Poster Presentations

PARE0001 #DOESNTSHOWDOESNTEXIST/#SYNSINTEFINNSINTE – AN AWARENESS CAMPAIGN FOR PUBLIC TRANSPORT BY SWEDISH NATIONAL ORGANIZATION FOR YOUNG RHEUMATICS

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Background: "Rheumatism amongst young people, is that really a thing?" "Isn't rheumatism something that only old people have?" "You seem so happy and so active, surely you can't be in pain?" These are all questions that young people with rheumatism have to listen to, and answer every day. Yes, it's possible to have rheumatism even as a young person, and to be in pain, even though we're not letting it show. We know adjustment is possible, and that we can live our life to the fullest and follow our dreams, despite rheumatism. But sometimes it demands some extra understanding from the people around us. That's what we wanted to recognize, for the second year in a row, but with another approach, and created a campaign together with AbbVie.

Objectives: It can be hard to understand and fully grasp something you can't see, something that is invisible. But as young people with rheumatism, we have to live and deal with our swollen joints, with the pain and the fatigue, and with the side effects of our medication. None of which should be questioned. We recognized that this was an issue for most people with rheumatism, especially young people, and especially in the public transport. Therefore, we wanted to start a conversation about that we, young people with rheumatism that doesn't show, can also need to sit down at the priority seats. The main purpose with our campaign was to acknowledge the fact that you can't always tell whether or not a person has a diagnosis, or is in pain. We also wanted to show young people with rheumatism that they are not alone in their situation.

Methods: We wanted to make a quiz. Each pair of person with and without rheumatism in the campaign is presented in a photo taken on a bus next to each other with a quiz question. For example: "Who of us needs to sit on the bus so we can hang out in the skate park this afternoon?" The whole idea of the quiz is to make people realize that it is impossible to see if a person needs to sit on the bus or not, that you have to trust us when we asks for a seat. Every answer is put together with the person's story about their passion in life and what it's like to live and deal with an invisible disability in public transport. The quiz was released on October 9th 2017, together with a new decal for public transport that all of our members helped us put on buses and trains all over Sweden, pins to wear all week for all our members, debate articles in local and national papers, interviews in radio and television, letters and decals to all public transport companies, and a social media campaign with photo and personal story each day. People were also told to share their own stories under the hashtag #synsintefinnsinte

Results: The campaign ended up being our organization's most successful campaign to this date, we reached over 4.5 million people – more than we could ever dream of. The campaign had more likes and shares on both Facebook and Instagram than any of our other campaigns has had so far. The debate articles in local and national papers were really important for the campaign and started a lot of discussions, debate and awareness. The photos combined with the personal stories make a powerful statement. We managed to show that young people with rheumatism some days also need access to the priority seats and we look forward to the conversation continuing on at #synsintefinnsinte.

Disclosure of Interest: None declared

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PARE0002 ADHERENCE TO THERAPY AND PATIENTS ENGAGEMENT IN ITALY: A CLOSE LINK

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Background: In the last years ANMAR Italia and the federated Regional Association worked hard to educate people with Rheumatic diseases (RMDs) to an appropriate adherence to the therapy prescribed, as the Mosaico project confirmed that even patients in bio-technological therapies reveal unwillingness to assume their drugs within the schedule prescribed by the rheumatologist (timing and doses).

"ANMAR we care", study by the Italian Association of patients with Rheumatic diseases (ANMAR) in 2017 thanks to an unrestricted grant from ABBVIE and the precious collaboration of the Engage Minds Hub Research Center of Università Cattolica del Sacro Cuore di Milano directed by prof. Guendalina Graffigna, intended to analyze the problem again after the campaigns acted in the last two years and to link adherence to therapies with the degree of patient engagement.

Objectives: to verify the percentage of adherent patients and their degree of adhesion to the therapy.

To appraise the relationship among adherence and engagement of people with rheumatic diseases.

Methods: in the study we administered to patients a specifically pursued questionnaire containing a fair number of questions on adherence to therapies.

This sub-analysis was made using the answers to those questions and data have been interpolated with those related to the level of engagement of the patients.

Results: overall data confirm that in Italy also in 2017 the percentage of people with RMDs adherent to therapies settles in dissatisfying degrees (54%) and that such includes patients partially adherent.

Looking at the relationship within adherence and engagement, if divided in the four groups anticipated by the PHE Model the percentage are: Blackout (cognitive blindness, deny, freezing) 47%, Arousal (superficial knowledge, alert, behavioral disorganization) 46%, Adhesion (cognitive adhesion, acceptance, formal adherence) 61%, Eudaimonic Project (sense making, elaboration, situated practices) 78%.

Notice that patients with Psoriatic Arthritis are the most adherent, followed by those with Fibromyalgia, Spondylitis and finally with Rheumatoid Arthritis.

Conclusions: this analysis highlights that the information and awareness campaigns made in the last years were useful, but results are still far away from the optimum.

As we expected, the engagement degree hardly affects the adherence process, but totally unexpected is that patients in "Arousal" are more confused and less adherent than those in "Blackout".

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PARE0003 PROVIDING PATIENT AND FAMILY EDUCATION AND SUPPORT FOR CHILDREN WITH RHEUMATIC DISEASES AND THEIR FAMILIES: CASSIE AND FRIENDS ANNUAL FAMILY DAY IN BC

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Background: Family Day, an annual patient education event starting in 2009, is organized and funded by Cassie and Friends, a registered BC charity dedicated to transforming the lives of children with rheumatic diseases and their families. It is a full day, multi-track conference held outside the hospital environment, organized collaboratively by the pediatric rheumatology team members at BC Children's Hospital and the Cassie and Friends' volunteer conference committee.

Objectives: To describe the growth and impact of an annual Family Day event on children with rheumatic diseases and their families in BC.

Methods: The program includes lectures, round table discussions, and patient panels for parents and caregivers, with both age-related recreational and educational activities for children and youth (i.e. peer to peer support). Content and format of the program is informed annually by feedback from previous Family Days and advice from pediatric rheumatology team members. Formal feedback from attendees (parents) is provided by a post-event survey.

Results: Registration has increased annually from just a handful of families in 2009 to 141 attendees in 2015, and 372 attendees in 2017 (with a waitlist). In 2017, attendees were 81 children and youth with rheumatic diseases, 68 siblings, and 150 parents and caregivers. A total of 72 speakers and volunteers