

Assessment of health and quality of life in patients with juvenile idiopathic arthritis who underwent surgery before age 40

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Abstract

Introduction: Juvenile idiopathic arthritis (JIA) is the most common chronic rheumatic disease of childhood and often persists into adulthood, leading to progressive joint destruction, disability, and reduced quality of life. Despite advances in pharmacological treatment, including biologic therapies, some patients still require orthopedic surgical interventions such as synovectomy and joint arthroplasty. The aim of this study was to evaluate the subjective physical and psychological functioning of adult patients with JIA who underwent knee synovectomy and/or hip and knee arthroplasty before the age of 40.

Material and methods: The study included 80 adult patients with JIA (56 women, 24 men) who underwent orthopedic surgery involving knee synovectomy and/or arthroplasty of large lower limb joints. Mean age at disease onset was 10 years, and mean disease duration at assessment was 25 years. Functional disability was assessed using the Health Assessment Questionnaire Disability Index, quality of life using the World Health Organization Quality of Life-BREF questionnaire, and pain intensity using the Visual Analogue Scale (VAS). Additional data included disease activity, pharmacological treatment, use of mobility aids, independence in daily activities, and psychological well-being.

Results: Persistent disease activity with periods of remission was reported by 55% of patients, while only 21% remained in remission for longer than two years. Before surgery, 86% of patients required mobility aids, compared to 13% after surgery. Severe preoperative pain (VAS 8–10) decreased significantly after surgery (VAS 0–2). Functional independence improved markedly, and 77% of patients reported resolution of major limitations in daily activities. Psychological well-being also improved; 77% felt ready to continue their education or seek better employment opportunities. Depression and anxiety disorders were diagnosed in 12.5% of patients.

Conclusions: Orthopedic procedures were associated with improvements in mobility, pain control, and quality of life in adult patients with JIA. However, most patients still presented with active disease and long-term disability, indicating the need for continued multidisciplinary care and long-term monitoring of surgical outcomes.

Key words: retrospective patient-reported assessment, invasive orthopedic procedures, juvenile idiopathic arthritis.

Introduction

Juvenile idiopathic arthritis (JIA) is the most frequently occurring rheumatic disease in children, with onset below 16 years of age and symptoms persisting for at

least 6 weeks. Apart from chronicity, it is characterized by heterogeneity in the number and types of joints involved, the presence or absence of enthesitis, systemic symptoms or psoriasis, and rheumatoid factor status. Heterogeneity of symptoms during the first 6 months

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of disease forms the basis for classifying JIA into subtypes. These include systemic JIA (S-JIA), oligoarticular persistent (Op-JIA), oligoarticular extended (Oe-JIA), polyarticular (P-JIA), enthesitis-related arthritis (E-A-JIA), and psoriatic arthritis (PS-JIA). The polyarticular form is further divided into seropositive and seronegative subtypes, depending on the presence or absence of rheumatoid factor in the serum. Additionally, an undifferentiated form is also included in the JIA classification [1, 2].

In adulthood, regardless of the subtype of JIA experienced in childhood, the disease may still retain features characteristic of JIA or develop features of rheumatic diseases typically seen in adults, most commonly rheumatoid arthritis (RA) and spondyloarthritis. Because the etiology of JIA is multifactorial and incompletely understood, disease progression can be halted in only a proportion of patients. In the remaining patients this progression can only be slowed. In about 50% of patients, despite the introduction of increasingly effective treatments, symptoms of the disease persist in adulthood [3, 4].

The introduction of disease-modifying drugs, including biological drugs over 20 years ago, substantially improved the clinical course of JIA. Effusions to joints, contractures, pain can often be controlled. Joint destruction affects a significantly smaller number of patients; nevertheless, pharmacological treatment is not effective in all patients. The range of drugs approved for JIA is limited in children, whereas a wider range of treatment options is available once patients reach adulthood, particularly when their diagnosis changes. Treatment difficulties stem partly from incomplete understanding of the pathogenesis of JIA. Its pathogenesis is complex and involves both autoinflammatory and autoimmune processes. Still the majority of patients requires invasive procedures in the form of intra-articular administration of glucocorticosteroids (GCS). Changes in treatment have not eliminated the need for synovectomy or arthroplasty in some patients [4, 5]. Synovectomy consists of the surgical removal of hypertrophied synovial membrane. It can be performed arthroscopically or as an open procedure. Arthroscopic synovectomy involves mechanical removal of pathologically altered synovial membrane using at least two openings in the joint (so-called ports). Open synovectomy may be performed when substantial synovial inflammation and vascular proliferation persist, through an incision similar to that used for joint arthroplasty. Pain and significant joint destruction visible in imaging examinations are indications for joint arthroplasty. Joint endoprotheses are biomaterials surgically implanted into the body to replace or support joint function; they differ in the components used and the method of fixation. In patients with JIA, these operations are most often performed only after closure of bone epiphy-

ses and completion of the growth process. Due to incomplete development of the osteoarticular system, arthroplasty in adolescent patients is performed exceptionally, only in selected cases [6], whereas synovectomy procedures are also performed in teenagers.

Apart from difficulties related to the surgical procedure itself, patients JIA face problems related to chronic disease, including potential complications, long-term pharmacotherapy, persistent joint inflammation in a substantial proportion of patients, postoperative rehabilitation in the presence of disability (particularly when the disease affects the upper-limb joints and spine), and sometimes multiple comorbidities [7]. The aim of this study was to evaluate the subjective physical and psychological functioning of adult patients with JIA who underwent knee synovectomy and/or hip and knee arthroplasty before the age of 40.

Material and methods

Study population

Initially, the study identified a retrospective group of 125 patients diagnosed with JIA who underwent surgery before the age of 40. Two hundred and five medical records were analyzed. Validated questionnaires assessing their postoperative condition were sent to the patients by mail. Most questionnaires were not returned. Ultimately, the study included 80 adult patients diagnosed with JIA who had undergone orthopedic surgical treatment involving knee synovectomy and/or arthroplasty of the large lower limb joints (hip and knee) before the age of 40. Among them, there were 56 women (70%) and 24 men (30%). The age at disease onset ranged from 2 to 15 years (mean 10 years), and disease duration at the time of assessment ranged from 21 to 36 years (mean 25 years).

Inclusion criteria

Patients were eligible for the study if they met all of the following criteria:

- diagnosis of JIA according to the International League of Associations for Rheumatology classification criteria,
- disease onset before the age of 16 years,
- history of JIA lasting at least 6 weeks at diagnosis and persistence of the disease into adulthood,
- age below 40 years at the time of orthopedic surgery,
- history of surgical treatment involving knee synovectomy and/or hip or knee arthroplasty,
- completed the Health Assessment Questionnaire Disability Index (HAQ-DI) and the World Health Organization Quality of Life-BREF (WHOQOL-BREF),
- provided informed consent to participate in the study.

Exclusion criteria

Patients were excluded if they had:

- history of lower limb trauma before JIA diagnosis,
- congenital abnormalities of the hip or knee joints (e.g., dysplasia),
- previous bone or joint infections,
- incomplete clinical documentation or incomplete questionnaires.

Surgical treatment

The time from JIA diagnosis to the first orthopedic procedure ranged from 2 to 17 years (mean 6 years) for synovectomy and from 3 to 36 years (mean 15 years) for arthroplasty. The analyzed procedures included knee joint synovectomy, hip joint arthroplasty, and knee joint arthroplasty. In some patients, synovectomy performed earlier did not prevent the need for subsequent arthroplasty in later years.

Clinical characteristics

Patients represented different clinical subtypes of JIA, including S-JIA, Op-JIA, Oe-JIA, P-JIA, E-A-JIA, and PS-JIA. In adulthood, some patients were clinically reclassified as having RA, spondyloarthropathy, ankylosing spondylitis, Still's disease, or psoriatic arthritis. However, for consistency in the analysis, the original pediatric JIA classification was maintained.

Outcome measures

Functional disability was assessed using the HAQ-DI, consisting of 20 questions grouped into 8 domains evaluating daily functioning and the need for assistance. Quality of life was assessed using the WHOQOL-BREF questionnaire, containing 26 questions evaluating four domains: physical health, psychological well-being, social relationships, and environmental conditions. Pain intensity and subjective disease activity were measured using the Visual Analogue Scale (VAS). Additional data included: pharmacological treatment, duration of remission, use of mobility aids before and after surgery, independence in daily activities, educational and occupational status, psychological well-being, including symptoms of anxiety and depression.

Statistical analysis

Statistical analysis was performed using standard descriptive and comparative methods. Quantitative variables were presented as mean values with standard deviations, and qualitative variables as absolute numbers and percentages. A p -value < 0.05 was considered statistically significant. Statistical calculations were performed using Statistica software (StatSoft, Poland).

Bioethical standards

The study protocol received approval from the Bioethics Committee of the National Institute of Geriatrics, Rheumatology and Rehabilitation (approval number KBT-5/4/2022).

Results

Clinical heterogeneity and disease characteristics

Some patient groups were too small or clinically heterogeneous to allow meaningful comparisons. The characteristics of the patients are shown in Tables I and II. As already mentioned, patients with S-JIA did not undergo synovectomy; joint destruction progressed rapidly, and most required arthroplasty of both hip joints within a relatively short period. Destructive changes also progressed quickly and also mainly in hip joints in patients with E-A-JIA. However, these patients developed the disease at an older age, resulting in a difference in the mean age at disease onset between these two groups. Synovectomy was performed in several cases. In patients with Op-JIA before the age of 40, synovectomy was sufficient in therapy in the vast majority. Patients with Oe-JIA and P-JIA underwent synovectomy and arthroplasty at similar frequencies. There were also two patients (PS-JIA) in whom only synovectomy was performed with good effect. In the remaining analyses, patients were not stratified by JIA subtype at disease onset, because the disease had been present for many years and the outcomes of interest did not differ substantially between the subgroups.

Disease activity and pharmacological treatment

According to the questionnaire responses, the disease persisted constantly in 55% of our respondents, with different periods of remission and exacerbations. Remission lasting more than 2 years was reported by 21% of patients; in the remaining patients, remission was much shorter, usually lasting only a few months. 94% of patients took periodically or permanently nonsteroidal anti-inflammatory drugs, 25% took methotrexate, 15% sulfasalazine, and 25% received various biological agents. Continuous low-dose GC treatment or periodic GC administration was reported by 32% of respondents.

Functional status and use of mobility aids

Before the operation, mobility aids (crutches, walkers, wheelchairs) were used permanently by 86% of respondents; after the operation, they were used by 13%, including 5% who reported continued use of one crutch

Table I. Number of patients by sex, form of disease, and type of surgery

Onset	Number of patients (M/F)	Patients with prostheses	Total number of prostheses	Total hip/knee prostheses	Patients undergoing knee synovectomy	Total number of knee synovectomies
S-JIA	13 5 M/8 F	13	26	23/3		
Op-JIA	25 6 M/19 F	2	4	2/2	23	23
Oe-JIA	7 2 M/5 F	3	3	2/1	4	4
PP-JIA	23 5 M/18 F	17	20	14/6	6	6
E-A-JIA	10 5 M/5 F	8	8	7/1	2	3
PS-JIA	2 1 M/1 F				2	2
Total	80 24 M/56 F	49	1	48/13	37	38

E-A-JIA – enthesitis-related arthritis juvenile idiopathic arthritis, F – female, M – male, Oe-JIA – oligoarticular extended juvenile idiopathic arthritis, Op-JIA – oligoarticular persistent juvenile idiopathic arthritis, P-JIA – polyarticular juvenile idiopathic arthritis, PS-JIA – psoriatic arthritis juvenile idiopathic arthritis, S-JIA – systemic juvenile idiopathic arthritis.

Table II. Mean age of patients at disease onset and at the current follow-up and mean disease duration before the first arthroplasty or synovectomy

Onset	Mean age of onset (years)	Mean disease duration until the first arthroplasty (years)	Mean disease duration until the first synovectomy (years)
S-JIA	6 (2–15)	17 (12–22)	
Op-JIA	11 (2–15)	20 (19–21)	6 (2–13)
Oe-JIA	9 (3–15)	22 (13–36)	10 (4–17)
P-JIA	9 (2–15)	12 (5–21)	8 (6–11)
E-A-JIA	14 (11–15)	6 (3–13)	2 (2–3)
PS-JIA	10 (8–12)		3 (2–4)

E-A-JIA – enthesitis-related arthritis juvenile idiopathic arthritis, Oe-JIA – oligoarticular extended juvenile idiopathic arthritis, Op-JIA – oligoarticular persistent juvenile idiopathic arthritis, P-JIA – polyarticular juvenile idiopathic arthritis, PS-JIA – psoriatic arthritis juvenile idiopathic arthritis, S-JIA – systemic juvenile idiopathic arthritis.

due to fear of falling and spinal pain, while the remaining patients reported that another hip or knee operation was planned.

Activities of daily living and functional independence

All patients before the operation(s) had problems with standing up, walking, and dressing, did not use a bathtub, and required help with showering. They could not perform housework, and had difficulties with getting into a car

and handling daily matters. After the operation(s), these problems were reported to have resolved in 77% of patients. Standing up, dressing (if there were no significant deformities of the hands and spine), walking on flat terrain, or climbing five stairs did not constitute a problem.

Pain intensity and postoperative outcomes

Before the operation, in all patients, severe pain (VAS 8–10) in the affected joints significantly interfered with daily functioning and mobility, and patients did

not feel safe. After the surgical procedure(s), pain was markedly reduced (VAS 0–2). A VAS score of 2 persisted in patients in whom rehabilitation did not fully restore expected joint mobility, mainly due to limited access to rehabilitation centers and non-adherence to rehabilitation programs.

Psychosocial status and quality of life

Similarly, improvement was observed in acceptance of appearance and ability to pursue personal interests. Seventy-seven percent of patients after surgery felt ready to undertake further education or seek more financially rewarding employment. This problem remained unresolved in 23% of respondents, who were still awaiting further surgical procedures or had significant deformities of other joints, especially the hands or spine. These patients reported psychological distress, anxiety, and feelings of exhaustion related to chronic disease management. Clinically significant depression and anxiety disorders were diagnosed and treated in 10 patients, including 8 women. Chronic fatigue was reported by all patients both before and after surgical procedures. However, depression was not analyzed in this study.

Discussion

Disability in JIA usually manifests as limitations in physical functioning and, if long-lasting, often has psychological consequences and social implications. It is known that age at disease diagnosis has no influence on quality of life and functional capacity; however, early clinical assessment according to some authors allows the approximate prediction of treatment outcomes and the likelihood of disability [8–10]. When performing synovectomy or arthroplasty in young patients with JIA, who often have active joint inflammation after many years of disease beginning in childhood, orthopedists consider the patient's preoperative treatment history, especially long-term use of cytotoxic drugs and GCs, particularly intra-articular injections, as well as joint infections, fractures, and previous synovectomies before endoprosthesis implantation. Because these procedures are performed in young patients, surgeons must consider appropriate implant selection and surgical techniques that will facilitate potential future revision or reimplantation. Before arthroplasty, all patients complained of chronic pain and limitation of mobility, often with deformity of positioning of the operated limb. These patients were young and, when their health permitted, potentially more active than most patients who undergo similar procedures for rheumatic disease at an older age. They had gait disturbances and used crutches for walk-

ing, sometimes moved with the help of a wheelchair, and function of the joint was significantly limited. They reported social withdrawal, sadness, and depressive symptoms. In the available literature, few publications have addressed surgery in patients with JIA younger than 40 years. With the early and aggressive use of disease-modifying drugs, including modern biologic agents, synovectomy and arthroplasty are now generally performed only after many years of disease and at an older age. As mentioned, because the osteoarticular system may not yet be fully developed, arthroplasty in adolescent patients is performed exceptionally, only in carefully selected cases. With the early use of biologic drugs, such procedures are now rarely performed in adolescents with JIA. Fifteen years ago, however, a bilateral arthroplasty procedure was performed in our clinic in a 15-year-old patient after 2 years of duration of JIA, with earlier history of osteoarticular tuberculosis [6]. In our patients, no intraoperative or postoperative complications were observed. Similar observations were reported by authors who performed shoulder joint arthroplasty in patients with JIA [11]. The response rate in our study was 64%, which according to sociologists is representative of the population under study [12]. All implantation and synovectomy procedures were completed without reported complications. No reoperations were recorded during the observation period.

It is worth comparing our findings with those of Beesley et al. [13] from the United Kingdom, published in 2024. The median age of patients in their study was 28 years, similarly as in our patients. Beesley et al. [13] reported that in 64% of observed patients with JIA the disease was still active in adulthood, and in 21% of patients during the whole period of the disease remission was never observed. In our study, 55% of patients reported disease activity interspersed with periods of remission. In the Beesley et al. [13] study, the median age at hip arthroplasty was 21.5 years and at knee arthroplasty was 35.5 years; in our study, the corresponding ages were 27 and 38.5 years. Among British patients, 62% used non-steroidal anti-inflammatory drugs, 36% biological drugs, 28% GCs, 27% methotrexate, and 14% sulfasalazine. Among our patients, the corresponding proportions were 94%, 25%, 32%, 25%, and 15%, respectively. However, our patients did not represent a cross-section of all patients with JIA, as in the Beesley et al. [13] study, but rather a selected group of young patients with highly active, destructive disease. 43% of Beesley's respondents used mobility aids, and 56% used orthopedic assistive devices. In our study, 86% used mobility aids before surgery, compared with 13% after surgery.

Chronic disease constitutes a significant psychological burden. In our study, 12.5% of patients had diagnosed

depression and neurotic symptoms, which persisted despite medical, surgical, and psychiatric treatment for JIA and its consequences. Anxiety symptoms, which can accompany depression, have also been reported in patients with RA and JIA [3, 14]. The long duration of the disease may also contribute to chronic fatigue, as emphasized by Tollisen et al. [15]. Evidence implicating pro-inflammatory cytokines, mainly interleukin-6 and interleukin-1, in the development of depression may partly explain these mechanisms [16].

Reduced quality of life is not attributable solely to sadness due to differences from peers, changes in appearance, and difficulties with mobility and performing other activities. Quality of life may improve after corrective procedures, including synovectomy and joint arthroplasty, particularly with respect to gait and limb alignment. However, other musculoskeletal deformities and persistently active disease were also common in these patients. In this group, all patients had a polyarticular, aggressive disease phenotype, with features also consistent with established RA (20 patients received biologic treatment). In patients with RA, depression has been associated with greater difficulty achieving remission [17].

From observations a clinic in Łódź, it appears that patients with RA after hip or knee arthroplasty had lower levels of anxiety and depression than patients before the procedure. The authors believe that implantation of endoprosthesis as treatment in the course of RA in cases of seriously damaged joints may therefore also alleviate anxiety and depressive symptoms generally occurring in these patients [18]. It remains unclear whether these findings can be extrapolated to young patients with many-year history of disease in the course of JIA subjected to orthopedic operations. Our earlier observations of patients with adult-onset RA suggest that, even after multiple lower-limb arthroplasty procedures, these patients remain optimistic about further operations, including revision arthroplasty [19].

Among the patients surveyed by us, we did not observe loosening or wear of implants, complications that have been reported by British researchers. Their findings suggest that surgical complications and wear of implants were more common in patients with the most severe, systemic form of the disease. Among the patients with systemic JIA in our study, the disease duration before arthroplasty was substantially shorter than in patients with other disease subtypes. We also did not observe intra- and perioperative complications, and infections did not occur. Mean time to performing arthroplasty was shorter among patients with earlier synovectomy, similarly as in the study of Lybäck et al. [20], although that Swedish study was performed many years ago. This finding is also consistent with the meta-

analysis by Badin et al. [21]. One possible explanation is greater disease activity in these patients. No patients in our study had undergone revision surgery during the observation period; however, revision procedures may be required in the future given the potential for ongoing disease activity [22].

It is worth noting that several patients have personally commented on the successful course of their pregnancies and the birth of healthy children. Other authors have also emphasized the satisfaction with the course of pregnancy in the setting of JIA [23]. The available literature lacks a comparison between short-term and long-term disability outcomes in JIA, both with and without surgery.

Study limitations

The limitations of this study include its retrospective design and the relatively small size of the study group, which may limit the possibility of generalizing the results to the entire population of adult patients with JIA. Another important limitation is the heterogeneity of the analyzed group, including different clinical forms of JIA and different types of orthopedic procedures, which makes direct comparison between patients difficult. The assessment of treatment outcomes was based largely on subjective questionnaires and patients' self-evaluation, which may be associated with recall bias, and the influence of current psychological condition on the responses. Additionally, the lack of a control group of non-operated JIA patients limits the possibility of unambiguous assessment of the impact of surgical treatment itself on quality of life and functional status. We also did not analyze in detail the influence of the type of pharmacological treatment on long-term orthopedic and psychological outcomes.

Conclusions

Orthopedic procedures were associated with improvements in mobility, pain control, and quality of life in adult patients with JIA. However, most patients continued to report disease activity and long-term disability, indicating the need for continued multidisciplinary care and long-term monitoring of surgical outcomes.

Disclosures

Conflict of interest: The authors declare no conflict of interest.

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Ethics approval: The study was approved by the Bioethics Committee of the National Institute of Geriatrics,

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Data availability: The data that support the findings of this study are available on request from the corresponding author (L. R.-S.).

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