

Pioneering Best Practices in Atopic Dermatitis: Results from the Quality of Care Initiative

This virtual symposium took place on the 29th October 2020, as part of the 29th European Academy of Dermatology and Venereology (EADV) Virtual Congress

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Disclosure:	Prof Guttman has received consultancy fees from AbbVie, Aditum Bio, Almirall, Amgen, Arena Pharmaceuticals, Asana, AstraZeneca, Bluefin, Boehringer Ingelheim, Boston Pharmaceuticals, Bristol Myers Squibb, Cara Therapeutics, Celgene, DBV Technologies, Dermira, EMD Serono (Merck & Co), Eli Lilly and Company, Evidera, Galderma, Ichnos Sciences, Janssen, Kyowa Kirin, LEO Pharma, LARRK Bio, Medscape, Novartis, Pfizer, Principia Biopharma, RAPT, Realm, Regeneron, SATO Pharmaceutical, Seanergy Dermatology, Seelos Therapeutics, Serpin Pharma, Siolta, Sonoma Biosciences, Vanda Pharmaceuticals, Ventyx Biosciences, Vimalan Biosciences, and Sanofi-Aventis; and has been a member of the scientific advisory board for Sanofi-Aventis. Prof Deleuran has received grants and personal fees, including research support, consulting/advisory board agreements, and/or honoraria for lectures, from AbbVie, Almirall, Eli Lilly and Company, LEO Pharma, Meda Pharma, Pfizer, Pierre Fabre, Regeneron, and Sanofi Genzyme. Prof Simpson has received grants and/or personal fees from AbbVie, Dermira, Eli Lilly and Company, Forte Bio Rx, Incyte, Kyowa Kirin, LEO Pharma, Menlo Therapeutics, Merck, Novartis, Ortho Dermatologics, Pfizer, Regeneron, and Sanofi Genzyme.
Acknowledgements:	Writing assistance was provided by Helen Boreham, HB Medical (UK) Ltd., Wetherby, UK.
Citation:	EMJ. 2021;6[2]:12-17.

Meeting Summary

Pioneering global best practices in atopic dermatitis (AD) and implementing them in the clinic are important steps towards optimising patient care. This satellite symposium, held as part of the 2020 European Academy of Dermatology and Venereology (EADV) Virtual Congress, featured a panel of leading dermatology experts who discussed key findings from the recently published Atopic Dermatitis Quality of Care Initiative.

Purpose and Mission of the Atopic Dermatitis Quality of Care Initiative

Professor Emma Guttman

For many years, AD has been deprioritised in favour of services deemed more medically urgent. New systemic therapies that are able to effectively treat both the disease and its comorbidities have also become available. More recently, patient advocates have taken important steps to increase awareness of AD. However, to reap the full benefits from these changes, Prof Guttman explained that AD care itself must also evolve.

Against this backdrop, the Global Atopic Dermatitis Quality of Care Initiative was conceived.¹ Its vision is to demonstrate the imperative for, and to improve the quality of, AD care worldwide. The mission of the initiative is to catalogue, analyse, and report the challenges to and best practices for quality AD care from renowned healthcare centres around the world. These key findings will then be disseminated to educate other healthcare providers on the priorities and best practices needed to improve and maintain quality care in AD.

The Global Atopic Dermatitis Quality of Care Initiative was overseen by an international steering group consisting of four leading AD experts with responsibility for guiding the initiative, providing practical clinical input, and evaluating the ensuing information. The study was conducted by KPMG, who carried out the collection, study, analysis, and interpretation of the data, as well as the preparation of the final report, which was commissioned and funded by Sanofi Genzyme and Regeneron.

The methodology of the initiative involved a five-step process.¹ Firstly, a stringent literature review was carried out to understand current challenges and good practices in AD care. This was augmented by in-person site visits to leading international centres using structured interviews to document key data with the aim of learning good practice directly from medical leaders in the field. A total of 32 centres from 17 countries around the world were visited, including sites in the USA, Europe, South America, and Asia.

The next step was the documentation of good practice interventions for AD care using specially created centre-specific reports and good practice case studies. These findings were then reviewed by the steering committee to ensure challenges and good practices were accurately captured and articulated. The final stage in the process was preparation of the finalised, comprehensive report, which is available online.

Global Challenges of Atopic Dermatitis and the Opportunities They Present to Improve Quality Care

Professor Mette Deleuran

Prof Deleuran discussed the four main challenges to quality of care that currently exist across the patient pathway in AD.

The first challenge is misconceptions regarding the causes and triggers of AD; people with AD can experience stigmatisation and isolation because of misconceptions that AD is contagious and are frequently affected by social and sexual issues. AD is also underappreciated by patients and often dismissed as simply a childhood disease. Even for healthcare professionals (HCP), AD can be difficult to explain and prone to misconceptions, not least because physicians themselves may have received limited training on the disease despite its prevalence. These issues are illustrated by findings from the Global Atopic Dermatitis Quality of Care Initiative, in which the vast majority of centres (91%) acknowledged that patient knowledge of, and education on, AD is lacking. Over one-half of centres (56%) also reported a need for dedicated programmes to further enhance HCP education.¹ Collectively, these medical and societal misconceptions around AD can often combine to exert a negative impact on a patient's quality of life (QoL).

The second key obstacle to quality of care in AD is delayed referral and access to AD specialists. Across healthcare systems, primary care referral is typically required to secure access to an AD specialist; however, the referral process itself is often inefficient and swamped by overwhelming demand. Prof Deleuran explained that in many

parts of the world it can be very difficult, or even impossible, to obtain an appointment with an AD specialist. Consequently, primary care physicians (PCP) remain the HCP most likely to encounter patients with AD, and misdiagnosis is commonplace. Several different diseases can mimic AD presentation, and individual patients often display widely disparate clinical manifestations. Accurately determining AD severity can prove particularly challenging for PCP. Together, these gaps in PCP education and healthcare system capabilities may hinder the ability of patients to receive timely referral and access to AD specialists.

The third critical issue is poor patient access to AD treatments coupled with suboptimal adherence. AD is associated with a significant treatment burden and patients often grow tired of regular and rigorous application of topicals that can be greasy, malodorous, and damaging to clothing. Fear of treatment side effects, in particular corticophobia, is another issue that can drive poor adherence and underdosing. Evidence indicates that corticophobia, which relates to worries and negative beliefs concerning topical corticosteroids, is present among both parents of children with AD and the HCP involved in caring for them.² In some healthcare settings, AD treatment may also carry a direct financial burden for patients. For HCP, time constraints are a perpetual problem resulting in limited capacity for patient education, particularly on dosage expectations. Prof Deleuran conceded that the biggest challenge in a busy practice can often be finding time to talk to patients and parents and answer all of their questions. In this respect, nurses can prove a vital resource for improving channels of communication with patients. Within healthcare systems, there may be limited, variable, or indeed any coverage of or reimbursement for AD therapies, with limited treatment options for paediatric patients. Collectively, these shortcomings across healthcare systems lead to limited treatment options and access for patients with AD.

The fourth and final challenge to quality of care in AD is managing disease complexity and comorbidities to reduce the burden on patients. Prof Deleuran explained that there has been an increasing realisation in recent years that AD is a multisystem disease driven by type 2 inflammation and is associated with multiple

comorbidities. It is important for HCP to recognise and respond to such potential comorbidities, including asthma and allergic rhinoconjunctivitis, as well as mental health disorders, such as anxiety, depression, and suicidal ideation. For patients with AD, comorbidities can have an impact on multiple components of their QoL. The lifelong requirement for medical management also exerts a heavy toll on patients. Within healthcare systems, managing complexity of AD and its comorbidities may be confounded by limited availability or access to relevant specialists within the setting of a multidisciplinary team (MDT). The overall result is that HCP, patients, and healthcare systems alike are all adversely impacted by the intricate nature of AD health management.

Good Practice Implementation Priorities that Optimise Quality of Care in Atopic Dermatitis

Professor Eric Simpson

The Atopic Dermatitis Quality of Care Initiative identified key challenges in achieving quality of care in AD that resonated with HCP globally. Prof Simpson reviewed five data-driven, good practice interventions devised to address these challenges and highlighted the important benefits they may yield. Interventions were organised into easy, difficult, and advanced steps that practising physicians can take to improve overall clinical care for their patients with AD.

Intervention 1 related to the clinical assessment and diagnosis of AD; easy steps that physicians could take to improve this aspect of care include taking a more nuanced clinical history, performing a thorough clinical assessment and evaluation of treatment response (what has worked, what has not, and why), and taking into consideration the psychological impact of AD. Prof Simpson stressed the importance of clinical assessment that encompasses the whole patient, focussing on accurately evaluating AD severity and understanding key disease drivers. More difficult next steps could include additional diagnostic assessments, such as patch testing for challenging cases or biopsy to rule out cutaneous T-cell lymphoma; shorter disease assessment tools; and consideration of the holistic impact

of AD. Advanced interventions may involve diagnostic criteria assessments, comprehensive disease assessment tools, and a focus on the long-term impact of AD.

Prof Simpson highlighted patient-reported outcomes as particularly useful assessment tools for clinicians and noted that validated 'AD control' instruments are now available online that can help to objectively determine if a patient's disease is well controlled. The potential benefits of improved clinical assessment and diagnosis for patients with AD include more timely and accurate diagnosis, quicker access to care, faster symptom relief, and improved QoL. In turn, HCP and healthcare systems stand to benefit from a reduced burden of misdiagnosis and costs, alongside an optimised disease management approach. Prof Simpson concluded that, above all, it is vital to ensure patients with AD receive a timely and accurate evaluation, diagnosis, and assessment of their disease using established instruments which will, in turn, accelerate access to care and prevent disease progression.

Intervention 2 aimed to wield the advantages afforded by a co-ordinated and structured MDT. Easy steps to enhance MDT collaboration include identifying appropriate specialists, pinpointing those providers who would make good AD team members, and assessing relevant comorbidities in clinical consultations. More difficult MDT implementation strategies could involve participating in meetings and training with external specialists, and collaborating in cross-speciality research. Multidisciplinary clinics, cross-speciality units, specialist patient teleconsultations, and cross-speciality patient group events represent examples of advanced MDT collaboration. Prof Simpson highlighted a number of examples of best practice in the area of MDT at all levels of intervention from participating centres in the study. These included increased involvement of nurse practitioners (Utrecht, the Netherlands), paediatric- and adult psychologist-led consultation and support groups (Sao Paulo, Brazil), and input from pharmacists to boost adherence to topical steroids (Barcelona, Spain). Patients managed in an MDT setting gain better access to diagnostic tests and advice from experts in their field, expedited treatment initiation, and a reduced travel burden. In turn, HCP and healthcare systems benefit from streamlined referrals and

more efficient patient management, improved communications, a reduced burden on resources, less duplication, increased effectiveness, and lower costs. Prof Simpson concluded that MDT involvement is vital for complex patients. This would include a structured and co-ordinated approach that provides holistic patient care and co-ordination between treating HCP and specialists, who serve to streamline and improve patient health management.

Medicine is increasingly focussed on assessing delivered quality of care, noted Prof Simpson, and good-practice Intervention 3 reflects this by monitoring and evaluating care quality. Easy steps towards achieving this include defining care goals, processes, and outcomes; analysis of patient outcomes; and implementation of patient surveys and satisfaction questionnaires. More difficult and advanced approaches could include cross-centre evaluation and HCP assessment, ongoing patient databases, patient dashboards, and external audit of services. Implementing measures to monitor and evaluate care quality gives patients the opportunity to provide direct input that can improve their quality of care, thereby instilling greater confidence in the care provided. HCP benefit from improved patient outcomes, increased patient satisfaction, and better care efficiency, as well as the ability to deliver consistent standards of care. Overall, monitoring and evaluation within centres and amongst wider networks allow for continuous improvement, explained Prof Simpson. Consistent standards of care raise awareness of improvement areas yielding better patient outcomes, patient satisfaction, and care efficiency.

Intervention 4 centres on the important area of patient education and communication, with the aim of improving patient and caregiver understanding of AD and its effective management. Consultant-led patient education, patient intervention plans, referral to patient support groups, and question and answer opportunities are all simple patient education strategies that can be easily applied in daily clinical practice. More difficult and advanced approaches could include intensive educational initiatives, in-house patient support groups and technologies (e.g., bespoke digital apps), patient games and role play, expert patients, and satellite clinics. The benefits of better patient and caregiver education and communication

are obvious, said Prof Simpson, because when patients understand something, adherence is greater and, in turn, outcomes are improved. HCP and healthcare systems therefore benefit from a reduced demand on time, services, and resources. Therefore, overall, better patient involvement in case decisions decreases the burden on patients, HCP, and healthcare systems alike, Prof Simpson concluded.

The final change identified by the Atopic Dermatitis Quality of Care Initiative focusses on the importance of collaboration and exchange with patient groups. The simplest and easiest approach, which can be adopted anywhere, is for all AD treatment centres to routinely direct patients to patient advocacy groups, and vice versa. Prof Simpson emphasised that working collaboratively and exchanging information with patient groups educates and empowers patients and caregivers to actively participate in their AD. Patient access to the resources of patient groups also improves self-management, which in turn decreases clinical and healthcare system burden.

A detailed summary of these key high-priority good practice interventions is contained in the Quality of Care Initiative report.¹

Launching the Global Atopic Dermatitis Quality of Care Initiative

Professor Emma Guttman

Prof Guttman discussed the launch of the Global Atopic Dermatitis Quality of Care Initiative, explaining that the final report from the initiative capturing best practice quality of care from all 32 involved treatment centres is now launched and available online.¹

This interactive website contains all key results from the report, logically presented and fully searchable. Prof Guttman described the report as having very useful applications for everyday clinical practice, in particular for improving clinical care for patients with AD and stepping up treatment where required to maximise QoL and reduce the burden on both patients and wider society. The report also provides the opportunity to compare and contrast clinical practice in AD

from around the world, noted Prof Guttman, allowing clinicians to understand regional differences and embrace examples of good practices wherever they occur.

Discussion

During discussions, all experts agreed that a shift in the landscape of care for AD is urgently needed and that the Global Atopic Dermatitis Quality of Care Initiative will have an important role in delivering this. The availability of the report as a free reference tool accessible by all will also help to raise wider awareness of AD, which panel members highlighted as a key priority. Prof Simpson pointed out that the amalgamated experiences from 32 centres across 17 different countries show that similar clinical challenges in AD are being faced around the world and that the five key strategies outlined in the report can be used successfully to overcome these.

The panel agreed that AD care is entering an exciting era with the availability of improved treatment options but that more needs to be done to optimise outcomes from this expanding therapeutic armoury. Prof Guttman explained that a common misconception amongst patients, fuelled by short-duration clinical trials, is that AD is not a chronic disease and that symptoms will resolve, and treatment can be stopped within a set timeframe (6–12 weeks). Another challenge is that patients with very severe AD can tolerate a high disease burden, so even a slight improvement in symptoms may be seen as treatment success. There is a need to educate patients on these critical issues, said Prof Guttman, to ensure that adherence is maintained over the long term and treatment outcomes improve. On the subject of patient education, experts agreed that this is particularly important at the outset of the patient journey, when it is vital to outline good practices and treatment expectations. Prof Deleuran suggested that it was worth investing more time in education upfront and adopting a holistic approach involving nurses, dietitians, and other members of the MDT to improve overall outcomes for patients. Enhanced collaboration with patient groups and patient organisations was also highlighted as a key focus area by the panel, who emphasised the importance of ensuring teenage and adult patients are not overlooked. “As dermatologists, it is essential

that we partner with patient organisations,” stressed Prof Guttman, “because, ultimately, to bring new drugs to patients we need to listen to the patients’ voices and understand the direction they want to go in.”

Considering comorbidities of AD, in particular the mental health impact, Prof Guttman explained that patients with depression can experience improvements in their depressive symptoms when they receive effective systemic AD therapies, especially if they present with severe AD that affects multiple aspects of their life. Therefore, it is important to understand that some of the comorbidities of AD are induced by the severity of the disease and once the condition is well controlled, these can be minimised or even resolved. Prof Simpson agreed that use of more aggressive therapy can often mitigate the impact of comorbidities on patients, in particular the mental health effects that can be directly attributed to the severity of skin disease.

All panel members acknowledged that primary care doctors currently have the biggest role in treating AD in the USA and Europe because of a lack of dermatologists. A key priority for

specialists is therefore to educate general practitioners so that they can better help patients with AD in the primary care system. Disease severity assessment, rather than diagnosis per se, represents one of the biggest challenges currently faced in AD management. It needs to be emphasised that, irrespective of time constraints, assessing the full body surface area is key, said Prof Guttman. This is the single most important factor that indicates the need to step-up treatment from topicals. Prof Simpson concurred, explaining that by making better therapeutic decisions for patients, QoL will be significantly improved and ultimately lead to a cost burden reduction for the healthcare system if patients are well controlled.

Drawing the symposium to an end, panel members issued a call to colleagues around the world to access and read the Global Atopic Dermatitis Quality of Care Initiative report. Even those who are considered experts in AD can learn something from this initiative, concluded Prof Guttman, who stated that there is always scope to evolve and improve our practices to help all AD patients globally benefit from the best care possible.

References

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