



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) is a rare disease and type of **autoimmune hemolytic anemia** characterized by autoantibodies that bind to red blood cells at below core body temperature [1, 2]. In addition to cold-induced symptoms, the anemia and hemolysis observed in CAD causes **numerous symptoms** including fatigue, dizziness, shortness of breath, headaches; 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.

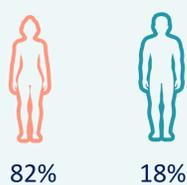
METHODS

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

RESPONDENTS' PROFILE (n=50)



Mean Age: 66.7 years old

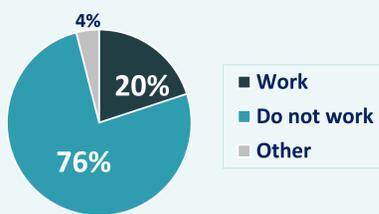


Fig. 1: Employment Status

Mean Time Since Diagnosis (range): 7.5 years (1-30)
Mean Age at Diagnosis (range): 59.2 years old (41-76)

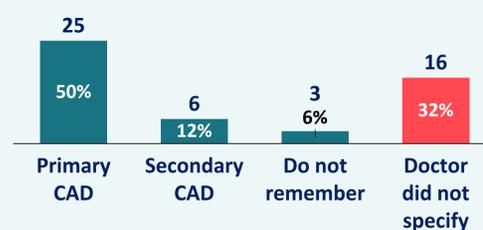


Fig. 2: Type of CAD

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%**) are 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**.

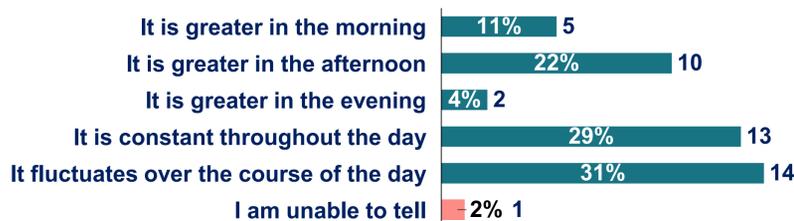


Fig. 3: Evolution of the Level of Fatigue throughout the Day (n=45)

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 \geq 8/10, with 10=very strong impact) or when they experience usual/regular symptoms (daily symptoms; median \geq 6/10).

Focus on impact on professional life

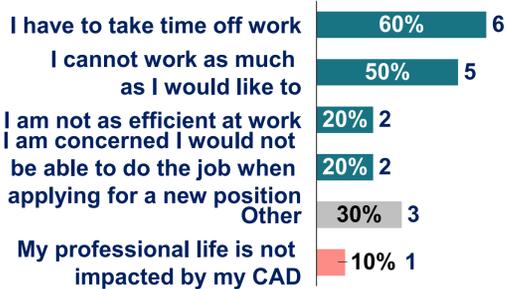


Fig. 4: Impact of CAD on Professional Life (n=10)

Focus on impact on household finances

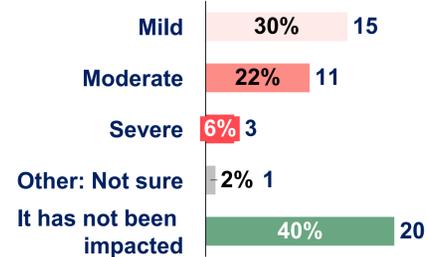
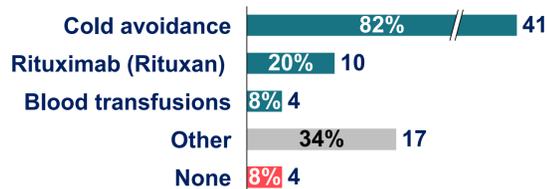


Fig. 5: Impact of CAD on household finances (n=50)

C. MANAGEMENT METHODS USED TO MANAGE THE CAD



Mean number of management method used by patient: 1.4

Fig. 6: Management methods used at the time of the survey (n=50)

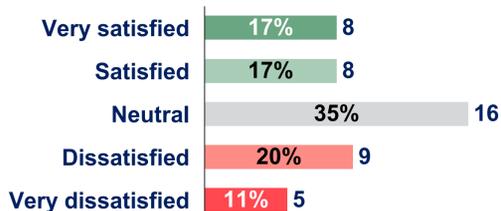


Fig. 7: Satisfaction regarding management methods used at the time of the survey (n=46)

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**.

Only **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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References: [1] Mullins M, et al. Cold agglutinin disease burden: a longitudinal analysis of anemia, medications, transfusions, and health care utilization. Blood Adv. 2017 May 19;1(13):839-848. [2] Swiecicki PL, et al. Cold agglutinin disease. Blood. 2013 Aug 15;122(7):1114-21. [3] Jäger U, et al. Diagnosis and treatment of autoimmune hemolytic anemia in adults: Recommendations from the First International Consensus Meeting. Blood Rev. 2020 May;41:100648.