The Impact of Solar Urticaria on Psychological Well-Being and Perceived Social Support

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ABSTRACT

Solar Urticaria (SU), an uncommon physical urticaria brought on by sunlight or certain UV wavelengths. The purpose of this study is to examine the psychosocial dynamics of SU and how it affects day-to-day activities and psychological well-being. Using interviews and personal insights from a purposefully sampled group of 11 individuals diagnosed with Solar Urticaria (SU) for over a year. Thematic analysis was incorporated in order to perform data analysis. The findings show that people with solar urticaria emphasise the value of adaptive coping strategies for lifestyle modifications, citing social isolation as a major obstacle. They also highlight the critical role that self-acceptance and self-awareness play in regulating psychological wellbeing.

Keywords: Social Isolation, Adaptive Coping, Psychological Impact, Quality of Life

INTRODUCTION

Solar urticaria is a rare photosensitivity condition characterized by symptoms like redness, itching, and hives upon exposure to sunlight or UV light. Treatment options include sun avoidance and various therapies, but responses vary, often necessitating combination treatments. Besides physical symptoms, patients often experience stress, anxiety, and depression due to lifestyle disruptions, underscoring the importance of social support. Psychological well-being, crucial for overall health and longevity, involves managing both positive and negative emotions effectively, with factors like self-perception and meaningful connections contributing to it. Perceived social support, reflecting one's subjective evaluation of support from their network, plays a vital role in enhancing resilience and coping with challenges, emphasizing the importance of fostering supportive relationships for mental well-being.

The study by Snast et al. (2019) investigates the treatment of solar urticaria (SU), employing a customised step-by-step therapy approach involving photo provocation testing and various medications. Results show that a combination of antihistamines and a leucotriene receptor antagonist (LRA) effectively managed SU symptoms in 74% of patients, highlighting the importance of tailored treatment for SU patients' quality of life. Pérez-Ferriols et al. (2017) conduct a retrospective multicenter study on SU, revealing its epidemiology and clinical features, predominantly affecting women in their third decade of life and often triggered by visible light. The study underscores the need for effective therapy to enhance patient well-being and provides valuable insights into SU's characteristics and management.

Uetsu et al. (2000) offer insights into SU's clinical and photobiological characteristics, noting limited treatment options and the complex of managing nature SU. underscoring the necessity for further research into treatment strategies. The collective review of studies on SU underscores the importance of tailored treatment approaches to improve patient quality of life and highlights gaps in understanding treating and this rare photosensitivity condition.

Furthermore, the review delves into the intricate relationships between perceived social support and psychological well-being, emphasizing their dynamic nature and the need for tailored interventions. Studies by Ognibene and Collins (1998) and Prezza and Pacilli (2002) explore how attachment styles and sociodemographic factors influence social support and perceived coping mechanisms, shedding light on the complex interplay between social support, attachment, and coping strategies. Lyyra and Heikkinen (2006) reveal the impact of perceived social support on mortality rates in older adults, emphasizing the importance of emotional support for overall health and well-being, particularly among older women. These studies collectively highlight the significant role of perceived social support in promoting well-being across various life stages and underscore the need for interventions to enhance social support systems and address individuals' unique needs.

The review integrates findings on psychological well-being, emphasizing its multifaceted nature and the diverse factors influencing it. Warr's (1978) study provides insights into positive and negative aspects of psychological well-being, advocating for a deeper exploration of individuals' daily experiences to understand psychological comprehensively. well-being Huppert's (2009) review explores the causes and effects of psychological well-being, proposing a new direction for research focused on interpersonal and personal flourishing. McLanahan and Adams (1987) examine the relationship between parenthood and

psychological well-being, suggesting policy interventions to support parents and reduce stress. These studies collectively contribute to our understanding of psychological wellbeing's determinants and underscore the importance of tailored interventions to promote flourishing across different life domains.

The purpose of this study is to investigate the complex dynamics of how SU affects the day-to-day activities and general well-being of those who are dealing with this illness. The paucity of current research on this topic emphasises the necessity to investigate the psychosocial elements of SU in order to provide light on the psychological and social consequences that those who are affected must deal with. Living with SU can be a lonely experience because those who have it often struggle with pain, suffering, and restrictions while going outside for everyday activities. These difficulties influence the psychological and social aspects of the life of those who are impacted in addition to the physical symptoms of the illness. Therefore, comprehending the complex effects of SU is essential to creating plans to improve the quality of life for those who are affected by this illness. The present study aims

- 1. Examine how well social support systems work to assist people in managing solar urticaria.
- 2. Explore lived experiences and coping strategies through qualitative interviews.
- 3. Examine the connection between psychological well-being, perceived social support, and solar urticaria

MATERIALS & METHODS Statement of the problem

This study aims to examine the experiences of individuals diagnosed with solar urticaria and the subsequent impact on their psychological well-being and perceived social support.

Research Design

A qualitative research methodology was used in this study to allow for a thorough examination of the relevant ideas and their relationships. It sought to reveal the subtleties of the phenomenon under inquiry through in-depth examination and interpretation. Through exploring personal narratives and viewpoints, it aimed to offer profound understandings of the intricate processes involved.

Participants

samples were collected through The purposive sampling. The eligibility criteria for the participants were that they are diagnosed with Solar Urticaria for more than a year and the age group should be from 25-Participants 45. Total of 11 were interviewed. Participants in this study represent a varied cross-section of people with solar urticaria diagnoses, living in Asia, North America, Europe, and Australia

Tools for the study

Multidimensional scale of perceived social support (MSPSS)

Zimet GD, Dahlem NW, Zimet SG, and Farley GK developed the Multidimensional Scale of Perceived Social Support (MSPSS), which was published in the Journal of Personality Assessment in 1988. This 12item survey is intended to gauge people's opinions on social support from three different sources: friends, family, and romantic partners. On a 7-point Likert scale, with 1 denoting very strongly disagree and 7 denoting very strongly agree, participants rate how much they feel supported by each source.

Affect Balance Scale (ABS)

The 10-item Affect Balance Scale (ABS) was developed by Norman Bradburn and Enoll to evaluate psychological well-being, with a specific emphasis on happy or mood states. Respondents to the scale indicate whether particular feelings or conditions apply to them using a yes-or-no scoring style.

PROCEDURE

Eleven individuals were chosen using a purposeful sample technique based on predetermined standards. To ensure accurate capturing of narratives and emotions, audio/video recordings were used during interviews. By taking notes during interviews, interviewers were able to better participants' comprehend opinions by recording both verbal and nonverbal cues. Informed consent was acquired and individuals completed questionnaires before the interviews. Online interviews were performed, with participants' permission, recorded, and then transcriptions were made for analysis.

Data analysis

Thematic coding was done using Maxqda software. Later, the codes were manually segregated into themes. Inductive data driven strategy was employed in order to address the research problem. The findings were divided into four themes a) Response to change, b) Hinderance to interpersonal dynamics, c) Self-acceptance and self-awareness, d) Quality of life.

Ethical Consideration

Before beginning the study, each participant gave their informed consent. Anonymity and confidentiality for the study's participants were rigorously upheld. All information will be safely kept in a password-protected file that only authorised researchers can access.

RESULT

The figure below shows themes that the participants shared and that were found during the data analysis process.

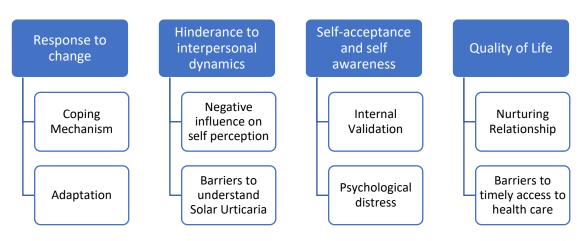


Figure 1: Representation of Themes

Main Theme. Response to Change

As individuals deal with the challenges presented by solar urticaria, individuals need to learn to adapt to change in a variety of ways. Adjusting daily routines and activities to reduce sun exposure becomes necessary when modifying one's lifestyle. Living with a chronic illness requires adjustment in many areas of life. (Stanton & Hoyt, 2017)

Sub Theme. Coping Mechanism

The findings of the study underscore the pivotal role of adaptive coping strategies in managing chronic illnesses like solar urticaria, resonating with existing literature on the subject. Participant 8 articulated, "the most helpful thing was just to both accept that this is happening and coming to accept that it is a disability. It's not an overly common one in terms of how people think of disabilities, but it is." This sentiment aligns with research emphasizing the importance of acceptance in coping with chronic conditions (Bussing, 2010). Conversely, maladaptive coping mechanisms can exacerbate psychological distress. as noted by Participant 7, who described how the physical symptoms of solar urticaria often lead to exhaustion and sleep, stating, "most of the time she sleeps because the moment she get rashes, she doesn't have energy to do anything." Such behaviours, including avoidance and self-blame, are linked to depression and poor psychosocial adjustment, reinforcing the need for effective

coping strategies (Bombardier, 1990). These findings highlight the critical role of adaptive coping mechanisms in enhancing psychological well-being in the context of chronic illness.

Sub Theme. Adaption

The impact of solar urticaria on the quality of life is profound, significantly affecting aspects of daily functioning. various Participant 7 reflected on how the condition has influenced their social interactions, stating, "I feel like I base all of my friendship off of my allergy because I always tell my friends who like to go out that I cannot go out with them... Mainly because we have nothing in common." Additionally, Participant 7 shared how others' reactions to their condition led to social distancing, saving, "And, you know, they were like, after they heard they got a little distance from me because they also were like, you know, I can't accept that. I want someone to go out with, which I completely understand." These narratives illustrate the challenges individuals face in maintaining relationships due to the limitations imposed by solar urticaria. Participant 5 described the psychological burden anticipating of symptoms, expressing, "oh my God, I got sunburn now... I'm like constantly thinking about it... It increases anxiety, stress, depression." Such experiences underscore the emotional toll of living with solar urticaria, contributing to sleep disturbances,

exhaustion, and difficulties in managing emotions, as observed in previous studies (O'Donnell, 1997; O'Donnell, 2014).

Main Theme. Hinderance to interpersonal dynamics

Given that flare-ups are unpredictable and interfere with regular interpersonal contacts, people living with this condition frequently experience social isolation. Interpersonal dynamics can be greatly impacted by chronic disease, and patients' views of others' expectations of them and their own capacity to meet those expectations are crucial (Hatchett, 1997).

Sub Theme. Negative influence on self-perception

The results of the study reveal profound impacts on individuals with solar urticaria. Participants expressed feelings of social isolation and a sense of being burdened by their condition, which significantly affected self-perception and interpersonal their Participant 10 dynamics. recounted, "Whenever I go out and my body reacts to the sun, they usually tell 'why did you even come' 'you should have just stayed home' so that time I ended up taking 3 avail tablets and health got bad." Similarly, Participant 7 articulated, "It does hurt my self-esteem in a way that whenever I'm invited to go out, especially on a professional occasion, I cannot. So it really makes me, less of a standard compared to others who are invited to a professional event." Participant 2 highlighted the personal struggles, stating, "There are a lot of limitations I have to overcome... I have to carry an umbrella. So like that, there are hurdles that I have to overcome." These underscores the profound psychological and social ramifications of living with solar urticaria. Moreover, these findings align with previous research by Charmaz (1983), who emphasized the significant impact of chronic illnesses on individuals' sense of identity and the constraints imposed on their lives.

Sub Theme. Barriers to understand Solar Urticaria

One of the main obstacles to comprehending solar urticaria is ignorance, which can result in misunderstandings and problems in human connections. When individuals downplay the seriousness of the allergy and attribute protective measures like sunscreen and umbrellas to mere cosmetic concerns or paranoia, it is clear how widespread the lack of awareness is, this was seen in the case of Participant 2. Furthermore, the lack of general understanding on solar urticaria feeds the development of myths and conventional wisdom. Participants 5 describe situations in which family members show doubt about the validity of the allergy due to beliefs conventional or cultural misconceptions. The impact of traditional traditions, such as the idea that the illness is the product of previous karma or that it can be treated by rituals unrelated to medical intervention, frequently exacerbates this doubt. These misconceptions make it harder for people with solar urticaria and their families to communicate with one another, which exacerbates feelings of miscommunication and strains relationships. Participants 8 contacts with paediatricians and other healthcare personnel who express astonishment at the rarity of such allergies demonstrate that the lack of understanding extends to the medical community as well.

Main Theme. Self-acceptance and selfawareness

According to Neff (2003), self-compassion is essential to both self-acceptance and selfawareness. It entails treating oneself with compassion and understanding, accepting that one's experiences are a natural part of being human, and mindfully observing one's painful thoughts.

Sub Theme. Internal Validation

The results of the study revealed significant insights into the psychological impact of solar urticaria on individuals' self-esteem and body image. For instance, Participant 11 expressed feeling self-conscious and desiring to hide due to the visible symptoms of solar urticaria, stating, "I get red everywhere, the sweating, starting itching and I don't feel like Good in those moments because I would like to hide myself." Similarly, Participant 9 articulated concerns about social situations impact self-confidence. and their on remarking, "What if when we are in a gettogether place, or when we are somewhere in a social place, when this comes up, that would give a little lower impression on my self-confidence." Participant 5 highlighted heightened self-awareness and skin-related anxieties following the diagnosis, emphasizing the emotional toll of managing the condition, stating, "I was very conscious about my face and everything, but after this, this diagnosis, I had to be very conscious that I am going because, when I apply sunscreen with the umbrella sometimes, if I stay too long in the sun, my skin gets rough." These accounts align with existing literature demonstrating the strong association between chronic illness and emotional vulnerability, particularly anxiety and sadness. Participant 2 shared experiences of sadness and withdrawal from social activities, illustrating the emotional distress caused by the lack of effective treatment options, while Participant 10 expressed feelings of hopelessness stemming from medical unsuccessful interventions, lamenting, "I feel loss of hope because every doctor I have gone to they have not given me any treatment and they failed to treat me." Similarly, Participant 9 conveyed frustration and disappointment over the absence of a cure, stating, "Oh, I feel irritated, I feel frustrated, I would say. And also disappointed that there is no cure." These findings underscore the profound emotional burden faced by individuals with solar urticaria, emphasizing the urgent need for comprehensive support and effective treatment options to address their psychosocial well-being. In addition to the participants' narratives, existing research corroborates the observed patterns, indicating that chronic illness can significantly impact body image and emotional well-being (Vamos, 1993). Hashizume and Takigawa (2006) further highlight the association between long-term emotional vulnerability, such as anxiety and sadness, and chronic illness, echoing the experiences shared by participants in this study.

Sub Theme. Psychological distress

The results of the study unveil a strong correlation between mental distress and social isolation among participants grappling with solar urticaria. Participant narratives vividly illustrate the profound impact of the condition on their mental well-being and interpersonal relationships. Participant 3 expressed, "It completely destroyed my marriage. My kids, I mean, I can't go and do things with them anymore, right? So that really takes a toll." Similarly, Participant 8 shared, "I was just kind of spiralling out of control... It's certainly an inconvenience, but I am not dying. And. Whilst my mental health does go up and down with it." Additionally, Participant 11 articulated, "There's basically no day where I don't have to think about it ... affecting my mood and my hope for the future." The emotional toll is further emphasized by Participant 3's revelation, "I spent basically the first two years not working and living in the dark." These accounts underscore the significance of addressing the psychological aspects of solar urticaria alongside its physical symptoms. These findings resonate with previous research highlighting the detrimental effects of prolonged stress and social isolation, particularly in individuals facing chronic health challenges (Zuckerman, 1964; Academies National of Sciences, Engineering, and Medicine, 2020).

Main Theme. Quality of life

Physical health, emotional well-being, social interactions, environmental conditions, and personal fulfilment are just a few of the components that make up quality of life. The quality of life can also be greatly impacted by the ongoing threat of exposure and the requirement for caution (Antolín-Amérigo, 2016).

Sub Theme. Nurturing Relationship

participant In the study. narratives illuminated the critical role of social support in managing solar urticaria. Participant 8, who grew up helping on a farm, described the shift in family dynamics, stating, "My family, we stay on a farm, but now my parents don't call me to help them. They're more scared and don't want me to come out in sunlight." Despite their support, the participant expressed feeling conflicted, saying, "It's weird not to go help them; I feel bad I cannot." This aligns with previous research emphasizing the importance of family affirmation and support in reducing depression and improving overall well-being (Primomo et al., 1990). Additionally, participant 8 shared their struggle with depressive episodes and anxiety, highlighting the necessity of seeking professional help and relying on support networks to cope with the emotional toll of the condition. Similarly, participant 9 acknowledged the unwavering support from their partner, stating, "My partner has been very supportive, and I have not seen any changes; if anything, the support has increased." Furthermore, participant reflected on the strengthening of friendships, "My friends have been really noting. supportive. They've been really good, going out of their way to make sure that I'm comfortable." These underscore the pivotal role of social networks in buffering the psychological impact of solar urticaria. Research by Korff (1997) emphasizes the necessity of a team approach for managing chronic illness, while findings by Primomo et al. (1990) highlight the positive association between family affirmation and reduced depression.

Sub Theme. Barriers to timely access to healthcare

The results of the study highlight significant barriers to prompt access to healthcare faced by individuals with solar urticaria.

Participant 11 expressed frustration, stating, "Bad. I mean, it's, I don't know. Um, there are some treatment. I don't know what, what's the word, but I mean, they're not paid by insurance or anything. I think it's probably everywhere around the world like this. So it's also like this in Germany. So, um, I would have to pay for it myself and it's really expensive and it didn't work for me. So that was really a bummer to me." This sentiment reflects a common challenge of inadequate healthcare coverage for treatments related to solar urticaria. Moreover, delayed diagnosis emerged as a significant impediment to timely healthcare access. Participants recounted struggles in pinpointing the precise allergies causing their illness, exacerbated by limited information sources and doubt from medical professionals. Such delays not only hindered the development of effective treatment regimens but also exacerbated the psychological burden on individuals, underscoring the urgent need for improved diagnostic processes and healthcare accessible resources. These findings align with previous studies, emphasizing the critical importance of addressing systemic barriers to healthcare access for individuals with solar urticaria (Pinzur, 2017).

DISCUSSION

The findings highlight significant patterns in participants' scores on several the dimensions, illustrating the complex difficulties that people with solar urticaria encounter. Eleven participants reported low support on the Multidimensional Scale of Perceived Social Support (MSPSS), with a range of 1.12-1.56, showing a widespread perception of insufficient social support. Additionally, the study sheds light on the impede interpersonal subtleties that interactions, revealing the isolating consequences of erratic outbursts and the strain participants' resulting on selfperception. Perceptual isolation is a type of emotional pressure that, according to Zuckerman (1964), can result in a variety of unfavourable emotional reactions. It

also highlights the many obstacles that impede our ability to comprehend solar urticaria in both medical and societal settings. The qualitative study explores the complex experiences of people who are dealing with solar urticaria, emphasising their "Response to Change." Participants' various responses are further revealed by the Affect Balance Scale, which shows that 3 people scored low, 3 moderate, and 5 high on positive affect and 3 people scored low, 4 moderate, and 4 high on negative affect. These ratings highlight the emotional difficulties associated with having solar urticaria and the necessity of developing flexible coping strategies and changing one's way of life to better handle the condition's problems. The study reveals a rich tapestry of coping strategies used by participants to manage the difficulties presented by this chronic disease, including modifications to everyday routines intended to reduce sun exposure. The study highlights how important adaptive coping strategies are to the management of chronic illnesses and shows how they have a significant influence comprehension on patients' of their symptoms and how they view themselves. Critical dimensions including selfacceptance and self-awareness are explored, along with internal validation and the psychological suffering that is closely associated with the disease. The results underscore the intricate relationship between psychological distress and social isolation, highlighting the necessity for а comprehensive strategy to improve overall quality of life. Accessible healthcare, supportive families. and nurturing relationships emerge as critical subthemes that have a major impact on participants' well-being. Sunlight urticaria sufferers encounter additional hurdles when it comes to timely access to healthcare, especially when it comes to health insurance and late diagnosis. One major obstacle to prompt access to healthcare is not having health insurance (Pinzur, 2017). Essentially, this research offers complex perspectives on the lives of people who suffer from solar urticaria and advocates for all-encompassing support networks and increased awareness in the medical and societal domains.

CONCLUSION

This study highlighted the many difficulties that people with solar urticaria face and clearly illustrates the widespread lack of social support that these people experience. The participants' low ratings on the Multidimensional Scale of Perceived Social Support, as demonstrated by the quantitative analysis, highlight the widespread belief that support is insufficient. Furthermore, the Affect Balance Scale reveals the emotional nuances by demonstrating the individuals' varying degrees of positive and negative affect. The results highlight the critical importance of lifestyle modifications and adaptive coping mechanisms, as well as the need for a comprehensive strategy to improve the general quality of life for those suffering from solar urticaria. The research highlights the importance of supporting relationships, easily available healthcare, and the pressing need for increased awareness in the medical and societal domains. This study promotes a more compassionate and inclusive environment that addresses the interconnected problems of psychological anguish and social isolation associated with solar urticaria by shedding light on the complex experiences and challenges faced by those who have the condition.

Although this study offers insightful information about the experiences of those who suffer with solar urticaria, it is important to recognise key limitations that may affect how the results are interpreted and how broadly they can be applied. First off, because the study only included a certain number of participants, its sample size may have limited the diversity of viewpoints. Results cannot be extrapolated to a larger context due to potential underrepresentation of the heterogeneity within the solar urticaria community. Last but not least, despite efforts to guarantee a broad participant pool, it's possible some marginalised that or underrepresented groups within the solar urticaria community had their experiences left out of the study. All of these restrictions highlight the need for careful interpretation and motivate greater research to address them in order to gain a more thorough understanding of the phenomenon and its implications.

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