Editorial / Uvodnik

Social stigma in the time of coronavirus (COVID-19): an epidemic we must not remain silent about

Družbena stigmatizacija v času koronavirusne bolezni (COVID-19): epidemija, o kateri ne smemo molčati

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The SARS-CoV-2 epidemic (COVID-19) we have unexpectedly found ourselves caught in presents an important challenge for humanity in many respects. In the context of nursing, 2020 was set out to be a particularly solemn year as the World Health Organization had designated it the International Year of the Nurse and the Midwife, with the aim of highlighting the key role of nurses and midwives in promoting health, preventing disease, and providing holistic healthcare.

At a time when nursing professionals should be celebrating their profession, highlighting its importance for people's health, and drawing the attention of politicians and the general public to their day-to-day struggles, nurses around the world are fighting a battle to provide crisis care. Their selfless role and efforts have by no means gone unnoticed; at the very least, they have further revealed the actual problems the profession has been facing (for example, the near proverbial understaffing). At the same time, along with the overwhelmingly positive social response, adverse reactions such as stigmatisation and discrimination have also been exposed, which show a lack of compassion and humanity towards those suffering from the coronavirus disease, as well as those who provide care for them. The fear of the disease has also resulted in the stigmatisation and discrimination of entire cultural groups associated with the characteristics of the initial virus and disease outbreak and the subsequent outbreaks in individual countries and continents. Although it was already in 2015 that recommendations for naming newly discovered infectious diseases were adopted by the World Health Organization (2015) in an attempt to reduce the pressures of disease-related stigmatisation and discrimination, and despite the efforts to assign it a neutral name, the coronavirus disease is still often called the "Wuhan / Chinese virus".

Ever since the outbreak of the epidemic, reports of social stigmatisation of patients and healthcare providers have come from virtually all places with the coronavirus disease – both from Slovenia's immediate vicinity as well as from Slovenia itself. In this regard, the residents of places such as Šmarje pri Jelšah and Metlika have been among those most exposed throughout the epidemic. Identified as potential sources of infection transmission due to the nature of their work, their working conditions and other unfortunate circumstances, healthcare professionals have been among the most adversely affected groups and have consequently been a target to social stigma (Centers for Disease Control and Prevention, 2020; Chung & Li, 2020; Huang & Liu, 2020; World Health Organization, 2020a). It was the daily case counts of the newly infected, dead and hospitalised, disdain for those infected and their caregivers in long-term care institutions, and monitoring of the location of positive cases and socio-demographic characteristics of patients that burdened people much more than the disease itself. Thus, for many, the fear of social stigma represented a burden disproportionally greater than that of the disease itself, leading to a disproportionally more reckless and riskier behaviours endangering human health and human lives.

In 1990, in his psycho-social model of an epidemic (Epidemic Psychology: A Model), sociologist Philip Strong attempted to explain human behaviour during major epidemics. His model comprises waves of fear, panic, stigma, moralising and calling for social action. He argued that an epidemic follows its own psycho-social course independent of the epidemic of the disease itself, but that, like the disease itself, it spreads rapidly from person to person and has both individual and collective impact. As it spreads, it takes on the

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various forms of psycho-social epidemics: namely the epidemic of fear, the epidemic of explanation and moralisation, and the epidemic of social action or calling for such action. From a sociological point of view, these three types of epidemics infect (much more intensely at the outbreak of a new, unknown disease) virtually every member of society, which is why each society experiences waves of individual and collective fear, outbreaks of interpretations of the causes for the epidemic, moral polemics, and floods of containment strategies, directed towards either controlling the disease itself or in controlling the epidemic of fear and social disintegration (Strong, 1990).

The "social course" of the disease may be completely independent of its biological course, especially during epidemics (Strong, 1990). For us to understand the social course of the disease, we first need to understand the subjective meanings and experiences people attribute to the disease. In so doing, we need to focus on the social and cultural values contributing to the formation of social perception of the disease. In this context, the disease also reflects the existence of stereotypes and prejudices against a specific cultural group or even becomes a cultural metaphor for existing social problems (Klinenberg, 2019), and hence also a social, economic and political issue. Since disease has always been and always will be a social marker, it is hence the subject of many social discourses which persistently raise doubts about the basic life strategies and decisions of individuals and entire societies or cultures (Ule, 2003), and also importantly contribute to social responses to the disease.

It was Goffman (2008) who proved that the borderlines of "normality" can only be defined through "abnormality". In this respect, stigma is regarded as a human universal which will always accompany humanity in times of social crises. It is precisely in such situations that stigma has the potential to erupt in new and more intense forms of stigmatisation (Strong, 1990). In an outbreak of a disease, this also means an outbreak of a psycho-social epidemic in which people are stigmatised, stereotyped, discriminated against, treated unequally and may lose their social status due to a perceived association with the disease. This negatively affects not only patients but also their carers, family, friends and the local community. Healthy individuals bearing those characteristics which society associates with the disease are thus stigmatised in exactly the same way. This is how stigma threatens social cohesion and requires social isolation of groups, which in COVID-19 conditions increases the likelihood of infection spread and jeopardises epidemic control. It leads individuals and / or groups to conceal illness; it prevents people from seeking appropriate help and discourages them from adopting healthy habits (World Health Organization, 2020a). On the other hand, not only do stigmatisation and discrimination adversely affect healthcare professionals' social status as well as that of their families, but the increases in violent acts more frequently perpetrated against health professionals during a crisis also hinder the provision of healthcare to people with COVID-19 (Huang & Liu, 2020; World Health Organization, 2020b).

What then can one do to reduce the social stigma associated with COVID-19? One can acknowledge the existence of stigma and develop an awareness that ignorance and fear are the most common barriers to an appropriate response. In order to work effectively against the disease and to avoid "inciting" fear, stigma and discrimination, it is crucial to provide information related to COVID-19 infection in a suitable way. While clearly condemning any stigma, discrimination and / or associated violence, we need to create a safe environment in which we openly, honestly and effectively discuss the disease and its consequences (Nyblade, et al., 2019; World Health Organization, 2020a). Among the ways in which to approach social stigma and prevent its reinforcement, the World Health Organization (2020a) emphasises that (1) all communication channels should use language which does not "criminalise" or dehumanise people, but empowers and conveys respect towards people; (2) action should be taken to disseminate verified facts and support, and implement measures against the spread of new coronavirus infections; (3) misconceptions, rumours and disinformation should be prevented by acting in a spirit of collective solidarity and global cooperation. Moreover, as healthcare professionals we must also be aware of the moral and social responsibilities we bear in our professional roles, and, despite the obstacles, maintain a culture of tolerance and remain dedicated to caring for our fellow human beings who, during an epidemic, need us most.

Slovenian translation / Prevod v slovenščino

Epidemija SARS-CoV-2 (COVID-19), v kateri smo se nepričakovano znašli, predstavlja z več vidikov pomemben izziv za človeštvo. V zdravstveni negi naj bi bilo leto 2020 še posebej slavnostno, saj ga je Svetovna zdravstvena organizacija razglasila za mednarodno leto medicinskih sester in babic z namenom, da bi izpostavili ključno vlogo medicinskih sester in babic pri promociji zdravja, preprečevanju bolezni in zagotavljanju celovite zdravstvene oskrbe.

V času, ko naj bi v zdravstveni negi še posebej slavili svoj poklic, izpostavljali pomen poklica za zdravje ljudi in tudi usmerjali pozornost politike in javnosti na vsakdanje težave poklica, medicinske sestre po vsem svetu bijejo bitko z zagotavljanjem zdravstvene nege v kriznih razmerah. Njihova požrtvovalna vloga in prizadevanja nikakor niso ostala neopažena, kvečjemu so še bolj razgalila dejanske probleme, s katerimi se sooča stroka (na primer z že skorajda pregovorno

kadrovsko podhranjenostjo). Sočasno pa so se ob množici pozitivnih družbenih odzivov razgalili tudi negativni, kot sta stigmatizacija in diskriminacija, ki sta pokazali na pomanjkanje človečnosti soljudi do obolelih za koronavirusno boleznijo kot tudi do tistih, ki zanje skrbijo. Strah ljudi pred boleznijo je botroval tudi temu, da so postale stigmatizirane in diskriminirane celotne kulturne skupine, povezane z značilnostmi pojava virusa oziroma z začetnim pojavom izbruha bolezni in v nadaljevanju z žarišči izbruha v posameznih državah in kontinentih. Čeprav je Svetovna zdravstvena organizacije leta 2015 sprejela priporočila za poimenovanje novoodkritih nalezljivih bolezni (World Health Organization, 2015) in tako poskušala zmanjšati pritiske stigmatizacije in diskriminacije zaradi bolezni, je koronavirusna bolezen še vedno (kljub trudu za nevtralno poimenovanje) povezana z imenom »vuhanski / kitajski virus«.

Poročila o družbeni stigmatizaciji obolelih in zdravstvenih delavcev so od začetka epidemije prihajala domala iz vseh krajev, kjer se je koronavirusna bolezen pojavila – tako iz naše neposredne bližine kot tudi iz Slovenije, zlasti prvih žarišč. Prebivalci krajev, kot so Šmarje pri Jelšah ali Metlika, so bili ves čas trajanja epidemije med najbolj izpostavljenimi. V negativnem smislu so bili izpostavljeni tudi zdravstveni delavci, saj so bili zaradi narave in pogojev dela ter drugih, tudi nesrečnih, okoliščin prepoznani kot relevanten vir prenosa okužbe in posledično tarča družbene stigmatizacije (Centers for Disease Control and Prevention, 2020; Chung & Li, 2020; Huang & Liu, 2020; World Health Organization, 2020a). Dnevno štetje primerov – na novo okuženih, umrlih in hospitaliziranih –, »zmrdovanje« nad okuženimi v socialnovarstvenih zavodih in njihovimi skrbniki, spremljanje lokacije pojava pozitivnih primerov in socialno-demografske značilnosti obolelih so ljudi obremenjevale veliko bolj kot sama bolezen. Strah pred družbeno stigmo je pri marsikom predstavljal neprimerno večje breme kot sama bolezen, kar vodi v neprimerno slabše in tvegano vedenje, ki ogrozi zdravje in življenje ljudi.

Leta 1990 je sociolog Philip Strong v psihosocialnem modelu epidemije (*Epidemic psychology: A model*) poskušal pojasniti človekovo ravnanje v času velikih epidemij. Zapisal je, da omenjeni model vodijo valovi strahu, panike, stigme, moraliziranja in pozivanja k družbeni akciji. Trdil je, da ima epidemija samosvoj psihosocialni potek, neodvisen od epidemije same bolezni, ki pa se ravno tako kot bolezen širi hitro od osebe do osebe in ima tako individualni kot tudi kolektivni vpliv. S širjenjem prevzema različne oblike psihosocialne epidemije: prva je epidemija strahu, druga je epidemija pojasnjevanja in moraliziranja, tretja pa epidemija družbene akcije oziroma pozivanja k njej. S sociološkega vidika ti trije tipi epidemij okužijo (veliko bolj intenzivno ob izbruhu nove, neznane bolezni) skorajda vsakega člana družbe, zato vsaka družba vzajemno občuti valove individualnega in kolektivnega strahu, izbruhe interpretacij vzrokov za pojav epidemije, moralnih polemiziranj in poplave strategij zajezitve, usmerjene bodisi v obvladovanje same bolezni bodisi v nadzorovanje epidemije strahu in družbenega razkroja (Strong, 1990).

»Družbeni potek« bolezni je lahko povsem neodvisen od njenega biološkega poteka, še posebej to velja v času epidemij (Strong, 1990). Da bi razumeli družbeni potek bolezni, moramo razumeti subjektivne pomene in doživljanja, ki jih ljudje pripisujemo bolezni. Pri tem se moramo osredotočiti na družbene in kulturne vrednote, ki prispevajo k tvorbi družbenega zaznavanja bolezni. V tem kontekstu bolezen odraža tudi obstoj stereotipov in predsodkov o določeni kulturni skupini ali postane celo kulturna metafora za obstoječe družbene probleme (Klinenberg, 2019) in s tem socialno, ekonomsko in politično vprašanje. Dejstvo je, da je bolezen vedno bila in bo socialni označevalec in s tem predmet mnogih družbenih diskurzov, ki vztrajno povzročajo dvom o temeljnih življenjskih strategijah in odločitvah posameznikov in celotne družbe oziroma kulture (Ule, 2003), s tem pa pomembno prispevajo k oblikovanju družbenega odziva nanjo.

Že Goffman (2008) je dokazal, da so meje »normalnosti« lahko definirane le skozi »nenormalnost«. Stigma je v tem pogledu človekova univerzalnost, ki bo vedno spremljala človeka v času družbenih kriz. Prav v takšnih situacijah ima stigma potencial, da izbruhne v novih in bolj intenzivnih oblikah stigmatizacije (Strong, 1990). Ob izbruhu bolezni to sočasno pomeni tudi izbruh psihosocialne epidemije, v kateri so ljudje etiketirani, stereotipizirani, diskriminirani, neenako obravnavani in / ali izgubijo status zaradi zaznane povezave z boleznijo. To negativno vpliva na obolele in njihove skrbnike, družino, prijatelje in lokalno skupnost. Na enak način so stigmatizirani zdravi ljudje z značilnostmi, ki jih družba povezuje z boleznijo. Stigma na ta način ogrozi družbeno povezanost in zahteva družbeno izolacijo skupin, kar v razmerah COVID-19 povečuje verjetnost širjenja okužbe in ogroža nadzor epidemije. Posameznike in / ali skupine vodi v prikrivanje bolezni; ljudem preprečuje, da bi poiskali ustrezno pomoč, in jih odvrača od prevzemanja zdravih navad (World Health Organization, 2020a). Po drugi strani pa zdravstvenim delavcem stigmatizacija in diskriminacija ne otežujeta le njihovega družbenega položaja in / ali položaja njihove družine, temveč tudi nudenje zdravstvene oskrbe ljudem s COVID-19, saj se v času krize zdravstveni delavci med drugim soočajo tudi s povečanjem števila nasilnih dejanj (Huang & Liu, 2020; World Health Organization, 2020b).

Kaj pravzaprav lahko naredi vsak posameznik za zmanjševanje družbene stigme, povezane s COVID-19? Prizna, da stigma obstaja, in vzpostavi zavedanje, da sta neznanje in strah najpogostejši oviri za ustrezen odziv. Za učinkovito delovanje proti bolezni, in da bi se

izognili »podžiganju« strahu, stigmi in diskriminaciji, je ključno, kako posredujemo informacije, povezane z okužbo s COVID-19. Razviti je treba varno okolje, da bomo lahko odprto, iskreno in učinkovito razpravljali o bolezni in njenih posledicah (Nyblade, et al., 2019; World Health Organization, 2020a), ter obenem jasno obsoditi vsakršno stigmatizacijo, diskriminacijo in / ali s tem povezano nasilje. Med načini, kako pristopati do družbene stigme in je ne poglobiti, Svetovna zdravstvena organizacija (World Health Organization, 2020a) poudarja, da je treba (1) v vseh komunikacijskih kanalih uporabiti jezik, ki ne »kriminalizira« ali razčloveči oziroma postavlja človeka na prvo mesto, ki spoštuje ljudi in jih opolnomoči; (2) aktivno ukrepati – širiti preverjena dejstva ter podpirati in izvajati ukrepe proti širitvi okužbe z novim koronavirusom; (3) preprečevati napačne predstave, govorice in neresnične informacije ter delovati v duhu kolektivne solidarnosti in globalnega sodelovanja. Vsi zdravstveni delavci se moramo obenem zavedati tudi moralne in družbene odgovornosti, ki ju nosimo v okviru svojih profesionalnih vlog, ter kljub oviram ohranjati kulturo strpnosti in ostajati zvesti skrbi za soljudi, ki nas v času epidemije najbolj potrebujejo.

Conflict of interest / Nasprotje interesov

Avtor izjavlja, da ni nasprotja interesov. / The author declares that there is no conflict of interest.

Literature

Centers for Disease Control and Prevention, 2020. *Reducing Stigma*. Available at: https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/reducing-stigma.html [12. 5. 2020].

Chung, R.Y.-N. & Li, M.M., 2020. Anti-Chinese sentiment during the 2019-nCoV outbreak. *The Lancet*, 395(10225), pp. 686–687.
https://doi.org/10.1016/S0140-6736(20)30358-5

Goffman, E., 2008. *Stigma: zapiski o upravljanju poškodovane identite*. Maribor: Aristej.

Huang, J. & Liu, R., 2020. Xenophobia in America in the age of Coronavirus and beyond. *Journal of Vascular and Interventional Radiology,* In Print.
https://doi.org/10.1016/j.jvir.2020.04.020
PMCid:PMC7188638

Klinenberg, E., 2019. Dying alone: the social production of urban isolation. In: P. Conrad & V. Leiter, eds. *The Sociology of Health and Illness*. 10th ed. Thousand Oaks: Sage, pp. 139–155.

Nyblade, L., Stockton, M.A., Giger, K., Bond, V., Ekstrand, M.L., Lean, R.M., et al., 2019. Stigma in health facilities: why it matters and how we can change it. *BMC Medicine,* 17(1), p. 25.
https://doi.org/10.1186/s12916-019-1256-2
PMid:30764806; PMCid:PMC6376713

Strong, P., 1990. Epidemic psychology: a model. *Sociology of Health & Illness,* 12(3), pp. 249–259.
https://doi.org/10.1111/1467-9566.ep11347150

Ule, M., 2003. *Spregledana razmerja: O družbenih vidikih sodobne medicine*. Maribor: Aristej, p. 35.

World Health Organization, 2015. *WHO issues best practices for naming new human infectious diseases*. Available at: https://www.who.int/mediacentre/news/notes/2015/naming-new-diseases/en/ [17. 5. 2020].

World Health Organization, 2020a. *Social Stigma associated with COVID-19*. Available at: https://www.who.int/docs/default-source/coronaviruse/covid19-stigma-guide.pdf?sfvrsn=226180f4_2 [19. 5. 2020].

World Health Organization, 2020b. *WHO calls for healthy, safe and decent working conditions for all health workers, amidst COVID-19 pandemic*. Available at: https://www.who.int/news-room/detail/28-04-2020-who-calls-for-healthy-safe-and-decent-working-conditions-for-all-health-workers-amidst-covid-19-pandemic [21. 5. 2020].

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