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Safety in the midst of stigma: Experiencing HIV/AIDS in two Ghanaian communities

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Preface

In this book, I have tried to present to the world what people infected with HIV, and their families and relations, go through amidst the very high levels of stigma related to HIV/AIDS that persist in Ghana. Stigmatization of people associated with HIV can be fatal, even more so than the virus itself. It kills hundreds of HIV positive people and sends the lives of thousands of others into chaos. All too often in Ghana, those who have no direct experience of HIV do not see the depth of the impact of stigma on individuals, households, and communities. This monograph brings to the fore the lived experiences of people infected with and affected by HIV from their own perspectives – in particular their negotiations between resignation to fate and the struggle for survival – as they cope with stigma. Their sentiments, extracted from their life stories, bring to the fore the urgency of dealing with this canker.

After providing a background to the HIV/AIDS situation in Ghana in Chapter One and the methodology of the research in Chapter Two, the subsequent chapters highlight the experiences of the respondents of HIV counselling, testing, and treatment, as well as the various strategies they deploy in order to live as normal people in society without the negative attributes associated with HIV. Their personal relationships before and after their encounter with HIV, including those with friends and family and society as a whole, are vividly presented, and their various negotiations, daily struggles, and dilemmas are emphasized. In all these accounts, I have tried to decipher emotions from reality, and exaggerations from details, both on my part and that of the respondents. Significantly, this book shows that being infected with or affected by HIV is as much (if not even more of) a social issue as a medical one, and those associated with HIV/AIDS require more than medical care and support. Concerted efforts from all stakeholders – social and political leadership, the untested, the uninfected, the infected, the affected, service providers, and policy makers – would go a long way to reduce the main problem that persists with regards to HIV prevention and treatment in Ghana – stigma.

Many of my friends and family have often asked about what motivated me to spend more than four years with people I am not related to, who may misunderstand my ambitions and intentions, and who may try to harm me by finding a way to infect me with the virus. After all, what better way to understand living with the infection than by being infected yourself? One of my friends once rhetorically asked. Indeed, there were times when I questioned my own motiva-

tions, especially when faced with shocking or deeply upsetting situations. Obviously, the process was sometimes depressing, but it was oftentimes deeply revealing and this, very much so, was my motivation. The PhD award aside, conversing with these friends who were HIV positive, with their concerned families and friends, and with the many others who felt lost and helpless when it came to understanding what their close friend or relative was going through, opened up more vividly the complexities of life itself. Life is complex, I kept saying. And the more I conversed with my friends the more complex I found life to be. It is my express desire that this study be an eye opener to many, including high level decision makers, as it was to me, and will bring about a radical shift in our perceptions and consequently a better health status and prospects for all Ghanaians.

In the conversations with my respondents, I sought to do just one thing: to understand and present the experiences of people living with HIV, and the many others affected one way or the other by the infection, from their own perspectives. What became clear to me was that as social animals, everyone wanted – and in fact demanded – love. If it was not given, it would be sought after. In the end, the complexities continued.

The complexities were, however, not limited to my respondents. My life as a researcher was also affected. During my early associations with my respondents, I must confess that I was not sure whether I was going to make it. I became involved in the everyday lives of HIV positive people for the very first time in my life. They became more than friends, and often we could eat and drink together, especially those who welcomed me into their homes. However, any time when I had a mild on-and-off headache, recurrent fevers, and mild insomnia, I became worried that I may have been infected. I tested myself for HIV several times while in the field using the rapid test kits I had obtained earlier from St. Patrick's Hospital, initially with the aim of using them as presentation materials. In all cases the test showed that I was not infected, and yet I kept repeating the test until I left the field. Interestingly, I realized that by the time I left the field I had used more of the kits on myself than I had kept for the presentations.

The completion of this work has been made possible by the assistance and cooperation of many people, too numerous to mention each by name. Nevertheless, the efforts of some cannot be glossed over, so I use this space to acknowledge a few. First and foremost, I owe a debt of gratitude to Prof. Dr. Sjaak van der Geest, my promoter. His depth of knowledge and particular interest in Ghana placed me on a most valuable track of enquiry. He definitely retuned my mind to undertake this project in the very difficult moments and was always a source of encouragement to me. Dr. Rachel Spronk, my supervisor in Amsterdam, was also

always a present help, no doubt because of her in-depth knowledge on issues in Africa. I am indeed grateful to you both for your professional and personal guidance throughout the fieldwork and the period of write-up.

To my co-promoter Prof. Kojo Senah, of the Sociology Department at the University of Ghana, Legon, I am appreciative and grateful for your constant encouragement and counsel throughout the period of data collection and write-up. In addition, I extend my thanks to Prof. Frances Owusu-Daaku from the Clinical and Social Pharmacy Department of Kwame Nkrumah University of Science and Technology (KNUST) and Dr. Phyllis Antwi of the School of Public Health, University of Ghana, whose persistent expectation for the completion and success of this work kept me going. Your concern for the work even transcended academic lines, and for this I am sincerely grateful.

Beginning in September 2007 – the first phase of fieldwork – I met, lived, ate, conversed, worked, and became friends with hundreds of HIV positive persons, who opened up their lives and homes to me. They assured me and offered me comfort, even when they themselves were in turmoil. They are numerous, more than the approximately fifty whom I lived with and spent most of my time. Some have not survived to see the fruits of their conversations immortalized in this text. Unfortunately, I cannot mention any of your names, but I know that you will have the opportunity to see that I have mentioned you here, just as promised. To all of you who offered me accounts of your shocking yet rewarding experiences, whose names I cannot list here for obvious reasons, I owe you an enormous debt of gratitude. Throughout this book, the names of the respondents have been changed to protect their privacy, including most of those living with HIV and all the medical staff I worked with in Kumasi and Offinso. To all of you who so generously agreed to subject your lives and those of your families to my impertinent anthropological scrutiny, words cannot express my deepest and sincerest appreciation. The time spent with you has not only given me a new perspective on life, it has also produced this manuscript, which will hopefully lead readers to better understand the experiences of living under the shadow of the stigma associated with HIV/AIDS.

I am also very thankful to all those whom I interviewed and those who assisted me in the interviews. To the various informants, the research assistants for the survey, the four secondary schools, and the teachers who helped, I am indeed grateful. To Dr. Maxwell Kankam, Nurses Rose and Josephine (both pseudonyms), and all the workers of the ART centre in St. Patrick's Hospital, the NGOs, peer educators, and various PLHIV associations in both Kumasi and Offinso, I have been privileged to know and work with you, and am eternally grateful. Your courage and perseverance will reap rewards one day, if not before your very eyes then certainly as your legacy in the future. To Mama Mercy at the

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Last but not least, as “all things were made by Him, and without Him was not anything made, that was made,” glory be to God.

Benjamin Kobina Kwansa
Accra, 30 November 2012