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Treatment for upper limb desmoid causing pain and joint contracture: the importance of medication and rehabilitation

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[Background] There are some cases in which desmoids cause deterioration in ADL/QOL, but physicians continue active surveillance (AS) without intervention. Upper extremity DF is occasionally painful and many patients suffer from limited range of motion. The purpose of this study was to investigate the clinical characteristics and treatment results of upper extremity DF, and to propose an appropriate treatment strategy.

[Methods] The subjects were shoulder girdle-upper extremity DF after 2003. Chemotherapy with methotrexate (MTX) and vinblastine (VBL) and rehabilitation with range of motion training have been performed for patients with limited range of motion due to tumor growth and/or pain, and decreased ADL/QOL. Clinical characteristics and treatment results were analyzed.

[Results] Twenty-two cases of shoulder girdle-upper extremity DF since 2003 were included. Twelve males, median age 39 years, median maximum tumor diameter 5.6 cm, CTNNB1 mutations included 11 T41A and 3 S45F, median follow-up time 51 months. Already at the first visit, 20 patients (91%) had pain and 15 patients (68%) had restricted range of motion. MTX+VBL was performed in 10 patients, and the final oncological assessment was 10 with tumor shrinkage and 9 with stable disease. At the final evaluation, limited range of motion decreased to 13 cases, and 4 worsened cases included 3 cases with increased tumor size due to chemotherapy refractory cases, and 1 case where rehabilitation could not be performed due to pain.

[Discussion and conclusion] There were many patients who had been treated with AS by their previous doctor, and had severe pain and restricted range of motion at the time of their first visit to our hospital. In these cases, MTX+VBL treatment was able to achieve tumor shrinkage and pain relief. In addition, it is possible to aim to improve the range of motion by concurrently administering rehabilitation including range of motion

training, and to improve the ADL/QOL of patients with upper extremity DF.