

**From Victims to Warriors: collective identity generation  
at cancer assemblies in South Africa**

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## ***Dedication***

I dedicate this work to all the Fighting Fairies, Cancer Crusaders, Betty Boobs and the more than 60 000 Relay For Life participants in South Africa who care about the impact of cancer on the lives of people they love – in their families, their communities, and beyond.

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## ***Abstract***

Interest in this topic was awakened by the rapid growth of Relay For Life in South Africa and its striking ability to bond people during mass cancer gatherings. Questions were raised about the generation of collective identities during these assemblies, the nature of the activated identities, and how these relate to the broader debates about cancer and identity. This inquiry investigates the unexplored intersection of cancer and identity in the context of a burgeoning solidarity movement that has found a strong following countrywide.

A contemporary hermeneutic perspective allowed a dual focus on the micro-sociological dimensions and the structural elements that converge to generate collective identities at assemblies. A theoretical scheme was synthesized out of the work of theorists who deal with collective identity, spaces set aside for people in crisis, social interaction during focused gatherings and illness narratives. A non-comparative case study was used to investigate the phenomenon at 20 cancer assemblies. Short-term ethnography, focus group interviews, photographs and YouTube videos provided the data that was analysed using the hermeneutic circle of interpretation.

The findings showed that personal illness identities and situation-specific role identities interact with a potent cocktail of elements – ephemeral space, a shared focus on cancer, collective action, illusion and emotions – to activate three symbolic identities: a dominant collective identity that relies on heroic warrior mythology, a secondary collective identity that draws upon a transformation ideal, and a hidden identity which has its roots in the notion of being wounded.

It is argued that assemblies rely on a dominant collective identity which is symbolic in nature and imposed on participants by the cancer movement. Participants are portrayed as positive, hopeful heroic warriors tasked with vanquishing cancer. Although ubiquitous at cancer assemblies, the dominant collective identity is nevertheless sufficiently fluid to allow a measure of hybridization, inversion and contestation. This inquiry gives credence to other work on cancer and identity which recognizes that the dominant identity provides benefits not offered by a victim representation. It also expresses reservations about the wisdom of expecting affected people to maintain a brave exterior in the face of an illness that causes emotional disequilibrium.

## ***Glossary of terms***

**Caregiver:** while this term is strongly associated with those who provide most of the care in an end-of-life situation to a close family member (Githaiga 2013: iv), in the Relay For Life environment the label is more broadly applied to family members, romantic partners, friends, home-based carers and a range of cancer service providers concerned with the care of people with cancer or those with a history of cancer, irrespective of the stage or gravity of the illness.

**Collectivity:** the concept is derived from the sociological definition given by Richard Jenkins (2008: 9). In this dissertation, the embodied group of participants at Relay For Life assemblies is defined as the collective actor. These are participants who recognize both the existence of Relay For Life as a social entity and their own sense of belonging to it.

**Crisis heterotopia:** a concept derived from the work of Michel Foucault (1986: 24–25) and applied in this dissertation to Relay For Life assemblies. Crisis heterotopias allow people to congregate for a transient period in a selected space away from the community at large, allowing them to reflect collectively on a shared predicament.

**Entrainment:** a term used by Randall Collins (2014: 47–101) to describe the process whereby participants become caught up and swept along during face-to-face social encounters through ritual elements such their shared focus, their emotions, collective symbols, talk and performance.

**Firebirds:** an identity label that is applied in this inquiry to participants at Relay For Life assemblies who portray themselves as transforming or transformed by the illness experience in a manner which embraces both the constraining and enabling aspects of cancer.

**Focused gathering:** a concept used by Irving Goffman (1961: 7–14) to describe social encounters where people gather in a real life, face-to-face situation for a sustained period of time with the express purpose of dealing with a particular matter that is of shared interest to the assembled group.

**Global Cancer Movement:** internationally more than 760 cancer organizations based in 155 member countries have been brought together under the umbrella of the Union for International Cancer Control, based in Geneva, Switzerland (UICC 2014). Together, these organizations work in unison on cancer control programmes. Relay for Life is the domain of

the American Cancer Society, but the member countries which manage Relay For Life programmes are also members of the Union for International Cancer Control.

**Heroes of Hope:** are people living with cancer appointed to act as inspirational role models by member countries in consultation with the global Relay For Life movement. These elite members of the movement act as spokespeople for Relay For Life. They represent ‘courageous voices of HOPE’ and highlight the need for all who care about the cancer cause to ‘fight back against cancer’ (American Cancer Society 2012: 1).

**Heroic Warriors:** an overarching term used in this dissertation to refer to one of the symbolic collective identities encountered at Relay For Life assemblies. The term is used in preference to the commonly used ‘survivor’ and can refer to any participant at a RFL gathering, irrespective of whether they are people with cancer, have a history of cancer, or are caregivers, team captains, team members or organizers. Heroic warriors are typified by an overtly hopeful and positive attitude towards the illness experience.

**Identity work:** this concept comes from the work of David Snow (2001: 7) and is used throughout this dissertation to denote the rich array of identity talk and performance used at RFL assemblies to activate, express, maintain and transform collective identities.

**Luminaria ceremony:** a commemoration ceremony performed at all Relay For Life gatherings all over the world to remember those who died as a result of cancer and to honour people who are struggling with cancer. The ritual is performed after sundown, when decorated candle-bags placed around the walking track are lit and suitable rituals, speeches and music are used to add to the reverential atmosphere.

**Survivor:** a ubiquitous label used in public discourse, in the global cancer movement and by the majority of contemporary scholars who write about cancer and identity to describe people with cancer who have completed their treatment. In the Relay For Life movement, however, the term has a particularly broad interpretation, referring to anyone who has ever been diagnosed with cancer, irrespective of the type of cancer, gravity of the illness, prospect of survival, or whether or not the person is in remission.

**Walking Wounded:** a term used in this dissertation to denote Relay For Life participants who are worn down by the illness, who experience ‘abject embodiment’ (Waskul & Van Der Riet 2002) as a result of cancer, feel victimized by the illness, or are dying. The term relates

most commonly to people with cancer, but can also apply to caregivers who feel worn down by the illness experience.

***List of abbreviations and acronyms***

ACS	American Cancer Society
CANSA	Cancer Association of South Africa
CAQDAS	Computer-assisted qualitative data analysis software
EHM	Embodied Health Movement (Brown et al. 2004)
FGI	Focus group interview(s)
GCM	Global Cancer Movement
HoH	Heroes of Hope
LGBT	Lesbian, gay, bisexual and transgender
MRG	Member Reflections Group
RFL	Relay For Life
UCT	University of Cape Town
UICC	Union for International Cancer Control
USA	United States of America
USD	United States Dollars
ZAR	South African Rand

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# Chapter 1

## INTRODUCTION

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### *Preamble*

It is a deeply upsetting experience to hear that you have cancer or to find out that someone you care about has been diagnosed. Cancer has the power to create havoc in the lives of affected people. Medical advances and changes in societal attitudes towards cancer have not completely eliminated the repercussions of the illness. The consequences of cancer – the physical effects of the illness, the indignity of treatment, the fear and depression, coupled with the impact on identity – can be extremely burdensome. Some affected people respond to the crisis by seeking out others who are in the same boat or on a similar quest to regain their equilibrium following the distress of the diagnosis. The hardship caused by cancer can seem more bearable when affected people find solidarity with others at treatment centres, through Internet forums, support groups, or cancer solidarity initiatives such as Relay For Life (RFL). These encounters offer an opportunity to embrace collective identities that give new meaning to an upsetting illness experience.

A decade ago, the Cancer Association of South Africa (CANSA) became the first African cancer organization to become involved in RFL, a successful global programme that had its origins in the United States of America (USA) three decades ago. After a tentative start in South Africa, RFL very quickly gained momentum. Currently more than 60 000 people in 87 towns and cities across the country participate each year in overnight RFL assemblies. RFL in South Africa continues to show steady growth, with increasing numbers of communities joining the collective effort each year.

This qualitative case study investigates collective identity activation at mass gatherings of the RFL movement in South Africa. It also examines the nature of the situation-specific identities encountered at assemblies and what these identities tell us about cancer and identity. Those who attend RFL assemblies have an affinity with cancer, either through having been diagnosed with the illness or through their concern for a family member, friend or colleague with cancer. Annual community-based assemblies are the lifeblood of RFL, allowing those who are dealing with the illness to experience togetherness, acceptance and a sense of community while engaging in collective action to improve cancer-control in their local

communities. Significantly from the perspective of this inquiry, these mass assemblies also create room for the refashioning of identities in the midst of the cancer experience.

In this introductory chapter, I situate myself as the researcher, explaining the aim of the inquiry and my rationale for doing this research. I present the central research question (CRQ) and three sub-questions, then sketch the backdrop to the study, give an overview of my chosen research perspective, and explain the structure of the dissertation.

### ***Situating myself as the researcher***

The choice of RFL assemblies in South Africa as my case study was influenced by both professional and personal factors. RFL was one of my key responsibilities while I was on the national senior management team of CANSA. As a practitioner I spent close on six years working for CANSA during the run-up, introduction and national rollout of RFL in South Africa. In 2005, RFL became a part of my life, when I was invited to observe the first local assembly and to meet representatives of the American Cancer Society (ACS). At the beginning of April 2006, I took over the national coordination of RFL.

I left CANSA at the end of March 2010, but there was a period of more than two years after this when I did not attend RFL assemblies. During this time a family member with whom I have a particularly close relationship was diagnosed with cancer, giving me first-hand exposure to a world of anguish and major readjustment. This personal experience was further strengthened by my relationship with two of my friends who underwent cancer treatment in the past year. I have never been diagnosed with cancer, so I cannot claim any first-hand experience of the illness.

Over the past decade, my relationship with RFL has varied between being a practitioner, a caregiver, an interested bystander and a researcher. I am neither an insider nor an outsider, but rather a hybrid of those two positions. It is not possible for me to bracket my insights into the RFL movement as I have been involved with the initiative for too long, and a distanced position has never been an option. I was particularly keen to explore the generation of collective identity, as I knew from my past experience that there would be an abundance of intense collective identity work at RFL assemblies and that these would provide me with a wealth of data. Collective identity generation is a prime example of a sense-making process on the part of solidarity groups, and I knew that the RFL constituency had already gone a long way in understanding their collective identities. However, I felt that as a researcher there

was an opportunity to explore this sense-making process on the part of RFL participants and to add another layer – or layers – of interpretation to the existing interpretations.

The aim I set myself with this study is to broaden understanding of how South Africans who belong to the world's largest cancer solidarity movement activate collective identities when gathered together at RFL assemblies, as well as the nature and meaning of the identities they generate. I use an eclectic theoretical scheme that weaves together different strands of knowledge. I do not limit myself to a particular group of theorists, although I rely heavily on the work of Foucault (1986) on crisis heterotopias, Frank (1991 & 1995) on the illness experience and narratives, Snow (2001) on collective identity, Lawler (2003) on collective identity generation, and Collins (2004) on interaction ritual chains. These theorists, and many others, gave me the stepping stones for the river I had set out to cross. It was only by combining the work of different theorists that I was able to arrive at the analytical insight that allowed me to develop the thesis.

As a researcher interested in hermeneutic research, I do not recognize definitive truth. From the outset, I understood that I would not find a single reality about collective identities at RFL assemblies. Instead, I would gain a momentary understanding of the phenomenon in the context of a dynamic cancer movement that was constantly evolving, a phenomenon which could be viewed from multiple vantage points. Guba and Lincoln (1989: 149) refer to this as the hermeneutic-dialectic process and see its purpose as the co-creation of understanding by all the stakeholders involved in the research. They see the 'process as hermeneutic because it is interpretive in character and dialectic because it seeks a Hegelian synthesis through comparison and contrast of divergent views' (Erlandson et al. 1993: 124). I therefore do not make any definitive claims regarding the discovery of 'facts'. Instead, I endeavour to uncover, layer by layer, an understanding of the meaning-making associated with collective identity activation at mass RFL assemblies. In order to accomplish this, I worked consciously with my own involvement in the RFL world and my personal insights into the cancer experience. In doing so I accepted that I and the other RFL participants were jointly producing an understanding about the phenomenon under investigation.

### ***Aim, rationale and research questions***

The collective identities, both of people with cancer and those who care about them, have implications for how they view themselves and how they are viewed by society. The past

decade has seen a fierce scholarly debate about the experience of cancer and its impact on identity (Kaiser 2008; Hubbard, Kidd & Kearney 2010; Bell 2012; Chambers et al. 2012; Bell & Ristovski-Slijepcevic 2013; Lewis 2013; Cho & Park 2014), as well as a popular debate (Koningsberg 2011; Bach 2014; De Clerk 2014; Hehir 2014; Jarvis 2014; *Leadership* 2014). This inquiry takes a further look at the issue of cancer and identity, but approaches it from a fresh angle. The theoretical scheme used in this study was specifically designed to enable me to construct new knowledge about collective identity generation in the context of focused cancer assemblies. This is not simply a return to existing theoretical schemes, but rather a novel way of pulling together dimensions that speak to this topic. I did this by drawing together elements that speak directly to the unexplored intersection of cancer and identity in the context of a burgeoning cancer solidarity movement that has found a strong following in South Africa.

I believe that this research is warranted in the context of South Africa, where an estimated quarter of the population will develop cancer in their lifetime (South African Medical Research Council 2013) and where many affected people seek out collective experiences in order to make sense of their experience of the illness. Cancer rates are climbing on the African continent and it is predicted that by 2028 more than 1.43 million new cases will be diagnosed annually and that 1.08 million people will lose their lives due to factors such as a growing population, an aging populace, lifestyle factors, and sub-standard screening and early detection services (Jemal et al. 2012: 4372).

The quest to gain a deeper understanding of collective identity activation at RFL gatherings in South Africa led me to ask the following **central research question (CRQ)**: How are collective identities activated at RFL cancer assemblies in South Africa, what is the nature of these identities, and what do they tell us about cancer and identity?

In order adequately to cover the terrain of the study, I also posed the following sub-questions:

**Sub-question 1:** How do the elements that form the backdrop to RFL assemblies create arenas for the intensification or weakening of collective identities?

**Sub-question 2:** How do RFL assemblies, once they are animated and in flow, facilitate the amplification or weakening of collective identities?

**Sub-question 3:** How are collective identities embraced, hybridized or disrupted during RFL assemblies, and how does this relate to the broader debates about cancer and identity?

Each era brings its own ways of representing people with cancer. Until the mid-1980s there was a common perception that those diagnosed with cancer were doomed to terrible suffering before their inevitable deaths (Kaiser 2008: 80), and there was little question of advocacy or activism to redefine victim identities. In the mid-1980s, however, the conversation in the global North started showing a marked change, with the adoption of the 'survivor identity' and the refusal of many diagnosed people to be seen as victims (Ibid.). Early diagnosis, regular screening and improved treatment options meant that more people were living longer with the disease. In South Africa, both affected people and local cancer organizations took two decades longer than their counterparts in the global North to show a noteworthy move away from identity labels such as 'patients', 'sufferers' and 'victims' to the alternative labels of 'survivors', 'heroes' and 'warriors'. This change was helped along by the growth of solidarity organizations such as People Living with Cancer and CANSA's introduction of RFL. Today there is great enthusiasm for the idea that people with cancer can afford to be optimistic about their futures.

The rapid growth of RFL in South Africa and the ease with which it seems to draw affected people into its fold made me settle on collective identity as a phenomenon needing analysis. Collective identity is a useful sociological concept, and one which has been used to derive insight into countless aspects of social movements, including how they evolve, how they generate commitment among their adherents, and how they sustain their interest over time. Other factors include how solidarity networks operate as action systems, the identity projects within movements, the tactical choices made to take advantage of opportunities in the social milieu of the movement, as well as collective processes that are hidden, silent or seemingly invisible (Melucci 1995: 41, 51–55; Polletta & Jasper 2001: 283; Snow 2001: 1; Hunt & Benford 2004: 433; Flesher Fominaya 2010: 393). Given the track record of collective identity as a useful concept in social science research, it struck me as a suitable fulcrum with which to open up my areas of interest and to explore the data that needed to be analysed.

South Africa is not a complete newcomer to health movements that are citizen-driven. At its peak, the Treatment Action Campaign attracted international recognition for its efforts in the HIV/AIDS field. In the main, however, social movements in health attract little attention from social scientists (Brown et al. 2004: 50) and I felt that this was another area in which I could make a contribution. RFL offered an opportunity for study brimming with expressive collective identity work that I believed would tell an intriguing story and be potentially

interesting to others concerned with collective identities in the context of a social movement dedicated to a major health issue. From the outset I felt that the exceptional richness of the social encounters between participants at RFL gatherings, the storytelling, flamboyant attire and adornments, and the emotional ceremonies, must play a role in bonding participants together and that these assemblies held great promise as a case study. In conducting this inquiry, I hoped to draw away the curtains to look into the world of an important cancer solidarity movement and discover how it worked with collective identities<sup>1</sup>.

Although mass assemblies are used by many social movement organizations as a means of engaging their constituents, empirical research is relatively silent on collective identity generation in the context of mass gatherings. I found no studies that converged on an illness experience, solidarity movements, mass assemblies and collective identity generation. Whereas there has been research elsewhere into other assembly-based initiatives that rely on a strong sense of belonging, such as Burning Man (Bowditch 2010; Gilmore 2010) and Sacred Harp (Heider & Warner 2010; Clawson 2011), no research has been devoted to collective identity generation at cancer assemblies – irrespective of whether it is RFL or a rival cancer movement. This study thus offers substantial insights into another under-researched aspect of social movements, namely collective identity activation during mass assemblies of a solidarity movement concerned with an illness experience.

This inquiry was not designed to offer the RFL movement guidance on best practice regarding collective identity generation and its outcomes. Despite this, I believe that some of the findings will be of interest to RFL, since much of the success of the movement is predicated on its ability to create a strong sense of collective identity. I hope that this work will bring a deeper understanding and will excite curiosity and speculation about the topic of the inquiry.

### ***Backdrop to the inquiry***

Globally, RFL is a citizen-based movement with millions of followers who congregate at its assemblies each year. The programme is the domain of the ACS and is maintained in

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<sup>1</sup> I speak about collective identities in the plural as I already knew from my past professional involvement with RFL that group representation is never distilled into a single collective identity, despite the best efforts of organizers to bring about a united group identity. Collective identity comes in different guises to capture the different meanings different participants at assemblies attach to the cancer experience and how they wish to be represented.

accordance with a license agreement between ACS and its global partners. In the 30 years since its inception, RFL has raised close to 5 billion USD (approximately 54 billion ZAR), while member countries outside the USA raise in excess of 90 million USD (approximately 1 042 884 000 ZAR) per annum (Global RFL Facebook Group 2014). The global rollout started in 1996 (Global RFL Facebook Group 2014). Today there are 24 member countries outside the USA; of these, South Africa, Zambia and Kenya are the only African member countries (American Cancer Society 2013). Turkey is the most recent addition, joining the movement in February 2015. RFL was introduced to South Africa in 2005, and is overseen by CANSA. During the period I conducted my fieldwork, August 2012 to March 2013, 85 communities staged assemblies and 60 122 people took part in these gatherings (Scholtz 2012). The average assembly had 707 participants.

Turning to the evolution of RFL in South Africa, we see that in the same way that the global RFL movement had humble beginnings, the South African movement started small. In the USA, RFL had its genesis in 1985 when Dr Gordon Klatt, a colorectal surgeon who wanted to honour his patients, ran around a track at the University of Puget Sound for a continuous 24 hours, and in an unforeseen way sparked a massive collective effort in the years to follow (Glenn & Krell 2014). I attended the first RFL assembly in South Africa on the grounds of the University of Pretoria in 2005. It was a small gathering that lacked many of the hallmarks that distinguish current assemblies. Teams were ill prepared for the gathering, made little attempt to dress up, few teams stayed the night, and the universal script was poorly executed. If we now project ourselves forward to the RFL assemblies I included in this inquiry, it is astonishing to see how quickly RFL gained momentum in South Africa and how sophisticated organizing committees have become in staging assemblies in the intervening years.

RFL assemblies are ephemeral gatherings that are brought to life once a year in a particular community. These assemblies are used to change attitudes towards cancer, to advocate for improved cancer-control programmes, and to raise funds. Efforts are further directed at issues such as survivorship, advocacy and cancer education. They are staged on municipal fields, at schools, universities, and the indoor and outdoor parking areas of major shopping malls. Organizers are drawn from local communities and staff input is purposefully limited to a single staff partner who works alongside a volunteer committee. Assemblies in South Africa last from 12 to 24 hours and range in size from a couple of hundred participants to

4 000 or more. The majority start in the late afternoon and end shortly after sunrise the following morning.

Participants who attend RFL assemblies gather to reflect on the cancer experience through collective talk and performance. During overnight assemblies, flamboyantly attired teams join in emotional victory parades, candlelit ceremonies, warrior-like storytelling, music, rousing calls to action, and carnival-like parading around a track. Teams dress up in their own team outfits, decorate their campsites and make banners, posters and other visual installations. Music, poetry, dancing and other performances are all commonplace. The ceremonies and activities heighten emotional intensity and generate the energy needed to carry the participants through the long night – few sleep during the night. The teams are comprised of cancer survivors, caregivers, friends and other supporters who face the challenge of keeping a team member on the track for the duration of the assembly. The only time when they alter the routine of walking the track is when ceremonies take place. The annual National Leadership Summit differs from the overnight assemblies, since it is a three-day gathering of volunteer leaders and a small contingent of paid staff, and is typically held in a conference centre.

### ***The research perspective***

Michael Crotty (1998: 13) makes the observation that few researchers start off by fully understanding the disciplinary foundations of their studies, and it certainly took me time to gain a clear sense of the philosophical underpinnings of my inquiry. My excursion into this field of study started very simply with my fascination with what makes RFL assemblies so compelling and the ways in which RFL creates a strong sense of belonging among those who take part in the assemblies. I wanted to understand how RFL managed to do this, and ‘collective identity’, as a sociological concept, was a good candidate for making sense of the strong bonds that seemed to exist between participants at RFL assemblies. My curiosity led me to read about collective identity, cancer and emotions. The exploration of these topics allowed me to pose my research questions, which in turn informed my gradually emerging inquiry. My topic pointed me in the direction of an interpretive case study, one that would allow me to deal with collective identity generation holistically and in the required micro-sociological detail.

In time, I settled on a contemporary hermeneutic approach in order to come to grips with the spatial dimensions, narratives and social interaction that underpin the generation of collective identities at RFL assemblies, as well as to understand the context in which the phenomenon plays out. For this study I adapted the principles of hermeneutic interpretation outlined by Johann Graaff (n.d.: 12), paying particular attention to: (1) the multiple layers of understanding present during RFL assemblies; (2) the possibility that participants do not always fully control, or understand, the meaning of symbolic narratives and social interaction during such assemblies; (3) the social milieu as an integral part of collective identity generation; and (4) meaning-making as containing real, as well as illusionary dimensions.

I opted to use Kevin Kelly's (2006b: 345–369) approach to contemporary hermeneutic inquiry as it honours the spirit of the hermeneutic-dialectic process, while combining elements of both the interpretive and constructivist perspectives. This is done by capitalizing on the benefits of both perspectives by using a circular process of interpretation which constantly moves from micro-sociological details to the bigger structural considerations. The hermeneutic process is described as follows:

The idea of the **hermeneutical circle** prescribes that, in the interpretation of a text, the meaning of the parts should be considered in relation to the meaning of the whole, which itself can only be understood in respect of its constituent parts. This is usually conceived of as a circular movement between part and whole. (2006b: 355)

Patton (2002: 497), like Kelly (2006b), sees the hermeneutic circle as illuminating understanding by 'relating parts to wholes, and wholes to parts'.

The subjective nature of collective identity generation is undeniable, but along with Collins (2004: 6) and Graaff (n.d.: 9–16), I take the position that structure is inherent even at the micro-level of investigation. A RFL assembly has structural elements by virtue of its relationship with the broader milieu of the community in which it takes place. This comprises South African society, the larger RFL movement, the global cancer movement (GCM), and public perceptions about the cancer experience. This moving between the micro and macro dimensions of the study allowed me to find an empathic resonance with the research material. As someone with a RFL history and insight into the cancer experience, I drew on my 'insider, local knowledge position' (Kelly 2006b: 349), but as the researcher conducting the inquiry and considering the structural aspects I took an 'outsider, expert knowledge perspective' (Ibid.).

Kelly (2006b: 348) argues that it is difficult to sustain a consistently empathic position and that researchers invariably step away from subjective experiences and insights to see the big picture which comes into view as they look at structural elements. This is necessary in order to move beyond simply understanding subjective experiences. Kelly (2006b: 350) bolsters this by observing: ‘... understanding does not go very far if it stops at summarising the way that people already understand their own realities.’ In order to make meaningful interpretations and arrive at a sensitive understanding of collective identity generation, it was therefore necessary for me to allow the micro-sociological insights that came from empathic understanding to emerge with a more distanced view.

The design of the inquiry and the methods I used to analyse data flowed from my research perspective. I used a non-comparative, in-depth single-case study, with two embedded sub-studies. Support for this type of design comes from Della Porta (2002: 296), who describes case studies which rely on a single case studied in depth as the ‘most intensive type of strategy’ in such research. Ethnographic work was the lynchpin of this inquiry and presented some unique challenges since assemblies are fleeting and only happen annually in a particular community. A short-term ethnographic approach (Knoblauch 2005; De Walt & De Walt 2011; Pink & Morgan 2013) fitted what needed to be accomplished in the field, together with the chosen broad micro-sociological approach. Given my approach, I was required to be open to the different realities of RFL participants, and this was best done by relying on a range of data sources. To achieve the understanding I was after, I synthesized, interrogated and interpreted data obtained from 20 RFL assemblies, using a variety of methods that included short-term ethnography, focus group interviews (FGIs), and analysis of YouTube videos, complemented with a collection of photographs. I also considered feedback given during a member reflections group (MRG) that I conducted once preliminary data analysis had been completed.

The practical strategies advocated by Pat Bazeley (2013) were used for qualitative data gathering and analysis, and the hermeneutic circle of interpretation (Patton 2002: 497–498, 569) was used as the method of analysis. I analysed narratives and social interaction to gain the required understanding of my chosen topic. NVivo computer-assisted qualitative data analysis software (CAQDAS) established a space in which to work with data and to speed up analysis. Data gathering activities ran concurrently with the translation, transcribing, coding and analysis of the data. Some of my FGIs were conducted either wholly or partially in

Afrikaans – one of the indigenous languages in South Africa. From the outset I set out to create a hermeneutic circle of interpretation that would move me deeper and deeper into analysis as my understanding developed. In Chapter 4, I separate data gathering and analysis in the interest of clarity, but it is important to note that in reality these two processes were simultaneously spinning together in the hermeneutic circle.

### ***Organization of the dissertation***

This dissertation has nine chapters and seven appendices. **Chapter One: Introduction** outlined how I am situated as the researcher, the aim of the inquiry, its rationale and research questions, before sketching the backdrop to the inquiry and my approach to research. **Chapter Two: Literature review** gives an overview of writing that deals with cancer, identity, and focused assemblies. It explores debates about the topic, the transition from personal illness experiences into collective experiences, the generation of collective identities at mass gatherings, and research into cancer and identity in group settings. **Chapter Three: Theoretical scheme and guiding concepts** deals with the nature of collective identities, defines the concept, presents the preliminary theoretical scheme and the sensitizing concepts that were used at the outset of the inquiry. **Chapter Four: Methodology, methods and quality** places the spotlight on the hermeneutical circle of interpretation, the case study design, the preparatory work I did before I embarked on data gathering, the pilot study, the two sub-studies, data analysis, and the strategies used to enhance quality. **Chapter Five: Findings – Behind the scenes at the battlegrounds** presents findings in response to a guiding question which asked how the elements that form the backdrop to assemblies create arenas for the intensification or weakening of collective identities at RFL assemblies. **Chapter Six: Findings – Animated Battlefields** takes the reader on a tour of the most pertinent findings related to a guiding question focused on how RFL assemblies, once they are animated and in flow, facilitate the amplification or weakening of collective identities. **Chapter Seven: Findings – Embracement, inversion, and disruption** delivers findings in response to a sub-question focused on understanding how collective identities are embraced, hybridized or disrupted during RFL assemblies and what this tells us about the debates about cancer and identity. **Chapter Eight: Discussion** responds to the central research question by looking at the big picture of how collective identities are activated during RFL assemblies, as well as the nature and meaning of these identities. **Chapter Nine: Conclusion** gives a summary of research findings, touches on my progression from practitioner to researcher, considers the contribution of this inquiry, the lessons learned during the course of the project,

the limitations of the inquiry, and possible areas for future research. The chapter ends with concluding reflections.

The seven enclosed appendices are: the Memorandum of Understanding I signed with CANSA, a sample of the letter I sent to prospective FGI participants, the informed consent form FGI participants signed, the FGI schedule, a pilot study report, a sample of the codebook, and a database and research path summary.

I now turn my attention to the literature review that guided this exploration of collective identity generation at RFL assemblies in South Africa.

## Chapter 2

# Literature review: Cancer, identity, and focused assemblies

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### ***Chapter introduction***

In this chapter, I give an overview of the literature that deals with cancer, identity, and focused assemblies. I show that much of the contemporary cancer debate about identity swirls around the embracement and contestation of particular cancer identities. I have grouped these thematically into three symbolic categories: (1) the walking wounded, (2) the transformational firebird identity, and (3) the heroic warrior identity<sup>2</sup>. I highlight the literature that addresses the choice made by some affected people to turn a personal cancer experience into a collective experience. I also consider both classical and contemporary thinking about large groups of people in the context of focused gatherings. I summarize empirical studies of cancer identity generation in group settings before ending the chapter with a short conclusion.

### ***Cancer identities embraced and contested***

Our established identities are hard-earned, built up through lessons learned and our efforts to become the people we want to be. Cancer, like other long-term illnesses, has the power to play havoc with the evolved identities of people who have come to see themselves in a particular way, but now have to incorporate the cancer experience into their understanding of themselves. Being diagnosed with cancer is a proverbial turning point. It brings in its wake ontological insecurities, the disruption of familiar routines, and physical changes (Kaiser 2008: 82).

People with cancer find themselves in the eye of an identity storm. Cancer is not a discrete event, but a trajectory without a predictable outcome, making identity renegotiation inevitable (Zebrack 2000: 238). The identity imposed on the affected person disrupts the normal process of identity construction, demanding a place next to the ‘ideal of who and what’ the person believes the self to be (Zebrack 2000: 240). These identity shifts have the potential to cause considerable distress. Deimling, Bowman and Wagner (2007: 759–760) highlight how notorious cancer and its treatment are for damaging established identities,

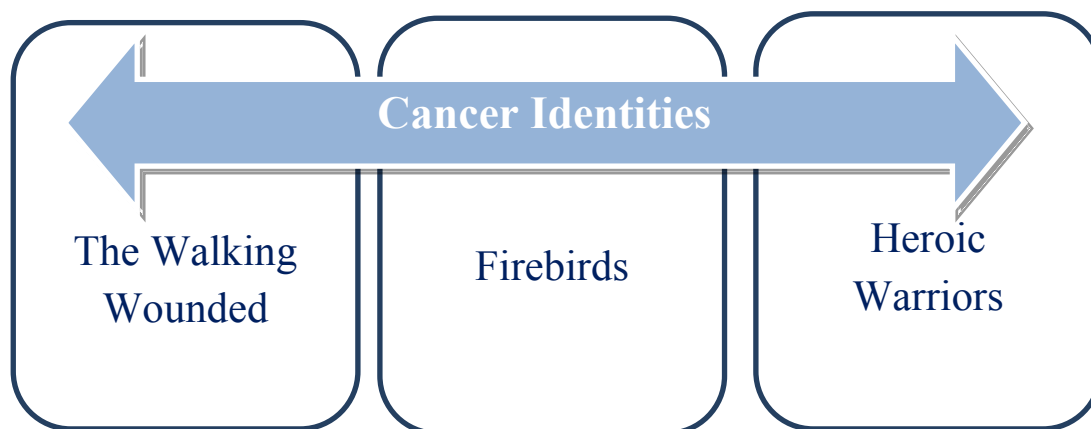
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<sup>2</sup> I prefer the use of the term ‘heroic warrior’ to the commonly used term ‘survivor’, as this dissertation deals not only with people who have been diagnosed with cancer but all those who are affected by it. My preferred term allows me to describe an overarching collective identity more accurately and to mirror what happens at RFL assemblies in a more precise manner than the ‘survivor’ identity label would have allowed me to do.

especially those that relate to self-concept and role identities both at work and at home. They say that cancer is the ‘one form of life-threatening illness that has the potential to alter the salience of specific identities, and replace primary identities with those related to the illness’ (Ibid.).

Throughout the process of reconsidering their identities, diagnosed people worry that the illness identity may become a permanent feature of their lives and overshadow other personality characteristics (Charmaz 1991: 101). This is particularly challenging for those living with cancer. The illness, combined with a fear of a recurrence, makes clinging to past identities incredibly difficult to sustain. A common strategy is to hold to the view that the illness is causing only a temporary muddling of identity and that all will be well once health is restored (Ibid.: 15). Charmaz explains that, as long as recovery is a possibility, the ill person can cling to the notion that everything will soon return to normal. For those with cancer, however, the assumption is valid only in instances where the prognosis is good.

Looking at the literature, I found three discernible strands in the contemporary debate about the identities of people with cancer. Placing these on an imagined continuum, I visualized a range that runs from the ‘walking wounded’ at the one pole, through a representation of the illness experience that portrays protagonists as ‘transforming or transformed firebirds’, to the opposite pole occupied by ‘heroic warriors’.



**Figure 2.1: Cancer identities**

These three illness identities – the walking wounded, firebirds and heroic warriors – run like a thread through this dissertation and appear repeatedly as I work my way towards presenting the argument.

The individuals, groups and health movements that embark on the process of rebuilding identities typically embrace one of these three symbolic identities as their master identity. It is important to stress that each of these identities draws upon foundational core narratives which are idealized (Bury 2001: 265). A review of the literature about the illness experience and my own research material point in the direction of what Bury refers to as ‘core narratives’ (2001; 265, 278–280) and Francesca Polletta terms ‘canonical stories’ (2006: 168–171). These are narratives that draw from much deeper cultural, metaphorical and mythical meanings associated with the experience of illness and suffering. In my inquiry, I specifically explored collective identity themes that revolve around the heroic, the tragic and tropes of transformation. Also included in this genre are didactic stories (Bury 2001: 278) which in this inquiry form a sub-category of the firebird identity.

Narratives offer a key strategy for giving expression to identity. Hunt and Benford (2004: 445) remind us that: ‘Fundamentally, collective identities are talked into existence.’ Frank (1995: 75–136) distinguishes between three illness narratives – the chaos narrative, the quest narrative, and the restitution narrative – each of which captures a particular story of choice. He shows that there can be interplay between the storylines, and that storytellers can move from one narrative to the next as circumstances dictate. I found the three illness narrative types outlined by Frank (Ibid.) particularly helpful in thinking about RFL, how it positions itself in the eyes of its constituents, and how these accounts are used to generate collective identities during focused gatherings of followers. It is also my view that these narratives find resonance in three parallel cancer identities: the walking wounded identity corresponds with the chaos narrative, the firebird identity with the quest narrative, and the heroic warrior identity with the restitution narrative.

Currently the main source of tension in the literature appears to be between the hegemonic heroic warrior identity, that portrays protagonists as perpetually optimistic and hopeful, and the firebird identity, which represents them as people who take the illness experience in their stride without denying that it is an emotional rollercoaster ride with both highs and lows. Authors such as Zebrack (2000), Deimling, Bowman and Wagner (2007), Parry and Glover (2011) and Chambers et al. (2012) are advocates for the survivor identity, with its emphasis on optimism, although they recognize some of the limitations of this representation. Others like Frank (1991), Waskul and Van der Riet (2002), Reisfield and Wilson (2004), Klawiter (2008), Kaiser (2008), Bell (2012), and Bell and Ristovski-Slijepcevic (2013) advocate representations of the illness experience that acknowledge that people with cancer have

a range of experiences – both enabling and constraining – and recognize that transformation may not necessarily rely on people representing themselves as either heroic or wounded.

### ***The Walking Wounded***

The oldest representation of people with cancer is as walking wounded or suffering victims. Sontag (1978: 50–57) traces the roots of the cancer illness identity, noting that in the nineteenth century there was a popular conception that grief triggered cancer. This idea evolved further in the popular press during the 1970s, when articles ostensibly drawing upon scientific research popularized the idea of the ‘cancer personality’, of people diagnosed with cancer because they were emotionally brittle and prone to negativity (Ibid.: 51). This notion of the ‘cancer personality’ was tightly woven into the identities of affected people, who were represented as victims. However, the advent of contemporary cancer treatment and myth-busting public education programmes debunked this idea, giving birth instead to the notion of affected people as cancer survivors, heroes or warriors. By the mid-1980s, the cancer illness identity was rapidly transforming from a stigmatized ‘victim’ identity into a more positive ‘survivor’ identity (Kaiser 2008: 80).

We cannot discount the suffering victim identity altogether, since historically it played an important role in defining people with cancer. It is still lodged in the DNA of the heroic warrior (or survivor) identity. In tracing the trajectory of cancer identities it is not difficult to see that the victim identity, which represents affected people as severely compromised by a relentless and cruel disease, is in fact the parent of the heroic warrior identity. The latter came about in opposition to the former, and is its mirror image. We now live in an era where few health movements would publicly embrace the victim identity. It is seen as *passé*, characterized by a profound lack of agency, extremely negative and politically incorrect. Its closest parallel in Frank’s scheme of illness narratives is with the ‘chaos narrative’ (1995: 97–114), also described by him as ‘mute illness’ by virtue of how paralyzing this state of mind can be for those who embrace this position.

Once I started working with data, I found the ‘chaos narrative’ as described by Frank (1995: 97–114) useful in illuminating the walking wounded. These storytellers feel hopeless and ‘reveal vulnerability, futility, and impotence’ (Ibid.: 97). Frank (Ibid.: 97–114) explains that words cannot span the void left by the illness, that there is little that is reflective in the narrative, and that there is a sense that nothing can be done to make things better.

The narrative lacks coherence, with no discernible storyline. It evokes discomfort in others and is difficult for its listeners to bear. On a larger scale, society may find it a challenge to cope with groups of people stuck in a chaos narrative. Listeners can try to intervene by steering the chaotic account in the direction of a restitution narrative, using platitudes about the need to be strong in the face of adversity or by offering solutions. The ‘chaos narrative is an anti-narrative’ (Ibid.: 105), the teller having no voice as a result of a muteness that has its origins in the body. What is striking about this narrative is how its characteristics preclude it from being shaped into a collective identity. Shame and hopelessness are emotions that affected people tend to hide away. As a result, this narrative is not a natural companion to collective action or collective identity generation.

Those who identify themselves as victims are naturally drawn to the chaos narrative. According to Frank (1995: 97–114), it is also an option for people who can no longer continue to cling to the promise of being restored to health – a promise implicit in the restitution narrative. Frank makes no attempt to deny how awful it is for the storyteller to be trapped in this chaos; nor does he offer it as an idealized alternative to the restitution narrative. However, there is a moral obligation for those who stand outside the chaos to bear witness to it and to hear the painful story. Frank (1995: 109) reminds us of this:

Until the chaos narrative can be honoured, the world in all its possibilities is being denied. To deny a chaos story is to deny the person telling the story, and people who are denied cannot be cared for. People whose reality is denied can remain recipients of treatments and services, but they cannot be participants in empathic relations of care.

The chaos must first be acknowledged and accepted before there can be any attempt to raise the storyteller out of the ‘narrative wreckage’ (Ibid.: 110). Chaos needs to be taken on board by society because the cancer experience can at times be chaotic.

Judging by the available literature, the victim identity has largely faded into the background in mass health movements, as it is no longer deemed helpful to people grappling with the challenges of the illness experience. It could be argued that the same distancing from this representation does not hold true for individuals, as there are still people who embrace this identity. Not all those with cancer feel compelled to use their voices, look for group support, join solidarity movements, or take action in the name of the cancer cause. Even in the twenty-first century, there are those who become ‘mute’ (Frank 1995: 97–114) or ‘passive’ (Chambers et al. 2012: 967) in response to the cancer experience. For those who identify

themselves primarily with the victim identity, the shame associated with the illness amplifies their isolation, further serving to separate them from others who share the same fate (Kaiser 2008: 81). People who feel ‘crucified’ by the cancer experience can become prisoners of their own emotional wounds, allowing their identities to become fused with the victim identity (Jarvis 2014).

Drawing on Goffman’s work on stigma (1963: 107–112), it is possible to put forward a proposition that people who identify themselves as wounded and are shamed by cancer are more likely to try to ‘pass’ undetected as healthy people and to deny their cancer status for professional, personal or social reasons. Passing is the process by which stigmatized people disguise the source of their shame, believing there is a social reward for conforming to the norm (Goffman 1963: 92–113). Fear that a stoma bag might give off odour, a wig be obvious to onlookers, or a ‘falsie’ slip out of a bra – are all linked to the embarrassment of being discovered, even in instances where others are aware that the person has cancer. Those who invest heavily in passing almost inevitably have to listen silently to others express misconceptions about the source of the shame, without being able to assert themselves for fear of drawing attention to their illness status (Goffman 1963: 92–113). They are the people least likely to join solidarity movements such as RFL for fear of having their status revealed through associating with others faced with the same challenge.

### ***Transforming and Transformed Firebirds***

The firebird collective identity stands between the walking wounded and heroic warriors. Much like mythological phoenixes or firebirds, those who take this position are able to balance the tension between being wounded and victorious, while finding the transformational potential in the illness experience. The idealized image of the firebird is that of someone who is assertive, vocal and able to use his or her agency, but without slipping into the manic defence of pretending to be positive and hopeful at all times. Charmaz (1995: 657) reminds us that adapting to illness and redefining identity are not limited to a single episode, but are part of a process of repetition. It is therefore important to recognize that transformation is a process and not an attainable goal. This position is embraced by those who believe in the importance of giving a true reading of the cancer experience. It is less popular than the omnipresent heroic warrior identity, since its adherents use their voices to ‘tell it like it is’ and exercise the right to ‘show it like it is’ if they so choose.

The firebird identity is typified by the quest narrative as described by Frank (1995: 115–136). The ‘quest narrative’ or ‘illness and the communicative body’ invites illness into the account, looks it squarely in the eyes, and puts it to work (Ibid.). Frank maintains that the experience of illness is an opportunity for growth and can be seen as part of a life-enriching journey en route to an unknown destination. He explains that it is also about remembering, showing solidarity and inspiring others. This is not a journey in the popular psychology sense of the word, but rather a voyage of reflective transformation which comes about by persevering through tough challenges. Compared to the other two types of narratives, the quest narrative offers the storyteller an authentic relationship with the illness and does not take flight into imagined heroism. It gives the storyteller a voice and agency.

This identity representation is most commonly embraced by health movements that fall on the activism side of the advocacy-activism continuum<sup>3</sup> described by Brown et al. (2004: 53). RFL is best typified as an advocacy movement and is therefore not in natural accord with the firebird identity. On the activism end of the advocacy-activism continuum are health movements that embrace a ‘tell it like it is’ cancer identity and contest the perpetually optimistic heroic warrior identity.

In her work on the bio-politics of breast cancer, Maren Klawiter (2008: xxviii, 168–172) turns the spotlight on contentious identity issues in the cancer world. She relates how feminist breast cancer initiatives in the San Francisco Bay area have challenged the collective identity of ‘breast cancer survivors’ by steering them away from prevailing hetero-normative portrayals of cheerful, healthy, feminine women. Klawiter (Ibid.: 169) talks about the mainstream media and cancer screening initiatives that rely on an ‘upbeat discourse of survival and the normalizing images of unmarred, unscarred, heterofeminine bodies’. Among organizations that embrace an alternative discourse, there is a refusal to soften the harsh realities of cancer by taking flight into the survivor identity and its associated pink breast-cancer symbols. Feminist cancer organizations strive to strike a balance between giving support and allowing authentic expression of emotions such as ‘sorrow, anger, grief, aggression, and accusation’. Alternative cancer discourses favour identity representations that refer to ‘women with cancer’ or ‘living with cancer’ (Ibid.: 172).

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<sup>3</sup> The distinction made here between advocacy and activism refers to the difference between health movements that work in harmony with the prevailing biomedical system, using non-confrontational tactics to facilitate change, and activist movements that are more forceful, more likely to challenge the system and more inclined to use disruptive tactics (Brown et al. 2004: 53).

This push to redefine the cancer discourse can also find expression in affected people refusing to hide the physical changes brought about as a result of cancer and its treatment. Activism is not limited to feminist cancer initiatives. The refusal to ‘make nice’ has its followers the world over, wherever people choose not to wear prostheses, wigs or hats to hide the illness or the effects of treatment. Surgery scars, the need to live with stomas, hair and nail loss, destroyed fertility and other consequences of cancer are no longer treated as shameful secrets, but as realities of living with cancer.

This identity representation too has a shadow side, as Lewis (2013) shows in his case study of the fictional protagonist, Walter White, in the popular TV series *Breaking Bad*. In a thought-provoking analysis (Ibid.: 656–669), Lewis shows how perverted empowerment through cancer is taken to extremes in Walter’s amoral behaviour. Another scholar who draws attention to the darker side of the transformational ideal is Bell (2012: 584–600). She argues that cancer has become so romanticized that it is seen as a vehicle for a total transformation (Ibid.). She highlights the coercive elements in this narrative, challenges the need for professionals to intervene in the lives of those with cancer to ensure that they deal with it in the ‘right way’, and contests the notion that cancer necessarily contains profound life lessons.

### ***Heroic Warriors***

I found it useful to consider the way in which cancer identities have evolved over the years. The heroic warrior identity did not arrive out of the blue, but was an inversion of the victim identity which dominated earlier cancer narratives. The most popular manifestation of this move away from the victim identity came with the adoption of the ‘survivor identity’. This became prominent in the mid-1980s and resulted in significant changes in the illness narrative, especially in North America, with ground-breaking articles such as the one written in *The New England Journal of Medicine* by Fitzhugh Mullan (1985), a physician who reflected on the phases of his own cancer survival (Kaiser 2008: 80; Bell & Ristovski-Slijepcevic 2013: 409). The article caught the imagination of many with its redefining of affected people as survivors. This new way of thinking about the experience of cancer, together with the advent of support groups and advocacy initiatives, spawned a new representation that quickly became embellished with hero mythology. Slowly but surely affected people were being redefined from suffering victims into brave warriors. After a long period of poor survival rates, translated into pessimistic identity labels, the survivor identity came as a welcome change (Deimling, Bowman & Wagner 2007: 758). The new version of

people with cancer as fighters also heralded a shift away from expert-centred paternalism (Lewis 2013: 658) to an openness to involving affected people in the cancer movement.

The momentum of the new representation was undoubtedly fuelled by early detection of cancer, enthusiastic cancer education programmes, screening programmes, and improved treatment which made it possible for more people to live longer. The recasting of victims as fighters called for the rejection of victimhood and the embracement of a fighting spirit (Lewis 2013: 656). Kaiser (2008: 80, 86) describes the cancer survivor identity as positive and cure-orientated, creating an upbeat, grateful image of people living with cancer. For her, this representation is ubiquitous and largely unquestioned in the cancer discourse. It has become so popular that nowadays we apply the survivor label to people as soon as they are diagnosed, not simply to those who have survived for many years (Deimling, Bowman & Wagner 2007: 759). For authors such as Breaden (1997: 978), the survivor identity is apt. She views it as carrying weight and working hard for the people and social initiatives that embrace it. She reminds us (Ibid.) that the term is typically used in relation to people who have survived shattering life events such as natural disasters. By appropriating this identity, the GCM is saying something about the gravity of the disease and the toughness of the experience.

The presentation of people with cancer as heroic warriors has found great resonance in the popular imagination and is used by the media, pharmaceutical companies and global cancer organizations as a way to entrain constituents (Reisfield & Wilson 2004; *Leadership* 2014). Reisfield and Wilson (2004: 4025) highlight the profound effect metaphors have on the illness experience. They acknowledge that the battlefield paradigm is empowering for some, but express grave concern about the impact this ‘inherently masculine, power-based, paternalistic and violent’ clarion call to fight cancer has on many who long for empathic understanding of the cancer-related challenges they face.

Nevertheless, there is a common consensus among scholars interested in cancer and identity that the survivor identity – and its associated hero and warrior identities – is a significant improvement on the victim identity. It is infinitely less stigmatizing than being referred to as ‘victims’, ‘sufferers’ or ‘patients’. For those who experience cancer as a ‘spoiled identity’ (Goffman 1963) or ‘damaged identity’ (Nelson 2001), the image of the survivor presents a socially acceptable alternative (Kaiser 2008: 82). It is energetically promoted by its proponents as an antidote to stigma and is believed to hold tremendous emotional and health benefits. Deimling, Bowman and Wagner (2007), for example, argue that it fosters health-

promoting behaviour, which in turn makes for better survival rates. They contend that the survivor identity does a better job than the victim identity at insulating people against the erosion of their primary identities by the cancer experience (Ibid.: 760).

Nelson (2001: 6–9) shows how groups who have problems with their identity can weave together a counter-story in an attempt to command respect and to limit damage to opportunities like employment, insurance, job promotion, and immigration. For Nelson (Ibid.), the purpose of a counter-story is to repair identities that have been damaged. Applied to people living with cancer, we can argue that for the longest time this group was seen as victims diminished by their fate. It was only in the mid-1980s that the survivorship counter-story emerged to challenge existing public perceptions. These counter-stories are by no means limited to the cancer world, and examples abound in studies dealing with stigma and identity. One example is Sousa's (2011) study of mothers of intellectually disabled children and their use of heroic warrior mythology.

The heroic warrior collective identity finds expression in labels such as 'cancer survivor', 'cancer hero' and 'cancer warrior'. It also finds resonance in most of the member organizations of the Union for International Cancer Control (UICC) and most mainstream cancer advocacy initiatives. This is the narrative that is the easiest to transform into a collective identity, given its proven success over the millennia in mobilizing adherents behind a cause. Frank's (1995: 75–96) description of the 'restitution narrative' or 'illness in the imaginary' provides great insight into this narrative, as it is the one most commonly heard in relation to heroic warriors. Frank explains that we live in an epoch where we believe 'that for every suffering there is a remedy' (Ibid.: 80) and that medical science must be able to come up with elegant solutions to vexing illnesses (Ibid.: 83). He notes (Ibid.) that this narrative is especially common during the early phases of an illness and is a good match for those who are likely to make a good recovery. Proponents of this storyline imagine the illness as fleeting or as something that can be conquered. Stories reflect the need to get better and to stay alive by defeating an imagined antagonist. The body is conceived as something that has broken down, much like a machine that simply needs to be taken for repair. However, in order to be restored to health, ill people need to abdicate much of their agency to care providers and comply with treatment plans over which they have little control.

The restitution narrative relies on overblown heroism that demands that ill people and those responsible for fixing the problem sacrifice for the greater good (Frank 1995: 93). Frank

shows how this trite heroism starts running into difficulties, especially when death is inevitable or when it becomes clear that there will be no return to health. Death and restitution are incommensurable, since restitution and survival are inseparable. He argues that talk of survival is the lynchpin that keeps the ‘banality of heroism’ (Ibid.: 96) together. In contemporary times, this lynchpin is placed under increasing strain as larger numbers of care providers and ill people are more interested in authentic accounts of illness – in being ‘moral people’ – rather than being heroes. This reference to morality comes from the work of Bauman (1992: 208–209), who posits that the ‘moral person’, in contrast to the hero, is focused on being true, rather than promoting the dominant ideas of the collectivity (Ibid.). Later in this dissertation, I will present findings showing that the restitution narrative is the most dominant narrative at RFL assemblies. It relies heavily on illusion and revolves around the image of the perpetual optimist and the importance of cure (Frank 1995: 75–96).

In its most utopian form, the heroic warrior identity does the work of a magical, self-fulfilling prophesy. Sontag (1978: 55–57) maintains that there is a lingering idea that by being positive we can overcome cancer. A positive attitude is seen as having the power to stop the cancer beast in its tracks. For Sontag, this ‘psychologizing’ of cancer gives affected people an illusionary sense of control over an illness that they cannot control. Unfortunately, it can also make those who cannot maintain a cheerful outlook feel guilty about their inability to use a positive attitude to regain lost health. The onus is on the ill person to get healthy and failure to do so potentially carries blame and shame for not having fought hard enough (Frank 1991: 108–114, 123–128).

Potential problems linked to an unquestioning embrace of a positive, cheerful identity include the following. People who face recurrent cancer, who are seriously ill or who are doomed to die may feel alienated when confronted by enthusiastic performances of an overly positive, hopeful representation of the illness experience. When talk of hope is conflated to refer only to cure-orientated outcomes, it becomes problematic for people struggling to live with cancer. When staying alive is equated with the ability to maintain a positive attitude, it places an unreasonable pressure on those who need to navigate complex emotions following diagnosis. People who have a recurrence of cancer may feel that they are to blame because of their failure to remain consistently positive. In an effort to be the epitome of a survivor, some feel unduly pressured to disguise the physical effects of cancer through reconstructive surgery, prostheses or clothing. This makes for a cosy relationship with the dominant scientific and

medical viewpoint of cancer, but potentially limits agency and dampens activism. The dominant identity is so compelling that affected people are told what to think, what to feel and what meaning the cancer experience should have for them (Frank 1991: 64–71; Deimling, Bowman & Wagner 2007: 764; Kaiser 2008: 81, 86; Elliott & Olver 2009: 609; Parry & Glover 2011: 402; Jarvis 2014).

The survivor identity has been made very appealing by the retail sector, which energetically markets cause-related products in support of cancer (Jain 2007: 502–504, 517–519; Kaiser 2008: 86; King 2010: 88; Sulik 2011: 141–146). Much effort is put into creating an imaginary, utopian image of the cancer survivor. The alternative quest to find an authentic cancer identity is forced to compete against big business and its attractively packaged images of what a survivor should look like. A less common way of navigating the cancer experience is to acknowledge the harsh realities of the illness and to come to terms with the fact that modern medicine is still looking for answers to cancer.

There are pockets of resistance that act to challenge and confuse the heroic warrior identity. *Time* Magazine ran an article on people with treatable forms of cancer who refuse treatment, or a part of the treatment that has been prescribed, despite being newly diagnosed and not in the palliative phase of care (Koningsberg 2011). These ‘refuseniks’, as they are described in the article, baffle and unnerve service-providers with their refusal to join the ‘war on cancer’. They are mainly older people, but not exclusively so. They refuse treatment not because they are depressed, but because they choose to use their agency rather than endure treatment. More recently, resistance to prescriptive portrayals of affected people has also been seen in South Africa. An article appeared in *Leadership* (2014), a South African business magazine, in which oncology practitioners raised concerns about the persistent use of the battlefield paradigm. It was argued that, although this metaphor might be empowering for some people living with cancer and be good for media headlines, it is damaging for those who will not survive cancer. A call was made for alternative metaphors that are gentler and more empathic (*Leadership* 2014). Other examples of popular resistance are to be found in the work of Bach (2014); De Clerk (2014); Hehir (2014), and Jarvis (2014).

An alternative way of making sense of the walking wounded identity is to subject it to Kübler-Ross’s (1969) stage theory of death and dying. Kübler-Ross developed a highly influential conceptual scheme that views people faced with life-threatening illness as going through particular emotional stages en route to an eventual acceptance of the inevitability of

death. She described the stages as denial and isolation, anger, bargaining, depression and acceptance (Ibid.: 34–121). It is tempting simply to explain the heroic warrior identity as a form of denial. I am going to resist the temptation. It is undeniable that much of stage theory could explain aspects of collective identity generation at RFL assemblies, especially the flight into optimism and the narrow definition of hope. Nevertheless, I do not align myself with stage theorists such as Kübler-Ross, as I see the identity work done at RFL assemblies as far more textured and complex than simply a form of collective denial. I believe that it is important to guard against writing off RFL collectivities as being in denial about the full impact of cancer, as this can serve to shut down an exploration of the topic.

### ***From Me to We***

Although there is much to celebrate, the harsh reality is that cancer remains a leading killer worldwide (World Health Organization 2014). Despite significant medical advances, there is still no cure for many cancers. Millions of people live with long-term disease in a no man's land, suspended between health and the threat of another episode, another round of treatment, and the possibility of death. Little et al. (1998: 1485–1494) describe this as a state of 'liminality', while Frank (1995: 8–13, 82) refers to this suspended state as the 'remission society' in which its members 'accept some level of illness as a permanent background and intermittent foreground of their lives' (Ibid.: 82). Those who live in this suspended state occupy a world coloured by both health and illness – never quite sure where they really stand or whether their wellness will endure (Frank 1995: 8–13, 82). Many continue to experience a range of health, emotional and social challenges even decades after their initial diagnosis (Little et al. 1998: 1485–1494; Deimling, Bowman & Wagner 2007: 759).

Initiatives such as RFL offer an opportunity for people who are a part of Frank's remission society (1995: 8–13, 82), and those who care about them, to gather together in a solidarity community. Collective identity is generated when participants develop a sense of connection with others who face similar challenges and care about the cancer cause. Brown et al. (2004) précis this by stating that 'a politicised collective illness identity begins the process of transforming a personal trouble into a social problem' (Ibid.: 61). Collective identity is a precondition for the empowerment of large groups of people, and organizers intent on promoting change need to find ways of boosting group identity (Drury & Reicher 2009: 722). Without collective identity, the group cannot act in unison against a perceived antagonist and shared goals cannot be pursued (Ibid.). If collective action is understood by the group as

pitting their identity against that of an antagonist, then empowerment can create a 'virtuous cycle of broader, deeper, and more advanced resistance' (Ibid.: 722). Movement organizers can bring about change only by acting as 'architects of the imagination' and by helping their constituents towards a vision of a transformed world (Ibid.: 722). In the RFL movement, the dream of a cancer-free world is energetically promoted as the ultimate goal, but one that can be attained only through a united fight against the disease. Turning cancer into an antagonist is a prime way of splitting-off or bracketing-out the illness experience so that it becomes externalized and can be pursued as the enemy (Hubbard, Kidd & Kearney 2010: 133). This, in itself, can be a necessary step in coping with cancer and is recognized by many therapists as part of the process of overcoming fear. It does, however, stand in contrast to those who adapt to the illness experience through what Charmaz (1995: 657) describes as an accommodation and willingness to 'flow' with the illness.

One way of turning a personal struggle into a collective struggle is by joining what Brown et al. (2004) refer to as an 'embodied health movement' (EHM). As a constituency-based initiative, RFL conforms to the three hallmarks described by Brown et al. (2004: 54–57), in the light of RFL's: (1) reliance on the cancer experiences of affected people, (2) collective effort directed at improving cancer control and raising funds for cancer research, prevention programmes and services, and (3) the promotion of partnerships between people living with cancer and a range of allies who include family, friends, colleagues, health care workers and cancer researchers. In South Africa, RFL assemblies receive strong support from health care workers, cancer researchers funded by CANSA, private pathology laboratories, and our National Health Laboratory Service. Health workers and scientists show their solidarity with cancer survivors by joining teams and participating in assemblies.

Brown et al. (2004: 55) argue that in the unique environment that constitutes EHMs, collective identities can be fostered only through personal illness experiences and the embodied nature of illness. Although EHMs rely on collective identity for the mobilization of their constituencies in exactly the same way as other social movements, they are unique in that they foster collective identities by also drawing on what happens to affected people as a result of their illness and the development of their illness identities (Ibid.: 54, 55, 59).

People who are new to the world of cancer quickly come up against scientific explanations of the disease, described by Brown et al. (2004: 61) as the 'dominant epidemiological paradigm'. Affected people will happily go along with scientific explanations, as long as they

do not become frustrated by slow progress in getting better, by inequitable services or the failure of the dominant group (biomedical researchers and care providers) to come up with solutions (Brown et al. 2004: 62). When this happens, an oppositional consciousness is born out of sheer frustration, and this can become a building block in the politicized collective illness identity of members of EHMs. EHMs are hybrid movements which synthesize the scientific knowledge of experts with the lived experiences of people affected by illness (Brown et al. 2004: 53). As EHMs mature, they move beyond their initial preoccupation with service delivery to look at the deep underlying structural issues that impact the lives of their constituents (Brown et al. 2004: 61). While the global RFL movement is three decades old, the South African initiative is only a decade old. It has reached a considerable critical mass, however, with assemblies being staged in more than 87 communities. Locally, the preoccupation is mainly with improving cancer-control and to a much lesser extent with structural issues such as inequality that affect the participants.

Brown et al. (2004) provide a framework for understanding the role of the illness experience in the genesis of collective identity. One of the functions of EHMs is to contest illness and to target areas where science has failed to provide satisfactory answers (Ibid.: 53). This is very evident at RFL assemblies, where the rallying cry of ‘there can be no finish line until a cure is found’ finds expression in words, on banners and in attire. People living with cancer and their families are in a love-hate relationship with medical science. The strides made by bio-medical research are recognized, but there is also a deep frustration about the fact that a cure for cancer remains so elusive. This battle becomes deeply personal when families helplessly witness loved ones being swept away by cancer.

### ***Collective identity generation at assemblies***

I found no literature that attempts to understand collective identity generation at the assemblies of the burgeoning cancer solidarity movement. Instead, I had to rely on literature that investigates the nature of crowds and their identity representations. As explained previously, the average RFL assembly in South Africa is attended by more than 700 people, with bigger assemblies attracting 4 000 or more participants. How to characterize the mass gathering of participants at RFL assemblies presented me with the same problem that Geertz (1972: 10) faced in describing the men who gather en masse at cockfights in Balinese villages. To describe the participants as a group suggests a closer relationship between them than might exist in reality, but describing them as a crowd seems too anonymous and

unstructured. Like Geertz (Ibid.), I find Goffman's (1961: 7–14) description of the 'focused gathering' a useful way of thinking about the collectivities at assemblies, as the concept recognizes that participants are absorbed in a shared activity that has a particular focus, the social encounters are not continuous but occupy particular timeslots, and they take their form from the cause that necessitated the gathering in the first instance, as well as the arena in which the gathering takes place.

There is a variety of theoretical approaches to the study of collective identity. They include the work of canonical, social-psychological and contemporary theorists, with the most substantial contributions coming from social movement theory (Hunt & Benford 2004: 437–438). It was beyond the scope of this dissertation to review the entire corpus of relevant literature. I therefore concentrated on work that would prove to be useful in understanding collective identity at focused gatherings and mass assemblies. I picked up a theoretical thread that I followed from the work of Gustave Le Bon (1896), Emile Durkheim (1912) and Max Weber (1947) to contemporary theorists such as Michel Foucault (1986), Alberto Melucci (1995), Edward Lawler (2003), Randall Collins (2004) and others.

A number of canonical theorists are important for this study as they provide insight into the compelling nature of crowd behaviour and the way collective identity can become salient when people gather in the name of a shared issue. The classic and highly influential text, *The Crowd: A Study of the Popular Mind*, was written more than a century ago by Gustave Le Bon (1896). Its influence is still discernible in the writing of the many theorists who followed in his footsteps, despite the work having come in for great criticism. Le Bon (Ibid.: 1–14) argues that when organized crowds assemble, their shared interests – their ideas and sentiments – dominate the individuality of participants. The transformation that the individual undergoes in a crowd can be profound. The organized crowd, no matter how diverse, becomes a force in its own right, and its representation – or collective identity – is much more than the sum total of the individuals present. The diversity in the crowd becomes drowned out by the sense of unity created by the collective whole. Le Bon sees the crowd as '... a new body possessing properties quite different from those of the bodies that have served to form it.' (Ibid.: 6). The 'collective mind' (Ibid.: 2) created during the assembly is fleeting and feeds off the energy that is generated by the group.

Le Bon (1896: 1–14) believes that organized crowds or psychological crowds are governed by laws that do not apply to random gatherings of people. He believes organized crowds

display specific characteristics. The influence of the crowd is so strong that individual views, behaviour and values are dominated by it. The crowd feeds off unconscious forces in the collectivity, and this fuels a lack of restraint, heroic and even unseemly behaviour. The individual may not only act out of character, but may also possess the ‘enthusiasm and heroism of primitive beings’ (Ibid.: 12). Individuals do not feel the need to keep their behaviour in check because they feel largely anonymous in the crowd and do not feel constrained by everyday etiquette. The energy of the crowd is contagious, and this results in the participants acting for the common cause, rather than out of personal motivation. The crowd is suggestible to emotions and participants are swept away by its magnetic influence, to the extent that they no longer question the wisdom of group actions. Le Bon takes a dim view of the ability of individuals to think and act independently under these circumstances.

Contemporary authors who eschew the ideas put forward by Le Bon include McPhail (1991), Schwengruber and Wohlstein (2005), and Drury and Reicher (2009). They argue that the characteristics of crowds put forward by Le Bon have attained mythical status, but are not supported by empirical research carried out in the intervening years. McPhail (1991) and Schwengruber and Wohlstein (2005) do not look at crowds from a social-psychological perspective, and in my view the evidence they offer does not always conform to Le Bon’s view of organized crowds. The one myth I think it important to flag is that of anonymity. I agree with them when they argue that people in crowds are typically surrounded by acquaintances, family or friends. Anonymity would certainly not apply in a RFL assembly, as participants attend these assemblies in tightly-knit teams composed of colleagues, family and friends.

Drury and Reicher (2009: 707– 725) are interested in social-psychological processes and take issue with Le Bon’s pessimistic view of crowds as primal entities and his failure to recognize that empowerment can flow from the crowd’s collective identity. They show that a significant body of empirical research has challenged the notion that crowds are irrational. The ‘exhilarating power’ of the crowd is not seen as irrational in the manner that Le Bon would have it, but as the social-psychological corollary of collective action (Ibid.: 709). Supported by empirical research, Drury and Reicher (Ibid.) view emotions such as joy and euphoria as positive forces in the lives of crowds. They recognize that empowerment can result from crowd events that are ‘passionate and exhilarating’, and that this group empowerment is an important element in social change (Ibid.: 719).

The other canonical work that is particularly useful in understanding assemblies is Durkheim's *Elementary Forms of Religious Life* (1912), which gives a seminal interpretation of religion from a functionalist perspective (Haralambos, Holborn & Heald 2008: 396). In this work, Durkheim points to a relationship between awareness of, and identification with, the collective and feelings of solidarity and social cohesion (Lawler 2003: 147; Hunt & Benford 2004: 434–435). For Durkheim, the most powerful illustration of this is when the group collaborates in a shared ritual activity that results in feelings of euphoria or 'collective effervescence', embracing collective symbols with shared significance that reinforce their sense of unity and belonging (Ibid.). This concept is one of the foundation elements in Collins's (2004) interaction ritual chains and will be discussed in more detail in Chapter 6 of this dissertation.

Max Weber (1948: 126) was a classical theorist who recognized that people who share a common situation – in my case study a shared concern with cancer – can form social relationships which speak of solidarity, provided certain conditions are met. He posits that the mere existence of shared qualities or being confronted by a common situation is not sufficient to generate solidarity relationships in an affected group. It also requires that feelings about the situation lead to what he calls 'a mutual orientation of their behaviour to each other' and feelings of belonging together as a group. This notion finds resonance in the work of Collins (2004: 47–101), with its emphasis on the need for the group to have a mutual focus in order to become emotionally entrained in face-to-face gatherings. Weber's writing on solidarity in social relationships is significant for my work, as it implies that, under certain conditions, solidarity rather than social class forms the basis for a group coalescing. It is notable that at RFL assemblies in South Africa social divisions that are still largely racially determined soften in the name of cancer when participants find themselves in focused gatherings.

Of the contemporary theorists, Alberto Melucci (1995) is considered by many to be the leading theorist in the field (Flesher Fominaya 2010: 394). He argues that collective identity is generated, that it entails a shared cognitive understanding about desired outcomes, and that the group has a common language and performs its identity through shared rituals and symbols (Ibid.). His writing about collective identity offers a valuable departure point for researchers interested in coming to grips with comprehensive theory, but is challenging because it is so abstract (Ibid.: 395). It is Melucci who reminds scholars that collective identity is 'multilevel, multifaceted, often contradictory' (1995: 60). He shows that collective

identity is fluid and that its relational dimension adds significantly to its complexity (Ibid.: 41–63).

### ***Identity generation in cancer-related group settings***

Most research into collective identity has been directed at broad populations of people, such as those found in nations, religions, ethnicities, sexuality and gender, rather than on micro-level groupings (Snow 2001: 5). Macro-level studies are far removed from my micro-sociological research interest in cancer and group identity. Rather than concentrating on macro-level empirical research, I opted instead to concentrate on research into cancer and identity generation in group settings. Two studies highlight the differences in how groups affected by cancer represent themselves. The previously mentioned study by Klawiter (2008) rejects the heroic portrayal of women with breast cancer, while a study conducted by Parry and Glover (2011) demonstrates the benefits derived from embracing the survivor identity.

Klawiter (2008) explores micro-level identity processes in the breast cancer movement. This allowed her to do a lateral investigation of issues pertinent to bio-politics, embodiment, regimes of practice that are historically-rooted, and identity issues. She investigated the breast cancer movement by focusing on breast cancer movement organizations in the San Francisco Bay region. To illustrate her argument she holds up the mainstream Susan G Komen Breast Cancer Foundation as the polar opposite of activist organizations. The network of organizations she researched was smaller in scope than the RFL movement in South Africa and also differed significantly in terms of its worldview. The organizations included in the Klawiter (2008) study fall mainly at the activist end of the advocacy-activism continuum and reject the dominant survivor identity in favour of a much more hard-hitting representation of the cancer experience. These feminist organizations challenge a purely biomedical approach to cancer, refuse to shy away from anger and hurt, and encourage members to demonstrate changes brought about by cancer by refusing to resort to cosmetic disguises. RFL in South Africa, in contrast, embraces an advocacy position that is more in step with mainstream biomedicine and the portrayal of people with cancer as grateful and accepting. The strength of the Klawiter study is undoubtedly its strong emphasis on the need for a micro-level, cross-cutting approach to the study of health-related social movements with their multiple sites. I set out to accomplish something similar with my inquiry by investigating collective identity in the micro-level context of cancer assemblies across 20 research sites, using multiple sources of data.

In a less critical vein, Parry and Glover (2011) touch on the framing done by a branch of the Gilda Club, a network of social clubs for people affected by cancer in North America. In their exploration of how members fashion liveable truths about the cancer experience and carry out emotional work, they found that club members ‘perform’ identities that are worthy of the survivor label. The framing done by the Gilda Club consciously promotes ‘hope, optimism, strength, appreciation of life, and friendship’ (Ibid.: 401). They found that upsets and hardship are not ignored, but the primary drive is for members to remain positive and strong. They recognize that this pressure to put up a positive performance is potentially harmful and rarely acknowledged. They look at this with great empathy, reasoning that this type of institutional framing is a two-sided coin, simultaneously both empowering and potentially problematic.

My own position is that I recognize how valuable identities that are fashioned on the brave survivor identity can be for representing affected people in a positive light and for countering the effects of stigma. However, I believe that these sunshine identities cease to be helpful and productive when they hinder people from living authentic lives, with the freedom to acknowledge suffering and hardship, abject embodiment and impending death.

### ***Summary***

In this chapter I located my inquiry in a body of literature that deals with cancer, identity, and focused assemblies of people confronted with cancer as a shared concern. I dealt with the depth and complexity of the available literature by tailoring my literature review so that it highlighted the conceptual issues relevant to my inquiry.

I have chosen to create a division between the literature review and my theoretical scheme by organizing the material into separate chapters. In the following chapter, I shift the focus away from the review of literature and move on to outline the theoretical scheme, with its associated guiding concepts, using this as a springboard into working with data.

## Chapter 3

# Theoretical scheme and guiding concepts

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### ***Chapter introduction***

My decision to focus on collective identity generation as a phenomenon and to investigate it in the highly interactive environment of RFL assemblies promised an inquiry that could potentially be difficult to tame. I first had to come to grips with understanding collective identity as my core concept, before I could add three additional guiding concepts that would help me to make sense of collective identity generation in the RFL assembly environment.

In this chapter, I start by explaining the difference between personal, role and collective identities. I look at how they interact with one another and determine how best to define the concept for the purposes of this inquiry. I justify my decision to give prominence to collective identity by pointing to theory which contends that collective identity, rather than personal or role identities, becomes the most salient when groups of people gather together. I then move on to giving an overview of the three guiding concepts I chose to work with, in order to illuminate collective identity generation in the context of RFL assemblies. These were crisis heterotopias, seen as specially created spaces for people faced with a shared crisis (Foucault 1986; Soja 1996; Johnson 2006), identity work, with particular reference to illness narratives (Snow 2001; Frank 1995), and social interaction in the context of focused gatherings (Lawler 2003; Collins 2004).

### ***The nature of collective identities***

One of my initial tasks was to sort out my own confusion about the different types of interacting identities. When people gather together, there is always a dynamic interaction between their individual, role and collective identities (Snow 2001; Lawler 2003). David Snow (2001: 2–3) sees personal identities as the qualities and descriptions individuals attribute to themselves, social identities as the qualities and roles we attribute to one another in social situations in order to place one another in that social milieu, and collective identities as a collectivity's joint and interactive sense both of being one and being able to act as one. Social identities are also referred to as role identities (Lawler 2003: 137) or categorical identities (Collins 2004: 272). To avoid confusion, I will use the term 'role identities' from this point onwards, as I consider it the most appropriate for the situation-specific roles assigned to participants at assemblies by the RFL movement.

Jenkins (2008: 37–38) believes that the ‘individually unique’ in personal identification and the ‘collectively shared’ in collective identification are entangled to such an extent that they cannot be teased apart. Identities become activated through social encounters. Individual identity and collective identity are generated in similar ways, so when theorizing about one it is necessary also to consider the other (Ibid.). As far as Jenkins is concerned, the only difference lies in where the emphasis falls. In the case of individual identification, it falls on what is unique about the individual, while in collective identity the emphasis is on what is shared by the collectivity (Ibid.).

The main differences between role and collective identities are outlined in the work of Snow (2001: 2–3), Polletta and Jasper (2001: 297), and Lawler (2003: 137–138). They can be summarized as follows. Role identities are part of the macro-level process in social movement (in this instance the GCM and the RFL movement), while collective identities reflect a micro-level process that draws upon social interactions and emotions shared by the group. Role identities are largely fixed in the social structure, whereas collective identities have their genesis in protagonist-antagonist formulations and are more fluid. Role identities are imposed from outside, are prescribed and carry clear expectations. Collective identities, on the other hand, are shaped by the group, with the help of things they choose to appropriate, such as collective symbols, ceremonies, music, stories, or metaphors. Role identities act as a growth medium for the emergence of collective identities, but collective identities provide overarching emblems or symbols which reflect the shared focus, activities and emotions of the group in its situated, micro-sociological context.

Different identities are tightly woven together at RFL assemblies. Thus it is possible for a component of one identity to become grafted onto another during the activation of a collective identity. Let me give an example of this by looking at a common RFL scenario. A woman in treatment for advanced ovarian cancer may incorporate the changes to her body and her life-threatening illness into her personal identity. These harsh realities are made to co-exist alongside other personal characteristics she attributes to herself, such as being hopeful or emotionally resilient. At a RFL assembly, she will be given a specific role identity and will be labelled a ‘cancer survivor’, irrespective of how ill she is or how confident she may feel about her prospects of survival. She will be in the company of others who share the same role identity, as well as those who have been given a variety of complementary roles, such as caregivers, team captains, team members or organizers. Once emotionally engrossed

in the activities of the assembly, it is possible that our ovarian cancer survivor will be transported into a deeper, more emblematic collective identity, one that is overarching and draws from archetypal material or what Mike Bury (2001: 265) describes as ‘core narratives’ in relation to the illness experience.

I foreground collective identity generation because I am interested in what transpires at cancer movement assemblies. Snow (2001: 4) maintains that when people are engrossed in social encounters with a strong shared focus, collective identities become more salient than individual and role identities. He views collective identities as more ‘fluid, tentative and transient’ (Ibid.) than either role or social identities, but contends that, despite their ephemeral nature, collective identities once activated nevertheless dominate the other two forms. If Snow is correct, collective identities will become amplified during RFL assemblies and will dominate personal and role identities. Collins (2004: 47–101) would attribute this to the ability of the mutual-focus, emotional-entrainment mechanism to engage participants gathered in a face-to-face setting. This is where my own interest lies – in understanding how collective identities are generated during RFL assemblies when participants find themselves face-to-face in a highly interactive social encounter in which there is a shared focus on cancer.

### ***Defining collective identity***

RFL offers an experience of solidarity for millions of followers globally. In South Africa, more than 60 000 people attend annual RFL assemblies in their local communities. Bauman (2004: 11) talks about ‘communities welded by ideas’ as entities that define our identities. RFL is certainly an example of such a community, with its ability to unite its adherents behind the movement’s vision of how best to deal with the experience of cancer and how to work towards a cancer-free world. Identity, however, is fluid and not necessarily enduring. We live in a ‘liquid modern era’, where our sense of belonging is ‘eminently negotiable and revocable’ (Bauman 2004: 11–12). Few of us have a stable sense of identity over a lifetime. Circumstances change and at different times we find resonance with those communities that are able to give us a sense of belonging (Ibid.: 13).

I find Snow’s (2001: 3) frequently cited definition of collective identity the most useful out of those I came across in the literature:

... a shared sense of “one-ness” or “we-ness” anchored in real or imagined shared attributes and experiences among those who comprise the collectivity and in relation or contrast to one or more actual or imagined sets of “others”. Embedded within the shared sense of “we” is a corresponding sense of “collective agency”. This latter sense, which is the action component of collective identity, not only suggests the possibility of collective action in pursuit of common interests, but even invites such action. Thus, it can be argued that collective identity is constituted by a shared and interactive sense of “we-ness” and “collective agency”.

As can be seen, defining collective identity is no simple matter, due to the complex nature of this ‘notoriously abstract concept’ (Flesher Fominaya 2010: 393). The multi-dimensionality of collective identity derives from the cognitive, emotional and moral drivers of the phenomenon (Snow 2001: 4). Understanding is further complicated by the blurring between the product and process definitions of the concept (Flesher Fominaya 2010: 397). Melucci (1995), for example, looks at it as a process. Snow (2001), on the other hand, sees it as both a process and a product (Flesher Fominaya 2010: 397). Flesher Fominaya (Ibid.) argues that, although process and product are frequently conflated, both are important since they refer to different things. Process refers to the ‘shared meanings, experiences and emotional ties’ of members of the collectivity, while the product definition is akin to a potted version of what the collective stands for and how it is packaged for outsiders (Flesher Fominaya 2010: 397). I too see both the inherent properties and the generated elements in collective identities as important.

In a nutshell, most theorists describe collective identity as the sense of cohesion, solidarity, ‘we-ness’ or ‘one-ness’ experienced by a group (Snow 2001: 3; Lawler 2003: 137; Flesher Fominaya 2010: 393). In the world of mass cancer initiatives, this implies that constituents view themselves as one and as acting as one in the name of the cancer cause. They not only recognize themselves as united, but are also recognized by others outside their world as a solidarity group working together for the greater good.

### ***Guiding concepts as a departure point***

My interest in collective identity generation is context-specific, as I set out to investigate the world of mass gatherings of people who have an affinity with cancer. Once I had a grasp of collective identity as a concept, I still needed additional guiding concepts before I could productively embark on this inquiry. Over time, confluence was created between the guiding

concepts presented here, the data I engaged with for a prolonged period, and my growing insights into my chosen topic. However, I needed a diving-board from which to launch myself and, to this end, I chose three guiding concepts: crisis heterotopias, identity work, and social interaction.



**Figure 3.1: Guiding concepts**

***Guiding concept 1: Crisis heterotopias***

I searched high and low for a theory about space that could facilitate my understanding of spaces created especially for people in crisis. I found what I was looking for in Foucault’s treatment of crisis heterotopias (1986: 22–27). Foucault (1986: 24) described crisis heterotopias as emplacements where people in crisis can step into a ‘counter-space’ – a world set apart from their everyday lives. Thus I conceive RFL assemblies as crisis heterotopias where those affected by cancer can gather in a specially created space for a dedicated period of time. Stepping away from their ordinary lives, they are able to reflect on the cancer experience through ceremonies, story-telling, special attire and adornment, music, dance and

other kinds of identity work. Here the impact of cancer can be mirrored, tinkered with and contested.

This focus on heterotopic space, or 'Thirdspace' as Edward Soja (1996) prefers to call it, was important. The RFL gatherings are staged only once a year in any particular community. During the early phases of this inquiry I decided it might prove to be interesting and productive to work with the concepts of space, as the temporary RFL villages constructed to accommodate assemblies are such a unique feature of these focused gatherings. My hunch was that an investigation of assemblies as 'spatio-temporal units' (Johnson 2006: 78) would provide me with an analytical tool which would go part of the way to explain what I was encountering at RFL assemblies.

I believe such assemblies to be an example of contemporary heterotopias, as they conform to the principles outlined by Foucault. Six basic principles define heterotopias. Although universally found, most are either crisis heterotopias for people who find themselves in a predicament in relation to their broader community, or heterotopias of deviance for those who fail to conform to normative behaviour. The epoch in which a heterotopia exists gives it a clear and determinate function in the society within which it operates. It is possible for a heterotopia to bring together in a specific space several contrasting influences that are highly varied or even contradictory, and to create a microcosm of the outside world it reflects. Heterotopias are often ephemeral, with participants taking a temporary break from the humdrum of their everyday lives when they step into the specially designated space. The site is not freely accessible to those who are not a part of the solidarity community, and participants gain entry through a gesture, by paying to enter the heterotopia, or by undergoing a ritual of sorts. Heterotopias function along a continuum, as places of illusion or of compensation in relation to the broader environment in which they exist (Foucault 1986: 24–27).

Although Foucault (1986: 27) presents these spaces of illusion and compensation as polar opposites, I find it difficult to think of them in absolute terms when considering my own data. Spaces of illusion stand in contrast to the spaces of everyday life, whereas places of compensation are idealized spaces where hopes and dreams can flourish and where existing conditions can be challenged (Foucault 1986: 27; Johnson 2006: 82). I believe that RFL assemblies draw on both elements in the generation of collective identities.

### ***Guiding concept 2: Identity work***

Those who take part in RFL assemblies denote their group identity through colourful team apparel associated with particular RFL role identities. They adorn themselves in a celebratory manner, make lavish use of colours, especially purple, and use a rich array of collective symbols such as candle-bags, balloon arches, sashes, angels, crosses, or hearts. Identity is expressed through performance story-telling, team names, ceremonies, music, dance, banners, slogans, battle-cries, group activities, and in parading around an athletics track for hours on end. I needed a guiding concept to explain both talk and performance during these assemblies. This was where Snow's theoretical concept of 'identity work' (2001: 7–8) fitted the bill perfectly. Snow uses the notion of 'identity work' to describe the expression and assertion of collective identities through talk and performance (Ibid.). Identity work is used to openly demonstrate and express the identity of the collectivity and what it stands for in relation to the rest of the world (Ibid.). Nowhere is collective identity work more apparent than during the RFL assemblies when they are in full flow.

Storytelling is an important feature of RFL assemblies. To gain a more nuanced understanding of the testimonies given by participants, I relied on Frank's (1995: 75–136) work on illness narratives. In the previous chapter, I gave an overview of three narratives – those of chaos narrative, quest and restitution. I found this trio of narratives and their associated identities useful in making sense of my data. In order to understand collective identity generation I needed to explore the nature of these narratives, how they harmonized with collective identity activation, and appreciate the extent to which the dominant narrative is imposed on RFL assemblies by the larger cancer movement. I included this as part of working in an iterative manner, from the micro-sociological detail of assemblies to larger structural considerations, and back again. All three of the illness narratives described by Frank (1995: 75–136) acted as important blueprints for understanding identity work at RFL assemblies.

### ***Guiding concept 3: Social interaction***

I knew that understanding social interaction would be crucial in investigating fully animated RFL assemblies and making sense of the identity work done by the participants. The two theorists I depended on greatly for understanding the interplay between social interaction and collective identities were Edward Lawler (2003) and Randall Collins (2004). Their work suggests that groups which operate at a micro-sociological level generate collective identities

through the interplay of the shared focus of participants, their social interaction and emotional involvement during face-to-face encounters. I worked with their ideas in tandem, as Lawler fills in some of the gaps not addressed by Collins, especially the interplay between individual, role and collective identities. Collins does not explicitly deal with collective identity as a concept, but writes extensively about the related concept of ‘solidarity’ in his work on interaction ritual chains.

In his interaction ritual theory, Collins (2004: xi) places the ritual process in the foreground. His work is largely an extension of Durkheim’s sociology of religion (Heider & Warner 2010: 76), but he also relies on Goffman’s (1967) studies on interaction ritual to flesh out his treatment of the interaction ritual chains at face-to-face gatherings of collectivities (Collins 2004: 47–101). In writing about his theory, Collins (2013) explains that he extends Goffman’s model of interaction rituals by expanding on its Durkheimian foundation of religious rituals. Through his amplification of the Durkheimian underpinning in Goffman’s work on rituals, Collins offers a framework that was particularly well suited to my inquiry. Collins sees the ‘mutual-focus, emotional-entrainment mechanism’ as being at the heart of the interaction ritual (2004: 47). At the face-to-face gathering of participants, the ritual process develops with the energy generated by different elements. These include the group’s mutual focus, their shared mood, rhythmic entrainment of their bodies, emotional effervescence facilitated by both talk and performance, and the embracement of collective symbols (Ibid.: 47–101).

I found the work of Edward Lawler (2003) very pertinent to what I observed and experienced at RFL assemblies. He develops a theory of collective identity that blends aspects of social exchange theory and structural symbolic interaction to explain the relationship between social interaction, emotions and the generation of collective identities (Ibid.). His theory assumes that the group is involved in a joint task. I found a parallel between this, Collins’s notion of ‘mutual focus of attention’ (2004: 47) and Snow’s insistence that identities are embedded in social interaction (2001: 2).

This inquiry places a great emphasis on the role of emotions, as cancer evokes such strong emotions in affected people, and RFL assemblies are saturated with emotional content. By uniting against a common enemy, and by being drawn into and transported by emotions, they set the stage for the cultivation of collective identities. Lawler (2003: 135–136) explains that emotions in group settings are ‘feeling states’ that participants are well aware of and are able

to pinpoint. However, grand emotions such as exuberance, sadness and pleasure are not under the full control of individuals in collectivities, but are strongly influenced by the social encounter. These powerful group emotions help participants to define the social situation and, together with shared interactional tasks, lay the foundation for collective identity formation. It is in the social situation that participants become aware of the feelings associated with being together as a group and their sense of being one.

Like Collins (2004: 47–101), Lawler links shared action to a heightened awareness and a progressive tuning in to the mood of the collectivity. He works on the premise that the social interaction in the group generates emotional energy which, in turn, feeds into the salience of collective identity (2003: 141). This escalates when the group becomes emotionally entrained (the Collins model) or is caught in the feedback loop of global emotions (the Lawler model). The level of emotional energy in the group affects how participants feel about their involvement in RFL. When assembly interaction entrains them, an amplification of collective identities will follow. The converse also holds. When the social interaction is weak, a sense of group attachment will be diminished. In short, social interaction, aided by emotions, activates collective identities (Lawler 2003: 141).

### ***Summary***

With a working understanding of collective identity generation as the principal phenomenon that needed to be explored and supported by three guiding concepts – crisis heterotopias, identity work and social interaction – I launched myself into the empirical phase of my research. The research process is described in the following chapter. It deals with my chosen methodology, methods and the strategies I used to enhance the quality of the study.

## Chapter 4

# Methodology, methods and quality

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### ***Chapter introduction***

In this chapter I deal with methodology, the methods used to gather and analyse research material, and the strategies I employed to enhance the quality of the inquiry. As a departure point, I motivate my choice of a single-case study and describe its design, with its short-term ethnographic and archival components. I highlight the preparatory work I did before I ventured into data gathering, including the pilot study I conducted. I show how I gathered data by relying on participant observation, focus group interviews (FGIs), audio-recording of ceremonies and speeches, YouTube videos, and a photographic collection. Together these proved the building blocks for gaining a deep understanding of the generation of collective identities at RFL assemblies. I describe how I systematically deepened interpretations to the point where I felt confident enough to present an argument. The final part of this chapter deals with matters of quality. I conclude the chapter with a short summary.

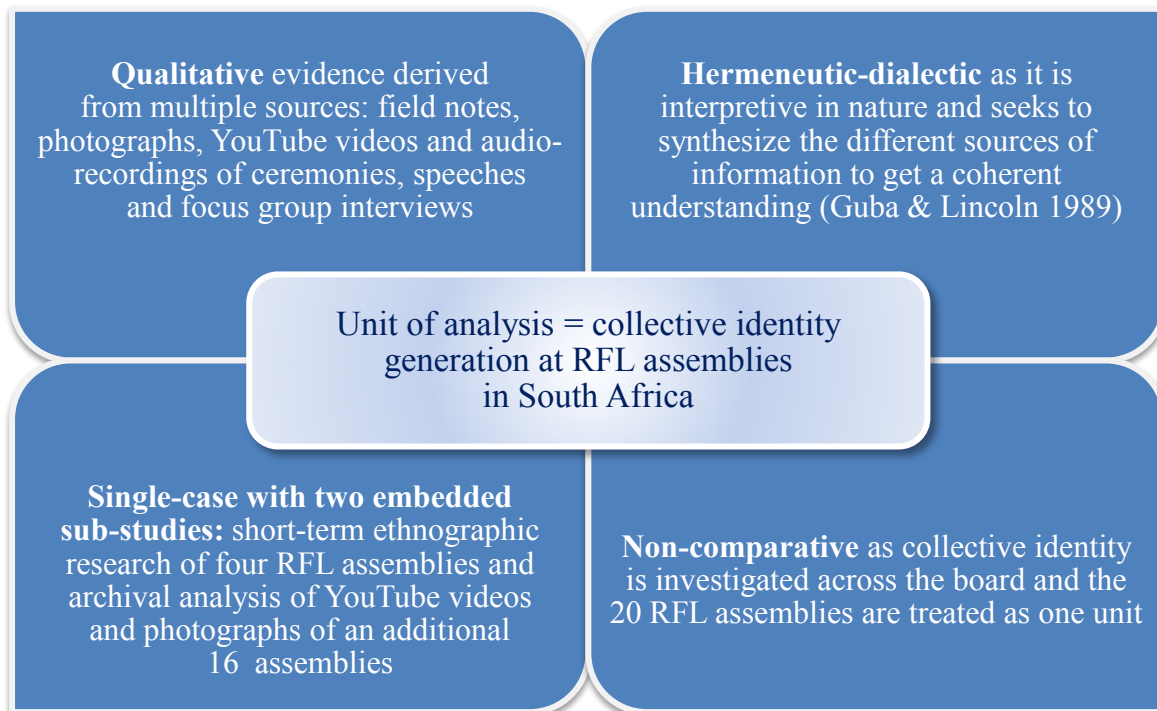
### ***The case study***

My primary reason for choosing to do case study research was because the *raison d'être* of case study is deep understanding of particular instances of phenomena' (Mabry 2008: 214), and because such a study offers the opportunity to deal with complexity. Mabry (Ibid.: 217) underscores this by saying that: 'Case study exhibits a profound respect for the complexity of social phenomena. Interpretivist methodology encourages the case study researcher to be alert to patterns of activities and the variety of meanings participants ascribe to their experiences.' Given my past experience with RFL, I knew that I would be working with a complex phenomenon. Case study research therefore seemed tailor-made for what I was hoping to accomplish.

Out of the available case study design options, I chose to do a non-comparative, single-case study. Snow and Trom (2002: 161) recommend this design as one which homes in on a key phenomenon as the centrepiece of a study. Collective identity generation as a phenomenon was manifested across the data sources used in this study. It was this phenomenon that constituted my case and was therefore my unit of analysis. For Yin (2009: 30), the unit of analysis is equivalent to the case. Although the data corpus incorporated material gathered at different field sites, as well as archival material, these varied sites and data sources were not

treated as distinct cases. The focal point of the inquiry was the different manifestations of collective identity generation at RFL assemblies. While the RFL movement formed an important backdrop to the study, my primary concern was with the activation of collective identity during RFL assemblies. Snow and Trom (2002: 161) elaborate by saying that this type of study pays homage to the larger movement to the extent that it provides the context in which the focal process is played out. Nevertheless, the focal process – in this instance collective identity generation – is the primary concern of the researcher.

The distinctive features of my case study can be visualized in the following way:



**Figure 4.1: Case study: defining characteristics**

Additional support for the use of non-comparative, single-case studies comes from Yin (2009: 48), who considers a ‘representative case or typical case’ suitable for this type of design. In South Africa, more than 87 communities stage RFL assemblies each year. The selection of assemblies was done so that the different elements of the case study would reflect the larger RFL movement in the country. While RFL assemblies take on some of the flavours of the communities in which they are staged, they are so highly scripted the world over that common features are to be found at all gatherings. In my view, my selection of RFL assemblies was done in such a way as to make this a typical case of RFL in South Africa.

A concern with depth of understanding and quality led me to choose two sub-studies that would allow for more extensive analysis (Yin 2009: 52–53). The first was a short-term ethnographic study, carried out at four RFL assemblies in the Western and Eastern Cape. The second sub-study was an ‘indigenously generated’ archival study (Snow & Trom 2002: 151), drawing on nine YouTube videos and 180 photographs captured by RFL participants at focused gatherings. I felt it would be advantageous to add the additional layer of archival material to boost the substantive validation of the inquiry (Angen 2000: 390–391).

### ***Preparatory work***

I approached the research division of CANSA about conducting this inquiry and enjoyed a receptive response. This organization is the single biggest funder of cancer research in South Africa and has a dedicated research division, making it a non-profit body with a particularly strong research capability. Despite my not being a biomedical researcher or a CANSA-funded researcher, there was great openness to my proposed study. I was asked to provide a concept paper and to sign a Memorandum of Understanding (Appendix A), as the organization needed to be assured that my research would meet acceptable ethical standards.

Gaining entry to the four RFL assemblies I wanted to observe, and accessing archival material, was made easy by my existing network of contacts in CANSA. In this familiar world, I was surrounded by people who were keen to assist me in whatever way they could. I was not confronted with the same challenges a newcomer would be likely to face, not knowing whom to contact or having to establish rapport with total strangers. Entering into the field and navigating my way through data collection was a smooth process. Research sites were chosen with the help of two senior managers at CANSA. To contain costs, I selected three sites in my own province and one in a neighbouring province. YouTube videos of RFL assemblies in South Africa were readily available on the Internet, and the photographic collection was provided by CANSA and later augmented by photographs taken during fieldwork.

The RFL Leadership Summit was the first assembly I attended. An information card about my research was placed in the conference packs of all the delegates. The summit had the advantage that it brought together leader volunteers from across South Africa, giving me the best possible geographical representation I could hope for in a single assembly. An added bonus was the opportunity to have face-to-face meetings with the leadership of the remaining

fieldwork sites and carry out preliminary planning for my short-term ethnographic visits to Worcester (Western Cape), Mossel Bay (Western Cape) and East London (Eastern Cape).

I opted to do a pilot study, believing that it would provide the groundwork for data collection and analysis. In retrospect I recognize some of the benefits, but I am also willing to concede that it added less value than I had hoped it would. Qualitative researchers do not routinely conduct pilot studies (Morse et al. 2002: 20), and those who do set out with little more than a tentative theoretical scheme, a central research question, broad interview questions, and a hazy idea of the results the study might eventually produce (Morse 1997: 323). My point of departure was no different. In my metaphorical haversack, I had only the tentative understanding brought about by having written a research proposal. I was nevertheless convinced of the importance of doing a pilot study, as proponents of such a study describe it as a small-scale version used by the researcher to prepare for the larger project, to refine data collection methods and to test interview schedules (Van Teijlingen & Hundley 2001; Yin 2009; Kim 2010). Pilot studies are also credited with illuminating substantive issues such as quality, ethics and the depiction of research participants, as well as highlighting issues around the researcher's well-being (Sampson 2004: 395).

As an inexperienced researcher, I felt I needed to do a pilot study, regardless of having attended many RFL assemblies in the past. At the same time, I understood that these were early days and that I needed to be open to what I might find in the data as the study progressed. There was a danger of rushing to premature conclusions, thereby obscuring the research terrain. I also knew I would be working in an iterative manner and that each field trip would result in further refinements. I nevertheless hoped that by carrying out a pilot study I could test myself in my role as a researcher, and assess both my data collection methods and the FGI schedule. For example, I wrote this note in my fieldwork journal after the first FGI:

*I experienced the focus group interview positively and was thrilled with how easily conversation flowed between participants. My interview schedule needs some refinement, but on the whole it worked well. The group sometimes automatically picked up on themes without me or my co-facilitator having to introduce the next discussion point. There was a single question that confused the group and required me to explain what I was looking for. I will make the necessary changes to the schedule once I have transcribed the audio-recording. (Journal Entry 2012/1)*

The pilot study helped me anticipate logistical issues I would encounter at the remaining RFL assemblies, as well as assisting me with methodological concerns. The three key outcomes were: (a) that I gained clarity on the mix of participants I needed in the remaining FGIs, (b) I was able to make slight modifications to the FGI schedule, and (c) it helped me acclimatize to my role as a researcher.

Yin (2009: 92) approves of pilot studies that are led by what is practical, affordable and accessible. I was fortunate that the opportunity to do a pilot study found me, before I could find it. A request from CANSA that I host a senior ACS delegation offered a chance that was simply too good to pass up, and I moved swiftly to make this assembly the focus of my pilot study. I knew there would be ample opportunity to gather data and to gain a better understanding of the challenges I would be facing during the remaining fieldwork trips. The pilot study, despite having fallen into my lap, was carefully planned and executed. I used data derived from the RFL Leadership Summit as the centrepiece and added archival material to it. See Appendix E for a more detailed account of the pilot study.

Limited as the pilot study was, the data proved to be too valuable to set aside. I therefore decided to incorporate the results into the full-scale case study. As Bazeley (2013: 55) points out, in qualitative research the data generated through pilot studies can add value to the larger study, even as the inquiry evolves over time.

It would be remiss of me not to mention some obvious limitations to conducting a pilot study. I have to agree with Morse (1997: 323–324) that at this stage of the research my data was thin, totally unsaturated and a poor indicator of the trends and themes that would emerge later. The most important themes to come from the pilot study were: (a) the survivor role identity, (b) the emotional reaction of loss, (c) identity talk, and (d) spiritual reactions. None of these themes would prove to be pivotal in the development of the thesis. Other benefits, such as getting used to my role as researcher and improving the FGI schedule, could as easily have been accomplished simply by going into the field to collect data and doing the analysis once I was back in the office. Careful and thoughtful refinements were made to my research practice at each phase of the main research and not only after the pilot study.

### ***Sub-Study 1: Short-term ethnography***

After the pilot study, I made a point of staying in touch with key people to ensure that the project would not quietly slip off their agendas. Sampson (2004: 394) talks about the

importance of continuously working to keep communication channels open when research involves organizations. To this end, I kept contact by phoning and emailing to remind organizing committees that all the plans for my visits to their RFL assemblies were still on track. Six weeks before arriving in any of the host communities, I would either do a site visit or telephone to confirm logistical arrangements and discuss the recruitment of FGI members. All agreements reached were summarized in emails that were sent to confirm arrangements. A week before going into the field, I would again telephone to verify all plans.

Fieldwork was carried out over seven months, between mid-August 2012 and mid-March 2013. Material was obtained from four sites, including the pilot site. I travelled to the host communities by road or air. Distances varied from 136 to 1 045 kilometres. The shortest period spent at a site was 19 hours (RFL Worcester 2012) and the longest was six days (RFL Leadership Summit 2012 in Diaz Strand). The RFL Leadership Summit included the preparatory days before the summit, when I joined staff of the ACS and CANSA in meetings, training sessions and social events. This extra time also allowed me to present the plans for my PhD to senior staff of both cancer organizations.

I drew heavily on my past experience of RFL in finding my way around the assemblies. Thus I knew what to expect, could anticipate the different elements of the programme, and was able to work in a focused manner. My inquiry called for ethnographic techniques that would compensate for the fact that focused gatherings are staged only once a year, at a set time in the calendar and are typically overnight. Only the annual RFL Leadership Summit was longer, since it was run like a conference, but even this assembly was short by traditional ethnography standards. Short-term ethnography proved to be the answer, since it is a systematic, modern-day research application suitable for fieldwork that needs to be carried out swiftly and accurately (Knoblauch 2005: 4–6; De Walt & De Walt 2011: 38; Pink & Morgan 2013: 352–354). I knew that a poorly executed attempt would mean having to wait a whole year for the same assembly to take place, or finding a costly alternative which would involve travelling to another site. This approach – with its close relationship between theory and research, reliance on a prior understanding of the research domain, short periods in the field, data intensity and a heavy reliance on audio-visual recording – was perfect for what I needed to do in the field (Knoblauch 2005: 7; Pink & Morgan 2013: 355–359).

At overnight assemblies, RFL participants try their best to stay awake all night and most succeed admirably. As a participant observer, I had the added pressure of needing to be alert

enough to gather quality data. I wore RFL attire, walked the track with other participants, observed ceremonies, wrote field notes, audio-recorded, conducted FGIs and took photographs which I later incorporated into my fieldwork journal. I wrote the reflection below in the days following an overnight assembly. Here I write about how daunted I felt about the long night of ethnographic work ahead of me:

*In my car I had almost everything I would need to get through the cold spring night: a warm jacket, scarf, beanie. I forgot my gloves, an oversight I would regret later when it was bitterly cold on the track. With 17-hours of research ahead of me and feeling sick, the challenge of staying awake and engaged, plus the prospect of driving home in a sleep-deprived state the following morning, made it necessary for me to dig deep to ensure that I remained focused. (Journal Entry 2012/6)*

I compensated for my brief, intensive bursts of fieldwork by putting extra effort into data gathering. Knoblauch (2005: 2) shows that this is possible by relying heavily on audio-visual recording which can be used to supplement field notes. Audio-recording and photography played a leading role in my data collection, while field notes, though still important, had the supporting role. Ceremonies, speeches and FGIs were captured with the help of colleagues, two cameras and two audio-recorders. All recording was done openly. It is notable that recording is a custom at RFL assemblies. The collective identity work at such events is eye-catching, and much of what participants do is there for consumption and display. There are literally hundreds of people taking photographs for their own records, social media, websites and print publications such as community newspapers. In addition, teams and sometimes commercial crews make videos as keepsakes or to use as promotional material on YouTube, television or websites. Participants expect to be recorded and frequently perform for the camera. These assemblies are every bit as visual, camera-friendly and flamboyant as any carnival or parade.

None of my assistants played any role in writing field notes or in the subsequent data analysis, but it was clear from the outset that I would have to rely on extra hands in the field. Knoblauch (2005: 2) and Pink and Morgan (2013: 352) agree that this type of research calls for the assistance of a team. The intensity of fieldwork made it crucial to enlist the help of colleagues and volunteers. In a memo I explain some of the division of the workload at assemblies:

*At each site I had to rely on others to assist me with data collection as the assemblies were too big and complex for me to cope as a solitary researcher. I needed to remain focused on observation, note-taking, the facilitation of FGIs and some audio-recording. I purposefully chose to let my assistant help with on-site logistics (e.g. fetching and carrying of equipment, setting up the venue for the FGI, registering members for the FGI, organizing refreshments for the FGI), audio-recordings, photography and co-facilitation of the FGI. I received help from different people at different research sites. (Memo dated 02/04/2013)*

FGIs proved to be a valuable aspect of this inquiry. In this, I relied heavily on the practical guidance given by Krueger and Casey (2009) for planning and executing these groups. Focus group interviews allowed me to explore belonging, meaning-making, why participants chose RFL as opposed to other cancer initiatives, and what they would miss if they were to stop their involvement. It is an ideal method for exploring a social process (Blee & Taylor 2002: 107–109; Johnston 2002: 83–85) and is the method of choice for those studying collective identity (Melucci 1995: 60–63). FGIs were conducted during RFL assemblies once participants were fully caught up in the flow of activities and before they tackled the long haul of walking the track between midnight and sunrise. The pilot group was done during an afternoon session of the second day at the National Leadership Summit. All the other groups started at 22:00 after the opening ceremony, survivors' walk and luminaria ceremony. It was imperative that participants first experienced the emotional roller-coaster of the assembly before I involved them in a discussion, as I wanted to catch them while they were emotionally entrained by the assembly activities.

I relied on the RFL leadership in each community to assist me with recruitment of FGI participants. Twenty-six participants were interviewed, the groups including men and women, people from the Christian and Muslim faiths, different ages, educational levels and income. Special attention was given to the inclusion of a range of HoH, cancer survivors, caregivers, organizers, team captains and team members.

I had to be flexible regarding the venues I had at my disposal for groups. For the FGIs, I tried to find spaces in the RFL temporary villages, away from noisy activities. The venues ranged from a plush functions room in a four-star hotel to a clubhouse shared with paramedics, to an unbearably noisy marquee on the edge of the walking track, to a changing room inside an

athletics stadium. It was important for me and my co-facilitators to take things in our stride, as most of the venues were ‘rough and ready’:

*After the luminaria ceremony it was time to set up the venue for the FGI inside the stadium complex. Graeme (co-facilitator) and I decided to be self-reliant as the organizing committee was very busy. A couple of practical problems had to be sorted out. There was no electricity in the section of the building where we were going to work, despite my having enquired about electricity before the trip. Once attention was drawn to the problem, the municipality quickly restored the power. Graeme made directional signs and pasted them along the interior route of the building. Simple snacks, juice and tinned cordial were put on the crowded table. Each place had a consent form, a printed information piece about the research, a table-tent with the participant’s name and a thank-you card with a R200 Woolworths voucher (just enough for coffee and cake for four people). The two digital audio-recorders were checked earlier that morning when we had a practice session to work through the interview schedule one final time. (Journal Entry 2013/4)*

Persuading participants to share information about their cancer experience and the things that fuelled their affinity with RFL required my sensitivity. With a single exception, all the participants in FGIs were strangers to me. To establish rapport, it was necessary for me and the two co-facilitators I used on different occasions to establish our ‘cancer credentials’. All three of us have close bonds with a person living with cancer. By positioning ourselves as being a part of the cancer world, I believe we made it easier for participants to allow us into their worlds.

The FGIs differed in length. The shortest interview was in Mossel Bay, where the small number in the group made it possible to work through the interview schedule (Appendix D) relatively quickly. The noisy venue was not conducive to lingering too long over questions, but I nevertheless managed to get this articulate group to share valuable insights. The longer groups were at the National Leadership Summit, where participants engaged very deeply with the questions, and in Worcester, where the group of nine participants needed extra time to work through the questions.

I felt that the inquiry needed more than just short-term ethnography to meet the hallmarks of case study research (Yin 2009: 41–42). In order to improve the quality of my research design,

I added the second layer of image-based archival material so that the study would contain multiple data sources.

### ***Sub-study 2: Archival photographs and YouTube videos***

The archival material used in this Sub-study 2 study comprised photographs and video recordings captured by RFL participants at assemblies. The video material was obtained from YouTube<sup>4</sup>, while the photographic collection was from the CANSA archives. RFL photographs are avidly collected by RFL participants and an impressive collection is in the custody of CANSA. This sub-study involved desk research, for which there was no need to travel. The analysis of material started in July 2012 and was completed in August 2014.

I used nine videos, uploaded on the YouTube, that were captured at overnight assemblies in South Africa between 2008 and 2013. The videos were produced in the following communities: Breederivier Luminaria (CRFLB 2013a), Breederivier Survivors (CRFLB 2013b), Corporate Johannesburg (JLT Productions 2012), East London (MediaTag 2009), East Rand (Jacobs 2012), Potchefstroom (Naude 2011, 2013), Soweto (Relayben 2011) and Western Gauteng (Cook 2008). The quality of the videos ranged enormously. I made a note about this in a memo I wrote while coding:

*The most rudimentary videos use simple text and photographs backed by song or voice. The more sophisticated videos combine a range of mediums, including film. Amateur teams sometimes pay scant attention to editing the product that gets posted and grammatical and spelling errors are common. In some instances there is almost no relationship between the titles, sub-titles and content. Two of the nine videos were of such a poor quality that I was tempted to exclude them from the study. However, repeated viewing convinced me that this would be a mistake, as they nevertheless contained data that spoke to the research topic. (Memo dated 13/09/2013)*

I also worked with a collection of photographs taken at 10 RFL assemblies across South Africa: Amanzimtoti (2012), Witbank/eMalahleni (2012), Frankfort (2011), Kathu-Kalahari (2011), Nelspruit/Mbombela (2012), Middelburg (2012), Parys (2012), Pietermaritzburg (2012), Polokwane (2011) and Soweto (2011). The communities ranged from big metropolitan centres to small towns in sparsely populated provinces. I purposefully selected

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<sup>4</sup> YouTube is a website on the Internet which enables amateurs and professionals to share videos with a global audience.

images of group attire, banners, visual installations, decorated campsites, ceremonies, performances, and other images that reflected collective identity work.

### ***Method of data analysis***

My analysis was based on the principles of naturalistic inquiry (Erlandson et al.1993), with its foregrounding of the hermeneutic circle of interpretation (Patton 2002: 497–498) as a way of analysing data. I used this circle as a conceptual space in which to make sense of the wealth of data I had at my disposal. I imagined the circle as a whirlpool, with one data source after another being drawn into the circle. I analysed data thematically, made interpretations as patterns revealed themselves, and connected data, theory and my growing insights during a prolonged engagement with the inquiry. This process continued to the point where I felt that I had reached saturation (Kelly 2006a: 370–387) and was able to free myself from the vortex to present the argument.

Interpretive methodologists such as Guba and Lincoln (1989b: 149–155), Erlandson et al. (1993: 124–125), Patton (2002: 497), and Schwandt (2007: 133–135) visualize the hermeneutic analytic process as circular – hence the reference to the hermeneutic circle of interpretation. In the words of Patton (2002: 497), the circle illuminates understanding by ‘relating parts to wholes, and wholes to parts’. In explaining the hermeneutic research process, Kelly (2006b: 350) describes two moves that repeat themselves throughout the process: (1) the interpretive dimension of the study that describes the subjective experiences of research participants, and (2) a social constructionist dimension which relies on a distanced interpretation by the researcher of the subjective experiences of the group being researched and facilitated by focusing on the bigger context of the inquiry. Patton evokes the image of nesting dolls in explaining the hermeneutic circle: ‘... interpretation is layered in and dependent on other interpretations, like a series of dolls that fit one inside the other, and then another and another ...’ (Ibid.: 497). By constantly moving between the micro-sociological detail of RFL assemblies and the larger structural aspects of the GCM I was able to advance progressively deeper into understanding my topic and closer to presenting an argument.

I now turn my attention to describing the three phases I went through in analysing data. Keep in mind that data gathering and analysis went hand-in-hand during the first two phases of analysis that I describe below. The process moved organically from one task to the next as I brought data into the hermeneutic circle and analysed it. However, I think it would assist the

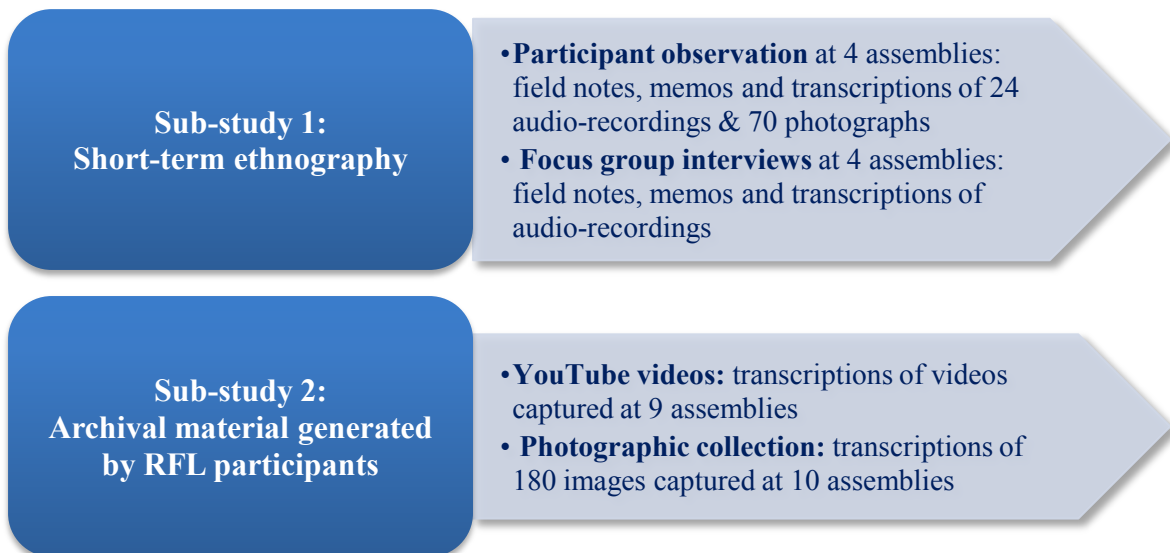
reader at this point to imagine a three-phase process, with a beginning, middle and end. Refinements to the coding list, theoretical scheme and interpretations were made continuously as data sources were added to the hermeneutic circle of interpretation.

The first phase of data analysis saw me mastering the basics of the CAQDAS programme, designing an a priori list of codes, immersing myself in data by doing my own translation and transcription work, expanding the list of codes as I explored each data source, and beginning the process of writing reflective memos. The second phase focused on refining codes and identifying patterns. Finally, I developed a three-part typology to provide my dissertation with a macro-structure and create the building blocks I needed for the argument. The deepening of the interpretive analysis was done during this final phase, allowing me to move beyond a description of what I found in the data to synthesizing data and theory in response to my research questions.

### ***Starting analysis***

During the early phase of analysis, I synthesized research material from 20 RFL assemblies that incorporated the views of HoH, cancer survivors, caregivers, organizers, team captains and team members. I worked on the data sources as soon as I felt able to do them justice. My fieldwork trips were booked in advance and became fixed milestones around which I fitted in work on archival material. I started by working on two videos, followed by two field trips within three weeks of one another, then moved on to some of the images in the photographic collection. I constantly alternated between video, photographic and ethnographic sources, fitting material into my work programme as suitable timeslots presented themselves.

Fieldwork generated a journal, reflective memos, audio-recordings and a wealth of photographs. Seventy fieldwork photographs were analysed, while others were used as memory markers in the write-up of field notes in the days following each trip. To this I added the nine archival YouTube videos and an additional 180 archival photographic images. The audio-visual recordings had the added advantage that they preserved complex details, remained available throughout analysis and could be scrutinized repeatedly (Collier 2001: 49; Pink & Morgan 2013: 355). The elements of the sub-studies can be summarized as follows:



**Figure 4.2: Sub-studies and data sources**

Management of the wealth of audio-recordings, videos and photographs was made possible with the aid of new generation CAQDAS. I chose NVivo software (QSR International 2011) as a tool with which to organize, code and analyse my data. As a stereotypical baby boomer with little natural aptitude for software applications, I nevertheless found the programme fairly easy to master with the aid of training videos, regular webinars, a workbook and a two-day workshop I attended in KwaZulu-Natal. I agree with Bazeley (2013: 18) that CAQDAS offers researchers a functionality that outstrips manual methods, and with De Wet and Erasmus (2005: 5, 34, 39) who recommend this software package as a way of expediting a systematic and scrupulous data analysis.

All data sources were imported into NVivo prior to translation and transcription. I did my own Afrikaans to English translation, as I am fluent in both languages, and also opted to transcribe all my data. This was done partly to save costs, partly to avoid the finer nuances being lost by someone who was a stranger to RFL, and because translation and transcribing proved to be easier in NVivo than I had initially imagined. It also converted audio-visual materials into transcripts. The biggest benefit of this time-consuming process was that I became totally immersed in the material and came to know the transcripts extremely well.

During the beginning phase of analysis, I designed a start list (Miles & Huberman 1994: 58; Bazeley 2013: 170–171) with 66 a priori codes, organized my material, did an early exploration of data, and went through an initial cycle of coding. I am in agreement with

DeWalt and DeWalt (2011: 80) on how important it is to have some basic understanding of the background of a study before venturing into the field:

While in earlier times researchers were often trained (or not trained) to go into the field with no preconceived theories or expectations, most researchers now enter the field with well-defined and specific research questions, well-thought-out theoretical and conceptual frameworks and ideas about social structure, social interaction systems, power relations, networks, etc.

I saw the start list as a necessity because the short-term ethnographic component of the case study called for a footing in a theoretical scheme (Knoblauch 2005: 9; Pink & Morgan 2013: 351, 357–358). I also could not pretend that I was a clean slate, given my prior involvement with RFL.

Each of these early a priori codes encapsulated my preliminary ideas about collective identity. Included in the start list were codes that related to time and space, portrayals of the cancer experience at RFL, religion, story-telling, ceremonies, the symbolic use of colour, embracement of the cancer cause, identity claims made by participants, and the use of military terminology. As the work progressed, I added data-derived codes and began transforming the coding list. Over time, this list became unwieldy, with many overlapping codes. The list needed to be consolidated, and this was mainly carried out during the middle phase of analysis.

### ***The middle phase of analysis***

During the middle phase of analysis, I did a second cycle of coding. I refined the codes and organized them into hierarchies (Bazeley 2013: 126) that reflected my growing insight into the generation of collective identities. Here I was more concerned with the big picture and with moving closer to my theoretical scheme. Major tasks included making sure that the patterns I was creating were a good fit with the developing overarching scheme, checking whether all the significant data segments had been incorporated into codes, and noting data in instances where new insight led to the creation of new codes or higher-level codes (Braun & Clarke 2006: 91; Bazeley 2009: 10–11; Bazeley 2013: 185). The more I engaged with the transcripts, the more it became necessary to add more codes, reassign data segments to more appropriate codes, merge some codes, and abandon others that were simply too lightweight to

stand their ground in the theoretical scheme (Bazeley 2013: 185). The longer I worked with the data, the more I could see what belonged where and how to construct patterns.

My thinking about religion at RFL assemblies offers an example of the evolution of a theme across time. Out of my first cycle of data analysis I arrived at a parent code called ‘spiritual reactions’ with five child codes: epiphanic experiences, miracles, religiosity, scripture readings, and signs from God. By the end of the second cycle of coding, all these were reduced to a single child code called ‘religion and/or spirituality’, attached to a higher-level code called ‘MFEEM elements’ – referring to Collins’s (2004) theory about the mutual-focus, emotional-entrainment mechanism. I no longer saw religion as an independent driver of collective identity. Instead, I now saw it as one of many elements in a bigger process which included elements such as attire and adornment, ceremonies, dancing, music, and storytelling.

A turning point came when I had coded approximately 80% of my data. It became evident that I needed to make sense of the role of emotions at RFL assemblies. Wave upon wave of evidence was showing me that I was moving into a conversation about emotions and what Collins refers to as interaction ritual chains (2004: 47–101). The data suggested that assemblies took participants on an emotional roller-coaster ride geared to creating emotional energy. I found an excellent overview of the sociology of emotions in the work of Turner and Stets (2005, 2006), before coming to grips with Collins’s (2004) theory. This new insight made me feel that the study was moving in the right direction.

I also increasingly found writing useful as a tool for analysis (Bazeley 2009: 18–20). Memos proved to be particularly valuable in clarifying my thinking about higher-level codes. Towards the end of this phase, the collection of memos had grown to a total of 89. I coded my memos and fieldwork journal just before I moved on to the final phase of interpretive analysis, so that my reflections about themes would be readily available when I printed each code before starting work on my final analysis. I did not stop writing memos at this stage, but once the original collection of memos had been coded I made a point of immediately coding all new additions.

Once the two major coding cycles were completed, I felt secure enough to start work on the bigger scheme for my thesis. I now had a workable model with higher-level codes and their accompanying sub-codes.

### ***Rounding off the analysis***

During this final phase of analysis, it became clear that by working with different theoretical lenses and with my findings I would create an ‘analyst-constructed typology’ (Patton 2002: 458–462). I would use this typology with its supporting data for a member reflection session at a later stage (Patton 2002: 460). The typology structured the dissertation into the three sections which became the chapters covering the findings of the research. Part 1 deals with how the context of RFL assemblies creates arenas for the intensification or weakening of collective identities. Part 2 revolves around how assemblies, once they are fully animated and in flow, facilitate collective identity amplification or weakening. Part 3 looks at how activated collective identities are embraced, hybridized and disrupted, and how this relates to the broader debate about cancer and identity. Ultimately these sub-sections would be consolidated into the final argument. I now felt more like a ship that knew which harbour it was heading for.

At this point, I stepped back from my reliance on CAQDAS and worked instead with the printed material collected under each of the codes belonging to my three central organizing ideas. Now it was no longer about simply describing what I unearthed in the data. It was time to move into an interpretive analytic account by making connections between concepts and tying these back to theory. Braun and Clarke (2006: 97) emphasize the need to make analytic claims against the backdrop of a theoretical scheme, as theory ‘anchors the analytic claims made’ (Ibid.). The process of interpretation went beyond what the text explicitly offered me, while my empathic resonance with the material allowed me to look beyond what was on the surface of the texts to what was implicit or veiled.

Hermeneutic interpretation was also helped along by the questions I constantly posed as I grappled with the data. Through triangulation appropriate to interpretive research, peer review and member reflections, I was able to challenge my assumptions and unearth divergent views. Many questions, together with my preliminary thinking about them, found their way into the memos I wrote to clarify my ideas. These questions were not only a result of prolonged engagement with the data, but were also considered during supervision. They included, for example: What significance does the emphasis on enduring suffering have in my understanding of this topic? Why do participants dress up and behave as if they are at a carnival, and how does this fuel emotional-entrainment? Is the exuberance a manic defence against suffering and death? If the assembly space is an imagined battlefield, then who or

what is the antagonist? What is the flipside of the heroic warrior identity? The memos I wrote while I was busy with data analysis proved to be helpful in the evolution of my understanding and ultimately helped in the construction of the argument.

Countless bedraggled daisy diagrams (Luker 2008: 81–82) and mind-maps were used during supervision sessions and peer review presentations. These became very important during this final phase of analysis, as I moved towards constructing the argument (Miles & Huberman 1994: 133–134; Bazeley 2009: 15).

I continued working with the research material to the point where I felt the data had become saturated and I was justified in freeing myself from the hermeneutic circle of interpretation to present the argument (Patton 2002: 497–498). I was now increasingly coming across more of the same findings as I worked my way through the data. I could have continued adding YouTube videos and photographs indefinitely, as RFL communities never stop uploading these onto social media and fresh material is always available from CANSA. For the purposes of this study, however, I decided that I would call it a day and move on to constructing the argument.

### ***The quality of the inquiry***

Throughout this inquiry, I felt caught on the horns of a dilemma between honouring my hermeneutic perspective on the one hand, and my anxiety about having to create confidence in my ability as a PhD researcher on the other. I knew the onus was on me to demonstrate that I had worked in a highly systematic way to ensure quality, but I knew full well that some of the strategies I had used had me glancing backwards over my shoulder at methods that had faint echoes of positivist research practices. This tension remained throughout the research process in the way I combined elements of Maureen Angen's (2000) and Sarah Tracy's (2010: 837–851) frameworks of qualitative quality criteria. Angen (Ibid.) is a true-blue interpretivist, while Tracy's eight 'big tent' hallmarks of quality are more traditional.

For the purposes of this discussion, I followed Angen's lead and divided my quality criteria into ethical validation and substantive validation (2000: 387–391). She prefers the term 'validation' over 'validity', as the former refers to 'the process of confirmation' (Ibid.: 392) and not to a positivist notion of the truth. I deal first with ethical validation, before moving on to a discussion of the substantive strategies I used.

### ***Ethical validation***

Ethical practice is crucial to ensuring trustworthy research and requires that certain research practices be followed. As researchers, we need to pay attention to formal ethical procedures, the context in which we conduct our inquiries, the impact we have on others, how we move in and out of research settings, and the safeguards we create to ensure that findings do not lead to blame being apportioned or research material being wrongly appropriated (Tracy 2010: 840, 846, 847). Angen (2000: 388–390) highlights the need for an inquiry to be inclusive, respectful of participants, and conducted in such a way that it opens up debate between a range of stakeholders. Interpretive research should move us beyond what we already understand about a topic towards generative learning that creates space for fresh insights (Ibid.: 389).

Throughout this study, I had to balance the macro-ethics associated with my status as a PhD researcher with the micro-ethical challenges I encountered at the rock-face of my research. Kubanyiovo (2008: 503–518), building on the work of Haverkamp (2005), writes about the need to reconcile both types of ethics in situated research in order to ensure ethical practice. Macro-ethics is defined as the ethical codes and protocols issued by institutions, based on the core principles of respect, beneficence and justice (Kubanyiovo 2008: 505). Here Kubanyiovo (2008) turns to the Haverkamp framework (2005) which distinguishes between ‘virtue ethics’ and ‘ethics of care’. Virtue ethics is the ability of the researcher to recognize situations which call for ethical decision-making, while ethics of care speaks to the relational nature of social research and the need to treat participants with the utmost respect and consideration (Ibid.: 505). The micro-ethical dimension is without institutional guidelines and is primarily concerned with the practical challenges researchers face as they deal with real-life situations.

The macro-ethical aspect of my study saw me moving systematically through the ethical requirements laid down by the Faculty of Humanities at my university (University of Cape Town 2013). I submitted my PhD research proposal, along with the required forms, the Memorandum of Understanding I signed with CANSRA and the FGI interview schedule for ethical review before I started working with the research participants. The faculty strikes a good balance between promoting responsible research practice and not hobbling the researcher with unnecessarily restrictive guidelines. My study fell on the ‘deliberative approach’ end of the continuum of research (Ibid.: 6) due to its qualitative nature, my role as

the only person involved in data analysis, the prolonged period I spent engaging with the data, and my fairly equal footing with my research participants.

My inquiry called for much more than just jumping the institutional hoops required by the university. Given the emotional nature of the study, I had to practise ‘ethics of care’. As a trained social worker with more than three decades of experience, I could finesse the emotional encounters that presented themselves during research. Hermeneutic research calls for empathy, and with that comes a need to honour what Frank (1995: 154–163) refers to as a willingness to bear witness to all stories, even those that are hard to listen to. At times, I was tempted to fall back on the stage theory of death and dying exemplified in the work of Kübler-Ross (1969) and to dismiss RFL participants as simply being in denial, angry or bargaining with providence. However, the nature of this study demanded that I walk a mile in the shoes of the people I was trying to understand (Haralambos, Holborn & Heald 2008: 874) and be sensitive to what was being said.

Virtue ethics (Kubanyiova 2008: 507), on the other hand, required me to pinpoint conflicts between macro- and micro-ethics by being reflective about the principles underlying my work. I agree with Haverkamp (2005: 146) when she contends that we need to move beyond simply meeting the requirements of an institutional ethical review and that it is equally important to pay close attention to our relationships with our research participants. Kubanyiovo (2008: 515) shows that applying macro-ethics to research practice can create dilemmas for researchers:

... when research becomes highly situated, it is as if suddenly a can of ethical worms is opened, and what seemed straight-forward and logical at the macro-level suddenly becomes ambiguous and problematic in the actual research practice, rendering existing ethical guidelines inadequate.

A good example of this conflict was the struggle I had with the representation of my research participants. This proved to be a particularly interesting virtue ethics dilemma in this study. While my faculty guidelines were very clear about the importance of the privacy of the participants and of their not being personally identifiable (University of Cape Town 2013: 41–42), some of my participants took issue with this. Cancer survivors in the RFL movement take pride in the ownership of their stories and rue the days when it was necessary to hide their diagnosis or their identities. This perceived secrecy was seen as retrogressive and a way of fuelling shame. For RFL participants, confidentiality and anonymity are regarded as

tantamount to having to hide their lights under bushels. We live in an epoch where people with cancer tell their own stories, own their stories and want to be identified as the people who went through those experiences (Frank 1995: 12). Many RFL participants have travelled a long road in overcoming feelings of shame about cancer and what it does to their bodies and emotional well-being. I was told by some participants that they certainly did not need me to protect them or their identities, as anonymity flies in the face of what RFL stands for.

Therein lay my dilemma. Not all my participants were fearless warriors, ready to face the world. Some were emotionally fragile, wounded, or shamed. Following a supervisory discussion, I decided to err on the side of being protective. I maintained the anonymity of my research participants and changed the names of those they referred to in their accounts of the cancer experience, fully aware that this was not a simple matter and that this decision would be seen as controversial by some in the RFL movement. For me, this affirmed Kubanyiova's (2008: 507) point that ethical decision-making is complex, dilemmas do not have simple answers, and researchers can feel torn about chosen routes. The macro-ethical principles that we value highly as researchers are not necessarily valued by our research participants.

### ***Substantive validation***

I used five criteria of quality recommended by Tracy (2010: 840) to improve the substantive validation (Angen 2000: 390–391) of this inquiry: rich rigour, authenticity (sincerity), credibility, resonance, and meaningful coherence. The practices that supported these quality criteria were the use of a variety of data sources, an extended period engaging with research material, reflexivity, praxis, transparency of process, the use of the hermeneutic process itself, triangulation, member reflections, and peer review.

### ***Hallmark 1: Rich rigour***

Rich rigour, according to Tracy (2010: 840–841), is seen in those inquiries that generously provide richness of description and interpretation built out of a multifaceted theoretical scheme, an array of data sources, prolonged time engaging with research material, the inclusion of different voices and opinions gathered in a variety of contexts, and data management processes befitting a qualitative inquiry. I therefore purposefully chose research sites which differed in their composition and offered a cross-section of participants in order to include as many perspectives as practically possible in this conversation about collective identities. To widen the net further, I added archival material captured across the country by

RFL participants themselves. The latter is what Snow and Trom (2002: 151) refer to as ‘indigenously generated’ archival material. Data from all nine provinces of South Africa, all cultural groupings, a range of ages and income levels were included in this inquiry. Expressions of the Christian faith were commonplace at RFL assemblies. The Muslim community was well represented at some of the gatherings, but not all of them. The host communities covered the entire spectrum from rural (e.g. Kathu in the Kalahari) to metropolitan (e.g. Johannesburg and East London). For the purposes of this study, I included a range of HoH, cancer survivors, caregivers, organizers, team captains and team members. I believe that the 20 chosen assemblies – the four I attended and the 16 I accessed through visual means – were a good reflection of RFL in South Africa and gave me considerable variety in terms of assembly composition.

Deep immersion in RFL while I was employed by CANSA and the 29 months spent collecting and analysing data allowed me to access interesting and significant material. I invested time in mastering CAQDAS. By doing my own translation and transcription, I drew close to the material and ensured that the finer nuances were retained. I believe that the use of participant observation, FGIs and the analysis of visual archival materials fitted the logic of the case study and provided sufficient data sources to enable me to construct an argument. I further enhanced rich rigour by using a complex theoretical scheme, drawing on the work of theorists such as Foucault (1986), Lawler (2003), Collins (2004), Frank (1991, 1995, 2010) and others. This too helped to make the study multi-textured and rich.

### ***Hallmark 2: Authenticity***

Authenticity is a further hallmark of quality research, and here I relied on reflexivity, praxis and making the research process transparent. In hermeneutic research, the effect of the researcher on the inquiry is unavoidable and indeed is considered necessary. Angen (2000: 383) emphasizes that reflexivity in interpretive research is not used to counter bias, since it is not possible to create objective distance when working in this perspective – nor is it desirable. A deep engagement with research material does not absolve the hermeneuticist from using her maturity and self-knowledge to reflect on her influence on the inquiry or the need to be transparent about her research practices. Tracy refers to authenticity as ‘sincerity’ and equates it with a researcher who is ‘earnest and vulnerable’ (2010: 842) in the way she reflects on how the inquiry is coloured by values, preconceived ideas and the approach to research.

Kapoor (2004: 635–636) takes an even stronger position and does not mince his words when he says:

When we act in accordance with personal, professional, organisational interests, our representations of the Other say more about us than about the Other, or at a minimum, they construct the Other *only in as far as* we want to know it and control it.

I understand that the authenticity of this study is necessarily coloured by my personal entanglement with the cancer experience through family and friends, my past employment at CANSA, and my ongoing relationships with colleagues and volunteers in the cancer world – both in South Africa and the USA. My attempts to shed light on collective identity activation at RFL assemblies inevitably include my own interpretations and not only those of research participants. I used reflexivity, praxis and transparency of process to make my insights more overt both to myself and others.

I practiced reflexivity through reflective journaling, memo writing, and chapter write-ups. In this way, I gained a better sense of how I contributed to understanding collective identity generation and how my understanding of the phenomenon deepened as the inquiry progressed. As Bazeley (2013: 102) puts it, ‘This kind of writing is like having a discussion with yourself, and the discipline of doing it adds enormously to the depth of your analytic thinking.’ Reflective writing may start as a private activity, but in time it becomes a wellspring for ideas and their justifications, especially during the latter phases of analysis when higher-level thinking takes shape (Bazeley 2013: 103, 131). I found memo writing especially helpful as a way to ask questions, to capture insights and to home in on my reflections about the inquiry.

Praxis enabled me to put a lifetime of my own learning into practice in conducting this inquiry, while remaining mindful of the fact that my research participants had their own perspectives which needed to be respected. The onus was on me to be responsible and honest in the manner in which I reported on the viewpoints of study participants and not to let my own views colour their accounts (Patton 2002: 65, 546). One area where I constantly had to check and re-check my reading of data was around religion. RFL in South Africa has strong religious overtones and, as someone who does not subscribe to conventional religion, I had to be extra careful in the way I honoured this material. I also battled at times with what I perceived to be exaggerated sentimentality. I had to see past my own prejudices and cast

myself in the shoes of a group grappling with the harsh realities of cancer. This called for an acceptance of things that I found sentimental, but were meaningful and important to RFL participants. In the context of this inquiry, this mattered infinitely more than my views.

In order to allow others to follow the footsteps I took with my inquiry, I strived for a transparency of process, maintaining a database, and an audit trail of my research path. I relied on CAQDAS to store and track the movements of data sources, coding information, research journal and memos. All my audio-recordings, videos and transcripts are stored in my NVivo archive, with electronic records that tell me when I first imported the material and when I worked on each segment. Owens (2012: para. 7) makes the point that the production of an audit trail is a key criterion for trustworthiness and that CAQDAS makes the ‘analytic process traceable and transparent, facilitating the researcher in producing a more detailed and comprehensive audit trail than manual mapping of this complicated process can allow.’ As readers do not have access to my computer, I have included a summary of my database and research path summary in Appendix G in which I: (1) list the communities included in the inquiry, (2) give an overview of the two sub-studies, (3) provide a synopsis of the stories analysed, (4) describe the key phases of data analysis, and (5) provide a schedule of peer review and member reflections sessions.

### ***Hallmark 3: Credibility***

Credibility means that research rings true (Babbie & Mouton 2001: 277) and that the researcher has the ability to recognize assertions that lack plausibility. In order to ensure the credibility of my inquiry, I needed to show that my findings were a true reflection of the issues investigated and that they rang true for the RFL participants who contributed to the inquiry, that trustworthy methods that rendered high-quality data were used and could stand up to systematic analysis, and that I conducted this inquiry with integrity and with a wholehearted commitment to my interpretive approach (Miles & Huberman 1994: 278; Patton 2002: 552–553; Tobin & Begley 2004: 391–392; Tracy 2010: 840, 843–843). For Tracy (2010: 840), the hallmarks of a credible study include a nuanced description of the inquiry, properly contextualized work, as well as ‘showing’ and not just ‘talking’ about the research. I enhanced credibility by using triangulation in line with my approach, offering the multi-vocality that is part and parcel of the hermeneutic approach, and member reflections.

I found the most important way of boosting credibility was to use the hermeneutic process itself. The dialectic-hermeneutic approach allows for a close spiralling relationship between

research materials, the insights of the researcher and the theoretical scheme. In this way, a balanced research project walks a tightrope between a detailed understanding of the parts and the big picture of the whole. Guba and Lincoln (1989: 244) believe this is a powerful quality control measure, especially when studies are scrutinized by means of the hermeneutic-dialectic process itself. Data is analysed in the hermeneutic circle by creating a confluence between insider-local and outsider-expert knowledge (Kelly 2006b: 348, 354–356). As new research material is pulled into the hermeneutic circle, it is immediately offset against material already in the researcher's conceptual space. This allows the researcher to move constantly between the micro-level and the structural level, making productive use of the tension between the empathic understanding of the engaged, insider perspective, and the critical insights that come from stepping back in order to see the larger picture (Kelly 2006b: 348). Embracing both perspectives is an 'epistemological necessity' (Ibid.: 349), and is crucial to the creation of insightful interpretation.

In the interpretive tradition, the existence of absolute truth is contested. Research findings are seen as interpretations that have been co-created between the researcher and the participants, with the aid of the theoretical scheme, during the time and in the places the study took shape (Patton 2002: 114). Interpretive researchers do not see subjectivity and objectivity as polar opposites, but instead fully embrace the hermeneutic nature of human existence (Schwandt 1998: 223–224). In this approach, interpretation becomes a methodological choice and is recognized as the 'very condition of human inquiry itself' (Ibid.: 224).

Patton (2002: 556) cautions against falsely assuming that triangulated data must provide precisely the same results. He argues that this is a misconception and that divergences show up finer nuances in the data. These should lead to further exploration which, in turn, could potentially yield an even deeper understanding of the phenomenon. Given that I was not attempting to uncover a single truth and that triangulation served a different purpose to that which it serves in positivist research, I needed it to flesh out instances of convergence, divergence and contradictions in my data (Miles & Huberman 1994: 267; Bazeley 2013: 406). Data convergences do not prove a reality (Tracy 2010: 843), but divergent views in the data can act as particularly useful beacons for signalling opportunities to deepen understanding which can be incorporated into the argument (Bazeley 2009: 12–13). I was constantly ferreting out data that seemed out of place (Patton 2002: 466) or at odds with what was 'commonly supposed to be' (Frank 2004: 434). I understood that, like hidden gems,

they held great promise. Divergences were always a prompt that I needed to ask more questions of the data.

An example of this was data that pointed away from collective identity generation. Whereas the overwhelming number of RFL participants become keenly focused on the cancer cause and are swept along by the energy of the assembly, others demonstrate their disconnection by flouting non-smoking rules, verbalizing their ambivalence about assigned role identities or free-riding during gatherings by promoting themselves, alternative causes or rival organizations. Frank (2004: 434) argues that without incongruity there would be no tension in the stories we need to convey and no vehicle for transporting us into the depths of the inquiry. Incongruity deepens our work and makes our research more compelling (Ibid.). It certainly helped me to unearth material that contested and inverted the otherwise ubiquitous heroic warrior identity.

I used triangulation of methods, data sources and theory. The aim here was not to arrive at a definitive truth about the topic, but to invite different voices and perspectives into my thinking about it (Angen 2000: 384). The triangulation of multiple methods is a hallmark of case study research without which it would be difficult to gain a nuanced understanding of a phenomenon (Snow & Trom 2002: 150). I worked with overlapping data sets obtained from participant observation, FGI and archival YouTube videos and photographs. Triangulation saw me weighing up data from my fieldwork journal, audio-recordings, YouTube videos, photographs, and reflective memos. I also used different theoretical lenses to gain insight into the same phenomenon and to construct my argument (Patton 2002: 556; Mabry 2008: 222).

The credibility of my research was enhanced by member reflections. Tracy (2010: 844) prefers the overarching term 'member reflections' to 'member checking', since it goes much further than simply making sure the researcher has her facts right. Member reflections speak to an openness to extend reflexivity, and are important in enhancing the credibility of qualitative research (Guba & Lincoln 1989: 239; Erlandson et al. 1993: 142). It differs from triangulation in that it is concerned with interpretations co-created by the research participants and the researcher, and not with comparing data from one source with another (Erlandson et al. 1993: 142). It is interesting to note that Guba and Lincoln (1989: 240) found that, while member checking of case studies sometimes highlights 'errors of fact', it rarely shows up difficulties with interpretation. They attribute this to the inherent integrity and high levels of trust of the hermeneutic process (Ibid.).

I used member reflections to share the conclusions I reached, to secure feedback on interpretive analysis, and to find out whether the inquiry resonated with RFL stakeholders. The aim of sharing my research findings with a group of stakeholders was not to establish absolute truth, but rather to add another layer of interpretation to the inquiry. I wanted to be sure that my conclusions were not disconnected from the reality of RFL participants and that the findings were a reasonable interpretation of the material I had gathered and analysed. To do this, I designed an A0-size research poster and a PowerPoint presentation which I used in the feedback session with a small group of RFL stakeholders. In October 2014, I worked with six RFL stakeholders in Nelspruit, Mpumalanga Province. Ninety minutes were allowed for the session. The participants signed consent forms and the session was audio-recorded. Five of the group members were heavily involved in RFL and were present at some of the assemblies included in this inquiry. A sixth participant, a clinical psychologist who runs a support group for people living with cancer, was able to give valuable input on the illness experience. I include material from this session in the chapters which deal with the findings of the inquiry.

#### ***Hallmark 4: Resonance***

Resonance is when an inquiry draws readers and audiences into the world being explored (Tracy 2010: 840, 844–845). In other words, it ‘influences, affects, or moves’ others (Ibid.: 844). Resonance calls for research accounts that are both well written and impactful, so that they open up the evocative world of the study (Ibid.: 844–845). An evocative account has aesthetic merit and promotes transferability in a qualitative sense of the word (Ibid.). The greatest advantage of a hermeneutic approach revolves around its capacity for empathic resonance and its ability to deliver insights which cannot be provided by positivist research. Interpretive research recognizes the value of ‘empathic reliving’ that allows the researcher, as the main research resource, a much more intimate look at the inter-subjective worlds that typify interpretive research (Terre Blanche, Kelly & Durrheim 2006: 275). Unlike with positivist research, no attempt is made to eliminate the closeness of the researcher to the material, as deep understanding is needed to do justice to interpretive inquiries. I did not strive for detached neutrality in the relational world of RFL. My goal was to be committed to the engaged, inter-subjective nature of my inquiry. As a ‘passionate participant’ (Lincoln, Lynham & Guba 2011: 110), it was crucial for me to engage in a wholehearted manner in order to ‘... fully address the topic.’ (Angen 2000: 383).

### ***Hallmark 5: Meaningful coherence***

In order to demonstrate a meaningfully coherent inquiry, I needed to show that I had accomplished what I had set out to do and that I had taken sufficient care in the execution of the case study (Tracy 2010: 840, 848). Studies that are meaningfully coherent have an internal consistency and logic that allow for a harmonious coexistence of the research question, research design, the chosen methods, literature and theoretical scheme (Ibid.: 848). I invested a great deal of time and effort in peer review as an important means of ensuring a proper alignment between the different elements of this study. The input of other researchers – many infinitely more experienced than I am – helped me with quality control as I went about the inquiry and arrived at interpretations. Peer review is when ‘... two or more researchers debate the various issues in a research project and eventually come to a reasoned consensus about these issues.’ (Babbie & Mouton 2001: 276). Interpretations that are opened up for regular review and subjected to ‘challenge, criticism, and counter example’ allow a heightened awareness of the interplay between the researcher and the inquiry (Guba & Lincoln 1989: 244). This strategy is frowned on by some qualitative researchers, who argue that the freedom of peers to comment on the inquiry is compromised, as they do not have the same vantage point as the main researcher (Angen 2000: 384). As an inexperienced researcher, I found the feedback from peers valuable, and felt that these sessions contributed enormously to the richness of my experience as a PhD researcher.

I presented my work at my university (the University of Cape Town) at regular intervals and did two conference presentations during 2013 on aspects of the inquiry (Appendix G). There were three collectives at the university where I regularly presented my work to fellow students and faculty members. During supervision sessions, I also had opportunities to reflect on my work and to receive guidance from two experienced supervisors. The two conference papers dealt with my ideas about short-term ethnography (South African Sociological Association in Pretoria, South Africa) and my preliminary thinking about fully animated RFL assemblies (Society for the Study of Symbolic Interaction in New York, USA). This ongoing dialogue with peers was crucial to my moving the project forward and sharpening my insights.

### ***Summary***

In this chapter, I showed how my chosen hermeneutic perspective and my research questions determined my choice of methodology and methods. Case study research allowed me to use

multiple methods and data sources to analyse data collected at 20 RFL assemblies from across South Africa. I highlighted the use of the hermeneutic circle and how it can work in harmony with the strategies I chose to enhance the quality of the study.

I now turn my attention to the three chapters that deal with the findings of this study. I somewhat artificially divide my findings into separate chapters that deal, in turn, with the backdrop to RFL assemblies, animated assemblies once they are in full flow, and the collective identities that are activated at assemblies. My research material is tightly woven together, so that inevitably there are ideas that cross-cut the chapters. This was intentional, as it helped me to make the connections I needed to present the final argument.

## Chapter 5

# Findings: Behind the scenes at the battlegrounds

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### ***Chapter introduction***

This chapter acts as a departure point for understanding the generation of collective identities at RFL assemblies. It is the first of three chapters in which I present the findings of the inquiry. The sub-question that I set out to answer in this chapter is: How do the elements that form the backdrop to RFL assemblies create arenas for the intensification or weakening of collective identities? The chapter explores: (1) the embracement of pride and gratitude, (2) the dominant storyline at assemblies, (3) the enlisting of participants, (4) the role played by anticipating, planning and preparing for assemblies, (5) the creation of ephemeral space, (6) the use of collective symbols, and (7) assembly sites as worlds in miniature. My aim in this chapter is to deal with the elements which form the scaffolding of collective identity generation, before I move on to the next chapter that gives an overview of the fully animated assembly and its dynamic processes.

### ***Pride and gratitude***

Living through the experience of an illness is in many ways an intensely private journey. Those who are affected spend many lonely hours trying to make sense of the fallout associated with cancer. How then does the mass gathering of people who have an affinity with cancer generate collective identities? The individuals who come to RFL assemblies to be part of a focused gathering have already started crossing the ‘me-to-we’ bridge to which Lawler (2003: 147) refers. Their shared focus on cancer forms the foundation on which situation-specific collective identities are built. RFL participants are the antithesis of those who struggle on their own in the privacy of their homes or behind the closed doors of the oncologist’s office. They are people who are poised to have a group conversation about the illness experience.

At RFL assemblies, constituents are offered a beautifully packaged experience in which an illness that was once seen as shameful and victimizing is redefined as something heroic and worth celebrating. By redefining the victim identity (the walking wounded identity) into the heroic warrior collective identity, the group plunges headlong into what Lawler (2003: 145) refers to as the ‘pride-gratitude cycle’ – a powerful mechanism for the generation of collective identities. However, it is difficult under the circumstances of a focused gathering to

completely divorce collective identities from individual and role identities, as these identities overlap and interact with one another (Snow 2001: 3). Lawler (2003: 145) shows that pride and shame are emotions directed at the self, whereas gratitude and anger are directed at the group. Given Lawler's ideas about feedback loops during social interaction, the collective action of participants at the RFL assembly will result in both pride in self and gratitude to others. I see the pride and gratitude cycle described by Lawler (Ibid.) as the fuel that generates the heroic warrior collective identity during assemblies. Shame-anger cycles, on the other hand, typically weaken the activation of collective identities, except in instances where the groups are able to project their shame and anger onto a third party (Ibid.: 145). This is where RFL does such a superb job of generating a sense of belonging, as the heroic warrior collective identity allows participants to project feelings of anger and shame onto cancer as the troublemaker and death as the ultimate antagonist.

Collective action at assemblies revolves around the global RFL slogan that urges participants to '*celebrate, remember and fight back*', as well as around challenging the notion that people with cancer need to be pitied and that the illness is shameful. The heroic warrior collective identity is reactionary and stands in opposition to being wounded. In an attempt to counter stigma, RFL participants embrace a positive, hopeful representation of people living with the illness.

FGI participants, YouTube video narrators and storytellers at assemblies object to the link between cancer and death in the popular imagination. They want to see cancer and death divorced from each other, as they passionately believe that this link results in an unwarranted representation of people with cancer as unfit for demanding work, unworthy of promotion, not deserving of unfettered medical aid benefits, and unsuitable as immigration candidates or as contract workers abroad. The combination of shrinking opportunities and messages about being doomed to die, paint people living with cancer into a corner. These are some of the reasons why participants distance themselves from death and treat it as a symbolic enemy. They understand that death is a possible consequence of cancer, but resent the damage done by too close an association with death and the implication that their mastery over life is severely compromised.

There is a strong sense of 'them and us' in the way RFL participants see themselves and a belief that the in-group has more insight into the cancer experience than outsiders:

*Most of the people here have experienced cancer with a family member. I know how my family members suffered. The public don't really understand and they haven't been through what we have been through. We know survivors can fight back and they can survive. It is not the end. (FGI 3, Participant 2)*

Participants believe that many people outside the movement still see cancer as a shameful illness and that there is a lingering tendency to hide cancer. Older people in conservative communities are deemed to be especially slow in being open about their cancer status:

*Certain age groups in conservative communities feel that health is a private matter. They'd rather not talk about prostate cancer or testicular cancer because some of their buddies might start making fun of them. The same applies to women, especially if they lose a breast or breasts. I know people that go away from their home towns to have mastectomies done, just to keep their privacy intact. The older generation can be very touchy and very private. (FGI 1, Participant 3)*

The insistence that a cancer diagnosis will inevitably result in death is illustrated by another FGI member who relates a story about the reactions of her daughter's peers after she was diagnosed:

*When I was diagnosed people avoided me and the issue. My daughter was 12 at the time I was diagnosed. All her friends said I was going to die. They told my daughter: 'Do you know that your mom is going to die? My granny had cancer and she died. My aunt had cancer and she died. My grandpa had cancer he died. So your mother is going to die.'*  
(FGI 3, Participant 4)

To compensate for negative perceptions about cancer, battlefield metaphors are employed. These counter the lingering echoes of an earlier era when the topic was avoided, spoken about euphemistically and people with the disease were seen as the walking dead. In the same way as coded language is used during wartime, euphemisms are still used outside RFL assemblies. A FGI member highlights prejudice in outsiders:

*They say the 'C-word'. The C-word! Let's pretend it is not cancer and call it the C-word. For as long as they can, they stick with the C-word. That is just an avoidance thing. Try to make it go away. (FGI 4, Participant 2).*

At assemblies, participants who pride themselves on holding fewer prejudices also reference the 'C-word' or the 'Big-C', but they reframe the euphemism to give it a new meaning:



This image of a team banner captured at RFL Pietermaritzburg 2012 shows the redefining of the C-word euphemism by the team. Their ‘Couragously [sic] Combating Cancer’ is active, assertive and warlike.

**Image 5.1: Redefining the C-word**

Claw (2001: 298) offers us an alternative view of the function of cancer euphemisms. She believes that, far from shutting the door on a difficult topic, euphemisms serve the function of putting a foot in the proverbial door and actually help people to diplomatically broach the subject. There is a notion among RFL participants that euphemisms must be bad and need to be challenged, as seen in Figure 5.1, where the makers of the banner are keen to show the collectivity that they are brave enough to tackle cancer head-on.

Past attitudes are recognized as worse than contemporary ones: *‘Look at biblical times. People with cancer were outcasts. People feared cancer. People didn't want others to know that they had the disease and hid it.’* (FGI 2, Participant 3). Participants acknowledge that there is less prejudice than in the past, but nevertheless feel that cancer is still seen as a death sentence by many outside RFL: *‘People have a strong association with the word ‘cancer’ and death. Our people still believe that once people are diagnosed they will die.’* (FGI 2, Participant 5)

Equating cancer with death has some currency even among RFL participants. One organizer talks about the reaction in her extended family to the diagnosis of her former husband. All concerned in this upsetting situation are actively involved in RFL, but despite this, react as if a death sentence has been handed down:

*James has gone around saying goodbye to his kids. His daughter is weeping, saying ‘I can't handle death’. I said to her ‘for goodness sake, let the man live, he is still breathing.’ I think this is what generally happens because cancer is such a terrifying*

*word. There is no good connotation. Nobody thinks about the cure. They think about death.* (FGI 4, Participant 1)

I shared material about perceived prejudice with the MRG, and a leader volunteer in the group responded by saying: *'I think as committee members we become desensitized. Hearing this is like a slap in the face. We work so closely with people, but we forget how prejudice still plays a role.'* (MRG, Participant 1). The group debated this issue and agreed that workplaces make it especially hard for those living with cancer. The practice of insisting that diagnosed people should drink out of separate cups was given as an extreme example of marginalization. A counter argument was offered:

*Separate utensils and the separate washing of those utensils can be out of concern and the need to protect people in active treatment from picking up the microbes of others. We need to make sure that we understand the reasoning behind some of these actions.* (MRG, Participant 5)

The group concluded that, although some acts of marginalization are motivated by a concern for the welfare of people with cancer, in many instances it is still because cancer remains a highly stigmatized illness, especially in poor communities in South Africa.

The need to be positive in the face of cancer ran like a thread through the data. Participants insulate themselves from the gravity typically associated with life-threatening illness by insisting that RFL is joyful, positive and life preserving. A young spokesperson on a YouTube video proclaims that: *'Whenever you hear the word 'cancer' you immediately associate it with a negative term. What I loved about the Relay was that everyone was so positive. Everyone had such joy, such hope.'* (MediaTag 2009). RFL is fun and very convivial:

*It is easy to get involved in Relay because it is fun and you are in a group. You don't get exposed as an individual. It is about a group. You can disappear into the crowd and for some people that is easier.* (FGI 3, Participant 4)

The relaxed solidarity among participants is highlighted by a survivor:

*There is a different spirit at Relay that I cannot even describe. People are more relaxed, more laidback, more determined to have a good time. In other settings you have to behave, here you can be spontaneous.* (FGI 3, Participant 3)

Participants view RFL as the positive representation of the cancer world. This is in contrast to some other cancer initiatives which are believed to represent the old-fashioned and gloomy side of cancer. These sentiments were especially marked among the elite group of HoH who distanced themselves from organizations that do end-of-life care and those run by ‘old ladies’. A HoH tells the group about her reluctance to go anywhere near palliative care facilities:

*I want to be very honest today. I have not been to Hospice. I'm grateful to God for Relay For Life because that is where I can see myself fitting in. Do you think I want to see how I will look when I'm dying? Dream on! Ten years later, even now, I'm not strong enough to go to Hospice. I'm not ready for that. I don't want to see what I will look like with sunken eyes, no hair and dying. (FGI 1, Participant 6)*

For some RFL participants, staying alive is best done by not gazing at death too directly. They place great store in remembering ‘those that lost the battle’, but believe it is best for the living not to dwell on death too much. The MRG confirmed this ‘unfortunate dislike of Hospice’ by affected people who see it as being the final stopover before death (MRG, Participant 6).

RFL assemblies offer a bulwark between death and cancer. Death is there, but it is allowed to have its voice in a controlled way during the 30 minutes or so of the scripted luminaria ceremony. References to death frequently reflect military terminology: ‘*A true hero of hope, she lost her battle with cancer in April 2012*’ (Speaker 16). The only other time death is invoked is when it is expedient to do so for the sake of cancer education. For example, an archival photograph captured at RFL Nelspruit 2012 shows a teenager with a homemade anti-tobacco poster. She has made a gallows out of cigarettes and the head of the dangling man is an ashtray. In this instance, it is acceptable to make the connection between lifestyle, death and cancer because now we are dealing with cancer prevention and the saving of lives.

### ***The dominant storyline***

At RFL assemblies, the master narrative of affected people as heroic warriors is wholeheartedly embraced by the majority of participants. This narrative hook is used to give the movement its dominant collective identity. We may well ask why this metaphor is so important for the generation of collective identities in mass health movements such as RFL? Why did cancer organizations globally find it necessary to switch from their former use of the

victim identity to its alter-ego, the heroic warrior identity, at a time when there was a growth in citizen-based health initiatives? I believe that in the context of volunteer-driven movements heroism is infinitely more acceptable to a constituency longing to find something hopeful and positive in an illness experience. The previously hegemonic victim identity, with its emphasis on shame and anger, did little to generate a sense of belonging.

Social movements need compelling storylines to generate collective identities, and RFL is a particularly good example of this. Step into any RFL assembly in South Africa and it soon becomes evident that cancer is seen as the trouble-maker, participants as the protagonists who have the agency to do something about the problem, and that death is viewed as the ultimate foe. Lewis (2013: 658) argues that: ‘The anthropomorphising of cancer into a sentient adversary comes naturally because, above all other diseases, this emperor of all maladies evokes negative reactions and feelings of betrayal.’ RFL participants are in the business of fighting this foe and the temporary RFL village acts as an imagined battlefield for the duration of the gathering. Cancer and everything that follows in its wake – treatment, the fear of recurrence, changed bodies, suffering, and possible death – make for formidable complications in the lives of those who are affected. Countless aspects of the focused gathering bear witness to the invocation of a battlefield and warrior mythology to counter the illness and its sequelae.

The assertion by Sontag (1978: 64) that the dominant cancer metaphor is borrowed from the language of armed conflict and relies on military terminology is highly relevant at RFL assemblies. Participants talk about fighting cancer, make pledges to win the war against cancer, remind themselves to remain strong in the face of the fearful antagonist, and reinforce the importance of putting their weight behind efforts to vanquish the disease. Battle mythology is underscored through storytelling, through battle cries on the track, in the design of the assembly site, through slogans on attire and banners, in a dedicated ceremony known as the ‘Fight Back Ceremony’, and in the names chosen for teams.

The battlefield and heroic warrior metaphors help those who are affected by cancer to sharpen their focus on the collective objective of RFL. Foucault (1986: 25) refers to this as the ‘precise and determined function’ of a group that has gathered together in the heterotopia, while Collins (2004: 47–101) talks about the mutual focus of participants at face-to-face gatherings. The precise function or shared focus of RFL is summarized by the narrator of the RFL Potchefstroom 2011 YouTube video, when he tells us that: ‘... *Relay For Life is an*

*international movement that celebrates the victories of cancer survivors, remembers loved ones lost to cancer, unites communities in the battle against cancer.*' (Naude 2011). There is absolutely no ambiguity about the collective task at the assembly, and this forms a powerful shared focus. The *'celebrate, remember, fight back'* call to action saturates the RFL village and is seen on banners, posters, candle-bags and attire. It is also constantly heard over the public address system and on the track through storytelling and ceremonies. Participants know they are at the assembly because of cancer.

The choice of words I found in the transcripts was highly reminiscent of wartime. Participants talk about cancer invading their world, how much they hate cancer, conquering cancer, fighting cancer, fighting for their lives, beating cancer, overcoming cancer, winning the battle or the war against cancer, the struggle against cancer, and so on. A caregiver describes the violent way in which cancer invaded his home:

*... and then cancer came to our door. C-A-N-C-E-R! It didn't knock. It didn't wait. It kicked the door in and came inside. I'm a big fellow and very few people kick my door in. This disease, this PEST came in. I reflected on the promise I made 10 years before to love and to honour, to cherish in sickness and in health, in good times and in bad times ... and BOY did the bad times come!* (Speaker 1)

I repeatedly came across language that pointed to an experience that can be incredibly arduous and heart-breaking. Participants variously describe cancer as a terrible ordeal, the old devil, a Goliath, a giant, the old enemy, a pest, an aggressor, an unrelenting disease, a merciless antagonist, this dreadful disease, the blasted devil and so on. They describe themselves as crusaders, survivors, soldiers, conquerors, ambassadors, fighters, survivors, superheroes, warriors, even as people who have achieved greatness. Teams choosing names reference the hero warrior metaphor and make this their group identity – *'The Pink Ribbon Warriors'* (RFL Middleburg 2012), *'CANSAs Crusaders'* (RFL Worcester 2012), *'Irene's Fighting Fairies'* and the *'Fighting Fairies'* (RFL East London 2013). In the South African context, where many of those who take part are religious, references to cancer as the devil are not uncommon: *'... the first time I had cancer the devil did not steal my joy. This is my greatest victory over cancer. I still have my joy'* (FGI 1, Participant 1); *'the old devil wanted to steal my physical body'* and *'just see how cunning the blasted devil is'* (Speaker 6).

The hope of survival through finding a cure for cancer saturates illness narratives at RFL assemblies. Elliott and Olver (2009: 609–638) advocate a broader conceptualization of hope,

one that is not only cure-orientated but also allows for the affirmation of meaningful relationships, dignified dying, and a bringing together of life and death. The fact that this narrow view of hope at RFL assemblies might be inappropriate for those with life-threatening cancer seems to be lost on both participants and organizers. This stands in contrast to health care workers who, in their one-on-one interactions with affected people, are trained to walk a delicate tightrope between telling the truth and not robbing people with end-stage cancer of all hope of prolonging life (Elliott & Olver 2009: 610). Not so at RFL assemblies, where the emphasis shifts to a preoccupation with survival. This is understandable, as these focused gatherings do not lend themselves to finer nuances and instead home in on the storylines that are most likely to captivate the majority. Hope-talk performances tend to be loud and proud at assemblies. They dominate the cancer narrative, with little hint that hope can be no more than a rudimentary, cure-orientated, death-defying state of mind and heart. This topic sparked a reflective discussion in the MRG:

*...we must leave a gap for people to attach different meanings to hope. Maybe that hope is not only the hope for survival. We are fighting to get a cure for cancer, but it might not be your personal victory. We walk to honour a great cause, but we must allow vulnerability in. I don't know how. (MRG, Participant 2)*

The group readily recognized that a myopic view of hope could have negative repercussions for some participants, but seemed to be at a loss as to how to broaden the conceptualization at assemblies. Support groups as part of the assembly were deemed inappropriate. Publicly acknowledging that some participants are close to dying and might want a broader conceptualization of hope is simply not in the spirit of RFL, with its emphasis on cheerful survival.

Talk over the public address system about hope and survival tends to be confident and in some instances even strident. Assembly speakers are hand-picked to act as role models for the movement. A proud caregiver motivates his involvement in the battle against cancer in positively heroic terms: *'... it gives me an opportunity to be an ambassador and a soldier and a gladiator in the fight against cancer.'* (Speaker 1). Speakers are enthusiastic in their determination to view life-threatening cancer as pure evil. Portrayed as the enemy that has to be annihilated by a brave warrior, it was described in graphic terms at the RFL Leadership Summit 2012:

*In 2002 cancer came to kill, to rob, to steal and to destroy! I have a secret for you. [Whispered over the microphone]. I'm not just a breast cancer survivor. I'm a breast cancer conqueror! [Loud applause and wolf whistles from the assembly]. I walked a painful, a tough, yet courageous cancer road.*

The same speaker then elaborates on this mythological theme:

*To all our cancer survivors today, I want you to know that you are born great. Why? Because not everybody gets this chance to actually face a giant like cancer. So if you can face cancer you can dream big. You have an opportunity to achieve greatness because as a survivor you are a fighter and you have greatness thrust upon you. Each one of you is a superhero. (Speaker 8)*

Not all speakers are equally upbeat about the illness experience. It is important, however, to note that vulnerability is typically allowed into the assembly through storytelling related to the past. When spokespeople admit to vulnerability, it is in the context of having overcome upsets and setbacks through faith and involvement in RFL. I found little evidence of speakers willing to admit to a current state of vulnerability in the public forum of the assembly. Storytelling about the past is a powerful vehicle for allowing past hurt into the assembly. A HoH told the RFL Leadership Summit 2012 of an intensely upsetting social encounter:

*One incident was very hurtful. Now I laugh about it, but at that time I could not. I had no hair, no eyelashes, nothing. I took my daughter to this party. An elderly man kept looking at me and I ignored him. When I wanted to leave he called me over and asked me who I was. I introduced myself to him. He looked at me and asked: 'What kind of a woman are you without breasts?' I was totally stunned. I said to him: 'I'm undergoing chemo.' That man's face! He gasped. It was like throwing hot water in his face. He couldn't apologize enough. I thought to myself, that's good, apologize, feel bad! (Speaker 6)*

This story seems intensely private and humiliating. So what could possibly be the motivation for sharing it with the audience? Goffman (1963: 136) shows that role models, in this instance a member of the RFL elite, who share stories of humiliation that demonstrate to the audience how insensitive people can be put in their place, offer the group a recipe for dealing with socially awkward situations. These shared recipes for success become the property of the collectivity, feed a sense of dignity and pride, and in the process activate collective identity.

Participants valiantly distance themselves from overt vulnerability, but the shield created by the heroic warrior collective identity is not always enough to keep references to feeling vulnerable completely at bay. A subtle seepage of vulnerability is seen in some of the non-verbal mediums at assemblies:



This image of a poster captured at RFL Amanzimtoti 2012 shows how, despite the cheerful, hopeful words and images that make up most of the piece, these are juxtaposed with sombre black writing about a chemo-therapy session and its date.

**Image 5.2: Light and dark emotions contrasted**

Nowhere does vulnerability float to the surface more than in talk about the future of children who could be orphaned through cancer. People with cancer express great anguish about the possibility of being separated from their children through death. This is often cited as a reason for enduring extreme suffering. A young single parent tells the RFL Leadership Assembly 2012 about her determination to stay alive:

*When I was told that the outlook was so bad, the first thing that came to my mind was my two boys. There was no way they were going to live without me or I was going to leave here without them. So I decided I was going to fight this. (Speaker 11)*

A married mother of three children shared this with the assembly:

*After hearing that it might be cancer, I wondered how my children would cope. I wasn't worried about the surgery, or being sick with chemo, or maybe dying. I wanted to know that my children would be safe. They needed to be safe. I knew that the support system that I had at home was not good enough for them to cope. A tidal wave of brain-paralysing anxiety engulfed me, lying on that bed after the doctor spoke to me. My mouth went dry. I started shaking. I was dizzy. I held onto the edge of the bed. (Speaker 6)*

For some parents, the threat of death is simply too real to ignore. A young mother facing an uncertain future talks about the possibility of dying:

*My oncologist told me to build as many memories with my family and my children, as time is against us. She is not sure whether we would beat cancer this time as the cancer is very aggressive. My cancer is exceptionally rare and treatment programmes are unpredictable. I have to rely on my faith and on prayer. (Speaker 3)*

A useful insight was offered by the MRG about the seepage of vulnerability during ceremonies. It was observed that, although survivors tend to look composed and rarely cry during the survivors' walk, it is a different matter once the focus shifts to their caregivers:

*You see far more survivors crying during the caregivers' lap. I always think of a colleague of mine and how she cried when her husband joined her on the track [the second round when caregivers join the parade]. It was the first time she could publicly acknowledge his support. This is when I see a lot of emotion. (MRG, Participant 4)*

Frank (1991: 64–65) makes the point that we rarely give positive reinforcement to ill people who openly show their grief and distress. The smiling mask must not slip, lest others be made to feel uncomfortable. Survivors during parades can let the mask slip, but only once the focus is on their caregivers and no longer directly on them.

It was only in the relative safety of FGIs, where participants were able to admit to feeling vulnerable at times, that a more nuanced picture could emerge. Here a mother of teenage children talks with great vulnerability about her illness experience:

*It is so hurtful when people avoid you. I did nothing wrong and it feels as though everybody is looking at me. I know lifestyle can play a role in cancer. I'm the only person in my family with cancer, and it didn't make sense that I got it. I have a friend who totally ignored me once I was diagnosed. She got updates about my health from my parents. I had to reach out to her and tell her that I'm fine and that I'm not contagious. (FGI 2, Participant 6)*

Members of the elite HoH group also talk of the double-edged sword of being cast in the role of heroes: *'I come off stage and people tell me that I'm so positive. It's a good thing that they tell me I'm positive because I feel I'm crumbling and that I cannot do it anymore.'* (FGI 1, Participant 6). Maintaining the pose of being an inspirational role model also takes a toll: *'It's tough and people think you are okay and most of the time you are not okay. It is like walking on eggshells. You always need to lead by example. You always need to walk the talk.'* (FGI 1, Participant 5).

This pressure to keep up appearances drains emotional energy (Frank 1991: 64–65) and is very taxing both for people living with cancer and the caregivers who have access to their private worlds. Particular concern was expressed by the MRG for members of the elite HoH group:

*They put so much pressure on themselves by feeling that they have to survive and get better. A recurrence of cancer can be devastating for them and when things are not going well there is no room for admitting it because that would be a failure. (MRG, Participant 4)*

Another member of the group remarks: *'Being too optimistic and not building realism into the situation is dangerous.'* (MRG, Participant 6)

This feedback prompted the MRG to remark on how acutely aware they were of how RFL participants put up a social face and what a big price they pay for doing this. The local CANSA office runs a support group for people living with cancer, where participants are constantly reminded by the psychologist who facilitates the group that they are allowed to 'sing the blues'. Group members need permission to show their vulnerability, because elsewhere the messages consistently tell them that they need to put on a brave face: *'I wish you can see the expression on people's faces when they are given permission to 'sing the blues'. Everyone tells them that if they stay positive they will be cured, so singing the blues is not on.'* (MRG, Participant 5). Overt permission to show vulnerability is lacking at RFL assemblies, where the emphasis falls squarely on being courageous and optimistic.

Most RFL participants understand that this is not a war which is going to be won overnight, irrespective of whether they are speaking publicly or in the relative safety of a FGI. Sometimes stories trace long drawn-out battles, while at other times they tell of mere scuffles with the illness: *'We were fighting our own little battle. We were not at war. We were having a little skirmish, but no war'*, and later, after a serious recurrence: *'in the car we cried and held each other and said we are going to fight this!'* (Speaker 1). It is also recognized that the threat of recurrence means that cancer battles can come in waves: *'There are difficult times. She has fought a battle in the past, and she is fighting it again at the moment'* (Speaker 2). In a single assembly, we can have participants who have just made their acquaintance with cancer, hardened old warriors who have been surviving for decades, and all the shades in between. Fighting shoulder by shoulder, there are spouses, children, lovers, friends, colleagues and health care workers. Sometimes the battle feels like a little skirmish and at

other times it is full-scale warfare. During the annual RFL assembly, battles – big and small – are re-enacted.

### ***Enlisting followers***

Different participants are drawn to RFL for different reasons. For some, it is an opportunity to have an annual memorial for a loved one who died, for many survivors and caregivers it is a time to celebrate another year of survival, while for others it is a chance to show their solidarity with the cancer cause, win an award for the team with the best spirit, the best banner, the most beautiful campsite, or the most funds raised.

Much of the success of RFL depends on its ability to recruit participants, but this recruitment is targeted and is never done in a haphazard fashion. I wish to underscore the point that, by managing boundaries through the targeted recruitment of participants, RFL creates a greater sense of unity and exclusivity among those who are given entry into the solidarity community. The boundary management at RFL is subtle, and care is taken not to offend prospective participants. Nevertheless, there is a gulf between RFL participants and those outside the assembly, and this gulf serves to heighten collective identities.

To become a part of this solidarity community, certain hoops need to be jumped. It would be naive simply to arrive at the gates of a RFL assembly and expect to gain admission. Much as it is the goal of the movement to grow its constituency, a great deal needs to be done by participants before they can gain access to an RFL assembly. For some, it is having been diagnosed with cancer, for others it is paying a commitment fee, or attending team captains' meetings to prepare for the assembly, raising a predetermined amount of money during the year, making costumes to wear on the track, or planning the team campsite.

Role identities at RFL assemblies are clear and unambiguous the world over. Participants understand that each role designation – HoH, survivor, caregiver, organizer, team captain, or team member – is there for a specific purpose. Some have more than one role identity and these dual roles add to prestige. For example, it is possible to be a survivor and an organizer, or a caregiver and a team captain, or different combinations of these prescribed roles. Indeed, it is common for people to fulfil more than one role at assemblies. Lawler (2003: 140) argues that the complementary role identities become transformed through shared tasks and result in negotiated collective identities. In the case of RFL, the shared tasks are performed during the

assembly, and the negotiated collective identities revolve around the battleground and heroic warrior metaphors.

Survivors and HoH pay the heftiest symbolic price in gaining entry to assemblies by virtue of their having been diagnosed with cancer. They are actively recruited and encouraged to attend assemblies as they are emblematic of the cancer cause, and they are rewarded by being treated as special guests. They do not pay an entry fee unless they are also part of a registered team. Survivors are the lynchpin of assemblies and are treated as people of great importance. They are afforded special parking bays, register separately from the rest of the participants, treated to a special reception in a designated reception area, and lavished with gifts, refreshments and entertainment. Bigger assemblies in South Africa host in excess of 350 survivors. The narrator of the Western Gauteng YouTube 2008 explains the role fulfilled by survivors:

*The Relay For Life event offers the community an opportunity to give recognition to long-term survivors. In turn, these survivors then offer great hope to those only beginning their journey with cancer. CANSA survivors add greatly to the impact of the event. In fact, the more survivors there are involved in the event, the more successful it becomes. (Cook 2008)*

HoH are hand-picked because they are inspirational and media-friendly. These are cancer survivors who are dynamic, have stories to tell, are articulate and are frequently physically attractive. Their role can be burdensome, as it is difficult to maintain an upbeat, hopeful and grateful image when times are tough. The love affair the media has with celebrity cancer survivors (Deimling, Bowman & Wagner 2007: 759) finds resonance in the HoH programme. Although they are only celebrities in the RFL world and are relatively unknown outside the movement, some members of this elite group readily mimic the celebrity role by working very hard at being inspirational figures, performing as motivational speakers, writing inspirational books, and securing trappings such as sponsored vehicles.

Another important group in the army of warriors are the caregivers. Frank (1991: 48–49) reserves the term 'caregiver' for people who are open to hearing the ill person and respond to the unique experience they are going through. Frank remarks on the emotional demands faced by caregivers: 'Caregivers are confronted not with an ordered sequence of illness experiences, but with a stew of panic, uncertainty, fear, denial, and disorientation, with bargaining quickly added.' (Ibid.: 49). In the RFL movement, all caregivers are

acknowledged and honoured, irrespective of whether they are paid care providers (nurses, general practitioners, oncologists, home-based carers) or family members and friends. The majority who join in the caregivers' walk at RFL are close family members, typically life partners and children.

Team captains are required to attend a series of preparatory meetings before the annual assembly, for the overall organization of their teams and to maintain team discipline. Teams are recruited from different quarters: families, friends, colleagues, services clubs, schools, universities. Team members form the biggest group of participants and generate most of the emotional energy at assemblies. Each team has a unique 'look and feel', with a distinctive name, banner, attire, war cry or song. Registered teams are allocated campsites which they occupy and decorate.

All RFL assemblies require money from teams wishing to participate. The amount differs from community to community, but a common scenario is that each team pays a commitment fee to register and then has the further responsibility of raising an additional amount. The supplementary amount can be raised before the assembly or at the assembly itself. Fundraising during the year takes many forms and can include raffles, bingo events, cake bakes, garage sales, or the making and selling of craft items. A survivor explains how this is done: *'I've spent quite a bit of time over the last months. We've had bingo, we've had garage sales, we've baked, sold coat-hangers. So instead of going to the movies, we get together and work on Relay'*. (FGI 4, Participant 4). Fundraising at assemblies includes auctions, food stalls, photography booths and the sale of a rich assortment of items such as cheap toys, cosmetics, glow-lights, costume jewellery and games. Participants directly associate the need to raise funds with the local community's ability to provide cancer services. The narrator on the YouTube video made at the RFL assembly in Western Gauteng motivates the need for fundraising as follows:

*To be able to fight back against cancer we need funds. To continue our services to cancer patients and their families in the community, as well as to empower the public at large with knowledge to beat cancer, we ask teams to pay a commitment fee and thereafter to raise funds for CANSA however they wish – be it before the time or on the night of the Relay. (Cook 2008)*

Fundraising contributes greatly to collective action in the RFL context and later, when I present the argument, I show what an important role collective action plays in the activation of collective identities.

The power of team fundraising in creating team spirit must never be under-estimated. Teams plan their fundraising activities with great care and have to work like well-oiled machines at RFL to execute these plans. A school principal (FGI 3, Participant 1) explained how important the running of their annual curry-and-rice stall has become to the school community. Everybody works together to plan, secure ingredients and assist with food preparation and sales on the evening. They set themselves a target each year and take great delight in doing better each year. Fundraising is a crucial element in the fun associated with RFL and in creating solidarity. Fundraising, gifts in kind, services in kind and sponsorships are all seen as ways of giving to the cancer cause and fighting back.

### ***Planning, preparation and anticipation***

RFL assemblies are imagined by teams long before they arrive at the annual gathering. Getting ready for the experience already starts to feed into a sense of belonging to RFL. Much like Mardi Gras or any other carnival, RFL teams visualize and plan for assemblies from one year to the next. I believe that the prior induction of teams into the RFL culture and the anticipation, planning and preparation influence the extent to which a collective effervescence will be generated during assemblies. RFL committees that invest in developing their teams are rewarded with assemblies that are vibrant, pulsating with energy and carnival-like. Collective effervescence, in turn, is an important element in the generation of collective identities (Collins 2004: 48–49).

Thus effort, time and money go into preparing for an assembly and in creating the paraphernalia needed for it, such as outfits, adornments, banners, posters and decorations for campsites. This is radically different to the process a solitary marathon runner undergoes in preparing for a road race. Teams jointly choose team names, slogans, songs and battle cries and spend many hours in work parties preparing attire, adornments and banners. Many make provision for a number of costume changes to enable them to join in themed parades such as the gender-bender, pyjama and blanket laps. Teams lose count of the personal cost and the impact on home and work life while preparing for the annual assembly. For volunteer organizers, the investment is especially big. A team organizer talks about ‘stealing time’ from

her employer during the year so that she can make sure participants are properly prepared for the assembly:

*I'm in a position where I spend a lot of time on this. A lot! For team captains' meetings I send out hundreds of emails. People run when they see me. I steal time from my boss because I do the emails at work. How much time? Hell! – Probably the equivalent of two months a year. (FGI 4, Participant 1)*

The people tasked with recruiting and preparing teams for assemblies play a vitally important role, since well-prepared teams are typically the ones best able to slot into social interaction at assemblies.

I found a marked contrast in the level of collective effervescence between those assemblies where participants were adorned and those where the teams made little effort with their dress, banners and campsites. Embracement of group membership through expressive mediums such as costumes, adornments and artful creations works best when prospective participants are inducted into the 'RFL way of doing things' or the RFL culture before they arrive. Pride is taken in becoming an expert at preparing for assemblies. A mother who lost her son to cancer two years earlier talks about preparing for the assembly:

*It's so enjoyable to prepare for a Relay. I bought myself a special chair, despite not using a chair much, as I spend most of the night on the track. Still, it is nice to have a chair and a cooler-bag. I love the preparations – packing the car with everything I'll need like candle-holders and luminaria bags. I take great care with the bags that have been so beautifully decorated. I love the anticipation. (FGI 2, Participant 5)*

There are a number of conduits for this transfer of the RFL culture – past experience of an assembly, word of mouth, team captains' meetings, launches, as well as traditional and social media. Fuist (2013: 1045) describes the culture of the collectivity as the customary way of doing things, encompassing the traditions, rituals, collective meanings, and expressive ways of turning particular spaces into sites suitable for the work of the movement. The MRG was of the opinion that novice teams often seem unsure about where precisely to fit into assemblies because they are not familiar with the RFL culture. Over time, returning teams become progressively immersed in the RFL culture, and this results in some '*experienced Relayers becoming Relay groupies that not only go to their own assemblies, but also to assemblies in neighbouring towns.*' (MRG, Participant 2). The sense here is that

identification with RFL deepens over time and that there is an interaction between being able to imagine assemblies and having a sense of belonging to RFL.

Irrespective of whether we are dealing with an overnight community assembly or the annual leadership summit, all gatherings have a fixed place in the calendar and have predictable scripts that repeat themselves each year. Although the venue for the leadership summit is moved between provinces, the time in the calendar is fixed. By conceptualizing RFL assemblies as heterotopias in a Foucauldian sense (1986: 26), we see that they are associated with ‘slices of time’ in the calendar and are fleeting. The fixed place in the community’s calendar and the association with a particular time of year make it possible to anticipate RFL assemblies in the same manner that we anticipate other calendar highlights such as Christmas, Diwali, Eid Al-Adha or Rosh Hashanah. Certain customs are associated with getting ready for the assembly: *‘I think for a lot of people getting ready for Relay is similar to the ritual of getting ready for Christmas. Relayers have certain rituals that are important to them and they cannot wait for the Relay to arrive.’* (MRG, Participant 1). Participants plan from one year’s assembly to the next, and eagerness builds as the annual gathering gets closer.

The prior investment of time, effort and money feeds into the extent to which the assembly can be whipped into an energy-filled mass of people. Only when participants have gone to the trouble to prepare for an assembly, knowing what to expect and how to behave, will it hold the promise of generating collective identities. Participants are drawn into their sense of togetherness by anticipating the assembly and making preparations. The foundation has been set for the emotional-entrainment (Collins 2004: 47–101) of those teams that take preparations seriously, even before they get to the assembly. Anticipating an assembly is almost as important as the gathering itself, as prior investment cements loyalty towards RFL and feeds into collective identity.

### ***Ephemeral space***

RFL assemblies are contained worlds that appear and disappear in a matter of 24 hours or less – in the case of the more than 87 assemblies staged each year in South Africa, or in a couple of days – in the instance of the annual RFL Leadership Summit. The gates to the assembly site usually open on the morning of the assembly a good eight to ten hours before the official opening. This allows teams to start erecting tents, portable toilets, gazebos, the makeshift stage, display branding and put up the enormous marquees that will later house the survivors’

function. Teams start drifting in to find their designated campsites and to settle into their spaces. The sound team gets there early to test systems, and music starts flooding the site long before the official opening. As the assembly space takes shape, the participants become energized. Music provides inspiration to the many workers doing hard physical labour to create the ephemeral village.

As part of my role as an observer, I made a point of doing site visits before assemblies started. This is a note about my morning visit to the RFL East London 2012 site:

*On Saturday morning at 10:00 my research assistant and I visited the windy, overcast site to walk the track and talk to some of the volunteers. This was really to make sure that we would be able to find the site later and to take some photographs of early preparations. The sound team was there and the music was already blaring all over the vast stadium. Hip-hop club music was the order of the day with tracks like: 'Girl on Fire' and 'Scream & Shout' creating a very upbeat, energized feel. Hired labourers pulling the sheets of the big marquees over the enormous structure were jiving to the beat. This was the same team that went on strike the night before when high coastal winds dictated that the covers had to come down for health and safety reasons. (Journal entry 2013/4)*

Assemblies can only get under way once the tented village has been constructed. There is no doubt that RFL organizing committees, during the short burst of time set aside for annual assemblies, set themselves the task of creating safe physical and emotional spaces for the many participants who flock to be a part of the RFL experience. Taylor and Whittier (1999: 179) see sites used for the cultural activities of solidarity groups as safe spaces where movement ideology can be expressed and resources can be generated. RFL is a prime example of an initiative which offers a safe space for people to share their cancer experiences and rally in support of the cause.

The space is designed to encircle participants and to create a sense of safety and unity. The master design is a tented village constructed around an athletics track. Concentric ovals are formed by team tents, the track, candle-bags placed around the track, circles of lights shining from tents, and sometimes braai-fires<sup>5</sup>. The importance of this design was confirmed by the MRG:

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<sup>5</sup> A South African term for barbecue fires.

*The design is very important. The Corporate Relay this year had a conventional track, but they also experimented with a pathway across the centre of the track to break the monotony of people going around in circles. Nobody used it! The only time the path was used was when there was sudden rain and people had to run for shelter. (MRG, Participant 4)*

The MRG also reported on RFL Nelspruit 2013 when inclement weather necessitated the use of indoor parking garages at big shopping malls where the track design was square: ‘... *we felt that something was missing, especially during the luminaria ceremony. We lost people because of this. Not working in the round makes a difference and it is important to keep this in mind.*’ (MRG, Participant 2). I think the problem with the square design of the track is that it hampers the natural flow of bodies and consequently interferes with the ‘rhythmic entrainment’ (Collins 2004: 48) of the collectivity. Another member of this group agrees: ‘... *when we have been forced to work in a square and participants had to contend with jagged corners we lost some of the spirit of Relay*’. (MRG, Participant 1). In the view of members of this group, the other track design that works well is the so-called ‘infinity shape’, or figure-eight shape, because it is two linked circles that still provide participants with a sense of containment.

Heterotopic spaces have boundaries (Foucault 1986: 26–27), and this is evident at all RFL assemblies. Overnight gatherings take place inside secured sites, with entrances manned by security staff. All new arrivals have to pass through a checkpoint where they either declare their VIP-status as invited cancer survivors or show evidence that they are part of a registered, paid-up team. Sites are not open to all and sundry in the same way that a public park might be freely accessible to the public. Similarly, leadership summits are by invitation only, and the gathering is confined to the conference centre chosen as the venue.

Gatherings have typical spatial elements that are found at all assemblies, irrespective of where they take place. Signature elements include the track, a stage, the survivors’ reception areas, ablution facilities and team tents.

The heart of the assembly is the athletics track on which participants walk, run and play for the duration of the assembly. The track is essentially a large, oval stage where expression is given to collective identities. It is used for all important ceremonies: opening and closing ceremonies, the survivors’ walk, and the luminaria ceremony. Even in under-resourced communities, an attempt is always made to create a track which conforms to the global ideal,

even if the facsimile is very humble, as can be seen in this example of an assembly held in the Kalahari region of the Northern Cape:



This image, captured at RFL Kathu 2011, shows a track created out of hazard tape and poles, with a small collection of candle-bags lining the route. There was not a single blade of grass and only a couple of trees were visible in the background. Despite these harsh conditions, a track was nevertheless created.

**Image 5.3: Kalahari track**

The stage is a further element common to the majority of assemblies. These temporary constructions vary greatly, depending on the finances of the organizing committee. Affluent communities build elaborate constructions, complete with expensive stage lighting, sound equipment, and overhead covers in case of rain. Other communities simply use truck trailers that they decorate with hessian, plants, posters, and banners. Most stage areas have as part of their composition ‘HOPE’ and ‘CURE’ signs and feather banners with the official RFL slogan. The stage and the grassy space in front of it together form another important performance space. Assembly speakers broadcast from the stage, invited performers perform on the stage or in front of it, depending on the size of the troupe, and many group games and activities – Relay Idols, musical chairs, dancing and so on – are directed from the stage.

Team campsites are placed either in a circle around the track, inside the track or both. Creating a comfortable campsite is seen as important by participants because the private space afforded by tents make long assemblies bearable. In the archival photographs I analysed there were countless examples of team campsites, and typical examples show tents, kettle-braais (BBQ equipment), cooking utensils, tables, chairs, bunting, balloons, flowers, fundraising essentials, banners and posters.



This image was captured at RFL Nelspruit 2012. It shows a typical example of a campsite in a well-resourced community. The gazebo in front is used as a public space where teams interact with other participants, while the smaller tents at the back are used as private spaces.

**Image 5.4: Team campsite with public and private sections**

In the same way that our everyday lives are marked by contrasting spaces – such as private space and communal space, family space and social space, work space and leisure space (Foucault 1986: 78; Soja 1996: 156) – so too is space organized in the RFL village. The different spaces give definition to identities and are used to reinforce the role identities of participants. The survivors' marquee is a privileged space, reserved for survivors, their partners, selected organizers, and invited entertainers. It is off limits to ordinary participants who can peep into the reception area, but are not at liberty to enter. Similarly, the organizing committee has an on-site caravan or office set aside as an operations centre and cash office. Not only is access to this nerve centre restricted, but the boundary is made extra secure with the presence of security personnel and a locked door.

It takes effort to create these campsites, which have to be dismantled as soon as the assembly is over. The FGI participant in light-hearted manner talks about the creation of campsites:

*Oh my word! I see them arriving with their tents, mattresses and bags. Every year Relay just gets worse! I think these people want to Relay for two days or something because they just keep bringing the stuff. There is a tent here tonight where they even planted poles and put lanterns on their little house – and they have a whole carpet-effect inside the tent. (FGI 4: Participant 4)*

Many participants live close to the assembly site and recognize that this is a great deal of trouble to go to for one night: *'If you consider how little the tent is used, you might as well not bring it and save the hassle of carting the darn thing home the next day'* (FGI 4, Participant 2). Construction of the RFL village is a high-spirited and generally good natured affair – provided the weather plays along. Strong coastal wind and unexpected rain can be a

nuisance. A team captain describes the battle with the elements and their determination to create some private space:

*We battled for three hours to put our tent up in the wind. It is for a good cause and you don't give up. We just carried on and on. We became dehydrated and I felt nauseous. Our neighbours were also struggling with their tent and I just had to help them because I felt sorry for them. You want to be in your tent. It is the cosiness and togetherness. That is what matters. (FGI 4, Participant 5)*

Motivated by the promise of winning the award for the best campsite, participants pull out all the stops to create unusual campsites – even if it involves considerable effort and expense. A student leader tells the RFL Leadership Summit 2012 about an assembly at the University of the Free State and the fun of creating a wacky traditional hut:

*The next time around we decided to build a Zulu hut. Well, it was supposed to be a Zulu hut but it ended up looking like a Swazi hut. Through stuff like that I realized it was worth my time. You just feel a part of something and we won the prize for the best campsite. (Speaker 5)*

Another example, cited at RFL East London 2013, was of a team that spent extra funds on getting paid help to erect their tents. A survivor explains the lengths they went to the previous year:

*Oh! It looked like a squatter camp last year. I actually got a guy to build it. He built the whole lot like a Meccano set and the material came on the back of his truck. He pulled this pole out – then that pole. Then he 'plakked' [stuck] it together with black plastic. Did you see my squatter camp last year? It was lovely and we loved it. (FGI 4, Participant 4)*

In this instance, the temporary nature of the construction reflects the kind of makeshift homes in which many South Africans, because of dire financial circumstances, are forced to live. As so often happens at RFL assemblies, the space mirrors elements of the outside world. The Amatole region surrounding East London has extensive tracts of land occupied by informal housing, and this type of image is lodged in the collective mind of residents of the area.

We now have this ephemeral village constructed out of tents, gazebos, portable toilets, caravans – all adorned with bunting, banners, balloons, candle-bags and other collective symbols associated with RFL. The gates to the assembly are manned by volunteers and

security staff who keep unwanted elements out. Inside the temporary RFL village, participants have gathered to reflect on the cancer experience. Let us pause for a moment to consider the role played by collective symbols at RFL assemblies.

### ***Collective symbols***

Collective symbols abound at RFL assemblies and are treated with great reverence. Drawing on Collins's interaction ritual theory (2004: 83), this inquiry supports the notion that a sense of belonging among participants is captured in a rich array of symbolic objects. Such collective symbols include balloon arches, candle-bags, medals, sashes, prints of little feet and hands, crosses, hearts, the colour purple, cancer ribbons, HOPE and CURE signs, the colour pink (by virtue of the domination of breast cancer in the cancer world), stars, moons, fire, doves, and the RFL logo. The longer these symbols are associated with the RFL experience and the more they are used, the more the emotions associated with them become fixed in the minds and hearts of participants – especially if they are incorporated into ceremonies (Collins 2004: 81–87; Turner & Stets 2005: 80). The passion for these symbols is proven by the millions of images taken and shared on social media networks, websites and print publications each year.

Over time, collective symbols become the unique cultural capital of a group (Collins 2004: 81–87; Turner & Stets 2005: 80). Nothing demonstrates this more powerfully than candle-bags in the RFL movement. Participants are very solicitous about their candle-bags during the assembly and make a point of keeping track of their own bags among hundreds, sometimes thousands of other bags:



This image was captured at RFL Polokwane 2011 and shows the trouble participants go to in decorating candle-bags with flowers, ribbons and other decorations. Bags that accidentally catch alight can cause emotional distress. Some teams keep a watchful eye to make sure that the candles do not go out during the night and have sufficient wick to last until sunrise.

***Image 5.5: Decorated candle-bags***

Fire and flame are used to great effect at RFL assemblies and are seen in lit candle-bags, burning Chinese lanterns released during ceremonies, in flaming torches, lanterns and candles on the track, and fires at campsites. Candlelight adds to the mood, as seen in this image:



This image taken at RFL Soweto 2010 of a pensive young woman was captured during a luminaria ceremony. She was surrounded by other participants, also holding candles and sharing in the reverence of the occasion. The combination of darkness, flame and ceremony turns this into a shared reflective moment during the assembly.

**Image 5.6: Candlelight as a shared symbol**

The battle metaphor finds expression in the use of triumphal arches at RFL assemblies. Makeshift victory arches are created by tying together balloons to mark the place on the track where survivors, caregivers and teams start their ceremonial parades. Victory arches have a long history that goes back to Roman times. Historically they were used for a variety of public commemorations, including funerary, civic, religious and political events (Frothingham 1904: 2–3). Participants congregate behind these arches with their banners, medals and sashes as they prepare to do their parade, before being led around the track with great ceremony by marching bands, Scottish pipers, luxury vehicles or motorbikes:



This image was captured at RFL Soweto 2010 and shows jubilant cancer warriors wearing their sashes, and singing and dancing their way through a balloon arch, in celebration of another year of survival. The arch is reminiscent of the victory arches that returning soldiers would march through to celebrate a victory in war.

**Image 5.7: Symbolic victory arch**

To make sense of the use of these collective symbols it is important to understand the counter narrative in the RFL movement that sets out to challenge victimization. Without the warmth and comfort of the hearts, flowers, crosses, angels, fairies and soft toys, people confronted with the harsh realities of cancer would be stripped of a layer of imagined warmth and love that is made visible through these symbols. These objects are used when words are not enough to bring comfort or when cancer realities need to be softened:



**Image 5.8: Teddy as proxy**

In this image, captured at RFL Frankfurt 2011, a team dressed as oncology staff pushes a giant teddy in a wheelchair, with a drip in its arm, around the track. Many of the things associated with a scary cancer experience, such as laboratory coats, face masks, head covers, stethoscopes, drips and rubber gloves, are given a friendly face by turning the cancer patient into a cuddly, jovial teddy.

Sometimes teddies become proxies for very sick survivors. Teddies, like inspirational cancer survivors, remain cheerful even when they are having a rough time.

Another collective symbol is the word ‘Hope’ that appears in RFL paraphernalia and, without fail, on elevated, well-lit signs:



**Image 5.9: Flaming hope**

This image of a flaming hope sign was captured at RFL Bonnievale 2012. For many RFL participants, hope is like a beacon of light. Together with faith, hope can bring about a miracle when medical interventions fail and death becomes a certainty. Hope is tightly stitched into collective identity work at assemblies and is relevant to all participants, irrespective of their religious affiliation.

The collective symbols used by the movement make RFL assemblies instantly recognizable. However, despite all the things that make RFL unique, these assemblies are also a reflection of the world and the communities in which they are staged.

### ***Worlds in miniature***

Participants bring with them into the assembly their lived experiences of the illness, the meaning they attach to cancer, and many facets of their lives outside the assembly. At first glance, RFL assemblies can overwhelm with their rainbow of colours, energy and flamboyance. Look carefully behind the assault on the senses, however, and a more familiar world is revealed. The RFL assembly includes everyday experiences and a cast of well-known characters – family, friends, colleagues, caregivers, and health care workers. You can catch glimpses of family life as you watch families going about their business at their campsites, see work life in the many workplace teams that come to the assembly, see places of worship reflected in the countless crosses and Bible verses around the site, catch sight of cemeteries in the candle-bags that act as small memorials to those who have died, and spot local schools and universities. Even popular culture finds its way into the assembly, with reality television series such as ‘The Amazing Race’ being referenced in the assembly theme for a particular year, in the names of teams or as slogans on attire and banners. Inevitably, there are also the reflections of oncology units seen on banners, in teddy bears on drips being pushed around the track in wheelchairs, and in people with bare heads, as well as others who shave their heads out of solidarity with those with cancer.

In a discussion with the MRG on the ability of RFL assemblies to create an ‘other space’ which somehow reflects all other spaces (Foucault 1986), a member of the group remarks: *‘I think it is like Lord of the Rings. It is like a fairy-tale village where all these hobbits live. People come. They are inhabitants of this village and part of one tribe – because of this space.’* (MRG, Participant 2).

Much as all RFL assemblies have certain hallmarks, the type of community in which an assembly takes place can make a difference to the presentation of the assembly. Those staged in affluent areas can be colourful, lavish affairs, while gatherings in cash-strapped communities can be modest or even down-at-heel. The distinctiveness of each assembly adds to the charm of the RFL movement, and visitors to remote areas where people have few

resources often remark on how touching these small, modest assemblies are. Thus assemblies are like vortexes that draw in surrounding influences.

The assembly in Worcester 2012 was staged during October – the month during which breast cancer is put under the spotlight all over the world. The assembly took up this theme and translated it into every imaginable aspect, from breast cancer prevention messages on posters and banners (e.g. ‘Check your Boo Bees’), to team names (e.g. Boobieliciois, Bettie Boob Left, Bettie Boob Right, Breast CANSA Beaters), to the attire of the participants.



**Image 5.10: Breast cancer theme at RFL Worcester 2012**

Assemblies include people of all ages – from babies in arms to the very old. RFL places great emphasis on making the assembly a welcoming space for entire families, groups of friends, colleagues and even family pets. I made this note in my field journal:

*It was lovely to see the usual mixture of babies in prams, serious walkers, young, old and disabled people in wheelchairs or motorized scooters – all on the track. Also walking the track was a handsome, immaculately groomed, long-haired dog on a lead, with pink ribbons in his hair. (Journal Entry 2012/8)*

Young people make the assembly their own and turn the space into playground. The strong presence of children and youth at assemblies is surprising, given that cancer mainly affects older people. There are young people for whom the cancer issue is highly emotive, due to their own childhood cancers, peers with cancer or significant others who live with the illness or have died as a result of cancer. Nevertheless, a significant number of young people come to assemblies with only a weak link with cancer. Despite this tenuous link, it is noticeable how emotionally captivated children, teenagers and young adults become at assemblies, and I think this is attributable to the opportunity to spend the night in a collectivity pulsating with energy and in the company of peers. The other ingredients in this recipe for success include

the opportunity to stay awake all night, combined with a rich offering of fun-filled activities that are counter-balanced by very touching ceremonies.

RFL assemblies mirror powerful stories about the cycle of life by including people in various states of wellness – those brimming with health, newly diagnosed people, members of the ‘remission society’ (Frank 1995: 8–13), the desperately ill and even the dying. A HoH talks about two dying men who insisted on doing the survivors’ walk shortly before they died:

*I want to give you two examples of men who came to Relay while terminal. Gert came to our Relay for the survivors’ lap, in a wheelchair, as he could no longer walk. His father had to bring him and he only managed to stay for two hours because he was so sick. Daan, the other survivor, was also dying and his wife was furious that he wanted to Relay. He said he needed to be there because he was still living. After he died his wife told me that she understood why he had to do that final Relay. (FGI 1, Participant 5)*

The same HoH hints at the possibility that these survivors’ walks done by dying survivors might be one last attempt to prolong life:

*Even people that are seriously ill and that can barely get to Relay, want to be at Relay. Once they have been to Relay, they need to get there again, even if it is for the last time just to be part of the spark of life, the spark of hope. People want to live just to make another Relay. (FGI 1, Participant 5)*

To emphasize these life-death contrasts even further, a muddle of messages of hope and finding a cure for cancer are juxtaposed with symbols and ceremonies that tell a story about those who lost the battle to cancer. This is a highly heterotopic space where RFL assemblies are ‘points that contain all other points’ (Soja 1996: 55).

## **Summary**

In response to the sub-question posed at the start of this chapter, I presented findings that showed that RFL operates in the broader context of the global RFL movement and that participants use a dominant illness narrative to counter negative group representations of people with cancer. I looked at the ways in which the RFL movement sets the tone for assemblies all over the world, how the RFL village is created as an imagined battlefield, how cancer acts as the complicating event in the collective illness experience of participants, how death is treated as the common antagonist, and how participants prepare for annual assemblies. I also considered who gets involved in assemblies, how collective symbols are

used, and how the assembly space is a world in miniature. Having shown how particular elements form the backdrop to the generation of collective identities at RFL assemblies, I now turn my attention to assemblies in full motion.

## Chapter 6

# Findings: Animated battlefields

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### ***Chapter introduction***

In this second in the series of three chapters about my research findings, I show how RFL assemblies, once they are animated and in full flow, employ expressive and symbolic means to produce collective identities. The sub-question that I set out to answer is: How do RFL assemblies, once they are animated and in flow, facilitate the amplification or weakening of collective identities? Findings are presented to support the conceptualization of assemblies as imagined battlefields which become animated by RFL participants during focused gatherings. This chapter demonstrates how a sense of belonging is brought to life through the process of participants milling around the assembly site before the ceremonial opening, the pomp and ceremony that go with the opening of assemblies, walking the track, commemoration, the telling of stories, the appropriation of religion, activities after midnight, and the prospect of doing it all over again a year later.

### ***Milling around and getting started***

From the moment the gates at the assembly site open and the first delivery vehicles roll onto the field, the mood of the RFL cancer assembly starts building up. Vehicles are unpacked and the participants start milling around, getting ready for the long night ahead while they meet and greet fellow participants. This gradual bringing together of the collectivity, as well as the construction of the tented village, helps to create a focus on the gathering and generates excitement about the prospect of spending the night with an energized group of people.

Collins (2004: 23) states that a crucial building block in interaction ritual chains is 'situational copresence'. In order to get people in the crowd to 'buzz or vibrate' together and to experience a sense the unity, they need to be in each other's company in a real-life, face-to-face situation. This cannot be accomplished remotely or via a virtual reality encounter. The more people are in each other's company ('copresent' with one another) and exchange greeting rituals with one another, the more likely they are to experience the first inklings of a shared mood and common focus of attention (Turner & Stets 2006: 34). In essence, this period before the assembly begins is an emotional warm-up for what is to follow during the night. This sense of being a cohesive group starts gaining momentum before the official

opening of the assembly, becoming even more pronounced during the opening ceremony in the late afternoon.

By the time the RFL assembly is officially opened, most of the participants will already have been on site for hours, erecting tents, wandering around greeting friends, admiring different campsites, getting dressed in team attire and assisting with endless tasks, from filling candle-bags with sand to preparing the special marquees for the survivors' reception.



**Image 6.1: Milling around at RFL East London 2012**

The organizing committees give awards for the teams with the best spirit, the most beautiful campsite, the best costumes, the most funds raised and so on. It is customary for teams to walk around to get a sense of who could potentially pose a threat in the various award categories. This friendly competition between the teams feeds excitement and conviviality.

Assemblies start at an appointed time and with an announcement over the public address system, telling everyone to settle down and pay attention. Everybody is rounded up for the opening ceremony, during which they listen to the welcoming addresses and experience the victory parades that take place in the strict order of survivors first, followed by caregivers and then teams. Opening ceremonies are characterized by the singing of the national anthem, and speeches and pledges that give way to the parades. In the following extract, an honorary chairman opens an assembly with this solemn pledge:

*... Earlier we sang the National Anthem and I felt like standing like the Springboks [national rugby team], with my hand on my heart. I want you to stand – survivors can sit; place your hands on your hearts while I read the pledge because we don't know if we could get cancer tomorrow. In the name of all Relay For Life participants, I confirm that we are here today to celebrate the lives of cancer survivors, to support those fighting cancer, and to honour those we have lost. Our commitment will be symbolized in every step we take. Each step will move us closer to our goal of a cancer-free world for future*

*generations. I now declare the CANSA Relay For Life Worcester officially open!*  
(Speaker 18)

Parading is an important way of expressing group identity at RFL assemblies. Opening parades blend inspirational music with the heart-warming sight of survivors dressed in special T-shirts, sashes and medals, doing a victory lap around the track, while the rest of the assembly cheers and applauds. The most spectacular survivors' walks are those where the procession is led by outriders on motorbikes, open-top luxury vehicles carrying survivor luminaries such as HoH, wheelchairs ferrying frail survivors, and military-style marching bands. I wrote this note about a You Tube video made at an assembly in East London (MediaTag 2009):

*A marching band is leading the survivors' procession. The band is dressed in military uniform and marks time for the survivors while they parade their way around the track. The band leader marches in a flamboyant manner, twirling a baton as if he is at a military parade.*

These bands are an institution in certain communities such as East London, where marching bands attached to churches are also used at important cricket matches and other community festivals.

Once the survivors have done a full lap, they are joined by their caregivers. In turn, this gives way to the introduction of the teams, carried out with much fanfare as they launch into their first lap on the track. I made this journal entry at RFL East London 2013:

*As is customary, each team is introduced to the assembly as they pass the podium. Their team name is called out over the public address system, and they then respond with a roar, a song or a war-cry. The teams are wearing outlandish outfits and have names such as Radio Chemo Rockers, NHLS Lab Rats, Fighting Fairies, Pixie Power, The Scarecrows, Club Eden, The Rainbow Warriors and many other names that speak volumes about group identity. (Journal entry 2013/4)*

This part of the assembly is loud, upbeat and full of emotion. Some people will cry as they watch the survivors doing their laps. These are tears of pride and gratitude about loved ones having survived another year and being able to join in another landmark assembly.

People touched by cancer need such ceremonies to acknowledge what they have been through. Frank (1991: 129–135) recognizes the need for ceremonies of recovery for those who have undergone the experience of a stigmatizing illness. They symbolically purify affected people, honour their safe passage through the illness, and acknowledge the hoped-for redemption from a potentially life-threatening condition (Ibid.: 129, 131). It is hard to imagine a more powerful ceremony of recovery than the survivors' walk at RFL assemblies. For those doing their first ceremonial walk through the victory arch, dressed in special attire and witnessed by the assembled crowd, it is tantamount to a ceremony of recovery. Opportunities to take part in these types of occasion are rare in contemporary society, and this is an important gift of RFL to its constituents.

Once the opening ceremony has been completed, the track is officially open. Each team is expected to have at least one member on the track at all times, except when the collectivity pauses for the remaining ceremonies. At this stage, people are still full of energy. The majority of the participants walk the track between the opening and the solemn luminaria ceremony which follows once it is dark. At campsites, some will start preparing dinner or open fundraising stalls selling food. Games and activities, both organized and spontaneous, start happening all over the tented village, and troupes of performers entertain the crowd at regular intervals. At this stage of the assembly, the mood is utterly joyful and energy levels are high.

### ***Walking the track***

Walking the track is a repetitive, synchronized activity. Collins (2004: 49) believes that people affect each other when they physically move together and that this is a key ritual ingredient in the generation of group solidarity. The hours of walking the track together can be highly symbolic for participants. These words, recited at RFL Mossel Bay 2012, highlight the reason for walking the track:

*I walked around the track today. I walked to help a disease go away. I walked because there is a need. I walked that bodies can be freed. I walked to give a small child hope. I walked to help someone cope. I walked for a husband and a wife. I walked to help along a life. I walked with my head held up high. I walked for the one about to die. I walked to help find a cure. I walked for everyone to see. I walked for you. I walked for me.*

Friends walk together in groups, couples hold hands as if on a date. Some treat walking as a silent meditation, while others use the track to joke around and have fun. Some survivors walk the entire night, making a symbolic statement about survival. Some walk to remember. A mother who lost her son talks about her reason for walking the track and her immensely powerful sense of community at RFL assemblies:

*My 11-year-old son died of cancer two years ago. Relay has become very important to me. Every step that I take around that track all night long is to cherish the memory of my son and everything that was so beautiful about him. I also walk for my fellow brothers and sisters, and not only because I was so personally affected. Walking the track makes for true contact with people. This is what is important about Relay. Every step I take around the track is for somebody that has died. (FGI 2, Participant 5)*

On the track, we see dynamic, spontaneous explosions of energy from exuberant participants as they parade around, striking poses for the many people taking photographs or making video recordings. The track is a space in which you can walk, run, dance, sing or roar out your battle cries. Let me demonstrate by describing a team called 'Irene's Fairies Fight Against Cancer', a group of young people who successfully blended humour and war-talk. The team dressed as fairies. They are on the track to entertain and be entertained – and to fight for Irene, a cancer survivor:



This image, captured at RFL East London 2013, shows the team in flamboyant attire. The young men demonstrated their 'pas de deux' skills as one beefy fairy flew into the arms of another. On the surface, the team's collective effervescence shouted spontaneous fun and vivacious energy, while their more serious mission was to honour Irene's fight.

**Image 6.2: Fighting Fairies on the track**

Images such as the one above demonstrate the extent to which participants play up to the camera. Constant photographic and video recording by all and sundry means that countless images are captured and disseminated via social media. The assembly will still be in progress

when the images and written commentary about it start flooding the outside world. RFL participants know that they belong to a global network and that these images and commentaries about an assembly quickly find their way into the virtual world through the professional and friendship networks that exist among constituents. They are acutely aware of this and literally ‘perform for the camera’, as well as for the benefit of the large audience that needs to be impressed.

Collective effervescence during RFL assemblies takes many forms, manifested through talk from the podium, outrageous attire and team performances. Participants in South Africa use the Afrikaans word ‘gees’<sup>6</sup> when they talk about the blending of exuberant behaviour and a heightened sense of solidarity. Expect to see clowns, pirates, grotesque hats and assorted animal costumes. Men feel at liberty to parade around in drag, wearing embellished bras and high heels. Humour abounds and everybody can sing and dance to their heart’s content – even if they are a bit short on talent. It is a shared task to inject humour into the proceedings. Some of the humour has a vaudeville quality, recalling an old-world script of courtly gentlemen flirting with desirable ladies. At RFL Worcester 2012, this scene played itself out in the run-up to the hat competition, as the master of ceremonies gathered the crowd for the impending excitement:

*The ladies with their beautiful hats can gather. How beautiful are these hats? Man! Out of the straw-cupboard! Check her out, man! My! She's not from around here! She's not from around here! Dynamite! [Belly laugh] Man, those doughnuts! [The woman wearing the hat giggles in a coy manner]. Man, man!! They should pay you to advertise like that! [Wolfish chuckle]. Beautiful! Beautiful! Man! Ladies and gentlemen, gather around and come and have a look! You can gorge yourself on some of these hats. Come and behold the creativity of these beautiful hats made out of wire, out of nails. Man, they are roses! [He whistles through his teeth in a playful, lecherous manner.]*

Once the assembly has moved into collective effervescence, it becomes characterized by its distinctive RFL ‘gees’ – unbridled fun, wacky behaviour and displays of affection towards both fellow team members and strangers. The more emotional effervescence is generated and the longer the encounter, the greater will be the sense of collective identity and the more likely people will be to demonstrate their sense of solidarity (Turner & Stets 2006: 34). Invigorated through ceremonies and collective effervescence, they feel like one large happy

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<sup>6</sup> ‘Gees’ is an Afrikaans word that means ‘spirit’. The term became popular in South Africa during the Soccer World Cup 2010 as a way of describing a collective sense of joy and unity.

family. Much like the traditional Bushman of the Kalahari, who spend long nights around a fire where they trance-dance, clap and sing, RFL participants experience the magic combination of performing ceremonies and moving together in a synchronized fashion, enhanced by sleep deprivation. This blend of ingredients is an intensely powerful element in the amplification of collective identities.

Music amplifies mood and plays an important role in keeping people moving around the track for hours on end. Jasper (2011: 294), commenting on how crowds generate emotional energy, points to the power of music when combined with movement: ‘Collective locomotion and music have unusual capacities to make people melt into a group in feelings of satisfaction, perhaps because so many parts of the brain and body are involved at once.’ A member of the MRG picks up on this theme and explains the nature of rhythmic entrainment to the group (Collins 2004: 48):

*Take a rave where you have a lot of people raving together. It’s that rhythmic thing they get into. The more they move together, the more they have a breakdown of neural connections in their brains. So all the body is doing is responding to the music or the footfall or whatever. It is the same thing at Relay. (MRG, Participant 6)*

The organizers of RFL assemblies know that music is a key element in creating a mood that will feed into feelings of solidarity. Carefully designed play-lists help the celebrants to walk, dance, sing and clown their way around the track all night long.

Efforts to disrupt collective effervescence reveal just how difficult it is to stop the juggernaut once it is in full motion. The MRG cited an example of an assembly in Nelspruit where heavy rain and serious damage to the field necessitated the removal of participants off the track at one o’clock in the morning. The assembly was in full flow and the celebrants were upset at the prospect of having to pack up and go home. For the teams, the rain, mud and discomfort were not sufficient reason to stop the fun. A member of the MRG explains the dilemma:

*As an organizing committee, we could see the extensive damage to the field and we were worried about being sued for damages. Participants shared none of these concerns. They were not simply going to walk away from the Relay and were deeply upset when we told them that they needed to stop walking. (MRG, Participant 2)*

Using Collins’s theory of interaction ritual chains (2004: 48), it is clear that in this instance the rhythmic entrainment of bodies was disrupted and the collective effervescence of the

collectivity stymied. Participants became resistant and irritated because, in their state of emotional entrainment, the perfectly sensible reasons for stopping the assembly in its tracks, simply felt like the organizers wanting to spoil their fun.

### **Commemoration**

Commemoration creeps into nooks and crannies at assemblies, and the shared work of remembering the dead is found at all RFL gatherings. Examples abound: in the ceremonial handing over of the sash of a young HoH to her loved ones after her death (Leadership Summit 2012), in candle-bags placed around the track, memorial teams who dedicate their participation to somebody who died, banners and team attire which speak of loved ones lost to cancer, the official luminaria ceremony, slideshows of the dead, and the symbolic walking of the track. The ubiquitous presence of commemoration seems paradoxical in the context of assemblies that work so hard to emphasize the hope for survival. I do, however, believe that the way in which the act of remembering is managed creates a particular approach to death and dying. This is first and foremost the honouring of fallen heroes, rather than an acknowledgement of death as a necessary element in the cycle of life.

The public commemoration of the dead at RFL assemblies is consistently described by those who take part as the single most important aspect in creating a sense of unity. The ability to help with bereavement is greatly appreciated: *'For me Relay is healing. My dad died as a result of cancer four years ago, just as Relay was getting going in this community. Relay was so healing at a time when everything seemed so dark'* (FGI 3, Participant 1). At assemblies, the feelings that go with remembering, grieving and paying tribute to loved ones can be shared, and participants report that it makes a positive difference to be surrounded by others in the same boat. A loss which may seem difficult to fathom in private can somehow be put into perspective in the context of an RFL assembly:

*We lost our mom to cancer, which was, thinking back, the biggest event in my life. We grew up without a father and she was everything. I was in my 30s when she died and I felt like an orphan. I think this [Relay For Life] has put it into perspective. I thought I was the only person in the world that had experienced this huge loss, because everybody around me seemed okay with it and I really was not okay with it. I was real mad. Relay shows exactly how many people go through what I went through. I walk around looking at the bags and it is just name, upon name, upon name – all people that have gone*

*through what I went through. That's what makes Relay what it is – just that feeling that you are not alone.* (FGI 4, Participant 2)

Many commented on how difficult it is to mourn outside the RFL assembly, how it provides an opportunity to cry about cancer losses in an emotionally safe environment. Emotions can be expressed away from the gaze of the larger community and in the safety of the company of others who understand the cancer experience. Grieving becomes normalized and is made socially acceptable. Outside the RFL assembly, it is difficult to show too much emotion or to grieve for too long. Inside the assembly, these judgements are less keenly felt. This feeling of being understood by like-minded people facilitates the activation of collective identity.

The official commemoration at RFL assemblies is the luminaria ceremony. It is mandatory and is celebrated after sundown, with the light of hundreds, sometimes thousands, of decorated candle-bags placed around the track. The mood during the commemoration ceremony is reverential and stands in stark contrast to the rest of the assembly that is energetic and joyful. It is a time of quiet reflection, as seen in this image:



This image shows both adults and children deeply involved in the luminaria ceremony. Participants stand or sit in front of candle-bags of loved ones. Most have their eyes closed in prayer. The assembly is solemn and focused on the ceremony. (RFL Polokwane 2011)

**Image 6.3: Luminaria ceremony**

The luminaria ceremony is accompanied by music, speeches and small in-built rituals such as the ‘Empty Table’. A detailed guideline for the observance of this short ritual is given by the RFL movement (International Relay For Life n.d.: 21–22). A small table is the focus of attention and a spotlight is placed on it while a narrator reads a moving piece explaining the symbolism of each element on the table – an empty chair, a white tablecloth, a single rose in a vase, a pink ribbon around the vase, a dinner plate with sliced lemon and sprinkled with salt, a candle, and an upturned glass. Each element of this tableau has a symbolic meaning.

For example, the salt references the many tears shed while suffering, the lemon signifies the bitter struggle against cancer, while the candle is the embodiment of hope. Commemoration is framed as a celebration of life and not as mourning the dead, while hope very specifically denotes the hope for a cure and for survival. This is illustrated in a YouTube video (MediaTag 2009) captured at RFL East London 2009, in which grief is counterbalanced with hope. The narrator emphasizes that, although the commemoration ceremony remembers those lost to *'this dreaded disease'*, a HOPE sign is lit *'at the same time'* to remind the assembly that there is always *'hope that cancer will be beaten'*. The assembly does not dwell on death too long, but moves back to walking the track after a reflective period which rarely lasts more than 30 minutes.

The ability to create empathic resonance through commemoration was underscored by the MRG. The group contended that RFL is so successful at facilitating empathy that even those who have yet to experience a cancer death are able to experience the pain of others. The MRG agreed that commemoration underpins the generation of collective identity. Sharing the experience of remembering the dead is comforting, since it turns a personal loss into a collective loss, creating room for mourning beyond what is deemed acceptable in our fast-paced world. The luminaria ceremony is richer in ritual than most contemporary, middle-class funerals in South Africa, where public displays of emotions are restrained. The strong contemporary emphasis on getting closure following death forces many people to drive their grief underground: *'In modern society you are allowed to cry for a week after the funeral. Boy! Then you need to pull yourself together because life continues.'* (MRG, Participant 5). Barriers to grief outside RFL are illustrated by a prominent HoH who waited almost 30 years to grieve for both his parents and brother, all of whom died from cancer in a single year. He tells the RFL Annual Leadership 2012 how, at the first assembly he attended, he could finally mourn their deaths in front of candle-bags dedicated to them:

*On the 28th of November, [silence as he exhales audibly in an attempt to regain his composure] during the luminaria function here in Hartenbosch ... [he starts to cry]. Sorry! For the first time in my life I could mourn their deaths. I was brought up in this tough professional world, never having the ability to mourn. That night I was alone on that track in front of those little bags [he weeps]. Thank you for allowing that, because in 1976 I lost most of what was precious to me. (Speaker 4)*

The collective remembering of the dead offers an opportunity to experience deep solidarity with others who share the experience of illness. A survivor-organizer who was diagnosed with advanced cancer describes her first experience of a luminaria ceremony:

*I was sitting in the pavilion when they lit the candle-bags and dimmed the lights. I will never in my life forget that experience. Then you start walking the track, looking at those bags. You have just 'gone to school' with some of them. You 'do chemo' with people you consider fellow students. You look at a bag of somebody you know through treatment and it is so lovely to see that somebody remembered the person. There was another chemo-friend that they simply could not get right and I wondered how she was doing. There I saw her [candle-bag with photograph]. She had died. As you walk looking at those bags, you are very aware that things could change very suddenly. (FGI 3, Participant 3)*

Assemblies are creative in the way they deal with commemoration. RFL Worcester 2012 used a slideshow of people who had died of cancer. The smiling faces of loved ones projected onto a large screen added to the reverential atmosphere and acknowledged that some people do not survive. A team captain pinpointed this as the highlight of the assembly for him: *'I was very touched by the slideshow because the pictures were of smiling people, not suffering people. This is how we should remember them.'* (FGI 2, Participant 2). We see the same trend in the way photographs are chosen for candle-bags. They are almost universally 'happy snaps', taken at a time when the person was happy and vibrant. The dead are portrayed in the way we want to remember them, not as the people who were gravely ill before they died. These are pictures taken at weddings, at graduations, on family holidays, at family gatherings, with parents holding children they obviously adore. Even the odd images of survivors in the throes of treatment show warriors with bald heads smiling at the camera.

The only evidence I found in the data of an assembly with a direct gaze at some of the practical realities of dying was RFL Parys 2012. At this gathering, photographic images showed the presence of two well-known firms of undertakers (Doves and Avbob) with their branded, decorated campsites. I had never encountered undertakers at any RFL assembly, and I believe that putting the spotlight on the disposal of the dead was a major deviation from the norm.

### ***Storytelling***

In dealing with the identity alignment of marginalized groups, Goffman (1963: 133) argues that stigmatized groups rely on experts to provide them with blueprints on how best to

manage their troublesome conditions. In an era of citizen-dominated mass movements, these experts are typically spokespeople from the ranks of those who are themselves affected, carefully groomed by the movements to which they belong. Hand-picked speakers are chosen by RFL organizers to offer the audience recipes on how to live with cancer, and are sometimes offered ‘media training’ to prepare them for their roles as spokespeople. Storytellers fulfil this role by universalizing the cancer experience, arousing confidence in the power of collective action, and inspiring the group to face adversity with courage and optimism. Stories about individual experiences are related for the benefit of the group, and those that succeed in emotionally captivating the audience feed into the pride-gratitude cycles that Lawler (2003: 145) sees as so crucial for the activation of collective identity.

I did a narrative analysis of 32 stories of RFL participants, including people with cancer, caregivers, team captains, team members, and organizers. Twenty-seven storytellers allowed me to take a closer look at their stories. Of these, five told their stories more than once in FGIs and in mass assemblies. In scrutinizing the stories, I classified them according to the themes which came through most clearly as they were being told. Most of them blend elements of the three storytelling genres I identified in the data, namely (1) heroic warrior stories, (2) stories of transformation (firebird stories) highlighting the power of the cancer experience to bring about personal growth and foster a sense of agency, and (3) accounts that testify to feeling wounded. Only one storyteller expressed cynicism and distanced herself from the cancer cause and RFL.

Story genre	FGI Stories	Assembly Stories	Number of Stories
Heroic warrior stories	3	12	15
Firebird stories	9	5	14
Walking wounded stories	2	-	2
Dissenting stories	1	-	1
<b>Totals:</b>	15	17	32

**Table 6.1: Types of stories**

The design of my inquiry allowed me to analyse stories told both in FGIs and in assemblies. Storytelling in FGIs took place in the context of small groups that never exceeded 10 people, while all the other storytelling was done for big audiences, ranging from 97 participants in the

case of the RFL Leadership Summit 2012 to approximately 3 500 at RFL East London 2013. As I explained in Chapter 4, all FGIs were conducted during assemblies and were started at 22:00, at a point when participants were already emotionally entrained by activities and ceremonies. Storytelling was not the primary purpose of FGIs, but out of the 25 people who took part in these groups I was able to piece together 15 stories. I have included additional information about the contributors and their role identities in *Appendix G: Database and Research Path Summary*.

Much like war stories told by soldiers, many of these stories revolve around the ordeal faced and the responses to that ordeal. Frank (1991: 115) contends that from the ill person's perspective the most important issue is suffering. It is hardly surprising, therefore, that enduring suffering is such a prominent theme in the stories, and that talk about the ability to endure suffering runs like a leitmotif through accounts. The stories designed for big audiences at RFL assemblies are essentially testimonials about the cancer experience and the meaning participants find in their own RFL involvement. When recalling their cancer experiences, survivors talk about forcing themselves to keep going, fearing that if they stumble they will never be able to get up again.

Looking at the approach taken by the storytellers, I found that the setting in which a story was told made a difference to the chosen storyline. Table 6.1 shows that heroic warrior stories were mainly employed for the benefit of the assembled crowd and that the other story genres played less of a role. Those chosen to speak in the public forum were typically people who were articulate and inspirational.

Stories told in small group settings differed in important ways from those crafted for big audiences, as the confidential nature of the small groups allowed more room for participants to speak their minds. The stories told in FGI had an intimate campfire quality to them and rendered a broader array of narrative plots than those told to big audiences at RFL assemblies. What was useful about the FGI stories was that they included the accounts of some participants who would not be invited to speak to the big audience by virtue of being deemed unsuitable by the organizers to act as spokespeople for the movement. Consequently a much broader range of stories was captured in these groups. FGI participants told more stories about the transformational potential of cancer and also made more references to vulnerability than those speakers who did public storytelling.

Two of these storytellers, both HoH, employed different storylines on the two occasions they spoke. In the FGI, they told stories of transformation, but once in front of the big audience they fell in line with the dominant heroic warrior narrative and crafted their stories accordingly by talking about cancer as the foe. To illustrate this, in the FGI one of these women used the metaphor of autumn in the vineyards to symbolize her emotional progression and her acceptance of family members who could not cope with her cancer:

*I drove through the vineyards and thought that this is so beautiful, all the different colours, the changing of the season. I fell in love with this autumn season. ... I was able to accept what I've lost and accept the people who could not cope with my cancer. I realized it was their way of coping and I was able to forgive. My eyes have opened to this autumn season, and thanks to Relay, I was able to speak my hurt out, but also got to know why people sometimes act in a hurtful manner. (FGI 1, Participant 5)*

In the FGI, she made no use of talk about cancer as the enemy. However, in front of the mass audience her story was peppered with battlefield talk: *'I was suddenly thrust into a life-threatening crusade' – 'I battled on diverse fronts fighting the physical and psychological manifestations of cancer' – 'cancer is an unrelenting, merciless antagonist with devastating effects.'* (Speaker 6)

The best storytellers know how to read their audience and how to make their stories soar. The better the speaker, the more often she or he will be asked to speak at assemblies and to develop performances in a way that will emotionally entrain the audience. At the RFL Leadership Summit 2012, I overheard audience members who equated 'beautiful talks' with those that drew tears. However, stories that draw tears are not the only popular stories, as many of the most inspirational speakers are those who take on the cancer challenge with fortitude and good humour. A survivor tells the audience how she reframed the loss of her breasts:

*Breast cancer was not the end of femininity. Your femininity does not sit in your breasts. It is in your head. I discovered a great passion for a beautiful bra. When I got my prosthetic breasts I started buying very beautiful, feminine bras. I celebrated by getting a cerise bra. When I got home I admired myself in the mirror. On the bra, written in silver were the words 'angel's wings'. Your prosthetic breasts are your angel's wings. They raise you up and make you fly. (Speaker 14)*

Frank (2010: 12) sees this pressure to deliver impactful stories as a complicating factor in the authenticity of storytelling: 'People are cast into stories, but storytellers invent themselves in the stories they tell, and some storytellers have to do more invention than others.' Many of the story-tellers at RFL assemblies become storytellers only as a result of their cancer experiences and grow in confidence as a result of their opportunities to speak in public. Through repeated opportunities and audience feedback they learn how to tailor their stories for maximum impact.

Heroic warrior stories cast cancer in the role of the antagonist, while the storyteller and fellow RFL participants take the role of protagonist, idealizing people living with cancer as unwaveringly positive and hopeful. Polletta (2006: 168–171) refers to stories based on familiar age-old tales as 'canonical stories'. Her use of the concept is very similar to the way in which Jungians use the notion of archetypes. These age-old stories are lodged deep in the collective unconscious and are reproduced from one generation to the next. Although many reference canonical stories, each one aspires to be a unique account of the struggle to make sense of the changed circumstances brought about by cancer. Canonical stories bring immense power to bear on RFL assemblies. The heroic warrior myth has pride of place in most of the stories, painting an idealistic picture of those who endure cancer with grace and forbearance. The same survivor who spoke in the previous vignette captures the spirit of living with grace under the cloud of cancer:

*There are tough days. Days that you don't feel well, but you need to create a dream. Throw a party. I always wanted to go overseas once I retired. ... Six weeks before I was due to travel I was diagnosed with cancer in the remaining breast. ... I told the doctor to immediately do the surgery because I was not going to miss out on my overseas trip. I told him I'm getting onto the plane with stitches if necessary. ... I visited my children and had no complications because my head was sorted out. I was positive. (Speaker 14)*

Once speakers are confronted with a big audience, they tend to refer to being wounded by cancer as a past event, rather than something that is bothersome in the present. There is little room for being wounded in front of the crowd. Devastating losses are overcome by being courageous and optimistic. Stories told at RFL assemblies often redefine setbacks as opportunities to behave with courage and to be an inspiration to others. Those that reference the heroic warrior metaphor are canonical stories which follow the form described by Polletta (2006: 168–171), where obstacles are seen as stepping stones to eventual triumph.

Organizers consistently employ the heroic warrior storyline promoted by the global RFL movement. This is understandable, as they stand in the service of the RFL movement and feel compelled to portray people in keeping with the dominant collective identity in the broader movement. Here an organizer gives a romanticized portrayal of survivors:

*You are a symbol of hope and courage and a beacon of hope for other cancer survivors. You have the ability to inspire other people with your stories. I have so often heard it said that the cancer journey enriches people and brings them closer to God. It provides more vision and makes life more meaningful. That is why cancer survivors embrace each day and live it to its fullest. That is where those of us that have not been diagnosed with cancer are at a disadvantage. We don't know how to live life to the full, but you are our example. (Speaker 15)*

In this story, the image of those with cancer has become so idealized that they are now elevated above other people through their closeness to God, their inspirational role in relation to others, and their ability to squeeze the last drop out of life. Bell (2012: 587) refers to these idealized visions of people with cancer as: ‘... the idea that cancer enables the self to be remade on all levels – psychological, spiritual, and physical ...’. I do not question for a moment the ability of cancer to be transformative, but this idealized representation raises concern about the pressure brought to bear on survivors to live up to an impossible ideal. I take up this issue in the discussion chapter.

Stories of transformation, or firebird stories, reflect both the light and the dark of the illness experience. Here, the storytellers do not gloss over their own vulnerabilities. They do not cast cancer in the role of the enemy, do not allow it to be totally defining, and do not incorporate battlefield or warrior metaphors into the stories. Many have a strong voice and are heavily committed to making a difference in the lives of other affected people. They do not feel that cancer has hijacked their sense of identity and are quick to express their gratitude to others for support received. A daughter (caregiver) reads a letter written by her mother who talks about cancer in a considered way, without casting the illness in the role of the enemy. Above all, the letter highlights both the need to care for others with cancer and the kindness she herself received from others:

*In 2008 I had 58 trips from Worcester to the Panorama Hospital in Cape Town. I had 20 intravenous chemo sessions, 33 radiation sessions and other consultations. It was such an uncertain time in our lives. On 11 occasions my family took me to treatment. The*

*other 47 times the Worcester community stepped in. If you have to drive to Cape Town on 58 occasions it all mounts up with paying toll-fees in each direction. People still care. It was an eye-opener. The way people rearranged their schedules. How people would foot the bill for petrol or the toll-fees at the tunnel. The way people stood together was just unbelievable and we experience it to this day. (Speaker 13)*

Lewis (2013: 660) highlights the use of ‘self-crafting narrative’ in accounts that emphasize phoenix-like transformations. In the vignette above, the protagonist not only talks about how she endured suffering but also humbly demonstrates to her audience the tremendous patronage she enjoyed from others.

Included in the group of transformational stories were two testimonies given in the mass assembly that had a distinctly didactic flavour. I include these examples under the firebird category, as both stories seen in totality best reflected a transformation narrative. A caregiver who shoulders the responsibility of a young wife with cancer, two preschool children, and a demanding business gives sage advice on becoming a caregiver:

*For those of you who are not caregivers I want you to notice that there are people out there that need your help. Caregivers in turn need caregivers. I have my own group. I have a men's group that supports me. I can go to them with things I cannot discuss with my wife. I can say to them: ‘Here is a situation. What should I do?’ We are all caregivers. Many of you will be caregivers in future. (Speaker 2)*

The other example was of a speaker who is both a survivor and a caregiver. She told the audience about the importance of accepting help from others while taking care of a loved one:

*My sister was also diagnosed with cancer ... it was the hardest thing to watch her suffer. As a caregiver I had to be there for her, but I was very stubborn. I didn't accept any help from friends. That was wrong. I should have accepted the help. Caregivers should also have support because it is more difficult for the caregiver than it is for the cancer sufferer as far as I'm concerned. (Speaker 23)*

Bury (2001: 265, 278) sees didactic stories as a type of core narrative that connects the storyteller to the hidden significance contained in the experience of illness. The two examples provided fulfil the purpose of giving advice and cautioning the audience against making common mistakes in fulfilling the caregiver role.

Walking wounded stories are told by storytellers who feel overwhelmed by the cancer experience, highlighting their humiliation and feelings of powerlessness. A young, sincere HoH from an impoverished community relates her feeling of utter frustration as she tries to do cancer education in a community where others are resistant to her message:

*I was asked to do cancer education and collect stories in my rural area. I said those people will not help because they say cancer is private. I start at the local clinic and talk about breast and cervical cancer. Those women there go 'blah, blah, blah!' They just make a lot of noise and I say 'Please! Just listen to me for once' and then I get angry. ... It is very difficult because people say 'no, we don't have cancer and we can't do pap-smears; it is painful and we can't do breast examinations' (FGI 1, Participant 4)*

This vignette was included in a long list about her losses, her surgery, feelings of inadequacy, the sadness about no longer having a romantic partner, and cancer losses. She acknowledges the many heartfelt attempts of co-workers to support her and build her confidence, but this is essentially a story about the struggle to find her voice.

Dissent is exceptionally rare at RFL assemblies. A speaker with a dissenting voice is someone who distances themselves from the illness experience and the RFL movement. An example is the story of a FGI participant who stated that, although '*we are cursed with a lot of people close to us that are affected by cancer – my mother, my aunt, my sister, my nephew, my best man, my teacher and friends*', her sole motivation for being at the assembly was to have fun. She made it clear that her primary attachment was to her LGBT team and that in her view resources mobilized through RFL might as well go to an animal charity. She distanced herself from her family, with their strong commitment to RFL, the cancer cause, cancer education efforts and RFL:

*We keep saying stop smoking, stop drinking, stop this-ing, stop that-ing! In fact, my grandfather died not of cancer and he smoked his entire life. I don't even know what all this lifestyle talk is about. Eat vegetables that are cultivated how and grown where? Drink the water from our dams? No! There is a lot of hype that is not fixing too much. I just think cancer is getting worse and worse. (FGI 4, Participant 3)*

In pondering this story it occurred to me that this caregiver's devil-may-care attitude, which manifested in her distancing herself from everything to do with cancer, might well suggest that she is wounded by one too many encounters with death. However, it is so rare to come across dissention like this that I chose to put her in a category of her own. Other walking

wounded in RFL speak openly about having been hurt by cancer, but still embrace RFL and the cancer cause. This participant does neither.

### ***Religion***

Religion adds significantly to the shared focus at RFL assemblies. Judging by the many displays of religiosity during gatherings, the majority of participants are overtly religious. Collins (2004: 48) shows that collective interests shared by the group constitute important ritual ingredients that feed outcomes such as collective identity. The reliance on religion during RFL assemblies is a uniting factor for the majority of participants. South Africa has traditionally been very religious, but is showing a steady decline in religiosity, to the point where only 64% of South Africans considered themselves as religious in 2012 (Vermeulen 2013: 15).

Globally, RFL is not a faith-based movement, and it strives to be inclusive of participants, irrespective of their belief systems. In South Africa, however, religion has been appropriated by RFL, and this gives the heroic warrior symbolism an even stronger footing, promoting the belief that it is crucial for participants to cling to faith in order to vanquish cancer. There is a taboo against taking too much personal credit for living well with the illness, and many feel compelled to credit God for their delivery from the clutches of cancer. For those who stand outside mainstream monotheistic faith, the ever-present use of religion at assemblies can be alienating, unless they have a high tolerance for overt religious practice. Despite running the risk of alienating this silent group, it is clearly in the interest of RFL in South Africa to remain closely aligned to its explicit religious affiliation, as this seems to be what the majority of RFL participants, on the surface at least, identify with.

Given that so many South Africans traditionally see themselves as religious, it stands to reason that RFL assemblies will incorporate the religion of the broader communities in which they are based. Collins (2011: 4) is of the view that sociologists after Emile Durkheim and before Erving Goffman placed too much emphasis on religious rituals being distinct from secular life. Collins believes that there is a great deal of borrowing from religious ritual in secular life and that religious rituals are widely used for non-religious purposes. Similarly, Richard Darnton (1999: 101) with his notion of ‘ritual punning’ shows how older ritual elements (in this case religious rituals) are imported into a new space to merge with newer ceremonial elements to fulfil a ritualistic purpose. RFL in South Africa certainly supports this

assertion, as faith talk and performance both feature prominently as mechanisms to emotionally entrain participants. RFL assemblies create echoes of the sacred through the use of religious symbols, religious talk and performance, the reverence with which survivors and HoH are treated, and the designated ‘sacred’ areas, such as the survivors’ reception area, which are off-limits to the majority of participants.

The expression of faith, especially a Christian faith, is tightly woven into collective identity work. Elements of this include gospel music, praise dancing, religious symbols and religious messages on gift boxes for survivors, candle-bags, banners, posters and T-shirts. Religious symbolism finds a ready home at assemblies. A special feature of the survivors’ reception at RFL Worcester 2012 was the inclusion of angels – Muslim and Christian girls dressed in white, with tinsel around their heads so that they looked like angels. These ‘angels’ walked with the survivors from the function hall onto the track and held their hands as they walked around the circuit as part of the opening ceremony. The topic of the angels was elaborated on during the FGI, and I realized how the illusion of these celestial beings had captured the imagination of participants:

*I was really struck by the angels that walked with the survivors – especially the little ones. The spirit was quite different because of them and the message I got through those angels was that God sent those angels to look over the survivors and to protect them. The symbolism was beautiful. (FGI 2, Participant 3)*

Another interesting expression of faith was the use of praise dancers. I first encountered praise dancing in Cape Town while still employed by CANSA and was interested to see that this expressive form of worship is also practiced in provinces such as the Free State:



In this image, captured at RFL Frankfort 2011, a small town in the Free State, a group of praise dancers, driven indoors by bad weather, performed in a big tent. Gospel music is used as background music. The women whirled in their long white robes in a manner reminiscent of dervishes, while the young men raised their arms to heaven as if to implore or praise God.

**Image 6.4: Praise dancers**

Some banners and posters send telegraphic messages to God: *'Dear God, strengthen us in our fight against cancer.'* (RFL Pietermaritzburg 2012), or the example found in a YouTube video urging participants to be faithful: *'I pray that God in whom you put all your trust, will fulfil every aspect of your faith-life through joy and peace'* (CRFLB 2013b). Other banners bear much longer messages, such as one with photographs and words that offers the assembly detailed advice:

*Communicate with one another! Come, let us pray for each other. Anybody can get cancer. Should you get sick - remember there is always Hope! Now is the time to dedicate ourselves to Jesus. Never will the illness get us down. With God we can overcome anything! Keep walking everybody – we are fighting cancer.* (Photographic image, RFL Kathu 2011)

Storytelling offers the most powerful vehicle for giving testimonies to the role faith plays in coping with cancer. A young HoH takes her audience through a series of devastating losses – being diagnosed with cancer at 26, the amputation of her leg, her father's cancer diagnosis, the recurrence of her cancer after six years, the termination of a pregnancy on medical advice, and difficulties in convincing her medical aid that they should continue paying for her treatment. Throughout this gruelling process she is sustained by faith. Even at her lowest point, after the medical abortion necessitated by the recurrence of her cancer, she finds solace in a message from God:

*The morning after losing the baby I told God I simply cannot get up, I'll never be able to get up again. My cousin phoned me and told me that she asked God to reveal to her what is happening here. She said she has never had such a clear vision as the one God gave her. She saw God sitting with my little baby on His lap. He said: 'It is not the end, it is the beginning.'* (Speaker 3)

Here the protagonist makes sense of these losses, not only for herself but also for her RFL audience, by recasting upsets as opportunities to grow in her faith. What some might see as a harrowing roller-coaster ride becomes a process of rising 'higher and higher' as part of God's bigger plan for her life. Four months later, the same HoH talks at another assembly, and this time she reports back on a miracle in her life. The scan she had shortly after the RFL Summit in August showed that the remaining five lung tumours had disappeared. The stressful watching and waiting game had taken its toll on all concerned, including her oncologist:

*The 29th of August when the scan was due my whole circle of friends was there to give support. It was a very emotional day. The results showed that the lesions were not smaller or fewer, they were gone! – and that was due to God. For me this was another miracle. My oncologist burst into tears and for the first time in six years showed some emotion. ... We serve a living God that still performs miracles and I've experienced it for a second time in my life. I want you to know that I don't receive more grace than others. We just need to be open to His mercy. (Speaker 3)*

Miracles are frequently cited by speakers and relate to both cancer miracles and to the successful staging of RFL assemblies under difficult circumstances. The first novice RFL to raise a million rands took place after an unusually short preparatory phase and with a thunderstorm threatening to derail the assembly. The Event Chair relates this story at the RFL Leadership Summit 2012:

*A big cloud came over our stadium and we all looked up and said 'Oh no!' and the cloud moved away. ... Folks, I have never in my life seen God work in my life as he did at that Relay. He turned it inside-out. We stood back as a committee because there was nothing more we could do. Nothing more we could plan. Nothing more we could fix. He took that Relay and just created the most awesome miracle. (Speaker 10)*

The elite group of HoH that I interviewed in the first FGI were all strongly identified as Christians. They communicated their faith both in the FGI and during assembly speeches. This is an influential group that receives invitations to speak at different assemblies. In their narratives, identifying with RFL and seeing RFL membership as a vehicle for promoting Christianity were indistinguishable from one another. This group in particular was frank about serving both purposes simultaneously:

*There is still hope for us, irrespective of the stage [of cancer] – there is still a God in control of all our lives and I'm passionate about it because I have an opportunity to tell them [the RFL constituency] about God. I always thought that I could not speak and stand behind a podium. I always looked at my husband and everyone can see what a loud-mouth he is. He [God] had to make me walk this road for me to see my purpose. For that reason I Relay. (FGI 1, Participant 6)*

I did not find the same degree of overt religiosity in the other FGIs. None of the other group participants, even if they were religious, mentioned this as a motive for being involved in

RFL. However, it was most unusual not to find references to God during mass assembly speeches.

Exceptions to overt religiosity were found in the speech of a student leader (Speaker 5) and speakers at RFL East London 2013, where there were hardly any references to religion. East London is a metropolitan area with a strong influence of liberal English culture, where overt expression of religion is downplayed. However, the absence of a religious tone in speeches from the podium did not preclude some teams from expressing their faith, as seen in this example:



This image, captured at RFL East London 2013, shows a team banner with a peace dove and burning cross associated with the Christian faith. This team gave free expression to their religious faith, even in the context of an assembly where there were few references to religion.

**Image 6.5: Banner with dove and burning cross**

At all the other assemblies included in this study, speakers seemed to feel compelled to reference religion as if there were an expectation on the part of the assembled crowd that they should do so. Not to acknowledge God would have been like swimming upstream.

I found that two groups, namely those who had suffered the most heart-breaking losses and survivors facing an uncertain future, were particularly inclined to use their faith in God to make sense of the cancer experience. I reflected in my journal about a mother who had lost two adult children to cancer and her use of religion to make sense of these deaths:

*My eye caught two candle-bags standing very close together. They were memorials to two young adults with the same surname – a young woman in a graduation gown and a young man on a beach. Two women standing with the candle-bags started telling the story. The one was the mother. Encouraged by her friend, she had driven five hours to attend RFL for the first time. She lost both her adult children to a hereditary cancer. The children were 31 and 33 respectively when they died. Her son died only 18-months ago. I*

*spoke to her about these colossal losses and she responded very calmly that she has found peace because she knew they were both 'beautiful children of God'. (Journal entry 2012/8)*

Assemblies that end on Sunday morning typically have short religious devotionals as part of their closing ceremonies. Faith leaders are invited to perform this duty and most are sensitive to just how exhausted the participants are at this point and keep the services short. There are exceptions, however. At RFL Mossel Bay 2012, a highly compliant but exhausted assembly sat sleeping through a sermon on the meaning of suffering. The Reverend joked that he had the power to keep the crowd there for as long as he pleased – and he did. Some assemblies have moved away from this practice and instead opt for simple rituals, such as releasing balloons or performing moving songs such as Leonard Cohen's *Hallelujah* (1984).

### ***After midnight***

Keeping the assembly energized between midnight and sunrise is the biggest test for organizers. This is when many participants start to flag. A lot of energy and interesting activities are required to keep them engaged both on and off the track – themed laps on the track, wheelchair races, fashion shows, Relay Idols, touch rugby, hopscotch, spinning on static bicycles, strongman competitions, dog trick demonstrations, dancers, bands and singers. Participants are quick to point out that exhaustion can sneak up on them and that they need to make a conscious effort to stay awake. A survivor talks about the solution she and her husband found to this challenge:

*We were determined to stay awake. The exhaustion can catch up with you. It hits you just like that! We walked and walked and walked. We would rest from time to time and then we'll carry on. We had counting beads around our necks and by the end of the night we had walked around the track 50 times and that equates to 20 kilometres. Us two old people! My son said: 'Mother! Do you realize you walked 20 kilometres?' You walk and you walk because something needs to keep you awake. (FGI 3, Participant 3)*

Keeping energy levels as high as possible is crucial to keeping people on the track and to keeping the crowd involved in entertainment next to, or in the centre of, the track. Young people are key drivers of this energy, which makes the challenge of staying awake easier for the whole assembly. The biggest test is always after midnight, and some organizing committees have a better understanding of the need to keep up the momentum than others. The best example I observed was at RFL Worcester 2012,

where zany activities were packed into the programme between midnight and sunrise. Cross-dressing fashion parades, hat competitions, tug-of-war competitions, humour and loud music set the pace for team members still resolutely walking the track as they waited for the sun to come up. There is no limit to what participants can dream up for the entertainment of others:



This image, captured at RFL Worcester 2012, shows a competition where recycled materials are used to create fashion pieces. Pictured here is the master of ceremonies in a clown outfit, and a man in an elaborate bridal gown made of plastic bubble-wrap, chicken wire, tinsel, an ostrich feather, a flower, ribbons, and orange-bag plastic netting – and holding a bouquet also created from recycled materials.

**Image 6.6: A 'bride' after midnight**

In this high-energy environment, away from their everyday responsibilities, people can let their hair down. The outside world feels remote, social hierarchies flatten or are turned on their heads. There is a feeling of freedom in the way people express themselves. It is totally acceptable for a respectable banker and family man to get into the spirit of the assembly by wearing a theatrical sequinned silver top hat, a purple feather boa and to brandish the microphone with the confidence of Freddie Mercury.

Still mostly living in racially divided communities, the participants delight in the opportunity to break out of the social constraints they contend with outside RFL assemblies and simply approach one another with warm abandon. A white, middle-class woman with a history of cancer describes the affection shown to her by three young girls while she was walking the track:

*I was walking by myself on the track and three little black girls, I'd say about 9 or 10 years old, came running to me, hugged me and said 'aunty you must have a lovely evening because we are all here to support you'. Just out of the blue. They just came all around me, they hugged me, they squeezed me and they were the most precious little*

*girls. If they were not at Relay I wonder if they would have thought about a gesture like that.* (FGI 4, Participant 4)

A sense of togetherness becomes possible when social taboos dissolve. The fond memories of these treasured encounters are carried back to life outside the assembly.

Locating an assembly in a conservative community makes no difference to the exuberant displays. There is a tacit understanding that participants are allowed to break the rules of everyday decorum as everything is done for a good cause:



This image of a group of men entertaining the crowd was captured at RFL Worcester 2012, where the spotlight was on breast cancer awareness. It was after midnight and the bemused audience watched as the man wielding the microphone, wearing a head scarf, pink tie, elaborate belly-dancing bra and black jeans, got the crowd motivated to join in the good-humoured fun.

**Image 6.7: Rousing the crowd**

The MRG told me that they could see how collective effervescence and the associated softening of social boundaries played a role in the genesis of collective identities at assemblies: *'I think Relay just levels the playing field. Everybody is equal and for that reason you don't have inhibitions.'* (MRG, Participant 1). Another member of the group elaborates on this theme:

*Talking about getting out of comfort zones – I'll never forget the Relay in a small neighbouring town where the first person to get on stage wearing a dress was the NG predikant<sup>7</sup>. Nobody said 'we are going to tell on him.' People understood that it was part of that evening's fun and in the spirit of Relay.* (MRG, Participant 4)

<sup>7</sup> 'NG predikant' is Afrikaans for a faith-leader in the Nederduitse Gereformeerde Kerk, a church in South Africa known for upholding traditional Protestant values.

The popularity of dressing up, especially cross-dressing, is something RFL shares with other carnivals. Men who might think twice about this type of madcap behaviour outside RFL feel that the special circumstances of the assembly give them permission to be outrageous:



Another image captured at RFL Worcester 2012 shows a man teetering on purple high heels while he moved across the field in a mincing, hip-swaying manner in a fashion parade held at about two o'clock in the morning. He wore a pleated satin skirt, big bra, pink wig and bulging net that gave him the stylized appearance of being pregnant. A large audience had gathered to watch the performance.

**Image 6.8: Strutting in high heels**

Children, teenagers and young adults form a significant percentage of the people at assemblies and after midnight they contribute hugely to the energy needed to carry the event through to sunrise. A guaranteed way of keeping the assembly energized is to get young people to take charge of entertainment and group activities. RFL East London 2013 was a good illustration of this, as young people created a storm of energy after midnight by singing and performing in the area in front of the stage. They were joined by line-dancing nurses, who thrilled the crowd with their well-rehearsed routines, and an assortment of singers. At 3 o'clock in the morning, the crowd went wild when a local club disk-jockey took control of entertainment. A big circle was formed, with the front row standing on the ground and the rest of the young people standing on chairs. Small groups or single participants would take turns to perform in the centre of the circle, while the rest of the group mimicked the action with hand signs, roaring their approval and singing along.

Celebrants need a justification for having to keep the assembly going all night long. The story goes that staying awake is symbolic of the many long nights when survivors cannot sleep because they are uncomfortable, in pain or experiencing emotional anguish. Overnight assemblies are seen as symbolic of the long nights when cancer survivors toss and turn,

unable to sleep, while those who love them sleep. By staying awake for a night at the assembly we show our solidarity with a symbolic act. Frank (1991: 29–35) writes hauntingly about pain, being awake at night with cancer symptoms while loved ones sleep and how this separates the person living with cancer from others. The narrator on the RFL East London 2009 YouTube video explains: *'Relay For Life is an overnight event because cancer does not sleep'* (MediaTag 2009). Banners reinforce the message: *'Walk Till You Drop Because Cancer Never Sleeps'* (Jacobs 2012). The association with night and death is also made by a HoH:

*... at two, three in the morning survivors often wonder if they will get through another day. It is a scary thought. So cancer equals death. So you don't want to associate yourself with death, you want to associate yourself with life.* (FGI 1, Participant 6)

In the process, cancer is also portrayed as an embodiment of evil that sneaks around at night, much like the mythological tokoloshe<sup>8</sup>. A FGI member warns darkly that: *'Cancer has no colour, no age and no race. It grabs anybody.'* (FGI 2, Participant 3). These types of warnings point to a more sinister reason why it is important for RFL people to take part in this symbolic night vigil. Cancer as the antagonist is up all night and, by implication, is getting up to its evil deeds. The repetitive refrain of *'cancer does not sleep'* is used to heighten awareness of its destructive potential and its power to work around the clock.

Participants wait for daybreak with great anticipation and sometimes wish the night away by imagining that it is getting light. At RFL Mossel Bay 2012, some expressed great relief about an imagined sunrise that turned out to be nothing more than the light of the massive petrochemical plant close to the RFL site.

### ***Same time next year***

The energy of the assembly begins to wane during the early hours of the morning, except in those communities where organizing committees have arranged high-energy activities to keep the crowd captivated and entertained. With the exception of survivors who are too sick to last the entire assembly, all the participants are expected to stay until the assembly has officially been declared closed for the year.

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<sup>8</sup> The tokoloshe is a shape-shifting mythological creature that has its origins in Zulu culture in South Africa. According to legend, the tokoloshe mainly causes mischief at night.

Assemblies are brought to a close in a scripted way. *'Same time next year'* are the words that reverberate around the field as the sun starts coming up. Exhausted teams start quietly striking their campsites and gather together for the closing ceremony. This includes handing out team awards, taking the opportunity to say thank you, and marking a ceremonial end to the gathering. The closing ceremony is also used to remind participants that the assembly will reconvene in a year's time and that it is not too early to start planning. During the closing ceremony at RFL Mossel Bay 2012, the drowsy assembly is told: *'Next year's dates are the 7<sup>th</sup> and 8<sup>th</sup> of November. Please make a note of the date. You have 365 days left to your next Relay.'* The assembly is not even finished, and participants are already planning for the following year and the many improvements they will be making to campsites, attire, team recruitment and fundraising.

The organizers take great care to leave venues clean when they depart, and when the final vehicle drives away nothing is left other than refuse and big equipment to be collected on Monday morning. Once that has happened, no traces remain of the group of people who gathered in solidarity to tell a story to one another about their shared fate. It is astonishing to see how quickly the RFL village disappears after the excitement of the assembly. Teams and organizing committees tackle the striking process like a military operation, as by now the celebrants are exhausted and anxious to get home to sleep. Seven hours after the RFL Mossel Bay 2012 ended, I went back to the site as I was curious to see what was left:

*On Sunday afternoon at 15:00 I walked back to the site to find it completely cleared of litter, with the rubbish skip piled high and absolutely no sign of any of the team tents on the field. All that remained was the radio station caravan, portable toilets and a Coca Cola trailer. These would be moved on Monday by their owners. Even the large stretch tent and the enormous survivors' marquees had gone. Another assembly done for another year! (Journal entry 2012/8)*

RFL assemblies come around like clockwork every year, and communities do detailed planning to ensure their success from one gathering to the next. Lawler (2003: 143–144) argues that there is a perception on the part of participants that they carry a shared responsibility for the success of the 'recurrent interaction episode' and that this leads them to feel that their emotional experience is shared and mutually generated. These collective feelings create a sense of being involved in something larger, more lasting and inspirational than could possibly flow from any individual effort.

## ***Summary***

In response to the sub-question posed at the start of this chapter, I presented findings which showed how a range of dimensions act as building blocks in the generation of collective identities once assemblies are in full flow. Having considered how the early stages of assemblies – walking the track, commemoration, storytelling, the use of religion and keeping momentum going throughout the night – all feed into the activation of collective identities, I now turn to the final chapter on the findings, in which I interrogate the multi-faceted and fluid nature of the collective identities generated at RFL assemblies.

## Chapter 7

# Findings: Embracement, inversion, and disruption

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### ***Chapter introduction***

In this final section of the research findings, I highlight the multi-faceted, liquid nature of collective identities at RFL assemblies. I show that participants are not all equally enthusiastic about the dominant heroic warrior collective identity and consequently respond to it in a variety of ways. I used the following sub-question to guide me in the presentation of findings: How are collective identities embraced, hybridized and disrupted during RFL assemblies, and how does this relate to broader debates about cancer and identity? I show that, whereas the idea that cancer has to be fought falls on fertile ground, there are nevertheless subtleties that suggest that embracement of the heroic warrior collective identity is not universal, that some participants either mould this identity to their own needs or that they distance themselves from it. In this chapter I therefore present data which gives evidence of: (1) the embracement of the dominant collective identity, (2) the liquid nature of this dominant identity and how it is hybridized in some instances and, finally, (3) how disruption and distancing can interfere with the generation of a dominant collective identity. Once I have shown how participants work with the heroic warrior collective identity, I move on to consider the bigger picture of the RFL movement and its relationship with the broader debate on cancer and identity.

### ***Embracement***

In this part of the analysis of data, I relied on the notion of ‘embracement’ drawn from the work of Snow and Anderson (1987: 1354), who hold that members of a group embrace a particular identity through the use of talk and performance. In keeping with this idea of embracement, I looked at the ways in which RFL participants talk about and give expression to their acceptance of, and attachment to, the collective representation of themselves as heroic warriors on a quest to create a cancer-free world. The heroic warrior identity is overarching in the RFL movement and neatly incorporates the entire cast of role identities at the assemblies. Irrespective of whether a participant is a HoH, a cancer survivor, caregiver, team captain, team member or organizer, everybody has a place in the cancer fighting army. Together with seeing themselves as warriors, RFL participants also make frequent references to being part of a family, a tribe or a collection of like-minded people.

An assembly is both a real and an imagined gathering place for people who are of one mind. Some assemblies are full of old-world charm and illusion. I was captivated by RFL Worcester 2012, held in a wine-growing town in the interior of my province (the Western Cape) which is home to about a hundred thousand people. The survivors' function felt like a small-town event during the Seventies – except that there was no apartheid. The elite of Worcester society mingled with illiterate farm workers, an urbane Muslim gentleman charmed the group with his respectable mother-in-law jokes, and Jim Reeves<sup>9</sup> songs played in the background. Much of the entertainment was provided by people with disabilities – a reflection both of the inclusivity of the function and the fact that the town is home to special schools for children with intellectual, hearing and sight disabilities. This assembly demonstrated beautifully how in this enacted utopia (Foucault 1986: 24) it is possible for Christian and Muslim believers to work together in a harmonious way, how wealthy people can reach out to poor people, and participants can forget about the racial divisions outside the RFL assembly. In Worcester, countless efforts were made to draw people into the collective activity that goes into the staging of a successful annual assembly. A team captain relates how, in his large extended Muslim family, they rope in family from far and wide to make up their award-winning team. He laughs when he says that *'When cousins drop out due to pressures like exams, we simply replace them with other cousins'* (FGI 2, Participant 2).

During the assembly, there is a sense of 'them and us' and recognition that involvement in RFL requires effort on the part of the collectivity. People outside RFL are described as outsiders who lack authenticity: *'Relay people are different. These people are genuine. We are a family.'* (FGI 2, Participant 5). In contrast to outsiders who are unwilling to put their weight behind the cancer cause, RFL participants are represented as committed, hard-working people: *'Relayers are activators. They are doers and they work hard. That is the difference between Relay people and other people.'* (FGI 3, Participant 1). An elderly organizer who is clearly not that enthusiastic about walking the track, sums up his affinity with other participants and some of the demands that come with membership of the group:

*When it comes to Relay I want to be with people who are like me. Survivors are people that I've come to love. This is a place where we all feel emotional about something or*

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<sup>9</sup> The music of American country-pop singer Jim Reeves found tremendous favour in South Africa between the 1950s and the late 1980s. South African fans were rewarded for their support by the singer, who recorded some of his songs in Afrikaans. His music is rarely heard nowadays.

*somebody. I go to a lot of trouble and I come here, even if I have to walk.* (FGI 2, Participant 4)

The data give many examples of RFL participants who are willing publicly to embrace the RFL movement, what it stands for, and how it chooses to represent its constituents. This is not only about feeling a sense of attachment to RFL; it is also about a willingness to prove one's commitment to the movement through action. In his discussion of the activation of collective identities, Lawler (2003: 143) refers to 'commitment behaviour' as the step beyond simply feeling a deep sense of belonging. At RFL, commitment talk and action are seen in calls to action, pledges and expressions of loyalty and solidarity. A newly inducted HoH graciously accepts his sash and his newly bestowed status at a special ceremony by telling the assembly: *'I'm proud to be a Relayer. It changed my life. Thank you for honouring me. I accept it in humility.'* (Speaker 4). In similar vein, an organizer describes her feeling for RFL as a burning passion:

*If I didn't have Relay, I would have to find another passion because I always need something that burns my soul. This is my passion all year long. I'm always working on Relay. I can't imagine that anything else could be big enough to take the place of Relay.* (FGI 4, Participant 1)

RFL participants like to demonstrate their belief that the RFL community is like a family or a tribe. An organizer responsible for coordinating survivor activities remarks: *'I've built up such a relationship with fellow survivors so that today was like seeing family that I haven't seen for a while.'* (FGI 3, Participant 3). Frequent references to RFL being a family also find expression in team paraphernalia:



**Image 7.1: We are family**

This image, captured at RFL East London 2013, expresses a common sentiment held by RFL participants throughout South Africa. 'Family' refers not only to being related to a family member with cancer, but also to belonging to other people who share their concern with the cancer cause.

The sense of being part of the collective effort is not seen as fleeting or inconsequential; instead it is believed to be a serious commitment which carries responsibilities:

*It is about being a member of a team. It is not something you can do alone. We need each other and we hand responsibilities from one person to the next. It is never-ending. We are doing this for life. There is a life vision in this.* (FGI 3, Participant 1).

The passing down of the RFL tradition is also valued in families: *‘One of the things I really enjoy is that the Relay experience gets passed down. I have two daughters and three grandchildren out there tonight. To me that is important as I want them to have awareness.’* (FGI 4, Participant 2).

Involvement with RFL is not haphazard, but has a specific purpose: *‘Every single person in this place is here for a reason. They are here for somebody or other. Somebody with cancer touched them. Somebody in their life is affected by cancer.’* (FGI 4, Participant 1). These passionate expressions of solidarity attest to the sense of being part of a larger whole that people experience during assemblies.

The RFL assembly as a place of compensation is best demonstrated in the way it creates an idealized world where people unite in a collective concern about cancer. This shared focus on cancer acts as a powerful bond while the assembly is in progress. In the bubble created by the assembly, the illness is seen as offering a *‘special journey and a privilege’* (Speaker 30). Suffering becomes universalized and the shame associated with being ill is redefined. A faith leader during the closing ceremony at RFL Mossel Bay reminds the crowd that:

*This shame I’m experiencing pales into insignificance compared to others and you realize it is a universal experience. It is part of life. Just by coming together we create a special bond. Look at Relay For Life. This is a group that thinks about enduring suffering ... we are close because of the pain and heartache.*

The assembly compensates for all the other spaces in the outside world, where affected people feel misunderstood, emotionally unsafe and isolated. An organizer tells the gathering that *‘nowhere, but nowhere, will you find this spirit and beautiful solidarity’* and that at RFL *‘we stand together, take each other’s hands, and help one another through these dark hours.’* (Speaker 20). A HoH at the RFL Leadership Assembly 2012 has a message to demonstrate her embracement of fellow participants: *‘I love you no matter how you look and what colour*

*you are. I've gone through a difficult time. You've gone through a difficult time. We've got something connecting us and nobody can take that away.'* (Speaker 6).

Emotions can be especially heightened following a cancer diagnosis, after the disappointment of recurrences, or as a participant approaches death. An organizer talks about her emotional experience at the assembly:

*This Relay has been a very personal one for me because of my ex-husband [newly diagnosed] and our children. When my daughter saw her dad she just cried. That is what has moved me this time. It is so in the house!* (FGI 4, Participant 1)

The power of the assembly and the support received from others rate highly in the lives of those survivors going through upsetting recurrences of life-threatening cancer. A young HoH tells the RFL Leadership Summit 2012 about a recurrence of her cancer, a holiday abroad that cut her off from her support system, and how she instantly rallied as soon as she was able to reconnect with others who understood her plight:

*The moment I landed in South Africa, I could SMS and ask friends to pray for me, say I'm battling to walk, that I'm having a difficult time, that I'm feeling down-hearted. I know at that moment people interceded and ensured that I could get up on Friday, after having been in a wheelchair on Thursday. I walked in here [RFL Leadership Summit] and my mood lifted. I realized that everybody that walks here, walks with me – I'm not fighting alone. I want to thank you that I can be a part of this incredible family – a family that is really, really like angels on earth.* (Speaker 3)

Many RFL participants are drawn from communities that still carry the trademark divisions between groups that were created and deeply ingrained during apartheid. The softening of etiquette boundaries and the ability of RFL to compensate for divisions in the outside world are important factors in the generation of collective identities. Participants marvel at the ability of RFL to draw people together – even if it is just once a year during the RFL assembly. A nurse and team captain from a previously disenfranchised group places a premium on the ability of RFL to build bridges: *'Seeing the people coming together and the diversity – that's what it's all about. I like that! We come from different backgrounds, but at the end of the day we have something in common.'* (FGI 4, Participant 5). This recurrent sentiment is expressed at every assembly, irrespective of whether it is a gathering in East London: *'What really impressed me was the camaraderie of the people of different cultures.*

*It was just awesome seeing people milling around right through the night enjoying each other's company with one goal of highlighting cancer' (MediaTag 2009), or in Worcester, for example: 'Relay has become a big family. You meet so many people: people with different cultures; people out of different faiths and different backgrounds; people out of different neighbourhoods ...' (FGI Participant 3). A school principal has this to say about the power of RFL to unite people from diverse communities:*

*Relay is the only place in town where the whole community is involved. There are no boundaries. If you look at churches there are boundaries. Cancer makes the playing field level and here we all fight together. That is part of the magic of Relay. I have colleagues in education and we sometimes battle to work together, but when we get here it is a different vibe. I have seen it develop over the years and I have seen the demographics change, which is great for me. I hate these dividing walls and maybe cancer is the magic thing that does it for us. (FGI 3, Participant 1)*

Nevertheless, this ability of RFL to unite people does not necessarily spill over into life outside the assembly. A team captain during a FGI remarks on how solidarity is limited to the assembly itself: *'Relay For Life brings a lot of magic into the lives of Relayers, but not yet to our communities'* (FGI 2, Participant 8).

Efforts to reach out can take the form of simple inclusive gestures. At an assembly in Kwa-Zulu Natal (RFL Amanzimtoti 2012), a breast health display was designed so that everyone felt included, irrespective of their skin colour:



**Image 7.2: Breast cupcakes**

This image, taken at RFL Amanzimtoti 2012, shows a table with dark-skinned and fair-skinned breast cupcakes. The breasts are bare, with obvious nipples and areolas. This is a humorous way to share information about breast health and to reach out to all participants. The cupcakes stand in contrast to the information brochures with the image of a pretty blonde woman on the cover. Supplied by a pharmaceutical company, the brochure is insensitive to an African context in which women from diverse communities are affected by breast cancer.

The willingness to accept all affected people into the RFL group goes beyond race and religion. Even homeless people are welcome at assemblies, provided they have a link with cancer. A volunteer organizer tells the annual RFL Leadership Summit about the three people who are her motivation for remaining involved with RFL. She lists her grandson, whom she wants to grow up in a cancer-free world, a small boy of five or six from her community who died of cancer, and a homeless man with cancer who found his way into her heart:

*I Relay because of a survivor who is basically a tramp without a house to stay in. He read about Relay in our newspaper and he arrived wearing a brace and he was on crutches. Hans decided he was going to walk 100 laps that night. ... He walked on crutches around that track the whole night. At about 3 o'clock in the morning I was one of the privileged Relayers to walk his 100th lap with him. I think he ended up walking about 110, 120 laps. ... He later came to the CANSA offices to say thank you for the hope that was given to him through Relay. (Speaker 9)*

Making identity claims is one of the strategies used in the generation of collective identities (Polletta & Jasper 2001: 292). 'Why I Relay', 'What we do as Relayers' and the 'RFL way' are all examples of collective identity claims. A student leader explains why he, as a busy university student, is involved with the staging of RFL at his university:

*The reason why I Relay is that I Relay for a future. Not just for a future where we keep on battling, but a future where we don't only celebrate the battle – a future where we have won the war against cancer – a future where the words 'you have cancer' are not so devastating. (Speaker 5)*

Another example is found in remarks about the willingness of others, including complete strangers, to work together in the name of the cancer cause. A HoH makes the following claims about the nature of RFL at the annual Leadership Summit 2012:

*Relay showed me that even strangers will walk for me. I got to know so many people through Relay. The commitment carries from one year to the next. Relay showed me that people will invest their time and effort, their own well-being, to help the bigger effort. I learned that I'm not the only one facing this challenge. (Speaker 6)*

Looking closer and taking apart the short cameo above, it soon becomes evident that there are multiple levels of meaning which might not have been immediately evident to the assembly

speaker or her audience. Let me demonstrate some of the hidden work that is being done in this segment:

*Relay showed me that even strangers will walk for me.* [She is conveying to her audience that it is not the norm for strangers to care for people they do not know. She wants her audience to recognize that this solidarity community is somehow different, and that in it people care about one another.] *I got to know so many people through Relay.* [RFL drew many others into her orbit, so that she is now part of a group and no longer isolated.] *The commitment carries from one year to the next.* [This commitment to care is not superficial or fleeting. It is authentic.] *Relay showed me that people will invest their time and effort, their own well-being, to help the bigger effort.* [In this solidarity community, the altruism of the collective is profound and marked by a shared effort. Members of the group are willing to make great sacrifices for the greater good.] *I learned that I'm not the only one facing this challenge.* [This is not about 'me'; this is about 'us'. The challenge she faces is the same challenge faced by others in the group. The entire group is bound together by shared hardship.] (Speaker 6)

This short segment reinforces collective responsibility and the sense of unity in the group. Underlying the story is a covert reminder to the group that they belong to a 'community of pain' (Frank 1995: 37), where like-minded members take care of one another. The members of this collectivity are portrayed as different from others by virtue of their enhanced ability to care for each other. There is also a strong claim for the authenticity of the altruism that characterizes the group. These identity claims about the RFL constituency are idealized and give the group a romanticized version of itself. The speaker is working with a utopian image and holds it up to her audience as a recipe or an ideal. In her role as spokesperson, this HoH transmits the idealized vision of the constituency held by the movement. She effectively becomes an instrument for the movement and transmits public claims about the identity of the group on behalf of the movement.

There are a number of ways in which these identity claims made during mass assemblies facilitate the amplification of collective identity. Frank (2010: 49) highlights how stories are used to 'teach people who they are'. The speaker in the selected cameo offers the assembly an identity blueprint and asks them in effect to 'acknowledge and act on a particular identity' (Ibid.). Polletta and Jasper (2001: 283) suggest a further function for identity claims, arguing that they give followers a rationale for committing to collective action. In turn, such action is a mechanism in the activation of collective identity. Snow (2001: 9) believes that collective

claims help to create an alignment between individual identities, role identities and ‘situationally specific collective identity’. The collective identities generated at RFL assemblies are context-specific, since the gatherings take place only once a year and are focused on the cancer experience. In the segment under review, the speaker helps her audience to cross what Lawler describes as the ‘me-to-we’ bridge (2003: 141). In other words, the participants make the transition from an intensely personal to a collective experience of illness.

Another way in which collectives amplify collective identity is through the advancement of group pride (Polletta & Jasper 2001: 296). A school principal during a FGI shares his pride in the power of RFL to unite people:

*Relay has activated my community to make a difference in other people's lives. I love seeing that. I love seeing how hard the teachers and the children work. Tonight again, we always do the curry and rice. We always sell out first and we are just so 'chuffed' about that and the motivation around that. You know it is for a good cause and it touches you every year. (FGI 3, Participant 1)*

In terms of group pride, cancer survivors are the most revered and are afforded the most attention at RFL assemblies. The special survivors’ function that takes place in a designated reception area is designed to generate group pride and a sense of privilege:



**Image 7.3: Smiling survivors**

This image, captured at RFL Polokwane 2011, shows participants at the survivors’ function. There is status attached to being a survivor and clear markers identify these participants as the VIPs of the occasion, with their purple survivor shirts and special medals. The reserved reception area and the identity markers are used to denote an elite status and to facilitate group pride.

Making pledges is commonplace and is done in a heartfelt manner during assemblies. They are not unlike the pledges people make when they get married. A caregiver at the RFL Leadership Summit 2012 makes this stirring pledge from the podium:

*Today I want to make this pledge and this promise in the presence of everybody: Relay For Life is not just for the 'life' part of living, but I promise ... for as long as I shall live, together with my wife, to serve in whatever capacity, to take this fight to another level so that when hope is enlarged in the lives of people, our fight will be victorious. (Speaker 1)*

The RFL movement has a sophisticated understanding of how to create opportunities to ritualize the embracement of the cancer cause. It dedicates one of its ceremonies called the 'Fight Back Ceremony' to this. This is typically performed late at night or during the early hours of the morning when it is important to inject fresh interest into assembly activities. A YouTube narrator explains the significance of this ceremony at RFL Corporate Johannesburg 2012:

*The Fight Back Ceremony inspires Relay For Life participants to take tangible action against a disease that has taken too much. This emotionally powerful ceremony inspires Relay participants to take action. The Fight Back Ceremony symbolizes the emotional commitment each one of us can make in the fight against cancer. The action taken represents what we are willing to do for ourselves, our loved ones and our communities to fight cancer year round and to commit to saving lives (JLT Productions 2012).*

The Fight Back Ceremony is a relatively new arrival on the RFL scene and was written into RFL assembly scripts only in the past decade. During this ceremony, people publicly pledge to change their lifestyles during the coming year by doing things such as giving up smoking or going for regular cancer screening tests. These pledges can also include the promise to put extra effort into mobilizing resources for cancer services through voluntary efforts and fundraising.

The sense of being one big loving family extends across national boundaries, and the association with the ACS as the parent body is especially highly valued. South Africa was the first African country to join the global RFL movement, and local assemblies attract ongoing interest from foreign partners. Membership of the global family is often emphasized and participants are frequently reminded that group membership extends beyond a particular assembly. An ACS volunteer summarizes the value of this international collaboration on a YouTube video featuring RFL Soweto 2010:

*The more voices we have in the fight, no matter what language they speak – and the more feet we have on the track at Relay, no matter whether it is in my hometown of*

*Boston or here in Soweto – if we are all walking in the same direction, the faster we'll get to a cure against cancer.* (Relayben 2011)

RFL Soweto 2010 welcomed a delegation of volunteers and staff from the ACS, as well as crew members from Delta Airlines who regularly work on the Atlanta-Johannesburg route and wanted to participate in the first assembly in Soweto:



This image, captured at RFL Soweto 2010, shows the team from Delta Airlines. The assembly in Soweto was a landmark for RFL in South Africa as it was the first assembly in this iconic township. The opportunity to participate in a gathering in the larger Johannesburg area was especially appealing to the Delta Airlines team, as Soweto was prized as being emblematic of a true African RFL.

**Image 7.4: Delta Airlines team**

Reminders about belonging to a global cancer-fighting army cement the sense of power and confidence in RFL experienced by local participants. It creates the sense that South African RFL participants are not in this fight on their own, but that they belong to a powerful force that counts millions of soldiers as part of its collective effort.

Heightened empathy with others is a trademark of collective identity generation at RFL assemblies. Affluent survivors voice their concern about the sub-standard care received by many survivors who depend on State health services. They relate how RFL pushes them into doing increasingly more in their communities to improve cancer control. A young, glamorous HoH out of the emerging black middle-class talks about her wish to deepen her commitment to the cause:

*I Relay to save lives – especially us, the black people in the black community. Now my job is to start a programme for prison. I'd also like to go to schools and educate people that don't know anything about cancer. Those people that think cancer has something to do with bewitchment. I want to change that state of mind. People should know it is there. It doesn't discriminate – young, old, white, black. I'm dreaming big, hoping big and I'm Relaying big.* (Speaker 11)

These encounters between the well-heeled and those living in poverty make for contacts rarely experienced outside the assembly. A survivor speaks passionately about these inequalities:

*In this community it is as if survivors don't know where to turn to for support. What really upsets me is the plight of our State patients. For them it is rough and tough. They simply do not get the moral support they need. I've spent a lot of time at this Relay talking to newly diagnosed people. Where else on earth are newly diagnosed people simply accosted in hospital corridors and told in an off-hand manner that they have cancer and that they need to come for surgery? State patients don't complain, but they need support. Do you now understand why I'm so involved? I was no sooner finished with the one State patient tonight when I was called to talk to another woman sitting in the survivor marquee. She heard this week that she has cervical cancer, Stage 2. I sat down on the ground and talked to her and her alone. These State patients have nobody to tell them that they are going to be okay. Initially people can be quite guarded, but the minute they hear that I'm a survivor, I have instant rapport with them. That is why I will carry on walking this road. (FGI 3, Participant 3)*

There is recognition that access to care is not equal and that for many RFL participants care is far removed from the respectful, expert attention that money can buy.

The overwhelming majority of RFL participants embrace the way in which the RFL movement represents them as heroic warriors and verbalize a strong sense of belonging to the group. What then of those who do not wholeheartedly fall in line with this representation of themselves as heroes and instead tinker with the dominant collective identity?

### ***Tinkering with the dominant identity***

The heroic warrior collective identity is not an entirely stable identity and displays some fluidity. However, I contend that the variations I found in the findings are not prominent enough to significantly disrupt the dominant identity. Although there is not always a perfectly aligned and shared vision of what the RFL collectivity is trying to accomplish, the constituency as a whole still has a sense of meaningful belonging. Understandably, meaning-making in the RFL context cannot be uniform, and there are bound to be contradictions and inconsistencies that flow from people who have loyalties to other causes, feel the need to proselytize, or simply do not understand the RFL culture sufficiently to fall in line with collective identity work. Participants vary enormously in their relationships with RFL.

At one end of the spectrum are those who have attended numerous assemblies, know what to expect, and are able to align their identity work with the ideals and the culture of RFL. At the other end of the spectrum are those who are new to the RFL experience, and have little understanding of the RFL culture or what the initiative strives to accomplish. However, it is not only novice teams who tinker with the dominant collective identity.

Split loyalties sometimes play themselves out during assemblies and some participants have no hesitation in piggybacking their own agendas onto the collective effort at an RFL gathering. Polletta and Jasper (2001: 289–290) talk about the perennial challenge of coping with the free-rider syndrome in the way collective identity is managed within social movements. Examples abound in the RFL movement in South Africa. They include estate agents blatantly building their business profiles at assemblies and the official political opposition using assemblies as an opportunity to brand both campsites and teams.

Even at the very heart of RFL there are instances of a muddling of collective identity due to spokespeople hybridizing the cancer cause with other heartfelt agendas. The best case in point is the group of HoH that I interviewed during the first FGI. This elite group made no bones about the fact that they use the RFL platform as an opportunity to evangelize, and demonstrated this powerfully in their storytelling. In the words of one of the group: *'I'm passionate about Relay because I have an opportunity to tell them about God. He [God] had to make me walk this road for me to see my purpose. For that reason I Relay.'* (FGI 1, Participant 6).

One way of tinkering with the heroic warrior collective identity is to fuse two good causes to create a new hybridized collective identity. Although much of the identity work at RFL gatherings references the illness experience, it is by no means the only preoccupation of participants. The utopian illusion of unity and goodwill created by RFL offers an emotional space for the blending of causes and different group agendas. An example of how teams simply cannot resist the opportunity of embracing two good causes at once is illustrated in this image taken at RFL East London 2013. It shows a team that references two causes in their group attire:



**Image 7.5: Hybridization of two causes**

This image shows the hybridization of the cancer and environmental causes. Cancer is referenced in the participants' headaddresses that bear the CANSA logo and stars associated with the RFL movement, the inverted cancer ribbon, and the use of the word 'cancer' on the T-shirts. Simultaneously, they explore the conservation theme, with the use of the symbolic green and the tree associated with conservation, as well as word-play on the word 'conservationists' with their creation of the neologism 'CancerVationists'.

Understandably, other groups which grapple with marginalization find a ready home in the warmth and acceptance of RFL assemblies. It is no longer unheard of for gatherings in bigger, more liberal communities to have warriors of another kind parading their group concerns and identities on the track. This image shows one of the LGBT teams that participated at RFL East London 2013:



**Image 7.6: Same symbolism, different cause**

There are strong parallels between identity work done by those primarily concerned with the cancer experience and that done by the LGBT movement. Like RFL, this movement also uses the heroic warrior collective identity as a corrective to marginalization, as well as symbols to generate collective identity. This team is called 'Rainbow Warriors' and team members use the rainbow colours associated with the LGBT movement to signal their group identity.

The research material also provided examples of teams that make no attempt to reference the illness experience. It is tempting simply to conclude that these are teams that have distanced

themselves from the heroic warrior collective identity, but this is not necessarily the case. Careful analysis of the data show that they are, in fact, grappling with another theme that regularly plays itself out at RFL assemblies in South Africa, namely that of racial harmony among participants:



**Image 7.7: Racial integration explored**

This image shows a racially integrated team of young people at RFL East London 2013. There is no evidence of the illness being referenced. The team is called ‘Black & White Fever’; the colours chosen (black, white and orange) are not associated with RFL, and neither are the cat and dog images. However, this team is still doing identity work by focusing on the theme of racial integration at RFL assemblies.

The overarching heroic warrior collective identity acts as a ‘one-size-fits-all’ that is meant to embrace all RFL participants. Its generation is supported by a RFL village, designed and created around the focal point of a track which offers a space that is contained and safe. However, the assembly can give mixed messages, hinting that the illness experience can be an emotional rollercoaster ride. Mixed messages serve to scramble emotions and, at times, can result in the assembly being emotionally unsettling. The luminaria ceremony is confusing for some, as it suspends participants between two worlds – the world of fallen heroes and that of brave warriors who are battling to stay alive. Candle-bags are made for both types of warriors, although most are dedicated to the dead. This brief glance at death and dying is juxtaposed with many hours during which survivorship is romanticized with messages which speak of the need to fight cancer and to be optimistic and hopeful.

The data further shows that the heroic warrior collective identity is liquid and can find expression in different ways. Whereas the majority of participants embrace the notion that they are brave warriors in a big cancer-fighting army, the dominant collective identity does not altogether stop people from expressing their vulnerability. In rare instances, storytellers reference both vulnerability and victories in a single speech or dialogue. A caregiver at the RFL Leadership Summit 2012 creates a binary by describing his ill wife as the most

courageous woman he knows, while also highlighting the fact that she is terribly emotional and that he has to contend with frequent bouts of crying when they are alone and out of the public eye (Speaker 2).

The assemblies cause discomfort for those who want to distance themselves from the idea that cancer is an enemy, who feel unworthy of the warrior status, who do not want to associate themselves with the scripted nature of assemblies, who are very ill, or who are facing death. A group of survivors who were part of the HoH programme was especially outspoken about some of these dilemmas. One of the group shares his extreme discomfort with the symbolic meaning of a hero identity that is unable to distinguish between degrees of suffering:

*I must tell you as a person from the rational communication world, I have to work very hard to come to terms with being called a hero. It is something I can associate with others in this group, but not with myself. I'm trying to work this out for myself. I was diagnosed, treated quickly and I've never been ill with cancer. For others, the hero identity might fit. For me it is an uncomfortable fit. (FGI 1, Participant 3)*

This participant was at pains to emphasize that he was not traumatized by his experience of cancer and therefore had difficulty in accepting the mantle of a hero. Bell and Ristovski-Slijepcevic (2013: 410) identify a similar dilemma for people who are labelled as 'survivors' but who wish to set themselves apart from survivors of genocide, war, rape, and other extremely traumatic events. In the context of RFL focused gatherings, the authentic sentiments of people such as the HoH cited above need to be subjugated for the sake of the assembly and the larger RFL movement. It is in these moments that the pieces of the collective experience no longer fit together snugly. The space has become unsettling because there is a lack of congruence between the inner emotional world of some participants and what is demanded by the assembly in terms of the dominant representation.

The RFL movement sets out to suggest to participants how the group should be represented. However, some simply cannot tailor their inner worlds to fit the group representation. Conflicted warriors need to be convinced that they are wrong. This was clearly demonstrated during my first FGI, when the participant mentioned earlier made it clear that he was not entirely comfortable with his status as a HoH because he felt unworthy of the honour bestowed on him. As soon as he airs his discomfort, the rest of the group intervene decisively to insist that he is worthy of the hero status and that he is being silly for thinking otherwise. I

raised this issue with the MRG and a member confirmed the difficulty some people who are living with cancer have with the idea of being called heroes or survivors:

*Some people cannot wrap their heads around that. They cannot grasp it and they don't want to, because they are still fighting the battle. It is as if there's dishonesty. I've really had people talking to me about it and saying 'Don't call me a survivor, I'm not a survivor'. (MRG, Participant 5)*

The group gave a further example, that of a male acquaintance diagnosed with breast cancer and his musing about the survivor identity label: '*... when he had his final chemo he dropped me an email and jokingly asked: "When do I become a survivor?" I think people need to work that out for themselves based on how they see themselves.*' (MRG, Participant 4). This statement acknowledges that there is more than one illness experience, that people respond differently during different phases of their illness, but that they also have the agency to decide for themselves how they want to be represented.

While the majority of participants become emotionally entrained by assembly activities and wholeheartedly buy into the idea of being cancer warriors, there are also some who express their reservations about the dominant identity representation and question its appropriateness.

### ***Distancing and disruption***

The organizers set out to create RFL assemblies that are harmonious, welcoming and give participants a sense of belonging to the group. However, there are certain elements which can disrupt the generation of collective identities. In this section, I consider how elevating breast cancer can undermine people with other types of cancer, how some participants distance themselves from the group, and how poorly executed rituals can derail interaction ritual processes (Collins 2004: 47–49) and work against the generation of collective identity at the assembly.

I rely on the concept of 'distancing' drawn from the work of Snow and Anderson (1987: 1348–1349) in my analysis of how RFL participants use collective identity work either delicately or overtly to demonstrate their opposition to RFL and what the movement stands for. Disengaged and cynical warriors present the RFL with its biggest challenge. Although assembly spaces are designed to be physically contained and emotionally safe, this very sense of safety creates a margin for contestation and allows some participants to subvert the heroic warrior collective identity. Sometimes cracks become visible in the joyful image associated

with RFL. One example was the cynical FGI participant who made it clear that she preferred other causes to the cancer cause (FGI 4, Participant 3). Another example was the YouTube video recorded at RFL Breederivier (CRFLB 2013b). Despite the manic background music, the images are sombre. The cancer survivors captured in the video appear to be downcast, disinterested, and frequently look away from the intruding camera. Considering the extent to which the dissemination of images – photographic and video recordings – is in the hands and under the control of participants through their ready access to social media, I find it remarkable how few negative images slip through the net. The norm of disseminating positive images is so compelling that it is very unusual to find any gloomy images being circulated.

Collective identity in the RFL movement is intended to give meaning, redefine suffering, recruit and retain members. The risk, however, is that it can also marginalize certain individuals and sub-groups from the mainstream of the collective (Polletta & Jasper 2001: 169). In particular, glorifying breast cancer at the expense of the more than 100 categories of cancers that are recognized (National Cancer Institute 2014) can be alienating for those who are not a part of this prominent group. Identity and identification are determined to a very large extent by whether groups within the larger collective see themselves as belonging to and accepted by the collectivity. Different types of cancers are not equal, as some are romanticized while others remain stigmatized. Breast cancer is a romanticized cancer that attracts a great deal of public support because it is associated with soft, sensual womanhood. It has been in the vanguard of collective action the world over and is the darling of the cancer world, given its success in attracting major commercial interest and public support (Kaiser 2008: 80). This preoccupation with breast cancer presents RFL in South Africa with a challenge, as some assemblies gear themselves thematically to breast cancer to the almost total exclusion of other cancers. People with breast cancer are placed on a pedestal and are able to capitalize on the positive sentiments swirling around in the social environment. It is striking how a YouTube video made at RFL Breederivier (CRFLB 2013b) mentions only the diagnoses of survivors with breast cancer, while the rest of the survivors are simply lumped together under the generic label of ‘cancer survivors’. The breast cancer grouping within RFL is like a ‘movement within a movement’. The manner in which this privileged group is elevated above the rest and the disproportionate amount of attention focused on breast cancer by RFL participants is seen in the enthusiastic use of the symbolic colour pink, in team names and slogans, in assemblies dedicated to breast cancer, in storytelling, choice of attire and in

collective use of the pink ribbon symbol. When people in the community with breast cancer find their way onto organizing committees, they can form a very prominent group at assemblies.

In contrast to people with breast cancer are those at RFL assemblies who are affected either directly – or indirectly by virtue of being a caregiver – by cancers that lack the same appeal (e.g. colorectal cancers) or cancers that are downright stigmatized (e.g. tobacco-related cancers and cancer resulting from sexually-transmitted viruses). These participants stand in the shadows at those assemblies where breast cancer is given prominence. It is commonplace for speakers to identify their cancer diagnosis, and this can be awkward if it is a stigmatized cancer such as cervical cancer, with its close association with poverty, and the sexually transmitted human papillomavirus. Similarly, people with lifestyle cancers (e.g. tobacco-related cancers) can be more sensitive to the opinions of others, as they may be perceived as having played an active role in causing the illness.

In the RFL assembly environment, successful social interaction translates into positive emotions, feelings of solidarity, and embracement of the heroic warrior collective identity. The converse also applies. When interaction ritual processes (Collins 2004: 47–49) fail to emotionally entrain people, the result is boredom, irritation, disappointment, and questions about the worth of going to the trouble to attend assemblies. Most gatherings have strengths and weaknesses, and even some communities renowned for staging excellent assemblies can display areas of inadequacy. Analysing ceremonies is an assured way of highlighting weaknesses in execution and to home in on the breakdown of interaction ritual processes. Ceremonies are impactful, provided that they follow tried and tested scripts, are afforded due respect by participants, and are carefully executed. Some organizing committees succeed at this better than others.

In the audio-recording of the opening ceremony at RFL East London 2013 it is apparent that the main speaker was worried that people might leave before daybreak. During his speech he repeatedly predicted that this might happen and in the process created a self-fulfilling prophecy which was later realized when many teams did exactly as predicted. His plea to them was to stay for the closing ceremony, yet they chose to act in opposition. Similarly, the luminaria ceremony at this assembly lacked impact because of challenges with the spatial design (the tents in the middle of the field obscured the candle-bags from being seen en masse), noisy children and teenagers in the background, and failure to focus the attention of

participants on the ritual. The result was that the ceremony lacked impact and did little to emotionally entrain participants.

As discussed in Chapter 5, it is always immediately evident when an organizing committee has not succeeded in getting team captains to prepare their teams for assemblies. This factor alone can turn an assembly that is impressive in many respects into an absolute damp squib, lacking in collective effervescence and emotional energy. A good case in point was the Mossel Bay 2012 assembly. This had many strong elements (good facilities, great care taken in providing survivors with a wonderful experience, good entertainment, quality sound, security, and so on), but failed to generate optimal collective effervescence because the teams were unadorned and the campsites were drab. It is my contention that this was symptomatic of poorly prepared teams. The default position for unprepared teams is simply to rely on their established group identities outside the assembly. Invariably when this happens, a high percentage of teams will express their group identities by simply clinging to their primary commercial, organizational or political identities.

Ceremonies reveal a great deal about collective identity generation at RFL assemblies. The luminaria ceremony is undoubtedly the most powerful ritual, with the greatest ability to emotionally captivate participants. I find it helpful to look at Hochschild's (1983: 63–68) treatment of how people behave at funerals to gain a better understanding of the development of social interaction processes during this particular ceremony. Hochschild (Ibid.) outlines the way in which the majority of people at funerals are sensitive to the tender nature of the occasion and readily go along with the crafted moment. The same happens at RFL luminaria ceremonies. There is a rule about feeling that operates for the duration of the ceremony which dictates that participants should use the opportunity to grieve not 'too much or too little' (Ibid.: 64). The announcement that the luminaria ceremony is about to start signals that this is the appropriate time during the assembly to feel sad. Approximately 30 minutes are reserved for this ceremony. While it is being conducted, participants are expected to pay attention, be quiet and to show respect. However, once the ceremony is completed, it is understood that they will shift back into an active, energized mood on the track. How well the ceremony is executed will determine the extent to which they become emotionally entrained. A participant in one of my FGIs contrasted two luminaria ceremonies – one that failed and one that hit the mark. She talked first about the previous year's ceremony, which had been poorly executed, and explained how this made it difficult for her to properly commemorate her dead son,

as there was too much background noise, the occasion was not afforded the respect it deserved, and did not feel authentic. She then contrasted the disappointment of the previous year's ceremony with the beautifully executed ceremony that evening:

*I was ecstatic tonight. Somebody made a bag for Michael and I was standing next to it. The luminaria moment was absolutely beautiful tonight. Time was given to that moment. I could stand with Michael's bag for a long time and every time the wind blew the little flame out, I could light it again. It felt like a true acknowledgement of the person I loved and lost. (FGI 2, Participant 5)*

The need to strike the correct emotional tone is similar to Scheff's (1979: 62, 63) treatment of emotional catharsis, where it is possible to 'over-distance' or 'under-distance' in the expression of emotions. Under these circumstances, failure to create the appropriate mood to match the ceremony will result in a disruption of interaction ritual processes (Collins 2004: 47–49).

Simple mishaps in the execution of assembly activities can derail the mood during a ceremony, spoil the moment, and disrupt the hoped-for activation of collective identity. An example was the luminaria ceremony at RFL Mossel Bay 2012. The music was suitably quiet and reflective until, out of the blue, 'Gangnam Style' by Psy (Jae-Song & Gun-hyung 2012) was played loudly over the public address system. This boisterous South Korean pop song went viral a couple of months before the assembly and was incorrectly cued by the sound team during the ceremony. This mishap provided an excellent example of a disrupted ritual chain (Collins 2004: 47–49), as it happened while the assembly was still in a reflective mood, lights were dimmed and many people were praying in front of burning memorial candle-bags – some of them with arms stretched heavenwards. This accident was incredibly jarring and had people looking at each other in utter bewilderment. My research assistant, who was busy making an audio-recording elsewhere on the site, came running to me to find out what had happened because the incident seemed so confusing. I had no idea what caused the perplexing episode, but realized that it made no sense to play that particular piece of music during the ceremony. Enquiries revealed that it was simply a clumsy mistake that resulted in a rowdy pop song being introduced at the wrong moment.

Another way that the generation of collective identities can be disrupted is when people behave badly, in an oppositional manner, or fail to conform to the Relay culture. RFL assemblies are generally harmonious, with a high tolerance for transgressive behaviour. It is

only when participants disturb others through unruly conduct that limit-setting enters the picture. The smoking of tobacco, not surprisingly given the focus of the assembly, is seen as particularly provocative and arouses strong emotions as it contributes greatly to cancer-related deaths. In South Africa, smoking is ranked as the second leading health problem after HIV/AIDS and more than 44 000 South Africans die of tobacco-related disease every year. (CANSAs n.d.). The anger and irritation provoked by smokers at RFL assemblies can be considerable. These rogue smokers are viewed as trouble-makers, especially as their actions fly in the face of South Africa's stringent tobacco control measures. Organizers vary in their response to the use of tobacco. At one assembly, there was a light-hearted but effective response to the problem. I made this note in my journal:

*Shortly after the dancers finished there was an announcement from the stage spelling out the consequences of people smoking inside the venue and on the track. Offenders were told that they would be hauled onto the stage and made to sing and dance for the rest of the assembly. This good-humoured threat seemed to put a stop to tobacco-use at the assembly for the remainder of the time. (Journal entry 2012/8)*

At another assembly I observed a much tougher tone and more overt irritation on the part of the Master of Ceremonies:

*We want to promote awareness against smoking, so if you want to smoke you need to go off the field down to the bottom parking lot. We do not want smokers in the crowd here tonight. Please! We would appreciate that. (Journal entry 2013/1)*

Alcohol use and out-of-control youth can also present organizers with headaches. Most committees deal with the alcohol issue by making their assemblies alcohol-free, as it is a long night and inebriated participants can at best be a nuisance and at worst need to be escorted off site by security staff. Organizing committees that fail to maintain discipline at their RFL assemblies also run the risk of teams withdrawing their support during subsequent years. A team captain relates her frustration with those who drink on the quiet and then behave inappropriately:

*They have a couple of beers and walk around the track. Then there is this woman standing there with her caravan [health educator offering breast examinations] and they say 'nobody is going to touch my boobs!' It is absolutely wrong and this drinking does not work with me. When you come here you must really support the health educators. To me it is confusing. (FGI 4, Participant 5)*

Unruly participants are brought into line by their team captains and in extreme situations removed by security staff. These discipline problems spoil the atmosphere and detract from a friendly, harmonious environment – and consequently also from the generation of collective identity. Organizing committees worth their salt know that the onus is on them to maintain order so that the values of RFL can be upheld.

Constituents turn their backs on initiatives when they feel that the group and what it stands for no longer represents them (Polletta & Jasper 2001: 292). The most strident criticism came from a dedicated organizer who took issue with mainstream biomedical treatment: *‘One day we are going to look back and think, “Oh my God! What did we do! We burned and poisoned and cut these poor people with cancer. Could we not have treated them differently?”’* She also took a swipe at the cancer movement in general: *‘I’ll probably be shot down in flames for this, but I think the cancer movement is a huge money-making thing that plays with people’s emotions’* (FGI 4, Participant 1). RFL participants are extremely restrained in their overt criticism of the RFL movement and are more inclined to direct criticism at the broader ‘cancer movement’. Melucci (1995: 41–63) argues that for the sake of unity and sometimes for outward appearances the constituency presents a united front. However, the collective identities that evolve over time might not be equally appealing to all groups within the collective, and some people will resist recruitment or leave the collective when they feel that the collective identity does not represent them or the things they strive for (Polletta & Jasper 2001: 291, 292).

### ***Illusion at a price***

The RFL assembly is an imagined world, with a particular reality crafted around the cancer experience. With ample use of the heroic warrior myth, an illusion of unity is created. However, not all participants identify with the heroic warrior collective identity, and there are those who come across as walking wounded and, in rare instances, even as cynical or mutinous warriors.

Matching the idealized image of the heroic warrior with the tough realities of the cancer experience can prove to be a tall order requiring tremendous expenditure of emotional energy. The RFL movement mythologizes brave cancer warriors, but what are the negative consequences for RFL participants who embody this dominant collective identity for the sake of the collectivity, but do so at the expense of what they are experiencing in reality? Hints of

how hard some have to work at maintaining the image of brave warriors are to be found in references to forcing themselves to keep going because they know that if they stumble they will never get up again (Speakers 3 and 13), a grim determination to take treatment in their stride by continuously telling themselves how good it is for them (FGI 3, Participant 3; Speaker 14), and talk about the importance of being grateful for the illness experience (Speakers 3, 6, 14; FGI 1, Participant 2; FGI 3, Participant 3).

Some of the most engaged and involved RFL volunteers have redefined the cancer experience as a destiny rather than a fate. A survivor with late-stage stomach cancer states: *'My family has always laughed at me when I've told them that I was destined to get cancer. I have learned so much. I have met the most incredible people. I'm glad this is my journey.'* (FGI 3, Participant 3). Getting cancer has introduced her to a community of people who are similarly affected, and this has made her retirement deeply meaningful. A HoH expresses similar sentiments when she tells the assembly during the commemoration ceremony that: *'I want to thank God for giving me cancer. Cancer has given me compassion with others, irrespective of the affliction.'* (Speaker 6).

Cancer can be deeply transformative for some people, but for others the pressure to be positive is punishing. Hochschild (1983: 39) compares the emotional work done in pretending to be in equilibrium at a time when one's inner world is in chaos as tantamount to giving orders to a stubborn horse. A young HoH relates how, between the time she did an interview with a magazine and the time the magazine was disseminated, she experienced a life-threatening recurrence of her cancer which thrust her and her family into a deep crisis:

*That was a hard time for me. They did this nice interview with me and they wrote nice things about me. A week later I was diagnosed again. I took this magazine and it was all about me being upbeat, sparkling and full of life. And I thought to myself this is the person I want to remain. I don't want to be another person because of cancer. I don't want cancer to take things away from me.* (FGI 1, Participant 1)

Her refusal to give in to feelings of vulnerability and her dogged determination to remain positive, however, required a great deal of emotional work.

Some situations can demand emotional labour from us that impairs the extent to which we listen to our own hearts and dulls our ability to experience authentic emotions (Hochschild 1983: 21, 34). I believe there is a danger of this happening when a social situation is as

entraining as RFL assemblies, and where there is tremendous pressure to do what is socially desirable and to act in the name of a good cause. The scripted nature of the assembly affects the collective behaviour and emotions of those who take part and, ideally, this should raise questions about the nature of collective identity representation. Yet my data shows little concern for, or awareness of, the possible negative consequences of representing the affected people in a particular way. There is an almost wholehearted embrace of the heroic warrior collective identity that demands that participants be the epitome of grace under pressure.

It is difficult for affected people to admit that they are feeling scared, shamed or discouraged. Many of us are socialized to take challenging situations in our stride and to pick ourselves up when tough things happen to us. This simple life philosophy is sustaining for many, but for those RFL participants who become over-invested in the need always to appear positive there is a price to be paid:

Those who make cheerfulness and bravery the price they require for support deny their own humanity. They deny that to be human is to be mortal, to become ill and die. Ill persons need others to share in recognizing with them the frailty of the human body. When others join the ill person in this recognition, courage and cheer may be the result, not as an appearance to be worked at, but as a spontaneous expression of a common emotion. (Frank 1991: 71)

Here and there in the data I found evidence of people who recognized that much of their emotional turmoil was being buried under a veneer of cheerfulness: *'It's tough and people think you are okay and most of the time you are not okay'* (FGI 1, Participant 6), and *'Some of us have not mourned; we have not even started mourning and now they think you should be fine.'* (FGI 1, Participant 5). A minister of religion during a closing ceremony dares to swim against the current by challenging the sidestepping of pain and suffering so often encountered at RFL assemblies:

*Nobody likes pain and heartache. Nobody longs for it. Our natural reaction is to avoid it. We want to run away from the situation and the feelings that accompany it. I deny that I feel bad. I don't want others to know that I'm experiencing pain and heartache so I put on a mask. ... Pain is seen as an assault on my happiness and it does not fit into my life.* (Speaker 22)

The principal way in which RFL assemblies create an illusion is by allowing affected people to keep up the appearance of being stoic through the embracement of the heroic warrior

collective identity. For those affected by cancer, getting on top of the challenge of the illness is like dealing with a finishing line that is never clear, because of the threat of a recurrence of cancer. For many this feels like perpetual uncertainty, with endless new challenges. Frank (1991: 64–71) described two kinds of emotional work that need to be done in response to this challenging situation: (1) the joint effort by the ill person and loved ones to deal with the fear, loss and frustration of trying to adjust to the illness, and (2) the work the person with cancer does in trying to keep up the illusion of equilibrium. Frank refers to this as 'keeping up appearances' (Ibid.: 64) and describes the pressure placed on the person living with cancer to be a 'cheerful patient' (Ibid.: 66). It is questionable how many of the speakers at RFL assemblies are able to maintain the pretence of happiness once they leave the assembly. In her work on managed emotions, Hochschild (1983: 48) explains that we use illusion in our everyday life frequently through what she terms 'deep acting', because we need it and it serves a purpose in particular situations. RFL participants cling to hope through collective identity work, but once the assembly is over and the last vehicle has driven away the created illusion softens or fades away – along with the generated collective identities. The participants return to their normal routines and go back to the emotional rollercoaster of living with their illness.

### ***Movement as Pied Piper***

How does the collective identity work that is done at RFL assemblies relate to the broader debate about cancer and identity? RFL was introduced into South Africa in 2005 and from that point onwards the ACS provided CANSA with energetic consultation services. As a much more powerful international player, ACS was regarded by CANSA as the expert in the field. Both the ACS and CANSA are extremely well-resourced national cancer organizations in their respective contexts. Arlie Hochschild's (1983: 75) views are apt about the power of experts, as she tells us that:

In times of uncertainty, the expert rises to prominence. Authorities on how a situation ought to be viewed are also authorities on how we should feel. The need for guidance felt by those who must cross shifting social sands only adds importance to a more fundamental principle: in the matter of what to feel, the social bottom usually looks for guidance from the social top.

Ilan Kapoor (2004: 627–647), in his application of Gayatri Spivak's (1988) work on the subaltern, argues that development sector organizations in the North take their superiority

over their Southern hemisphere partners for granted. It is assumed that the global North knows what is best for member countries, even in instances when organizations in the global South deal with substantially different challenges (Ibid.: 629).

I know that CANSA and RFL adherents would object to a portrayal of controlling cancer organizations – ACS as a well-resourced, major global player and CANSA as the major player on the African continent – as the ‘social top’ and people affected by cancer as the ‘social bottom’, but the reality is that cancer causes mayhem in the lives of people and many supporters join RFL in a state of emotional disequilibrium looking for answers and support. The findings of this inquiry make it patently clear that participants, especially those in leadership, look to the RFL movement for guidance on how to feel and how to represent the collectivity.

Kapoor (2004: 630) argues that leaders attached to powerful agencies are inclined to speak on behalf of the people they serve and to impose their ‘developmentalist/ethnocentric mythologies’ on them. I do not believe that the strong presence of volunteers in leadership counters this problem. Volunteers and paid staff are equally anxious to protect the vested interests of the controlling organizations, as both groups enjoy personal growth and status benefits derived through their involvement with RFL. The storytelling at RFL assemblies was a powerful demonstration that nobody in leadership deviates from the heroic warrior collective identity. How followers should feel and how they should imagine themselves are written into training courses, scripted into RFL assemblies, and worked into a wealth of resource materials. Member countries use blueprints provided by ACS. Local assemblies do not determine their own scripts; instead, the parent body does. Although local assemblies absorb some of the flavour of the communities in which they are based, standing in the wings of even the smallest gathering in the deepest rural community is an entire global movement which meticulously sustains RFL through monitoring, training, leadership summits, social media, resource materials and staff support.

Brown et al. (2004: 56) argue that in the emotionally fraught world of illness, health movement adherents are constrained in their activism precisely because those who carry the most moral authority are ill and depend on service providers. RFL participants, especially survivors and HoH, may be placed on a pedestal at assemblies, but the controlling organizations have the power and are in charge of the resources that make support programmes, advocacy programmes, cancer education and cancer screening possible. The

onus of group representation falls principally in the lap of the movement and along with it there inevitably have to be some concerns about possible negative consequences of the manner in which the constituency is represented. The cancer organizations that control the RFL programme have gone to extraordinary lengths to involve volunteers in the RFL movement and can rightly claim that RFL is 'volunteer-driven'. However, RFL is not 'volunteer-controlled' or 'volunteer-led', and therein lies the dilemma. There will never be a level playing field in the power balance between controlling organizations and the people they serve (Kapoor 2004: 631).

Globally, RFL is one of the best resourced and most powerful citizen cancer initiatives. While it is conceivable that organizers on the ground may not always fully understand the working of the forces that come into play in the activation of collective identities, the insight of the global RFL movement into what binds people together should not be underestimated. Hochschild (1983: 48–54) contends that sophisticated organizations make excellent use of techniques that suggest to their constituents how they should imagine themselves and how they should feel. The RFL movement does both these things in an effective and confident manner. Again, to quote Hochschild: 'Some institutions have become very sophisticated in the techniques of deep acting; they suggest how to imagine and thus how to feel.' (Ibid.: 49). All over the globe, RFL captures the imaginations and the hearts of people who live with cancer.

### ***Summary***

This review of the embracement, hybridization and disruption of collective identity generation at RFL assemblies concludes the presentation of the findings of this inquiry. I showed that, although the majority of participants readily embrace the dominant collective identity and work in harmony with assembly processes, there are also those who hybridize or disrupt the generation of collective identity. I also discussed the influence of the RFL movement and where the heroic warrior collective identity fits into a larger debate about cancer and identity.

I now move onto the discussion chapter in which I present the thesis through an integration of research findings, the theoretical scheme and accompanying literature.

## Chapter 8

# Discussion

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### ***Chapter introduction***

RFL is the leading cancer solidarity initiative in South Africa. It addresses a need in the lives of some people affected by cancer for social encounters that offer support, acceptance and community. The rapid growth of RFL got me thinking about the ability of the RFL movement to bind people together through the activation of collective identities, about the nature of these identities, and the meaning of the generated identities. In my quest to gain a deeper understanding of how collective identities are activated, I set about doing a case study of the phenomenon at RFL assemblies in South Africa.

This chapter is my opportunity to take a step back to look at the big picture and to consider the essence of my findings in relation to the evolution of my theoretical scheme and the associated literature dealing with cancer and identity. I weave together the strands developed in the preceding chapters by offering my interpretations of the findings of the study. This is a good place to again pose the central research question: How are collective identities activated at RFL cancer assemblies in South Africa, what is the nature of these identities, and what do they tell us about cancer and identity? This requires me to consider both the ‘how’ and the ‘what’ of collective identity generation at RFL assemblies. By focusing on both these elements, I again touch on the distinction between the process and the product definitions of collective identities. While it is important not to conflate these two aspects (Flesher Fominaya 2010: 397), there is a lurking question about the extent to which one can actually separate process and product.

I respond to the ‘how’ part of the question by arguing that social interaction processes identified by theorists such as Goffman (1963), Lawler (2003) and Collins (2004) come into play in the generation of collective identity at RFL assemblies. The case study highlighted a potent cocktail of five key elements (or pivots) used to shape collective identities: ephemeral space, a shared focus on cancer, collective action during assemblies, illusionary elements, and the use of emotions during these focused gatherings.

In response to the ‘what’ part of the question, I consider the nature of the three most noteworthy symbolic identities discernible during assemblies. I found no evidence to suggest that identity work deviates from the main narrative strands identified by Frank (1995), so I

worked within these parameters, with the exception that I customized the themes to better suit the environment of RFL assemblies. They are referred to as (1) the heroic warrior collective identity, (2) the transforming/transformed firebird collective identity, and (3) the walking wounded identity. I contend that all three are symbolic in nature and that they precede RFL assemblies. The dominant collective identity is imposed on its adherents by the RFL movement. Whether or not the heroic warrior identity becomes intensified depends on the success with which focused gatherings employ the five elements that amplify collective identity. The presence of a secondary firebird identity was also revealed in the data. However, scant evidence was found to support the notion that the walking wounded identity has sufficient salience to be considered a collective identity. In this chapter, I also examine the ways in which people negotiate and renegotiate different symbolic identities during assemblies.

### ***Social arena and zeitgeist***

Cancer brings in its wake a tremendous burden of disease and, understandably, is viewed as a calamity by the GCM, as represented by the authoritative UICC. The World Health Organization Fact Sheet (2014) tells us that cancer was responsible for 8.2 million deaths in 2012 and that more than 30% of these deaths could have been prevented if the general public had had a better understanding of risk factors. In the effort to highlight the gravity of the situation, cancer statistics are cited by organizations affiliated to the UICC. The public is reminded of how many people are likely to be diagnosed each year, the numbers that will perish, and how unnecessary suffering could be averted if people acted together. Defining cancer as a serious threat is used with external audiences, as well as inside the GCM. Calls to action are compelling, and many feel duty-bound to mobilize against the threat.

The way in which people affected by cancer are represented in the popular discourse and by the extensive network of cancer organizations is informed by the spirit of our times. As the dominant collective identity, the heroic warrior seeps into every imaginable aspect of the GCM, including the RFL movement and its assemblies – even in the smallest, remotest of locations. People with cancer are universally portrayed as optimistic survivors, and it is extremely difficult for those who are affected not to embrace this image (Frank 1991: 83–90; Kaiser 2008: 79; Bell 2012: 586; Chambers et al. 2012: 962; Jarvis 2014). The dominant identity is, for the most part, unquestioned by volunteers and staff attached to cancer organizations, big business (most notably cosmetics and pharmaceutical companies), and

mainstream media. The master portrayal is used to attract support, to retain followers and to ensure the sustainability of cancer initiatives, irrespective of whether they are non-profit or designed to make profits. The RFL movement's wholehearted embrace of this popular symbolic representation simply reflects the discourse of the larger GCM.

The cancer survivor movement and RFL were both born in the mid-1980s in opposition to the hegemonic view at the time of cancer as a victimizing disease. The start of RFL also coincided with the rise of volunteers as powerful partners in cancer organizations. Power-sharing between employed professionals and volunteers was slower to take root in South Africa. When it happened, however, it was accompanied by pressure to change identity labels. Whereas salaried staff in the past could get away with a paternalistic labelling of people with cancer as 'sufferers' or 'cases' or 'patients', the sea change brought about by RFL called for the reimagining of group identities – both role and collective identities – that would be acceptable to volunteers who were asserting their growing influence. Thus RFL redefines an illness that can be arduous and heart-breaking into something hopeful and inspirational, far removed from the days of shame and hopelessness. New labels such as 'survivors', 'warriors' and 'heroes' proved to be infinitely more acceptable to people with cancer and their loved ones. The zeitgeist had changed and with it the mythology underpinning the narrative. We now find ourselves in an epoch where there is great enthusiasm for the idea that people affected by cancer are heroic.

Self-reflection allows movements to work with collective identity in a goal-directed manner, based on a clear understanding of opportunities and constraints in the social field of operation (Melucci 1995: 42, 46; Polletta & Jasper 2001: 284). RFL has evolved a particular group representation that is appealing to followers, with their considerable talents and material resources. Leadership might not consciously set out to activate the heroic warrior identity or even fully understand the finer nuances of collective identity generation. Nevertheless, I maintain that RFL, through its training, monitoring and communication divisions, has the ability to leverage the dominant identity for the benefit of member organizations such as CANSA. As an astute movement, RFL has a clear understanding of how to work with collective identity to unite its followers in order to meet its objectives. I do, however, concede that, at the level of assemblies, neither the organizers nor the participants are entirely conscious of the full power of the heroic warrior collective identity or how this borrows from unconscious, spontaneous symbolic material drawn from older, adapted versions of an

archetypal storyline. This is the process described by Polletta (2006: 168–171) as ‘canonicity’ and by Frank (2010: 197) as ‘intertextuality’.

The case study showed how well-executed RFL assemblies can capture the hearts and the imaginations of participants. Hochschild (1983: 48–54) maintains that when powerful institutions become involved in the emotional management of their stakeholders, they effectively remove elements of agency from individuals and impose institutional forces on the group. The elements used by RFL at its assemblies to intensify collective identities – space, a shared focus, collective action, illusion, and emotions – comprise a potent cocktail. Authors and cancer activists such as Frank (1991), Kaiser (2008), Bell (2012), Lewis (2013) and Jarvis (2014) recognize the power of the hegemonic narrative in the cancer world. They caution against static identity representations which contain prescriptions on how people with cancer are supposed to feel and react to their situation.

Cancer is big business, and RFL represents an important income stream for member countries. Collins (2004: 141-142, 149-158) depicts a marketplace where ritual communities compete for adherents. In South Africa, RFL operates in a highly competitive environment. It vies for the affection of its followers with other cancer initiatives, such as People Living with Cancer and Reach for Recovery. RFL stands or falls by how well it maintains a collective identity among its followers. If competing solidarity communities, of which there are many, do a better job of capturing the hearts and minds of affected people, RFL could stand to lose its more than 60 000 followers in South Africa. Those solidarity communities which have effective mechanisms to bind people together will have the loyalty of their followers, be chosen above competitors, and be seen as the authentic and the natural habitat for the group (Goffman 1963: 137). To succeed, cancer solidarity communities need the same type of market acumen as commercial organizations in the way they manage collective identity work.

I argue that RFL has aligned its dominant collective identity to suit this era of mass solidarity movements and to represent its constituency in a manner acceptable both to the constituency and its partners. Polletta and Jasper (2001: 291–292) speak about movements using ‘interpretive packages’ (or frames) to attract prospective followers and to define group identity in such a way that it suits the aims of the collective. They argue that these representations reflect the collective identity of constituents and assist in creating boundaries between protagonists and antagonists. The packaged collective identities need not be unique to the group, but could be crafted out of more universal collective identities swilling around

the social environment. I believe that this holds true for the heroic warrior collective identity, as it has been adopted by many causes and not only by the cancer movement. Other groups concerned with a negative public image of their members – such as the environmental and disability movements, HIV/Aids and LGBT initiatives – also use the heroic warrior identity in order to mould public perception of their constituencies. However, the cancer movement's sense of ownership of this collective identity is unrivalled in contemporary mass movements. The representation of the group is used as a way to align the illness experience of participants with the collective identity of the group (Brown et al. 2004: 59). In short, the heroic warrior identity meets the needs of the RFL movement, the global constituency, and its partners.

### ***The process explained***

The situation-specific collective identities generated at RFL assemblies draw on personal illness identities, the role identities written into assembly scripts, and the pre-existing master collective identity promoted by the RFL movement. The aim is to present an accessible, symbolic description of the group, what it stands for, and what it needs to accomplish (Melucci 1995: 44). Collective identities at RFL assemblies become amplified through five pivots, namely (1) the ephemeral, enclosed assembly space, (2) a shared focus on cancer, (3) collective action during the assembly, (4) the illusion of interpersonal closeness and a romanticized representation of affected people, and (5) the emotional entrainment of those who take part in an assembly through a rich array of collective identity work.

The interacting identities, intensified through the five pivots, form the larger gestalt of overarching collective identities generated at assemblies. Three interacting identities and the five identity intensifying dimensions are elements in dynamic interaction with one another and are so tightly entangled during RFL assemblies that they cannot be prised apart.

### ***Interacting identities***

Although personal and collective identities are distinct, they nevertheless interact and influence each other (Polletta & Jasper 2001: 298; Snow 2001: 3). Collective identities draw upon personal identities, but are more than the sum of the individual identities of those who constitute the collectivity (Polletta & Jasper 2001: 298). Participants come to highly scripted and emotion-fuelled gatherings with personal experiences of illness that become moulded during the social encounter. Individuals need to engage with others in a social encounter before the collective identification process can be activated (Jenkins 2008: 200). Collective

identities, once activated, can be so compelling that they can influence personal identities – even after ties have been cut with the solidarity movement (Polletta & Jasper 2001: 296).

To understand the process by which private feelings are subjugated so that they match the expected outward emotional display of the larger group, it is useful to consider the insights offered by Hochschild (1983: 19). She describes a 'transmutation' (Ibid.) of the emotional system whereby a private act links up with a public act. An example of a private act in the RFL context might be the struggle to make sense of the illness experience, while a public act could be embracing the heroic warrior identity. Through this embrace of the dominant collective identity, private feelings come under the sway of the greater good. In this instance, it will take in the cancer cause, the RFL movement, and the pressure to maintain an unwavering image as a loyal, brave and victorious member of the battalion. Loyal participants effectively lend their emotions to the assembly so that the RFL movement can accomplish its goals. For those who feel vulnerable, there is the pressure to be what they believe others would like them to be, with the associated risk of their becoming trapped behind the mask of the glorious warrior.

Lawler (2013: 135–149) provides help in gaining an understanding of the process whereby highly complementary role identities – HoH, survivors, caregivers, team captains, team members and organizers – become transformed into overarching collective identities. He shows (Ibid.: 137) that role identities are structurally imposed by the larger movement and that the different identities are complementary and interdependent. Role identities are important building blocks in creating a shared focus for those who come together at RFL assemblies. A process of feedback allows for a progressively deeper interaction between complementary role identities, generating a deepening of social engagement and commitment to the shared objectives of the social encounter (Ibid.: 135–149). As the assembly moves deeper into collective effervescence and people become entrained by group activities, progressive 'feedback loops' take them to the point where their embracement of role identities creates a bridge that allows them to shift from 'me' to 'we' (Ibid.: 141). This bridging from a role identity (e.g. being a caregiver) to a collective identity (e.g. heroes or firebirds) is facilitated by the heightened emotions and social interaction experienced during the encounter (Ibid.).

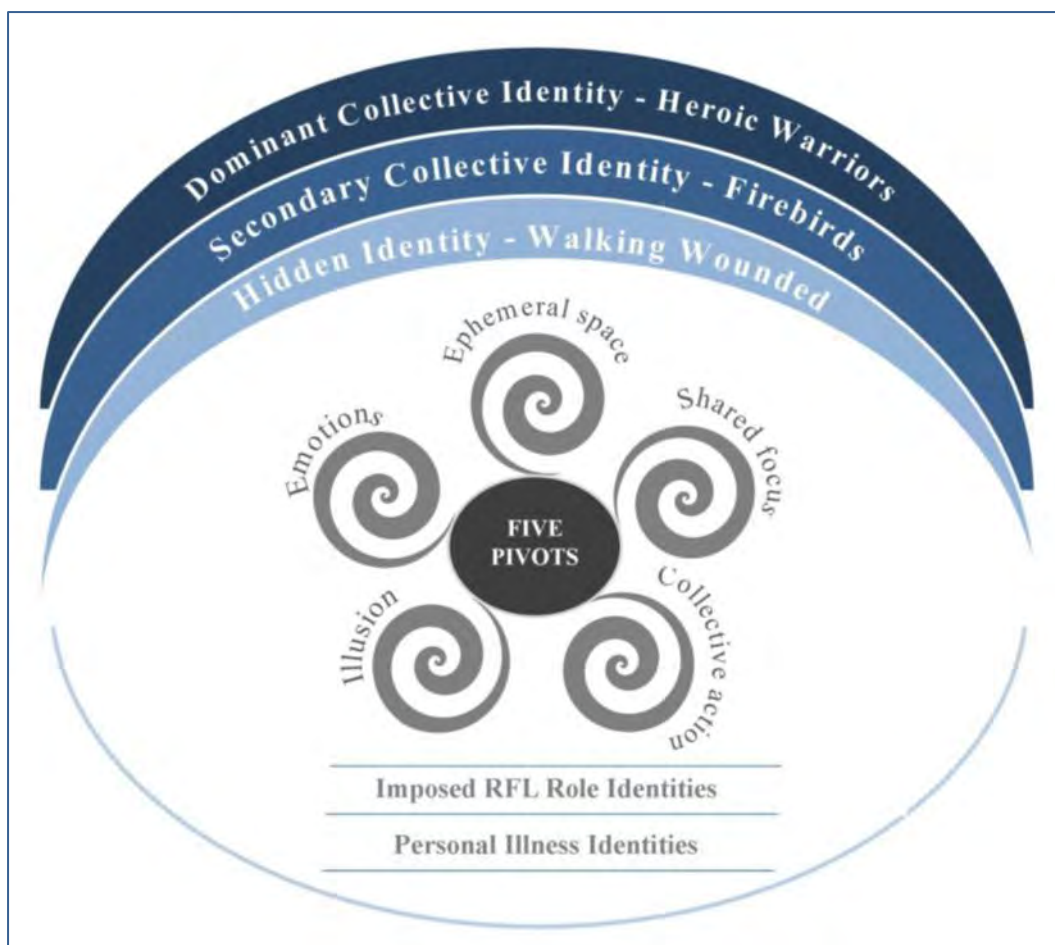
From the outset, the role identities (HoH, survivor, caregiver, and so on) assigned by the RFL movement steer group identity in a specific direction – one which places a high premium on

being optimistic and hopeful about the prospect of survival and a cancer-free future. The preferred heroic warrior collective identity is given enormous support by the scripted nature of assemblies and by the roles imposed by the movement. Because roles are defined in the way they are, the heroic warriors trump the firebirds and the walking wounded. The cast of characters are fixed, and the script leaves little room for people to embrace alternative collective identities. The role identities are primed while participants prepare for the annual assemblies, and are constantly driven deeper into the collective understanding through training courses, annual leadership summits, a wealth of social media resources, and constant monitoring by controlling cancer organizations (in this instance CANSA and the ACS).

To build interpersonal links and strengthen the group's sense of collective identity, pride and gratitude are brought into play during the social encounter (Lawler 2013: 145). It is hard to imagine a narrative that fits the bill better than the heroic warrior storyline, as it offers ample scope for setting 'pride-gratitude cycles' (Ibid.) in motion. It has the further advantage of offering the group an imagined enemy onto whom they can project all their feelings of shame and anger. Pride and gratitude, combined with anger, inspire the collectivity to feel pride in itself (e.g. surviving the illness experience with dignity and grace), gratitude towards others (e.g. providence and the solidarity community), and anger towards cancer as the imagined enemy. Facilitating pride and challenging public perceptions are done through collective identity work and can be an important goal for social movements, especially those which deal with marginalization (Polletta & Jasper 2001: 294).

Lawler (2013: 146) argues that role identities (e.g. caregivers) and collective identities (e.g. heroic warriors) are entangled, in as much as the participants' sense of mastery is connected to, and arbitrated through, shared activities. During the gathering, each role carries with it certain obligations. For example, survivors are encouraged to be positive and to endure suffering with grace and fortitude, while the idealized image of caregivers characterizes them as patient and loving. The reverse also applies. Collective identities speak back to role identities, especially in the execution of those shared tasks which boost a sense of self-mastery, esteem and authenticity (Lawler 2013: 146–147). The heroic warrior identity carries the ideals of the collectivity as altruistic, hopeful, buoyant, and willing to act together to overcome cancer.

I visualize the activation of collective identities at RFL assemblies as follows:



**Figure 8.1: Collective identity activation**

***The five pivots***

The participants included in this study arrived at assemblies with their pre-existing relationship with cancer and came into interaction with the symbolically-embedded heroic warrior identity imposed by the movement and present at all RFL gatherings. Whether this preferred dominant collective identity became salient during any particular assembly depended largely on the success with which the collectivity leveraged key pivots.

***Pivot 1: Ephemeral space***

Ephemeral space as an intensifier of the heroic warrior identity at RFL assemblies begged to be considered. Assemblies are staged by the gathering group only once a year, at the same time in the calendar. These ‘slices of time’ (Foucault 1986: 26) out of the community’s calendar are reminiscent of the ‘high days and holidays’ that appear like clockwork at a particular time of the year. Fixing the time in the calendar allows the group to visualize the upcoming assembly and to carry out detailed planning and preparation. This, in turn, heightens the anticipation and the shared excitement of the group.

I believe RFL assemblies to be a contemporary manifestation of crisis heterotopias, as they offer participants a safe place in which to gather and reflect on their experience of illness. The work by Foucault (1986: 24–25) on crisis heterotopias and Soja's (1996) subsequent work on 'Thirdspace' proved to be helpful in conceptualizing the RFL assembly space. Crisis heterotopias have become rare in contemporary society, but their traces are still found in some dedicated spaces set aside for those grappling with some crisis or other (Soja 1996: 159). Another contemporary example of crisis heterotopias is the special containment areas in airports for family of the victims of aircraft disasters in the days following these calamities. In the RFL space, participants are able to work with both the real and illusionary aspects of cancer, to shut themselves off from others whom they believe do not have the same insight into the cancer experience, and make dedicated time for one another. Whereas the body is a symbolic battlefield in the minds of many living with cancer (Frank 1991: 85), at the RFL assembly the assembly space acts as the proxy for the battlefield.

RFL gathering spaces are curious and quite different from the spaces the participants move through in their everyday lives. Temporary assembly spaces conform to the appearance of RFL assembly spaces all over the world, while still managing to absorb some of the flavours of the local communities in which gatherings are staged. The case study showed how RFL events bring together regional languages, local customs, popular culture, and a myriad of other influences present in the environment of the hosting community, while sticking to the design blueprint given by the global RFL movement. Heterotopias can recreate in small, encapsulated spaces the bigger world in which they are embedded (Foucault 1986: 25). When participants step into a RFL assembly, they bring with them the influences of the outside world. Foucault (1986: 27) makes it clear that heterotopias are microcosms of all the spaces they reflect and contest. In these single spaces, all other places are thrown together in a jumbled hotchpotch (Soja 1996: 55, 160). A useful analogy is to think of the organizing committee as a dressmaker who has to follow a particular dress pattern meticulously, but has the liberty of choosing any fabric and embellishments in order to give the garment a unique character.

One of the important hallmarks of the crisis heterotopias is the setting of social and physical boundaries. Participants see themselves as unique and set apart from non-participants and therefore maintain symbolic and real boundaries around RFL assemblies. A strong thread in this inquiry was the 'them' and 'us' theme, or what Flesher Fominaya (2010: 395) refers to as

what ‘we are’ and what ‘we are not’. Collins (2004: 48) believes that this imagined boundary around the group adds to the shared mood and focus of the assembly, and acts as a crucial ritual ingredient that intensifies a sense of belonging to the group.

RFL celebrants are distinctive and are instantly recognizable all over the world through their attire, adornment, ceremonies, use of collective symbols, use of the colour purple, storytelling, and the way in which assemblies are scripted. Even in the context of the larger CANSA, RFL participants are different and are not easily to be confused with supporters of other CANSA programmes such as Shavathon or the Daredevil Run. These perceived social boundaries around RFL events play an important role in activating collective identity. To the social boundaries, physical boundaries are added. The perimeter around the assembly is guarded to ensure that only those with legitimate business are allowed to enter.

RFL assemblies are not only physical spaces, but also symbolic spaces. As a space of illusion, the area of the assembly becomes an imagined battlefield where participants form a united front in the battle against cancer. It was Foucault (1986: 23) who pointed to the link between our inner worlds and the physical spaces through which we move. Far from being empty or devoid of qualities, the RFL assembly space is imbued with all sorts of nuances, including those that pertain to illusion. Heterotopias are not only ‘localized and real’, but also mythical spaces (Johnson 2006: 78), as we will see when we later consider the illusionary aspects of these gatherings.

### ***Pivot 2: Shared focus***

RFL gatherings bring together groups of people who share a concern with cancer. Frank (1995: 37) refers to the community of people affected by illness as a ‘community of pain’, and I see RFL assemblies as a prime example of a highly organized solidarity community. The inquiry showed that participants set themselves apart from others through symbolic means such as ceremonies and collective symbols. The unique commonalities of the collectivity are recognized by insiders and outsiders alike, affirming solidarity and making it clear who belongs and who does not (Taylor & Whittier 1999: 176). RFL participants, who know what it is to be touched by cancer, feel that within the RFL community there is a shared understanding about the illness experience and that this sets them apart from others.

Another source of shared focus which is notable in the South African context is religion. The encounter with illness and the need to have faith in God are closely associated in the minds of

many RFL participants. I found frequent references to faith, to its importance, to miracles and epiphanies. Whereas religion is not commonly incorporated into RFL assemblies by most international member countries, it is an outstanding feature of RFL in South Africa.

### ***Pivot 3: Collective action***

Snow (2001: 1) believes that collective identity lives in a group's 'shared and interactive sense' of being united and being able to act together. We should keep in mind that RFL participants are community-spirited people who willingly invest time, energy and money in preparing for and attending annual RFL assemblies. These are not people who are disconnected from collaborative effort, but rather people who are open to giving of themselves in the name of the cancer cause. They stand in contrast to others who resist recruitment. This willingness to get involved in collective action is crucial, since it acts as a 'fertile seed-bed for the generation of collective identities' (Snow 2001: 7). At RFL assemblies, people interact for the duration of a long social encounter that typically lasts for more than 12 hours. Lawler (2003: 146) is of the view that positive emotions will be attributed to a social encounter when there is a shared task which requires high levels of collaboration. The shared task (e.g. spending the night together at a RFL assembly) and roles that complement each other (e.g. survivor, caregiver, team captain and so on) create the optimal situation for feelings of unity and the generation of collective identities (Lawler 2003: 146).

Lawler (2003: 135) emphasizes the importance of shared action, as it allows individuals to transition from personal to group concerns through becoming aware of the group and its sense of cohesion. Collective action at RFL assemblies is heavily permeated by what Snow (2001: 7–8) terms 'identity work'. This refers to the many ways in which collective identity is signified and expressed to create a shared understanding of identity within the group. Snow (Ibid.) argues that, in a similar manner, outsiders looking in on the group interpret the shared identity of the group by taking note of its unique attire, adornment, use of collective symbols, and meaning-making through expressive means such as story-telling and ceremonies. The mishmash of identity work that typifies RFL assemblies serves the function of signalling that group members are in an association with one another and that they are set apart and different from people outside the RFL constituency. Identity work demarcates a symbolic boundary around the group. Together, this jumble of identity signifiers and expressive means give symbolic weight to what makes the group distinctive (Ibid.: 8).

The study showed that much of what transpires at RFL assemblies is flamboyant and carnival-like in nature. People not only perform on the track to amuse each other, but also for the benefit of the many recording devices that are constantly capturing images and sending them into the world through social media. What happens inside assemblies is almost instantly relayed to the outside world, making the closed event somehow permeable to a wider audience. Nothing is off-limit in the broadcasting of photographic and video images, and even seemingly raw and tender moments, such as the ones encountered during the luminaria ceremony, readily find their way onto Facebook, Twitter, and Pinterest. Foucault (1986: 26) wrote about heterotopias before the advent of social media, but always recognized their potential to be simultaneously closed and penetrable. This too is the case with RFL assemblies, where participants do a great deal to gain entry into the gathering, but also make the experience accessible to others through virtual means.

#### ***Pivot 4: Illusion***

In this study, the notion of illusion presents itself in three distinct ways. In the first instance, there are the frequent references by RFL participants to the ‘magic’ they experience at assemblies. This has its roots in the collective effervescence of the assembled group and the breakdown of social barriers. Secondly, there is the idealized representation of RFL participants as heroic warriors. Finally, there is the mythological foundation on which the heroic warrior collective identity is built.

Collective effervescence opens the door to transgressive behaviour. Many assemblies walk a tightrope between offering an exuberant, fun-filled event and controlling behaviour that threatens to overstep the boundaries of decorum. The participants have licence to behave with more abandon than they would in their everyday lives. There is a tacit understanding that the cancer cause demands that they throw themselves into the spirit of the encounter. They need to keep themselves awake and entertained for a prolonged period. Were it not for the collective effervescence that fuels acts of transgression, RFL assemblies would be boring affairs that would disband long before sunrise.

The ease of racial integration at most RFL assemblies pricked the interest of the research participants, who recognized that this is not the norm outside RFL. Goffman (1961: 79) takes the view that striking a balance in the diversity of participants in a social encounter raises the level of excitement in the group. He contends that those at social encounters enjoy being

stretched socially, but not beyond the point where they start feeling alienated (Ibid.). The findings of this inquiry showed how often the ease of racial integration at assemblies was noted as unusual and exciting by research participants. However, they also point out that the ‘RFL magic’ of feeling unusually close to others is confined to the assembly and prone to dissolve once they leave the gathering. They instinctively seem to understand that while they are at the assembly they are engaging with something out of the ordinary and indulging in what Hochschild (1983: 33, 35–36) would term ‘deep acting’ – a state of being so deeply entrained that the illusion of unity created by the assembly seems real.

The illusion created during assemblies is of the collectivity as a close-knit force on a symbolic battlefield where participants answer the clarion call to defeat cancer as the antagonist. Le Bon (1896: 53–60) believed that crowds think in images, are drawn to the flamboyant, and that legends and the heroic have particular appeal. Crowds call into play the ‘marvellous and legendary side of events’ (Ibid.: 54), and theatrical representations abound. During RFL assemblies, imaginary and staged performances are treated as real by the celebrants, who make little distinction between the real and the imagined. There is a religious fervour in the way the group focuses on cancer and its determination to put an end to suffering and cancer deaths. RFL as a symbolic battlefield is powerful in the way that it creates illusions and captures the imagination of participants. Assemblies offer an effective vehicle for the use of expressive elements aimed at intensifying collective identity and are highly theatrical, with flamboyantly attired teams, banners, music, dancing and humour. Add to this the inspirational speeches, as well as touching ceremonies aimed at eliciting emotion, and the necessary ingredients are in place to emotionally entrain participants.

An additional benefit of the heavy reliance on symbolic means at RFL assemblies is that it offers people a rare opportunity to take part in what Frank (1991: 129–135) refers to as ‘ceremonies of recovery’. These rituals represent a symbolic emergence from the turmoil caused by the cancer diagnosis and treatment. It is extremely difficult for affected people to find spaces where they can collectively stage ceremonies of symbolic cleansing. RFL makes an important contribution in this regard. The survivors’ and caregivers’ walks are victory parades and are prime examples of ceremonies of recovery. They feed the pride-gratitude cycles that Lawler (2003: 145) writes about and clearly have an important role to play in the intensification of collective identities.

Drawing on the work of Polletta (2006: 168–171) and Frank (2010: 14), I argue that the symbolic identities present at RFL assemblies – heroic warriors, firebirds and the walking wounded – derive from familiar plots passed down through the ages. These symbolic identities are reinvented to suit mass assemblies and the needs of constituents affected by cancer. However, the victim identity (the walking wounded) lacks salience and cannot be regarded as a collective identity in the context of RFL assemblies.

It is evident that collective identity ‘patterns’ itself in response to forces inside the movement, as well as those in the larger environment (Melucci 1995: 50). I see the RFL assembly as a storytelling opportunity from the beginning of the gathering to the very end. Stories that are symbolic, such as the ones told at these assemblies through talk and performance, have what Frank (2010: 37, 137, 202) refers to as stories that have ‘resonance’ or ‘intertextuality’. They are archetypal and reference older versions of themselves, but they are also re-crafted to suit the RFL assembly. None of the storytellers included in this inquiry showed an awareness that they were borrowing elements from archetypal sources. For them, the stories seemed immediate, real and totally compelling. Older editions of the story (e.g. the heroic warrior story, firebird story, and stories about being wounded) shape the narrative and resonate with the current edition. However, not only does the past echo in collective identities, but so does the present. As Melucci (1995: 50) points out, collective identification processes draw from ‘... metasocial foundations like myths, gods, and ancestors, but also from the more recent avatars of God ...’.

It is the function of collective ceremonies and symbols to bind RFL participants by dramatizing their collective identity work to such an extent that the illusion being created becomes more accessible and more believable to the group. The ceremonies and collective symbols used by the RFL movement resonate with their military, funerary and religious roots. Tremendous effort is put into play-acting during assemblies, so that hardly any aspect of the social encounter remains untouched. Participants create a temporary village at considerable expense and with great collective effort. They dress the part and re-enact the same ceremonies year after year, making elaborate use of collective symbols, and offering testimonies to support the creation of shared identity. I suggest that once the imagined (e.g. a united group of heroic warriors) becomes real in the minds of participants, it is also much easier for them to fuse their individual experiences of illness with the imposed dominant collective identity as it is ‘rehearsed, presented and developed’ (Jenkins 2008: 157).

At RFL assemblies, participants re-enact an idealized illness experience that draws upon heroic mythology. The research results show how such an assembly, once participants are emotionally entrained by imaging themselves as a cancer fighting force, becomes a tightly bonded ‘superorganism’ (Geertz 1972: 3). So why is it necessary to work with mythological representations and how does illusion bind participants together during the gathering? It is deeply human to embrace heroic warrior mythology and to treat cancer as the enemy. Frank (1991: 30–31) accounts for the creation of this mythology by explaining that it is a reaction to feeling threatened and being unable to make sense of the experience of illness:

When we feel ourselves being taken over by something we do not understand, the human response is to create a mythology of what threatens us. We turn pain into "it", a god, an enemy to be fought. We think pain is victimizing us, either because "it" is malevolent or because we have done something to deserve its wrath. We curse it and pray for mercy from it.

This personification of cancer is, of course, an important emotional coping mechanism, as it endows an amorphous entity with a name that can be identified and pointed to, and that can be engaged with and collectively acted on at RFL assemblies. It brings the ‘trouble’ out of the dark and into the light, where the collectivity can have some imagined power over it.

We are never free from metaphor and mythology. We live in a world full of symbolic images and their incorporation into our lives is part of who we are as vulnerable people. Sontag’s (1978) valiant attempt to convince people and organizations to let go of symbolic representations was never realized. Clow (2001: 310), in her critique of Sontag’s work on illness metaphors, argues that it is naive to think that it is possible to separate cancer from its metaphors and myths, as these are crucial in helping people to understand the illness. I too contend that mythology cannot be removed from the experience of illness – or from life or death for that matter. Each myth has its place and has the power to act as an identity blueprint for groups of affected people grappling with tough realities. It has become apparent that Sontag’s dream of cancer becoming a purely medical issue as treatment improves will not be realized, and that cancer will continue to be imbued with symbolic associations (Ibid.: 297).

The heroic warrior myth has pride of place at RFL assemblies. It is in this representation that RFL participants find their greatest source of symbolic material. I place the walking wounded (people hobbled by the illness experience) and heroic warriors (those who remain optimistic in the face of the illness) at opposite poles of a continuum. I argue that the victim identity was

inverted to give birth to the heroic warrior collective identity in an attempt to present affected people in a more favourable light. The warrior image is essentially oppositional, as it arose in reaction to the victim identity. By creating a binary with these two group identities, I highlight a third position – that of people who represent themselves as mythological firebirds transformed by illness. These are RFL participants who do not refer to cancer as a bitter enemy, do not shy away from the hardship caused by the illness, and recognize that the experience of illness can be transformative.

I do not believe that any one of the three identity positions is more authentic or appropriate than the other. Each has its place at a particular time in both the individual illness experience and in the life of a mass cancer movement. While all three positions offer emotional shelter, they also come with potential problems when used to prescribe how people should feel, think and react. Just as it is not ideal for groups to become locked into victimhood, it is also not productive to encourage followers always to be optimistic and hopeful. The firebird identity might offer the most choice, with its ability to take on board both vulnerability and perseverance, but not all affected people are able to comfortably straddle both positions and still find the transformational potential they need. There is also the danger that a romanticized idea about the transformational nature of cancer can promote the illness as a catalyst for a ‘... physical, emotional and spiritual makeover.’ (Bell 2012: 584). Cancer can be transformative, but this is not a given; nor is it necessary for people to get cancer in order to grow. None of these representations can be considered ‘authentic’ or ‘inauthentic’ in the final analysis, as they all contain illusionary elements and all offer emotional shelter of one kind or another.

### ***Pivot 5: Emotions***

Without emotions there can be no sense of belonging and collective identities cannot become salient (Melucci 195: 45; Brown et al. 2004: 59). The research participants drew attention to how shared emotional experiences during assemblies act as an accelerant of their sense of belonging to the RFL community. RFL assemblies are particularly rich in emotions. The positive emotions people associate with the solidarity community are so captivating that they ensure commitment, even when objectives are not being met (Flesher Fominaya 2010: 395). Participants are taken on an emotional rollercoaster ride typified by contrasting emotions, ranging from periods of elation to very quiet, reflective moments. For example, the collectivity will watch in awe as survivors take their victory lap around the track, only later to weep in front of the candle-bags of loved ones struggling to survive cancer or those who have

died. This, in turn, is followed by many hours of fun on the track, while people dance, sing, shout slogans and are entertained by troupes of performers. This emotionally charged situation fuels the intensification of collective identities.

Lawler (2004: 146) argues that meaning is attributed to emotional encounters when people find themselves in a situation where there is ample opportunity for social interaction. Lengthy RFL assemblies have a distinct advantage, as interacting participants are confined to the assembly space for at least 12 hours. The entire gathering is geared towards prolonged, high-energy group interaction, and intense emotions are awakened as the shared experience makes room for the negotiation, renegotiation and contestation of collective identities.

These shared emotional experiences have the power to boost both the role identities prescribed by the RFL movement and the symbolic collective identities intensified during gatherings. Drawing on Lawler's (2003: 146–147) and Collins's (2004: 47–101) theoretical propositions about collective identities, I argue that participants interpret the RFL assembly experience by trying to gauge why they feel the way they do. This process of trying to pinpoint emotions becomes part of how they attribute meaning to the situation in which they find themselves. RFL is often credited with redefining fear and shame into pride and optimism through activities such as the survivors' walk and inspirational speeches by role models within the collectivity. A positive engagement during the assembly will initially strengthen commitment to the assigned role identities associated with RFL, followed by the genesis of more symbolic collective identities activated through identity work. Such identities only become salient when the assembly is successful in emotionally entraining participants. When that happens, emotions will be interpreted as meaningful in relation both to the self and to the collectivity. Conversely, the importance of collective identities is diminished when the staging of an assembly misses the mark, fails emotionally to captivate participants, and thus weakens emotional forces. The more successful the collectivity is at staging an enthralling assembly, the more likely it will be to embrace the preferred dominant collective identity.

### ***Generated collective identities***

Polletta and Jasper (2001: 288, 295) underscore the point that some collective identities are movement-generated and are imposed on collectivities, rather than having their genesis during social encounters. The heroic warrior identity precedes RFL gatherings and is offered to organizers in a packaged format at training courses, leadership summits and through a

wealth of resource materials. It is not generated at RFL assemblies per se, but rather is imposed on them by the global RFL movement and then shaped by participants themselves. A received representation, it is interpreted through identity work during the assembly, where it is intensified or weakened, depending on how well the assembly is staged.

Collective identities are not static, but act like vectors that are in tension with one another (Melucci 1995: 50). The dynamic interaction between different collective identities can be characterized as a 'system of relations and representations', and Melucci argues that attempts will be made by participants to bring the different representations into alignment (Ibid.). At RFL assemblies, this system of representation relies primarily on the heroic warrior collective identity which holds sway in South Africa. The secondary and hidden identities too have their genesis in popular discourse and, like the dominant collective identity, are readily available for people to draw on during assemblies. However, the ubiquitous nature of the heroic warrior collective identity suggests little overt tension between symbolic identities at RFL assemblies in South Africa. There are variations, as I showed in Chapter 7, but none of these has sufficient authority to unsettle the dominant group representation.

The symbolic representations used at RFL assemblies are cobbled together by combining illusionary elements, cultural elements from South African society, and views about the illness experience. Collective identities have a rich lineage and according to Snow (2001: 7) are 'not fabricated whole cloth but typically knit together by drawing on threads of past and current cultural materials and traditions, structural arrangements, and even primordial attributes'. In similar vein, Robert Darnton (1999: 101) works with the notion of 'ritual punning', where fragments of, and passing references to, other cultural threads are brought together in a new space to create fresh meaning. These symbolic representations – irrespective of how fleeting or fluid a collective identity is – help the collective to align itself to the social encounter and what it represents, by guiding the group in what to feel, how to think of themselves in the situation, and how the group should represent itself. This is done for the benefit of the collectivity, as well as for external audiences (Snow 2001: 4).

Collective identities tie adherents to the causes they wish to support, and in many instances these identities are 'intrinsically appealing' to followers (Polletta & Jasper 2001: 284). RFL sells its heroic warrior identity as a dream to its followers, who find resonance with it because it is so emotionally appealing, hopeful and positive. Through the imposition of this collective identity, the RFL actively promotes the qualities it wants to see in its followers. The call to

action asks them to unite and fight cancer for all they are worth. Staying positive is seen as a recipe for survival and an insurance policy against death. Positive and hopeful RFL participants are more likely to move the mountains that need to be moved through collective action than a depressed constituency that feels victimized.

I found a proliferation of symbolic representations in the research literature. I follow suit by acknowledging the centrality of symbolism in the way participants work with overarching collective identities. My own research findings pointed at three overarching identities that I conceptualize in their reified form as (1) the dominant collective identity based on heroic warrior mythology, (2) a secondary collective identity based on transformation or firebird mythology, and (3) a third, largely hidden identity, based on victim mythology that I refer to as the walking wounded.

### ***Dominant collective identity***

The heroic warrior identity is king at RFL assemblies in South Africa, and the overwhelming majority of participants throw their weight behind it. Out of the trio of identities considered in this inquiry, the heroic warrior identity best lends itself to being translated into a collective format. Hero stories have an ancient tradition of being performed, through talk and action, in front of crowds, making them a prime candidate for collective identity generation.

In the context of the ‘crisis heterotopia’ (Foucault 1986: 24–25), the RFL assembly sites offer a symbolic battlefield where participants can imagine themselves as heroic warriors determined to fight cancer. The entire RFL assembly is geared towards upholding this overarching, dominant portrayal that gives the gathering its orientation. However, upholding this utopian image during the social encounter calls for energetic collective identity work. Keeping the negative aspects of the cancer experience at bay demands hard work, and this accounts for the flamboyance and expenditure of exuberant energy during these assemblies. Geertz (1972: 7) maintains that embracing an idealized image during the social encounter implies that participants are indirectly acknowledging what is being avoided. Flesher Fominaya (2010: 396) makes a similar observation, pointing out that collective identity generation in essence is oppositional. Heroism disguises the depression, weariness and shame that form an integral part of many cancer experiences and renders the assembly a true ‘enacted utopia’ (Foucault 1986: 24).

It is not mere chance that the dominant collective identity receives such an enthusiastic embrace at RFL assemblies. It earns its keep and works well on many levels. It creates a bulwark against death by portraying affected people as determined protagonists. It counters stigma by inverting negative perceptions associated with victimhood, aligns with the constituency's need to embrace pride in the way the illness is managed and how gratitude towards others is expressed, and defines cancer as an antagonist. It is difficult not to become emotionally entrained by RFL's enthusiasm for the heroic warrior identity, as it is held up to the gathered crowd as the optimal response to the illness experience.

The chief representatives of the dominant collective identity are those participants who are hand-picked to speak to the crowd. The more impact an assembly speaker has on an audience, the more likely she or he will be invited to speak at other assemblies as well. The speakers most likely to be invited are those who are the epitome of heroic warriors. Being called on to work the RFL assembly circuit might start off as affirming, but can become burdensome over time, unless sensitively managed both by organizers and the speakers themselves. The challenge for RFL is not to overuse or burn out their most effective speakers. There are dilemmas contained in the public telling of intensely personal experiences and much of the predicament revolves around telling stories that ring true (Frank 2010: 11). The pressure is especially severe on HoH who attend many assemblies where they are required to retell their stories. I tracked three HoH (Speakers 3, 4 and 6) as they gave their testimonies at different assemblies. In each instance, it was an almost identical retelling of the story, although one of the speakers slightly varied hers by including an update on her recent treatment successes. These performance pieces can turn popular speakers into one-trick ponies, irrespective of how compelling their testimonies are. A tension develops between the storyteller and the story, with the story gradually coming to resemble a bug caught in amber and preserved for perpetuity.

As I shifted my focus from one assembly to another, I found that the collective identity work done during assemblies followed the master narrative closely. There was enormous pressure on participants to be cheerful and grateful. I do not for one moment dispute the value of embracing survivorship, but I do not think it is always appropriate to place unrealistic expectations on people who have to deal with the tough consequences of cancer and its treatment. As a recipe for living with cancer, the heroic warrior collective identity has a great deal to say about maintaining a facade of cheerfulness and hopefulness, but is less able to

deal with vulnerability and suffering. Frank (1991: 123) believes that society has a responsibility to 'see and hear' what people who are sick have to share about the experience, that an ill person should have the room to talk honestly about the cancer experience, and that bystanders should be ready to listen without putting pressure on the person to keep up appearances. In the RFL assembly space, there is little room for this. Bravery in the face of adversity is but one dimension of the illness experience.

### ***Secondary collective identity***

Binaries have mid-points, and somewhere in between the heroic warrior collective identity and the walking wounded are those RFL adherents who see themselves as neither of those things. Instead they view themselves as both empowered and vulnerable. I found that these alternative voices told a different story about how they wished to be represented. Narratives about transformation might not be as strident as the voices of those who embrace the idea of fighting cancer as a foe, but they speak their own truth all the same. Those who embrace the transformational nature of cancer feel no need to use war talk or to idealize themselves as perpetually courageous warriors. RFL participants who embrace this alternative identity refuse to make cancer their defining identity and are able to work with both the tough aspects and the growth aspects of the illness experience. They are proverbial firebirds who are as much about fire and ash as they are about taking flight after the devastation of the illness. The possibility of going back to fire and ash remains firmly in the picture, as the threat of a recurrence of cancer never goes away. The identity work that supported this secondary collective identity attested to the fact that the protagonists are simply human – sometimes strong and sometimes vulnerable – rather than glorious heroes. Transforming and transformed firebirds are people whom I believe are able to 'flow with the experience of illness' (Charmaz 1995: 657), rather than fighting illness tooth and nail or insisting on clinging to their victim identities.

Cancer is the enemy in the minds of many affected people, but this is by no means the only possible response to this calamity. Charmaz (1991: 66) argues that it is possible for people to incorporate the illness into both their lives and their identity. It is made to co-exist with other aspects of the person's life and stops being something that has to be fought off. In his earlier work, Frank (1991: 84) objects to the personification of cancer as the enemy because he does believe that cancer can be separated from the people it affects. He advocates for an integrated body, with or without disease. For Frank (Ibid.), this acceptance of a body that has not been

fragmented into healthy and sick components, with the sick component turned into an enemy, is emotionally gentler on those living with illness. Rather than fighting cancer as the antagonist, changes in the body need to be accepted. Talking about his own cancer experience he writes:

There was no fight, only the possibility of change. Making this possibility real involved suffering and struggle, but not fighting. Thinking of tumours as enemies and the body as a battlefield is not a gentle attitude toward oneself, and ill persons have only enough energy for gentleness. Aggression is misplaced energy. (Frank 1991: 85)

The secondary collective identity lacks salience at the present time at RFL assemblies, and few participants are willing to embrace it openly. This version is more subtle, finely graded and more difficult to translate into a collective format. It simply does not have the same power as the heroic warrior collective identity to emotionally captivate large groups of people. I found that embracing the firebird identity took place mainly in FGIs and was largely avoided in the presence of the full assembly, where the heroic warrior identity was simply too compelling. I do not believe that the secondary collective identity encountered at RFL assemblies presents a threat to the movement at the present time. In many ways, the firebird identity does not show up on the radar of the RFL movement, as it has too many similarities with both the walking wounded and heroic warrior identities. It simply does not register as alien.

### ***The hidden identity***

The group that is left out on a limb are those participants who feel wounded and worn down by cancer. The victim identity is based in shame and naturally tends to hide itself away. The chaotic nature of these stories makes them poor candidates for public performance, so this identity representation is consequently the least likely to be translated into a collective format. However, it is my contention that the walking wounded do have a presence at RFL assemblies. It is *de rigueur* for participants to present themselves as cheerful and hopeful, but I believe that hidden wounds have a way of oozing through bandages and that the cheerful public masks worn at assemblies hide emotions that are infinitely more nuanced than the advocates of the heroic warrior identity would have us believe.

There is little in assemblies to affirm these voiceless participants. It is therefore hardly surprising that this silent group was barely visible in the data, except for the two FGI

participants who shared their feelings of being victimized by cancer (FG1, Participant 4 & FGI 2, Participant 6). I found little evidence of the presence of the walking wounded at RFL assemblies, and those who gave hints about their vulnerability were certainly not willing to draw attention to themselves from podiums. It is difficult for RFL participants who feel defeated, shamed and humiliated by their illness to make their feelings explicit at RFL assemblies, given the dominance of the heroic warrior identity. The zeitgeist is such that the walking wounded have largely been forced underground, and it is only possible to catch glimpses of them in limited testimonies in FGIs, through indirect seepage in assembly speeches when participants talk about past hurt, and in confidences shared about living behind masks or quietly crumbling under brave exteriors (FGI 1, Participants 5 & 6).

Another reason for the low profile of this identity is simply that those who feel wounded by cancer, especially if they experience it as shameful, are highly unlikely to attend RFL assemblies. There is simply too much attention paid to people with cancer at these assemblies, with special treatment (VIP parking, a designated reception area, the reception itself and gifts), special attire (survivors' sashes, T-shirts and medals) and the survivors' walk. This is not a natural habitat for people who feel wounded and wish to be inconspicuous. The enthusiastic celebration of survivorship attracts those who are ready for collective action and want to be part of a group experience, rather than those who wish to remain hidden. Even when walking wounded are in the crowd, they are the sub-group most unlikely to make their presence felt in an environment dedicated to being upbeat, hopeful about survival, and confident that a cure for cancer will be found.

### ***Liquidity and contestation***

Collective identities at RFL assemblies are not uniform, and the liquidity of such identities is evident in the blending with other agendas (e.g. when the cancer issue comes into competition with political, faith, environmental, or LGBT issues) and preoccupations (e.g. when the focus falls on racial integration during assemblies, rather than on cancer). This inquiry confirmed that collective identities are notorious for their refusal to remain absolutely static. Even the heroic warrior identity is not entirely stable, despite the best efforts of organizers to school participants in the idea that they are heroic fighters. Major theorists specializing in collective identity such as Melucci (1995), Polletta and Jasper (2001), Hunt and Benford (2004) and Jenkins (2008) all agree that it is fluid. While most participants embrace the heroic warrior collective identity imposed on them by the RFL movement, some

tinker with it, contest it and, depending on their audience, move between identity representations. This echoes what Polletta and Jasper (2001: 298) say about the liquidity of collective identities: 'It is fluid and relational, emerging out of interaction with a number of different audiences (bystanders, allies, opponents, news media, State authorities), rather than fixed.' A degree of fluidity is inevitable, given that behind the stable collective identity there is a dynamic process, with the collectivity actively trying to align with the preferred collective identity (Melucci 1995: 46, 50). Although the heroic warrior is symbolically present during RFL assemblies, 'a range of diversity and heterogeneity exists' (Jenkins 2008: 157) in terms of how participants respond to it. No matter how much the similarities between participants are emphasized during assemblies, the focus on commonalities cannot completely disguise the differences that nevertheless exist. Inevitably, some participants will attempt to renegotiate or resist the heroic warrior collective identity.

A RFL assembly is an island of acceptance where the cancer experience is honoured and celebrated, but it is also a space where this sense of safety allows wiggle room for the contestation and subversion of the dominant collective identity. A notable feature of heterotopias is their ability to unsettle the things we feel certain about (Soja 1996: 151). I believe that it is precisely the sense of safety at RFL assemblies which creates a margin of freedom for some participants to distance themselves from the heroic warrior collective identity or to vacillate between identity positions. Foucault (1966: xix; 1986: 24) was fascinated by the power of heterotopias to function as enacted utopias that provide consolation and make room for parables and discourse, while at the same time also disturbing, dissolving and tangling myths. This is precisely what we see when we look more closely at how participants work with identity representations during assemblies.

Polletta and Jasper (2001: 290) highlight how acting on behalf of a cause can generate a 'desirable self', one which meets the individual's need for esteem. This can be taken a step further when individuals use their position to promote self-interest under the guise of working for the common good. I found a stark illustration in the group of elite HoH. Some of these hardworking 'poster children' get extra mileage out of their elite status by appropriating certain benefits (e.g. sponsored cars, book promotions, using constant self-references during testimonies, and securing speaking engagements in sought-after destinations). The appropriation of these benefits seems to go unquestioned by their fellow participants. Only half of the HoH included in this inquiry managed successfully to make the 'me-to-we'

transition (Lawler 2003: 141). This allure of the celebrity role ('me') was simply too compelling to allow them the transition to a collective identity ('we') where they would stand in the service of RFL. In these instances, preoccupation with self and self-promotion proved to be irresistible. I found it surprising how well these pseudo-celebrity identities are tolerated and even encouraged by organizing committees, which play along by treating these participants as glitterati. At assemblies, personal, role and collective identities happily interact most of the time. However, there are times when they can be brought into conflict with one another and this example is one such instance.

Embracement of the heroic warrior collective identity was not absolutely uniform and other examples were found in the data of the reinterpretation of the dominant collective identity. Examples included the hybridization of the cancer cause with the environmental cause (Image 7.5), the use of the heroic warrior identity to promote another cause (Image 7.6), and the foregrounding of the racial harmony sub-theme (Image 7.7). In addition to these examples, there were the mutineers on the periphery who seemed largely unaffected by group processes and showed their disregard for the collective effort by behaving badly during assemblies. These individuals acted out by smoking, becoming inebriated, or not showing due respect during ceremonies. Goffman (1961: 78) argues that the transactional rules that apply during focused social encounters dictate what will be tolerated and what needs to be controlled. For the most part, participants know that this is neither the time nor the place to disrespect the cancer cause or what RFL is trying to accomplish. Those who fail to grasp the transactional rules are either ignored (provided the indiscretion is small), diplomatically managed, or disciplined.

Organizing committees which lack the skill to stage impactful assemblies leave room for contestation of the dominant collective identity. Collins (2011: 3) explains that, unless rituals are performed with 'sufficient emotional energy' and the collective symbols appropriated by the solidarity community are honoured, the group runs the risk of losing momentum. The findings of this inquiry showed that organizing committees are not all equally skilled at staging emotionally entraining assemblies. Collins (2004: 50–53; 2011: 3) links strong interactive rituals with robust solidarity, mild rituals with weak outcomes broken by occasional flashes of enthusiasm, and describes weak rituals as 'emotionally cold, leaving participants indifferent, and open to being recruited by rival ritual communities' (Ibid. 2011: 3). This inquiry fully supports Collins's view on this matter.

## ***Conclusion***

Well organized social movements work hard to stabilize the collective identity of the group, making it as coherent as possible. While this maintains the focus of the movement, it inevitably creates some tension, as collective identity generation is a dynamic process that is impossible to ring-fence (Melucci 1995: 46). The findings of this case study showed that there is little threat to the dominant collective identity imposed on the group by the global RFL movement during assemblies in South Africa. By embracing the heroic warrior collective identity, the RFL movement in South Africa is able to (1) strategically use the heroic warrior collective identity to mobilize and retain adherents, (2) further its objective of improving cancer control and working towards its ideal of a cancer-free future, (3) mobilize and retain more than 60 000 volunteers willing to put their weight behind the cancer cause, and (4) navigate its way through an ocean of opportunities and constraints for the benefit both of RFL and CANSA. The RFL constituency is as successful and as united as it is precisely because RFL has such a clear dominant collective identity.

Assemblies that are well run by organizing committees have an exceptional ability to enhance the preferred collective identity. This case study looked carefully at what happens to focused assemblies of people who live with cancer when they are brought together in contained spaces for unusually long assemblies which may last 12 hours or even longer. I found that, once participants are at the RFL assembly, the interaction between individual, role and collective identities becomes accelerated through five pivots – (1) the ephemeral space of the assembly site, (2) their shared focus on cancer, (3) collective action during the gathering, (4) illusion, and (5) emotions – thereby creating optimal conditions for the amplification of collective identities.

The RFL movement has been successful in helping to put a stop to the representation of people with cancer as pitiful victims. The harsh realities of cancer become more bearable when participants are surrounded by others who are similarly motivated to embrace the heroic warrior collective identity and its ideal of fighting for a cancer-free future. Compared to people who stand outside the RFL solidarity community, RFL participants see themselves as a group with a heightened understanding of cancer and sensitivity to the demands made by the illness. They express their collective identity through a rich array of symbolic means including, but not limited to, storytelling, calls to action, pledges, team attire, banners, slogans, emotional ceremonies, music, dance, carnival-like parading around a track, and

collective symbols such as victory arches, candle-bags, illuminated hope signs, angels, crosses, hearts, and colours such as purple and pink. At RFL assemblies, the cancer experience is mirrored, contested and turned on its head. Participants laugh, weep, poke fun at cancer and indulge in war talk in their drive to destabilize the common perception that cancer is a shameful disease.

The collective identity project undertaken during RFL assemblies challenges the notion of victimhood by presenting a flip-side image of victorious cancer warriors and valorizes the preferred identity representation. It is this very process of inversion that makes the heroic warrior collective identity oppositional. However, as the findings showed, the project does not succeed entirely in removing from its hidden core the walking wounded. The dominant collective identity offers followers the gift of a positive, victorious portrayal of themselves, but also has the distinct limitation of discouraging overt vulnerability. RFL assemblies offer hope and support, but the shadow side of these gatherings also begs critical interrogation. It can be problematic when participants are compelled to believe that cancer is the enemy and that they are warriors under a moral obligation to fight back. Some people with cancer never stand a chance by virtue of the gravity of the illness. For others, there is the real prospect of living many more years. Either way, I agree with Frank (1991: 89) that cancer should not be turned into an imagined enemy, as this is an unnecessarily punishing way of living with the illness:

Illness is not a fight against an other, but a long struggle. Some prevail by continuing to live; some prevail in dying. Those who are ill and those who witness illness can only have faith in the wholeness of either outcome. Faith must displace will, just as struggling with cancer must displace fighting against it.

Instead of this aggressive approach to illness, there is an alternative. Charmaz, for example, sees the ability to ‘flow’ with the illness as more adaptive than fighting it. She says: ‘... ill people adapt when they try to accommodate and flow with the experience of illness’ (1995: 657). I agree with this position and argue that RFL assembly spaces need to make more room for vulnerability.

Inevitably the question will arise whether the RFL initiative – and the GCM, for that matter – faces a dilemma in the way people with cancer are represented. There is a growing opposition among scholars to the unquestioning way in which affected people are represented (Frank 1991 & 1995; Kaiser 2008; Klawiter 2008; Bell 2012; Chambers et al. 2012 and others), as

well as in the popular media, as seen in the TED Talk given by hospital chaplain Debra Jarvis (2014), at slam-poetry competitions at universities (Hehir 2014), and in local print media (*Leadership* 2014). A more empathic representation, one that acknowledges that the illness is a rollercoaster ride with ups and downs, and highs and lows, would encourage people to embrace the illness, rather than locking them into a collective identity where they are exhorted to live up to an unattainable ideal. I believe that a more nuanced representation of affected people is inevitable because the tide is turning. I am also of the view that dialling-back the aggressive cancer-fighting rhetoric will result in a more empathic representation of affected people. I contend that there is a tension between the strategic objectives of the GCM, with the use of the tried-and-tested heroic warrior collective identity, and a moral dilemma over the emotional harshness of this identity that is increasingly being highlighted.

By linking RFL assemblies to the epoch in which we live, it becomes clear that an initiative which emerged out of a victim representation and evolved into the heroic warrior representation did so because it needed to counteract stigma. Movements that represent people who are marginalized can use collective identity to advocate for the group and promote its recognition as being worthy of support (Melucci 1995: 47). When dealing with marginalization, a key strategy is to counter it by embracing what seems, on the surface at least, to be a diametrically opposite position. This straightforward embracement of an alternative representation is a hallmark of collective identity generation.

It is possible to conceive of the RFL movement in its current form as a somewhat immature, almost adolescent movement, in the way that it tries to make sense of the illness experience. However, collective movements are dynamic, and RFL will no doubt continue to evolve. Successful movements adapt, change and incorporate new definitions demanded by changing times into their collective identities (Polletta & Jasper 2001: 292). If the heroic warrior identity evolved out of the victim identity, then it is conceivable that, as RFL matures, the firebird identity may in turn evolve from the heroic warrior collective identity. As the spirit of the time changes, it is likely that a more nuanced representation of affected people will be created, room will be made for voices that are silenced at present, and the heroic warrior identity will be tempered. I believe that as RFL matures, a natural progression will allow more expressions of vulnerability into collective identities at assemblies. Once that happens, the RFL movement will be able to take heed of Frank's (1995) call that we should bear witness to all illness experiences.

## Chapter 9

# Concluding thoughts

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### ***Chapter introduction***

One of the challenges I faced with this study was to move beyond the more than three decades I had spent working as a practitioner in the non-profit sector to become a researcher. I had to swop a practitioner's gaze for that of a researcher. Mercifully, I was led slowly into this new world with the aid of fieldwork, my research participants, chosen theorists, supervisors, peers, and the rich data that constituted this project. As a former CANSA employee, I felt I already knew RFL well. However, conducting this inquiry soon proved that practical experience, although important, was not nearly enough to explain the phenomenon under investigation, and I realized that I had a great deal to learn. Curiosity was a useful departure point, but told me little about the intricacies of collective identity as a social phenomenon. Instead, I turned to the hermeneutic circle of interpretation (Patton 2002: 497–498) in order to look at RFL assemblies from different perspectives, while constantly moving backwards and forwards between the big picture horizon and smaller elements. In this way, my interpretive insights gradually developed, and it became possible to move across the divide between what I knew at the outset of the inquiry and what I know today. Fry (2014) describes this crossing of the divide as the big challenge facing hermeneutic researchers. Although I am at the end of this particular inquiry, I remain acutely aware that there is more to learn and to understand about my topic.

In this my final chapter, I summarize my research findings, reflect on the process of becoming a researcher through this study, consider the contribution of the inquiry, and reflect on the lessons learned, the limitations of the research and possible areas for future study. I end by making some concluding reflections.

### ***Summary of research findings***

The central research question in this inquiry was focused on the generation of collective identities during RFL cancer assemblies, the nature of the activated identities, and how these identities relate to the broader debates about cancer and identity.

In response to the question of how collective identities are generated, my findings showed that a dominant heroic warrior collective identity precedes RFL assemblies, is scripted into

these assemblies, and is ever-present in the data included in the inquiry. The heroic warrior collective identity enjoys an advantage over the other two identities, as it is supported by both the role identities prescribed by RFL and the scripted nature of assemblies. Collective identity can be either intensified or weakened. This depends on the extent to which the transition from personal illness identities and role identities into an overarching collective identity is facilitated through the use of the pivots identified in this inquiry: ephemeral space, the shared focus on cancer, the collective action, illusion, and the use of emotions.

In examining the nature of the activated collective identities, I pinpointed a trio of symbolic identities: (1) the heroic warrior collective identity, which was the dominant identity, (2) a secondary identity in the form of the transformed firebirds identity, and (3) an almost hidden identity, the walking wounded identity. I found that assemblies relied heavily on the heroic warrior identity, embedded through symbolism and imposed by the RFL movement on its participants.

Looking at how these identities related to the broader debates about cancer and identity, I found that RFL as a movement is in harmony with the larger GCM. Internationally, the RFL movement is a billion-dollar initiative, dependent for its success on committed volunteers. RFL underpins the work of cancer organizations tasked with offering comprehensive cancer control services. Member organizations are highly dependent on RFL both for their income and for the mobilizing of a powerful constituency. The key to the growth and success of the initiative was its use of the dominant collective identity, and its finely-tuned understanding of how to use elements which amplify it during the RFL assemblies which are the lifeblood of the movement.

While the success of the heroic warrior collective identity is undisputed, a tension was revealed in RFL's reliance on this identity. It acts as a glue to bind the constituency together and contributes to the unity of the movement, but this dependency on a particular group representation comes at a price. Embracing the heroic warrior collective identity benefits the RFL movement and many of its adherents, as it is positive and offers a corrective to the view that people with cancer are victims. However, there is a shadowy side to this representation, as it allows little room for vulnerability and places pressure on the constituency to put up a brave face. The pressure to fight cancer and to treat it as an antagonist is especially hard on those who act as spokespeople for the movement, as well as on those who are worn down, very ill or resist being told how they should react to cancer.

Three sub-questions were used to explore the issues at hand in more detail. The first dealt with how the elements which form the backdrop to assemblies create arenas either for the intensification or weakening of collective identities. The heroic warrior identity did not arrive out of the blue. Instead, it evolved from the mid-1980s onwards as cancer treatment improved, and volunteers began exerting their power in cancer organizations. In particular, the damage done by the victim representation needed to be redressed. RFL followers look to the controlling cancer organizations for guidance on how they should represent themselves. Before being given expression at assemblies, the hegemonic heroic warrior identity is made available to RFL assembly organizers through training courses, leadership summits and a large volume of resource materials. This dominant identity offers followers affirmation, with a beautifully packaged, romanticized vision which boosts the ‘pride-gratitude cycle’ (Lawler 2003: 145) and creates a bulwark against the fear of death. Protagonists embrace an optimistic, one-dimensional interpretation of hope and project their anger about the illness onto cancer as the antagonist.

Immersion in the RFL culture takes place prior to assemblies through collective efforts such as planning and preparation, launches, training sessions and team captains’ meetings. These form a foundation for the generation of emotional energy, collective effervescence and the activation of collective identities during mass gatherings. Both social and physical boundaries are used to create unity among RFL followers and to keep at bay those whom they believe do not have the will to put their weight behind the collective effort to secure a cancer-free future. Those who take part need to meet certain requirements (e.g. register a team, pay a commitment fee, raise money and so on) before they are allowed into the solidarity gathering. Physical boundaries ensure that only those who have legitimate business are given access. Despite these energetic boundary-making efforts, countless images are disseminated via social media while assemblies are still in progress – making them simultaneously closed to outsiders but open to the outside world via social media.

The second sub-question placed the spotlight on how RFL assemblies, once they are animated and in flow, facilitate either the amplification or weakening of collective identities. I found that assembly sites as symbolic battlefields become animated through the performance and talk, which together constitute the collective ‘identity work’ (Snow 2001: 7–8) of the RFL constituency. Collective identities are expressed through rousing music, parading around the track, in ceremonies, shared activities, the display of flamboyant attire

and adornment, and bodies moving together in harmony. The many hours of walking the track are a symbolic expression of endurance which resonates strongly with the parallel process of enduring cancer. A symbolic motivation is given for staying awake by equating the challenge with the long nights endured by those who are ill. Young people and other energetic participants drive high-octane, fun-filled activities to keep everyone entrained throughout the night. There is a tacit agreement to sanction zany behaviour, such as cross-dressing, since this is all for the sake of the cancer cause.

Both ceremonies and collective symbols feed the illusion that participants are symbolic cancer warriors. The ceremonies are made more compelling through the lavish use of collective symbols, and most of these – victory arches, sashes, medals, luminaria bags, crosses, fire, doves and so on – resonate with religious, funerary or military symbolism. RFL thus makes an important contribution by giving affected people a rare opportunity to engage in ceremonies which speak directly to the experience of illness.

Assemblies rely on feelings of both joy and sorrow to emotionally captivate participants. The track offers an arena where teams can give expression to joyful exuberance and carnival-like behaviour. As celebrants become progressively entrained by group activities, the boundaries of conventional etiquette start to soften, making room for the illusion that those taking part are closely bonded and on a shared mission to defeat cancer. Sorrowful emotions find expression through commemorating the dead, and this gives people ceremonial permission for the free expression of grief. Even in the RFL context, however, grieving is not given free rein. Death is explicitly coupled with the hope for survival of those who are still alive, and a time limit is placed on the luminaria ceremony to allow for a speedy return to fun-filled group activities.

RFL uses handpicked spokespeople who are articulate and inspirational to testify to their illness experiences and to offer blueprints on how best to deal with cancer. Analysis of the narratives shows that people were more open to talking about their vulnerabilities during FGIs than in open assemblies. The testimonies at mass assemblies revolve around courage and victory, so some adjust their accounts to reflect the heroic warrior identity once they are confronted with the mass audience. It is notable that all three of the identified storylines – heroes, firebirds and walking wounded – are archetypal, and that the narratives also draw significantly upon the religious feeling that predominates in many of the host communities.

The final sub-question considered how collective identities are embraced, hybridized or disrupted during assemblies. I felt it important to examine how people used expressive identity work to engage with the dominant heroic warrior identity, given just how ubiquitous this overarching collective identity proved to be at the 20 assemblies covered in this case study. The data showed that such assemblies abound with shared activities, commitment talk, the making of pledges, and identity claims confirming adherence to the RFL vision of followers as people who care for one another and are determined to beat cancer. This romanticized image of the RFL ‘family’ or ‘tribe’ encourages them to challenge the stubborn racial divisions in their communities and to reach out to each other. However, FGI participants also drew attention to the fact that this sense of racial harmony rarely spilled over into community life and instead was considered only as a situation-specific hallmark of collective identities at RFL gatherings.

The liquidity of the dominant collective identity was seen in instances where people failed to align themselves with the heroic warrior identity and deviated from the carefully crafted script of the assembly. In some instances, this was simply a case of novices who had not been sufficiently inducted into the RFL culture and were at a loss as to how to give expression to their group membership. In other cases, teams seemed to be torn between cancer and other good causes, and resolved this tension by hybridizing two group identities (e.g. Image 7.5). I also found instances of participants whose first loyalty was to another good cause, but who used the heroic warrior collective identity to counter their marginalization (e.g. Image 7.6), and teams who picked up on somewhat submerged themes, such as racial harmony or the lack thereof (e.g. Image 7.7). However, people who expressed ambivalence about the identity labels of the RFL movement, who openly verbalized their cynicism about the cancer cause, or who behaved badly by smoking, drinking or disrespecting ceremonies were few and far between.

Cancer commands such respect that few RFL participants dare to oppose the preferred collective identity of the movement. Other than a couple of mutineers who overtly disrespected RFL, any distancing from the heroic warrior identity appeared to be unintentional or because people had not thought through the implications of certain identity portrayals or collective actions. Occasionally less than flattering material escapes through the net, such as the amateur YouTube video (CRFLB 2013b) showing downcast survivors, rather than the happy images preferred by the movement. Similarly, I do not believe that organizing

committees that glorify breast cancer at the expense of other cancers are aware that they may be marginalizing those with less romanticized cancers, especially those that remain stigmatized due to their association with lifestyle choices or sexually transmitted viruses.

### ***From practitioner to researcher***

I came to this study having been part of the pioneering team that introduced RFL to South Africa, bringing with me my existing insights into what happens at assemblies. After a break of two years, returning to the world of RFL felt like a homecoming. In this familiar world, I was surrounded by people who were keen to assist me with my research project in whatever way they could. I was not confronted with the same challenges a newcomer would have faced with entering the field or navigating through data collection. Yet there were things that were different. I was back as a researcher, not as a project leader. I could not pretend that I had no history with RFL or ignore the fact that I had a particular grasp of my proposed topic. I was not a clean slate, and this prior knowledge had the potential to be both a help and a hindrance.

RFL has never been researched in South Africa, and as far as I could establish has never received any sociological attention elsewhere. Judging by the reactions of research participants I encountered at field sites, my interest in my topic sounded positively esoteric and my new role as a researcher, for those who knew me from my days as a CANSA employee, was regarded with curiosity. If anything, participants were more interested in my decision to go back to university as a mature student than they were in my research project. In the field, I found myself constantly moving between my position as a former practitioner and my new role as a researcher. CANSA colleagues and volunteers with whom I had long established relationships treated me as though I still worked for CANSA, while new RFL participants encountered me purely as a researcher. Thus I was constantly moving along the continuum of the former insider who had become an outsider.

My path throughout the research process was smoothed by the generous support of people in the RFL world. However, the danger was that this prior involvement might have the power to block out useful evidence and that I would search high and low for proof of those things that I thought RFL people would like to hear. I fretted that past loyalties would curb my critical interrogation of the topic. I also understood that, unless I took up Melucci's (1995: 60–63) challenge to bring my full 'cognitive resources' to bear and produce knowledge about collective identity in all its 'multilevel, multifaceted, often contradictory aspects', this study

might not make a worthwhile contribution. The onus was on me to honour my scholarly responsibility and to make a commitment to giving a frank account of what I had found. The deeper I immersed myself in the data, the more the inquiry developed a life of its own. Gradually, the elements which needed to be highlighted came into view. I still feel some residual anxiety about the findings, but I hope that the project will prove to have intrinsic merit. I continue to care about RFL and the desperate need for effective cancer control in South Africa, in the same way that I care about this inquiry and its findings.

### ***Contribution***

My particular contribution to the debate about cancer and identity was to carry out a case study of collective identity generation in the context of an African member of the world's biggest cancer solidarity initiative. While the ever-growing corpus of scholarly work on cancer and identity has focused mainly on the implications of cancer for personal identity, this study turns the spotlight on collective identity. Collective identity as a worthy topic is supported by many sociologists, among them Melucci (1995), Polletta and Jasper (2001), Snow (2001), Lawler (2003) and Flesher Fominaya (2010). I found the concept theoretically interesting, timely and significant in this era when RFL has developed a significant following in Africa. Prior to this study there was a gap in the research on collective identity generation in the cancer movement, with few bricks in the wall of understanding of the mass health movement and its practices in relation to collective identity activation.

This investigation of the unexplored intersection of cancer and identity in the context of a burgeoning cancer solidarity movement is especially important in an African context. The burden of cancer is on the increase in Africa (Jemal et al. 2012: 4372), and growing numbers of affected people are seeking out collective experiences that affirm and embrace them in their attempts to cope with the illness. This study opened a window onto fascinating narratives and social interaction between participants at mass RFL gatherings. It raises awareness about the effectiveness with which many followers at these assemblies are emotionally entrained and the many ways in which collective identity work feeds a sense of belonging to the RFL constituency. It was revealing to discover how the majority of RFL participants embrace the heroic warrior collective identity handed down by the greater movement – though some adherents do manipulate this identity to suit their own needs.

This type of research is especially relevant for mass health movements such as RFL, which have emerged out of a background in which their adherents historically suffered prejudice and marginalization. It is important to understand how these types of movements deal with identity representation and what makes them so successful. Focusing on collective identity helps both scholars and practitioners to better understand how movements recruit and retain adherents, manage relationships with outsiders, form strategic partnerships, and keep competition at bay – and explains why some members turn their backs on solidarity initiatives (Polletta & Jasper 2001: 283–284, 292, 295–296; Hunt & Benford 2004: 433). In addition, collective identity offers leads about why some people resist recruitment in the first instance.

RFL is by no means unique in its use of the heroic warrior collective identity. It appears to be the universal default position for the vast majority of cancer organizations. I hope that this inquiry will extend the debate about cancer and identity, opening the way for more discussion about how people with cancer are represented. Melucci (1995: 61) makes the point that the study of collective identity reveals the tensions which exist in movements. The present study showed that the heroic warrior collective identity is hegemonic. It is largely unquestioned within the RFL movement, and this at a time when there are rumblings outside RFL from cancer activists, in social media and among scholars about the difficulties inherent in this dominant collective identity. The contestation about the representation of affected people has not found its way into RFL in South Africa to any noticeable degree. Whilst I recognize the many positive spin-offs of RFL membership, I share concerns previously raised by theorists interested in cancer identities about the manner in which people with cancer are represented, especially those who prefer not to put up a brave face, adherents who refuse to be locked into a particular illness identity, the very sick, the weary or the dying (Frank 1991, 1995; Brown et al. 2004; Klawiter 2004; Reisfield & Wilson 2004; Kaiser 2008; Bell 2013; Bell & Ristovski-Slijepcevic 2013; Lewis 2013).

The research questions I posed required me to create theoretical coherence between the main theorists on whom I relied: Foucault on crisis heterotopias (1986), Frank on the experience of illness (1991, 1995, 2010), Snow on collective identity (2001), Lawler on collective identity generation (2003), and Collins on interaction ritual chains (2004). I used theory in a considered manner to design a theoretical scheme in order to make sense of the case study. The inquiry contributes to the stock of available knowledge by integrating and extending

what was previously understood about collective identity activation, cancer solidarity movements, focused assemblies, and the illness experience.

I did not set out to do applied research and my intention was never to come up with a list of recommendations for RFL organizers in South Africa. Even without a convenient label for the phenomenon, the RFL leadership in South Africa already knows how best to activate the heroic warrior collective identity at assemblies and has a good sense of the role this dominant identity plays in sustaining RFL. However, feedback received from the MRG gave me an indication that some of the findings might be of interest to RFL audiences. The MRG found resonance with key findings and showed great insight into the heroic warrior collective identity with its strengths and inherent challenges. I do not anticipate any dramatic changes in the way RFL portrays its adherents in the immediate future, but I believe that in time RFL will scale back its harsh fighting rhetoric as more people distance themselves from the heroic warrior collective identity to make room for vulnerability and a gentler image of themselves. Should this multi-voice study prove to be a small step in making what is hidden more overt and raise awareness of some of the complexity that lies behind the blustery heroism, that would indeed be an unexpected boon.

### ***Lessons learned, limitations and future research***

Given that this inquiry was so much about the representation of people affected by cancer, it is ironic that representation was one of the issues that tripped me up. I did not anticipate for one moment that any of the research participants would object to anonymity on the grounds that this time-honoured research practice feeds into the shame associated with the illness. It is not in the spirit of RFL for people to have their identities disguised. It has been a long battle to get past the fear and shame of the illness and so it was with considerable regret that I stuck to my original decision not use the identities of the people who so generously shared their experiences. Most movement participants consider themselves as advocates, not as victims who need to hide their identities. However, out of consideration for those who shared sensitive material, I chose not to divulge the identities of informants or those referred to in accounts. Where names were mentioned during accounts, I changed them. I realize that RFL is a loud and proud movement, and people want to stand up and be counted. Given the same opportunity again, I would make more room for flexibility during the consent process, allowing those who felt strongly about this issue to carry their personal identities with pride.

Inherent in my chosen theoretical perspective and the design of the inquiry were some limitations. This type of inquiry takes time, and both data collection and analysis demanded intricate, time-consuming work. Almost inevitably it was tempting to return to the analysis again and again, to see if it were possible to make more meaningful connections and interpretations. I found the decision about data saturation easier than the decision about when to call a halt to writing up the dissertation. However, I had to reach a point where I could swim free of the hermeneutical circle of interpretation and reach a reasoned understanding from the safety of an intellectual embankment where I could bring the thesis to a conclusion.

The scope of this study was limited to collective identity generation at RFL assemblies. Other than touching on the role of planning and preparation for assemblies, I did not consider how such identities are maintained from one year's assembly to the next or how compelling they are once RFL participants have returned to the routine of their everyday lives. I did not ask to what extent the heroic warrior identity becomes a permanent feature in the lives of participants or whether it has any enduring emotional benefits. Collins (2004: 81–87) believes that a sense of group solidarity is stored in, and prolonged through, collective symbols. RFL assemblies are awash with such symbols. This line of enquiry would have been interesting to pursue, but was simply beyond the scope of a study already bursting with complexity.

The case study was designed to incorporate data from 20 assemblies from across all nine of the provinces in South Africa. Despite this, the study took moments out of the life of a dynamic and constantly evolving cancer movement and fixed data under a hermeneutic lens for analysis. Such an inquiry can tell part of the story, but not the whole story. It cannot hope fully to account for the generation of collective identities at RFL assemblies, as both the movement and the phenomenon are constantly in flux. Like all studies of identity, at best it can only hope to open a conversation about a topic by delving into what goes beyond the obvious and the unquestioned. It is important to keep Alexander's (2002: 109) words in mind when she concludes: 'A study of identity constitutes something of a chimera: it reifies a momentary transaction, fixes what is constantly in flux; it creates, almost by default, the very essence it claims to deny.' This study opened a window on collective identity activation in the RFL movement in South Africa in a period that spanned from 2008 to 2013. It fixes time, place and participants in the assemblies covered in the study. Since then, the participants have

progressed on their journeys. Some of them have died. Most go about their lives in their communities, secure in their membership of RFL.

As to future research into this topic, I think RFL is highly deserving of more research. From a purely micro-sociological perspective it would be interesting to know who the people are who do not find resonance with RFL and who walk away, and why? As a cancer initiative, RFL has a strong global following, and its constituency is important in supporting the cancer-control efforts of controlling cancer organizations. I hope that this inquiry will open up more research into how the people who belong to solidarity initiatives such as RFL wish to be represented, as well as into alternative symbolic representations that might work equally well for adherents and the cancer organizations to which they look for guidance.

It will be interesting to see how the collective identities used in the cancer movement transform over the coming decade as cancer solidarity movements mature and affected people increasingly assert themselves over their representation, both within cancer movements and in the public discourse. The professionals who currently control both non-profit and commercial cancer interests are unlikely to move away from the heroic warrior identity, but a groundswell of activism in the years to come may well start changing how affected people are represented. Along with theorists such as Bell and Ristovski-Slijepcevic (2013: 411), I realize that issues around the representation of those affected by cancer remain unresolved. Like them, I hope that an awareness of the language used and the deeper subtexts associated with collective identities will become stepping stones to new representations that benefit those grappling with the experience of cancer.

### ***In closing***

I draw the conclusions presented in this dissertation with circumspection. This topic could have been approached in many ways. I chose to do it from a hermeneutic perspective. I set out to construct a corpus of understanding about collective identity generation at RFL assemblies, rather than discovering any ultimate ‘truth’ about it. I hope I have managed to shed some light on the topic and that this study will generate further speculation and interest.

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## *Appendix A: Memorandum of Understanding*

MEMORANDUM OF UNDERSTANDING  
BETWEEN  
ERNA LOUISA PRINSLOO (ID 5610270063085)  
AND  
THE CANCER ASSOCIATION OF SOUTH AFRICA (CANSA)  
FOR THE PROVISION OF ACCESS TO PhD FIELDWORK

This Memorandum of Understanding (MOU) is entered into by and between Erna Louisa Prinsloo, a PhD student at the University of Cape Town, hereinafter referred to as 'the student', and the Cancer Association of South Africa, hereinafter referred to as 'CANSA'. This MOU contains the guidelines for the qualitative research project the student will be conducting into collective identity construction in the cancer movement.

### **1. Timeline**

Fieldwork shall span the period between 1 April 2012 and 31 March 2013. However, the parties shall be bound by confidentiality until such time as the PhD thesis has been completed and has been awarded.

### **2. Confidentiality**

The study is not contentious or political. However, should the CANSA Research Operations Committee upon review of thesis chapters feel that it is in the interest of the organisation to have its identity and that of its programmes disguised this will be done by referring to CANSA as a 'national cancer organisation' and to the initiatives researched as 'assembly-based programmes'.

Both the student and CANSA agree to maintain confidentiality while the study is being conducted.

### **3. Research Requirements**

#### **3.1. Funding:**

The student has received funding from the National Research Foundation and will not rely on CANSA to fund any of the costs associated with her fieldwork. This MOU does not include the reimbursement of funds between the student and CANSA.

#### **3.2. Data sets**

Images, the spoken word and interaction in archival photographs, video recordings, at face-to-face assemblies and during focus group interviews will be analysed using

Miles and Huberman Qualitative Data Analysis (1994)<sup>10</sup>. This study will use six (6) data sets:

1. Ten (10) YouTube video recordings made at face-to-face assemblies in South Africa from 2008 to 2012 (inclusive).
2. Five (5) longer video recordings stored in the CANSA archives produced at face-to-face assemblies in South Africa during the same period.
3. Two hundred (200) archival photographs taken at assemblies.
4. Participant observation with structured interviews at three (3) assemblies in the CANSA Southern Division.
5. Three (3) focus group interviews with the organisers of these assemblies.
6. Three (3) focus group interviews with selected participants at these assemblies.

#### **4. Student Responsibilities**

4.1. The student shall design and execute fieldwork in such a manner that it benefits social science, humanity and research participants while avoiding harm, risk and wrong.

4.2. The student shall design, conduct and report her qualitative study in accordance with recognised standards of ethical research and will conform to the ethical standards of the University of Cape Town. If an ethical issue is unclear the student shall seek to resolve the issue through consultation with her supervisors at the University of Cape Town and the CANSA Operational Research Committee.

4.3. The student will also be responsible for the ethical conduct of others under her supervision or control, e.g. co-facilitators used in focus group interviews. Assistants will be permitted to only perform those tasks for which they are appropriately trained and prepared.

4.4. Co-facilitators and the transcriber<sup>11</sup> used by the student will be required to sign confidentiality agreements.

4.5. The informed consent to conduct participant observation of assemblies and focus group interviews with organisers and participants at three (3) selected communities will be cleared with the *Business Unit Manager: Southern Division*, as well as community leadership two (2) months prior to the student's arrival in any of the three (3) chosen research sites.

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<sup>10</sup> At the time of signing the Memorandum of Understanding I was intent on using Miles and Huberman (1994). However, with the subsequent publication of Bazeley (2013) that builds on the work of Miles and Huberman I decided to use the Bazeley's practical strategies for data analysis.

<sup>11</sup> I decided not to use a transcriber once I started working with data.

4.6. The student shall obtain informed consent from research participants prior to recording focus group interviews. Recording will be used in a manner that will not cause personal identification or harm.

4.7. Fieldwork research will be conducted in accordance with the research protocols for participant observation and focus group interviews designed under the supervision of Dr Jacques de Wet and Dr Johann Graaff of the Sociology Department, University of Cape Town.

4.8. The student will work with CANSA to secure appropriate venues for focus group interviews. Should there be costs involved in venue hire the student will cover this expense.

4.9. The student will be responsible for arranging and paying for all refreshments served during focus group interviews.

4.10. The student shall plan her research so as to minimize the possibility of misleading results.

4.11. The student shall take reasonable steps to protect the rights of all research participants and will exercise due concern with regard the dignity of research participants.

4.12. The student shall provide CANSA with a prompt opportunity to obtain information about the nature, results and conclusions of the research.

4.13. The student will acknowledge the assistance of CANSA in her thesis.

4.14. Copyright in a thesis vests in the student who has written the thesis, subject to the rights of the University of Cape Town provided in rules for degrees, diplomas and certificates. In terms of Rule GP8 of the University of Cape Town, when presenting a thesis for examination, a student shall be deemed by so doing to grant free license to the University to publish it in whole or in part in any format that the University deems fit. The student takes note of this requirement should she enter into an agreement with a publisher to publish their thesis.

4.15. On having been awarded the degree to which this MOU pertains the student will provide CANSA with an electronic version of the thesis via e-mail or CD.

## 5. CANSA Responsibilities

5.1. The CANSA Marketing and Communication Department will assist the student in getting access to five (5) amateur and/or professional produced archival video recording of face-to-face assemblies filmed during the period 1 January 2008 to 30 June 2012 (inclusive).

5.2. The CANSA Marketing and Communication Department will assist the student in getting access to two hundred (200) archival photographs taken at assemblies during the period 1 January 2008 to 30 June 2012 (inclusive).

5.3. The *Business Unit Manager: Southern Division* will assist the student in getting access to community leadership in three towns/cities responsible for staging assemblies and will pave the way for fieldwork research by communicating to these groups that the CANSA Research Operations Committee has approved the research project.

5.4. CANSA regional staff in consultation with the *Business Unit Manager: Southern Division* will assist the student in securing space conducive to focus group interviewing. CANSA will not be responsible for venue costs or refreshments served during focus groups.

5.5. The student will liaise with the *Business Unit Manager: Southern Division* regarding all practical fieldwork requirements and provide the CANSA Research Operations Committee with quarterly updates regarding progress with fieldwork.

5.6. CANSA will identify a suitable member of its Research Operations Committee that has an understanding of qualitative social science research to discuss with the student any data that CANSA might consider sensitive information.

## 6. General Provisions

6.1. Research will be carried out in compliance with South African laws and research outputs will be used entirely and wholly for legal purposes.

6.2. Nothing contained in this MOU shall be construed as creating the relationship of employers and employee, or principal and agent, between the student and CANSA or any of CANSA's staffers, volunteers or service-users.

6.3. For resolution of conflicts between CANSA and the student in regards to the provisions of this MOU a conference call shall be held between a duly authorised representative of the CANSA Research Operations Committee, the *Business Unit Manager: Southern Division* and the student.

6.4. This MOU represents the entire understanding of the parties with respect to the subject matter. No change, modification, extension, termination or waiver of this MOU, or any of the understandings herein contained, shall be valid unless made in writing and signed by duly authorised parties hereto.

Wherefore, the parties hereto have executed the Memorandum of Understanding.

\_\_\_\_\_  
Erna Prinsloo  
PhD Candidate

\_\_\_\_\_  
Sue Janse van Rensburg  
Chief Executive Officer  
CANSA

Dated: \_\_\_\_\_

Dated: \_\_\_\_\_

*Appendix B: Sample Letter – Focus Group Interview*

**ERNA PRINSLOO**

E-mail address: [erna.prinsloo@telkomsa.net](mailto:erna.prinsloo@telkomsa.net)

Prospective Focus Group Participant  
CANSAs Relay For Life East London

1 February 2013

Dear Relayer

This is an invitation for you to participate in a social science research project by joining a focus group interview at the upcoming Relay For Life gathering on Saturday, 16 March 2013.

I am a PhD student in the Sociology Department at the University of Cape Town and I was part of the original team that helped CANSAs introduce Relay For Life to South Africa. I left the organisation three year ago and I am now involved in research to get a deep understanding of what it is about Relay For Life that people find so captivating and how we go about creating solidarity within the cancer movement in South Africa.

I will be running a focus group interview at your Relay For Life from 22:00 (10 pm) onwards and these groups typically last between 1½ to 2 hours. The group discussion is a very informal and relaxed and will give you an opportunity to reflect on your involvement in Relay For Life. I will lead the discussion and will be assisted by a research assistant. The group will be audio-recorded and your name will not be used in my thesis.

I am attaching a sample of the consent form that participants sign when they register for the focus group on the evening, as well as a printed information piece that will give you more background about the project.

Please join us in the stadium room set aside for our group at 22:00 (10 pm) for some light refreshments and an interesting exchange of ideas. The room will have signage on the door, but you are also most welcome to speak to ... or ..., or to contact me should you be unsure about the venue.

You are also most welcome to contact me should you wish to ask any questions about the focus group interview.

With kind regards and much appreciation

Erna Prinsloo



University of Cape Town

Sociology Department

## **Consent Form**

**Title of research project:**

From Victims to Warriors: collective identity construction at cancer movement assemblies in South Africa

**Names of PhD student:**

Erna Louisa Prinsloo

**Department/research group address:**

Sociology Department  
University of Cape Town  
Private Bag X3  
RONDEBOSCH  
7701

**Telephone:**

082 298 6071 (Mobile)

**Email:**

erna.prinsloo@telkomsa.net

**Nature of the research:**

This focus group is a part of a qualitative research project into collective identity generation at cancer movement assemblies (gatherings).

### Participant's involvement:

*What's involved:* a focus group interview with Relay For Life participants on the night of Relay For Life. The group will start at 22:00 (10 pm) and will last approximately 1½ to 2 hours. The group will explore solidarity with the Relay For Life movement and the meaning participants attach to their involvement with the Relay For Life movement.

Refreshments will be served.

### Agreement

- I agree to participate in this research project.
- I have read this consent form and the information it contains and had the opportunity to ask questions about them.
- I agree to my responses being used for education and research on condition my privacy is respected, subject to the following: I understand that my contribution to the focus group interview might be included in the PhD thesis and that I can choose not to be personally identifiable.
- I understand that I am under no obligation to take part in this focus group interview.
- I understand I have the right to withdraw from this focus group interview at any stage.

Name of Participant: \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

Contact details of participant: \_\_\_\_\_

Signatures of PhD student: \_\_\_\_\_

Date: \_\_\_\_\_

## *Appendix D: Focus Group Interview Schedule*

### PRE-INTERVIEW TASKS

During this phase of the focus group interview participants were welcomed, registered for the group, and refreshments were served. The group started with an overview of the purpose of the interview and by reminding participants that different views on topics were welcome and expected, that the interview was being recorded, that it was not obligatory to respond to each and every question, and that all views were important. The consent form was also reviewed prior to participants signing it and before the focus group interview started.

The Krueger and Casey (2009: 35–61) guidelines were used to develop a questioning route for the interview schedule.

### OPENING QUESTION

#### **Discussion Topic 1**

Let us get the ball rolling – tell us briefly who you are and where you fit into Relay For Life?

### INTRODUCTORY QUESTION

#### **Discussion Topic 2**

What is the first thing that comes to mind when you hear the words ‘Relay For Life’.

### TRANSITION QUESTIONS

#### **Discussion Topic 3**

How do you think the general public views people living with cancer?

#### **Discussion Topic 4**

Is there a difference in approach to cancer when you compare those who are not a part of Relay For Life and people who belong to Relay For Life?

### KEY QUESTIONS

#### **Discussion Topic 5**

What does Relay For Life mean to you?

#### **Discussion Topic 6**

What about being here tonight has made the deepest impression on you?

**Discussion Topic 7**

Tell me about ‘making time’ for Relay in your life? Why is this important to you?

**Discussion Topic 8**

Tell the group about your campsite at Relay For Life? What did you do to create it and what is notable about your campsite?

**Discussion Topic 9**

In what way is the Relay For Life experience different to the rest of your life?

**Discussion Topic 10**

Why this involvement with Relay For Life and not another initiative or something else?

**Discussion Topic 11**

Is there a way in which Relay For Life provides a special magic to your community?<sup>12</sup>

**Discussion Topic 12**

What would you miss about Relay For Life if you ever stopped your involvement?

**ENDING QUESTION****Rounding-off**

Have we missed anything? Is there anything else you would like to talk about before we go back to the track?

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<sup>12</sup> Participants in the first FGI recommended that this question be included in the interview schedule.

## *Appendix E: Pilot Study Report*

This report presents a reflection of the lessons learned by doing a pilot study and summarises the aspects of my inquiry that changed as a consequence. Sub-study 1 data was drawn from audio-recordings captured at the annual RFL Leadership Summit, and Sub-study 2 data from two RFL assembly YouTube videos.

### **The purpose of conducting a pilot study**

The purpose was to test a range of elements that might affect the success of the large-scale study. Using the guidelines provided by Van Teijlingen and Hundley (2001: 2) I set out to achieve the following:

- Assess whether my data gathering plan was realistic and achievable.
- Get a better understanding of what resources would be needed for the remaining fieldwork trips: for example, venue requirements and refreshments for the FGIs, audio-visual equipment, and how much assistance I would need from helpers at assemblies.
- Assess the FGI recruitment strategy and make adjustments where necessary.
- Gauge the design of my case study and whether it would deliver the data I hoped to get.
- Test the adequacy of my FGI interview schedule in getting the responses that spoke to the focus areas of my study.
- Pinpoint complicated questions in the FGI schedule that needed to be changed.
- Settle into my role as a researcher and become comfortable with the tools chosen to assist me with my study: the printed research brochure, field notes, digital audio recorder, camera and CAQDAS.

### **Data included in the pilot study**

I used a selection of material from the summit: (a) a focus group interview, and (b) three speeches given by a survivor, a caregiver and an organiser. To this I added two archival YouTube videos made at assemblies in Potchefstroom and West Rand respectively. Six transcripts were analysed as part of this pilot study:

Data type	Background information
1. Audio-recording of a speech given to RFL Leadership Summit by a HoH	Young woman in her early 30s. A cancer survivor of seven years. She is married with two pre-school children. She reflected on her cancer journey and a serious recurrence of her cancer two months prior to giving this address.
2. Audio- recording of a speech given by a RFL organiser	A Chairperson of a RFL. The novice RFL organised by her and her committee mobilised more than 3 000 participants in two-and-a-half months. More than R1 million was raised for cancer services. She spoke about the meaning RFL has for her and her community.
3. Audio-recording of a speech given by a caregiver and RFL organiser	A businessman who is a caregiver to a wife who was diagnosed 10 years ago. He is also an organiser of a RFL. He reflected on the experiences they had had since his wife had been diagnosed and why he values his RFL involvement.
4. Focus group interview	The focus group was attended by six HoH, as well as a caregiver.
5. YouTube video filmed on the West Gauteng (Cook 2008)	Produced at the RFL assembly in 2008.
6. YouTube video produced in Potchefstroom, North West Province (Naude 2011)	Produced at a RFL assembly in 2011.

### Data analysis

I personally gathered the data for the pilot study, imported the material into NVivo, transcribed it, translated from Afrikaans to English where necessary, and then coded the transcripts. Although a slow process, this thorough work with the material allowed me to become closely acquainted with the data.

Once all the data sources were subjected to first-level coding, I generated simple ‘coding by node’ reports to make sure that I was getting adequate coverage of my preliminary theoretical focus areas. I wanted to see how well data would correspond to my study propositions. References to codes were well distributed across all the focus areas and the codes that showed many references across data sources were: (a) role identity: survivors, (b) emotional reaction (later renamed as ‘cancer as crisis’): loss (later renamed ‘sadness, grief and grief-work’), (c) identity talk (later merged with ‘embracement of cause and/or the RFL experience’), and (d) spiritual reactions.

## **Concerns that were addressed and necessary adjustments to the research protocol**

The following areas were highlighted and certain adjustments were needed prior to returning to the field:

### **Concern 1: Establishing whether the plan for data gathering was realistic and achievable**

I was satisfied that the remaining short-term ethnographic trips I had planned, combined with archival data, would give me the data I needed. Practicalities around fieldwork had been considered and access to all the communities had been carefully negotiated.

### **Concern 2: Getting entry into fieldwork sites**

The reception I received at the RFL Leadership Summit was warm and welcoming. People showed a genuine interest in the research project. I was fortunate that I knew a lot of people at the conference and could anticipate much of what would be happening during the three days. It was easy to establishing rapport and I was very fortunate that I could meet contact people for the remaining three assemblies while at the summit. My history in RFL proved to be an advantage with getting entry into research sites. As one of 96 delegates, I easily found my place alongside volunteers, caregivers, survivors, HoH, the ACS delegation, and former colleagues. The contact list in the conference pack showed a ratio of 78% volunteers to 22% staff.

### **Concern 3: Obtaining a better understanding of fieldwork logistics by meeting with RFL organisers**

I met the RFL organisers I would be collaborating with during the remainder of my case study at the RFL Leadership Summit. This enabled me to find practical solutions to a range of logistical challenges I could potentially be facing at open air, over-night assemblies. The organisers gave guidance on where to find suitable accommodation in their communities on those occasions I arrived the day before and/or stayed for another night because I was too tired to drive home after attending an all-night assembly.

We also had an opportunity to discuss the recruitment of FGI participants, how and where to create FGI venues at busy, noisy assemblies, and who best to enlist to assist me with audio-recordings, photography, co-facilitation of FGI, setting up and striking down FGI venues. The contacts made at the summit paved the way for a smooth passage at other assemblies.

#### **Concern 4: Determining whether case study research would render the required data**

I was satisfied that the combination of short-term ethnography, FGIs, audio recordings of speeches and ceremonies, and archival material will provide the necessary data. In short, the pilot study drew on sufficient data sources to cover all aspects that my study will interrogate.

#### **Concern 5: Getting a better understanding of language issues that could affect FGIs**

South Africa is a multi-lingual, multi-cultural country and this is reflected at RFL assemblies and in FGIs. Babie and Mouton (2001: 244–245) recommend the feasibility testing of interview schedules, especially in instances where different cultural and language groups will be included. All the participants in the pilot FGI spoke languages other than English, but English was used as the medium as it was the language that everybody understood and could speak with relative ease. Group members represented a range of cultural groups. With the exception of one question, group members experienced no difficulty in understanding the questions.

There will be a need for me to conduct FGIs in Afrikaans in Worcester and Mossel Bay. I have a good command of the language, the interview schedule has been translated in preparation for these groups, and I got a HoH to edit the interview schedule. This proved to be very useful as he not only has an excellent command of Afrikaans, but was in the pilot FGI and has a sensitive understanding of what I was trying to accomplish.

#### **Concern 6: Testing the FGI schedule**

The interview schedule performed well in the pilot FGI and only minor changes were made to obtain improved methodological coherence:

- Participants were asked for feedback at the end of the interview and they suggested that I add this Closing Question: *Is there a way in which Relay For Life provides a special magic to your community?*
- Careful review of the audio-recording showed that one of the questions was unclear, and it was altered and divided into two questions: *How do you think the general public view people living with cancer? Is there a difference between this view and the way you see survivors in Relay For Life?*

#### **Concern 7: Representation**

The FGI participants in the pilot group were the first to raise concern about representation. I had been so sure that I was doing the right thing by reassuring them about their privacy being

respected and that they would not be named in the thesis. It came as a great surprise when some members of the group pointed out that it was not the 'Relay way' to disguise identities and that this practice could feed into stigma. This left me with a real dilemma as some of the information shared was sensitive and, in some instances, could be hurtful to caregivers. This matter was discussed in supervision and I decided to honour the agreement with CANSA (Appendix A) and the ethical code of my university.

#### **Concern 8: Mastering of research equipment and tools**

The Pilot Study introduced me to digital voice recorders and CAQDAS. I was comfortable with these tools. It was exciting importing photographs, audio-recordings and YouTube videos into NVivo and mastering the features of the programme.

#### **Concern 9: Acclimatising to my new role as researcher**

I had a particular challenge in moving from my past CANSA management position to that of a PhD researcher. The break from the organisation undoubtedly helped, but many of my former colleagues and volunteers in the RFL movement used a default way of relating to me as if I were still an employee. My challenge was to see myself as a researcher and to get others to do the same. I think the pilot study helped, as all delegates received a printed information card about the case study in their conference packs, the research project was mentioned from the podium, and I was very open in the way I recorded sessions at the summit. Facilitating the FGI further reinforced the new role.

#### **Summary**

Time constraints and a looming fieldwork trip meant that there were still eight (8) audio-recordings of speeches made at the RFL Leadership Summit that were waiting to be transcribed and analysed. However, the six (6) data sources that were subjected to initial coding started to give me insight into the study and provided a glimpse into my theoretical focus areas. The early experience of data gathering and analysis aided me in planning better for the remainder of the case study. In summary then, this pilot study provided the opportunity to refine my plan for data analysis, including minor adjustments to my FGI interview schedule. I feel confident that the envisaged design will generate useful data that will be relevant to my study. This feasibility study has determined that the chosen case is researchable.

## Appendix F: Sample Codebook

Example of Codebook captured in June 2014 at a time the coding scheme was still evolving.

2014/06/16 01:02 PM				
Name	Description	Number Of Sources Coded	Number Of Coding References	Hierarchical Name
Affinity link through loved ones	Instances where participants cite a family history as their reason for being involved in RFL.	16	40	Nodes\MFEEM elements\Affinity link through loved ones
Anger	Hochschild (1983) sees anger as the discrepancy between what is desired and what is wanted, and the frustration of not having it.	5	10	Nodes\Cancer and emotions\Anger
Attire & adornment	Attire & adornment as elements in the identity work. Teams typically have a team uniform/outfit. Attire & adornment tend to be flamboyant.	49	60	Nodes\MFEEM elements\Attire & adornment
Banners, posters & their slogans, messages	Banners, posters and the slogans form an important component of identity work. The images and words on banners and posters distil what the group wishes to communicate to the rest of the collectivity.	71	88	Nodes\MFEEM elements\Banners, posters & their slogans, messages
Boundary-making	RFL assemblies are not freely accessible in the same way that a public space might be freely accessible.	6	8	Nodes\Heterotopias\Boundary-making
Broken ritual chains	Contestation: (1) distancing from the cancer experience, RFL identities and RFL, and (2) free-riding. Also included failed rituals and empty rituals.	37	66	Nodes\MFEEM model\Broken ritual chains
Calls to action & pledges	Part of identity talk. These calls to action are common utterances by narrators on RFL videos and are also heard from podiums at assemblies.	19	21	Nodes\MFEEM elements\Calls to action & pledges
Cancer education	Some participants see the opportunity to educate others about cancer as the reason for getting involved and staying involved in RFL. They equate this with saving lives.	12	19	Nodes\MFEEM elements\Cancer education

Cancer the antagonist	In the RFL world cancer is the shared focus and the enemy. Included here are data segments that demonstrate this.	60	112	Nodes\\The antagonist\Cancer the antagonist
Caregivers	Caregivers are people who care about and care for survivors.	22	39	Nodes\\Role identities at RFL assemblies\Care-givers
Celebrities	Some HoH get trapped in their celebrity status and find it difficult to make the 'me-to-we' transition.	26	46	Nodes\\Collective identities\Celebrities
Ceremonies	Ceremonies are an impactful part of identity performances and form an integral part of identity work.	80	114	Nodes\\MFEEM elements\Ceremonies
Collective symbols	RFL collective symbols: luminaria, victory arches, the use of the colour purple, HOPE signs, fire, etc.	100	181	Nodes\\MFEEM model\Collective symbols
Compassion & altruism	An often cited motivational emotion at RFL assemblies. Participants feel they grow through their RFL involvement.	18	54	Nodes\Cancer and emotions\Compassion & altruism
Conflicted warriors	The hero-warrior identity is contested. Here I included data segments that reflect this.	16	34	Nodes\\Collective identities\Conflicted warriors
Dancing	Dancing is a form of expression at RFL. Troupes dance on the field, on the track and on the stage. Some of these performances are carefully choreographed to tell a story, while others are purely for fun.	16	20	Nodes\\MFEEM elements\Dancing
Directing & rousing the crowd	MCs and other performers actively work at directing and rousing the crowd at assemblies. Various devices are used for this: cajoling, humour, admonishing, music, etc.	17	37	Nodes\\MFEEM elements\Directing & rousing the crowd
Embracement of cancer cause and, or RFL	Instances where RFL participants talk or demonstrate (e.g. writing on banners) their acceptance of the cancer cause, RFL and what it stands for.	45	222	Nodes\\MFEEM elements\Embracement of cancer cause and, or RFL
Emotional effervescence	Includes under this code are examples of emotional effervescence at RFL assemblies.	55	115	Nodes\\MFEEM model\Emotional effervescence

Enduring suffering (cancer & assembly)	Enduring suffering is reflected in the assembly. Participants are regularly reminded that 'getting through the night' is symbolic to all the long nights endured by people with cancer.	33	78	Nodes\MFEEM elements\Enduring suffering (cancer & assembly)
Faith leaders	Faith leaders feature at most RFL assemblies as guest speakers. Most are Christian, but some communities go out of their way to include Muslim clergy.	3	3	Nodes\Role identities at RFL assemblies\Faith leaders
Fallen warriors	People that died as a result of cancer, but that are nevertheless honoured and remembered at the RFL assembly.	39	69	Nodes\Collective identities\Fallen warriors
Fear and anguish	Hochschild (1983) sees fear as something threatening more powerful than the person. Many survivors stop trusting their bodies and live in fear of a recurrence.	21	49	Nodes\Cancer and emotions\Fear and anguish
Focus Group Interviews	Data segment that relate focus group interviews.	6	22	Nodes\Research\Focus Group Interviews
Framing participants	The 'interpretive packages' used by RFL participants to understand their group identity.	23	49	Nodes\Identity management\Framing participants
Framing Public	The 'interpretive packages' participants believe that others use to understand them and the cancer experience.	6	24	Nodes\Identity management\Framing Public
Fundraising, sponsorship & incentives	Fundraising is a crucial element in the fun associated with RFL and in creating solidarity. Teams raise funds during the year and at RFL.	22	52	Nodes\MFEEM elements\Fundraising, sponsorship & incentives
Gathering and greeting	The early stages of the assembly that include the creation of the RFL village, the Opening Ceremony and Survivors' Walk.	17	40	Nodes\MFEEM model\Gathering and greeting
Guilt	Hochschild (1983) sees guilt as the person believing that they are responsible for an unwanted event in their lives.	2	5	Nodes\Cancer and emotions\Guilt

Heroes of Hope	These are carefully selected spokespeople chosen by CANSA to represent RFL.	26	43	Nodes\Role identities at RFL assemblies\ International Heroes of Hope
Heroic warriors	Those participants that see themselves as part of a heroic, cancer-fighting army.	100	194	Nodes\Collective identities\Heroic warriors
Hope	A common theme at all RFL assemblies. It is stitched into identity work. This universal concept is understood by different religions.	27	55	Nodes\Cancer and emotions\Hope
Insider	Data segments that reflect my insider position.	6	11	Nodes\Research\ Insider
Logistics	Data segments that relate to the logistics of my inquiry.	1	16	Nodes\Research\ Logistics
Loneliness	Sadness as a result of feeling isolated by the illness experience.	3	3	Nodes\Cancer and emotions\Loneliness
Love	Love, like hope, is seen as being able to transcend the hardships of cancer by some RFL participants.	15	22	Nodes\Cancer and emotions\Love
Music	RFL uses music to create atmosphere at gatherings, to uplift and inspire, to deepen emotion, and to provide entertainment and fun.	36	71	Nodes\MFEEM elements\Music
Organisers	Each RFL has an organising committee with specific portfolios. These volunteers work all year to organise the annual assembly in their communities.	23	32	Nodes\Role identities at RFL assemblies\ Organisers
Outsider	Data segments that relate to my outsider position.	2	2	Nodes\Research\ Outsider
Participant observation	Data segments about the participant observation I did as part of the inquiry.	3	18	Nodes\Research\ Participant observation
Precise, determinate function	The RFL village is a physical, augmented space next to other real spaces in the community in which it exists. It mirrors the community/society around it and has a precise function.	42	73	Nodes\Heterotopias\ Precise, determinate function

Pride	Pride in dealing with the cancer experience.	7	11	Nodes\Cancer and emotions\Pride
Recording	Data segments that reflect the recording of data for this inquiry.	4	4	Nodes\Research\ Recording
Religion and / or spirituality	Data segments that demonstrate religious or spiritual belief.	44	132	Nodes\MFEEM elements\Religiosity
Repressed emotions & denial	Scheff (1979: 63, 65, 125– 127) writes about repressed emotions as ‘under-distanced emotions’. Data segments that speak to an avoidance of emotions or a denial of cancer.	24	34	Nodes\Cancer and emotions\Repressed emotions & denial
Rhythmic synchronisation of bodies	Under this node I include examples of how bodies at RFL assemblies fall into rhythmic synchronisation.	31	41	Nodes\MFEEM mode\Rhythmic synchronisation of bodies
Roller-coastering	Emotionally participants are taken on a roller-coaster ride following the diagnosis. People move between hope and fear/disappointment. Medical setbacks can take a huge emotional toll. This gets reflected at assemblies.	33	83	Nodes\MFEEM elements\Roller-coastering
Sadness, grief and grief-work	Scheff (2003: 256) views grief as another social emotion as it ‘signals the loss of a bond’. Hochschild (1983) sees as the primary focus loss of something/ somebody that used to be available.	34	82	Nodes\Cancer and emotions\Sadness, grief and grief-work
Shame related to abject embodiment	Scheff (2003) views shame and its many cognates as the premier social emotion. Cancer changes bodies through surgery, chemotherapy and radiation. Bodies can become abject and shameful (Waskul & Van Der Riet 2002).	22	73	Nodes\Cancer and emotions\Shame related to abject embodiment
Space-work	The RFL village appears and disappears in 24 hours or less. The village juxtaposes several real spaces in one. It is a physical, augmented space that has illusionary elements. It has public and private spaces.	37	57	Nodes\Heterotopias\ Space-work

Story-telling	Polletta (2006): canonical stories bring immense power to bear on social movements and in shaping collective identity. This code includes examples of story-telling at RFL assemblies.	34	110	Nodes\MFEEM elements\Story-telling
Survivors	People who have been diagnosed with cancer.	68	125	Nodes\Role identities at RFL assemblies\ Survivors
Team captains	Team captains lead teams of participants at RFL assemblies.	3	4	Nodes\Role identities at RFL assemblies\ Team captains
Team members	Team members fall under the control of team captains. All teams have a unique name, banner and attire. They have their own campsite that they occupy and decorate.	77	101	Nodes\Role identities at RFL assemblies\ Team members
Teamwork	Data segments that reflect the use of assistants in the field.	3	8	Nodes\Research\Teamwork
Time-work	Foucault (1986) talks about the time associated with heterotopias as 'slices of time' and 'other time' set aside from our everyday activities. It is a break from traditional time.	39	68	Nodes\Heterotopias\ Time-work
Transgression	The breaking of normal rules of etiquette and flattening of social hierarchies.	46	78	Nodes\Heterotopias\ Transgression
Walking wounded	Despite the pressure to display bravery and to cling to hope, survivors and HoH sometimes let slip that they feel discouraged or wounded.	25	49	Nodes\Collective identities\Walking wounded

## *Appendix G: Database and Research Path Summary*

This enclosure includes the following:

1. Communities included in the case study
2. Overview of sub-studies
3. Key phases of data analysis
4. Summary of peer review and member reflections group episodes.

### *1. Communities Included in the Case Study*

Data was drawn from 20 assemblies that took place between 2008 and 2013. The following assemblies were included in this study and are listed in chronological order: Western Gauteng (2008), East London (2009), Frankfort (2011), Kathu/Kalahari (2011), Polokwane (2011), Potchefstroom (2011), Soweto (2011), Amanzintoti (2012), East Rand (2012), eMalahleni/Witbank (2012), Leadership Summit (2012), Middelburg (2012), Mossel Bay (2012), Nelspruit/Mbombela (2012), Parys (2012), Pietermaritzburg (2012), Worcester (2012), Breederivier (2013), East London (2013), and Potchefstroom (2013). Participants at the National Leadership Summit were drawn from across South Africa.

Other than the data obtained from the National Leadership Summit, all nine the provinces were also represented in the remaining assemblies analysed:

<b>Province</b>	<b>Communities represented in the study</b>
<b>Eastern Cape</b>	East London
<b>Free State</b>	Parys and Frankfort
<b>Gauteng</b>	East Rand, Soweto and Western Gauteng
<b>Kwa-Zulu Natal</b>	Amanzintoti and Pietermaritzburg
<b>Limpopo</b>	Polokwane
<b>Mpumalanga</b>	eMalahleni/Witbank, Nelspruit/Mbombela and Middelburg
<b>North West</b>	Potchefstroom
<b>Northern Cape</b>	Kathu/Kalahari
<b>Western Cape</b>	Breederivier, Mossel Bay and Worcester

## 2. Overview of Sub-Studies

### *Sub-study 1: Short-term ethnography:*

What	When	Where	Strategies used	Data sources for transcription and analysis
<b>Annual Leadership Summit / Pilot study</b>	17, 18 and 19 August 2012 (Additional days were spent beforehand in preparation for the Summit with colleagues from the ACS and CANSA)	Diaz Strand, Western Cape	Participant observation	Field notes
			Focus group interview	Audio-recording
			Recording of speeches and ceremonies	12 x audio recordings
			Photography	20 x photographs
<b>Community assembly</b>	13 and 14 October 2012	Worcester, Western Cape	Participant observation	Field notes
			Focus group interview	Audio-recording
			Recording of speeches and ceremonies	6 x audio recordings
			Photography	20 x photographs
<b>Community assembly</b>	3 and 4 November 2012	Mossel Bay, Western Cape	Participant observation	Field notes
			Focus group interview	Audio-recording
			Recording of speeches and ceremonies	3 x audio-recordings
			Photography	10 x photographs
<b>Community assembly</b>	16 and 17 March 2013	East London, Eastern Cape	Participant observation	Field notes
			Focus group interview	Audio recording
			Recording of speeches and ceremonies	3 audio-recordings
			Photography	20 x photographs

### *Estimates of Number of Participants Included in Sub-study 1*

These estimates were obtained from CANSA and are based on the number of delegates at the National Leadership Summit and on team registration for community assemblies.

<b>RFL Leadership Summit</b>	<b>Worcester</b>	<b>Mossel Bay</b>	<b>East London</b>
96	700	1 250	3 500

### *Summary of Audio-recordings Made During Sub-study 1*

<b>Type of recording</b>	<b>Site</b>	<b>Hours: minutes: seconds</b>
<b>Focus Group Interviews</b> – times excluding the registration of participants, offering of refreshments beforehand, and settling into the venue by the group.	RFL Leadership Summit	1:40:09
	Worcester	1:42:45
	Mossel Bay	0:57:10
	East London	1:16:42
<b>Survivors' Function</b> , including speakers 12, 13, 14, 15	Worcester	2:46:40
<b>HoH Sash Ceremony</b> , including speaker 16	RFL Leadership Summit	0:22:57
<b>Opening ceremony</b> , including speakers 17 & 18	Worcester	0:17:35
<b>Closing ceremony</b> , including speakers 20, 21, 22.	Mossel Bay	0:36:40
<b>Opening Ceremony</b> , including speaker 23	East London	0:12:37
<b>Survivors' Walk</b>	East London	0:12:50
<b>Luminaria Ceremonies</b>	Worcester	0:42:02
	Mossel Bay	0:38:27
	East London	0:11:08
<b>Fight Back Ceremony</b>	Worcester	0:22:48

<b>Assembly speaker 1</b>	Leadership Summit	0:13:52
<b>Assembly speaker 2</b>	Leadership Summit	0:07:52
<b>Assembly speaker 3</b>	Leadership Summit	0:32:36
<b>Assembly speaker 4</b>	Leadership Summit	0:18:09
<b>Assembly speaker 5</b>	Leadership Summit	0:06:53
<b>Assembly speaker 6</b>	Leadership Summit	0:22:25
<b>Assembly speaker 7</b>	Leadership Summit	0:05:30
<b>Assembly speaker 8</b>	Leadership Summit	0:09:10
<b>Assembly speaker 9</b>	Leadership Summit	0:03:56
<b>Assembly speaker 10</b>	Leadership Summit	0:08:18

*Sub-study 2 – Collection of archival material*

*YouTube Video Collection:*

<b>Name of contributor &amp; year of production</b>	<b>Hosting community</b>	<b>Transcribed</b>	<b>Final coding</b>	<b>Recording length</b>
Naude (2011)	Potchefstroom	May 2012	October 2013	0:04:19
Cook (2008)	Western Gauteng	July 2012	October 2013	0:09:41
Relayben (2011)	Soweto	August 2012	October 2013	0:06:58
MediaTag (2009)	East London	February 2013	October 2013	0:08:27
JLT Productions (2012)	Corporate Johannesburg	February 2013	October 2013	0:05:25
Jacobs (2012)	East Rand	May 2013	October 2013	0:06:48
CRFLB (2013a)	Breederivier Luminaria	August 2013	October 2013	0:07:27
CRFLB (2013b)	Breederivier Survivors	August 2013	October 2013	0:04:55
Naude (2013)	Potchefstroom	August 2013	October 2013	0:03:14

***Photographic Collection:***

<b>Hosting community and year of RFL assembly</b>	<b>Transcribed</b>	<b>Final coding</b>	<b>Number of images analysed</b>
Amanzimtoti 2012	February 2013	May 2013	20
eMalahleni/Witbank 2012	February 2013	March 2013	20
Frankfort 2011	March 2013	March 2013	20
Kathu/Kalahari 2011	September 2013	September 2013	10
Nelspruit/Mbombela 2012	March 2013	March 2013	20
Middelburg 2012	March 2013	March 2013	20
Parys 2012	March 2013	March 2013	20
Pietermaritzburg 2012	September 2013	September 2013	20
Polokwane 2011	September 2013	September 2013	20
Soweto 2011	September 2013	September 2013	10
<b>TOTAL NUMBER OF PHOTOGRAPHS:</b>			<b>180</b>

***Number of Participants Captured in Each Category:***

<b>Focus Group Interviews Audio Recordings</b>	<b>RFL Assembly Speakers Audio Recordings</b>	<b>YouTube Videos</b>
25 participants	30 participants	32 participants/narrators

***Focus Group Interviews Participants – Primary Role Identity:***

<b>HoH</b>	<b>Survivors</b>	<b>Caregivers</b>	<b>Organisers</b>	<b>Team Captains</b>	<b>Team Members</b>
6	3	5	3	5	3

*Assembly Speakers – Primary Role Identity:*

IHoH	Survivors	Caregivers	Organisers	Faith Leaders
7	4	4	12	3

*YouTube Videos – Primary Role Identity:*

Survivors	Caregivers	Organisers	Team Captain	Narrators
16	4	5	1	6

*Number of Stories Captured per Role Identity Category:*

Category	Number
HoH	13
Survivors	23
Caregivers	13
Organisers: volunteers	16
Organisers: staff	4
Team captains	6
Team members	3
Faith Leaders	3
Narrators	6
<b>Total:</b>	<b>87</b>

**Note:** Six HoH participated in this study. They all participated in the first FGI. Five members of the group also spoke at the National Leadership Summit. Three of them went on to tell their stories at community-based RFL assemblies in the Western Cape.

### 3. Key Phases of Data Analysis

What?	How?	Why?	Commencement month/year
<b>Initial encounter with archival material</b>	Imported the first YouTube video into NVivo. Transcription/translation process starts	Getting a feel for data and learning how to use NVivo	May 2012
<b>Start list of codes</b>	A priori list based on my preliminary literature review, theoretical framework, CRQ, and study propositions	The chosen short-term ethnographic approach requires a theoretical basis from which to work	July 2012
<b>Initial encounter with short-term ethnography</b>	Short-term ethnography at the annual National RFL Leadership Summit	Short-term ethnography process gets underway	August 2012
<b>Field notes journal</b>	Reflective writing and information about data collection strategies written up in field journal. The journal also included a collection of photographs to act as memory aids and to illustrate the narrative	Together with the memos, this was a key way of capturing my reflections about the research process	August 2012
<b>First-level coding</b>	First-level coding commences on the data collected during the first fieldwork trip. Pilot report written and early impressions formed on themes that might prove to be important going forward	To create an initial structure for thinking about the data	August 2012
<b>Memos</b>	Memos written in NVivo from early on in the analytic process and continued throughout. Memos were coded at a later stage	Memos were used as a reflexive log. Part of reflecting on the research, to capture fresh insight, analytic moves, higher-level concepts	September 2012

<b>Pilot study</b>	Pilot study report	To test my research plan, to establish whether the chosen methods would render the required data, to test the FGI schedule, and to come to become comfortable with audio-visual equipment	October 2012
<b>Concurrent data gathering and analysis</b>	Transcribing, translating, first-level coding of Sub-study 1 and 2 data as progressively more material is introduced into the hermeneutic circle of interpretation. More codes added to the list to the point where the list was too detailed and impractical for accurate coding	Iterative work to get the bulk of the data transcribed and coded	October 2012
<b>Turning point in the research with the emergence of emotions and emotional energy as themes</b>	Return to literature. Incorporation of sociology of emotions and interactive ritual theory literature.	This was necessary as the refinement of codes could only take place with a better theoretical understanding	March 2013
<b>Pattern coding</b>	Sorting and merging codes, as well as getting better definitional clarity. Iterative work between micro-sociological details and the structural aspects of the inquiry.	To refine thinking about the data	September 2013
<b>Creation of three broad data sets that cluster around space, social interaction and generated collective identity.</b>	Data sets created through countless iterations of working through the data.	To capture higher-level codes that could be used to structure the thesis.	September 2013

<b>Coding of memo collection</b>	The collection of 89 memos provided a reflexive log. All memos were written in NVivo and were coded using higher-level codes.	I felt that it was time to integrate memos with the rest of my higher-level codes as I was close to embarking on exploring and describing research evidence.	December 2013
<b>Deepening of analysis</b>	Gradual development of a theoretical scheme encompassing interacting identities and collective identity intensifiers.	To arrive at coherent interpretations.	January 2014
<b>Reformulation of sub-questions</b>	Periodic changes were made in response to emerging understanding of research material.	To ensure an alignment between sub-questions and deepening insight into data.	January 2014
<b>Chapters Write-Up</b>	The account of the inquiry arranged into the chapters of the dissertation	To provide a succinct account of the research project	January 2014
<b>Member reflections group</b>	A member reflections group was conducted in Nelspruit, Mpumalanga on 14 October 2014.	To establish whether research findings resonate with RFL stakeholders.	October 2014
<b>Rounding-off and argument solidified</b>	Bringing chapters to conclusion through a process of making connections, reviewing, refining, editing, and re-writing	A final reflection on the inquiry prior to submission	October 2014

#### ***4. Summary of Peer Review and Member Reflections Sessions***

<b>Aspect of work presented</b>	<b>Group/Audience</b>	<b>Date</b>
<b>PhD research proposal</b>	Thursday Writing Circle, Centre for Higher Education Development, UCT	22 March 2012
<b>PhD research proposal</b>	PhD Collective chaired by Dr Jacques de Wet, UCT	8 May 2012
<b>PhD research proposal</b>	Sociology Department, UCT	14 May 2012
<b>Early stages of analysis</b>	PhD Collective chaired by Dr Jacques de Wet, UCT	15 June 2012
<b>Overview of proposed research</b>	Senior staff of CANSA and the ACS in Hartenbos, Western Cape.	15 August 2012
<b>Fieldwork review</b>	PhD Collective chaired by Dr Jacques de Wet, UCT	30 Nov 2012
<b>Interim case study report</b>	PhD Collective chaired by Dr Jacques de Wet, UCT	18 February 2013
<b>Focus group interviews</b>	Sociology Honours Class and Dr Jacques de Wet	19 April 2013
<b>Overview of methodology</b>	Thursday Writing Circle, Centre for Higher Education Development, UCT	2 May 2013
<b>Preparation for the writing of conference paper</b>	PhD Collective chaired by Dr Jacques de Wet, UCT	6 May 2013
<b>Short-term ethnography: preliminary conference paper</b>	PhD Circle, Sociology Department, UCT	5 June 2013
<b>Short-term ethnography: preliminary conference paper</b>	PhD Collective chaired by Dr Jacques de Wet, UCT	17 June 2013

<b>Short-term ethnography: conference paper</b>	South African Sociological Association, Pretoria	2 July 2013
<b>Emotional roller-coasting at RFL assemblies: conference paper</b>	Society for the Study of Symbolic Interaction, New York	08 August 2013
<b>Emotional roller-coasting at RFL assemblies</b>	Thursday Writing Circle, Centre for Higher Education Development, UCT	22 August 2013
<b>Preliminary analysis and findings</b>	PhD Collective chaired by Dr Jacques de Wet, UCT	26 Sept 2013
<b>Trail of evidence</b>	Thursday Writing Circle, Centre for Higher Education Development, UCT	27 Nov 2013
<b>Ontology, epistemology and methodology overview</b>	Thursday Writing Circle, Centre for Higher Education Development, UCT	23 January 2014
<b>Methodology and methods</b>	PhD Circle, Sociology Department, UCT	11 February 2014
<b>Strategies for enhancing quality</b>	PhD Collective chaired by Dr Jacques de Wet, UCT	03 March 2014
<b>Ethical considerations</b>	Thursday Writing Circle, Centre for Higher Education Development, UCT	08 May 2014
<b>Strategies for enhancing quality</b>	Thursday Writing Circle, Centre for Higher Education Development, UCT	2 July 2014
<b>Findings on space creation</b>	PhD Collective chaired by Dr Jacques de Wet, UCT	5 September 2014
<b>Preparation for member reflections group</b>	Thursday Writing Circle, Centre for Higher Education Development, UCT	2 October 2014
<b>Member reflections group</b>	Volunteers and staff involved in RFL leadership in Nelspruit/Mbombela, Mpumalanga Province.	14 October 2014

<b>Storytelling</b>	Thursday Writing Circle, Centre for Higher Education Development, UCT	27 November 2014
<b>Key findings related to theory</b>	PhD Collective chaired by Dr Jacques de Wet, UCT	11 December 2014
<b>Dissertation Abstract</b>	Thursday Writing Circle, Centre for Higher Education Development, UCT	19 February 2015