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A framework for capturing the interactions between laypersons' understanding of disease, information gathering behaviors, and actions taken during an epidemic

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Abstract

This paper provides a description of a methodological framework designed to capture the inter-relationships between the lay publics' understanding of health-related processes, information gathering behaviors, and actions taken during an outbreak. We developed and refined our methods during a study involving eight participants living in severe acute respiratory syndrome (SARS)-affected areas (Hong Kong, Taiwan, and Toronto). The framework is an adaptation of narrative analysis, a qualitative method that is used to investigate a phenomenon through interpretation of the stories people tell about their experiences. From our work, several hypotheses emerged that will contribute to future research. For example, our findings showed that many decisions in an epidemic are carefully considered and involve use of significant information gathering. Having a good model of lay actions based on information received and beliefs held will contribute to the development of more effective information support systems in the event of a future epidemic.

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1. Introduction

There is a great deal of current interest in preparing for outbreaks of infectious disease. Both national and international efforts are aimed at developing strategies for rapid containment in the event of an outbreak [1]. Government officials seek to contain an infectious disease through the cooperative efforts of the public by providing information either directly (pamphlets, Web sites, posters, etc.) or through mass media news. The public also finds information concerning an outbreak from television programs and newspaper articles as well as

from various “non-official” sources (e.g., socially through word-of-mouth). Recent initiatives [2] show support for research that concerns tailoring public health messages during an outbreak disaster to the lay public “with care so that information reported is easy to understand, is appropriate and is relevant.”

In this paper, we propose a qualitative methodological framework that characterizes human behavior during epidemics. This methodological framework, based on narrative analysis, is a tool for learning about how laypersons use information to build representations of an epidemic situation and how the results of this process influence their decisions to act. Two factors, social influences and emotional triggers, are considered as mediators of actions and are therefore also of concern to this work. The methods we use allow insights into

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actions taken that are interpreted within the participant's *situation* (i.e., from the participant's own viewpoint). This type of work is essential for tailoring health messages that are useable by people during an epidemic and effective at changing risky behaviors.

We outline our methods using illustrative examples from data collected during the SARS epidemic of 2003 [3]. Section 1 discusses theoretical background with a specific focus on lay information gathering, lay understanding of disease, and lay health decision actions in a naturalistic setting. In Section 2, we outline the basis for our methodological approach and describe our techniques used for capturing the interactions between the informational influences on lay actions. The data analysis techniques are also presented in Section 2. An illustrative example using data collected during the SARS outbreak of 2003 is discussed in Section 3. Our methodology was refined through application of the framework to the analysis of these data. In Section 4, we summarize the lessons learned and provide direction for future research. The authors of this paper argue that a qualitative approach is necessary in order to obtain a macroscopic view of lay reactions to an epidemic crisis and to map out variables for large-scale studies.

1.1. Theoretical background

The related work we cite in support of this study does not fit neatly into the boundaries of a single field. Health-related information seeking theories [4] and guidelines for constructing health messages for the public [5] have not been explicitly connected to lay explanations of illness and their behaviors during an epidemic. The main purpose of presenting our methodology is to demonstrate how the data analysis techniques can characterize the relationships between lay information gathering, understanding of information received, and actions taken. We briefly review literature related to information seeking, perceiving information needs [6,7], and emotional effects that play into lay perceptions of information [8]. We also point to cognitive theories related to lay comprehension and reasoning about illness [9,10] in addition to theories of naturalistic decision-making [11,12].

1.1.1. Health-related information gathering

We have defined "information gathering" in the broad sense, to include both passive reception of informational messages in the environment and active searching [13]. General models of active information seeking [6,7] describe the process of how a person seeks information, from an emerging awareness of a "gap" in current knowledge to communication of this information need as a query that will locate the missing information. Within the domain of health information seeking, the models that relate to a gap in knowledge

alone were found to be insufficient because they focus exclusively on rational processes. They cannot explain information-seeking behavior when patients do not seek medical information even though they are aware of gaps in their knowledge [4]. For health-related information seeking, theories of stress and coping have been integrated with two cognitive states that have been proposed as central to understanding an individual's response to an adverse health-related situation: orientation towards a threat (referred to as *monitoring*) and turning attention away from the threat (referred to as *blunting*) [14–16].

The first studies that incorporated stress/coping theories with monitoring/blunting divided people according to personality types, as measured by the Miller Behavioral Style Scale (MBSS). van Zuuren and Wolfs [17] studied 47 undergraduate students using the Miller Scale to assess whether a person is a *monitor* or a *blunter*. They found a direct association between problem-focused coping and monitoring. This study also showed that monitoring is related to unpredictability. They concluded that monitoring was positively related to the perceived *degree* of threat in a situation, that is, the higher the perceived threat the more information would be sought.

Using van Zuuren and Wolf's techniques of dividing a sample based on the MBSS, researchers such as Baker [18] studied the information preferences of health consumers (in Baker's study using women with multiple sclerosis). Her results indicated, "monitors were more interested in information about MS than were blunters and further, that their interest occurred earlier in the disease than did the interest of blunters." In recent articles, the notion of personality type influencing information seeking has been challenged. Rees and Bath [19] studied information seeking behaviors of women with breast cancer with results indicating that individuals may fluctuate between seeking and avoiding information, with the process being dependent on situational variables, such as how controllable the threat is perceived to be.

Due to the results given above, our data analysis attends to participant's discussions about risk perceptions that are connected with information seeking acts. Our expectation is that narrative data will reveal how information-seeking behaviors are affected by emotional stress and fear of infection (high risk perception). This idea is further supported by the literature from the field of public health that examines how health information disseminated during a crisis is interpreted by laypersons [5,20].

1.1.2. Lay understanding of disease

After information is gathered, it must be understood in order to be useful. Gaining an understanding, or mental representation, occurs through the process of comprehension [21]. Research on lay mental

representations has shown that knowledge about disease consists of a combination of representations constructed from both informal social channels (i.e., traditional remedies learned from extended family) and formal instruction of scientific knowledge [10]. These two types of knowledge may be partly overlapping and contradictory when they deal with different aspects of the same disease. In cases where more than one model is used, a person tries to satisfy the requirements of each model even though this results in some redundant activity.

Research by Keselman et al. [43] concerning adolescents' reasoning about HIV provides an example of contradictory and overlapping models. They found that middle and high school students often relied on practical knowledge of disease, rather than on known facts about HIV. For example, one student acknowledged known facts about HIV, such as the fact that it is incurable. However, other explanations of the disease process later came into play while reasoning through a scenario about HIV. The scenario asked the student to discuss whether it was possible to expel HIV from the body. The same student who acknowledged the fact that HIV was incurable also believed that by drinking and exercising heavily it would be possible to expel HIV from the body. This student stated, "Cause people can stop it like that. By exercising, like they said. Like that lady, like I told you, she exercised her way out of cancer, so I think this is true, you can exercise your way out of HIV probably."

Informally learned remedies and cultural beliefs sometimes play a major role in determining lay interpretations of epidemic events. For instance, Raza et al. [24] examined lay understanding of the plague with persons belonging to the economically weaker sections of society in Delhi and Gurgaon India. In identifying the factors that influence the public understanding of science, they found significant amount of lay understanding based on "extra-scientific belief systems" (e.g., sins committed by people contributed to the outbreak), which were prevalent in the context of the plague epidemic.

Other studies have also looked specifically at the use of mental representations in relationship to decision-making. Patel and colleagues [44] showed how physicians with different levels of expertise construct dissimilar problem representations on the basis of the same source information, which leads them to differing diagnostic decisions. As another example, Sivaramakrishnan and Patel [10] showed how understanding of pediatric illnesses influenced mothers' choice of treatment for their children. Their study showed how mothers interpreted concepts related to biomedical theories of nutritional disorders. They found that traditional knowledge and beliefs played an important role in interpretation and reasoning, which lead to decisions that were influenced by non-scientific traditional ideas.

1.1.3. Lay decisions to act

Our work focuses on comprehended representations that are constructed by laypersons based on the information received during the epidemic (e.g., mass media, conversations with friends). We are interested in how these resulting representations lead to actions.

The naturalistic approach to decision-making investigates decisions made in constantly changing environments, with ill-structured problems and multiple players [11]. These studies are conducted in real-life settings and investigate high-stakes decisions by looking at how people assess the situations they face, determine the problems they need to address, then plan, make choices, and take actions. This approach is related to our work since the actions taken by laypersons during an outbreak occur in an uncertain environment, with information changing over time, and with a highly personal threat.

Blandford and Wong [12] has taken the key features of naturalistic decisions and combined them to form his Integrated Decision Model. He used this framework for investigating decision processes and strategies of ambulance dispatchers. The ambulance dispatcher study used retrospective narrative data to build a model of decision-making in a dynamic, high-stakes environment. In summary, this model is based on the decision features: (1) *situation assessment is important* to decision making, (2) *feature matching and story building are key* to situation assessment because of missing information and uncertainty about available information, (3) *piecing together the situational information is difficult* because it arrives over a period of time and not in the most optimal manner, and (4) *analytically generating and simultaneously evaluating all possible actions does not occur in dynamic environments*. Instead decision makers seek to identify the actions that best match the patterns of activities recognized in the situation assessment, one option at a time. Although the framework provided by this study was formed from investigations of medical personnel's decisions, we believe that these observations will apply to our work and can be extended to laypersons' actions in a high stress health-related situation.

1.2. The case of SARS

In our study, the infectious disease we are concerned with is severe acute respiratory syndrome (SARS), which is a highly contagious respiratory illness that emerged in the Guangdong Province of China during the winter of 2003. The SARS virus caused widespread public concern as it spread with exceptional speed to countries in Asia, the Americas, and Europe. There were 55 confirmed cases in March 2003 when the World Health Organization (WHO) officially announced the global threat of a SARS epidemic. In one month, the number of cases jumped to 3000 with more than 100

deaths. The SARS epidemic had been halted by July 2003, with a total of 8427 cases reported to WHO and 813 deaths [3].

The countries affected by the outbreak of SARS launched mass media campaigns to educate the public. Information about what actions to take, the symptoms of SARS, and other essential news changed on a daily basis as scientists and doctors treating SARS cases reported new findings. The public's ability to understand and react to the information they obtained played a key role in stopping the spread of SARS. The multifaceted control efforts including quarantine, tracing the contacts of SARS patients, travel restrictions, and fever checks were essential to containment. All of these required that the public understand the SARS-related information being conveyed and take actions to help protect themselves and others from spreading the disease. The SARS epidemic provided a useful test case for our work and provided us with an opportunity to refine our narrative analysis-based methodology.

2. Methodological framework

There have been various methodologies used to study human behavior during epidemics and these offer different perspectives on lay response patterns. One approach is to study historical accounts [21–23]. These are usually told from a single person's perspective on a group's response. While conclusions drawn from these types of texts might lend themselves to a global picture of an epidemic situation, there are potential drawbacks to using these as a basis for our present day outbreak preparation efforts. For instance, the occurrence describes people's reactions during a different time period (not living in our current culture) and these texts might be biased towards the view of the author. Another method of understanding lay reaction is through questionnaires/surveys following a real-life episode [24] or a simulation of an outbreak [25,26]. These questionnaires use pre-defined categories leading to large amounts of data on select variables of interest (e.g., whether or not people believe they would follow quarantine restrictions). The questionnaires impose a pre-determined structure onto the respondent and force the respondent to reply using the investigators' categories.

In our work, participants discuss events occurring during a recent outbreak that directly affected their life (occurring in close proximity to their home). A "story-based" interview allows data analysis of what information was obtained through the environment (e.g., media, web searches, rumors, and conversations with friends), reactions to the information, and the actions taken in the context of the participant who experienced it. These personal accounts, or narratives, of first-hand experience are a valuable source of data that can offer insight

into a situation as it unfolded over time. By studying a sequence of events told as a retrospective narrative, an investigator can see how individuals temporally and causally link events (episodes) together. This approach falls under the qualitative paradigm and is referred to as narrative analysis [27]; these methods have to do with the "systematic interpretation of interpretation [28]."

Narrative analysis is commonly used as a methodological tool in health psychology [29,30] and anthropology [31]. Stories people tell are based on their mental representations of illness or "learned internalized patterns of thought-feeling that mediate both the interpretation of ongoing experience and the reconstruction of memories" [32]. Narratives tell us something about how individuals understand events and construct meaning out of a situation. Illnesses are often explained by reconstructing events in a cohesive story-like manner. For example, Garro [33] discusses how people talk about illness; they link their experiences from the past with present concerns and future possibilities.

2.1. Research questions

Narrative analysis is best used for exploratory purposes, for helping a researcher understand how individuals view a particular situation, and also for illustrating (but not by itself validating) theory. It is based on inductive techniques, rather than deductive hypothesis testing. This means that the researcher outlines top-level questions, which will be elaborated on and altered as the process of data analysis proceeds. Personal narratives tell us a great deal about social, cultural, and other beliefs that cannot be accounted for at the onset of the study.

The questions used to begin a study are broadly stated and are used, along with background literature, to focus on the initial set of boundaries delimiting the research. We ask *how* and *why* (i.e., meaning we are asking for a description) rather than *what* (e.g., a list of factors) questions. The main idea is to characterize the inter-relationships between layperson's information needs/gathering, comprehension of information received, and actions during an epidemic.

2.2. Selecting participants

Participants in qualitative studies, narrative analysis included, are usually selected based on specifically defined criteria. In a study of lay reactions to an epidemic, it is therefore important to select participants who lived in close proximity to the outbreak. The participants should tell their stories to the researcher as close in time to the actual experience as possible (perhaps while the outbreak is still ongoing). Depending on whether the researcher wants to do comparative analyses, participants might be selected by and grouped according to various dimensions such as age, socio-eco-

conomic status, ethnicity, and/or geographical location. The number of participants selected is dependent on the number of comparisons to be made, and whether the researchers' goals are to continue capturing narratives until the majority of the data contain overlapping experiences (almost all of the possible reactions to the epidemic have been uncovered).

2.3. Semi-structured interview

Narrative data are usually collected through the use of an interview. We advocate a semi-structured interview [27] that lists a pre-determined set of "loosely ordered" questions or issues that are to be explored. The guide serves as a checklist during the interview so that the same types of information will be obtained from all participants. The advantage of this approach is that it is both systematic and comprehensive in delimiting the issues to be taken up in the interview. The interviews can remain conversational while at the same time allow the researcher to collect specific data. In many qualitative studies an Interview is usually. In many qualitative studies an interview is usually organized around question–answer exchanges, but narrative studies require the use of free open-ended "tell me" questions as the most effective way to elicit a story-like response. It is important to avoid the use of closed, "yes/no" questions in order to facilitate narrative, rich descriptions.

2.4. Data analysis

Decisions about how to transcribe data and conventions used for analysis are driven by current theory, the research questions of interest, as well as the personal philosophy of the researcher. Our analytic interpretations of epidemic narratives progress through three stages: (1) thematic coding of the factors emerging from the stories told concerning the epidemic, (2) organization of various aspects of the story according to chronological order, and (3) "influence diagrams" of factors influencing actions taken.

2.4.1. Thematic coding

Thematic coding [34] is a type of content analysis and this technique is based on grounded theory (using a bottom-up procedure to identify categories present in the text). Narratives may also be coded according to categories deemed theoretically important by the researcher. Initially, a set of categories can be derived in conjunction with the semi-structured interviews based on theory from related literature (an initial top-down approach to coding), and this list of categories can grow as the rich descriptive data (a bottom-up procedure) is analyzed. One of the purposes of the "thematic coding" stage is to support the subsequent analyses. The categories are

used to help untangle the interrelationships between information, understanding, emotions, social factors, and actions taken and systematically map our observations. In addition, an accuracy check can be done to determine whether participants are correct about their understanding of the disease. Actions participants stated they have taken can be compared with guidelines from official sources (e.g., CDC).

2.4.2. Reorganization of events into chronological order

When participants speak freely in telling stories about the events happening this results in quite a bit of "jumping around" in time. People do not always begin their stories with the first event that occurred. Researchers frequently find it helpful to organize the narrative according to temporal sequence (see Labov's work [36]). For this work, classifying the temporal order of events is a necessary process leading to proper analysis of informational and comprehension-of-situation influences on actions taken. Data are temporally coded in order to consolidate events participants expressed as occurring at the same time period (according to the participant's perception of events). To illustrate, "time 001" is assigned to link together the segments 01–10 shown below and the same code "time 001" is assigned to segments of text lines 101–104 found later in the interview.

- 01 And I spoke to my girlfriend and she said that she was going to leave Hong Kong
- 02 and I was really shocked because she was the one that was like myself,
- 03 just kind of sticking around and saying oh it's not a big deal
- 04 and we'll manage and uh she um felt that she just got into a panic herself.
- 05 And what happened around that time at the end of March that there was a rumor
- 06 that a teenager actually started on the Internet,
- 07 he put it on he like, he said that the airport had been closed
- 08 and that people couldn't get in or out of Hong Kong
- 09 and they later deemed of course it was a hoax.
- 10 But at the time my girlfriend heard this, she didn't know, she panicked and she was leaving. . . . later in the interview . . .
- 100 I did a bit more internet grocery shopping because I did not want to go to the grocery stores.
- 101 Usually, it was really strange because right around, right. . . a week or so before I left I would go to the market.
- 102 It was actually; it was right around the time that that rumor came out that the Hong Kong airport had shut down.
- 103 The store was so packed it was unbelievable.

104 I thought it was a holiday, and I even asked a friend. I said, what is going on with the market?

2.4.3. Informational, lay understanding, social, and emotional influences on actions

The construction of causal-link maps, sometimes referred to as “influence diagrams,” is used for modeling interactions between events [37]. These types of diagrams formalize laypersons’ explanations into connected logical structures that can be examined as an overview of all the events occurring for a subset of time during an epidemic. This process maps the influences on actions taken for each time period identified (following chronological organization of the data described in Section 2.4.2). Figs. 3–5 are each influence diagrams.

An example of how we created these diagrams is given using data from the Taiwanese participant (see Fig. 1). We first identify the associative “participant-stated” relationships between coded themes. In these data segments, we can see that officials are promoting (successfully) washing hands and we can also see that family pressures have an influence on hand washing behaviors. Thus, “Informational: officials <promotes> Action: washing hands” and “Social: family pressure <leads one to> Action: washing hands.” The categories

of interaction labels (e.g., <promotes>) must be standardized for consistency.

This process facilitates asking research questions across conditions (e.g., comparisons by socio-economic status) for numerous participants. Eventually, the objective is to be able to make generalizations about the interactions between factors/events that influence layperson reactions during an epidemic. What are laypersons’ decisions based on? How does social pressure affect decisions? What motivates active searching of information?

2.5. Validity

The evaluation of the validity (or trustworthiness) of a narrative analysis is a critical issue that does not have an easy solution. One way to test whether the results are valid is related to persuasiveness. An analysis can be said to be persuasive when “the claims made are supported by evidence from the data and the interpretation is considered reasonable and convincing in light of alternative possible interpretations” [27]. Another way of checking validity is to conduct what is called a “member check” [38]. During a member check, participants in the study are given copies of the research report and asked to appraise the analysis conducted by the researcher, interpretations made, and conclusions drawn. These two measures of validity assess whether the interpreta-

Participant:

001 [**Informational (source): officials (they)**] But they’re trying to promote it more about the whole handwashing thing you know?
 002 Because you actually touch a lot of foreign objects when you go outside.
 003 So for in preparation for SARS, this is something you do.
 004 [**Informational (source): officials (they)**] They actually prefer you to wash your hands more frequently, especially when you come back.
 005 Or take a shower, just kind of get rid... because I think the germ dies off at temperatures over 38.
 ...
 010 So, you know but the hand-washing thing because a big...
 011 [**Informational: TV news**] there was TV advertisements,
 012 like the celebrity person coming up and she’d be like “I wash my hands” you know?

Interviewer:

013 Did you wash your hands a lot more?
 014 Did you take more showers?

Participant:

015 [**Action: washing hands**] Yeah, I actually do.
 016 [**Social: family pressure**] I mean, even if you don’t, your family members kind of remind you to, you know?
 ...

Coding of Interactions Example:

[Informational (source): officials (they)] <promotes> [Action: washing hands]
 [Informational: TV news] <promotes> [Action: washing hands]
 [Social: family pressure] <leads to> [Action: washing hands]

Fig. 1. Example of coded interactions.

tions of the data reflect the views held by the participant; there is no way to compare the results obtained with an objective truth. However, a community of scientists validates knowledge as they share results obtained across multiple studies.

3. Narrative analysis of SARS

As the SARS epidemic unfolded, we were in the process of exploring methodologies that would focus on the interactions among the information requirements of laypeople concerning an outbreak of infectious disease, their understanding of that disease, and their actions taken during an outbreak (or during a simulated outbreak). The SARS epidemic was used as a test study to refine the narrative analysis-based methodology. In the following sections, we show how these methods were applied and what we learned in the process.

3.1. SARS research questions

Our specific research objective is to characterize laypersons' reactions during an epidemic. Specifically, we ask why participants take certain actions (or recommended actions stating what should be done) and how their actions are linked to (1) their understanding of epidemic/SARS infection, (2) the influential informational events (including information gained from a social situation), and (3) other factors such as feelings that come into play. Other research questions can be answered using the data that report on what happened during the SARS outbreak. For example, the interview texts also result in a list of information needs expressed by the lay public concerning an outbreak as well as a general list of actions taken for SARS prevention.

3.2. Participants

We interviewed eight residents from three SARS outbreak regions. Two of them were living in Asia (1 from Hong Kong and 1 from Taiwan) and six were from Toronto, Canada. Participants recalled events taking place from the time when news began about the "mysterious" illness until the time of the interview, a time span of approximately 90–120 days. None of the participants had a medical background or a degree in biology, or related fields. All of the participants except for the Taiwanese male were native English speakers.

The interviews with the residents from Asia took place in the late Spring of 2003. These interviews were conducted in the United States by the first author. The Hong Kong resident was an American Caucasian female who had been living in Hong Kong for the past four years. She decided in late March to return to the United States temporarily because of the SARS outbreak. She

was 37, married and had a one-year-old daughter at the time of the interview. She was interviewed in her home in Washington, DC. The other resident of Asia was a Taiwanese male, aged 24, of Chinese descent, who was living in Taipei, Taiwan for the entire duration of the epidemic. The interview took place in New York City while he was vacationing. Both participants had an undergraduate degree from a university in the United States.

The interviews with the Toronto residents took place during the early summer of 2003. These interviews took place in Toronto and were conducted by a research assistant from the Information Technology Division, Department of Mathematics and Statistics, York University, Toronto. Toronto resident 1 was a 31-year-old male, resident 2 was female (no age recorded), resident 3 was a 35-year-old female, resident 4 was a 38-year-old female, resident 5 was a 42-year-old male, and resident 6 was a 45-year-old male. Toronto residents all had Bachelor's degrees, and residents 3 and 6 also had a Master's degree.

3.3. Interview

The complete semi-structured interview is presented in [Appendix A](#). The procedure for using this interview guide is to allow for flexibility when probing the respondent. When interviewing, we stressed the importance of keeping in mind the purpose behind each of the probes. We linked lay understanding to information sources using probes, for example, "How does SARS affect a person's body?" followed by "Can you tell me how you learned about this?" We asked about the action of seeking information and connected this with the participant's current information needs. The two-part probe "What questions did you have about SARS and what caused you to look for information about [fill in with the topic of the question asked]" is of this type. Other actions concerning self, family, or community protection were connected to understanding of SARS using probes such as "For example, did you buy a facemask, vitamins, or do something else?" "Why did you decide to [repeat preparation given by respondent]?" and "How is [repeat preparation given by respondent] going to help prevent SARS?"

This instrument design was based on our research goals to link interactions between understanding, information received, and actions taken. The questions ask about the participant's SARS experience over time, from the time prior to the outbreak and then ask the participant to project their own scenario about what they believe will happen in the coming weeks following the interview. The arrangement of the interview into time periods (before, during, and upcoming events related to the epidemic) facilitates the data analysis when looking at the interactions and influences between informa-

tion received, lay understanding, and actions taken. We believe that this type of interview could be used during any epidemic outbreak.

3.4. SARS data analysis

The strategy we used for the reduction and interpretation of our narrative data consisted of three stages. In the first stage, we identified the categories of SARS epidemic-related events and concerns discussed by our participants. We did thematic coding, in which we “let categories emerge from the data rather than assign them from a pre-defined list” [34]. Using the qualitative software program, NVivo [35], we iteratively coded emergent categories by marking segments of text that are instances of actions the participant said they took, explanations given concerning SARS, information sources used, and information needs expressed. The second stage consisted of reorganizing the events in the narrative into the correct chronological order. This was necessary because participant’s stories and anecdotes were not always told in the same order that they occurred during the epidemic. The last stage used the time-ordered data from phase two in order to evaluate influences on actions taken. For each action identified during thematic coding (stage one), we looked at participant’s explanations, reasoning process, and emotional state prior to the action.

3.4.1. Thematic coding

We began the process of coding by constructing a rudimentary coding scheme based on the interview probes and by reading through the first transcript. For example, we could anticipate that participants would discuss “wearing face masks” and “washing hands” as

actions taken and these were included in the initial scheme. This coding scheme changed incrementally as we carefully scrutinized all the interview texts (from Hong Kong, Taiwan, and Toronto) resulting in the final version of the coding scheme in Appendix B.

This process is clarified using an illustrative example. The transcripts, in rough form, are read and the researchers specify codes at the phrase level, sentence level or paragraph level. For example, the code “risk assessment of SARS” was assigned to the phrase 02 (from participant 1):

01 in March, early March I started to hear about the SARS virus that was in Hong Kong
02 but it did not seem very, ahhh quite epidemic mode

After seeing similar texts concerning the same type of expression, we assigned a more general code called “SARS risks” to all similar instances in all interviews, such as in phrase 01 (from participant 4):

01 However, it was on the news but they didn’t put a lot of seriousness into the broadcast.

Each category was defined for further coding consistency. For example, “Information Need: Containment Status” was defined as “An information need or question stated that is about any topic related to control of the outbreak (e.g., “Has the virus peaked?”). Multiple codes could be assigned to the same text.

Fig. 2 shows our first pass at coding a small portion of an interview transcript. The codes we assigned are in bold text, such as “[**explanation: SARS transmission**]” corresponding to “you know and that’s mostly where it

Interviewer: Do you wear the mask everywhere?

Participant: Um, pretty much I wear the mask [**action: wear mask**] when I get on the street [**location: street**], and especially when I get on the subway [**location: subway**] because that’s pretty much how we travel most of the time [**public transportation**], so you have to wear the mask you know [**mask is required**]? And then when I went to like those Costcos, those things where you buy stuff [**location: store**], yeah, you wear a mask [**action: wear mask**] too. Well, with SARS, the main thing is actually infecting a lot of people that work in hospitals, like nurses, doctors [**SARS population: hospital staff**], [**explanation: SARS transmission**] you know and that’s mostly where it spreads because it’s in a really tight confined area [**location: tightly confined area**] like a hospital room [**location: hospital room**] you know? So, [**SARS transmission risk: not as high as newspaper statements**] it’s not as bad as what the newspaper [**information source: newspaper**] used to say, but somehow, [SARS: origin of epidemic] it all started in an elevator in a hotel in Hong Kong [**location: Hong Kong hotel elevator**] that’s according to the news [**information source: news**], that [**explanation: SARS epidemic origin**] how it is started, and the guy that spread it [**person: origin of SARS epidemic**] was somebody that went to Guang Jong (?) in China [**location: Guang Dong, China**]. He was a doctor [**person: origin of SARS epidemic; person: doctor**]. So [**explanation: SARS epidemic origin**] he [**person: origin of SARS epidemic; person: doctor**] probably got it from a patient [**person: origin of SARS epidemic; person: patient**]. in Guang Jong [**location: Guang Dong, China**].

Fig. 2. Example of the initial phase of coding for a segment of interview text. The themes coded are placed in bolded brackets following the text segment coded. The coded segment of text is underlined. A double underline is used to indicate when multiple codes are assigned to a segment of text.

spreads because it's in a really tight confined area **[location: tightly confined area]** like a hospital room **[location: hospital room]**” The double underline is used when overlapping categories (i.e., **[location: tightly confined area]**) are assigned to text already coded in another category (i.e. “really tight confined area”).

The process of thematic coding resulted in a list of instances of actions, explanations, and information needs expressed by participants in our data. We also looked for “new” categories of entities and events that would help us to make sense out of what people were experiencing during the SARS outbreak and what factors influenced their perceptions of the epidemic response. Although not initially themes in our work, we also coded policy, location of events, persons involved, and other major categories that emerged from the data. From the codes that emerged, we get a sense of:

- (1) the types of actions people took (e.g., avoiding others),
- (2) social situations they observed during the epidemic (e.g., people are banned from entering someplace because of elevated temperature),
- (3) types of actions the participants recommend doing for SARS prevention (e.g., get proper rest),
- (4) types of explanations described by participants about SARS (e.g., cultural influences and cultural factors),
- (5) the information needs participants expressed (e.g., participants wanted to know what the potential outcome was for a person who contracted SARS),
- (6) what emotions people expressed concerning SARS (e.g., “eerie feeling/freaked out”), and what information sources people consulted (e.g., TV media).

We began to see some patterns emerging from our eight personal narratives. Within the list of explanations of SARS, there are none concerning the physiological processes of a virus within the body (because we did not observe a single instance in the data). The SARS participants in the Asian cities seemed to have a great knowledge of certain facts (about what actions to take). This is not surprising since they were living in places where the threat is presented on a daily basis (e.g., everyone wearing masks on the street) and they were bombarded with information in the media. What was interesting was that these two people felt a need for further information about the mechanisms behind the viral processes and not just a superficial list of what to do. Another pattern observed was the expression of suspicion by participants from Canada. Many of the emotions that were expressed in the coding scheme inventory are related to fear and anxiety. Participants, notably the Toronto residents, expressed suspicion about a possible cover-up of outbreaks, (i.e., “why did this occur in Toronto and not in the US?”). These

participants had questions and concerns about government policy [39].

3.4.2. Guideline comparison

To illustrate how the thematic data can be employed to evaluate current guidelines, we used the coded narrative texts to further conduct a comparison of participants’ knowledge of SARS symptoms, treatment, transmission, and preventions with CDC Web site information [40]. We made this comparison using guidelines from the same time period as when the interviews occurred. To do this, we coded CDC guidelines using the same methodology described in Section 3.4.1. We then took each sentence from interviews that were coded as a symptom, transmission mechanism, treatment or prevention, and compared those with sentences from the CDC guidelines.

Overall, participants had beliefs that were consistent with current understanding of SARS, with almost 95% (155/164) of the sentences from the interviews concerning symptoms, transmission mechanism, treatment, or prevention of SARS corresponding to those found in the CDC guidelines. Such a high level of consistency would be very unlikely in a larger more diverse sample.

3.4.3. Reorganization of events into chronological order

Reorganization of events was necessary to facilitate data reduction and to assist in the interpretation of the narratives. One result of this time ordering was unexpected and resulted in further separation of each personal narrative into several time segment blocks. For each participant, we found that some events were mentioned multiple times and signaled major changes in the participant’s emotional state, actions taken, understanding, or informational needs and we marked these as “trigger” points for change. For example, as the outbreak in Hong Kong became more serious and more people were infected, the participant’s behavior and reaction naturally changed leading to new actions taken, a greater understanding, and more attention focused on the daily news report. The data were separated for each narrative so that the end of each time segment block signals major shifts in thinking about the epidemic (e.g., “and at that point it really got into my consciousness about this virus and that it was very serious”). Examples of the “triggers” that propelled the participant to change their viewpoint and signaled the beginning of each new time period are marked in italic type in Figs. 4 and 5 shown in the section below.

3.4.4. Influences on actions example

We then performed the analysis described in Section 2.4.3 to capture the connections between the events in order to organize and standardize the relationship between information, lay understanding, and actions. We found that constructing visual representations of interactions

was very useful for characterizing each overall causal explanation. To illustrate with an example, we use our Hong Kong participant. Figs. 3–5 correspond to time segment blocks for that participant from the start of the epidemic (Time Period 1) until the time the participant decided to leave Hong Kong (Time Period 3).

In Fig. 3, we show that she was passively watching the news and did not feel that there was a heavy emphasis on the “mysterious illness” that was occurring in the “new territories.” Her understanding of the disease was

generated from these reports and primarily consisted of a belief that “it was not affecting us.” (because she is a Westerner in Hong Kong) She did take one precaution, that is, to wash her hands more often and wipe her child’s hands. This was based on her concern over her child’s well being to; nevertheless, take precautions against the illness that she thought was “like a cold or pneumonia.”

In the second time period, Fig. 4, we began to see her concern increasing. This change was triggered by the

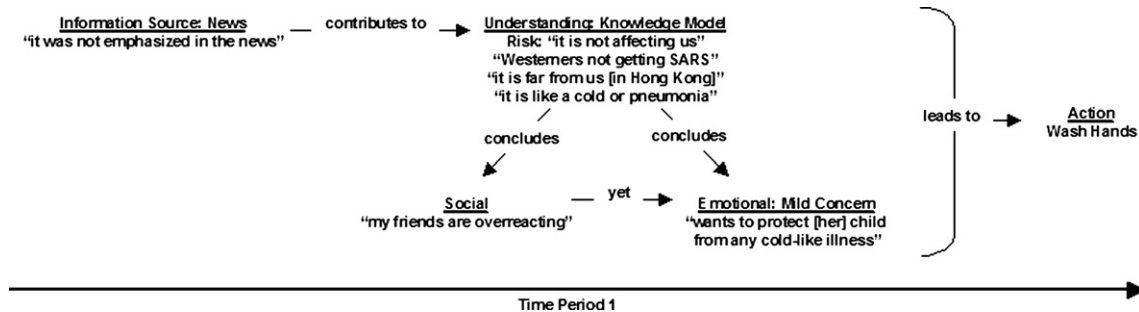


Fig. 3. Example of coded interactions from the Hong Kong participant: Time period 1 (early weeks of the SARS outbreak).

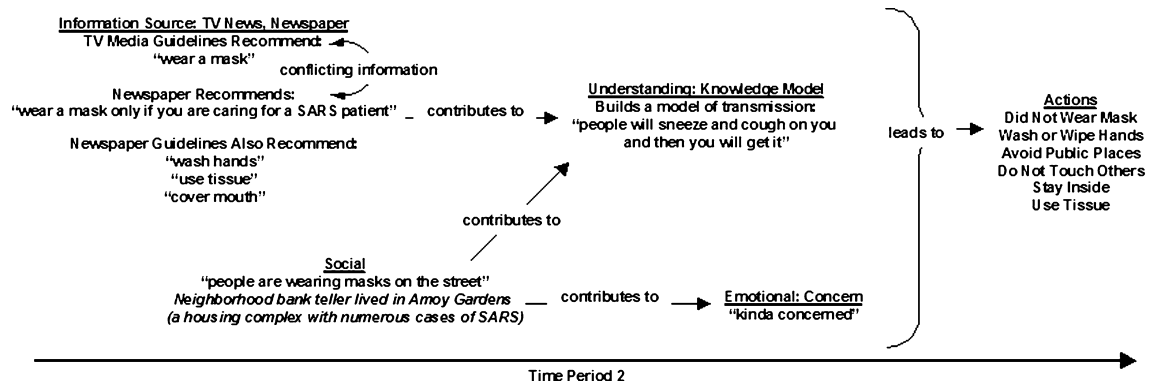


Fig. 4. Example of coded interactions from the Hong Kong participant: Time period 2 (weeks leading up to awareness of SARS as an epidemic in Hong Kong). The trigger leading to increased concern is shown in italic type.

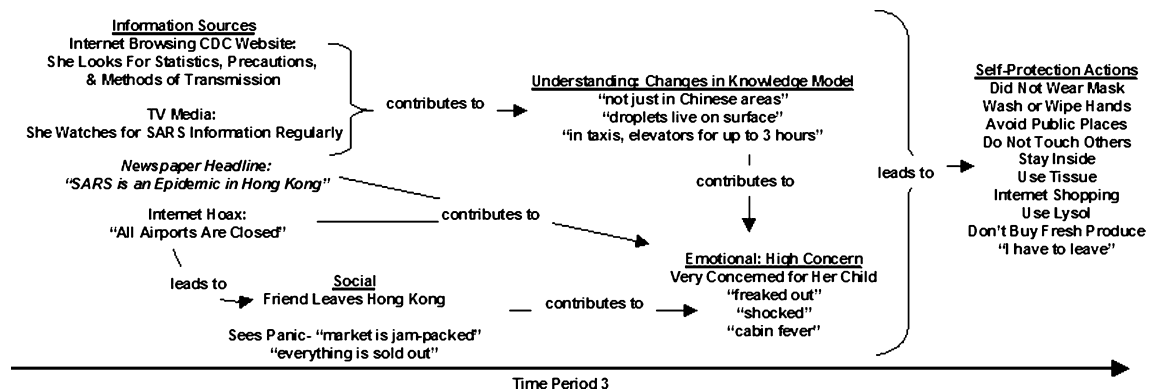


Fig. 5. Example of coded interactions from the Hong Kong participant: Time period 3 (from an increased awareness of SARS as an epidemic to a decision to leave the region). The trigger leading to increased concern is shown in italic type.

realization that her neighborhood bank teller lived at Amoy Gardens and that it could possibly spread to her family. She builds her understanding of SARS, focusing on the model of transmission. All of her actions taken are based on this model. For the most part, she followed the guidelines presented in the media, except that she did not wear a mask, in spite of the fact that there was social pressure “people wearing masks on the street,” and that she also avoided walking past people because “I didn’t want somebody to sneeze or cough on me and me get caught in the drift of that and get it on me”

We see major changes in anxiety level, actions taken (precautions), understanding, and informational factors in the third time period, shown in Fig. 5. Many interactions were recorded that form larger “influence interrelationships.” For instance, she made a decision to leave Hong Kong. This was strongly related to a friend’s decision to leave as well. The friend’s decision increased her anxiety and shock, pushing her to make the same choice. She stated that her friend (but she did not state *she* felt panic) was panicked due to an Internet hoax that stated the airports of Hong Kong were closed and no one could get out.

3.4.5. Actions and information needs summaries

Across all the narrative data, we looked at people’s reasons for actions. The major influences on actions are in Table 1 below. One important influence on

actions was the vocabulary used by an information source (in particular, mass media), which served as a catalyst for major changes in lay reaction. As an example, use of the word “epidemic” caused emotional and behavioral changes. A Toronto resident stated that seeing the word “epidemic” was key “uh, I wanted to know how fast it was spreading because if I thought it was an epidemic I would make the decision to stay home and not go to work.” The Hong Kong resident provides another example of this. After seeing the headline “SARS an epidemic in Hong Kong,” this lead her to conduct Web searches, which in turn lead to further learning about transmission. She therefore updated her understanding of the virus through the Web searches, learning that the “virus lives on surfaces up to 3 hours.” These were considered a specific type of “trigger” based on source. These media triggers are “emotionally loaded” words that caused participants to experience major shifts in thinking about the epidemic. They were identified while reorganizing the narratives to consolidate all events (according to the participants’ perceptions) that happened in the same time period. Participants stated certain media events (i.e., “triggers”) over and over again in separate stories, linking different aspects of their experience.

We found that there were several primary types of influences on expression (or realization) of an information need. These are listed in Table 2. Although partici-

Table 1
Common reasons for taking actions

Reasons for actions	Example text
Influence of friends	“I had many friends who left with their babies”
Cultural differences	No westerners were wearing masks
Information source	“because I read it in the newspaper that unless you are caring for someone...”
Because of model of infection/transmission	Walked far away because “I didn’t want anyone to sneeze on me”
Fear	“it kinda freaked me out”
—concern over family	“but since I did have a child”
Perception of safety	“so that leads me to believe that the general public is somewhat safer”
Because “you have to” (social pressure)	“so you have to wear the mask”

Table 2
Motivations behind information needs

Types of motivations	Example text
Check suspected conspiracy	“Was there anything being hidden?”
— Motivation behind media role	“I want to understand why the media blew it out of proportion”
Part of decision-making process	
— confirmation of decision	“lends me some comfort to know I can go back and have somewhat of a normal lifestyle”
— whether to act or not	“if I thought it was an epidemic I would make the decision to stay home”
Incomplete model of disease	Why doesn’t the germ die off when you get a fever?
—further investigate hearsay	—I heard that...
—lack of explanation in media	—They have not told us very clearly.
—update of information already known	—in reflecting I would probably want to know the symptoms again.
Prevent transmission to self	Mainly I wanted to find out how it was transmitted so I could protect myself.
Prevent transmission others	I’d like to know what policies were in place... so we can prevent it from happening again.

pants knew the symptoms of SARS (as shown in Section 4.1.1), we found that they realized there was a lack of an understanding of internal bodily processes. This became apparent as participants expressed their information needs. In one case, the participant realized that he needed a more complete understanding of the processes involved during a SARS viral infection. To illustrate, this participant from Taiwan (who had a Bachelor's degree in Computer Science) states a question (line 5 below) concerning his lack of knowledge of immune system functions:

- 01 Or take a shower, just kind of get rid...
 02 because I think the germ dies off at temperatures over 38
 03 yeah, that's the rumor.
 04 But the ironic thing is, hey the symptoms are you get a fever.
 05 So when you get so heated up why doesn't the germ die?

We considered line 05 an "information need" statement. Types of information need statements in the data were consolidated as Table 2.

3.5. Emergent hypotheses

This methodology leads to emerging hypotheses from our data that can be explored in subsequent work. These suggestions were derived after examination of the participant-stated relationships between coded themes (as described in Section 3.4.5). The descriptions of these emerging ideas refer back to Figs. 4 and 5.

In Fig. 4, we begin to see that epidemic decisions were not based on quick emotional reactions (panic) or social influences entirely. Rather, they were based on strong connections between knowledge building, information gathering, and making decisions (e.g. whether to wear a mask). The participant's understanding of disease transmission and epidemic status (containment) influenced decisions either directly, or indirectly (through increasing negative emotions). Evidence that many decisions in an epidemic are carefully considered and involve use of significant information gathering prior to the actual decision is consistent with some of the literature in public health [39]—but not in the literature related to decisions in emergency situations [12]. We found that as concern increased, participants became more aware of information until they felt the need to move beyond scanning to searching databases for information (passive viewing switched to active as fear increased). Thus, we hypothesize (1) that future studies will show this relationship between reactions of concern and increasing use of information sources to investigate the various actions to take during an epidemic.

Contrary to the effortful, and systemic information seeking described by participants that related to increasing concern, we saw several occurrences in the data when social factors lead to quick and resolute precautionary actions. For example, the participant described a change in her understanding of risk between time periods two (Fig. 4) and three (Fig. 5) "And I spoke to my girlfriend and she said that she was going to leave Hong Kong and I was really shocked because she was the one that was like myself, just kind of sticking around and saying oh it's not a big deal and we'll manage ... And once I heard that she was leaving, then it put me into motion thinking I need to get out of here. This is not the place to be right now." Social aspects tend to highly "personalize" the risk involved and alter thinking "it can affect me." The hypothesis (2) that emerges from this data is that information that personalizes the epidemic can affect the actions taken, leading to quick decisions to protect against infection.

In terms of information seeking, the results we have found related to hypothesis 1 are similar to those of van Zuuren and Wolfs [17] and Rees and Bath [19] described in Section 1. As the person's concern (perceived degree of threat) increases during an epidemic, so does information seeking. However, we did not find any intentional avoidance of information that occurs in patients with a serious illness. In the epidemic situation, lack of information seeking was only observed when there was a perceived need to make a quick decision.

The two observations made in the above paragraphs are consistent with dual-process models of social reasoning; the Elaboration Likelihood Model [41], and the Heuristic-Systematic Model [42]. These models predict that there are two routes of information processing. In one route information is processed and decisions are made fast and superficially, and in the other route people engage in more time consuming, effortful, and systematic information processing and problem solving. These models, specifically, Chaiken et al. [42] predict that the fast and superficial (like hypothesis 2) information-processing route is used in situations when people are not motivated and/or do not have the ability for making decisions. In the case of people in an epidemic situation, future work may pinpoint the situational factors that result in thoughtful versus hasty actions.

4. Conclusions

We have outlined a methodology for characterizing factors that affect information gathering, comprehension, and preventative behavior by lay people during epidemics. We approached the task using literature from all three areas as a framework, where the cognitive

aspects underlying acts (behavior) is given a major focus. This perspective suggests that decisions and actions are largely based on individuals' cognitive representations of events, which are in turn shaped by prior knowledge and new information, as well as by social and emotional factors. Given the complexity of the influencing factors, and the interconnections among these variables, a structured qualitative approach was considered as most appropriate for gathering data.

Public health guidelines concerning ways to tailor communication describe aspects of messages that are effective during a crisis event [5]. The goal of this methodology is to be able to specify ways to increase compliance with guidelines and how to reduce behaviors that increase risk. Use of this methodology captures the major themes that emerge related to information needs and actions. This allows officials to address the public's concerns and learn about the actions they are taking. Yet, the major contribution of this methodology is related to developing detailed causal/temporal models showing the influences between factors. With this, it is possible to identify problematic situational variables and intervene when they may lead people to make rash decisions.

This methodology was applied to study lay reactions to the SARS virus outbreak of 2003 but might be applied to other viral infectious disease outbreaks, either naturally occurring or through terrorism. Having a better understanding of the reactions of the layperson will lead to developing information support systems as well as guidelines for preparedness in the event of a future epidemic. Information provided through guidelines or "just-in-time" (depending on the needs) could help the lay public to respond appropriately during future epidemics. Results from studies using these methods can also be used to educate professionals (e.g., hospital administrators, the media, and government policy makers) by providing models to explain, for example, what strategies laypersons use to assess the situation during outbreaks of an infectious disease.

Acknowledgments

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Appendix A. Semi-structured interview protocol

1. Before SARS came to [participants' home city], tell me about the information you received concerning SARS or what was known as "the mysterious illness." Where did you get this information?
2. Before SARS came to [participants' home city], did you actively search for information about SARS? If so...
 - a. What questions did you have about SARS?
 - b. What caused you to look for information about [repeat question topic given by respondent as a result of answering 3a]
 - c. Where did you look for an answer to that question?
 - d. If you were able to find information related to your question, tell me about the usefulness of the answer(s) that you found to your question.
3. Before SARS came to [participants' home city], did you make preparations in case the disease would spread to [participants' home city]? If so, tell me about what you did and why.
 - a. For example, did you buy a facemask, vitamins, or do something else?
 - b. Why did you decide to [repeat preparation given by respondent as a result of answering 4a]?
 - c. How is [repeat preparation given by respondent as a result of answering 4a] going to help prevent SARS? (note: use if further elaboration is necessary)
4. Think back to the time when you first remember hearing about the SARS cases in [participants' home city] and tell me about how you heard this news and how you reacted.
5. Over the past few months have you actively sought more information about SARS? If so, ...
 - a. What questions did you have about SARS?
 - b. What caused you to look for information about [repeat question topic given by respondent as a result of answering 6a]
 - c. Where did you look for an answer to that question?
 - d. Why did you look for an answer to the question in [repeat information source given by respondent as a result of answering 6c]?
 - e. If you were able to find information related to your question, tell me about the usefulness of the answer that you found to your question.
 - f. What questions do you currently have about SARS?
6. Tell me about what you currently know about SARS:[Following each of these probes (a–e) ask, "Can you tell me how and when you learned about this?"]
 - a. How does SARS affect a person's body?
 - b. How is SARS treated?
 - c. How can SARS be prevented?
 - d. When and how does SARS cause a person to die?
 - e. Do you think that you or one of your family members will get SARS? Why or why not?

7. If you have taken steps to prevent getting SARS since hearing about the outbreak in [participants' home city], tell me about what you did and why.
 - a. For example, did you buy a facemask, vitamins, or do something else?
 - b. Why did you decide to [repeat preparation given by respondent as a result of answering 7a]?
 - c. How is [repeat preparation given by respondent as a result of answering 7a] going to help prevent SARS? (note: use if further elaboration is necessary)
8. Tell me about what do think is going to happen in the next few months concerning SARS cases in [participants' home city]?
9. How will you and your family be affected by SARS in the coming weeks?

Appendix B. Coding scheme

1 Actions taken (by participants)

- 1.1. Avoiding contact with others
- 1.2. Check temperature
- 1.3. Cover mouth when coughing
- 1.4. Use own utensils only
- 1.5. Wearing mask
- 1.6. Leave area (leave town)
- 1.7. Self-quarantine
- 1.8. Buy supplies (e.g., anti-bacterial wipes)
- 1.9. Search for information
- 1.10. Take vitamins
- 1.11. Use disinfectant cleaning products
- 1.12. Wash hands

2 Social acts observed

- 2.1 Person banned from entering place
- 2.2 Item shortage
- 2.3 Mass panic
- 2.4 Rumor/hoax
- 2.5 People stocking up on food

3 Recommended actions

- 3.1 Get medical checkup
- 3.2 Cover mouth/wear face mask
- 3.3 Stay home/do not travel
- 3.4 Less stress lifestyle
- 3.5 Get proper rest
- 3.6 Eat properly
- 3.7 Take vitamins

4 Explanation of a process

- 4.1 SARS
 - 4.1.1 SARS symptoms
 - 4.1.2 SARS etiology
 - 4.1.3 SARS evolution
 - 4.1.4 SARS containment
 - 4.1.5 SARS incubation period

- 4.1.6 SARS risks
- 4.1.7 SARS transmission & prevention
- 4.1.8 SARS treatment
- 4.2 Making a decision
- 4.3 Reasoning about something
 - 4.3.1 Assessment of a recommended action
 - 4.3.2 Inconsistency in information source
 - 4.3.3 Cultural influences/factors
- 4.4 Description of something
 - 4.4.1 Burial of SARS victims
 - 4.4.2 Sanitation
 - 4.4.3 Travel
 - 4.4.4 Participant's family life
 - 4.4.5 How to wear a mask
 - 4.4.6 Quarantine procedures

5 Information sources

- 5.1 Mass media
 - 5.1.1 Television
 - 5.1.2 Newspaper
- 5.2 Social
 - 5.2.1 Friends
 - 5.2.2 Relatives
- 5.3 Internet/Web
- 5.4 Government Press
- 5.5 Product Manufacturers' Messages
- 5.6 Scientists' Messages
- 5.7 Medical Press
- 5.8 Popular Press
- 5.9 Employer

6 Information need

- 6.1 Containment status
- 6.2 Viral effect on body
- 6.3 Origin of disease
- 6.4 Outcomes of having SARS
- 6.5 Transmission & Prevention
- 6.6 Future outbreak
- 6.7 Policies/procedures to follow

7 Emotional

- 7.1 Fear
- 7.2 Comfortable
- 7.3 Concern/worry
- 7.4 Eerie/freaked out
- 7.5 Nervous
- 7.6 Serious
- 7.7 Peace of mind
- 7.8 Surprise
- 7.9 Suspicion

8 Location

- 8.1 Subway
- 8.2 Store
- 8.3 Street
- 8.4 Airplane
- 8.5 Hospital

8.6 Geographical Area

8.6.1 USA

8.6.2 Singapore

8.6.3 Japan

8.6.4 Canada

8.6.4.1 Toronto

8.6.5 China

8.6.5.1 Hong Kong

8.6.5.2 Guangdong

9 Characteristics of location

9.1 Confined

9.2 Unventilated

9.3 Cleaned

10 Person

10.1 Ethnic Chinese

10.2 Family member

10.3 Doctor

10.4 Participant

10.5 Friend

10.6 Health care staff

10.7 Westerner

10.8 SARS patient

11 Policy

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