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Stigma toward Worker with Occupational Diseases: A Qualitative Study

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ABSTRACT

Objectives: Despite a growing awareness of the prevalence of such stigma, there is little research that focuses on the sources, nature and consequences of stigma workers with occupational diseases (OD), which directly arises from risks in the workplace. The present study aims to advance knowledge related to stigma towards workers with OD, specifically to explain the nature and processes stigma and their effects on workers.

Methods: This study was qualitative research. The workers with OD were selected to represent the most common diagnoses, then invited for an interview. Thirteen in-depth individual interviews were recorded, transcribed and evaluated using content analysis. The stigmatization was analyzed in two axes as its internal and external features.

Results: A large diversity in the stigmatizing actions and attitudes toward workers with the occupational disease were identified in this study. It was observed that 12 (92.3%) participants had experienced internal and external stigmatization in work-life.

Conclusion: In general, variables, such as the continuation of work, type of occupational disease, presence of complaints and drug use due to illness, were revealed as factors determining the severity of stigma. If occupational health professionals are aware of the stigmatization due to occupational diseases, they may have an effective role in the workplace.

Keywords: Social stigma, occupational diseases, qualitative research



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INTRODUCTION

Work does not only provide money, personal needs, shelter but also provides the opportunity to integrate with society, giving people respect and a role in daily life.^[1] Thus, the emerging problems in work-life may have many effects on the personal as well as social life of people.

It is estimated that there are approximately 217 million workers per year diagnosed with occupational diseases (OD) that defined as diseases directly arise from risk factors in the work environment.^[2, 3] Due to its social and economic aspects, the workers diagnosed OD do not only encounter with medical problems but also social, economic, legal and psychological problems during the process of the diagnosis, treatment, and returning to work. OD and injuries have been tended to focus on medical aspects, including diagnosis and treatment, work disability, compensation, and somewhat preventive measures.^[4-6] However, the broader social consequences of the OD have been investigated rarely. The reciprocal and complex relationships are rather complicated than can be figured out based on the theoretical framework described as the parties involved in the process of work and work-related health outcomes. Dembe described a wide range of “hidden” and “clear” social consequences of OD and injuries, including psychological stress, retaliatory reactions by the employer that

might stimulate anger, drug abuse, or other behavioral reactions, such as stigmatization, isolation among the injured people and co-workers.^[7] Kirsh et al. highlighted many difficulties directed at injured workers, which compounded their physical injuries and brought on psychological harm.^[8] These complex relationships among the individuals and the institutions that involved and/or affected from the results of health and safety problems cause difficulties for researchers attempting to study the social consequences of workplace injuries and illnesses. Therefore, some authors proposed qualitative techniques to better capture the full range of social effects of OD.^[7]

The concept of stigma is frequently associated with the now classic work of Erving Goffman, who in his 1963 book, *Stigma: Notes on the Management of Spoiled Identity*, argued that stigma is “an attribute that is significantly discrediting” and that the stigmatized individual is one who possesses “an undesirable difference”.^[9] Recently, authors have used the term stigma in a wider sense-internal stigma and external stigma. While internal stigma is considered as anticipation and internalization of the stigmatization by individuals, external stigma is related the treats from the others.^[10, 11]

Since Goffman’s writings, the concept of stigma has been considered in relation to many chronic diseases, including cancer, tuberculosis and HIV in different societies. It has been shown that processes of stigmatization may lead to denying diagnosis, non-compliance to the treatment, and poor quality of life and furthermore may give rise to discrimination that may lead to further deterioration of health.^[12–18] There are very few studies on stigma among workers with chronic diseases.^[19, 20] Puhl et al. stated that 54% of workers with obesity were stigmatized in their workplace.^[21] Stergiou-Kita et al. reported the same situation for cancer patients.^[22] Krupo et al. also reported it for mental illness.^[23] Stergiou-Kita has been described that consequences of stigma adversely influence, efforts to stimulate treatment compliance and reduce delays in diagnosis and treatment.^[22]

To our knowledge, there is no study on exploring the extent and nature of stigmatization among workers of those diagnosed with OD. It has been previously hypothesized that due to its complex nature, hindering social, economic and legal aspects of OD may lead to stigmatization of the workers.^[24] Thus, this research aimed to explore the stigmatization among the patients diagnosed with OD.

METHOD

This study is qualitative research. The research group were thirteen workers who were diagnosed OD or work related diseases between November 2013 and February 2016. The study progression is depicted in Figure 1. The most

common and typical cases were considered to select the study cases. The cases were selected with non-probabilistic sample methods. Patients diagnosed with pneumoconiosis 4 (30.7%), occupational asthma (OA) 5 (38.4%) disc hernia 3 (23.0%) and occupational dermatitis (ODe) 3 (23.0%) were selected. Workers were invited to OD Clinic after the completion of the diagnosis process. During the interview, one interviewer conducted the interview; the other interviewer took the notes.

Participants were interviewed using a semi-structured interview guide (Appendix 1). The interviews were tape recorded, transcribed and then evaluated using content analysis. Content analysis was conducted manually. The texts were coded separately by the three researchers. In the analysis, the phenomenon of stigmatization was defined as internal and external stigmatization.^[10, 15]

Internal stigmatization is defined as the feeling of inferiority, shame, concealment and hesitation, which is the result of negative thoughts of a person himself.^[10, 25] Internal stigmatization perception was evaluated under two main themes as “hesitation/shame/loss of self-confidence” and “feel of self-worthlessness”.^[9]

External stigmatization is defined as the positive/negative stigmatizing words, movement, and behavior that one has

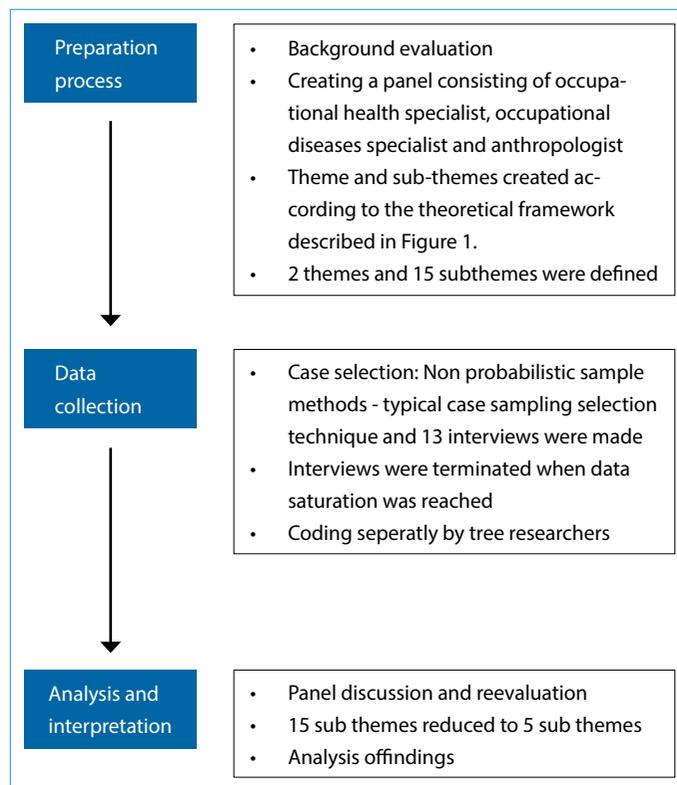


Figure 1. The study progression.

experienced or reflected by other individuals.^[10,26] External stigmatization perception was evaluated under three main themes as social exclusion, the need to hide the illness and the fear of being dismissed/unable to find a work.^[9]

As a result of the interviews, besides the above-mentioned main themes, the similarity of the OD to infectious disease, malady or cancer was considered as the separate themes in the post-hoc evaluations. The results were provided in accordance with the above-mentioned theoretical framework under the themes internal and external stigmatizations and as well as the selected texts, which were obtained from the interviews, that were in italics below.

Descriptive findings were expressed as a mean and standard deviation, and minimum and maximum values. The entire analysis is carried out by SPSS 15.0 package program.

This study was approved by the University Ethics Committee (No: 2016/120-38). The verbal and written consent were obtained from the participants before the interview.

RESULTS

There were 862 patients referred to a university outpatient clinic with the suspicion of OD between November 2013 and February 2016. Of 862 patients, 708 (82.1%) patients were male, and 154 (17.9%) patients were female. Among 862 patients, 352 (40.8%) cases were diagnosed with OD or work-related diseases. The most common OD diagnoses were as follows: pneumoconiosis 161 (45.7%), 71 (20.1%) OA, 38 (10.7%) cervical disc hernia, 24 (6.8%) lumbar disc

hernia, 24 (6.8%) hearing loss, 19 (5.3%) cubital/carpal tunnel syndrome and 15 (4.2%) lead intoxication. We summarized the main characteristics of the participant in Table 1. The mean duration of the interview was 35.4±5.3 minutes. The following discussion elucidates the two main areas of worker with OD—how stigma is exhibited and perpetuated, and the effects of this stigma upon workers. The theoretical framework describing the stigmatization phenomenon is depicted in Figure 2. According to this, the stigmatization may arise from the following three relationships: in work-life, in family relationships and in non-work [and family] relationships. Internal and external stigmatization may occur in each of these sections.

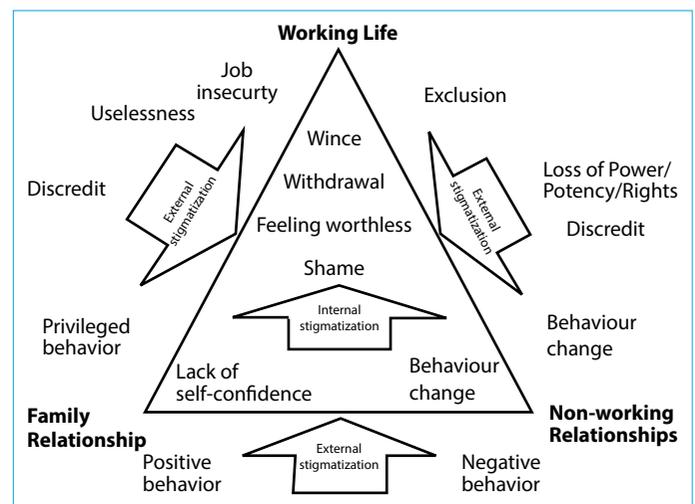


Figure 2. Theoretical framework of the internal and external stigmatization.

Table 1. Sociodemographic characteristics of the participants						
Patient Number	Age/gender	Marital Status	Education	Job Before OD Diagnosis	Type of OD	
1	28y/M	Single	Primary school	Dental technician	Silicosis	
2	42y/F	Married	Secondary school	Factory worker	Lomber disc hernia	
3	36y/F	Married	Primary school	Textile worker	Dermatitis	
4	40y/F	Divorced	Primary school	Chemical jeans bleaching worker	Asthma	
5	27y /F	Married	High school	Nurse	Allergic rhinitis, asthma and dermatitis	
6	27y/F	Single	High school	Nurse	Dermatitis and asthma	
7	38y/F	Married	Secondary school	Pool cleaning worker	Asthma	
8	34y /M	Married	Primary school	Denim sandblasting worker	Silicosis	
9	51y/M	Married	Primary school	Ceramic workers	Silicosis	
10	50y/M	Married	Primary school	Dental technician	Silicosis	
11	41y /M	Single	Secondary school	Ceramic worker	Lomber disc hernia	
12	48y/F	Married	High school	Nurse	Lomber disc hernia	
13	43y/M	Married	High school	Prosthesis worker	Asthma	

OD: occupational diseases

Internal Stigmatization

Self-esteem/hesitation/shame; I have no courage

We observed that the patients diagnosed with OD, compared to the pre-diagnosis period, and had a lack of self-confidence, being timider in their work-life, especially having a tendency to hesitate about a new job application. While one of the patients was explaining why he did not apply for a new job, he was considering the employer would be right when he/she does not consider him as a worker. It was seen how he had interiorized the stigmatization:

(W1) *"I wonder if I can get a new job. I wonder why a lab owner would hire me. Those like me can no longer find a job, they (employer) are right; if I were them, I wouldn't hire people like me."*

After the OD diagnosis, workers started to think that they were no longer good enough for work and worried that they would not be preferred or would be dismissed in the first instance. The loss of self-confidence was less among the younger patients. Elderly workers, on the other hand, had these problems to a great extent as they said, *"I wonder if I can do it", "I don't have the courage" and "My age has already passed."*

In addition to the work-life self-confidence problems, workers tended to spread these feelings that he/she was not able to meet the expectations of society over time. Continuing to work or not was an important factor in the occurrence and acceleration of discouragement about social life.

Feeling worthless, a useless freak!

Most of the workers were already feeling the sense of worthlessness following the OD diagnosis. Particularly in the case of dismissal, some of the patients used "freak", "infirm", "useless", "half-man" and alike words to describe themselves. A 51-year-old worker who was dismissed after the diagnosis of the OD defined himself and his health condition as:

(W9) *"Whenever they see my reports, they consider me an infected freak boy. Like the unsuitable report in the army, namely, if you were disabled, they gave you a report, and nobody gave you a job"*

Similarly, another worker said that:

(W11) *"This is because I am troubled, I am sick. They see me as insufficient; I feel worthless"*

Other cases often used same words related to worthlessness as well. It is thought that a worker diagnosed with OD who is expected socio-economic support than other work-

ers due to health problems would consider him/herself as a person who cannot produce an added-value. It was observed that this process was related to continue to work in the workplace after diagnosis, same as in the theme of self-confidence.

External Stigmatization

Social exclusion "those like us" and "others"

Nine (69.2%) cases defined themselves as "those like us", and stated that other workers considered themselves differently or that they thought they were treated differently in workplace. The patients with OD stated that they were subjected to more or fewer duties by their supervisors, forced to resign, forced to do things that were not his/her duty, forced to work in more difficult sections, being isolated by colleagues, being exposed to bad words and behaviours. After the diagnosis of OD, a worker who sued the employer stated his experiences with his supervisor and colleagues as:

(W2) *"I'm mostly angry with my colleagues. However, I'm trying to take some action for mitigation of working conditions, which is good for my colleagues. However, they do not talk to me. They (colleagues) even deleted social media friendship. This is difficult for me. My colleague intentionally didn't look at me when I saw him in the mall last night."*

Another female worker, who works as a quality control staff, was doing the job of checking out every day about 1000 jeans under the light diagnosed with photodermatitis (kind of ODe) on her face and hands. She needed personal protective equipment to protect herself from light, by the advice of the workplace physician. Her colleagues had sewn a hat from denim instead of buying a professional protective face and head equipment. She shared her feelings as:

(W3) *"I first went to my workplace physician, he was just saying, "it's okay." Then when my face got worse, they said, "Let's enclose your place." They put a grey curtain on the surroundings of my desk; actually, they had to buy me a hat to protect me from the light, but they didn't. The workers in our shift sewed a hat. They sewed a rose on the top of the hat. They were teasing me, saying that there was a crazy here (me); there is a rose in his head (a local sing). I didn't remember being so humiliated in my life."*

In the examples given above, workers may be exposed to similar treats with mobbing. It was a dramatic example that a hat was given to a worker, glued a rose as a marker on that to show the worker was different. It seems that external stigmatization may have the potential to bring on group behaviors against the OD patients. Furthermore,

the stigmatized individual will no longer be in the “normal” group unless he changes his workplace. Although s/he is actually a person like everyone, s/he cannot any longer be the same as before.

Need to hide the illness/being ashamed of disease; is this disease contagious to us?

The theme of hiding the illness was observed in several different ways in the present study. The first experience was that workers did not want to be called sick. Thus, most of the workers who continued to work in the same workplace did not talk about the disease with the other workers. They just tried to maintain their performances and catch the production targets. For example, they were not using their medication in the workplace when close to other workers because drug use was an indication of being sick according to the most of the workers. A participant said about drug use at work:

(W7) *“I have often secretly used my medicines in the workplace. Because I have been feeling so bad at that time, I wanted to avoid that they would think I was sick.”*

Some other participants said that they did not hide their diseases in the workplace. Workers in sectors where pneumoconiosis was common, they consider their illness as a natural consequence of their works. If the patient with OD was the first cases diagnosed in the respected workplace, it was seen that the workers were more worried and had a tendency to hide it.

Another reason for the hiding of the OD is lack of insurance. A worker was mentioned about this as follows:

(W4) *“I have not talked about my illness at the new workplace. I've been working in this office for almost two years and never visited the workplace physician. I go to the toilet to use my medicines when I work. I do not want to use drugs in front of everyone because workers are afraid of such sick people. In my previous workplace, they told me that “you may be a bad example for new workers, use it in the dressing room or in the toilet.”*

This situation was observed in almost all of the workers. All of the participants in this study who left the workplace and applied for a new job stated that they had concealed their illness in the new job application. They were afraid to be treated as worthless or useless. They also tended to conceal their illnesses from their new colleagues. Unlike these two reasons, another important reason for concealing was physical disability, regardless of an OD diagnosis. Especially the women workers were more concerned about their

physical symptoms and trying to hide it. In particular, dermatological complaints have caused serious psychological problems and loss of self-esteem among female workers. It was notable that workers with skin diseases compared their illness to infectious diseases. On this issue, two female participants expressed their discomforts from their own physical appearance:

(W6) *“[...] At that time (at work) my face was very bad, and I did not even want to look to the mirror. They thought I was sick. Some people were asking if it could infect them. I used my medicines secretly (crying).”*

(W5) *“When I had scars in my hands, I always wrapped up my hand and heard negative words from patients and his relatives. My nose was always swollen and red, I think that everyone was looking at my nose. When rhinitis was very bad, sometimes my slime dripping into the bed of patients, they did not want me to help them; sometimes they scolded me.”*

The fear of being dismissed/unable to find work

Both workers diagnosed with OD are reluctant to get diagnosis and they have a fear of being dismissed from the work. Many of the workers stated that they withdrew from the OD outpatient clinic application for this reason. One of the participants involved in this issue said that:

(W4) *“I got out of work 15 days before getting the OD report. But when I first came here (polyclinic), I was still working. And I certainly did not say that I came here. Because they would fire me. I'm unemployed now. And I'm afraid I cannot find a job. Similarly, a friend of mine thinks the same thing that if he takes the OD report. He would not come to get the report, although his health condition is worse than mine.”*

They thought that they would be dismissed after the diagnosis of OD because of the risk of inspection of the workplace or the risk for an employer to be sued by the workers. Those who continued to work in the same workplace said that they would accept fewer personal benefits because of their fear of being fired from work. Workers who make a new job application hide their illnesses, fearing that they will not be able to find a job.

The fear of being dismissed or unable to find work is seen as a prominent theme among workers. All of the workers in the private sector who have been diagnosed with OD talk about the fear of job insurance. Another noteworthy point is that other workers cannot apply for the OD evaluation process due to this fear.

The OD as a metaphor (comparing OD to a malady/cancer/tuberculosis)

During the interviews, it was observed that the patients avoided saying "occupational disease", and instead, they tended to use the word "malady". Some of the patients compared their diseases by "infectious disease", "cancer", and "tuberculosis". Some of the patients' relatives also had some kind of ambiguity related to OD. One of the patients was saying to his wife about the disease, expressing his concern:

(W1) *"They said to me, "You are ill, you are infected with silicosis, go to the Social Security Institution." My wife told me, "I wish you were healthy. I wonder if the disease is going to get me too". What a dirty disease! No remedy! Like tuberculosis! The disease ate my lungs."*

These words depicted the helplessness and despair. Failing to have enough knowledge about OD is thought to be an important factor in the formation of this belief. The fact that workers with OD are treated differently from the others suggests that these diseases are somewhat different and worse than non-OD. For example, when asked about the difference between occupational asthma and non-occupational asthma, most of the participants said that they considered occupational asthma as worse.

DISCUSSION

To our knowledge, our study is the first study exploring the perception of stigmatization in OD. In this study, in-depth interviews were performed with patients diagnosed with OD, in a different age, gender, and type of disease. The stigmatization was analyzed in two axes as the internal and external stigmatization.

In this study, it was observed that 12 of the 13 participants had encountered some extent of stigmatization. We have observed that the type of OD may affect the stigmatization process. For example, in diseases, such as silicosis, which is very well-known in the society and workplace, it is more likely to observe internal stigmatization. Notably, even though there were no significant functional losses or impairment related to OD, stigmatization may occur in those patients. The findings of this research highlight the many sources and types of stigma directed at workers with OD from a variety of actors, including the person himself.

One of the important findings in our study was that the patients diagnosed with OD were feeling worthless and had experienced the loss of self-confidence and therefore tended to be timid in their work and social life. They spent less time with colleagues in leisure times and gave a less break in the workplace to hide diseases that caused stigmatization. A stigmatized individual, with particularly vis-

ible symptoms, tend to hide his/her illness. It was also observed that the loss of self-confidence and worthlessness increased in proportion to the presence of symptoms, the severity of the disease and taking any medicine. It was reported that the perception of stigmatization leads individuals to isolate themselves and move away from their close surroundings.^[11]

Phelan et al. reported similar perceptions in colon cancer patients with a colostomy.^[15] The appearance of colostomy bag by others increases the sense of worthlessness and loss of self-confidence of patients. Kent et al. reported that 80% of the workers with ODe had a loss of self-confidence.^[27] The important thing to emphasize here is that a worker who can escape from social activities can hardly solve the problem of being visible in the work environment. Thus, a worker who is stigmatized tries to disguise in the new job application or even chooses not to apply for the job. That is, it can be speculated that stigmatization may lead to an early exit from work-life.

A worker who is unable to find a new job after diagnosis or who thinks that he will be among the first rank to be dismissed from the job starts to despise himself. This could be considered as the initiation or early sign of the internal stigmatization. Some workers identify themselves with words, such as "diseased," "freak" and "useless" in our study. These descriptions are very important in terms of their content. They labelled themselves with derogatory words, considering as unwanted, unacceptable, and useless people. The workers, who describe themselves with a useless, etc. show that they are inclined to group, by saying "they are", "like us", "they", "normal people" and "other". According to Link and Phalen, this is one of the five components of the stigma.^[28] Grouping behaviors have been frequently demonstrated, especially in labeled people with unacceptable diseases, such as HIV.^[29] However, in this situation, this is not a kind of group behavior or solidarity, but rather a situation that describes unwanted groups of unwanted people. In our opinion, the people who stigmatized in that way trying to cope with this situation by realizing that there are "other people like us".^[9]

Another prominent finding in our study is the problems of OD due to being mostly chronic diseases. Individuals with chronic illness are vulnerable to stigmatization in the workplace, where values of productivity and the ability to maintain a regular schedule conflict with the unpredictable nature of chronic illness symptoms and the need to be away from work for treatment. Stergiou-Kita et al., varied examples of employment discrimination (from job attainment to job advancement) and job termination/dis-

missal have been reported in cancer patients.^[22] Similar to Stergiou-Kita's study, most of all participants pointed the fear of being dismissed and discrimination in our study. Since there is an inherent relationship between work and disease in ODs, it would be expected a higher degree of fear of dismissal among OD patients than chronic disease patients. However, it seems that stigmatization adds some more burden unrelated to the working capacity of the workers. For example, in our study, some of the workers have dismissed during a health examination without being diagnosed. The majority of new job applicants stated that they were hiding their illnesses because of the concern about the lack of recruitment. We have even found clues to suggest mobbing in some interviews. Although mobbing was not systematically questioned in the present study, the obtained incidental findings thought that OD diagnosed workers are prone to mobbing in the workplace. Some patients that continue to work at the same workplace stated that they had been isolated or excluded by their colleagues. In the experience of some patients, the brutality of other workers is more remarkable. This may be because other workers consider such patients with OD to be favored. Kirsh et al. stated that the patients returning to work after the work accident was considered lazy, easy-money-seeking, a useless worker who lie and not have a real problem.^[8] Dionne et al. reported that workers returning to work after a back pain were constantly being judged by other workers, and that even they do not believe in such patients and that they think patients with OD were pretending as sick.^[30] Mobbing after OD could be an important research topic to investigate for further interpretation of our findings.

As an unexpected result, when talking about diseases, some patients also used other stigmatized diseases, such as cancer, tuberculosis and malady and refused to refer it as OD. This kind of association between OD and these diseases also reflects "irrational" considerations of the patients about their illnesses. OD is perceived as a metaphor in a similar way to the above-mentioned diseases. In fact, they want to show their desperation about this issue by likening their diseases to a persistent disease that is difficult to treat. Nonetheless, there are a few limitations and considerations that must, however, be noted when utilizing findings from this study. In the present study, sample was limited to individuals with OD. Different stakeholders, such as family members, co-workers, employers and workplace physicians, would be important concerning understanding the different aspects of stigmatization. Much work remains to be done to understand better the connections between OD, work and stigma.

CONCLUSION

We have observed that workers diagnosed with OD had experienced the internal and external stigmatization in work-life. One of the significant findings of our study is that job security and continue to work are important determinants for prevention from stigmatization. Providing adequate information, including disease and stigmatization, at the diagnosing health centre, can help to cope with stigmatization. Furthermore, if occupational health and safety professionals are aware of the stigmatization, they may have an effective role in preventing it in the workplace. Occupational health professionals also have a key role in supporting job applicants and employees who disclose OD.

Disclosures

Peer-review: Externally peer-reviewed.

Conflict of Interest: None declared.

Ethics Committee Approval: This study was approved by the University Ethics Committee (No: 2016/120-38).

Authorship Contributions: Concept – A.C.B., S.E., Y.D.; Design – A.C.B., S.E., Y.D.; Supervision – Y.D.; Materials – A.C.B., S.E.; Data collection &/or processing – A.C.B., S.E., Y.D.; Analysis and/or interpretation – A.C.B., S.E., Y.D.; Literature search – A.C.B., S.E.; Writing – A.C.B., S.E., Y.D.; Critical review – Y.D.

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Appendix 1.

Name-surname

Date

Interviewer

Internal stigmatization

After Occupational disease (OD) diagnosis;

- 1 Did you think any change in your life? Positive or negative manner?
- 2 Did you feel worthless?
- 3 Did you blame yourself because of disease?
- 4 Did you need to hide your diagnosis?
- 5 Did you feel shame?
- 6 Are you worried about your future ?
- 7 Do you think you can work as before?

External stigmatization

- 8 Did you tell about your diagnose to your colleagues?
- 9 Have you been asked any question about your sickness (By colleagues)?
- 10 Did you hide your diagnosis ?
- 11 Did you think your colleagues' behaviours have been changed after your OD diagnosis?
- 12 If there is any changes in your work schedule after the OD?
- 13 What did your friends think about your illness?
- 14 Did your friends ask questions about OD? What they were ask?
- 15 Did your colleagues blame you because of your illness?
- 16 Did they consider you kind of lucky because of your illness? Since your work reduced or sick-leave
- 17 Whether your supervisor treat you as s/he used to be?
- 18 Do you think your job security is decreased after diagnosis?
- 19 Have you been used your medicines comfortably at work?
- 20 Does your income have changed after the diagnosis of OD?