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**‘Wounded bodies’ and illness narratives: a history of  
attitudes and behaviour towards HIV-positive homosexual  
men in New Zealand between 1983 and 1997**

A thesis  
submitted in fulfillment  
of the requirements for the Degree  
of  
**Master of Arts**  
at the  
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**Cheryl Ware**



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## **Abstract**

New Zealand had its first case of the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) in 1983, two years after the disease was identified in America. The HIV/AIDS epidemic devastated a society that was unprepared for the social and medical implications of a deadly disease, and many New Zealanders were thrust into a state of moral panic.

This thesis contributes to New Zealand's social and cultural histories of health and illness by examining individual homosexual men's experiences living with HIV/AIDS. It examines the previously untold individual experiences of homosexual men with HIV/AIDS as discussed in their life narrative interviews. The thesis considers that while these men's experiences are individually subjective, dominant thematic threads emerge across the narratives which indicate patterns in gay men's experiences with HIV/AIDS in New Zealand.

Homosexual men with HIV/AIDS faced the double stigma of being gay in a society that condemned homosexuality, and living with a previously terminal disease. Images of homosexual men as 'guilty', and 'deviant' were spread through public channels including newspaper and magazine articles, which fuelled pre-existing anti-homosexual feelings.

By drawing on the men's individual narratives, the thesis describes and analyses the negotiations that occur between their individual and collective memories. The participants used their individual narratives both to obtain agency, and also to dispel derogatory archetypes that have been constructed about homosexual men.

These men's individual narratives have not previously been recorded, and are valuable to New Zealand history because they offer first-hand accounts of the patients' experiences living with HIV/AIDS in New Zealand.

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## **List of abbreviations**

AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
MP	Member of Parliament
MSM	Men who have sex with men
NZAF	New Zealand AIDS Foundation
PWA	People with AIDS
STD	Sexually transmitted disease



## Introduction

This thesis examines the recent histories of the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) in New Zealand through the oral narratives of homosexual men living with the disease since the 1980s.<sup>1</sup> It argues that social histories of health and medicine in New Zealand have yet to uncover the patient's histories' of HIV/AIDS. It places the disease in its social and cultural context, also setting out a new approach to its history. It begins by examining the social and political context of homosexuality and HIV/AIDS in New Zealand until 1997. By 1997, medical development had advanced so that the progression from HIV to AIDS could be prevented, and a positive HIV diagnosis was no longer fatal. This thesis then identifies and analyses common themes that emerge in the life narratives of homosexual men who participated in this study, most of whom were diagnosed with HIV between the selected dates. Finally, this thesis focuses on oral history theories; particularly the diverse ways the men interviewed for this thesis construct their individual life and illness narratives. Two main aspects of inquiry frame this thesis. The first is New Zealand's response to the outbreak of HIV/AIDS. The second is the impact that public responses to the epidemic had on homosexual men infected with the virus. Both aspects of inquiry interweave throughout this thesis as most of the men that participated in this study initially shared the wider public response to the epidemic. While extensive research about the social implications of the HIV/AIDS epidemic has been completed internationally, New Zealand scholarship, particularly historiography currently lacks such valuable insight into recent medical history, and the way New Zealand society responded to disease.

New Zealand had its first case of HIV/AIDS in 1983, about two years after the disease was first identified in five homosexual men in San Francisco, following a pattern of the spread of the epidemic in developed western nations of that time. The HIV/AIDS epidemic has had a severe social impact on a nation that was largely uneducated about the contagious disease, and feared its fatal consequences. Because homosexual men are overrepresented amongst HIV/AIDS diagnoses, particularly during the early years of the epidemic, the disease has

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<sup>1</sup> The Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) are commonly referred to as 'HIV/AIDS' in recent scholarship. In this thesis, I will refer to the disease as HIV/AIDS also.

often been conflated with homosexual sex through the media and public opinion. Homosexual men with HIV/AIDS therefore faced the double stigma of being gay in a society that condemned homosexuality, and suffering from the lethal disease. Like other western countries, New Zealanders immediately responded to the threat of an epidemic by stigmatising infected individuals and groups who were perceived as ‘at risk’, namely homosexual men and drug users. In his work about illness narratives, Arthur Kleinman identifies that stigma is a common social response to disease, and the sufferer is ‘shunned, derided, disconfirmed, and degraded by those around him’.<sup>2</sup> Kleinman suggests that hostile reactions to disease occur so often that the victim internalises the stigma in a deep sense of shame and adopts a negative self-perception.<sup>3</sup> The stigma attached to disease is an important aspect of this thesis because few diseases carry such a degree of stigma as HIV/AIDS. Sufferers of stigmatised diseases, like HIV/AIDS, are often ostracised by society, with the affected person being labelled as sinful and immoral.<sup>4</sup> However, as this thesis will show, the sense of stigma a sufferer of illness or disease faces also varies, depending on the individual’s social, cultural and political background. Our lives are influenced by our upbringing, and also our experiences prior to being diagnosed with an illness. Therefore, this thesis investigates the ways individuals and groups responded to HIV/AIDS. Social stigma is only one part of this story; there were also support organisations and networks established by the gay community, and later, government policies and Law Reform. Most importantly, this thesis uncovers the individual social experiences of a small group of HIV-positive homosexual men, as expressed in their life narrative interviews.

In New Zealand, very few patients’ experiences with HIV/AIDS are documented.<sup>5</sup> This thesis makes an important contribution to New Zealand histories of health because it predominantly focuses on the illness narratives of six HIV-positive homosexual men, who shared their individual experiences of living with HIV during life narrative interviews. This thesis therefore not only documents these men’s individual experiences, but offers an analysis of their illness narratives from an oral history perspective. Like Kleinman, Arthur Frank also focuses on illness narratives, and asserts that by telling stories, individuals attempt to ‘give a

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<sup>2</sup> Arthur Kleinman, *The Illness Narratives* (United States of America: Basic Books, 1988), p. 160.

<sup>3</sup> Kleinman, p. 160.

<sup>4</sup> Kleinman, p. 159.

<sup>5</sup> For examples see: Tom McLean, *If I should die, living with AIDS* (Auckland: Benton Ross, 1989), J. Myers. ‘Moving on the margins: emotional geographies of HIV in Auckland, New Zealand,’ (Unpublished PhD Thesis: University of Auckland, 2009), J. Myers, ‘Health, sexuality and place: the different geographies of HIV-positive gay men in Auckland, New Zealand’, *New Zealand Geographer*, 66.3 (2010), pp. 18-227.

voice to an experience that medicine cannot describe'.<sup>6</sup> Frank identifies that people tell their illness stories through a 'wounded' body, giving their body a voice and creating new familiar stories after disease disrupts old ones.<sup>7</sup> Using Frank's term, the storytellers I interviewed for this thesis are 'wounded', as they narrate their life stories after being infected with HIV. Frank also identifies three types of illness narratives: the restitution narrative, which focuses on medicine's triumph over illness; the chaos narrative, which focuses on one's devastating suffering; and the quest narrative.<sup>8</sup> A quest narrative accepts illness, and is 'defined by the ill person's belief that something is to be gained through the experience'.<sup>9</sup> The narratives in this thesis are mostly quest narratives, and the men individually accept their positions as living with a chronic illness. The different quest narratives that feature in this thesis present the ill person's perspectives living with HIV, which is currently missing from New Zealand health historiography.

Also writing about illness narratives, medical historian Roy Porter argues that gathering illness narratives can be emotionally damaging for both the narrator and their audience. Porter claims that experiencing illness and sharing it through illness narratives can produce feelings of pain and fear, and thus pose a threat to the individual and their companions.<sup>10</sup> Yet patient pathographies are relatively common in current studies of disease and illness, and despite Porter's cautions he does not undermine the value of illness narratives.<sup>11</sup> In this thesis, illness narratives are crucial to understanding the patient's views, and enriching New Zealand's medical historiography. Writing about medical historiography, sociologist Mike Bury identifies that traditional illness and disease narratives are important indicators of doctors' relationships with their patients.<sup>12</sup> Bury asserts that the patient's perspectives were traditionally silenced by authoritarian medicine, until medical treatment became more democratic and accessible in the twentieth century.<sup>13</sup> A similar claim is made by medical historians, who often adopt an interdisciplinary approach while examining the history of

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<sup>6</sup> Arthur W. Frank, *The Wounded Storyteller* (USA: The University of Chicago Press, 1995), p. 18.

<sup>7</sup> Frank, p. 2.

<sup>8</sup> Frank, p. 115.

<sup>9</sup> Frank, p.115.

<sup>10</sup> Roy Porter, *The Greatest Benefit to Mankind: a medical history of humanity from antiquity to the present* (London: HarperCollinsPublishers, 1997), p. 33.

<sup>11</sup> A. H., Hawkins, 'Pathography: patient narratives of illness', *Western Journal of Medicine*, 171.2 (1999), pp. 127–129, Roy Porter, 'The Patients' View: Doing medical history from below', *Theory and Society*, 14 (1985) pp. 175-98, Michelle Edith Campion, 'Narratives from the Mind's Eye: The Significance of Mental Health Pathography in New Zealand, 1980-2008.' (MA thesis, University of Waikato, 2009).

<sup>12</sup> Mike Bury, 'Illness narratives: fact or fiction?' *Sociology of Health & Illness*, 23.3 (2001) p. 265.

<sup>13</sup> Bury, p. 268.

medicine.<sup>14</sup> Modern disease narratives allow the patients to convey their experiences from their own perspectives.<sup>15</sup> These narratives typically focus on an individual's emotional response to their diagnosis. During their narratives, the HIV-positive men in this study all discuss being diagnosed with HIV, and their immediate reactions to their diagnoses.

The historiography of the HIV/AIDS epidemic dates back to the outbreak of the disease in the 1980s. Medical historians Elizabeth Fee and Daniel Fox initially urged historians to proactively study the epidemic as it unfolded, maintaining that 'historians need to be documenting this epidemic as it occur[ed] – on local, national, and international levels'.<sup>16</sup> Fee's and Fox's claims are based on the limitations of researching the distant past, in which circumstances 'historians have only the dead and each other with whom to contest their interpretations; in dealing with the recent past and the present, they must confront the living'.<sup>17</sup> The AIDS epidemic was an opportunity for historians to modify their research techniques, and rather than relying on 'scattered and often inadequate sources left by past events [historians] have an opportunity in the AIDS epidemic to help gather more complete records of contemporary events'.<sup>18</sup> Also writing about historians and HIV/AIDS, Virginia Berridge and Phillip Strong argue that the majority of HIV/AIDS social research focuses on America, and that 'the disease appeared earlier there, has been on a far greater scale and has generated considerably more public controversy'.<sup>19</sup> Therefore, while the proactive historical research that Fee and Fox encourage has been achieved on an international level, there remains limited academic scholarship in New Zealand that captivates individual's living experiences with the disease.<sup>20</sup> This thesis provides a significant contribution to New Zealand historiography regarding the AIDS epidemic because it consults individuals who are currently living with the virus. It considers their personal experiences and places them in the social and political context of New Zealand's recent history.

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<sup>14</sup> Nancy Pippen Eckerman, 'Medicine, History of', in *Encyclopedia of Historians and Historical Writing*, Volume 1, ed. by Kelly Boyd (London and Chicago: Fitzroy Dearborn Publishers, 1999), p. 790.

<sup>15</sup> Bury, p. 268.

<sup>16</sup> Elizabeth Fee and Daniel M. Fox 'The Contemporary Historiography of AIDS', *Journal of Social History*, 23, 2 (1989), p. 312.

<sup>17</sup> Fee and Fox, 1989, p. 307.

<sup>18</sup> Fee and Fox, 1989, p. 312.

<sup>19</sup> Virginia Berridge and Philip Strong, 'AIDS and the Relevance of History', *Social History of Medicine*, (1991), p. 130.

<sup>20</sup> For examples see Paul Goldwater, *AIDS: The Risk in New Zealand* (Auckland: Penguin Books (N.Z.) Ltd, 1986), Heather Worth, *Gay Men, Sex & HIV in New Zealand* (Palmerston North: Dunmore Press, 2003).

Roy Porter argues that the outbreak of HIV/AIDS had a significant impact on historiography, and historians who previously documented world history with indifference to disease now acknowledge the impact of pandemics such as plague and cholera.<sup>21</sup> Popular approaches to the epidemic include historians associating the virus with past plagues and labelling HIV/AIDS a unique disease in their recent histories. Writing about historians and HIV/AIDS, Berridge and Strong argue that scholars from various disciplines applied historical methodology while researching the virus, many of whom were searching for a 'lesson of history'.<sup>22</sup> In other words, these researchers aimed to identify how past societies responded to, and eventually overcame the outbreak of disease, and apply these strategies to the recent outbreak of HIV/AIDS. Medical historian Charles Rosenberg also focuses on historians' determination to identify a 'lesson of history', claiming 'historians and policymakers concerned with epidemics tend to look backward and ask what "lasting impact" particular incidents have had and what "lessons" have been learned'.<sup>23</sup> The purpose of history in this instance was to find useful analogues and identify the meaning and significance of past diseases in terms of how they were understood.<sup>24</sup> One major comparison historians made is between HIV/AIDS and Syphilis in the early-twentieth century. Like Syphilis, AIDS 'arouse[d] fears that reveal deeper social and cultural anxieties about the disease, its transmissibility, and its victims'.<sup>25</sup> However, some historians challenge comparisons between HIV/AIDS and past diseases, and their eagerness to find a 'lesson of history'. Berridge and Strong claim this strategy carries 'a whiggish assumption that there was indeed a "lesson of history" which could be learnt: that the past could be used to provide a very specific blueprint for a present day policy reaction'.<sup>26</sup> Allan M. Brandt raises a similar argument to Berridge and Strong, and he notes 'the historical record is not a fable with a moral spelled out at the end'.<sup>27</sup> Although Brandt affirms one cannot clearly predict future events by understanding the past, he acknowledges that there are lessons in past societies' responses to epidemics that may deepen the understanding of the AIDS crisis.<sup>28</sup>

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<sup>21</sup> Porter, p. 5.

<sup>22</sup> Berridge and Strong, p. 131.

<sup>23</sup> Charles Rosenberg, 'What is an Epidemic? AIDS in Historical Perspective', *Daedalus*, 118 (1989), p. 9.

<sup>24</sup> Allan M. Brandt, 'AIDS and Metaphor: Toward the Social Meaning of Epidemic Disease', in *In time of Plague: the History and Social Consequences of Lethal Epidemic Disease*, ed. by Arien Mack (United States of America: New York University, 1991), p. 92.

<sup>25</sup> Allan M. Brandt, 'AIDS: From Social History to Social Policy', in *AIDS: The burdens of History*, ed. by Elizabeth Fee and Daniel M. Fox (California: University of California Press, 1988), p. 153.

<sup>26</sup> Berridge and Strong, p. 133.

<sup>27</sup> Brandt, 1991, p. 92.

<sup>28</sup> Brandt, 1991, p. 92.

This thesis is particularly focused on HIV-positive homosexual men, and considers how pre-established homophobia escalated amidst the panic of HIV/AIDS. Social prejudice against HIV/AIDS victims was particularly intense for homosexual men, who were already marginalised in New Zealand society prior to the outbreak of HIV/AIDS.<sup>29</sup> Although some scholars argue that homosexual sex between men was accepted as part of society prior to the nineteenth century, changing social attitudes prohibited any homosexual activity in contemporary society.<sup>30</sup> Historians of sexuality have covered public attitudes towards homosexuality. The history of sexuality indicates the antecedents of homophobia, and is ‘a protean discipline that allows us to enter a world of meaning, to understand the most fundamental assumptions about everyday life’.<sup>31</sup> Writing about the history of sexuality, Michel Foucault depicts western society prior to the seventeenth century as a time of sexual fluidity and social tolerance, where ‘sexual practices had little need of secrecy’.<sup>32</sup> However, according to Foucault, sexual practices were restricted to the private homes of legitimate heterosexual couples during the Victorian era, and ‘on the subject of sex, silence became the rule’.<sup>33</sup> Homosexuality was suppressed, and heterosexual relationships were considered ‘natural’, and ‘an innate reproductive or family instinct, that it is the basis of the survival of the species’.<sup>34</sup> Theories that promoted opposite-sex relationships severely condemned homosexual sex, labelling it sinful as it does not lead to procreation. Steven Seidman claims that during the twentieth century, ‘homosexuality changed from behaviour (sodomy) in the nineteenth century, to a deviant individual identity’.<sup>35</sup> Therefore, sexuality is socially constructed, and is defined by labels based on sexual orientation that were developed as a result of twentieth-century notions of sexuality formed through expert and popular discussions.

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<sup>29</sup> For examples, see Laurie Guy, ‘“Straightening the Queers”: Medical Perspectives on Homosexuality in Mid-Twentieth Century New Zealand’, *Health and History*, 2.1 (2000), Chris Brickell and Ben Taylor, ‘What it means to be a gay man’, in *Queer in Aotearoa*, ed. by Lynne Alice and Lynne Star (Palmerston North: Dunmore Press Ltd, 2004), Parkinson, Phil G., Homosexuality as a medical condition, [pamphlet], (Wellington, NZ: Lesbian and Gay Rights Resource Centre, n.d).

<sup>30</sup> Michel Foucault, *The Use of Pleasure: The History of Sexuality*, volume 2 (United States of America: Random House, Inc., 1985), Steven Seidman, *The Social Construction of Sexuality* (United States of America: W.W. Norton & Company, Inc., 2003).

<sup>31</sup> H.G. Cocks and Matt Houlbrook, ‘Introduction’, in *The modern history of sexuality*, ed. by H.G. Cocks and Matt Houlbrook (United States of America: Palgrave Macmillan, 2006), p. 3.

<sup>32</sup> Michel Foucault, *The will to knowledge, The History of Sexuality: Volume 1* (Great Britain: Allen Lane, 1979), p. 3.

<sup>33</sup> Foucault, 1979, p. 3.

<sup>34</sup> Steven Seidman, *The Social Construction of Sexuality* (United States of America: W.W. Norton & Company, Inc., 2003), p. xv.

<sup>35</sup> Seidman, p. xiv.

Although historically ‘there was no notion of the heterosexual as a type of person to be contrasted to the homosexual’,<sup>36</sup> it is this comparison today that sustains homophobia in predominantly heterosexual societies. In New Zealand, social restrictions of homosexuality are evident in post-colonisation history. Foucault’s representation of the history of sexuality, and more specifically homophobia, parallels New Zealand’s more recent history of sexuality. Heather Worth argues that homosexual and fluid heterosexual behaviours were common features of traditional Māori culture, and were widely accepted within Māori communities. However, from the beginning of colonisation, colonial powers labelled non-procreative sex as sinful, and ‘aspects of sexuality were often omitted from the written historical records’.<sup>37</sup> Consequently, very little evidence of European or Māori male homosexual behaviour is present in the written history of New Zealand.<sup>38</sup> In this thesis, I aim to uncover some of the individual histories of homosexuality in New Zealand, and the influence suppressing homosexuality had on the men’s lives. Uncovering the participants’ experiences specifically as gay men enables this thesis to identify how the men’s lives with HIV are distinct, even among other groups affected by the virus.

In this thesis I use a social history approach, and more specifically an oral history approach, to examine the individual experiences of gay men who have been living with HIV since the 1980s and 1990s. Social history primarily aims to rescue ‘marginal and voiceless people from the past, restoring their agency and understanding their worldview [which] made their testimony extraordinarily important’.<sup>39</sup> The emergence of social history meant people whose voices have been silenced, including patients in medical history, and homosexual men, became important. In this thesis, my primary aim is to uncover the participants’ experiences as patients, and more specifically as homosexual men who became patients. My small research cohort for this study was marginalized because they faced the double stigma of being gay and having HIV. Most of the men in this study have not yet had the opportunity to tell their life narratives and share their opinions, and have certainly not had their stories documented. This thesis therefore also aims to give agency to the men who participated in this study by providing them with the opportunity to narrate their life histories from their own perspectives.

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<sup>36</sup> Seidman, p. 46.

<sup>37</sup> Heather Worth, *Gay Men, Sex & HIV in New Zealand* (Palmerston North: Dunmore Press, 2003), 16.

<sup>38</sup> Worth, p. 16.

<sup>39</sup> Cocks and Houlbrook, p. 5.

I use a life narrative approach which has more flexibility than other possible modes of the oral history interview, and it is my priority to enable the men to convey their experiences as thoroughly as possible. Given the fact that this thesis investigates gay men's personal experiences of living with HIV, it is heavily dependent on their oral testimonies. Like social history, oral history aims to empower groups and individuals who were previously 'considered too unimportant to merit such attention since they were too ordinary'.<sup>40</sup> Oral history is driven by the passion for a personal story, and assumes every individual experience can be made into a purposeful story.<sup>41</sup> Oral history is focused on collecting 'memories and personal commentaries of historical significance through recorded interviews', which can range from questionnaires to life narratives.<sup>42</sup> Although oral history aims to 'empower' so-called marginalized individuals and groups, Alessandro Portelli argues that oral history interviews differ from other autobiography because the basis of authority is different; in oral history it is the interviewer who takes the initiative to ask the interviewee for their story.<sup>43</sup> He also suggests that not all individuals assume the right to speak about their experiences, which is particularly true for the socially disadvantaged groups that historians most frequently address themselves.<sup>44</sup> Therefore, to ensure the interviews were a success, I established a rapport with the participants to ensure they felt comfortable and confident enough to discuss their life events, as I explain below.

After receiving approval from the Ethics Committee (Appendix 1), I began searching for participants through various channels including the New Zealand AIDS Foundation (NZAF), and Body Positive Incorporated.<sup>45</sup> I aimed to interview six HIV-positive homosexual men for this study, which was a substantial amount to provide insight into patients' experiences with HIV. Potential participants were then approached via telephone or email, and each provided with an individual introductory letter, an information sheet, and a copy of the consent form,

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<sup>40</sup> Stephen Caunce, *Oral History and the Local Historian* (United Kingdom: Longman Group UK Limited, 1994), p. 7.

<sup>41</sup> Paula Hamilton and Linda Shopes, 'Introduction: Building partnerships between Oral History and Memory Studies', in *Oral History and Public Memories*, ed. by Paula Hamilton and Linda Shopes (United States of America: Temple University Press, 2008), xi.

<sup>42</sup> Donald A. Ritchie, *Doing Oral History: a practical guide* (New York: Oxford University press, Inc., 2003), p. 19.

<sup>43</sup> Alessandro Portelli, *The battle of Valle Giulia: oral history and the art of dialogue* (United States of America: University of Wisconsin Press, 1997), p. 9. In this instance 'empower' refers to giving individuals an opportunity to share their personal stories.

<sup>44</sup> Portelli, 1997, p. 9.

<sup>45</sup> Body Positive Inc. is a New Zealand organisation established by people with HIV/AIDS, which offers services including advocacy, education, and therapies. See Body Positive Inc., *About us*, 2010, [http://www.bodypositive.org.nz/Pages/Home/About\\_Us/](http://www.bodypositive.org.nz/Pages/Home/About_Us/) [accessed 10 June 2011].



which was discussed with them prior to, and after, the interviews (Appendices 2, 3 and 4). Oral interviews can be aided by the interviewer following a body of principles, most of which are based on social etiquette. These principles were particularly important to this study because the men discussed events that included highly sensitive topics, such as ‘coming out’ narratives and sexual experiences. However, an oral interview can also be hindered by a number of often unpredictable factors, like the narrator’s inability to recall events, and the interviewer’s failure to successfully establish a rapport with the participants.<sup>46</sup> Louise Douglas, Alan Roberts and Ruth Thompson argue that an effective interview structure is one where the interviewer guides the interview by following a list of predetermined points, but also allows enough flexibility for the interviewee to discuss topics not on the agenda.<sup>47</sup> The life narrative interviews conducted in this study began with the interviewee speaking freely about their experiences, and were often followed by a semi-structured discussion based on a short list of open-ended questions I brought to the interview (Appendix 5). The interviews were deliberately intended to be flexible with the aim of uncovering the individual’s entire experience as a homosexual man with HIV, and to ensure each interview subject felt comfortable sharing personal experiences. In this respect, my own subjectivity was another factor that needed to be considered when undertaking this research. As an outsider to the gay community, and to the HIV-positive community, I did not want participants to feel uncomfortable discussing sensitive issues. To counteract these limitations, I strived to develop a rapport with the participants prior to the recording of the interviews by meeting with gay community members of Hamilton Pride Incorporated. Coming to know members in the community and ensuring a more informed understanding of their aspirations, feelings, and circumstances enabled a more respectful and empathetic communication between myself and the interviewee prior to the recordings.<sup>48</sup>

Historians, particularly during the early decades of oral history, sometimes claimed their sole role was simply to ‘give voice’ to those who had been silenced.<sup>49</sup> Luisa Passerini asserts that fighting against silence, or even using the term ‘silence’ is not enough to describe oral historians responsibilities, who more accurately deal with what she terms ‘distortions of

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<sup>46</sup> Douglas et al, p. 47.

<sup>47</sup> Douglas et al. p. 53.

<sup>48</sup> Hamilton Pride is a New Zealand organisation based in the central Waikato region. It aims to celebrate and support members of its gay, lesbian and transgender community. See Hamilton Pride., *Home*, n.d, <http://www.hamiltonpride.co.nz/> [accessed 25 April 2011]

<sup>49</sup> Luisa Passerini, ‘Introduction’, in *Memory and Totalitarianism*, ed. by Luisa Passerini (United States of America: Oxford University Press, 1992), p. 16.

“false memory””.<sup>50</sup> Historians are therefore faced with a much larger task than ever anticipated, and are responsible for analyzing and interpreting individual narratives. Methods of interpretation have advanced to the extent that it is not enough for scholars to rely on the claim of ‘being the mouthpiece for the dispossessed’, and historians need to unravel the ‘complex layers of construction and meaning in the sources’.<sup>51</sup> Passerini describes the historian’s task is to ‘participate in different memories, to share their differences not in any way in an attempt to demonstrate their universality but rather to insist on the diversity and plurality of memory’.<sup>52</sup> As Passerini asserts, the oral historian’s contribution will be to invent ways of detaching human memory from totalitarianism, and work towards forming a democratic consciousness.<sup>53</sup>

Despite the established arguments of scholars such as Portelli and Passerini, oral history has been placed under scrutiny, and critics are skeptical about the reliability of oral narratives, and the high levels of subjectivity it allows. A main criticism of oral history is that individuals are involved in both their own life experiences, and how their experiences have been interpreted by the media and by historians.<sup>54</sup> In other words, individuals’ personal memories are influenced by others writing about the events in which they were involved. This is particularly applicable for individuals involved in events that have aroused high media interest and coverage, such as the HIV/AIDS epidemic. Another criticism of oral history is that an individual’s remembering during his or her narrative is influenced by the interview context, the narrator’s relationship with the interviewer and by the way the events they are recalling are perceived by the public.<sup>55</sup> One’s life narrative can, therefore, alter at any time, with critics arguing that oral history exposes ‘the fallibility of memory’.<sup>56</sup> However, because historians are interested in the ways the past is resonant in modern society, ‘oral testimony’ is then ‘essential evidence for analysis of the interactions between past and present, and between memory and mythology’.<sup>57</sup> Oral historians have successfully counteracted these criticisms arguing that all historians commonly rely on primary documents such as letters and

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<sup>50</sup> Passerini, p. 16.

<sup>51</sup> Mary Chamberlain and Paul Thompson, ‘Introduction’, in *Narrative and Genre*, ed. by Mary Chamberlain and Paul Thompson (London: Routledge, 1998), p. 16.

<sup>52</sup> Passerini, 1992, p. 18.

<sup>53</sup> Passerini, 1992, p. 18.

<sup>54</sup> Roy Hay, *The Use and Abuse of Oral Evidence* (Australia: Deakin University Press, 1986), p. 5.

<sup>55</sup> Alistair Thomson, ‘ANZAC Memories: Putting popular theory into practice in Australia’, in *The houses of history: A critical reader in twentieth-century history and theory*, ed. by Anna Green and Kathleen Troup (Manchester, United Kingdom: Manchester University Press, 1999), p. 234.

<sup>56</sup> Lynn Abrams, *Oral History Theory*, (United Kingdom: Routledge, 2010), p. 23.

<sup>57</sup> Thomson, p. 241.

diaries that help them understand the individual's real experiences, while 'enlivening history with a human touch'.<sup>58</sup> Oral history has the same qualities as other primary documents, with the benefit that participants may be asked to elaborate on points they have made.<sup>59</sup> Therefore, while oral history is subjective, it offers valuable insight into the past that other historical sources do not.

Despite the scepticism about oral history, oral narratives offer first-hand accounts that are far too often absent from other archival materials. HIV/AIDS narratives especially are invaluable because the patients' stories are often suppressed, and hidden from the public. Fee and Fox argue that some 'memories are notoriously fallible and, often self-serving, although they may also provide insights and information not otherwise available'.<sup>60</sup> In other words, while some memories are highly influenced by the narrator's subjectivity, the memories are still useful to analyse and uncover the speaker's motivations, and their perspectives on past events. Portelli also asserts that 'oral sources are credible but with a different credibility'.<sup>61</sup> He explains that imagination, symbolism and desire emerge in oral history and that historically inaccurate statements are still psychologically true for the interviewee.<sup>62</sup> In this sense, 'there are no "false" oral sources, and that the psychological truth 'may be equally as important as factually reliable accounts'.<sup>63</sup> Therefore, it is up to the researcher to uncover the hidden messages and motives embedded in life narratives. These messages can provide crucial insight into the lives of marginalised individuals and groups, including possible reasons for their memories to change.

In addition to using oral histories, I also analyse written primary documents including the *New Zealand Parliamentary Debates* regarding the Crimes Bill, and the Homosexual Law Reform Bill. The *Hansard* debates function 'as the standard source for nineteenth-and twentieth-century parliamentary history'.<sup>64</sup> Analysing the debates allows this thesis to identify the political and social impact the epidemic had on New Zealand legislation. Bronwen Lichtenstein argues that HIV/AIDS had a major impact on New Zealand, and notes

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<sup>58</sup> Caunce, p. 16.

<sup>59</sup> Caunce, p. 16.

<sup>60</sup> Fee and Fox, 1989, pp. 310-11.

<sup>61</sup> Alessandro Portelli, *The death of Luigi Trastulli, and other stories: form and meaning in oral history* (New York: State University of New York Press, 1991), p. 68.

<sup>62</sup> Portelli, 1991, p. 68.

<sup>63</sup> Portelli, 1991, p. 68.

<sup>64</sup> Paul Readman, 'Speeches', in *Reading Primary sources, the interpretation of texts from nineteenth-and twentieth-century history*, ed. by Miriam Dobson and Benjamin Ziemann (Oxon: Routledge, 2009), p. 215.

that 'New Zealand was the first country to reform sodomy laws relating to homosexuality *because* of the threat of AIDS'.<sup>65</sup> Similarly, Christopher Burke argues that *Parliamentary Debates* indicate public fears around the HIV/AIDS epidemic, namely that the disease would spread to the heterosexual population.<sup>66</sup> My analysis of the parliamentary debates uncovers political arguments that were used to justify the criminalisation of homosexual sex, and how these debates changed amidst the outbreak of HIV/AIDS.

Recorded speeches, like those contained in *Hansard*, are crucial to this research because political leaders were dependent on speech to communicate their ideas and persuade their listeners of the merits of the policies they wished to enforce.<sup>67</sup> In this thesis, the *Debates* are analysed in terms of rhetoric and public reception, both of which have been contextualised to determine their contemporary effect. When analysing *Hansard*, Paul Readman reminds us that 'rhetoric is *never* 'mere rhetoric': as speech-act theory teaches us, words themselves have agency'.<sup>68</sup> In this thesis, I also applied similar analysis strategies to other primary sources, particularly contemporary newspaper and magazine articles.

A range of newspaper and magazine articles were examined for this study, most of which were published prior to 1997. Although the primary focus remained on New Zealand, it was beneficial to also analyse the perspectives advanced in the international media and the extent to which they influenced New Zealand popular public opinions and perspectives. The media both produces and reflects public attitudes towards HIV/AIDS victims. Stephen Vella asserts that by critically reading newspapers, one can identify how societies and cultures perceived themselves and the world around them.<sup>69</sup> Therefore, analysing newspaper and magazine articles enabled me to examine past attitudes towards HIV/AIDS and gay men. I located newspaper and magazine articles by searching online, and at the New Zealand AIDS Foundation Library and Information Service in Auckland. My main focus when analyzing media articles is the different images about homosexual men the media constructed. The

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<sup>65</sup>Bronwen Lichtenstein, 'Tradition and experiment in New Zealand AIDS policy', *AIDS & public policy journal*, 12, 2 (1997), p. 84. Lichtenstein's argument is based on interviews by Geraldine Taylor of the Christchurch Intravenous Drug users Group (8 December 1993), and Phil Parkinson of the NZAF interview (17 November, 1993)

<sup>66</sup> Christopher J. F. Burke, 'Diversity or Perversity? Investigating Queer Narratives, Resistance, and Representation in Aotearoa / New Zealand, 1948-2000', (Unpublished MA Thesis: University of Waikato, 2007), p. 41.

<sup>67</sup> Readman, p. 217.

<sup>68</sup> Readman, p. 218. 'never' is italicised in original text also.

<sup>69</sup> Stephen Vella, 'Newspapers', in *Reading Primary sources, the interpretation of texts from nineteenth-and twentieth-century history*, ed. by Miriam Dobson and Benjamin Ziemann (Oxon: Routledge, 2009), p. 192.

media articles are useful in identifying New Zealand public attitudes towards homosexual men with HIV. These written sources help create an understanding of New Zealand's social and political context amidst the onset of HIV/AIDS. This context forms the basis of Chapter One.

After completing a life narrative interview with Steve Williams in 2010 as part of a separate project, I became increasingly aware of the impact the media had on New Zealand society regarding HIV/AIDS. Analysing New Zealand and international media is crucial to understanding public attitudes towards the virus, how the media fuelled public opinion, and the impact media representations had on gay men with HIV/AIDS. I searched online, and manually in libraries to find a range of newspaper and magazine articles about the virus, and then selected nine articles to focus on. Although it is a small selection, these nine articles provide diverse representations of gay men and HIV/AIDS, and were selected because of the depth of their content. I found some of these articles online through the Australia/New Zealand Reference Centre database, by searching a combination of any of the following words 'AIDS', 'HIV', 'homosexual', 'gay' and 'New Zealand'. I also found insightful *Metro* articles in the University of Waikato library. Finally, I searched newspaper and magazine articles by date at the New Zealand AIDS Foundation Library and Information Service in Auckland, New Zealand. Therefore, while the selection of articles in this section is relatively small, I have read and analysed many more than are included in this thesis, and conclude these articles provide a wealth of insight into New Zealand's recent history.

This thesis is separated into three chapters. Chapter One examines the social and political context of HIV/AIDS in New Zealand. It considers international and national debates about homosexuality, and how anti-homosexual attitudes escalated amidst the threat of HIV/AIDS. Chapter One contains an analysis of the *Parliamentary Debates* and media representations of the virus to comprehend the social attitudes that HIV-positive gay men faced. Writing about homosexuality, Phil Parkinson asserts that medical writers in the eighteenth and nineteenth centuries lived in a society where they were taught that any sexual act that did not result in pregnancy was sinful and unnatural.<sup>70</sup> Science and religion were used to justify the prohibition of non-procreative sex, and Parkinson argues that suggestions of “‘masturbatory insanity’” underlies the whole nineteenth century conception of sexuality and has had an

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<sup>70</sup> Phil G. Parkinson, *Homosexuality as a medical condition*, [pamphlet], (Wellington, NZ: Lesbian and Gay Rights Resource Centre, n.d), p. 2.

immense influence on our [contemporary] view of homosexuality as well'.<sup>71</sup> Although nearly a decade prior to the outbreak of HIV/AIDS medical professionals determined homosexuality was not a mental illness as was previously believed, underlying notions of homosexuality as sinful and an illness remained embedded in society. Anti-homosexual feelings, along with a disproportionate number of HIV/AIDS victims being homosexual men meant the gay community were targeted as likely carriers of the virus. Late-twentieth century prejudice towards homosexuality is reflected in public newspapers and magazine articles. Anti-homosexual feelings also fuelled debates in the New Zealand House of Representatives, particularly regarding Homosexual Law Reform, a discussion of which features in Chapter One of this thesis.

While Chapter One sets out the social and political context of HIV/AIDS in New Zealand, Chapter Two identifies and analyses thematic threads that emerge in the men's life narratives. It presents each participant's individual experiences, and common themes that emerge which indicate the men's shared experiences. Six HIV-positive homosexual men participated in this study, as well as one homosexual HIV-negative man who previously worked with the New Zealand AIDS Foundation. While this is a small scale study, and these men's experiences may not represent all homosexual HIV-positive men in New Zealand, this thesis indicates a group of individuals shared and diverse experiences with HIV. Common themes that emerged in the interviews include New Zealand's conformist social environment and the men's naïveté about homosexuality growing up. During the men's adolescence, an unspoken vow of silence suppressed talk of sexuality, particularly homosexuality, which in many cases resulted in their own internalised feelings of self-loathing about being gay. Ignorance within and outside the gay community about HIV/AIDS and safe-sex, and the subsequent conflation of homosexuality and HIV also feature in their narratives. Chapter Two specifically focuses on the men's representations of their HIV statuses, life living with the virus, and their diverse understandings of death and mortality. While the men discuss the physical implications of HIV, they explain that the social impact HIV has on their lives is far more significant.

Finally, Chapter Three investigates the diverse ways the men construct their life narratives, and the negotiations that occur within their individual and collective memories. My analysis of the oral interviews conducted as part of the research for this thesis centres on the men's

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<sup>71</sup> Parkinson, n.d, p. 2.

personal understanding of their experiences. Chapter Three also focuses on whether or not the individuals align with dominant archetypes the media and public opinion have created about HIV-positive homosexual men. These archetypes include homosexual promiscuity, the AIDS ‘carrier’, and the helpless victim. In Chapter Three, I also engage with scholarship by prominent oral historians to accurately identify the homosexual men’s experiences with HIV. Mike Bury argues that narratives about chronic illnesses focus on the emotional consequences of managing symptoms in daily life.<sup>72</sup> Although illness narratives are particularly concerned with the reactions of an ill person’s family, friends, and their medical treatment suggested by doctors, the narratives also indicate the interviewee’s ability to cope with illness.<sup>73</sup> In this thesis, I focus specifically on illness narratives about HIV/AIDS, and the men’s narratives reflect their own abilities to deal with their chronic illnesses. Yet Bury also warns that one’s positive narrative can implicate others. When an individual develops their narrative of “‘successful living” in the face of illness, or by suggesting that reflexive and “meaningful” deliberations have been achieved’, the individual may, even unintentionally, be implying criticism of others who have not yet achieved this state of acceptance.<sup>74</sup>

Overall, this thesis utilises various primary and secondary materials to investigate social attitudes and behaviour towards HIV-positive homosexual men in New Zealand, and considers the impact societal prejudice or acceptance had on gay men with HIV. The oral history life interviews that feature in this thesis are particularly valuable as they represent gay men’s experiences living with a chronic illness from their own perspectives. This thesis contributes to New Zealand’s recent medical historiography by capturing the individual’s experiences as a patient with a stigmatised virus, which has not been previously documented.

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<sup>72</sup> Bury, p. 271.

<sup>73</sup> Bury, p. 271

<sup>74</sup> Bury, p. 277.

## Chapter One

### **Homosexual men in New Zealand: the social and political impact of the AIDS epidemic**

In 1990, Steve Williams accompanied his partner Pablo to a specialist, as his partner had an abscess on a tooth that refused to heal. Steve recalls, the specialist ‘looked in Pablo’s mouth and poked at this, um, abscess, and then he said, “you’ve probably got AIDS”’.<sup>1</sup> At this time, there was no effective cure for HIV/AIDS, and many who were diagnosed with the virus died shortly after. Steve, Pablo, and the specialist were all well aware of this tragic reality. Steve then accompanied Pablo to the hospital where he had tests, and based on the specialist’s suspicion, Pablo ‘was isolated, and, anyone who went to see him had to wear a mask – a painter’s mask’.<sup>2</sup> Pablo was one of seventy three people diagnosed with AIDS in New Zealand in 1990.<sup>3</sup> Pablo passed away nine years later, and his experience, as retold by Steve, is consistent with stories of fear and prejudice evident in New Zealand’s recent history of the disease.

This chapter sets out the social and political context of the New Zealand HIV/AIDS epidemic, in which this study’s participant’s life narratives are set. In particular, it investigates the social and political impact the HIV/AIDS epidemic had in New Zealand from 1983 onwards. The outbreak of HIV/AIDS in western countries revived prejudice against behaviours that many societies had already deemed ‘immoral’: particularly homosexual sex, promiscuous heterosexuality, and drug use. This chapter investigates the social discrimination homosexual HIV-positive men endured, which was in many ways heightened by the legislation that outlawed homosexual sex. The outbreak of HIV/AIDS in New Zealand, predominantly among the population of gay men, forced the government and health officials to acknowledge homosexual sex existed in society. In political terms, HIV/AIDS also redefined ideas about social discrimination. Medical professionals who worked closely with HIV/AIDS victims were encouraged to ignore their personal biases against behaviour that often led to men and

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<sup>1</sup> Steve Williams, *Life Narrative*, 21 August 2010, interviewed by Cheryl Ware, Rotorua, New Zealand, 50.54-51.02

<sup>2</sup> Steve Williams, 51.18-51.26

<sup>3</sup> Nigel Dickson, ‘Epidemiology of AIDS in New Zealand’, in *Readings in AIDS Research*, ed. by Stephen Lungley (New Zealand: New Zealand Department of Health, 1991), p. 2



women contracting the virus. Such ‘behaviours’ include homosexual sex which was often either ignored or condemned by the public. This chapter examines all of these issues to provide an explanatory background and framework for the stories told by gay men with HIV/AIDS about their personal experiences with the disease over this period of time examined in subsequent chapters.

In addition, this chapter focuses on historians’ responses to HIV/AIDS in New Zealand and elsewhere. Early historical writing about HIV/AIDS reflects the general social reluctance to admit HIV/AIDS was like recent diseases: deadly and in need of cure. Historians initially associated HIV/AIDS with past plagues, and indirectly reassured victims and their families that the epidemic would soon pass, just as historical plagues had. Through this association, ‘historians helped to encourage a wishful thinking: they helped to create a story about the epidemic as a time-limited incursion of virulent plague’.<sup>4</sup> The idea that HIV/AIDS was not like past plagues, but more like recent and different world diseases, was a reality that individuals at the beginning of the epidemic were unwilling to accept. Despite this initial reluctance, diagnoses continued to rise, and the government, health officials, and the general public, were faced with an epidemic they could no longer ignore. The gay community, too, had to galvanise its own approach to the disease. In addition, this chapter examines policies that were implemented both by the gay community and the government, most of which promoted safe-sex practices and were primarily targeted at ‘risk groups’. Chapter One also specifically focuses on Māori, who were perceived as a ‘risk group’, yet health officials knew so little about Māori sexuality. Health officials were concerned for Māori health because of the youthful structure of Māori culture, and socioeconomic factors which is investigated in this chapter. Finally, this chapter examines media representations of HIV/AIDS, as depicted in newspaper and magazine articles, both in New Zealand and internationally. Analysing media articles is crucial in this thesis as the media provided the main means through which people who were not directly impacted by the epidemic learnt about HIV/AIDS. Therefore, on many instances the media fuelled misconceptions and public hostility towards gay men.

### **Homosexuality in New Zealand 1980s-1990s**

Steve’s narrative indicates that some homosexual HIV/AIDS patients and their partners had emotionally traumatic experiences with medical professionals. Although Pablo’s experience

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<sup>4</sup> Elizabeth Fee and Daniel M. Fox ‘The Contemporary Historiography of AIDS’, *Journal of Social History*, 23, 2 (1989), p. 312.

is personal, his story, as retold by Steve, reveals the prejudice they encountered which may be shared by others. The HIV/AIDS epidemic in New Zealand brought homosexual men and particularly homosexual sex into public focus. As a result of the outbreak of HIV/AIDS, homosexual men were in a vulnerable position to be scrutinised, and in some instances were blamed for the disease. Gay men with HIV/AIDS encountered social hostility through their interactions with doctors and nurses, the law, and through daily interaction with peers.

In New Zealand's recent history, homosexuality was not only silenced, but condemned, and anti-homosexual attitudes were particularly prevalent in the early-twentieth century. Homosexual sex was also criminalised, and socially condemned in Australia at this time.<sup>5</sup> The notion of homosexuality as a medical condition was particularly damaging for gay men. The development of New Zealand's health culture meant that 'homosexuality became linked to mental illness[es]',<sup>6</sup> and was perceived as in need of cure. Laurie Guy's work on homosexuality in New Zealand depicts a highly conformist culture. Guy suggests that the 1960s focus on medically changing homosexual men was motivated by the men's lack of conformity to the rest of New Zealand society.<sup>7</sup> Homosexual men were taught 'that the guilty deserve punishment. Punishment is atonement for guilt. A "cure" is a sacrament, taking away his sin'.<sup>8</sup> Consequently, many homosexual men were forced to undergo extreme and sometimes brutal treatments in an attempt to 'cure' their homosexuality. In the 1950s and 1960s for example, some homosexual men were subjected to electric shock treatment as part of doctors attempt to turn them into heterosexuals.<sup>9</sup> Such treatment aimed to suppress homosexual desire and eliminate the 'threat' homosexuality was believed to pose to society. Psychoanalysis was used in New Zealand, which involved the male homosexual patient undergoing counselling to understand the motivation for his behaviour.<sup>10</sup> However, psychoanalysis was based on the assumption that homosexuality is a result of deviant

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<sup>5</sup> Ruth Ford, "'Filthy, obscene and man": engendering "homophobia" in Australia, 1940s-1960s', in *Homophobia, An Australian History*, ed. by Shirleene Robinson (NSW: The Federation Press, 2008), pp. 86-112, Barbara Baird, 'Putting police on notice: A South Australian case study', in *Homophobic violence*, ed. by Gail Mason and Stephen Tomsen (Sydney: The Hawkins Press, 1997), pp. 118-131, Robert Aldrich, *Colonialism and Homosexuality* (London: Routledge., 2003).

<sup>6</sup> Heather Worth, *Gay Men, Sex & HIV in New Zealand*, (Palmerston North: Dunmore Press, 2003), p. 17.

<sup>7</sup> Laurie Guy, "'Straightening the Queers": Medical Perspectives on Homosexuality in Mid-Twentieth Century New Zealand', *Health and History*, 2.1 (2000), pp. 107-8.

<sup>8</sup> Phil G. Parkinson, *Homosexuality as a medical condition*, [pamphlet], (Wellington, NZ: Lesbian and Gay Rights Resource Centre, n.d), p. 5.

<sup>9</sup> Parkinson, n.d, p.4. Electric shock treatment is a variant of Lobotomy, which is the process of removing part of an individual's brain in the attempt to 'cure' them of their mental illness and emotional problems, in this case homosexuality. This was not used in New Zealand as a treatment for homosexuality.

<sup>10</sup> Parkinson, n.d, p.4.

parenting, and consequently severed familial relationships and made the homosexual patient feel guilty.<sup>11</sup> Not all homosexual men voluntarily underwent treatment, and because homosexuality was illegal, some gay men were forced to undergo treatment as an alternative to imprisonment.<sup>12</sup> In other circumstances, some men volunteered themselves for treatment after internalising the guilt associated with being gay in New Zealand's conformist society.

Hostility towards homosexuality is also apparent in New Zealand's recent history through some medical professionals' reluctance to work with HIV/AIDS patients. Homosexuality and HIV/AIDS has been conflated from the early years of the epidemic, and such prejudice among medical professionals reflects a disapproval of homosexual sex, as well as fear of contagion, and thus ignorance about the virus. Jeffrey A. Kelly argues that physicians often carry the same attitudes towards HIV/AIDS patients as the wider community does.<sup>13</sup> Yet a physician's prejudice towards HIV/AIDS patients carries stronger implications than the general public, as it hinders their ability to establish a positive, open relationship with their patient.<sup>14</sup> In New Zealand, some medical professionals expressed overt discriminatory behaviour, which was emotionally damaging for the patients under their care. The impact discrimination at the hands of medical professionals has on their patients is evident in Dan Coomby's narrative. Dan was formerly employed with the New Zealand AIDS Foundation, and recalls an HIV-positive friend needed urgent medical attention. According to Dan, 'the ambulance was there, they'd stopped out on the road, and put on – um, gowns and masks and gloves and everything – out on the street for the whole neighbourhood to see'.<sup>15</sup> The medical professional's lack of discretion and compassion in this instance meant the HIV-positive patient was deprived of the dignity and privacy to which all patients are entitled.

New Zealand medical professionals' attitudes towards homosexual men also influenced the men's experiences as patients. Some nurses were uncomfortable with working closely with HIV/AIDS patients, and had difficulty meeting their patient's psychological needs, and dealing with the trauma that was likely to result from a positive diagnosis. In 1988 the Department of Health identified that after a person received a positive diagnosis; he or she

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<sup>11</sup> Parkinson, n.d., p. 4.

<sup>12</sup> Parkinson n.d., p.5.

<sup>13</sup> Jeffrey A. Kelly, 'Stigmatization of AIDS Patients by Physicians', *American journal of public health*, 77.7 (1987), p. 789.

<sup>14</sup> Jeffrey A. Kelly, p. 791.

<sup>15</sup> Dan Coomby, *Life Narrative*, 11 May 2011, interviewed by Cheryl Ware, Hamilton, New Zealand, 10. 24-10.38.

may experience a range of emotions, including anger, denial, withdrawal, but also possibly short-term relief and acceptance, as many patients speculated they were positive before receiving their results.<sup>16</sup> While these anticipated reactions are not exclusive to homosexual men, a disproportionately high number of positive HIV/AIDS diagnoses in western countries were gay men, especially during the early years of the epidemic. Because of the widely shared conflation of homosexuality and HIV/AIDS, an individual's positive diagnosis often exposed details of their personal life they wished to remain private, and potentially resulted in the patient's increased psychological suffering.<sup>17</sup> Many people were aware of the stigma attached to HIV/AIDS, even those who had limited knowledge about the virus itself. Therefore, a major cause of distress for patients was their fear of being rejected by family and friends, as well as feeling guilty about being gay and having possibly infected others.<sup>18</sup>

The patient's trauma of being diagnosed with HIV/AIDS, and the guilt and shame that accompanied homosexuality came to the attention of medical officials in the late 1980s. In 1988, the Department of Health identified that the nurses' reluctance to work with HIV/AIDS patients was a result of inadequate training. Nurses had not yet received substantial training in skills including counselling and understanding lifestyles contrary to their own, such as unprotected sex and drug use.<sup>19</sup> Consequently, the Department of Health released a report providing guidelines for nurses to abide by while caring for HIV/AIDS patients. The report emphasises the nurses' responsibility to approach their patients objectively, some of whom may be drug addicts, homosexuals, and bisexuals, and maintains that the nurses must refrain from expressing any embarrassment or disgust, both of which can cause psychological damage to their patients.<sup>20</sup> These guidelines meant nurses had to encounter and tolerate behaviour they would rather ignore, to the extent that they could establish professional, caring relationships with their patients. It is unlikely this movement would have been possible without Homosexual Law Reform that decriminalised male homosexual sex and had a lasting social impact on New Zealand.

Although many New Zealanders preferred to ignore that homosexual behaviour existed in their communities, men who have sex with men became a major public focus during the

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<sup>16</sup> Department of Health, 'Nursing Guidelines on the management of patients suffering from HIV illness/AIDS in hospital and the community', (Wellington: Department of Health, 1988), p. 28.

<sup>17</sup> Department of Health, 1988, p. 30.

<sup>18</sup> Department of Health, 1988, p. 30.

<sup>19</sup> Department of Health, 1988, p. 5.

<sup>20</sup> Department of Health, 1988, p. 28.

epidemic.<sup>21</sup> Homosexual relations between men were traditionally tolerated in New Zealand society, but became morally and legally prohibited with colonisation.<sup>22</sup> Homosexuality was forbidden under the English Laws Act of 1858, which ruled that all laws in force in England on 14 January 1840 also applied to New Zealand.<sup>23</sup> Support for criminalising male homosexual sex is evident in *The New Zealand Parliamentary Debates*, where some political leaders claimed New Zealand's future would be in jeopardy if homosexual sex was allowed. The legal status of homosexual sex is addressed during debates for the Crimes Bill, which became the Crimes Act in 1961. This law maintains that men accused of homosexual 'crimes' were legally defenceless on trial because 'if both parties are adults it is still a crime', and 'if both parties consent it is still a crime'.<sup>24</sup> The debates that led to the criminalisation of homosexual sex reflect New Zealanders attitudes towards homosexuality, as in many cases politicians spoke on behalf of the communities they represent. For example, Hon J. T. Watts was particularly opposed to homosexual sex, and asserts that 'enough is being done to erode moral standards without Parliament, which should be the bulwark, taking the step proposed and making it no offence for consenting males to go in for this type of moral crime.'<sup>25</sup> Hon. Watts' concerns were based on cases in the United Kingdom, where men who engaged in homosexual sex did not face legal retribution, like they would in New Zealand. Referring to these cases, Hon. Watts felt 'a great deal of uneasiness about the future of Western civilisation'.<sup>26</sup>

The debates for the Crimes Bill took place during the early 1960s, in a society predominantly opposed to homosexuality. However, other changes were also happening in New Zealand society regarding Law Reform. Guy argues that during the early 1960s, major attitudinal changes were occurring in New Zealand, which was becoming increasingly more exposed to international influence through overseas travel and the media.<sup>27</sup> One of these major shifts in attitudes was about sexuality, which was triggered by the introduction of the contraceptive

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<sup>21</sup> While the term 'men who have sex with men' or 'MSM' is commonly used in HIV/AIDS research, this thesis focuses specifically on men who identify as homosexual, gay, or Takatāpui.

<sup>22</sup> See Chris Brickell, *Mates and lovers: a history of gay New Zealand* (New Zealand: Godwit, 2008).

<sup>23</sup> Alison J. Laurie, 'The Aotearoa/New Zealand Homosexual Law Reform Campaign, 1985-1986', in *Twenty years on, Histories of Homosexual Law Reform in New Zealand*, ed. by Alison J. Laurie and Linda Evans (New Zealand: Lesbian and Gay Archives of New Zealand, 2009), p. 15.

<sup>24</sup> Dr. W. C. Hodge, 'Homosexual Law Reform: Questions and answers concerning the legality of male homosexual conduct in New Zealand', (A discussion paper), (New Zealand: University of Auckland, 1985), p. 7. Words are underlined and bold in the original text.

<sup>25</sup> Hon J. T. Watts, *New Zealand Parliamentary Debates*, Vol. 322, 19 July 1960, p. 669.

<sup>26</sup> Hon J. T. Watts, *New Zealand Parliamentary Debates*, Vol.322, 19 July 1960, p. 669.

<sup>27</sup> Laurie Guy, 'Between a hard rock and shifting sands: Churches and the Issue of Homosexuality in New Zealand, 1960-86', *Journal of Religious History*, 30.1 (2006), p. 65.

pill.<sup>28</sup> Guy asserts that the contraceptive pill symbolised sexual freedom, and undermined earlier arguments that homosexual sex was ‘immoral’ because it did not lead to procreation.<sup>29</sup> Prejudice towards homosexual sex based on procreation was one of the many arguments about homosexuality that were undermined from the 1960s onwards.

Ideas about homosexuality as a mental illness were also being contested in New Zealand in the 1970s, which Guy claims is most likely based on the medical failure to effectively ‘cure’ homosexuality.<sup>30</sup> For example, psychologists and psychiatrists who attempted to determine the emotional health differences between homosexuals and heterosexuals concluded that there are no differences between the two groups.<sup>31</sup> Finally, in 1972, the Australian and New Zealand College of Psychiatrists affirmed homosexuality was not a medical condition and that patients should only undergo treatment if they voluntarily asked for it.<sup>32</sup> Although homosexuality was no longer formally considered a mental illness, its former medical status was the foundation for later discrimination against gay men, particularly during debates for homosexual Law Reform.

Significant movements towards Law Reform began in 1984, when Member of Parliament (MP) Fran Wilde agreed to introduce the Homosexual Law Reform Bill, which she had previously suggested but was forced to drop. Law Reform aimed to decriminalise homosexual sex between consenting men over 16 years old, and prohibit discrimination on the grounds of sexual orientation. Criminalising homosexual sex was particularly problematic since HIV/AIDS arrived in New Zealand. With homosexual sex being illegal, gay and bisexual men who suspected they have HIV/AIDS may refrain from seeking medical advice for fear of being prosecuted.<sup>33</sup> Also, potentially infected sexual partners would be harder to identify, and public education programmes about HIV/AIDS would be difficult to target accurately.<sup>34</sup> The debates surrounding Law Reform revived several derogatory stereotypes about gay men that were already ingrained in New Zealand society, including arguments about homosexual promiscuity, and homosexuality as a mental illness. Anti-Law Reform activists rekindled early-twentieth century suggestions that homosexuality was a mental

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<sup>28</sup> Laurie Guy, 2006, p. 65.

<sup>29</sup> Laurie Guy, 2006, p. 66.

<sup>30</sup> Laurie Guy, 2000, p. 118.

<sup>31</sup> Parkinson, n.d, p. 7.

<sup>32</sup> Parkinson n.d, p. 5.

<sup>33</sup> Hodge, p. 26.

<sup>34</sup> Hodge, p. 26.

illness, and claim ‘whatever causes [homosexuality], it needs treatment, not a change in the law’.<sup>35</sup> However, politicians including Labour MPs Trevor Mallard and Fran Wilde promptly negated claims that homosexuality was a mental illness. Wilde based her arguments on the Department of Health’s findings, suggesting that the mental stress homosexual individuals experience is a result of the law and wider social attitudes, ‘not from the orientation itself’.<sup>36</sup> Other pro-Law Reform activists hoped Law Reform would reduce the wrongful discrimination that homosexual men faced. According to C.J.F Parkin, Law Reform ‘will rectify a long-standing injustice. It is intolerable that nearly 50,000 men should be condemned as potential criminals on account of their emotional make-up’.<sup>37</sup> Despite hopes that Law Reform would bring more equality to New Zealand society, and eliminate discrimination based on sexual preference, the proposed Homosexual Law Reform Bill faced heavy opposition.

Politicians both in favour of, and opposed to Law Reform used HIV/AIDS related issues to support their arguments. Christopher J. F. Burke identifies that opposition to Law Reform was based on New Zealand’s religious and wider social beliefs.<sup>38</sup> While pro-Law Reform activists maintained successful safe-sex education campaigns were dependent on decriminalisation, anti-Law Reform groups assumed decriminalisation would result in a severe increase in HIV/AIDS infections. For example, Hon. Mrs. T. W. M. Tirikatene-Sullivan, a representative of Southern Māori, feared HIV/AIDS diagnoses would increase if Law Reform passed. Hon. Tirikatene-Sullivan acknowledges that the significance of the proposed Bill was its decriminalisation of sodomy, which she identifies as ‘the principal means by which people who do not have AIDS become infected and infected fatally’.<sup>39</sup> In other words, Hon. Tirikatene-Sullivan argues that by permitting homosexual sex, the government was eliminating one of the only barriers to infection. The debate about Law Reform is one of the many instances in New Zealand’s recent history where homosexuality has been conflated with HIV/AIDS. Like Hon. Tirikatene-Sullivan, Mr Lee also addresses the House with his concerns about HIV/AIDS infections increasing as a result of Law Reform.

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<sup>35</sup> Parkinson, n.d, p. 1.

<sup>36</sup> Fran Wilde, *New Zealand Parliamentary Debates*, Vol. 466, 9 October 1985, p. 7255.

<sup>37</sup> Parkin, C. J. F., *The Queer Law* (New Zealand: Homosexual Law Reform Society, 1968), p. 8.

<sup>38</sup> Christopher J. F. Burke, ‘Diversity or Perversity? Investigating Queer Narratives, Resistance, and Representation in Aotearoa / New Zealand, 1948-2000’, (Unpublished MA Thesis: University of Waikato, 2007), p. 58.

<sup>39</sup> Hon. Mrs. T. W. M. Tirikatene-Sullivan, *New Zealand Parliamentary Debates*, Vol. 467, 6 November 1985, p. 8051.

Mr Lee draws his argument from negative homosexual stereotypes already embedded in New Zealand society, and claims that members of the gay community are sexually promiscuous and Law Reform should not pass due to ‘the public health threat of AIDS alone’.<sup>40</sup> Despite political opposition, the Homosexual Law Reform Act was signed into law on July 11 1986, and ‘came into effect on 8 August, ending 128 years of criminalising male homosexual acts in Aotearoa/New Zealand’.<sup>41</sup> The Law Reform debate was a turning point in New Zealand’s social development; as Maryan Street writes, ‘it was historic; it was political; it was visionary; it was inclusive and it was sensible public policy’.<sup>42</sup>

While Law Reform is a remarkable event in New Zealand’s recent history, it did not entirely eliminate anti-homosexual societal attitudes, which were exposed during the HIV/AIDS epidemic. In particular, public attitudes towards homosexuality influenced gay men’s experiences as HIV/AIDS patients, with some gay men encountering hostility from medical professionals. The Department of Health identified flaws in the medical system, where nurses were not catering to the needs of gay men with HIV/AIDS. Homosexual Law Reform indicates the changing roles that homosexuality plays in New Zealand’s recent history. The *Parliamentary Debates* offer important insight into New Zealander’s attitudes towards homosexuality prior to, and during the early years of the AIDS epidemic.

### **New Zealand’s response to the threat of an epidemic**

HIV/AIDS was first identified in 1981 in San Francisco, two years before New Zealand had its first diagnosis.<sup>43</sup> Therefore, New Zealanders essentially had two years warning about the virus. Different communities in New Zealand responded to the threat of an epidemic, beginning with the gay community, who made preventative efforts before HIV/AIDS arrived in the country. The government, despite its own relatively late response, allocated funding which meant that safe sex education campaigns and support programmes for positive people could be established. Campaigns included the 1985 AIDS Prevention publicity campaign by the Department of Health, the 1986 TVNZ AIDS documentary and studio programmes, and

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<sup>40</sup> Mr Lee, *New Zealand Parliamentary Debates*, Vol. 466, 9 October 1985, p. 7270.

<sup>41</sup> Laurie, p. 20.

<sup>42</sup> Maryan Street, ‘Homosexual law reform-the aftermath’, in *Twenty years on, Histories of Homosexual Law Reform in New Zealand*, ed. by Alison J. Laurie and Linda Evans (New Zealand: Lesbian and Gay Archives of New Zealand, 2009), p. 11.

<sup>43</sup> Roy Porter, *The Greatest Benefit to Mankind: a medical history of humanity from antiquity to the present* (London: HarperCollinsPublishers, 1997), p. 594.



the New Zealand AIDS Foundation's print material and publicity hotline.<sup>44</sup> This section of the chapter focuses on the ways New Zealanders responded to the threat of HIV/AIDS, from smaller community groups to the government-funded national campaigns. While Māori were initially overlooked as a 'risk' group, health officials became concerned about Māori risks of infection based on international indigenous populations, and health officials limited knowledge about Māori health. Therefore, this section also focuses on Māori as a specific group who were potentially at risk.

In New Zealand, the gay community were the first to respond to the threat of HIV/AIDS, and were followed much later by the government. New Zealand gay community leaders were aware of the HIV/AIDS epidemic in other countries, and proactively began HIV/AIDS prevention and education work before the virus reached New Zealand.<sup>45</sup> For example, the National Gay Rights Coalition of New Zealand published pamphlets to inform people about the risks of HIV/AIDS, and similar information was spread by the AIDS Support Network, some of which was funded by *Out!* Magazine.<sup>46</sup> Gay community support is particularly apparent in Dan's narrative. Dan is HIV-negative, and has worked extensively with the NZAF. He explains that the majority of volunteers were members of the gay community, both men and women.

The New Zealand government initially failed to respond to the AIDS crisis which indicates both anti-homosexual attitudes, and also a reluctance to acknowledge that behaviour like homosexual sex and drug use occurs in their communities. However, effective public health policies could not be established without the government openly addressing these behaviours.<sup>47</sup> Writing about dominant responses to HIV/AIDS in the United Kingdom, Virginia Berridge asserts that officials were 'slow [to react] because only gay men were initially affected; high level intervention came only when the threat to the heterosexual population became clear'.<sup>48</sup> In other words, following the experience in other places, the official reluctance to intervene in the HIV/AIDS epidemic possibly indicates intolerance of

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<sup>44</sup> Colleen Ireland, 'AIDS prevention education – The Health Education Unit Response, New Zealand AIDS Foundation, *Prevention Education Workshop*, (New Zealand: NZAF, 1986), pp. 1-2.

<sup>45</sup> Phil Parkinson, 'Prevention Education and the Gay Community in New Zealand', New Zealand AIDS Foundation, *Prevention Education Workshop*, (New Zealand: NZAF, 1986), p.1.

<sup>46</sup> MS Papers 143, AIDS Support Network.

<sup>47</sup> Kingman, Sharon, 'Aids and the Social Outcast', *New Scientist*, 10 March 1988, (magazine), p. 30.

<sup>48</sup> 'Virginia Berridge, 'The early years of AIDS in the United Kingdom 1981-6: historical perspectives', in *Epidemics and ideas: essays on the historical perception of pestilence*, ed. by Terence Ranger and Paul Slack (Great Britain: Cambridge University Press, 1992), p. 304.

homosexuality in New Zealand, and the public's preference to exclude them from the rest of society. Charles E. Rosenberg argues that the delayed governmental response to the HIV/AIDS epidemic follows a pattern that had been repeated for centuries, where 'bodies must accumulate and the sick must suffer in increasing numbers before officials acknowledge what can no longer be ignored'.<sup>49</sup> However, due to pressure placed on the government by the gay community, increasing reports of new infections, and the threat that HIV/AIDS could spread to the heterosexual community, government and health boards were pressured to respond.<sup>50</sup> From 1985 onwards, government-funded HIV/AIDS organisations were established in New Zealand, and specifically targeted at sexually-active homosexual men.

A major government-funded organisation is the NZAF, which was established in 1986.<sup>51</sup> The Foundation's main goal was to promote HIV/AIDS prevention by educating people of all sexualities about safe sex, and it has produced a number of safe-sex campaigns. These campaigns ranged from subtle suggestions to promote condom use (Figure 1.1), to powerful images of the impact HIV/AIDS has on the body (Figure 1.2). Heather Worth argues that the Foundation aimed for lasting success, and 'to establish and maintain safe sex as a gay community norm'.<sup>52</sup> Prior to 1997 there was no effective treatment for HIV, and there continues to be no cure for HIV/AIDS. Therefore, prevention of the virus became the main message of the HIV/AIDS organizations. While the NZAF made a significant contribution to HIV/AIDS prevention campaigns, and provided emotional support for positive people, other organisations also accepted this role. In New Zealand, Body Positive was another one of the main organisations that were established to promote awareness of HIV/AIDS and support its victims. Virginia Berridge asserts that '[HIV/AIDS] provided a gay organizational and political focus which was lacking after the disintegration of some of the gay political organisations [by the 1980s]'.<sup>53</sup> These AIDS organisations had multiple objectives; including preventing what she terms an 'anti-gay backlash by stressing – as the Gay Medical Association had done – the idea of AIDS as, potentially and actually, a heterosexual disease'.<sup>54</sup>

<sup>49</sup> Charles Rosenberg, 'What is an Epidemic? AIDS in Historical Perspective, *Daedalus*, 118.2 (1989), p. 4.

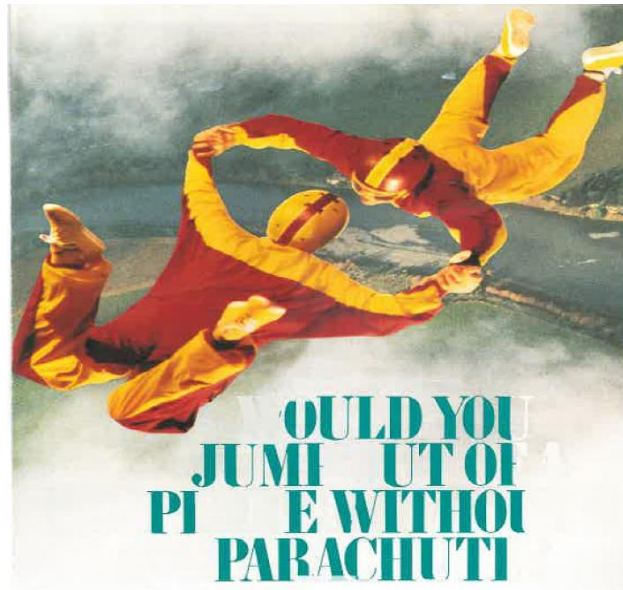
<sup>50</sup> Worth, 2003, p. 27-8.

<sup>51</sup> Worth, 2003, p. 27-8.

<sup>52</sup> Worth, 2003, p. 29.

<sup>53</sup> Virginia Berridge, 'The early years of AIDS in the United Kingdom 1981-6: historical perspectives', in *Epidemics and ideas: essays on the historical perception of pestilence*, ed. by Terence Ranger and Paul Slack (Great Britain: Cambridge University Press, 1992), p. 308.

<sup>54</sup> Berridge, 1992, p. 309.



**Figure 1.1 NZAF HIV/AIDS information brochure**

Department of Health, New Zealand, 1986. [C4174]. NZAF Library and Information Service.



**Figure 1.2 HIV/AIDS awareness advertisement**

Cited in Nigel Gearing, *Emerging Tribe: gay culture in New Zealand in the 1990s*, (New Zealand: Penguin Books (NZ) Ltd., 1997)

In addition to government-funded HIV/AIDS organisations, New Zealand officials also responded to the threat of an epidemic through a biomedical model, by establishing nationwide HIV testing. HIV testing was made accessible to all New Zealanders through the New Zealand AIDS Foundation and various medical clinics throughout the country.<sup>55</sup> Writing about venereal diseases, Antje Kampf argues that a wide range of services for treating gonorrhoea and syphilis were established in New Zealand in the early-twentieth century, but that doctors were often visited as a last resort after treatment given by herbalists and chemists failed.<sup>56</sup> Therefore, HIV/AIDS testing was introduced to a society that had already experienced accessible testing for sexually transmitted disease, especially during and after world wars. HIV/AIDS testing was perceived as a positive public health measure on the condition that an individual's confidentiality was maintained, and that the patients receive adequate counselling after receiving their results, regardless of whether they test positive or negative.<sup>57</sup> Because of the stigma that surrounded HIV/AIDS as well as its known disease trajectory, anticipated reactions following a positive diagnosis include depression, anxiety and low self-esteem. HIV/AIDS testing, in addition to specifically targeted safe-sex promotion campaigns, aimed to reduce the spread of HIV/AIDS through awareness and education. While HIV/AIDS organisations and testing were available to all New Zealanders, officials had a specified target audience, or 'risk groups'. By the early 1980s, the government had identified specific 'risk groups', whom they believed to be at a particularly high risk of HIV/AIDS infection. These 'risk groups' include sexually active homosexual men and intravenous drug users (Figure 1.3).

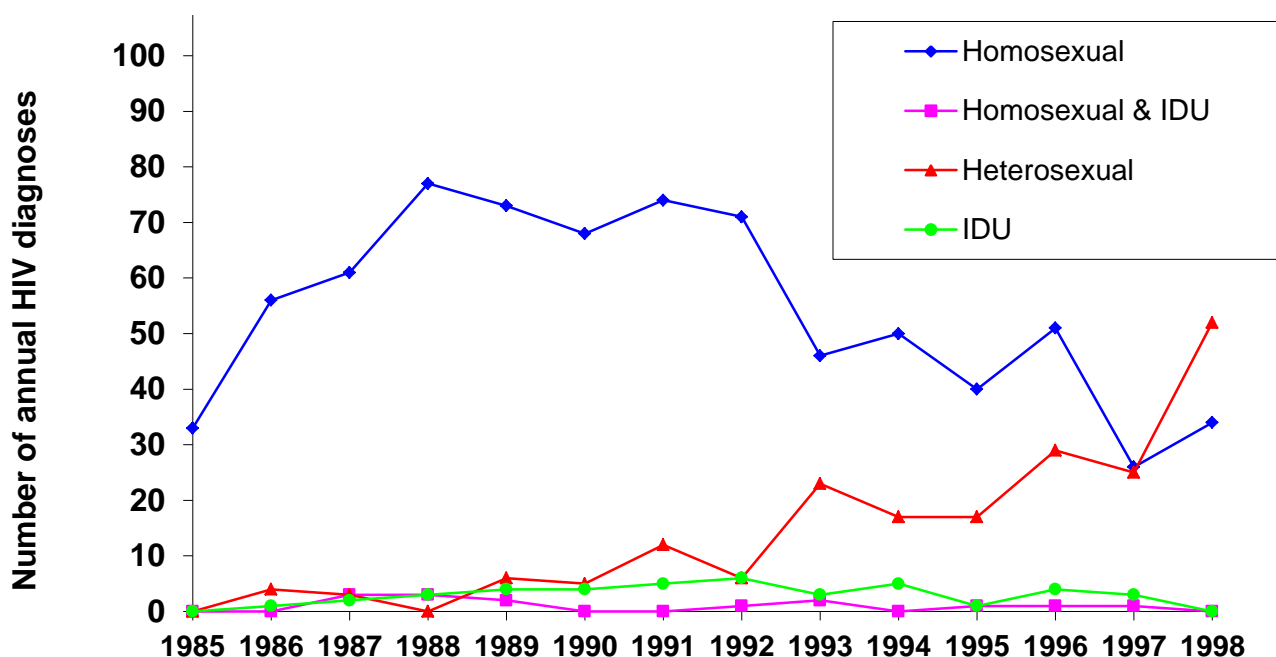
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<sup>55</sup> National Council on AIDS, *The HIV/Aids Epidemic, Towards a New Zealand Strategy*, A policy Discussion paper (New Zealand: National Council on AIDS, 1989), p. 4.

<sup>56</sup> Antje Kampf, *Mapping Out the Venereal Wilderness, Public Health and STD in New Zealand 1920-1980*, (USA: Transaction Publishers, 2007).

<sup>57</sup> National Council on AIDS, p.4.

**Exposure category: Annual HIV diagnoses by Western blot antibody testing, 1985-1998 (Note: Does not distinguish between infections acquired in NZ and overseas)**



**Figure 1.3 Exposure category: Annual HIV diagnoses by Western blot antibody testing, 1985-1998**

Data provided by AIDS Epidemiology Group, Department of Preventive and Social Medicine, University of Otago: Updated May 2011

Graph produced by Research, Analysis and Information Unit, New Zealand AIDS Foundation 2011.

Another main target group was youth as they have a high level of sexual and social experimentation, and a tendency to conform to peer pressure.<sup>58</sup> Peer pressure includes drinking and drug use, both of which can hinder one's ability to consciously consider protected sex. By identifying risk groups, public health measures that aimed to prevent the spread of HIV/AIDS were accurately targeted. The National Council on AIDS identifies that prevention strategies were 'based on principles of consultation with affected groups and empowerment of groups working within their own communities'.<sup>59</sup> This strategy was particularly effective for members of the gay community, many of whom became heavily involved in the HIV/AIDS cause. Historian Paul Sendziuk credits the success of Australian HIV/AIDS prevention and education campaigns to the government working collaboratively

<sup>58</sup> National Council on AIDS, p. 5.

<sup>59</sup> National Council on AIDS, p. 4.

with members of affected communities.<sup>60</sup> He notes that the success of Australian prevention strategies was internationally recognised, and a model from which other countries could benefit.<sup>61</sup> However, the government's identification of 'risk groups' also had damaging consequences. By identifying risk groups, the government unintentionally spread feelings of relief and complacency amongst groups who did not identify themselves as 'at risk' of contracting the virus, such as non-promiscuous heterosexuals. It was therefore crucial to inform all New Zealanders about the risks of HIV, and effective prevention strategies. As a result of complacency, the Department of Health ran its first AIDS prevention campaign in 1986, which was aimed at all sexually active people in New Zealand, not just homosexual men.<sup>62</sup> However, an evaluation of the 1986 campaign concludes that some heterosexual men and women still remained unaware of their risk of contracting HIV/AIDS.<sup>63</sup> One reason the 1986 campaign was not entirely successful is that some individuals outside of the 'risk groups' were unwilling to become educated about HIV/AIDS. This may have been due to a reluctance to identify themselves as 'at risk' due to the fear and stigma attached to the virus. Māori were also identified as a risk group, particularly because health officials knew so little about Māori sexuality, and homosexual Māori men's affiliation with the gay community.

The New Zealand government and the media initially overlooked Māori as being at a high risk of contracting HIV/AIDS. Early media portrayals of HIV/AIDS as 'a white middle-class male disease' made Māori and Pacific Island men and women complacent about their own risks of infection.<sup>64</sup> By the mid-1990s, limited research had been completed about Māori sexual behaviour, and health officials were unable to determine the amount of support Māori were receiving within their own whanau and hapu. The Ministry of Māori Development identifies that prior to 1994, there was no published data about Māori men's homosexual experiences, nor was there any information about homosexual Māori men's condom usage, involvement with the gay community, or specific sexual behaviors.<sup>65</sup> Although health officials knew so little about the impact of HIV/AIDS on Māori, they believed Māori to be at a higher risk of infection than non-Māori. Officials primarily based these predictions on

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<sup>60</sup> Paul Sendziuk, 'AIDS Politics', in *The Oxford Companion to Australian Politics*, ed. by Brian Galligan (Melbourne: Oxford University Press, 2007), p. 24

<sup>61</sup> Sendziuk, p. 24

<sup>62</sup> Colleen Ireland, 'AIDS prevention education – The Health Education Unit Response, New Zealand AIDS Foundation, *Prevention Education Workshop*, (New Zealand: NZAF, 1986), p. 1.

<sup>63</sup> Ireland, p. 1.

<sup>64</sup> Department of Health, *AIDS are you in the picture?* (New Zealand: Department of Health, 1988)

<sup>65</sup> Ministry of Māori Development, *Mate Ketoketo/Arai Kore, A report about HIV/AIDS and Māori*, (Wellington: Te Puni Kōkiri, 1994), pp. 12-13.

infection rates of indigenous populations overseas.<sup>66</sup> Specific features of Māori culture also alarmed health officials. The main concern of health officials was the youthful age structure of Māori culture, which automatically places them at greater risk of infection due to earlier ages of sexual experimentation.<sup>67</sup> Although research proves that many gay men readily adopted safe sexual practices, younger homosexual men were less likely to maintain safe sexual behavior, and were influenced by alcohol and drug consumption, and emotional trauma caused by the breakdown of romantic relationships.<sup>68</sup> Therefore, officials identified the need to intervene in Māori sexual health, as they did in other aspects of population health for Maori and Pacific Islanders from the 1960s.<sup>69</sup>

Homosexual Māori men faced social challenges within their own communities, and from wider society. Clive Aspin identifies that homosexual Māori men sometimes faced racial discrimination from the predominantly Pakeha (non-Maori) gay community, and were sometimes excluded from the Māori community because of their sexualities.<sup>70</sup> The Ministry of Māori Development was concerned that gay Māori men were excluded from, or isolated themselves from the gay community. Māori men's isolation was problematic because when homosexual men disconnect themselves from the gay community, they deprive themselves of social support and information about safe sex that the community provides.<sup>71</sup> Many safe-sex promotion campaigns were specifically targeted at the gay community, who became knowledgeable about ways to protect themselves and others from the virus. Involvement in the gay community was considered beneficial for homosexual men because of the community's access to safe sex campaigns, and access to support groups for individuals dealing with a positive HIV/AIDS diagnosis.<sup>72</sup> Health officials were also concerned for Māori because safe sex promotion campaigns and gay community support groups were not always relevant to, or effective for Māori. Specifically, terms such as 'gay' may not have been culturally appropriate for Māori men who have sex with men. For example, James Mauke, a participant in this study, identifies the importance of the term Takatāpui. James

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<sup>66</sup> New Zealand AIDS Foundation, *Male Call/Waea Mai Tane ma, Report Three: Māori men who have sex with men*, (New Zealand AIDS Foundation: 1998), p. 1.

<sup>67</sup> Ministry of Māori Development, p. 13.

<sup>68</sup> Ministry of Māori Development, p. 12.

<sup>69</sup> Lavinia Denise Strathern, "'Much remains to be done': the changing health profile in the urban region of South Auckland, 1956-1972." (Unpublished MA thesis, University of Waikato, 2003).

<sup>70</sup> Clive Aspin, 'Takatāpui – Confronting Demonisation, in *Sexuality and the Stories of Indigenous People*, ed. by Jessica Hutchings and Clive Aspin (Wellington, New Zealand: Huia Publishers, 2007), p. 161.

<sup>71</sup> Ministry of Māori Development, p. 12.

<sup>72</sup> New Zealand AIDS Foundation, *Male Call/Waea Mai Tane Ma, Report Nine: HIV testing and sero-status*, (New Zealand AIDS Foundation: 1999), p. 9.

asserts that ‘for me it meant, first and foremost being Māori. Um, it means being Māori and being attracted to the same sex.’<sup>73</sup> James notes the term is more culturally appropriate for Māori, and ‘the term Takatāpui itself I like also because it’s inclusive of bisexual and transgender, as well, as gay, lesbian. Um, and I like it as well because it’s a – it’s a ancient Māori word’.<sup>74</sup> Like James, some Māori men respond better to the identity as ‘Takatāpui’, which for them is culturally relevant, and not as stratified as ‘gay’, ‘bisexual’, and ‘homosexual’. As well as identifying culturally appropriate terms, officials needed to create prevention campaigns that were specifically appropriate for Māori, and eliminate misconceptions that they are not at risk.

Health officials initially struggled to establish successful and effective health policies for Māori as they were limited by knowing so little about Māori sexual health practices. Statistics showed that health promotion strategies that were based on sexual issues such as HIV/AIDS, were not effectively communicated to Māori and may not be appropriate due to cultural and social factors.<sup>75</sup> This was particularly problematic because Māori were considered a ‘risk group’. As a result of their findings, in 1994 the Ministry of Māori Development recommended that a ‘comprehensive Māori health promotion and education policy and strategy should be developed for the control and prevention of the HIV/AIDS epidemic in Māori’.<sup>76</sup> Te Puni Kokiri responded to the report by recommending that principles of the Treaty of Waitangi be the basis for developing an HIV/AIDS policy for both Māori and non-Māori.<sup>77</sup> For example, Article 1 of the Treaty recognizes that it is the government’s responsibility to ‘ensure that the health of New Zealanders’ is promoted, protected, and enhanced, and that health care is available and accessible to all people’.<sup>78</sup> Te Puni Kokiri stated the ideal outcome would be that Māori receive acceptable standards of health, as determined by Māori.<sup>79</sup> These movements by the Department of Health and Te Puni Kokiri aimed to reduce Māori risk of HIV/AIDS infection, by ensuring Māori men and women were aware of safe-sex strategies, and their own risks. In addition, in 1995, Mate ‘ketoketo/Arai Kore Project’, a joint project of the New Zealand AIDS Foundation and Te Waka Awhina Takatāpui Incorporated., produced postcards that spread awareness of Māori risks of

<sup>73</sup> James Mauke, *Life Narrative*, 20 May 2011, interviewed by Cheryl Ware, New Zealand, 01.29.17-01.29.28.

<sup>74</sup> James Mauke, 01.29.38-01.29.53.

<sup>75</sup> Ministry of Māori Development, p. 18.

<sup>76</sup> Ministry of Māori Development, p. 19.

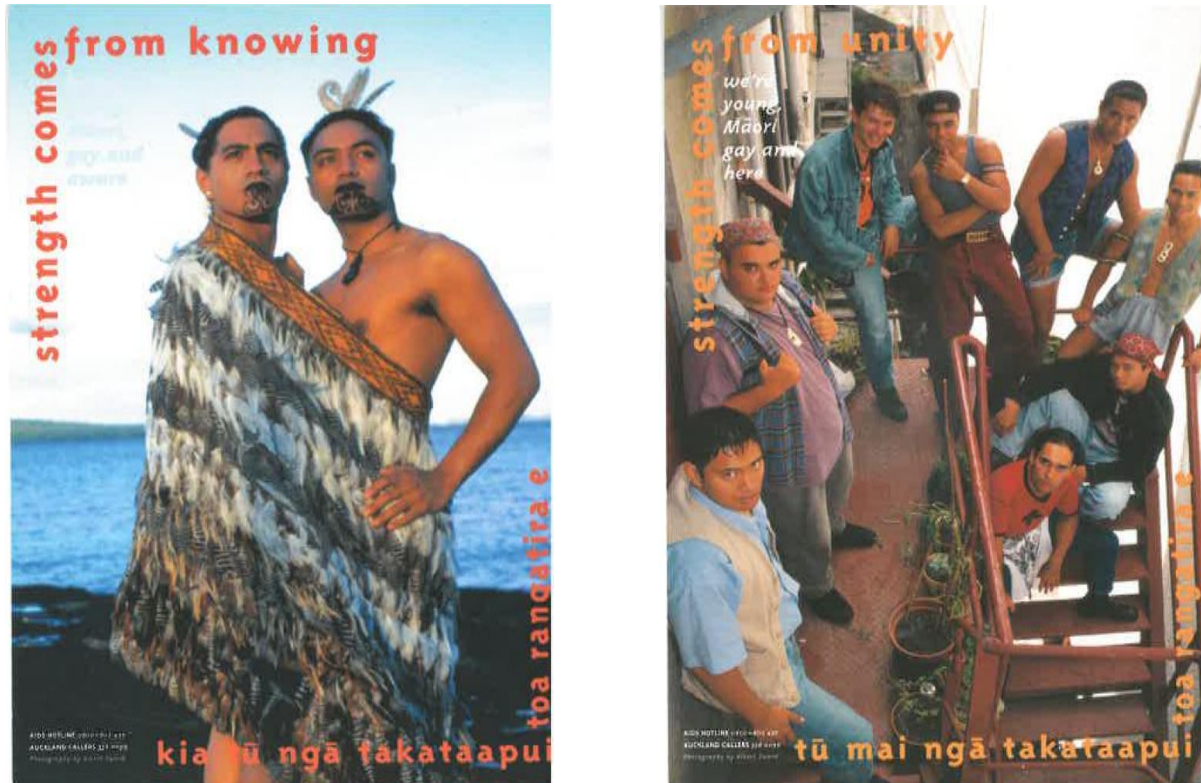
<sup>77</sup> Ministry of Māori Development, p. 22.

<sup>78</sup> Ministry of Māori Development, p. 22.

<sup>79</sup> Ministry of Māori Development, p. 23.



HIV/AIDS (Figures 1.4). These campaigns were specifically targeted at Māori who were initially overlooked as a risk group, and were not catered for in mainstream HIV/AIDS awareness campaigns.



**Figure 1. 4 Mate ‘Ketoketo/Arai Kore Project’**

Mate ‘Ketoketo/Arai Kore Project’, postcards, 1995. NZAF Library and Information Service.

Government-funded organisations and safe-sex campaigns initially only catered to the needs of ‘risk groups’, like gay men, drug users and youth. While these organisations initially overlooked Māori as at risk, more time and resources were allocated to making campaigns culturally appropriate for Māori from the mid-1990s onwards. Many New Zealanders’ hostility towards ‘risk groups’, and complacency amongst those who do not identify as ‘at risk’ represents the New Zealand responses to the HIV/AIDS crisis. Some peoples’ eagerness to separate themselves from those ‘at risk’, and thus to isolate people with HIV/AIDS, reflects the fear that the disease spread. As the following section explains, one of the most influential representations of HIV/AIDS was in the media, which both reflects and fuels public opinion.

## **Media representations of HIV/AIDS victims: The innocent and the guilty**

Public perceptions of people with HIV/AIDS were heavily influenced by the media. This section features a textual analysis of nine newspaper and magazine articles that were published during the AIDS epidemic in New Zealand and elsewhere, and includes references to other media materials. The newspaper and magazine articles discussed in this section reflect public attitudes towards people with HIV/AIDS in recent history. During the epidemic, the media helped to mould public perceptions of HIV/AIDS by publishing stories that aligned with pre-existing fears and assumptions. For example, the media emphasised ‘risk groups’, and at times helped spread fears of contagion. Writing about HIV/AIDS and the media, Deborah Lupton identifies that common media representations of HIV/AIDS include personalising experiences of people with the disease, dramatic news coverage producing panic amongst its viewers, and failing to acknowledge the epidemic when gay men were the only perceived victims.<sup>80</sup> Arguably, magazine and newspaper articles, such as those examined in this chapter, were particularly influential as many people who lacked any direct contact with the virus were exposed to it exclusively through press coverage.<sup>81</sup> Although some articles aimed to represent the perspectives of people with HIV/AIDS, the majority of media coverage created negative depictions of people with the virus.

Australian media were particularly notorious for evoking fear and anxiety among their audiences. Like other western countries, Australian news media drew distinctions between who they perceived as innocent and guilty people with HIV/AIDS, and spread fears of contagion amongst the wider community.<sup>82</sup> In Australia, one particularly infamous advertisement became known as the ‘Grim Reaper’ campaign. This advertisement appeared in both televised and print media (Figure 1.5), which portrayed the skeletal figure bowling in a bowling alley, yet instead of pins, the Grim Reaper was knocking down a diverse group of individuals that represented ‘ordinary’ Australians.<sup>83</sup> The victims in the advertisement included men, children, and a mother holding her infant. The Grim Reaper campaign aimed to produce panic in its viewers, and ‘the dominant metaphor in the campaign was attempting

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<sup>80</sup> Deborah Lupton, *Moral threats and dangerous desires, AIDS in the News Media* (London: Taylor & Francis Ltd, 1994), p. 21.

<sup>81</sup> Edward Albert, ‘Illness and Deviance: The Response of the Press to AIDS’, in *The Social Dimensions of AIDS: Method and Theory*, ed. by Douglas A. Feldman and Thomas M. Johnson (United States of America: Praeger Publishers, 1986), p. 163.

<sup>82</sup> Lupton, p. 40.

<sup>83</sup> Lupton, p. 52.

to convey by the use of the “Grim Reaper” icon was that “AIDS is death”.<sup>84</sup> Writing about responses to HIV/AIDS in Australia, Paul Sendziuk asserts that the imagery of the Grim Reaper advertisement remains present in the minds of many of its viewers.<sup>85</sup> Sendziuk identifies that the campaigns imagery was particularly powerful because it ‘portrayed the medieval icon of Death, the Grim Reaper: a macabre scythe-carrying, skull-headed creature swathed in a black hood, bowling in a fog-filled, graveyard-like bowling alley’.<sup>86</sup> The campaign also gained recognition outside of Australia. New Zealand resident Steve Williams, whose partner was diagnosed with AIDS in 1990, remembers the campaign when I interviewed him in 2010. Steve recalls ‘it was a pretty scary time, you know. And the, the ads – the AIDS awareness ads that were on television and so on were things like the “grim reaper”’.<sup>87</sup> The Grim Reaper campaign reflects the media’s tendency to evoke fear in their audience, which they also accomplished by using terms like ‘AIDS’ when referring to all levels of HIV/AIDS.



**Figure 1.5 Grim Reaper Campaign**

Avert, *History of AIDS 1987-1992*, n.d, <http://www.avert.org/aids-history87-92.htm>  
[accessed 5 December 2011]

<sup>84</sup> Lupton, p. 58.

<sup>85</sup> Paul Sendziuk, *Learning to trust, Australian Responses to AIDS* (Australia: University of New South Wales Press Ltd, 2003), p. 137.

<sup>86</sup> Sendziuk, p. 137.

<sup>87</sup> Steve Williams, 56.00-56.09.

During the AIDS epidemic, media articles over-used the term 'AIDS', which fuelled panic about the fatality of the virus. J.W. Jones identifies that journalists commonly referred to "Aids-sick, "Aids-infected," "Aids-diseased," and "Aids-positives"" when discussing both HIV and AIDS.<sup>88</sup> By assuming the two cases as one, the media categorises all individuals with some form of the virus as suffering from the most extreme case. In doing this, the media spread the idea that 'HIV infection leads inevitably to AIDS, which leads inevitably to death; thus, if one is HIV-positive, then one has AIDS and is consigned to the realm of the threatening and the dying.'<sup>89</sup> In New Zealand, the media also dramatised their stories by using the powerful phrase 'full-blown AIDS', when referring to highly developed AIDS cases. Such articles often feature predictions of future HIV/AIDS diagnoses, or numbers of reported infections.<sup>90</sup> The term AIDS is particularly powerful for individuals living with, or associated with people living with either HIV or AIDS. For example, Jonathan Smith was diagnosed with HIV in 1993. He notes, 'I think that's another major psychological effect for people, is when they're actually told "you've got AIDS". I think the connotations of that word is quite different to somebody saying "you're HIV-positive"'.<sup>91</sup> Therefore, because the term 'AIDS' is commonly linked to death, references to people as having 'AIDS', or 'full-blown AIDS' means the individuals with the virus are immediately portrayed as dying. The media used a range of strategies which dramatised their accounts of people with HIV/AIDS, and the spread of the virus. In the media, HIV/AIDS was often positioned as an enemy to society, and was embodied in the people who had the illness.

The media also personified HIV/AIDS, and 'the metaphor "AIDS is a vengeful killer" featured commonly in articles'.<sup>92</sup> In these campaigns, the media positioned HIV/AIDS as an enemy and used war metaphors to support these depictions of the virus. Lupton identifies war metaphors that Australian media used prior to 1988, which include 'that of "AIDS is an enemy": "we are all in a danger zone ... an AIDS crusade ... AIDS has the potential to kill more Australians than World War II"'.<sup>93</sup> Like the Grim Reaper campaign, the media's uses of

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<sup>88</sup> J. W. Jones, 'Discourses on and of AIDS in West Germany 1986-90', *Journal of the history of sexuality*, 2. 3. (1992), p. 442.

<sup>89</sup> Jones, p. 442.

<sup>90</sup> 'AIDS stigma keeps lid on figures', June 7, 1987, *Sunday Star*; 'Aids rise inevitable if education fails', May 30, 1987, *New Zealand Herald*; 'Aids finding should be notified', February 27, 1987, *Dominion*; 'Aids total up to 7500, August 3, 1988, *Herald*.

<sup>91</sup> Jonathan Smith, *Life Narrative*, 21 June 2011, interviewed by Cheryl Ware, Auckland, New Zealand, 19.07-19.19.

<sup>92</sup> Lupton, p. 59.

<sup>93</sup> Lupton, p. 59.

war metaphors sent powerful messages to its audience, and have lasting impacts. Shane Kelly was diagnosed with HIV in 1984, and participated in this study. Shane engaged with the war metaphor in his narrative, and recalls he educated himself about the virus because ‘I started to think you know I wanna get to know my enemy right from the bottom’.<sup>94</sup> In his narrative, Shane positions HIV/AIDS as his opponent. He also personifies the virus by stating that educating himself ‘gives me a bit of power over it I think, just to – to know what to do to annoy the little bastards’.<sup>95</sup> Shane’s interpretation of the media’s war metaphors positioned himself, and others with HIV/AIDS as a united body against the virus. However, Lupton argues that war metaphors of HIV/AIDS directly link the virus to homosexuality. Lupton maintains the battle metaphors ‘position the “ordinary heterosexual population” as fighting a war against the invasion of the deviant “other”’.<sup>96</sup> In this metaphor, homosexuals and intravenous drug users, like HIV/AIDS itself, spread disease into the heterosexual population through promiscuous sexuality.<sup>97</sup> In other words, Lupton argues, the war metaphor suggests society is fighting against invasion from the gay population. During the epidemic, the undesirability of homosexuality and more overt forms of homophobia were also presented in the media through the metaphor of the ‘Gay Plague’.<sup>98</sup>

Most western countries, including New Zealand, blamed homosexual men for the virus, and the media helped to spread this message. New Zealand society had already adopted ideas that HIV/AIDS was a punishment for social deviants, and that homosexual men were to blame for the virus. Dorothy Nelkin and Sander L. Gilman suggest that ‘the placing of blame has been a pervasive theme in the popular discourse on AIDS’.<sup>99</sup> For example, before the term Acquired Immune Deficiency Syndrome was established, medical experts and the media initially called the virus ‘Gay-Related Immune Disease’.<sup>100</sup> Other derogatory names that connected the virus exclusively to homosexual men, and stigmatised its victims include ‘Gay Plague’, and ‘sex killer bug’.<sup>101</sup> Using these terms inflicts blame onto people with HIV/AIDS. Therefore, distinguished identities of innocent and guilty were already being established when

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<sup>94</sup> Shane Kelly, *Life Narrative*, 12 September 2011, interviewed by Cheryl Ware, Wellington, New Zealand, 28.48-28.52.

<sup>95</sup> Shane Kelly, 29.03-29.10.

<sup>96</sup> Lupton, p. 133.

<sup>97</sup> Lupton, p. 133.

<sup>98</sup> Lupton, p. 123.

<sup>99</sup> Dorothy Nelkin and Sander L. Gilman, ‘Placing Blame for Devastating Disease’, in *In time of Plague: the History and Social Consequences of Lethal Epidemic Disease*, Arien Mack (ed.) (United States of America: New York University, 1991), p. 40.

<sup>100</sup> Porter, p. 594.

<sup>101</sup> James T. Patterson, ‘How do we write the History of Disease?’ *Health and History*, 1.1 (1988), p. 24.

heterosexual adults and children with HIV/AIDS began appearing in the media.<sup>102</sup> Media representations of people with HIV/AIDS often fell into three categories; innocent victims who are depicted through photographs of sick children and unlucky haemophiliacs, the suspect, and the guilty.<sup>103</sup> These categories helped society determine who are worthy of concern and sickness benefits, and those who are not.<sup>104</sup>

The media in New Zealand focused on homosexual men leading up to, and during the outbreak of the AIDS epidemic.<sup>105</sup> Some newspaper articles focused on specific individual's criminal behaviour, and create suspicion amidst its readers that these men are representative of the rest of the gay community. One of the most damaging international newspaper article topics featured a man identified as 'patient zero'. Stories of patient zero surfaced in 1987 and labelled the homosexual HIV-positive airline steward Gaetan Dugas as the first man to bring the virus to America, and articles claim he inflicted it onto his numerous sexual partners.<sup>106</sup> Dugas embodied the title of 'the "sexual polluter" in the traditional terms of the iconography allocating blame for sexual disease'.<sup>107</sup> The media constructed stories that emphasise Dugas's sexual promiscuity, and suggest that HIV/AIDS was his deserved punishment. During the late 1990s, New Zealand media also featured stories of men with HIV/AIDS who were accused of deliberately spreading the virus by having unprotected sex with people who did not know their status. Although unlike Dugas, these men's behaviour was intentional and therefore criminal, New Zealand representations of these men parallel the American articles that feature Dugas. For example, *The Press* portrayed Christopher Truscott as extremely sexually promiscuous, and as a man who dangerously and carelessly infected others with HIV/AIDS. The article claims that upon his release from a care facility, 'the world became his sexual oyster'.<sup>108</sup> The same article identifies other HIV-positive members of the gay community practicing similar behaviour, which Truscott was facing charges for. Although these men's criminal acts should not be denied, the articles suggest these men are representative of the majority of homosexual men, particularly in regard to sexual promiscuity.

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<sup>102</sup> Lupton, p. 125.

<sup>103</sup> Albert, p. 174.

<sup>104</sup> Albert, p. 174.

<sup>105</sup> 'Various Offences', *Evening Post (EP)*, 3 November 1944, p. 3., Terry Stewart, 'Time for parents of gays to "come out"', *The Evening Post (TEP)*, 10 July 1996, p. 23.

<sup>106</sup> Bronwen Lichtenstein, 'Creating icons of AIDS: the media and popular culture', in *Intimate details & vital statistics: AIDS, sexuality, and the social order in New Zealand*, ed. by Peter Davis (Auckland: Auckland University Press, 1996) p. 69.

<sup>107</sup> Lichtenstein, 1996, p. 69.

<sup>108</sup> Yvonne Martin, 'Men behaving BADLY', *The Press, (TP)*, 11 December 1999, p. 3.

International and national media contributed to the stigma attached to being HIV-positive and homosexual by focusing on the dangers of homosexual promiscuity. In doing so, the media inflicts blame on adult HIV/AIDS victims, who are seen as responsible for their sexual behaviour, and therefore responsible for the consequences. One particular article titled 'Being gay is a health hazard' explains 'the epidemic is primarily affecting homosexual men who are highly sexually active'.<sup>109</sup> This article also states homosexual men have a higher incidence of gonorrhoea and syphilis and other sexually transmitted diseases than the heterosexual community.<sup>110</sup> Such representations combine to portray homosexual men as promiscuous sexual deviants, and their diagnosis is a deserved consequence of carelessness. Bronwen Lichtenstein identifies the media's representation of homosexual promiscuity in James Allan's 1987 article in the New Zealand magazine *Metro*.<sup>111</sup> In his article, Allan expresses remorse for his sexual promiscuity and concludes that 'AIDS forced a lifestyle re-evaluation upon gay men, making them appreciate that there was more to being gay than simply having gay sex'.<sup>112</sup> Allan accepts dominant homosexual archetypes about promiscuity, and recalls that 'most of my close friends would carelessly sexually connect with four of five strangers a day. And I did nothing to dissuade them from this behaviour.'<sup>113</sup> Lichtenstein argues that in this article, Allan 'reaffirm[s] for the reader the popular perception of a link between promiscuity and disease'.<sup>114</sup> Like Allan, international media also inflicted blame upon HIV/AIDS victims. An article in *Ebony*, a magazine for the African American market, claims African Americans have higher rates of HIV/AIDS as they perceive it as a disease that 'afflicts only the gay white community'.<sup>115</sup> Dr Nigel Jackman was quoted in the article stating 'Blacks have heedlessly ignored the precautions that should have been taken, leaving themselves prey to the deadly virus'.<sup>116</sup> Although the two articles are aimed at different audiences, both inflict blame on adults who contract the virus through unprotected sex. Another similarity between the two, albeit different, articles is their focus on 'risk groups'. The African American community are identified as a 'risk group' in America, and the gay community are considered a 'risk group' in most western countries.

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<sup>109</sup> Barry Vinocur, 'Being gay is a health hazard', *Saturday evening post*, October 1, 1982, p. 73.

<sup>110</sup> Vinocur, p. 73.

<sup>111</sup> Lichtenstein, p. 70.

<sup>112</sup> James Allan, 'Vindi vici veni: The memoirs of a sex maniac', *Metro*, 70, (1987a), p. 86.

<sup>113</sup> Allan, 1987a, p. 80.

<sup>114</sup> Lichtenstein, 1996, p. 70.

<sup>115</sup> Thad Martin, 'AIDS: is it a major threat to Blacks?' *Ebony*, October 1 1985, p. 91.

<sup>116</sup> Martin, p. 91.



New Zealand and international media focused on target ‘groups’ like homosexual men and drug users, rather than risky behaviour like unprotected sex and sharing needles. Focusing on risk ‘groups’ helped develop HIV/AIDS iconography in New Zealand as the media contrasted negative portrayals of ‘effeminate’ gay men with a sympathetic portrayal of Eve van Grafhorst, the HIV-positive child in the 1980s.<sup>117</sup> Contrasting images of Eve and HIV-positive gay men supported pre-existing ideas of innocent and guilty patients. In the media, Eve epitomised innocence, and media articles portrayed Eve as an unlucky and undeserving victim of the virus.<sup>118</sup> Representations of Eve (Figure 1.6) significantly differ from images of adult homosexual men who are sometimes portrayed as deserving of their condition. Eve’s story generated sympathy from many New Zealanders, who followed events from her life through the media. Photographs of Eve’s physical decline were made public, and her image was framed around icons including the princess and the angel.<sup>119</sup>



**Figure 1. 6 Eve van Grafhorst**

*New Idea*, ‘Eve’s spirit will live on ... ’ December 01 1993, p.2.

<sup>117</sup> Lichtenstein, 1996, p. 66.

<sup>118</sup> For articles about Eve, see ‘New Zealand mourns Eve’, November 22, 1993. *Oamaru Mail*; ‘Gallant “Little Eve” laid to rest’, November 24, 1993, *Bay of Plenty Times*; Jason Barber, ‘Tolerance and love Eve’s legacy’, November 25, 1993, *New Zealand Herald*.

<sup>119</sup> Lichtenstein, p. 75.



The media represented Eve as pure innocence, and attempted to disconnect her from negative AIDS imagery of pollution that circulated the press.<sup>120</sup> Eve also came to represent the complete opposite of people previously identified with HIV/AIDS, and the media juxtaposed her clean image with the sinful ‘STD’ called AIDS.<sup>121</sup> Like Eve, the media also portrayed other groups as undeserving victims of the virus. Female partners of injecting drug users, recipients of infected blood other than haemophiliacs, and babies born with the virus from their mothers were portrayed as innocent victims of the virus.<sup>122</sup> These sympathetic portrayals in turn heightened the stigma attached to ‘guilty’ people with HIV/AIDS.

Although the media incriminated gay men with HIV/AIDS, and portrayed homosexual men as deserving victims, the media was also a useful tool for individuals to speak publicly about discrimination they felt the gay community suffered. After the initial reports of AIDS were released in 1981 that explain the seriousness of the disease and its potential fatality, AIDS remained almost absent from the press for the following two years.<sup>123</sup> In New Zealand, the media published few articles about HIV/AIDS during the early years of the epidemic. Media reporting and the wider public only began to focus frequently on AIDS when groups other than homosexual men and intravenous drug users were identified as susceptible to contracting the disease.<sup>124</sup> Some New Zealanders became frustrated with this silence that once again surrounded homosexuality, and voiced their concerns through the media. In *Metro*, James Allan asserts ‘this is what infuriates me about AIDS – like so much that is seen as being inherent in the gay lifestyle, it is unacceptable and unmentionable, irrelevant to polite society, and all so hidden’.<sup>125</sup> In another article, Allan illustrates medical professionals reluctance to acknowledge homosexual victims of the virus, who despite talking extensively about heterosexual transmission of the virus, ‘avoid mention of male/male, penis/anus. Why? It’s homophobia, stupid.’<sup>126</sup> Allan claims that the ‘media worldwide can’t and won’t deal with “guilty” gay man’, which implicates homosexual men who become complacent, believing

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<sup>120</sup> Lichtenstein, p. 75-6.

<sup>121</sup> Lichtenstein, p. 75-6.

<sup>122</sup> Andrea J. Baker, ‘The Portrayal of AIDS in the Media: An Analysis of Articles in the *New York Times*’, in *The Social Dimensions of AIDS: Method and Theory*, ed. by Douglas A. Feldman and Thomas M. Johnson (United States of America: Praeger Publishers, 1986), p. 184.

<sup>123</sup> Baker, p. 179.

<sup>124</sup> Baker, p. 183.

<sup>125</sup> Allan, 1987a, p. 88.

<sup>126</sup> James Allan, ‘Reclaiming AIDS’, *Metro*, 161, November 1994, p. 48.

they are no longer at such a high risk of contracting the virus.<sup>127</sup> Finally, media reports against homophobia are evident in the late nineties also. New Zealand writer Nigel Gearing shared his frustration about the lack of interest into gay and lesbian suicide rates in New Zealand. Gearing claims ‘no one wanted to know. Either they were being arrogant or were afraid to confront it. It’s a big issue’.<sup>128</sup> While the media incriminated homosexual men with HIV/AIDS, and other groups ‘at risk’, it was also an avenue for people to express their frustrations at homophobia in New Zealand.

This chapter has examined the recent social and political history of homosexuality, and HIV/AIDS in New Zealand. It has demonstrated that pre-established prejudice against homosexuality, the over-representation of homosexual men as HIV/AIDS victims, and the media contributed to homosexuality and HIV/AIDS being conflated in people’s minds. Although the New Zealand government was relatively late to respond to the outbreak of the virus, triggering frustration within the gay community, government-funded organisations were established during the mid-1980s onwards. Successful safe-sex promotion campaigns raised awareness of the virus, and attempted to show all sexually active individuals as potentially at risk of infection. However, early-twentieth century ideas that condemned homosexual sex, and stigmatised HIV/AIDS victims had a lasting impact on society. In the following chapter, the participant’s life narratives are carefully analysed to show that their personal experiences with homosexuality and HIV/AIDS in New Zealand society can be linked to these aspects of stigma that have emerged throughout New Zealand’s recent history. These powerful accounts of living with HIV/AIDS shed light on the histories discussed here.

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<sup>127</sup> Allan, 1994, p. 48.

<sup>128</sup> ‘Gay writer uncovers tales of stigma’, March 14, 1998, *The Daily News*, p. 2.

## Chapter Two

### **Illness narratives: key themes that emerged in the men's life narrative interviews**

While Chapter One set out the social and political context of homosexuality in New Zealand, and the many different responses to HIV/AIDS, this chapter focuses on the common themes that emerged in the men's life narratives. It examines the life narratives of six homosexual HIV-positive men in order to uncover their individual experiences living with HIV in New Zealand. This chapter focuses specifically on their experiences as gay men, and therefore also features the life narrative of one homosexual man who has worked with the New Zealand AIDS Foundation. It asserts that homosexual men's collective experiences differ from other groups affected by HIV/AIDS, because HIV and homosexuality were conflated in the public's minds long before any of the men in this study were diagnosed with the virus. Homosexual men therefore face the double stigma of being gay and living with a stigmatised disease.

Life narratives are particularly valuable because they allow the interviewee to share experiences that are important to themselves that the researcher may otherwise overlook. Yet oral history also places significant focus on diverse ways individuals construct their life narratives. Therefore, while this chapter examines the content of the men's illness narratives, Chapter Three focuses on oral history theory to present a thorough portrayal of the life experiences of HIV-positive homosexual men. Arthur Frank argues that the content of illness narratives is valuable as the narrator reorders their life stories, provides guidance for those who will follow, and gives medical professionals and other caregivers an understanding of their experiences as patients.<sup>1</sup> Frank also argues that bodies are living testimony of illness stories, and 'only the ill person herself can *be* the story, and that being – the excess of any content – is the plenitude of testimony and its demand.'<sup>2</sup> Frank claims these illness stories expose the moral dimensions of ill people's everyday lives even when they are not considered 'patients'.<sup>3</sup> People with chronic illnesses spend more time not being patients, in what Frank

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<sup>1</sup> Frank, Arthur W., *The Wounded Storyteller* (USA: The University of Chicago Press, 1995), p. 140.

<sup>2</sup> Frank, p. 141.

<sup>3</sup> Frank, p. 156.

calls a ‘remission society’, and the ethical questions they face are not necessarily about health but more about how one can live a ‘good life’ while having an illness.<sup>4</sup> The majority of the men that participated in this study are living with a chronic illness, and arguably are therefore part of a ‘remission society’. Their narratives therefore reveal their experiences of *living* with a chronic illness.

While each individual’s experience is personal, common themes emerged in the life narratives of the men that participated in this study. Many participants engaged with the theme of suppressing homosexuality because it conflicted with their social expectations to comply with the predetermined ideas of masculinity that existed in mid-twentieth century New Zealand society. The men in this study all grew up in environments where being gay was believed to deviate from the masculine ideal. Public hostility towards homosexuality also influenced the men’s experiences throughout their lives, and continues to have an impact on their adulthood. In this chapter, I also discuss the men’s naïveté about safe sex, and their direct experiences with HIV/AIDS as told in their narratives. Many of the participants were unaware of any safe sex campaigns, and credit this to New Zealand’s conservative culture, which silenced discourses about homosexual sex. Despite a lack of awareness about safe sex campaigns, some participants recall seeing people with HIV/AIDS in public, and witnessing their physical deterioration.

In this thesis, using an oral history approach enabled me to gather a thorough insight into the narrators’ experiences as homosexual men living with HIV in New Zealand. Writing about oral history, Alessandro Portelli argues that oral narratives inform the listener about what people wanted to do, what they believed they were doing, and their present understandings of past actions.<sup>5</sup> While oral narratives may not add to a researcher’s so-called factual knowledge, they reveal the psychological costs of events.<sup>6</sup> In other words, oral history enables people to share their personal perspectives of historical events. Oral history differs from other sources because the oral source gives the researcher the freedom to challenge subjectivity, and to, in Paul Thompson’s words, ‘unpick the layers of memory dig back into its darkneses, hoping to reach the hidden truth.’<sup>7</sup>

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<sup>4</sup> Frank, p. 156.

<sup>5</sup> Alessandro Portelli, ‘The Peculiarities of Oral History’, *History Workshop*, 12 (1981), p. 100.

<sup>6</sup> Portelli, 1981, p. 100.

<sup>7</sup> Paul Thompson, *The voice of the past, Oral History* (2<sup>nd</sup> edition), (Oxford: Oxford University Press, 1988), p. 150.

The subjects of this chapter, James Mauke, Craig Robertson, Michael Stevens, Jonathan Smith, Carl Greenwood, and Shane Kelly were diagnosed with HIV between 1983 and 1997, and each shared their experiences through audio recorded life narrative interviews.<sup>8</sup> As a counterpoint to these narratives, this chapter also features the life narrative of Dan Coomby, who is HIV-negative and has worked extensively with the New Zealand AIDS Foundation. Dan's narrative also enriches this study as he provides further insight into growing up homosexual in New Zealand, as well as into working with HIV-positive individuals during the early years of the epidemic. Louise Douglas, Alan Roberts and Ruth Thompson identify general principles that one may follow to produce successful interviews, which include general social skills of friendliness, discretion and sensitivity.<sup>9</sup> I followed these principles closely when communicating with the men that participated in this study, as their comfort was a high priority. I am also aware that I am an outsider to both the homosexual and HIV-positive community, and my sole insight into the men's experiences was through written documents and their spoken word. While I approached each man because they are homosexual, and most were diagnosed with HIV between 1983 and 1997, they were not limited to only discussing their experiences with HIV. I was eager for the men to discuss any life experiences they wished to, and this flexibility enabled me to gather a more thorough understanding of their lives, and the messages that were emerging in their life narratives.

Overall, as explained above, this chapter focuses specifically on the content of the men's illness narratives. It examines the themes that emerge as they recount their experiences growing up, and living as homosexual men in New Zealand, and the impact that having HIV has on their lives. This chapter is organised thematically, and I focus on the six main themes that emerged in the men's life narratives: suppressing homosexuality and individual conflict; gender categories and gay men's experiences; brotherhood and social hostility within the New Zealand gay community, sex culture and gay men's naïveté about HIV/AIDS, seeing AIDS in public, and the physical and social implications of living with HIV.

Each man's story is individually subjective, and does not necessarily represent all other New Zealand HIV-positive homosexual men. However, the men's narratives are valuable because they are a diverse cohort, and their illness narratives reflect some patients' experiences with

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<sup>8</sup> Some of the names listed are pseudonyms, as offered to the men at the time of the interview.

<sup>9</sup> Louise Douglas, Alan Roberts and Ruth Thompson, *Oral History: a Handbook*, (Australia: Allen & Unwin Australia Pty Ltd, 1988), p. 63.

the virus. These illness narratives have not been recorded, nor written before, despite the valuable insight they shed into New Zealand's medical and cultural history. By documenting the men's individual experiences, this thesis fills a gap in New Zealand health historiography.

### **Suppressing homosexuality and individual conflict**

The government and the majority of the New Zealand public preferred to ignore the fact that homosexual behaviour existed in society, yet they were forced to address these 'issues' after the onset of HIV/AIDS in America in 1981. The media portrayed homosexual men as deviant, and on many instances blamed gay men for the disease. Chapter One set out the social and political context of HIV/AIDS in New Zealand, in which the narratives that I analyse in this chapter are set. A key part of the men's narratives focuses on their lives growing up in New Zealand. All participants were born between 1941 and 1968, and therefore grew up in a society where homosexual sex was illegal. Laurie Guy explains that while homosexuality was not entirely invisible, New Zealand society, particularly during the 1950s, avoided any discussion of same-sex activity.<sup>10</sup> In other words, homosexuality was suppressed by both legal and social pressure.<sup>11</sup> In his account of gay people and spirituality, B. R. Simon Rosser identifies social hostility towards homosexuality, and argues that some people believe homosexuality should not be part of sex education, and that a lack of sex education maintains 'innocence'.<sup>12</sup> However, Rosser also undermines this idea, and claims the 'taboos associated with sex education and homosexuality appear to combine together to maintain a silence, which in turn leaves the developing gay child or adolescent vulnerable to exploitation and abuse'.<sup>13</sup>

Growing up, Jonathan understood little about homosexuality, yet he was aware of the hostility that surrounded it. Jonathan was raised in a small rural town in the Waikato, New Zealand, which for him meant that 'I wasn't privy to anything except for what you see on the television or what you hear people say in the community, so there was just – there was no understanding for me'.<sup>14</sup> Although Jonathan had speculated he was homosexual growing up,

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<sup>10</sup> Laurie Guy, *Worlds in Collision: The Gay Debate in New Zealand, 1960-1986* (Victoria University Press, 2002), p. 25.

<sup>11</sup> Guy, 2002, p. 25.

<sup>12</sup> B. R. Simon Rosser, *Gay Catholics Down Under: The Journeys in Sexuality and Spirituality of Gay Men in Australia and New Zealand* (United States of America: Praeger Publishers, 1992), p. 208.

<sup>13</sup> Rosser, p. 210.

<sup>14</sup> Jonathan Smith, *Life Narrative*, 21 June 2011, interviewed by Cheryl Ware, Auckland, New Zealand, 47.54-48.04.

he did not openly identify as gay until he was living in London in his early twenties. The change of environment allowed Jonathan to disclose his sexuality, and he claims ‘I could never have done it in Te Aroha because of that small town mentality – back then it was very much frowned upon’.<sup>15</sup> Jonathan’s ability to disclose his sexuality in London parallels Carl’s experience of ‘coming out’. Carl also moved to New Zealand from England as a young child, and returned to England in his early twenties. Carl’s main motivation to return to England was based on his strained relationship with his parents, and he recalls, ‘I think I knew that the answers lay in England’.<sup>16</sup> Living in England allowed Carl to disclose his sexuality to his extended family, and he recalls ‘within weeks of being there I pretty much was “out”’.<sup>17</sup> Jonathan’s and Carl’s narratives suggest that returning to places they perceived as ‘home’ enabled them to confront their sexualities, neither of whom felt they could do so in New Zealand. Their narratives also suggest that New Zealand was delayed in accepting same-sex activity, in comparison to England where they both recall that being gay was more acceptable.

Like Jonathan and Carl, James also grew up in an environment where homosexual discourse was suppressed. As a teenager, James saw homosexual men protesting for Law Reform on the news, and recalls his family’s hostility towards the broadcasts, ‘just saying “oh those stupid poofters, they should go get a real life”, you know, just things like that’.<sup>18</sup> Partly due to his family’s overt intolerance of homosexuality, James felt he was unable to discuss his sexuality, and recalls ‘um, it didn’t feel like a safe place for me to go and talk to anyone in my family about it. Um, so I had no one there that I could talk to about possibly having, you know, these feelings of same-sex attraction’.<sup>19</sup> Feeling like he didn’t have anyone to confide in meant James began to resent being gay, and ‘by fifteen I certainly felt that I was gay and um, it’s just how it was. I didn’t understand it, and I – I didn’t want to – want to be gay’.<sup>20</sup> James was aware of public hostility towards homosexuality, and felt compelled to suppress his homosexual feelings. During his youth, James was also influenced by the public

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<sup>15</sup> Jonathan Smith 03.12-03.18.

<sup>16</sup> Carl Greenwood, *Life Narrative*, 12 September 2011, interviewed by Cheryl Ware, Wellington, New Zealand, 13.17-13.20.

<sup>17</sup> Carl Greenwood, 13.45-23.50.

<sup>18</sup> James Mauke, *Life Narrative*, 20 May 2011, interviewed by Cheryl Ware, New Zealand, 11.03-11.10.

<sup>19</sup> James Mauke, 11.16-11.26. For this thesis, I have transcribed the extracts directly as they were spoken. For discussions about transcribing interviews, see Megan Hutching, ‘The Distance Between Voice and Transcript’, in *Remembering Writing Oral History*, ed. by Anna Green and Megan Hutching (Auckland: Auckland University Press, 2004), pp.168-177; Cynthia Stokes Brown, *Like It Was: A Complete Guide to Writing Oral History* (New York, Teachers and Writers Collaborative, 1988); Catherine Kohler Reissman, *Narrative Analysis* (United States of America: Sage Publications, Inc., 1993).

<sup>20</sup> James Mauke, 11.29-11.40.

conflating gay men and HIV/AIDS. At fifteen, James knew he was gay, and ‘to me I just thought, well when you’re gay you, especially at that time you, it’s more than likely you’re gonna get AIDS’.<sup>21</sup> This misconception was particularly problematic when he donated blood at school. James had sexual encounters with other gay men, and ‘not really understanding how it was transmitted, terrified that they were going to find AIDS in my blood that I was donating at school, which meant that they were going to find out I was gay’.<sup>22</sup> During his adolescence, being gay conflicted with James’ family’s expectations, as well as with wider public attitudes.

In their narratives, the interviewees also engaged with the idea that homosexuality conflicted with their social roles and expectations. All participants grew up in the highly conformist post-war New Zealand society, and ‘despite private deviation there remained *public* adherence to the mainstream Christian position on sexuality—that sexual expression was valid only within marriage’.<sup>23</sup> This conformist culture meant all groups that did not align with the Pakeha male heterosexual ideal were suppressed, including homosexuals.<sup>24</sup> Dominant public hostility towards homosexuality influenced the men’s views of themselves. For Michael, ‘being gay was a majorly disruptive event, um in terms of my social history and my personal history’.<sup>25</sup> Michael was raised in Parnell, Auckland and attended a private secondary school before disclosing his sexuality to his family at age sixteen. Michael feels that being homosexual disrupted his life because ‘it took me outside the, paradigm for um familial and social expectations that I’ve grown up with’.<sup>26</sup> Such expectations included marrying a woman from an equally prosperous background and starting a family.

Religious teaching also influenced the men’s understanding of their sexualities. According to Catholic instruction, all people are ‘inherently heterosexual, [therefore] traditional Catholic teaching maintains that while orientation is morally neutral, homosexual behaviour is always wrong.’<sup>27</sup> Rosser identifies the stereotype that the Catholic Church’s intolerance of homosexuality meant gay religious men ‘suffered great guilt because they thought themselves

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<sup>21</sup> James Mauke, 11.49-11.52.

<sup>22</sup> James Mauke, 15.57-16.07.

<sup>23</sup> Guy, 2002, p. 28.

<sup>24</sup> Guy, 2002, p. 25

<sup>25</sup> Michael Stevens, *Life Narrative*, 21 June 2011, interviewed by Cheryl Ware, Auckland, New Zealand, 0.54-1.00.

<sup>26</sup> Michael Stevens, 1.01-1.10.

<sup>27</sup> Rosser, p. 217.



to be sinful and who spends their life on the fringes of Church life being rebutted by the Church'.<sup>28</sup> However, Rosser asserts that 'most homosexually active men cease any form of religious practice,' and that guilt is rarely the cause of their departure from the Church.<sup>29</sup> Some of the men that participated in this study are from religious backgrounds, and grew up understanding their sexuality was sinful. When individuals 'come to terms with their homosexual identity, they must also explore how this identity connects or does not connect to who they are as racial, ethnic, and religious individuals.'<sup>30</sup> Andrew K. T. Yip states that many consider being homosexual and Christian incompatible due to the Bible's condemnation of homosexuality.<sup>31</sup> Some of the men in this study felt homosexuality and religion cannot co-exist in their lives, and they in turn ceased religious practice. Religion played a minor role in Michael's family, yet clearly had a powerful impact as he mentions his moderately religious upbringing during his life narrative interview. Michael recalls '[my parents were] not fanatically religious but my parents were quietly religious. And so, I had this whole idea that it was sinful and it was evil, um, and I just didn't know what to do or where to turn'.<sup>32</sup> In this instance, religion was not only a source of guilt in the Michael's narrative, but also meant he felt isolated from the rest of his family.

Carl also discusses suppressing his homosexuality because of his religious background. During Carl's childhood, his parents became 'born-again Christians', which proved to be emotionally damaging for him. Carl recalls the impact his parents Christianity had on his youth, stating;

As someone who really should be, should've been coming out then, um, it was a real "you're a sinner". And it was actually very, it was bad, it was bad, it was bad for my self-esteem, it was bad for my morale, it was bad on every human level that you could imagine actually.<sup>33</sup>

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<sup>28</sup> Peter Sweasy, *From Queer to Eternity: spirituality in the lives of lesbian, gay, and bisexual people* (London: Cassell, 1997), p. 9.

<sup>29</sup> Rosser, p. 3.

<sup>30</sup> Richard Allen Stevens, 'Understanding Gay Identity Development within the College Environment', *Journal of College Student Development*, 45, 2 (2004), p. 187.

<sup>31</sup> Andrew K. T. Yip, 'Attaching the Attacker: Gay Christians Talk Back', *The British Journal of Sociology*, 48.1 (1997), p.13.

<sup>32</sup> Michael Stevens, 45.24-45.35.

<sup>33</sup> Carl Greenwood, 01.15.10-01.15.31.

Writing about homosexuality and religion, Yip argues that ‘having internalized the conventional Christian sexual ethics that do not affirm homosexuality, gay Christians often experience a substantial amount of guilt and shame when they first became aware of their sexuality’.<sup>34</sup> Carl experienced the guilt and shame that Yip alludes to, however his experience is different from many gay Christian men because Carl identified as homosexual before his parents turned to Christianity. Therefore, Carl faced the dilemma of working Christianity around his homosexuality, not vice versa as is often the case.

Dan also recalls homosexuality conflicted with his former role as a married man who was heavily involved in the Catholic Church. This identity conflict is particularly apparent in Dan’s life during the debate for Law Reform in the mid-1980s, when anti-Law Reform activists created a petition against decriminalization.<sup>35</sup> The petition was presented to parliament in September, as part of a highly publicized protest that attracted 800,000 signatures.<sup>36</sup> Dan recalls ‘when uh the [anti-Law Reform] petition came around for everybody to sign outside Church one day – they were going around with this and I was ducking and diving ’cause I didn’t wanna sign the damn thing’.<sup>37</sup> Dan’s blatant refusal to sign the petition may have affected his role in the Church and his relationships with other members of the congregation, and therefore Dan resorted to ‘ducking and diving’. Dan’s reference to himself ‘ducking and diving’ reflects the conflict between religion and homosexuality he experienced, and in this instance Dan felt they could not co-exist.

These thematic threads all show that public hostility towards homosexuality impacted the men’s experiences growing up in New Zealand. The threads reveal the men felt compelled to suppress their homosexuality because of family values, religious teaching, and social expectations. The narratives underscore the discussion in Chapter One that reveals the stigma attached to HIV-positive homosexual men is heightened because of their sexualities. While homosexuality was suppressed, the onset of HIV/AIDS, and debates for Law Reform were well publicised events, and for many people were an opportunity to voice their anti-homosexual feelings. As well as debates about the legal status of homosexual sex, the men

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<sup>34</sup> Yip, p.13

<sup>35</sup> Michael Stevens King, *After the War: New Zealand since 1945* (Auckland: Hodder & Stroughton Ltd., 1988), p. 196.

<sup>36</sup> King, 1988, p. 196.

<sup>37</sup> Dan Coomby, *Life Narrative*, 11 May 2011, interviewed by Cheryl Ware, Hamilton, New Zealand, 38.41-38.56.

faced conflict with New Zealand's rigid gender categories. In the following section I explore gender categories, and the static definition of masculinity that most New Zealanders accepted.

### **Gender categories and gay men's experiences**

During the men's narratives, they express their experiences growing up amid predetermined notions of masculinity in post-war New Zealand. Michael King asserts that, for Pakeha in the 1940s and 1950s, "Girls were girls and men were men", in the words of the popular song, and each sex was allocated a set of pre-determined roles'.<sup>38</sup> In this section, I focus specifically on male identity, discourses about masculinity, and the impact a static definition of 'masculinity' had on the men in this study. Many of the men I interviewed resented New Zealand's ideal of the rugby-loving heterosexual man who embodied masculinity, as this archetype feminized anyone who did not comply with it.

Writing about New Zealand culture, King asserts that post-war New Zealand was uniform, and families comprised of married opposite-sex parents, and three or four children.<sup>39</sup> Writing about masculinity in New Zealand, Jock Phillips argues that rugby formed a major part of New Zealand male identity which revived traditional virtues of the pioneers, and maintained expressions of masculinity within controlled boundaries.<sup>40</sup> Rugby was therefore perceived as an essential part of New Zealand culture. Rugby, as an organized sport, enabled men to exercise their physical strength and maintain traditional virtues, whilst sustaining civility.<sup>41</sup> Phillips identifies that the national rugby team reinforced New Zealand men's values throughout the twentieth century.<sup>42</sup> New Zealanders identified with the All Blacks, who became role models, and for many men and women epitomized what a New Zealand man was.<sup>43</sup> Rugby became a key part of New Zealand culture, and was instilled in people since childhood.<sup>44</sup> This notion of masculinity featured in some men's narratives, who felt isolated because they did not fit with the traditional New Zealand male stereotype. For example, Michael recalls resenting school because,

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<sup>38</sup> Michael Stevens King, *Being Pakeha* (Auckland: Hodder & Stroughton Ltd., 1990), p.11.

<sup>39</sup> King, 1990, p.11.

<sup>40</sup> Jock Phillips, *A Man's Country? The Image of the Pakeha Male-A History* (Auckland: Penguin Books (NZ) Ltd, 1996), p. 86.

<sup>41</sup> Phillips, p. 87.

<sup>42</sup> Phillips, p. 108.

<sup>43</sup> Phillips, p. 109.

<sup>44</sup> Kai Jensen, *Whole Men, The masculine tradition in New Zealand literature* (Auckland: Auckland University Press, 1996).

I was a young gay man in – in Kings College and, just didn't feel like it was a very good fit. It was much more traditional then than it is now, it's very um, you know, rugby, cricket, all of that sort of thing. I just didn't like it, I didn't want to be there, I just didn't feel like I fitted in.<sup>45</sup>

Michael experienced loneliness growing up because he did not fit with his school's traditional values, which indirectly prohibited homosexuality. However, in the latter half of the twentieth century, the traditional male archetype was widely questioned and New Zealanders began to realize the social impact that such an exclusive definition of masculinity had.<sup>46</sup> While women were the most obvious victims of the stereotype, men were also victims, particularly those who society deemed in some way effeminate, such as homosexuals.<sup>47</sup> Ideas that conflate sport and masculinity were instilled in New Zealand schools throughout the country. Like Michael, Jonathan was also frustrated by his school's dominant focus on sport. Jonathan recalls his schools culture diverted from his interest in drama, and notes 'my college days were terrible because I went to a college that was very, very sports orientated, it wasn't Arts orientated, so that was quite a challenge for me'.<sup>48</sup> Michael and Jonathan's narratives reveal that these strict gender categories were instilled in New Zealanders throughout their youths, and did not leave room for other forms of masculinity.

Like Michael and Jonathan, James also felt his own masculinity was challenged because he did not fit with elements of the traditional male stereotype. James recalls,

Of course there was the rugby, I hated – absolutely hated playing rugby, and, you know, it was a natural progression. We were all expected to know how to play rugby. But I – I didn't know how to play it, didn't have a clue. No one taught me so it made it even worse.<sup>49</sup>

In James' narrative, it is clear that he harbors resentment towards the social pressure to conform to traditional masculine frameworks. James was not guided, but rather expected to automatically adopt the traditionally male persona. In James' narrative, it is clear that

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<sup>45</sup> Michael Stevens, 43.09-43.31.

<sup>46</sup> Phillips, p. 279.

<sup>47</sup> Phillips, p. 280.

<sup>48</sup> Jonathan Smith, 01.46-01.57.

<sup>49</sup> James Mauke, 04.07-04.22.

masculinity also signifies heterosexuality. While James openly identified as homosexual amongst close friends, he undertook a major behaviour change when he moved back to his home town. James went from identifying with, and living with Fa'afafines in a populous New Zealand city, to living in a strictly traditional masculine environment. Eve Kosofsky Sedgwick notes that 'the gay closet is not a feature only of the lives of gay people. But for many gay people it is still the fundamental feature of social life'.<sup>50</sup> Sedgwick asserts that although some homosexual men and women receive support within their communities, there are few for whom the 'closet' is not a major presence.<sup>51</sup> This was the case for James, who after moving home 'got a job in the timber mill – and [laughs] totally changed the way I behaved, and looked, walked and talked. And suddenly I um – I became conscious of sounding effeminate and gay and, because I was surrounded by all these masculine men'.<sup>52</sup> James' narrative parallels notions of the conventional 'macho' man, which conflates heterosexuality and masculinity.<sup>53</sup> Appearing heterosexual was important at this stage in James' life as he claims 'I didn't want to be hassled by them so I pretended to be straight'.<sup>54</sup>

In his life narrative, Carl also identifies with strict gender categories and assumptions that homosexuality and masculinity cannot co-exist. Carl recalls 'I left school and went dairy farming at seventeen, went – moved to Taranaki and went dairy farming which was, you know, a mad thing to do as a gay boy'.<sup>55</sup> The farming environment Carl immersed himself in conflicted with his homosexual identity. Carl's experiences working in a strict masculine environment parallels James', and Carl acknowledges that 'when I went farming I just, went straight back, you know, really into the closet and actually had a girlfriend and tried to be quite heteronormal'.<sup>56</sup> Both Carl's and James' experiences as homosexual men in strictly masculine environments reveal their isolation, and they in turn suppressed their homosexuality and conformed to heterosexual behaviour. In Carl's narrative, he emphasises the incompatibility of his homosexual and heterosexual identities. For example, at one point in his life, Carl had both a boyfriend and a girlfriend, and notes at that point 'there really

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<sup>50</sup> Eve Kosofsky Sedgwick, 'Epistemology of the Closet', in *The Lesbian and Gay Studies Reader*, ed. by Henry Abelove, Michele Aina Barale & David M. Halperin (Great Britain: Routledge, 1993), p.45.

<sup>51</sup> Kosofsky Sedgwick, p. 45.

<sup>52</sup> James Mauke, 30.47-31.07.

<sup>53</sup> Andrea Cornwall and Nancy Lindisfarne, 'Dislocating masculinity: gender, power and anthropology', in *Dislocating Masculinity, comparative ethnographies*, ed. by Andrea Cornwall and Nancy Lindisfarne (London: Routledge, 1994), p. 13.

<sup>54</sup> James Mauke, 31.10-31.13.

<sup>55</sup> Carl Greenwood, 04.54-05.04.

<sup>56</sup> Carl Greenwood, 07.30-07.41.

[were] two quite separate circles in my life. There's a circle of gay men or people, you know, on that fringe, and then there's the rest of my life and there's – they don't meet at all'.<sup>57</sup> These two opposing identities reflect Carl's determination to suppress his homosexuality in what he deems a masculine environment.

Masculinity features in the men's narratives, and aligns with their understanding of heterosexuality. Yet in regard to gender categories, the men also engaged with effeminacy and the common stereotype that 'all homosexuals are effeminate and ineffectual'.<sup>58</sup> Despite some public acknowledgement that 'not all "effeminate" men are homosexuals and that by no means homosexuals are "effeminate" in appearance and manner',<sup>59</sup> gay men are often stereotyped as more effeminate than heterosexual men. David M. Halperin argues that traditionally, effeminacy 'functioned as a marker of so-called sexual inversion in men, of transgenderism or sexual role reversal, and thus of homosexual desire'.<sup>60</sup> James engages with effeminacy and recalls that he saw few homosexual public figures during his youth. One of these few figures was Mr Humphreys from the British sitcom 'Are you being served?' Mr Humphreys was overtly effeminate, and a source of both humour, and sometimes detestation. James found humour in the sitcom, and particularly in the protagonist's overt effeminacy. James recalls, 'he was a very camp effeminate gay character. Um, all the characters on TV were very camp and effeminate and made fun of, and people laughed at them, and they made others laugh as well.'<sup>61</sup> However, while James found enjoyment in the show, the same show fuelled hostility in Jonathan's immediate surroundings, and added to his isolation because of his sexuality. Jonathan recalls watching the show as a teenager, and 'my parents saying "oh God look at that he's camp as ace-queer old thing"'. Queer old thing – but again I didn't understand that, I didn't understand what that meant'.<sup>62</sup> Although Jonathan did not entirely understand what his parents meant by their comments, he understood the hostility that they, and others felt towards gay men.

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<sup>57</sup> Carl Greenwood, 12.07-12.21.

<sup>58</sup> Rosser, p. 208.

<sup>59</sup> Church of the province of New Zealand, 'Diocesan Committee on Homosexuality', Report and recommendations of the Christchurch Diocesan Committee on Homosexuality, New Zealand, 1979, p. 48.

<sup>60</sup> David M. Halperin, 'How to do the History of Homosexuality', *GLQ: a journal of Lesbian and Gay Studies*, 6, 1 (2001), pp. 87-123.

<sup>61</sup> James Mauke, 08.15-08.26.

<sup>62</sup> Jonathan Smith, 48.16-48.23.

In their narratives, Dan and Craig also engage with the stereotype that homosexual men are effeminate. Particularly prior to 1986 Law Reform, many homosexually active men in New Zealand were forced to deal with anti-gay jokes, and work, live, and socialise with homophobic individuals.<sup>63</sup> While Dan acknowledges homosexual men were targets of public abuse, he refuses to portray them as victims. Dan recalls walking with his male partner and being verbally abused by a group of three men, and ‘you know we sort of, uh, gave them some abuse back cause there were two of us’.<sup>64</sup> Craig also describes homosexual men fighting back against abuse in his narrative. Craig has remained silent about his sexuality and more recently his HIV-positive status, with the exception of a small group of family and friends. Craig felt that disclosing his sexuality during his school years was impossible because of the harassment he witnessed his fellow students receiving. Craig attended school with two other boys who he describes as effeminate and overtly homosexual. Craig recalls the boys were treated with ‘gross contempt, you know, they were bullied, and nobody had a nice word to say to any of them, yeah their lives were a misery at high school’.<sup>65</sup> However, like Dan, Craig acknowledged the boys strength and ability to defend themselves, thus opposing the stereotype that effeminate gay men are helpless victims of social harassment. Craig recalls, ‘the bullies tried to beat them up at one stage, but both of them were so effeminate they just went in, and both of them deliberately grew their fingernails long – and a couple of the bullies had some real ... [Motions fingers down his face in the form of scratches].’<sup>66</sup> Andrea Cornwall and Nancy Lindisfarne argue that physical assault is sometimes interpreted as an indication of a man’s masculinity, for both the perpetrator and victim.<sup>67</sup> The victim’s response to physical assault, which can range from running away, refusing to fight or retaliating ‘may be interpreted as enhancing or diminishing the masculinity of either or both parties.’<sup>68</sup> In these anecdotes, Dan and Craig interpret the victim’s ability to fight back against their bullies as an indication of gay men’s masculinity.

The narratives therefore also show that loneliness was a feature of the male gay experience. The men in this study felt isolated from their families and peers because they were aware of

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<sup>63</sup> B. R. Simon Rosser, *Male Homosexual Behaviour and the Effects of AIDS Education: A Study of Behaviour and Safer Sex in New Zealand and South Australia* (United States of America: Praeger Publishers, 1991), p. 61.

<sup>64</sup> Dan Coomby, 47.28-47.35.

<sup>65</sup> Craig Robertson, *Life Narrative*, 17 May 2011, interviewed by Cheryl Ware, New Zealand, 57.41-57.53.

<sup>66</sup> Craig Robertson, 58.02-58.16.

<sup>67</sup> Andrea Cornwall and Nancy Lindisfarne, ‘Dislocating masculinity: gender, power and anthropology’, in *Dislocating Masculinity, comparative ethnographies*, ed. by Andrea Cornwall and Nancy Lindisfarne (London: Routledge, 1994), p. 14.

<sup>68</sup> Cornwall and Lindisfarne, p. 14.

the social and religious hostility towards homosexuality. The men also felt isolated because homosexuality did not align with the traditional New Zealand perception of masculinity, from which they felt excluded. To combat this loneliness, the men had to create their own ideals of masculinity, and fight dominant ideas that gay men are effeminate. Dan and Craig fought suggestions that gay men are effeminate by recalling instances when they, or other gay men used verbal or physical strength to overpower oppressors. These anecdotes oppose constructions of gay men as effeminate and victims of abuse. Homosexual men also formed their own bonds through the gay community, many of whom mobilised around HIV/AIDS. Although the men in this study received familial support, they also discuss their isolation from the heterosexual, and at times, the gay community, after disclosing their status.

### **New Zealand gay community: Brotherhood versus social hostility**

Another thematic thread that emerged in the men's narratives is their social relationships within the gay community. Simon Watney explains that members of the gay community share a common sense of safety and security in each other's company. Watney claims 'few heterosexuals can imagine the sense of relief and safety which a gay man or lesbian finds in a gay bar or dyke bar in a strange city in a foreign country. Even if one cannot speak the local language, we feel a sense of identification'.<sup>69</sup> In other words, Watney argues that gay men and women feel a sense of belonging in the gay community which heterosexuals cannot relate to because they do not have the same history of oppression that the gay community shares. In this section, I examine the men's relationships within the gay community. HIV/AIDS primarily affected homosexual men, and the gay community initially provided emotional support for many of its positive members. However, some of the participants in this study also experienced hostility from members of the gay community, particularly in recent years.

The men's narratives discuss the different levels of support they received from different communities. Craig explains he received support from his family after being diagnosed with HIV, and states 'the whole family have rallied behind I've had no problem with family, all support right down the line, and with close friends'.<sup>70</sup> However, he also clarifies that not all men receive familial support, hence the strong sense of brotherhood within the gay community. For example, Craig recalls witnessing a young Samoan man crying at an

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<sup>69</sup> Simon Watney, 'AIDS and the Politics of Queer Diaspora', in *Negotiating Lesbian and Gay Subjects*, ed. by Monica Dorenkamp and Richard Henke (Great Britain: Routledge, 1994), p. 61.

<sup>70</sup> Craig Robertson, 06.17-06.24.



Auckland Sauna after his family rejected him once they learnt of his sexuality and status. Craig explains the young man's mother, father and siblings 'beat the crap out of him and then threw him out, and told him never ever to come back he was no longer their child'.<sup>71</sup> The gay community support is particularly evident in contrast to the man's family's reaction. Craig recalls, 'he was just completely – you know, didn't know where – where he was going, what he was going to do. And it was just watching the gay boys come around and support him'.<sup>72</sup> In this instance, Craig recalls the gay community were a substitute for the man's family, and offered him the support his family deprived him of. Yet the gay community was also a source of comfort for HIV-positive men who received family support.

Like Craig, Michael received support from his entire family about being HIV-positive and homosexual, and acknowledges 'I know some people, um, have horror stories to tell about their families – I didn't. My family was fine – including – including you know, extended family uncles, aunts, cousins, all of that.'<sup>73</sup> Although he is grateful for the support his family offered, Michael suggests there is a clear distinction between the support a gay man receives from his family, and from the gay community. The different levels of support are based on 'so many gay men [knowing] somebody who had it or had it themselves, whereas in a family you'd be the only person that knows, so the kind of support's different'.<sup>74</sup> Michael credits the bonds of brotherhood that members of the gay community establish to a shared history of homosexual oppression. Gay men and women who have internalised their history of social and legal persecution banded together amidst the threat of HIV/AIDS. Michael suggests that a shared sense of marginalisation between both gay men and lesbians has been the backbone of the gay community. Gay men with HIV/AIDS, 'were [initially] treated – you know as pariahs, um people wouldn't touch them, people wouldn't, you know, didn't wanna be in the same room as them sort of thing, so there was a really strong reaction from within the gay world'.<sup>75</sup> The strong gay community reaction is possibly because HIV/AIDS revived memories of oppression in gay history, therefore, the gay community are portrayed as a foundation of support for HIV/AIDS victims.

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<sup>71</sup> Craig Robertson, 18.18-18.26.

<sup>72</sup> Craig Robertson, 18.30-18.39.

<sup>73</sup> Michael Stevens, 24. 51-25.05.

<sup>74</sup> Michael Stevens, 30.21-30.30.

<sup>75</sup> Michael Stevens, 29.21 -29.34.

The gay community brotherhood I discuss in this section does not refer exclusively to HIV-negative men emotionally supporting HIV-positive gay men, but investigates the relationship as one of mutual respect and reciprocity. Some of the participants, all of whom contracted the virus through unprotected sex, explain an eagerness to protect other gay men from the virus. Immediately after being diagnosed, Craig states he ‘contacted the, um, the [sauna] I went to, after I’d been told, and I said, “look” I told them, “look I’ve been tested HIV-positive and I got it at your sauna”’.<sup>76</sup> Craig did not disclose his status to many people, but in this instance his anonymity came second to his determination to make others aware of safe sex. Jonathan also took a proactive approach to supporting the gay community after his diagnosis. Jonathan became heavily involved with the New Zealand AIDS Foundation, and was the first HIV-positive chair of the Foundation. Being associated with the Foundation was important for Jonathan, who recalls the nine months leading up to his partner’s death. Jonathan states ‘leading up to that period I got a lot of support from the AIDS Foundation. So after he died I – I needed, for me, to give back to them’.<sup>77</sup> While this reciprocal relationship of support within the gay community is ideal, it unfortunately does not represent all HIV-positive gay men’s experiences, and some men receive severe hostility because of their positive status.

Some of the men that participated in this study have experienced hostility from members of the gay community in New Zealand. Allanah Ryan identifies in her 1991 New Zealand study about HIV/AIDS and the gay community, that some men who do not have HIV/AIDS tend to distance themselves from those that do, and positive men ‘are seen as being separate from “us”, that is those that don’t have “it”’.<sup>78</sup> Both Jonathan and Michael identify the gay community’s fear and hostility towards HIV/AIDS. Jonathan believes ‘there’s people that still won’t talk to me knowing that I’m HIV-positive – within our own community’.<sup>79</sup> He argues that such hostility is based on individual’s fear of HIV/AIDS, and questions ‘whether or not that’s because people just – it’s too close to them. It’s too much in their face they don’t wanna know it. Maybe they’ve done something that they think was high risk’.<sup>80</sup> Like Jonathan, Michael also questions the motives of gay men fearing HIV/AIDS, and suggests ‘a lot of gay men are very ... scared of it because I think it – its, um it reminds them of the risks

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<sup>76</sup> Craig Robertson, 41.52-42.07.

<sup>77</sup> Jonathan Smith, 35.53-35.58.

<sup>78</sup> Allanah Ryan, *Community, AIDS and Sex: a study of aspects of the New Zealand gay community* (Report to the New Zealand AIDS Foundation, Palmerston North: Massey University, 1991), p. 25.

<sup>79</sup> Jonathan Smith, 21.41-21.44.

<sup>80</sup> Jonathan Smith, 21.46-21.55.

that they take themselves at times'.<sup>81</sup> Jonathan and Michael understand their HIV-positive statuses may impact others as they are living reminders of a potential consequence of unprotected sex. Yet Michael also suggests hostility within the gay community is based on a lack of understanding and awareness of HIV/AIDS, and fear of contracting the virus. Michael recalls 'um [younger generations] haven't had the direct personal experience [with HIV/AIDS] that my generations have – and so they tend to be quite judgemental about it'.<sup>82</sup> Michael's narrative reveals the value a historical understanding of oppression had on the gay community, which the younger generations lack and subsequently judge.

Carl also engages with discrimination within the gay community, which he claims is based on fear and ignorance. However, Carl's narrative is particularly distinct because he discusses why gay community hostility is more damaging than hostility from the wider heterosexual community. Carl notes,

some of the most hurtful stuff is from within our own community. I mean you sort of expect the wide – you know the wider heterosexual community to still have an element of ignorance and “bigotedness”, and lack of compassion and empathy but from within your own community you expect a lot more love and care.<sup>83</sup>

From this extract, it is evident that Carl is particularly affected by gay community hostility because he did not expect it from members of a group with a shared history of oppression. Carl's frustration towards unsympathetic gay men may be based on his collective memory. As discussed in this chapter, the gay community have experienced a history of oppression, and drew strength as a group during the HIV/AIDS epidemic. However, collective memories are not static, and 'how we make sense of experience, and what memories we choose to recall and relate (and thus remember), changes over time'.<sup>84</sup> Because memory is fluid, an individual may engage with many collective memories at any given time. Also, 'even if members of a group have experienced the events being remembered, they typically do not interpret or remember these events in the same way'.<sup>85</sup> Although members of the gay community may

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<sup>81</sup> Michael Stevens, 28.16-28.29.

<sup>82</sup> Michael Stevens, 38.28-38.35.

<sup>83</sup> Carl Greenwood, 49.04-49.28.

<sup>84</sup> Alistair Thompson, *Anzac Memories: Living with the legend* (Melbourne: Oxford University Press, 1994), p.9.

<sup>85</sup> James V. Wertsch, *Voices of collective remembering* (United Kingdom: Cambridge University Press, 2002), p. 25.

share the collective memory of oppression and stigmatization during the epidemic, this does not necessarily mean they have the same interpretation of the epidemic as others have, like Carl. Although individuals engage with a range of collective memories in their life narratives, individual subjectivity is crucial to understanding the participants' personal experiences, which is the main focus of Chapter Three.

Many members of the gay community banded together during the HIV/AIDS epidemic, after sharing a history of social and legal oppression. Some of the men in this study found the gay community to be an incomparable source of support, who could not only offer gay men emotional guidance, but in many cases knew people with HIV/AIDS. Therefore, the gay community could relate to people with HIV/AIDS, and offer a more intense level of support than one's family and other friends could. Some men in this study experienced hostility from other gay men, and attribute this to fear and ignorance about HIV/AIDS, and an inability to relate to the trauma past generations experienced. Naïveté about HIV/AIDS is also evident in the men's personal histories. All participants contracted the virus through unprotected sex, and claim naïveté was a key factor, due to New Zealand's conservative sex culture.

### **New Zealand's sex culture and gay men's naïveté about HIV/AIDS**

The men that participated in this study, with the exception of James and Dan, regularly practiced unprotected sex. This section examines the naïveté about safe sex and HIV/AIDS that the men discussed in their narratives. It also investigates the various ways the men explained their 'unsafe' sexual practices. Naïveté about the importance of protected sex is reflected in New Zealand STD rates. Male Call/Waea Mai, Tane Ma 'was the first nationwide survey of men who have sex with men (msm) in New Zealand'.<sup>86</sup> The survey took place in 1996, when no other large scale data on men who have sex with men was available.<sup>87</sup> Respondents to the survey were asked about specific sexually transmitted diseases (STDs) they had contracted, and whether or not they had been tested for STDs in the twelve months preceding the survey.<sup>88</sup> Of the 1852 men who responded to the survey, 37.1 per cent reported having an STD at some point in their lives.<sup>89</sup> Yet the researchers of the study warn that like

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<sup>86</sup> New Zealand AIDS Foundation, 'Report Ten: Sexually Transmitted Diseases and Hepatitis', *Male Call Waea Mai, Tane Ma*, (Auckland: New Zealand AIDS Foundation funded by the Health Research Council of New Zealand, 1999), p.5.

<sup>87</sup> New Zealand AIDS Foundation, 1999, p.5.

<sup>88</sup> New Zealand AIDS Foundation, 1999, p. 5.

<sup>89</sup> New Zealand AIDS Foundation, 1999, p. 6.

HIV/AIDS, not all infected individuals will have been tested; therefore the number of diagnoses is often an underestimation and must be treated with caution.<sup>90</sup> The high STD rate indicates that condom use faltered at times. Lack of condom use is not limited to New Zealand, and appears to have been an issue throughout western countries that led to the transmission of HIV/AIDS.

A study conducted in America about HIV/AIDS preventive behaviour among gay men in the early 1990s identifies monogamy was a reason for men not using condoms, and ‘in most of the monogamous relationships, there was a reported tendency to rely on monogamy as the *sole* means of protection against HIV infection’.<sup>91</sup> Reliance on monogamy may be due to some public education advertisements about the dangers of HIV/AIDS being severely misdirected. For example, an article in *Health* magazine states that one is not in danger of contracting HIV/AIDS if they have sex with one regular partner, and that most reported cases of HIV/AIDS in America are highly promiscuous people, particularly promiscuous homosexuals.<sup>92</sup> Like the result of identifying ‘risk groups’ that I discussed in Chapter One, labeling HIV/AIDS as an issue exclusively for promiscuous people made others who do not fit in this category feel complacent about their own risks, particularly those in monogamous relationships. As argued by Jacqueline Horn and Jane Chetwynd, men in relationships risked HIV infection because trust altered their perception of their own, and their partner’s risk levels.<sup>93</sup> Jonathan was naïve about safe sex, and was in what he believed to be a monogamous relationship when he contracted the virus from his late partner. For some individuals, their acquisition of the virus can trigger suspicion of infidelity in stable relationships.<sup>94</sup> Jonathan’s naïveté about safe sex is evident in his narrative as he claims he and his partner ‘weren’t privy to it, we didn’t even think about [protected sex]’.<sup>95</sup> Rather than making a conscious decision to have unprotected sex, Jonathan explains that using a condom did not register in their minds.

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<sup>90</sup> New Zealand AIDS Foundation, 1999, p. 2.

<sup>91</sup> Jessica T. Offir, Jeffrey D. Fisher, Sunyna S. Williams, William A. Fisher, ‘Reasons for Inconsistent AIDS-Preventive Behaviors among Gay Men’, *The Journal of Sex Research*, 30. 1 (1993), p. 64.

<sup>92</sup> J. Clements, ‘AIDS – The Facts’, *Health*, 35. 3 (1983), p. 3.

<sup>93</sup> Jacqueline Horn and Jane Chetwynd, *Changing sexual practices amongst homosexual men in response to AIDS: who has changed, who hasn’t and why?* (Report to the Department of Health, September 1989), p. 13.

<sup>94</sup> Brian Kelly and Beverley Raphael, ‘AIDS: coping with ongoing terminal illness’, in *International Handbook of Traumatic Stress Syndromes*, ed. by John P. Wilson and Beverley Raphael (New York: Plenum Press, 1993), p. 519.

<sup>95</sup> Jonathan Smith, 24.16-24.19.

The thematic threads that emerge in the men's narratives suggest that none of the participants made a conscious decision to have unprotected sex, but rather did not consider it as a necessity. During Shane's narrative, he expresses frustration at his own lack of awareness about safe sex. Although sex education was available at Shane's school, his school schedule meant he missed out on these classes.<sup>96</sup> Shane was diagnosed with HIV in his early twenties, and in his narrative suggests that education may have prevented him from contracting the virus. Shane did not receive sex education in school or from his parents, and identifies that 'I never had sex education. My father or mother would *never* talk about that'.<sup>97</sup> Shane's understanding that his parents would '*never*' discuss sex aligns with the tension he felt growing up in a strict Christian household. During Shane's youth, not only homosexuality was suppressed, but all discourses about sexuality in general. Missing out on sex education hindered Shane's personal development, and he acknowledges that 'in spite of the fact that I was well read, dimwit didn't put two and two together at all. Smart in some ways and *dumb* in others'.<sup>98</sup> Shane is clearly frustrated at his ignorance about safe sex, and refers to himself as 'dimwit' and 'dumb'. His frustration is justified as it was this lack of knowledge about sex that Shane blames for his diagnosis. Shane notes 'I think my biggest erk is that people are not given the power to protect themselves'.<sup>99</sup> Shane claims that 'if someone had given me the power or knowledge to say "hey do you know there's something called syphilis or gonorrhea or Chlamydia or anal warts or MSU" but no! Nothing! Secret! Don't tell!'<sup>100</sup>

Shane was also naïve because he had a false sense of security living in New Zealand. Although Shane was aware of the virus, he recalls thinking 'we're in New Zealand, thousands of miles away from where it's happening. So yeah, I knew about it, but not in my back yard it's too far away'.<sup>101</sup> In other words, Shane was uninformed about safe sex and HIV/AIDS on many levels, particularly because he did not receive safe-sex education. Lack of safe-sex education, and later a lack of knowledge about HIV/AIDS meant people like Shane were not only unable to protect themselves from the virus, but also bought into common stereotypes. Because so little information was available, Shane recalls people stereotyped, and

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<sup>96</sup> Sex education was commonly provided by schools and parents in post-War New Zealand. See Claire Gooder 'A History of Sex Education in New Zealand, 1939-1985.' (PhD Thesis, University of Auckland, 2010).

<sup>97</sup> Shane Kelly, *Life Narrative*, 12 September 2011, interviewed by Cheryl Ware, Wellington, New Zealand, 41.17-41.26.

<sup>98</sup> Shane Kelly, 41.24-41.34.

<sup>99</sup> Shane Kelly, 42.35-42.42.

<sup>100</sup> Shane Kelly, 42.18-42.31.

<sup>101</sup> Shane Kelly, 06.34-06.42

‘[HIV/AIDS] was an American thing and all we were doing was saying “oh just stay away from the Americans,” and “stay away from the Africans”’.<sup>102</sup> These stereotypes emerge in Shane’s narrative as misconceptions, and a further indication of his naïveté. Abiding by these social ‘rules’ kept few people safe from the virus, and stereotypes about homosexual men quickly spread.

Lack of awareness about safe-sex also emerges in Carl’s narrative, and he confirms he regularly practiced unprotected sex. Carl was not well educated about HIV/AIDS, and recalls ‘I just had those – quite basic knowledge of um, of HIV really, um, I knew condoms were good but I’d spent most of my adult life or my sexual life not using them’.<sup>103</sup> However, low self-esteem may have also been a factor. Paul Sendziuk argues that anti-homosexual behaviour was a barrier to prevention, and states that ‘there was little prospect of gay men taking pride in their health while they were humiliated or bashed at school, vilified in the community or rejected by their families.’<sup>104</sup> This was also true in New Zealand, and Carl recalls ‘there was an element of me, even before HIV that I was here for a short time not a long time – I was here for a goodtime not a long time’.<sup>105</sup> Carl suggests that some form of illness was inevitable, recalling that his casual mentality towards life and death resulted in risky behaviour, like unprotected sex and drug use.

Carl was also in denial about the severity of the virus. Carl lived in Taranaki when New Zealand had its first case of AIDS. Because the infected man lived in Taranaki, HIV/AIDS featured heavily in the local media. Carl remembers reading about the individual, and ‘I also remember going “oh what’s the big deal?” Everyone who’s at risk or might think they are, everyone will go out and have a test and those who have it won’t pass it on, and that will be the end of it’.<sup>106</sup> Such feelings of false security resulted in the men taking risks that resulted in infection.

Proscriptive masculinity was also a cause of men having unprotected sex. Homosexual and heterosexual men experience the same pressures to adhere to dominant sexual scripts, which in the case of masculinity conventionally includes the willingness to take risks without

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<sup>102</sup> Shane Kelly, 11.57-12.04.

<sup>103</sup> Carl Greenwood, 31.22-31.44.

<sup>104</sup> Paul Sendziuk, ‘Denying the Grim Reaper: Australian responses to AIDS’, *Eureka Street*, 13.8 (2003), pp. 18-19.

<sup>105</sup> Carl Greenwood, 35.03-35.12.

<sup>106</sup> Carl Greenwood, 21.01-21.15.

concern for health, isolate emotions from sexual experiences, and have numerous sexual partners.<sup>107</sup> Michael describes ‘coming out’ prior to the HIV/AIDS epidemic in the wake of the 1960s and 1970s notions of sexual freedom. Michael suspects he contracted the virus sometime between 1984 and 1985, which he describes as wild party days. Michael identifies he spent six months in New York:

Um, and I had a pretty wild party time there. So somewhere along that line is most likely where I got infected – um, but we’ll never know for sure, but somewhere between 1984 and ‘85 I expect is where I contracted HIV. And again a lot of that was that ethos of um, you know sex is good in itself, um so – that was, that was sort of the world I came out of. It’s quite a different – it was a very different gay world and gay sensibility than what we have today.<sup>108</sup>

While notions of masculinity influenced Michael’s sexual behaviour, he also explains it was due to the positive sex ethos that was a key element of the gay community. This ethos had emerged from a history of oppression, and gay men found their own identities in fluid sexual behaviour. Michael’s mentality about sex did not directly influence his unsafe sexual practices, but rather condom use did not feature in his mind.

All participants contracted HIV through unprotected sex, which they mostly attribute to their own ignorance about safe-sex. Lack of sex education and naïveté about the severity of the virus were key factors. Additionally, other reasons for unsafe sex emerged in the men’s narratives, including the false security of monogamy, and ideas about masculinity. Although the men were naïve about safe-sex and HIV, some were made aware of the virus by seeing others physical deterioration. Seeing AIDS in public was particularly memorable for gay men, many of whom knew someone with the virus and were already identified as a ‘risk group’.

### **AIDS in Public: Seeing individuals’ physical deterioration as a result of HIV/AIDS related illness**

While New Zealanders, like those in other countries, were reluctant to publicly address HIV/AIDS, the visible symptoms of the virus meant the public could not avoid the topic so

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<sup>107</sup> Michael R. Stevenson, ‘Gender roles’, in *Encyclopedia of AIDS: a Social, Political, Cultural, and Scientific record of the HIV epidemic*, ed. by Raymond A. Smith (Chicago : Fitzroy Dearborn, 1998), pp. 236-8.

<sup>108</sup> Michael Stevens, 06.39-07.09.



easily. Extreme weight loss and Kaposi's Sarcoma quickly became identified as symptoms of HIV/AIDS. Kaposi's Sarcoma was one of the first and most common illnesses associated with HIV/AIDS, and most commonly appeared in homosexual men.<sup>109</sup> This type of cancer was identifiable by coloured patches on an individual's skin, and the physical disfigurement that resulted was a cause of stigma and psychological trauma.<sup>110</sup> One's physical deterioration not only causes stress for the sufferer, but also for their family, friends, and others who are perceived as at 'risk' of contracting the same disease. Jean Scandlyn argues that all societies share criteria of how a healthy person behaves, looks and feels, and this criterion stigmatises individuals who fail to live up to these standards.<sup>111</sup> This was the case with people living with HIV/AIDS. In the early years of the epidemic, 'when AIDS was an acute illness, the diagnosis was delivered as a death sentence.'<sup>112</sup> Therefore, people who contracted the virus in the early years faced a particularly strong stigma because their health rapidly declined from a disease that would almost certainly kill them. When the participants in this study witnessed other men's physical decline, they had already identified as homosexual, and were considered members of a 'risk group'. Therefore, the impact witnessing others physically deteriorate would differ from those who were not stereotyped as 'at risk'. Also, as Michael and Shane were diagnosed particularly early in the epidemic, it is likely they were already living with the virus when they saw others bearing physical symptoms. This section indicates a change over time, as HIV/AIDS was much more visible in the public eye during the 1980s and 1990s than it is now.

Dan first encountered HIV/AIDS in the mid-1980s when he collected his brother from the airport. Dan's brother arrived from Perth, and Dan recalls he was carrying a letter, 'which explained that he was carrying medication for Acquired Immuno Deficiency, uh, um Syndrome. And of course that didn't mean – he showed me this letter and it didn't mean a thing to me. I'd never heard of it at this stage'.<sup>113</sup> However, as his brother's illness progressed, Dan became much more aware of the physical implications of the virus. Writing about death and HIV/AIDS, Mindy Machanic argues that the process of death itself has a major impact on

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<sup>109</sup> Michael Marco, 'Kaposi's Sarcoma (KS)', in *Encyclopedia of AIDS: a Social, Political, Cultural, and Scientific record of the HIV epidemic*, ed. by Raymond A. Smith (Chicago : Fitzroy Dearborn, 1998), p. 315.

<sup>110</sup> Marco, pp. 315-7.

<sup>111</sup> Jean Scandlyn 'When AIDS became a chronic disease', *Western Journal of Medicine*, 172.2 (2000), p. 132.

<sup>112</sup> Scandlyn, p. 133.

<sup>113</sup> Dan Coomby, 02.22-02.37.

the individual, and their loved ones.<sup>114</sup> An individual's physical decline as a result of HIV/AIDS related illnesses can be emotionally and physically devastating, and 'waiting for the death of a PWA can become a significant stress for everyone and can strain and test relationships'.<sup>115</sup> This was the case with Dan, whose brother died as a result of AIDS-related illness. Dan recalls visiting his brother in the few days before his brother's death, and notes 'when I saw my brother, I hardly recognised him. He has, he was so thin and his hair had gone – and he was always so proud of his hair'.<sup>116</sup> In his narrative, Dan confronts his brother's decline from the proud man he knew to a mere shadow of his former self.

Some of the men in this study, James and Carl in particular, state that while some people displayed visible symptoms of HIV/AIDS, the virus was still suppressed in the public's eye. James lived in Sydney, or what he informally calls 'a big gay city' during the early years of the epidemic, and saw many people suffering from the illness. Although individuals' physical decline was apparent, James did not initially relate to HIV/AIDS as he did not personally know anybody who was infected with the virus. James recalls 'I think [HIV/AIDS] wasn't a big deal for us in our circle because none of us had HIV, so we didn't really understand it'.<sup>117</sup> However, he became aware of HIV/AIDS in Sydney by seeing men terminally ill, and bearing physical signs of the disease. James recalls 'even though ... everyone was hush hush about it there was a certain amount of visibility'.<sup>118</sup> This silence further stigmatised HIV/AIDS patients, who were already marginalised in society. While many of the patients experiences are beyond recall, this thesis aims to dignify homosexual HIV-positive men's suffering, and uncover their lives as patients with the disease. HIV/AIDS symptoms were particularly visible in large cities, and James recalls 'we could be walking down Oxford Street and, you know, there'd be a couple of guys being pushed down in a wheelchair who were like living skeletons'.<sup>119</sup> Seeing men essentially dying is a powerful image in James' memory. Writing about images of health and illness, Sander L. Gilman identifies the models of 'health/beauty' and 'illness/ugliness'.<sup>120</sup> Gilman asserts that while the person at risk of HIV/AIDS, but uninfected is perceived as 'healthy' and 'beautiful', an HIV-positive

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<sup>114</sup> Mindy Machanic, 'Death and dying' in *Encyclopedia of AIDS: a Social, Political, Cultural, and Scientific record of the HIV epidemic*, ed. by Raymond A. Smith (Chicago: Fitzroy Dearborn, 1998), p. 168.

<sup>115</sup> Machanic, p. 168. PWA refers to person with AIDS and is commonly used in literature.

<sup>116</sup> Dan Coomby, 05.19-05.28.

<sup>117</sup> James Mauke, 34.14-34.20.

<sup>118</sup> James Mauke, 33.04-33.09.

<sup>119</sup> James Mauke, 32.56-33.02.

<sup>120</sup> Sander L. Gilman, *Health and Illness, Images of Difference* (London: Reaktion Books Ltd, 1995), p. 119.

individual is a reminder of ‘the necessary presence of death even in a seemingly healthy world’.<sup>121</sup> Seeing HIV/AIDS in public reminded the men of the ever-present threat of death, and the reality of suffering.

Michael also discusses seeing HIV/AIDS in public, and recalls witnessing men’s physical deterioration as a result of the illness. Michael notes, ‘people will get what we call “the look”. So it would be that, typically from the wasting they’d get really really thin, very very frail. Um, often Kaposi’s Sarcoma, so purple blotches from skin cancer ... Um and you could just tell’.<sup>122</sup> However Michael notes that is no longer the case, and ‘we definitely used to see people around who looked like that. We don’t – I couldn’t think of the last time I saw anyone get that sick from AIDS’.<sup>123</sup> According to Gilman, while society acknowledges that death is inevitable for everyone, people construct categories like ‘beauty’ and ‘health’ that deny dying.<sup>124</sup> While Michael witnessed other men portraying ‘the look’, he was spared from the ‘dying’ persona as he does not recall displaying physical symptoms, like some other men did.

The men’s narratives reveal that seeing people with serious physical symptoms of HIV/AIDS was an indication of the severity of the virus, and the death that was associated with it. Shane was diagnosed with HIV in 1984, and was therefore aware of the virus from the very early years of the epidemic. Shane’s narrative reflects the suspicion that circulated the virus, and he claims a main indicator ‘was when someone got real skinny – that was a dead giveaway.’<sup>125</sup> Shane also identifies that a common image of HIV/AIDS was ‘someone who looks like they’ve had the flu for a long time, you know, dark bags under their eyes, always looking really exhausted and tired. You always had a suspicion.’<sup>126</sup> This ‘suspicion’ Shane recalls about people who potentially had HIV/AIDS aligns with the stigma that was attached to the virus. People with HIV/AIDS, particularly those with visible symptoms were easily identified, and essentially excluded from the ‘healthy/beautiful’ society Gilman discusses. Yet visible symptoms of HIV/AIDS did not only affect the patients who displayed these symptoms, but also had potential consequences for others with the virus.

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<sup>121</sup> Gilman, p. 119.

<sup>122</sup> Michael Stevens, 31.04-31.22.

<sup>123</sup> Michael Stevens, 31.48-31.56.

<sup>124</sup> Gilman, p. 119.

<sup>125</sup> Shane Kelly, 45.53-46.03.

<sup>126</sup> Shane Kelly, 46.08-46.20.

Seeing physical symptoms of HIV/AIDS was traumatic for people who were identified as members of a 'risk' group, like the men in this study. Brian Kelly and Beverly Raphael identify that the fear of death is likely to occur shortly after a positive diagnosis, and may be an ongoing source of distress for the individual.<sup>127</sup> Witnessing the progressive decline and death of peers can increase a sufferer's fear of death and feelings of vulnerability from HIV/AIDS.<sup>128</sup> Jonathan's and Carl's experiences are distinct because they both nursed a partner with HIV, while they were also infected with the same illness. HIV did not feature in Jonathan's mind until he and his partner received positive diagnoses in 1993. However, after Jonathan was diagnosed with HIV he became aware of the visible signs of the virus. Jonathan recalls seeing people with HIV/AIDS during the mid-1990s, and 'you could tell when people were – infected. They had terrible wasting, or they were in wheelchairs, they had KS, um, but they really really looked ill.'<sup>129</sup> Carl also recalls seeing people with visible symptoms of HIV/AIDS, 'all degrees as well. I mean from people getting pneumonia and dying within a week, to actually people ending up in wheelchairs and not being able to walk, um, dementia was really visible, but also weight loss.'<sup>130</sup> Despite witnessing patients' physical decline, Carl maintains discourses about HIV/AIDS were still suppressed, and notes 'people were fearful, um and still ignorant, like still chose to ignore. Um, even though you could see it, it still wasn't talked about'.<sup>131</sup> Although seeing HIV/AIDS in public was undeniably traumatic for some individuals, a patient's visible symptoms may have also had positive outcomes. Jacqueline Horn and Jane Chetwynd argue that safe sex was commonly practiced among people who were HIV-positive, or knew people that were, and an understanding of personal vulnerability is often needed to encourage people to change their behavior.<sup>132</sup> In other words, ignorance and naïveté were the main barriers to preventing infections, which prevailed despite the amount of visibility.

Although HIV/AIDS was not openly discussed during the early years of the epidemic, individual's physical deterioration as a result of HIV/AIDS related illnesses could not be ignored. Seeing HIV/AIDS in public was traumatic for all the men that participated in this

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<sup>127</sup> Brian Kelly and Beverley Raphael, 'AIDS: coping with ongoing terminal illness', in *International Handbook of Traumatic Stress Syndromes*, ed. by John P. Wilson and Beverley Raphael (New York: Plenum Press, 1993), p. 520.

<sup>128</sup> Kelly and Raphael, pp. 520-521.

<sup>129</sup> Jonathan Smith, 23.04-23.17.

<sup>130</sup> Carl Greenwood, 45.43-45.59.

<sup>131</sup> Carl Greenwood, 47.26-47.40.

<sup>132</sup> Jacqueline Horn and Jane Chetwynd, *Changing sexual practices amongst homosexual men in response to AIDS: who has changed, who hasn't and why?* (Report to the Department of Health, September 1989), p. 22.

study, all of whom were identified as members of a 'risk' group. People's visible HIV/AIDS symptoms served as a constant reminder of the severity of the virus, and that death is inevitable. Jonathan's and Carl's experiences are particularly personal because they nursed their partners while living with the same illness, which they had contracted from the men for whom they cared. In their narratives, the men subtly engage with images of health and illness, and despite being identified as 'at risk', do not recall displaying visible symptoms of HIV. Seeing HIV/AIDS in public was emotionally scarring for both the individuals displaying these symptoms, and others already infected with the illness.

### **Living with HIV: the physical and social implications**

Finally, in this chapter I analyse the men's experiences of living with HIV as a chronic illness in New Zealand. Social Psychologist Alan Radley defines a chronic patient as 'someone whose disease cannot be cured'.<sup>133</sup> While substantial progress has resulted in 'prolonging and improving the quality of life of those infected with HIV, we still have neither a cure for, nor a vaccine to prevent, this disease.'<sup>134</sup> Therefore, HIV/AIDS remains a chronic illness. The men in this study continue everyday life, and are not necessarily resigned to the bedridden role of 'sick people', yet they attend regular appointments with doctors for help with their diagnosed illnesses.<sup>135</sup> Although sufferers of chronic illnesses can continue to live their everyday lives, the social implications of their illnesses can make this difficult. Patients' lives can be restricted by physical impairments, or they can experience social isolation, either enforced by themselves or by others.<sup>136</sup>

The men who participated in this study were diagnosed with HIV between 1983 and 1997 and have therefore experienced a wide variety of anti-retroviral medication, most of which has extreme side effects including severe nausea and diarrhoea. While the physical impact of HIV is evident in their narratives, it is overshadowed by the social impact the virus has had on their lives. James identifies that living with HIV is physically manageable, and notes 'when I do catch a cold now it's – it'll last for a few weeks, um, and not a few days anymore. And otherwise, otherwise it will be easy for me to forget that it's there, that it's even in

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<sup>133</sup> Alan Radley, *Making sense of illness, the social psychology of health and disease* (London: SAGE Publications LTD, 1994), p. 138.

<sup>134</sup> Martin Fishbein, 'The role of theory in HIV prevention', in *The Health Psychology Reader*, ed. by David F. Marks (London: SAGE Publications Ltd, 2002), p. 120.

<sup>135</sup> Radley, p. 136.

<sup>136</sup> Radley, p. 147.

me'.<sup>137</sup> Like James, Jonathan explains that living with HIV is physically manageable, yet he is constantly reminded he has the virus. Jonathan notes, 'some days it's very easy, um, other days it's – it's quite difficult. You're reminded that you've got HIV at least twice a day when you take your meds in the morning and meds at night'.<sup>138</sup> However, although HIV does not take up much of the men's time, it remains ever-present in their lives. Michael summarises his experiences with HIV by stating 'a metaphor I often use is it's like you take a glass of water and you put just even a little tiny drop of ink in it. You may not be able to see the ink but you can never take it out of the water again it's there'.<sup>139</sup> In this metaphor, the drop of ink may not only refer to the virus itself, but also to the threat of infecting others and the fear of impending death.

Death plays a key part in the men's narratives, and most of the participants engage with losing large numbers of friends to the virus. Kelly and Raphael identify one of the most tragic aspects of HIV infection is 'the exposure to multiple loss, such as the death of friends and partners, creating a gradual erosion of social networks, with illness and death at a level comparable to a community disaster'.<sup>140</sup> The mass deaths that result from HIV/AIDS have made a huge impact on the gay community. Nigel Gearing argues that in particular, younger gay people feel older generations of the gay community have experienced the loss that often accompanies old age, and 'large chunks of the gay community have been wiped out. The only comparison is with people who live and lose through a war'.<sup>141</sup> James identified he was part of a community of gay New Zealanders that were living in Australia during the early 1990s, and although none of his immediate friends were diagnosed with the virus, they were aware of the huge amount of death that surrounded them. James recalls 'people like Carmen um, she's been quoted as saying she's been to at least 40, 45 funerals over in Sydney of young Māori gay men who died of AIDS. Um, you know she – she remembers all of them'.<sup>142</sup> Carmen was part of the community James refers to, and James expresses these losses were a loss to the community, as well as to individuals.

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<sup>137</sup> James Mauke, 1.12.50-1.13.06.

<sup>138</sup> Jonathan Smith, 54.03-54.17.

<sup>139</sup> Michael Stevens, 33.53-34.04.

<sup>140</sup> Kelly and Raphael, p. 519.

<sup>141</sup> Nigel Gearing, *Emerging Tribe: gay culture in New Zealand in the 1990s* (New Zealand: Penguin Books (NZ) Ltd., 1997), p. 63.

<sup>142</sup> James Mauke, 37.58-38.08.

Kelly and Raphael also identify that witnessing large amounts of death likely impacts upon a patients' psychological ability to deal with their own illnesses and expected death.<sup>143</sup> Michael recalls 'at one stage I can remember going to – it seemed like going to a funeral nearly every month, uh, for quite a time. It wasn't unusual hearing of people dying here of in Australia or in England who were friends'.<sup>144</sup> Witnessing others death and anticipating his own had significant effects for Michael, who recalls,

When I was in Hearn Bay house at one time, um the head um took me aside once and sort of said to me "you know you're being such a – a bastard that we're – you know if you don't change your attitude we might have to ask you to leave". So, you gotta be pretty bad to do that in a hospice.<sup>145</sup>

Having friends die as a result of HIV/AIDS meant Michael felt death was inevitable. This was particularly traumatic for him when he fell sick and thought he was dying. Dan experienced a similar situation with his brother, who was given a maximum life expectancy of five years after being diagnosed with AIDS. Dan recalls as his brother's health declined,

I'd be reading the newspaper and he'd pick up headlines off the back of the newspaper and apply them to himself. I'd take him to an appointment at the hospital and he'd see workmen digging, uh, on the side of the road and he'd say they were digging his grave. When I took him down to Tokoroa to see his mother um, he reckoned I was taking him down there to put him in the furnace at – at the mill.<sup>146</sup>

Dan and Michael's narratives reveal the psychological impact HIV/AIDS had on men when it was considered a terminal illness, rather than a chronic illness. Both Michael and Dan's brother were diagnosed with the virus before effective medical treatment was developed, and were both told their illness was fatal.

Being aware of others dying from HIV/AIDS, and witnessing their physical and emotional deterioration impacted the men's perception of their own mortality, sometimes leading to thoughts of suicide. Shane notes he went to twenty funerals then stopped because it was too

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<sup>143</sup> Kelly and Raphael, p. 519.

<sup>144</sup> Michael Stevens, 30.35-30.48.

<sup>145</sup> Michael Stevens, 14.53-15.05.

<sup>146</sup> Dan Coomby, 03.33-03.59.

emotionally draining. Like others Shane knew, he attempted to passively suicide by refusing to take pills, which resulted in him being hospitalised with Tuberculosis. This close encounter with death has resulted in his relaxed attitude towards dying. Shane notes ‘I’ve been so close to death that – with TB – that I get really blasé about death you know, like I’ve been so close.’<sup>147</sup> Shane has also attempted suicide, and acknowledges ‘I’ve actively suicided with sleeping tablets and alcohol. Um, I’m not a strong swimmer so I’ve gone out into the water as far as I could’.<sup>148</sup> Suicidal thoughts also feature in Carl’s narrative, and he has also lost a lot of friends due to HIV/AIDS-related deaths. Carl recalls that from ‘89, ‘90 to about ‘93 honestly so many people died. I mean I could not – we lost count. We’re talking not, not one or two, we’re talking tens up to, you know, hundred, maybe more’.<sup>149</sup> Like others he was aware of, Carl thought ‘actually having watched other people die it was like “oh I’m gonna commit suicide, I’m not gonna allow myself just to get that sick and that sick and that sick”’.<sup>150</sup> While having large amounts of friends die made some men hostile towards their own deaths, it also made some men complacent about dying, and potentially committing suicide.

In conclusion, this chapter has explored the main themes that emerge in the participant’s life narrative interviews. In addition, the content of the men’s illness narratives is important as it reveals intimate details about the men’s experiences specifically as gay men with HIV, and these stories are currently missing from New Zealand’s medical history. This chapter has also examined the men’s experiences growing up as homosexual men in New Zealand, naïveté about safe sex and HIV/AIDS, reactions from within the gay community, and their individual experiences seeing and living with HIV. Gendered identity categories and the men’s understanding of masculinity and effeminacy, the latter of which has been traditionally conflated with homosexuality, formed an important part in this chapter. Such categories signify common public attitudes towards gender, and expectations of ‘men’. The men’s experiences are personal as they were diagnosed with a stigmatised virus through socially disapproved behaviour. However, although they share experiences as a collective, the men’s narratives are also individually subjective. Chapter Three focuses on the men’s collective memories and the individual subjectivity inherent within these collective memories. Chapter

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<sup>147</sup> Shane Kelly, 55.38-55.46.

<sup>148</sup> Shane Kelly, 55.17-55.27.

<sup>149</sup> Carl Greenwood, 32.57-33.14.

<sup>150</sup> Carl Greenwood, 57.42-57.50.



Three specifically examines the diverse ways the men construct their experiences, and how their narratives disrupt common archetypes inherent in the public eye.

## Chapter Three

### **‘Us’ versus ‘them’: how the men construct their illness narratives living with a chronic illness in New Zealand**

Individual memories and collective memories are inherent in the life narrative approach, and play an important role in the HIV/AIDS narratives that feature in this thesis. Myths and stereotypes are part of the collective memories that individuals remember, however, ‘shared individual memories do not constitute a collective memory unless they remain *stable* over time.’<sup>1</sup> While the previous chapter focused on the content of the narratives, this chapter focuses on the collective memories that the participants evoked during their life narrative interviews. It considers the individual subjectivity inherent within life narratives, and the diverse ways the participants negotiated their individual and collective memories of HIV/AIDS in New Zealand. The main method I used in this chapter is narrative analysis. Oral historians ‘are keenly attuned to the many layers of meaning, because they not only read the words but also hear the voices.’<sup>2</sup> By carefully unpacking the dimensions of oral testimony, historians are able to gain a deep understanding of individuals past experiences, both in terms of what happened, and the meaning of that experience for the narrator.<sup>3</sup> Catherine Kohler Reismann argues that the purpose of narrative analysis is to identify how interviewees order their experiences in ways that make sense of events in their lives.<sup>4</sup> She claims that narrative analysis allows researchers to question the ways people convey their experiences, and rather than simply focus on content, ask ‘why was the story told *that way*?’<sup>5</sup>

Writing about individual and collective memories, Anna Green affirms that ‘individual and collective remembering reveals memory as a site of cultural conflict’, and individuals draw from a range of, sometimes conflicting, collective memories at various times in their life narratives.<sup>6</sup> In this thesis, HIV itself is identified as a site of cultural conflict, which is based on the discourses surrounding the virus, and homosexual men. The men in this study share

<sup>1</sup> William Hirst and David Manier, ‘Towards a psychology of collective memory’, *Memory*, 16, 3 (2008), p. 193.

<sup>2</sup> Anna Green, “‘Unpacking’ the Stories”, in *Remembering Writing Oral History*, ed. by Anna Green and Megan Hutching (Auckland: Auckland University Press, 2004), p.11.

<sup>3</sup> Green, 2004, pp. 11-12.

<sup>4</sup> Catherine Kohler Reissman, *Narrative Analysis* (United States of America: Sage Publications, Inc., 1993), p. 2.

<sup>5</sup> Kohler Reismann, p. 2.

<sup>6</sup> Anna Green, ‘Individual Remembering and “Collective Memory”: Theoretical Presuppositions and Contemporary Debates’, *Oral History*, 32, 2 (Autumn 2004), pp. 35-44.

collective memories of being homosexual men, and living with HIV. However, their individual subjectivity influences the diverse ways their collective memories emerge in these life narratives. Collective memories are not static, and ‘how we make sense of experience, and what memories we choose to recall and relate (and thus remember), changes over time’.<sup>7</sup> Because memory is fluid, an individual may engage with many collective memories at any given time.

Collective memories often emerge in the form of the ‘myths’ or archetypes a society has created about a group to which they do not belong. In the case of homosexual men living with HIV, these myths are often negative, and place blame on the individual. On the topic of collective memory, Marie-Francoise Chanfrault-Duchet defines ‘myths’ as ‘those features that may be identified through markers such as stereotyped images, gestures, attitudes, behaviors, or simply the connotations of particular words’.<sup>8</sup> In this thesis, I use Chanfrault-Duchet’s definition of myths, which is synonymous with archetypes, and therefore the terms will be used interchangeably. Chanfrault-Duchet argues that the myths that appear in a narrative allow the speaker to communicate the meaning he or she wishes to express from their experiences in social terms, and reveal the value a speaker places on their life experiences.<sup>9</sup> In this chapter, I analyse the myths that emerged most strongly and frequently in the men’s narratives. To identify which myths featured most prominently across the narratives, I listened to and indexed each interview. By reading the indexes several times, I was able to determine the dominant myths that emerged. These myths form a major part of the men’s collective memories, which include notions of homosexual promiscuity, deviant men who deliberately infect others, sufferers of a stigmatised illness, and HIV-positive men who are targets of discrimination.

Analysing the individual memories is important as these men’s life narratives of living with HIV/AIDS in New Zealand have not previously been documented. This thesis gives the participants agency by prioritising their experiences as individuals, and understanding whether or not their narratives fit with the wider collective memories that already exist. In this thesis, I have included the memories that featured most prominently throughout the

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<sup>7</sup> Alistair Thompson, *Anzac Memories: Living with the legend* (Melbourne: Oxford University Press, 1994), p. 9.

<sup>8</sup> Chanfrault-Duchet, Marie-Francoise, ‘Narrative Structures, Social Models, and Symbolic Representation in the Life Story’, in *Women’s Words: The Feminist Practice of Oral History*, ed. by Sherna Gluck and Daphne Patai (New York and London: Routledge, 1991), p. 81.

<sup>9</sup> Chanfrault-Duchet, p. 81.

men's narratives. The five collective memories in this thesis provide substantial insight into the men's individual and collective experiences.

While some of the men acknowledge some myths about homosexual HIV-positive men like promiscuous behaviour, on many instances their individual subjectivity dispels these myths. Not all myths are fictitious, and in this thesis myths are used to identify social misunderstandings from realities. Myths about homosexual men with HIV/AIDS are often constructed by members of groups who are uninfected, and not primarily identified as 'at risk', such as the wider heterosexual population. These myths are often demeaning, and construct ideas about HIV-positive men living 'immoral' lifestyles. Patricia G. Devine, E. Ashby Plant and Kristen Harrison suggest that HIV/AIDS stigma is fuelled by individuals determination to maintain their own secure social identities, and 'a great deal of negativity toward PWAs arises out of uninfected people's need to protect their identity as healthy and nondeviant'.<sup>10</sup> Uninfected groups often claim that people living with HIV/AIDS are responsible for their condition, which reflects one's desire to protect their own social identities, and to perceive oneself as safe from the virus.<sup>11</sup>

In their narratives, the men engage with the collective memory that HIV/AIDS is a shameful illness. Their understanding of the shame they are made to feel is created by publicised social hostility towards HIV/AIDS, and prejudice against people living with the disease. This is particularly true for homosexual men, who are often believed to be responsible for contracting the virus, and deserve little sympathy. References to terms like 'clean' heighten the stigma associated with HIV/AIDS, and establish segregation between HIV-positive, and HIV-negative people, even within the gay community itself. Although the men that participated in this study are aware of the stigma associated with HIV/AIDS, they refuse to position themselves as victims in their narratives. In doing so, the men arguably disrupt the 'helpless victim' archetype, and invert AIDS metaphors by likening the virus to other common illnesses.

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<sup>10</sup> Patricia G. Devine, E. Ashby Plant and Kristen Harrison, 'The problem of "Us" versus "Them" and AIDS Stigma', *American Behavioral Scientist*, 47.7 (1999), p. 1214.

<sup>11</sup> Devine et.al., p. 1220.

## **Wounded bodies: living with a stigmatised chronic illness**

Using Frank's term, the storytellers in this study are 'wounded', and ideas about being 'sick' or 'ill' feature prominently in their illness narratives. In regard to illness, Jean Scandlyn argues that 'a basic tenet of medical anthropology is that illness is socially constructed'.<sup>12</sup> Scandlyn maintains that while disease produces physical symptoms, it is the sick person's friends, family and medical professionals that interpret their symptoms and decide whether or not the affected person is ill.<sup>13</sup> In other words, one's families and friends responses to perceived illness symptoms have a stronger impact on a patient's lives than their physical deterioration. Because all societies have an established criterion for how a healthy person looks and behaves, one is stigmatised when one fails to meet these standards.<sup>14</sup> Sufferers' of illness often internalise stigma as they know they do not meet the public standard of being 'healthy'.<sup>15</sup> This may be particularly true for people with HIV/AIDS, as the disease has received significant public attention. Writing specifically about the stigma of HIV/AIDS, Devine, Ashby and Plant argue that the prejudice towards the virus can lead to 'hostile and avoidant behaviors directed toward people with AIDS'.<sup>16</sup> The AIDS acronym is itself a particularly stigmatising term, which elicits a range of feelings including anger, fear, shame, pity and revulsion towards the disease as well as to those who have come to be associated with HIV/AIDS.<sup>17</sup>

In the early years of the epidemic, HIV/AIDS was identified as an acute illness, and a positive diagnosis was delivered as a death sentence.<sup>18</sup> People were given a number of years, or months to live, and some HIV/AIDS patients' physical deterioration was visible in the public eye. Although visible symptoms of HIV/AIDS are no longer common, and HIV/AIDS is now considered a 'chronic illness', patients still experience some of the major social implications of having a stigmatised illness.

This section focuses on the how the participants recall their experiences living with a stigmatised illness. It considers their individual subjectivity as homosexual men living with HIV, and the different ways they accept and disrupt common assumptions about chronic

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<sup>12</sup> Jean Scandlyn, 'When AIDS became a chronic disease', *Western Journal of Medicine*, 172.2 (2000), p. 130.

<sup>13</sup> Scandlyn, p. 130.

<sup>14</sup> Scandlyn, p. 132.

<sup>15</sup> Scandlyn, p. 132.

<sup>16</sup> Devine et. al, p. 1212.

<sup>17</sup> Devine et.al, p. 1212.

<sup>18</sup> Scandlyn, p. 133.

illnesses. Andrea M. Whittaker conducted a study in 1992 about people living with HIV/AIDS, and argues that ‘positive people in this study invert metaphors commonly associated with AIDS.’<sup>19</sup> In other words, people with HIV/AIDS attempt to strip the virus of its negative connotations by redefining HIV as nothing more than a common illness. In doing so, people living with HIV/AIDS reject the idea that it is a punishment for perceived deviant, immoral behaviour, and rather consider it ‘capable of affecting any person, not just gays and “undesirables”’.<sup>20</sup> Whittaker also claims that some people living with HIV invert metaphors associated with the virus by rejecting labels like ‘AIDS carriers’ and ‘AIDS sufferers’, and adopting terms like ‘positive people’.<sup>21</sup> In this instance, Alistair Thompson’s theory of composure is useful for analyzing the interviewee’s life narratives. Thompson argues that individuals compose their memories to make sense of their past and present, and that people ‘compose memories that help us to feel relatively comfortable with our lives and identities’.<sup>22</sup> Therefore, in this section I will also analyse the ways the men composed their memories of living with HIV by redefining it as a common illness.

In his narrative, James redefines HIV as a common illness. James constructs his narrative by prioritising his identities as a middle-aged man of Māori and Polynesian descent, and he acknowledges that ‘I’m entering a risk phase of – of my life for um, high blood pressure, heart disease, stroke, diabetes and all those things which um affect my age and ethnicity’.<sup>23</sup> In this instance, James composes his narrative alongside others of the same age and ethnicity as himself and feels that he, like others in his age and ethnic group, must be careful about their health, regardless of his HIV-positive status. In his individual memory, James redefines HIV as a common illness and therefore disturbs the collective memory that HIV/AIDS is a stigmatised disease. However, people with HIV/AIDS are often conscious of, and sometimes internalise the shame and stigma they carry. For example, James also engages with the collective memory of living with a stigmatised illness, citing an encounter with a medical professional. The collective memory is maintained by James, who is a victim of stigma in this encounter. Arthur Frank identifies that ‘people’s memories of illness are often remarkable in their precision and duration’.<sup>24</sup> Therefore, James remembers acutely because

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<sup>19</sup> Andrea M. Whittaker, ‘Living with HIV: Resistance by Positive People’, *Medical Anthropology Quarterly*, 6.4 (1992), p. 387.

<sup>20</sup> Whittaker, p. 387.

<sup>21</sup> Whittaker, p. 387.

<sup>22</sup> Thompson, p.8.

<sup>23</sup> James Mauke, *Life Narrative*, 20 May 2011, interviewed by Cheryl Ware, New Zealand, 01.12.12-01.12.29.

<sup>24</sup> Arthur W. Frank., *The Wounded Storyteller* (USA: The University of Chicago Press, 1995), p. 59.

he is identified as different. James needed a standard blood test, and recalls the nurse ‘goes “oh, what are we testing again?” and she looked at the card, she goes “oh CD4 count and viral load” she goes “oh” and she went to go and put some gloves on to finish the procedure’.<sup>25</sup> This potentially traumatic encounter heightened James’ awareness that HIV/AIDS is a stigmatised illness. However, he manages to undermine this perception in his individual narrative by redefining HIV, and prioritising other identities he has.

Like James, Jonathan’s awareness that HIV is a stigmatised illness was also heightened by his interaction with medical professionals. Also like James, Jonathan composes his experiences with HIV alongside other people who are living with less stigmatised illnesses. Jonathan explains that living with HIV is ‘it’s little things like – and this is no different to somebody who’s probably on diabetes medication of whatever – it’s making sure that, you know, if you’re going out that you’ve got – you’ve got your tablets’.<sup>26</sup> Jonathan redefines HIV in his individual narrative, and composes his experiences with the virus alongside others living with a commonly identified illness. Yet Jonathan also engages with the collective memory that HIV/AIDS is a stigmatised illness, which he is made aware of through his interaction with medical professionals. Jonathan composes his experiences alongside that of other gay HIV-positive men, and states ‘if we go back historically – let’s talk about the medical treatment we used to get – so if I go back to nine, ten years ago. Um, I’ve had two instances back then when I was refused treatment by a dentist ‘cause of my status’.<sup>27</sup> By using the term ‘we’, Jonathan suggests that his experiences with HIV are representative of other gay men’s experiences. Jonathan also encountered discrimination from a doctor, who conflated homosexuality with HIV. The doctor altered a procedure Jonathan needed, as he feared Jonathan may infect other patients. Jonathan recalls ‘so I said to him, I said “well so if I said – if I hadn’t told you I was HIV-positive”, he said “oh I would have guessed anyway ‘cause you’re gay”’.<sup>28</sup> The individual narratives are powerful because they acknowledge collective memories, but in many instances divert from them. The individual memories reflect the men’s true experiences, and how these conflict with dominant archetypes. In their individual narratives, James and Jonathan acknowledge social stigma

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<sup>25</sup> James Mauke, 01.22.05-01.22.14.

<sup>26</sup> Jonathan Smith, *Life Narrative*, 21 June 2011, interviewed by Cheryl Ware, Auckland, New Zealand, 55.47-56.01.

<sup>27</sup> Jonathan Smith, 01.00.13-01.00.28.

<sup>28</sup> Jonathan Smith, 01.01.47-01.01.53.

towards HIV, yet they compose their experiences alongside other illnesses and suggest that stigma towards HIV is unjustified.

Carl also uses his individual narrative to disrupt the collective memory that HIV/AIDS is severe and stigmatised. Carl recalls that he participated in 'risky' behaviour during his youth, and composes his narrative alongside other illnesses that can be transmitted through taking such risks. Carl contracted HIV through unprotected sex, yet maintains that if he did not have HIV, 'I probably would've had other issues, I probably would've had, you know, hepatitis from needle use or, you know what I mean? There's other things that you could end up living with, Hepatitis C or something'.<sup>29</sup> By likening HIV to other illnesses, Carl dismisses ideas that HIV is particularly serious. Although the men compose their experiences living with HIV alongside other illnesses and reduce the severity of the virus, some men are reminded of the stigma of HIV by medical professionals. Yet gay men with HIV/AIDS also encounter hostility from other sources.

Prejudice towards homosexual men with HIV/AIDS sometimes occurs within the gay community, particularly regarding dating. Devine, Plant and Harrison identify that individuals infected with HIV/AIDS are considered by non-infected members of society as an 'outgroup', which enables the uninfected individuals to maintain their social identity as an 'ingroup'.<sup>30</sup> This 'us' versus 'them' mentality helps establish boundaries between the two groups, which seems rigid and impenetrable.<sup>31</sup> The notion that homosexual men living with HIV/AIDS are not 'clean' has been constructed, and is used by people who are not living with the illness. James' understanding of the term 'clean' is particularly powerful as it follows his progression from a member of the 'ingroup', as identified by Devine, Plant and Harrison, to a member of an 'outgroup'.<sup>32</sup> James recalls his first HIV/AIDS test was negative, and remembers 'even then we were using terms like "clean", which I don't like that term at all 'cause, you know, when you've got HIV it implies that you're unclean'.<sup>33</sup> James' narrative also indicates that he has internalised some of the hostility, and prejudice that labels HIV-positive homosexual men as 'unclean', which features at another point in James' narrative. James recalls 'I've never had anyone come up to me, you know, from a negative perspective

<sup>29</sup> Carl Greenwood, *Life Narrative*, 12 September 2011, interviewed by Cheryl Ware, Wellington, New Zealand 55.33-55.50.

<sup>30</sup> Devine et.al., p. 1213.

<sup>31</sup> Devine et.al., p. 1213.

<sup>32</sup> Devine et.al., p. 1213.

<sup>33</sup> James Mauke, 01.28.38-01.28.45.



and say, you know, “dirty filthy faggot” (laughs), or anything like that. Um, but I know of others that have.’<sup>34</sup> James’ recollection of the terms ‘dirty filthy’ reveal his understanding that homosexual men with HIV are part of this ‘outgroup’. Jonathan and Carl share James’ resentment of the term ‘clean’, because it positions them as isolated, and rejected from the rest of society. Ryan’s 1991 study concludes that some gay men without HIV perceived HIV-positive men as distinct, and ‘they are seen as being separate from “us”, that is those that don’t have “it”’.<sup>35</sup> Jonathan also resents the term ‘clean’, which he states is commonly used throughout the gay community,

There’s a term that’s used which I find quite repulsive, so I mean if guys wanna connect up with other guys they ask if they’re “clean”. So for me that – that’s a really, really disgusting terminology. It’s like them saying to me I must be unclean.<sup>36</sup>

In Jonathan’s narrative he opposes suggestions that he, like other gay men with HIV are rejected from the rest of society because of their illnesses.

Carl seeks agency in his individual narrative and fights against terms like ‘clean’. Like Jonathan, Carl identifies the use of the term ‘clean’ throughout the gay community, stating, ‘on any dating sites it – they often use the word “clean”. Um, “clean U B 2”, well actually that just means don’t be positive’.<sup>37</sup> On behalf of other homosexual HIV-positive men, Carl resents the term ‘clean’ and states ‘I know some guys who will send back and go “I’ve had a shower this morning”’.<sup>38</sup> By deliberately misinterpreting this prejudice, men seek agency by condemning the use of ‘clean’.

The men’s individual memories disturb the collective memory that HIV/AIDS is a stigmatised illness, and the myth that people infected with the virus are justifiably segregated. Ryan’s New Zealand 1991 report identifies gay community reactions to HIV/AIDS, and concludes that some homosexual men distance themselves from people living with HIV/AIDS, which they believe is ‘a problem of those less in control of themselves’.<sup>39</sup> This

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<sup>34</sup> James Mauke, 01.21.20-01.21.36.

<sup>35</sup> Allanah Ryan, *Community, AIDS and Sex: a study of aspects of the New Zealand gay community* (Report to the New Zealand AIDS Foundation, Palmerston North: Massey University, 1991), p. 25.

<sup>36</sup> Jonathan Smith, 22.16-22.35.

<sup>37</sup> Carl Greenwood, 50.07-50.15.

<sup>38</sup> Carl Greenwood, 50.18-50.21.

<sup>39</sup> Ryan, p. 25.

segregation occurs within the gay community and some members use the term 'clean' to identify themselves as separate from those living with HIV. In Andrea Whittaker's 1992 study, one of her participants inverted the AIDS metaphor of being 'clean', and despised the term, stating that they do not feel dirty yet are suggested so.<sup>40</sup> This detestation of the term 'clean' occurred in my study also, and the term appears to be a cause of distress for the participants. The myth that homosexual men with HIV are 'unclean' is established, and maintained by people who are not living with the virus. In their narratives, the men engage with, and fight against the myth that HIV-positive men are excluded from the 'clean' ingroup. Collective memories of living with a particularly stigmatised illness, and being excluded from the wider gay, HIV-negative community emerge in the men's life narratives. Although the men compose their own experiences with HIV alongside other illnesses, and redefine HIV/AIDS as little more than a common virus, the participants are constantly reminded of the stigma they face by medical professionals and the wider public. The gay community's use of 'clean' is a particularly harsh reminder that they are excluded from the rest of society. Living with a particularly stigmatised chronic illness means experiencing discrimination and shame, even among people living with other chronic illnesses.

### **Silence and shame: life with HIV/AIDS**

The hostility that the men received at the hands of medical professionals and other members of the gay community creates the collective memory that HIV is a shameful illness, particularly when it is contracted through unprotected sex. Although some of the men who participated in this study had not directly experienced overt discrimination or hostility, they are aware of the negative attitudes towards other gay men with HIV/AIDS. In these instances, their collective memories have been constructed through other people's experiences. B. R. Simon Rosser's 1991 study of homosexual New Zealand men's daily encounters and life events concludes that 'having to put up with anti-gay jokes appears an almost universal experience of NZ homosexually active men'<sup>41</sup> which justified the need for anti-discrimination legislation. Rosser also notes that 56 per cent of his homosexual participants reported being physically or verbally attacked '*again, because of their sexual orientation*'.<sup>42</sup> This hostility was heightened by the onset of AIDS in the early 1980s.

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<sup>40</sup> Andrea M. Whittaker, 'Living with HIV: Resistance by Positive People', *Medical Anthropology Quarterly*, 6.4 (1992), p. 387.

<sup>41</sup> B.R. Simon Rosser, *Male Homosexual Behavior and the Effects of AIDS Education* (United States of America: Praeger Publishers, 1991), p. 61.

<sup>42</sup> Rosser, p. 61. Italicised in original text.

Craig has kept his homosexuality and his HIV-positive status hidden from many people, with the exception of a few family members and close friends. The few people Craig disclosed his status to have been supportive, and he has not experienced any overt discrimination about his sexuality or illness. While Craig does not recall being the victim of discrimination, he engages with the collective memory that HIV-positive homosexual men are targets of shame by recalling others publicised experiences. Writing about memory, Alon Confino argues that generations create memories of the past through “‘vehicles of memory”, such as books, films, museums, commemorations, and others’.<sup>43</sup> In other words, individuals remember events they have not been part of through the media, or other memorabilia. Craig’s decision to remain silent about being HIV-positive was influenced by other men’s experiences that were portrayed in the media. Craig recalls;

there was a piece in a paper where a gay man had died from AIDS and the landlord found out, and kicked his partner out, and had professional cleaners in and cleaned the whole place out, and then sold it, he wasn’t prepared to rent it again. And that was the attitude towards gay men and HIV back then.<sup>44</sup>

The belief that HIV/AIDS is a shameful illness influences some men’s decisions to remain silent about their own positive diagnoses. Although Craig was able to eventually tell close family and friends, some people living with stigmatised illnesses are isolated, and often refrain from telling anyone in their desire to conceal their condition.<sup>45</sup>

Unlike Craig, James was vocal about having HIV, and has publicly spoken about his condition on numerous occasions as a member of Body Positive. James’ narrative is influenced by the collective memories of being HIV-positive, homosexual, and Māori. These different collective memories all emerge at various points in his narrative, and he is empathetic towards others who share these collective memories. HIV-positive individuals encounter social, psychological and ethical issues about whether they will disclose their

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<sup>43</sup> Green, pp. 36-7.

<sup>44</sup> Craig Robertson, 31.38-32.01.

<sup>45</sup> Karolynn Siegel, Howard Lune, and Ilan H. Meyer, ‘Stigma Management among Gay/Bisexual Men with HIV/AIDS’, *Qualitative Sociology*, 21.1 (1998), p. 6.

status, and in whom they will confide.<sup>46</sup> As Craig's narrative shows, these decisions are sometimes influenced by others' experiences. However, while disclosure may encourage social support, it can also lead to discrimination and stigmatisation for some individuals.<sup>47</sup> People living with HIV/AIDS are often aware of the possible responses to their diagnoses. In some instances, after considerable time has lapsed, the individuals may seek out others in the same situation and establish a community, yet this is not always the case, and some people living with a stigmatised illness remain in isolation.<sup>48</sup>

In his narrative, James expresses particular sorrow for young Māori men who died during the early years of the epidemic. James claims that these men 'died with very little dignity. They died with very little hope – that they were gonna live through it or live – you know, to live longer.'<sup>49</sup> Because HIV/AIDS was considered shameful, and a disgraceful way to die, Māori men who died from HIV/AIDS-related illnesses were deprived of the same honour and farewell other Māori receive. Anne Salmond explains that traditionally in Māori culture, when one dies they are given a ceremony, usually lasting several days where family and friends gather and mourn the dead. This is called a tangi, which 'is revered as the most "Māori" gathering of all, and some informants in fact do not regard it as a type of *hui* at all but place it in a category of its own.'<sup>50</sup> The tangi is a key event in Māori culture, and when a death occurs, other gatherings in the district are halted so the deceased's body may lie on the marae, where it is kept company for a number of days by family and friends.<sup>51</sup> Yet James recalls that Māori men who died as a result of HIV/AIDS received a shorter farewell, which was influenced by the early 1980s and 1990s ignorance that surrounded the disease. James states that Māori families were denied the full grieving process before burying their dead, and that a Kaumatua said 'instead of having three days like we'd normally have for our funerals, we're gonna have one day and this [man is] gonna be buried tomorrow'.<sup>52</sup> Salmond argues that some Māori funerals no longer follow the traditional pattern, and the funeral is held in

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<sup>46</sup> Robert Klitsman, 'Disclosure', in *Encyclopedia of AIDS: a Social, Political, Cultural, and Scientific record of the HIV epidemic*, ed. by Raymond A. Smith (Chicago: Fitzroy Dearborn, 1998), p.181.

<sup>47</sup> Robert B Hays, Leon McKusick, Craig Robertson Pollack, Robert Hilliard, Colleen Hoff and Thomas J Coates, 'Disclosing HIV Seropositivity to Significant Others', *The family and HIV*, ed. by Rober Bor and Jonathan Smith Elford (London: Cassell, 1994), p. 45.

<sup>48</sup> Seigel et.al. , p. 6.

<sup>49</sup> James Mauke, 02.02.10-02.02.22.

<sup>50</sup> Anne Salmond, *Hui: a study of Māori ceremonial gatherings* (edition 2) (New Zealand: Taylor & Francis, 1975), p. 180. Hui here refers to a type of gathering or ceremony.

<sup>51</sup> Salmond, a marae is a Māori meeting house.

<sup>52</sup> James Mauke, 02.03.18-02.03.20.

the chapel of the funeral parlour, and follows European etiquette.<sup>53</sup> Salmond argues that these funerals, which are managed and controlled by the undertaker would not be considered ‘tangi’, and are an inappropriate way to farewell someone of Māori descent.<sup>54</sup> However, these ‘inappropriate’ farewells that Salmond refers to parallel the funerals that were held for Māori men who died from HIV/AIDS-related illnesses.

Shane also engages with ideas that HIV/AIDS is a shameful illness, which was influenced by his individual and collective memories. Shane was highly revered by his family, and recalls

I tried to isolate myself entirely from my family, only because that would just be shameful. They all put me on a pedestal and said “yay, Shane’s the only one to get out of [laughs] out of Stratford” [laughs]. So, yeah that would be shame, I would’ve imagined it brought shame on me.<sup>55</sup>

In this instance, Shane’s individual and collective memories intersect to create an understanding that his HIV-positive status was something to be ashamed of. Yet Shane’s narrative is subjective because he is recalling events from 27 years ago. Shane was diagnosed with HIV/AIDS in 1984, and has therefore been through many life changes since he was diagnosed. Alessandro Portelli acknowledges that ‘today’s narrator is not the same persona as took part in the distant events which he or she is now relating’.<sup>56</sup> He also argues that today’s narrators have undergone many changes including age, their social standing and their economic condition, therefore it is valuable to investigate what the informants hide, and why.<sup>57</sup> Silence is crucial when analysing oral interviews as researchers must listen to what the interviewees ‘fail to say, because it is in their silences and omissions that their underlying power structures frequently reveal themselves most clearly’.<sup>58</sup> Silence through omission is evident in Shane’s narrative when he was asked to recall his reaction to his diagnosis;

It’s like thirty years ago, this is another thing people say you know, they seem to remember what they felt at the time but me it’s like blank. I barely remember my

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<sup>53</sup> Salmond, p. 187.

<sup>54</sup> Salmond, p. 187.

<sup>55</sup> Shane Kelly, 26.27-26.45.

<sup>56</sup> Alessandro Portelli, ‘The Peculiarities of Oral History’, *History Workshop*, 12 (1981)1981, p. 102.

<sup>57</sup> Portelli, 1981, p. 102.

<sup>58</sup> Pendas, p. 228.

birthday let alone... You would think it being such a – an important event in my life I would remember it but not really, not the emotional stuff it was too long ago.<sup>59</sup>

In this instance, silence and memory are connected because silence in a narrative can indicate memory loss, or deliberate exclusion.<sup>60</sup> Because being diagnosed with HIV is traumatic, particularly in the early 1980s when a positive diagnosis was essentially delivered as a death sentence, it is likely that Shane's silence about his reaction to a positive diagnosis indicates the huge trauma that he experienced.

Carl also engages with the collective memory that HIV is a shameful illness, and uses what Chanfrault-Duchet identifies as 'key phrases'. Chanfrault-Duchet argues that key phrases 'aim to define a type of relation between the self and the social sphere,'<sup>61</sup> which includes the relation between an individual and their community or society. Carl engages with the shame associated with being HIV-positive, and contracting the virus through unprotected sex. He notes,

I had to come out twice and once was as a gay man and once was as a HIV-positive man, and actually in some ways it was harder for the HIV because 'the gay man' you can't help that, but you could've helped being HIV-positive.<sup>62</sup>

Carl uses the key phrase 'I had to', which indicates an obligation. The key phrase Carl uses reveals the distance between his sexual identity and the wider heterosexual society, and later his HIV-positive status. Seidman argues that in order to rebel against the gay "closet", individuals 'must have the inner resources and moral conviction to contest heterosexual domination'.<sup>63</sup> When people with HIV/AIDS are believed to have control over their behavior, and thus the power to prevent infection, they are believed to be responsible for their condition.<sup>64</sup> Carl contracted HIV through unprotected sex, and was therefore considered by some people to be responsible for his illness. This idea that people are responsible for their

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<sup>59</sup> Shane Kelly, 25.49-26.05.

<sup>60</sup> Diana Gittins, 'Silences in the case of a Psychiatric Hospital', in *Narrative and Genre: contexts and types of communication*, ed. by Mary Chamberlain and Paul Thompson (London: Routledge, 1998), p. 46.

<sup>61</sup> Chanfrault-Duchet, pp. 77-92.

<sup>62</sup> Carl Greenwood, 01.04.18-01.04.33.

<sup>63</sup> Steven Seidman, *The Social Construction of Sexuality* (United States of America: W.W. Norton & Company, Inc., 2003), p. 31.

<sup>64</sup> Devine et.al., p. 1218.

condition triggers judgment within the uninfected community, and often results in the rejection of people with HIV/AIDS.<sup>65</sup>

While the men's individual memories remain distinct, some participants engage with the collective memory that HIV/AIDS is a shameful illness, a memory constructed by people who are not living with the illness. The shame associated with HIV/AIDS has been spread through the media, and through some positive people's experiences with medical professionals, and other members of their communities. Homosexual men with HIV/AIDS were considered shameful because they contracted the disease through unprotected sex. Other archetypes that circulated about homosexual men fuelled these ideas of shame, particularly suggestions about homosexual promiscuity.

### **Unsafe, promiscuous sex: myths about homosexual men's sexual experiences**

During their narratives, most of the participants engaged with the collective memory of homosexual promiscuity. This centres on the myth that homosexual men have casual, anonymous sex which has no emotional connection, and is purely physical.<sup>66</sup> Because of these assumptions, some men felt that 'AIDS was the not entirely undeserved consequence of the unbridled popped promiscuity of the 1970s'.<sup>67</sup> In other words, the promiscuous homosexual male archetype helped fuel ideas that HIV-positive homosexual men should be blamed for their conditions. In public opinion, homosexual sex is often reduced to one that is 'first and foremost founded in physical pleasure, and participation in it is just something to do'.<sup>68</sup> This archetype came into media and public focus during the early years of the AIDS epidemic, as unprotected sex placed individuals at high risk of infection. Deborah Lupton identifies that a dominant HIV/AIDS archetype that featured in Western media during the 1990s is that of the sexually deviant homosexual man, whose illness is the deserved punishment for his sexual activity.<sup>69</sup> Such media representations produced public discourses about promiscuous, HIV-infected homosexual men which produced the stereotype that all homosexual men are likely to have HIV/AIDS.

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<sup>65</sup> Devine et.al., p. 1218.

<sup>66</sup> P. M. Davies, F. C. I. Hickson., P. Weatherburn, and A. J. Hunt, *Sex, Gay men and AIDS* (London: Routledge, 1993), p. 130.

<sup>67</sup> Leo Bersani, *Homos* (United States of America: Harvard University Press, 1996), p. 50.

<sup>68</sup> Davies et.al., p. 130.

<sup>69</sup> Deborah Lupton, 'Archetypes of infection: people with HIV/AIDS in the Australian press in the mid-1990s', *Sociology of Health & Illness*, 21. 1 (1999), p. 38.

At the beginning of the AIDS epidemic, ‘some of the information from medical sources was translated through the media in a climate of panic and misunderstanding’.<sup>70</sup> This aroused fear among homosexual men in New Zealand to keep away from American men. Yet among the heterosexual New Zealand population, ‘HIV has in many respects served to reconstitute homosexuality and identities founded upon homosexual desire.’<sup>71</sup> Therefore, homosexuality and HIV/AIDS are often conflated. This conflation results in bisexual and homosexual men, as well as intravenous drug users experiencing the stigma associated with HIV/AIDS, regardless of whether or not they have been infected.<sup>72</sup> People living with HIV/AIDS are therefore stigmatised because their sexual behaviour is already considered morally suspect, and people believe they must have engaged in morally degrading behaviour to become infected.<sup>73</sup> Yet it is not only homosexual promiscuity that is socially frowned upon. When HIV/AIDS is contracted through heterosexual sex, the infected individuals are often blamed for promiscuity, ‘which further serves to protect the uninfected person’s ingroup status as a nonpromiscuous heterosexual’.<sup>74</sup>

A common myth the men engaged with in their narratives is that homosexual men have promiscuous sex lives and contract HIV/AIDS through unsafe sex. Frank describes the process of one sharing memories of past actions as an ‘ethic of recollection’, which involves one displaying their past to others and accepting responsibility for past actions.<sup>75</sup> While listeners may disapprove of one’s past actions, they cannot be changed, and Frank argues that ‘the story is a moral opportunity to set right what was done wrong or incompletely’.<sup>76</sup> Although the men in this study engaged with the same myths, their individual subjectivity is reflected clearly in their narratives, and is based on their social, cultural and political backgrounds. The promiscuous homosexual archetype emerged when the men described their life events prior to being diagnosed.

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<sup>70</sup> Heather Worth, *Gay Men, Sex & HIV in New Zealand* (Palmerston North: Dunmore Press, 2003), p. 144.

<sup>71</sup> Simon Watney, ‘AIDS and the Politics of Queer Diaspora’, in *Negotiating Lesbian and Gay Subjects*, ed. by Monica Dorenkamp and Richard Henke (Great Britain: Routledge, 1994), p. 68.

<sup>72</sup> Devine et.al., p. 1216.

<sup>73</sup> Devine et.al., p. 1217.

<sup>74</sup> Devine et.al., p. 1217.

<sup>75</sup> Frank, p. 131.

<sup>76</sup> Frank, p. 131.



It is not only the myths that emerge in the men's narratives that are important to oral history, but also the way the participants convey their experiences. For instance, Michael, Jonathan and Shane used humour when describing their sexual encounters. Although humour initially lightens the tone of their narratives, Alistair Thompson identifies that 'jokes and laughter are often ways of discharging difficult or painful memories'.<sup>77</sup> It is likely that although their sexual experiences may not be painful to discuss, it was during these sexual encounters that the men contracted the virus. Thompson also argues that individuals also have the power to recreate, or repress memories of trauma that is yet to be resolved, and are deemed painful and 'unsafe' for the individual.<sup>78</sup> Some participants in this study appear to repress their traumatic experiences by using laughter.

Michael's political consciousness may have influenced his sexual promiscuity, and he argues that homosexual promiscuity was 'part of that whole – I think that whole sex-positive attitude from the '60s '70s was, you know, being gay you shouldn't try and imitate heterosexual obsession. We should create new social forms and new ways of – of being'.<sup>79</sup> Michael had also been involved with gay movements at his University before he travelled overseas, and his sexual behaviour may have been a way of seeking agency by opposing the heterosexual ideal that dominated western culture. The promiscuous homosexual male archetype emerges in Michael's narrative, which reveals that he previously adhered to dominant perceptions of promiscuous homosexuality. Although Michael engages with the promiscuous collective memory, his individual subjectivity is equally powerful. Michael recalls he cannot identify when, or where he contracted HIV, because 'I basically fucked my way from San Francisco to New York. I spent six months in New York having sex and taking drugs (laughs) so, God knows where it was (laughs). But somewhere along that line ... um something happened'.<sup>80</sup> Michael casually recalls his sexual experiences; however, his use of humour indicates that the outcome of these experiences, contracting HIV, is a painful memory.

Shane also engages with the collective memory that homosexual men have promiscuous sex. Like Michael, Shane's own sexual promiscuity was influenced by his previous social experiences. Shane reveals that he was severely overweight throughout his childhood and

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<sup>77</sup> Thompson, p. 44.

<sup>78</sup> Thompson, p. 240.

<sup>79</sup> Michael Stevens, *Life Narrative*, 21 June 2011, interviewed by Cheryl Ware, Auckland, New Zealand, 37.52-38.05.

<sup>80</sup> Michael Stevens, 26.59-27.13.

teenage years, and quickly lost weight after moving to Wellington. Shane recalls his first night in a gay club;

It was like you have a thirty stone body and suddenly you lose weight and you're attractive to people. And you're doing a job which is two thirty in the afternoon 'til nine at night so not only can you sleep in but you can go out. And I did (laughs), I did.<sup>81</sup>

Shane's extreme weight loss, and flexible job fuelled his sexual experiences and frequent appearance at gay night clubs. Shane's use of humour in this part of his narrative reveals a sense of embarrassment and pain, as it was this promiscuity that resulted in him contracting HIV in his early twenties.

The collective memory that homosexual men have promiscuous sex also emerges in Jonathan's narrative. However, Jonathan's narrative is again distinct because he is recounting experiences from his individual memory, and discusses his former partner's promiscuity, rather than his own. Jonathan contracted the virus from a long-term partner, and recalls 'I was in what I thought was a monogamous relationship'.<sup>82</sup> Jonathan's job required him to frequently travel away from home, and he notes 'unfortunately while I was away it was obvious that um, his term monogamous and mine was slightly different (laughs)'.<sup>83</sup> Jonathan's use of humour in this instance reveals his genuine uneasy feelings about the situation. Green asserts that interviewees sometimes use humour to deflect embarrassing or uneasy anecdotes, and therefore 'emotion and humour are central to the interpretive and persuasive dimensions of oral history'.<sup>84</sup> In other words, it is likely Jonathan used humour because the memory of his partner's infidelity, which resulted in him contracting the virus is still a painful memory. Jonathan also further dispels the belief that homosexual men are to blame for being HIV-positive, as his HIV-positive status is a result of his former partner's betrayal of his trust in an agreed monogamous relationship.

The promiscuous homosexual archetype also emerges in James' narrative, yet his experiences remain distinct as he, like Jonathan, did not contract the virus through anonymous sex.

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<sup>81</sup> Shane Kelly, 36.05-36.24.

<sup>82</sup> Jonathan Smith, 04.06-04.09.

<sup>83</sup> Jonathan Smith, 04.17-04.23.

<sup>84</sup> Green, p. 19.

Despite acknowledging anonymous sex occurs within the gay community, James rejects the commonly shared belief that HIV/AIDS is the consequence, and punishment for homosexual promiscuity. He does this by stating he contracted HIV from a partner, and not during an anonymous sexual encounter. James recalls that while overseas, he met a man and ‘fell in love and had a lovely holiday romance, and made plans to live with each other, um which never happened. Um, but I, you know, I had unsafe sex with him in New York City’.<sup>85</sup> In James’ narrative, he rejects suggestions that promiscuous sex contributed to him contracting HIV. Also, although James’ individual memory deviates from the collective memory that homosexual men have promiscuous sex, this collective memory emerges during his narrative. James’ earliest sexual encounters mainly involved what he terms ‘public sex environments’. James recalls, ‘I was meeting up with men, um mostly through public sex environments, like toilets, um and parks. Um, and these places I just instinctively stumbled across’.<sup>86</sup> James also confirms these places were frequented by many homosexual men, claiming ‘there’s places where guys can have sex with each other in the blink of an eye and sometimes words are not even spoken. Get your rocks off, have sex, and then go home and get – go on about your day’.<sup>87</sup> Therefore, while James engages with ideas about homosexual promiscuity, he maintains he did not contract HIV as a result of his own promiscuity.

The promiscuous homosexual male archetype emerges in many of the narratives while the men describe their life events prior to being diagnosed with HIV. Although some men recall their own promiscuous sexual experiences, they oppose public opinions that HIV/AIDS is a deserved consequence of promiscuity by recalling their individually subjective experiences. They do this by explaining their motivations for promiscuous sex, such as Michael’s political background and determination to deviate from heterosexual ideals of marriage, and Shane’s extreme weight loss and newly discovered attractiveness. James and Jonathan in particular oppose the claim that gay men are to blame for the virus because they contracted HIV through a partner, with whom they shared romantic relationships. Of the myths the men engaged with, humour is most apparent in the telling of the promiscuous homosexual archetype. This is possibly because the men’s memories of contracting the virus are the most painful. Another reason humour may have been used in the men’s narratives is because of my subjectivity as a woman from a younger generation. Other negative collective memories that

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<sup>85</sup> James Mauke, 39.29-39.42.

<sup>86</sup> James Mauke, 16.36-16.48.

<sup>87</sup> James Mauke, 17.10-17.22.

emerge in the men's narratives are based on ideas about 'AIDS carriers', and HIV/AIDS being a shameful disease. Like the promiscuous homosexual myth, the men engage with other collective memories in diverse ways. The HIV/AIDS 'carrier' archetype is particularly damaging as it portrays homosexual HIV-positive men as social deviants, and highly dangerous.

### **'AIDS carriers': men who set out to infect others with HIV/AIDS**

Another damaging myth the men engage with is what Deborah Lupton calls, the 'AIDS carrier'.<sup>88</sup> Lupton argues that the 'AIDS carrier' archetype is often embodied in the gay man who carelessly and at times maliciously spreads the virus by engaging in unprotected sex with his naïve victims.<sup>89</sup> Therefore, 'AIDS carriers' are often identified as a source of infection, and not a victim of the virus.<sup>90</sup> 'AIDS carriers' initially referred exclusively to homosexual men, who were already publicly scrutinised for perceived immoral promiscuity. However, during the mid-1990s, the media's focus shifted from focussing on homosexual 'carriers', to promiscuous heterosexuals, who were perceived as lacking self-control, and being vengeful.<sup>91</sup> Although media focus did not remain on homosexual men, ideas about gay 'AIDS carriers' were firmly embedded in the wider social discourses around HIV/AIDS. The men's narratives also reveal that archetypes of homosexual 'AIDS carriers' remained in their collective memories.

Shane directly confronts the 'AIDS carrier' myth by accepting he knew some gay men who fit this archetype. Some men Shane was acquainted with during the early years of the epidemic became so devastated and angry about their own diagnoses, that they intentionally infected others. This myth emerged while Shane was discussing the early peer support programme for HIV-positive individuals called 'twelve on twelve'. These support groups ideally consisted of twelve HIV-positive people sharing their own experiences, yet Shane recalls recruiting participants was difficult because of the stigma and hostility that surrounded HIV/AIDS. Shane recalls that '[twelve on twelve] worked in a way so long as it was all private, but um, after a while people talked and things got out and accusations started, and the

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<sup>88</sup> Deborah Lupton, 'Archetypes of infection: people with HIV/AIDS in the Australian press in the mid-1990s', *Sociology of Health & Illness*, 21. 1 (1999), p. 39.

<sup>89</sup> Lupton, 1999, p. 39.

<sup>90</sup> Lupton, 1999, p. 39.

<sup>91</sup> Lupton, 1999, p. 48.

Glenn Mills thing'.<sup>92</sup> The 'AIDS carrier' archetype is evident in Shane's narrative through his reference to infamous Glenn Mills, who was convicted of deliberately infecting others with HIV/AIDS. Glenn Mills' crimes have been highly publicised in national media, and he embodies the 'AIDS carrier' archetype.<sup>93</sup> Shane accepts Glenn Mills (Figure 3.1) was not the exception, and recalls, 'there was a lot of that too, "if I'm going I'm gonna take people with me", a lot of that vicious cycle'.<sup>94</sup> By naming Glenn Mills in his narrative Shane, perhaps subconsciously, ensured his narrative would be accepted and affirmed by others. Alistair Thompson argues that 'our memories need the sustenance of public recognition, and are composed so that they will be recognised and affirmed'.<sup>95</sup> Therefore, Shane composes his narrative about the 'AIDS carrier' around a well-known New Zealand case, and ensures his narrative will not be disregarded as speculation. Recognition is crucial during this part of Shane's narrative, as the 'AIDS carrier' myth is very serious and possibly damaging if it was discussed without being affirmed by a publicly proven story.



**Figure 3.1 Glenn Mills**

*Metro*, 'Deadly Sex', March 01 2010, p. 30

The 'AIDS carrier' archetype also emerges in Craig and Carl's narratives, yet their individual memories disturb, rather than accept this collective memory. Craig contracted HIV from a sauna, and after his positive diagnosis was confirmed, he adopted safe-sex practices to ensure

<sup>92</sup> Shane Kelly, 24.02-24.14.

<sup>93</sup> For newspaper articles about Glenn Mills crime, see 'Deadly Sex', 01 March 2010, *Metro*; 'HIV infection accused named', June 19 2009, *NZ Herald*; 'HIV-positive man accused of infection four others', May 29, 2009, *NZ Herald*.

<sup>94</sup> Shane Kelly, 24.34-24.39.

<sup>95</sup> Thompson, p.11.

he did not infect anybody. Craig recalls that after being diagnosed he went to a sauna, and ‘I immediately started right safe-sex from now on. Do not pass it on’.<sup>96</sup> By expressing his own determination not to infect anybody, Craig disturbs the ‘AIDS carrier’ archetype and explains how his own beliefs diverted from that of the ‘AIDS carrier’. Craig’s determination not to infect anybody is probably based on his own naïveté about the virus, as he had not thought about protected sex before being tested positive.

Carl, like Craig also disturbs the ‘AIDS carrier’ archetype in his narrative. Carl contracted HIV from his former partner, who lied about being tested. This deceit which may have influenced Carl’s determination to ensure he did not infect anybody else. After being diagnosed with HIV, Carl recalls, ‘I remember saying to my mum, “I’m not going to infect anyone like it stops with me”. So I can pretty much lay claim to that as well I know that there’s – there’s, I haven’t infected anyone.’<sup>97</sup> By maintaining he has not infected anybody with HIV, Carl fights the ‘AIDS carrier’ myth, by showing this is not representative of all homosexual HIV-positive men.

The ‘AIDS carrier’ archetype emerges in Shanes, Craig’s and Carl’s life narrative interviews. Although the homosexual male ‘AIDS carrier’ was most prominent in western media prior to 1990, the men’s narratives reveal that this myth remains in their collective consciousness. The men disturbed this myth by explaining their own determination to ensure they do not infect others with HIV. HIV/AIDS is a particularly stigmatised illness, and individuals living with the virus often face discrimination, which results in feelings of shame. While the men in this study fought against beliefs that they are to blame for having HIV, and ‘AIDS carriers’, they also disturb other collective memories that centre on HIV/AIDS being a shameful virus.

### **Living with an illness, but not a victim**

Finally, this chapter focuses on the wider HIV-negative community’s determination to exclude themselves from a ‘risk’ group, or more importantly, exclude people living with an illness from their own social circles. Michele L. Crossley argues that it is difficult to live with the ever-present fact that disease could impact anybody at any given time, therefore ‘when we see “other” we tend to implicitly dismiss the threat to ourselves by pointing to some

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<sup>96</sup> Craig Robertson, *Life Narrative*, 17 May 2011, interviewed by Cheryl Ware, New Zealand, 21.08-21.15.

<sup>97</sup> Carl Greenwood, 34.14-34.29.

lifestyle factor which distinguishes “us” from “them”.<sup>98</sup> People living with HIV/AIDS are sometimes the target of this exclusion, which is often based on suggestions that they are responsible for their illnesses. But this ‘othering’ mentality also occurs within groups of people living with an illness. For example, Crossley interviewed members from the National Long Term Survivors Group, many of whom constructed positive images of themselves as ‘survivors’, which often involved creating images of others as HIV ‘victims’.<sup>99</sup> These ‘victims’ were described as ‘weak minded’, or as having a ‘negative’ attitude towards their condition, are obsessed with the fear of dying, and are determined that they will die from their illnesses.<sup>100</sup> These images are not only created by other people living with an illness, but are also heavily dependent on the media. Journalists and artists often create derogatory images of ‘AIDS’ victims that are often embodied in already marginalised groups such as people of colour, gay men and intravenous drug users.<sup>101</sup> These images fuel pre-existing stereotypes about people with HIV/AIDS.<sup>102</sup> In their narratives, the men use their individual subjectivities to distance themselves from the myth of the ‘HIV/AIDS victim’. Although the men acknowledge they are living with a chronic illness, they portray themselves as survivors and reject any suggestions that they are ‘victims’.

While the majority of participants acknowledge that HIV has impacted upon their lives, they refuse to portray themselves as victims. Some participants also suggest that they are lucky in comparison to others who are living with an illness, or who share similar backgrounds to themselves. For example, Craig recalls his actions immediately after receiving a positive diagnosis, stating,

After they told me I sort of sat out in the car for about an hour and, just thinking about it and getting over the fact that I’ve got it and then I thought “well I can’t go back and change it, I’ve got the damn thing, adjust your life to accommodate it and get on with it!” Because sitting in a puddle of self-pity is not *me*.<sup>103</sup>

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<sup>98</sup> Michele L. Crossley, ““Survivors” and “victims”: Long-term HIV-positive individuals and the ethos of self-empowerment”, *Social science and medicine*, 45.12 (1997), p. 1863.

<sup>99</sup> Crossley, p. 1869.

<sup>100</sup> Crossley, p. 1869.

<sup>101</sup> Douglas Crimp, ‘Portraits of people with AIDS’, in *Cultural Studies*, ed. by Lawrence Grossberg, Gary Nelson and Paula Treichler (United States of America: Routledge, Chapman and Hall, Inc., 1992), p. 125.

<sup>102</sup> Crimp, p. 125.

<sup>103</sup> Craig Robertson, 28.46-29.05. Italicised because of emphasis in digital recording.

While Craig remained composed after receiving his diagnosis, his emphasis on '*me*' suggests that others may adopt self-pitying behaviour after receiving similar information. Craig also appears to accept HIV, and notes that he is healthy, and 'at the moment there is no cure for HIV. So, not a hell of a lot you can do. Just stick with it. Apart from [the medication] I'm fine'.<sup>104</sup>

James also constructs a positive image of his life, regardless of having HIV. According to Douglas Crimp, HIV/AIDS victims are often depicted in ways that show them as 'ravaged, disfigured, and debilitated by the syndrome; they are generally alone, desperate, but resigned to their "inevitable" deaths'.<sup>105</sup> The men disturb this archetype of the 'AIDS victim' in their individual narratives. James acknowledges that 'I really am and should – should be and I am thankful that I'm, you know, not sick with anything major right now'.<sup>106</sup> Although James eliminates any suggestions that he is an 'AIDS victim', he does not reject the myth entirely. James notes that 'I'm one of the lucky ones, definitely I think, um, you know I'm not – not sick or I've never even been to hospital'.<sup>107</sup> By claiming he is 'lucky', James implicitly acknowledges some people with HIV/AIDS fit the 'victim' archetype, but he is fortunate enough not to.

Jonathan also disturbs the 'victim' archetype by accepting his HIV-positive status, and does not express any remorse or regret. Jonathan accepts his illness and suggests that he would need to be cautious of his health regardless of having HIV. A main struggle Jonathan faces is ensuring he does not become paranoid about his illness, and recalls that if he feels unwell, 'trying to define is it the HIV medication? Or am I feeling ill? Or would this have happened anyway because of my age etc, etc?'.<sup>108</sup> In Jonathan's narrative, he suggests that his declining health is inevitable, and positions himself alongside others his age.

This chapter has focused on the different ways the men construct their narratives, and the ways they interpret their own life experiences. It has considered the collective memories that emerge in the life narratives, and the negotiations that exist between the men's individual and collective memories. Collective memories about HIV/AIDS and homosexual men are often

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<sup>104</sup> Craig Robertson, 01.02.10-01.02.21.

<sup>105</sup> Crimp, p. 118.

<sup>106</sup> James Mauke, 01.16.15-01.16.21

<sup>107</sup> James Mauke, 01.18.30-01.18.42.

<sup>108</sup> Jonathan Smith, 55.12-55.20.



created by people who do not belong to either group. These collective memories emerge in the form of myths, or archetypal figures that feature in the media, and public consciousness. In their narratives, the men engage with these collective memories, but on many occasions disrupt the archetypes by expressing their individual experiences. This chapter has not only focused on what the men say, but more importantly what is implicitly conveyed in their narratives through silences and key phrases. It provides a thorough analysis of the men's life narrative interviews, and reveals important aspects of their experiences as homosexual men living with HIV in New Zealand.

## Conclusion

Through interviews with HIV-positive homosexual men in New Zealand, this thesis has described a history of New Zealand attitudes and behaviour towards gay men diagnosed with HIV during the 1980s and 1990s. It presents their experiences specifically as members of a marginalised group who faced the double stigma of being gay in a society that condemned homosexual sex, and contracting the disease through unprotected sex.

This thesis focuses on illness narratives told by, using Frank's term, 'wounded storytellers'. It engages with the life narratives of individuals who were directly affected by HIV/AIDS in New Zealand. This study also gives the individual participants agency to tell their own life narratives, and share their perspectives on events of which they were part. While modern disease narratives commonly focus on the patient's perspective, as in personal studies and accounts of illness or 'pathography', New Zealand historiography is severely lacking in patients' narratives about HIV/AIDS. This thesis addresses this omission by contributing the life narratives of six men who have survived the HIV/AIDS epidemic, and are currently living with HIV as a chronic illness. This thesis accepts the challenge set out by Elizabeth Fee and Daniel Fox, as by consulting individuals currently living with the illness, historians might create new historical sources, as well as analysing pre-existing documents.<sup>1</sup>

Chapter One sets out the political and social context of the New Zealand HIV/AIDS epidemic. It includes analyses of a range of primary material, including *Parliamentary Debates*, selected newspaper and magazine articles, and material from archived safe-sex campaigns. These sources show New Zealanders' diverse responses to the outbreak of HIV/AIDS, which ranged from an anti-gay backlash, to support organisations and gay liberation. Setting out the context of the epidemic in Chapter One was necessary to show that stigma is only one part of the story. While the epidemic revived prejudice against homosexuals, networks of support were also established to cater to men and women infected with the formerly fatal disease, and to prevent further infections. This chapter also contextualised the New Zealand case amidst

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<sup>1</sup> Fee, Elizabeth, and Daniel M. Fox 'The Contemporary Historiography of AIDS', *Journal of Social History*, 23. 2 (1989), p. 312.

the international epidemic, and reveals that relatively late government intervention was a worldwide issue.

Chapter One also focused on the powerful imagery that appeared in New Zealand and international media, which conflated HIV/AIDS with deviance and death. The media helped fuel public fears about the epidemic, and created archetypes about gay men with HIV/AIDS. These archetypes are thoroughly examined in chapter three. The media was particularly notorious for depicting homosexual men as villains, and unworthy of sympathy. Stories about homosexual promiscuity circulated in New Zealand and international media, and were often contrasted with images of ‘innocent’ victims. The media also helped create the damaging ‘AIDS carrier’ archetype, which stemmed from fears that people with HIV/AIDS would deliberately infect others.

Chapter Two and Three move onto a thorough analysis of the seven individual oral history interviews that I conducted with men as part of this research. I interviewed six HIV-positive homosexual men, and one HIV-negative homosexual man, Dan, as a counterpoint to these narratives. Dan’s interview is valuable because of his experiences working with the NZAF, his relationship with his brother who died from AIDS-related illnesses, and his status as a member of a group perceived as ‘at risk’.

Chapter Two offers an analysis of the content of the men’s narratives, and the different themes that emerge as they discuss their life events. The content of the men’s narratives uncovers their experiences growing up gay amidst post-war notions of masculinity, and the pressure to conform to heterosexual ideals. This chapter is set in New Zealand’s social and political context that is examined in chapter one. Chapter two explores the men’s perceptions of their own, and others HIV-positive statuses, and their individual experiences living with a chronic illness. Therefore, while each man’s experience is individually subjective, chapter two highlights the thematic threads that emerge across the narratives, uncovering the men’s experiences as a collective.

Finally, Chapter Three examines the diverse ways the men construct their illness narratives, and the individual and collective memories that emerge. It uncovers the dominant archetypes that the men either engage with, or disturb. While some men acknowledge the partial reality of some derogatory stereotypes including the ‘AIDS carrier’, and homosexual promiscuity,

their individual subjectivity is also apparent, and their narratives are influenced by their diverse social, cultural and political backgrounds and experiences. In their narratives, the participants disrupted many of the derogatory myths by sharing their personal experiences, and revealing that these archetypes do not always accurately represent homosexual men living with HIV.

The men's experiences growing up gay was influenced by New Zealand's conformist culture that idealised traditional conceptions of masculinity. The participants' experiences are distinct amongst other HIV/AIDS diagnoses because of their sexualities. While many of the men in this study were oppressed by social prejudice, they found ways to counteract hostility they were targeted with. These included creating new masculine ideals, and disturbing stereotypes about homosexual men as effeminate. While these men's experiences are individually subjective, their narratives uncover some collective aspects of gay men's lives with HIV.

This thesis also establishes a foundation for further research about the impact of HIV/AIDS in New Zealand's recent history. The men's life narratives included in this thesis are valuable, and it is crucial that historians take the opportunity to document the individual and collective experiences of individuals currently living with HIV in New Zealand. In doing so, historians will be able to enrich New Zealand's medical history by including a larger number of life narratives, thereby creating an accurate depiction of the patient's lives and perspectives. Further study in this area would also benefit from a strong focus on gay Māori men, or Takatāpui, which was not possible in this research due to time constraints, and the difficulty accessing participants.

Oral history provides an opportunity to uncover personal histories from marginalised individuals and groups who are often omitted from written documents. By focusing on the oral histories of gay men living with HIV, this thesis contributes the patients' perspectives to New Zealand histories of health and medicine. Using an oral history approach enabled this thesis to uncover the participants' personal stories, and the diverse ways their individual subjectivity was shaped by outside influences, namely the media and public opinion. This thesis has taken a proactive approach to historical research, and consults individuals with living memories of the epidemic. In doing so, it not only examines the impact HIV/AIDS had

on New Zealanders in general, but particularly the way gay men with or without HIV were implicated inside the unfolding histories of HIV/AIDS in late-twentieth century New Zealand.

## Appendices

### Appendix 1: Ethics approval

John Paterson

<johnp@waikato.ac.nz>

‘Application for Ethical Approval: FS2011-16’

30 April 2011

Personal email

(Accessed 30 April 2011)

30 April 2011

Dear Cheryl

Application for Ethical Approval: FS2011-16 **“A History of New Zealand social attitudes and behaviour towards HIV positive homosexual men in the Central North Island from 1983-1997”**

Thank you for submitting a revised Application in response to my letter of 21 April. This, along with the list of changes you had made, was received by email on 27 April. I appreciate the hard work you have done in dealing with these issues and in clearly setting out your responses.

The revisions you propose fully satisfy the points raised by the Committee.

This letter is to provide formal ethical approval for your project.

I would be grateful if you would provide Dellie Dellow, the Committee’s secretary, with one hard copy of your revised application, signed by yourself and your supervisor, so that it may be added to the Committee’s files.

With best wishes,

John Paterson

*Chair*

*FASS Human Research Ethics Committee*

## **Appendix 2: Introductory letter for participants**

Dear Sir,

I am a student at the University of Waikato, and am currently completing a Master of Arts Degree in History. My research is partially based on oral interviews, and I will conduct a semi-structured interview with up to six individuals about their life experiences as HIV positive homosexual men. I also intend to conduct up to two interviews with individuals who work/worked in HIV/AIDS organisations. If you are able and willing to participate, I would be very interested in interviewing you as part of my research.

This project is titled 'A History of New Zealand social attitudes and behaviour towards HIV positive homosexual men in the North Island from 1983-1997', and focuses on the experiences of HIV positive homosexual men during the AIDS epidemic. I have enclosed an 'information sheet' which discusses my project in finer detail, and I would greatly appreciate if you could take some time to read it to ensure you are aware of the interview process, and the focus of my research. The information sheet details the steps I will take to ensure confidentiality is maintained, and the steps I will take towards maintaining anonymity should you wish to remain anonymous.

My research primarily focuses on personal experiences, and the impact that social fears and attitudes in New Zealand had. After completing interviews with individuals from different backgrounds, I hope to draw some conclusions about how attitudes towards homosexuality and HIV changed over the fourteen year period. The interview is expected to take about 90 minutes, however as all the questions are open-ended, you may decide how long or short the interview will be. You may also choose to decline to answer certain questions, or may withdraw from the interview at any time.

I am very excited about completing this research, as I believe it will be a rewarding experience for both myself, and those who wish to participate. I am very interested in listening to your life experiences, and any insight you may have on the AIDS epidemic in New Zealand. I will contact you in a few days to progress towards deciding upon an



interview time if you are interested, and to discuss confidentiality and any questions regarding this research that you may have.

Thank you for your time and please do not hesitate to contact me if you have any questions.

Sincerely,

Cheryl Ware

caw25@waikato.ac.nz

### **Appendix 3: Information sheet for participants**

I am a student at the University of Waikato currently completing my Master of Arts Degree in History. I am particularly interested in social history regarding gender rights and sexuality in New Zealand. Therefore, I am conducting research about HIV/AIDS and homosexuality in New Zealand society by interviewing up to six HIV positive homosexual men, and up to two individuals who worked in organisations that offered support to HIV positive individuals. These interviews will hopefully shed light on previous social attitudes regarding homosexuality and HIV.

I would like to interview you about your experiences and any events that have been significant to you.

By completing this research, I wish to draw some conclusions about attitudes and behaviours towards HIV positive homosexual men in New Zealand society, and if these changed amidst the fear of AIDS.

The interview is expected to take about an hour to 90 minutes; however, the length of the interview will be determined by the experiences that you may be willing to share. Therefore, you may choose the length of the interview, as I have not set a time limit.

If you wish to participate, I will discuss the consent form with you, and I will do everything within my power to ensure confidentiality is maintained. If you wish to remain anonymous, we can discuss the use of a pseudonym to obscure, as much as possible, your identity. Should you choose anonymity, I will take great care when writing my final report to ensure you cannot be identified in any way.

In future, I may publish this thesis, which will be addressed in the consent form. After I have completed the thesis, an electronic copy will be available online.

I would like to record the interview so that I have a record of your life experiences that is accessible to me at various times during the academic year while I am completing the course. The recordings will then be securely stored in a secure cabinet in the History department at the University. Potential long-term storage of the recordings and various other options will be

discussed with you. You will also have control over whether or not your recorded interview may be accessed by other researchers while it is in storage.

I do not plan to transcribe the entire interview, but I will send you transcribed extracts of your interview that I plan to use in the thesis for you to read and comment on. I will do this within two weeks of completing the interview.

This research project has been approved by the Human Research Ethics Committee of the Faculty of Arts and Social Sciences at the University of Waikato, and I will work hard to ensure my research is respectful of your rights.

Should you agree to the interview, you are welcome to refuse to answer any questions, or withdraw from the research entirely up until two weeks after the interview has taken place. I will respect your decisions and cease from using your interview in my study if this is the case.

If you have any questions please do not hesitate to contact me: Cheryl Ware  
caw25@waikato.ac.nz and I will hastily reply.

Any questions may also be directed to my supervisor:

Dr. Catharine Coleborne

cathyc@waikato.ac.nz

Any questions regarding the ethical conduct of this research may be sent to the Secretary of the Human Research Ethics Committee.

fass-ethics@waikato.ac.nz

## Appendix 4: Consent form for participants

### History Programme

School of Social  
Sciences

*Te Kura Kete Aronui*

The University of  
Waikato

Private Bag 3105

Hamilton,

New Zealand

Phone +64 7 838

4048



THE UNIVERSITY OF  
**WAIKATO**  
*Te Whare Wānanga o Waikato*

### CONSENT FORM.

Name \_\_\_\_\_

Date \_\_\_\_\_

Interviewer \_\_\_\_\_

Place \_\_\_\_\_ of  
interview \_\_\_\_\_

1. I agree that the original recording of my interview will initially be securely stored in a secure cabinet in the history department at the University of Waikato.

I want my recording destroyed after five years: Yes No

I want my recording kept for long-term storage at one of the following locations:

- a) Archives New Zealand
- b) Lesbian and Gay Archives of New Zealand (LAGANZ) in the Alexander Turnbull Library in Wellington
- c) Hamilton City Library
- d) Local Iwi Archive: \_\_\_\_\_
- e) Other \_\_\_\_\_

2. I allow access to the recording of my interview, and the information sheet I have read, and the consent form for researchers after the following time has lapsed:

- a) Never
- b) Immediately
- c) 6 months
- d) 5 years
- e) Other\_\_\_\_\_

3. The recording of my interview and accompanying material may be published, or quoted in published work: Yes No

4. I wish to remain anonymous: Yes No

5. I agree to have my interview audio recorded: Yes No

6. I agree to have extracts from my interview, and any findings published in the thesis:  
Yes No

7. I have read the Participant Information Sheet for this study and have had the details of the study explained to me.

8. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

9. I understand that I am free to withdraw from the study up until two weeks after the interview, or to decline to answer any particular questions in the interview.

10. I understand that under the terms of the Privacy Act 1993 I may have access to this interview and request amendment of any information about me contained within it.

11. Comments

Name of interviewer:

Date:

Signature of interviewer:

Name of interviewee:

Date:

Signature of interviewee:

Any questions or comments may be directed to the Researcher: Cheryl Ware  
[caw25@waikato.ac.nz](mailto:caw25@waikato.ac.nz)

Or the supervisor:

Dr. Catharine Coleborne    [cathyc@waikato.ac.nz](mailto:cathyc@waikato.ac.nz)

## **Appendix 5: Interview questions**

**This is a list of questions I will take to the interview. The questions I will ask may vary depending on what the interviewee discusses. However, I aim to cover all these points in the interview.**

1. Tell me about your life growing up?

I have selected this as my first question which will encourage the interviewee to start talking freely about their life experiences. It will also provide me with insight into their personal background prior to the HIV positive diagnosis.

2. How much did you know about HIV/AIDS before being tested?
3. What reactions to HIV/AIDS were you aware of?
4. Tell me about your decision to get tested for HIV/AIDS. Did you notice symptoms?  
Did you postpone getting tested for any reason?
5. What happened after a positive diagnosis was confirmed?
6. Do you think your social experiences as a HIV positive individual were influenced at all by being homosexual?
7. Did the reaction to your HIV positive diagnosis differ between the heterosexual and the gay community?

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