



Stigmatisation and discrimination: a guide for healthcare workers

WP3 Prototype Online Course for Primary Care Staff

Responsible Partner: ZADIG
Contributing partners:

Dissemination level: PU



Document Management

PROJECT FULL TITLE	Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
PROJECT ACRONYM	TELL ME
	Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks”
GRANT AGREEMENT	278723
STARTING DATE	01/02/2012
DURATION	36 months

Stigmatisation and discrimination: a guide for healthcare workers

Task: 3.3

Leader: ZADIG – Other contributors: none

History of changes:

Vn	Status	Date	Organisation / Person responsible	Reason for Change
V1	Draft	30/1/2014	ZADIG	First draft
V2	Draft	14/5/2014	ZADIG	Second draft
Vf	Final	22/5/2014	ZADIG	Final draft

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INTRODUCTION

Being at the interface between institutions and citizens, healthcare workers play a fundamental role within public health. They represent the first line of intervention during an infectious disease outbreak and must be involved in preparedness and emergency plans from health authorities. This also implies that they should be aware of the importance of an effective risk communication in case of an epidemic and the best approaches to be followed, in order to properly manage it. Amongst the many relevant issues of risk communication during infectious disease outbreaks, there are those concerning stigmatisation and, in general, all violation of human rights, which constitute a serious problem for healthcare.

At first, it is important, for healthcare workers, to know why stigmatisation represents a serious issue for public health. Thus, the first section of this dossier will go further into the concept of stigmatisation and describe its negative consequences in terms of health, both in general and in the specific context of an epidemic or pandemic. The second chapter will provide useful information and advices to deal with stigmatisation-related issues within the doctor–patient relationship, while the third part of this dossier will examine the categories most at risk of suffering for stigmatisation. The fourth chapter will explain what differentiates human rights from medical ethics, and show their application in case of an epidemic.

1. The concept of stigmatisation

Since Greek times, a stigma was a mark or sign that indicated the individual who had it was of inferior moral quality, such as a slave, a criminal, a prisoner of war (Jones, 1987). Despite the different meaning given to the term by Christianity, related to the virtuous wounds of Christ (Ganzevoort, 2008), modern day use of the word seems to have returned to the original purpose: identifying individuals as not belonging to the normal social class of persons, thus indicating that they merit a higher level of concern than individuals considered normal (Hsin Yang et al, 2007). Stigmatised individuals can perceive themselves of being thought of in such way with psychological harms that can influence behaviour.

Individuals suspected to be carrying infectious disease are at risk of stigmatisation. Differential treatment of individuals in the healthcare process can cause or worsen an already pre-existing situation of stigmatisation than results because of the individual being part of a minority group. Such groups can range from the classic examples that are prone to stigmatising and discriminatory behaviour (e.g. racial, religious, sexual orientation, age) to more specific groups that only arise in specific healthcare contexts.

1.1. Negative Effects of Stigmatisation

Stigmatisation can create and exacerbate healthcare inequalities. This is because stigmatised individuals can often act differently in terms of their behaviour in seeking healthcare than others. Such behaviour often results from the negative self-judgment that these individuals have made as a result of their stigmatisation and could lead them not to seek help (Courtwright, 2009). For instance, an individual with a particular diagnosis – like HIV or hepatitis – could be scared by the expected social reaction that is likely to result from his condition and could thus feel a need to hide such condition from not only the public but also health care professionals.

In addition, during the context of an epidemic, marginalised groups that are already the source of stigmatisation (HIV again being a prominent example), may often be more at risk of contracting the condition itself, thus reinforcing the stigmatisation that such groups feel by both the epidemic and the healthcare response to it. It is thus clear that stigmatisation has many possible ways to bring about negative outcomes, which can be classified into both direct and indirect effects.

1.1.1 Direct Effects on Health

There is evidence that individuals who perceive themselves to be lower in the social order often undergo a chronic physiological stress response. Furthermore, stress has been shown to be more prevalent in more unequal societies. This response is associated with an increase in the production of stress hormones that, in the long term, can lead to a condition of chronic stress, which has been linked to negative health effects like poorer level of cardiovascular health (Marmot, 2004). The relationship between social positioning and health problems has also been recently used to explain why more equal societies do better (Wilkinson & Pickett 2010).

Another possible negative of such chronic stigmatisation is depression (Deacon, 2006), which is harmful in itself but which can also increase the likelihood of substance abuse and other harmful behaviours, including the refusal to follow health prevention measures that can lead to an increased risk to contract a disease, which would in turns strengthen the stigmatisation.

1.1.2. Indirect Effects on Health

In addition to the direct stress response, stigmatisation may also trigger a range of indirect negative effects that can be attributed to the notion of self-loathing or lack of individual self-worth (Courtwright, 2009). This alters individual behaviour so as make in several ways that can bring about negative consequences.

One of the main issues is the reduced desire to seek healthcare when needed, typical of group whose members, in attempting to obtain healthcare, are the subject of stigmatisation as a result of their membership of the group itself (Gornik, 2000). For instance, black or other groups with a perceived lower socio economic status are slower to seek treatment than their white counterparts, mainly because they feel they are to be judged more responsible for the condition through irresponsible behaviour than the white peers (Chesney, 1999). It is thus important not to exacerbate pre-existing stigmatisation and to always keep in mind that individuals who are stigmatised may have an increased aversion to using medical services.

Individuals that are the subject of stigmatisation often suffer a lesser motivation to secure important resources in social life. Among these resources, together with education or employment opportunities, there is also healthcare (Courtwright, 2009). It has been demonstrated that lower levels of education and lower incomes have a clear association with lower levels of personal health, which in turns result in disparities in personal health levels between stigmatised and non-stigmatised groups (Courtwright, 2009). Medical authorities should, during the context of an epidemic, aim in so far as is possible not to further worsen such problems.

1.2. Stigmatisation during epidemic/pandemic situations

In the context of epidemics, groups that are prone to stigmatisation include people that have a perceived connection with the geographic and/or animal origin of the outbreak, members of the medical profession, those who are part of pre-stigmatised groups and those individuals who actually become infected themselves. It is important to note that stigmatisation can occur even where there is no actual discrimination occurring.

The existence of such individuals and their susceptibility to stigmatisation must be taken into account when planning public health responses to epidemic situations. Stigmatisation should be avoided not only because of the moral issues that may be involved, but also because stigmatisation can create or augment certain very deleterious effects that can have negative consequences for both the individuals involved and also for society as a whole. In addition, these consequences could endure even after the epidemic has disappeared.

During a pandemic, as it may be obvious, the group of individuals that will experience the most stigmatisation issues are those who become infected. The stigmatisation of other groups (other than those who are infected) in an epidemic situation is based on assumptions that, because of their various characteristics, they are at increased risk of infection and therefore pose a threat. Individuals who are actually infected obviously pose a greater 'threat' than those who may be infected and so will be subject to a higher level of stigmatisation. Individuals who become infected therefore suffer from two conditions, the disease itself and the stigmatisation that comes with infection.

The SARS outbreak provided a recent example of the potential stigmatisation issues that individuals can face, even after their deaths (Kleinman & Lee, 2005). In China, instances of stigmatisation and discrimination included refusal by some funeral homes to handle the bodies of SARS victims, reluctance of certain medical and paramedical staff to care for SARS patients, discrimination of health professionals, e.g. refusing a service in the barber shop, forcing of employees to take annual leave as they had recently been to the hospital or to parts of mainland China hit by SARS.

2. Dealing with stigmatisation

There are two important ways for public institutions and health professionals to act in order to protect individual ability for self-respect and therefore to guard against stigmatisation (Rawls, 1971). First, individuals should be treated equally, irrelevant of any social group they belong to. This is of great importance for healthcare professionals, since they represent the first line of interaction with patients and should therefore act in order to ensure that all minorities and groups in society receive equal protection and treatment in response to epidemic threats. However, stigmatisation can also manifest as private behaviour that prevent individuals in stigmatised groups from using public services to the same extent as individuals in non-stigmatised groups.

An effective method that has been proposed to minimize such sources of stigmatisation was the establishment of independent associations that represent groups prone to stigmatisation, which are able to provide a secure space for stigmatised individuals to associate with other such individuals (Rawls, 1999). Healthcare workers should be aware of the existence of such groups and should foster communication with them, in order to encourage individuals to maintain "self-respect", thus being more likely to continue to seek

access to the required public goods such as public healthcare. Such an approach has shown itself to be very efficacious in the reduction of stigmatisation for those individuals who are HIV positive. The engagement of such groups could be optimised not only through the identification of such groups (where possible) long in advance of an epidemic but also through constructive dialogue in the planning of a response to a potential epidemic.

Communication strategies aimed to tackle risks of stigmatisation should not be targeted only at those persons belonging to minority groups; it is of great importance to remind all the people that the risks of contracting the infectious agent in question from individuals from the minority group is not usually higher than from someone in the general population.

2.1. Being ready and being trustworthy

It is very important to note that all the strategies and approaches that can be adopted to deal with stigmatisation require a good level of trust, which is not something that can be built at the moment but needs to be pursued way before the beginning of an epidemic. This is true at all levels of the healthcare hierarchy and particularly for healthcare workers, since they are those who daily and directly interact with patients.

It is thus important for a healthcare worker to be perceived as trustworthy; during an emergence, such perception will make people, even those at risk of stigmatisation, more likely to ask him for medical help and advice. In fact, the response of medical professionals can be important in the decision of stigmatised individuals to seek medical attention. Individuals are less likely to seek treatments from individuals that hold stigmatising views. This is an important factor that may help in explaining why, even in societies that create systems of equal access to healthcare, one does not always see the same levels of utilisation for the various groups that make up that society.

Stigmatisation in the context of epidemics may result from being part of a minority group, having some kind of “special” connection with the disease due to geographic, ethnic or working reasons, or having particular lifestyles. Healthcare professionals should be aware of these elements when dealing with their patients, in order to be able to identify potential stigmatisation issues in advance and to face them properly. Knowing people’s experiences, values and beliefs, and sharing their preoccupations, are two fundamental points on which to build a trust-based relationship, which in turns plays a key role in an effective risk communication, particularly when dealing with stigmatisation.

Healthcare professionals should also report in advance every possible case of stigmatisation they are aware of, in order to help health measures planning and to increase the surveillance level of potential cases.

2.2. Social Contact

Social contact plays a key role in every aspect of the doctor–patient relationship. Communication is characterized by two aspects: the content and the way by which it is delivered. A message is not only made of spoken or written words but also of non-verbal elements, such as expressions, gestures, tone of the voice, et cetera. An effective communication with patients should not be considered as a one-way transmission of information by the healthcare professional. The impact of such information on the patient and its awareness should always be taken into account and this may be done through listening, empathy, interaction and

feedback. Such an approach helps the doctor to know the patient's history, which is one of the best ways to notice in advance those elements that could lead to stigmatisation.

Social contact is associated not only with individual happiness and contentment but also with human health. Research has shown a clear link between level of social support available to individuals and morbidity and mortality (Uchino et al, 1996). Social contact can also provide an important coping mechanism for those who feel stigmatised. In recent decades, this is a topic that has received a considerable amount of attention from researchers (Reblin & Uchino, 2008). Social isolation has been indicated as an increased risk factor for most types of mortality. Additionally, in recent years research has highlighted that individual health is not only improved by receiving support but by the ability of individuals to bestow care on others.

2.3. Personal privacy

Another aspect that every healthcare professional should always keep in mind is the importance of personal privacy as a tool against stigmatisation. Individuals should be allowed to seek care in a manner that will not unnecessarily compromise their personal privacy. In some cases this may mean not adding too much information regarding their condition to the record in order to assuage individual fears – whether rational or not – that the presence of their condition on their record will be used in a negative fashion by future employers or insurers.

The availability of anonymous testing and even treatment would likely mean that an increased number of individuals would feel less restricted by potential stigmatisation and seek treatment for their condition. In order to take advantage of the benefits that an anonymous environment would offer it would not be enough to have anonymous testing procedures in place, but such procedures would have to be actively publicised and disseminated so that individuals were aware of them (Herek et al, 2003).

2.4. Facing misinformation

In the early stages of an outbreak of an infectious disease it seems that individuals make use of the little information they have in order to protect themselves as much as possible. This will likely include, for instance, finding information on the possible geographical origins of the infectious agent in question. In an age where non-official sources of information are numerous and, to a certain extent, uncontrollable, individuals will always have access to a wealth of information even if no officially sanctioned information is yet available.

The Internet and social media has the potential to provide both reliable and unreliable information during an epidemic. During a vacuum in terms of official information, such facilities can spread rumour and conjecture widely and almost instantly. In the absence of official information, human instinct tends to take over with a likely result that assumptions will be made as to what constitutes a danger in terms of infection.

Healthcare professionals must be aware of the main rumours and conjectures that are circulating, in order to be able to better debunk them, thus decreasing the risk of stigmatisation they may provoke. They should also report any case of misinformation to medical authorities, allowing them to act by targeting the release of more accurate information designed to dispel any harmful unfounded rumours that may be circulating.

3. Categories at risk

Some categories of individuals are more likely than others to suffer stigmatization during the context of an epidemic. These include:

- pre-stigmatised groups e.g. the poor, homeless, immigrants, the old, individuals with conditions that result in a reduced immunity, ethnic minorities;
- individuals that become infected;
- individuals associated with the perceived origin of the outbreak in question;
- individuals that are to be vaccinated;
- medical Professionals.

3.1. The “origin issue”

Epidemics of infectious diseases have often been linked in popular perception to groups of individuals that have a particular origin. A good example for that is what happened in 2009, during the H1N1 pandemic: Mexico was perceived as being the origin of the new virus and this caused the outbreak to be called the Mexican flu in many states because it was thought to have first originated there (Gallagher, 2009). Information on the possible origin of an infectious agent is often the source of fear and anxiety and this came out clearly in 2009: for instance, there have been ships refusing to dock in Mexican ports, even in areas where there had been no incidence of infection, but which were willing to dock in US areas where infections had actually occurred. H1N1 fears led Haitian officials to turn back a Mexican ship carrying humanitarian food aid (CNN, 2009). Also, the identification of Mexico as ground zero of the emerging pandemic led to Mexican individuals experiencing numerous problems around the world and even in their own country, like unnecessary quarantine procedures or, in the US, the case of conservative media personalities who blamed Mexican immigrants for spreading the disease across the border, continuing their scapegoating of immigrants (Allison T, 2009).

There are plenty of similar examples in epidemiology: the great influenza pandemic at the end of the First World War, which was mistakenly given Spanish origins by many (Barry, 2004); an outbreak of hantavirus in the southern US, which was attributed to native Americans and dubbed the Navajo disease (Pearson et al, 2004); the Chinese community around the world being the source of negative attention in 2003 due to the SARS outbreak (Xinyu Jiang et al, 2006).

The problem of the disease origin is not merely a geographic one. The H1N1 influenza virus was, in addition to being popularly known as the “Mexican flu”, also named the “swine flu”. This resulted not only in negative outcomes for humans but also for pigs and the related livestock sector. Numerous media stories were reporting the connection between the virus and the porcine industry. This resulted in a reduced consumption of pork and also triggered fear of those individuals such as pig farmers who worked in close proximity these animals. These reactions caused considerable economic damage to individuals and regions that depend heavily upon the pork industry. This also appeared to provide fuel to religious prejudices against the pork industry in lands such as Egypt where the prevailing religion amongst the majority deems the consumption of pork to be unacceptable. This led to the slaughter of the entire pork stock in that country. This was despite the fact that there was no real danger from exposure to pork whether it was dead or alive. Whilst the virus in question had likely arisen from a recombination of various genetic materials in an infected pig, this was a

one-time event. As a consequence, pigs presented no running health risks to humans despite the name “swine flu” being commonly used.

This is why it is therefore necessary for health authorities to be very careful when attributing origins to outbreaks of an infectious disease; references such as “Mexican flu” or “swine flu” should be avoided in favour of a more technical language. Unfortunately, it seems like such a cautious approach still need to be recognized by health authorities, as demonstrated by the recent case of the new SARS, quickly renamed Middle East Respiratory Syndrome (MERS) due to the location of its first cases. Healthcare workers should always keep in mind the importance of the “origin issue” and be ready to face it when dealing with patients, especially when the first ones to mistake are health authorities, as in the case of MERS.

3.2. Vaccination

Vaccination is one the most effective methods of combatting outbreaks of infectious disease (Ehreth, 2003) but it may also constitute a possible cause of stigmatisation. One of the irrational fears that many individuals often have about vaccines is that there is a risk that they will become infected with the virus contained in the vaccine. This may give rise to the fear of becoming infected and thus stigmatised as a consequence of vaccination.

Also, there are cases where certain lifestyle behaviours may be associated with an increased risk of infection. Thus, accepting a vaccination could represent a signal to others indicating that an individual is devoted to stigmatised activities. For instance, HIV vaccine trials have encountered difficulties recruiting individuals since many feared to be stigmatised as being sexually promiscuous or as intravenous drug users (Nyblade et al, 2003). This could also result from vaccination campaign targeted to some minorities that are considered at risk for lifestyle or health reasons (e.g. those who are elderly or obese) and that may suffer for stigmatisation as a consequence.

These are some significant examples of how the use of an effective medical instrument may lead to some negative effects. Healthcare workers should be ready to inform people belonging to these groups in order to prevent them from avoidance behaviours that could result in increased health risks, both for themselves and for the others.

3.3. Medical professionals

Medical professionals are not immune to stigmatisation. The large amounts of time they spend with individuals that are suspected of being infected or are indeed actually infected, can make them prone to stigmatisation issues and this is a problem, both for them and for their relationship with patients. For instance, general practitioners who worked with SARS patients in China reported higher levels of anxiety and social dysfunction (Verma et al, 2004). Stigma of this type flows from the fact that such workers are perceived as being at a higher risk of infection. Healthcare workers may also face the threat of quarantine under certain circumstances. In the SARS crisis in Canada, healthcare workers accounted for almost a quarter of total infected cases (Flood & Williams 2003). Such a stigmatisation may also come from colleagues who have not had the same contact with infected individual and can be long-term, even after the disease in question has disappeared. In addition, healthcare workers involved in the treatment of individuals during the early stages

of an outbreak can feel blamed by other colleagues for allowing the infection to proliferate (Mitchel et al, 2002). Negative media reports and new stories over the performance and behaviour of healthcare workers can add to this sense of stigmatisation and stress.

4. Medical Ethics and Human Rights

It is somewhat universally accepted that public health information campaigns should be examined from an ethical or moral perspective, but there are disagreement over which approach to use. Contemporary medical ethics represents a collaboration between different theoretical schools of ethical philosophy (Peel, 2005). There are four principles that have been claimed to represent a combination of the various moral theories accepted throughout the world (Beauchamp & Childress, 1994):

- respect for autonomy;
- non-maleficence;
- beneficence;
- justice.

Medical ethics have been used by physicians and those providing health interventions for centuries, if not millennia, to decide upon the moral acceptability of possible treatments.

There are advantages to the use of principals in medical practice. They provide a concise and coherent set of principles that doctors can use when making decisions. The system is easily taught to trainee medical professionals and does not require an advanced prior training in ethical or legal issues. The simplicity of the principals allow them to act as ethical trigger points in situations where individual medical professionals are required to make quick decision in urgent circumstances (Fauce, 2005).

This is in contrast to human rights, which, to a certain extent, represents a more complex discipline that is usually the domain of experts in the field. Human rights are designed to provide fundamental protections for individuals that allow them to have as equal as possible a level of participation in society and are therefore also applicable with regards to the provision of healthcare, which in most societies the state is seen as having an important responsibility in regulating. The principles found within Human Rights have been used increasingly by legal systems in the past decades to regulate healthcare provision. For instance, the Australian National University Medical School now teaches its students that human rights will, in the course of their careers, become more important in professional regulation than medical ethics (Fauce, 2005).

One key practical difference between the two systems is that one (human rights) focuses on the relationship between the state and its citizens and the other (medical ethics) is more concerned with a person to person relationship (i.e. between the physician and his or her patient). This results in an emphasis shift from trusting that the doctor always knew what was best for his patient to a situation where individuals were to be regarded as the best arbiter or what exactly was in their own best interests.

The increasingly high level of education and the ability to access types of information, including medical ones, has led to a change in the patient-physician relationship. The result of these developments was that many

patients felt able to conduct their own research into their conditions and, where necessary, question or even refuse their physician's desired course of treatment.

Another factor that should be recognised is that the practice of medicine has changed considerably throughout the ages: in times gone by, physicians would act largely alone whilst modern medicine is organised on a greater scale and often by the state (Rastegar, 2004). On such a scale, systems of human rights are often better placed to adjudicate disputes than systems of medical ethics which are better adapted to dealing with dilemmas involving one or a few individuals. Also, human rights principals are also recognised as carrying more legal force. Healthcare workers represent the junction point between health institutions and patients, a position that requires them to know human rights and how to deal, in order to better manage every kind of situations they could deal with.

4.1. Human rights relevance to outbreaks of infectious diseases

The primary international sources of human rights are the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). Each of these contains principles that may be pertinent during the course of an epidemic. It is of crucial importance for the planners of public health responses to epidemic situations to ensure that their potential strategies are compliant with such principals. This is not only to ensure moral consistency, but also to prevent such strategies from being halted by legal obstacles at what could be critical junctures during the course of an epidemic. Such problems could result in graver epidemics than otherwise might have been the case and a consequent increase in both morbidity and mortality.

Strategies designed to tackle outbreaks of infectious disease often curtail individual freedoms. Prominent examples of such rights or freedoms can include the right of privacy of the individual, the right to bodily integrity and also the right to physical liberty. Poverty and communicable diseases also often have a close correlation (Dute, 2004). State organisations that engage in public health campaigns usually have good intentions – most notably the limitation of the spread of dangerous infectious diseases. Unfortunately, however, this aim is often pursued without adequate attention to the problems such public health campaigns can cause. The HIV/AIDS epidemic has shown that the potential exercise of public health powers and in particular powers of a compulsory nature have the potential to impact upon human rights, most notably individual liberty, physical integrity and privacy (Dute, 2004).

The human rights that are applicable during epidemic situations vary, from very precise duties to other more general principles that will inevitably apply in such contexts. The most important principles to consider are:

- the Right to life, which concerns primarily negative duties upon states not to take the lives of individuals (except in exceptional circumstances like war);
- the Right to health, which is a social and economic right that foresees a duty upon states to provide healthcare for individuals in need of such services. This right has been used by groups of individuals, most notably in the developing world, to secure access to vital healthcare services such as vaccinations or antiretroviral therapy;
- the Right to freedom from inhuman or degrading treatment, which provides important guarantees to individuals regarding their bodily integrity. In the area of medical practice the right has been closely linked to the concept of informed consent;

- the Right to liberty and security of person, which can be significantly engaged during a serious epidemic. In fact, such a right envisages freedom for individuals from arbitrary detention and there is obvious scope for conflict with such a right with techniques such as quarantine, which have been employed for many years during epidemics.
- the Right to a private and family life, which, in the context of healthcare it has been linked to both positive – a state can be required to act where such action is likely to protect an individual’s private or family life – and negative - obligation upon states to desist from acts that may prevent individuals from realising this aim – duties;
- the Right to freedom against discrimination, which may can only be engaged in conjunction with another right and applied to a range of groups such as race, ethnicity and religion and, as been more recently accepted to those who have a different health status. It states that individuals cannot be denied their rights under the convention because they belong to one of the groups in question.

However, whilst human rights principals are useful protecting the fundamental rights of individuals in the context of an epidemic they are not able to completely prevent stigmatization during an epidemic. This is because the self-loathing needed for stigmatisation to exist can arise even where the state has itself done nothing to foster such a feeling. This is due to the fact that stigmatization can occur without discrimination and sometimes even when discrimination is prevented. Individuals that feel that they have been stigmatized by public health campaigns may therefore find that unless one of their fundamental rights has been engaged that they have little recourse under human rights instruments.

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