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Achten, Diana; Westendorp, Tessa; Herweijer, Hester; Reneman, Michiel F.

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ORIGINAL ARTICLE

Pain Rehabilitation During Adolescence; Work in Adulthood? A Long-Term Follow-Up Study to Explore the Facilitators and Barriers for Work

Diana Achten , MSc*; Tessa Westendorp, PhD[†]; Hester Herweijer, MSc[‡]; Michiel F. Reneman, PhD*

*Department of Rehabilitation Medicine, Center for Rehabilitation, University Medical Center Groningen, University of Groningen, Groningen; [†]Research and Development Department, Riindam Rehabilitation, Rotterdam; [‡]Revalidatie Friesland Center for Rehabilitation, Beetsterzwaag, The Netherlands

Abstract

Background: Adolescents with chronic musculoskeletal pain face different impairments in daily life. After an inpatient pain rehabilitation program, adolescents function better on several domains. The aim of this study was to explore the long-term work participation of adults who followed inpatient pain rehabilitation during adolescence because of chronic musculoskeletal pain and to identify potential facilitators and barriers regarding work in later life.

Methods: A mixed-methods study with standardized questionnaires and semi-structured interviews. The questionnaires measured pain, disability, work status, and the quality and quantity of the work. The interviews contained questions about work participation. Potential participants were all patients who had participated in an inpatient pain rehabilitation program 15 to 20 years previously. Analyses were performed by thematic analysis. Using the Sherbrooke model as guidance, themes were classified into 4 systems: healthcare, workplace, legislative/insurance, and personal.

Address correspondence and reprint requests to: Michiel F. Reneman. PhD, Department of Rehabilitation Medicine, University Medical Center Groningen, University of Groningen, Dilgtweg 5, 9751 ND Haren, Groningen, The Netherlands. E-mail: m.f.reneman@umcg.nl.

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Results: Fourteen patients consented to participate (12 females). Seventy-one percent of them had paid work. The mean self-reported quality of the work delivered was 9.6 (standard deviation = 0.5). Eighteen facilitators and 12 barriers regarding work participation later on in life were mentioned. The inpatient pain rehabilitation program was the most frequently mentioned facilitator (n = 5), while the personal system and coping-related factors were the most frequently mentioned barriers (n = 5).

Conclusions: Ten out of 14 participants are currently working, most of them despite experiencing pain. Several factors based on the 4 systems of the Sherbrooke model contribute as facilitators or barriers regarding current work participation. Pain rehabilitation is mostly regarded as a facilitator for work participation later on in life.

Key Words: rehabilitation, chronic pain, work participation, adolescence, Sherbrooke

INTRODUCTION

Chronic musculoskeletal pain in children and adolescents has a prevalence that varies between 4% and 40%. 1-3 Research among Dutch school children shows that 24% have experienced chronic pain for more than 3 months. 1,4 Children with chronic pain face impairments in social life and the inability to indulge in hobbies and meet friends.^{2,5} They have a significant amount of school absence and, due to the pain, also function worse across all school domains than their peers who do not experience chronic pain.⁶⁻⁸ After a multidisciplinary inpatient pain rehabilitation program, almost all of the children who participated returned to a regular school program, with school absences subsequently decreasing.^{6,9-12} After 1 and 6 years of follow-up, school attendance was still better than at the baseline.^{11,13,14}

Chronic pain during adolescence often occurs intermittently over time and is associated with chronic pain in early adulthood. 15,16 It is known that chronic musculoskeletal pain in adults can lead to serious impairments across different life domains, such as family care, daytime activities, and work participation. 17-19 Work participation is important because it increases the financial independence, self-esteem, and social contacts of the adult.²⁰ In a recent study on the social functioning of young adults who underwent inpatient rehabilitation during adolescence because of chronic musculoskeletal pain, 63% reported ongoing or new pain complaints. Ten years after finishing the rehabilitation program, 72% of the participants had a paid job, of whom 22% had taken sick leave in the past month. A higher pain level pre-treatment was identified as a predictor for worse participation in the workeducational domain.12

However, long-term follow-up studies with specific regard to the self-reported barriers and facilitators and the impact of an inpatient pain rehabilitation program on the ability to work in adulthood after experiencing chronic musculoskeletal pain in adolescence have not yet been published.

The purpose of this study was to investigate the work participation of adults who participated in an inpatient pain rehabilitation program during adolescence because of chronic musculoskeletal pain, as well as to identify potential facilitators and barriers regarding current work participation. Knowledge in this respect may help to improve the inpatient pain rehabilitation program with regard to education and employment. This will help prepare adolescents with chronic pain better for work participation during their transition into adulthood. This may lead to less financial dependency on the government or others, while experiencing more social interaction and enlarging their self-esteem.

METHODS

The study adopts a mixed-methods approach, consisting of a qualitative part and a quantitative part. The quantitative part consists of standardized

questionnaires, while the qualitative part comprises semi-structured interviews. The study design was presented to the Medical Ethics Committee of the University Medical Center Groningen. Since by their opinion the study was not covered by the Dutch law concerning medical research into humans, dispensation for the application for permission was granted.

Participants

In 2011, all adults who had participated in the Friesland cohort study and with current contact information were contacted with a view to participating in a long-term follow-up study. 12 The Friesland cohort study contains all former patients who had participated in an inpatient pain rehabilitation program because of chronic musculoskeletal pain during adolescence, at the Revalidatie Friesland Center for Rehabilitation, located in the north of the Netherlands, between 1992 and 2000.9 Inclusion criteria for starting treatment at the time were chronic musculoskeletal pain for at least 6 months, which led to functional impairment, and age between 6 and 21 years. Exclusion criteria for the program were other diseases that negatively influenced physical or mental functioning, and treatment elsewhere.9 The treatment consisted of a 3-month multidisciplinary inpatient pain rehabilitation program based on cognitive behavioral treatment. Education was an important part of the rehabilitation. During the treatment, school hours were progressively extended, initially only in the school affiliated with the rehabilitation center, but later on, partly in the children's own school. Throughout the rehabilitation process, weekend leave was extended.²¹ All participants who had consented to participate in the long-term follow-up study were asked whether they might be approached for future research. Those who agreed were called by the principal investigator in April 2014, using the contact information earlier collected, and asked whether they would participate in our study. 12 After they gave informed consent, an interview was planned. Where the telephone number was incorrect, a letter was sent to the available address containing information about the study and an informed consent form. If a form was not returned, the respective participant was identified as not wishing to participate in the study.

Data Collection

Questionnaires. Four weeks before the interview, standardized questionnaires were sent to the participants,

which were returned during the interview. The standardized questionnaire contained questions about demographics, current work status, past and present complaints, and self-reported assessment of (influence of the pain on) the quality of work delivered. All questionnaires were validated Dutch language versions.

Demographics. Demographic characteristics obtained were sex, present age, and age during the rehabilitation program.

Current Work Status. This contained questions about profession, working hours and days per week, and absences in the previous month.

Past and Present Complaints. With the numeric rating scale, the highest and mean pain scores from the past week were measured.²² A higher score meant more severe pain, ranging from 0 (no pain) to 10 (worst pain ever). Our questionnaire also consisted of questions about the complaints that participants experienced during the rehabilitation program and the present complaints. The self-reported influence of pain on participation and autonomy was measured by the Impact on Participation and Autonomy questionnaire, which consists of 32 items (Cronbach's alpha 0.81 to 0.91).²³ We only used the 6 items of the work and education subscale, which contained questions about paid and voluntary work, education, and training. These items could be scored on a scale from 0 (very good) to 4 (very poor). The subscale score is calculated by summing all outcomes and dividing them by 6. The higher the score, the more barriers to participation. For the Impact on Participation and Autonomy questionnaire, we used the data from the long-term follow-up study of Westendorp et al., ¹² as it consisted of the same population as in the present study.

Self-Reported Assessment. The present working status was measured using the Work Ability Index²⁴ (Cronbach's alpha 0.7) and the Quality/Quantity Index. 25 The Work Ability Index measured self-reported work capacity related to the physical demands of work in the previous 4 weeks and consists of a score ranging from 0 (no work capacity) to 10 (maximal work capacity). The Quality/Quantity-Index, which is a subscale of the Productivity and Disease Questionnaire, measured selfreported work productivity in the previous 4 weeks by asking questions about the quantity and quality of the work delivered.²⁶ The quantity scale measured the real work delivered in the previous 4 weeks and ranged from 0 (nothing) to 10 (as much as normal). The quality scale measured the quality of the work delivered in the previous 4 weeks and ranged from 0 (very bad quality) to 10 (as good quality as normal).

Interviews

Participants were visited at a location of their choice. They could choose to be interviewed alone or with their partner or parent(s). The semi-structured interviews were conducted by the first author (D.A.) in 2014 and 2015. They consisted of open questions about present complaints, education, work participation in the past and present, reasons to work or for not working, and the self-reported influence of the inpatient pain rehabilitation program on education and work. Interviews were conducted until no new information or insights were collected. This went on until we had interviewed all participants who wanted to participate in our study.

Analyses

Descriptive statistics were used to present demographic and pain characteristics, and characteristics of work participation. The data were analyzed using the SPSS package, version 22.0 (IBM Corp., Armonk, NY, U.S.A.).

The interviews were audio-recorded and transcribed verbatim by the interviewer. After that, they were verified and corrected. The data were analyzed according to the thematic analysis method using a deductive thematic analysis approach. For this, the Atlas.ti computer program (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) was used. Themes were based on the Sherbrooke model.²⁷ This model is based on the biopsychosocial model and considers the working capacity of an individual as an interaction between biological, psychological, and social conditions and therefore consists of several determinants. It considers the interaction between the macrosystem (social environment, culture, and policy), the mesosystem (stakeholders), and the microsystem (the individual) on staying at work. Several stakeholders, related to the healthcare system, the workplace system, the legislative and insurance system, and the personal system, are involved in the staying at work process. Actions of the individual and all stakeholders in these 4 systems, and the interaction between them, determine the possibility of work participation by an individual.²⁸ Based on this model, quotes from the participants were identified in terms of indicating a "facilitator" or "barrier" in 1 of the 4 systems.

RESULTS

Questionnaires

Seventy participants were potentially eligible for this study. Among these, 39 participated in the long-term follow-up study in 2011, of whom 21 gave permission to be contacted in the future for further research 12, with 14 of them eventually consenting to participate in the present study. Figure 1 presents a flowchart of the recruitment of the participants. Demographic, pain, and work characteristics are presented in Table 1. Participants' mean age at the time of the present study was 34.1 years (standard deviation [SD] = 2.9) and the average time since rehabilitation was 18.7 years. Ten participants were working at the time of the study. On average, they worked 28 hours (range: 16 to 40) over 3.5 days per week (range: 2 to 5). None of the participants was absent from work in the past month because of pain. The reported mean pain score was 3.6, while the highest pain score in the previous week was 4.7. The frequency of the complaints varied from continuous to a few times per year. The mean self-reported quantitative and qualitative work productivity in the past 4 weeks was 9.6 (SD 0.5) and 9.4 (SD 0.9), respectively.

Interviews

We conducted 14 interviews. All participants chose to be interviewed at home. Most participants chose to be interviewed alone, while 1 chose to be interviewed with her parents and 3 with their partner. The interviews lasted between 45 and 75 minutes. From the last interview, still new facilitators and barriers regarding work participation could be identified. Therefore, saturation was not reached. In general, participants were able to remember what they had done and learned in the rehabilitation program and in the period after. Only 2 participants indicated that they were unable to remember what they had learned or not learned from the rehabilitation program at that time. We classified all mentioned items across all 4 systems of the Sherbrooke model. Table 2 provides a summary of the facilitators and barriers regarding work participation that were identified. In the table, specific rehabilitation-related facilitators and barriers were identified as being influenced (healthcare system and coping-related factors of the personal system).

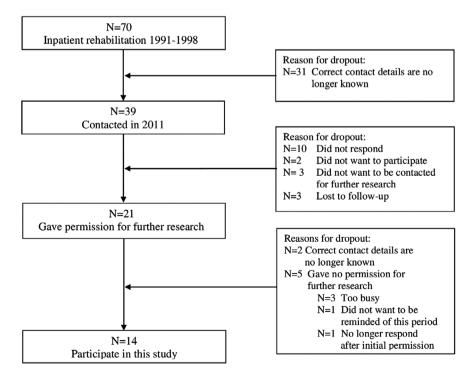


Figure 1. Flowchart of participants.

Table 1. Patient Characteristics

Participant Gender		Present Age	Diagnosis at Admission	Present Complaints	NRS Pain Last Week (Mean)	Paid Work	Reason for not Working	Working Hours (per Week)	QQ-Index (Quantity)	QQ-Index (Quality)	IPA (Work/ Education)	WAI (Physical)
- 0	ш.	37	NS pain right ankle	Same	9	Yes	100% disabled	27 NA	AN A	4 N	0.67	AN A
1 W	. 1	40	NS chronic back		1 9	Yes		16	(6	(o	1.00	€ ∞
4	ш	30	pain CRPS right foot	Ehlers-Danlos	4	No	80% to 100%	NA	ΑN	NA A	2.00	NA A
2	ш	36	CRPS right leg	Hypothyroidism	0	Yes	nagagin	23	6	8	1.00	8
9	ш	37	CRPS left ankle	None	0	Yes		28	10	10	0.83	10
7	Σ	35	NS chronic back	None	0	Yes		40	10	10	0.17	
			pain									
8	ш	33	CRPS left leg	Same	9	Yes		24	10	10	1.00	10
6	ш	33	NS pain multiple	Same	4	No	Cannot find a	NA	NA	NA	3.40	NA
10	ш	31	Joints NS chronic back	Same	ıc	Yes	suitable Job	24	6	œ	1 00	٠
2			pain		1	}			1)		,
11	Σ	32	Ns chronic back pain	Same	2	Yes		40	6	10	0.33	10
12	ш	34	NS pain left foot	Same	7	Yes		27	10	10	3.00	10
13	ш	30	Fibromyalgia	Same	2	Yes		30	10	10	0.33	8
14	ш	31	NS pain knee after	All joints	5	No	Chose to care	NA	NA	NA	1.00	AN
			Lyme disease				for children					
Mean (SD)		34.1			3.6 (2.4)			27.9 (7.4)	9.6 (0.5)	9.4 (0.9)	1.41 (1.21)	8.56
		(5.9)										(1.50)

CRPS, complex regional pain syndrome; IPA, Impact on Participation and Autonomy questionnaire; NA, not applicable; NRS, numeric rating scale; NS, multifactorial; QQ, quantity and quality; SD, standard deviation; SLE, systemic lupus erythematosus; WAI, Work Ability Index.

Table 2. Facilitators and Barriers Regarding Current Work Participation of Adults Who Followed an Inpatient Pain Rehabilitation Programme for Chronic Musculoskeletal Pain During Adolescence

Barriers	Facilitators
Healthcare system-related Too little or negative advice about	Healthcare system-related No pain at the end of the
study/work*	rehabilitation*
Absence of adequate follow-up after rehabilitation*	Finished high school without repeating a class*
	Received advice about suitable study/work*
	Adequate ergonomic principles learned*
	Better energy dispersion*
Workplace system-related	Workplace system-related
Fired from work because of the pain	Modified duties in collaboration with a company doctor and employer
	Employer unaware of pain history
	Colleagues' support
	Option to work part-time
Legislative- and insurance-related	Legislative- and insurance-related
Declared 100% unfit for work	Adaptive devices paid for
Incorrect reintegration process	Refusal to be declared unfit for work
No incentive to apply for work	Incentivized to apply for work
because of receiving disability benefits	Compensation for loss of wages
Personal system-/coping-related	Personal system-/coping-related
Pain limits productivity	Working despite the pain*
Cannot do all the tasks of the job	Higher productivity*

work

Pain makes work impossible

Need to search for another job

Parents' negative attitude towards

Pain limits the choice of work

Healthcare System. The reported influence of the inpatient pain rehabilitation program on current work varied greatly (see Table 2). In particular, the received advice about suitable study and work later on in life was experienced very differently among the participants.

Parents and/or partner encourage

Partner help: housekeeping and

Parents/partner support/accept the

going to work

decision to work

childcare

During the inpatient rehabilitation, they gave me advice about which work I could do best with my complaints

During the inpatient rehabilitation, I missed the advice about making the right choices for further education and employment

Several rehabilitation-related factors, which positively contributed to the participants' current work participation, were named:

When I finished the rehabilitation program, I had fewer complaints and could do more

Workplace System. One of the facilitators that was mentioned concerned employers being unaware about the pain history. Participants had not told their employer about the chronic pain because they were as productive as their healthy colleagues or they no longer had complaints.

My employer knows nothing about my pain history. I haven't told them because I can do my work without any problems

These participants said that none of these employers suspected anything. Employers who were aware of the complaints supported the respective participants in terms of identifying modified duties or working part-time.

In collaboration with my company doctor and employer I did modified duties, so there was no sick leave

Participants chose to work part-time for several reasons. One of the reasons was that they expected that working full-time would decrease the quality of their work. Another reason mentioned is they thought they would not have enough energy to fulfil their working hours or would not have enough energy to care for their children and household after work. And finally some were afraid that their complaints would increase, or that they would end up applying to the health insurance scheme.

When I have to work full-time, my productivity remains the same, but I think I will apply to the health insurance scheme because it consumes too much energy

When I work full-time, it decreases my productivity

Other reasons for working part-time were related to caring for one's own children (independently of the complaints) or because the work was never a full-time matter. The free days were generally used to recover from the working days and to build up new energy levels to sustain their work. Participants were generally satisfied with their working hours. One participant would have liked to work fewer hours per week, but financial reasons made that impossible.

Legislative and Insurance Systems - Participants reported both positive and negative influences of the insurance system on their present work participation

^{*}Rehabilitation-related factors.

(see Table 2). Adaptive devices being paid was regarded as positive.

I could continue my study because the health insurance scheme paid for my taxi costs.

The negative influences that were reported concerned the lack of an adequate reintegration process and being declared unfit for work.

I followed a reintegration program through the health insurance scheme, but that was not appropriate for me

At age 18, I was declared unfit for all kinds of work for the rest of my life

Personal System and Personal Coping – The personal system consists of the influence of complaints, parents, and partners on current work participation. Complaints were almost always mentioned as a barrier, while the influence of parents or partners was primarily seen as a facilitator.

My parents encouraged me to graduate and find a job, because they considered it was important for me to satisfy my own needs.

My partner supports me in everything, but when necessary, he limits the things that I do

Reasons for working are social contact, pleasure in working, and income. Self-reported productivity was regarded as both a facilitator and a barrier. As a facilitator, participants said they were as productive as their healthy colleagues or reported an increase in productivity because of being more efficient at work by completing their workload earlier.

My productivity is higher than that of healthy colleagues because I work faster and I am more focused

A decrease in productivity represents a barrier, especially as a result of reduced concentration or with worsening of complaints and increased pain levels. The participants' coping strategy generally helped them to stay in work. They work despite the pain or modified their duties in such a way that they experienced fewer complaints.

Despite the pain, I go to work. Sometimes that's probably a bad idea, but when I'm working, I continue working

I know what my limitations are. I adapted my work in such a way that I have received no increase in complaints

DISCUSSION AND CONCLUSIONS

This mixed-methods study investigated the work participation of adults who followed an inpatient pain rehabilitation program during adolescence and the possible contributing facilitators and barriers. Ten out of 14 participants were found to be currently working, most of them despite experiencing pain. Various factors classified as barriers or facilitators based on the Sherbrooke model were mentioned in relation to current work participation. The influence of the inpatient pain rehabilitation program on work participation later in life was mostly regarded as a facilitator. As expected, these factors were related to the personal system (coping) and healthcare system. The possibility to graduate from high school, as well as advice given about further education and work, contributes to this facilitation.

The questionnaires in this mixed-methods study yielded additional quantitative information, which may help by better interpreting the interviews like demographics, current work status, past and present complaints, and self-reported assessment of (influence of the pain on) the quality of work delivered. Although our sample was small, our observations regarding the percentage of participants who are currently working is similar to those of other studies (71% vs. 72% and 60% to 70%, respectively). 12,29 Furthermore, our participants reported taking less sick leave in the previous month (0% vs. 22%), a higher incidence of pain (77% vs. 63%), and a lower mean pain intensity in the previous week (3.6 vs. 4.1). 12 These numeric observations might implicate that our participants find their work a meaningful part of their lives, and were motivated and able to overcome or accept negative aspects that accompany working with chronic pain. This was confirmed during the interviews: our participants stressed the importance of continuing to work despite pain, in particular its social contacts, pleasure in working, and income. These facilitators are similar to the motivators mentioned in a previous study.²⁹ Besides motivation, a person must also be able to work, in particular with regard to coping strategies and ability to modify their duties. Compared to coping profiles distinguished in workers with asthma and chronic

obstructive pulmonary disease, our participants resembled the eager worker and adjusted worker profiles.³⁰ Eager workers are highly motivated to continue their work; they do not talk about their complaints and experienced few limitations to work, resulting in a low rate of sick leave. Adjusted workers accept their limitations due to the pain and find a way to reduce the workload in order to reduce their limitations and save sufficient energy for leisure time.³⁰ It is unclear whether our participants used a better coping strategy compared to the study of Westendorp et al. 12 or if this reflects a selection bias. 12 We recommended further research of the coping strategies to stay at work among adults who had participated in pain rehabilitation during adolescence. Knowledge about this might help to improve the rehabilitation program regarding work participation later in life. Finally, our participants reported little influence of pain on work and education and relatively high self-reported work productivity and capacity. The self-reported influence of pain on work and education is slightly lower in our participants than the sample in the study of Westendorp et al. 12 (1.41 vs. 1.57). The Quality/Quantity-index scores in our study (9.6 and 9.4, respectively) were higher than those among workers with any type of health problem (8.9 and 8.2, respectively) and only slightly lower than among a population of workers without health problems (9.7 and 9.7, respectively).26 A possible explanation given by our participants is their better concentration skills at work, which enable them to deliver the same productivity levels as their healthy colleagues. This, in contrast to other studies where a negative correlation between pain and cognitive function was observed, is mostly due to a reduced stress coping ability. 31,32 From our findings it is unclear what the exact relation is. It might be interesting to further investigate the relation between coping with stress and work ability in our population.

We are the first to identify the numerous barriers and facilitators regarding work participation later on in life based on qualitative research with the Sherbrooke model as a guide. Our interviews revealed rehabilitation-related modifiable factors that may have a positive or negative influence on current or future work. Both negative and positive factors can be used to improve rehabilitation programs and prepare for work participation later on in life. Rehabilitation-related modifiable factors that could be influenced during the rehabilitation program were the ability to function despite the pain, advice about suitable study or work, and involving the network (parents, partners). Participants regarded the

given advice on ergonomic principles and energy dispersion during rehabilitation as a facilitator for staying at work. Paying attention to these factors contributes to staying at work despite the pain and can be an important part of the rehabilitation program. Another rehabilitation-related modifiable factor is advice about suitable study or work. Participants who received good advice noticed this as a facilitator, while participants who missed this advice noted this as a barrier for staying at work. For this reason, it is important to involve experts with knowledge about working with chronic pain during the rehabilitation program. Parents and partners positively influence the current work participation of our participants by supporting and accepting the decision to work, encouraging them to go to work, and helping with housekeeping and childcare. These findings are similar to another study, which found a positive influence of family members on the current work participation in adults with chronic musculoskeletal pain.³³ These findings emphasize the importance of involving parents and partners in the rehabilitation program. Except for rehabilitation-related factors, participants reported a positive influence of their employers and colleagues in staying at work. As a coping strategy, almost all our participants worked part-time with the support of their employer. Job, task, or duty modifications are wellestablished facilitators for enabling workers with a health condition to stay at work.³⁴ In summary, our participants generally experienced support of the healthcare system, personal system, work system, and legislative/insurance system to stay at work.

Despite its strengths (a lengthy follow-up period, providing information about a new scientific subject, and a relatively large number of participants who compared the follow-up time), our study had some limitations. We could include 14 out of 70 potential participants. It is unknown whether these participants were a representative part of the whole cohort and thus applicable to the entire population. Although the total number of participants was small, especially for the quantitative part of this study, the percentage of participants was relatively large for the follow-up time of 15 years. There was a lengthy gap between the inpatient pain rehabilitation program and the interview. As such, participants probably did not remember everything correctly or adjusted their memories. This was also reflected in the interviews. It is known that simple information can be recalled with useful accuracy after a long term, while more detailed information is recalled less accurately.³⁵ Several co-factors and decisions during their transition into adulthood may also have influenced their present work participation, independently from the chronic pain and the inpatient pain rehabilitation. Further, because the last participant still referred to new facilitators and barriers, the list of facilitators and barriers mentioned is most likely incomplete.

This is the first study reporting on barriers and facilitators of work participation of adults who had participated in pain rehabilitation during adolescence. The facilitators and barriers identified might help to improve awareness on this subject during rehabilitation treatment and subsequently enable better work participation by future patients. Future research is recommended about facilitators and barriers regarding work participation later on in life. In clinical practice, special attention might be paid to the advice given about suitable study or work during pain rehabilitation programs, the ability to function despite the pain, and the involvement of parents and partners in the rehabilitation program. Besides, learning different coping strategies to stay at work can have a positive influence for future work participation.

We concluded that, 15 years after inpatient pain rehabilitation for chronic musculoskeletal pain, 10 out of 14 participants were currently working, most of them despite experiencing pain. Several facilitators and barriers, as identified in the Sherbrooke model, were contributory factors in relation to ongoing work participation. An important finding was that the inpatient pain rehabilitation program was generally regarded as a facilitator. Rehabilitation-related modifiable factors were the ability to function despite the pain, advice about suitable study or work, and the involvement of parents and partners in the rehabilitation program.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

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