

Lupus and Employment: Equal Economic Access for Invisible Disability

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Abstract. Not all disabilities are visible. Invisible disability refers to medical condition that limit individual ability to carry out normal activities and not visible to others. One of the examples is Lupus, a systematic autoimmune disease that can attack various organs and have significant impact on individual capability. Individuals with Lupus are often considered as physically capable and experiencing “you don’t look sick”, especially in a workplace. The aim of this study is to examine experience of individuals with Lupus for equal economic access including employment and other economic resources in Indonesia. This study employs Interpretative Phenomenological Analysis (IPA) to explore the experiences of individuals with Lupus, focusing on their opportunities and challenges in accessing financial resources in both formal and informal employment sectors. As a result, individuals with Lupus who succeed in maintaining employment typically benefit from a supportive work environment bolstered by sufficient knowledge about lupus. Conversely, those who transition to the informal sector often face difficulties in accessing financial facilities commonly available to people with disabilities. Therefore, it is crucial to raise awareness about Lupus as an invisible disability to ensure equal economic access in both formal and informal employment, with adjustments made to accommodate their capacity to perform.

Keywords: Invisible disability, Lupus, Employment, Economic Independence

1 Introduction

Not all disabilities are visible. Invisible disabilities refer to various symptoms that are not always obvious for others but may limit daily activities such as mental health disorders, hearing and vision impairments, cognitive dysfunctions, pain and fatigue. The symptoms are varied between persons and consist of mild to severe limitations. As the result, the invisible nature of illness may cause to disbelief that leads to misunderstanding and rejection by surrounding people (family, friend, health worker) who lives with people with invisible disabilities. Even worse, people with invisible disabilities may accused by laziness or faking an illness [1]. One of the examples of invisible disability is Lupus. Lupus or Systematic Lupus Erythematosus is an autoimmune disease which ‘the immune system attacks its own tissues, causing widespread inflammation and tissue damage in the affected organs’[2]. Lupus can involve several organs such as brain, lungs, kidneys, blood vessels, joints and skin with various symptoms from mild to life threatening. The causes of Lupus are unknown but genetic, hormonal and environmental factors are suspected to contribute on the illness. Lupus cannot be cured but can be controlled through medical treatment and lifestyle changes. Nowadays, the survival rate of Lupus is increasing due to the advancement in medical treatment.

Research by Garris [3] has shown that fatigue (99%), pain/stiffness in joints (98%), and muscle pain (93%) were the most common symptoms that reported by people with Lupus. For employed

people with Lupus, it resulted on difficulty on maintaining a normal work pace, shorter working hours or missing more hours of work because of the health problem. More than 2/3 employed people with Lupus has reported that Lupus significantly impacted their productivity both on work and daily activities [4]. On the other hand, the symptoms of Lupus can be both severe and invisible with no physical changes at the same time [5]. People often unable to see the sickness and therefore have limited understanding and empathy for what it seems unexplainable lost productivity as they dismissed the symptoms as normal [6].

Even though Lupus can affect all ages, people between 15 – 44 years old especially women are the highest people at risk [2]. Given that Lupus is frequently diagnosed during individuals' prime working years, it has a profound impact on their careers and employment prospects. The largely invisible nature of their disabilities can lead to expectations of performance comparable to that of individuals without disabilities, despite the challenges posed by their condition. This disparity often complicates access to employment opportunities and the ability to meet employer standards due to these unseen physical limitations. Nevertheless, when symptoms are mild and manageable, individuals with lupus can continue to work effectively with appropriate accommodations, similar to other disabilities. Therefore, examining the workplace activity limitations will be beneficial to understand the level of difficulties and work challenges for people with Lupus [7]. Acknowledging the limitation of people with Lupus may be able to provide better opportunity to be productive, generating income, and contribute to their quality of life by providing access to economic resources.

Previous studies on Lupus and its impact on employment within the Indonesian context are particularly limited. Furthermore, research on Lupus and employment has predominantly utilized quantitative methods, which often limit the exploration of personal experiences of individuals with Lupus. Therefore, this research aims to examine the experiences of individuals with lupus in achieving economic empowerment through both formal and informal sectors by identifying: (1) What challenges are faced in accessing employment in both formal and informal sectors, and what support is necessary to maintain economic empowerment; (2) To what extent does Lupus affect work productivity and impact employment status. The study employs a qualitative methodology, utilizing Interpretative Phenomenological Analysis (IPA), and includes interviews with individuals with lupus from Yogyakarta and Solo, Indonesia and enriched by the experiences of rheumatologist in accompanying adult Lupus patient. The findings reveal that individuals with Lupus working in formal and informal sectors face diverse conditions related to their illness, leading to different needs for survival. By understanding their perspectives on invisible disabilities that affect their performance, along with the dynamics in the workplace and other economic sectors, this study aspires to lay the groundwork for providing support that fosters economic independence and improves the quality of life for individuals with Lupus.

2 Lupus and Employment

Lupus can manifest with a range of symptoms, from mild to severe, which significantly influence an individual's capacity to work and sustain employment. The most prevalent symptoms include fatigue and pain. Unlike typical fatigue, which can often be alleviated through rest, Lupus-related fatigue is characterized by its frequent, persistent, and unpredictable nature. It is typically resistant to conventional remedies such as sleep, often being attributable to underlying medical conditions such as anemia, renal or thyroid disorders, or adverse effects of long-term treatment. Additionally, pain in lupus patients commonly presents as joint or

muscle pain, headaches or migraines, and cramps. Another example includes sensitivity to ultraviolet (UV) light and cognitive impairments, such as difficulties with short-term memory and diminished concentration. These issues are further complicated by the unpredictable nature of the disease. Such symptoms collectively contribute to limitations in mobility, functional capacity, and the ability to engage in outdoor activities involving direct sunlight exposure. Indeed, individuals with Lupus experience a substantial reduction in work productivity, often losing nearly four times the number of work hours per week compared to those with mild Lupus. The repercussions of this diminished productivity include income loss, premature work disability and retirement, career changes whether voluntary or compelled, increased absenteeism and unemployment [7][3][5][4].

Unfortunately, most individuals living with Lupus appear outwardly healthy despite experiencing significant physical suffering. This leads into misunderstanding, disbelief and lack of support from employers, co-workers, and others. On the other side, the role of employer and working environment is pivotal to prevent severity level/ flares of Lupus in order to minimize the risk of lost productivity [4]. Since disease activity score at diagnosis is not a predictor for work participation, effective treatment and manageable disease activity will enhance work participation for employed people with Lupus [8]. This can be supported by health professional assessment with the purpose to measure workplace difficulties and individuals needed [9]. With appropriate support and understanding, people with mild symptoms and manageable Lupus activity will be able to work and economically empowered.

Similar to other disabilities, individuals with Lupus face numerous challenges in entering the workforce and securing employment. Individuals with disabilities encounter difficulties in obtaining employment due to several factors such as: lack of understanding from the employer about the condition of person with disabilities; inappropriate skills due to the low education level caused by disabilities; and insufficient role of the government to provide support, knowledge, and incentives for the employer [10]. Not only that. In many cases, individuals with disabilities are perceived as burdensome to employers. Even when they succeed in obtaining employment, it is often neither sustainable nor inclusive. This issue similarly affects individuals with Lupus, given the nature of their invisible disability.

However, the aforementioned challenges can be addressed through various strategies. For example, third parties can play a crucial role in providing information and enhancing understanding regarding the recruitment of individuals with disabilities. Additionally, training institutions, particularly those supported by the government, can have a pivotal role in providing basic skills and education to individuals with disabilities. Government can also provide various policy and program for example: incentive for employer to recruit person with disabilities, or skill and financial support for people who want to create their own entrepreneurship. This support is substantial since people with disabilities often have to experience discrimination during the recruitment and employment. In the context of Indonesia, these challenges are intensified with lack of public facilities to support people with disabilities, lack of understanding on human rights-based approach towards disabilities, lack of employment access for people with disabilities, and most of the training program are solely focus on physical disabilities [10].

3 Method

This study employed interpretative phenomenological analysis (IPA) in order to capture the perception of people with Lupus towards their experience to survive on employment or access other economic resources. In-depth interviewed were conducted with six individuals living with

Lupus and one rheumatologist. The participants were recruited from two Lupus Community in Yogyakarta (Sahabat Cempluk) and Solo (Yayasan Tittari), Indonesia. Meanwhile, the rheumatologist involved in this research is affiliated with a leading government hospital in Yogyakarta. To address ethical considerations, the interviews commenced with informed consent from all participant, all participant may withdraw from participation at any time, were audio recorded, and verbatim transcribed. The profiles of the participants with Lupus are presented in Table 1.

Table 1. Profile of individual participant with Lupus

Initial	Age	Sex	Marital Status	Education	Employment status	Lupus duration (years)
HV	32	Female	Single	Undergraduate	Civil servant	13
PT	32	Female	Married	Undergraduate	Private sector employee	17
AW	25	Male	Single	-	Cellphone repairmen, food stalls	10
IS	40	Female	Married	Undergraduate	Reseller for online product	8
IN	50	Female	Divorce	Undergraduate	Professional freelancer	21
ND	22	Female	Single	Senior high school	Reseller for online product and affiliate for online platform	7

Source: interview

The analysis process involved repeatedly reviewing the verbatim transcripts of the interviews to capture the meaning of each narrative provided by the participants. Subsequently, themes emerging from each participant's experiences were identified. The identified themes were then analyzed to uncover patterns or relationships across the interviews, leading to the formulation of conclusions. The verbatim transcripts and research procedures can be reviewed to support the credibility of the study's findings. Meanwhile, interviews with the rheumatologist serve to reduce or mitigate potential biases from the interviews with individuals with Lupus. Interviews were conducted in September and October 2023. The process of data verification with participants was carried out concurrently with the writing process until January 2024. The interviews took place in Yogyakarta and Solo, corresponding to the participants' residences, and lasted between 20 to 88 minutes.

To address the research questions, the interview process began by identifying the socio-demographic profile, including age, gender, marital status, educational background, and occupation; as well as any changes in employment status before and after being diagnosed with Lupus. The medical history was reviewed to determine the age at which Lupus symptoms first appeared, the timing of the Lupus diagnosis, and the symptoms and treatments used up to the present. The experiences of individuals with Lupus were explored through several questions,

including the challenges faced in accessing employment, the impact of Lupus on work productivity, experiences of discrimination or negative treatment due to Lupus, and the types of support needed to remain economically empowered.

4 From Employee to Self-employment

Each participant had a unique narrative regarding their perceptions and experiences in entering the job market, sustaining employment, and transitioning to self-employment due to the impact of Lupus. These narratives encompassed a spectrum of emotions, including optimism and feelings of despair, ultimately culminating in strategies for survival. ND serves as an illustrative example of resilience in the face of Lupus. Prior to her diagnosis, she was an accomplished student with numerous achievements, even securing a scholarship for higher education. Following her diagnosis, ND had to relinquish her dream of attending university but remained hopeful about her future. Leveraging her creativity, ND successfully earned 10 million rupiahs (approximately USD 667) per month as an affiliate on an online platform, which is equivalent to five times the minimum wage in Yogyakarta. Her role involves promoting online products and earning a commission when purchases are made through the links she shares on her online account. Through this income, she was able to finance her dialysis treatments. Currently, her average income ranges from 1.5 to 2 million rupiahs by utilizing online shopping platforms. These platforms offer her the flexibility to work without requiring physical exertion. Working in the informal sector does not always present an easy experience for everyone, for example: AW. AW was compelled to discontinue his education at the elementary level due to the significant impact of Lupus on his cognitive abilities. Currently 25 years old, he generates income as a cellphone repairman, having received free training from a supportive neighbor. Additionally, he assists his family in operating a food stall in front of their house. Despite his efforts, his income remains insufficient, rendering him dependent on his family. He expresses hope that the government might provide support through soft loans or access to capital, enabling him to open his own store.

Another account involves IS and IN, who were compelled to relinquish their employment due to Lupus. A graduate of a prominent university, IS previously worked as a consultant in a private company. Following her diagnosis, she decided to resign and opted to become a reseller of online products to generate additional income for her family. Her living expenses are now dependent on her husband, who works as an online driver. She attempted to access soft loans to establish her own online business. However, she faced challenges in obtaining these loans as most providers require an offline store to qualify for their loan programs. IN also turned to self-employment after being significantly impacted by Lupus. Previously, she had an excellent career in the entertainment sector, but the onset of Lupus caused numerous setbacks and disbelief from her colleagues. As a result, she had to restart her career as a professional freelancer, offering public speaking training to her clients. However, IN frequently faces challenges in securing projects or clients due to her limitations. What she needs is an opportunity to be productive again in order to generate income.

Does this mean that individuals with Lupus cannot sustain employment? The experiences of HV and PT offer different narratives. HV, who works as a civil servant, was reassigned to administrative duties once her head office recognized her susceptibility to illness, fatigue, and physical limitations. This understanding facilitated her acceptance among colleagues. Similarly, PT, employed in the private sector, benefited from an understanding supervisor who also has Lupus. PT's supportive team is fully aware of her limitations, preventing any misinterpretation

of her condition as laziness or feigning illness. This appropriate support enables HV and PT to maintain their work pace and productivity effectively.

From the various narratives presented, it can be concluded that self-employment frequently emerges as an option for individuals with Lupus to achieve economic empowerment. This is attributed to several factors. Firstly, the physical capacity changes associated with Lupus often hinder individuals from adapting to formal work environments. In cases where Lupus is diagnosed at an early age, the symptoms can present obstacles to accessing the education and foundational skills necessary for formal employment. Conversely, individuals with Lupus who manage to remain in formal employment typically benefit from adequate support within their work environment. This support is often facilitated by workplaces that possess sufficient knowledge and awareness of Lupus, thereby mitigating misunderstandings and providing workload adjustments that can enhance the productivity of individuals with Lupus.

5 More opportunity and less barriers

Financial burden for people with Lupus is not only because of the cost of medication in a long-term but also indirect cost such as loss of income as the result of absenteeism, unemployment, or early retirement [5][6]. It is exacerbated by the fact that not all of people with Lupus have strong economic support from their family. The findings of this study indicate that the invisible disabilities associated with Lupus frequently result in disbelief and misunderstanding. In addition to the challenges posed by unrecognized disabilities, individuals with Lupus also face barriers to employment and economic opportunities, including educational attainment, lack of capital and skills, and limited physical mobility. As noted by IN, "what we need is a chance." It is important to recognize that not all individuals with Lupus are incapable of working or being productive. Individuals with Lupus can also enable productivity if the working environment demonstrates understanding and concern similar to that afforded to other disabilities.

To increase opportunities for individuals with Lupus, several measures should be undertaken. Firstly, it is essential to raise awareness about Lupus as an invisible disability. All participants concurred that Lupus constitutes an invisible disability, and they have all experienced where their limitations were not recognized by others. For instance, they are sometimes judged for using priority seating designated for individuals with disabilities, even as they endure muscle or joint pain that is not visible to others. The physical limitations, which are often not apparent, also impact the workplace, where individuals frequently encounter stigma and are perceived as lazy or malingering. Raising awareness about Lupus, particularly within the workplace, can help prevent misunderstanding and disbelief towards individuals with this condition. Indonesia has already ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which is crucial for transforming perspectives on disabilities. Disabilities should be understood not solely as medical conditions, but also as human rights issues grounded in principles of equality. This implies that individuals with disabilities have the same rights and opportunities as other citizens, including access to economic resources. According to Indonesia Regulation [11], disability encompasses not only physical impairments but also mental and intellectual conditions. This underscores the need for the Indonesian government to acknowledge invisible disabilities, such as Lupus, and ensure that individuals with such conditions are afforded equal opportunities in all aspects of citizenship. Yet, it is fully understandable that raising awareness about invisible disabilities is a process that requires considerable time and effort.

The second consideration pertains to the implementation of inclusive work systems, particularly within the formal sector. This can be achieved through the establishment of flexible working arrangements, which encompass variations in work schedules, locations, and types of tasks, alongside the provision of supportive infrastructure and systems. According to rheumatological expertise, individuals with Lupus may be able to maintain employment if they can effectively manage their symptoms. Individuals with Lupus often experience reduced physical capacity compared to others, and activities that may be inconsequential for the general population can exacerbate pain in those with lupus. For instance, sensitivity to ultraviolet (UV) light can be managed through the application of sunscreen and by avoiding outdoor activities. HV's experience serves as an example of how top management at their organization effectively recognized the constraints leading to assignment on administrative role to alleviate physical workload. Understanding these limitations will facilitate effective symptom management and contribute to maintaining productivity. Additionally, Indonesian regulations stipulate that employers are obligated to provide supportive infrastructure and flexible working arrangements tailored to the needs of individuals with disabilities, while ensuring that job responsibilities are not compromised.

Certainly, the government can play a critical role by offering incentives, particularly to the private sector, to promote equal economic opportunities for individuals with disabilities. Additionally, ensuring safe and lawful access to loans or capital for self-employed individuals, along with providing accessible training, is essential. Facilitating access to secure and legal soft loans enables individuals with Lupus to develop and expand their businesses. Furthermore, inclusive training programs are crucial for addressing the needs of individuals with both visible and invisible disabilities.

6 Conclusion

From discussion above, it can be concluded that acknowledge Lupus as invisible disability will provide them broader opportunity to get into the employment and access any assistance that provided for people with disability (for example, inclusive training and soft loan). Raising awareness of Lupus play significant role to support people with Lupus to access economic resources both in formal and informal sectors.

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