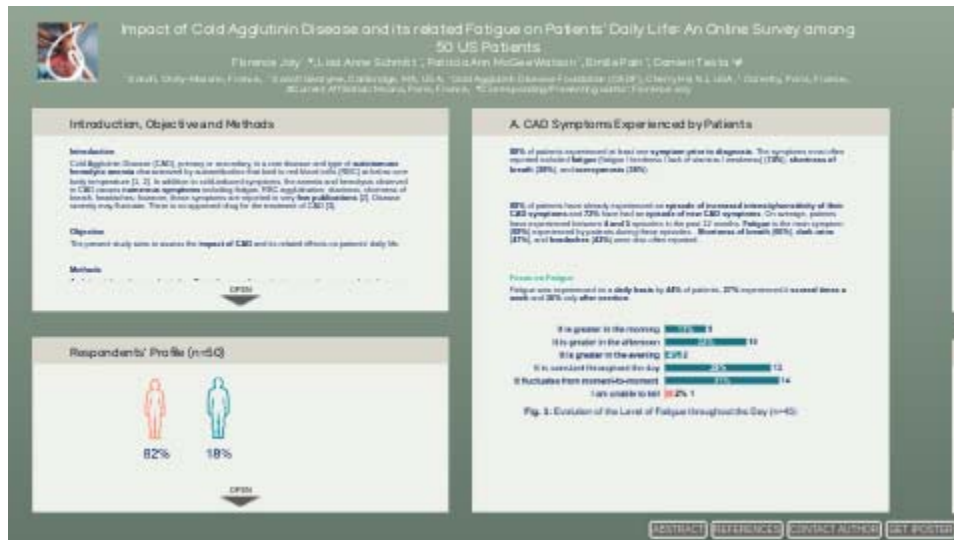


Impact of Cold Agglutinin Disease and its related Fatigue on Patients' Daily Life: An Online Survey among 50 US Patients



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INTRODUCTION, OBJECTIVE AND METHODS

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 (RBC) 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, 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/> (<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)



82%



18%

Mean Age: 66.7 years old

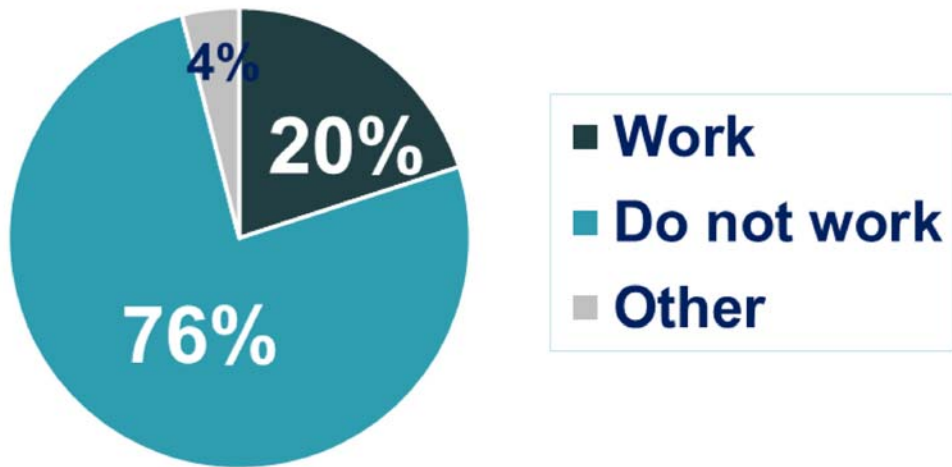


Fig. 1: Employment Status

Mean Time Since Diagnosis (range):

7.5 years (1-30)

Mean Age at Diagnosis (range):

59.2 years old (41-76)

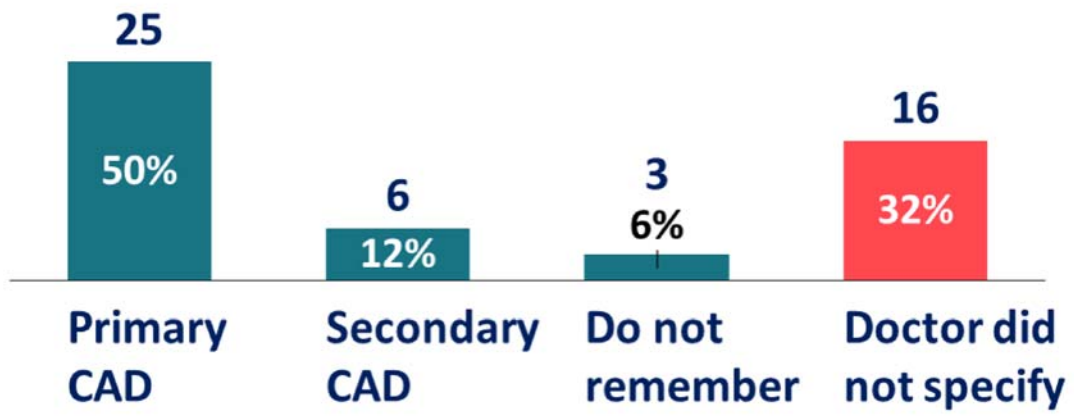


Fig. 2: Type of CAD

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**.

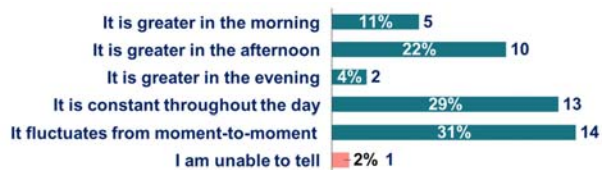


Fig. 3: Evolution of the Level of Fatigue throughout the Day (n=45)

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 (i.e. symptoms experienced on a daily basis) (median $\geq 6/10$).

Focus on impact on professional life

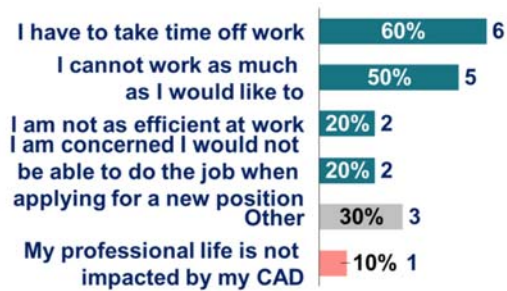


Fig. 4: Impact of CAD on Professional Life (n=10)

Focus on impact on household finances

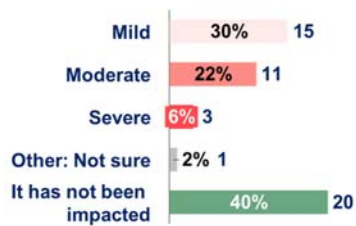


Fig. 5: Impact of CAD on household finances (n=50)

CONCLUSION AND ACKNOWLEDGMENTS

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.

Acknowledgments

The authors wish to thank all the CAD patients who participated in this survey and Cori Forster for her contributions to the design of the online survey.

C. MANAGEMENT METHODS USED TO MANAGE THE CAD

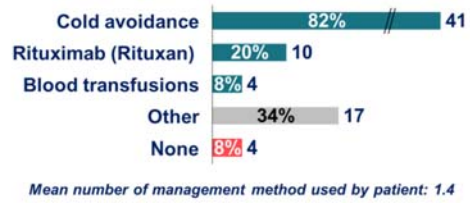


Fig. 6: Management methods used at the time of the survey (n=50)

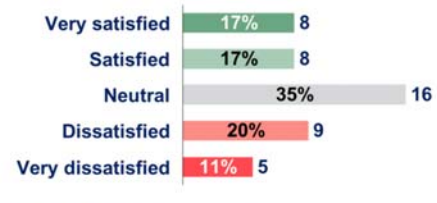


Fig. 7: Satisfaction regarding management methods used at the time of the survey (n=46)

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.

ABSTRACT

Objectives: To assess the impact of Cold Agglutinin Disease (CAD) and its related effects on patients' daily life.

Methods: An Internet-based survey hosted on Carenity was conducted in September 2020 among patients registered on the CAD Unraveled website and members from the Cold Agglutinin Disease Foundation, through a questionnaire composed of 39 closed questions and 5 open-ended questions. Adult patients living with CAD in the USA were eligible.

Results: Fifty respondents (mean age 66.7 years, 82% female) were included in the study, of which 76% were unemployed. Mean time since diagnosis was 7.5 years.

Ninety percent of patients experienced fatigue due to CAD. Fatigue was experienced on a daily basis by 44% of patients, 27% experienced it several times a week and 16% only after exertion. When fatigue was experienced, 31% mentioned that it usually fluctuated from moment-to-moment, 29% reported that it was constant throughout the day and 22% that it was greater in the afternoon.

More than half of the patients considered their disease as severe or moderate. All aspects of daily life (emotional well-being, physical well-being, etc.) were greatly affected by CAD, particularly by the related fatigue. Ninety percent of employed patients had their professional life impacted and 60% of patients mentioned their household finances were impacted by their CAD.

Cold avoidance was the main management method used (82%) by patients. 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%). However, only one-third of patients were satisfied with the management method used and solutions implemented.

Conclusions: CAD is a challenging and life-impacting condition, primarily due to the severe fatigue. Professional life and household finances are some of the most impacted aspects of patients' lives.

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