skin 'n' bones connection

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Dear Reader

It is interesting to ponder on the quote "*There are three kinds of lies: lies, damned lies, and statistics*", which is often reported to have been said by American novelist Mark Twain, who in turn attributes it to British Prime Minister Benjamin Disraeli, although there is little evidence in print that Disraeli said it, which is somewhat ironic.

Whether Twain or Disraeli said it originally is perhaps not important, but the sentiments are still of value.

You will find in this issue many uses of statistics, which, depending on whether you view life's cup as half full or half empty, will influence your opinion about the findings of any piece of research.

As with the old wives' proverb "the proof of the pudding is in the eating", which means that the real value of something can be judged only from practical experience or results and not from appearance or theory, so time will prove whether such statistical data are correct.

So, what does this mean for patients? Without context, many of those data provide a stark viewpoint, but adding the lived-experience of real people adds value and provides a richer view for those who need some form of affirmation that the research data makes sense.

You can help by providing your views and getting involved. Go to page 18 to see how you can contribute and provide the much-needed truth.

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COVER PHOTO:

Portrait of woman with colourful make-up and body art.

By Mike Orlov ©www.shutterstock.com

As a scientifically based charity, PAPAA is committed to supporting innovative research. Here we interview Dr Ashley Elliott, one of our grant recipients, to find out what brought him to his speciality.

What is your current position?

I am a clinical academic at Queen's University, Belfast Northern Ireland, and a final-year rheumatology registrar.

Why did you choose medicine as a career?

I was drawn to medicine because it was a vocation in which I could utilise science in a very practical way and (hopefully) make people's lives better.

Why rheumatology?

I wanted to be a rheumatologist because I loved the fact that the specialty required blending the traditional skills of medicine, like history-taking and examination, with modern scientific advances in immunology. My interest in psoriatic disease began quite early on when I realised that it has a lot of unanswered questions and needs to be treated differently to rheumatoid arthritis; I'd like to address these questions.

What is your latest research?

My latest research in psoriasis has involved studying enthesitis (inflammation at the point where tendons or ligaments attach to bone) with imaging and laboratory work to help answer some of the unmet needs in psoriatic disease.

Are we making progress in treating psoriasis?

Yes, most certainly. I think we are beginning to better understand how patients with psoriatic disease present and how they progress and, as such, tailor treatments accordingly. We now have a lot of good treatments for skin and joint disease, but it's about stratifying patients and treating those with more aggressive disease earlier. We are getting closer to diagnostic panels to help make better decisions for patients sooner.

Have expectations changed?

Yes, indeed. For example, in drug trials we are now in a position where the target for psoriasis is complete skin clearance. So, in essence, the threshold for a drug to be successful is complete resolution. On the question of whether we can treat skin disease and stop it coming back for all patients, this is a more distant target but, if we look at the advances in psoriasis over the last 20-years, is readily achievable.

How would you spend a research grant of £1m?

If I had one million pounds, I would set up a prospective study to assess a huge cohort of psoriasis patients, using genetic and protein markers, clinical assessment, and sophisticated imaging studies. I would then follow them for 10 years to see what happens. I would hope this would help us to better identify those with psoriasis who go on to develop joint disease or enthesitis, so that we can give patients the right treatment at the earliest possible stage.

To see what research PAPAA has funded and how, visit: www.papaa.org/research

PsA gender differences

Why is psoriatic arthritis worse in women than in men?

Although psoriatic arthritis (PsA) affects men and women in equal numbers, females with PsA tend to have a worse overall outlook than males. They have more severe disease activity, more debilitating pain, lower remission rates and greater loss of function. This article will briefly explore these differences and suggest some possible explanations.

The epidemiology

Estimates vary, but the overall prevalence of psoriasis in the general population is around 2-3%.[1] Given that approximately one third of patients with psoriasis go on to develop arthritis, the prevalence of PsA in the general population is probably around 1%.[2]

Symptom differences

The specific symptoms of PsA are broadly the same between males and females, but according to recent research,[3,4,5] women are more likely to experience:

- **severe pain**
- **greater loss of function**
- **higher levels of fatigue**
- **lower quality of life**
- **poorer response to treatment**
- **higher levels of disease activity**
- **lower remission rates**
- **polyarthritis - arthritis that affects five or more joints.**

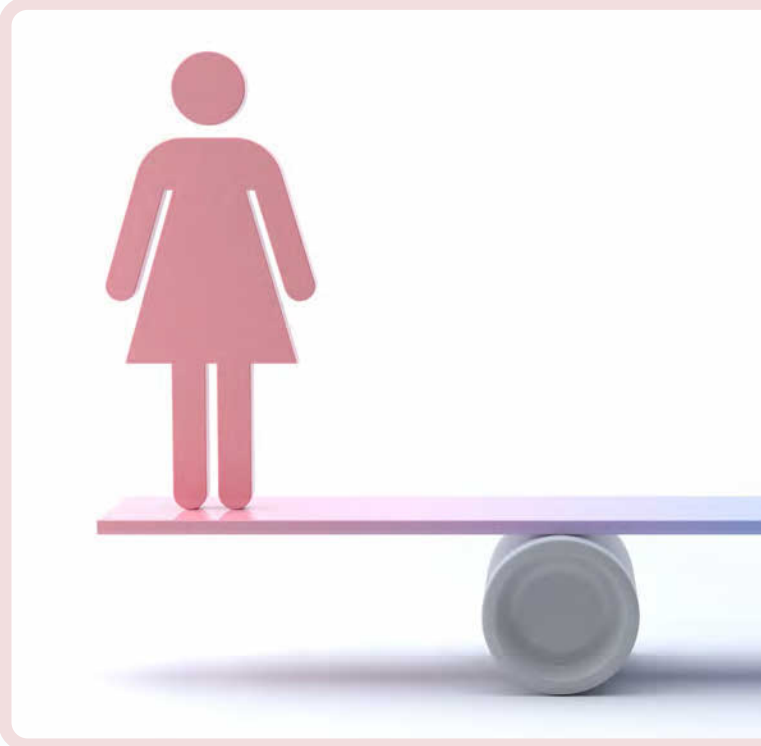
Moreover, in the 10 years after PsA diagnosis, women are more likely to develop psoriatic spondylitis – psoriatic arthritis affecting the spine and the joints in the pelvis. This may have a severe negative impact on general mobility and activities of daily living.[6]

Responses to treatment

Recent evidence suggests that a major part of the reason why females have poorer outcomes and lower remission rates is because they respond less well to treatment. There are three recently published studies which illustrate some of these differences.

The first, a 2018 study from the Danish Health Care Registry, investigated gender differences in disease manifestation, patient-reported outcomes, and treatment effectiveness among 1750 patients (935 women) with PsA, treated with their first TNFα inhibitor (TNFI). *[NB: TNF inhibitors – e.g., adalimumab and infliximab – are a type of biological medication which is often used in the treatment of psoriasis and psoriatic arthritis].*

Women enrolled in this study were older, had higher smoking rates and were more likely to have a history of depression or anxiety.



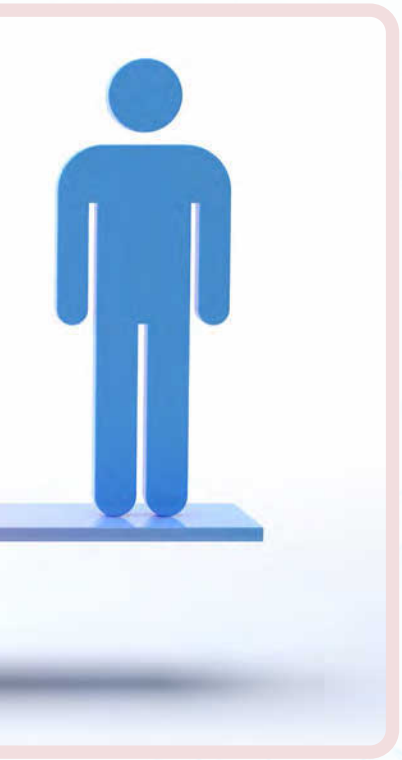
Overall results showed that three-month and six-month treatment response rates were significantly better among men than women. In addition, males had a lower level of disability after one year of treatment.[7]

The second is a 2022 Dutch study involving 273 men and 294 women with PsA.[5] At the time of enrolment, there were no significant differences in age, smoking habits, or ethnicity between the two groups. The prevalence of obesity was higher in women than in men (36% versus 28%) and fewer women than men were in paid employment. Moreover, women reported longer duration of symptoms prior to diagnosis of PsA.

Patients were first treated with methotrexate, though other drugs – including biologicals – were introduced as required. After one year of treatment, minimal disease activity rates were achieved by 58.1% of men, compared with only 35.7% of women. While women experienced some improvement, compared with their male counterparts they still had:

- **higher disease activity**
- **higher levels of pain**
- **lower functional capacity.**

The third is a 2022 study from researchers in Toronto, who used pooled data from two randomised trials that evaluated the efficacy of ixekizumab (Taltz) in adults with PsA.[8] Of the 679 study participants, the mean age was 51 years and 369 were women. *[NB: ixekizumab is a biologic medication that is used to treat psoriasis and psoriatic arthritis].* At the time of enrolment, women were older, had higher body mass index (BMI) and had worse baseline health scores than the men.



A number of measures were used to assess treatment outcomes. However, the main efficacy endpoint was measured as the proportion of patients achieving 20%, 50%, or 70% improvement from baseline as per the American College of Rheumatology criteria (ACR20/50/70).

In the group receiving ixekizumab every two weeks, the proportion of women achieving ACR70 at week 156 was 28.1% vs 41.2% among men. Trends were comparable in the group receiving ixekizumab every four weeks, with women significantly less likely to achieve ACR50 at week 156 than the men (38.3% vs 53.8%).

Importantly, men were significantly more likely to achieve complete remission of their disease. Among those receiving ixekizumab every two weeks, 17.3% of women vs 31.4% of men were in remission at week 156. For those taking the drug every four weeks, the figures were 16.8% and 28.4%.

It's worth noting that while figures for ACR20/50/70 are given here, scores across all outcome measures used showed women faring significantly worse than men.

What accounts for these differences?

Scientists do not understand the exact causes of the rather stark differences in outcomes between males and females when it comes to treatment for PsA, but it's clear that many complex factors are involved.[9]

One obvious point is that, in all the studies above, women tended to have poorer health at the time of enrolment; they were older, had lower levels of employment, were more often smokers and had higher rates of obesity. These factors may impact on how well they respond to treatment. Some of them can be adjusted for, but even when this is done, the differences in outcomes remain.

There is some evidence to show that women discontinue drug treatments earlier than men. If they are less compliant with regard to medication, then their treatment outcomes are likely to be worse. This raises questions as to why they seem less willing or able to tolerate medication than men.

Evidence also suggests that women tend to have greater levels of anxiety and depression than men, which may result in poorer self-reported health outcomes following treatment. One may speculate as to why this is the case.

Other factors also likely to contribute, including:

- **sex hormones – both pre- and post-menopausal**
- **genetic makeup of the individual**
- **environmental and climatic factors**
- **lifestyle factors – including diet and physical activity.**

Summary

- Although psoriatic arthritis (PsA) affects men and women in equal numbers, females with PsA tend to have a worse overall outlook than males.
- Women with PsA have more severe disease, more debilitating pain, lower quality of life and greater loss of function.
- On all outcome measures, including remission, women respond less well to treatment than men.
- Multiple factors may explain these sex differences and more research is needed to understand the mechanisms involved.

Conclusion

Gender-specific medicine is the study of how diseases differ between men and women in terms of symptoms, clinical signs, therapeutic approaches, and prognosis. Until quite recently, it has been a neglected dimension of medical practice, but that is now beginning to change. It is now increasingly recognised that while a given disease in a male and female may bear the same name, in terms of presentation, symptoms, response to treatment and prognosis, they may be very different. Psoriatic arthritis (PsA) is a very good example of such a condition. Understanding sex differences in PsA will pave the way for better outcomes in both sexes.

In the meantime, family doctors and others caring for women with PsA should be aware of the fact that women may have more pain and therefore experience a greater impact on activities of daily living. They should also recognise that women may be more likely to suffer with depression and anxiety, which may require intervention in its own right. And finally, they need to recognise that women may be less compliant in taking medication, possibly because of unwanted side effects. Only if these differences are attended to early can outcomes for women with PsA begin to improve.

Dr David Ashton MD PhD

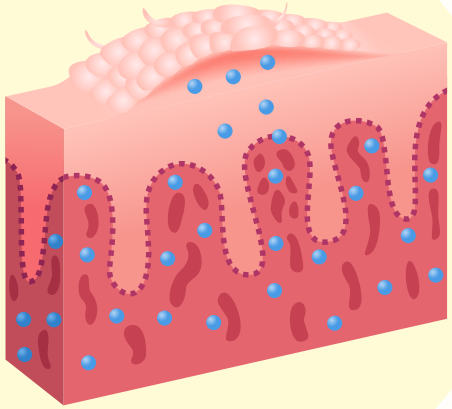
September 2022

Scientific References

1. Hagg D, Sundstrom A, Eriksson M, Schmitt-Egenolf M. Severity of Psoriasis Differs Between Men and Women: A Study of the Clinical Outcome Measure Psoriasis Area and Severity Index (PASI) in 5438 Swedish Register Patients. Am J Clin Dermatol 2017; 18: 583–59
2. Gladman DD, Antoni C, Mease P et al. Psoriatic arthritis: epidemiology, clinical features, course, and outcome. Ann Rheum Dis 2005; 64 (Suppl II): ii14–ii17.
3. Duruöz MT, Gezer HH, Nas K et al. Gender-related differences in disease activity and clinical features in patients with peripheral psoriatic arthritis: A multi-centre study. Joint Bone Spine 2021; 88: 105177
4. Grivas A, Kapniari I, Tzannis K et al. Gender differences in psoriatic arthritis disease characteristics: evidence for worse disease in women. Annals of the Rheumatic Diseases 2020: (79 (Suppl 1)):1692-1693
5. Passia E, Vis M, Coates LC et al. Sex-specific differences and how to handle them in early psoriatic arthritis. Arthritis Research & Therapy 2022; Volume 24, Article number: 22
6. Nas K, Kilic E, Tekeoğlu I et al. The effect of gender on disease activity and clinical characteristics in patients with axial psoriatic arthritis. Modern Rheumatology 2021; 31: 869-874
7. Højgaard P, Ballegaard C, Cordtz R et al. Gender differences in biologic treatment outcomes — a study of 1750 patients with psoriatic arthritis using Danish Health Care Registers. Rheumatology 2018; 57:1651–1660
8. Eder L, Tony HP, Odhav S, et al. Responses to ixekizumab in male and female patients with psoriatic arthritis: results from two randomized, phase 3 clinical trials. Rheumatol Ther. Published online April 9, 2022
9. Bragazzi NL, Bridgewoods, C, Watad A et al. Sex-Based Medicine Meets Psoriatic Arthritis: Lessons Learned and to Learn. Front.Immunol.2022; 13: 849560

Generalised pustular psoriasis (GPP) is a rare, heterogenous (of different origin) and potentially life-threatening neutrophilic (high white blood cell count) skin disease, which is clinically distinct from plaque psoriasis. GPP is caused by neutrophils (a type of white blood cell) accumulating in the skin, resulting in painful, sterile pustules all over the body.

The clinical course varies, with some people having a relapsing disease with recurrent flares, and others having a persistent disease with intermittent flares. While the severity of GPP flares can vary, if left untreated they can be life-threatening due to complications such as sepsis and multisystem organ failure. This chronic, systemic disease has a substantial quality of life impact for patients and increased healthcare burden. GPP has a varied prevalence across different geographical regions and more women are affected than men.



A new therapy has recently been approved for GPP by the U.S. Food and Drug Administration (FDA), called spesolimab and manufactured by Boehringer Ingelheim under the brand name Spevigo. The treatment is also subject to a UK licence application with the Medicines and Healthcare products Regulatory Agency (MHRA) and, at some stage, will be assessed by both the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC).

As the first approved treatment option for generalised pustular psoriasis (GPP) flares in adults, spesolimab is a novel, selective antibody that blocks the activation of the interleukin-36 receptor (IL-36R), a key part of a signalling pathway within the immune system shown to be involved in the cause of GPP.

"GPP flares can greatly impact a patient's life and lead to serious, life-threatening complications," said Mark Lebwohl, M.D., lead investigator and publication author, and dean for clinical therapeutics at Icahn School of Medicine at Mount Sinai, Kimberly and Eric J. Waldman Department of Dermatology, New York. "The approval of Spevigo is a turning point for dermatologists and clinicians. We now have an FDA-approved treatment that may help make a difference for our patients who, until now, have not had any approved options to help manage GPP flares."

It is estimated that one out of every 10,000 people has GPP. Given that it is so rare, recognising the signs and symptoms can be challenging and consequently lead to delays in diagnosis.

In the 12-week pivotal Effisayil 1 clinical trial, people experiencing a GPP flare (N=53) were treated with spesolimab or placebo. After one week, 54% of those treated with spesolimab showed no visible pustules compared to 6% taking the placebo.

With all new treatments, safety is a key part of the research process. Spesolimab is no exception. In Effisayil 1, the most common adverse reactions (around 5%) in people that received spesolimab were asthenia (weakness; lack of energy and strength), fatigue, nausea and vomiting, headache, pruritus and prurigo, infusion site bruising, and urinary tract infection.

"GPP can have an enormous impact on patients' physical and emotional wellbeing. With the FDA approval of this new treatment, people living with GPP now have hope in knowing that there is an option to help treat their flares," said Thomas Seck, M.D., senior vice president, medicine and regulatory affairs, Boehringer Ingelheim. "Spesolimab represents Boehringer Ingelheim's commitment to delivering meaningful change for patients living with serious diseases with limited treatment options."

PAPAA will be submitting evidence to appraisals for this treatment, so if you have any experience of living with GPP, please send us your personal perspective, which we will add to our lived-experience evidence submission. See page 2 for how to contact us.

Source:
Press release Boehringer Ingelheim

The rise of health ignorance

When it comes to looking after our health, statistics reveal that many of us are ignoring the warning signs, don't know what to look out for, or aren't checking for them in the first place. For example, a YouGov survey found that in 2021 at least one in five women had not checked themselves for signs of breast cancer in the past year.

There is truth to the saying prevention is the best medicine. Catching serious illnesses early is often one of the best ways to get treatment for and/or manage the illness. However, it's clear that there are several barriers that stop people from seeking medical advice and treatment. This can lead to potentially serious consequences for health, both physical and mental, including delayed diagnosis and worse outcomes.

So, what are the reasons why people ignore their health?

Age: With age comes varying attitudes towards illnesses that can mean individuals do not seek out treatment. One study from supplement supplier Healthspan found that 24% of adults had ignored symptoms because they felt they were too young to worry about potentially serious illnesses.

For older generations, there is also a tendency to take a 'stiff upper lip' attitude towards health, which often means not seeking help. This is particularly true when it comes to mental health. Research from 2020 found that the majority of people over the age of 65 who had experienced depression and anxiety did not seek help because they saw it as something they should just 'get on with'.

Socioeconomic status: Much research has been done into health inequalities in poorer and wealthier areas in the UK, which can often be seen through mortality rates and the types of health conditions experienced.

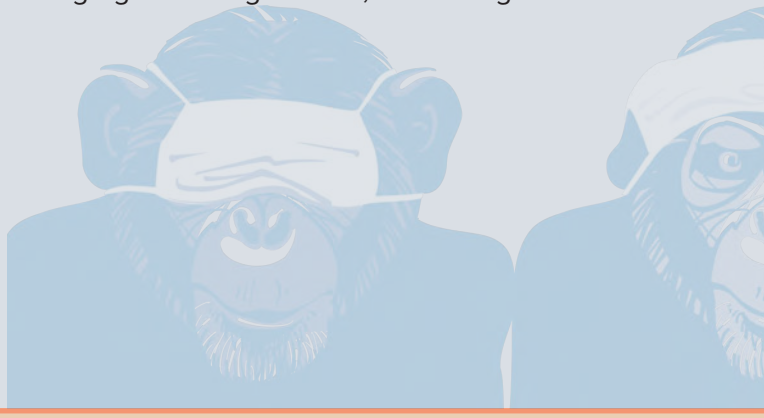
An important aspect is how it can also impact an individual's likelihood to go to their doctor with health concerns. Worries about taking time off for appointments or being unable to work throughout treatment can contribute to this. Recent research from the Nationwide Building Society found that 43% of people would put off going to the doctors because of financial concerns, even if they were worried about a serious illness.

Feelings of shame and embarrassment: Other common reasons for avoiding or delaying treatment are feelings of shame, embarrassment, or not wanting to be a burden on healthcare providers.

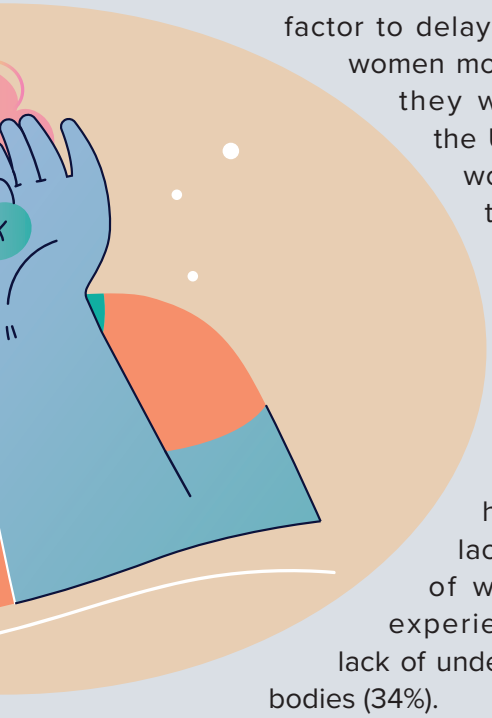
One recent survey, commissioned by Pancreatic Cancer Action, found that 27% of people were too embarrassed about their symptoms to seek out treatment. The same survey also found that 37% of people were worried about wasting a doctor's time with their concerns. Research shows that as many as three in five people avoid accessing healthcare because they don't want to bother the NHS.

Fear of diagnosis: For some individuals, it's the fear of diagnosis that causes them to ignore their health and thus avoid potentially bad news. One study revealed nearly 6 in 10 people's biggest healthcare fear is getting a cancer diagnosis, which could lead to some ignoring symptoms or just not checking for them.

The fear of diagnosis can lead to denial over health concerns, but this can have terrible consequences. In the case of most cancers, the difference between detecting it early or at a later stage can be life changing. For lung cancer, according to Cancer



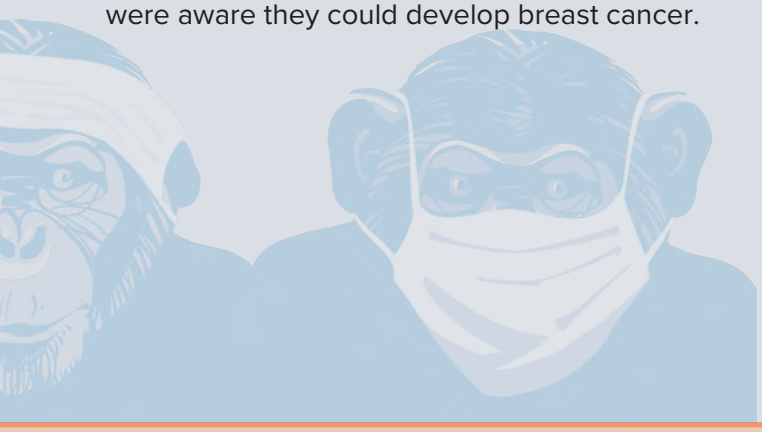
Research UK, 9 in 10 people will survive for at least one year when the cancer is detected at its earliest stage. But if it is not found until an advanced stage, this number falls to 2 in 10.



Gender: Gender can also be a contributing factor to delaying treatment, with women more likely to feel like they will be ignored. In the UK in 2022, 44% of women reported that they felt like their health concerns weren't being taken seriously by medical professionals. The next two main barriers to accessing healthcare were a lack of understanding of women's lives and experiences (39%) and a lack of understanding of female bodies (34%).

Another survey, conducted by the Department of Health and Social Care (DHSC) in 2021, found that 84% of women had experienced feelings of 'not being listened to' by healthcare professionals. This is a problem that urgently needs addressing, as it may cause some women to downplay their own concerns when it comes to their health.

Common assumptions can also lead to disparities for certain illnesses more commonly associated with men or women. The same survey from YouGov mentioned earlier found that nearly 70% of men had never checked themselves for signs of breast cancer at all. This is despite 80% reporting that they were aware they could develop breast cancer.



For trans and gender-diverse people, the picture can be even more worrying. Current research reveals discrimination as a reason individuals ignore their health. One study from TransActual in 2021 found that 57% of transgender people had delayed seeing or had chosen not to see their GP because of fears of transphobia or being refused treatment.

Racial barriers: A recent review led by the University of Manchester into ethnic healthcare inequalities in the UK discovered that people from ethnic minority backgrounds were also delaying treatment due to fears of experiencing racism.

Cultural stigmas can also be a contributing factor to avoiding seeking help. For example, diagnosing dementia early is hugely important for the patient to be able to plan for their future. Yet the stigma surrounding mental health is often cited as one of the main reasons that Muslim communities, for example, tend not to seek help for dementia until it reaches a crisis point.

The lack of culturally sensitive services available can be another reason for patients from ethnic backgrounds to feel locked out of healthcare.

What does this mean?

Whatever worries or fears you may be experiencing, they shouldn't come before your health. Much work is still needed to improve health services and break down the barriers that are stopping people from accessing healthcare, but help is always available. Whether you use the National Health Service or private health insurance, don't bury your head in the sand when it comes to your health.

It can be unpleasant or even scary, but the importance of seeking help if you have concerns about your health cannot be overstated. Doing so can dramatically increase survival rates or improve outcomes.

Source:

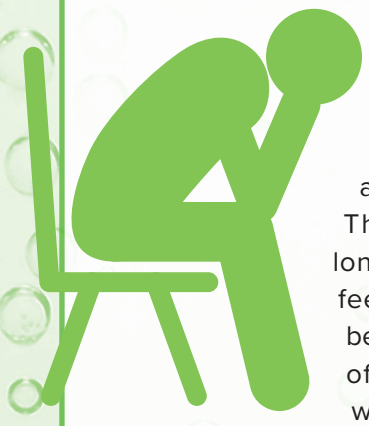
Media release

Media, stigma and the arts

The world has become increasingly digital, and social media platforms such as Instagram can blur the line between reality and fake. Recently, there has been a public suggestion to regulate influencers and content creators who use software such as Photoshop or alternative editing programmes to distort images on social media. This suggestion stems from unrealistic yet convincing images of bodies and faces causing a rise in self-esteem and mental health issues surrounding body image. Edited images present an unrealistic and unobtainable body shape, and cosmetic alterations encourage unrealistic beauty standards and reinforce existing stigmas. Individuals diagnosed with genetic conditions become bombarded with images of 'perfect' bodies and skin, increasing anxiety and low self-esteem. The World Health Organisation (WHO) suggests that "society, not psoriasis, causes the exclusion and discrimination faced by people with this disease", and this needs to be communicated to the general public for all medical conditions to be accepted and recognised.[1]

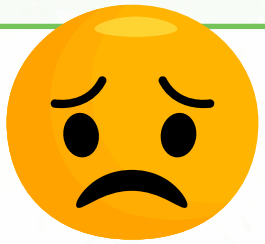
This article explores how stigma related to skin conditions and mental health-related issues can change through positive representation in the media and arts.

One method to destigmatise skin conditions is through focused media and visual campaigns that educate society on the cause, cures and treatments for conditions, to encourage acceptance. A report published by the WHO in 2016 "recognises the urgent need to pursue multilateral efforts to raise awareness regarding the disease of psoriasis and to fight stigmatisation" that many individuals are exposed to in their everyday life.[1] The stigma and discrimination many individuals suffer are often in the form of social and work-related activities, such as swimming and other activities that involve public visibility, which exacerbate anxiety and low self-esteem. These environments cause loneliness and anxiety around feeling excluded and isolated because of other people's lack of understanding, especially when they are uneducated on



conditions like psoriasis. To help destigmatise and educate society on illnesses, governments should use varied methods, including social media, to reach a diverse audience.

A display included in the Wellcome Collection's Being Human permanent gallery in London explores how skin conditions are used as inspiration to create expressive artwork. The artwork installation entitled *Medical Heirloom – Acne; Osteoporosis; Cancer; Psoriasis; Ichthyosis (2007-11)*, by the artist Tamsin van Essen, features slip cast jars where the "surfaces and shapes of these vases each suggested a different health condition that can be inherited", such as acne, brittle bones from osteoporosis, rapid cell division causing cancer and flaky skin from psoriasis.[2] Tamsin van Essen is a ceramic artist who explores "notions of beauty and impermanence through examining scientific, medical and social historic themes".[3] This artist explores these conditions through the metaphor of inheriting a family vase in the same way we can inherit genetic health conditions. In some ways, this piece suggests that while we may not want the family vase, we inherit it without choice and learn to live with this object in our everyday lives. It also explores the link between visual art and dermatology, recognising patterns in skin conditions can help early diagnosis and help individuals destigmatise these conditions through visual learning. Furthermore, forms of artistic expression could help an individual come to terms with and understand their condition more deeply by creating unique and beautiful artwork.



A study by the University of London investigated the impact of social media on pressuring women to change their appearance and how they perceive themselves. The study involved 175 18-30-year-old women and non-binary members of the UK general public. The research discovered that 75% of those involved in the survey have spent ten minutes creating and editing a photo before posting it on social media, with the most common answers being 'to even out skin tone', 'to brighten skin' and 'to make teeth whiter'.[4] The results of this study emphasise the growing pressure many people in society experience from the continual unrealistic environment created by social media and how this can increase feelings of depression, anxiety and low self-esteem. Moreover, many participants in the study highlighted the lack of representation of young people with disabilities, with seven out of ten disabled participants feeling that their "body and appearance will never be good enough". Over 50% expressed feelings of depression, lack of self-confidence and feeling "invisible" and "hidden from view" regarding edited images in the media. Participants suggested that "there's not much correct representation of people with mental health problems" and personal experiences of daily activities and healthcare that have media focus are "often different to the media's representation". One concluding point emphasised the need for "bolder, more creative and more imaginable ways forward" than taking personal responsibility for the media we consume and deconstructing damaging representations in media. Therefore, if media is constantly present in our daily activities, then we need to create a safe, representative and less judgemental space on social media. This could include enforcing media regulations that ensure the owner clearly states an image has been edited, and target cosmetic companies that use socially constructed standards of skin, body and lifestyle 'imperfections' as a marketing tool.

In conclusion, the use of arts to help understand and educate society on health and skin conditions could be beneficial through normalising the visual symptoms of these conditions. This visual normalisation could help individuals with skin conditions feel accepted within social settings through increased visibility of the physical signs of these conditions. Self-expression and visibility of unedited images and artistic thought create education opportunities and heightened awareness of realistic skin and body images.

Author:

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References:

1. World Health Organisation (2016). Global Report on Psoriasis. World Health Organisation, pp 6,30.
2. Medical Heirlooms (Undated). Wellcome Collection.
3. Tamsin van Essen (2022). About. Tamsin van Essen. Available from www.tamsinvanessen.com/about [Accessed 2 November 2022].
4. Rosalind Gill (2021). Changing the Perfect Picture: Smartphones, Social Media and Appearance Pressures. University of London. Available from www.city.ac.uk/__data/assets/pdf_file/0005/597209/Parliament-Report-web.pdf [Accessed 2 November 2022].

NHS waiting times

A study of more than 1,000 health and social care workers, conducted by Florence, the tech platform providing health & social care workers access to available shifts, three quarters (76%) stated quality of care is already being 'severely' impacted as high vacancy rates sweep across the industry.

With A&E wait times at their highest levels in over a decade and more than 6.5 million people on the waiting list for hospital treatment, there are clear concerns about the sector's capacity to cope with the demand for treatment.

However, research suggests that things are set to get a lot worse, with nearly 9 in 10 (85%) health and social care workers expecting wait times to increase over the rest of 2022. Shockingly, many health workers expect wait times to double this year, while a further one in five (19%) expect times to more than double the current records.

Healthcare workers also cited that not having enough staff is causing the most pressure in their role (50%), followed by low pay (39%) and high workload (35%).

A reduction in wait time is important to mitigate quality of care being further impacted. The study shows that to reduce wait times a third (30%) believe the government needs to put an increased focus on recruitment, more than a quarter (27%) are calling for the whole system to be overhauled, and more than one in five (22%) feel the government needs to do more to encourage people into the sector early on (e.g. at school or college).

Fiona Millington, chief nurse at Florence, has long argued that vacancy rates are a big problem within the sector: "The biggest challenge for the industry at the moment is, without a doubt, staffing. There are more nurses leaving the industry than joining, at a time when the demand for nurses is increasing, the number of nursing vacancies still sits above 105,000 and remains much higher than the overall unemployment rate.

"As unemployment falls, social care vacancies rise, with pay being a huge factor. A couple of years ago we had in excess of 120,000 social care vacancies, this number has been growing since and now sits at a much higher figure. The NHS is plugging vacancies with resources from other countries and areas but it has become just a constant cycle of crisis management, without developing long-term solutions to the problem."

Dr Charles Armitage, former NHS doctor and CEO and founder of Florence, added: "If you've got fewer people there on-shift to look after people, the quality of care decreases because the people that are there are overstretched. They're trying to do too many things, they make mistakes, they're not able to spend as much time with people and provide that really important patient-centred care."

Source:

Florence Technology

The owner of a London medicines wholesale business was recently sentenced at Southwark Crown Court to 20 weeks' imprisonment, suspended for 12 months, and community service after pleading guilty on 20 June 2022 to importing and distributing medicines worth over £2.9m sale value without holding the correct licences.

Between July 2017 and June 2018, Amr Mosa (36), director of Wimpole Pharmacie Ltd in London's West End, imported medicines such as Herceptin, Avastin and Enbrel (used for psoriasis and psoriatic arthritis) from Egypt to the UK and then distributed them from the UK to a company based in Germany.

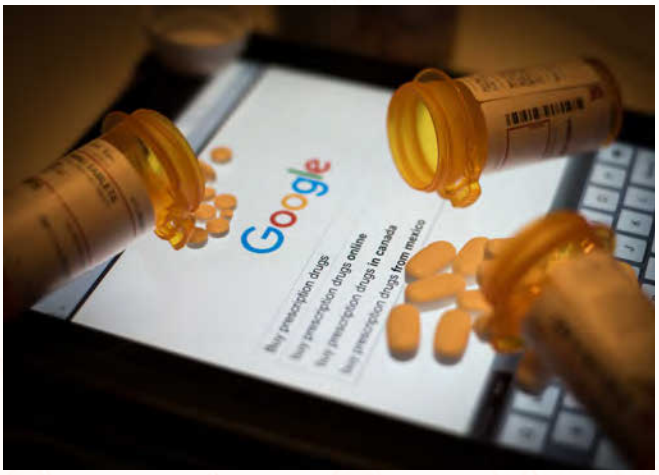
These medicines are prescription-only medicines to treat conditions as diverse as cancers and Crohn's disease, and require storing at low temperatures. These are known as cold chain products.

Although Mosa's company was granted a licence to distribute medicines within the European Economic Area (EEA), the licence did not authorise the distribution of cold chain products, nor did it allow these to be imported into the UK from outside of the EEA.

In August 2018, the European Medicine's Agency's Rapid Alert Notification system flagged that a batch of medicines supplied to Germany by Wimpole Pharmacie Ltd had originally been stolen from Italian hospitals.

In response, the MHRA investigated the business and proved that the drugs were imported and exported without the correct licences, allowing unauthorised medicines to enter the European market.

The defendant was sentenced to a total of 20 weeks' imprisonment, suspended for 12 months, as well as 100 hours of unpaid work.



Andy Morling, deputy director of criminal enforcement at the MHRA, said:

"It's a serious criminal offence to import and distribute medicines without the right licences. We work closely with regulatory and law enforcement partners to identify and bring to justice those who fall short of legal compliance.

"It's important that all suppliers understand and follow the regulatory requirements around importing and distributing medicines and medical devices. If not, they could fail to meet our safety standards, endangering patient health.

"While there is no evidence that these medicines posed a risk to patients, they had been stolen from hospitals in Italy before being imported from Egypt. This case illustrates that failing to comply with the regulations and conditions of the relevant licences can have serious consequences.

"We will investigate any report of suspected illegal activity involving medicines and medical devices so that patients can be confident their medication and medical devices are acceptably safe."

Source:

Medicines and Healthcare products Regulatory Agency

Over the past two decades there has been a revolution in our understanding of psoriasis and psoriatic arthritis, in terms of basic immunology, disease mechanisms and therapeutics. This section is taken from our new online newsletter, which is designed to provide a summary of recently published research. The aim is to produce two issues a year, April and October. To access and download all issues, go to www.papaa.org/news/pso-pscience

Contents of issue 2:

The Global Psoriasis Atlas (GPA)

This excellent resource on psoriasis was first published in 2019 and provides detailed information about the worldwide epidemiology of psoriasis. The website contains data on the number of psoriasis cases in adults and children in every country of the world, as well as personal accounts of people with psoriasis worldwide.

It shows that:

- Western Europe has the highest prevalence of disease (1.52%)
- East Asia the lowest (0.14%)
- Norway has the highest rate in Western Europe (2.36%)
- Switzerland the lowest (0.11%)
- The UK has a prevalence of around 2%.

Comment

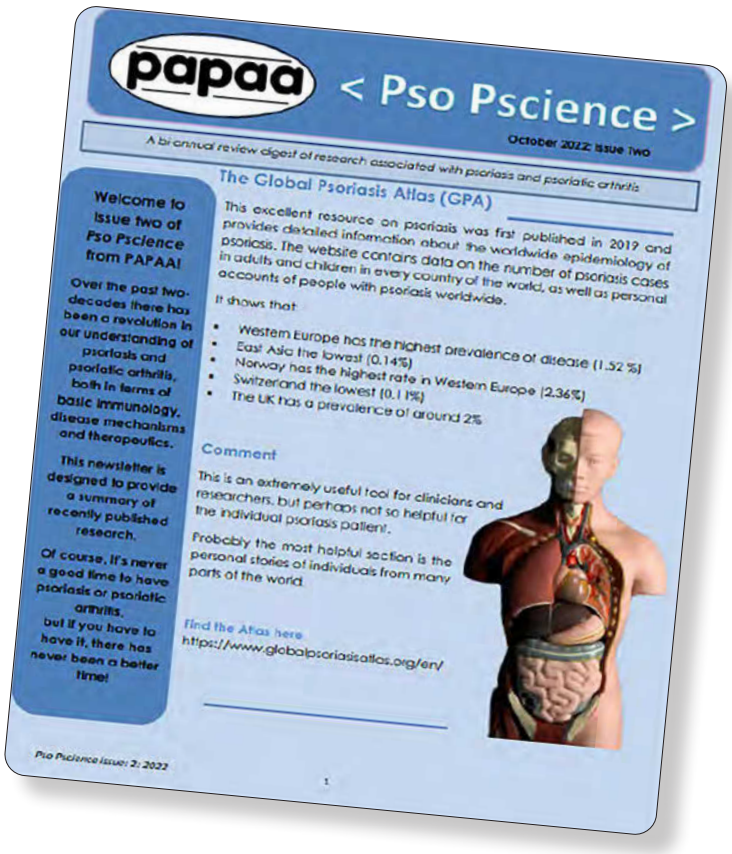
This is an extremely useful tool for clinicians and researchers, but perhaps not so helpful for the individual psoriasis patient. Probably the most helpful section is the personal stories of individuals from many parts of the world.

Find the Atlas here
www.globalpsoriasisatlas.org/en

Gamechanger in psoriasis treatment

A novel drug – bimekizumab - almost entirely cleared moderate to severe psoriasis in over 60% of the patients who took part in two clinical trials carried out by the University of Manchester and Salford Royal NHS Foundation Trust.

The new drug is an addition to the already large group of biologics – drugs which target specific parts of the inflammatory pathways which lead to psoriasis.


papaa < Pso Pscience >

October 2022: Issue Two

A bi annual review digest of research associated with psoriasis and psoriatic arthritis

Welcome to issue two of Pso Pscience from PAPAA!

Over the past two decades there has been a revolution in our understanding of psoriasis and psoriatic arthritis, both in terms of basic immunology, disease mechanisms and therapeutics.

This newsletter is designed to provide a summary of recently published research.

Of course, it's never a good time to have psoriasis or psoriatic arthritis, but if you have to have it, there has never been a better time!

The Global Psoriasis Atlas (GPA)

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Pso Pscience Issue: 2: 2022

1

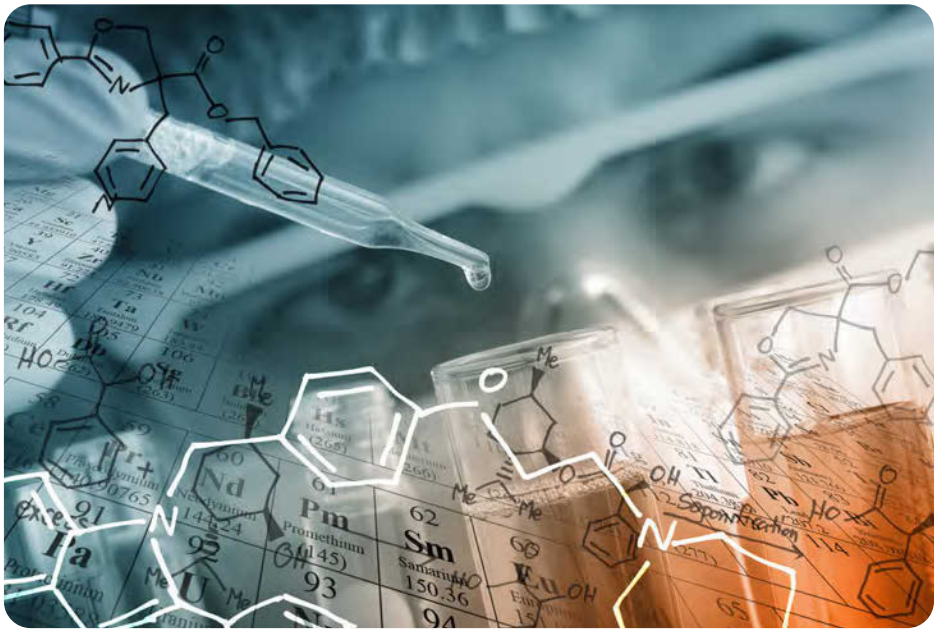
Bimekizumab is given by subcutaneous injection and works by blocking the action of two interleukins – specifically IL 17A and IL 17F – both of which are involved in the inflammatory response.

The clinical trials compared bimekizumab with two other existing biologics: adalimumab and secukinumab. Researchers assessed the efficacy of the treatments using the Psoriasis Area Severity Index (PASI) with PASI 100 indicating clear skin.

At week 16 in the first trial, 230 patients (61.7%) on bimekizumab reached complete skin clearance (PASI 100), whereas only 181 (48.9%) of those taking secukinumab achieved the same result. At week 16 in the second trial, 275 (86.2%) of the patients

on bimekizumab achieved a PASI 90, whereas only 75 of the patients on adalimumab (47.2%) had the same result.

Side effects were rare, though oral thrush - usually an easily treatable mouth infection - occurred in some patients.



Comment

Bimekizumab (who thinks these names up?!) showed significantly higher rates of skin clearance compared with secukinumab and adalimumab, setting a new standard in psoriasis treatment. Bimekizumab is currently available in the UK and offers an attractive treatment option for patients with moderate-severe psoriasis.

References:

Warren RB, Blauvelt A, Bagel J et al. Bimekizumab versus adalimumab in plaque psoriasis. N Engl J Med: 2021; 385:130-141.

Reich K, Warren RB, Lebwohl M et al. Bimekizumab versus secukinumab in plaque psoriasis. N Engl J Med: 2021; 385:142-152.

Does drug treatment influence the development of psoriatic arthritis?

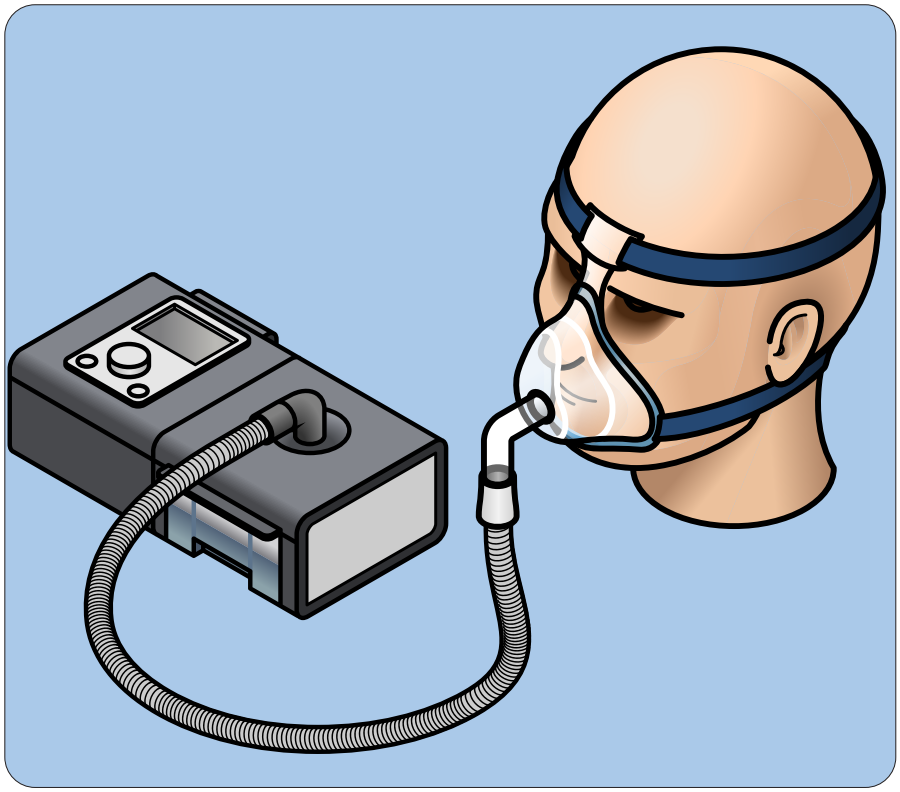
In most cases, diagnosis of plaque psoriasis may precede that of psoriatic arthritis (PsA) by an average of 5-10 years. In only a minority of cases does PsA precede the skin disease or occur simultaneously. The question of whether different treatments may influence the development of PsA is clearly of great importance, and two recently published studies have helped to provide an answer. In the first (Acosta et al), researchers compared the incidence of psoriatic arthritis (PsA) in patients with psoriasis according to three different treatments: (1) topicals – i.e., topical applications/phototherapy/no treatment; (2) conventional disease-modifying drugs (cDMDs) such as methotrexate and cyclosporine; and (3) biologicals (bDMDs) such as adalimumab and secukinumab.

A total of 1719 patients with psoriasis were included, of which 1387 (81%) were in the topicals, 229 (13%) in cDMDs, and 103 (6%) in the bDMDs group.

Results showed that the risk of developing PsA in patients with psoriasis treated with bDMDs was significantly lower compared with topicals, but not compared with cDMDs

Thus, treatment with biological drugs was associated with a lower risk of developing psoriatic arthritis when compared with topical treatments, though not with conventional disease-modifying drugs.

In the second study (Gisondi et al), investigators compared the risk of PsA development in patients treated with biological disease-modifying drugs (bDMDs) versus those treated with narrow-band, ultraviolet light B (nb-UVB) phototherapy. Once again, a lower risk of developing PsA was found in those treated with biologic drugs, compared with those treated with nb-UVB phototherapy.



Comment

This may look a bit of a dreary study, but it's actually very important. Given that the use of biologic agents is becoming more common, it is reassuring to know that their use may actually reduce the risk of developing PsA in patients with moderate-to-severe, chronic plaque psoriasis. This fact should be taken into account when considering the risks and benefits of various treatment options.

References:

Acosta Felquer ML, LoGiudice L, Galimberti ML, et al. Treating the skin with biologics in patients with psoriasis decreases the incidence of psoriatic arthritis. Ann Rheum Dis 2022; 81: 74-79

Gisondi P, et al. Biological disease-modifying antirheumatic drugs may mitigate the risk of psoriatic arthritis in patients with chronic plaque psoriasis. Ann Rheum Dis 2022; 81:68–73.

Obstructive sleep apnoea and psoriasis

This study examined the relationship between two commonly associated conditions, obstructive sleep apnoea (OSA) and psoriasis, in a huge population of more than 5.5 million subjects.

Psoriasis is an autoimmune disease, characterised by systemic inflammation. Various comorbidities have been linked to it, including obesity, cardiovascular disease, and type 2 diabetes.

Obstructive sleep apnoea (OSA) is a chronic disorder of intermittent upper airway collapse during sleep, resulting in reduced oxygen supply. Typical symptoms include loud snoring, recurrent awakening, and excessive daytime sleepiness. Moderate to severe OSA is a common condition and occurs in 10-17% of middle-aged men and 3-9% of middle-aged women. The main risk factors for OSA include obesity, ageing, male gender, and heavy alcohol consumption. OSA is important because it is associated with an increased risk of hypertension, cardiovascular disease, and various metabolic disorders, especially type 2 diabetes.

The generally accepted view is that OSA is primarily due to obesity, which is an inflammatory condition. This inflammatory response then increases the risk of psoriasis, which is known to be more common among obese subjects. Thus, obesity is seen as a common origin for both conditions.

The findings of this study challenge that assumption.

Investigators found a bi-directional relationship between psoriasis and OSA. In other words, psoriasis may increase the risk for sleep apnoea

and sleep apnoea may increase psoriasis risk. Importantly, the association between OSA and psoriasis was independent of body weight. This suggests that underlying inflammation is a common pathway for both psoriasis and OSA.

Comment

The fact that inflammation is fundamental to both OSA and psoriasis does not diminish the importance of achieving and maintaining a healthy weight. Weight loss not only reduces inflammation, but by reducing fatty deposits in the neck and tongue also reduces the mechanical dysfunction of the upper airways in OSA.

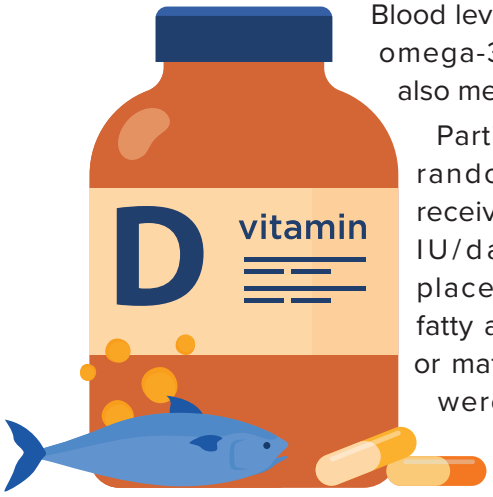
Reference

Tzong-Yun Ger; Yun-Fu; Ching-Chi Chi. Bidirectional association between psoriasis and obstructive sleep apnoea: A systematic review and meta-analysis. Nature Scientific Reports; 2020, Volume 10, article number: 5931

Fish oils and vitamin D

Both vitamin D and omega-3 fatty acids derived from seafood are known to have a beneficial effect on inflammation and immunity. However, until now, no scientific trials have been carried out to establish whether taking these supplements can lower the risk of psoriasis and other autoimmune problems, such as rheumatoid arthritis. This study did just that.

Some 26,000 US adults (average age 67 years) provided information regarding age, ethnicity, region of residence, income, education, lifestyle, weight, medical history, diet and supplement use. Blood levels of vitamin D and omega-3 fatty acids were also measured.



Participants were then randomly allocated to receive vitamin D (2,000 IU/day) or matched placebo, and omega-3 fatty acids (1,000mg/day) or matched placebo, and were asked to report any diagnosed autoimmune disease – including psoriasis and rheumatoid arthritis - over an average five-year period.

Over the full duration of the trial, vitamin D and omega-3 supplements reduced the incidence of autoimmune disease by 22% and 18% respectively. There was, however, a stronger effect the longer supplements were taken. When the last three years of the trial were considered, vitamin D and omega-3 supplements together decreased autoimmune disease by 30%.

Comment

This was a large and well-conducted study in a diverse, although older population. We don't know whether these findings would apply to younger individuals or what the impact of other doses and formulations of supplements might be. Moreover, the impact on psoriasis specifically is not known. Still, this is an important milestone, because this is the first direct evidence that long-term, daily supplementation with vitamin D and omega-3 fatty acids significantly reduces the risk of autoimmune disease.

If you have psoriasis, it might be well worth discussing supplements with your GP.

Reference

Hahn, J., et al. (2022) Vitamin D and marine omega-3 fatty acid supplementation and incident autoimmune disease: VITAL randomized controlled trial. The BMJ. doi.org/10.1136/bmj-2021-066452.

Get involved

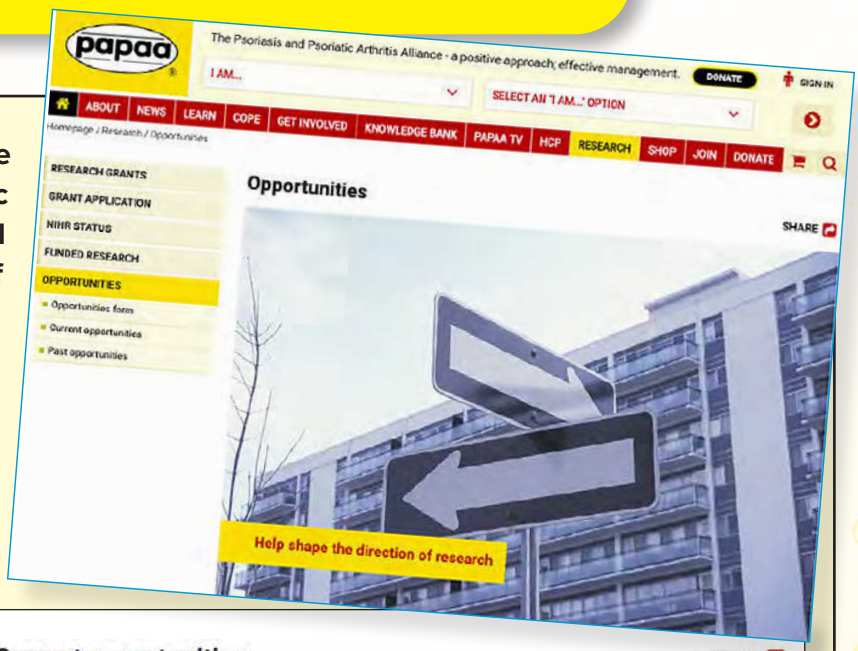
As a charity representing people affected by psoriasis and psoriatic arthritis, PAPAA is continually asked to provide input into many areas of activity, including:

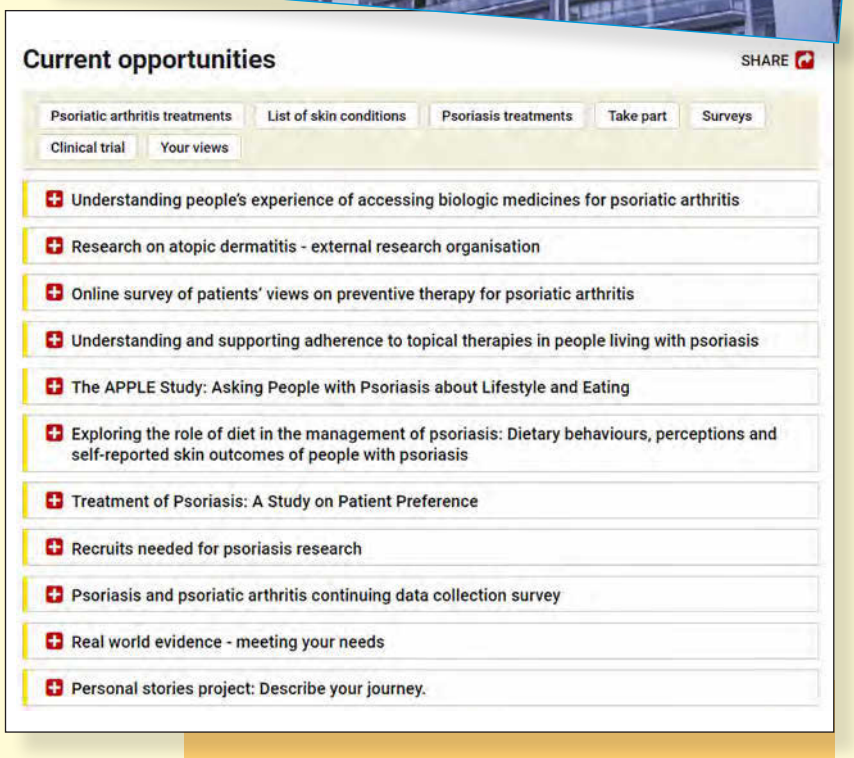
- **research**
- **studies**
- **regulatory input**
- **treatment appraisals focus groups**
- **surveys**
- **media activity**
- **patient perspective input**
- **real-world evidence development**
- **lay reviews.**

To help us gather the broad views of those we represent, we offer lots of ways for you to get involved.

Our ongoing PAPAA survey is the main source of data for monitoring the changing needs of people. We also gather personal stories, anecdotal data and conduct other surveys as part of our endeavour to bring real, lived experiences of what it's like to live with psoriasis and psoriatic arthritis to the people who need to know.

Tell us what you think and find out how you can help others learn about the condition by looking at our current research opportunities: www.papaa.org/research/opportunities





Calling researchers and health-care professionals

If you are looking to gather views, opinions, feedback or recruit for related research studies, fill out our opportunity form. We'll add all legitimate and ethical requests to the current opportunities page.

PAPAA provides materials that can be trusted. They are evidence-based and contain no bias or agendas beyond raising awareness and supporting improved understanding and outcomes.

We aim to produce accurate information that is based on a wide-ranging set of recognised criteria. This allows you, the reader, to begin to understand the many characteristics and implications of having psoriasis and or psoriatic arthritis.

In some instances, the information may appear complex, but we aim to increase your knowledge through education and by providing a gateway into the difficult language that often surrounds medical conditions and treatments.

- We use a consistent documented approach to produce material.
- We only use evidence from reliable and credible sources.
- We record sources of evidence and review regularly.
- We endeavour to meet the needs of those we support, using our ongoing user lived-experience surveys and submissions.
- We involve and engage with patients and public in the development of our information.
- We write to meet the health and digital literacy, language and accessibility needs of our target audience.
- We try to make information clear, easy to access and navigate.
- We provide a clear process for users to give feedback.
- We disseminate and promote to maximise access to all those that need support.
- We measure impact and adjust our services based on user need and changing societal values.

This is a pledge of our desire to see a better and greater level of understanding of psoriasis and psoriatic arthritis among all those who have, care for or support people affected by these and associated conditions.

Whether to include material that is solicited or unsolicited is the decision of the editorial team, who reserve the right not to enter into discussion about such decisions.

Read the PAPAA Pledge:
www.papaa.org/pledge

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Marketplace

Promotional material

If you are thinking about supporting PAPAA or raising awareness on behalf of PAPAA about psoriasis and/or psoriatic arthritis, why not check out some of the merchandise we have available?

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PAPAA's position on pharmaceutical funding

PAPAA does not receive funds (either directly or in kind) from the pharmaceutical industry or commercial sector. All activities are funded via donations, subscriptions, charitable grants, legacies or other income generation. We believe that this allows us to act in an open, non-biased way and free from any perceived influence or agendas that may arise. We do not link our activities to commercial marketing or public relations campaigns and will only link our name or logo to an activity if we believe it is beneficial to our constituent group.

Supporting PAPAA

- As a charity, in order to continue our work, we need to raise funds. Apart from direct donations, there are other ways to help us too.
- AmazonSmile is particularly easy – and free to you. AmazonSmile donates 0.5% of your total purchase to us as a charitable donation. So, it doesn't cost you anything.
- You may also be interested in other ways to support us online, such as JustGiving, The Charities Aid Foundation (CAF),
- Total Giving, PayPal Giving Fund, Give a car, Easyfundraising, Easysearch and Everyclick. Links to these sites can also be found at:

https://www.papaa.org/donate/ways-to-support-papaa/

Join the conversations

If you have a social media presence, then why not follow us and join the conversation to see what others have to say?

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Pinterest: **www.pinterest.co.uk/psoriasisuk**