment easier for them. The children were invited to answer the question in writing or by drawing a picture. Open-ended questions were asked in the survey, allowing the participants to share anything

that had not been covered in the survey questions. Examples of the survey questions are shown in Table 4.

Table 4

Example questions from the survey

Closed-ended questions	Open-ended questions
Select which treatment the child in your care is currently undergoing.	In this section, you were asked about your journey to the diagnosis of JDM. Is there anything further you would like to add?
Do you get subsidised or free parking at your place of treatment?	If yes, what were some of the things you did to help ease their anxiety?

The quantitative aspect of the survey allowed me to gain practical information on which treatment the children were receiving, ensuring the participants met the participation criteria, and allowed me to identify key areas where their experiences may vary due to country of residence (Flick, 2022). The questions were developed using my insider status based on what I experienced throughout my time in treatment with my daughter who has JDM, alongside the gaps that I identified in the literature review.

The qualitative survey questions were used to generate diversity and depth within the research (Jansen, 2010). Like the quantitative survey questions, I used my lived experience and the literature to develop open-ended questions regarding various treatment areas focusing on both medical and holistic aspects of treatment, including home-based treatment, and the impact on the family due to travel time.

It was important to me to allow the children the opportunity to respond to the survey. This was done by including an additional consent form for the child that the parent

agreed to on their behalf at the end of the parent survey. It then asked the child to answer the questions 'Describe what it is like to have JDM' and 'Is there anything that could help make treatment better?' Due to the wide age range of the children answering this question, I invited them to either write a sentence or a story or draw a picture.

Recruitment

I requested permission to advertise in the form of a Facebook post along with the poster from the administrators of a Facebook page called 'Juvenile Dermatomyositis (JDM) Parent and Caregivers.' This was where I was hoping to get the majority of my data sample due to the members being from the countries of my target population. The primary countries included in this study were New Zealand, Australia, and the United Kingdom, chosen for their relatively comparable healthcare systems. Countries with fee-for-service healthcare systems, such as the United States, present distinct challenges that can impact treatment experiences; therefore, they were excluded from this study. The request from this Facebook site was declined; the admin advised that they do not allow advertising information on their support page. Consequently, I put in an amendment to my ethics application to include seeking permission to advertise on hospital and government-funded health sites (see Table 5) and creating a paid Facebook advertisement utilising keywords to reach my target audience. Once the ethics amendment was approved, I created the paid Facebook advertisement and went live. I sent emails to multiple websites asking if they would be willing to advertise my poster on my behalf.

Table 5

Websites contacted and their responses

Website	**Did they respond**	**Response to advertising on my behalf**
Madison https://www.childrens.health.qld.gov.au	Yes	Yes
Arthritis Australia https://arthritisaustralis.com.au	Yes	Yes
Myositis Association https://myositis.org.au	Yes	Yes
Starship hospital www.starship.org.nz	Yes	No
Myositis UK www.myositis.org.uk	Yes	Yes
Cure JM Foundation www.curejm.org	No	
Juvenile Arthritis Foundation Australia (JAFA) www.jafa.org.au	Yes	Yes
Facebook Group	**Did they respond**	**Response to advertising on my behalf**
Juvenile Dermatomyositis (JDM) Parent and Caregivers'	Yes	No
Cure JM	Yes	Yes
Juvenile Myositis Australia Inc. Parents/carers and JDMers only 18+	No	
Myositis Support Community (Worldwide)	Yes	Yes
Our Story with Juvenile Dermatomyositis	No	

Data collection and survey participants

Twenty-four participants responded to the survey, of which eight were removed due to incomplete answers to critical information, leaving sixteen survey responses. Thirteen

respondents were mothers, and three were fathers of children with JDM. One survey response was from New Zealand, five responses were from Australia, seven were from the United Kingdom, and three did not specify their country of residence. I chose to keep this data in the set due to their thorough answers (a more complete breakdown of the survey results can be located in Chapter 4 – findings, see Table 8.) One child from New Zealand and three from Australia responded to the question for the child section (these details are outlined in Table 6).

Table 6

Child responses

Age	Gender	Country
5	Male	Australia
12	Female	Australia
10	Male	United Kingdom
8	Female	New Zealand

Data analysis of survey

Once the survey results were complete, I exported the Qualtrics data using a CSV file and converted it into an Excel file. I checked for any double ups in IP addresses and found none. I then cleaned the data set by removing any identifying columns, such as IP addresses. To streamline the data, columns containing non-essential information, including start and end times and completion dates, were eliminated. Following this, I performed a descriptive statistical analysis of the survey data. The results were presented in sections, starting with demographics and then moving to treatment questions. I summarised the frequency, central tendency, and dispersion of the data to gain a clear understanding of the

findings. The results were displayed using tables, pie graphs, and charts to give a visual of the survey results. The analysis was interested in displaying the overall treatment satisfaction with different areas of treatment such as communication, specialist knowledge, wait times and follow-up appointments. It was also interested in displaying the medications, medication frequency, and time since diagnosis. Additionally, it was interested in showing the results of the symptoms experienced pre-diagnosis. To present responses involving categories such as 'satisfied, extremely dissatisfied' in graphical form, numerical values were assigned to each category. Thematic analysis was used to analyse the open-ended questions alongside the interview transcripts and presented in Section B of the findings.

Interview questions

The interview questions were designed to elicit responses surrounding the participant's experiences during JDM treatment in the public healthcare system (a copy of the interview questions can be located in Appendix G). My research focused on the dialogue between participant and researcher to ascertain meaning and an in-depth understanding of the participant experience (Riley & Chamberlain, 2022).

There were four key areas of focus: the journey to diagnosis, the treatment experience, healthcare interactions, and holistic care offered, such as mental health support. The interview also included key questions around life stressors, network support systems, and further questions of how school and home life were affected throughout treatment. The interviews also gathered information on background and psychosocial health. This research emphasised these critical areas due to a gap identified during the literature review. While the medical treatment of JDM was well-researched, few studies with a phenomenological focus on the experiences of children undergoing long-term treatment for JDM or other rare

chronic childhood illnesses were found. I included opportunities for participants to provide supplementary information that was not covered during the interview.

All participants were supplied with an information sheet and a consent form outlining their rights to opt-out at any time during the survey or interview and the right to refuse to answer any question (a sample of the consent form is located in Appendix E, and the information sheet is located in Appendix B). The semi-structured interviews took up to two hours to complete. I ensured adequate time was allotted for each interview to allow participants to feel at ease and provide detailed answers, including the opportunity to expand on any particular area.

The interviews were transcribed, de-identified, and then analysed using Braun & Clark's (2006) reflexive thematic analysis. A primary strength of using reflexive thematic analysis is its ability to provide a flexible framework for both the generation and interpretation of large datasets. A primary limitation of reflexive thematic analysis is its inherent subjectivity. Rigorous reflexivity is essential throughout the research process to mitigate potential interpretive bias.

Recruitment Process

Once the Massey University ethics committee approved the ethics proposal, the data collection commenced. A poster was created to advertise the survey, displaying a “register now” button that linked to the information page and a consent form (a copy of the poster can be found in Appendix C). I employed a purposive sampling method, ensuring I targeted an appropriate population to generate an adequate sample pool. The poster was sent to my primary connection to the JDM community: a JDM support page on Facebook (FB) called ‘*Juvenile Dermatomyositis (JDM) Parents and Caregivers.’* The request to advertise on the FB

page was declined. The denial of the advertisement request on the Facebook page was a setback, particularly because that page has the highest concentration of individuals with JDM outside of the United States. As I could not recruit through this page, it meant that I needed to re-submit the ethics application with alterations for recruiting through the hospital system and websites such as Juvenile Arthritis Foundation Australia (JAFA) and Myositis UK. Once the ethics resubmission was approved, the poster was sent to multiple websites in New Zealand, Australia, and the United Kingdom. A paid Facebook advertisement was also created, including keywords such as 'JDM', 'JDM research', chronic illnesses, and 'myositis'. To create the paid advertisement on Facebook, I was first required to create a page from which the ad could be generated. I created a Facebook page called 'Juvenile Dermatomyositis Parents and Caregivers New Zealand, Australia, and the UK'. Once the page was created, I could create a paid Facebook ad (a copy of the Facebook ad can be found in Appendix D). I used the poster as the main focus for the ad with a short blurb outlined below:

> Hi, my name is Megan, I am a mother of an 8-year-old JDM'er called Georgia-Rose. We are 18 months into treatment and live in New Zealand. This little lady has been such an inspiration with her strength and resilience throughout this process. I am currently doing my master's Thesis research at Massey University, and she has inspired me to dedicate it to exploring the experience of children and their parents undergoing long-term treatment for JDM with the aim to identify and strengthen support systems where needed. If you or anyone you know has a child with juvenile dermatomyositis, I invite you to please take part in this online survey which will take approximately 15 minutes. More info if you click on the link below which will take you to the information sheet and the start of the

survey. Thanks so much in advance for your time. The survey will remain anonymous. There is an option to go into the draw to win a $20 voucher to thank you for your time for the survey and a $40 voucher for those who choose to have an interview with me to further enrich my research data.

Interview Process and Participants

Five participants agreed to take part in an online interview via Zoom. Three interview participants were mothers from Australia, and two were fathers from the United Kingdom. The interviews were scheduled for the times that suited both parties' time zones with an allowance of one hour made for each interview. I allowed extra time so the participants did not feel rushed (see Table 7 for interview times). The first interview took nearly two hours, and the interviewee reported feelings of gratitude and excitement that "*someone was doing something*" and that she was grateful to speak to someone who understood what they are going through. Interview four was brief and took only 15 minutes. This could be due to a culture or gender difference as both interview two and interview four were conducted with fathers and interviews one, three and five were with mothers, which were much longer and in-depth.

Table 7

Interview timeframes and participant details

Interview	Mother/Father	Country	Length
Interview 1	Mother	Australia	1 hour and 53 minutes
Interview 2	Father	United Kingdom	28 minutes
Interview 3	Mother	Australia	47 minutes
Interview 4	Father	United Kingdom	15 minutes
Interview 5	Mother	Australia	47 minutes

The interview process was organic in that while I had a semi-structured interview to follow, the interviews were conversational and did not necessarily follow the order of the questions as I developed them. I shared my story with the participants to let them know that I was an insider in this research and understood the journey they were on. This helped build rapport with the interviewees who all responded positively to having someone to talk to who understood. I was conscious of my bias and was careful not to assume or speak for them. I was also conscious of monitoring distress and letting the interviewee take the lead with how long we spent on each section of the interview.

Data analysis of interviews

I acknowledge my positionality as an insider and my active role in generating themes from the data. Through reflexive thematic analysis I endeavoured to own my perspective (Braun & Clarke, 2022). I stated my position with all five participants that I interviewed, clearly acknowledging my position and perspective. I included stories from my own experience in the findings to link common themes that emerged that aligned with my own

to enrich the data with a) personal experience and owning my positionality and b) A New Zealand perspective to see where commonalities were linked with Australia and the United Kingdom. I did this because I did not have any interviews with parents from New Zealand. Additionally, I did not want to try and suppress my perspective and have insider bias occur due to not acknowledging my position enough. Instead, I chose to include my perspective and make it clear that it was mine. As Braun & Clarke (2022) write, to own my perspective. I maintained consistent reflection throughout the analysis, often revisiting the raw data files to read through them again and identify themes I had not identified through earlier readings. I performed this process multiple times through the analysis phases and while writing up findings to ensure a constant, flexible narrative that was based on what was emerging from the data and not pre-empted by my assumptions.

I closely examined the data to identify common topics, ideas, and patterns of meaning that came up repeatedly using Braun and Clark's (2006) six steps of reflexive thematic analysis: familiarisation, generating codes, generating themes, reviewing themes, defining and naming themes, and creating the final report. This meant that I adopted a fluid approach to the data, interpreting and constructing data through multiple layers of reflexive thematic analysis. Firstly, I read through each transcript, using a selective and highlighting approach, as outlined by van Manen (1997). Familiarisation was a high-level first take of the data, noting any patterns, and this was done as I highlighted every sentence or phrase that stood out. I then colour-coded the interviews and numbered them, then listed every quote under a heading corresponding to the appropriate interview. I then studied the quotes and began grouping them into themes that were emerging from the data. I then generated some initial coding. I did this by using the online whiteboard software Miro (Appendix H). From these codes, I could look at ideas and themes and play around with groupings. I did this

multiple times so that new themes that may not have been noticed initially could be included. Subsequently, common sentiments were analysed to reveal overarching themes in the data. Continual data analysis, including grouping and re-grouping the themes, deepened the insight into the individual and family experiences (Björk et al., 2009). I then started to develop interpretive stories around united meaning, which were the shared sentiments and similar yet unique experiences of the participants. Once I was satisfied with a thorough review, themes were finalised and named to help understand the data. An in-depth exploration of each theme is presented in the results section.

Ethics

This research project was reviewed and approved by the Massey University Human Ethics Ohu Matatika 3. The full application ID is OM1 24/24. The same application was used for both the survey and interview.

Survey ethics

The main ethical considerations were distress, the children's responses, and cultural safety. The surveys were anonymous, and participants accessed the survey through an anonymous link, which ensured their identity was not shared. No identifying information was requested during the survey so that participants could be as honest as possible. This was up until the end of the survey where they were asked if they wanted to enter the draw to win a $20 voucher or be willing to have an interview. The participants had the right to not answer any question, with the main screening question being that they must be a parent of a child with JDM. The participants were informed that they had the right to opt out of the research up until two weeks after the survey had ended. If no contact had been made that would be taken as consent to use their survey answers as a part of the research. To deal with

distress, I provided information on free helplines from New Zealand, Australia, and the United Kingdom. Cultural considerations were made during survey development with my supervisor.

There was an additional consent section for the 'question for the child.' This section was completely optional, and parents were told that if the child did not complete the section, their results would still be used.

Ethics interview

The main considerations were that the research asked participants questions regarding their experience and their child's experience. Consequently, there was some potential for distress. This was managed in the interviews by giving the participants time and space, making sure they were aware of their rights, and using my experience as a mother of a child with JDM to understand, relate, and build rapport. I left the decision of whether the child was present at the time of the interviews to the participant. I discussed cultural considerations with my supervisor and was prepared to seek cultural guidance if required. As my interviewees were from Australia and the United Kingdom, I used the same principles across all the interviews and made sure to provide enough time for the interview as a whole and for the individual questions to be answered. I made sure to build rapport at the beginning of the interview so that the interviewee felt safe and supported and comfortable to stop at any time. Additionally, I allocated sufficient time to end the interview in a way that the participants felt that their time was valued and that what they had to say contributed to the research.

Reflexivity

Researchers are encouraged to acknowledge their place and role in the formation of knowledge and to self-monitor through reflexivity of their biases, beliefs, and experiences to maintain the balance between the personal and the universal (Finefter-Rosenbluh, 2017). As Finefter-Rosenbluh (2017) stipulates, reflexivity is the practice of having a continual internal dialogue and critical self-evaluation of the researcher's positionality. I occupy an insider position in this study, grounded in my personal experience as a mother of a child diagnosed with JDM. I managed this by keeping a diary of thoughts to facilitate meaningful reflection throughout each stage of the research and by speaking with my supervisor, Kathryn McGuigan. Reflexivity has been recognised as a critical strategy in qualitative research. To aid in checking my bias, my supervisor checked the survey questions and the interview structure to ensure that the research questions were being answered and that I maintained the focus of the research. I also reflected on each stage of the analysis to ensure that I was not focusing on only the aspects that I was familiar with or that interested me. I made sure to include all information that emerged as important for the participants, generating a theme regardless of my familiarity with it as an insider. As discussed previously, I attempted to own my perspective by integrating my own experiences through the findings to have a clear understanding of my position and not attempt to suppress it and form an unconscious bias.

Chapter 4 – Findings

This chapter firstly outlines the results from the online survey's findings. The quantitative findings are conveyed using a series of graphs and figures (Section A). The chapter then presents the principal themes emerging from the qualitative thematic analysis conducted on the interviews and the open-ended questions in the survey (Section B). The chapter also incorporates stories from my own experience as an insider. Finally, the chapter presents the answers to the 'question for the child' (Section C).

Section A: Survey Results

The results from the survey show that, overall, parents were *somewhat satisfied* with the time it took for their child to receive a diagnosis and somewhat satisfied with their experiences during treatment. The results revealed that while treatment remained mostly child-centred, there were gaps in the psychological and social domain that required further support. Additionally, there was a strong vein of consistent advocation required with participants' responses showing that they visited multiple GPs in search for answers. The results showed that while they were somewhat satisfied with their experiences there was room for improvement across all areas of treatment experience. The results from the survey are presented firstly covering the demographics (Table 8) and then move to diagnosis and symptoms, followed by treatment experiences.

Table 8

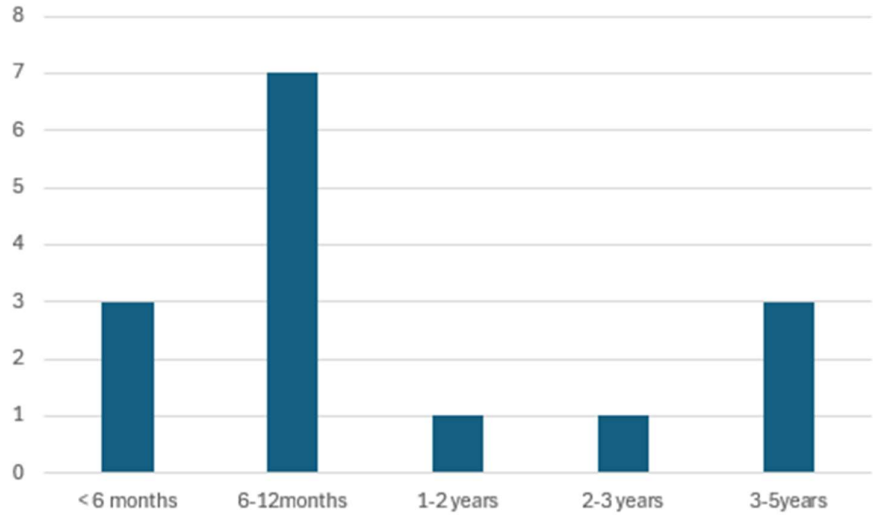
Demographics of survey participants

Participant	Age of onset for child	Gender of child	Location	Ethnicity of the child	Time since diagnosis
Mother	10	Male	Not specified	Latin	6 months or less
Mother	12	Female	Not specified	Southeast Asian	6-12 months
Father	11	Male	United Kingdom	European	6 months or less
Mother	Under 5	Female	United Kingdom	European	3-5 years
Mother	Unknown	Male	United Kingdom	Not specified	Not specified
Mother	Unknown	Female	United Kingdom	European	3-5 years
Mother	7	Female	Australia	Australian European	6-12 months
Mother	5	Male	Australia	Australian European	6-12 months
Mother	11	Female	Australia	Southern Asian	6-12 months
Mother	Under 5	Female	Australia	Australian European	3-5 years
Mother	Unknown	Male	Australia	Not specified	6 months or less
Mother	Under 5	Female	Not specified	European	2 – 3 years
Mother	7	Female	United Kingdom	European	6-12 months
Father	8	Female	United Kingdom	European	6-12 months
Father	5	Male	United Kingdom	European	6-12 months
Mother	5	Female	New Zealand	New Zealand European	1-2 years

Sixteen parents answered the survey (13 mothers and three fathers). There was one response from New Zealand, five from Australia, seven from the United Kingdom, and three did not specify which country. The parents reported that six of the children were male and ten were female. The average age of onset for JDM was 6.5 years (Figure 2).

Figure 2

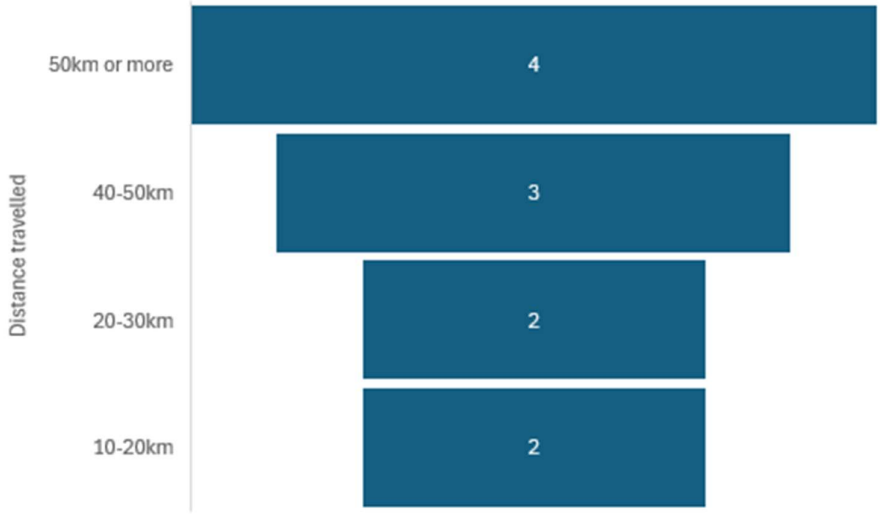
Time since diagnosis for the child with JDM



Travel was a significant element of treatment experiences. Four out of sixteen (25%) parents were required to drive 50 km or more to get to treatment (Figure 3). The frequency of these long journeys ranged from weekly to monthly. All participants had to pay for parking regardless of the time spent travelling, which again could be for weekly or monthly appointments. Only one participant received subsidies for travel, and two participants received subsidies for parking.

Figure 3

Travel distances to treatment for participants

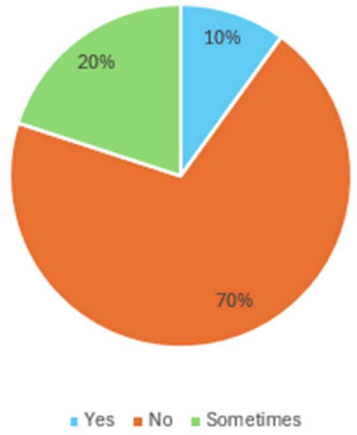


Note: The chart above shows the distance travelled on the vertical axis and the number of participants that travelled those distances alongside

Only three out of sixteen (19%) participants had the option to receive treatment at home. With 80% of families then taking their children to the hospital for treatment, the following data is important to understand the experiences of children and parents receiving treatment in the hospital. These appointments could range from one hour to all day and involve a range of medical interventions as outlined in the literature review. While children receiving hospital treatment over mealtimes were provided food, their parents were not offered food for the most part or if they were, this was inconsistent (Figure 4). Worrying about feeding yourself and your child is another layer of stress to add to the day, I would often pack backup lunches as the hospital would frequently miss my daughter's lunch or send the wrong one. My child is gluten-free, so we would request a simple gluten-free cheese sandwich, but this would rarely be supplied.

Figure 4

Answers to the question: Were you as the parent fed during hospital stays



In terms of support for the children either with treatment, for example, needle phobia, or coping with having JDM, of those who answered this question, only three out of sixteen children (19%) were offered the support of mental health services. One participant reported having a family therapist available during treatment. Figure 5 shows that 70% of respondents who answered the question indicated they were not offered support.

Figure 5

Mental health support offered during treatment

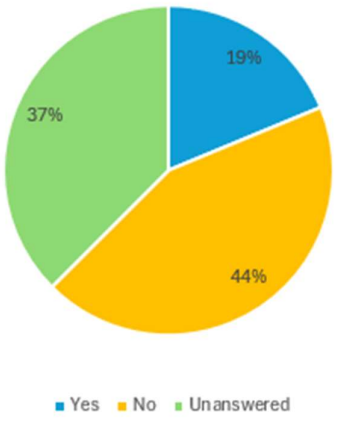
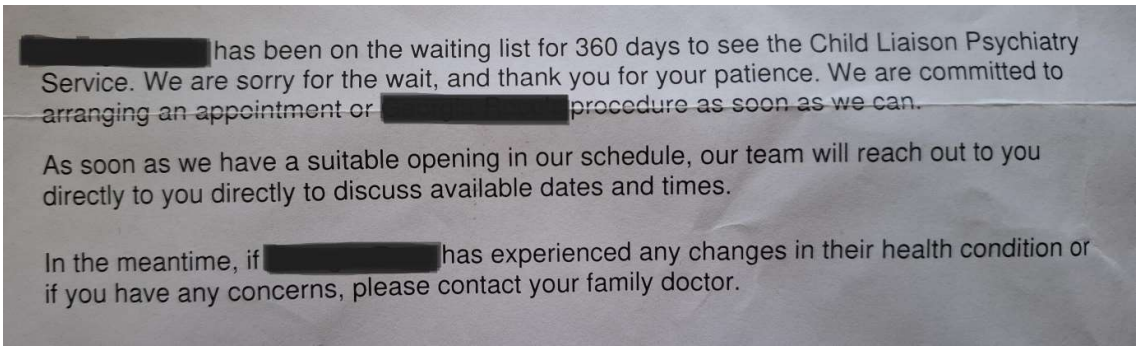


Figure 6 shows a letter from a hospital sent to one of the parents advising that the system acknowledges that the child has been on the waiting list to see a psychiatrist for longer than 360 days. Included is an apology and a thank you for their patience, but no timeframe for when they can expect an appointment.

Figure 6

Letter from a health organisation to the parent of the patient


[redacted] has been on the waiting list for 360 days to see the Child Liaison Psychiatry Service. We are sorry for the wait, and thank you for your patience. We are committed to arranging an appointment or [redacted] procedure as soon as we can.

As soon as we have a suitable opening in our schedule, our team will reach out to you directly to you directly to discuss available dates and times.

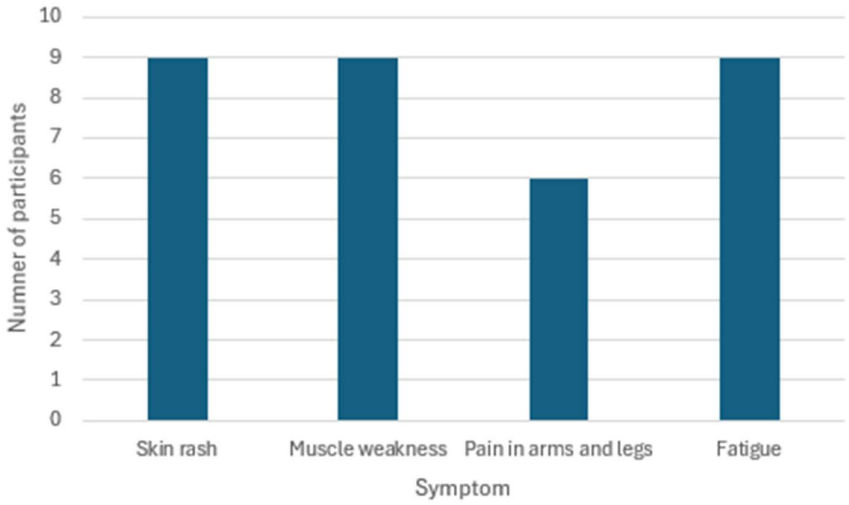
In the meantime, if [redacted] has experienced any changes in their health condition or if you have any concerns, please contact your family doctor.

Diagnosis and symptoms

During the survey, participants were asked about the symptoms their children experienced pre-diagnosis. Of those who answered this question, the results were fairly consistent, with nine participants each reporting skin rash, muscle weakness, and fatigue (See Figure 2). The survey revealed that 66% of participants reported pain in the arms and legs. Furthermore, 80% of participants reported that their child experienced at least two or more of the symptoms shown in Figure 7.

Figure 7

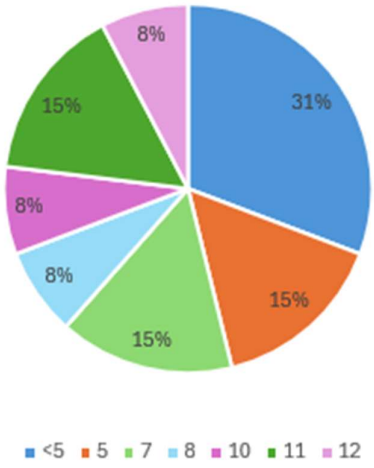
Symptoms experienced pre-diagnosis



The mean age of onset of JDM symptoms in this study was 8 years (Figure 8), with a predominance of female children. This finding aligns closely with the literature, which reports an average age of onset to be 7 years old (Wu et al., 2020) and the girl-to-boy ratio being 3:1 (Enders et al., 2017).

Figure 8

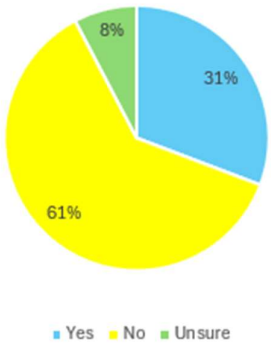
Age of onset of symptoms



The survey did not collect specific information about the types of autoimmune diseases present, but 31% of participants reported a family history of autoimmune disease, 61% indicated no family history of autoimmune disease, and 8% were unsure (Figure 9).

Figure 9

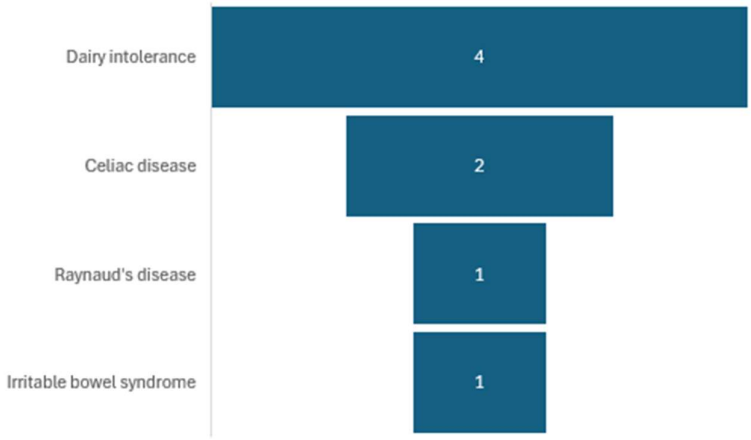
Family history of autoimmune disease



Children who receive a JDM diagnosis are frequently diagnosed with other conditions. Figure 10 shows four children had dairy intolerance, two had a diagnosis of celiac disease, one had Reynaud's disease, and one child also experienced irritable bowel syndrome.

Figure 10

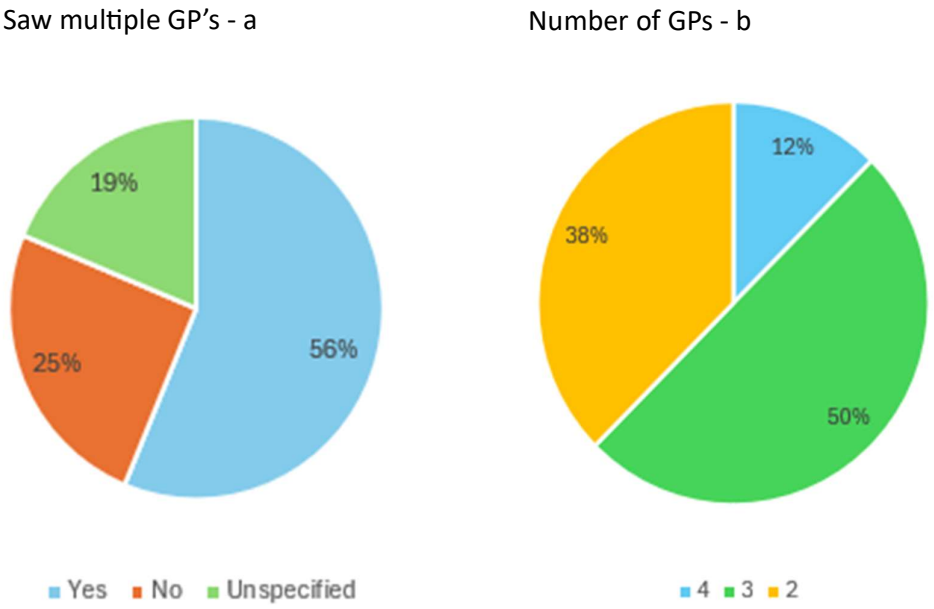
Additional conditions



The survey asked participants if they had sought advice from multiple General Practitioners (GPs) during their journey to diagnosis, to which 56% answered yes (see Figure 11, part a). Of those 56% percent, 12% sought the advice of 4 GPs, 50% sought the advice of 3 GPs, and 38% sought the advice of 2 GPs before they obtained the JDM diagnosis for their child. This can be seen in Figure 11-part b.

Figure 11

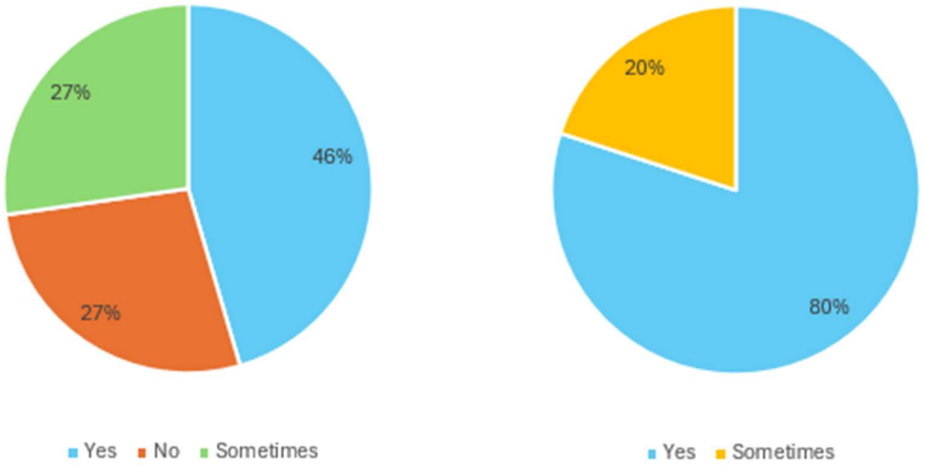
Percentage of participants who sought advice from multiple GPs (a) and the number of GPs sought (b)



The survey revealed that over half of the participants sought advice from multiple GPs in their search for answers, with 62% of participants seeing three or more. Additionally, 54% of participants reported that they were not or were only sometimes listened to and taken seriously by their GP (Figure 12-a). Conversely, 80% of participants shared that they felt listened to by their specialist (Figure 12-b).

Figure 12

Did parents feel listened to by their GPs (a) Did patients feel listened to by their Specialists (b)

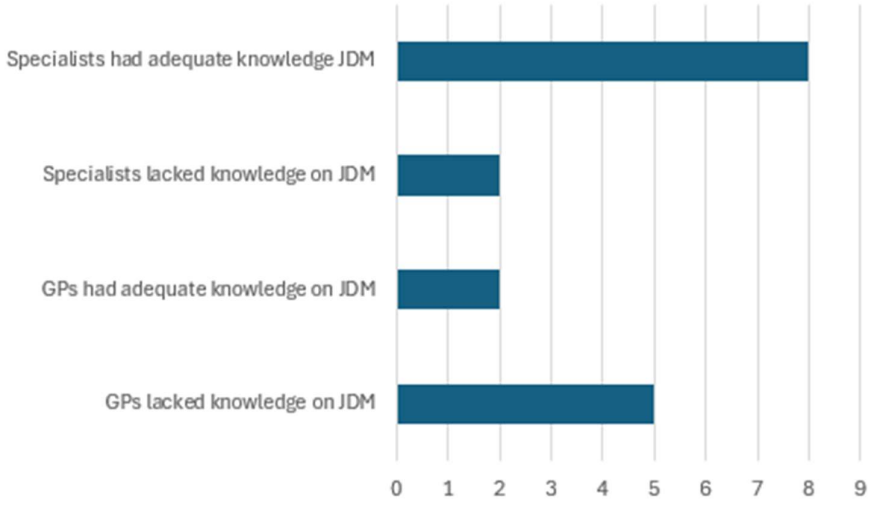


a *b*

Figure 13 shows parents were reasonably happy with their specialist's JDM knowledge but not happy with that of the GPs. This finding emphasises the knowledge gap concerning rare autoimmune disorders within general practice.

Figure 13

Parents' beliefs on the knowledge of JDM held by their GPs and Specialists



Treatment satisfaction

Figure 14 shows the overall satisfaction with follow-up appointments. Follow-up appointments can vary in their frequency and timeframes, depending on available resources, funding and time of year and the size of the rheumatology team in each country of residence. It is promising that 30% of participants shared that they were extremely satisfied with follow-up appointments. However, 70% of participants shared that they were somewhat satisfied, dissatisfied, or extremely dissatisfied, which highlights why understanding the experience of children and their parents is crucial to identifying areas where extra support is required.

Figure 14

Overall satisfaction with follow-up appointments

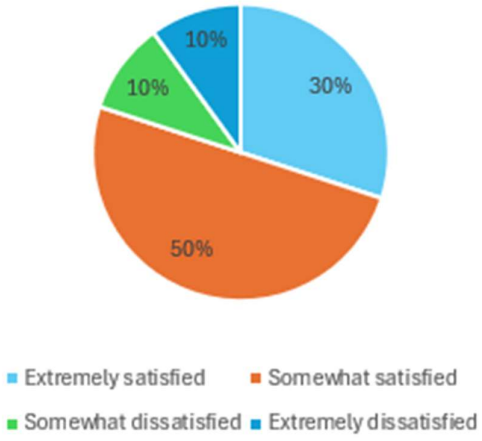


Figure 15 presents the participants' overall satisfaction with wait times. Again, this reflects resources, funding, the size of the rheumatology team, and the time of year. Wait times were satisfactory for 60% of participants, meaning 40% were neither satisfied nor dissatisfied, or extremely dissatisfied.

Figure 15

Overall satisfaction with wait times

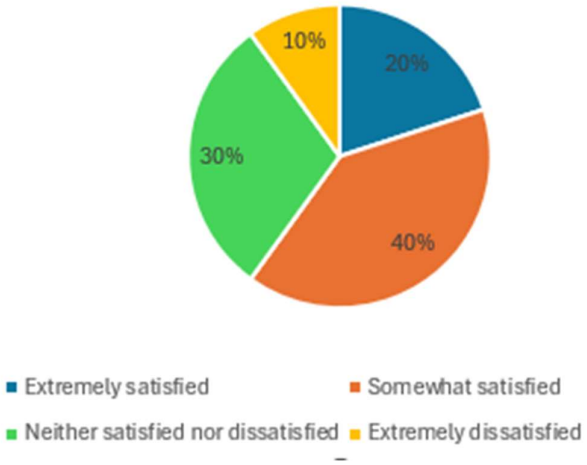


Figure 16 shows that while overall satisfaction with treatment was reported by 78% of participants, a closer look reveals that 67% did not express 'extremely happy' sentiments. This suggests that while basic needs are met, there is room to improve the treatment experience.

Figure 16

Overall Treatment Satisfaction

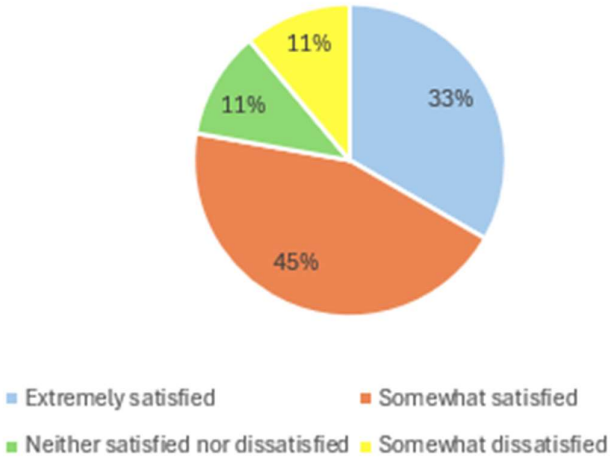
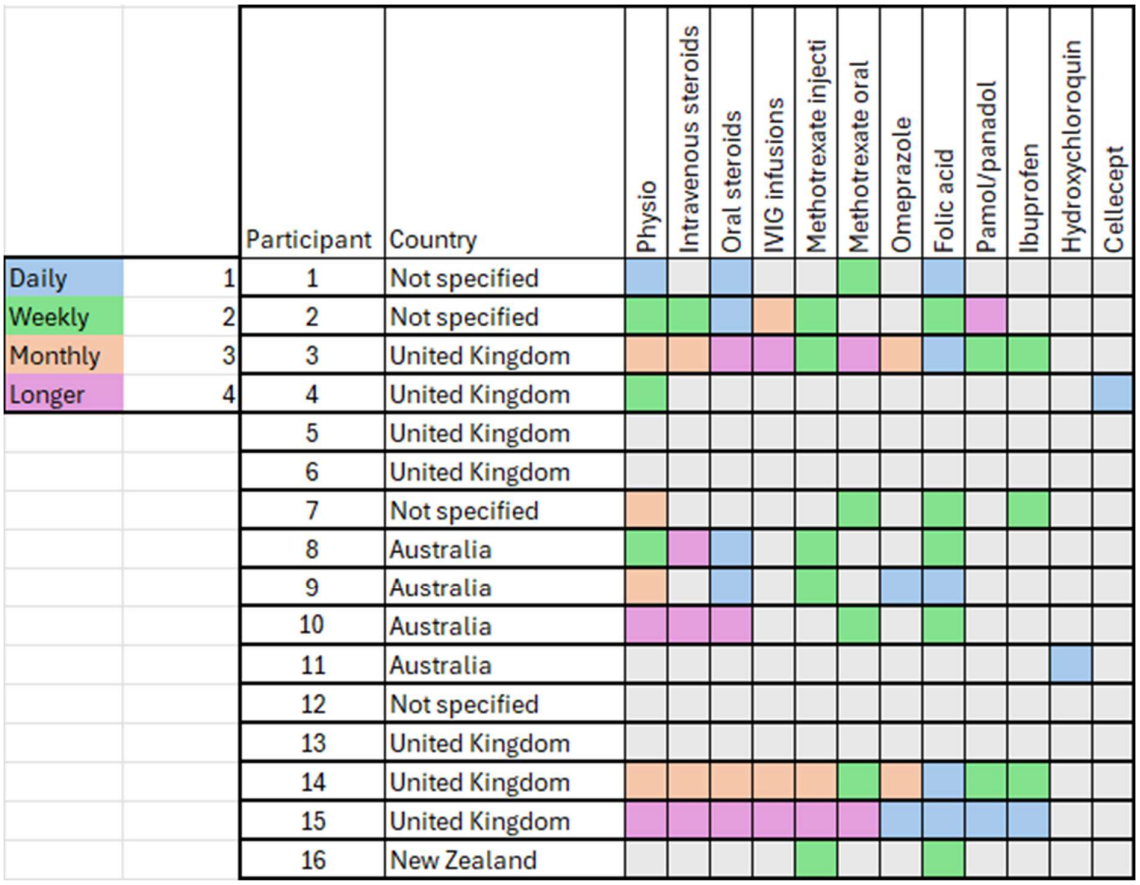


Figure 17 shows the treatments administered and their frequency. The figure shows the complexity of JDM treatment options. Physiotherapy is the main form of physical intervention, which is usually done in conjunction with an occupational therapist. The occupational therapist's job is to organise any support required to help the patient return to their daily activities, schools, families, and social lives. Temporary mobility parking permits for use in disabled carparks can be handed out, and wheelchairs can be organised for patients who are in the early stages of treatment. Due to the varying nature of JDM symptoms, not all patients will require a physiotherapist, for example, if the symptoms are majority skin involvement. Medications can also vary across patients, countries, and healthcare centres. The widely accepted first-line treatment is high-dose intravenous steroids followed by daily oral steroids (prednisone) and methotrexate all respondents having been offered one or both at different frequencies. Omeprazole and folic acid are usually prescribed to protect the patient's stomach lining during extended treatment periods. The remaining medications and their frequency are subject to change between medical providers, depending on which medications are funded, what course of the disease is presenting, whether it affects skin, muscle, or both, or further complications such as calcinosis or Gottron papules. Figure 17 shows the different mixes of medications used by participants and the countries in which they reside. Something to note is that this is a snapshot of the medications *currently* taken. I did not ask about medication history so the table is not reflective of total medication that may have been prescribed.

Figure 17

Physio and medications used and their frequency



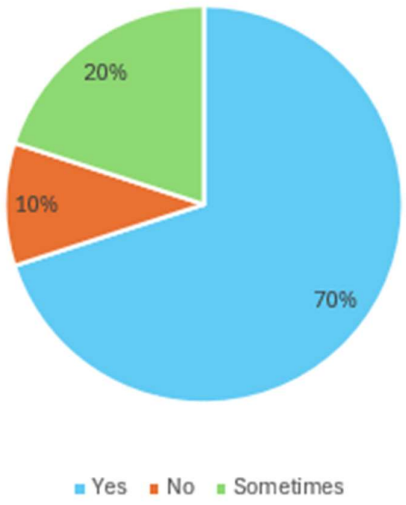
		Participant	Country	Physio	Intravenous steroids	Oral steroids	IVIG infusions	Methotrexate injecti	Methotrexate oral	Omeprazole	Folic acid	Pamol/panadol	Ibuprofen	Hydroxychloroquin	Cellecept
Daily	1	1	Not specified												
Weekly	2	2	Not specified												
Monthly	3	3	United Kingdom												
Longer	4	4	United Kingdom												
		5	United Kingdom												
		6	United Kingdom												
		7	Not specified												
		8	Australia												
		9	Australia												
		10	Australia												
		11	Australia												
		12	Not specified												
		13	United Kingdom												
		14	United Kingdom												
		15	United Kingdom												
		16	New Zealand												

In the survey, participants were asked if their child was provided a comfortable chair during their hospital treatments, to which 100% of respondents replied yes. However, also asked in the survey was the question if parents were also offered a comfortable chair during their child's hospital treatments. The majority (70%) of respondents reported they had been, however, 30% indicated negative or mixed responses (Figure 18). Among the positive responses, specific comfort standards were unclear. Even small changes can dramatically alter how patients and their support persons experience treatment and hospital stays.

Hospital stays can be long and arduous days of undergoing often uncomfortable and sometimes painful and exhausting procedures. The support person bears a significant amount of mental, emotional, and physical exhaustion, and having a comfortable chair during their child's treatment can significantly alter the treatment experience. It is positive that the children were offered comfort highlighting patient-centred care, whereas encouraging whanau care would be beneficial for the child and the family. The research revealed a tendency for patients to express gratitude for existing care rather than request additional resources from an overburdened hospital system.

Figure 18

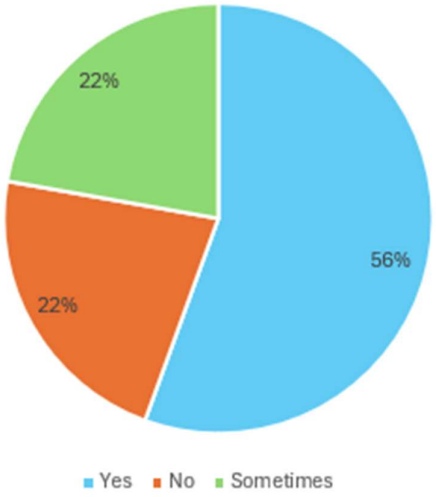
Were you as the parent offered a comfortable chair during hospital stays



Parents were asked if their children experienced increased levels of anxiety leading up to hospital appointments (Figure 19). With the majority (78%) answering yes, this begs the question of what support is available to not only the children but also the parents who are supporting the child.

Figure 19

Did your child experience anxiety leading up to hospital appointments?



It seems evident that parents are often left to 'figure' it out on their own throughout the process, with little support offered through the hospital system and a high reliance on their own support system.

Section B: Interview Findings

A thematic analysis was conducted to extract major themes from the interview transcripts and open-ended survey responses. This helped further the understanding of the treatment experience for children aged five to thirteen years old and their parents. Three major themes were identified, as shown in Table 9. Advocation was originally a sub-theme of 'Journey to diagnosis'; however, it emerged as such a strong theme throughout the data that it was decided it would be a main theme. In addition to the major themes, subthemes were identified, which are also outlined in Table 9.

Table 9

Major themes and their sub-themes

Theme	Sub-theme	Description
Advocation	• Journey to Diagnosis *Fighting to be believed* • During treatment *Standing up for your child's treatment needs*	Having the strength and courage to advocate for their child during the journey to diagnosis and throughout treatment
Treatment	• Parent and child experience of treatment *Disease experiences* • Communication *With doctors, school and family* • Travel • Associated costs • Family impact	Experience of undergoing long-term treatment for JDM for parents and children. This includes treatment experiences in hospital and at home, communication in three main domains of education, medical and social, and the impact on the family. The costs of travel, especially for rural families. Hidden emotional costs as well as the mental labour, lost time of work and school
Parent knowledge	• Parenting a child with JDM • Becoming experts on their child and their illness	Parents are becoming experts on their child's illness through their own research and experience.

Advocation

Advocacy emerged as one of the strongest themes throughout this research. The data showed that despite the adequate level of treatment satisfaction, all participants faced challenges and were required to advocate for their child. While grouping quotes under the theme 'advocation', two sub-themes emerged through the data: 'advocating during the journey to diagnosis' and 'advocating during treatment.'

Advocating during the journey to diagnosis: "Let's find the answer; this shouldn't be such a big fight."

Advocating during the journey to diagnosis is a vital role that parents play for their children to ensure their child's needs are met. Due to the insidious nature of JDM symptoms, parents can often find that they are not listened to by their GPs when expressing concern over their child's health. One parent shared that "*It took months of begging the GPs to listen to me to send me to the specialist to have someone believe us*." This notion is shared by another participant who stated that "*Her GP would often dismiss my concerns and say I was overreacting. We eventually took her to a dermatologist who was convinced she had eczema. No one seemed to take her symptoms seriously despite her rapid decline*." Another patient shared their journey trying to get into the system: "*The Specialist asked us to present to the emergency in our hometown. Doctors in ED told us that if it was up to them, they wouldn't admit us, left us in the waiting area despite our son struggling with congestion and unable to even sit in a chair due to his JDM symptoms."*

Parents often find their concerns invalidated by their GPs, even when they repeatedly come back to be seen with the same issue. Interview one shared an experience of repeatedly going back to her GP "*not backing down*" when her doctor would not believe her child had a serious problem due to presenting well at every appointment. She ended up filming her daughter so she could bring in videos to show the doctor, saying, *"Look at her in tears walking from my kitchen to my lounge room, look at this child!".* Interview one visited two different GPs and two different hospitals multiple times before receiving a diagnosis and shared that, *"after diagnosis was received, we were flown to a third hospital for treatment. It*

was a very drawn-out process, and we felt we were brushed off multiple times by health professionals."

The journey to diagnosing a rare autoimmune disease in children is a difficult path. Doctors often put symptoms down to 'growing pains' or other more common childhood ailments, with one doctor consistently misdiagnosing a participant's daughter with a fractured ankle: "*We went to a GP, then two different orthopaedic surgeons, then a podiatrist who thought it was a hairline fracture in her ankle. Initially treated with a moonboot.*" It took many months of advocating and multiple visits and insistence until the patient and their parent began to be taken seriously. It was not until her second ankle started hurting that the doctor entertained the idea that there could be something more sinister occurring. The same participant reported that "*it was a remedial massage therapist who pushed me to go to an osteo…. And the osteo got shut down by everyone else.*" "*Once the osteo told me about the disease and I started doing my own research, it just clicked.*" This demonstrated that even with other professionals in the healthcare field supporting the parent's concerns of a serious health condition, she was still not taken seriously. The participant kept pushing back against what multiple specialists were telling her, advising that it was a hairline fracture that was not getting better, and that the other ankle had started hurting due to overuse. "*No one was listening to me.*" Not feeling heard or being shut down was a widespread experience on the road to diagnosis. Another parent shared, "*Whilst we only visited about 4 GPs, she was sent to several physios over the years, and a specialist in bone diseases."*

Parents felt increasingly discouraged when their healthcare providers offered no solutions. Advocating for answers and going against medical professionals' advice demands

significant mental strength and stamina. The relentless advocacy required when seeking a diagnosis for rare diseases places an immense mental burden on individuals and families. The work required for advocacy requires constant learning and research and staying informed on complex issues. The constant requirement of communicating the same message to different groups of people in healthcare, school, and personal settings can be significantly draining on an individual. The mental energy required is a significant but often hidden cost of advocacy, with one participant sharing that they are *"tired, I'm just tired."* Another parent shared. *"The journey to our JDM diagnosis was challenging, with delays and misdiagnoses before the correct answer was found. Persistent symptoms and family support were key, and I hope for greater awareness to enable earlier diagnosis for others."*

The diagnostic tests involved in JDM diagnosis are expensive, and the doctors usually only generate referrals after the 'wait and see' approach has been exhausted. The feeling of constantly being told to wait and see while your child gets progressively worse with what can be subtle but persistent symptoms is very frustrating. One participant said, "*Every time I go back, it's the one complaint I have. And every time, we walk away with not an answer."* Parents often find themselves having to build a case for their child, including concrete proof of their often-unbelieved symptoms. One parent videoed her child after numerous failed attempts to get the doctor to believe her. "*So, you're telling me basically you don't believe us because she presents really well.*" The challenge here is that going through the healthcare system takes time, energy, and finances. However, early treatment for JDM has been shown to be effective and minimises further complications such as calcinosis and Gottron papules. Thus, any delay in starting treatment can have a detrimental effect on the patient and their long-term prognosis.

The effects of prolonged diagnosis are also felt by the child, with one participant sharing that her child "*just stopped playing full games (of soccer) and that's when I knew something was really wrong".* While parents are fighting for a diagnosis within the healthcare system, their child is slowly deteriorating before their eyes. Due to the insidious nature of the disease and how the symptoms present, it can be difficult for a specialist to see the whole picture within a fifteen-minute consultation. One participant who went through multiple misdiagnoses with her GP felt that she and her GP had been on the journey together: "*It's like a learning curve for him now. Like that's probably something he'll never miss again.*"

As parents of a sick child, instincts are strong and often correct; it takes advocating and "*not backing down*" to gain a diagnosis for rare diseases through a pressured and stretched healthcare system. One participant shared her journey to diagnosis and how something simple like the appointment time (mornings) contributed to the delayed diagnosis. The appointments she was given for her daughter to be seen fell in the mornings when her daughter was at her best. She would be told by the specialists that "*she presents really well*" despite being told that early mornings are the best time because she "*had barely used her legs."* She attributed her perseverance to her family, who insisted she keep pushing for an answer and not to listen to the GP. She shared that her auntie, who lives in a different state but is in the healthcare profession, visited the family and watched her daughter for half a day and immediately confirmed her suspicions that something was not right. With the encouragement of her family, this participant pushed for a referral from her GP despite her GP thinking she did not need one. The participant stated, "*Let's find the answer; this shouldn't be such a big fight*."

Advocation during treatment: "I want to try this a different way, and they sometimes have an issue with that."

Advocation is not only needed to gain a diagnosis but is an ongoing necessity throughout treatment. Mistakes can be made during procedures due to human error, preventing treatment from being administered during the planned timeframe. When a patient or their caregiver picks up on it, they can experience some pushback and, on occasion, gaslighting. There are several aspects to this. One is the feeling that the parents are blamed when the system has broken. The next is advocation for different types of treatment options (important for rare conditions but complicated due to the country-specific healthcare), and due to this, the idea arises that the protocols cannot be changed.

One participant spoke about a time where they were delayed by a matter of hours and the reason they were given was not the whole truth. The nurse blamed the parents for the delay, as they wanted their child treated in a less painful way, but outside of the standard practice. The truth, however, was that the protocol of administering that day's infusion was not followed properly as a consequence of human error during the preparation of the medication so the treatment could not be administered as planned, the parent was told by another nurse that "*they'd ordered the wrong amount of IVIG, got the procedure slightly wrong."* The parent called out the staff and asked why the delay to which the response was that it was because she was choosing to go for an alternative treatment that involved semi-sedation and was advised that there would be a delay. The parent had accepted the delay due to her choice in treatment, but the delay experienced was significantly more than what they had expected and were told. When the parent questioned the wait time, she was told that "it was because of you." The parent then told the nurse that

she had been advised it was due to the wrong amount of IVIG ordered, to which the nurse responded, "*Oh, yeah, well, that was happening too*."

There are standard protocols for all treatments in hospitals that are rarely changed unless they are re-examined for a reason. Most protocols remain as the status quo even if there are 'better' or alternative ways to approach treatments that may better suit some children. One parent proposed an alternative treatment style for her child that was met with resistance, with the parent sharing, *"I want to try this a different way, and they sometimes have an issue with that."* When standard protocols are questioned by patients, it is received poorly, with one participant noting, *"Yeah, like have nurses and doctors telling you how things are done or how things are usually done, and you have to push back if it doesn't work for your kid."* Parents noted further instances where nurses "*got the procedure the protocol slightly wrong*" and "*had the dosage wrong and they weren't sure which procedure they were following.*" Heightening advocacy requires becoming an expert in the field that you are advocating for. Parents learn the names of the medications their child is prescribed often through their own volition as they can often feel ill-informed regarding the full extent of side effects the medications prescribed can have. Interview one stipulated that she "*did all my own research…. I didn't know what to expect with that medication, and I didn't feel informed."*

As the main advocates for the child, parents need to advocate or source mental health services for the child. As shown previously in Figure 6, there can be long wait lists for children to be seen by a psychiatrist or other mental health professional. Interview 5 shared that they did all their own research to find out what is available in her area in terms of mental health support and what support is funded. She discovered that she could source a

psychologist through a government-funded agency. This information was not offered through the hospital, instead, she had the initiative to research what was available to her. She noted, "*the hospital is not necessarily informing.*"

When standard medical protocols are challenged, it can threaten the structure of the system and the trust patients and health professionals put in their routine and directives. Additionally, the doctors and nurses treating patients with JDM may not necessarily be experts in the field nor up to date with the most recent research in the available treatment protocols. Therefore, the hospital could be functioning on out-of-date research to guide their treatment protocols while the overall system remains rigid and unresponsive to varying requirements. The only constant in JDM treatment is the child's main support person, as they are the conduit between specialists, treatment centres, GPs, and other healthcare professionals. The parents felt this role strongly, knowing how important it is to their children and their prognosis.

Treatment: *"No support is being offered."*

When there is no clear prognosis or treatment pathway, flexibility and adaptability to change are necessary skills required to navigate the treatment experience of JDM. The daily, weekly, and monthly medications and trips to different specialists for appointments and treatments all take their toll on the child, the parent, and the rest of the family. There are a multitude of aspects contributing to the experience of undergoing treatment for a long-term chronic illness. Furthermore, there are multiple specialists that children need to see, sometimes needing to travel between states to access the appropriate medical care. The parents' and children's experiences can range between and within the organisations they visit regularly.

Whilst some participants reported feeling extremely satisfied with their overall treatment, it became clear that along the way there were many instances where they were not. One participant reported that "*no support is being offered*" for needle phobia, while another reported that there was a play specialist available for cannula insertions. Further participants reported that they were offered other strategies to help their children with treatment, such as virtual goggles and numbing cream. One participant shared that the play therapist did not think to offer alternative styles of support. Their main technique was distraction, but some children prefer to watch the procedures that occur. However, the system does not cater to the diversity of illness experiences or the child's wishes.

The other issue regarding treatment experiences that gives context to the subthemes is the unpredictability of treatment outcomes. For example, one participant says, "*We're doing a lot better now, but it's still very up and down and lots of tweaking with medication still, and so he's not stable*." Another parent noted that *"it's very much, we don't know. We hope that this medication will work, and our goal is in 12 months, we would say she's in remission and happy days and we'll start to back off on everything, but the truth is, we don't know".* Additionally, everything can change suddenly during sickness; the child can take a sudden downturn where the medication will need to be tweaked, and in a lot of cases, the steroids will increase again. This is an uncertain time for both the child and the parent; they are crossing their fingers, hoping for the best. One participant said they were told by their specialists, "*We can keep her comfortable, and if it doesn't go back to where it was, we will have to completely change the course of what we're doing.*" The uncertainty of the treatment schedule and disease outcome adds a significant amount of stress to the child, parent, and the healthcare system.

Time spent in the hospital can be a rollercoaster on the best of days. Due to the multitude of treatment strategies and disease monitoring children can be sent to many different departments in the hospital to receive the appropriate care. One parent reported that "*we're there for half a day, we've gone and seen the doctor, he'll send us to the nurse then the nurse will send us to imaging and then imaging will send us to the blood test."* Due to the many complications that can occur related to JDM there are monitoring tests that are required, such as lung function tests, assessment of liver function, and other major organs that can be affected from the medication. Blood markers are used to track the disease; thus, many blood tests are performed throughout treatment. Additionally, the usual monitoring of height and weight for medication purposes are tracked alongside physical therapy for physical functioning monitoring and occupational therapy to support the child back into daily living. This multifaceted treatment schedule can become hectic and exhausting for both the child and the parent.

Parent experience: feelings of exhaustion and frustration during treatment

Participants shared a strong theme of both gratitude for getting into the system and frustration at the lack of answers regarding prognosis and treatment. One participant stated, "*It's a bit hit and miss like sometimes you'll get a doctor and they'll be great and sometimes you'll get a doctor, and they'll tell you almost nothing."* This tension between gratitude and advocation continued throughout the research. The participants relayed feelings of exhaustion and isolation from the diagnosis process and going through the multidisciplinary treatment required for JDM. One participant stated, "*It's nothing I can relate with anyone*."

Despite feeling exhausted and isolated, the participants are still showing gratitude for their position, with one saying, "*It could be so much worse."* During long days in the

hospital, children are often offered food, but the parents are most often not. When the children get fed, dietary requirements can be missed with gluten-free sandwiches not provided or requests for simple cheese sandwiches ignored. One parent shared that they "*don't like asking*" for any food if meals are forgotten. There is a constant conflict on the hospital's part between the desire to provide the best services and the lack of resources to fulfil patient needs at a consistent standard. It should be noted that there are volunteer groups at some hospitals who visit the wards to brighten up children's days and give them colouring books and craft activities.

The extensive treatment protocol for JDM can be both physically and emotionally exhausting for the child. Alongside this, they have to deal with the side effects of being on high-dose daily steroids, which are known to cause both physical and emotional side effects during long-term use. One parent shared an experience she had with her daughter experiencing extreme emotional states, saying, "*She's screaming at me to get out of her room, and I'm thinking, oh my god you know, is she going to do anything? Because you do you have to think like that.*" Parents shared their stories of not being offered any mental health support or guidance on where to find it. The majority of parents had to do their own research to find out what's available and source it themselves. This is an added layer of responsibility alongside managing their child through the treatment process, researching the disease and how they can support them; they also need to manage their emotional and psychological needs. One parent was a single parent who lived rurally, so the responsibility to manage all these aspects was on her alone.

As well as the emotional storm that the child is required to navigate, the parent also needs to navigate their own emotions while also managing their child's. This can become

very confronting and difficult for the parent as they watch their child deteriorate. One parent recalls when their child was experiencing a flare-up, "*it seemed to have just attacked every joint. I literally had to carry her, she couldn't even push up onto the couch. How is this fair for an eight-year-old? She can't live like this.*" Experiences like these can be overwhelming, and the immense unfairness can weigh heavy on parents' shoulders and increase feelings of isolation and burden. Despite this, parents report feelings of hope with the same parent saying, "*I'm all for whatever we can do to advocate and get it out there because it's just pretty much non-existing down here so what good can come of this?".*

Treatment: *"Just take me, just take me away."*

The child's experience of treatment can be fraught with big scary words and big scary medical procedures, which can be nothing short of terrifying for the child. Children are required to have blood tests often, and if they are on IVIG they have infusions anywhere from weekly to fortnightly to monthly, and their veins get used up and are difficult to access. They are put in large, loud MRI machines where they have to stay as still as possible for twenty to thirty minutes. Sometimes, a biopsy of their muscle is required to confirm the diagnosis, and X-rays of their limbs and lung function tests are performed. Their eating and swallowing are monitored as the muscles of the oesophagus can be affected. They start physiotherapy as soon as they can tolerate it, which can be uncomfortable, frustrating, and sometimes painful. They take daily medications that have mild to severe side effects.

These experiences are demanding on children, and they can struggle with the constant barrage of treatments required for their illness. One child says to her mum while sitting on her lap being held down for an injection, "*Just take me, just take me away*". While suicidal ideations are rare in children, they can express feelings of "*not wanting this life,*"

and feelings of regret and unfairness can be felt. Whilst these feelings are valid, they are difficult to hear as a parent while we have to force our children through medical procedures. The parents tell them that they love them while at the same time they are forcing them through uncomfortable procedures day after day.

Another parent shared their journey of her child not being able to cope with the methotrexate injections, so they learnt how to swallow a table instead. However, the child developed a reaction to the tablets and started experiencing nausea after taking them. The parent reported that "*they lessened her dose, but like for the first few weeks she spent the first month every weekend, sick like all weekend.*" Moreover, the child experienced a negative psychological reaction to the medication. After building up a tolerance and likely experiencing less of a therapeutic effect, she developed a conditioned gag reflex. This was driven by her conviction that taking the tablets would induce nausea. This increases feelings of isolation for the child as they are unable to attend social events or take part in daily family life.

The side effects of methotrexate can make daily functioning difficult as children can experience severe headaches and a decrease in appetite, which in turn decreases energy levels and leaves the child feeling sore and lethargic. This also increases feelings of unfairness due to the constant grind of treatment life and managing academic school functioning. The child can manage to get to school during the week, then spends the weekend feeling the effects of the medication taken on a Friday night. Once they recover from the side effects of the medication, it is time to go back to school, leaving little free time for socialisation or leisure. One parent reported how her close friends and family have watched her daughter "*gradually decline in her physical capabilities, they've watched her fall*

behind with friendship groups and not be able to keep up and even emotionally, she was a shell of who she was, she was just in so much pain. She was always angry and upset like the world was against her; it just oozed out of her."

Children can be great at hiding their pain, to an extent that it can be detrimental to their treatment. There can be many reasons why children hide their pain; they can hide it due to wanting to go to a birthday party or because they do not want to have to undergo the particular treatment they are on, so they pretend like they do not need it. One parent reported that her child would "*sit so calmly wanting to like please them all, he's (the doctor) like, I need you to be really honest now, and she's like, oh, okay, it's a nine out of ten.*" Due to the often-invisible nature of the disease presentation, parents and doctors rely on the child's self-report of pain levels, so it is important that children feel safe and secure to report how they are feeling accurately. This can be difficult for the child when there is a fear of missing out if they say they are too sore. Children can often push harder than they need to through daily life in order to not admit how much pain they are in so they can avoid certain medications or hospital visits.

Psychosocial: *"This isn't fair."*

In addition to dealing with the medical treatment side of things, children are required to face the psychosocial aspects of living with JDM. They need to communicate with their peers, parents of their friends and their teacher and other school staff about their disease. While parents take care of the formal side of communication, children still need to face the sometimes-critical judgements from their peers or teachers who may lack understanding of what JDM is and the implications of the disease. The side effects of the steroids can be highly visual, with significant weight gain in the face and the stomach. As

well as the weight gain, children can form a 'moon' face which is a round and puffy face. Children can be mean and tease JDM children about their weight gain or pass innocent observational comments that can make the JDM child feel self-conscious.

Children can often mask their true pain through treatment. One parent shares that her daughter is strong-willed and determined with a 'get on with it' type of attitude, however she has started to mask her pain levels so much so that "*her pain threshold is too high now like she won't complain, I'm the one having to pull her out of stuff because I can physically notice it", "she'll put a grin on her face and she'll want to stay at a birthday party for really long and I can see that its getting too painful and then when we get in the car she'll cry saying she's so sore."* Children can often miss out on many things both in school, socially, and in the family, developing feelings of "*this isn't fair, why does it have to be out of school, why do I have to be like this*."

Parents expressed feelings of stress, hope, empathy, and despair for their children as they guided them through a treatment course that is constantly subject to change with no firm outcome or timeframe. Parents shared, "*It's been really stressful", "It could be so much worse",* and *"Hopefully then they'll find a cure."* Parents also shared that "*It's a completely different experience as a parent", "I don't know how to help her", and "I find it hard to say no to her now.*" These quotes extracted from interview transcripts showcase the array of often conflicting feelings experienced by parents. In addition to experiencing these feelings, they also have to compartmentalise for the sake of their children. One parent shares, "*So whatever it is that's going on in your life, it's not just about you*."

Social and family support systems are important, and without these systems in place, parents rely on the hospital support systems. Hospital support systems vary with each

hospital in terms of what they offer. In New Zealand, the Ronald McDonald house can be offered as a place to stay if there is room, but it is usually full. Some hospitals offer playrooms and play therapists to break up the child's day and to give the parents a break. The constant onslaught of treatments, logistics, and managing children's expectations wears parents down. If their child is experiencing anxiety before treatments or needle phobias, it can add another layer of challenges that require an additional level of support. One parent says, "*It's not just like you're doing it once, and then you can work through it, you're expecting them to do bloods all the time. So every time you do it, you need to prepare them like it's yeah, you need to make sure it's okay so the next one is.*"

Disease: "*She is just in her room and can't move.*"

There are also visual aspects of the disease that the child has to manage, such as skin lesions, rashes, and sometimes Galtrons papules, which appear as a thickening of the skin on the knuckles and elbows and calcinosis, which are lumps underneath the skin formed by calcium build up. As children get older, they can become more self-conscious especially if it is coinciding with natural developmental milestones such as puberty.

The physical pain of the disease can truly hinder everyday activities. A parent shares their child's experience, "*There are periods where she is just in her room and can't move".* "*She couldn't get out of bed" and "walking is pain… down the shoulders and sides and inner thigh."* Maintaining a sunny disposition whilst enduring extreme physical pain is challenging. The exhaustion that can result from enduring chronic pain can increase the risks of developing adverse mental health conditions, which is why JDM children's mental health must be monitored during treatment.

Further to the treatment journey are the side effects of different medications. These can vary from minor headaches and stomach aches to vomiting and severe migraines. High-dose steroids are known to have harsh side effects, including psychological effects. Parenting a child experiencing these symptoms is a challenging journey to navigate. One parent recalls "*his behaviour was off the charts like, hitting and lots and lots and lots of issues with anger";* another parent shared "*the prednisone, it does affect her emotionally and she's obviously a lot more emotional.*" In addition to managing these symptoms at home, parents are required to communicate these changes and side effects to the school. It can prove challenging to gain understanding from schools when the child is presenting with what can be an invisible disease and is acting disruptive in class or having emotional outbursts disproportionate to the event that occurred. Children can swing between extreme fatigue and high energy throughout the day, making it difficult to learn (and teach) consistently. Communicating to the teachers that it is a mixture of the disease and the medications does not make it easier to manage in the classroom; it requires patience from the school, the parent, and the child's peers as they navigate the journey through treatment and its effects.

Communication

Three main areas of communication were highlighted during the interviews. These were communication with doctors and specialists, communication with the child's school, and communication with friends and family.

Communication with doctors and specialists. "*Sometimes it feels like it's a very need-to-know basis.*"

Due to the multidisciplinary treatment required for JDM, parents are required to interact with different specialists from different hospitals on multiple occasions for long

periods throughout treatment. The quality of communication can vary between health professionals, and treatment strategies and standards of treatment vary to a degree between hospitals. As the child can be seen at varying times of day over the week, the health professionals they encounter are constantly changing. For example, within one infusion, the child can experience multiple shift changes between staff. It can be challenging for the parent to keep up with the process of their child's treatment, what procedures have already been completed, and what further procedures are required. Humans make hospital handover notes and are, therefore, prone to human error.

The treatment experience is intensified by the onslaught of constant communication between specialists, booking and re-booking appointments, and organising the logistics of the family and transport between treatment centres. Additionally, parents are required to organise time off school for treatment and recovery, so they are required to communicate with schools frequently. This is also aiming to maintain academic performance at home using homework books and alternative learning activities. Juggling an intensive treatment plan alongside other family responsibilities, including managing other siblings' schooling, family, and social life, can be challenging.

It is up to the child's parent to remain vigilant and up to date with their child's needs. From my own experience, the phlebotomist who gave my daughter her finger prick test the previous night had put her paperwork in an unusual place. The procedure was traumatic for my daughter, and I had promised her that she would not have to do another finger prick test, instead, we would opt for a traditional blood test performed through the vein in her arm. The following morning, a different phlebotomist was doing the rounds and insisted that my daughter needed a blood test; she was also insisting on a finger prick test. Finger prick

tests are the preferred method for children because that is most children's preference because it does not involve a big needle. I held my ground and would not let them perform the finger prick test, stating that my daughter had already had her test the previous night and we were waiting for the results so they could start her intravenous steroids. Intravenous steroids are best administered as early as possible, as they can interfere with sleep. I had to speak to the nurse, then the head nurse, the registrar, and then, finally, the senior doctor on the wards. I repeated my story to all of them, not allowing them to follow through with an unnecessary procedure. One of the nurses eventually found the form from the previous night's blood test. This caused a significant delay in the first-line treatment of JDM; it also caused significant stress to those involved and demonstrated that the parent of the child was not listened to.

Interview 5 shared a similar story where she requested a blood test to be performed through the cannula to not cause any further unnecessary trauma for her son, who was experiencing moderate needle phobia. She found that she needed to spend a certain amount of time preparing her son before each blood test for it to run smoothly; if she did not, he would struggle and resist the procedure. One morning, a phlebotomist came to see them unexpectedly to perform a blood test. Her son was not ready as she had not prepared him for it; no one had told her that this blood test was coming. She requested that the blood test be performed through the cannula to avoid the resistance that was bound to happen if they attempted this blood test. Her request was denied. She was advised that they only take blood from the canula when it first goes in, to which the mother responded, "*But I saw them take blood from the cannula two days ago*". They still refused, until the nurse who had been

looking after them came in and "*was a real advocate for us*" and pushed for them to take the bloods from the canula.

Another participant talked of their child who was experiencing severe needle phobia, making treatment challenging. Her doctor wanted to put her on methotrexate, which is one of the most effective medications for slowing the progression of JDM. The child struggled to get through injections or blood tests, and each time, it took a lot of energy for the child, the parent, and the hospital staff. It got to a point where they needed to weigh up the benefits of the medication against the child's emotional health. I asked the parent if she had play therapists or something similar available to help her and her daughter through this process, to which she answered, "*No, like I'm sure they're available down here, but no one's even kind of mentioned them*". This family is required to travel 1.5 hours to treatment with a child who is struggling with needle phobia, and they have not been offered support services of any kind to help the child through this process. There are many ways children can be supported through needle phobias or other necessary medical procedures such as play therapists, mental health nurses, counsellors or psychologists, yet this family had been given no information and has been left to struggle through this experience.

A significant side-effect of being on high-dose daily steroids is that it is an immunosuppressant. Consequently, it means that each time a JDM child gets sick, there is an increased risk of experiencing a flare-up of JDM symptoms. Parents and children must be aware of this so they can have a plan in place and prepare themselves both practically and emotionally. It can be scary experiencing a sudden decline in physical function and overall health. Interview 3 shared that they were not informed of this possibility of a sudden decline due to sickness. She stipulated, "*Sometimes it feels like it's a very need-to-know basis. Like, I*

didn't know that this is what could potentially happen when she gets sick. Like it was just a cold. And then all of a sudden I was like, oh my God, like, why can't you move?"

There were further reports of participants facing uncertainty around medical treatment and prognosis, with one participant reporting, "*She could do this her whole childhood, we don't know. It's not that common, but she could have it in adulthood. We just don't know, we would love to say we know, but we don't*." One parent stated, "*it seems to be like sometimes we get lots of information and sometimes we get none at all."*

There were, however, reports of a doctor apologising to one family after their daughter got the official diagnosis, stating that "*I've just never seen it in a kid before."* This underscores the profound challenge of navigating an extremely rare disease for which even healthcare professionals are often ill-prepared.

Communication with the child's school: "*I've been trying to get through to the school….. one of the teachers made her do something."*

Due to the multitude of treatment types required for JDM, children often need to take extended periods off school. In addition to this, children can require special treatment when they are in school. For example, the child may need to excuse themselves from particular sports events or physical education due to their muscles not being strong enough to participate. It could be the child needing to be excused from mat time due to their legs being too tight to sit down on the floor, so they sit on a chair instead. The child may need to attend school for half days or half weeks. Additionally, children often want to perform well for their teachers and peers and not be seen as too 'different' so they push through the pain. This often results in the child experiencing extreme fatigue and pain after school and can set them back in their recovery.

These situations require constant and thorough communication between the parent(s) and the school. While some schools are very receptive to children's extra needs, some schools can be difficult to work with, especially with a rare disease that can sometimes present invisible symptoms. One parent noted that "*communication with the school at first it was actually hard but later on, I think it got improved."* Another parent shared their frustration with the communication challenges she had with the school "*I've been trying to get through to the school….. one of the teachers made her do something*", "*I sent a video to the school to try and get the teachers to understand what it could be like*", "*There was a girl on TV who could not walk. I sent a video of that to the school, along with a video of a famous Indian actress who sadly passed away from Juvenile Dermatomyositis*." After sending in these videos to the school and having no specific response to them, the participant reported, "*I just don't think people get it*."

Communication with friends and family: "*I find that sometimes some of our family members can be really careless when their kids are sick."*

The final theme of communication was between the parent and their friends and family and the child's friends. One parent noted how the burden of communicating their disease to their friends and friends' parents while at their houses could be challenging for their child. "*They've got to communicate to their peers about something that they know nothing about and have never heard of before.*" If the child is not presenting with visible skin issues and is not visibly limping or in a wheelchair, it can be difficult for other parents and the school to grasp the seriousness of the condition. Additionally, a downturn can happen suddenly, and symptoms can flare very quickly. Families, despite having the best intentions, can often not realise the seriousness of the disease, especially when they see the child

functioning normally and appearing happy, one participants noted, ”*I find that sometimes some of our family members can be really careless when their kids are sick, it's like it's an invisible like you know unless you're seeing the pain on her like it's easy to forget that that's what she's going through*.”

Communicating with friends, family, and school, the importance of sun protection and how easily children with JDM can become fatigued can be difficult when the child presents fairly normally. Parents need to communicate emergency plans for different scenarios to schools and other parents, such as steroid emergency plans. What can seem like a mild, small mishap or accident can be a major incident for a child with JDM. One participant says, *“I said, we have a steroids emergency plan. And if he’s bleeding, I need to know how much. I need to know what happened.*”

Travel: “*I'm doing this for him because we have to go there monthly now. So, it needs to be as pleasant as it can be.”*

Of the five participants interviewed, three shared that travel was a significant factor for them throughout the journey to diagnosis and treatment. The two who did not share that travel was a significant factor live in the United Kingdom and were close to any treatment centres required. The three participants who live in Australia shared that travel was a significant factor. One of the Australian participants shared that it was a 10-hour round trip to treatment, which occurred once a month, and another had a three-hour round trip to treatment.

Travel can be demanding on both the parent and the child, but it can be especially tiring for the child when it is at the beginning and end of long treatment days. The travel can start as a novelty, but once the novelty wears off, it can become arduous. There is very little

to be done to avoid it, so parents and children must choose to make the best of these situations to help make the experience as pleasant as possible. One parent shared, "*I'm doing this for him because we have to go there monthly now. So, it needs to be as pleasant as it can be.*"

One interviewee who lived in rural Australia shared what their journey to and from treatment is like, illustrating the financial cost, the time associated with treatment, and the impact on all members of the family.

> *We are up at 5:15 am to leave at 6:15 am to make the 7:30 am ferry, we have to be there 30 minutes beforehand. The ferry takes about an hour. The journey to the city centre is another 1.5 hours. We have to leave the day before to ensure we make the appointment, as sometimes the ferries get cancelled due to high winds. I do get part funding, but it is only 1/3 of the true cost, and overnight accommodation is not included. Each time we go for an infusion it is a minimum of 4 nights for 3 days of treatment. Our pets need to go to the kennel which costs $40 per animal per day, and the kennel is in the opposite direction to the ferry, which adds on an extra 40 minutes of travel*.

Associated costs: "*It can cost $20-$30 each time for parking.*"

A sub-theme that emerged from travel was the costs associated with it, such as the petrol involved in driving to appointments and treatments and paying for parking: "*It can cost $20-$30 each time for parking.*" The lesser obvious costs emerged, such as lost income due to time off work and time off school, which can have effects on the wider family.

Sometimes, participants found it difficult to get other siblings to school when looking after their child with JDM, which means time off school for their siblings. Taking time off work to get their children to treatments reduces income. With big treatment days often come special treats, presents or rewards for bravery, or special dinners and snacks throughout the day. Parents are often not provided with meals during their stay in hospitals, which means if they do not bring a packed lunch for themselves, they will need to buy their own food, adding to the costs of the day. Earlier on, during the journey to diagnosis, there can be many trips to the GP and other specialists, which means more time off work and school for appointments. Furthermore, there is time off work and school for 'bad' days when the symptoms worsen and recovery days. The participant facing a 10-hour round trip chose to stay in a hotel room for the night with her child, which presents further costs. These costs were ongoing, with the treatment needing to be administered every month with no closer available treatment. This is due to a lack of resources required at the local clinics if the child experiences a severe reaction to the medication.

The emotional cost is immense, stemming from the constant mental work of coordinating treatments, appointments, and various forms of leave, alongside the logistical challenges for the family. One parent was a sole parent who had no one to lean on during these difficult times, which highlights the importance of also monitoring the parent's mental health during treatment.

Family impact (time off work, time off school), favouritism/special treatment: "*It's hard to say no to her now.*"

Family impact also emerged as a sub-theme. Being the parent or sibling of a child with a chronic illness requiring intensive/complex treatment is difficult. Impacts include time

off work and school for the siblings or both parents instead of one. Loss of income can create a stressful family environment, especially when still on the journey to diagnosis. One parent mentioned that she found it challenging to get her son to school on the days that her daughter was really sick. Children with JDM can take up a lot of space in the family home physically, mentally, and emotionally while they come to terms with what they are experiencing. Some children with JDM require additional support in the home, such as wheelchairs or walkers, or in-home visits from specialists such as physiotherapists and occupational therapists. Avoiding favouritism or special treatment can be difficult for parents of more than one child. Parents often want to shower their child with JDM with gifts or special treatment to make up for the disease they have to endure, which is out of anyone's control. One parent shared that "*it's hard to say no to her now*", sharing the feelings of how difficult it is to refrain from giving their child anything they ask for as it helps to create feelings of compensation for the parent to be able to make their child feel better. This can be seen as favouritism by other children or the other parent. Depending on how old the siblings are, it can be difficult to communicate why one sibling gets certain things and they do not. If the other sibling gets special treatment as well to not ostracize them, it can take away the 'specialness' from the child with JDM, making it very delicate waters to navigate as a parent.

Further difficulties stem from managing the emotions of a child with JDM. The rollercoaster of emotions spans from processing and digesting the diagnosis, through to the side effects long-term high dose steroids can have on children. One parent shares how her daughter "*just cries at the drop of a hat,*" with another parent sharing that her son "*had lots and lots of issues with anger*". These personality changes can be confronting and difficult to navigate while also navigating a new and rare diagnosis. Children require space to

experience their feelings while still being provided boundaries, which can be challenging to impose as a parent who is feeling a mixture of guilt, fear, anger, and uncertainty around their child's illness.

Parent knowledge: Becoming experts on their child, their illness, and their needs: *"I did all my own research."*

Out of the five interviewees, four of them had not heard of JDM before their child received a diagnosis. One participant stated, "*I had no idea that kids could actually get arthritis.*" One patient claimed they had a friend who has a daughter with JDM. Overall participants felt they were not well-informed with doctors adopting a "*need to know*" basis. This in turn, made participants inform themselves about the treatment and treatment outcomes for patients with JDM. One participant stated, "*I did all my own research*."

Parents often find themselves becoming experts in their child's illness. This is due to a multitude of factors, including research during the journey to diagnosis to ascertain what is going on with their child, research into treatment plans, medications and their side-effects, and prognosis and outcomes. The level of research parents put into their child's disease is often driven by the lack of information they receive from their healthcare provider. This can be because JDM is a rare disease with little known about its epidemiology, which makes providing a prognosis difficult. Additionally, there are three main courses the disease can take: monophasic, polyphasic, and unilateral. Doctors often withhold information to manage the expectations of their patients and their parents. As a result, parents learn how to read peer-reviewed articles of the latest research on treatment developments for JDM.

Through their child's illness, parents gain not only medical expertise but also an intimate understanding of their child. The subtle and insidious nature of the symptoms of

JDM creates parents who are hyper-aware of their children's physical movements, strength, and mannerisms. There is always a possibility that children can have a flare-up, which can be caused by sickness, the sun, or for no reason at all. Consequently, parents become hyper aware of their children during sickness, because a mild cold can put their child in hospital and the decline can be sudden and rapid as they are on immunosuppressants, which makes them immunocompromised. Most children have an emergency steroid plan if they start to decline due to sickness.

Outside of sickness, parents still need to be diligent in how their child is reacting to the treatment. Once the disease is under control after the aggressive first-line treatment is complete, weaning is begun to ascertain if the child can maintain recovery without the medication keeping the disease suppressed. This is a very slow process, and it is a delicate time during treatment. As a consequence, parents continually maintain states of heightened awareness and increased feelings of stress and anxiety. Assuming the role of primary medical provider is an aspect of parenting that often proves unexpectedly challenging. As one parent reflected, "*It's a completely different experience as a parent,*" and another parent added, "*It's actually been quite stressful*".

Parents of chronically ill children often become experts in alternative therapies and treatment approaches out of necessity and the need for advocation. Support groups can be magnificent places for parents to find support outside of the medical system with other parents who understand what they are going through. These support groups are most often found on social media, such as Facebook. There is an organisation doing awareness work called 'Cure JDM' but they are based in the United States of America, so they have a different health system and differing access to medications. Their website has resources

available for parents, with sections dedicated to the most recent research in the treatment and outcomes for JDM. Other websites, such as arthritis Australia (https://arthritisaustralia.com.au) have sections dedicated to JDM and keep their site up to date with the most recent developments. These websites also shared my survey to help generate more research and awareness for such a rare disease.

Additionally, parents will often turn to support groups and other sources of information to find answers to what their child could be facing so they are as prepared as possible. When facing such uncertainty, parents find ways to feel like they are contributing to gain a sense of control. One parent shares, "*I did all of my own research, I didn't know what to expect with that medication and I didn't feel informed*". Another parent shared that they obtained psychological support through their own research as nothing was offered through the hospital: "*It's all been through my own like less through the hospital, and more through my own research, finding what's available in Australia*".

Parents reach out to these communities attempting to understand more about the disease their children are fighting in a non-confronting environment with peers who are also facing similar experiences (White, 2001). Support groups, whether online or in person, create a shared narrative that generates a community that can provide additional support to supplement where the healthcare system may fall short (Whelan, 2007). There is a paucity of literature regarding the experience of long-term treatment for rare autoimmune disease such as JDM and Barak et al., (2008) suggests that the main reason parents seek support groups outside of the healthcare system is to gain a sense of belonging and wellbeing through being a part of a community where they feel heard. In turn, parents gain knowledge and expertise about the treatment and possible prognosis, which they do not gain through

their specialists. This is due to the often open and honest ways that people in these communities share their experiences. The parents often back up their experiences with lab reports from their children's hospital visits and recent peer-reviewed research they have sourced online.

Section C: Question for the child

At the end of the survey, additional consent was sought to ask the child a question. This question was kept broad as it addressed a wide age range of 5-13 years old. The question could be answered with a drawn picture, a sentence, or a paragraph. The question was phrased as "What is it like to have JDM?" and "What could make your treatment experience better?" The responses have been presented below and have been kept true to their author with no changes. These are discussed further in the discussion chapter of this thesis.

Child one:

"*It's bad, I have bad scary days, I want to be able to walk on my feet normally again. (He toe walked due to calf contractures)"*

Child two:

Originally I didn't really understand what was happening. And when I was little I never understood that I was in pain. I didn't know how to tell my parents that my muscles hurt. I pushed through all the pain. As I got older and it progressively got worse, I found it hard to walk, carry things, hold my hand up at school, get out of the shower, get out of bed and swallow. As we went to many different doctors, I constantly felt disappointed, as every specialist or physio never knew what was wrong. When I finally

got diagnosed, I was very relieved. At school, I struggled to do simple tasks and would be exhausted by the time I got home. I slept for 12 hours or over, and I could only eat soft bread. As treatment went on I struggled to keep exercising as it was very difficult. But now that I am off meds and doctor-free, I do sport every afternoon. One thing I will say about the treatment is that one of the medications I was on caused me to have more hair growth. Which has caused on going effects of insecurity, over the hair on my back, tummy, arms, legs and face. I also believe we did not get the amount of support we needed. One thing I would've loved to have was a rail to help me get out of the shower. Also at school not all of my teachers were informed, and would often get mad at me for walking to slow up the stairs or across the oval. But overall having JDM is difficult, but because I have had the right treatment I am able to do more than a lot of other people my age can physically.

Child three:

Living with Juvenile Dermatomyositis has been a mix of physical challenges and emotional resilience. The muscle weakness made even simple tasks exhausting, and the skin rashes were a constant reminder of the condition. Flare-ups brought pain and unpredictability, while treatments required patience and adaptation. It's been a journey of learning to listen to my body and finding strength in small victories.

Child four:

"The thing that I think could be better is if the doctors' asked kids if they want to watch the tube going in"

Chapter 5 – Discussion

This research aimed to understand the lived experiences of children undergoing long-term treatment for Juvenile dermatomyositis (JDM) and their parents within the public healthcare system. Additionally, to understand the main barriers to gaining a confirmed diagnosis, and what challenges families face when they do not receive adequate wrap-around support. The main objective was to identify areas where extra support is required. I achieved this by exploring the treatment experience of children diagnosed with JDM primarily through the perspective of the parent to identify systematic challenges that have a significant impact on the treatment experience. Also highlighted through this research were the specific challenges that rural families face when undergoing long-term treatment for chronic illness.

Summary of findings

Sixteen parents (13 mothers and 3 fathers) completed a survey about treatment experiences with the addition of a question for the child at the end, to which four children responded. Five interviews (3 mothers and 2 fathers) were completed with parents. The interviews delved into the whole experience of parenting a child with JDM, including the journey to diagnosis, treatment experience, and the family impact, including managing the emotions and expectations of the child. The three main themes that emerged from the interview data were: Advocation, Treatment, and Parent knowledge. These themes were also reflected in the qualitative open-ended survey responses that asked participants to expand on their answers.

Findings overall focusing on treatment experiences revealed there are stressors, hidden costs, and barriers for families at structural levels. Throughout the survey and

interview responses, there was a common theme of parents being adequately satisfied with the healthcare system and grateful for what they receive. However, upon further questioning, it became clear there were frustrations with the healthcare system mostly related to barriers to diagnosis and treatment protocols. There was a common thread that told of the fight for answers, the shock of getting a diagnosis and being left largely alone to navigate a rare autoimmune disease with an unknown prognosis. There were immense psychological, practical, and social impacts throughout the entire journey on the child, parent, and the family.

The research identified key areas where small changes could be made to significantly impact the treatment experience of children and their families. These key areas were increased communication about diagnosis and available support services, an increase in practical resources such as ultrasound machines, an increase in creature comforts such as comfortable seating for both the child and the parent and both being fed, and an increase in subsidies to help with the hidden costs associated with a strict multidisciplinary treatment regime. Additionally, offering flexibility around treatment protocols and available medication to customise treatment plans to suit the individual where possible could significantly impact the way children (and parents) experience treatment. Parents added that there were multiple times throughout the journey to diagnosis and treatment where they felt they weren't listened to, which impacted their treatment experience. As described in Rafferty (2017), conflict with medical professionals is often due to parents feeling like they are not being listened to and experiencing communication breakdowns. This is often where parents find themselves needing to become an advocate for their child to ensure they are getting the standard of treatment deserved and expected.

Despite experiencing various frustrations and stressors during the journey to diagnosis and treatment, participants expressed feelings of hope and a willingness to increase awareness and do ‘what they can’ to help. This is echoed in Kountz-Edwards et al.'s (2017) research, which showed that parents often felt increased empathy and compassion after the diagnosis. There also were positive health interactions at times especially with the nurses. Nurses often tried to compensate for the shortcomings of the healthcare system by offering parents extra numbing cream and doing what they could to ensure their child was comfortable.

Stressors and practicalities of JDM

Living with JDM presents a multitude of psychological and physical stressors alongside practical challenges. The physical challenges for the child include limitations due to muscle weakness, which can hinder daily activities and require extra support from their parents or equipment such as wheelchairs (Cox, 2016; Sag et al., 2021). Pain and fatigue are common symptoms of JDM, which can lead to psychological distress. This can be due to the nature of JDM requiring long periods of treatment with no outcome guarantees, which requires resilience to push through treatment for the child. Frequent medical appointments, monitoring tests such as blood tests, and physiotherapy sessions can be disruptive to daily life, including schooling and doing fun activities (Kelly et al., 2025). Children can experience feelings of isolation due to the impact JDM has on their ability to attend school and social gatherings. Allowances need to be made but are not always practical, meaning the child can feel like a burden.

Both the physical and emotional nature of living with JDM is demanding and draining for the parents as well. For the parents, there is an immense amount of mental labour to

keep track of the multiple medical appointments in varying areas and sometimes different time zones. There is coping with the child's experiences of treatments managing things such as needle phobias, anxiety, and worry over treatment or expectations about long-term outcomes. There is also the physical task of getting the child to appointments while managing other family members and/or work that require a lot of time and effort (Kelly et al., 2025). These emotional and psychological drains extend to the family and wider support system, requiring patience and empathy for and from all those affected. The uncertainty of not knowing what the progression of the disease or treatment will be can cause significant distress to both the child and the parent.

Increased sun protection is crucial for children with JDM, as UV exposure can exacerbate their condition and lead to systemic symptoms like fatigue and skin lesions (Wan & Lara-Corrales, 2019). Furthermore, extended exposure to UV light can heighten the risk of a 'flare-up.' Conveying the severity of UV light's impact on schools and extended family members can be challenging. Children require high-SPF sunscreen and protective clothing, such as a wide-brimmed hat, when in the sun, and should only stay outside for short periods, but parents indicated schools, and some family members did not understand the seriousness of these issues. This is just one example of the communication and advocation that parents are required to do for JDM.

Children and parents need to make lifestyle adjustments when living with JDM, such as implementing strategies to manage pain and fatigue and making sure they are getting adequate rest and nutrition (Kelly et al., 2025). Schools need to make accommodations for the children as well, such as allowing the child to sit on a chair instead of the floor, allowing them shortened physical education classes and in the early stages of the disease, staggered

starts back to school, working up to full-time days often starting with half days and/or half weeks. Support systems also need to be flexible with the additional requirements needed to support a child living with JDM. Accessing support groups with other children and/or parents going through similar situations can be a source of support and validate parent experiences (Rafferty, 2016).

It is known that individuals living in rural areas face significant barriers to accessing healthcare when managing chronic illnesses (Gizaw, 2022). These challenges are multifaceted for the parents in his study. For some of the parents in Australia, there are longer distances to travel, the added cost of greater levels of fuel needed, and hotel rooms if required due to the distance travelled (Kelly et al., 2025). Additionally, traveling while sick is a heavy physical and emotional burden on both the parent and the child. This has been reflected in the findings of this research, with three out of five of the interview participants noting the toll it takes on them traveling long distances on either side of treatment. One participant stated that it took them five hours to get to and from treatment, resulting in a ten-hour round trip. This is in addition to a seven-hour infusion with extra time required on either side of treatment. This results in a long and challenging day. Another participant spoke about not being able to go to their local clinic due to the clinic not having the required equipment available should a severe reaction from the medications occur. Additionally, longer travel times lead to more days off work required. This reinforces the current literature on how rural living provides extra challenges when needing specialised treatment (Kelly et al., 2025). Kelly et al. (2025) highlighted the compounded stress faced by rural families, burdened not only by managing a rare chronic illness but also by the heightened anxiety of medical emergencies due to their remote location and the isolation of being the only family affected by a rare chronic illness in their community.

There are many costs associated with living with a chronic disease. It has been well-documented that living with a chronic disease can create a significant financial burden both on the economy and the individual (Kelly et al., 2025; Parry, 2012). Extending beyond medication and treatment costs, there are additional costs of paying for parking, buying extra food if necessary, buying treats for children when they have been brave, celebrating wins, or commiserating losses. The cost of a hotel and lost income due to reduced hours, and lifestyle adjustments including adapting to new diets if the child is experiencing dairy intolerance or develops celiac disease. Updated healthcare legislation could help support families and mitigate catastrophic healthcare spending at the healthcare level (Parry, 2012). This legislation could look like reducing or eliminating parking fees at hospitals, increasing food offerings to caregivers of child patients, and providing subsidies for travel expenses.

Diagnostic delay caused by not being listened to

> *"And in this whole time, her ankles were locking. She was in pain like I've got so many videos of her in tears just not being able to walk throughout a day like it was just insane."*

Early and aggressive treatment has been shown to be effective for increasing the chances of a positive prognosis for JDM (Kelly et al., 2025; Matin, 2011). This is difficult to achieve when facing the challenges of navigating health professionals who are not listening to the parents or dismissing symptoms as typical childhood issues. Parents felt they knew their child best (what is typical and what is not) and felt unheard in multiple settings. The story that the parent tells the specialist is a critical part of gaining a diagnosis. Videos, photos, and detailed accounts of the symptoms the child has been experiencing for how long, and any other medical history that may be relevant. Through my journey, I was praised

for the detailed account of my daughter's history that brought us here and how helpful it was to put all the puzzle pieces together. If it was not for the detailed background provided to the specialists, she would not have received a diagnosis as quickly.

The medications for JDM are aggressive and can cause severe side-effects such as extreme fatigue, vomiting, and severe headaches alongside stomach issues, and appetite can increase or decrease (Pachman, 2021). Both parents and specialists need to constantly weigh up the benefits of how much the medicine will help the child versus how much the side effects will hinder their daily life. In line with the literature on 'Best practise', this highlights how parents are the appointed experts on their child's health and well-being.

Although individuals with IIM can experience significant diagnostic delays of up to six years, a study by Namsrai (2022) across IIM and its subtypes has shown that the average diagnostic timeframe for JDM is six and a half months. This is in line with the participants in this study who received a diagnosis between six and twelve months. According to Kelly et al. (2025), and in line with this research, parents expressed increasing frustration while seeking a diagnosis and struggled to comprehend the absence of a clear aetiology for the disease.

Psychosocial impact

Psychosocial considerations for JDM, similar to other rare chronic illnesses, are emotional distress associated with uncertainty and fear around prognosis and disease progression. Additionally, having to deal with the side effects of medications, constant medical follow-ups, and changing of treatment plans can all have effects on the psychological health of children and their parents.

Wellen (2022) stipulates that although research is scarce in paediatrics, the rates of depression and anxiety are known to be higher in adults experiencing chronic illness. With

this known correlation for adults, it is a logical deduction that children could also experience higher rates of depression and anxiety when facing similar challenges. Children experience emotional distress related to frequent medical trips and medication management challenges (Wellen, 2022). Furthermore, children experience emotional distress brought on by side-effects of long-term steroid use, which is challenging to manage. The visible symptoms of JDM can be damaging to the child's self-esteem (Wagner, 2005). Their peers can notice and comment on their red rashes, skin lumps, bumps, weight gain, and 'moon' face, and make the child feel self-conscious. One parent relayed that the boys in her daughter's school notice and comment on her rashes which made the child feel self-conscious. Furthermore, children can experience feelings of anxiety, depression, and isolation due to the physical limitations and visible signs of their illness. One parent recounted a time when her daughter was yelling and screaming and not letting her in her bedroom. This behaviour was very out of character and confronting for the parent. The emotional weight of these experiences is clear in the research, as participants shared accounts from their children that were deeply confronting. One parent shared that they found self-harm marks on their daughter's arm, although her daughter claimed she just wanted to know why her friend was doing it. These discoveries can be deeply shocking for parents, creating a challenging situation to navigate.

Parents and children are often left to face these challenges on their own while they sit on a wait list for professional psychological help. Due to the chronic nature and potential progression of autoimmune diseases requiring long-term treatment, psychosocial considerations are a vital and often overlooked aspect of care, as noted in Wayland (2022). This is reflected in the research, with 70% of participants reporting that they were not offered mental health support. In addition, there was a letter provided that showed the hospital acknowledged that there had been a 360-day wait for one patient, but did not

provide a timeline to expect an appointment. This demonstrates a severe lack of support in the mental health space for paediatric care. As Rohan (2022) notes, it is thoroughly documented that improved overall health can be achieved by improved psychological functioning and adaptive coping methods. Providing psychological support early in the diagnosis-treatment process would help equip children and their parents with a tool kit to navigate the emotional storm that is often a part of living with a chronic illness. The findings in this research were consistent with current literature outlining that parents often feel heightened states of anxiety around their child's health alongside feelings of exhaustion (Kountz-Edwards et al., 2017)

Kountz-Edwards et al. (2017) stipulated that while the family impact can be negative whilst the disease is active, with increased stress and conflict, it has also been shown that the family's functioning improves substantially once the disease enters remission. While the Kountz-Edwards et al. (2017) study did not include children who are currently in remission, it is positive to see research where families come out the other side in a better state than they were going into it. Kountz-Edwards et al. (2017) reported that parents often felt more compassionate and empathetic and that their perspective had shifted post-diagnosis. The findings of this research support the literature that illustrates a child's JDM status can have a significant impact on the state of a parent's mood, level of distress, and growth.

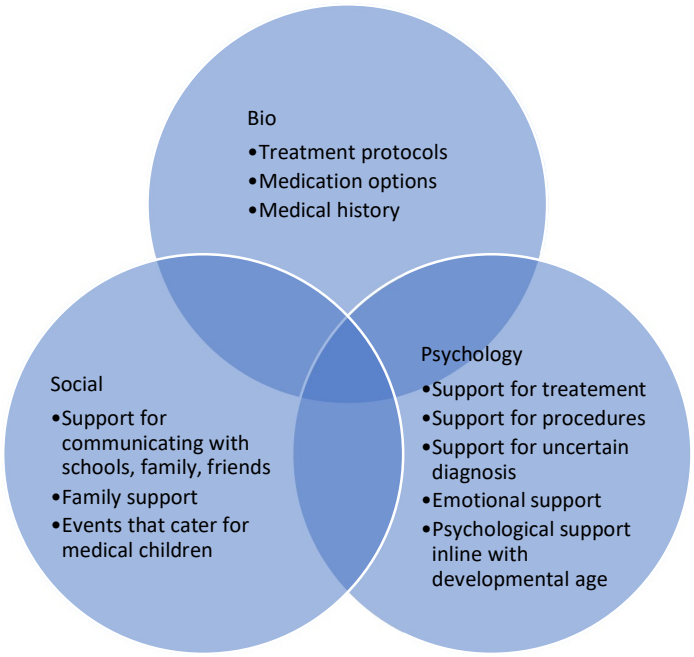
Biopsychosocial model for JDM

Ideally, biopsychosocial support for both the child and parent would be offered as a standard practice of care. This is happening somewhat but not consistently with inconsistent findings across participants, with some being offered food and mental health support and adequate treatment while others are not. Below is a biopsychosocial model of care adapted

for JDM based on the findings in this research (Figure 20). In the middle is the well-being of the child and primary caregiver. Surrounding them are the three main areas of support required, including biomedical aspects of treatment protocols and having flexibility in how procedures are performed to give children agency over their bodies. Medication options are surveyed and assessed for best fit for the child, as some medicines can have significant side effects for some children. The social domain includes areas where having support has significant benefits when experiencing chronic illness, and these areas need consideration if they are lacking for patients. Finally, the psychological domain includes areas such as treatment support when undergoing painful or scary procedures, such as play therapists, emotional and psychological support for children to help them process what they are experiencing in line with their developmental age and making available someone for the child to speak with that is outside of their immediate support network.

Figure 20

Biopsychosocial model for JDM



Biological

Findings showed that treatment protocols are inconsistent, which can be understood from the perspective that JDM is rare, disease progression is uncertain, and there is a lack of JDM-specific research. However, parents become experts from experience and their own research and using community on-line forums from around the world. Parents are not feeling heard when they question treatment protocols or want answers. Additionally, parents felt there was a lack of knowledge among the medical community, which is also reflected in Kelly et al. 's (2025) study on parental experience of a child with JDM. Standard treatment protocols are revealing that it is not a one-size-fits-all when it comes to treating a child with a rare chronic illness, and a more holistic approach that includes multiple medical specialities and the parents would be ideal.

Support for the children and parents undergoing the medical procedures should be everyday practice however, this research showed that while some children are offered play therapists during procedures, the majority of participants were not. Additionally, play therapists often fail to facilitate the child's agency over their body and jump into assumptions of how best to manage the child during a procedure instead of asking the child first.

Psychological

This research revealed that there was very little psychological support for children offered and none for parents – leaving them to cope largely alone. Additionally, when parents did want to access mental health services for their child, they had to advocate for mental health services through the hospital system or do their own independent research to find out what was available to them in their area. When information is not readily available

through the hospital there is the chance that not everybody would have the knowledge or initiative to research other services that could be available. Financial barriers may also exist if parents want specialist support for themselves or their children. Consequently, this leaves vulnerable families without the support they need.

Rabbitts et al. (2020) found that children are more susceptible to developing depression or anxiety when living with chronic pain, which highlights the importance of making information on where to access support readily available. Additionally, the main caregivers of children with chronic illnesses tend to experience increased levels of stress and anxiety, which also highlights the need to extend these services to the caregivers and family network (Essner et al., 2020). Consistent with the literature (Rafferty, 2016), this research's findings reveal that persistent advocacy leads to emotional exhaustion, including frustration, anger, and sadness. This highlights the importance of examining what wraparound services can be offered through the healthcare system as a standard process for both the patient and their main support person.

Livermore et al. (2021) surveyed rheumatology services in the UK and got 100% survey completion. Of the responses, seven (47%) did not have a named psychologist as part of their rheumatology team, despite the majority [13 (87%)] having >200 paediatric rheumatology patients. Only 8% of professionals rated their service as excellent with regard to psychological support. The respondents highlighted many challenges, including limited psychology provision, lack of time, and difficulties in offering support across large geographical areas. Notably, all respondents saw the value of providing these services.

Social

The social worlds of the child require support, including parents and wider networks. The research revealed that extra support is required during the journey to diagnosis, (being listened to when insisting that something is not right with their child), openness to alternative treatments that suit individual needs when practical, better communication between specialists and parents/caregivers, and increased practical needs when in the hospital such as feeding the whanau and ensuring parents have not just adequate but comfortable seating. Lost time from school also means lost time from social circles. It can be difficult to maintain social connections while being away from school often. It is important to manage children's social connections alongside academic progress due to the increased feelings of isolation that chronic illness can bring.

As identified in the literature, parents feel the need to advocate due to feeling that there are gaps in information provided by medical professionals and the emotional and psychosocial support for parents and children (Thomas et al., 2023). Highlighting the seriousness of the illness that can often present as invisible requires the constant re-telling of the same story to multiple institutions and fighting to be believed to ensure that their child's extra needs are being met. Maintaining continuity of information is crucial. As the child advances through each year at school, it is essential that their teachers are informed of their background and needs at the start of each year. This constant repetition is emotionally draining on the parents but is necessary to ensure their child's needs are met. Some schools respond positively and are happy to accommodate any extra needs that children require. Other schools struggle to understand the unique nature of chronic illnesses, especially if children are presenting normally.

Recommendations

The parents and children had a multiple suggestions that would make their treatment experiences better. These were across all areas of the biopsychosocial model of health. Some of these are small practical solutions that would have a significant impact to treatment experience. Further suggestions would help remove systemic barriers.

1. Ensure parents have a comfortable chair to sit on during long treatment days
2. Increase resources such as ultrasound machines
3. Feed the parents, if not meals, then biscuits to go with their tea/coffee
4. Ask the children before they undergo procedures what will help them cope instead of assuming. Give them agency over their own body and treatment processes like an adult would have.
5. Increase resources and funding for more rheumatology professionals as it is noted that autoimmune diseases are on the rise and more awareness needs to be generated in the public and within the healthcare system. It is also noted in the research that there is a shortfall of rheumatology staff to cover the patient list adequately
6. It would be beneficial if hospitals offered information about alternative outside services to support the child and the family holistically. For example, information around mental health services that could be government funded through an alternative foundation. Alongside more specific play specialists to support children during procedures that support the feelings associated with treatment as well as the medical aspect.

7. More information about communities of support provided to parents and children. This requires health professionals to have this information to hand about organisations such as CureJDM and guide parents to information that is helpful whilst being evidence-based. Useful information, such as a one-page handout that includes links to further information to give to families and schools to explain the health condition. An official 'Fact Sheet' with tips and tricks for supporting children and their families through chronic illness
8. Access to a social welfare advocate to advocate on behalf of parents who are unable to advocate for themselves.
9. Normalising treating parents as the experts on their children and listening to them when they propose alternative treatment strategies.
10. Increasing awareness of rare diseases within the healthcare system and the symptoms to look out for.

In summary, the findings of this study corroborate the existing, albeit sparse, literature regarding patient experiences with JDM treatment and other childhood chronic illnesses. The relentless need for advocation while navigating diagnosis and treatment can lead to emotional burnout in parents. To help mitigate this, one of the most effective interventions would be to raise awareness of rare rheumatic diseases across the general healthcare system to help reduce diagnostic delay. Additionally, flexibility in treatment protocols and medications to tailor to individual preference where practical would positively impact the treatment experience of children and their parents. Increasing the focus on a more holistic model of care, such as the biopsychosocial or Te whare tapa wha model, would ensure that the full needs of the child and their family are met. There are small systematic changes that could be implemented that would not cost the healthcare system much but

would have a significant impact on the treatment experience of children and their parents/family. An increase of consistent wrap-around support truly encompassing the biopsychosocial model of care is recommended.

Strengths and Limitations of the Research

My positionality throughout this research was that of an insider (Finefter-Rosenbluh, 2017). Having an insider status for this research was positive for these reasons: It gave me the insider status of understanding, which enabled me to build rapport and show genuine understanding in response to participant answers during the interview. This also fostered a sense of community and hope by generating feelings of proactiveness against a disease that has no cure. However, it also required me to be judicious in my reflexivity throughout the research to ensure that I am not imposing my own bias on the meaning of the data or failing to identify themes that are present. Other additional strengths were the mixed methods study, which allowed more data to be included for a very rare condition, and generate practical suggestions for parents and health professionals.

This research focused on the treatment experience. This could be broadened out to encompass to a greater extent the family, social and psychological impact. However, there is scarce research focusing on treatment experience for chronic illness, this research aims to add to that literature. The mixed-methods approach was utilised to access a wide range of voices, which it succeeded in given the rarity of the disease. While the sample was geographically diverse, the majority of participants were Caucasian and were assumed to be from economically stable backgrounds. Future research could aim at exploring the diversity of experience within a wider range of socioeconomic status and culture.

It would be beneficial for there to be future research that focuses on minority groups in New Zealand, Australia, and the United Kingdom and beyond who have been shown in previous research to experience greater complications from the disease, such as calcinosis, Gottron's papules, and major organ damage, including lung disease. Twelve out of sixteen children were identified as European by their parents, it would be useful to obtain sample data for future research that encapsulates a wider range of cultures. For example, Māori and Pasifika or Aboriginal Torres Strait Island. Capturing these minority groups in future research can contribute to raising awareness of the inequities between treatment outcomes and treatment experience.

The survey did not require every question to be answered to be complete; future research should ensure that every question is answered, if feasible, to help enrich the data. Furthermore, future research should make an effort to increase sample size through additional networks to increase statistical power.

There are multiple areas in which parents require extra support through their journey, and this should be explored further. To ensure ongoing progress in establishing evidence-based care, mental health support should be offered to both the parents and the children at or shortly after receiving a diagnosis. This will ensure that crucial psychological assistance is available during a challenging period. Research is then needed to explore what the best support is for the child and the family.

Small changes can have a significant effect on the experience of children undergoing long-term treatment for JDM. As Cox (2017) stipulated, the most effective intervention would be the education of general medical staff to improve recognition of rheumatic disease and reduce diagnostic delays. Research is then needed to explore the best way of doing this.

Conclusion

This thesis examines the emotional and practical challenges faced by children with Juvenile dermatomyositis and their parents during treatment. The main findings showed the need for advocation during the journey to diagnosis and throughout treatment, treatment experience and parent knowledge. There was a common thread of emotional resilience required for constant advocation, mental labour for treatment logistics, and the need for independent research due to lack of information given around prognosis and treatment options. The research revealed a significant lack of mental health services offered for the child or the family, highlighting the need for psychosocial support for both children and their families due to the ripple effect that treatment experience has. Increasing the focus on a more holistic model of care, such as the biopsychosocial or Te whare tapa wha model would ensure that the full needs of the child and their family are met. Future research would benefit from prioritising the voices of the children and gaining access to a larger, more diverse sample pool.

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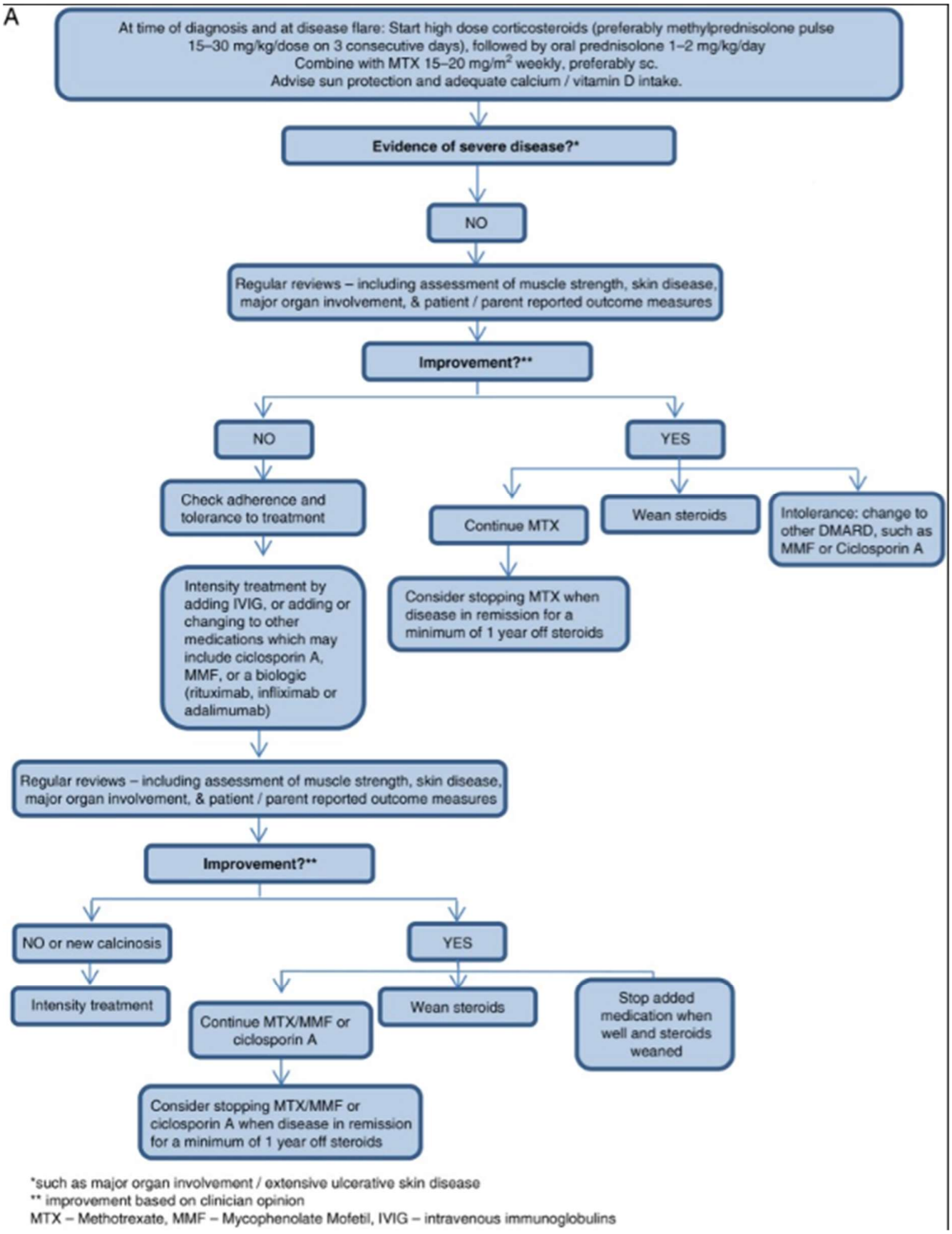
Appendices

Appendix A: Consensus Treatment flow chart for JDM



Appendix B: Information sheet

Understanding the experience of children aged 5-13 and their parents undergoing treatment for Juvenile Dermatomyositis in New Zealand, Australia, and the UK.

INFORMATION SHEET - SURVEY

Researcher(s) Introduction

Kia ora, hello, my name is Megan Jeffries. I am completing a master's thesis at Massey University exploring the experience of children aged 5-13 years old and their parents undergoing treatment for Juvenile Dermatomyositis in New Zealand, Australia, and the UK.

Project Description and Invitation

I invite you to participate in research exploring the experience of parents whose children are undergoing treatment for Juvenile Dermatomyositis. There is currently a gap in the literature that explores the experiences of parents and their children undergoing treatment for rare chronic illnesses. Often spending long periods in and out of the hospital for treatments and appointments, I aim to explore the holistic support the children and their parents are offered and to identify areas where it could be strengthened.

Participant Identification and Recruitment

Inclusion criteria

- Participants must be the parent of a child aged between 5-13 years old and their parents undergoing treatment for juvenile dermatomyositis.
- Participants must reside in New Zealand, Australia, or the United Kingdom as these countries share a similar healthcare model.
- Participants must be over the age of 18 years.
- Participants must have access to a strong internet connection to enable completion of the survey.
- The survey will be in English.
- Two parents can complete the survey, but we ask you to complete two separate surveys.

Project Procedures

Parent survey

You will be asked to complete a survey which will take approximately 20 minutes and can be completed within the online platform of Qualtrics. The questions focus primarily on experiences within healthcare settings. There are both closed and open-ended questions. The benefit of answering this questionnaire is that we could inspire real change to better support rare chronic health conditions. The risks are that supporting your child with JDM can be distressing so we encourage you to use your existing support networks and look at the support organisations at the end of the survey.

You will be asked after the survey if you would be willing to have an interview if you would like a summary of the research, and if you would like to go into a draw for a voucher. These details will be kept separate from your responses so your responses will remain anonymous.

Child involvement

Within the survey there is one section where you can invite your child to complete a question -**this is completely optional**. The consent for this will be separate from your questions so if the child does not want to participate that is completely fine and your responses can be still used. We encourage you to discuss this with your child and talk about the value of thinking about what they might like people to know about JDM. Children can answer the question in either the written word or by drawing about their experience of JDM.

The pictures or responses from the child will be only used for the purposes of this Master research project. They will NOT be used in any other publication such as journal articles or non-academic work

Data Management

Data will be stored safely and securely. Survey data will be anonymous (deidentified) and be stored on my password-protected computer in a password-protected One-Drive. The data within Qualtrics will be deleted once the research is completed. Any personal details for prize draws or summary of findings will be stored on a password-protected computer for the duration of the study and then destroyed. This data will be kept separately from other data within a password-protected computer. Only I will have access to data – my supervisor and I have a Sharepoint drive to share thesis work and she will only see de-identified data. My

supervisor will be responsible for the safekeeping and eventual disposal of data. The data will be transferred to the supervisor's university OneDrive and destroyed after five years.

- The survey will be anonymous.
- Parents will consent separately and formally for the response by their child - this is completely optional.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- *decline to answer any particular question*
- *withdraw from the study by not submitting your answers.*
- *ask any questions about the study at any time during participation.*
- *provide information on the understanding that your name will not be used except for the prize draw or summary of findings.*
- *be given access to a summary of the project findings when it is concluded.*

Project Contacts

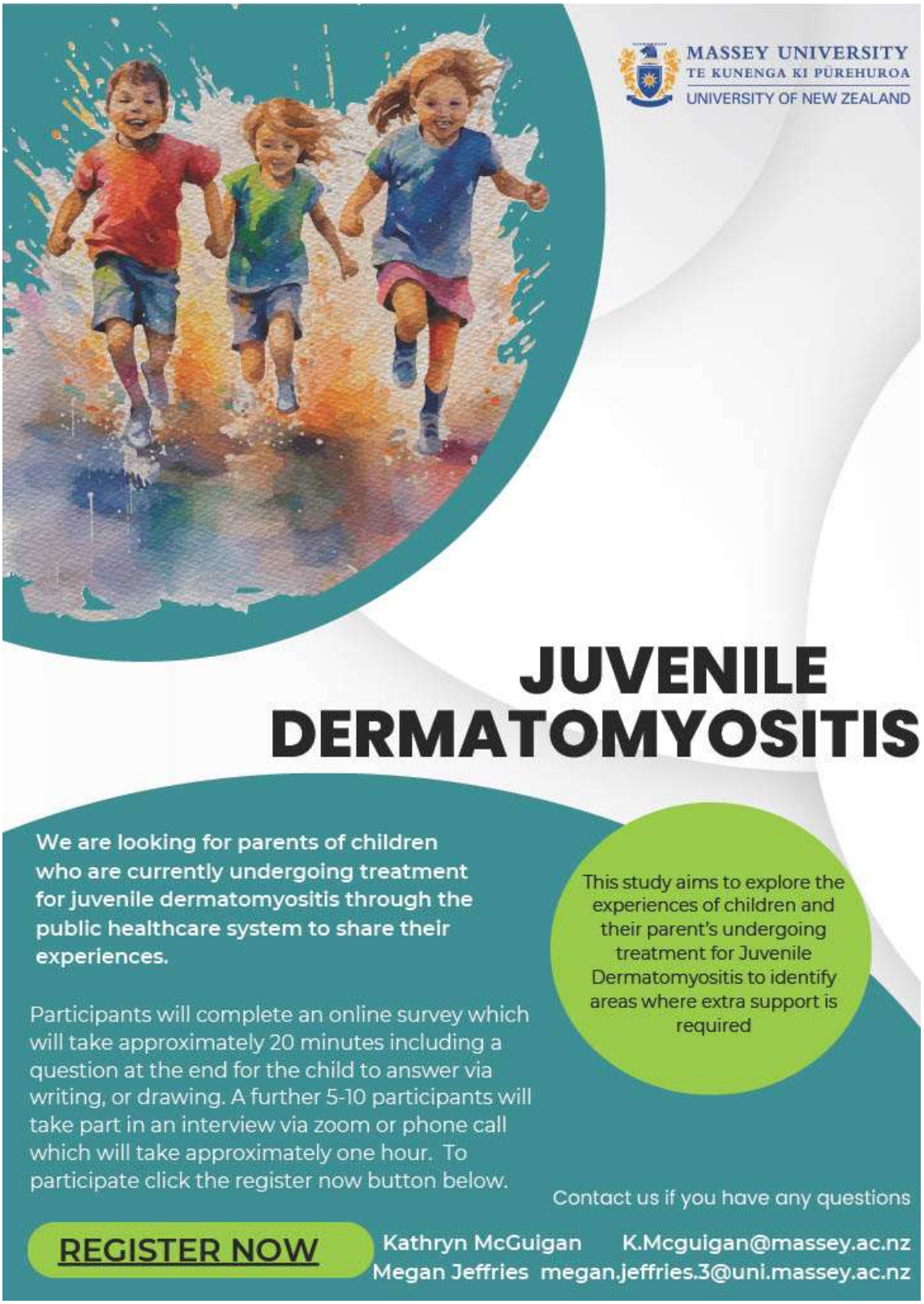
Feel free to contact the researcher or supervisor with any questions.

Kathryn McGuigan (supervisor) email: k.mcguigan@massey.ac.nz

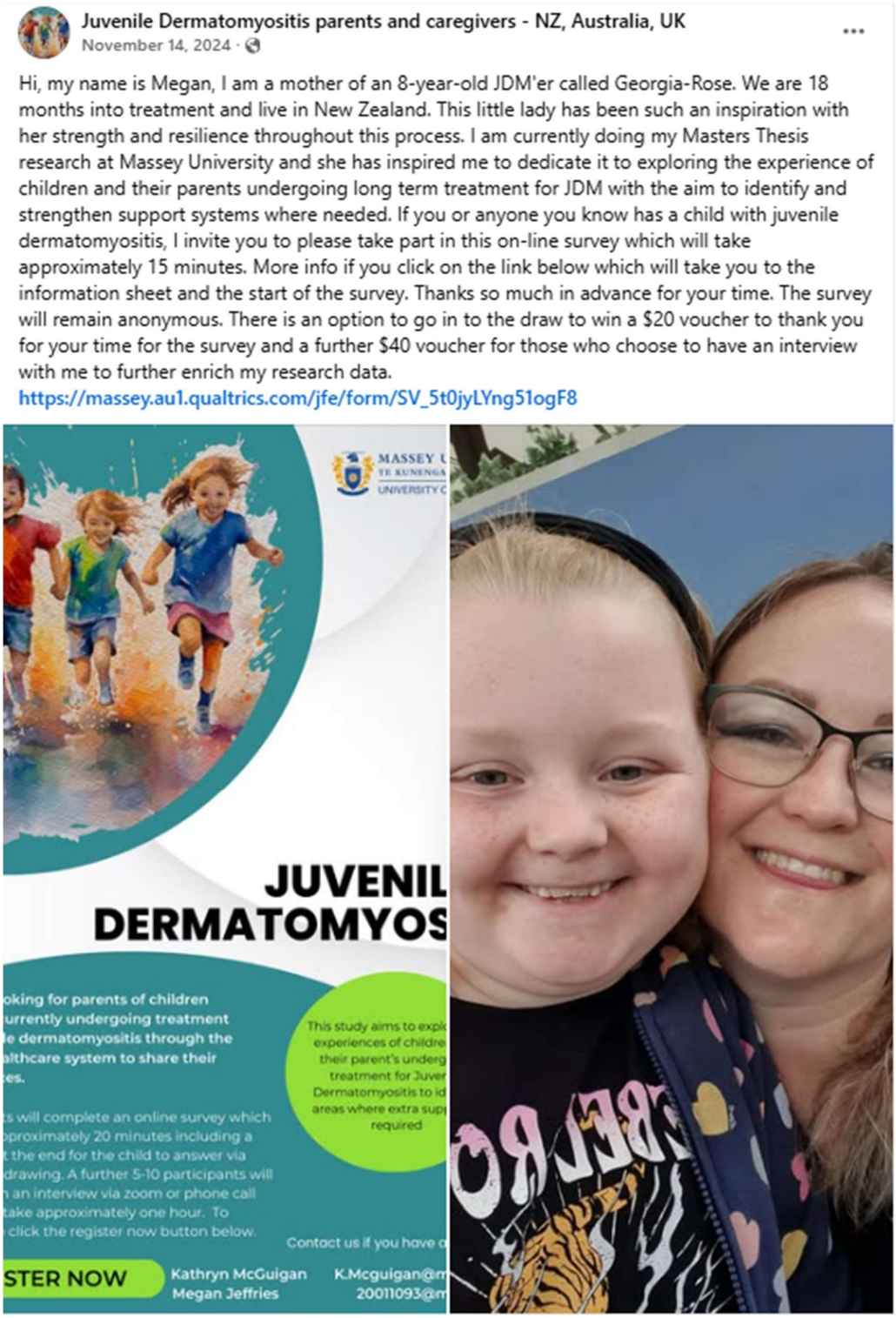
Megan Jeffries (researcher) email: [redacted]@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 24/24. If you have any concerns about the conduct of this research, please contact the Chairperson, Massey University Human Ethics Ohu Matatika 1, email humanethics1@massey.ac.nz*.*

Appendix C: Advertisement



Appendix D: Facebook advertisement



Appendix E: Consent Form

Understanding the experience of children aged 5-13 years old and their parents undergoing treatment for Juvenile Dermatomyositis in New Zealand, Australia, and the UK.

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read and understood the Information Sheet attached as Appendix I. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

1. I agree/do not agree to the interview being sound recorded.
2. I wish/do not wish to have my recordings returned to me.
3. I agree to participate in this study under the conditions set out in the Information Sheet.

Declaration by Participant:

I _____ [print full name]_____ hereby consent to take part in this study.

Signature: _____ Date: _____

Appendix F: Copy of the Survey

Demographic Information

1. Has the child in your care received a confirmed diagnosis of juvenile dermatomyositis?
    - Yes
    - No
    - In process

2. What is your gender?
    - Woman
    - Man
    - Transgender
    - Non-binary
    - Other (please specify) _____

3. What is your relationship to the child?
    - Mother
    - Father
    - Other (please specify) _____

4. What age is the child in your care?
    - 5 years old
    - 6 years old
    - 7 years old
    - 8 years old
    - 9 years old
    - 10 years old
    - 11 years old
    - 12 years old

5. Which ethnic group does the child belong to?
    - _____

6. Which region do and the child in your care currently live in?
    - New Zealand
    - Australia
    - United Kingdom

7. How long has it been since diagnosis?
    - 6 months or less
    - 6months - 1year
    - 1-2 years
    - 2-3 years
    - 3-5 years

- 5 plus years

8. Is the child in your care currently undergoing treatment for juvenile dermatomyositis?
    - Yes
    - No

Journey to Diagnosis

9. How old was the child in your care when they received a diagnosis?
    - Under 5 years old
    - 6 years old
    - 7 years old
    - 8 years old
    - 9 years old
    - 10 years old
    - 11 years old
    - 12 years old

10. Approximately how old was the child in your care when they started experiencing symptoms of juvenile dermatomyositis?
    - Under 5 years
    - 6 years old
    - 7 years old
    - 8 years old
    - 9 years old
    - 10 years old
    - 11 years old
    - 12 years old

11. Approximately how long did they experience symptoms before seeking advice from their GP?
    - Less than 1 year
    - 1-2 years
    - 3-4 years
    - 5+ years

12. What was your primary symptom/s prior to diagnosis? (Select all that apply)
    - Pain in arms and legs
    - Skin rash
    - Muscle weakness
    - Fatigue
    - Other (please specify) _____

13. Do you have a known family history of autoimmune disease?
    - Yes
    - No
    - Unsure

14. Did you discuss your symptoms with multiple GPs?
    - Yes
    - No

15. If yes, approximately how many different GPs did you visit?
    - 2 GPs
    - 3 GPs
    - 4 GPs
    - 5+ GPs

16. Approximately how many times did you visit your GP to discuss your symptoms before receiving a referral to a specialist?
    - 1 visit
    - 2-3 visits
    - 4-5 visits
    - 6-7 visits
    - 8-9 visits
    - 10+ visits

17. Did your child exhibit symptoms of other conditions such as:
    - Celiacs disease
    - Reynolds phenomenon
    - Dairy intolerance
    - Irritable bowel syndrome
    - Other (please specify) _____

Section Summary

In this section, you were asked about your journey to diagnosis of JDM. Is there anything further you would like to add?

_____

Facilitators and Barriers to having a positive experience during treatment.

18. Do you receive clear communication of appointment details including adequate lead time to prepare? Choose a statement below.
    - I receive adequate warning of upcoming appointments every time.
    - I receive adequate warning of upcoming appointments some of the time.
    - I receive adequate warning of upcoming appointments never.

19. Select which treatment the child in your care is currently undergoing.
    - Physio
    - Intravenous steroids
    - Oral steroids
    - IVIG infusions

- Methotrexate injections
- Methotrexate oral
- Omeprazole
- Folic acid
- Pamol/panadol
- Ibuprofen
- Other (please specify) _____

20. Please outline the frequency of the medications/treatments prescribed (i.e. daily, weekly, monthly etc)
    - Physio_____
    - Intravenous steroids_____
    - Oral steroids_____
    - IVIG infusions_____
    - Methotrexate injections_____
    - Methotrexate oral _____
    - Omeprazole_____
    - Folic acid_____
    - Pamol/panadol_____
    - Ibuprofen_____
    - Other (please specify) _____

21. Do you get subsidised or free parking at your place of treatment?
    - Yes
    - No

22. How far do you have to travel to receive treatment?
    0-5kms
    5-10kms
    10-20kms
    20-30kms
    40-50kms
    50kms or more

23. Do you receive subsidies for travel?
    - Yes
    - No

24. If yes, do you utilise these subsidies?
    - Yes
    - No

25. Do you get the option of at-home treatment (i.e. receiving IVIG treatments at home)
    - Yes
    - No

26. Is the child in your care provided with meals while they are in for **day stays** in hospital?
    - Yes
    - No
    - Sometimes

27. Are you as the caregiver provided meals during **day stays** in hospital?
    - Yes
    - No
    - Sometimes

28. Is the child in your care provided a comfortable chair or bed during **day stays** in hospital?
    - Yes
    - No
    - Sometimes

29. Are you as the caregiver provided with a comfortable chair during **day stays** in hospital?
    - Yes
    - No
    - Sometimes

30. Do you receive clear and straight forward information conveyed in layman's terms about changes to the child in your care's treatment plan?
    - Yes
    - No
    - Sometimes

31. Do you have any rituals you like to do before/after or during treatment?
    - Yes
    - No

    If yes, please provide examples _____

Perceived Education of Healthcare Providers

32. Reflecting on your journey to receiving a diagnosis, how educated/knowledgeable did you perceive the healthcare providers you interacted with regarding JDM and its treatment? (Please select all that apply)

    I believe the **GP's** I encountered were **adequately educated** about **JDM**
    I believe the **GP's** I encountered l**acked knowledge** about **JDM**
    I believe the **specialists** I encountered were **adequately educated** about **JDM**
    I believe the **specialists** I encountered **lacked knowledge** about **JDM**
    I believe the **GP's** I encountered were **adequately educated** about **JDM**
    I believe the **GP's** I encountered **lacked knowledge** about **JDM**
    I believe the **specialists** I encountered were **adequately educated** about **JDM**
    I believe the **specialists** I encountered **lacked knowledge** about **JDM**

33. On reflection, I feel that my GP failed to recognise the symptoms as being related to JDM.

1 2 3 4

(extremely satisfied) (extremely unsatisfied)

Interactions with Healthcare Providers

34. Did you feel listened to and taken seriously when interacting with your GP?
    - Yes
    - No
35. Did/do you feel listened to and taken seriously when interacting with your specialist(s)
    - Yes
    - No
    - Sometimes

36. Were there times when a health care professional made an error during the treatment of the child in your care i.e. prescribing the incorrect dose, forgetting to put the tourniquet on, missed the vein etc
    - Yes
    - No

If yes, please provide an example _____

37. Did you need to refuse treatment at any point during treatment?
    - Yes
    - No

If yes, please provide an example _____

38. Did you feel listened to and taken seriously when interacting with hospital staff?
    - Yes
    - No

39. Were there times when you felt like you weren't heard?
    - Yes
    - No

40. If yes, please provide further details or one or two examples.

41. Overall, how satisfied were you with your interactions with healthcare providers?

1 2 3 4

(Extremely Satisfied) (Extremely Unsatisfied)

42. Were you and the child in your care offered counselling services and directed in clear and simple language on how to access these services?
    - Yes
    - No

43. If yes, how long were these services provided for?
    - 0-4 sessions
    - 4-8 sessions
    - 8-12 sessions
    - 12 or more sessions

44. Were these sessions offered as in-person sessions or online sessions?
    - In-person sessions
    - online sessions
    - I was offered a choice

45. Did/does the child in your care experience any needle phobia during treatment?
    - Yes
    - No
    - Sometimes

46. If yes, what support were you and the child in your care offered?
    _____

47. Did the child in your care experience anxiety leading up to in-hospital treatments?
    - Yes
    - No
    - Sometimes

48. If yes, what were some of the things you did to help ease their anxiety?
    _____

49. Did the child in your care experience anxiety before accepting injections if they were on methotrexate?
    - Yes
    - No
    - Sometimes

50. If yes, what were some of the things you did to help ease their anxiety?
_____

51. Were play specialists offered to you during time inpatient stays in hospital and/or day stays?
    - Yes
    - No
    - Sometimes

52. Do you have any additional comments to make about your interactions with healthcare providers?

Section Summary

53. In this section, you were presented with a range of facilitators and barriers that contributed to yours and the child in your cares experience during treatment. Is there anything further you would like to add regarding your journey to diagnosis?

QUESTION FOR THE CHILD

In this part of the survey I would like to invite your child to describe what having JDM is like for them either through written sentences or drawing a picture. If they would like to add anything that would make treatments easier I invite them to include that information as well.

- Does your child understand what is being asked of them?
    - Yes
    - No
    - Unsure

- Do they consent to this being used as part of the research?
    - Yes
    - No
    - Unsure

- Do you consent on their behalf to this being used as part of the research?
    - Yes
    - No
    - Unsure

Appendix G: Interview Structure (semi-structured interview)

Thank you for taking the time to sit with me here today to discuss further the survey you recently completed.

Tell me a little bit about yourself and your family

- How are you feeling today?
- How did filling out the survey make you feel?
- Did you find it helped you reflect on your journey thus far?
- Had you heard of JDM before the diagnosis?

Can you tell me a little bit about your experience gaining a diagnosis of JDM

- On reflection, is there anything you would have liked to have happened differently during your journey to diagnosis?

Can you tell me a little bit about your treatment experience?

- How has family life/life of the child in your care changed since diagnosis?
- Does one person predominantly take care of the medical/treatment labour i.e. drive the child to appointments and stay with them through infusions or is it shared between family members?
- How has it effected your relationship to the child?
- How did the child adapt to these changes in routine?
- What were some of the major struggles that you and/or the child in your cares faced?
- On reflection, is there anything you would have liked to have happened differently during treatment?

I am particularly interested in experiences of treatment and healthcare interactions.

- Do you feel like you and the child in your care has been well taken care of despite any minor challenges in gaining a diagnosis?
- Do you feel like you received a diagnosis and started treatment within an acceptable time frame?
- Do you feel you received adequate information on the disease at diagnosis and throughout treatment?
- Did you and the child in your care feel comfortable during your hospital visits?
- What made you feel un/comfortable?
- Did you ever have any disagreements with any of the healthcare staff during treatments?

- How was this resolved?
- In your view, how has the child in your care's coped with undergoing treatment thus far?
- Does the hospital staff fully inform the child in your care of any treatment they are about to undergo?
- Do they hospital staff fully inform the child in your care of what disease they have and how it is treated and the possible outcomes?
- Do you as the caregiver inform the child in your care of what disease they have and how it is treated and the possible outcomes?
- Have they voiced any suicidal ideation throughout this process?
- Are they aware that this could be on going for the rest of their lives?
- What are some of the things you practise to help each other debrief after treatment or hospital stay?
- What coping strategies have you implemented to help the child in your care deal with these big changes?
- What coping strategies have you implemented to help you as the caregiver deal with these big changes?
- Have you faced any challenges with extended family or support network with communicating what having JDM means for the child?

Thank you for taking the time to speak with me, is there anything I have missed that you would like to add?

Appendix H: Working thematic analysis Miro board