Holistic clinical management of ATTR amyloidosis with cardiomyopathy

Olga Azevedo[a], Christine Chiti[b], José González Costello[c], Keith Dares[d], Agnes Farrugia[e], Hiroaki Kitaoka[f], Olivier Lairez[g], Simone Longhi[h], Isabelle Lousada[i], Hansie Mathelier[j], Katharine McIntosh[k], Caroline Morbach[l], Paul Pozzo[m], Ronald Witteles[n] and Julian D. Gillmore[b]

[a]Cardiology Department, Hospital Senhora da Oliveira, Guimarães, Portugal; [b]UCL Centre for Amyloidosis, National Amyloidosis Centre, Royal Free Hospital, Rowland Hill Street, London NW3 2PF, United Kingdom; [c]Cardiology Department, Hospital Universitari de Bellvitge, Bellvitge Biomedical Research Institute (IDIBELL), Universitat de Barcelona, CIBER-CV; Carrer de la Feixa Llarga, s/n, 08907 L'Hospitalet de Llobregat, Barcelona, Spain; [d]Amyloidosis Patient and Board Director of the Canadian Amyloidosis Support Network, National & International Amyloidosis Advocate, Nova Scotia, B0N 1Z0, Canada; [e]Association Française contre l'Amylose, 13 rue Raymond Losserand, Paris 75014, France; [f]Kōchi University, Department of Cardiology and Geriatrics, Kōchi Medical School, Kōchi University, Kōchi, Japan; [g]Cardiac Imaging Center and the Cardiac Exploration Unit, Toulouse University Hospital, 1 Av. du Professeur Jean Poulhès, 31400 Toulouse, France; [h]Cardiology Unit, Cardiac Thoracic and Vascular Department, IRCCS Azienda Ospedaliero – Universitaria di Bologna, Bologna; [i]Amyloidosis Research Consortium, 320 Nevada St, Newton, MA 02460, USA; [j]Penn Presbyterian Medical Center, 51 N 39th St, Philadelphia, PA 19104, USA; [k]Cardiomyopathy UK, 75a Woodside Road, Amersham, Buckinghamshire, HP6 6AA, United Kingdom; [l]Dpt. Clinical Research and Epidemiology, Comprehensive Heart Failure Center & Dpt. Medicine I, University Hospital Würzburg, Am Schwarzenberg 15, 97078 Würzburg, Germany; [m]Amyloidosis UK, Hackamor House Grove Lane, Redlynch, Salisbury, SP5 2NR, United Kingdom; [n]Stanford University School of Medicine and Stanford Amyloid Center, 300 Pasteur Dr, Lane #154, Stanford, CA 94305, USA.

1 Background

ATTR-CM significantly affects patients' physical, mental, and psychosocial well-being. There's a need to assess current provision for holistic care, highlight unmet needs, and identify ways to improve clinical practice.

2 Objectives

Characterise current provision of holistic clinical management for people with ATTR-CM. Identify areas of high unmet holistic need. Develop potential solutions.

3 Methods

An international group of clinicians, patients, and advocates came together to review current holistic care for ATTR-CM and agree on key unmet needs and practical solutions.

4 Outcome

- Expert recommendations were developed to address gaps and guide best practice in six key areas of holistic care.

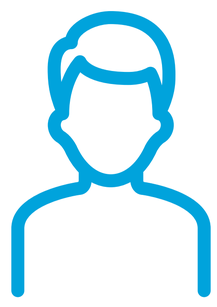
Areas of unmet holistic need

ACCESS TO TREATMENT

Access to treatment for ATTR-CM remains uneven, and limited availability of diagnostic tools and specialists often results in delays. High costs, complex reimbursement systems, and varying national policies create significant barriers for patients. These challenges contribute to disparities in care and can negatively impact health outcomes, particularly when treatment is not initiated early.

BEYOND MEDICAL SUPPORT

Patients with ATTR-CM and their carers often lack consistent access to support networks, tailored education, and practical resources. Opportunities to connect with peer groups, receive information suited to changing needs, or engage with local services are not always clearly signposted. This can leave individuals feeling isolated and under-supported in managing both the condition and its wider life impacts.



N=15 healthcare professionals, patients, and advocates from seven countries

ORGANISATION OF CARE AND DISEASE MONITORING

Care for people affected by ATTR-CM is often fragmented and lacks consistent coordination across specialties. Monitoring practices vary, and regular assessments of clinical status, cardiac function, and quality of life are not uniformly implemented. Patients may face logistical challenges in accessing timely evaluations, and multidisciplinary input is not always integrated into routine care. This can lead to gaps in disease tracking and hinder optimal management.

MAINTENANCE OF MENTAL HEALTH

Patients with ATTR-CM require care that encompasses a wide range of physical, emotional, and social needs. These complexities also affect those who support them, such as family members or carers. Inconsistent input from mental health practitioners can result in missed opportunities to address underlying factors that influence patient well-being.

PEOPLE WITH HEREDITARY AND WILD-TYPE ATTR-CM HAVE DIFFERING HOLISTIC NEEDS

The needs of people with different types of ATTR (hereditary or wild-type) are likely to vary due to their differing ages and clinical profiles, as patients with hereditary ATTR may have more neurological and systemic disease. Patients face a complex interplay of clinical, psychological, and socioeconomic challenges that can hinder their ability to manage their condition effectively.

Beyond the direct cardiac implications of their condition, individuals may experience unmet nutritional and emotional needs, limited access to rehabilitation services, and external barriers such as financial hardship, food insecurity, poor hygiene conditions, and transport limitations. These factors can significantly impact treatment adherence and overall.

PATIENT–HEALTHCARE PROFESSIONAL COMMUNICATION AND SHARED DECISION-MAKING

Patients with ATTR-CM may struggle to articulate their personal goals and treatment priorities during clinical interactions, often due to concerns about burdening healthcare professionals or appearing overly dependent. This can limit the depth of shared decision-making and obscure contextual factors that influence care. Additionally, external challenges – such as fragmented access to community support – can go unnoticed.

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Abbreviations: ATTR, transthyretin amyloidosis; ATTR-CM, transthyretin amyloidosis with cardiomyopathy.