

Rheumatoid arthritis patients' experience of climate care

Katrin Vaks¹, Rita Sjöström^{2,*}

¹Department of Sports Science, Linnaeus University, Kalmar/Växjö, Sweden

²Region Jämtland Härjedalen, Unit of Research, Education, and Development, Östersund, Sweden

The purpose of this qualitative study was to understand and examine how patients with rheumatoid arthritis (RA) experience climate care and its effects. A qualitative approach was chosen for the study. Two men and six women were interviewed according to a semistructured interview guide. The text was analyzed using a manifest content analysis. The analysis resulted in four categories and 10 subcategories. The interviewees experienced climate care positively. The training was perceived increasing gradually. The patients felt that they performed to a maximum capacity during training and were impressed by the staff's enthusiasm and encouragement. The patients felt that they were involved in the goal setting and the choice of treatment, and the staff noticed individual needs. There was a feeling among the patients of being acknowledged by the staff. Information about the disease was perceived as individualized. The climate and beautiful surroundings were viewed as encouraging physical activity and a feeling of well-being.

Patients made new friends, had fun together and also shared experiences about their disease. Furthermore, the patients described a sense of belonging to a group as well as a feeling of not being the only one that was sick among the healthy. Not having to do everyday tasks and having time to themselves were perceived positively. Several factors contributed to the positive experiences of climate care; climate, environment, physical activity, social context, staff involvement, and information about the disease were described as interacting together and resulting in a sense of well-being. A proposal for future research would be to examine if/how the various factors might interact and affect the RA patients' illness and quality of life.

Keywords: Climate, Content analysis, Physical activity, Rheumatoid disease

INTRODUCTION

Rheumatoid arthritis (RA) is a chronic autoimmune disease with a prevalence of about 0.5%–1% within a population. Geographically, it has an unequal distribution and is more common among women. The onset of RA, is usually between 45–65 yr (Alamanos and Drosos, 2005). The exact etiology of RA is unknown, but a combination of an autoimmune reaction, genetics, and environmental factors has been suggested. RA causes synovial inflammation, which leads to joint destruction and joint deformation and with time impaired physical function and decreased joint mobility. Impaired physical function and decreased joint mobility combined with decreased muscle strength and aerobic capacity, common amongst RA patients, may lead to difficulties in performing everyday tasks in the Activities of Daily Living (ADL) and have negative

psychosocial effects in general, which altogether result in a negative effect on the quality of life (QoL) for the individual (Van den Ende et al., 1998).

Medication is the main treatment for RA, with remission as the ultimate goal. If remission is not achieved, the goal with the treatment is to control the disease activity, prevent or control joint damage, prevent loss of function, decrease symptoms such as pain and joint stiffness, prevent loss in ADL, and increase QoL (Newsome, 2002; Scott et al., 2010). To reach these goals, various physical exercises are recommended in addition to medication, as treatment for RA patients (Van den Ende et al., 1998).

Exercise is both safe and beneficial for RA patients (Hurkmans et al., 2009). It is considered safe, since no increase in disease activity or joint destruction has been shown as a result of the exercise (Breedland et al., 2011; Häkkinen et al., 2001; Iversen and

*Corresponding author: Rita Sjöström
Region Jämtland Härjedalen, Unit of Research Education, and Development, 831
27 Östersund, Sweden
Tel: +46-70-660-2155, Fax: +46-76-830-5802, E-mail: rita.sjostrom@regionjh.se
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Brandenstein, 2012). It is considered beneficial because it increases the joint mobility, muscle strength, and aerobic condition; furthermore, a decrease in disease activity has been shown (Häkkinen et al., 2001). An increase in QoL, self-esteem, and decreased pain has also been shown (Bilberg et al., 2005; Luqmani et al., 2006). Strength training changes the relationship between the muscle mass and the fat tissue, which is beneficial for RA patients who, otherwise, have an increased risk of cardiovascular disease (Lemmey et al., 2009). Strength training is recommended at 50–80% of the maximal voluntary contraction, 2–3 times a week and can be either static or dynamic. Aerobic training is recommended at a moderate to difficult level, 60%–80% of maximal heart beat 3 times a week, 30–60 min. Progression from lower to higher load is recommended in both strength and aerobic training (Stenström and Minor, 2003). Exercises in the water, twice a week, during a 12-week period, increase the muscle mass in both the lower and upper extremities among RA patients. Exercises in the water during a longer period of time increase the QoL (Bilberg et al., 2005). Exercises in the water are recommended in order to decrease the pain and to increase the self-esteem (Luqmani et al., 2006).

RA patients in Sweden have been admitted to rehabilitation in warm, dry, and stable climates, so called “climate care,” since the 1960s. Climate care is a concept of care, which includes factors such as temperature, humidity, and weather changes. When patients with rheumatic diseases are referred to rehabilitation abroad, the climate is considered as being part of the intervention. The main intervention, however, is exercise. Exercise treatments under climate care are intensive physiotherapy, exercises in water, “self-management” group therapy, patient education, and group exercises (Forseth et al., 2010; Staalesen Strumse et al., 2009; Staalesen Strumse et al., 2011). Climate care is performed by a multidisciplinary team and is shown to be effective as a form of rehabilitation for rheumatic diseases, leading to increased physical function, mobility, balance and hand strength, and decrease of symptoms such as pain and stiffness (Forseth et al., 2010; Luqmani et al., 2006; Staalesen Strumse et al., 2009; Staalesen Strumse et al., 2011).

Ahlmén et al. (2005) describe that treatment, which allows one to live a normal life, perform everyday tasks without help, have a sense of independence, and a sense of well-being (described as bright and breezy, to be happy, and to be able to enjoy life) is important to RA patients. Does climate therapy lead to these important results for RA patients? The benefits of exercise on symptoms, physical function, and QoL, for RA patients, are well

known (Bilberg et al., 2005; Hurkmans et al., 2009; Stenström and Minor, 2003). The benefits of climate therapy on RA patient's symptoms, physical function, and QoL are also well-known (Forseth et al., 2010; Gutenbrunner et al., 2010; Luqmani et al., 2006; Staalesen Strumse et al., 2009; Staalesen Strumse et al., 2011). However, knowledge about the effects of climate care on the experienced health of the RA patients and other experiences of climate care is missing. To increase the understanding and to possibly increase the development of suitable interventions for RA patients, the authors of this qualitative study want to explore how RA patients experience climate care and which health effects they describe in relation to that.

The purpose of this qualitative study was to understand and examine how patients with RA experience climate care and its effects.

MATERIALS AND METHODS

Participants

The study population consisted of individuals, who were recruited at a climate care rehabilitation center abroad during the autumn of 2013 and spring of 2014. Patients at the rehabilitation center with a diagnosis of RA, over 18 yr of age, were asked by their respective physiotherapists if the first author was permitted to contact him/her to give more information about the study. After permission was received, the patients were contacted. Out of nine patients contacted, six women and two men, aged 41–65, became participants, and one declined. The onset of the RA varied between seven months and 16 yr ago within the study population. Four patients experienced climate care for the first time, and four patients had experienced climate care 1 to 5 times before. All of the patients were living in a big city or in a suburb to a big city in Sweden. The patients who were at climate care at the same period of time came from the same region in Sweden. Employment status varied from working between 50% to 100% of total working time, being unemployed, or retired. Social status was single, single with child, married with children, and married with grown-up children not living at home. Six of the eight patients were academics.

The Ethical Advisory Board in South East Sweden reviewed the study (EPK 199-2013) and raised no objections from an ethical point of view. All participants gave their signed informed consent before the start of the study.

The climate care lasted four weeks, five days a week, starting at 8.30 a.m. until 5.00 p.m. The program was comprised of lectures,

individual therapy and group therapy sessions, exercises, mindfulness, and individual treatments. On one of the days, there were three to seven activities, where at least two of them were some form of exercise. The schedules were individualized, and the exercises varied between water exercises, walk with walking sticks, mobility training, foot training, hand training, group strength training, individual training, relaxation, spinning, qi gong, yoga, balance training, dance classes, Pilates, and core depending on the patient's wishes and goals during the climate care period. Personnel involved in the rehabilitation were physiotherapist, nurse, behaviorist, and health personnel. Physicians were present at the clinic when requested.

Procedure

Data were collected through semistructured interviews after the patient's rehabilitation period. The patients received written and oral information about the study before the interview. The interview was performed at a place chosen by the patient. Five patients were interviewed at a clinic, one patient was interviewed at home, and two interviews took place by telephone. The first author asked questions pursuant to an interview guide. The interview guide had questions about health, physical ability, and climate care. The interviews lasted 15–50 min. All the patients were given the opportunity to talk without any time restrictions. After each question, the patients were asked if they wanted to add something more. The interview was digitally recorded and later transcribed by the first author. To test the interview questions, a test interview was performed. This interview was included in the study because no changes were made to the interview guide.

Data analysis

To describe the explicit substance in the transcribed text, a manifest qualitative analysis was carried out (Graneheim and Lundman, 2004).

The analysis was performed in the following steps:

- The text was read, and at the same time the first author listened to the interviews several times to obtain a sense of the whole.
- After reading and listening to the interviews, meaning units were identified and condensed to shorten the content but maintain the essence.
- The condensed units were coded and grouped into subcategories and categories, in order to organize the text in a way that mirrored the central content of the interviews (Graneheim and Lundman, 2004).

The analyses were conducted by the first author and revised together with the second author. They were then adapted until the authors reached consensus. Subcategories and categories were found to be mutually exclusive and exhaustive.

RESULTS

The analysis resulted in nine subcategories and four categories, which describe the patients' experience of climate care and the effects of climate care. The categories were: (a) physical activity, (b) social context, (c) receive and use knowledge, and (d) effects of climate care. The results are described in the categories and the subcategories.

Physical activity

Physical activity is divided into two subcategories: (a) stimulation to exercise and (b) the approach of personnel.

Stimuli to exercise

All of the patients talked about an intense schedule with several exercises at various intensities every day, with relaxation in-between. The patients said that they worked as hard as they could during the exercises. Three of the patients expressed feelings of being privileged to attend this rehabilitation and thus wanted to give all they had during the rehabilitation in return. The exercise was perceived as fun, especially the water gymnastics. Beautiful surroundings and sunny weather increased the enjoyment of moving the body, thus stimulating the desire to exercise. Four patients enjoyed exercising outdoors and walking with sticks by the ocean, which increased the motivation to train. All patients described that they received alternative movements during the group training to be able to continue the exercise without pain. They all received individualized programs.

“... the physiotherapists... had focus on the individual even though they worked with the whole group.”

Even though the exercise was experienced as being difficult, six of the patients experienced that they managed to do more than they thought they would. All of the patients felt that they got started with the exercise and wanted to continue to exercise when they came home. All patients had individual sessions with the physiotherapist where they got treatments to increase function or/and reduce pain, which enabled them to attend the classes. The training was viewed as affecting the whole body in a good way.

Encouraging personnel

The personnel were perceived as knowledgeable and professional and by their commitment to the patients, increased the patient's efforts during the exercises. Two patients felt motivated during the exercise, thanks to the enthusiasm of the personnel and added that this contributed to their positive results during the physical tests given at the end of the rehabilitation period. Six of the patients felt that the personnel taught the exercises in a pedagogical way.

"... that is why it's a little bit personal... the movements were good, she is very good at training, to teach, to show, explain..."

Two of the patients talked about their experiences of receiving energy from the personnel. One patient, however, discussed about a meeting with one of the personnel, which was not good because they did not have good chemistry.

Social context

Social context can be divided into two subcategories: (a) to learn from each other and (b) community.

To learn from each other

The experience of receiving and giving support, sharing experiences, and discussing the illness was documented. Discussions with other patients about the symptoms and treatments were perceived as a good experience. In this way, the patients received information about alternative treatments, possibilities for surgery, and new ways for pain relief, and alternative treatments. To share experiences about their illness and to discover that you were not alone in having difficulties were perceived as positive.

"... you look at your hands and feet, how they look, yes, you have the same and it looks the same for you too, does this have to do with the illness..."

One patient experienced the opportunity to support a younger patient in the same situation as herself, and conveyed the importance of accepting one's body.

Community

All of the patients talked about the positive experiences relating to the social activities at the clinic. They had fun together and socialized during the evenings and weekends, with activities such as

dining out, taking walks by the ocean, training in the gym, and doing excursions.

"Oh, I feel much better now and, of course, you do, because you have got as much vitamin D as you can get and meet happy people and have had a social life that has been fantastic..."

Five of the patients described that they received support from the group and that they made new friends. Several of the patients mentioned that they maintained contact with the new friends after coming home, and they supported each other to continue training. Three patients described the feeling of being understood, not having to explain, and not being alone with their illness. One of the patients expressed that she gained hope for the future after conversations and socialization with people in the same situation as herself. One patient felt lonely at certain periods, and two patients described some ill feelings in the group after a couple of weeks. They stated that the intense socialization during the days, evenings, and weekends after a while undermined the social community. Two patients experienced the good feeling of having their own rooms, due to the intense socialization.

Receive and share knowledge

Receive and share knowledge can be divided into two subcategories: (a) management of symptoms and (b) inclusion and confirmation.

Management of symptoms

Receiving advice and tools to manage the disease, getting information about the disease, and learning new coping strategies through the lectures, group discussions and individual sessions with the personnel were described as positive aspects by all of the patients.

"... very good pedagogic, very good lectures, ehm... we had lectures about the hand, foot, disease, food... and all of it was super."

Most of the patients thought that the lectures were constructive. Two of the patients talked about the lectures that led to insight about their symptoms and increased their awareness of the body. Some of the patients thought that the information flow was too much with several lectures. It was not until the third week of the rehabilitation that the information about the food, training, ergonomics, and medication could be used, according to some of

the patients. Three of the patients talked about being able to benefit from the information about the disease due to former rehabilitation periods.

Inclusion and confirmation

To have ones needs met by the personnel was an experience shared by all of the patients. One patient described the relief of finally getting acceptance for her food intake. Five patients shared the feeling of being acknowledged by the personnel both individually and during the classes. During the classes, when a patient, found him/herself in pain, they were given alternative movements so they could complete the whole class. This made the patient feel like being part of the group.

“... she was observant and saw when one had difficulties and gave advice: do this, do that instead, and if that does not work...”

Four patients described how the rehabilitation was adapted to fit their needs and that the personnel were responsive to individual wishes. Almost all of the patients believed that they were part of the goal setting as well as the choice of treatments during the rehabilitation. One patient described that she was acknowledged as accomplishing the training in a positive way.

Effects of climate care

Effects of climate care can be divided into three subgroups: (a) physical effects, (b) emotional effects, and (c) quality time.

Physical effects

All patients described the body as being light and had fewer symptoms during the climate care period. The reasons for the decreased pain, fatigue, and stiffness were thought to be the warm weather and the intense exercises. They described increased physical function, for example, the ability to open a jar and, to walk faster and longer without a break. The positive test results at the end of the rehabilitation period were experienced as enhancing the feeling of being physically healthy and were greater than expected among the first time patients. One patient experienced looking healthier with a suntan, and another patient was not aware of her pain. One patient felt that the exercise decreased the pain, which made it possible to increase the amount of exercise. One patient slept better due to the decreased pain, which made her feel energetic during the day. One patient experienced increased function but still loss of ability to do a task and was content anyway.

“I have not been able to walk on my toes, and I’m not able now but I can, I have reached... I’ve started to be able to lift my heel a little bit. That feels very good.”

By the third week, the patients felt physically worn out by all the exercises; however, they described that by the fourth week their body was used to the hard work and the positive effects of climate care started to really show. One patient stated that her recent onset of symptoms, such as swollen and painful small joints, subsided during the climate care. Several patients expressed that symptoms such as joint stiffness and swollen joints returned as soon as they went back to the cold and humid climate in Sweden.

Emotional effects

The positive emotional effects of climate care were the same among the patients, namely, to feel good, which was described as being happy, enjoying life, and having fun. To have more energy and full of spirit were mentioned in the same context as being happy. Four of the patients mentioned the ability to socialize more due to the increased energy. Some of the patients regained a joy of life.

“I have forgotten the last time when I was so positive and laughed; I’m back in life.”

Six of the patients described that they were more relaxed in the sun, which felt good in the soul, and contributed to their well-being. One patient stated that the relaxation increased the ability to absorb information. Motivation to exercise during and after the climate care period was described by all patients. Many of the patients came to understand the importance of exercise and realized that they could positively affect their illness by exercising.

Two patients talked about a change in their thinking pattern and adaption in everyday tasks as a possibility to affect their symptoms. One patient experienced an acceptance of the illness for the first time. Another patient realized how one’s behavior affects the illness.

Quality time

All of the patients expressed that they enjoyed the climate, which included the blue sky, sun, and warmth. Several patients experienced the surrounding to be beautiful and enjoyed the proximity to the ocean.

“... it is amazing to sit by the ocean between four o’clock, half past five, five, before dinner and to experience this feeling of

tranquility and to hear the waves come and go.”

To have time to oneself, to be relaxed, and to feel good were the most common answers to the question “what has contributed to the effects of climate care.” Five of the patients experienced both time to relax and to exercise and felt that relaxation was just as important as exercise to feel good. To get away from home and everyday tasks and to only care about oneself were described in positive terms by seven of the patients.

“First, it is the warm weather: it is good to only have to care about oneself, it gives so much...”

One patient felt that it was difficult to be away from home; however, after coming home, there was a positive change in sharing household tasks because her husband realized how uneven the household work had been when he had to do it all by himself. Three of the patients were missing someone at home or felt homesick.

DISCUSSION

The results of this study show that the patients experienced climate care positively, with only a few negative experiences. The patients who were at climate care for the first time were surprised about the intensity of the care and the great impact it had which was more than expected. The patients felt that they managed to exercise more than they thought they would be able to. Several factors lead to the positive experience of climate care. According to the interview material, it seems that factors such as physical activity, social context, receiving information and using knowledge, and effects of climate care interact with each other, that is, they seem to affect each other in a positive spiral. The authors of this study reflect on the preliminary knowledge that the participants might have had of climate care, where social context, inclusion and personal commitment were not considered, but which in this study seemed to play a major role in the total positive experience.

In this study, the patients describe in different ways that climate care contributed to an increase in their well-being. Important results of the interventions for RA patients were discussed during a workshop with RA patients from 11 different countries. During the workshop, it emerged that well-being is an important result to be measured (Kirwan et al., 2009). This is in line with the results of the study by Ahlmén et al. (2005) where interventions that led to well-being were viewed as important to RA pa-

tients. Despite that, instruments to evaluate the well-being of RA patients are lacking to date. Kirwan et al. (2009) discuss that well-being might not only be related to the disease RA but to the context of health. According to World Health Organization, the meaning of health includes not only the absence of illness but also the access to physical, psychological, and social well-being, which are associated with QoL (World Health Organization [WHO], 2013). In this study, the patients experienced enhanced physical, psychological, and social well-being after and during the climate care. It seems that these are outcomes that are important to evaluate when climate care is compared to other interventions for RA patients.

All patients in this study experienced reduced pain. RA patients have been shown to benefit from dry rather than humid and warm, but not hot, climate, especially close to the skin, with reduced symptoms (Patberg and Rasker, 2004). An increase in pain among RA patients in humid, cold, and high pressure weather has been shown in the study by Strusberg et al. (2002). In the study by Smedslund and Hagen (2011), it was proven that there is a connection between pain and weather among some of the RA patients. The reactions to weather changes were different among the RA patients and could not be shown on a group level. They also discussed if there was a mood-pain-connection, where RA patients were more depressed on rainy days. However, there was no explanation as to how this possible connection might function (Smedslund and Hagen, 2011). Another speculation about the reason for reduced pain, according to a study by Harari et al. (2011), is an increase in vitamin-D, where a direct connection between the levels of pain and the level of disease has been shown. One patient in this study experienced that her recent onset of symptoms never came in to full inflammation but rather disappeared during the climate care. The reason for the decreased symptoms in her case is not known but may be due to an increase in vitamin-D. The level of disease activity among RA patients seems to be related to seasons with a higher degree of disease activity and a lower degree of vitamin-D during the winter. This study was conducted in Canada which has the same variation of seasons as in Sweden (Sabbagh et al., 2013). Another study that showed a higher degree of disease activity in the winter was conducted in Turkey, but it showed no correlation with vitamin-D. The number of hours of sunshine is the same year round in Turkey, so the authors of this study speculate that other factors than vitamin-D, which varies with seasons also might affect the degree of disease activity. This factor might be associated with one's mood, which the patients in this study experienced with increased

well-being and feeling happy in the sun.

The patients in this study described that they exercised intensely several times a day and experienced that they performed at a maximum during the exercise classes. The reasons for maximal performance were, among other things, enthusiastic personnel, the feeling of gratitude to receive climate care, and the limited time of climate care. It has been shown in the study by Hafström (1997) that warm climate increases RA patients' ability to exercise but not why (Hafström, 1997). Less fear of pain during the activities is one effect of climate care that was found in the study by Forseth et al. (2010). The authors of this study speculate that less fear of pain may have contributed to the experience of maximal performance that the patients had in this study.

The patients in this study exercised together, and the exercises were individualized. Alternative exercises were received during the classes, which led to the experience that the patients managed the exercise. This might have enhanced both self-efficacy and self-esteem. Patient education that leads to knowledge about pain management increases QoL for RA patients, according to Parlar et al. (2013). The patients in this study also mention the lectures and discussions with other patients that enhanced their knowledge in pain management. Pain management, together with this possibly enhanced self-efficacy and self-esteem might have increased these patients QoL, according to the authors of this study.

The experienced effects of climate care in this study include not only relieved illness and reduced symptoms, but also new good relationships, increased self-esteem, and well-being. Social well-being with good relationships is connected to health and QoL. The ability to resist difficulties/diseases has to do with relationship, self-esteem, diet, physical activity, relaxation, identity and meaning (WHO, 2013). Thus, making new friends can positively have affected the patients' health in this study. Health and medical care primarily work to cure and relieve diseases, but the authors of this study speculate that health promotion factors probably should be included and evaluated in interventions for RA patients and are implications for further research.

A manifest qualitative analysis was carried out with eight patients with a semistructured interview guide. Kvale and Brinkman (2009) recommend 5–25 informants. All interviews were conducted and transcribed by the first author which was an advantage because all interviews had identical questions. Moreover, the answers, not only what was said but how they were said could later be used during the analysis. The analysis was carried out by both of the authors, and the interview material was discussed until a consensus was reached. The trustworthiness of the study was

secured by quoting the patients. The distribution of age, gender, and family situation among the patients is representative of the RA population. The weakness of this study is that all patients came from the same region in Sweden. Another weakness of the study is that the recruitment of the patients for this study was limited to one climate care institution.

All patients shared experiences of a feeling of well-being, increased physical function, decreased symptoms, increased self-esteem, and motivation to exercise, which were positive effects of the climate care. The climate care was experienced positively by the eight interviewed patients, with only a few negative elements. Climate and surroundings, personnel treatment, social context, disease information, physical activity, and manual treatment were factors that the patients described contribute to the positive experience and to affect the results of climate care. The factors seem to interact and enhance each other in a positive way. Thus it is recommended to plan for and to increase these factors that promote health as much as relieve disease in future interventions for RA patients.

CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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