

Cross-Cultural Research in Health, Illness and Well-Being

Pranee Liamputtong
Editor

Children and Young People Living with HIV/AIDS

A Cross-Cultural Perspective

 Springer

Cross-Cultural Research in Health, Illness and Well-Being

Series editor

Pranee Liamputtong, School of Science and Health, Western Sydney University,
Penrith, NSW, Australia

This new series examines determinants of health from a cross-cultural perspective. The focus of this perspective is on factors which could influence and determine the health and well-being of people. These factors include biological and genetic factors; health behaviors; socio-cultural and socio-economic factors and environment factors. This series fills a gap by including books which are research-based and contain diverse issues relevant to determinants of health including emerging health issues, such as HIV/AIDS and other infectious and non-infectious diseases/illnesses from a cross-cultural perspective. Volumes in the series will be a valuable resource for researchers and students in sociology, quality of life studies, anthropology, medicine, public health, social work and medicine.

More information about this series at <http://www.springer.com/series/13178>

Pranee Liamputtong
Editor

Children and Young People Living with HIV/AIDS

A Cross-Cultural Perspective



Springer

Editor

Pranee Liamputtong
School of Science and Health
Western Sydney University
Penrith, NSW, Australia

ISSN 2366-6056 ISSN 2366-6064 (electronic)
Cross-Cultural Research in Health, Illness and Well-Being
ISBN 978-3-319-29934-1 ISBN 978-3-319-29936-5 (eBook)
DOI 10.1007/978-3-319-29936-5

Library of Congress Control Number: 2016942861

© Springer International Publishing Switzerland 2016

This work is subject to copyright. All rights are reserved by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

The publisher, the authors and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, express or implied, with respect to the material contained herein or for any errors or omissions that may have been made.

Printed on acid-free paper

This Springer imprint is published by Springer Nature
The registered company is Springer International Publishing AG Switzerland

This book is dedicated to:

*My late father, Saeng Liamputtong, who
passed away in March 2014*

*My mother, Yindee Liamputtong, who brought
up eight children amidst poverty
and*

*My two children: Zoe Sanipreeya Rice and
Emma Inturatana Rice*

Preface

Children and young people are at the center of HIV/AIDS epidemic. In 2014, UNAIDS reported that some 36.9 million (34.3–41.4 million) people were living with HIV. Every day, around 7000 persons become infected with HIV and 5000 persons die from AIDS, due mostly to lack of access to HIV prevention, care, and treatment services. Globally, AIDS-related illnesses remain a leading cause of death. The epidemic has spared no country in the world, although in some countries prevalence rates are still low.

HIV/AIDS have caused a “social assault” on the lives of children and young people in the world. Chapters in this volume attest to this. Many have been orphaned by the death of their HIV-positive parents. Young people, according to the United Nations, are “at the center of the HIV/AIDS epidemic.” Many young people also bear the burden of caring for family members living with HIV/AIDS. Marginalized young people such as refugees, migrants, street children, and those who have been seen to have transgressed their gender norms (e.g., MSA, lesbians, bisexual, gays and transgender individuals) are most at risk due to the use of illicit drugs, their exposure to unprotected sex (in exchange for food, money and protection), and stigma associated with their marginalized lives. Worldwide, we have witnessed the impact that HIV/AIDS has on the opportunities for these young people to be able to lead healthy adult lives. It is crucial that the voices of these children and young people are heard, and their lived experiences and needs are better understood by health and social care providers, as well as researchers in the field so that culturally sensitive health and social care can be implemented for them.

The focus of this book is on the issues that these children and young people face and their lived experiences associated with HIV/AIDS (both directly and indirectly) throughout different parts of the globe. Chapters in this volume indeed affirm the need for us (health-care providers, researchers, and policymakers) to understand and better respond to the social conditions that dictate the health and well-being of children and young people living with HIV/AIDS.

Up until now, many articles have been written to portray children and young people living with HIV/AIDS in different parts of the world. But to my knowledge, there has not been any a single and recent book which attempts to put together results from empirical research that relates to children and young people who are living with HIV/AIDS. This book is written with the intention to fill this gap. The book comprises mainly chapters written by researchers who carry out their projects in different parts of the world. Each chapter contains theoretical and/or empirical information which is based on real-life situations. The volume also includes some chapters which are based on systematic review of literature. I contend that these chapters can be used as evidence for health-care providers to implement socially and culturally appropriate services to assist individuals and groups of children and young people who are living with HIV/AIDS in many societies.

I hope that the book will be of value to health-care providers who have their interests in working with children and young people living with HIV/AIDS from a cross-cultural perspective. The volume will be useful for students and lecturers in courses like anthropology, sociology, social work, nursing, public health, and medicine. In particular, it will assist health workers in community health centers and hospitals in understanding issues related to HIV/AIDS among children and young people and hence provide culturally sensitive health care to these individuals from different social and cultural backgrounds. The book will also be useful for anyone who is interested in children and young people living with HIV/AIDS in diverse social and cultural settings.

In bringing this book to life, I owe my gratitude to many people. First, I would like to thank all contributors who helped make this book possible. Second, I thank Esther Otten and Hendrikje Tuerlings of Springer who worked with me to bring this book to the final form. Last, Rosemary Oakes has helped edit some of the chapters for me.

This book is dedicated to my parents who brought their children up amidst poverty in Thailand. They believed that only education would improve the lives of their children and hence worked hard to send us to school. I have made my career thus far because of their beliefs and the opportunity that they both have provided for me. I thank them profoundly. I also dedicate this book to my two daughters who have been part of my life and for understanding the ongoing busy life of their mother.

Penrith, Australia
November 2015

Pranee Liamputtong

Contents

1	Children, Young People and HIV/AIDS: A Cross-Cultural Perspective	1
	Pranee Liamputtong	
Part I Children, Young People and Living with HIV/AIDS		
2	Unpacking ‘OVC’: Locally Perceived Differences Between Orphaned, HIV-Positive and AIDS-Affected Children in Zimbabwe	23
	Morten Skovdal, Catherine Campbell, Zivai Mupambireyi, Laura Robertson, Constance Nyamukapa, and Simon Gregson	
3	Children’s Experiences of Living with HIV-Positive Parents Within the Family Context of Bangladesh	43
	Md Shahidul Islam, John Scott, and Victor Minichiello	
4	Adolescents Living with HIV: Emerging Issues in Public Health in South Africa.....	65
	Nataly Woollett	
5	Living Optimally with HIV: Youth Experience in a Metropolitan Canadian City	89
	Michelle Di Risio, Peri J. Ballantyne, and Stanley Read	
6	“There’s More to You Than Just This Virus”: Young People Growing Up with Perinatally-Acquired HIV in Australia	107
	Asha Persson, Christy E. Newman, and Angela Miller	

Part II Children, Young People, HIV/AIDS, Identity and Risk

- 7 Masculinities, Femininities and the Burden of Culture Among Rural South African Teenagers in the Context of HIV** 127
Deevia Bhana
- 8 “Digging Your Own Grave”: Ghanaian Young People’s Construction of Vulnerability Within the Context of HIV/AIDS** 147
Georgina Yaa Oduro
- 9 HIV/AIDS Knowledge and Risk of HIV/AIDS Among Youth in South Africa** 169
Sylvia Niele and Pranee Liamputtong
- 10 “I Definitely Want Kids, But I Think the Risks Are Pretty High”: Fertility Desires and Perinatal HIV Transmission Knowledge Among Adolescents and Young Adults with Perinatally-Acquired HIV** 191
Cynthia D. Fair and Jamie Nicole Albright
- 11 Men Who Have Sex with Men (MSM) in Accra, Ghana and Lome, Togo: Sexual History and HIV Risk Behavior** 207
Ami Moore and Adobea Owusu
- 12 Mental Health Problems and Associated Socio-Ecological Factors Among HIV-Positive Young Migrant Men Who Have Sex with Men in China** 223
Haochu (Howard) Li, Joseph T.F. Lau, Eleanor Holroyd, and Xiaoming Li
- 13 Young LGBT People, and HIV/AIDS Risks: A Metasynthesis** 241
Pattaraporn Moolchaem and Pranee Liamputtong

Part III Children, Young People, Health Care, Interventions and Policies

- 14 Protecting HIV-Positive Children in Jamaica: Exploring Policy, Practice and Institutional Responses** 273
Paul Miller and Stephen Wallder
- 15 HIV Prevention for Adolescent Women in Africa: Structural Driver Interventions** 289
Catherine MacPhail and Audrey Pettifor
- 16 In Search of Entrepreneurs, Children and HIV/AIDS in Cameroon: A Marginalized Issue?** 309
Larissa Kojoué

17 Disclosure as a Positive Resource: The Lived Experiences of HIV-Positive Adolescents in Botswana	321
Vivian Midtbø and Marguerite Daniel	
18 The Power of Online Patient Communities for HIV Youth	339
Gonzalo Bacigalupe, Kathryn Cantrell, and Rachel Chickerella	
19 The Power of Peers: Self-Stigma Impacts, Peer Support and Engagement	359
Magda Conway	
20 Teens and Transitions: Supporting Youth with HIV to Move Successfully from Pediatric to Adult Healthcare	379
Corry Azzopardi, Robyn Salter, Stephanie Savage, Jason Brophy, Ari Bitnun, and Stanley Read	
21 “I Can Still Be Happy, I Can Still Get My Life Again”: Psychological Interventions with Children, Young People and Families Living with HIV in the United Kingdom	399
Tomás Campbell and Jayne Griffiths	
22 Lay Definitions of Antiretroviral Treatment: Unpacking the Paradoxes and Dilemmas of Therapeutic Efficacy in Rural Tanzania	421
Mangi J. Ezekiel	
Part IV Children, Young People & Research	
23 Ethical Considerations of Conducting Research among Children and Young People Affected by HIV: A View from an Ethics Review Board	445
Katie D. Schenk and Saumya RamaRao	
24 Can Pictures Influence Policy? Ugandan Children Share Stories Utilizing Photovoice	459
Bonnie Fournier and Olenka Bilash	
Index	485

Contributors

Jamie Albright is a clinical psychology doctoral student at the University of Virginia. She received her BA in Public Health from Elon University in 2013 and her MA in Psychology from the University of Virginia in 2016. Her research is aimed at identifying ways to support marginalized adolescents' psychosocial well-being using a resilience framework.

Corry Azzopardi received her PhD and MSW from the University of Toronto's Factor-Inwentash Faculty of Social Work. She has been a social worker with the Hospital for Sick Children in Toronto since 2002. Her clinical practice, teaching, and research concentrate in the areas of child maltreatment and pediatric healthcare.

Gonzalo Bacigalupe is professor and director of Family Therapy and Counseling Psychology Programs at the University of Massachusetts Boston and is Ikerbasque Research Professor at the University of Deusto Bilbao. Bacigalupe is coprincipal investigator of a Patient-Centered Outcomes Research Institute Pilot research project. He is research faculty in the Health Equity Scholars Program (HESP) of the UMass Center for Health Equity Intervention Research (CHEIR). His research focuses on the impact of media on family health. He is president of the American Family Therapy Academy, fellow of the American Psychology Association, and member of several peer review journal editorial boards.

Peri J. Ballantyne a health sociologist, is an associate professor in the Department of Sociology, Trent University, Peterborough, Canada, and is affiliated with the Leslie Dan Faculty of Pharmacy, University of Toronto. Her research interests include the social determinants of health across the life course, professional-lay interactions in health care and lay interpretations of health and illness, and the sociology of pharmaceuticals. In qualitative research, she uses in-depth interviewing and focus group methods to understand the impact of social context on the meaning of human phenomenon such as health, illness, dis-/ability, and work/non-work.

Deevia Bhana is a professor in the School of Education, University of KwaZuluNatal, South Africa. Her research includes a focus on childhood sexualities, gender, schooling, and inequalities. She is a coauthor of *Towards Equality? Gender in South African Schools During the HIV/AIDS Pandemic* (2009, UKZN Press) and a coeditor of the book *Babies and/or Books: Pregnancy and Young Parents at School* (HSRC, 2012).

Olenka Bilash is professor of second language and intercultural education in the Department of Secondary Education, Faculty of Education, University of Alberta, Canada. She teaches and publishes in the areas of action research, qualitative research methodology, professional development, transformative practice, and intercultural communication and has worked on projects in Cameroon and South Africa.

Ari Bitnun is an associate professor of Pediatrics, University of Toronto, and a staff physician in the Division of Infectious Diseases, Department of Pediatrics, the Hospital for Sick Children. Ari received his MD from the University of British Columbia and completed his pediatric residency training in Israel and subsequently clinical and research infectious diseases fellowships at the Hospital for Sick Children. He has been involved in pediatric HIV clinical research since 1999 and has been a member of the Family-Centered HIV Clinic at the Hospital for Sick Children since 2004.

Jason Brophy is a pediatric infectious diseases physician and researcher at the Children's Hospital of Eastern Ontario and an assistant professor of pediatrics at the University of Ottawa. He completed his clinical and research fellowships in pediatric infectious diseases fellowship and HIV at the Hospital for Sick Children, University of Toronto. He has a Masters of Health Research Methodology from McMaster University. He is the current chair of the Canadian Pediatric/Perinatal AIDS Research Group. He has also worked as a pediatric HIV clinical advisor with the Clinton Health Access Initiative in Vietnam.

Catherine Campbell is professor and head of social psychology at the London School of Economics, where she directs the Health, Community, and Development Group. She has a particular interest in health inequalities and the role of small-scale collective action in supporting the well-being of marginalized groups, with particular reference to HIV/AIDS, mental health, and the health of women and children. She has published over 150 peer-reviewed papers on these topics.

Tomás Campbell is a clinical psychologist and neuropsychologist and has worked in the HIV field since 1990. Tomás spent 2 years working in an HIV NGO in Zambia in 1993-1994 and realized that psychological interventions with people with HIV had to be intensely practical in order to assist people with HIV to face the everyday challenges of living with the disease. This principle has guided his clinical work and his research interests. His research interests include the identification and mitigation

of the neuropsychological impact of HIV in the developing brain, the impact of HIV-related stigma on the mental health of people with HIV and the development of psychological resilience in young people to and their families to face the challenges of life as a positive person. Tomás is a committee member of the British Psychological Society's Faculty for HIV & Sexual Health and a past chair. He is also the former president of the Royal Society of Medicine's Black Ethnic Minority Health Section (2013). He is a trustee of the UK-based Children's HIV Association (CHIVA) and chair of the trustees of AfricAid which supports the Whizzkids Academies in South Africa and Ghana.

Kathryn Cantrell is a doctoral student at University of Massachusetts Boston where she conducts research related to e-health interventions for individuals with chronic illnesses. Kathryn is a certified child life specialist with Developmental Therapeutic Source, LLC, where she provides psychosocial care to children with chronic illnesses. Prior to Kathryn's current positions, she worked at St. Jude Children's Research Hospital as a child life specialist for youth with HIV. Kathryn received her master of arts in child development from Tufts University where she currently lectures courses in pediatric psychology. Kathryn's research interests include supporting coping in youth with chronic illnesses and designing virtual interventions for coping.

Rachel Chickerella was born in Columbus, Ohio, and lives in Boston, Massachusetts. She completed her undergraduate degree at Xavier University majoring in psychology with a double minor in criminal justice in philosophy. While completing her degree, she worked as a research assistant in the Epilepsy Adherence Lab at Cincinnati Children's Hospital, was a peer mediator in a girls' after-school club, and participated in the Inside-Out Prison Exchange Program. Rachel is currently working on her masters in mental health counseling at the University of Massachusetts, Boston. She works as a research assistant for Dr. Bacigalupe looking at the efficacy of online support communities. She also researches trauma informed practice in early childhood education.

Magda Conway has worked with children and HIV for 11 years, being the UK policy lead at the National Children's Bureau and then as a freelance consultant, supporting (among others) the Children's HIV Association and UNICEF. Magda has set up peer support groups, developed numerous participation and peer support projects, delivered training, and written extensively about this group.

Marguerite Daniel is currently an associate professor of development-related health promotion at the HEMIL Centre, University of Bergen. Her research interests include children affected and infected by HIV, the impact on social cohesion of international aid targeting children, and local and global perspectives on child protection, in southern and eastern Africa, in particular Botswana and Tanzania. Her theoretical stance is salutogenic and is concerned with how children thrive in adversity.

Michelle Di Risio is a flex-time PhD student in the Department of Pharmaceutical Sciences, University of Toronto, Toronto, Canada. She is also employed at Hoffmann La Roche in the Medical Affairs Department. Her academic interests are in applying sociological approaches to examine the broader social, political, cultural, and historical organization of various medical concepts such as the meanings of illness and the dying process.

Mangi J. Ezekiel is an employee of Muhimbili University of Health and Allied Science as Lecturer in the Behavioural Sciences department. His background is in medical sociology and anthropology. Prior to joining MUHAS, he worked briefly as a community development worker at Plan International. He is an excellent team worker with interpersonal communication and social skills. After completing his undergraduate and postgraduate studies in Tanzania, he conducted extensive research with young people that culminated into a PhD (medical anthropology) at the University of Oslo in Norway.

Cynthia D. Fair is a professor of human service studies and coordinator of public health studies at Elon University. Her clinical and research interests include HIV-infected and affected youth and women as well as HIV-related stigma and discrimination. Her most recent research is focused on the transition of youth with HIV from pediatric to adult infectious disease care, as well as the reproductive decisions of youth with perinatally acquired HIV infection.

Bonnie Fournier is a PhD candidate and lecturer at the University of Alberta, Faculty of Nursing. Her recent research projects have focused on the role of Ugandan nurses caring for individuals with HIV and AIDS and the experience of Ugandan children who are orphaned and HIV seropositive. Her qualitative research expertise is in participatory action research, photovoice, and other arts-based methods. She has many years of international experience in Zambia working for MSF (Medecins Sans Frontieres), in Uganda, working with children affected by war, in Zimbabwe working as an HIV and AIDS research consultant, and in Qatar teaching nursing.

Simon Gregson trained as demographer at the London School of Economics and Political Science in the late 1980s before completing a DPhil at the Centre for Epidemiology of Infectious Disease at the University of Oxford. He was appointed to the academic staff in the Department of Infectious Disease Epidemiology at Imperial College London in 2001 and was awarded a chair in Demography and Behavioural Science in 2008. Simon set up and directs the Manicaland Project, a longitudinal study using quantitative, qualitative, and mathematical modeling methods to describe and interpret trends in the spread and control of HIV in eastern Zimbabwe.

Jayne Griffiths is a London-based clinical psychologist who has been centrally involved in designing and delivering clinical psychology interventions to HIV-positive people since 2008. She is a member of the Looking Forward Day project

group that runs a long-term group based program for young people over the age of 12 years who are aware of their diagnosis. She has also run parenting courses for HIV-positive parents. She is interested in systemic approaches to her family-based clinical work and has also led the Looking Forward group in the development and application of the Tree of Life approach. Jayne has contributed to the development of UK standards about HIV disclosure to HIV-positive young people and has undertaken teaching, advice, and support to primary health-care clinicians working with HIV-positive adolescents in South Africa.

Eleanor Holroyd is a Professor of Nursing, School of Clinical Sciences, Auckland University of Technology, Auckland, New Zealand. She is a senior medical anthropologist working on researches of sex workers, HIV/AIDS, sex education and barriers for condom use.

Md Shahidul Islam completed his PhD at the School of Health, University of New England, Armidale, Australia. He completed MSc in International Health from Royal Tropical Institute, Amsterdam, the Netherlands; Queen Margaret University, Edinburgh, UK; and Karolinska Institutet, Stockholm, Sweden. He received his bachelor (Hon's) and master degrees in sociology from the University of Dhaka, Bangladesh. Currently, he is teaching at the School of Health, University of New England, Armidale, Australia. He is also an associate professor of sociology discipline at Khulna University, Bangladesh. His teaching and research interests include the sociology of health and medicine, HIV/AIDS, gender, and sexuality.

Larissa Kojoué has a PhD in political sciences. She is a research associate at Les Afriques dans le Monde (LAM, Bordeaux) and African Studies Centre (ASC, Leiden). Her areas of interest include HIV/AIDS, global health, public policies, children, social movements, and human rights in Cameroon.

Joseph T.F. Lau is a Professor and Head of the Division of Health Improvement and the Director of the Centre of Health Behaviors Research of the School of Public Health and Primary Care, the Chinese University of Hong Kong. He is a senior public health scholar working on interdisciplinary evidence-based and theory-based research on HIV prevention and care in China.

Haochu (Howard) Li is an Early Career Researcher in the UNC Project-China, Institute for Global Health and Infectious Diseases, University of North Carolina at Chapel Hill, NC, United States, and a postdoctoral fellow in the School of Public Health, Shandong University, Jinan, China. He is a medical anthropologist trained in multiple disciplines, obtaining a master degree in anthropology, a master degree in health social sciences, and a PhD in public health. His research topics included sexual identity, sexual health, sexual culture, sexual risk behavior, mental health, and health service seeking among men who have sex with men in China. Some of his researches have been published in peer-review journals or presented in international conferences.

Xiaoming Li is a Professor and SmartState Chair for Clinical Translational Research, Department of Health Promotion, Education, and Behavior, Arnold School of Public Health, Columbia, SC, United States. He is a senior psychologist working on interdisciplinary HIV/AIDS studies among migrants, sex workers, and family affected by HIV/AIDS.

Catherine MacPhail has worked in HIV prevention in South Africa for the past 15 years, specifically focusing on adolescents. She is currently working on examining the role of cash transfers and community norms for preventing HIV infection in young South African women, investigating the issues associated with aging, HIV, and sexual health in South Africa and Australia and sexual health of Australian adolescents. She holds a postdoctoral fellowship at the Collaborative Research Network at the University of New England and an honorary appointment at the Wits Reproductive Health and HIV Institute, University of the Witwatersrand.

Vivian Midtbø is currently employed as a researcher at the National Centre for Emergency Primary Health Care, Uni Research, Bergen. She is previously trained as a nurse, and she completed her master of philosophy of health promotion at the University of Bergen in spring 2012. Her research interests include children and adolescents living with HIV, health promotion, primary health care, and clinical development for nurses in the primary health-care sector.

Angela Miller was a senior social worker at the Paediatric HIV Service at Sydney Children's Hospital for 10 years where she provided psychosocial support and counseling to children, families, and pregnant women with HIV. In addition, she coordinated Camp Goodtime and the Positive Kids camps. Angela recently took up a new position as senior social worker/counselor at the Short Street Sexual Health Centre in Sydney.

Paul Miller is a director in the Institute for Educational Administration & Leadership-Jamaica (IEAL-J) and a former professor of Educational Leadership & Management in the School of Graduate Studies, Research & Entrepreneurship, University of Technology, Jamaica. He is currently a reader in education at Brunel University London, where he is also a program leader for the MA education. He has a master of laws degree specializing in minorities (children) rights and the law.

Victor Minichiello is emeritus professor at the University of New England; adjunct professor at The Australian Research Centre in Sex, Health & Society, La Trobe University; and section editor of *BMC Public Health*. He has published extensively on topics related to sexual health, sexualities, and ageism. His recent research projects focus on the sexual and intimacy experiences of older women, male sex work and society, and the use of e-technology to facilitate positive health outcomes.

Pattaraporn Moolchaem is a PhD candidate in the School of Public Health and Human Biosciences, La Trobe University. Her PhD thesis is focusing on the lived

experiences, health, and well-being among male-to-female transgendered individuals in Thailand. Pattaraporn has experience working in behavioral and medical research on HIV/AIDS and other sexually transmitted infections among males who have sex with males and transgender people. She has also held a position of lecturer at the Faculty of Nursing, Ratchathani University, Thailand, and associated researcher in gender identity and transgenderism at Transgender ASIA Research Centre based in Hong Kong. Pattaraporn identifies herself as a transsexual woman.

Ami Moore is a social demographer at the University of North Texas, Denton. Her research interests are in health-related studies as well as gender and place of birth factors in the economic assimilation of immigrants in the USA. She has conducted HIV and AIDS research on different population groups in Ghana and Togo. She uses both qualitative and quantitative methodologies in her research. She teaches graduate and undergraduate courses in demography and sociology. She was a Fulbright Scholar twice.

Zivai Mupambireyi is a Zimbabwe-based qualitative social scientist with 13 years of research experience in the field of HIV/AIDS. She obtained a Wellcome Trust Masters fellowship in 2008 and undertook an MSc in health, community, and development at the London School of Economics and Political Science (LSE; www.lse.ac.uk), with a focus on health services research. She is currently enrolled as a PhD student at the University College London (UCL; www.ucl.ac.uk). Her research interests lie in adolescent health, HIV/AIDS, Children and Antiretroviral Therapy with the aim of making recommendations on the best methods of service delivery/implementation.

Christy E. Newman is a senior research fellow at the Centre for Social Research in Health (formerly the National Centre in HIV Social Research) at UNSW. She is a qualitative researcher interested in the social aspects of engaging different populations and professional groups with contemporary health imperatives and health services, particularly in relation to HIV and sexual health care.

Sylvia Niele is currently a registered psychologist working in private practice in Melbourne, Australia. She has also worked in various public mental health settings and been involved in longitudinal research on healthy ageing. Sylvia's interest in HIV/AIDS was sparked while doing volunteer work among street youth in Durban, South Africa, witnessing the devastating impact of the pandemic first hand. This posed the question, "Why is HIV/AIDS continuing to spread in this developing country?" and inspired a return trip to Durban to collect data exploring the role of culture, attitudes, beliefs, and stigma toward HIV/AIDS among this disenfranchised and vulnerable group.

Constance Nyamukapa is currently employed by Imperial College London as Research Associate. Her first degree was in social work (University of Zimbabwe-1996). In 1998 she joined the Manicaland HIV/STD Prevention Project

and has been with the project since. In 2000–2001 she was awarded Wellcome Trust fellowship to do an MSc in population and development at London School of Economics and Political Science, UK. In 2003–2007 Constance was awarded scholarship to do PhD at Imperial College London, and her thesis focused on psychosocial well-being of HIV-affected orphans in eastern Zimbabwe. Areas of interest center around HIV impact on OVC (psychosocial well-being and educational outcomes) and general population.

Georgina Yaa Oduro is a lecturer at the Department of Sociology and Anthropology, University of Cape Coast, Ghana. She holds a PhD from the University of Cambridge, UK, and an MA in Human Resource Management from the University of Westminster, London. She completed her PhD in 2010 having researched the topic “Gender relations, sexuality and HIV/AIDS education within the context of Ghanaian youth cultures”. She has an interdisciplinary background in sociology, education and management. She is a qualitative researcher with expertise in creative data collection methods such as drawings, stories, essays, body mapping, etc. Her research interests include gender relations, youth cultures, sexuality, sexual health, social contexts of HIV/AIDS and other medical practice in Africa. She has been involved in both local and international research projects and has some publications to her credit. She has also won a number of scholarships and awards.

Adobea Owusu holds a PhD and MA from the University of North Texas (UNT), Denton, Texas, and an MPH from the UNT School of Biomedical Sciences at Fort Worth, Texas, USA. She also holds graduate diploma and bachelor of science (Hons.) from the University of Ghana, Legon. She has a faculty position at the University of Ghana, Legon. Adobea is currently the head of the Social Division of the Institute of Statistical, Social and Economic Research at the University of Ghana, where she teaches graduate courses. Her current research focuses on sexuality, access to health care, and HIV/AIDS.

Asha Persson is a social anthropologist by training and a research fellow at the Centre for Social Research in Health (formerly the National Centre in HIV Social Research) at the University of New South Wales where she does sociologically informed qualitative research on various cultural and lived aspects of HIV, with particular focus on the experiences and needs of previously hidden or under-researched populations within the Australian epidemic, including heterosexuals, children, and couples with mixed HIV status.

Audrey Pettifor is an associate professor in the Department of Epidemiology at the University of North Carolina at Chapel Hill and a faculty fellow at the Carolina Population Center. Her research focuses on determinants of HIV/STI in sub-Saharan Africa with the goal of identifying modifiable risk factors and developing novel interventions to prevent new HIV infections—particularly in young women. Audrey has conducted HIV research in South Africa for over 15 years and also has worked in Malawi, Zimbabwe, Kenya, the Democratic Republic of Congo, and Madagascar.

She has experience in conducting structural interventions including the role of incentives for HIV prevention, community mobilization to change negative gender norms, and interventions to promote linkages to care. She received her PhD in epidemiology and MPH in maternal and child health from the University of California, Berkeley.

Saumya RamaRao is a senior associate with the Population Council's Reproductive Health program. She oversees major product introduction research, generates evidence about health systems and the people who use them, and provides technical assistance for program design and implementation. Her areas of research interest include safe abortion, safe motherhood, and family planning. She conducts on-the-ground research to identify specific reproductive health needs, works closely with Ministry of Health officials and service-delivery organizations to expand their range and quality of services, and provides technical assistance and support to program monitoring and evaluation. She is also a member of the Council's Institutional Review Board providing ethical oversight to institutionally developed projects.

Stanley Read is professor emeritus of Pediatrics at the University of Toronto. He is a consultant in Pediatric Infectious Diseases at the Hospital for Sick Children. He has been director of the HIV/AIDS Family-Centered Care Program since its inception in 1988. He chairs the Scientific Advisory Committee of the Canadian Foundation for AIDS Research and is consultant to the Ministry of Health of the Bahamas. His major research interests include exploring determinates of a functional cure, HIV transmission in babies of HIV-infected women, neurocognitive development in children exposed to antiretrovirals, and gene therapy in HIV infection.

Laura Robertson worked as a social epidemiologist in the Department of Infectious Disease Epidemiology, Imperial College London from 2006 to 2013. While studying for her PhD, she researched orphanhood and its impact on children and young adolescents in the context of the HIV/AIDS epidemic in sub-Saharan Africa, particularly in Zimbabwe. She later evaluated a cash transfer program for orphaned and other vulnerable children, in Manicaland, Zimbabwe. She is currently training to be a mental health nurse at Middlesex University.

Robyn Salter has a master's degree in social work from Carleton University, Ottawa, Ontario, Canada. She is a social worker of the Infectious Diseases Program at Sick Kids in Toronto and has been a social worker in the HIV program since it started in 1988. Her clinical practice and research have focused on psychosocial issues for children, teenagers, and families with HIV including parenting children with HIV, stigma and disclosure of HIV status to children, teens transitioning to adult health care, and issues for parents going through treatment to prevent transmission during pregnancy and early infancy.

Stephanie Savage holds a master's degree in social work from the University of Toronto. She also completed a Universities Without Walls HIV research fellowship. She is currently working with children and families affected by HIV. In her clinical practice, she specializes in health and mental health. Her research has focused on issues for people living with HIV and practice considerations for support providers working with them including HIV nondisclosure criminalization, peer support, and mental health.

Katie D. Schenk is a research assistant professor in the Department of Global and Community Health at George Mason University, Virginia, USA. She is the principal investigator of an NIH-funded research study exploring HIV status disclosure among children and caregivers in Zimbabwe. She teaches courses on global health and research methodology to graduate students. She has extensive research experience focused on mitigating the impacts of HIV on children and families in sub-Saharan Africa. She has conducted fieldwork at diverse research sites, including in Kenya, South Africa, Tanzania, Uganda, Zambia, and Zimbabwe. From 2002 to 2014, she led a portfolio of applied social and behavioral research studies in HIV and sexual and reproductive health at the Population Council, where she now serves on the Institutional Review Board.

John Scott is a professor at the University of New England Australia. He has published approximately 80 books, articles, and book chapters on a broad range of issues associated with the sociology of health and illness and sociology of gender and sexuality. A common theme in his research has been a concern with marginalized social populations and the development of critical and interpretive perspectives to understand the experiences of and social reactions to such populations. His most recent book (edited with Minichiello) is *Male Sex work and Society* (Harrington Park Press).

Morten Skovdal is an associate professor of Global Health at the University of Copenhagen. Morten trained as a community health psychologist at the London School of Economics and Political Science and received his PhD in 2009. Before taking up his academic post, Morten worked as a senior advisor on impact and evidence with Save the Children. Much of his research is focused on children's experiences of the HIV epidemic in sub-Saharan Africa, inspired by the need to appropriate and align HIV technologies and development interventions with local realities.

Stephen Wallder is lecturer in business and management in the Faculty of Educational Studies at the University of Technology, Jamaica. He has over 25 years teaching and industry experience. He has led workplace education programs and advised companies on workplace policies in relation to HIV/AIDS. He was the both chair and vice-chair for the Jamaica Business Council on HIV/AIDS (the Business response umbrella organization to HIV/AIDS in Jamaica).

Nataly Woollett is currently a technical team head at Wits Reproductive Health and HIV Institute (WRHI) where the focus is to integrate psychosocial aspects of health and HIV into public health systems. Nataly, in collaboration with WHO, is also the principal investigator of an RCT intervention study conducted in antenatal clinics for pregnant women experiencing intimate partner violence. Nataly has particular expertise in areas of mental health and HIV, gender-based violence and HIV, trauma and traumatic bereavement, and the special needs of OVC and child/adolescent witnesses of violence. Nataly has trained in the fields of psychology, art therapy, and play therapy. She is currently completing her PhD at Wits University School of Clinical Medicine on the mental health outcomes of HIV-positive adolescents.

About the Editor

Pranee Liamputtong is a medical anthropologist and professor of Public Health at the School of Science and Health, Western Sydney University, Sydney, Australia. Until early 2016, Pranee held a personal chair in Public Health at the Department of Public Health, School of Psychology and Public Health, College of Science, Health and Engineering, La Trobe University, Melbourne, Australia. Pranee has also previously taught in the School of Sociology and Anthropology and worked as a public health research fellow at the Centre for the Study of Mothers' and Children's Health, La Trobe University. Pranee has a particular interest in issues related to cultural and social influences on childbearing, childrearing, women's reproductive and sexual health, and the health of children. She has published several books and a large number of papers in these areas.

Some of her recent books in the health and social sciences include: *The Journey of Becoming a Mother Amongst Women in Northern Thailand* (Lexington Books, 2007); *Community, Health and Population* (Oxford University Press, 2009); *Infant Feeding Practices: A Cross-Cultural Perspective* (Springer 2011); *Motherhood and Postnatal Depression: Narratives of Women and Their Partners* (Springer, 2011); *Health, Illness and Well-Being: Perspectives and Social Determinants* (Oxford University Press, 2012); *Women, Motherhood and HIV/AIDS: A Cross-Cultural Perspective* (Springer, 2013); *Stigma, Discrimination and HIV/AIDS: A Cross-Cultural Perspective* (Springer, 2013); and *Contemporary Socio-Cultural and Political Perspectives in Thailand* (Springer, 2014). Her new book on *Public Health: Local and Global Perspective* has recently been published by Cambridge University Press in early 2016.

Pranee is a qualitative researcher and has also published several method books. Her most recent method books include: *Researching the Vulnerable: A Guide to Sensitive Research Methods* (Sage, 2007); *Performing Qualitative Cross-Cultural Research* (Cambridge University Press, 2010); *Focus Group Methodology: Principles and Practice* (Sage, 2011); *Qualitative Research Methods, 4th Edition*

(Oxford University Press, 2013); *Research Methods in Health: Foundations for Evidence-Based Practice, 2nd Edition* (Oxford University Press, 2013); and *Participatory Qualitative Research Methodologies in Health* (Sage, 2015). She is currently working on a series of books on research methods in the health social sciences for Springer and the third edition of *Research Methods in Health* book for Oxford University Press (due in early 2017).

Chapter 1

Children, Young People and HIV/AIDS: A Cross-Cultural Perspective

Pranee Liamputtong

Contents

1.1 Children, Young People and HIV/AIDS.....	1
1.2 Living with HIV/AIDS and Mental Health Issues.....	3
1.3 HIV/AIDS, Stigma and Discrimination.....	4
1.4 HIV/AIDS, Secrecy and Disclosure.....	5
1.5 Resilience and HIV-Positive Young People.....	6
1.6 Social Support, Interventions and Health Promotion Programs.....	7
1.7 Researching with Children and Young People Living with HIV/AIDS.....	10
1.8 About the Book.....	11
1.9 Conclusion.....	11
References.....	12

1.1 Children, Young People and HIV/AIDS

In 2013, UNAIDS reported some 35.3 million (32.2–38.8 million) people were living with HIV. UNAIDS also suggests that every day, around 7000 persons become infected with HIV and 5000 persons die from AIDS, due mostly to lack of access to HIV prevention, care and treatment services. Globally, AIDS-related illnesses remain a leading cause of death (UNAIDS 2013). The epidemic has spared no country in the world, although in some countries prevalence rates are still low. However, it should be noted that low prevalence rates at national level may mask pockets within a country where the rate is high.

Children and young people, according to the United Nations (2013), are “at the center of the HIV/AIDS epidemic” (Lowenthal et al. 2014a: 143). Currently, about 5.4 million people aged 10–24 are living with HIV/AIDS. Many of these young people acquired HIV perinatally but about 780,000 young people aged 15–24 are newly infected (UNAIDS 2013). Approximately 97% of the new infections take

P. Liamputtong (✉)

School of Science and Health, Western Sydney University, Penrith 2751, NSW, Australia
e-mail: p.liamputtong@westernsydney.edu.au

place in low- and middle-income nations (UNAIDS 2013), and about 90% of these young people live in resource-poor settings in sub-Saharan Africa (UNAIDS 2012; Lowenthal et al. 2014a, b).

Children and young people who are living with HIV/AIDS are from the most marginalized and vulnerable groups in the world (Orban et al. 2010; Kumar 2012; UNAIDS 2013; Bell and Aggleton 2014). For most young people living with HIV/AIDS, they have to deal with multiple issues including stigma, fears about illness and contamination, concerns about their life expectancy, clinic appointments and medication regimens, as well as a desire to be a 'normal' person, engaging in intimate relationships, and concerns about reproductive health needs (Brown et al. 2000; Jaspan et al. 2009; King et al. 2009; Fair and Albright 2012; Snyder et al. 2014; see also Chaps. 4, 6, 10, 18, 19, 20, and 21 in this volume). Natalie Woollett contends in Chap. 4 that HIV-positive young people are affected by the HIV epidemic in various ways. Not only that they have to deal with their own illnesses and uncertain futures, they also "suffer trauma and grief as they watch their parents and family members die, many lose siblings and their home at the event of a parents' passing as siblings are displaced to various family members and areas in the country". Similarly, Shahidul Islam, John Scott and Victor Minichiello (Chap. 3) write that existing research has pointed to many risks and pressures on the lives of children living with HIV/AIDS. These include withdrawal from school, increased household activity burdens, lack of access to health care, malnutrition, emotional stress, social stigma and discrimination, as well as increased risks of HIV infection, abuse, and exploitation (see also Beard et al. 2010; Leeper et al. 2010; Chi and Li 2013).

Many children have been made orphan by the death of their HIV-positive parents (Watts et al. 2005; Kang et al. 2008; Kumar 2012; Nyberg et al. 2012; Campbell et al. 2014; see Chaps. 2, 3, 4, 9, 16, 20, and 24 in this volume). Often, death of parents leads to the loss of family income and property and this has a detrimental impact on the lives of young people in the family. Many children and young people are forced to withdraw from school and work in order to pay for the medical and household expenses of the family (Harms et al. 2010; Kumar 2012; Chi and Li 2013). Islam and colleagues (Chap. 3) contend that "the passing of one or both parents ultimately results in single parenthood or being orphaned, and possibly placement with alternate caregivers and unstable living arrangements. These experiences can trigger intense grief, feelings of abandonment, and disruptions in attachment security". For young people living in a household infected with HIV/AIDS, they bear the burden of caring for their parents and other family members who are no longer able to take care of themselves (Cluver and Gardner 2007; Evans and Becker 2009; Skovdal et al. 2009; Kumar 2012; Skovdal and Campbell 2013; Pearlstein et al. 2014; see also Chaps. 2, 3, and 16 in this volume). This has great impact on their health and well-being.

There are particular groups of children and young people who seem to be affected more by HIV/AIDS. Young people who have a marginalized gender norm such as men having sex with men (MSM) are at great risk for HIV/AIDS and mental health burdens (Courtenay-Quirk et al. 2006; Beyrer et al. 2010; Geibel et al. 2010;

Dahoma et al. 2011; Kemeny 2011; Semple et al. 2011; Okonofua 2012; Zanoni and Mayer 2014; see also Chaps. 11, 12, 13, and 18 in this volume). Other marginalized young people such as refugees, migrants, ethnic minority groups, and street children are most at risk due to the use of illicit drugs, their exposure to unprotected sex (in exchange for food, money and protection), and stigma associated with their marginalized lives (Orban et al. 2010; MacDonell et al. 2013; see also Chaps. 9, 13, 18, 20, 21, 22, and 24 in this volume). Children and young people from migrant and refugee backgrounds face additional marginalization and challenges resulting from the burdens of trying to adapt into a new living situation, losses and traumas in their country of origin, social isolation, barriers to employment, and poverty (see also Chaps. 9 and 20).

Perinatally-infected children and young people are often referred to as a “hidden population”. They are “a forgotten part of the AIDS epidemic” (Dorrell and Katz 2014: 454). Little research has paid attention to the social and psychological impact of living with HIV among this group of young people (Bell et al. 2003; Green and Smith 2004; Fielden et al. 2006; Mellins et al. 2009; CHIPS 2012; Dorrell and Katz 2013, 2014; see also Chaps. 5, 6, 18, 19, 20 and 21 in this volume). Nevertheless, Michelle DiRisio and Peri Ballantyne (Chap. 5) and Asha Persson, Christy Newman and Angela Miller (Chap. 6) have suggested that these young people do have positive experiences if there are sensitive interventions or programs that cater for their needs and concerns.

Girls and young women are affected by HIV/AIDS much more than boys and young men. Similar to gender inequalities among women in general, gender play a significant role in the health and well-being of HIV-positive children and young people (Gupta et al. 2011; Ramjee and Wand 2014; see also Chaps. 3, 4, 7, and 15 in this volume). It has been recognized globally that gender inequalities render girls and young women vulnerable to HIV/AIDS (UNAIDS 2013). Deevia Bhana argues in Chap. 7 that “gender inequalities and harmful gender norms create a burden on women and girls reducing their ability to negotiate safe sex... Unequal gender power relations play a significant role in HIV settings and drives young women’s vulnerability to disease” (see also Gupta et al. 2011; Jewkes and Morrell 2010, 2012; Liamputtong 2013a; Fleming et al. 2014; Chap. 15 in this volume).

1.2 Living with HIV/AIDS and Mental Health Issues

Globally, HIV/AIDS and depression are the main causes of the burden of disease for young people (UNICEF 2011; Betancourt et al. 2013; United Nations 2014). Depending on the research methodology and samples of the study, it has been shown that major depression is highly prevalent among HIV-positive individuals, ranging between 18% and 81% (Arseniou et al. 2013). In poor nations in particular, mental health problems are at the foreground of disease burden in young people (United Nations 2014). Research has pointed to the increased risk for poor mental health outcomes among young people living with HIV/AIDS (see also Chaps. 3, 4, 9, 12,