

What have we heard?

- There was discrimination against people with SARS and their families
- Some older people and services for the elderly were stigmatised because of suspicion that they might have cryptic SARS
- There was no psychological counselling available to patients who had been exposed to SARS in hospitals
- Better rehabilitation and follow-up is required for people recovering from SARS
- Better support is required for the families of deceased SARS patients
- SARS patients and families of the deceased felt neglected because tribute had only been paid to healthcare workers
- More work needs to be done to understand the psychosocial impact of SARS on the community, and on healthcare workers in particular

INTRODUCTION

16.1 After-effects of SARS will be felt for a long time to come, the most painful of which will be on the families of the deceased. The Committee extends its sympathies to those who have lost loved ones as a result of SARS. The disease will also have left an indelible mark on those who suffered from it, their carers, families and friends, and the many individuals who contributed to the fight against SARS, both in the frontline and behind the scenes. Finally, the community as a whole has had to come to terms with the potentially devastating effect of a new and frightening infection.

THE IMPACT OF SARS ON PATIENTS AND THEIR FAMILIES

16.2 Hong Kong experienced one of the highest attack rates in the world for SARS. Now that the epidemic is over, it is important not to forget the continuing needs of the large numbers of people who have been affected. There should be a careful assessment of the rehabilitation needs of people recovering from SARS. Medical follow-up studies should be carried out to collect data on the long-term effects of SARS, and to clarify whether symptoms (such as a lack of concentration, fatigue, depression) may persist or recur.

16.3 SARS brought trauma to patients and their families. They may require psychological, social and financial support. The Committee notes that the Social Welfare Department and non-government organisations provide a range of services in this respect, including referral services of medical social workers,

psychological therapy, assessment of the needs of SARS-affected children and their surviving parents, advice on post-crisis coping and stress management. Special relief funds for SARS victims and their families have also been set up. The authorities should ensure that support services to those in need are followed up.

Fear and prejudice

Mystic, highly contagious and deadly, SARS has all the makings of a dreadful disease that instils fear in the masses. The Committee had heard first-hand testimonies of people who had grappled with the disease, either as patients, healthcare workers, or persons living in the vicinity of a community outbreak. Amidst their accounts of heartwarming heroism were heartrending stories of discrimination and ostracism.

The Committee heard from Amoy Gardens residents that during the outbreak, some of their employers had forbidden them to go to work even though they were not infected. They also cited an example whereby persons sitting near to a resident at a restaurant had asked to change their seats as soon as they learnt that he was from Amoy Gardens.

The Committee could only imagine how the residents must have felt at that time, as it came across that 'Amoy Gardens' was taken by some to be a synonym for 'the infected'. This is illustrated by the following quote from a desolated healthcare worker working in a ward with SARS cases, *"It seemed that all our colleagues in the ward were regarded as infectious patients. Even when we took the lift or went to the canteen, despite the fact that we had washed our hands and taken all the precautions, others treated us like the residents of Amoy Gardens. Our colleagues turned away from us and we felt very lonely at that time."*

It was distressing for the Committee to learn that some recovered SARS patients had even lost their jobs to SARS. Family members were also affected in some cases. The following are quotes from two recovered patients whom the Committee had met.

"I am no longer working. I have left my company because my company regarded SARS patients unfavourably I live in a very small neighbourhood; my wife was a saleslady there. Everybody in the neighbourhood knew about my contracting the illness, and she was also discriminated against; and we had a hard time."

"A lot of people in the community had fear about contracting the virus because of inadequate knowledge about the disease. My wife was given a warning letter from her company because she had to take care of me, and her salary also got cut because of that."

16.4 SARS patients and their families badly need the support of their community. However, there were reports of cases of discrimination, in the workplace and in the community, against family members or contacts of SARS patients whose identity had become known in the course of contact tracing. Some of these cases are being investigated by the Equal Opportunities Commission. The authorities should provide support for such cases, and educate the general public with a view to galvanising the support of the community.

- ◆ HA should assess the medical and psycho-social needs of recovered SARS patients and develop a programme to cater for their needs.
- ◆ Social Welfare Department should assess the needs of the families of deceased SARS patients and offer follow-up support as appropriate.
- ◆ A study should be undertaken to assess the extent and impact of discrimination against former SARS patients, their families and contacts. Appropriate support for those discriminated against should be considered.

An extract from press release issued by
Equal Opportunities Commission on 28 July 2003

Survey on SARS Related Difficulties in Work and Social Lives in Hong Kong

Date: 28-07-2003

Background Statement

In July 2003, the Equal Opportunities Commission (EOC) collaborated with the Chinese University of Hong Kong to conduct an opinion survey about the impact of SARS on our community, in an effort to analyse attitudes and behaviour for future development of a methodology for the Commission to deal with in similar crises, and to establish a strategy for public education.

Since the end of March this year, the Commission has received more than 520 enquiries and complaints from the public as a result of possible discrimination related to SARS. As it is the first time that Hong Kong has faced such a public health crisis, and the social stigma attached to it, there is value and benefit for the Commission and the authorities to learn more about public behaviour and attitudes associated with SARS. ***The findings of the impact study will assist the Commission to refine strategies on information dissemination, public education and promotion of different aspects of communicable diseases control.***

The findings of the survey are consistent with our own experience in handling the public's enquiries and complaints on the issue. ***The majority of respondents stressed the need for more information in understanding the disease, and advisory guidelines in the work environment. Sufficient information, better knowledge and good practices adopted by employers are necessary steps for the public to come to informed decisions, and therefore more rational behaviour in conducting their daily lives.***

An extract from press release issued by
Equal Opportunities Commission on 28 July 2003 (continued)

The survey also revealed that unnecessary fears and concerns could be eased as more factual and reasonable information became available, improving discriminatory attitudes as a result. In handling enquiries and complaints, the Commission was able to assist in a majority of cases by way of early response and quick settlement, offering practical advice and flexible solutions. As parties were willing to resolve the problems at hand, this minimized the negative effects on individual employees, and further economic losses for many businesses were avoided.

The EOC has embarked on the initial steps to disseminate information about dealing with different scenarios related to SARS. In our monthly training programmes for HR managers, NGO staff and training materials for civil servants, we are adopting several themes incorporating problems arising from SARS which many have faced in recent months. The implications of having an infected staff member, those with family members who have become patients, pregnant employees, colleagues living in an infected housing block and staff members exhibiting SARS like symptoms; all these will be considered and discussed.

During the SARS crisis, many employers adopted good management practices, facilitating and providing solutions for their companies and staff. The provisions not only gained staff loyalty but at the same time cut economic losses for their businesses. The EOC is interested to find out more about the successful measures, and urge these employers to contact the Commission, as many more can share and benefit from their experiences.

THE IMPACT OF SARS ON THE WIDER COMMUNITY

16.5 The impact of SARS on the wider community tends to be neglected, as most people will breathe a sigh of relief with the passing of the epidemic. Further study on the psycho-social impact of SARS, the role of the media, and their influence on public reaction and behaviour is desirable since these factors have a bearing on the effectiveness of many community infection control measures.