Impact of Cold Agglutinin Disease and its related Fatigue on Patients’ Daily Life: An Online Survey among 50 US Patients

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INTRODUCTION

Cold Agglutinin Disease (CAD), primary or secondary, is a rare disease and type of autoimmune hemolytic anemia characterized by autoantibodies that bind to red blood cells (RBCs) at below core body temperature [1, 2]. In addition to cold-induced symptoms, the anemia and hemolyis observed in CAD causes numerous symptoms including RBC agglutination, dizziness, shortness of breath, headaches; however, these symptoms are reported in very few publications [2]. Disease severity may fluctuate. There is no approved drug for the treatment of CAD [3].

OBJECTIVE

The present study aims to assess the impact of CAD and its related effects on patients’ daily life.

METHODS

An Internet-based survey hosted on Carenity, an online patient community, was conducted among patients registered on the CAD Unraveled website (https://www.cadunraveled.com/) and members from the Cold Agglutinin Disease Foundation.

Study Characteristics

- Inclusion criteria: Adult patients living with CAD in the USA
- Sample size: 50 respondents
- Number of questions: 39 closed questions and 5 open-ended questions
- Data collection period: September 2020
- Framework of the study: Voluntary, opportunity to withdraw at any time and no financial incentive

RESULTS

A. CAD SYMPTOMS EXPERIENCED BY PATIENTS

88% of patients experienced at least one symptom prior to diagnosis. The symptoms most often reported included fatigue (fatigue / tiredness / lack of stamina / weakness) (74%), shortness of breath (38%), and acrocyanosis (36%).

88% of patients have already experienced an episode of increased intensity/sensitivity of their CAD symptoms and 72% have had an episode of new CAD symptoms. On average, patients have experienced between 4 and 5 episodes in the past 12 months. Fatigue is the main symptom (89%) experienced by patients during these episodes. Shortness of breath (66%), dark urine (47%), and headaches (43%) were also often reported.

Focus on Fatigue

Fatigue was experienced on a daily basis by 44% of patients, 27% experienced it several times a week and 16% only after exertion.

B. IMPACT OF CAD ON PATIENTS’ DAILY LIFE

More than half of the patients considered their disease as severe or moderate.

Personal life and physical well-being are the most impacted aspects. Patients also spontaneously reported impact on their emotional well-being (22/50). Patients are more affected during episodes of increased intensity/sensitivity (median: 8-10), with 10-very strong impact) or when they experience usual/regular symptoms (i.e. symptoms experienced on a daily basis) (median: 6-10).

Focus on professional life

I have to take time off work
I cannot work as much as I would like
I am not as efficient as I used to be
I am concerned I would not be able to do the job when applying for a new position
My professional life is not impacted

Focus on household finances

Mild
Moderate
Severe
Other: Not sure it has not been impacted

C. MANAGEMENT METHODS USED TO MANAGE THE CAD

Cold avoidance
Rituximab (Rituxan)
Blood transfusions
Other
None

Focus on Fatigue

Almost all patients who experienced fatigue had also implemented a solution to cope with it: taking breaks during the day (71%), managing supply of energy (60%) or taking vitamins (58%). On average, patients implemented 5 solutions.

28% of patients are satisfied with the solutions they have implemented to cope with fatigue.

CONCLUSION

CAD is a challenging and life-impacting condition. Fatigue has a significant impact on the different aspects of patients’ daily lives. Personal life and physical well-being are some of the most impacted aspects of patients’ lives. This survey shows that there is a need for a better management of this disease.

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