



翠鸟虫鸣希望人间

双溪毛糯麻风病院社区的故事

A Valley Where Birds and Insects Sungai Buloh Leprosy Settlement ^{Stories of} Sing for Hope

曾维龙 罗彩绵 编撰

Compiled by Chou Wen Loong & Loh Choy Mun

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序一

Preface I

曾维龙 Chou Wen Loong

故事背景是英殖民统治时期成立的双溪毛糯麻风病院，一个由病人所形成的社区。这个社区之所以形成，与权力当局所采取的隔离政策息息相关。

2007年，当我们知道麻风病院建筑即将被拆除后，即开始进入这个病院社区了解病人，了解他们的历史。讶然发觉，在社会主流中，从上个世纪即生活在此处的麻风病人几乎被人遗忘。因此，我们组织了一个公民小组，尝试关注这批弱势群体的权益问题，重新定义和理解文化古迹保育的意义。最后形成一个社会运动。对这个社区的院民，我们称呼他们为“阿公”“阿嬷”，尝试与他们接触；对社会群众，我们则宣扬文化古迹保护的理念，唤醒公民社会意识。

我有幸从2007年开始参与这个社会运动。当时的参与者还有陈亚才、庄白琦、张

集强、林永隆、梁莉思、蔡依霖、司徒旨祥、廖秋怡、黄文达、罗彩绵等，以及许多未列下姓名的大专青年。我们在这个运动中各自扮演着不同的角色，共同致力于社区营造。作为一位学术人员，我关注的是如何将该社区历史、精神价值等等问题作一系统的整理，以传于后人。口述历史显然是一项迫切的工作。

2007年开始，我第一次带着从台湾来到马来西亚实习的中原大学景观系学生到病院社区进行田野访问。之后又试着带领新纪元学院中文系的学生陆陆续续地访问病院社区的阿公、阿嬷。这几年的时间，学生是以自愿的形式参与这项工作，所需的经费也由我个人承担。

2010年，经林永隆穿针引线，我申请获得日本笹川纪念保健协力财团赞助的研究经

The background of the stories in this book is Sungai Buloh Leprosy Settlement which was established during the British colonial period. It is a place where a community of leprosy patients has been living for decades. The emergence of this Settlement has been closely related to the policy of segregation of leprosy patients as implemented by the authorities concerned.

In 2007, when we got to know that some of the buildings at the Settlement would be demolished, we started to go to this Settlement to understand more about the patients and their histories. We were surprised to note that these leprosy patients who had been staying here since the last century were almost forgotten by the mainstream society. Hence, we organized a civil group aimed at taking up issues pertaining to the rights of this less privileged group as well as seeking new understanding of the meanings of heritage preservation. The group subsequently gained more support from the public and eventually developed into a social movement. For the remaining inmates at the Settlement whom we fondly called "Ah Gong" and "Ah Ma", we made efforts to approach

them and show our concern. For the public, we tried to promote the concepts of cultural heritage preservation and endeavoured to upgrade the level of awareness about civil society.

I was fortunate to have the opportunity to join this social movement since 2007. The participants then included Tang Ah Chai, Choong Pai Chee, Teoh Chee Keong, Lim Yong Long, Leong Lih Sih, Chua Yee Ling, See Tho Chee Seong, Lian Chiew Yi, Wong Wen Tat, Loh Choy Mun and many college and university students whose names are too many for me to mention here. We all played our respective roles in this movement, working together towards community empowerment. As an academician, I was concerned with how the information regarding the history and cultural values of the Settlement could be systematically compiled into proper records to be passed on to the future generations. In this regard, gathering information using methods of oral history was deemed imperative.

In 2007, a group of students from the Department of Landscape Architecture of Chung Yuan Christian University (CYCU) in Taiwan came to

费。在该基金的支持下，我领着拉曼大学（拉大）中文系学生于2010年至2011年之间顺利完成了7位对象的录音访谈，同时还收集了他们的旧照片。如果加上前期访问，我们共收集了44小时，9位阿公阿嬷的录音访谈。

除此之外，2010年10月4日至9日，我与拉大中文系学生以及另一批同样来自台湾中原大学景观系的实习学生，在麻风病院的佛堂住了近一个星期，进行田野工作。期间除了陆续收集约40多位院民基本资料外，也同时为参议会绘制了社区文物馆建议草图和制作模型。

本书是上述口述历史工作的部分成果。以中英双语为媒介语，目的是为了让更多人从个别院民的生命历程，了解双溪毛糯麻风病院的过去。当然，每个人的故事不尽相同。然而他们对这个社区，对这个疾病却拥有着共同记忆。

本书分为三个部分。首先从抢救希望之谷运动开始，逐步介绍我们如何进入社区，继而接触和访问阿公、阿嬷。这个部分将展示阿公阿嬷自己的故事。他们从哪里来，他们如何感受生活等，都会在这部分逐一叙述。第二部分则是介绍这一麻风病院社区的历史。里头附上了延伸阅读书目，以方便读者进一步深入阅读和研究麻风病院的过去。最后是司徒旨祥等一批摄影爱好者，在2007年东院社区拆除前的摄影作品。优美的希望之谷，如今只能透过他们的镜头捡拾和回味。

从参与抢救希望之谷小组开始，直到推动这项口述历史，我必须感谢所有给予协助的人。特别要感谢的是林永隆、张集强、梁莉思、傅向红、户引理小姐，以及参议会的陈兴、梁志君和李初成。他们提供了许多宝贵意见和帮忙。

去年欣闻双溪毛糯麻风病院社区将局部被指定为国家文化遗产。这是一件值得高兴的事情。然而，我们也不能忘记，目前尚有200多位住在麻风病院社区的阿公和阿嬷，他们还需要社会的关怀。我衷心希望这本图文并茂的小书，能引起更多人对他们的关注。

Malaysia for their practical training session and I had the chance to bring them to carry out fieldwork studies at Sungai Buloh Leprosy Settlement. Subsequently, on an intermittent basis, I also brought students from the Department of Chinese Language and Literature in New Era College to interview the inmates at the Settlement. For these recent few years, the students took part in this work voluntarily and I personally paid for all the expenses involved.

In 2010, with the help of Lim Yong Long, I applied to the Sasakawa Memorial Health Foundation in Japan and was granted its research fund. With the support of this Foundation, I led my students from the Chinese Studies Department of Universiti Tunku Abdul Rahman (UTAR) finish interviewing seven inmates at the Settlement in 2010 and 2011. We recorded all these verbal interviews and at the same time collected the old photographs provided by the inmates. Together with the interviews conducted earlier, we had recorded in total 44 hours of verbal interviews with nine old inmates.

In addition, from 4 to 9 October 2010, I brought my students from the Chinese Studies Department of UTAR to the Settlement again and we were joined by another batch of students from the Department of Landscape Architecture of CYCU in Taiwan who came for their practical training session. We stayed at the Buddhist temple in the Settlement for almost a week and conducted more field work. During the week, we gathered the basic information on 40 more inmates and assisted the Sungai Buloh Settlement Council to prepare a draft drawing as well as an architectural model of the Cultural Heritage Museum proposed for the Settlement.

This book is the partial result of the oral history field work mentioned above. It is written in Chinese and English so that more people can gain a better understanding about Sungai Buloh Leprosy Settlement through the life stories of the respective inmates interviewed. These inmates certainly have told stories that are very different but they all share common memories of this Settlement and the disease they had suffered from.

This book comes in three parts. Part I starts with "Save Valley of Hope" movement and then shows how we entered the Settlement to approach and interview the old inmates. This part tells the real stories of these inmates, describing where they came from and how they felt about their lives etc. Part Two introduces the history of the Settlement and provides a list of extended reading for the convenience of readers who are keen to read more about the past of the Settlement. Part Three presents a gallery of pictures of the sceneries at the Settlement taken by a group of photography enthusiasts before the demolition of the buildings in the Eastern Section. By now, the beauties of the Valley of Hope can only be remembered and cherished by viewing these sceneries captured through the artistic senses of the photographers.

For my involvement in the "Save Valley of Hope Solidarity Group" and the oral history field work conducted for the Settlement, I must convey my gratitude to those who have rendered their assistance in one way or other. In particular, Lim Yong Long, Teoh Chee. Keong, Leong Lih Sih, Por Heong Hong, Aya Tobiki, and also Tan Hing, Leong Chee Kuang and Lee Chor Seng who are committee members of Sungai Buloh Settlement Council, have provided me with many invaluable opinions and much appreciated help.

I was glad to hear the announcement last year that some of the buildings at the Sungai Buloh Leprosy Settlement would be gazetted as national cultural heritage. It was certainly good news for all of us. However, we should not forget that there are still more than 200 old inmates currently staying at the Settlement. They still need the kind concern of the society. I sincerely hope that through this little book of stories and pictures, more people can be encouraged to give attention and care to these inmates.



序二 Preface II

罗彩绵 Loh Choy Mun

双溪毛糯麻风病院是阿公阿嬷命运的交集点。在进入病院之前，他们有着各自的人生经历。其中相似之处，或许就是患病，遭歧视，最后进入病院。麻风病院一度代表了绝望。文良港等麻风病院就有好些病患出逃的案例。然而，双溪毛糯并没有。它甚至在后来成了阿公阿嬷的家，一个他们再也离不开，不愿意离开的地方。

麻风病院是时代的产物，是人类基于对疾病的恐惧制造出来的隔离场所。大规模隔离麻风病患是19、20世纪之交全球医疗体系普遍采取的政策。时任州高级卫生官员的Dr E.A.O. Travers为了减轻隔离政策的暴力与不人道的一面，以兼顾人的基本生理和心理需求为前提，提出建立双溪毛糯病院社区的构想。于是刚进入病院的阿公阿嬷会意外地发现里头有“屋仔”、有学校、有宗教场所

等。后来者甚至惊讶于病患可以结为夫妻这件事。

阿公阿嬷对病院的前线医疗人员大都怀着感恩的心，尤其是英殖民时期的“大医生”、“Missy”和“医生仔”，还有独立那一年上任的Dr K.M. Reddy。他们给予了阿公阿嬷在外界生活难以感受的温暖。如沈金群阿嬷仍记得年纪小小的她如何被护士称赞。麻风病患被隔离在一个小小的空间里，病院社区也只能赋予他们小小的自由——免除外界的歧视目光。

双溪毛糯麻风病院社区的存在提醒了我们，麻风病院从最初以纯粹“病院”的形式出现，到后来以自给自足的“社区”的形式存在，是Dr Travers等相关决策人员将“人道主义”进一步付诸实践的结果。我们应该关注的是，我国现在的、未来的医疗队伍，是

Sungai Buloh Leprosy Settlement has been the place where the fates of the "Ah Gong" and "Ah Ma" converged. Before coming here, they had their own life experiences and the only similarities they shared might be the disease they suffered from, the agony of being discriminated against and the eventual entry into the Settlement. Leprosarium was, at one time, synonymous with a place where all hopes were dashed. In some leprosy centres, such as the one in Setapak, there had been cases of leprosy patients trying to escape. However, in Sungai Buloh Leprosy Settlement, there were no such cases. The Settlement had subsequently become the cherished home of the inmates. They could no longer leave the Settlement and neither did they want to go elsewhere.

Leprosarium was the product of the era, a place of segregation created by human beings due to their fear of the disease. Large scale segregation of leprosy patients was a policy commonly adopted by the healthcare systems around the world at the end of the 19th century and the beginning of the 20th century. Dr E. A. O. Travers, then the State Senior Health Officer,

had proposed the idea of building the Sungai Buloh Leprosy Settlement in order to alleviate the brutal and inhumane aspects of the segregation policy and to cater to the physiological and psychological needs of the patients. As such, the leprosy patients who were new to the Settlement had many pleasant surprises to find that the Settlement had chalets, schools, religious premises etc and that the patients could even get married.

Inmates at the Settlement were mostly grateful to the front-line medical staff, particularly the "Big Doctor", "Missy" and "Little Doctors" during the British colonial period as well as Dr K. M. Reddy who served there in the year when Malaya gained its independence. These were the people who made it possible for the inmates to experience the warmth of human concern which they could hardly feel while living outside the Settlement; for example, Sim Kam Kuang could still remember how a nurse had praised her for being a good girl. While the leprosy patients were made to live in a small place in segregation, the Settlement had made it possible for them to enjoy some freedom - free from being discriminated against

否能够延续这样的精神？“隔离政策”无论从哪个角度来审视谈论都是不人道的。然而公共卫生政策决策者却可以赋予它较为人道的机制。

麻风病之所以备受诅咒，很大程度在于这种疾病会使患者的身体发生异变。因此，病患除了必须忍受疾病带来的身体伤害，还要承受疾病隐喻强加给他们的羞辱与歧视——人们始终将该病与“不洁”挂钩。这样的偏见延续了很长一段时间。进入病院接受隔离似乎是阿公阿嬷和家人唯一能够选择的路。与其在外界遭遇歧视，给家人带来负担，不如进入病院获得治疗，或许还能在康复后回到家人身边。

1960年代初，世界卫生组织及国际癫痫病协会分别提出反对隔离政策。在此之前，刚接任院长一职的Dr Reddy已于1957年开始着手一连串的康复计划，进一步致力于消除社会人士对麻风病的偏见，协助病患重归社会。然而至今麻风病在马来西亚尚未完全去除污名。

阿公阿嬷所经历的伤痛告诉我们，除了疾病本身，还有时代的偏见让他们进入与世隔绝的麻风病院。制度性的隔离强化了人们对该病的恐惧。我们根深蒂固的偏见让病患在康复很多年以后都不敢正视自己，甚至让他们的孩子隐瞒身世。医学界和公共卫生部门有责任消除人们对疾病的想象和误解。Dr Reddy和病院的医疗队伍完成了一部分。余下的魔咒必须得由后来的医疗人员和我们自己去解除。

我们自以为大规模高危传染病流行的时代将随着医学的发达一去不复返。可是，万一有那么一天，与麻风病相类似的不知名且不可治愈的传染病突然爆发，我们该如何应对？是否再度重复历史的错误，接受如今备受指控的“隔离政策”？还是我们可以有其他更好的选择？这或许将仰赖于我们对历史的反思，以及对于病人作为生命个体的尊重究竟有多少。

因此，仅仅对“隔离政策”提出控诉是不够的，还应当检讨当前的公共卫生政策。尤其提醒当下在职的医疗人员和即将毕业的医学院学生，除了救命，还要尊重生命。这样，对我们活着的每一个人以及我们的下一代才有更深层的意义。如此，我们才不会愧对病患们曾经经历的伤痛。

whenever they were outside the Settlement.

The existence of Sungai Buloh Leprosy Settlement reminds us of the fact that the leprosarium was initially established purely as a hospital but subsequently it was able to develop into a self-sustained settlement, all thanks to Dr Travers and other decision makers involved who took the bold step to put humanitarianism into practice. We should thus ask: Can the medical professionals in our country, now and in future, continue to serve with such a spirit? Viewed and discussed from whatever perspective, the policy of segregation is regarded as inhumane. Nevertheless, decision makers involved in the formulation of public health policies can put in place some mechanism to make it more humane.

To a large extent, leprosy had been a cursed disease because it could cause physical deforms. Therefore, apart from suffering physical pain due to the disease, leprosy patients had to endure the humiliation and discrimination hurled at them due to public perception of the disease – the public had always associated the disease with something "unclean". Such a prejudice had continued for a very long time. To be admitted to the leprosarium and accept segregation seemed to be the only choice for the leprosy patients and their families. Instead of being discriminated against and burdening their own families if they chose to stay outside, it was better for them to enter the leprosarium to get treatment as this could still give them some hope that they might be able to recover and return to their families.

In the early 1960s, World Health Organization (WHO) and International Leprosy Association had begun to oppose the policy of segregation. In fact, prior to this, Dr Reddy, director of the Settlement, had started to implement a series of rehabilitation projects in 1957 in efforts to eliminate public prejudice against leprosy and to assist the patients to return to the society. However, until today, leprosy in Malaysia is still not totally stripped of its social stigma.

The pains suffered by the old inmates at the Settlement have revealed to us the fact that leprosy patients were forced to live in the leprosarium and be

cut off from the outside world not merely because of the disease itself, but also due to the social prejudice prevalent then. The institutionalized segregation had intensified fear of the disease among the public. Due to the deep-rooted prejudice in the society, many leprosy patients who have recovered many years ago are now still unable to face up to their own fates, and they would even want their children to conceal their own backgrounds. The medical profession and the public health department have a responsibility in eliminating unwarranted imaginations and misunderstandings of the leprosy disease. Dr Reddy and the medical team had partially fulfilled this mission and the remaining curse has to be dispelled by healthcare professionals after him and every one of us today.

We may have thought that the era of massive spread of high-risk infectious diseases would never return with the advancement in the medical field. However, if it happens that some day in future, an unknown infectious disease similar to leprosy has suddenly emerged and no cure is available, how should we handle it? Should we repeat the mistake in history and accept the policy of segregation that is now bombarded with criticisms? Or do we have better choices? This may eventually boil down to our reflection of history and our respect for patients as living individuals.

Therefore, it is far from enough to merely criticize the policy of segregation. We should also make real efforts to review the existing public health policies. In particular, the serving medical professionals and the medical students who are graduating soon should be reminded that apart from the need to save lives, there is a greater significance to recognize that lives should be respected and revered. Such awareness will bestow deeper meanings for every one of us who is now living as well as our future generations. In this way, we will clear ourselves of the guilty conscience for the sufferings that the leprosy patients had gone through.



沈金群于2008年1月27日提供。

Photo provided by Sim Kam Kuang on 27.1.2008



Part 1

希望之谷的故事

Stories of Valley of Hope



缘起 The Beginning

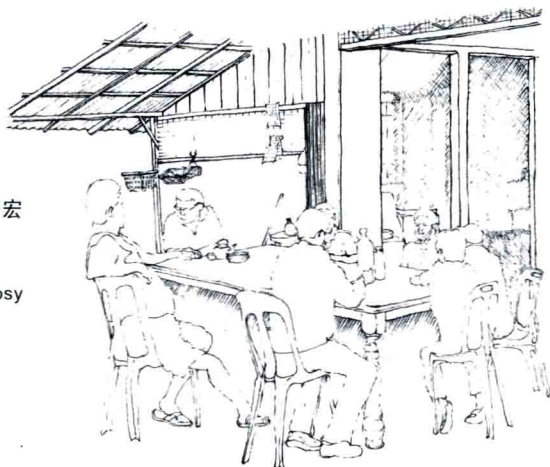
2007年，双溪毛糯麻风病院东院约有40英亩的社区建筑面临拆迁。那一年，东南亚现代建筑研究员林永隆在偶然情况下发现这个社区，并且惊觉玛拉工艺大学已经征用上述土地用以建立医学院。他以个人名义写了一封信，分别寄给文化、艺术及文物部、卫生部、雪州卫生局及高等教育部，阐述双溪毛糯麻风病院社区的历史价值。他在信中明确地提出这一社区在人类医疗史上的贡献和意义，要求完整地保留这片极为特殊的文化遗产。另一方面，他也身体力行，带着自己的学生进行测绘工作，并且上下奔波，承担起导览工作，带领公众进入社区，浏览社区。

2007年7月22日，马来西亚古迹协会执行

主任Elizabeth Cardosa在《新海峡时报》发表“*There's Hope for the Valley of Hope*”，引起国人注意。双溪毛糯麻风病院社区古迹保育成为公共议题，内阁政府不得不回应此课题。8月12日，隆雪华堂青年团举办社区导览活动，率领参加者到双溪毛糯麻风病院社区进行实地讲解和考察。总共有52人报名参加，领队是陈亚才，导览员为林永隆和张集强。除了参观麻风病院社区之外，全体学员也和双溪毛糯地方参议会的成员交流。从那个时刻开始，教师、大专生、记者、社会运动工作者、艺术工作者等来自不同领域的人士，渐渐聚在一起，关心并讨论双溪毛糯麻风病院社区的价值。还有这个曾经被称为“希望之谷”的地方，它的未来应该归于何处？

双溪毛糯麻风病院社区的公平咖啡馆素描。(刘修宏绘。)

Sketch of Kong Peng Kopitiam at Sungai Buloh Leprosy Settlement. (Drawn by Liu Hsiu Hung on 9.10.2010.)



In 2007, the buildings in an area of about 40 acres in the Eastern Section of Sungai Buloh Leprosy Settlement were faced with demolition. It was then that Lim Yong Long, a researcher on modern architecture in Southeast Asia, discovered the Settlement by chance but he was shocked to know that Universiti Teknologi MARA (UiTM) had acquired the land to build its Faculty of Medicine. He wrote a letter in his personal name and sent it to the Ministry of Culture, Arts and Heritage, Ministry of Health of Malaysia, Selangor State Department of Health and Ministry of Higher Education, pointing out the historical value of Sungai Buloh Leprosy Settlement. In his letter, he stated clearly the contributions and significance of the Settlement in the history of medical care for mankind, and requested the relevant authorities to preserve this unique cultural heritage in its totality. At the same time, he initiated a series of actions, bringing his students to conduct mapping work and personally running around to organize guided tours for the public to visit and know more about the Settlement.

On 22 July 2007, Elizabeth Cardoso, Executive

Director of Heritage of Malaysia Trust (Badan Warisan Malaysia), published an article entitled "There's Hope for the Valley of Hope" in *New Straits Times*, generating much attention nationwide. The preservation of Sungai Buloh Leprosy Settlement as a cultural heritage had thus become a public issue and the Cabinet of the Federal Government had no choice but to give its response. On 12 August in the same year, the Kuala Lumpur & Selangor Chinese Assembly Hall (KLSCAH) Youth Section organized a community guided tour of the Settlement. There were 52 participants led by Tan Ah Chai and guided by Lim Yong Long as well as Teoh Chee Keong. Apart from visiting the Settlement, the participants also exchanged views with members of the Sungai Buloh Settlement Council. From then on, many concerned individuals from various fields such as teachers, students from higher educational institutions, reporters, social activists, artists etc gradually gathered to show their concern and to discuss more about the value of the Settlement as well as the future of this unique place which was once called "The Valley of Hope".