SATURDAY, 06 JUNE 2020

Psychosocial support

PARE0018

WEBSITE FOR PARENTS OF CHILDREN WITH JUVENILE IDIOPATHIC ARTHRITIS REDUCES PARENTING STRESS.

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Background: Having a child with JIA presents many challenges. Many parents experience considerable stress. Parental distress and functioning have been found to be related to child outcomes (Cousino, 2013), therefore interventions that help parents to manage their child's illness are important for both parents and child. We developed a website for parents of children with newly diagnosed JIA to help increase parental confidence in managing their child's arthritis and reduce parenting stress.

Objectives: To evaluate the efficacy of a web-based tool 'WebParC' for parents of children with JIA.

Methods: Design: Multi-centre randomised controlled trial conducted in 16 tertiary paediatric rheumatology centres in England.

Participants: Parent(s) of children aged ≤ 12 years, diagnosed with JIA within the previous six months.

Procedures: Parents were enrolled when they attended the rheumatology service and were randomised by household to either the intervention arm (I) who were given access to the website in addition to their child's standard care or the control arm (C) who received standard care alone.

The primary outcome was parenting stress, measured with the Pediatric Inventory for Parents (PIP) (Streisand, 2001), which parents completed prior to randomisation and at 4-months and 12-months post randomisation.

Website content was developed by a multidisciplinary team including rheumatology, physiotherapy, ophthalmology, social work, podiatry, occupational therapy, clinical and health psychology along with parents of children with JIA. It includes information about JIA and its treatment plus a 'toolkit' for parents. The toolkit is based on cognitive-behavioural principles to develop skills for managing JIA-related issues.

Analysis: We conducted linear mixed models to examine the main effect of trial arm (I vs C), main effect of time (between 4M and 12M scores), and interaction between trial arm and time on PIP scores, after controlling for baseline scores.

Results: A total of 220 parents (183 mothers, 37 fathers) of 203 children were randomised, 106 intervention and 114 controls. Parents mean (SD) age was 36.5 (6.5). Their children with JIA were mostly female (137/203, 67.5%), mean (SD) age of 6.1 (3.4) years. There were 107 (52.7%) with oligoarthritis, 65 (32%) polyarthritis, 8 (3.9%) systemic and 23 (11.3%) other JIA subtypes. Seventy (34.5%) were prescribed methotrexate.

Trial arms did not differ significantly at baseline except for parent education, which was higher in the intervention group and was controlled for in the analysis. Follow-up assessments were completed by 133 (I60, C73) at 4M and 124 (I58, C66) at 12M.

We found significant main effects of trial arm on PIP Difficulty ($p=0.022$, Control (Mean=93.62, SE=2.717) > Intervention (Mean=84.23, SE=3.025)) and PIP Frequency ($p=0.008$, Control (Mean=95.78, SE=2.400) > Intervention (Mean=86.23, SE=2.622)), with Controls reporting significantly greater frequency and difficulty of stressful events than the Intervention group (Fig 1).

Conclusion: This trial found that a website for parents of children with JIA can help to reduce parenting stress.

References:

- [1] Cousino MK, Hazen RA. J Pediatr Psychol 2013; 38(8):809-28
- [2] Streisand R, Braniecki S, Tercyak KP, Kazak AE. J Pediatr Psychol 2001; 26(3):155-62.

Figure 1. Pediatric Inventory for Parents (PIP) - measure of childhood illness-related parenting stress

A higher score is worse, reflecting more frequent stressful events / greater difficulty experienced

Acknowledgments: We thank all parent participants, the health professionals and parents who developed website content and the clinical teams who supported recruitment.

Funded by NIHR RfPB.

Disclosure of Interests: Kathleen Mulligan: None declared, Shashivadan Hirani: None declared, Sally Clarke: None declared, Neil Evans: None declared, Chris Flood: None declared, Jo Taylor: None declared, Lucy Wedderburn Speakers bureau: Pfizer, Stanton Newman Grant/research support from: Yes Baxter Healthcare Educational Grants not in relation to rheumatology, Speakers bureau: Yes Baxter Healthcare and Merke Sharp and Dome

DOI: 10.1136/annrheumdis-2020-eular.3510

SATURDAY, 06 JUNE 2020

Work and rehabilitation

PARE0019

DON'T DELAY - TIME2WORK

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Background: Employment process of people with RMD is very sensitive and tough subject, especially in Republic of Serbia. For people with RMD it is very hard to get employed or to find a suitable job. Based on study 33% of the total health care costs was allocated to employers.

Objectives: Raise awareness about employment of people with RMDs and identify barriers and bottlenecks of the process of employment. Connect with all relevant stakeholders and figure out a way to ease the whole process of employment.

Methods: A round of surveys were conducted, one for employers and the other for people with RMDs. A round table was organized with participants from various relevant institutions. A series of articles were published online and in writing. A series of interviews were emitted on various TV stations.

Results: Total of 136 persons with RMD took the survey and a total of 75 companies took the survey for employers. 56.7% are employed. 31% of people with RMDs that took the survey said that they did not get the job because they have RMD. 37.1% are missing from work just when they are feeling really bad. 87.1% are open for prequalification and retraining. 90% is not familiar with process of qualifying for disability act. 42.60% are looking for a job via Internet. 45% does not get help at the workplace from their colleague when they are not feeling well. 42.3% met the difficulty of employer not understanding disease and it's forecast. 39.7% does not get any feedback after interview. 40% of employers are not familiar with benefits from the state when employing person with disability act. 68% have not used any benefit provided by state. 2/3 of employers are giving advantage to work experience and probation impression over other when deciding about employment of person. Active communication between round table participants and our organization. Employment brochure, digital and hard copies.

Conclusion: People with RMDs are more than interested and willing to take courses and prequalification in order to get employed. More than half that are not employed at the moment are actively seeking for a job opportunity. Employers are willing to employ people with RMDs and also send them for prequalification. They are not familiar with benefits that they can get when employing person with RMD. More than 2/3 of employers that took the survey stated number of benefits that they would see fit them when employing person with disability act, and 95% of those benefits are already on benefit list provided by Republic of Serbia. If more people with RMDs are employed causes less health care cost to the state, more funds for new medicines, more people on innovative drugs, which results in more people getting employed. The other thing that needs raise of awareness is the process of getting act of disability, since people with RMD in Serbia are not familiar with it.