

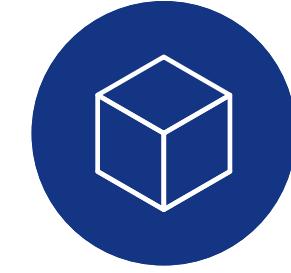
## Educational needs assessment of nurses involved in the care of patients with myasthenia gravis

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### Summary



Nurses have an important, multifaceted role, bringing unique perspectives to patient care



There is an urgent need for tailored nurse-specific resources in MG



The development of targeted educational resources for nurses involved in the management of patients with MG will facilitate their professional development, help to clarify the MG nurse career path, and ultimately improve disease management



The MG Global Nurse Steering Committee is a dedicated community of nurses with specialized experience in MG who are working to develop resources, exchange ideas and solidify the importance of the nurse in MG management

### Background

Nurses with specialized disease knowledge have an integral and diverse role in providing coordinated care and support to patients, as part of a multidisciplinary team<sup>1,2</sup>

MG is a rare, chronic, autoimmune neuromuscular disease characterized by fluctuating and fatigable muscle weakness<sup>3,4</sup>

Due to the heterogeneity of MG, a multidisciplinary team is essential for effective patient management<sup>1</sup>

— It follows that nurses with specialized experience in MG care are an essential part of the MG clinical team

### The importance of the role of the nurse in MG management, as described by physicians specializing in the treatment of patients with MG:



"In our clinic, a neuromuscular physician [diagnoses] all the new patients...Then our APPs take over the **day-to-day management**...get to know the patients well and provide them with **support on all aspects of their MG care**...They also bring their **expertise to our research activities**...This arrangement allows the doctors to have time to see new patients expeditiously and to initiate treatment with the least delay. I travel frequently and am **absolutely confident** that my patients are in **expert hands** when I am not in the clinic."

Professor Vu,  
University of South Florida, USA



"Having a nurse with specialist MG knowledge has **enhanced the care** we provide to our patients living with MG. We can share workload, enabling **closer monitoring** of our patients, and **better address their medical, social and psychological needs**."

Dr Burke,  
University Hospital Southampton, UK

**Objective:** This learning needs assessment aimed to elucidate the educational needs and professional practice gaps of nurses caring for adults with MG

### Methods

To answer the question "What are the key learning and practice needs of nurses involved in the treatment and management of MG?" we conducted:



\*The MG Global Nurse Steering Committee guides the development of nurse-specific materials for MG on the Rare Disease Connect in Neurology website.

The Steering Committee comprised six nurses with specialized experience in MG care

## Nurses fulfilled roles as coordinators, educators and patient advocates, but reported an absence of educational provisions throughout their career

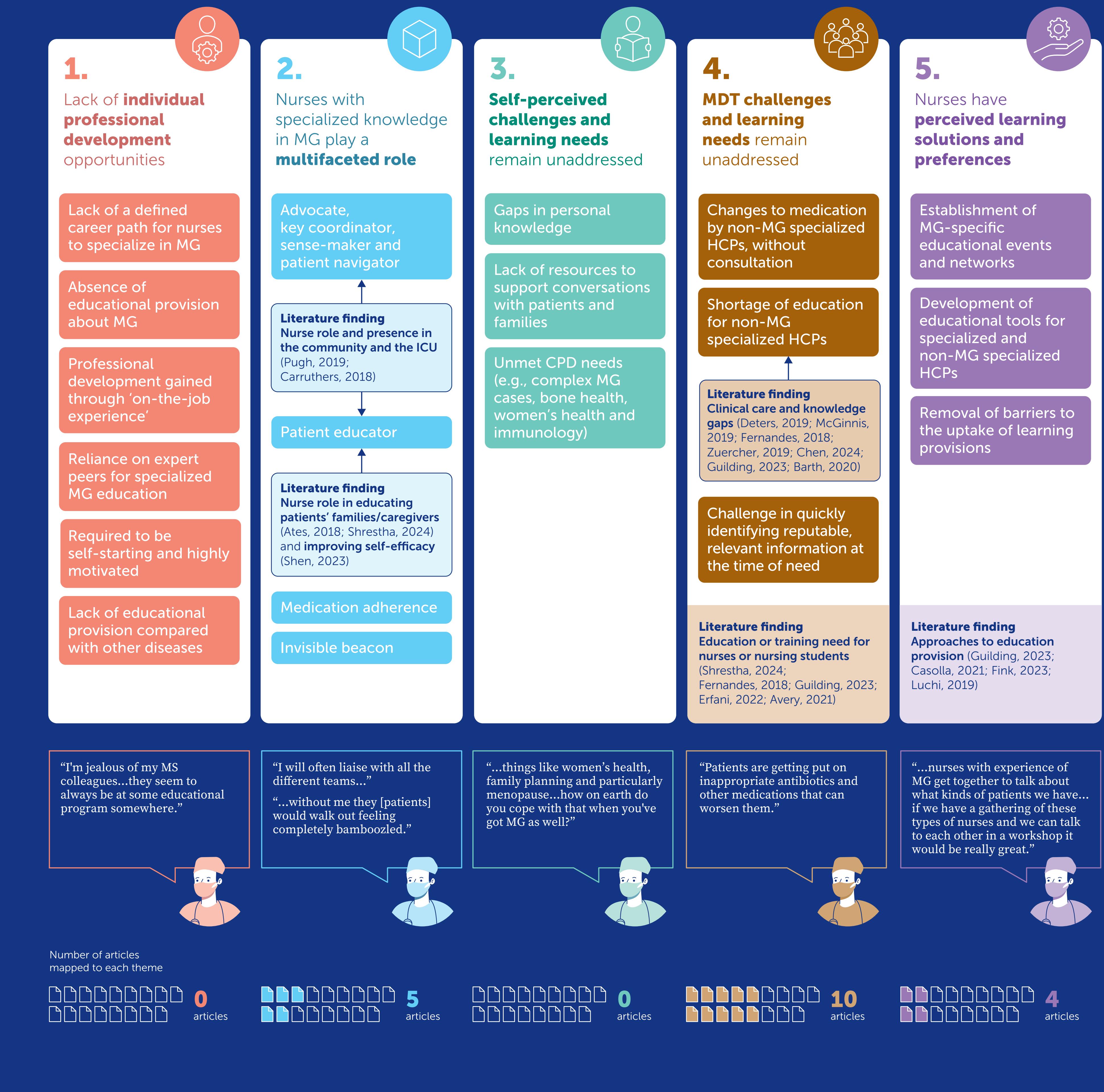
### Results

The literature search yielded **24 articles** (17 reviews, five primary research reports, one clinical practice guideline and one case review), which were analyzed to identify system, practice, knowledge and skills gaps

**Five overarching themes**, each with a number of subthemes, were identified from thematic analysis of the semi-structured interviews with **six nurses** (UK: n=2; Spain: n=1; USA: n=2 and Japan: n=1)

In total, **17** of the retrieved articles from the literature search **mapped** to these overarching themes or the identified subthemes

The overarching themes of **individual professional development** and **self-perceived challenges and learning needs** which both highlighted the individual experiences and needs of the interviewed nurses, were **uniquely reflected in the interviews**



**Abbreviations:** APP, advanced practice provider; CPD, continuing professional development; HCP, healthcare professional; ICU, intensive care unit; MDT, multidisciplinary team; MG, myasthenia gravis; MS, multiple sclerosis; PCP, primary care physician.

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