THE MEDIATIZATION OF PHILANTHROPY
An ethnographic study of why and how cause-champions are contributing to the
Michael J Fox Foundation for Parkinson's Research.

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Abstract:

This study seeks to better understand the motivations and mechanics of individuals contributing to nonprofits organizations today. Through the prism of our highly "mediatized" (Hjarvard, 2008) social environment, this study examines the individual motivations and actions of "cause-champions" running in the 2013 NYC marathon and fundraising through social media and offline on behalf of the Michael J Fox Foundation (MJFF). To gain the necessary detail and understanding of these micro-actions of an intimate participant group, ethnographic and auto-ethnographic methods are employed. The research has shown that in our current neoliberal context of philanthropy and social media, intrinsic motivations (Shirky, 2010) are an important part of why individuals are compelled to act on behalf of a nonprofit organization, and that these motivations possess both altruistic and self-directed characteristics. Results also show that much of the work produced by these cause-champions, both in-person and through social media, is regarded as "affective" labour (Hardt, 1999) and is characterized by physicality and emotion which helps to build social connections and engagement with the cause.

Keywords: *running, charity sports, intrinsic motivation, civic narcissism, mediatization, social media, philanthropy, affective labour, alliances of suffering*

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This research has been a labour of love, aptly about, a labour of love. My endeavor was to find out more about the capacity individuals have to contribute the greater good through their own physical capital, media and technology. My connection to this research is as personal as the cause of fighting to end Parkinson's disease is. As a researcher-participant in this context, the experience provided for some challenging moments of self-reflection and self-critique which are not always the easiest to manage. I am thankful for the feedback and guidance of my supervisor Mervi Pantti, and the feedback and encouragement of Minna Aslama, Marko Ampuja, Tuula Lehtonen and Yonca Ermutlu at the University of Helsinki.

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This is for my Dad, the best man I've ever known and my inspiration, and my mom, a lady whose strength and love are at the center of my heart always.

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1.Introduction

1.1 My Story and Motivation

I ran cross-country in school growing up, and have always been an athlete is some way, but my journey to become a *cause-champion* began when my father was diagnosed with Parkinson's disease more than a decade ago. I took up the mantle of the cause and fundraised for 'Parkinson's walks' long before there was Facebook, Twitter or Instagram. In 2010, I re-connected with running. I had heard of people running marathons for charity, a phenomenon that was starting to take off in the United States in particular (Mahoney, 2013)**.** I began looking for the right non-profit organization (Parkinson's disease-related) that I could throw my energy behind for this new challenge of endurance running. The longest that I had ever run in the spring of 2010 was 10km. My plan was to run a marathon (42.1km) and raise money and awareness for Parkinson's disease (PD). As I was searching for races to run, I discovered the Michael J Fox Foundation for Parkinson's Research. The more I read, the more it sounded like the organization was in business to go out of business- to end PD, nothing else. It also sounded like a community, a team I could be a part of. The Michael J Fox Foundation for Parkinson's Research (MJFF) offered me a guaranteed entry to the New York City Marathon that November and I pledged to raise funds on their behalf. It was April. In June of that year my father passed away due to complications related to PD. I began running with even more purpose, every step in his honor, and an increasing earnestness to make my efforts matter.

As I trained for that first marathon (2010 NYC marathon) my personal motivation was reinforced by interactions and engagement on social media. As I ran, I began sharing my actions more consistently and as I did I began forging increasingly strong connections through social media platforms with others in the Parkinson's community, and more broadly, runners who were passionate about causes. Since

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that first marathon in 2010, I have run four more, one in Paris and Boston and two more in New York City in support of MJFF. I did not begin running again, or training for that first marathon for Team Fox with the intention to become a cause-champion, I just started running. There was and is something simple and evocative about giving your personal physical efforts towards a cause, the story has become one that has been repeated many times over, to much fulfillment for individuals and benefit to nonprofit organizations.

Without social media my story would not reach those I do not know. I began with Facebook, my most personal network at the time and since have communicated through Twitter, tumblr, Instagram, Vimeo, created my own website with Flavors.me, written for the Huffington Post, and for the blogs of Charity Miles, the University of Helsinki, and the Michael J Fox Foundation. This communication has built connections which have become some of the strongest and most enduring relationships in my life.

I continue to run because I am motivated to contribute to the cause, I want to be a part of ending Parkinson's and run faster than ever (goal to run 2013 NYC marathon in under 3hrs) as a way to share my voice and passion with the world. I also want to understand the larger forces and ramifications related to individual action on social media, the potential power it holds has and the challenges it faces.

1.2 Study Aim and Research Questions

This study has the goal of examining a small group of cause-champions running a marathon to support the MJFF to understand how and why they help raise funds and awareness for the cause and help build community through social media and their offline actions. The behaviors and experiences of these cause-champions shed light on a context that is specific and relevant to the ongoing study of social

media and how individuals can make a difference to a cause in today's mediatized environment.

Research Question 1: What are the motivations for these cause-champions to run a marathon, fundraise and help to build community for the Michael J Fox Foundation?

Research Question 2: How is social media combined with offline action by these cause-champions in ways that enable them to raise funds, awareness and build community for the Michael J Fox Foundation?

1.3 Relevance of study within existing research

This study fills a gap in current literature related to charity sports participation and social media. As stated by Mahoney (2013, 68) there is a clear lack of literature "addressing the intersection of social media and charity sports events." Many recent studies examine the philanthropy in light of its increasing pervasive neoliberal characteristics (Arnesson, 2012; Bajde, 2013; Eikenberry, 2009; King, 2003, 2007, 2010; Nikel & Eikenberry, 2009; Vestergaard, 2011). This study endeavors to show both the potentials and challenges of the actions of individuals working on behalf of nonprofits within this mediatized context. Specifically within the field of social media research, organizational foci are common (Lovejoy & Saxon, 2012; Lovejoy, Waters and Saxton, 2012; Boeder, 2002; Curtis et al., 2010). These studies work to identify the ways that companies and nonprofit organizations can leverage social media as a part of their marketing mix. Even when pointed more precisely at the phenomenon of charity sport events, the studies have focused on how the organization can leverage this type of event to fundraise and build awareness for their cause (Wharf Higgins & Lauzon, 2002) and not the actions and motivations of individuals.

Studies that have focused on the individual versus the organization, have looked at motivation for charity sports participation (Mahoney, 2013; Taylor & Shanka, 2010) or notions of 'active citizenship' as in Nettleton and Hardy's (2006) seminal study of 'charitable bodies' which examined individuals running in the London marathon on behalf of those who cannot. These studies provide insights into individual motivations for event participation and Mahoney's (2013) study specifically shared results on how nonprofits can use of social media to sustain connection of charity sports participants to their cause. Sports ethnography is a area with considerable research and often focuses on the experiences of the individual (Smith, 1998) and distance running specifically (Shipway, 2010). Even ethnographic studies have been done on groups running a marathon and raising money for a nonprofit (Kramer, 2005) but have not considered participant social media use.

1.4 Methods

This study is qualitative, and designed to gain understanding into the motivations and mechanics of building communities through social media and offline action. Ethnographic methods are employed in this study in order to gain an intimate perspective to the actions and behaviors of a small group of marathoners-in-training working on behalf of nonprofits,. Participant observation, semi-structured interviews and auto-ethnographic entries from the researcher-participant were used. Ethnography was chosen because it allows for subjectivity and interpretation to be a part of the discourse of the study; emotions and thoughts are central to understanding the world inhabited by the participants, and in this case the researcher as well, lending to their richness (LeCompte & Schensul, 1999). Ethnographic studies (including auto-ethnographies) are inductive, meaning that the research moves from small details and observations towards

results, generalizations and potential theories. This structure and strategy for collecting and analyzing data is deliberate to allow key trends and outcomes to present themselves over time and be influenced by the rest of the data set. This inductive approach influenced research decisions in many areas of this study, including the sampling, which determined itself based on the engagement and social dynamic within the group of participants. So while the group is small, it is the most appropriate sample to get the richest information precisely because it was not pre-determined or imposed. A version of grounded theory was used to analyze the collected data, a process which began as soon as data started to be collected, or as soon as observations began. Grounded theory involves the coding of data into increased specific and relevant categories over time, in this case the entirety of the data collection period.

1.5 Key Concepts

Mediatization: The growing influence of media on today's social interactions

The most broad of the concepts to be employed in this study is *mediatization.* Mediatization is the process of how the media has come to influence social interaction of all types amongst individuals as well as communication with other social institutions in society. Starting with Hjarvard (2008) as a theoretical basis, and Couldry (2010), Krotz (2007), Schulz (2004), and Vestergaard (2011) for further dialogue, the study examines the influence of media within our current social and communications environment and how it pertains to the world of philanthropy, and ultimately individual cause-champions themselves.

Philanthropy: Origins and charity in a contemporary digital-capitalist context.

The concept of philanthropy does require some contextualization within the current media environment, as well understanding current trends in its application in academia today. Beginning with Van Til (1990) and Sulek (2010) classical definitions are examined. Samantha King's (2003, 2007, 2010) research on the commercialization and branding of Breast Cancer philanthropy explains important dynamics as nonprofit organizations become more market-orientated and mediatized in their strategies and communication. Nickel & Eikenberry's (2009) explanation and critique of what they call 'marketized' philanthropy is important as the political-economy perspective connects our current philanthropic and media environments with other economic, social and political forces at work, particularly in the United States.

Social Media and Affective Labour

A layer beneath philanthropy is the nonprofit organizations themselves. Charity sporting events and their participants, is where the cause-champion is located in the ecosystem. Mahoney's (2013) dissertation shares with us some of the most important motivations for participants in charity events and how nonprofit organizations can leverage the relationships of these individuals to help build awareness for their cause and to build their own communities through social media. Social media is discussed from the optimistic (Castells, 2009 and Shirky, 2010) and the critical (Fuchs, 2014) viewpoints, sharing their most relevant arguments to the context of this study. Taking into account these theoretical foundations, the concept of *affective labour* is discusses for its applicability for both in-person and online as a representation of the work being facilitated by cause-champions. Terranova (2000) and Hardt (1999) provide key discourse here.

The concept of 'intrinsic motivation' (Shirky, 2010) is considered in the context of this study in relation to individuals running a marathon for a charity and sharing their story on social media. This sharing satisfies a need for socialization, including emotional connection with their online and offline communities. In addition to this altruistic motivation is the notion of "civic narcissism" that represents a "preoccupation with the self that is self-directed, but not selfishly motivated. (Papacharissi, 2009, 13). This concept reflects in the self-oriented nature of social media as a communication environment, but also more broadly relates back to current societal norms of citizenship and morality.

1.6 Structure of Study

The presentation of this study will be organized in the following manner: next will be a description of the field of study that was considered. Following that is a review the related literature with respect to relevant concepts: mediatization, philanthropy, affective labour and intrinsic motivation. These sections will provide a more detail of the theories as they relate to the work these cause-champions are contributing to the MJFF. After the literature review is a detailed account of the methods used (ethnography and auto-ethnography). The data analysis process is then be described, followed by key findings with supporting examples from the data and associated theory. Finally, conclusions, limitations and further discussion will pose unanswered questions, and suggest areas for future research.

2. The Research Field: Development of Charity Sports Participation

This section discusses the growth in the nonprofit industry, particularly in the past two decades, from absolute the number of organizations to revenues generated. Nonprofit organizations themselves have also changed as their number has proliferated, from their financial goals and strategy regarding income generation, to the tools and events they employ for marketing purposes. One of methods nonprofits are marketing is through sports events and major city marathons. This section will describe the key characteristics related to these developments, including a description of the nonprofit (the Michael J Fox Foundation for Parkinson's Research) that provides the connection to the cause-champions being examined here.

2.1 Nonprofit Growth

The United States is an example of a nation with a robust philanthropic culture. It "has traditionally been considered unusually 'civic'" (Putnam, 1995, 65). This 'tradition' stems back to observations of America made by Alexis de Tocqueville in the 1830s, and "it was Americans' propensity for civic association that most impressed him" (Putnam, 1995, 65). Nonprofit (charitable) organizations are an important part of the fabric of American society. For example, in the United States, the number of organizations, their revenue and their share of GDP on aggregate has steadily increased, particularly in the last decade. According to the National Center for Charitable Statistics (NCCS), as of 2012 there were more that 2.3 million nonprofit organizations working in the US, producing more than $1.5 trillion in revenues that account for 5.5 percent of US GDP. Also, since 2000, this growth is outpacing business or government in terms of employment change (+17% vs +8%) and wages (+29% vs +23%) (NCCS, 2012). These numbers are particularly impressive as a large portion of the labour connected to the nonprofit

sector is volunteer (which is unaccounted for in the aforementioned statistics). In 2010 this labour was valued at almost $290 billion (as much as all donations from individuals, corporations, foundations and bequests combined). While a poignant example, the United States is not unique in possessing a highly-developed nonprofit sector. The Netherlands, despite its tradition of welfare economics, employs 13% of its workforce in the nonprofit sector, versus 8% for the United States (Burger and Veldheer, 2001).

From a technological perspective, research on how nonprofits utilize social media tools (from an organizational perspective) is relatively limited. The information that has been gathered presents a broad analysis that Nonprofits are increasingly adopting social media tools though they fail to leverage their potential as community-building vehicles, particularly through interactive elements (Lovejoy & Saxton, 2012). A crucial part of building a community online is two-way communication and interaction with the public, which gives the organization real-time feedback and discourse with stakeholders, allowing them to connect more deeply. (Briones et. al., 2011, 39). Lovejoy and Saxton (2012) and their research on the American Red Cross, showed that 58.6% of their tweets were informational and only 25.8% were interactive, or what could be classified as 'community-building,' highlighting an important opportunity for nonprofits generally. Research (Lovejoy, Waters and Saxton, 2012) specifically into nonprofits use of Twitter shows they are not effectively using this tool to maximize constituent involvement. This inability is known to most nonprofits, as is reflected in a survey by the fundraising software company Blackbaud (2013), shows that the majority of nonprofits in the UK see themselves as ineffective in fully leveraging social media tools and are aware of its potential to help grow their community and donor base.

2.2 The Rise of Charity Sports Events

Charity sports events encompass a broad spectrum of activities from walks, to spinning (stationary bikes), to 5k to marathon-distance running, some with obstacles (i.e. ToughMudder races) swimming and triathlons, and endurance cycling events, all for the benefit of a cause or nonprofit organization. Around the world, the popularity of these events has increased as nonprofits have seen an opportunity to leverage new ways to market themselves. Higgins and Lauzon (2003) have noted in their research of Canadian charities, that sports events are becoming increasingly popular and that these special events present an opportunity for new ways for nonprofits to raise funds and build community at the same time. In preparation for these events, and in their execution, a broad section of the nonprofit's constituents are brought together, building a sense of inclusion and facilitating further participation. Samantha King (2003, 307) states of this rise in charity sports events:

> The contemporary association of moral worth with both participation in volunteerism and self-responsibility for one's health and bodily maintenance converges in and is exemplified by the proliferation of physical based fundraising activities.

Participating in a sporting events and fundraising for a nonprofit is described as this 'peer-to-peer' fundraising. Team In Training (TNT), the community fundraising group connected to the Leukemia & Lymphoma Society was one of the first to enter this fundraising arena. Created in 1988, TNT has raised more than $1.4 billion for cancer research (TeaminTraining.org). It is partly due to the success of TNT that so many nonprofit organizations have adopted this fundraising approach. In the United States in 2013, the 30 largest peer-to-peer fundraising events raised nearly $1.7 billion for their respective charities and involved almost 9 million participants. The largest event, American Cancer

Society's Relay for Life generated $380 million in donations and had more than 3.3 million participants (Peer to Peer professional forum, 2014).

Nonprofits in other countries are also seeing growth in revenue streams through peer-to-peer fundraising. In a survey (Blackbaud, 2014) of nonprofits in the United Kingdom, 69% of organizations stated to have received revenue from peer-to-peer fundraising, compared to 38% in 2012 and in their annual global survey (Blackbaud, 2013) reported that two the fastest growing fundraising methods in all countries were social networking and peer-to-peer fundraising. These two aspects define the work being done by cause-champions running marathons and leveraging social media to encourage cause-engagement and donations.

Running Marathons for a Cause

Marathons are growing in number and participation in North America and around the world. In 2013, more than 1100 marathons were run in the United States alone, a new record, with more than 541,000 finishers. This is a 53% increase in finishers compared to the year 2000 (Running USA, 2013), including the largest marathon in history, in New York City, the first on record with more than 50,000 finishers (NYRR, 2014). As major city marathons are increasingly intertwined with charitable causes, providing non-profit organizations with additional revenue streams and marketing opportunities. While the exact number of charity runners cannot be documented, the growth of the charity program for the second largest marathon in the world, the Bank of America Chicago Marathon (2013 finishers: 38,879) is a good indicator. According to Running USA, in the Chicago Marathon in 2006 there were 1,674 runners raising $2.95M for charity and in 2009 there were 8,768 runners with charity entries raising $10.1M for charity. This growth is indicative of a national charity running phenomenon, but is not unique to the United States. The London Marathon is said to be the single biggest fundraising

event in the world. More than 80% of runners participate for charity and in 2010, runners raised $81M for charity (New York Times Blog, 2010). In return for the opportunity to run marathons in the world's greatest destination cities, marathoners become peer-to-peer fundraisers are guaranteed a bib (entry), and in some cases travel and accommodation are a part of the nonprofit's package in return for a guaranteed fundraising minimum each participant commits to. Other than a charity spot, entry to many of the most popular destination city marathons are only procured through a random lottery process (for example, the New York City Marathon).

The Michael J Fox Foundation for Parkinsons Research (MJFF) is the nonprofit that our sample of participants run and fundraise for. The Foundation was started in New York City in 2000 by the actor Michael J Fox with the simple goal to end Parkinson's disease (PD). After being diagnosed with PD in 1991, Fox kept the news a secret until 1998 when his condition affected his ability to work normally. Since 2000, the MJFF has funded more than $450 million in research, making it the largest nonprofit funder of Parkinson's research worldwide (michaeljfox.org). The organization employs 90 people and donates 89 cents of every dollar raised directly to research grants without holding an endowment. Team Fox is the grassroots fundraising program of the Michael J Fox Foundation started in 2006. It is a group of individuals with some connection or interest in curing PD through their own individual or collective (group) actions. Today, Team Fox is made up of more than 1600 members worldwide who participate in a variety of events to raise money and awareness for the work being done by the Michael J Fox Foundation. From hosting pancake events to running in marathons, the events that this group engages in are broad-ranging and can raise anywhere from a few hundred dollars to more than three-hundred thousand. At end of 2013, Team Fox members have raised more than $27 million for Parkinson's research.

Each year the MJFF is competing for peer-to-peer fundraising dollars in the NYC Marathon and other races they buy bib (or entries) for. As an organization they must market themselves to runners, both with a personal connect, and even more so, those without. Each nonprofit sponsoring entries like this will have a minimum fundraising goal for each individual that must be met or the difference must made up by that runner. For the MJFF, the fundraising goal was $3000 for the 2013 NYC Marathon (this is event-dependent). Each runner that signs up and is accepted by the MJFF to run in the NYC Marathon on their behalf receives a Team Fox jersey to train and run the marathon in and supporting tools to be successful as a runner and fundraiser. Among these are a fundraising page that allows the runner to share their story, on which they can attach a photo or video that represents them. This page is where donors can contribute directly to their efforts online. Athletic mentors and coaches are provided to support new and experienced runners with their marathon training. Most nonprofits offering bibs to high-profile races offer similar packages as incentives for runners.

Cause-champion is the term I have chosen to describe the participants of this ethnographic study. Prior to this study, it has been used to describe individuals or stakeholders who are highly-engaged with a cause, working in an awareness-building or advocacy-related role. Cause-champions are not paid by the organizations they champion, they freely give of their time because they typically because they have connection to the cause or simply are highly motivated to act on its behalf. These actions are represented online and offline. For this study specifically cause-champion refers to individuals training to run in the New York City Marathon while raising awareness and funds for the MJFF via social media and other avenues online and offline. To train for a marathon and fundraise for a cause at the same time requires substantial personal investment of time and energy and thus embodies this notion of 'cause-champion' (Cause champion, 2014).

Charity Miles is a free iPhone/Android application that enabled the cause-champions to fundraise additional funds for the Michael J Fox Foundation. Corporate sponsors make a contribution on their behalf to the cause for mile every completed. When miles are completed, the user is able to share the activity with their social network (Twitter or Facebook). This application was a key ingredient in the social media sharing of the participant group. Posts to Facebook and Twitter mentioned the mileage completed, that the miles were being donated to the MJFF as well as an individual statement (for example dedicating the miles to someone, or sharing how they felt about the activity). Charity Miles began in May of 2013 and now has earned more than $1Million for its partnering charities, and more than $210,000 for the MJFF. As of October 17, 2014, users of the app (more than 350,000) have totaled more 5 million miles walked, run or biked (Source: Charity Miles).

3. Literature Review: Cause-champions combine social media and running to become community-builders

This section identifies the key concepts involved and the current, related research. The key concepts are: *mediatization, philanthropy, social media, intrinsic motivation,* and *affective labour.* For purposes of this study, as the term will be referred to often, online 'community' is defined as "any virtual space where people come together to get and give information or support, to learn or find company" (Preece, 2001, 349).

3.1 Mediatization of social interaction

The micro-actions of individuals working as cause-champions on behalf of nonprofit organizations do not happen in a vacuum, they are the manifestation of the social and communications environments that they inhabit. In order to effectively describe and situate these actions, it is necessary to describe the field and forces at work, beginning with the most broad, the meta-process of mediatization. Within this section, the concept, its challenges, and its particular relevance will be discussed.

It is difficult to argue that the influence of media is an important consideration when examining societal interaction. The theoretical construct of mediatization is an effort to explain this. Stig Hjarvard's (2008) article 'The Mediatization of Society' provides its central theoretical basis. Within media studies, the search for a term that describes the effects of the media on society has brought forth different versions of mediatization. Hjarvard's is the strongest, presenting the media and its 'logic' in the most powerful position, while Hepp (2012) and Krotz (2007) describe a more dialectic process of interaction between the media and other social institutions.

While the interaction between the media and social institutions are nuanced, and context-specific, there are general processes within mediatization that provide further insight. Schulz (2004) describes mediatization as having four important processes that change human interaction. *Extend:* communication now can happen across space and time (a process also described by Castells (2009)). *Substitute:* the replacement of face-to-face actions with electronic interactions. *Amalgamation:* the combining of face-to-face interaction with mediated communication, pushing all social interaction together, media becomes ubiquitous. *Accommodate:* People in all social institutions learn to work within the media logic (rules) in that specific institution from politics to business to academia. These characteristics help to identify certain processes and the social pressures exerted by contemporary media. These processes are not uniform, as the medium, society, individual, and social media platform all matter in some way to the extent to which these aspects of mediatization are presence and their ultimate effect. Schulz (2004) and Krotz (2007) state that mediatization is not the media usurping the power from other social institutions in society, but rather forcing them to adapt to the logic of the media, whether it be brevity of messaging, what type of content is most effective, when communication is released, and to where.

Similar to this idea, Hepp (2012) states that mediatization acts with 'moulding forces' which are based on media 'logic' that pervades all other social institutions. Thus, the term also refers to the ways that media channels filter and disseminate information and how individuals interact and communicate with one another. With the pervasiveness of online communication, social routines and communication attached to them become normalized. Mediatization describes the behavior of media logic and its influence on other social institutions, but this influence is always changing, evolving, both with technological advances and evolution of social and cultural norms. Part of what makes mediatization a fluid

concept is that "...by its very definition, (it) is always bound in time and cultural context" (Krotz, 2007, 39). This is particularly evident today in the most developed countries in the world (for example in the United States) where markets for technology communications and its corresponding infrastructure are abundant (Krotz, 2007). Nick Couldry (2003a, 2003b, 2008, 2013) has written extensively on the evolution of media and communication studies and specifically on the concept of mediatization. Couldry and Hepp (2013) state that mediatization is a term to be used to examine the interrelationship of media and our social world. Mediatization in this context has been employed in a number of areas of social research, thus stretching its effectiveness as an analytical concept. While most frequently utilized to research in politics (Mazzoleni & Schulz, 1999), but has also to describe trends in war (McQuail, 2006), and journalism (Kammer, 2013).

While the media is influencing other societal institutions, there are reciprocal forces that act upon the media and influence its logic. Vestergaard (2011) states a less determinist version of the term, and describes the interaction between media and other social institutions as fluid and dialectic. Krotz (2007) adds that other meta-processes such as globalization, individualization and commercialization have a dynamic interaction with mediatization; and there are strong forces action upon the media and its logic at all times. Critical theorists (Ampuja, 2011; Fuchs, 2014) argue against what they describe as the overly "media-centric" theory of mediatization claiming that not enough consideration is given to political or economic circumstances. Critical theorists view the current state of the media as a step an evolutionary process and not an example of epochal change as is espoused by Castells (2009). While Couldry (2013, 199-200) has stated that media research is in need of another term to describe these forces, but that at present mediatization, and its "'logics,' 'forms,' 'objectivations,' 'institutionalizations,' or 'moulding forces,'..." is the best example of the understanding of the media and its power within our social environment. As it pertains to this study, mediatization

is the most appropriate term to describe how the routines and expectations that are a part of our media environment.

3.2 Philanthropy in today's mediatized environment.

This portion of the review examines the notion of philanthropy, and how it interacts and is shaped by the pressures today's media and economic landscape. Firstly, classical definitions of philanthropy are considered, traditionally associated with the human actions of giving of individuals. Following this, the study examines contemporary discourse that places philanthropy, and subsequently, nonprofits and cause-champions into an increasingly 'marketized' environment. This context produces certain types of behaviors from nonprofit organizations, and more intimately, individual cause-champions. King (2003, 2007, 2010) and Eikenberry (2009) provide insight into the characteristics and ramifications of this context.

Jon Van Til (1990, 34) describes philanthropy as "the voluntary giving and receiving of time and money aimed (however imperfectly) towards the needs of charity and the interests of all in a better life." This definition captures the essence of the notion of philanthropy and speaks to the interests of the greater society. Today the notion of philanthropy, and the corresponding strategies and actions of nonprofit organizations have increasingly been connected to processes of mediatization and commercialization. One of most widely known and accepted definitions is offered by Lester Salamon (1992,10) who defines philanthropy as "the private giving of time or valuables (money, security, property) for public purposes" also as "one form of income of private non-profit organizations." The language of neoliberalism is woven throughout contemporary conceptions of philanthropy. In this context, nonprofit organizations have come to resemble businesses, taking on similar strategies for growth and efficiency. "Recent changes in these relationships are compelling nonprofit organizations to become

more market-like in their actions, structures, and philosophies" (Eikenberry &
Kluver, 2004, 133). While nonprofit organizations do not have the goal of profit
per se, their goals depend on financial solvency (and funding programs or
research) and as such must adhere to the economic conditions and expectations of
the society in order to be successful. One of these business-like characteristics is
the partnership with private, for-profit businesses. This phenomenon has blurred
the between marketing and philanthropy (King, 2010). Nonprofits are seeking to
promote their brand to new donors. corporations looking for a ways to
differentiate themselves from their competition have seen philanthropic
affiliations as a gateway to new customer and brand loyalty (King, 2007). Some
of these relationships are problematic as King (2010, 287) writes,

> It is often the corporations responsible for selling products most
> closely linked to deaths from cancer that have been most successful in
> linking their brand image to the disease.

These conditions and relationships presents challenges for nonprofit organizations
as they attempt to manage the mediatized pressures of commercialization and
branding and the responsibilities of education and awareness building.
Eikenberry and Kluver (2004, 138) describe the impact of market pressures as
"compromising the nonprofit sector's civil society roles as value guardians,
service providers and advocates..." Beyond this, it is the consumer, who now
perceives the corporation in a new, positive light as they are connected with a
worthy cause, who does their "moral" duty as a consumer/citizen and purchases
products associated product as a part of their civic responsibility (King, 2010). A
key component of the process of individualization and marketization of the civic
is how it is accomplished. The media, including social media channels, are the
central vehicle for the dissemination of this ideology. As Nettleton and Hardy
(2006) state that media coverage and attention is central to the relationship
between commerce and charity.

These pressures do end with nonprofit organizations. Discourses that connect the individuals and "proper citizenship" and philanthropic activities have increased. (King, 2010). As Nettleton and Hardy (2006, 445) write,

> Conceptualizations of citizenship that embrace 'rights' and 'responsibilities' are now a central part of the state rhetoric as welfare dependency in increasingly view as undesirable.

These notions of citizenry are increasing embedded within this context of mediatization, branding and consumerism. Raddon (2008, 42) describes the current context as the era "new philanthropy," characterized by neoliberal discourse that "exalts a mode of citizenship defined by personal acts of generosity."

3.2 Social Media as a tool for connection and change

The philanthropic environment that nonprofit organizations reside in today is complex and highly mediatized. In the following section perspectives on the potentials and challenges of social media as a tool for nonprofit marketing and individual self-expression are explored. Beginning with Shirky (2008, 2010) and Castells (2009) the optimistic perspective is considered. Following this Gladwell (2010) and Morozov (2009) present the skeptical position and finally, the key critical arguments of Christian Fuchs (2014) are discussed. The study then considers the motivations and actions of individual cause-champions within this mediatized landscape. Affective labour (Hardt, 1999) is used to describe how connections and communities are formed through the emotion laden actions of cause-champions on behalf of the cause. Finally the concepts of intrinsic motivation (Shirky, 2010) and civic narcissism (Papacharissi, 2009) are employed to describe why cause-champions participate in charity sports and share their stories of "running for a cause" on social media.

For the purposes of this study, Mahoney's (2013, 8) definition of social media will be employed:

> Online communities built through communications platforms, whereby individuals collectively create, share and improve information and user generated content while interacting with others.

3.2.1 The Optimistic View, Social Media as a catalyst for change

The predominance of social media research extoll its virtues giving individuals new-found voice, and ability to connect with others, forming unprecedented bonds that defy geography (Castells, 2009). Clay Shirky (2008, 20) states that social media and social software are tools that,

> increase our ability to share, to co-operate with one another, and to take collective action, all outside of the framework of traditional institutions and organizations.

This is where optimists see the transformational aspect of "new media" as a fundamental break from the traditional forms. It is this new-found ability to connect that is the catalyst for social change through individual participation. Shirky (2008, 16) espouses the unprecedented potential of social media, and our new ability to connect with one another, stating that "more value can be gotten of voluntary participation than anyone previously imagined."

Manuel Castells is one of the most cited social theorists writing on new media today. He has written predominantly on the new power and empowerment of the individual within the 'new public sphere' (online). Individuals have gained the ability to live and communicate based on their own personal beliefs and values- it is their uniqueness- their story, that can now be shared. Castells (2009, 362) sees this networked individualism as inscribed in the social structure of our new

networked society, and that it "reconstructs social relationships on the basis of self-defined individuals." Social media is a primary location of this self-definition, it is a place where individuals create themselves through the information they filter and share and through the the stories they tell. Papacharissi (2010, 252) describes this "highly selective version of themselves" as the "symbolic creation" of their world. This sharing is the basis for these new social relationships. Social reality becomes how it is represented online, however the individual may choose to define it. To Shirky (2009) new media is fundamentally changing how individuals interact in society and that their participation- sharing through social media has facilitated a new age of social and public participation.

Axel Bruns also holds the view of that the "new media" have a transformative potential. Bruns' (2007, 2008) notion of "produsage" speaks to how individual, user-generated content is changing how information is produced and shared on the internet through social media tools. He states that this user-led collaborative process represents a paradigm shift in our media environment and will have a "profound impact on social practices, the media, economic and legal frameworks and democratic society itself" (2007, 99). Optimists, as have been reviewed here, perceive the power of social media to be transformational to societies social routines, and thus to expectations and definitions for individual participation.

3.2.2 The Skeptical and Critical view on Social Media: Small Change

Social media has an unprecedented *potential* to connect people. While this potential is an important attribute, skeptics and critical theorists alike argue it should be tempered with thorough examination to understand how and why it is used and its manifestations. Critical theorists posit that the dialectical relationships with other sources of influence in society including political and

economic factors are absent from the optimistic exaltations of the power of social media to bring revolutionary social change.

Malcolm Gladwell (New Yorker Magazine, 2010), journalist and author, wrote one of the seminal pieces on the 'power' of social media in the New Yorker magazine, titled "Small Change: Why the revolution will not be tweeted." He contends that because social media platforms like twitter are based on weak ties, including connections with people one does not even know, and that the potential for 'high-risk activism' is low within networks like this. In this generally skeptical position on the potential power of social media, he does acknowledge anecdotally that there is potential in these weak ties to solve problems on the micro-scale, such as finding a lost cell phone, but not the revolutionary social change that optimists have stated social media has been responsible for.

Morozov (2009) also represents skeptical view of the participation that social media engenders. In his article about what he calls "slacktivism" he states that the online activism is the perfect for a "lazy generation" that gives the illusion that actions taken online are automatic imbued with meaning if they are picked up by the media but actually has no social impact. He states that these digital tools are simply distracting us from the real activism necessary to generate social change.

From the critical view, Christian Fuchs, whose book (2014), *Social Media: A Critical Introduction*, endeavours to separate the real use and benefit of social media from the perception of its power and potential to bring social change. Fuchs (2014) states that critical theory is always political and works from the position of analyzing structures of domination within society. From this perspective, he writes that while social media provides more potential for connection amongst individuals with like interests, the power that resides in these connections, and within each individual is inherently unequal. The potential influence or power that one has online still is rooted in existing power relations

offline and is situated within the larger power structures of society. It is rooted in historical, political, technological developments over time, social media being one of these developments, and accordingly social media as a communications tool acts as an extension of the exisiting power structure.

Social media and the online public sphere are not interpreted by critical theorists as transformational tools to deliver social revolution but the next stage of advancement or modernization, and ones that come with their own challenges and discourses. Critical theory acknowledges that the potential for connection through social media and the latest technology is greater than ever, but it also reiterates that this potential and individualized power is working within the capitalist economic framework and is influenced by forces and interests of corporations seeking to exploit the efforts (labour) produced by individuals.

3.3 Affective Labor: Physicality and emotion facilitate connection

Affective labour is not 'work' in the tradition sense, particularly on social media. It is made up of conversations and connections and the sharing of content and communication amongst individuals online. Hardt (1999) describes affective labour within a larger content of immaterial labour and that it is defined by its emotive dimension. Affective labour also holds a physical or bodily aspect which stems from its feminist roots in critique of women's labour (Smith, 1987). Many of the products of affective labour are intangible, including, "a feeling of ease, well-being, satisfaction, excitement, passion-even a sense of connectedness or community" and ultimately what affective labour produces are "social networks, forms of community, biopower (Hardt, 1999, 96). These immaterial and emotive actions have the same community-building potential in virtual environments as

they do in-person (Hardt, 1999). Terranova (2000, 38) notes that this digital-affective labour is often characterized by "forms of labor we do not immediately recognize as such: chat, real-life stories, mailing lists, amateur newsletters, and so on." In the case of cause-champions, their engagement on social media: sharing marathon training updates, commenting on other runner's posts, and posting photos of their activities is precisely what can drive connections and build community. Hardt (1999, 90) describes the significance of affective labour:

> The processes of economic postmodernization that have been in course for the past twenty-five years have positioned affective labor in a role that is not only directly productive of capital but the very pinnacle of the hierarchy of laboring forms.

Hardt is stating here that not only do affective actions (social interactions, connection, feelings and emotion) produce capital as well as immaterial assets that include relationships and the sense of community, but that these actions are becoming the most characteristic labour type in our information-based society. More specifically in the online environment, the provision of affective labour "is a fundamental moment in the creation of value in the digital economies" (Terranova, 2000, 36). Castells (2009) acknowledges the primacy of emotion in social interactions specifically on social media. This emotionality is a common thread throughout the affective labour of cause-champions and messaging seen from nonprofit organizations hoping to build new connections and brand loyalty to their cause. Chouliaraki (2010, 118) states that "without emotion, no appeal to action could be legitimate." Nonprofits need to create affective responses from the target audiences in order to compel them into action, whether it be donating to the cause, or taking up the mantel themselves and participating in their own charity event and fundraising.

From the organizational perspective of nonprofits, research has shown that it is this personalized, interactive dialogue that builds connections and communities online and through social media tools (Kent & Taylor, 1998; Lovejoy & Saxton, 2011). Mahoney's (2013) research also showed the importance of nonprofit interaction through social media. Evocative, personal stories of challenge are used to engage communities, profiling the actions and journeys of individuals. The use of these "origination" stories (Thorpe and Rinehart, 2012) are effective tools to elicit hope through what they call "technologies of affect," and this is the emotion connection that serves to compel engagement.

As Throsby (2012, 2-3) argues, all charitable fundraising in sport relies to some extent on the "trading of suffering for donations," but that when it comes to endurance events, like marathons and beyond, that "suffering - as a facet of the excessive or extreme nature of the practice - becomes the defining feature." For example, when a person who is not a runner, decides that they will run for more than four or five hours, and for 26.2 miles, the significance of this personal challenge is a key driver for eliciting support and donations. It is important to note that this suffering is always contextualized as a part of overcoming the obstacle ahead, a part of the challenge, not a reason to stop, or a consideration to dwell on. The themes of physicality and emotion (suffering) goes beyond just the individual contribution. As Nettleton and Hardy (2006, 451) note:

> The media commentaries and the strategies adopted by charities construct
> an image of a communal event that brings individuals into a collective
> struggle so that they can utilize the 'physical capital' of their own bodies in
> order to 'give' to those with 'sick' bodies.

This refers to the phenomenon of the mass marathon, and the partnership with charity organizations to present examples of what Hart-Brinson (2011) would call physically, morally and socially fit citizens regardless of what cause each is running for.

Positivity is a consistent thread amongst the studies analyzing the communication connected to nonprofits and the telling of individual stories as marketing. The "tyranny of cheerfulness" is what King (2010) describes as the message of breast cancer philanthropy. King's (2003, 2007) research on the portrayal of women with cancer shows that as nonprofits are increasingly aligned with corporations and act with similar goals and strategies as their for-profit counterparts, happiness rules. King (2010, 287) states that despite its horrific effects on so many women, that due to its pretty pink packaging and affiliated sponsors and products, "it has become increasingly hard to think of the disease as an injustice to rally against rather than an enriching and affirming experience."

There are concepts that attempt to describe how the value produced through affective labour, and more specifically the resulting connections, relationships and community can be translated into capital or power. Social capital is the most often cited descriptor that seeks to measure this value and potential. The most nuanced and applicable definition to be associated is from Pierre Bourdieu (1985, 248), "the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition..." The second concept associated with the manifestations or products of affective labour is called *biopower*. This Foucauldian term is defined by Hardt (1999, 98) as "...the production of collective subjectivities, sociality and society itself." The endeavor to quantify the value of the affective labour of cause-champion is beyond the scope of this study, but does show how affective labour is being considered theoretically and how it can be translated into capital and power, online and beyond.

3.4 Motivations for Charity Sports Participation and Social Media Use

In this section, this study will consider the motivations present for participation in a charity sports event. Here the study seeks to understand the self-directed nature of this participation and connect it with current literature related to altruistic intensions. Following this, the concept of intrinsic motivation is applied to social media communication specifically.

In Ryan and Deci's (1985) research and development of self-determination theory, they made a fundamental distinction between types of motivations to better understand why people are compelled to act. At the most basic level, individuals are motivated either by intrinsic or extrinsic sources. The difference being that intrinsic refers to "doing something because it is inherently interesting or enjoyable," while extrinsic means "doing something because it leads to a separable outcome" (Ryan and Deci, 2000, 55). These distinctions allow for the situating of intrinsic motivation to be reviewed.

*"*To be motivated means *to be moved* to do something." (Ryan & Deci, 2000, 54) Being moved requires emotion. One of the most common starting places for charity sports participation, particularly a endurance or challenge event like a marathon, is a personal or familial connection. Throsby's (2012) describes this connection as a specific type of "alliance of suffering." The associated motivation is connected with the cause is "memorialisation," or the idea of participating or running *for someone*. The suffering endured by the participant to complete the event is drawn on as a parallel to the suffering endured by the person they are participating or running *for*. This concept of memorialization is repeatedly seen at charity events as participants' shirts often have photos or names of who they are honoring with their efforts and fundraising.

The majority of research on charity sports participation has stated that a primary motivation is the cause. Bennett, Mousley, Kitchin and Ali-Choudhury (2007), Hendriks and Peelen (2013), and Mahoney (2013) each showed that the "cause" was the most consistent motivation for participant in a charity sporting event. This can be simply an extension of the personal connection that has just been described, but also represents a wholly different cohort of participants. The idea is that these participants "want to do something good for someone else," though there may not be a specific individual identified as the "recipient" of their fundraising efforts. Throsby (2012) states that this is also an "alliance of suffering," and one that serves to inspire the participant to accomplish their challenge. Much like those with a specific recipient in mind, participants who simply "run for charity" also ally their suffering with those of the charity's recipients (albeit in a more general sense). What is described here is an altruistic motivation, but as Throsby (2012, 2) claims, "Giving (and therefore, fund-raising) is always *more than* altruism."

There is always another component, one related to the self, an intrinsic form of motivation. As Hart-Brinson (2011, 31) notes of civic recreation that "It feels good to actually *do* something for a cause you believe in." This feeling, this sense of doing good is a motivation for charity action and has been identified as a key motivator for charity involvement. An important component of this motivation associated with the self is the notion is to be seen as a "compassionate and socially engaged individual" (Throsby, 2012, 3) As Nettleton and Hardy (2006) the display of a fit body is the display of good citizenship. As such there is a perception of reward socially from participating in a marathon (in this case) for charity. Hart-Brinson (2011, 31) also engages this notion of citizenship and charity sports engagement, stating that "civic recreation tries to unite the value of individual fitness with judgements of social and moral fitness in a *healing* way." Other studies have also made the same connection between charity sports

participation, voluntarism and acts of philanthropy and notions of morality (Raddon, 2008) and citizenship (King, 2010).

 As endurance charity event participation goes, the sense of accomplishment a runner feels is an important motivator for action and fundraising for a cause is a necessary counter to the "inevitable self-directedness" of training and preparing for an endurance event. Throsby (2012) has found that there is pressure on participants of endurance events to dedicate their efforts to someone or to a cause and states that it is socially risky to simply participate "for yourself" as you can be perceived as "excessively self-absorbed."

Social media communication also requires motivation. Many of the reasons given for participating in charity sports events thread through individuals' sharing on social media as they leverage their online networks to fundraise and share their story. Specifically related to social media sharing two examples of motivation are considered. "Intrinsic motivation" and social media communication put forth by Castells (2009) and Shirky (2010) and the concept of "civic narcissism" (Papacharissi, 2009).

As it pertains to the idea of self-fulfilling labour online, Clay Shirky (2010, 88) states that "social media rewards our intrinsic desires for membership and sharing as well." This desire to share and to be a part of a community is a fundamental part of new media and social media platforms. Social media has proven to be a powerful tool for communication and for sharing information and stories (Hanna, Rohm & Crittendon, 2011; Shirky, 2011) and building community beyond the reaches of traditional media (Castells, 2008, Shirky, 2009). In his analysis of online communication and interaction, Castells (2009), stated that it is our heart, our feelings, versus our cognition, that drive the conceptualizations of ideas, affiliations and ultimately, loyalty- whether it be to an individual or to an

organization. The sharing of this information, particularly personal and emotional is intrinsic to how individuals interact online, is a primary source of meaning-making and community-building in the context of new media (Pantti & Tikka, 2013, Shirky, 2010). This action attracts others to engage, share feedback and validation and connections form and deepen.

Both Shirky (2010) and Castells (2009) have written of this 'intrinsic' motivation to share as a important characteristic of social media, and most relevant for our study is how this motivation drives the affective labour that contributes to online community-building. "Adding the social motivations of membership and generosity to the personal motivations of autonomy and competence can dramatically increase activities." (Shirky, 2010, 172) The motivation to be a part of a community online, particularly one with deeply personal passions and interests (i.e., a specific cause or nonprofit organization) can be an highly engaging context for communication, affiliation and support. The development of these relationships satisfies intrinsic motivations of individuals. Individuals that feel intrinsically motivated give their affective labour largely voluntarily and openly as the work is enjoyable and fulfilling.

Papacharissi (2009, 13) states that web 2.0 communication channels (social media and personal blogs) thrive on personalization and self-expression, and that within an environment that emphasizes these values "a particular breed of civically motivated narcissism emerges." Much like the action of participating in a charity sports event is self-directed, as is the sharing of this action on social media. When speaking of narcissism in this context, it is not a pejorative term, but rather as a "preoccupation with the self that is self-directed, but not selfishly motivated" (Papacharissi, 2009, 13). There is a common thread of self-directedness that weaves through the offline and online actions of charity sports participants sharing and fundraising through social media tools.

4. Methodology

The principle aim of this study is to develop a deeper understanding for how and why individual cause-champions are leveraging social media to help build the communities of nonprofits they advocate for. Central to this study is an intimate accounting for the individual motivations and actions of cause-champions, and as such, ethnographic methods are employed to gather the requisite data. Ethnographic studies generally contain a number of different procedural methods for data collection and analysis. Ethnography will be discussed first in theoretical terms, then the specific procedures utilized to gather data and synthesize it. Following this, justification for the methods used and their applicability and appropriateness will be explained.

4.1 Ethnographic and Auto-ethnographic Study

When situating ethnography within qualitative research, one must first conceptualize the term. Ethnography is a search for meaning, for truth, and through the development of what Geertz (1973) called 'thick descriptions'. Central to this method is that the researcher is a part of the research, and that their personal observations and interpretations of the context and participants are an important element of the meaning-making. Increased researcher subjectivity and closeness to the data is valuable in gaining perspective on the behaviors observed and participated in (Atkinson & Hammersley, 2007). Detailed and thorough field notes of observations and interactions are an important part of the documentation the experience of all involved (Emerson, Fretz and Shaw, 2011). These notes also include the perceptions and thoughts and interpretations of the researcher.

Ethnography is most often characterized by the features is possesses, which most commonly are (Atkinson & Hammersley, 2007, 3):

1) People's actions are studied in everyday contexts, not those created by the researcher.
2) Data is gathered from a range of sources, but participant observations and information conversations are the main ones.
3) Data collection is relatively unstructured in two ways; detailed research design not specified at the start of the study, and categories for interpreting data are built in to collection process, but rather generated out of the analysis.
4) Focus on a cases, generally small-scale, even a single group, to facilitate in-depth study.
5) Analysis involves interpretations of meanings, functions and consequences of human actions. What are produced for the most part are verbal descriptions, explanations, and theories. Quantification and statistical analysis play a subordinate role at most.

These features describe the methodological priorities of this project. The focus in on qualitative data, the conversations, observations, actions, feelings, sentiments and emotions that the participants shared. At the starting point of this study, there was no formal theory or hypothesis of what the research would prove and how, only general research questions to provide guidance (Fetterman, 2011). As the data collection began, the analysis began. The interpretation of events and social interactions was immediate as well as continuing throughout the data collection period as it connected with other pieces of information, forming (or not) broader themes.

Auto-ethnography is a method provided an opportunity for myself, the researcher, to both to document and reflect on my own behaviors and actions within in the group, my interpretations of their meaning and observe their connections to

others' actions. As Holman Jones (2005) explains, auto-ethnographers view their writing with a goal of making it accessible and influencing change within those who read it and the broader society for the better. These are not the typical, canonical aims of positivist social research. Auto-ethnographers do not attempt to construct objective research, though this does not mean that it is at odds with social research more broadly, but rather seek an objective of resonance with the reader (Ellis, Adams & Bochner, 2010). Ethnographies introduce a layer of personal interpretation and meaning that can not be found in other methods. As Ellis, Adams & Bochner (2010, 10) describe, "Auto-ethnographers believe research can be rigorous, theoretical, and analytical *and* emotional, therapeutic, and inclusive of personal and social phenomena." The introduction of emotional and personal elements to the research serve to enrich the project and deepen understanding and are complimented by rigorous analysis and interpretation of key information and themes.

Through auto-ethnography, this study seeks to understand and construct meaning around individual experiences and motivations in a naturally subjective social interaction. Recording, interpreting and reflecting upon one's own feeling as a member of a participant group is the closest thing to unfiltered documentation and research, and thus is the least inhibited to connect with the reader and build its validity. This validity is found in the similarities brought forth by the experiences and perspectives of the reader. As Bochner (2012, 155) states, "auto-ethnographies attempt to make social science something more than an end in itself." This speaks to the learning through the process of research as an overt goal. The reflexivity of the study, and of how it is conducted makes the research itself part of the experience of the participants.

Ethnographies of sport represent a considerable body of research that has analyzed many different aspects of running and even marathons specifically. Many studies are focused on health and fitness or individual or group identity

(Shipway, 2010). Perhaps the ethnographic study with the most resemblance to this is one was completed by Kramer (2005) which examined the communication within a fundraising group that was running a marathon to raise money for diabetes. Kramer's study looks at the strength of relationships within this group and the impact of multiple affiliations on the motivation for team members to continue with their training and fundraising on behalf of the nonprofit organization. Kramer's (2005, 258) stated goal was to "examine communication processes and outcomes in a temporary life enrichment group." Some of the findings here hold relevance to this study as it relates to the formation of bonds and motivations of the group over the course of the training-fundraising period. Kramer's (2005) study does not consider social media in the analysis of communication within the marathon fundraising group.

4.2 Data Collection:

This section starts with a description of the study sample, then outlines the methods employed in the data collection. The procedures utilized in this ethnographic study were: participant observation, in-depth interviews and auto-ethnographic entries. Each of these methods is detailed, followed by a description of how they were implemented and their corresponding applicability.

4.2.1 Study Sample, Members of the 2013 Team Fox NYC Marathon Team

The 2013 Team Fox NYC marathon team was 221 members strong (the largest ever). The race is the flagship athletic event for the Michael J Fox Foundation (MJFF) and in 2013 had a $1 million fundraising goal. There is strong support locally as the office is located in Manhattan and many Team Fox members and marathoners live in NYC. Runners do come from around the world to run for Team Fox in the NYC Marathon. The 2013 marathon was my third in New York City with Team Fox, but the first time that I lived in the city throughout the entire

training season (August to November). As the training season started, Team Fox staff began organizing group runs and social outings for runners in NYC to build camaraderie and momentum for more runners to join the team. The participant group for this study was not pre-determined or intentionally made to fit a certain size, but rather evolved into a close-knit group organically based on the consistent participation in group runs and being highly-engaged on social media for the cause throughout the training timeframe. In total there were 4 members in participant group including the researcher. Each of the members in the group (including the researcher) had a pre-existing relationship offline and online prior to the data collection period. Each of the participants were connected to one another through the main social media channels (Facebook, Twitter and Instagram).

Participant A is a woman in her mid-forties and is running in her first marathon, she is not a runner (self-proclaimed) and never has been. she wanted to run the marathon because she was challenged to do it by others in the Team Fox community. She has a personal, familial connection to Parkinson's disease as one of her parents has it and has been a long-standing supporter of the Michael J Fox Foundation and has strong relationships within the Team Fox community and organizes one of the MJFF's largest fundraisers of the year.

Participant B is a male with young-onset Parkinson's. He is in his late 30s and until his diagnosis a few years ago, had no connection to the cause or to the MJFF. He began is engagement with Team Fox by hosting social events, and due to his fundraising success, and positive, outspoken presence on social media has become an inspiration to many within the Team Fox and Parkinson's community. His longest running event before the NYC marathon in 2013 was a half-marathon.

Participant C is a female in her mid-thirties. She has a familial connection with Parkinson's as well. She has run marathons in the past with Team Fox, mostly without time goals. She was not intending to run in the 2013 NYC Marathon but decided she would through her interaction with other members of the participant group throughout the training season. She is highly engaged and savvy with social media and been connected to the MJFF for years.

4.2.2 Participant observation

From a methodological perspective, participant observation holds a great deal of importance in ethnographic studies. As Schensul, Schensul and LeCompte (1999, 91) write, "Participant observation represents the starting point in ethnographic research." It is a method in which, as DeWalt and DeWalt (2011) state, that the researcher participates in the intricacies that make that social context what it is. It is through this physical presence, observation and interaction that the nuances of life reveal themselves. Participant observation is where the research begins to show a view to the intimacy of the participants, their motivations, thoughts and actions that would not otherwise be possible.

The primary method for recording participant observation is through field notes (Emerson, Fretz and Shaw, 2011). Geertz's (1973, 19) idea that "the ethnographer 'inscribes' social discourse" is key. This concept was responsible for creating the idea that the researcher is both the recorder and explorer in ethnographic studies and that this is where the research really begins. The notes taken from participant observation "provide context for sampling, open-ended interviewing, construction of interview guides and questionnaires..." (DeWalt and DeWalt, 2011, 3) Participant observation is the method that provides the spring-board for ethnographic studies, allowing small details to be captured and brought forth into inspection and further developed or discarded as appropriate.

As DeWalt and DeWalt state (2011, ix):

> Participant observation challenges the researcher to relinquish control of the study and where is it headed, even more than other qualitative methods. The investigator is reacting to and interacting with others in the events and situations that unfold before him or her. At the same time, investigators are bringing their own unique background and experience into the situation. Therefore, any discussion of 'how to do it' must be necessarily abstract.

Participant Observation holds the same central position in this study as well. Watching and listening to the participants as they interacted was a fundamental source of my understanding of them as people in this context and the motivations behind their actions, but also their challenges and frustrations regarding marathon training, fundraising or life. These observations happened in a number of contexts, most frequently as a part of weekly training runs or events related to fundraising for the Michael J Fox Foundation. During these occasions, there was consistent discussion related to the participants' marathon training experiences as they were the primary reason for our meeting. Over the course of the training season there were a number of races, and social gatherings in which the group of participants (in whole or in part) would be present. I always had my iPhone with me as I used it to track my runs, and to photo-document experiences and to share to my social media networks. I also used my iPhone to take note of key observations and recurring themes. A large portion of my notes began on my iPhone and then were transferred from abbreviations and jotted sentences or phrases or quotes, and at times emotions or feelings.

On a weekly basis these notes were re-written, expanded and imbued with additional context or discarded depending upon their importance to the ongoing data collection and analysis (typically two pages per week). I wrote as much detail as I thought applicable at the time, and would often write down similar ideas later, making connections and adding new insights. As these observations

became notes, the analysis began immediately. Themes and parallel ideas were connected and reinforced, others become less prominent. This note-taking, and referencing to these notes continued throughout the data collection period, some themes recurred, others were always present, some only connected to a unique circumstance. The field notes were analyzed through a version of grounded theory throughout the collection period. This is the essence of grounded theory of analysis- to build meaning and understanding throughout the experience. It is also a key attribute of ethnographic studies that work constantly to evoke meaning and evolve with the continue discovery and analysis of new data.

4.2.3 Semi-structured Interviews

This method allows the researcher to "gather rich, detailed data directly from participants in the social worlds under study" (Heyl, 2001, 379). Semi-structured interviews allow for direct questions to be asked that were a part of the participant observation at some point in the research or in the reflections of the auto-ethnographic entries. These interviews served as a fleshing-out point for specific ideas, and to determine their consistency and broad relevance within the participant group, or to cast them aside as a coincidence or not primary to the study. Particularly in studies that have an auto-ethnographic portion, interviews can provide important perspective to the study as the researcher turns the focus of the research back upon the other participants (DeWalt & DeWalt, 2011).

Individual, semi-structured interviews were conducted with the three study participants. The focus of these was to gather more specific information from participants to provided more depth to the study in particular areas or to flesh out ideas requiring resolution. Two of the three interviews were completed in person. These interviews took place in the offices in the Michael J Fox Foundation for Parkinson's Research. Each interview utilized the same initial script of questions and both lasted approximately 60 minutes. Each interview was audio-recorded. The third cause-champion was interviewed via email due to scheduling conflicts.

In this case I gave that participant an open-ended expectation for answers, but followed the same script of questions that were given to the other two participants. The interviews were organized thematically. First the questions probe into the individual's motivations, answering the 'why' they were involved and then examine the mechanics of their use of social media and its contribution to their efforts, answering the 'how.' I explained prior to the interview questions that cause-champion was an term I had created and that while they (the interviewee), might not define themselves as such, for the purposes of the research, it was how their involvement was regarded.

Interview Questions:

Motivation (Why)

- How did your engagement with the Parkinson's cause begin?

- Why are you running a marathon as a fundraiser?

- What keeps you engaged/motivated to continue to work/advocate on behalf of the Michael J Fox Foundation on a daily basis?

- Why is running a part of your engagement with MJFF? Is there any significance to this for you?

- How has social media influenced your actions on behalf of the MJFF?

- Do you receive feedback/validation for your actions? What does this look like?

- Is validation (comments/likes/favorites/retweets) an important part of your motivation to train for the marathon and to fundraise for the cause?

Mechanics (How)

- Tell me about the online community you interact with?

- Describe to me how you connect/communicate on topics related to Parkinson's disease.

- Tell me about relationships you've formed through social media. How do they form? How would you compare them to those offline?

- How much do you think about you social media identity? Does this affect what you communicate? How does this impact your Parkinson's-related communication?

- How do you communicate about PD to your online networks? What is the most effective strategy to rally support?

- What do you think is the greatest benefit to using social media as a person trying to build awareness for a cause? What is the greatest drawback?

4.2.3 Auto-Ethnographical notes

From August through mid-November I made auto-ethnographical notes typically when noteworthy interaction occurred or when reflection motivated documentation. Depending upon the events in that week, there could be more or less to document. The quantity of information was not a focus for me, but rather the nature of the interactions, reflection and their connection with related themes already documented. Some of these notes would be on my iPhone, some would be on my computer, and some would be reflections on social media. For example, when I arrived in NYC and began my research I was reflecting on how I had arrive there to conduct my research on a phenomenon that I was a part of. I thought a lot about why I started running marathons for Team Fox, and what I had learned from my experience. Often notes would begin with a keyword that served to remind me of a conversation, or a statement made by one of the participants, or of a feeling or thought that I had during or as a result of a discussion. Quite often thoughts would come to me seemingly out of the blue and I would write them down, some of them ended up having relevance to the study, others did not. Every week there was a training run that would bring together the other participants and myself. Following the events (runs, etc) I would make general notes of anything noteworthy, . As with the other methods, generally I started

with broad categories, these were described as feelings and actions, similar to the motivations and mechanics categories, but with my own perspective and perceptions.

As themes evolved in my notes, as I sought to connect similar ideas over the weeks of experiences and self-reflection. My notes which were either long and verbose or very short, would inevitably have both themes and part of the challenge in analyzing them was understanding the relationship between them. Typically notes focused around relationships with the participants or others in the MJFF community. I was committed over the time of the data collection, to be present and aware. Therefore the process of taking auto-ethnographic notes was characteristically done as memory work, which is acknowledged as a common practice in ethnographic study (Coffey, 1999). The process of recording meaningful statements or portions of conversations came to be a natural process and one that was enjoyable as I reflected on an interaction or event.

Example auto-ethnographic entry dated September 30, 2013

The ability of social media to connect in undeniable, it has brought many incredible people into my life, but the more that I think of these connections, event the ones that begin solely online, I am reminded that it is the passion and engagement of individuals that give life to all of its potential. Recently I connected with a fellow runner on Twitter. She runs, walks and bikes using the Charity Miles application on her iPhone, and is quite active with the app and very supportive of others via social media. We have gone back and forth getting to know each other through our respective posts. She seems quite engaged on social media and works for a non-profit in the US. She came to NYC for the social good summit this week. My friend from Charity Miles has also invited me to go with him and listen to some of the speakers, I was inspired by the work of so many to make this world a better place. I found out over the course of two days at the summit that this individual has a step-father with Parkinson's disease. She runs in his honor through Charity Miles. I asked her if she knew anything about the Michael J Fox Foundation? She replied, a little. I shared with her my story, my father and the work that I was doing on behalf of MJFF. Later the next day I asked her if she wanted to join a Team Fox run in Central Park. She said sure. There she met a number of engaged members of Team Fox and some staff

members as well. We all went out for a beverage after and many of the team shared stories about how they first came to be involved with the Foundation, their experiences and challenges with running, and other things. One week later this woman had signed up to be a Team Fox member and one week after that committed (via Facebook) to running in the 2014 NYC Marathon for Team Fox. I am reminded here that social media alone would not have made this connection what it is, the Team Fox community facilitated this, and that not of it would have been possible without the initial connection through social media. //

This entry highlights a particular connection that began through sharing my marathon training runs on Charity Miles through Twitter. As I have lived away from my home country and the site of the core MJFF community, many of my relationships are all online. This relationship highlights to me the power of passionate communication on social media. Emotion is a key contributor to connection, and when there is something in common (in this case, running for a cause through an app called Charity Miles) that is shared, relationships begin with ease and are often intensify quicker because of this alignment of interests.

The auto-ethnographic portion of the research has been documented firstly through notes and journaling, but also shared through various social media channels, blogs and my personal website (list of social media used below). Facebook worked as the hub for communications as it the most established of my networks. Every training run that was completed was shared on Facebook via the Charity Miles application. These shares were important on a number of levels, as will be discussed in the analysis portion of my project. I also shared my Charity Miles activity on Twitter. This network is larger, but more loosely connected than Facebook, and it is also more diverse, from geography to how I am connected with my followers, and has a wider potential reach as it is an open social network. Twitter became a highly effective vehicle for storytelling and communication when sharing blog posts and particularly when it was also shared by the Twitter account of the Michael J Fox Foundation or the grassroots fundraising program Team Fox.

Another network that became an important part of my community-building was the iPhone App Instagram (IG). In a short time, this photo application has been the strongest gateway application to deeper online and offline relationships. Over the time period of my training for the NYC marathon, I connected with more new contacts through IG than any other social media channel or offline. Often these connections would then also become members of my community on other platforms. IG was the application through which I visually documented my experience of preparing for the marathon.

Here is an example of a post to Instagram, sharing a photo from a race in Central Park, my stated goal for the NYC marathon (to break 3 hrs), some motivational text content and hashtags (dated September 21, 2013, from my personal Instagram account @hamiltonguevara).

My posts to Twitter related to Team Fox consistently revolved around themes of positivity and accomplishment (Charity Miles and training) and community, from supporting others through validation and sharing of their story to celebrating team members group coming together in the name of the cause. Theses tweets from my personal Twitter account (@hamiltonguevara) and include the date posted.

Matthew Mitchell @hamiltonguevara · 17 Oct 2013
I ran 9.388 @CharityMiles 4 @MichaelJFoxOrg w @akuchinad - lets raise $50K 4 a cure by 11/3. #ThinkAble //#Break3toCurePD in full effect.
3

Matthew Mitchell @hamiltonguevara · 1 Oct 2013
Read my post on @jackmc9984 & #TEAMPULLI running the @ingnycmarathon 4 @TEAMFOX ow.ly/pnXnd Cc: @MichaelJFoxOrg @charitymiles
3   3

Matthew Mitchell @hamiltonguevara · 16 Oct 2013
Awesome @TEAMFOX group run in Central Park! Perfect night for it!

1   View more photos and videos

Social Media channels for sharing:

- Charity Miles Application (activity shared directly to Facebook and Twitter)
- Facebook (Personal)
- Facebook (Break3toCurePD)
- Twitter (Personal @hamiltonguevara)
- Instagram (Personal @hamiltonguevara)
- Vimeo (Break3toCurePD)
- Website/Blog (Break3toCurePD.com)

This image is the from the front page of Break3toCurePD.com. At the top are links to other social media and blog content and Team Fox fundraising page.

4.3 Data Analysis: Versioned Grounded Theory

The data collecting in this study was analyzed using a version of grounded theory. Grounded theory was not followed to its theoretical point, as it was more appropriate for the study and the information involved, to be more flexible in relation to the coding of terms and themes. In general terms, grounded theory seeks to aggregate and pull together similar themes, using key phrases and key words as anchors in conversations. According to Clarke (2003, 557) grounded theory is "an empirical approach to the study of social life through qualitative research and analysis." In grounded theory analysis, capturing of key ideas is paramount and the re-reading and filtering of relevant information will help to bring forth clear results as the results are analyzed. Glasner and Strauss (2009) describe grounded theory as a the discovery and testing of theory. Over the course of the study and the analysis of the ongoing data collection, new results are found and tested again prior findings, and as newer data comes, it is again tested in the light of ongoing analysis. If it a fluid process that continually seeks to verify the information being collected for its relevance.

The data analysis for each of the methods followed a similar procedure of a version of grounded theory as data moved towards more discernible results. As has been described by Strauss and Corbin (1990) the process of coding began with simply collecting information into broad categories (known as open coding). Following this comes 'axial coding' where connections were made within notes for similarities of themes and recurrent ideas.   This process generated connections but also additional questions and reflection that served to inform future interactions. This portion of the documentation and review of data was immediate and ongoing throughout the study. The categories changed fluidly as different data influenced the overall. The major categories were relatively static as they were the general guide for the research, but the details within them changed over

the course of the observation period. The first is the 'motivation' of the participants, garnering insight into the why behind their actions and behaviors and the second is the 'mechanics' or the 'how' which attempts to shed light on the intricacies involved in online and offline community-building in this particular context.

For example in the case of motivations, the responses, observations and reflections led to distinguishing between intrinsic and extrinsic motivation, to the importance of the cause, altruism, to a sense of community, to personal connection, to daily validation of action, to civic narcissism. This process was not a progression and the notion of motivations did not follow a linear path to a predestined finish, but was characterized by ambiguity and fluidity. Participants, including myself as the researcher-participant, felt differently at different times throughout the timeframe of the project, influenced by interactions with fellow participants and other factors, including familial and work considerations. For example, frustrations were shared that altered ideas and their importance to that participant's experience. At times these were simply outliers to a more established train of thought and other times new experiences were the catalyst for a broader change in how they interacted with participants and with their networks on social media.

4.4 Ethical Considerations

The ethical considerations for ethnographers are often associated with relationships held by the researcher. Generally these concerns are related privacy and the sharing of sensitive, personal information. The sharing of this information can potentially lead to challenges afterwards if the identity of the participants are revealed. It is here where the researcher must weigh the pros and cons of publishing the data (Atkinson & Hammersley, 2007). In regard to the participant observation and auto-ethnographic entries, no information shared in this study

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was personally compromising or of a sensitive nature. Participants were not identified, and their comments were anonymously attributed. In the formal interviews each participant accepted that their responses would be expressly used for this research and provided consent. As such, there are no further ethical considerations for this information.

4.5 Reliability

Generalizability is not naturally associated with ethnographic research due to its focus on intimate portrayals of personal experiences. However, ethnographic studies still hold broader relevance despite their acknowledged subjectivity and nuance. The participants of this study, while in a very context-specific, temporary group, provide insight into how they share through social media and influence one another in their online and offline communication that is applicable to groups that share similar contexts. As such, in ethnographic research, the term "transferability is preferred to generalisability" (Shipway, 2010, 63). Transferability meaning, can the theoretical pillars of this study be applied to a similar context to answer similar questions?

Ethnography seeks to provide understanding as a priority, to show subtlety, to describe context of action and feeling. As such its reliability is found in its interaction with the personal reader's subjectivities and experiences. Ellis (1999) states that these personal writings are in fact tested by each and every reader and that the connection and similarities between their respective experiences defines its broader applicability. It is the interaction, the connection formed between the reader and the researcher that defines the validity, and thus the generalizability of the understanding or meaning create through the auto-ethnography. It is a method that speaks to the inherent subjectivity in building understanding of most social interactions, which are highly individualized as well as context and culturally specific. Ellis (1999, 674) highlights the uniqueness of auto-ethnographies:

I start from the position that language is not transparent, and there's no single standard of truth. To me, validity means that our work seeks verisimilitude; it evokes in readers a feeling that the experience described is lifelike, believable, and possible. You might also judge validity by whether it helps readers communicate with others different from them- selves or offers a way to improve the lives of participants and readers or even your own.

The test then, for ethnographic (and auto-ethnographic) research is whether a study presents ideas and theories that inform readers and other researchers with understanding of a particular setting and experience, and if the research shows reflexivity, awareness and insight that contributes to the development of social research as a practice.

5. Analysis: Results from Ethnographic study of cause-champions for the MJFF.

The structure of this analysis will follow a thematic organization of the findings from the three forms of data collection (participant observation, semi-structured interviews and auto-ethnographical notes). The experiences, comments, observations and interpretations from the data set are expressed within the following themes: (5.1) Where the actions of cause-champions begin: personal connection, (5.2) Motives for running a marathon and fundraising for the Michael J Fox Foundations are altruistic *and* self-directed, (5.3) Social media, interaction and building community, and (5.4) Affective labour of cause-champions: positivity, emotion and selling. Each of the sections will contain ethnographic data and auto-ethnographic data. I have tried to ensure that there is a balance of evidence from each of the methods where appropriate and applicable to show that the result was important in some way to each of the participants, even if there are divergent opinions. As the sample was four participants, comments and quotes from the collected data have not been attributed in any way other than in the auto-ethnographic entries to protect anonymity. The findings represent the culmination of the versioned grounded theory analysis that extended throughout the data collection period, and as such may be from any given time within the period of observation, unless otherwise stated.

5.1 Where the actions of cause-champions begin: personal connection

Each participant brought their own experiences and story of connection to the Michael J Fox Foundation (MJFF) and reasons for running a marathon with Team Fox (TF) to signal their contribution to the cause. The motivations are personal, the connections are emotional and they provide the basis for why these individuals are described as cause-champions.

The following auto-ethnographical entry is an excerpt from a larger post that speaks of my personal connection to the cause. It shares the story of how I became involved with the cause and why running a marathon was how I was going to do make my contribution. While the story is my own, many of its characteristics hold consistency with the other participants in the study. The post was written and published on the *Huffington Post Impact Blog* in late July 2013 as self-reflection on my experiences running marathons and fundraising for the MJFF (Mitchell, 2013a). The post was also posted on the Michael J Fox Foundation's Blog as a call to arms to join the Team Fox community and to run in the 2013 NYC to support the MJFF (Mitchell, 2013b).

> Three years ago I signed up to run my first marathon, the world's largest in New York City. It had been 10 years since I had run regularly. I was intimidated, scared of not being able to finish; scared to fail. I signed up in a moment of inspiration, and of apparent faith -- in myself, that I would find a way to accomplish something I had previously never even thought of trying. There was, and continues to be something irresistible in the 'impossible' and that was the spark.
>
> My parents were my motivation to run my first marathon. My father endured Parkinson's disease for more than a decade and as I watched him gallantly fight, with my mom by his side, against its irreversible tide, I knew that I wanted to be a part of ending the disease. I would run to end Parkinson's. Each stride would signal my voice, my contribution to the cause. It is here when my connection was made with The Michael J. Fox Foundation for Parkinson's Research. Within this organization I saw the vision and the fearlessness necessary to achieve the 'impossible' -- a cure for Parkinson's disease. I would run the NYC marathon wearing the Team Fox (the Foundation's community fundraising arm) jersey and raising awareness for their pioneering research. I had joined a team of passionate, driven people, all pulling in the same direction, it was awesome.

In dedicating my training, running and suffering to my father and mother I was "memorializing" my efforts in their honor. I was running *for* them. The Parkinson's cause and the Michael J Fox Foundation were an extension of this

connection. I was taking on a challenge that was extreme, one that I had defined

as "impossible" at one point in time. In running for my dad, I made what Throsby

(2012) calls an "alliance of suffering." I was connecting the effort and pain I

would endure with what I interpreted to be the pain my father endured living with

Parkinson's. Portions of this post were also used in the MJFF video "Letters to

the Michael J Fox Foundation" (Michael J Fox, 2013v).

Letters to The Michael J. Fox Foundation
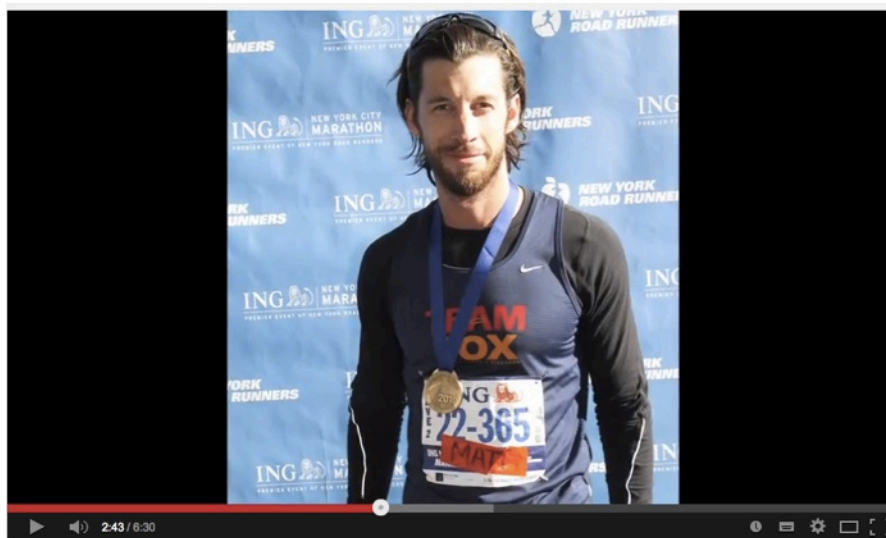
Letters to The Michael J. Fox Foundation

These screenshots are from the "Letters to the Michael J Fox Foundation" video. The first frame shows a photo of my father and I, and the second, a photo after I had completed my first NYC Marathon in is honor and to support the MJFF. This video was shared with the public sharing individual connections to the Foundation.

This personal connection was echoed in the fundraising messages from other participants on social media often referencing this personal connection, "I am running for my dad." These personal connections are defined by emotion, but also intimacy, as a participant mentioned, "its horrible, seeing the progression of the disease in someone you love." Other participants shared similar messages of dedication as they share the same familial connection to the disease.

> Living with a family member that has Parkinson's allows you to see and feel the reality of life with the disease, it makes the experience intimate and you come to understand the depth of the need for a cure.

The participant who is a person living with Parkinson's disease and brought a different perspective to the notion of personal connection to the cause. This individual was diagnosed and soon after became active in the Parkinson's community. "I knew I had to do something. It just didn't make sense to sit there and let it take over and hide from it." When he ran in the NYC Marathon he had a statement added to the back of his Team Fox running shirt that read "I have Parkinson's, Parkinson's doesn't have me." For this individual the personal connection was about engaging with a challenging new reality and taking positives steps to find a cure but also in a way taking back a measure of control that had been lost when after being diagnosed with PD.

Speaking to the study more broadly, the fact that each of the participants has a personal connection did result a certain alignment of perspectives and

motivational associations. This limited the diversity within the data that nornally occurs within the general population.

5.2 Motives for running a marathon and fundraising for the Michael J Fox Foundation are altruistic *and* self-directed

Running a marathon is a powerful metaphor for the challenges of life, whether they be personal or collective. There is a paradox in the motivations of these cause-champions running a marathon for the Michael J Fox Foundation. The connection of altruism and self-directness of their actions seem to be countervailing at first, but upon further examination, work hand in hand with contemporary notions of social and moral fitness and that perceptions of narcissism are balanced with social engagement (Hart-Brinson, 2011). The personal investment and accomplishment are a part of something larger, a contribution to the betterment of others. Running is a physical, human act, one that requires energy, persistence, and most poignantly, suffering. On the other hand, it is also fulfilling, the work itself while arduous and exhausting is a source of self-confidence and strength for those who submit to its rigors.

A central motivation for all participants was the "cause." This connection not only to a family member, but also to the larger MJFF and Parkinson's community was seen as extricably connected to their actions (fundraising, training for and running in a marathon). Here again Throsby's (2012) notion of "alliances of suffering" resonates with the motivations and experiences of the participants. These connections are between cause-champions who are running a marathon, with people living with Parkinson's and with those who are impacted by the disease. Here is an example:

> I think for me it brings me closer to understand the struggles someone with Parkinson's has on a daily basis. You are in pain, tight, and cold after the a

long run and I think that is how people living with Parkinson's feel every day. A lot of heart goes into running. I love that part of it.

Another participant spoke to the accountability they felt to the community to keep going:

It isn't necessarily for the love of running that got you out there for the long runs it is for the deep desire to put an end to a disease. It would have been extremely difficult to train for this without knowing others were relying on you…to show up at the park, go to races or even helping others just by listening.

Again there is an emotional aspect of this connection that is threaded through how these cause-champions share their perspectives. "I'm motivated by the families and friends also affected daily by Parkinson's disease. It's this engagement that provides the strength to continue."

There is also a self-directed motivation, that of the personal benefit of fitness and achievement, which is communicated by participants within the broader context of the cause though acknowledged all the same and that is the   In Taylor and Shanka's (2008) study of participant motivation "achievement" and "involvement" were the most important, as were "camaraderie," "cause," and "competency" in Filo, Funk and O'brien's (2009) research. Accomplishing something personally and physically unprecedented is also an important part of the experience and is associated with the idea of overcoming obstacles and fighting on. The representation of the battle of those living with Parkinson's disease remains a key theme, and again, accomplishments are tied back to the greater good. This has direct relevance to marathon runners as for most people, the challenge to run a marathon (though becoming more common) as akin to this intense self-investment and training. As Nettleton and Hardy (2006) stated that in the running community, "there is something heroic in the struggle to achieve the transformation that is marked by completing a marathon." The acceptance that

this type of endeavor and personal challenge is only really admirable if the actions are accompanied by a simultaneous, parallel project of fundraising for a cause (Throsby, 2012) intertwines these personal and civic motives. As one participant put it, "The personal pride from physical accomplishments in the name of a cause."

The expected connection between the individual accomplishment and the cause was also something that came up in a relationship I formed during the study, this entry highlights its discourse:

Auto-ethnographic entry (Dated October 13, 2013):

> I have found it interesting to be a part of a general phenomenon that seems to exalt individual challenge and investment (into a healthy body) as only valid if the actions are also being connected to the betterment of others in some way. I have been providing some training advice to an individual who is preparing for the NYC marathon as well and I finally asked her the other day what charity she was running for an I didn't see any associative statements or fundraising messages on any of her social media posts. I have to say that I found it hard to believe she couldn't be running for a cause and talking about it through social media as it was the central pillar for my action, I found a certain self-righteousness well up inside me, I thought to myself, does she think its all about her? She replied that she was just running to be fit and healthy. This individual had struggled with weight issues years before and running was a means to take control of her health and her life, it was a very personal journey and statement. Why is it less worthwhile to run for yourself alone, why does it need to be connected to a cause? It seems like it is just the way things are done now. Why do I interpret this as selfish?

This idea is similar to findings in Throsby's (2012) analysis of charitable Channel swimmers and pressure to "swim for" a cause. For a participant, the "decision to swim because he wanted to swim was a socially risky one in a context where 'swimming for' was the norm and "swimming for yourself can appear excessively self-absorbed" (Throsby, 2012, 6). The idea that one can only participate in a

marathon, or compete in an endurance if they run on behalf of a nonprofit organization represents the personalization of morality. As Erikson (2014, 155-6) describes:

> Suddenly, a marathoner-fundraiser finds herself among a community of other runners in a space that is filled with other people who also embody the characteristics we expect of our moral citizens. They wear their badges of honor – the free race shirts, other shirts and tote bags they purchase at the race expo – to identify themselves as such. They have not only completed a marathon, something very few Americans will accomplish, but they have completed that marathon *for* someone else.

This constricted conceptualization of morality and citizenship also means that one's own fitness is increasingly tied to expectations of social and moral fitness as Hart-Brinson (2011) describes it through "civic recreation." Taking a step back this seems like a distorted and narrow view despite the fact that I've been involved in running marathons and fundraising for the Michael J Fox Foundation since 2010. It seems as though personal freedom is being infringed upon by the connection of self-betterment to this conceptualization of the "moral" citizen and its ties to current neoliberal constructions of philanthropy.

5.3 Social media, interaction and community

Social media has proven to be a vital tool to cause-champions to contribute to nonprofit organizations. As Shirky (2010) has stated, there is an intrinsic motivation to share and connect using social media. Social media enables connection and does so be providing spaces for online social interaction to take place. The ability to reach a wider audience with a personal story is one aspect, but social media also facilitates the validation and support of sharing. This give and receive (sharing and validation) is an integral part of online community building for a cause. As Chen (2011) states, in her research on Twitter use, the

amount of of validation and interaction mediates the relationship between active

social media use and gratifying a need for connection. Quan-Haase and Young

(2010) describe a main use for Facebook gratification was "affection" which

included "to show others encouragement," "to thank others," and "to help others."

These emotion-laden acts are all important parts of interaction on social media.

Each of the participants in this study have spoken to this in their own way and

here enters the primacy of the notion of sharing and building connections. Social

media tools are the vehicle that amplifies the actions of cause-champions and

gives them the ability to reach more people with their story, and allows them to

support and be supported by those beyond their close family.

> If it weren't for social media, most of my casual social ties wouldn't know
> about my connection to Team Fox or Parkinson's disease. I have a larger
> circle of supporters because of social media.

In this comment is the theme of self-directedness, the idea of gaining a larger

audience for you to share your story with. This is what Papacharissi (2009) is

referencing when speaks of civic narcissism. He states that this communication

(for example telling one's own story) is not selfishly motivated action. As has

been expressed through the review of literature related to conceptualizations of

citizenship and morality, they are increasingly intertwined with the physical acts

of voluntarism (Hart-Brinson, 2011) and current philanthropic discourse

(consumerism) (King, 2010).

These considerations aside, social media represents an instrumental part of the

messaging and connection for these cause-champions:

> That's why social media is so important in my life – having the power to
> affect positive change over thousands of miles away with the click of my
> mouse.

Here is an excerpt auto-ethnographic entry (dated November 5, 2013)

> I have traveled a lot in the past year, I am thankful that now more than ever, wherever I am, I can connect with kindred spirits. Through social media, I have become part of an amazing, borderless community of people like me who use their running to inspire social change. By simply sharing my passion, I find it from others, runners and champions, from all corners of the world, from Mt Hood, Oregon to Louisville, KY, to London, UK, there is no end to the daily inspiration my connections provide me with. Their stories give me strength, help build my resolve. We motivate one another to take on new challenges, to reach for new goals, and to continue to champion our cause. This community, initially built exclusively through the online world has become my family.

This entry shares the importance of social media connections to me, particularly as a share my story of contributing to finding a cure to Parkinson's disease by running marathons and fundraising for the MJFF. These connections, though virtual, hold an emotional characteristic and because many of them are based on similar passions and interest, even Parkinson's and the MJFF specifically, they often become an important part of my social life.

When listening to the participants and reflecting upon my own experience, it is important to acknowledge the power of validation that is a part of the communication and sharing on social media in particular. All participant spoke to receiving comments and "likes" on Facebook or Instagram, or favorites on Twitter as indicators for the success of their posts and gave them momentum to continue their behaviors of acting and sharing.

> Posting the runs and words of encouragement or just likes inspires you to get out there again... At times it gave you that extra push to do more. It is about discipline and fun because you are sharing the experience with so many people who understand why you are doing it.

This validation, these interactions are build community as a part of this two-way dialogue online (Lovejoy & Saxton, 2012). Working from the intrinsically motivated (self-fulfilling) actions and affective labour to bring people together to support the cause. One participant described succinctly, "The act of sharing is driven by validation." When asked about the daily motivations connection through social media was significant.

> The daily inspiration and validation from other members of Team Fox and my online communities serves as a constant reminder to keep fighting when I'm tired or overwhelmed. In the years since joining Team Fox I seek out that interaction more than ever. My online community reminds me of what truly matters when I get bogged down by the grind of work or the challenges related to Parkinson's. These day-to-day interactions are so important when times are tough. While I've grown a bit dependent on that feedback loop, it has also pushed me beyond my own limits of what I believed possible.

The theme of inspiration and overcoming challenges, to 'fight on' is strong and persistent over the course of the marathon training season:

> Connecting with the PD community via my work with Team Fox is the fundamental reason why I continue to push my limits and raise money for research on a day-to-day basis.

Committing to running and training daily for a marathon is symbolic of the daily commitment to friends who are living with or taking care of someone living with Parkinson's or in honor of someone who had Parkinson's disease. These symbolic acts are a fundamental part of the engagement of cause-champions, they are a driving force for continued action through the cycle of communication and validation.

Somewhat of an outlier perspective is related to community is the participant living with Parkinson's. While he is champion in the PD community, he also has a community of peers in the patient community. His connection with this

particular group is an important source of his motivation, he has another layer of "alliances of suffering" (Throsby, 2012). He mentioned that "I really feel good about helping people with Parkinson's with their problems" and that "I want to inspire others with PD to get involved and the money will come." These statements while context-specific to the community of people living with Parkinson's connect to the combination of altruistic *and* self-directed motivations associated with the actions of cause-champions in this study. Also present in this statement is the idea of affective labour (to inspiring others (with positivity)) and how that helps in fundraising efforts, as will be discussed in the following section.

5.4 Affective labour of cause-champions: positivity, emotion and selling

As the Michael J Fox Foundation pursues its goal of ending Parkinson's disease, along with the cause-champions who work on its behalf, positivity is an overarching theme, this is their mediatized image to the world. A recent project of the organization is the think/able campaign, it is a simple message, that there is power in optimism. This image is from the front page of MichaelJFox.org, showing their positive stance on the challenge ahead to cure Parkinson's disease.

I have included an article I wrote for the *Huffington Post Impact Blog* on October 18, 2013 as a part of my social media auto-ethnography, called "think/able," (Mitchell, 2013b) as it is representative of this theme of positivity and my interpretation and personal experience of how it is applicable to running a marathon for the Michael J Fox Foundation.

Life often presents challenges and roadblocks that can seem insurmountable. In fact they are all impossible until they are overcome. think/able, a project of the MJFF and inspired by Michael J Fox himself, represents the power of optimism and of community.

There is energy and momentum in the simple act of positive thinking, and while it is not everything, it is the foundation for future success and fulfillment. The consistent application of a positive perspective is a deliberate and practiced behavior requiring it's own diligence. Both success *and* failure represent progress. It is how we respond, how we interpret our experiences that precipitate and motivate our steps forward. These actions in aggregate become the path we walk. There will always be reasons to *not* do something, reasons to stop, to give up, but as we cast these aside we begin to manifest our own future. As I watch friends living with Parkinson's run marathons, and thrive, I can't help but be swept up in the strength these acts imbue.

Every day I work to apply this perspective to my own marathon training. I run as a part of Team Fox (the grassroots fundraising program of the Michael J. Fox Foundation), a committed group with a single goal -- to end Parkinson's. It is this community that helps to push me forward. They are my accountability -- an accountability first to myself to let go of the fear of failure and embrace the discomfort of the unprecedented. It has been said that the marathon is a quest for more life. As we begin to challenge what has come to be accepted and expected of us, we leave behind the comfortable and confining boxes we once resided in to achieve what we are truly capable of. We all have our own "marathons" and our success is as much in our perspective as it is in our performance. Think/Able is a reminder of the power within all of us to overcome, and the ability we have to inspire others to new heights. I can and I will. We can and we will. #Think/Able

This post sums up my perspective on how I train for marathons and how I share my training. It is a perspective that has served to help me get through the challenges of each of my marathons. To overcome challenges requires, at some point, the faith that it can be done and it simply acknowledge unprecedented milestones as you pass by them.

It is one thing to be positive about the opportunity to find a cure for Parkinson's or to finish a marathon, or run it faster than ever. Another is the filtering of messages on social media to almost entirely exclude the negative. Communication related to the cause on social media revolved around themes of positivity, challenge, emotionality and pain (positive) and inspiration. Positivity is a crucial part of the life perspective of the participant living with Parkinson's. He feels that maintaining, or working to maintain this point of view is a crucial part of how he lives his life and how others in the community interpret his actions and messages.

> I identify myself as a person living with Parkinson's, I never say suffering or make it a derogatory thing, even though for some people it can be, you just don't want to make it a negative.

The filtering of messages amounted to self-censorship by the participants, based on their own perception of what was classified as negative and attempting to protect the forward momentum of their own quest to the marathon and the accompanying fundraising. There is an across the board sensitivity to negativity.
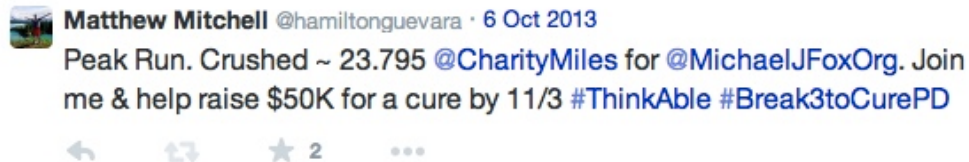
> I think my posting habits are an honest reflection of who I am, although I tend to only post more hopeful and positive updates online. PD is an incredibly challenging disease and my father and family have a tough time with it. I don't share those moments as often via social media. I feel better about sharing these challenging moments in my offline interactions.

From auto-ethnographic entry dated October 6, 2013:

> Today was a very challenging long run. My body was just not feeling it, I feel tired physically and drained mentally, it was grueling. I'm sure that I

was compensating in the last few miles, which I am sure will isn't good for my hips going into peak training weeks. I felt almost disingenuous being so positive, really *I* got crushed today, but I didn't say that. I feel like my job is to inspired and give others the motivation to continue through their own challenges.

This entry contrasts with my post to Twitter about the same run:

Matthew Mitchell @hamiltonguevara · 6 Oct 2013
Peak Run. Crushed ~ 23.795 @CharityMiles for @MichaelJFoxOrg. Join me & help raise $50K for a cure by 11/3 #ThinkAble #Break3toCurePD

⤺   ⇄   ★ 2   •••

Why do I, as a cause-champion filter my social media messages? I feel compelled to provide as motivating a message as possible. I have been given many blessing in my life, and I feel showing my appreciation for them, even if they are difficult, is a part of my contribution to the discourse. I don't hear or see negative posts from anyone about the challenges of Parkinson's, if my friends with PD are running a marathon and not complaining, I'm certainly not going to. There is also the fundraising consideration, which is not just about me and my challenges, it is about the MJFF and all those impacted by Parkinson's. To put it simply, happiness sells, inspiration wins. As Samantha King (2010), the "tyranny of cheerfulness" which she has coined to describe the how marketing messages and branding have overtaken the injustice of the disease. I think this optimism is also an "accommodation" as Schulz (2004) described, as cause-champions adhere to the media logic as it pertains to nonprofit communication and tenets of cause-marketing.

When is discussion with the group about presenting real, striped down messages on social media that show the realities of Parkinson's, he asked rhetorically, "do I want to put that out there? -is that a downer?" Participants were aware of the lack of negativity in their communication, and discussed it on a number of occasions.

A notable comment was, "People don't think Parkinson's is a big deal because we are such positive people, and if you're constantly about it, others don't realize how difficult it really is." There was some trepidation about the unsustainable nature of ever-more-extreme spectacles on behalf of the cause. It was stated "there is a constant need to out-do yourself." Self-doubt was expressed by each of the participants on a number of occasions as was the conflict with them whether or not to share those feelings on social media.

This theme of positivity also extended to the discourse of the MJFF, and of philanthropy more broadly, but even in offline conversations within the group. Within the context of group runs or social outings, I felt an unspoken pressure to be positive in general terms. I felt that I had a duty to support my fellow participants through my own optimistic view of our collective efforts and those of the MJFF. It was very rare to here anything that questioned the MJFF actions, and never their motives. Personally reflecting on these questions, I would not be so sure that there was such perfect performance record or that all were aligned in such a view.

For my own sake, as a five-time marathoner and fundraiser, there is no longer room in the discourse for "challenging" runs unless they are beyond the marathon distance, or take place in the mountains with thousands of meters of elevation to climb. I know that this is not sustainable, particularly from the fundraising perspective, but there are no other options in this context, other than not participating. When one's self-directed marketing or fundraising message includes "impossible is nothing" as the slogan, expectations predictably climb. I often hear, "so what are you going to do next?"

6. Conclusion

The goal of this study was to better understand the motivations and actions of cause-champions on social media as they relate to the nonprofits they are connected to. This small group of individuals training to run a marathon for Team Fox and raise money and awareness to end Parkinson's provides an intimate perspective on the micro actions that contribute to awareness-building, fundraising and community-building on behalf of the Michael J Fox Foundation. This final chapter shares key results and interpretations of the analysis and addresses whether the findings appropriately resolve the study's research questions. This section also acknowledges limitations within the presented research and poses questions for future studies.

Research Question 1: What are the motivations for these cause-champions to run a marathon, fundraise and help to build community for the Michael J Fox Foundation?

Research Question 2: How is social media combined with offline action by these cause-champions in ways that enable them to raise funds, awareness and build community for the Michael J Fox Foundation?

A key consideration of this study was the *motivation* for action of cause-champions both in the their online communications and offline actions. Beginning with the reason why they became involved with the cause, the result was personal connection. Each of the cause-champions had a familial or personal relationship to Parkinson's disease. This relationship was a precursor to their association with the Michael J Fox Foundation. Participants (including myself) often described that they were running *for* someone. This extends to the participant living with Parkinson's disease (PD) though the recipient of his

energies was not centered on a specific person (including himself), but rather dedicated to those also living with PD. This participant, whose community of fellow PD patients, acted as an additional "alliance of suffering" (Throsby, 2012) from the other participants. Each participant possessed a personal connection to the cause, this characteristic of the group and thus a peculiar "alliance of suffering" that undoubtedly shaped the interactions with one another and perspectives on motivation and notions of citizenship and morality.

Beyond this first, instrumental motivation, the most characteristic was its intrinsic nature. This motivation type had two specific manifestations that worked in conjunction as participants carried out their cause-related engagement. This first being altruistic (the "cause") and the second personal (fitness, achievement or accomplishment). This combination of motivations has also been found amongst studies of charity sports participants including Hendriks and Peelen (2013) and Mahoney (2013). What is interesting here is how these motivations inform the actions carried by cause-champions within the current social context of philanthropy and mediatization. The "cause" motivation in this case encompasses the participant group, the MJFF community and more broadly, those impacted by Parkinson's disease, whether they be anonymous or not. The "community" of was often cited by participants as a daily motivation for their actions. Participants felt good about doing something for someone else. This fulfillment (an aspect of intrinsic motivation) was described as a part of the cause motivation, and thus cannot be entirely separated from the self-directed themes of motivation.

The second key participant motivation is self-directed and based on personal goals held by the participants. Physical fitness and achievement were described as a part why they are running a marathon and fundraising for the MJFF. However these motivations related to the self remain within the construction of the cause. These inward focused goals were always attached back to the broader

social context of who they are running for. Throsby (2012) articulates a growing normative position that increasingly requires the individual investment and training required to complete an endurance event to be connected to a charity, nonprofit organization, or cause. This position is reiterated by King (2003) who identifies the contemporary association of moral worth and participation in voluntarism (regardless of the cause as it seen as civic and personal).

As it pertains specifically to communication on social media, participants spoke of it as a natural extension of their offline actions and enabler of social sharing and connection. Leveraging an intrinsic motivation to connect (Castells, 2009) social media tools "increase our ability to share, to co-operate, with one another, and to take collective action, all outside of the framework of traditional institutions & organization" (Shirky, 2008, 20). As participants shared through social media, they generated the opportunity to connect with others through their positive and emotion-laden messages of support and contribution to the cause. With the added connection to a cause, the personal and emotional nature becomes more intense. The second aspect of this motivation for online sharing is connected to the individualization of the civic. In the term "civic narcissism," (Papacharissi, 2009) is not a selfishly motivated act, "but a desire to connect the self to society" (Mendelson & Papacharissi, 2010, 269).

Current conceptualizations of *philanthropy* consistently make reference to increased market-like characteristics. Increased "entrepreneurialism" within the nonprofit sector and the larger neoliberal philanthropic environment are important considerations for understanding the individual actions of these cause-champions. Eikenberry (2009) describes one of the key problems connected to what she calls the contemporary context of "consumptive philanthropy" is the individualization of collective or societal problems. The constriction of the civic to the personal has influenced notions of citizenship and morality and attached them to individual

physical acts of voluntarism and financial, philanthropic giving and consumerism (Hart-Brinson, 2011; King, 2010). As such both the altruistic and self-directed intrinsic motivations for running a marathon also have their contextual roots in the context of a "new philanthropy" (Raddon, 2008)

These participant motivations are actualized on behalf of nonprofits through their mediatized, emotion-laden, *affective labour*. This affective labour is an emotional appeal, not only for connection, but also what it facilitates. The sharing of stories, commenting on other's posts, liking, or retweeting messages or photos, all of this interactive, two-way communication is at heart of online community building through social media (Lovejoy & Saxton, 2012). Chen (2011) found this interaction to be an important individual motivator for further social media engagement; validation was a key gratification for individuals in this context. This engagement is what these cause-champions performed when they were sharing their stories and connecting with others in the MJFF community.

Emotion was a key aspect of what participants described as facilitating connections and fundraising success. Inspiring messages, and the symbolism of suffering (ultimately positive) for the cause were key. More specifically and importantly, by "mediatizating" (or more specifically, Schulz (2004) would describe this as "accommodation") their messages and fundraising calls through the filter of positivity, cause-champions are adhering to the tenets of cause-marketing. Participants noted the unspoken pressure to conform to a positive discourse related to the cause.

These motivations and actions in aggregate represent the experiences and contributions of cause-champions connected to the Michael J Fox Foundation. From the construction of motivation and display of action, to self-representation and self-critique, mediatization has influenced what we see and how it is

construed. The individualization of civic responsibility and morality that inform the actions of cause-champions, and their interpretations of their world and themselves are part of our mediatized world. Within this environment individuals have the ability through their physical actions and affective labour to contribute to a cause they are passionate about. Social media has provided new tools to connect and to self-represent that adhere to the prevailing social constructs of civic responsibility and morality and thus reinforce the individualization of our social world.

Limitations to this study begins with the small participant group size, there is a tendency for conformity in opinion related to the motivations for action and the worthiness of the actions themselves. Each of the participants have a personal or familial connection to the cause, which does not provide for the best diversity of experience to draw from. Each of the participants have also been connected to the MJFF community for multiple years. There was little open critique of the MJFF and more broadly of the philanthropic context in which the participants worked, so while there were inclinations of contrariness (debate of the exclusively positive messaging) overall the study's nature was not critical. It is possible that the strength of the finding of positivity as a theme for communication and in affective labour, my participation was also a limiting factor to exploring a more critical view of the research and its data.

I am (as researcher-participant), intimately involved with the community surrounding the MJFF and the efforts involved in running a marathon and fundraising for a cause. This experience may, in and of itself have blinded to some of the nuanced data that unaccustomed eyes would perceive. This study was also an emotional experience. I was and am very close to this project as well as being a part of the participant group. All of participants also all had pre-existing relationships with one another. This also may led to many tacit

understandings in place of actual conversations that might have brought up a different or more critical discussion. Many times I had to separate my beliefs from my observations, and allow them to align freely. This was a practice in patience and gaining perspective on the data to see my experiences and those of my fellow participants for what they were and what they were not.

Future research needs to increasingly examine the phenomenon of charity sports events (particularly endurance-related) in conjunction with the use of social media as an advocacy tool. Focusing on content of social media posts, and frequency without losing the intimacy of ethnography would present the most worthwhile data. Also further investigation is needed into the individualization of civic and how ever-increasing connections between morality and wealth will influence the nature of the nonprofit industry with the retrenchment of the welfare state and the persistence of current global economic challenges.

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