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Reflective Practice

The most important needs and preferences of patients for support from health care professionals: A reflective practice on (transitional) care for young adults with Juvenile Idiopathic Arthritis

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ABSTRACT

In this manuscript, presented as a Reflective Practice, the learning experiences and reflections of a healthcare team on redeveloping the transitional care for young adults with a juvenile rheumatic disease are described. In this process of redeveloping care, the healthcare team experienced that small step, driven by patient stories and involvement of patients in all phases from development to evaluation, led to meaningful results. The eHealth interventions, developed to support the transition and to increase self-management were found to be feasible and evaluated positively by the young adult group. But the healthcare team also experienced that the focus on the patient alone, is not enough to implement self-management interventions and sustain patient centered care in daily practice. How healthcare professionals personally think and feel about patient centered care is essential and needs to be discussed in daily care. It determines the way of being present with attention and commitment in daily health care. It affects the hands, head and heart. A daily reflection on shared answers of the patient and the health care professional to the question 'what is the most important to you?' may help to implement patient centered care in health practice.

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1. Introduction

Due to research, technology and innovation, people are getting older and therefore the number of patients with a chronic disease is increasingly growing [1,2]. Having a chronic disease, such as arthritis, imposes daily challenges upon those affected and necessitates patients to make daily decisions about the way they manage their illness [3–5]. The question is not *whether* patients manage their (chronic) illness, but *how* they do this. The (individual) ability to manage sometimes invalidating symptoms, changing treatment strategies, day to day physical and psychosocial consequences, the flexibility to perform life style changes,

inherent in living with a chronic disease, is often defined as self-management [6]. Living with a rheumatic disease is challenging at any age. However, these challenges may be particularly difficult for young adults with juvenile idiopathic arthritis (JIA), since their chronic condition and treatment affect both physical and socio-emotional development [7,8]. Although in the past decade many new treatment options for JIA have been developed, to date it is not possible to cure this disease [9]. And so, many of these children are growing into adulthood with JIA. One of the main challenges young adults with JIA have to deal with is to increase their own capability, to think critically and to make autonomous, informed decisions: they have to become a self-manager [10,11]. To enhance young adult's self-management, the child- and adult treatment teams of the departments Paediatric Rheumatology and Rheumatology & Clinical Immunology of University Medical Center Utrecht, consisting of pediatricians, rheumatologists and rheumatology nurses, had to adjust care [12]. Therefore, an outpatient transition clinic was developed where the young adult and their parents/caregivers are guided, based on their individual needs,

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circumstances and life-stage towards self-management and adult care (Box 2) [12]. Besides that, different eHealth tools like an informative website and a peer guided self-management training were developed to support the transition. During this process of development of transitional care, storytelling [13] and initiated purposefully conversations with young adults on life experiences, needs and preferences were used to 'put them in the centre of care'. Next to that, there was an intensive collaboration between health care professionals and young adults in the process of development, including the presence of young adult patient partners in the research group. The input of these young adults on defining goals but also their input on the structure and content of the eHealth tools (Box 2), was crucial and influenced the actual use, adherence and effectiveness of it [14,15]. Presently, we are expanding these experiences towards developing care interventions for also the adult group. The aim of this article is to share our experiences, the lessons we have learned, and to share our reflections on the question: are we there yet?

2. May I ask how you think we should organize your treatment?

Our present health care system does not adequately accommodate an increasing diversity of patient's needs and preferences, especially those of young adults with a rheumatic disease who are in transition from child to adulthood [8,12,16,17]. Due to health policy in the Netherlands, young adults make the transition at the age of 18yrs from child to adult care. In our centre, every year, up to 40 patients make this transition where the children and adult departments are housed in different buildings. In the past, continuity of care was depending on a summary of the disease history within the medical record of the young adult. In spite of good intentions, communication between the children and adult team was scarce where at the same time; both teams were experiencing significant problems during the transition [12]. These problems were mostly caused by mutual prejudices and high rates of treatment dropout, non-adherence to medical treatment and rebellious behavior of young adults. Gradually, pediatricians and rheumatologists realized that their mutual mistrust, lack of communication and coordination interfered with optimal care. They concluded that sharing responsibility and working together on developing knowledge and supporting the young adult was needed [12].

In order to bridge the distance between the children and the adult departments, to improve understanding and coordination between pediatricians and rheumatologist and to support parents and the young adults towards adolescence, young adults were invited to share their experiences on growing up with a rheumatic

disease and to reflect on these experiences, as well as their needs and preferences for support from health care professionals. Two questions were leading in these conversations: 'What is the most important for you?' and 'How would you like us to organize your treatment?' The answers were honest, simple and down to earth. "Listen more and speak less", "I don't want to be an exception", "your recommendations should fit into my daily life", "information should meet my language" and "I want to be prepared and I want to be in charge" were needs they shared [12]. The young adults also suggested some solutions including the use of internet for contact and to provide information targeted to their age. Next to that, they expressed the need for a professional who's main focus was on 'self-management and dealing with the consequences of rheumatism on daily life'. Based on the outcomes of the conversations with the young adults, an outpatient transition clinic was developed where young adults and their parents/caregivers meet their future rheumatologist at an early age and where a transition nurse guides and supports them during the transfer from child to adult care [12]. To improve the young adults' knowledge and to meet the needs for information fit to their language and preferences, an informative website www.jong-en-reuma.nl with written and video information was installed [14]. To encourage active involvement and to stimulate the feelings of control, a web-based portal with access to the personal medical record, self-monitoring and eConsult functionalities was developed [14]. Young adults who used these eHealth tools expressed their needs for a training program, where they could practice self-management skills. To meet these needs, two versions of a self-management training program were developed: a face-to-face and a web-based version [15]. The two programs www.reuma-uitgedaagd.nl (in Dutch) are led by young peers themselves. The described interventions are outlined in Box 2.

3. Keep asking the question

The described interventions developed to support knowledge and self-management, proved to be feasible in dealing with problems in daily live and were appreciated by the young adults [14,15]. Reflection on the process of development, we as health care professionals experienced that especially small steps, driven by dialogue and by patient stories, in day-to-day practice, gave meaningful results for our patients. But are we there yet? We don't think so. Our focus on the patient alone, appears not to be enough to change daily practice of professionals. Also we ourselves, being a professional, need to be supported towards patient centered care. We still have a way to go.

Box 1. Anne – a patient story (1)

The pediatrician introduced the next patient on the outpatient clinic as a 'vulnerable young-girl', with no friends and severe systemic juvenile arthritis. The door opened and there was Anne, a young girl of 17 years, sitting in a wheelchair. Her mother pushed the wheelchair into the consultation room. Her father came along too. He walked with the coats and the bags of Anne and her mother and in a second, the consultation room was filled with the pediatrician, a family, a wheelchair and me. The pediatrician started the consultation and asked: "How are you today, Anne?" Anne replied, quietly, as she looked at the ground, "good", while father and mother looked worried. I looked at Anne's nose and lips where impressive piercings were placed. I also noticed a bracelet on her arm with the name of a popular festival on it, a sign that Anne had been there. Mother took the floor and expressed her concerns. She had tried not interfering with the medication regime and to leave it to Anne, as had been agreed during the previous consultation. But it didn't work. Anne did not take any pill and mother felt helpless. Father also took the floor: he was worried about Anne. She did go to school but seemed to have no interest in her future. Discussions about this subject gave a lot of stress and since two weeks, father and daughter were not on speaking terms, due to this situation. Anne gave her father the silent treatment. The pediatrician nodded understandably and tried to make eye contact with Anne. He cleared his throat and stressed the importance of taking the drugs and of focusing on the future. Anne nodded too and murmured that she understood what he was saying. The parents still looked worried. Anne looked at the ground.

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