"Peer-Led Support for Long Term Health Conditions: Its functions, benefits and challenges

and how the role of a Facilitator could increase effectiveness"

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PREFACE & ACKNOWLEDGEMENTS

Achieving happiness and life satisfaction in the modern world is seemingly difficult; thus, when someone is affected by a serious or chronic illness it can feel impossible to cope. My personal encounters with long-term health conditions (LTHC) have presented a considerable challenge. There have been many times I have felt hopeless, lonely, frustrated, angry and overwhelmed. Yet, in spite of it all, the support I have received from family, friends, healthcare staff, workmates and peers has allowed me to utilize these difficult experiences to make me into a more empathetic, resilient, grateful and overall happier person.

Since the commencement of this Masters Thesis I have had the incredible privilege of engaging with people involved in peer-led support groups for LTHC across the Mid-Central District Health Board. I initially believed talking to people affected by LTHC would be an emotionally trying and often disheartening process; however, I couldn't have been more wrong. From the peer-leaders who dedicate their valuable time to bringing people together in a shared community, to the health professionals that go the extra mile to ensure their patients thrive, to the people affected by long-term health conditions who continue to persevere through the most difficult times, I have been left with an overwhelming sense of hope.

To my supervisors Don & Sara, who have supported me through this entire process- I am forever grateful for this opportunity. To the people involved in support groups for health conditions, both those who participated in my study and those who I have not had the pleasure of meeting- thank you for all that you do for the community. Lastly, for the people like myself who's daily lives are affected by LTHC – you are brave, strong and important and you are not alone.

"Lean on me, when you're not strong

And I'll be your friend

I'll help you carry on

For it won't be long

'Til I'm gonna need

Somebody to lean on"

- Bill Withers

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Abstract

Peer-led support groups for long-term health conditions are inexpensive and beneficial

resources. However, literature on peer-led support is minimal and suggests that these groups

face many challenges. The current study endeavored to explore the challenges and functions

of peer-led support groups for long-term health conditions; further, examining how the

implementation of the role of a Facilitator for these groups could negate some of the

challenges and increase the prevalence and effectiveness of groups. Through focus groups

and individual interviews with Group Leaders, Health Professionals and Group Participants

involved in peer-led support groups, the current study identified 7 emergent themes. These

themes were discussed and analyzed, particularly in relation to the experience of peer-led

support groups and the possibility for the development of the role of a facilitator in the future.

Chapter 1

Introduction

1.1 Introduction

The prevalence of physical Long Term Health Conditions (LTHC) is continually increasing in New Zealand (Holloway & Talemaitoga, 2007). These LTHC place a large burden on the nation's health services and require ongoing resources to treat both physical and psychological effects (Valderas, 2009). The need for support for individuals with LTHC has incited the development of peer-led support groups. Such support groups aim to provide ongoing support and increase self-efficacy and self-management of one's condition (Simoni, 2011). However, there is little research available on how peer-led support groups function, how they are maintained and why they are an effective resource for people with LTHC.

1.2 Background

The past half-century has seen medical advances that have decreased the fatality of acute illnesses. However, this has resulted in a greater number of individuals living with long-term or chronic health conditions (Nolte & McKee, 2008). This has presented a unique challenge for healthcare professionals regarding how to deal with the physical and psychological impact of LTHC. Overall, the global burden of LTHC on healthcare systems has incited the conceptual move away from acute-care models and a greater focus on self-management and patient autonomy.

As LTHC often persist for several years (WHO, 2002), patient self-management is imperative to increase positive outcomes and decrease the strain placed on health systems (Nolte & McKee, 2008). Bandura's Social Cognitive Theory is at the fore of the development of self-management resources for LTHC (Bandura, 1977); this theory is centred around the concept of self-efficacy- the belief that one has the ability to incite positive change. Bandura also sights observational learning as a predictor of one's future actions, reactions and coping skills (1988). The notion of self-efficacy has informed the development of The Chronic Care Model (CCM) (Wagner, Bodenheimer & Grumbach, 2002). The CCM has been a key implementation to healthcare systems in dealing with the rise in LTHC, and views the psychological outcomes of LTHC as influenced by the community and health system in which they exist. The CCM focuses on the provision of community resources and polices that promote patient self-efficacy. Furthermore, this model suggests that well organized health systems will provide comprehensive information and support in medical decisions for patients. Consequently, these systems result in the development of an "informed, activated patient" and a "prepared, proactive, practice team" (Wagner, Bodenheimer & Grumbach).

Despite the development of the CCM, some modern healthcare systems are still somewhat grounded in acute healthcare models (Singh, 2010). However, as LTHC and long-term comorbidities continue to rise (Ministry of Health New Zealand, 2009), the application of the CCM in healthcare contexts increases. One of the major contemporary implementations of the CCM is a greater focus on psychosocial support resources for individuals with LTHC. Professional-led psychosocial support resources are considered to have a positive impact on patient condition self-management and overall psychological wellbeing (Pickett, Heller & Cook, 1998). However, professionally-led groups are expensive

resources and consequently, are not widely available or accessible (Grande, Meyers & Sutton, 2006).

Peer-led support groups are a cost-effective alternative to professionally-led support groups for LTHC (Fisher et al, 2015). As Fisher and colleagues suggest, peer-led support has comparable effectiveness to formal types of psychosocial support. The CCM supports the development of peer-led support groups, particularly due to their focus on developing 'communities of support' (Wagner, Bodenheimer & Grumbach, 2002). These groups provide external social and emotional resources that can tackle psychologically maladaptive behaviours that arise when coping with a LTHC (Kinderman, Schwannauer, Pontin, Tai, 2013). Peer-led support is an important part of the CCM and when used in conjunction with medical intervention, can result in the creation of a dynamic, integrated system of chronic illness care (Wagner, Austin, Von Korff, 1996).

However, peer-led support is not merely a supplement for professionally-led psychosocial resources; it has unique benefits due to the non-hierarchical nature of the relationship between leader and members (Peers for Progress, 2016). Bandura's Social Learning Theory (1971) suggests that individuals are likely to adopt positive behaviours modelled by others in social environments. In the context of peer-led support, these adopted behaviours can surround condition self-management and prosocial actions that could result in a greater sense of self-efficacy for an individual with a LTHC. Importantly, increasing self-efficacy results in LTHC patients facing emotional and physical hurdles with a greater sense of confidence and autonomy (Walter & Shoda, 1995).

Overall, as the field of medicine continues to legitimize the practice of Health Psychology, the importance of peer-led support has also been recognized (Fisher et al, 2015). However, research indicates that peer-led support groups for LTHC have struggled with development and maintenance (Payne, 2001). Miyamoto & Sono (2012) provided a review of literature on peer-led support, and found that peer-leaders cited many common challenges. The most prominent challenges outlined by the authors were boundaries, role conflict and ambiguity, low compensation and and limited hours of work. Peer-led support is less formulaic than professional-led support or individual therapy, and the management of the group by lay-persons or paraprofessionals can make it difficult to regulate members and ensure the positive development of the group (Miyamoto & Sono).

Further, though it is apparent that peer-led support groups are an important part of comprehensive care models for LTHC, there is limited financial and educational support for them. As Scott, Doughty & Kahi (2011) suggest, peer-led support groups struggle with maintenance due to the variable nature of funding sources. Though compared to professional psychosocial support resources peer-led support is relatively inexpensive, they still require some level of financial stability to continue to operate. Furthermore, the lack of compensation for peer-leaders can make it difficult for leaders to dedicate considerable time to the group (Miyamoto & Sono, 2012).

There is also a historically apparent disconnect between the healthcare system and peer-led support groups for LTHC. Research has indicated that health professionals often neglect to refer patients to peer-led support groups (Sheffield, 2003). Wituk, Shepard, Warren & Meissen (2002) examined this phenomenon, suggesting that healthcare professionals are often hesitant to refer to peer-led support groups because they are generally unregulated. This

is unsurprising due to the limited in-depth research on the functions and benefits of peer-led

support. Not only does the lack of research on the importance of peer-led support contribute

to the inadequate resources provided to many groups (Dennis, 2003), it could contribute

to the reluctance of health professionals to endorse these groups.

1.3 Definition of Terms

The two most important terms utilized in the current study are 'Long Term Health

Conditions' and 'Peer-led support'. These terms are defined in the following section.

Long Term Health Conditions

The most widely accepted definition of LTHC is provided by the WHO. The WHO

states that LTHC are illnesses or diseases that are long in duration and slow progressing"

(WHO, 2014). The WHO also states that LTHC are conditions that persist for 12 or more

months (2003). As part of this definition, The WHO cites the 4 main examples (or 'Big 4') of

LTHC as stroke or heart attacks, cancers, diabetes and respiratory diseases. While this

definition helps provide a basic understanding of LTHC, it is somewhat problematic and has

limited the scope of research on LTHC (Goodman et al, 2013).

Though apparently simple, the WHO definition of LTHC has generated some

ambiguity. The definition itself is inherently contradictory; for example, strokes and heart

attacks are utilized as main examples of LTHC, however they are both episodic, acute events.

Relatedly, the WHO suggests that LTHC are 'slow progressing' and this implication can be

misleading as many forms of cancer, for example, are fast progressing (Yokota, 2000).

Further, not all LTHC are progressive, such as non-progressing Chronic Kidney Disease

(Reich et al, 2011); other conditions, such as Chronic Pain can improve with lifestyle

regimes, medication and self-management.

However, the largest issue with the WHO's definition of LTHC is the narrow

conception of the division between long term and acute illnesses. This definition neglects to

include conditions such as bacterial meningitis, that are short in duration, but often result in

long-term disabilities and consequences such as limb amputation (National Collaborating

Centre for Women's and Children's Health, 2010). Ostensibly, the WHO conception of

LTHC has provided consistency in the way in which LTHC has been defined for research

purposes. However, this definition does not encapsulate the many LTHC that fall outside

these traditional parameters. Consequently, the current study introduces a new means of

conceptualizing LTHC through Treatment and Condition Outcomes Approach.

The Treatment and Condition Outcomes Approach explains why non-conforming

conditions such as heart attack or stroke are considered as LTHC (WHO, 2014). The

Treatment and Condition Outcomes Approach conceptualizes LTHC as either:

1) *"A Primary Disease, Illness or Condition"* that is long in duration (chronic or

   terminal) and generally slow progressing

2) *A "Treatment Outcome" (TO),* whereby the treatment of an acute or chronic health

   condition results in a long-term outcome that may have physical and psychological

   impacts. Examples of TO include: amputation of limbs, instalment of stomas, chronic

   medication (and the side effects of this) and treatment-induced infertility. Further,

   secondary conditions or disabilities which are induced by the treatment of a pre-

   existing condition are also considered TOs (Turk, 2006). Examples of secondary

conditions include Cushing's Syndrome from corticosteroids (Ferri, 2016) or

Serotonin Syndrome from the treatment of Chronic Pain (Lamberg & Gordon, 2012)

3) *A "Condition Outcome" (CO)* whereby an acute or chronic health condition directly

results in a long term-term outcome. Based on the traditional definition of a LTHC as

'long in duration and slow progressing' (WHO, 2014) , a heart attack or stroke should

not be considered a LTHC; however both can result in fairly significant long-term

deficits such as hypertension, paralysis or cardiovascular weakness or other

disabilities (American Heart Association, 2013), all of which are COs. Alternative

examples of COs include paralysis (from an accident, for example), brain or

neurological damage, severe burns and vision or hearing damage.

The current study will define LTHC through this approaches to avoid the definition

ambiguity that often plagues health psychology research (Schulman-Green et al, 2013).

Peer-Led Support

Existing literature has habitually defined peer-led support as being run, at least in part

by individuals affected by a LTHC (Adams, Paasse & Clinch, 2011). Dennis elaborates on

this definition, suggesting that peer-support is "the provision of emotional, appraisal and

informational assistance by a created social network member who possesses experiential

knowledge of a specific behaviour or stressor and similar characteristics as the target

population". Problematically, there are several limitations when utilizing this definition in

wider contexts; for instance, patients with degenerative diseases such as Alzheimer's or

Motor Neuron Disease (MND) would likely not be able to lead a support group, particularly

in the later stages of illness. In this case only their carers, partners or family would be able to

be peer-leaders under this definition. Perhaps, the delineation of whether a group is defined as peer-led support or professional-led support depends upon how the leader views themselves. For instance, some peer-leaders may have professional roles within the healthcare system, but choose to run groups outside of work hours, and define themselves in this context as a peer-leader (Peers for Progress, 2016). Further, a healthcare professional may be personally affected by a LTHC and lead a support group as a social equal, despite their occupational knowledge.

When examining the definition of 'Peer-Led Support Group' it is apparent that the purpose of the group is at the fore of how it is classified. Ussher and colleagues (2006) state that peer-led support aims to provide an ongoing, emotionally supportive social community. While this is often undertaken by a leader that has experience with a condition, modern conceptions of peer-led support suggest that it is defined by what it does, rather than who is doing it (Dennis 2003; Fisher, Ballesteros et al 2015). Perhaps the difficulty in outlining what peer-led support truly is, surrounds the word 'led'. Peer-led support is beneficial because of the social community of shared experience that is created for members (Delman, Delman, Vezina & Piselli, 2014). Where professional-led support often facilitates functional discussion and provides education, there is a distinct difference between these two forms of support

The current study will continue to utilize the term 'peer-led support' to avoid confusion- as it is ubiquitous in the relevant literature. However perhaps a more suitable term would be peer-oriented support, as conceptually, peer-led support is focused on developing intergroup relationships and ensuring equal power dynamics. As opposed to professional-led

support, these groups possess a leader that facilitates group engagement rather than directs

group discussion and activity (Toseland, 1998).

1.4 The Current Study: Role of The Facilitator

The current study examines peer-led support groups for LTHC in the context of New

Zealand; specifically focusing on the Mid-Central District Health Board (MDHB) which

covers the Horowhenua, Manawatu, Palmerston North City and Tararua Districts, as well as

Otaki (which is part of the Kapiti Coast District) (Mid-Central District Health Board, 2016).

It is apparent that there is limited specific research on support groups for LTHC in New

Zealand; however, it is also clear that there is a need for peer-led support resources for

individuals affected by LTHC across the nation (Scott, Doughty & Kahi, 2011).

Consequently, the MDHB funded an 18-month initiative to pilot the role of a 'Facilitator' for

peer-led support groups. The Facilitator has been designed to be a resource for Group

Leaders and Health Professionals involved in peer-led support groups. The role was intended

to aid in the recruitment of new members, fundraising and raising awareness, developing new

groups, assessing the need of existing groups and aiding in the communication between peer-

led support groups and the District Health Board (DHB), Non-Government Organizations

(NGOs) and Primary Health Organizations (PHOs).

The term 'Facilitator' was chosen as the MDHB felt it avoided ideas of management

or non-collaborative aid. It was important that the current study did not confuse the role of

Facilitator with a 'co-ordinator' or 'overseer'. The purpose of the Facilitator in the MDHB is

to make contact with group leaders and provide support where requested and to be part of a

cooperative effort to increase the visibility, effectiveness and sustainability of existing groups

and help create new ones where required. This role is not to audit support groups or provide

critical feedback. The MDHB felt the term Facilitator was non-threatening and not

confusable with other roles within support groups.

1.5 The Current Study: Purpose

The purpose of this study is to examine the functions, benefits and challenges of peer-led

support groups for LTHC in the MDHB from the intimate perspective of individuals directly

involved; namely, Group Leaders, Health Professionals and Group Participants. Furthermore,

the current study aims to discover how the role of the Facilitator has functioned over the 18-

month period and the potential it has to benefit peer-led support groups in the future.

Importantly, the current study aims to give a voice to those involved in peer-led support and

affected by LTHC and provide a unique perspective on the importance of these groups

Chapter 2

Literature Review

2.1 Introduction

This chapter will begin with presenting the history of peer-led support for LTHC. Next, the key psychological research on peer-led support will be outlined. This chapter will present literature that discusses how the effectiveness of peer-led support can be increased; as well as examining the minimal literature available on the role of a Facilitator in peer-led support groups. Finally, the gaps in the current body of literature will be discussed, alongside the ways in which the current study aims to address these. The chapter will finish by delineating the research questions of the current study.

2.2 The History of Peer-Led Support

Peer-led support is said to have origins in the 18th century France, where Bicētre Hospital in Paris found value in employing ex-patients as hospital staff, due to their increased empathy and compassion (Tang in Peers for Progress, 2013). In the 1930's peer-led support for Alcohol Abuse was introduced in the form of Alcoholics Anonymous, whereby recovered alcoholics lead others in recuperation (Fiegeilman, 2012). Following this, Tang suggests that peer-led support experienced a resurgence in the 1960's, when paraprofessionals were beginning to be valued as effective in helping individuals with mental illness and reducing the apparent strain on the healthcare system.

Over the past half-decade there has been a significant imbalance in the literature on peer-led support groups for mental illness (Faulkner & Kalathil, 2012). Mead and MacNeil (2006) suggest that psychological literature focuses on peer-support for mental, rather than physical illness because mental health support groups are more common. Furthermore, peer-led mental illness support groups tend to be more popularized as they are generally grounded in strong political contexts. The authors infer that many peer-led support groups for mental illnesses were developed to address concerns surrounding over-medication, patient rights, and improper resources.

However, contemporary healthcare systems have recognized the unique challenges posed by the increase of chronic illness in the global population (Nolte & McKee, 2008). In the gradual move away from acute-care models, the goals of chronic care have been outlined as increasing functional status and quality of life for individuals with LTHC. Clarke (2003) infers that patients with LTHC should be incited to engage in physical activities and therapeutic social scenarios, have a positive and symbiotic relationship with healthcare providers, adhere to medication and other treatment regimes, self-manage their condition and attempt to regain a semblance of normalcy and routine. Unfortunately, this extensive list of tasks can be difficult for an individual with LTHC to complete alone and both fiscally draining and time consuming for healthcare systems to adequately oversee (Ward, Schiller, Richard and Goodman, 2014).

Consequently, peer-led support continues to act as a supplement for formal support for individuals affected by LTHC and the prevalence of these support groups has only increased over the past decade (Lawn & Shoo, 2010). It is predicted that healthcare systems will begin to utilize peer-led support as a resource for proactively tackling negative

psychological and social behaviors as well as maladaptive coping when dealing with LTHC

or mental illness (National Institute of Mental Health, 2017). Conceivably, moving away

from a reactive model of condition management is likely to increase self-efficacy, self-

confidence and overall wellbeing of individuals affected by LTHC.

2.3 Peer-Led Support: Models

Peer-Led Support comes in many forms, though the majority of psychological

research focuses on the archetypal group, lead by a paraprofessional and attended by

individuals with a specific LTHC (Repper & Carter, 2011). Typically, the goal of peer-led

support groups is to create a positive social network of shared experience that provides

support and friendship to members (Sawyer, Drew, Yeo & Britto, 2007). In Chapter One, the

ways in which the current study defines peer-led support was outlined. However, Heisler

(2006) provides a more in depth model of the seven models of chronic illness management

via peer-led support, as outlined below (Table 1).

Table 1: Seven Models of Peer-Led Support (based on Heisler, 2006)

Number	Name	Description
1	Professional-led groups with peer-exchange	Healthcare provider facilitates a peer group
2	Peer-led face-to-face self-management programs	Self-management group with a peer leader
3	Peer Coaches	One-on-one mentoring & council with a peer leader
4	Community Health Workers	Worker bridges gap between healthcare system & patients
5	Support Groups	Gatherings of people sharing general common experience
6	Telephone-based peer support	Peer-to-peer engagement over the phone
7	Internet based programs	Peer-to-peer support over email, blog or online forum

Table 1

Ostensibly, peer-led support groups are diverse in the way in which they are run, the individuals that run them and the over-arching goals of the group. Even within the 7 Models outlined by Heisler (2006) there are differences across individual groups. The literature on peer-led support groups tends to focus on different models of purpose; namely, social support, education-oriented, 'shoulder to shoulder' or activity based and community health-oriented (such as raising awareness, lobbying and fundraising). The most commonly cited model in psychological literature is social support oriented peer-led groups. These groups tend to focus on emotional support, troubleshooting problems, expressing challenges or issues and celebrating triumphs with peers in analogues situations (Sawyer, Drew, Yeo & Britto, 2007). As the authors suggest, this type of support is considered 'face-to-face' and often involve peers providing experiential practical and emotional advice. These are often conducted in meeting rooms, or less formal contexts such as cafés. Education-oriented support groups

Education-oriented peer-led support groups are focused on the provision of practical knowledge (Ansell & Insley, 2013). Though this model of support is generally delivered by healthcare professionals with educational backgrounds, in some cases it may be part of peer-led support (Delman, Delman, Vezina & Piselli, 2014). Peer-leaders could provide practical knowledge to one another from personal experience; for instance, regarding how to manage medication side-effects or dietary requirements (Sharif et al, 2010). Further, peer-leaders could organize professional speakers for a group and orient subsequent discussion around this. Overall, education-oriented groups follow the approach of 'Integrated Theory of Health

Behaviour Change' (Ryan, 2009). This approach suggests that increasing one's knowledge of their personal health issues or predispositions ultimately increases self-efficacy and positive health behaviors.

Activity-oriented peer-led support groups exist in many different contexts; examples include walk-and-talk support groups (Breast Friends, 2001), groups working on a project such as fixing a car (Men's Health Forum, 2014) or disability-friendly activities such as modified cycling (We Are Cycling UK, 2016). The Men's Health Forum introduced the term 'shoulder to shoulder' support in regards to activity-oriented peer-led support groups. As opposed to face-to-face support, shoulder to shoulder peer support can reduce anxiety in individuals who do not want to attend support groups that confront emotional issues head-on. Furthermore, activity-oriented support groups can be instrumental in creating a fun and positive support environment as well as encourage and endorse physical activity (Faulkner & Kalathil, 2012).

Finally, another model of peer-led support is community health oriented groups. These groups are focused on raising awareness of LTHC, fundraising for NGOs or LTHC related causes, lobbying and providing medical advocacy (Bhagwanjee & Steven, 1999). According to the authors, community health functions of peer-led support groups often compliment other models of support groups. Further, engaging in prosocial community behaviours can increase self-efficacy through the process of meaning-making, allowing participants to feel they are using their negative experiences with LTHC to benefit others (Arvaja, 2011).

Understandably, some support groups may have multiple purposes or are comprised of more than one model. Outlining the variety within peer-led support groups displays their diversity and adaptability. Further, it allows for a greater understanding of their functions and benefits.

2.4 Peer-Led Support: Target Groups

The question 'who is peer-led support for?" is one that emerges in psychological literature (Peers for Progress, 2017). Unlike medical treatment and intervention, peer-led support extends beyond the patient with a LTHC. Peer-led support groups also exist for individuals affected by the LTHC of a family member, partner or friend (Chien, Thompson & Norman, 2008). Further, Dennis (2003) suggests that peer-led support groups also exist for people experiencing 'transitional stressors', such as bereavement; examples of bereavement in the context of LTHC include loosing a child to cancer or a partner being diagnosed with Alzheimer's. Peer-led support groups can also be proactively oriented, for instance Prospero and colleagues suggest that support groups for females who discover they have the 'BRCA' gene (a genetic mutation resulting in a significantly increased risk of developing both breast and ovarian cancer) are beneficial in preparing them to cope with the possible stresses of a future cancer diagnosis or preventative surgeries (2001).

Though the majority of literature on peer-led support groups for LTHC tend to be focused on common, popularized conditions such as cancer, diabetes, and HIV/AIDS (Reblin & Uchino, 2009) they have the potential to benefit a variety of individuals in diverse situations.

2.5 Key Literature: Functions of Peer-Led Support

Psychological research has recognized that peer-led support is beneficial to individuals affected by LTHC (Dennis, 2003). Yet, literature describing the contexts in which it is effective and the specific mechanisms behind this is minimal. However, the existent body of literature addresses some of the reasons why support groups might improve the psychological wellbeing of individuals affected by LTHC.

Self-Efficacy and Self-Management

The notion that peer-led support groups increase patient self-efficacy and condition self-management was explicated in Chapter 1; this is arguably one of the most important functions of peer-support.

Psychological literature on the effect of peer-led support for mental illness on self-efficacy and self-management indicates a positive correlation (Vayshenker et al, 2016). Vayshenker and colleagues conducted a 6-month analysis of individuals diagnosed as being on the schizophrenia spectrum or having bipolar disorder who attended peer-led support groups in Brooklyn, New York. At the beginning of the 6-month period participants completed psychological tests surrounding aspects of their life affected by mental illness; this included personal empowerment, social functioning, hopelessness and coping behaviors. Over the 6-month period, participants who regularly attended peer-led support groups displayed greater levels of self-efficacy, self-confidence, condition self-management and positive socialization and coping. The researchers surmised that these benefits came from the minimization of the stigma of mental illness, the modelling of positive behaviors of peers and

positive encouragement and reinforcement from peers. Overall, participants experienced

greater adherence to treatment and subsequently a lower impact of mental illness on their life.

Similarly, Lee, Lee, Oh & Kim (2013) examined the effects of a dyadic peer-led

support intervention (DPSI) on the self-management and self-efficacy of women diagnosed

with breast cancer in Korea. The study placed participants into either the control condition or

the DPSI condition and compared their self-reported outcomes after the 6-week period.

Women in the DPSI condition reported significantly higher levels of self-efficacy and self-

management compared to the control. Women in the DPSI condition reported greater

autonomy and control over health outcomes and greater self-confidence. This effect was not

only apparent in women; Weber and colleagues (2007) found that men who had a radical

prostatectomy and subsequently attended a DPSI were more self-efficacious than those who

did not attend.

The increase in self-efficacy and condition self-management in individuals involved

in peer-led support groups is not only relevant to participants. Charlesworth and colleagues

(2017) conducted a longitudinal study on the peer-leaders of Dementia support groups in

England; leaders were carers of individuals (generally family members or partners) of people

with Dementia. Through conducting one-on-one interviews, the researchers found that over

time, peer-leaders experienced an increase in self-efficacy which positively affected their

confidence in their abilities as a carer. Overall, the existing literature indicates a positive

relationship between peer-led support and self-efficacy and self-management for both

participants and leaders.

Social Engagement & Shared Experience

One of the emergent ideas regarding the effectiveness of peer-led support surrounds social engagement and shared experience. Finlay and Elander (2016) conducted semi-structured interviews with 12 participants who had a diagnosis of Chronic Pain and attended a peer-to-peer oriented support group. They asked participants about their reasons for participating in the support group and the ways in which they felt it benefit them. Of the strongest themes that emerged was 'the thirst for comparative friendship'. Finlay and Elander suggest that participants valued the social dynamic of the support groups because it decreased social isolation, created new supportive friendships and allowed for the freedom of social referencing. The researchers noted that the socially-oriented aspects of peer-led support were the greatest attraction to participant attendance.

The social aspects of support groups differ between peer-led support and professional-led support. Stevinson, Lyndon & Amir (2010) surveyed 315 leaders of cancer support groups in the UK. The authors endeavored to examine the differences between the social environment of different types of cancer support. Leaders of peer-led support groups reported higher incidence of social support external to group meetings; including home visits, telephone and internet support and group social events compared to professional-led support groups. Furthermore, peer-led groups were shown to be less restrictive regarding who can attend (ie. including family, friends, partners and survivors) promoting a larger and more diverse support group. Stevinson, Lyndon and Amir suggest that these differences may impel peer-led support to have more effective and inclusive social dynamics.

It is apparent that one of the most prominent benefits of support groups is the social networks built between members and the development of a community of shared experience.

Peer-led support in particular has the ability to provide a sense of normalcy and shared understanding for members (Sawyer, Drew, Yeo & Britto, 2007). As Sawyer and colleagues suggest, this has important benefits for the development of positive coping mechanisms and self-care behaviours in individuals affected by LTHC. Understandably, friendships forged through mutual support are extensively beneficial to psychological wellbeing.

Decreased Psychological Comorbidities

The therapeutic benefit of social interaction on depression, dysthymic disorder and anxiety is well-established in psychological literature (Turner & Kelly, 2000). Research further indicates that LTHC often have comorbidities with mental illness, particularly anxiety and depression (Lee, Lee, Oh & Kim, 2013). Thus, it is unsurprising that support groups have been utilized as a means of decreasing negative mental health outcomes in individuals affected by LTHC.

Lorig, Ritter, Villa & Armas (2009) conducted a study examining peer-led support for individuals with diabetes. The researchers found that participants who attended a 6-week community based peer-led support group had significantly decreased levels of depression and anxiety. The effects of the support group persisted at 6-month and 12-month follow-ups. Specifically, they found that participants engaged in more proactive behaviours such as healthy eating, regular exercise, reading food labels and adhering to medication than the control group. Such behaviours had a positive impact on participant mood and ability to emotionally cope; this is likely a product of increased self-efficacy.

Comparably, Montazeri et al (2001) studied breast cancer patients attending 3 different Iranian support groups. The researchers compared anxiety and depression levels of women at baseline and at a follow-up after attending the support group. Through utilizing psychological scales measuring psychological wellbeing, it was found that participants reported significantly lower levels of anxiety and depression when compared to their individual baseline. The researchers hypothesize that this is the result of psychological 'buffering' whereby the social support of other group members buffers the impact of negative or stressful life events.

Further, Legg, Occhipinti, Ferguson, Dunn & Chambers (2011) surveyed 251 breast cancer patients who attended peer-led support groups. They found that participants experienced lower levels of depression and anxiety than individuals who did not attend support groups. The researchers noted that women who appraised their diagnosis as threatening showed the most decrease in depression and anxiety; they posited this was due to women making positive upwards comparisons (PUC) to other members of the group. Through the process of PUC participants felt as though they were capable of surviving their breast cancer, which diminished feelings of anxiety and depression.

Ostensibly, social support buffers the effects of situational stress on depression and anxiety (Cohen, 2004). The reduction of psychological comorbidities of LTHC through peer-led support is an indubitable benefit to both individuals affected by LTHC and the healthcare system as a whole.

Community Functions & Meaning-Making

Research on peer-led support has depicted the positive community functions these groups can have. Peer-led support groups can incite public awareness of LTHC through fundraising campaigns and lobbying (Bhagwanjee & Steven, 1999). Uniting a group of individuals through their experience with a LTHC presents a unique opportunity to encourage proactive and preventative health behaviours in the community (Steginga et al, 2002).

There is limited anecdotal evidence on the intersect between peer-led support and LTHC awareness. However, Karawalajtys and colleagues (2009) examined peer-educators involved in a Cardiovascular Health Awareness Program (CHAP) in Ontario. Participants iterated the importance of the peer-education component of health condition awareness groups. The researchers suggested that peer-educators provided a unique subjective perspective on LTHC and that this likely increased public interest in CHAP. Further, the authors inferred that getting patients with LTHC involved in community awareness and fundraising campaigns was mutually beneficial.

Peer-led support can also be instrumental in lobbying for greater resources for, and awareness of LTHC. Wynchank (2002) examined the social and political role of mental health support groups- specifically, the South African Depression and Anxiety Support Groups (DASG). The DASG has nationwide telephonic support as well as over 100 groups across South Africa. Wynchank found that the function of these groups goes beyond social support; many support groups engage in public lobbying. In the context of South Africa, the DASG groups petition for greater visibility of mental illness from the government and healthcare systems. While this study involved a variety of peer-led and professional-led groups it is clear that the engagement in social and political lobbying is applicable to a variety of support groups.

Though a reasonably old study, Gray, Fitch, Davis & Phillips (1997) conducted an in-depth qualitative analysis of support groups for women with breast cancer in Canada. Twenty-five group members were asked about their individual experiences and the informational and practical benefits of attendance. While the majority of women perceived the paramount purpose of the support group to be the provision of emotional support and aid in coping with the impact of breast cancer on their lives, a strong secondary purpose was advocacy. Members varied in their opinion of the importance of peer-advocacy in healthcare contexts, as well as fundraising and community awareness. However, many groups felt as though it was part of their overall purpose to engage in such activities. Again, the authors noted that advocacy and community engagement was mutually beneficial.

However, the function of community-oriented behaviours of support groups goes beyond informing the public; engaging in such behaviours increases self-efficacy and wellbeing of participants. Cabrera & Cabrera (2007) suggest that self-efficacy and self-confidence can be a product of feeling as though one's contributions and actions can make a difference to the lives of others. Similarly, engaging in altruistic community behaviours can give purpose to the difficult journey of individuals affected by LTHC (Park, 2010). Cureton (2003) interviewed 6 individuals who currently had cancer or were in remission from cancer and participated in support groups. Cureton found that participants conceptualized 'healing' on several different levels (ie. emotional, spiritual, physical). One of the components to emotional healing that participants addressed was engaging in meaning-making. Through this process, participants indicated that they were able to be at peace with their experience with cancer and believed that they could use their experiences to benefit others. This process of

helping others, individually or on a community-level allowed participants to reframe and appraise traumatic experiences as 'meaningful'.

Conclusion

The aforementioned benefits of peer-led support are only a small selection of many. Psychosocial support for people with LTHC is imperative to self-management and self-efficacy, emotional support and shared experience, decreased psychological comorbidities, community functions and meaning-making. While individual counselling or professional-led support services can be costly, peer-led support is comparatively inexpensive (Fukui, 2010). Peer-led support groups reduce patient reliance on traditional support services and reduce expenses associated with condition mismanagement and the psychological stress of LTHC (Insel, 2011).

2.6 Key Literature: Challenges & Critiques of Peer-Led Support

When executed appropriately, peer-led support is comparably effective to professional psychosocial support resources (Toseland, Rossiter, Peak & Hill, 1990). However, peer-led support is still met with considerable cynicism within the healthcare system. In order to understand how to develop and sustain effective peer-led support groups, the critiques and challenges presented in psychological literature must be understood.

Challenges of Paraprofessionals

Peer-leaders, peer-educators and informal support volunteers fall under the category of 'paraprofessionals'. Paraprofessionals are defined by Giangreco, Yuan, McKenzie, Cameron & Fialka (2005) as individuals who are substituted for professionals in a variety of roles but do not possess the educational qualifications of the aforementioned professional. In the case of peer-led support for LTHC, paraprofessionals are generally volunteers who do not have an educational healthcare background but may possess experiential knowledge that makes them suitable to undertake the role of a peer-leader (McLean et el, 2009). However, the paraprofessional status of peer-leaders can result in unique difficulties for the leader themselves and the group as a whole.

McLean and colleagues (2009) produced an in-depth report on the unique challenges experienced by leaders of peer-support groups. In analysing the self-reported issues experienced by peer leaders, the researchers found that there were several commonalities among participants. One challenge was the issue of confidentiality in obtaining potential group participants; leaders found it difficult to identify and approach participants due to doctor-patient confidentiality. Another challenge was the unique relationship between participant and group-leader and the blurring of boundaries due to the peer status of the leader. McLean and colleagues also cited difficulties with group sustainability due to limited funding and issues garnering new participants. Further, group-leaders reported difficulties with monitoring and mediating the group; the researchers suggest that this may arise from a lack of professional input and leader screening and training. McLean and colleagues comprehensively outline the challenges faced by peer-leaders that may ultimately impact the effectiveness of the group.

Further, Miyamoto & Sono (2012) conducted a comprehensive systematic review of literature on peer-led support for mental illness. The authors reviewed fifty-one studies, including nineteen qualitative studies on the topic. Similar to McLean and colleagues (2009), Miyamoto & Sono found that 'role' and 'relationship' issues most often plagued peer-leaders. Specifically, the authors noted that role conflict was a considerable challenge for peer-leaders; it was noted that peer-leaders often had difficulties abandoning their personal conceptions regarding treatment and healthcare and adopting a more neutral, professional belief system. Miyamoto & Sono's review also revealed a plethora of issues surrounding boundaries between peer-leaders and group members; they suggested that it was difficult for peer-leaders to discern what kind of group friendships were inappropriate. Understandably, the authors found that in many instances, this resulted in dependant relationships forming between leaders and members that ultimately undermined patient self-efficacy.

Davidson, Chinman, Sells & Rowe (2006) conducted 4-randomized control trials comparing peer-led support to conventional professional-led support for adult mental illness. The researchers found that peer-led support did not produce the same level of therapeutic benefit to patients as professional-led support. Davidson and colleagues further illuminated that peer-leaders were inexperienced in navigating issues of confidentiality and boundaries. They found that while peer-leaders were expected to uphold the same considerations surrounding patient confidentiality and leader-member boundaries, they reported not knowing how to adequately do so. Understandably, this was a considerable concern for the healthcare system and has underpinned the trepidation of health professionals referring to peer-led support groups. The researchers concluded that while peer-led support has promise as a mental health support service, it remains unregulated and its effectiveness, unproven. Though the Davidson and colleagues study was published in 2006 more contemporary

literature presents similar assertions that the effectiveness of peer-led support groups remains

mostly unproven (Lloyd-Evans et al, 2015).

Group Domination & Member Management

Further, Anderson & Kilduff (2009) conducted research on face-to-face peer groups

and the effects of dominant personalities on group dynamic. Though this research did not

specifically involve support groups for LTHC, the information is applicable to such contexts.

The researchers suggest that due to the lack of a distinct hierarchy in peer-led groups, they

are more susceptible to group imbalance from dominant members. Anderson & Kilduff found

that in order to increase dominance in the group, some members feigned competence

regardless of their actual knowledge. In the context of peer-led support groups for LTHC this

could result in other group members being misinformed regarding practical, medical or

emotional advice.

Analogously, Salmivalli (2010) reviewed literature on bullying and dominance in

peer-led and peer-to-peer groups. The researcher examined over 100 publications that

covered a wide variety of peer interaction, including peer-led support. Salmivalli found that

peer-groups were more predisposed to group imbalance than professional-led groups; this

included member dominance, aggression and inter-group conflict. The opportunity for group

imbalance is greater in peer-led groups for two reasons. Firstly, the peer-leader themselves

may not be formally trained in leadership techniques and could posses a dominant, aggressive

or paternalistic leadership style that is not beneficial to group members. Secondly, peer-

leaders are less likely to have group management training and may struggle to manage

problematic group dynamics. As Salmivalli suggests, dominant individuals often generate

inter-group conflict and propagate unproductive discussion; understandably, peer-leaders may be less trained to recognize and combat such dynamics early. Ultimately, such issues may also negate or decrease the benefits of psychosocial support groups.

Lack of Evidence on Effectiveness

Though peer-led support groups have functioned within the healthcare system for almost a century (Fiegeilman, 2012), there is still limited longitudinal evidence for its effectiveness. Understandably, this has been a barrier to peer groups garnering support from the medical field.

Lloyd-Evans and colleagues (2015) conducted a meta-analysis of peer-led support groups for mental illness. The authors initially noted difficulties with finding research that depicted peer-led support outside of individual case studies. Overall, only 25 papers met the criteria for analyses, of these, 17 were used in the final meta-analysis. The authors iterated several concerns with the existing body of literature on peer-led support; firstly, they noted concerns over the true definition of 'peer-led support' and discovered that many groups were overseen or managed by external professionals. Secondly, they noted that literature on peer-led support did not provide adequate information on the acceptability, feasibility, generalizability, clinical effectiveness, cost-effectiveness and equity of access; the authors inferred that it was paramount to detail these aspects in order to analyze effectiveness. Thirdly, Lloyd-Evans and colleagues noted that the comprehensive effectiveness of peer-led support groups was weak within the existing literature; also, the consistency with which 'effectiveness' was measured was inconsistent. Overall the researchers inferred that peer-led

support was not a substantiated resource and required greater in-depth and longitudinal

research.

Similarly, Kohut, Stinson, van Wyk, Giosa & Luca (2015) conducted a systematic

review of the literature on peer-led support for adolescents with chronic illness. The authors

selected a small number of studies focused specifically on interventions for people aged 13-

17; the final analyses included 11 studies. It was found that there was limited consistency on

what constituted a peer-led support group across the studies. Furthermore, the measurement

of 'effectiveness' differed considerably. Overall, Kohut and colleagues found that there was

some evidence that peer-led support for chronic illness had emotional and social benefits for

young adults. However, the authors also suggested that there was no significant support for

the improvement of physical symptoms from peer-led support groups. Despite discovering

some consistent benefits of peer-led support, the researchers suggested that the available

literature was too limited and specified to provide an adequate examination of effectiveness.

Ultimately, Kohut and colleagues suggested that peer-led support remains unproven, and

greater research on the topic is required.

Finally, Shilling and colleagues (2013) conducted a review of qualitative and

quantitative literature on peer support for parents of children with disabling health conditions.

The authors selected 17 studies to examine, the majority of which were parent-to-parent

support groups. It was found that consistent themes emerged across the analyzed research,

including, shared identity, learning from others, personal growth and supporting others.

Despite the positive nature of these themes, the overall effectiveness of peer support on

psychological wellbeing and coping was inconsistent. Shilling and colleagues suggest that

while parents of children with disabling conditions may perceive peer support to be effective,

there is little comprehensive evidence detailing this. The authors suggest that research on

peer-support groups is inconsistent and greater insight is required to accurately examine its

effectiveness.

Issues with Diversity

In order to fully conceptualize the function of peer-led support groups, the

applicability of these services to diverse communities must be considered. Psychological

research on support groups (both professional and otherwise) has noted a considerable lack of

participation from cultural minorities (Vrabec, 1997), young people (Tumwikirize, Torpey,

Adedokun, Badru, 2015) and males (Madiba &Canti-Sigaga, 2012; Krizek et al, 1999).

Understandably, this is a prominent issue that limits reach and overall effectiveness of these

groups.

Vaughn, Foshee & Ennett (2009) examined the effects of peer-support on depression

in adolescent subjects. The study examined self-reported levels of depression on 3,444

adolescents who received peer-support over the course of 2 years. Participants were obtained

from 3 rural areas, two of which were predominantly white and one of which was

predominantly African-American. The researchers inferred that the literature supported the

notion that peer-to-peer support was valuable in reducing depressive symptoms in

adolescence. However, Vaughn and colleagues found that peer-support was only significantly

predictive of decreased depression in white individuals. Understandably, this study presents

concerns over the applicability of peer-support to African-American individuals and the

potential need to develop more robust services of support for minority individuals.

Janz and colleagues (2008) conducted a study examining minority experiences within the healthcare system of the United States of America. The researchers explored the experiences of African-American, Latin-American and Asian-American individuals; these minority individuals reported greater levels of difficulty in understanding communications from medical professionals than Caucasian individuals. Janz and colleagues suggest that the lack of adequate communication between cultural minorities and medical professionals has resulted in feelings of isolation and decreased exchange of information surrounding medical and psychosocial support services. The researchers offer this as an explanation as to why support groups have low attendance by minority individuals. Furthermore, Janz and colleagues suggest that minorities feel ignored or minimized by the healthcare system, which discourages proactive health behaviours. Similarly, in New Zealand, Māori report high levels of racial discrimination in healthcare contexts (Harris et al, 2009). Harris and colleagues suggest that this results in decreased engagement with the healthcare system.

Few publications offer explanation as to why peer-led support may be less effective for cultural minorities. Heisler (2009) suggests that minority individuals often report feeling 'out of place' when attending groups that are predominantly attended and run by Caucasian individuals. Harper (2010) supports this notion, suggesting that African-American individuals participating in peer-led leadership programs reported greater benefits from groups lead and attended by other African-American individuals. In a New Zealand context, this notion may be applicable to Māori individuals. Whilst Māori have poorer physical and mental health outcomes than other ethnic groups, they paradoxically are minimally represented in support groups (Harris et al, 2009). Consequently, support groups have negligible involvement from Māori individuals, thus continuing the cycle. Crengle and colleagues suggest that the New

Zealand healthcare system must develop culturally integrative initiatives to increase positive

health outcomes for Māori (2012)

Though cultural and ethnic diversity is the most cited in psychological literature, there

is also a lack of gender diversity in many peer-led support groups. Peterson, Newton, Rosen

& Skaggs (2006) examined the coping strategies of men and women who struggled with

infertility. The researchers utilized self-report coping questionnaires on 1026 men and

women who experienced personal fertility issues or biological infertility. The results of the

study displayed a marked difference in the coping strategies of men and women. Specifically,

women engaged in more prosocial coping strategies such as engaging in support groups,

sharing with others and actively seeking social support. Men tended to engage in more

distancing and dissociating behaviours including distraction and transference. Peterson and

colleagues suggest that this provides one explanation as to why men are less likely to attend

support groups.

While men require the same level of psychological support as women, particularly

when dealing with LTHC (Steginga, Occhipinti, Dunn, Gardiner, Heathcote & Yaxley,

2001), men are less likely to utilize psychosocial support resources (Addis & Mahalik, 2003).

Okoro (2016) examined self-management oriented peer-led support groups for individuals

with Type 2 Diabetes. The researcher interviewed males and females via written or

telephonic responses; it was found that while men and women both engaged in peer-led

support, women were more likely to attend peer-led support groups. Furthermore, women

were more likely to focus on mutual emotional support, whilst men engaged in more practical

and informational support. Okoro suggests that developing peer-led support groups that are

tailored to the needs of males may be beneficial in increasing gender diversity.

Finally, age diversity is a prominent issue in peer-led support. Young people, specifically aged between 12 and 25 are less likely to attend health support groups (Shah et al, 2000). Gulliver, Griffiths & Christensen (2010) suggest that young people resist support groups due to their increased autonomy regarding help-seeking behaviours. The authors conducted a thematic analysis of research on young people's engagement with mental health services. In examining 22 published studies, the authors discovered several distinct barriers for young people with mental illness attending support groups. Barriers included stigma surrounding group attendance and mental illness, availability of resources, reduced health-literacy and a strong desire for autonomy and self-reliance. Gulliver and colleagues suggest that whilst many mental health support groups are open to young people, there are a limited number of groups that specifically target young people. Understandably, the authors infer that creating groups aimed and young people is an important future step in tackling the mental health epidemic of the current socio-cultural climate.

Indisputably, there is a lack of gender, cultural and age diversity in peer-led support groups; A lack of diversity exists in other areas as well, such as education, sexuality, religion and socio-economic class. The available literature presents few strategies on how to address these issues, despite the increasing need for inclusive psychosocial support resources.

Conclusion

Understandably, peer-led support has some critics, particularly within the healthcare system. Critical analyses of peer-led support reveal unique challenges of the role of the paraprofessional and susceptibility to group domination and improper member management.

The literature on peer-led support has failed to adequately substantiate the benefits of these

informal support resources, particularly in a modern day context. The emergence of mediated

support groups (ie. online forums or peer-to-peer email support) has further complicated this.

Finally, support groups in general have been shown to have limited age, gender and racial

diversity; though this issue is not unique to peer-led support for LTHC, it must be considered

as a potential barrier to effectiveness. Overall, peer-led support is not without substantial

challenges, which must be considered when understanding both their functioning within the

healthcare system and their potential for the future.

2.7 Addressing the Challenges of Peer-Led Support

Many of the aforementioned challenges of peer-led support impair its effectiveness.

The limited comprehensive research on peer-led support has made it difficult to determine

how to create and sustain effective peer-led support groups. However, some literature

provides information on what factors affect the provision and effectiveness of support and

how this can be increased.

Social and Environmental Factors: Support Provision

There are several social and environmental factors that can affect the provision of

adequate psychosocial support to individuals with LTHC. Laverack (2006) presented an

analyses of the effectiveness of peer-led support, and suggested that support groups are most

effective when they are located in a community that prioritizes psychological wellbeing.

Laverack conceptualizes wellbeing as a product of empowerment from both an individual

and community level; this idea is distinctly related to Brofenbrenner's Ecological Systems

Theory (1979). Brofenbrenner suggests that the national and social context in which a person

exits is a primary predictor for how negative life events will impact them. According to

Brofenbrenner and Lavarack's assertions, nations that recognize the important psychological

component of LTHC are likely to endorse psychosocial support programs and increase their

validity, sustainability and effectiveness within communities. For instance, Sweden has

greater psychological and physical health outcomes for patients with LTHC (Priebe, Watts,

Chase & Mantov, 2005). Priebe and colleagues suggest that this is a direct product of the

nations prioritization of wellbeing, the systematic organization of health and disability leave,

the provision of comprehensive healthcare and health information and importantly, the

provision of support resources.

Another social factor predicting the provision of peer-led support is the type of

condition a patient has. A plethora of literature has inferred that diseases such as some types

of cancer, diabetes or HIV/AIDS that are popularized in media tend to have greater support

resources available (Harvey, 2010). As Harvey suggests, this is likely a result of greater

funding for popularized LTHC. Carter and Nguyen (2012) examined funding and resources

across several nations for cancer and compared this with Years of Life Lost (YLL) and

Disability Adjusted Life Years (DALY). The researchers found that breast cancer, prostate

cancer and leukaemia had disproportionately greater resources than other cancers.

Social and Environmental Factors: Increasing Diversity

As mentioned, psychological literature has noted a lack of diversity in peer-led

support groups for LTHC and support groups in general. Specifically, research tends to focus

on the lack of ethnic minorities, men and young people partaking in support services. However, some research has also provided information as to how to increase the applicability of support groups to diverse communities.

Reduced minority participation in support groups can be partially attributed to the use of Westernized models of psychological support that may not be cross-culturally applicable (Cunningham & Stanley, 2003). Hinote (2002) conducted a study of men with psychiatric illness who partook in a support group. The participants were African-American, Black Caribbean and Latino; however, the group leaders were predominantly white females. Hinote found that the effectiveness of the support intervention was reduced by socio-cultural barriers between the leader and the participants. Specifically, the status of the leader as a white, educated female made it difficult for participants to relate. It was suggested that aligning the cultural identities of group leader and participants would increase the effectiveness of support services

As Nikora, Karapu, Hickey & Te Awekotuku (2004) suggest, New Zealand's support services for Māori could be improved with regards to their cultural competency. The researchers examined the availability and applicability of mental health services for Māori. Firstly, it was suggested that formal support services should work with Maraes, Kaupapa Māori services and iwi health centres to assess where the needs of Maori patients are not being met. Secondly, the researchers stated that when developing support services for Māori, it is imperative to ensure the Māori community is involved; this process allows for Te Whare Tapa Whã or 'the four cornerstones of health' to be incorporated in healthcare principals. Finally, the researchers suggested that Western perspectives on healthcare should not be

pushed on indigenous communities; it is more effective to find a balance with cultural understandings of social support and wellbeing.

The lack of male attendance to peer-led support groups is influenced by the stigma associated with support services. As Seale, Ziebland & Charteris-Black (2006) suggest, males tend to seek disease education and information or distraction from support groups, whereas women tend to seek emotional and social support; according to the researchers, societal perceptions of what peer-led support tends to align with the latter. Ostensibly, this can make support groups seem unappealing or even distressing to some males. Madiba & Kekana (2013) examined this phenomenon in the context of HIV/AIDS. The researchers suggest that support groups targeting males could advertise their focus on the provision of education and practical support. Further, it was suggested that male-oriented support groups could move away from traditional psychosocial support models and include activities, such as going for coffee, walking, working on cars or volunteering at a local homeless shelter. The Men's Health Forum (2014) provided similar advice on how to increase male participation in support groups; they suggested that groups focused on 'shoulder-to-shoulder' interaction, rather than 'face-to-face' are more appealing to and effective for men.

Finally, the lack of young people attending support groups is another palpable concern. Handley (2004) examined the participation of youths with chronic conditions in support groups. The researcher presented several distinct needs of young people that may not be met by general support services; namely, a heightened need for emotional support from peers, a sense of normalcy and a sense of autonomy. Handley suggested that support groups targeting young people would benefit from a heightened focus on intergroup friendship. Similarly, Gulliver, Griffiths & Christensen (2010) examined 22 studies on young people's

participation in support groups for mental illness; they suggested that young people are unlikely to benefit from support groups that are comprised of, or led by people considerably older than them. Consequently, psychosocial support resources for young people should shift towards peer-support models that are focused on the unique challenges of living with a psychological or physical condition as a young person. Further, Gulliver and colleagues suggest that these groups should be advertised as social environments where friendship and shared experience is valued.

Increasing Effectiveness

Conceivably, there are many elements influencing the effectiveness of peer-led support that can be difficult to tackle. However, research presents tangible ways in which effectiveness of both pre-existing and emergent or developing groups can be increased.

Simoni, Franks, Lehavot and Yard (2013) analysed the literature on peer-led support groups that promote health and wellbeing, focusing on what makes these groups effective resources. Simoni and colleagues suggest that peer-support models that encourage self-efficacy and positive upwards self-comparison result in greater outcomes for participants. Further, the researchers found that groups with advocacy or community functions had increased benefits for patients; this is likely a product of both meaning-making and self-empowerment. Overall, the research indicated that peer-led support groups that were dynamic in their overall goals (ie. providing both practical and emotional support) and delivery (ie. face-to-face and shoulder-to-shoulder based meetings) were the most effective for members.

Further, Heisler (2007) investigated peer-led support interventions for diabetes self-management. The article presents different perspectives on how to mobilize peer-led support and the ways in which its effectiveness can be increased. One of the main points made by Heisler is that peer-led support can be made more effective by having peer-leaders that are efficiently and comprehensively trained. Further, it is suggested that peer-led support groups are more beneficial to participants when there is some influence or support from healthcare workers; this is likely a product of the leader having increased support and increased resources. Heisler also suggests that patients with Diabetes reported reservations regarding attending a non-formal support group; as a result, peer-led groups experience lower attendance than professionally-led groups. In order to combat this Heisler states that there needs to be greater amalgamation of peer-led and professionally-led psychosocial support resources in order to maximize the unique benefits of both.

Another publication focused on increasing the effectiveness of peer-le support is one conducted by Guidugu and colleagues (2015). The researchers conducted interviews with individuals who had attended at least 10 sessions of a peer-led support group or program. Participants were questioned on their experience with peer-led support and in particular, their retrospective reflections on their expectations of the support service. Guidugu and colleagues found that participant's expectations of peer-led support significantly differed to what they experienced. Many participants expected peer-led support to be a supplement for formal support services; however, the limited time of volunteer peer-leaders often resulted in insufficient comprehensive support for patients. The researchers suggest that peer-led support was exceedingly more sustainable and effective when the leader was paid for their time. This is likely a result of leaders having increased time to dedicate to the group. Furthermore,

Guidugu suggests that leaders that receive greater training and supervision from the

healthcare system deliver more effective support.

It is clear that the effectiveness of peer-led support can be influenced by several

factors, however literature on the topic fails to consider the difficulties in increasing

resources. Indubitably, if peer-led support groups were given more financial assistance,

greater support from the healthcare system and increased leader training, the effectiveness of

groups would increase. However, this process is costly and in many cases, improbable in the

foreseeable future (Ministry of Health New Zealand, 2016).

2.8 Addressing the Challenges of Peer-Led Support: The Role of the Facilitator

The role of the Facilitator has been implemented in the MDHB as a way of

combatting some of the challenges faced by people involved in peer-led support. There is no

evidence in contemporary literature of a role analogous to this. Therefore, it is difficult to

present literature directly in support of the implementation of a Facilitator. However, some

research has explored how roles somewhat similar to this have worked in the past, or

presented support for the existence of a similar role in the future.

Cowie & Wallace (2000) discussed the challenges of peer-led support in their study.

The researchers suggested that the implementation of a coordinator or facilitator-type role

was effective in taking some of the workload from a peer-leader. In this instance, the

coordinator was allocated to one particular group and acted as an advisor to the peer-leader

and a second point of contact for group participants. Though it is not clearly outlined in the

research, it is presumed that this leader is a professional based on the advisory nature of the

role. Though in this example, the facilitator is confined to a singular group, Cowie and Wallace provide evidence that peer-leaders, and as a result the peer-support group benefits from external assistance.

Jinks and colleagues (2016) produced a report on the role of Patient and Public Involvement in Research (PPI) advisors. The researchers stated that PPI advisors aided in patient involvement in the healthcare system, including research and policy-making. Jinks and colleagues acknowledged the importance of the advisory roles in ensuring patient's safety and wellbeing, whilst continuing to encourage the involvement of lay-people in healthcare development. Again, while this role is not analogous to the role of the Facilitator, it is clear that the researchers perceived great value in having patient support external to researchers and medical staff.

Finally, the following studies all infer a need for some sort of formal support role for peer-led support groups. Heisler, Vijan, Makki, Piette (2010) examined reciprocal peer-support in Diabetes; their main finding was that peer-support resulted in comparable patient benefit to that of nurse care management. However, the researchers suggested that the main concern of utilizing peer-support in place of nurse care management was the lack of sustainability of the former. Heisler and colleagues suggested that some implementation would be needed to train, aid and advocate for peer-leaders and reduce their workload in order for these volunteer-based support services to be sustainable.

The New Zealand Health Commission (2016) outlined the benefits of peer-led support. The authors suggest that one of the largest benefits of these support services is their unique community-focus and their non-medicalized approach to wellbeing. The New Zealand

Health Commission suggests that peer-led support has the potential to significantly decrease patients' reliance on the healthcare system. However, the report also noted that there are many obstacles to increasing the presence and sustainability of peer-led support; particularly, regarding the reluctance of healthcare professionals to refer to groups. The New Zealand Health commission ultimately suggested that the development of greater links between peer-led support and the healthcare system are imperative. The role of a Facilitator would be one way of initiating this. Similarly, Miyamoto & Sono (2012) present several concerns surrounding the relationship between peer-leaders and group participants. The researchers suggest that there is a palpable need for external advisors to peer-leaders; such roles could provide training and advice and a direct link to healthcare professionals.

It is clear that modern research has identified the need for a facilitator-type role in the context of peer-led support. The current study aims to discuss how the role of the Facilitator has been developed to support peer-leaders and the ways in which people in peer-led support conceptualize this role, and how they would engage with and utilize the Facilitator in the future.

2.9 Gaps in The Literature

The available literature on peer-led support is by no means comprehensive. The literature presents a disjointed and uncomprehensive narrative on the functions, effectiveness, benefits and challenges of peer-led support. This section will illuminate the most prominent gaps in the current body of literature.

The initial issue that arises when examining the literature on peer-led support for LTHC is the lack of consistency in how both 'peer-led support' and 'long-term health conditions' are defined. Several publications on peer-led support for LTHC provide ambiguous definitions, making it difficult to understand the nature of the group and participants. The lack of consistency of these definitions is likely reflection of the varied nature of peer-led support and the medicalized models of defining health conditions. However, there is a palpable need for future research to adequately outline how they are defining peer-led support and LTHC.

A prominent gap in the literature on peer-led support is the homogeneity of samples. The majority of literature on peer-led support focuses on select few conditions; namely, mental health, cancer, diabetes and HIV (Funnell, 2009). Understandably, this makes it difficult to generalize the results of these studies to other, less publicized health conditions. Furthermore, it provides a limited look into the support resources in a given community; this results in an inadequate picture of the provision of psychosocial support in a given context. Additionally, the saturation of peer-led support literature on only a few health conditions indubitably contributes to the popularization of certain illnesses and the subsequent negligence of others (Hong, Koo & Koo, 2008).

Next, the majority of literature on peer-led support focuses solely on the individual receiving the support. Understandably, the provision and effectiveness of peer-led support is also a product of the group-leaders and health professionals involved. The available research that focuses on the role of healthcare professionals or group leaders in peer-led support tends to be external, critical and evaluative (Lawn et al, 2009). The presence of literature that provides a comprehensive picture of peer-led support from the perspectives of healthcare

professionals, group-leaders and group participants is non-existent. However, this kind of research would be valuable in providing a comprehensive understanding of how informal support interacts with the healthcare system and, in turn, how this affects patients.

Further, the current study's evaluation of the existing literature has depicted an absence of individual 'voice' in qualitative research on peer-led support. Lyons and Chamberlin (2006) suggest that the voices of patients differ significantly from the 'academic voice', and thus it is imperative that the voices of subjects of research be accurately and substantially presented. The majority of literature analyzing peer-led support is done utilizing questionnaires and other quantitative self-report measures. Understandably, this type of research neglects to depict the nuances of individuals' experiences. Further, as Lyons and Chamberlin suggest, qualitative literature on peer-led support has a tendency to present limited examples of participant discussion and dialogue; as a result, the 'voice' of the participant is lost in academic jargon.

Most importantly, the current body of research on peer-led support has not presented a tangible, community-grounded example of how to overcome the aforementioned difficulties. Specifically, the role of a 'Facilitator' as it has been conceptualized in the current study, has not been piloted for peer-led support groups.

The current study endeavored to discover how this role has functioned over the past 18-months in the MDHB. Further, through exploring the experiences of people involved in peer-led support, the current study aimed to discern whether this role has the potential to benefit these support groups in the future and how it could be further developed to maximize its community value.

 2.10 Research Questions

The researcher of the current study examined the pre-existing literature on peer-support engaged with peer-led support groups for LTHC in the MDHB in order to develop research aims. Based on this, the following concise research questions were developed:

1) What challenges, issues or barriers do peer-led support groups for LTHC face?

2) What are the functions and benefits of peer-led support groups for LTHC?

3) Does the role of the Facilitator have the potential to benefit peer-led support groups for LTHC in the future, and if so, how?

2.11 Conclusion

The present chapter aimed to present an overview of peer-led support for LTHC. It explored the functions of support groups and their benefits, challenges and applicability to diverse communities. Further, it illuminated the need for the role of a Facilitator to aid in the maintenance and development of peer-led groups. The gaps in the literature were also outlined and the research questions of the current study were presented.

The current study endeavoured to examine the role of peer-led support for patients with LTHC in the MDHB. The dynamic nature of the participants and the close contact the

researcher has had with the community allows for an in-depth look at the nature of peer-led

support. Through speaking with Group Leaders, Health Professionals and Group Participants,

the current project has examined how the role of the Facilitator has functioned in the MDHB

and what potential it has for the future.

Chapter 3

Methodology

3.1 Introduction

The aim of this section is to outline the methodological approach undertaken in the current study and the justification for this approach. This section will outline the participants and participant selection process, the procedure of data collection and subsequent analyses and present the ethical and cultural considerations made.

3.2 Research Philosophy

The current study has employed an interpretivist research philosophy to gathering and analysing data. Epistemologically, the interpretivist approach perceives knowledge as inherently subjective (O'Donoghue, 2006). Further, Ponterotto (2005) suggests that interprevist studies address the biases of the researcher. Most importantly, the interpretivist approach suggests that research must be examined in relation to the context in which it is conducted (Willis & Jost, 2007).

The current study aims to acknowledge that it is examining peer-led support in an isolated context within the MDHB. Further, as the researcher had prolonged contact with many participants throughout the year, the current research cannot be considered objective. However, by utilizing the interpretivist approach, the current study hopes to illuminate some of its limitations; and further, to reconceptualise the ways in which the data can be

generalized. To achieve the aims of the current study, a qualitative, interpretative

methodological approach was employed.

3.3 Qualitative Research Method

Initially, the current study planned to conduct a semi-structured focus group for each

of the three outlined groups. However, based on the time constraints of participants and some

participant's electing for individual interviews, only two focus groups were conducted. The

remainder of participants engaged in a semi-structured, one-on-one interviews. One

participant chose to engage in a phone interview, as they were outside of the Mid-Central

area at the time of data collection. Another participant chose to have an unrecorded interview;

in this instance, formal notes were taken by the researcher during the discussion.

Understandably, this variation in data collection methods could have influenced participant

responses. However, Szolnoki & Hoffman (2013) suggest that telephone interviews are a

suitable replacement for face-to-face interviews if required. Further, as the study was not

conducting a conversation analysis, the method in which the data was collected is not as

salient (Have, 1986). Based on the relatively benign nature and low emotional valance of the

research topic, the method of data collection was unlikely to significantly skew participants'

responses (McCosker & Gerber, 2001).

The current study necessitated a qualitative approach for several reasons. The most

important of these was the need to allow for a flexible narrative from participants

(Brinkmann, 2014). Though a topic guide (Appendix A) was utilized by the researcher, the

questions allowed for participant elaboration or deviation from the set topics. Participants

also had varying levels of interaction with and awareness of the role of the Facilitator. Thus,

the flexibility of the topic guide questions allowed for prompts from the researcher to be

tailored to participants' familiarity with the role.

The researcher was aware that qualitative research processes is not without flaws. In

semi-structured interviews and focus groups, the individual style of the researcher and the

dynamic between the researcher and the participants can influence responses (Ritchie, Lewis,

Nicholls & Ormston, 2013). However, the current study does not focus on emotionally

salient, embarrassing or controversial issues, which reduces issues with social conforming or

censoring of opinions (Morse, 1994). Further, the generalizability of qualitative research can

be considerably lower than quantitative research, in part due to sample size (Morse, Barrett,

Mayan, Olson & Spiers, 2002). However, the current study does not claim to provide largely

generalizable information; rather it aims to examine peer-support in the context of the MDHB

and in relation to the specific role of the Facilitator.

3.4 Participants

The current sample consisted of 18 participants. These participants came from one of

three groups: Group Leaders, Health Professionals and Group Participants. Of the overall

sample, 6 were Group Leaders, 4 were Health Professionals and 8 were Group Participants.

The Group Leaders came from 6 different support groups. Each of these support

groups represented a different LTHC. The sample of Health Professionals was made up of: a

member of a medical board, a physiotherapist, a social worker, and a healthcare councillor.

The Group Participants all came from the same peer-led support group for one LTHC.

The current sample consisted of 5 males and 13 females; with an age range of 20-85. Due to the small nature of the sample size, the specific racial and cultural demographic information was not noted. The researcher felt that including this information could be damaging to specific cultural groups if it was generalized beyond the context of the research (Salkind, 2010). Further, due the small number of ethnic minorities participating in support groups in the MDHB, it was felt this information could compromise participant anonymity.

3.5 Selection of the Sample

Participants for the current study were selected as randomly as possible, given the small population of the MDHB and the confidentiality restraints of the medical system.

The names and/or contact details of Group Leaders were obtained directly from the Facilitator's publically available database (Appendix B). All listed individuals were contacted directly by the researcher via email. The researcher provided an invitation to participate in the research alongside the information sheet (Appendix C). Individuals who responded either agreed to attend the set focus group date or arranged an alternate interview.

Finding a suitable group of Health Professionals was less straightforward. The researcher contacted a Project Manager for the Central PHO in the MDHB. The researcher provided the Project Manager with the information sheet and a brief paragraph introducing the project. The Project Manager distributed this to Health Professionals in the MDHB on her contact list, alongside the contact details for the researcher. Interested individuals responded directly to the researcher. All of the Health Professionals had some involvement with support groups for LTHC; two regularly referred to peer-led support groups (one of them also

occasionally helped out at a support group), one had been the recipient of peer-support and a proponent for groups in the area, and one used to run a support group voluntarily.

The individuals who formed the Group Participants group were the most challenging to obtain. The researcher set out to obtain participants from several different support groups. The researcher asked Group Leaders to approach the members of their group regarding participation in the study. Alternatively, the researcher offered to attend a group meeting and discuss the study with group members. However, issues with group time-constraints, the effects of illness and confidentiality issues resulted in only one Group Leader agreeing to this invitation. This Leader organized a group of participants from their support group to partake in a focus group.

All participants in the study were informed that their participation was voluntarily. They were also informed that transport could be arranged for them to and from the focus group or interview location if required.

3.6 Materials (Topic Guide)

A different topic guide was produced for each of the three groups of participants (Group Leaders, Health Professionals and Group Participants). These topic guides were fairly similar but reworded to suit each group. The topic guide contained mainly open-ended questions, based on Geers (1988;1991) assertion that they are a pertinent way to evaluate public opinion and incite participant elaboration. Open-ended questions based on topic guides are one of the most commonly used methods of data collection in qualitative research

(Gubrium, 2012). The researcher endeavoured to give participants time to express their thoughts cohesively, and allowed for pause where necessary (Geers, 1988).

The current study aimed to write questions that utilized language common in health psychology research. Miles & Gilbert (2015) suggest that semi-structured interview questions should be written and delivered in simple language and avoid double negatives or convoluted wording. For instance, one of the questions for Group Leaders is written:

"I*n your experience, what do participants get out of the support group?"*

Further, where possible, the interview questions were developed and asked in a way that was non-leading (Miles & Gilbert), such as the question below:

"Is there anything you think encourages or discourages ethnic participation in support groups"

Questions that give participants the option to discuss positive and negative aspects reduce the potential for response biases, such as acquiescent responses, which are responses that continually agree with questions that have positive connotations (Watson, 1992).

3.7 Data Collection & Procedure

Prior to formal data collection the researcher met with several potential participants and individuals involved in peer-led support within the community. Further, the researcher attended several support groups for observational purposes, and spoke with a few groups

about the research project. These pre-research meetings were vital in establishing links within

the community and gaining some idea of the emergent themes surrounding peer-led support,

LTHC and the relationship between support groups, the medical community and the MDHB.

This also gave the researcher a context in which to develop and pilot the topic guide

questions.

The topic guide was piloted with two peer-leaders in one-on-one meetings. Further, it

was also piloted with two university peers. These pilot interviews were not recorded,

however the researcher documented important ideas by taking notes. This information helped

inform the development of the final topic guides.

The formal data collection took place October 2016- January 2017. All interviews

were recorded with two recording devices. These recordings were transcribed by the

researcher thereafter. Though the researcher transcribed the interviews verbatim, some

personal stories that were irrelevant to the research topic were omitted from transcriptions for

both irrelevance and confidentiality reasons. These instances have been denoted on the

respective transcripts. Participants were not named in the transcripts, but did state their name

on the recordings.

The focus groups took place in local, disability-accessible community centres with

private meeting rooms. However, individual interviews took place in a variety of quiet,

centrally located meeting areas. The researcher offered participants being individually

interviewed the option of choosing a private location or meeting in a university meeting

room. At the commencement of the interviews or focus groups coffee, tea, water and a light

snack were offered to all participants. The researcher talked casually with participants during

this time to develop a rapport before the formal interviews or focus groups began. Participants were given the information sheet to read through and a consent form (Appendix D) to sign.

Once the consent forms were signed, the interview or focus group began. The researcher announced that the recorders were being turned on, and subsequently stated the date. Participants were asked to state their name and their affiliation or involvement with support groups. The researcher then proceeded to initiate discussion based on the topic guide.

Once the group or individual had covered the questions in the topic guide, the researcher asked participants if they had any further comments. Participants were then thanked for their time and told that they would receive an email with a synopsis of the study once the Master's thesis was submitted. The researcher then announced that the recorders were being turned off. Participants were told that they were welcome to leave, or stay back to discuss the project with the researcher.

3.8 Data Analysis

The current study employed the qualitative method of thematic analysis in order to analyse the data. Braun & Clarke's (2006) process for utilizing thematic analysis in psychology was used to inform the analytical process. The current research progressed through the steps outlined by Braun and Clark for breaking down the qualitative interview and focus group data (Table 2.)

Table 2. Thematic Analysis based on Braun & Clarke (2006)

Thematic Analysis

Phase	Description
Familiarization with data	Transcribing data, reading and re-reading the data and noting ideas
Generating initial codes	Coding features of the data systematically
Searching for themes	Collating codes into potential themes
Reviewing themes	Extracting specific data, checking if the themes work with codes
Defining and naming themes	Refining each theme & it's importance to research question
Producing the report	Selecting examples, analysing extracts & producing formal analysis

Table 2

The data was coded, and 7 distinct themes emerged. Excerpts from the data were extracted to exemplify these themes and differences and similarities across groups and participants were addressed.

3.9 Data Presentation

The results section presents data excerpts within a narrative of each theme. In order to present verbatim speech in a succinct way, some excerpts were simplified or edited.

Square brackets were utilized to indicate where speech has been simplified or edited, particularly to remove linguistic fillers (Benjamins, 2010). Further, this is done to add context to an excerpt, without having to provide the entire section of conversation. For instance, in the example below:

Original Text:

Researcher: I just want to hear about your experiences from the point of view of a health professional and what you think about Sara's role and peer-led support groups as a general concept

Participant 7: Right OK, well I first had experience as a patient, when I was in Auckland being treated for cancer and all of the information and support was sent via the mail so yeah they sent me the current magazine from the ostomy society and I thought I am not going to get in touch with this bunch of moaning minnies!

Edited Text:

*"Well I first had experience **[with peer-led support]** as a patient when I was in Auckland being treated for cancer and all of the information and support was sent via mail. So they sent me the current magazine from the ostomy society and I thought I am not going to get in touch with this bunch of moaning minnies!" (Participant 7, Health Professional)*

Further, ellipses were utilized to indicate where a section of talk has been cut out. This is often done when the researcher wants to join one particular though that is broken by extraneous talk or interruption. For example:

Original Text:

"Yeah I don't see it as going that well if it keeps going as it has because well it is like too much for me to take on alone especially as I have been unwell and numbers and interest have

dropped and yeah I haven't been able to run as many meetings. But if I can't attract someone

to help me with running the meetings the group well won't uh last" (Participant 6)

Edited Text:

"Yeah I don't see [the sustainability of the group] going that well if it keeps going as it has

*because well it is too much for me to take on alone**… [The group won't last] if I can't** attract*

someone to help me (Participant 6, Group Leader)

These implementations allow the reader to easily understand the excerpts, without

being disrupted by linguistic fillers or lack of context. The researcher has taken precaution to

ensure this process has not changed the meaning of the discussion by consulting with a

university academic who specializes in conversation analysis and transcription.

3.10 Methodological Considerations

This section will consider the differences in assessing reliability and validity in

qualitative research. Further it will discuss ethics and address the generalizability of the study

and the chosen method.

Reliability & Validity in Qualitative Research

Assessing the reliability of qualitative research is much more difficult than that of

quantitative research (Golafshani, 2003). However, as Leung (2015) suggests, reliability in

qualitative research is grounded in consistency. The current study developed a topic guide

that was used for each focus group and individual interview. Small changes were made for

each group (group leaders, health professionals and group participants) but the content of the

questions was similar among each topic guide. Further, the interviewer was the same person

for each group, and utilized the same techniques for developing rapport and asking questions.

In regards to analytical procedures, the current study transcribed and coded all data in the

same manner, as a way of increasing reliability (Noble, 2015).

Analogously, validity is difficult to examine in qualitative research. The current

research followed Whittlemore, Chase & Mandle's (2001) techniques for demonstrating

validity. These techniques include design consideration; such as aiming to give a voice to

participants through an interview-based qualitative design. Further, the current study has

displayed validity techniques in data generation, by completing verbatim transcription as well

as having prolonged engagement with participants and observation of many of the

participants outside of the official interview. Analytically, the current study displayed validity

by preforming a literature review, acknowledging the limitations of the research and coding

and analysing the data in a reflexive manner.

Ethics

A full ethics application was submitted to the Massey University Human Ethics

Committee: Southern A, Application 16/47. The current study was considered low-risk,

however completing the full ethics allowed for the researcher to explore potential ethical

issues in depth.

The most pertinent ethical issue was the anonymizing of the data. Ensuring the identity of participants remains anonymous in the study is a difficult process, particularly without compromising the integrity of the data (Sgier, 2012). The current study eliminated participant names in transcription, and instead gave them a number; for instance, 'Participant 3'. The institutions participants were affiliated with were also anonymized in transcription. Further, excerpts from the data utilized in the analyses were edited with square brackets so they did not contain identifying information; for example:

*"Participant 8: Exactly, because most people **[with this LTHC]** aren't working"*

The cultural sensitivity of the current study was another ethical issue encountered. Before participant selection occurred, it was assumed that participants could come from a variety of ethnic backgrounds, including Māori. Thus, particular attention was taken to ensure the focus groups and interviews were sensitive to Māori cultural customs; they were run following the process of *whanaungatanga*, which relates to developing a rapport with participants before engaging in research. This process involved speaking casually with participants before recorders were switched on and conducting interviews over food and drink. Further, participants were not asked to provide their ethnic background, as the researchers were conscious of the problems with drawing conclusions about ethnic minorities from small sample research (Okazaki, Sumie & Stanley, 1995).

Generalizability

Producing generalizability in qualitative research is difficult (Morse, 1997). However, the current study has conceptualized generalizability as not how the results of this study can be applied to other populations, rather how the outcomes of the study could be applicable in other contexts.

The current study has been conducted within the MDHB and is focused on the specific experiences of individuals with the Facilitator and the local healthcare system. Understandably, this is difficult to translate across other nations and cultures. To combat this, the current study has included macro-level aims, to discuss how peer-led support functions for people affected by LTHC. Conceivably, such information could be generalizable to other contexts.

Further, the procedure of the current study could be generalized. This study could be replicated by researchers in the future based on the information provided in this chapter.

3.11 Conclusion

This chapter discussed the methodological considerations undertaken by the current research. Through the interpretivist, qualitative approach of the study, data was gathered and analysed from a small group of participants through semi-structured discussions. The current study presents a unique look into the individual voices of group-leaders, health professionals and group participants in relation to support groups for LTHC. This chapter outlined how the data has been analysed through thematic analyses in order to illuminate some of the key ideologies that emerged from these discussions. The following chapters will delineate these

analyses, and discuss how they address the research questions and provide information as to

how the role of the Facilitator has functioned and how it can progress in the future.

Chapter 4

Findings & Results

4.1 Introduction

This chapter will present the thematic analysis conducted with the data from the current study. Firstly, the 7 distinct themes that emerged from the data will be outlined. These themes will each be discussed under their respective subtitles, utilizing excerpts from the data. In some instances, in order to contextualize these excerpts, information on the participants will be provided. Ultimately, the aim of this chapter is to present and group the qualitative data and to set the stage for the Discussion chapter of this report.

4.2 Coding The Themes

As presented in the Methodology section, Braun & Clarke's (2006) Thematic Analysis guide was utilized to code and analyse the data. Though a plethora of themes emerged across the interviews and focus groups, there were 7 prominent themes identified:

1. Referrals from Health Professionals

2. Resources for Support Groups

3. Barriers to Attendance

4. Group Sustainability and Stagnation

5. Issues with Diversity

6. Group Purpose (Emotional and Practical Support)

7. Condition Discrimination

Within these themes, participants presented unique and sometimes conflicting perspectives, which will be discussed. Furthermore, these themes can be related back to the role of the Facilitator and how it could evolve and progress in the future to address concerns surrounding peer-led support for LTHC. Furthermore, though the current study presents a thematic analysis, many of these themes relate to wider discursive ideas of institutionalized biases, and institutionalized medical ideologies.

4.3 Theme 1: Referrals from Health Professionals

The majority of participants in the current study iterated some frustration or concern with lack of referrals to support groups from health professionals (particularly doctors). Many Group Leaders presented analogous narratives explaining this phenomenon. Participants were considerably congruent in expressing ideas surrounding this. These ideas have been assembled into sub-themes; namely, experiences with lack of referrals, participant explanations for non-referral, referrals as a product of relationships with Health Professionals and pessimism regarding referrals. It is pertinent to note that many participants related the lack of referrals from Health Professionals to a general sense of a lack of support for peer-led support groups in the healthcare system.

<u>Experiences with Lack of Referrals</u>

Many participants discussed their experiences with not receiving referrals from Health Professionals. For instance, one peer leader, who has struggled with getting participants to attend her group, stated:

Also, getting the medical team behind [the support group] we're struggling with that,

like I did a presentation to the [medical team] at the hospital kind of expecting people to

refer patients onto it but we haven't heard anything from that and they're all keen for it to

happen but they wont actually [refer patients] (Participant 4, Group Leader)

In this instance, the participant struggles to make sense of the reasons why Health

Professionals will not support her group, despite appearing to be interested in its potential

benefits. There appears to be a need for Group Leaders to feel legitimized by the medical

community. Thus, when health professionals do not actively endorse and refer to peer-led

support groups, it can undermine the confidence of peer-leaders, particularly in the initial

phases of starting a group. The exasperated manner in which the participant explicated these

concerns, reflects the notion that the lack of support from healthcare professionals could

diminish her desire to continue developing the group.

Similarly, another Participant suggested that gaining support from Health

Professionals for starting up a new peer-led group can be met with resistance:

So support groups- the hard thing about those is trying to get one established. I had a

friend who wanted to start one for one of the breathing difficulties and he had no support

from the professionals so it never got of the ground (Participant 7, Health Professional).

Again, the lack of support from Health Professionals is discouraging for peer-leaders,

especially in developing support groups. The practical element of desiring referrals to garner

participants is important; however, the psychological impact of being supported by Health

Professionals is equally as imperative. If Health Professionals do not encourage peer-led

support groups by providing referrals it could be difficult for these groups to acquire

members; thus, making it difficult for them to move forward in increasing their presence in the community.

In an individual interview, a Group Leader, when asked where the referrals to their group came from, suggested none were done by health professionals, including GPs:

Yeah in terms of the medical referrals I don't think we have had any (Participant 5, Group Leader).

This same leader also suggested that the rarity of the condition his group supports necessitates a greater need for participants to be referred by Health Professionals:

Well the worst thing is that we can't get access to patients to find out who [has the condition] and might need help. And of the people with [this condition] the majority don't know about us (Participant 5, Group Leader)

Arguably, for rarer conditions, the reliance on support from Health Professionals is even more apparent. If group leaders feel there are extensive barriers to reaching potential participants it could also hinder the autonomy and self-efficacy of the group.

A Group Leader suggested that the Facilitator for peer-led support groups could increase referrals from Health Professionals:

I think [the Facilitator] could be good in getting the numbers [of the support group] up… and to help get the professional side on board, like the GPs to the referral system (Participant 6, Group Leader).

Many participants echoed the idea that the Facilitator could act as a mediator between the health sector and the support groups. A Facilitator might also help to partially shift the 'locus of control' (Lefcourt, 1992) of group leaders in regards to their ability to affect the outcomes of attendance to the group. In the current study, most individuals affiliated with peer-led support groups had a high external locus of control regarding recruiting participants. Essentially, this means that they believed they had little control over whether or not they got referrals (Rotter, 1966). Though participants may not be able to independently address the lack of referrals from Health Professionals, there are many ways in which they could reach potential participants on their own (advertising, fundraising, visiting GPs); the facilitator could help leaders to explore these methods, with the idea of increasing their confidence in garnering members on their own in the future.

Participant Explanations of Non-Referral

Some participants offered explanations as to why Health Professionals may or may not refer patients; such as in the excerpt below, from a Group Leader:

The doctors, well a lot of it is jealousy [that brings about] doctors not referring (*Participant 5, Group Leader)*

In context, the participant was relating the notion of 'jealousy' to the 'ego' of the doctor. In this discussion, the Group Leader stated that they believed Health Professionals often acted as though they possessed the greatest amount of knowledge. However, in actuality, it is often argued that patients with LTHC are 'experts' in their condition (Greener, 2008). However, this idea of the 'ego' of the doctor, surgeon or nurse is prevalent in literature (Shapiro, Mosqueda & Botros, 2003).

Two participants expressed their experience with a lack of Health Professional referral and overall engagement with peer-led support. They inferred this had to do with patient privacy and confidentiality:

Participant 2: [not referring patients] all comes down to the privacy

Participant 4: [yeah] and that's what we're struggling with, is the whole

confidentiality [and privacy thing] (Participants 2 and 4, Group Leaders)

Participants framed 'confidentiality and privacy' as excuses used by Health Professionals to not refer to peer-led support groups. Many participants discussed how they believed confidentiality and privacy were not violated through direct referrals; these assertions reflected some distrust of patients towards Health Professionals and an uneasiness with the distinct hierarchy in these relationship. This can be damaging to the autonomy of patients and undermine the focus on self-efficacy and condition self-management.

Referrals as a Product of Relationships with Health Professionals

Some participants suggested that the receipt of Health Professional referrals to peer-led support groups was dependent upon the established relationships between Group Leaders or Participants.

For instance, contrary to most other participants, one Group Leader did report having doctor referrals. He suggested this was because his groups were professionally moderated, and that he has a rapport with the health professionals:

[It's the] specialists [that are involved with the groups], those are the ones that I get

referrals from, because they are getting something from me and they feel they can

reciprocate. Whereas if [you're just] providing a service to their clients there is kind of a

disconnect between you and them (Participant 3, Group Leader)

The idea that peer-led support groups have to have existing relationships with Health

Professionals in order to get referrals was pervasive. In the focus group, Group Participants

noted a specific employee in the hospital who was helping to refer people to the group:

> *Participant 12: And that's what we are missing upstairs we don't know if people are giving out the packs [of information about the group]*
>
> *Participant 16: Yeah and I'm not even sure if [name of a health professional] is up there anymore doing it for us*
>
> *Group Leader/Researcher: Did she do referrals?*
>
> *Participant 16: Yes, and gave the information*
>
> *(Participants 12 & 16, Group Participants)*

This might explain why a Health Professional who ran a support group was one of the

few participants who did not have issues with patient referrals:

I get a lot of referrals [from medical professionals] and then I can send people to the

group- and one guy, even his GP mentioned that he was glad he was back walking with us,

and others have recommended that people come see us, so yeah- they have been really

good(Participant 10, Health Professional)

Logically, it is problematic if the assertions that Health Professionals are only like to

engage with support groups where they are affiliated with the leader are true. Due to this,

Health Professionals appear reluctant to aid emerging support groups; this results in peer-

leaders being unable to develop a rapport with Health Professionals that would lead to

referrals. The cyclic nature of this pattern is indubitably discouraging for leaders developing new groups, particularly for illnesses that are less visible (Hoppe & Reinelt 2010)

Pessimism Regarding Referrals

The majority of participants appeared to have little faith in Health Professionals referring or recommending patients to peer-led support groups, even when they made the resources to do so available. The sub-theme of pessimism regarding referrals was evident in several excerpts, such as the one below:

We also send [out a newsletter] to every doctors' office, like to the GPs... but we don't know if it gets left in the bin or not!" (Participant 5, Group Leader)

A Health Professional spoke of this himself:

There was this lady who worked for a Diabetes group and she was going around to GPs and giving them posters for the groups, and she said in so many places the nurse the PHO nurse would put it straight in the drawer and say she'll put it out when she sees fit- well that is just not good enough" (Participant 7, Health Professional)

And Group Participants felt a similar sense of doubt in Health Professionals willingness to provide patients with information about peer-led support:

Participant 14: Well we have got to get more doctors on board

Participant 11: So we don't miss people

Participant 12: And that's what we are missing upstairs we don't know if people are giving out the packs [of information about the group]

(Participants 14, 11 & 12, Group Participants)

Again, this sense of doubt towards Health Professionals only perpetuates the pervasive divide between these professionals and lay people. Greater communication between the two parties is necessary to break down these barriers.

Finally, a Health Professional working as a field worker (as well as running her own support group) suggested that medical staff often can't see how these resources are beneficial

Simply put, they figure these patients are terminal, they are going to die anyway, why would they need a support group? (Participant 9, Health Professional)

This was perhaps the most saddening of all the reasons given as to why Health Professionals don't refer to peer-led support groups. Whether or not this assumption is actually adopted by Health Professionals, the fact that people involved in these services believe that the medical community cannot see the utility of peer support is concerning. Again, assertions like this display a sense of doubt in Health Professionals and reiterate the idea that people affected by LTHC feel their needs are not considered.

Conclusion

These excerpts are only a few of many assertions that referrals and recommendations of patients to peer-led groups from Health Professionals are hard to come by. Furthermore, this theme relates to a greater sense of a lack of support for peer-led support groups from the healthcare community.

4.4 Theme 2: Resources for Support Groups

The resources available to a support group are dependent upon the type of group, the type of condition and the environmental context in which it exists (Scott, Doughty & Kahi, 2011). The theme of resource provision and the need for greater resources was evident; this has been divided into sub-themes, including the lack of resources on how to run a group and lack of resources for group maintenance, Below are some excerpts from the data that exemplify this theme

Lack of Resources on How to Run a Group

A prominent sub-theme was that many participants felt there was a distinct lack of resources guiding the effective management of peer-led groups.

One Group Leader explained the difficulties she had with communicating effectively with participants:

It would be good to learn how to effectively communicate and run the group, I feel like I am floundering a little, well and I don't know if there are some prompts I am not giving to people or am I not communicating in the right way (Participant 6, Group Leader)

Further, she also stated:

[Your way of running the group] is not going to appeal to everyone and there is not one approach that is going to suit everybody, but [having] some solid models that we know work might be helpful in finding an approach that works for most people

Similarly, another Group Leader suggested that support groups need greater consistency surrounding communication and management practices:

[We need to know] things such as what are the universal principals of support groups, [things like] a basic code of practice that keeps everybody who is involved safe [like what's] an appropriate way to communicate and how do you resolve conflict when it comes up (Participant 3, Group Leader)

Some participants expressed concern surrounding the ethics of group leadership, and a desire for resources guiding practice. The ethical issues of running peer-led support are broad; including coercion when garnering participants, the burden of the leader to mediate intragroup advice, monitoring of participant safety and managing conflict, to name a few (Cowie & Wallace, 2000). Understandably, group-leaders were concerned with the lack of guidelines surrounding group management.

To solve this issue, one Group Leader suggested that having an open forum between leaders could be a beneficial resource:

I think there are some things that some groups might find more challenging than others and issues that some groups face more than others, so if people have found ways of resolving an issue like how do you engage with young people, how do you engage with marginal communities and things like that [If they've] found a way to do that then they can share it and I think that kind of knowledge could be really powerful

As some participants inferred, the exchange of knowledge amongst group-leaders could be very effective. Further, it could result in the development of intergroup networks; inciting the exchange of resources between groups and conceivably, the expansion larger united group of advocates for LTHC.

Lack of Resources for Group Maintenance

Participants displayed concern surrounding the lack of resources in developing new groups and sustaining existing groups.

One Group Leader suggested that establishing a support group can be an arduous and confusing process and more resources are needed to help potential leaders:

One of the difficulties of setting up a support group is ((exhale)) how do you spread the word, how do you get it out there?...Until people are aware that there are support groups [how do you] create a situation where they will find out that there is such a group[?] (Participant 1, Group Leader).

Many leaders involved in peer-led support come from non-medical, non-psychological backgrounds. Statements like the one above reflect the notion that leaders may require a sense of direction and reassurance to feel competent in their role.

Several participants cited a more general lack of resources for support groups, possibly stemming from a lack of investment from the government:

It's a government issue too [the lack of resources to support people with LTHC]. We need to invest more in support resources (Participant 7, Health Professional)

Another Health Professional involved in social work stated:

Our key workers are run into the ground with trying to support patients, there's just not enough resources out there for them (Participant 8, Health Professional)

Further, a Group Participant simply said:

We don't have nearly as many resources as we could (Participant 13, Group Participant)

Participants displayed a sense of dismay regarding the resources for their support groups. Whilst these groups were managing to stay afloat, many struggled with financial and time burdens. Based on this, it understandable that Group Leaders and Group Participants would not feel that their support groups were valued by the medical community.

This dismay was exacerbated when group resources are taken away or decreased:

Participant 11: It's [like with a specialised exercise program for LTHC), they work with respiratory patients and our group isn't included even though they might really benefit from it

Participant 15: Yeah well that is hard, because our partners [with a LTHC] could also sit on chairs and do it too!

Participant 11: At one point we did have [access to that program] but it was taken away

(Participants 11 & 15, Group Participants)

Another participant suggested that when resources for peer-led support were provided by the DHB, they were often misplaced:

[Support Groups are] sometimes more effective when they are taken over by national bodies... [but then] you have 'professional charity workers' and that can be a problem... The other thing is the DHB is establishing [peer-led support groups] alongside clinical ones and all the indications are that they are going to be dominated by health professionals- not the people and not the family, and so it's not going to be able to do its job" (Participant 7, Health Professional)

This excerpt is a prominent example of the conflict many people involved in peer-led support groups experience. On one hand, it is apparent that support groups for LTHC need greater resources to thrive within the community. Alternatively, most participant's agreed that they did not want these groups to be taken over by Health Professionals, NGOs or government agencies.

The discussion of resources also surrounded the longevity of peer-led support groups. One Health Professional suggested that in order to stop groups from dying off, there needs to be new people to take over existing groups:

It's a bit of a worry to think of some group leaders leaving after years and years, and there is no one there to take over for them (Participant 9, Health Professional)

The sustainability of peer-led support groups is discussed under the theme of "Sustainability and Stagnation"; however, it is important to note that the longevity of groups and the engagement of new members are related to resource provision as well.

Groups with greater financial resources and a greater public platform are likely to have less trouble appointing new leaders. Contrarily, smaller groups with less visibility are unlikely to have the resources to do so. This could be attributed to issues such as the cost it takes to advertise for new leaders or train new leaders (Latkin, 1998). Uncertainty over a support group's future was distressing to participants and leaders alike in the current research.

Conclusion

Overall participant's discussed the concept of 'resources' for peer-led support in terms of the deficits groups experience. Many participants' conceptualized the role of the Facilitator as a way of, at least partly, solving some of the issues whilst still maintaining the autonomy of the group.

4.5 Theme 3: Barriers to Attendance

Attendance and attrition were recurrent themes of discussion. Participant's cited a variety of barriers to attending peer-led support groups; these barriers were practical and psychological. Often non-attendance could be considered as a result of a combination of the two.

Psychological Barriers to Attendance: Distancing & Stigma

Psychological barriers to attendance can be broad and are often complicated to combat (Pietrzak, Johnson, Goldstien, Malley & Southwick, 2015). Participants recognized a variety of psychological barriers in discussions.

Distancing

One participant suggested that people don't always want to be associated with their LTHC, especially if they have partially recovered. Understandably, this can result in non-attendance, especially in LTHC that don't result in substantial Treatment Outcomes or Condition Outcomes.

We'll you see, a lot of people get it, get over it and want nothing to know about [the condition] (Participant 6, Group Leader)

This excerpt addresses the pervasive notion of Psychological Distancing (Liberman, Trope & Stephan, 2007); whereby people attempt to distance their current selves from their past selves in order to avoid emotional rumination. In the context of peer-led support this can be problematic as it relies on individuals affected by LTHC to continue to be involved with the condition, even if it has been some time since their initial diagnosis. Ultimately, Psychological Distancing is a threat to group longevity; the aforementioned leader realizes that such behaviours can affect the sustainability of the group.

Similarly, the idea that people who still have a LTHC may want to distance themselves from their condition is a salient barrier to attendance. One group leader stated:

See if I go and talk about XYZ condition that means that I am regularly reminding myself that I have this and I am going to be publically announcing to people that I have this thing (Participant 3, Group Leader)

Another group leader iterated a similar idea:

[Young people don't want to attend support groups] because they're admitting that they

might need help (Participant 2, Group Leader)

A Group Participant speaks of her experience of this:

[Someone] has a stroke and they want to go and hide for a while and [that's when]

someone has to force them to do things (Participant 17, Group Participant)

In the context of this discussion, the Group Participant was suggesting that someone had to

encourage the individual to seek psychosocial support and social interaction, despite their

reluctance.

Furthermore, a person may develop a psychological condition from having a LTHC

that adds to this demotivation to attend. A Health Professional recognized that experiencing a

LTHC can be emotionally distressing; and that without the proper provision of support,

individuals can become depressed, anxious and stressed (Nikbakhsh, Moudi, Abbassian &

Khafri, 2014). This participant recognizes the salience of having psychosocial support when

dealing with a LTHC:

Some people might get a health condition and it makes them anxious or depressed

and they don't want to go anywhere or get help" (Participant 8, Health Professional)

The idea that people affected by LTHC struggle with admitting they need support is a

significant barrier to attendance. Participants recognized that people with LTHC require

psychosocial support, even if they experience psychological barriers. Based on these

excerpts, it is clear that people involved in peer-led support groups are concerned about not

being able to reach potential participants who are engaging in maladaptive coping strategies

such as social isolation (Scheier, Wentraub & Carver, 1986).

Stigma

Further, participants also cited certain stigmas surrounding LTHC that can detract

people with LTHC from attending. In the context of discussion, one Group Leader suggested

that the embarrassing nature of the condition might make individuals hesitant to join a group:

[The condition] affects the bowel and if they are really bad they might just spend half

the day on the toilet… it's quite, sort of, embarrassing (Participant 6, Group Leader)

Another Group Leader suggested:

I mean specific to cancer, there is sort of a lot of stigma around the support groups

(Participant 3, Group Leader)

This Group Leader further addressed stigma and attendance:

That is one of the key challenges I think is this sort of stigma we put on ourselves of

it's like something that we don't want other people to know about, even if it's to someone

who has the same condition… (Participant 3, Group Leader)

Participants addressed the pervasive intersection between LTHC and stigma (Golden,

Conroy, O'Dwyer, Golden & Hardouin, 2006). From these excerpts, it is clear that Group

Leaders displayed a concern that social stigma of identifying oneself with a disease, and the

stigma of attending a support group, presents a large barrier to attendance. These issues are

important to address when looking at why people affected by LTHC do not accept support

services (Turner & Kelly, 2000).

Conclusion

Though psychological barriers to attendance may be broad, it was clear that

participants focused on distancing and stigma as the most salient. However, one participant

offered a novel explanation of a psychological barrier; simply that people with LTHC might

perceive support groups as focused on negative aspects of having a condition:

Well I first had experience [with peer-led support] as a patient when I was in

Auckland being treated for cancer and all of the information and support was sent via mail.

So they sent me the current magazine from the ostomy society and I though I am not going to

get in touch with this bunch of moaning minnies! (Participant 7, Health Professional)

The Health Professional appears to understand that there might be pervasive misperceptions

of what peer-led support is. Such misconceptions can be damaging to the peer-led support

movement. In the context of this discussion, the participant recognized that peer-support

services were not just places for emotional support, but also for the provision of education,

promoting wellbeing, group socialization, group activities and proactive engagement in the

community (such as fundraising or raising awareness).

Overall, the psychological barriers to attendance were a concern to participants in the

current study.

Practical Barriers to Attendance

For people with LTHC, practical barriers also impact attendance. Two Group Participants suggested that the distance to the support group and the cost of transport combined to make attendance difficult for some:

Participant 4: And some people are too far away [to the support group venue] and it's just too much of a cost on a fixed income to get there in a taxi

Participant 8: Exactly, because most people [with this LTHC] aren't working (Participants 4 & 8, Group Participants)

A Health Professional addressed the notion that some LTHCs are debilitating and make attendance and participation very difficult:

Some conditions leave people paralysed or disabled, and that makes it so hard for them to get to the group, and be part of the group (Participant 10, Health Professional)

Further, a Group Participant suggested that for her husband, the inability to speak made being part of a peer-led support group very difficult:

My husband, he can't really speak much, and he can't really talk [so he can only really] be part of groups that have the activities (Participant 14, Group Participant)

Overall, developing peer-led support groups with strong leaders is only half of the battle. Gaining and sustaining participant's is a challenge in and of itself. As one Group Leader suggests:

Getting to new people, that's the hardest and most important thing (Participant 5, Group Leader)

The practical barriers to attendance are arguably more surmountable than emotional barriers. Perceived practical barriers affect participant's willingness to attend support groups (Taylor & Gutteridge, 2013). Interestingly, where participants did not discuss how the role of the Facilitator could help overcome emotional barriers to support, many did suggest the Facilitator could aid in addressing practical barriers. This might be due to the notion that psychological barriers are often more complex than practical barriers to address (Gulliver, Griffiths, Christenson & Brewer, 2012). Gulliver and colleagues suggest that this is because psychological barriers to help-seeking tend to be tied to deeply ingrained attitudes.

It is important to note that barriers to attendance surrounding diversity and outlying groups will be discussed under the theme of Issues with Diversity.

4.6 Theme 4: Group Sustainability & Stagnation

It might not seem logical to group the terms 'Sustainability' and 'Stagnation' together; yet, these terms were discussed concurrently by participants. The current study defines the term 'Sustainability' as a group's ability to provide consistent, ongoing beneficial support and its ability to adapt to internal and external changes. 'Stagnation' will be defined as a group's inability to adapt to internal and external changes, or a lack of alteration to accommodate the needs of group members, particularly new members. Ultimately, the sustainability and stagnancy of a group can affect its benefit for participants.

Sustainability

One Group Leader discussed how she believed her group was unsustainable because its upkeep relied solely on her.

Yeah I don't see [the sustainability of the group] going that well if it keeps going as it has because well it is too much for me to take on alone… [The group won't last] if I can't attract someone to help me with running the meetings (Participant 6, Group Leader)

A Health Professional and field worker shared the assertions of this participant, suggesting that the group would not likely continue when she retired:

When I go, when I leave the group, I think it'll just die off (Participant 10, Health Professional)

One Health Professional, discussed her experiences with helping peer-led support groups, and suggested that in one instance, the sustainability of a group came from having several health professionals involved in its running and maintenance:

I mean I think because it's not just me there… we have another person who helps [out with the group] and two people including a physical health specialist… so I think it's good that there isn't just me. And I saw when I was away sick [for several] weeks the groups did just fine when I was away (Participant 10, Health Professional)

The notion that one leader is responsible for a groups longevity can be anxiety-provoking for members. Participants asserted that many groups would benefit from having co-leaders to share the responsibility of the group with. Introducing co-leaders would help to share the burden of organizational responsibilities and reduce the psychological stress on the Group

Leader. Participants suggested that the Facilitator could help to recruit co-leaders for existing groups.

Further, one participant suggested that funding also had a huge impact on her group's ability to be sustainable:

Funding is a big deal especially when it's just me trying to run the group, and we don't have any funding so we are relying on a gold coin donation for a cup of coffee or tea and a biscuit. I don't know if that's something the Facilitator could help with, but it would mean [the group could keep running] (Participant 2, Group Leader)

Money is a significant factor when it comes to the sustainability of peer-led support groups. As discussed under the theme of 'Resources for Support Groups' some groups are incredibly under-funded and this can result in effective support groups dissolving. Scott, Doughty & Kahi (2011) suggest that support groups need adequate funding to advertise, rent spaces, subsidize group activities and pay leaders or speakers for their time. The majority of participants appeared aware that government funding for peer-led support was limited. The uncertainty and instability of funding for support groups in New Zealand incites a sense of uneasiness (Scott, Doughty & Kahi). Whilst funding is a complex issue, it is clear that research on the benefits of peer-led support could incite greater government investment.

Lastly, a Health Professional who works as a social worker suggested that chronic conditions required groups that were sustainable and ongoing. Ostensibly, by their very definition, patients with LTHC require long term support:

I know, from experience, that people with Mental Illness need support from the system

for their whole lifetime [and I think it would] be the same for people with chronic health

conditions (Participant 8, Health Professional)

This final excerpt highlights the importance of stable, ongoing support for people with

LTHC. The majority of participants were concerned that the longevity of the group hinged on

one or two key leaders. Increasing the sustainability of existing support groups is paramount,

and the role of the Facilitator could help with this process in the future.

Stagnation

Stagnation is a concern for some support groups. One Group Leader spoke of his

experience with stagnant groups:

Because the groups can be co-opted by things like, for us, survivorship, the groups

started as support groups but now they are social groups, to a greater extent… So the focus

[of that group] at some point changed. In that case, sometimes there needs to be a transition

of the group to make it easier for new people to join (Participant 3, Group Leader)

This Group-Leader suggested that groups need to be re-evaluated after a certain period of

time and repurposed or renamed to fit the needs of the group members. Understandably, this

participant also recognized that new groups might need to be formed through this process,

particularly in the context of diseases like cancer that can result in full recovery.

Another Group Leader suggested that groups can grow stagnant over time and it makes it exceedingly difficult for new members to join or find benefit in these groups, particularly because of behaviours like in-group favouritism (Otten et al, 2000):

[For instance] The [a well established group for a specific LTHC], when it originally started was dynamic and it was really interested in advocacy and everything else, and now a whole lot of those people [have been] there for 20 years and it is the same old, same old, kind of thing and new people wanting to come in think 'oh what are they on about why can't we look at what is new today (Participant 1, Group Leader)

The same participant also suggested that while ongoing support is important, there needs to be a healthy flow of participants moving on, developing new groups and making way for others who may be at the beginning of their illness.

So if we are talking about the sustainability of these groups somehow or another those people who started off [in the group] need to be pushed on

Similarly, a Group Participant acknowledged that the stagnation of their group is a barrier to new people coming in:

Well our group is so set, it can be hard for new people to come in (Participant 14, Group Participant)

Stagnation of support groups is an issue rarely addressed in health psychology literature. However, the participants in the current study did note a trend of groups becoming 'fixed' and not evolving to incorporate new members. Positively, participants did see a problem in group stagnation and did not suggest that this form of homeostatic maintenance was constructive. Further, the participants in the current study also addressed the idea of

'breakoff' groups developing. Though 'breakoff' groups are traditionally seen as deviant participants showed understanding that this is often necessary, particularly of conditions that progress through distinct stages. Overall, it is natural for groups to evolve, divide, dissolve or progress over time (Levine & Hogg, 2009).

Despite group stagnation being a salient issue, participants were cognizant that this could be overcome- as one participant suggests:

[I know of a group] that had this collective experience through this group that they couldn't get anywhere else and they wanted to maintain it, so rather than that group expand, and have the intent of that group changed [they said] right were going to have sustainability, it is just going to shift. [And they need to do this] because that group of people will want to stay a nucleus of people and stay connected and may be less likely to get new people or to have new people come into that group because they've already shared all of those experiences with those people (Participant 3, Group Leader).

Conclusion

Overall, sustainability and stagnation are two intersecting themes relating to peer-led support groups. It is important that individuals involved in support groups be aware of the difference between sustainability and stagnation. Problems with stagnation are likely to be remedied if addressed early on (Paine-Andrews, Suarez-Balcazar, Fawcett, Jameson, 2016). Arguably, some degree of stagnancy is normal for an established group; however, it is the responsibility of the Group Leaders to ensure the group remains an effective resource for new members. Furthermore, increasing Group Leader's awareness of the necessity to balance the

existing needs of members as they progress through various stages of grief, coping self-

management and acceptance is imperative.

4.7 Theme 5: Issues with Diversity

The lack of diversity in peer-led support, and in fact, all types of psychosocial support

is concerning. Statistically speaking, ethnic minorities are less likely to receive medical and

psychological support (The Association of Black Psychologists, 2003); this may explain why

there is a lack of ethnic minorities attending support groups. Further, young people,

particularly adolescents are less likely to attend support groups, even though research

suggests they might experience the greatest benefits from peer support in particular (Shah et

al, 2000). Further, Vlasoff suggests that men are less likely to engage in help-seeking

behaviours surrounding physical and mental health (2007); which may affect their inclination

to attend support groups. These groups: ethnic minorities, young people and men, were the

most cited by participants in the discussion of diversity.

One participant summarized the pertinent issue of barriers to attendance surrounding

identity:

I think [group support] probably is universally beneficial… but there is always going

to be some age groups and some communities that find it really difficult (Participant 3,

Group Leader)

Age Diversity

Firstly, age was a recurrent issue with diversity; many participants felt support groups did not cater to younger people:

We tried to get an under 65 [support] group going, but it's hard. People often don't think about what the young guys need (Participant 11, Group Participant)

Interestingly, this Group Participant conceptualized individuals under 65 years of age as 'young'. This demonstrates the fairly pervasive lack of understanding that many people under the age of 30 have LTHC and require psychosocial support.

A Group Leader spoke of her experience attending a support group for a LTHC as a young adult:

Participant 1: Why wouldn't you go to [The support group]

Participant 4: One, because it's during work hours… and because two, they are all way older than me and yes they have [the same condition] but they cannot relate to me… And I don't want to put them down but they definitely cater for older people (Participants 1 & 4, Group Leaders)

Another Group Leader, responded to this, providing an explanation for why age diversity is such a salient issue:

And a long term condition can impact on people differently at different phases of life; like I think of [the example] of cancer, so somebody who is 45 and has 3 kids and who was working but has no insurance and was expecting to be working for another several years, well that person's experience is not the same as a 14-year-old who has lost a parent, or a 70-year-old who might be thinking 'oh this is a bit crappy [but I am older] and I have accepted it (Participant 3, Group Leader).

Another participant, when asked, suggested that her group wouldn't appeal to younger

members, even though there is a high incidence of the condition in young people:

Researcher: Do you think the way the current group is it would be appealing to a

younger group of people?

Participant 6: No, not the way the group is. I think there would need to be [separate

groups] to target young people

(Participant 6, Group Leader)

Even in peer-led support groups that consider themselves diverse in age, the overall

range tends to neglect children, youth, adolescents and young adults:

I think the [age diversity] has a pretty good range. We have people from 40-ish all the

way to 85, so it is a pretty broad age group (Participant 10, Health Professional)

These excerpts all addressed the notion that there is limited age diversity in peer-led

support groups in the MCDHB. Participants were particularly cognizant of the lack of

support resources for young people. Most participants provided clear reasoning for why they

believed peer-led support has difficulty capturing a younger cohort; namely, that established

support groups within the community were comprised of older members who could not relate

to the experiences of young adults. This is a vicious cycle that is difficult to address; young

people don't attend support groups, and in turn the support groups' demographic gets

progressively older. Understandably, while some support groups for young people such as

'CanTeen' in New Zealand- which supports people aged 13-24 who are affected by cancer

(CanTeen New Zealand, 2015) do exist, participants in the current study inferred there is a

need for a greater number of support groups that target young people within the community.

<u>Ethnic and Cultural Diversity</u>

Another issue with diversity that was addressed was cultural and ethnic diversity in support groups:

I think there's some challenges in an area like Palmerston North... but this is where the hospital has deeply embedded patriarchy and institutionalized racism and those sorts of things that can be a challenge if our goal is to get people of diverse backgrounds into a support group. My experience is that the hospital gets predominantly referrals for middle class white people, even though, statistically Māori people are more likely to be affected by cancer. But we get no Māori referrals and this is something [that I know is] experienced by other people in my field. (Participant 3, Group Leader)

Another Group Leader suggested that ethnic minorities, particularly refugees and immigrants might be unaware of the support groups that exist:

Those people [immigrants, refugees and people who don't speak English well] are quite lost and often don't know all sorts of things about [what groups are out there] (Participant 1, Group Leader).

Further, ethnic minorities might be discouraged from attending support groups that are predominantly Caucasian:

I think sometimes you feel more comfortable talking with people that you're related strongly with... I sort of think culturally one of the issues we have is mostly white people or mostly Pakeha people coming into the Cancer Society and [that is] how we are seen as- an organization for white, middle class people (Participant 3, Group Leader)

Overall participants provide a solid understanding of diversity, or lack thereof, in peer-led support groups across the MCDHB. Participants proposed ideas as to why there is limited diversity, such as community demographics, institutionalized racism, inability to access diverse communities and self-segregation. However, participants appeared reluctant to make definitive judgements on why Māori and other minority groups were not represented in peer-led support; this is understandable, considering the sample was mostly Pakeha individuals. However, this reluctance to directly address issues of diversity in peer-led support could ultimately contribute to the ethnic homogeneity of groups in the MCDHB.

Contrarily, other participants suggested that ethnic diversity was not a problem for their groups:

Well we have a pretty even representation of Māori and Pakeha participants, and we don't really seem to have any Asians or Pacific Island representation but I also don't have any I am aware of on my records (Participant 10, Health Professional)

Another stated:

Ethnic Diversity isn't as much of a problem because [the disease] is generally a white man's condition. You do get a few Indians and a few Māori but I don't think I've had any Pacific Islanders effected, so yeah (Participant 6, Group Leader)

Despite these assertions, it is hard to know whether these observations are a result of minority individuals being missed further back in the health system (Scheppers, Dongen, Dekker, Geertzen, Dekker, 2006). Participants appeared reluctant to delve into specific issues

surrounding diversity in support groups. Therefore, it was difficult to understand the true

nature of the demographic of the groups they were affiliated with.

Gender Diversity

The final area of diversity that was consistently addressed was gender inequalities in

peer-led support group attendance:

Participant 14: Our men [who have LTHC] don't socialize as much as they should

Participant 15: And I think maybe that comes from right when you are married and

the wife always makes the plans to socialize and when the children come along you're

at school with them… and when that's all over the men don't go out and do that

Participant 16: We need more for the men for sure

Participant 18: Yeah because it's hard when they aren't working too

(Participants 14, 15, 16 & 18, Group Participants)

Another participant discusses men's 'need' to maintain their masculinity can often

prevent them from participating in support groups:

Well we had a guy who couldn't work out at the gym [with the support group]

because if he did he'd push himself too far just to prove to himself he is still that man that he

was (Participant 2, Group Leader)

Another participant suggests that pride can often prevent men with LTHC from seeking

psychological help:

And I think men, well men also don't ask for help or reach out because of pride

(Participant 17, Group Participant)

A large number of participants noted difficulties in getting men to attend peer-led

support groups. However, women outnumbered men in the current study and therefore, there

were limited anecdotal experiences cited. Participants cited some tropes surrounding

hegemonic masculinity, such as the concepts of pride, and the male as the 'provider'. Further,

they discussed the societal pressure for men to prove their manliness. These notions likely

contribute to the non-attendance of men at peer-led support groups; however, these

statements must be considered contextually. It is likely that there are many more nuanced

reasons for the gender imbalance in peer-led support groups that were not addressed in

discussions in the current study, particularly due to the mainly female participant sample.

Despite male attendance in peer-led support groups being low, participants suggested

that the psychological need for this socio-emotional support is still present; particularly with

other males:

> *Participant 11: And it is also good for men to have these groups with just men where*
>
> *they can talk to each other or be in each other's company…And it's not so much [the*
>
> *activity part] it is the social element of it all*
>
> *Participant 14: Yeah, it is that, because I took him in this morning, and it's the first*
>
> *time that people were like 'oh hey mate' and to him, that's everything*
>
> *(Participants 11 & 14, Group Participants)*

Arguably, men affected by LTHC need support resources just as much as women do

(Yates, 1995). However, participants articulate the notion that females are inherently more

social than men. Research has indicated that in many health contexts, women are more likely

to engage in help-seeking and prosocial behaviours (Peterson, Newton, Rosen & Skaggs,

2006). While participants have not entirely articulated the reasons for reduced male

engagement in support groups, it is clear that they understand that there are complex

psychosocial reasoning's behind this.

 Conclusion

Overall, diversity in peer-led support groups is an area that requires close examination

and intervention. Promisingly, the results of the current study show awareness of people

involved in peer-led support of the relative homogeneity of group demographics. To conclude

this section, one participant provides a pertinent quote on diversity in support groups.

Well [the diversity in support groups] is not good, but I think that's the least of our

problems... We need groups up and running first, then we can deal with the issues with

diversity (Participant 7, Health Professional)

There is a plethora of issues with diversity in peer-led support. These issues are complex and

time-consuming for support groups to address. Ultimately, peer-led support groups need to

first be available, stable and sustainable. By developing support groups across communities,

for a variety of illness, the provision of resources for people of all backgrounds can be

increased.

4.8 Theme 6: Group Purpose (Emotional and Practical Support)

The notion of 'purpose' is salient in the context of peer-led support groups. The

current study found that participants cited emotional and practical forms of support provided

by these groups. Emotional Support is defined as support that assists with someone's

thoughts, feelings and/or fears (Burleson, 2008). In the context of peer-led groups, emotional

support might involve a member giving someone a shoulder to cry on, providing a hug or

calming words. Practical Support is defined as forms of support that are tangible or

educational (Burleson). In the context of peer-led support groups, practical support might

include offering up advice on self-management of medications, sharing recipes or exercises,

providing items, or cooking dinner for a member when they are struggling. It is important to

note that some forms of support can have both practical and emotional aspects. Overall,

support groups are prosocial resources and the focus of participant's on 'group purpose' only

highlights this notion.

Emotional Support

One Group Leader suggested that the most important part of peer-led support was the

emotional support it provided:

The biggest part is just meeting up with other people who have the condition, even if

they don't talk [about it], just so they know, look I am not the only one suffering from this- I

don't feel quite as alone because there are other people out there. [especially if the condition

is] a bit more uncommon, people don't seem to understand that there are other people going

through this too if they haven't met anybody (Participant 1, Group Leader)

This sentiment is echoed by the Group Participants of a peer-led group:

Participant 15: Yeah and you just, you need to have that social connection [through

the support group] so you can realize that you are not alone, you are not the only one

going through this

((communal mutterings of agreement))

Participant 16: And it's amazing, the similarities with the survivors [of the LTHC]

and their partners, you know? We are here talking about the things that affect us, and

someone is like 'oh yes, me too!'" (Participants 15 & 16, Group Participants)

Participants repeatedly addressed the concept of shared experience in the context of peer-led support groups. Research addressing the notion of shared experience is extensive; it is a powerful form of psychosocial support and allows for participants to feel understood (Davidson, Pennebaker & Dickerson, 2000). Further, this development of shared, communal experience can result in strong social networks and friendships developing. Participants incorporated these ideas into their narratives surrounding group purpose, suggesting that they are aware of the unique benefits of peer-led support that might not be achieved through therapy or professional support.

Similarly, the social interaction was cited by a Health Professional as a benefit of peer-led support:

For some of these people, it's just having that social interaction and getting them out of the house and with other people. I have one guy who comes [to the support group] and he says that he looks forward to it every fortnight- like it is his only social interaction you know? And that's so valuable (Participant 10, Health Professional)

Conceivably, participants are aware that social contact and social support are imperative when dealing with a LTHC. Participants discussed the ways in which experiencing a LTHC can be socially isolating, and explained the importance of having support groups where social interaction needs can be fulfilled:

Participant 14: There is a lot of stress and sadness when you are going through [a

LTHC] and having someone there [is important]

Participant 16: It's not just like when someone has a stroke, life stops... like I don't

know about you girls but we used to go dancing and stuff, and all of that stops- for the

partner too...

Participant 11: It's hard, it's very hard- that isolation...

Participant 14: And that's why we do need the support group, to provide that contact.

(Participants 16, 11 & 14, Group Participants)

In this excerpt, participants recognize the psychosocial benefit of being around others; suggesting that while the provision of emotional coping skills, education, advice and activities is important, at the very heart of support groups is human interaction.

Comparably, another participant suggests that for people with terminal illness, support groups can provide a sense of comfort, especially when they don't have a close family network to rely on:

You know some people; they know they are going to die. So getting them to the group

means that they can talk about their fears and their emotions and have people support them

(Participant 9, Health Professional)

The idea that for some attendees, support groups are a supplement for close family or friends only reiterates the importance of maintaining them within the community. Participants displayed reflexive understanding of how peer-led support is not only a tool for self-management of one's condition, but for some, as a way of accepting mortality and coming to peace with a prognosis.

Another sub-theme of emotional support was the notion of life adjustment. One Group Leader discussed how in LTHC that have substantial Treatment Outcomes or Condition Outcomes, individuals require ongoing support to help them learn how to live under new and sometimes difficult circumstances:

[The number of people with the condition] is very small, but there are those people, like me, with lasting effects and they need us to do what we are doing (Participant 5, Group Leader)

Emotional support is not limited to helping people cope with the issues born from living with a LTHC. Some participants discussed how having mutual understanding and group rapport allowed for them to talk freely about anything:

Participant 11: If you unload onto someone who is not in [the same] position as you, they might [not know what to say]

Participant 17: Oh yes, some people are shocked...

Participant 12: You know we just want an ear to talk to about these things

Participant 14: Yes, because sometimes it's the stupidest, silliest things...

Participant 17: Like him putting the TV on and it's too loud when I am trying to read... and he hasn't even got his hearing aids in

Participant 13: But you can't just tell that to anybody, because [your partner] has had this bad thing happen to them

(Participants 11, 17, 12, 14 & 13, Group Participants)

The participants in the current study recognized the multitude of ways in which peer-led support functions as emotional support for members. While participants did not explicitly link the effective provision of emotional support to healthy coping, self-management and self-efficacy (Turner, 2000), it is clear that they understand support groups are imperative to these positive outcomes.

Practical Support

Research on support provision often gives less attention to practical support (Shrout, Herman & Bolger, 2006). However, practical support is an imperative part of forming interpersonal relationships in support groups (Shrout, Herman & Bolger). The provision of practical support can increase participant's self-confidence and autonomy (DiMatteo, 2004). It can also allow for better coping and the stresses of everyday life to be minimized during trying times (White, D'Abrew, Katris, O'Connor & Emery, 2011).

Firstly, one participant cites education as an important form of practical support:

The benefit [of the support group] is basically people coming together and learning about the condition if they are looking for more, and hearing information they have never heard about (Participant 6, Group Leader).

Analogously, one of the Group Participant's suggested that her relationship with the Group Leader allowed for her to get first-hand advice regarding her partner's LTHC:

The [good thing is] too, that we can ring [the group leader] and ask her anything and she'll give us a straight answer. And also, for the rest of us, I think coming and sharing

[these questions] you feel better, you feel more able to cope (Participant 16, Group

Participant)

The exchange of knowledge is an important sub-theme that emerged in participant's discussions of practical support. In addressing this theme, some participants inferred that they were not getting all the information they needed from doctors, nurses or specialists.

A Group Leader suggests that peer-led support can have an advocacy function for people with LTHC, particularly when it comes to treatment choices:

I think some of our peer support people that are involved in the support groups would [advocate for other peers] ... I think particularly if you've had that kind of experience say, say you've been through chemotherapy and you're sort of willing to go alongside somebody and be an advocate and be a support person, that is usually beneficial for both parties (Participant 3, Group Leader).

Similarly, another group leader said:

Yeah I would love to be able to advocate for people who have [a LTHC] (Participant 4, Group Leader)

Advocacy as a practical function of peer-led support has not been substantiated by a large amount of research. However, participants recognized the utility of the community of a peer-led support group. Advocacy, lobbying and raising awareness are all potential external functions of peer-led support groups, and positively, participants understood this.

From a health perspective, practical support can also be oriented around medication, such as members sharing experiences and advice on how to deal with side effects:

[Support Groups] can help people deal with the side effects of medications and such, like some medications that slow your metabolism and then that has effects on your health… And making sure people adhere to their medications (Participant 7, Health Professional)

Based on these ideas, it is unsurprising that one Health Professional suggests that participation in peer-led support can reduce patient's reliance on GPs and specialists for reassurance:

[Participation in support groups], well it reduces hospital admissions for patients for sure (Participant 10, Health Professional)

Other ideas of practical support provision from peer-led support groups includes the exchange of more tangible forms of information, take this excerpt for instance:

Participant 14: The support group helps us find that there are plenty of places that are accessible for people [disabled by a LTHC]

Participant 15: Oh and in general, some people aren't aware that there are lots of places you can go, where there are wheelchairs available and different places that you can use, like the plaza or like Mitre 10.

Participant 14: And they are accessible

Participant 11: Yes, but I never knew that before, I never thought about it [before joining] the group

Lastly, another practical function of support groups is helping people to manage their everyday duties alongside their LTHC:

For patients I think a practical focus [of support groups] is good. Like for instance,

helping them find and keep a job (Participant 7, Health Professional)

Two of the Group Participants also stated:

Participant 16: But I think though too, that the wives, we need help too

Participant 15: Yeah because a lot of us women, we have to keep working- so we

might not be isolated but we are working a long day and then working at home and it

can be hard.

(Participant 16 & 15, Group Participant)

The 'everyday life' support functions of peer-led groups are important. Participants

recognized that life continues after a LTHC and managing this can be difficult. It is

imperative to note that this form of practical support encourages autonomy and self-efficacy.

Further, it allows for participants to realize that the practical barriers of a LTHC are not

insurmountable.

Overall, these excerpts provide strong evidence that peer-led support groups have

practical and emotional support functions that help participants to cope with their LTHC.

Participants displayed a coherent understanding of the difference between these two types of

support and recognized the distinct benefits of both. The theme of 'Group Purpose' emerged

in the majority of the discussions in the current study. It is clear that individuals involved in

peer-led support understand these groups have a strong purpose.

4.9 Theme 7: Condition Discrimination

The topic of 'Condition Discrimination' was addressed by several participants in the current study. As previously discussed, the funding and resources that certain conditions receive is disproportionate to their prevalence and incidence. Many of the participants in the current study echoed this notion, citing that they felt some conditions were neglected.

One participant discussed how the embarrassing nature of LTHC relating to bowel function reduces public attention and sympathy:

Because of the type of disease it is [involving the bowel] it isn't really marketed well (Participant 6, Group Leader)

Further, when speaking of a degenerative, terminal condition, one Health Professional suggests that these types of diseases are often ignored because of poor prognosis. This excerpt was presented under the theme of 'Referrals from Health Professionals' but it is applicable here too:

Simply put, they figure these patients are terminal, they are going to die anyway, why would they need a support group? (Participant 9, Health Professional)

Other participants explored the idea that Cancer is given much greater resources because it has a high media profile:

Participant 2: That's the thing with cancer though, it has a huge profile [and therefore they have more resources] … And pretty much everyone would know someone who's had cancer, where as some of our groups are quite low profile…

Participant 4: But asthma [for instance] there's one in four people with asthma

Participant 2: Yes, and the same with stroke… but you just don't get that same type of

profile [as with cancer]

(Participants 2 & 4, Group Leaders)

Another suggested that some conditions are not taken as seriously by medical

professionals, even when they have a significant impact on quality of life:

Well [For example] there are only 12 thousand members of the Blind Foundation but

there are 20 times that number of people with poor vision and they have nowhere to

go. And the doctors are really, really unhelpful to say the least. And the doctors have

certain criteria for the Blind Foundation so that leaves some people with nowhere to

go for help…(Participant 1, Group Leader)

A few participants cited examples of how mental health receives less visibility in

media, and in turn less resources because it isn't as 'popular' as other conditions:

People who have mental health issues tend to be hidden away from society; its not

like with physical illness. Mental illness scares people... it's seen as dirty (Participant 8,

Health Professional)

Another participant, speaks of how there is often resources available for a condition

based on how 'popular' they are, using the example of schizophrenia:

Participant 7: [Schizophrenia] wasn't a very visible condition… at least until several

years ago when a local GP was murder by his son with Schizophrenia

Group Leader: Well that must have brought some attention to it

Participant 7: Yes media attention can be the difference between a condition getting seen and not… it is the same for physical illness too, this visibility thing

Further, another participant stated that disabilities from certain LTHC are often not considered:

We need to increase the public's tolerance around people who have [a disability from LTHC] (Participant 12, Group Participant)

The concept of condition discrimination is pervasive in both the data from the current study and in literature on LTHC. The notion that some types of cancer receive significantly more funding than other types, and other conditions can be frustrating for people with underfunded LTHC (Carter & Nguyen, 2012). In an article written by David Meldrum (2017) he states "I wish I had cancer. Not every day. Some days I don't. But some days I do. Instead I have Ankylosing Spondylitis". Meldrum goes on to explain how the lack of resources, funding and support for his condition makes him wish he had a more visible disease. Conceivably, this way of thinking could lead to intergroup jealousy.

In order to encourage progressive development of peer-led support groups, these institutionalized and often mediated discourses surrounding disease 'popularity' and 'attractiveness' must be tackled. This by no means suggests that the resources for individuals with cancer should be reduced, but rather, become more inclusive to people with other LTHC.

4.10 Conclusion

The purpose of this chapter was to outline the prominent themes that emerged in the interviews and focus groups with Group Leaders, Health Professionals and Group Participants. Through the 7 themes described, this chapter outlines several ideologies surrounding peer-led support for LTHC. Participant's noted a plethora of problems with peer-led support including lack of referrals, lack of resources, barriers to attendance, lack of stability, group stagnation, issues with diversity and condition discrimination. However, participants also addressed the ways in which peer-led support is improving and moving forward, and importantly, the significant purpose it serves to members. The plethora of perspectives on this topic provided by participants, aids in the understanding of how peer-led support functions, and where it can be improved. The following chapter will discuss how these themes relate to the new approaches introduced by this study, as well as their relation to wider societal discourses.

Chapter 5

Discussion

5.1 Introduction

Before the data collection process commenced, the current study developed the following 3 research questions:

1) What challenges, issues or barriers do peer-led support groups for LTHC face?

2) What are the functions and benefits of peer-led support groups for people with LTHC?

3) Does the role of the Facilitator have the potential to benefit peer-led support groups for LTHC in the future, and if so, how?

In speaking with Group Leaders, Health Professionals and Group Participants, the current study identified 7 emergent themes in relation to peer-led support for LTHC. The following chapter will address the research questions and discuss how they relate to the results of the current study. Further, the results will be compared and contrasted with previous literature, and the applications and limitations of the current study will be outlined.

5.2 Research Question 1: What challenges, issues or barriers do peer-led support groups for LTHC face?

Several of the themes presented in Chapter 4 relate to the challenges faced by peer-led support groups. Individuals involved in peer-led support indicated that there was ample room for improvement of these psychosocial support services; they suggested that maintaining these groups within the community was often an arduous task. It is important these challenges, issues and barriers are addressed as a first step to improving the resources available to peer-led support in the future.

Perceived Lack of Support from Health Professionals & The Healthcare System

One of the strongest themes that emerged in the current study was the challenge that the lack of referrals from health professionals posed. Receiving direct referrals allows for peer-support groups to reach a larger number of individuals who could benefit from these services (Sheffield, 2003). However, participants in the current study expressed their disillusionment with the lack of support from healthcare professionals. Furthermore, participants in the current study were concerned with the palpable condition discrimination in the healthcare system; they expressed concerns surrounding the lack of recognition and support for LTHC outside of the 'Big 4' (WHO, 2014). Understandably, if such issues are not addressed, they will continue to reinforce the barrier between the healthcare system and informal psychosocial support services.

Previous literature expressed the notion that healthcare professionals often fail engage with support groups. Dizzazo-Miller, Pociask & Samuel (2013) conducted research with the carers of individuals with dementia. The researchers stated that many participants reported a lack of referrals to social support services from healthcare professionals. Dizzazo-Miller and colleagues surmised that carers' overall ability to cope with the diagnosis and subsequent care duties could be significantly increased if they were proffered psychosocial support. Similarly, when examining the psychosocial support provided to women with post-natal depression, Holopainen (2002) found that women seeking support from healthcare professionals were not directed to peer-led support groups. Furthermore, Wituk, Shepard, Warren & Meissen (2002) examined healthcare professionals' attitudes towards paraprofessionals. The researchers suggested that healthcare professionals were hesitant to refer patients to peer-led groups because of the lack of substantiation of their effects.

In the current study, Group Leaders and Group Participants were negatively affected by the lack of engagement in peer-led support from healthcare professionals; participants suggested that this undermined the important work that these services do in the community. Further, Group Leaders and Group Participants felt as though they were unable to access individuals that could utilize their support due to the lack of referrals from healthcare professionals. Group Leaders in particular believed that receiving direct referrals to the support groups was imperative to their growth and success. It was unsurprising that participants in the current study felt as though referrals were so important; previous literature has suggested that individuals are almost twice as likely to attend support groups if they are recommended or referred to them by GPs, nurses or specialists. Group Participants in the current study felt that this was a considerable challenge faced by their support groups, and something that needs to be addressed in the future.

Participants in the current study discussed 'Condition Discrimination'; this theme is

another example of how the perceived lack of support from the healthcare system negatively

affects people involved in peer-led support. The available literature suggests that conditions

that are rarer, less physically evident or less mediated receiving minimal or negligible support

(Luengo-Fernandez, Leal & Grey, 2014). Similarly, Gillum and colleagues examined the

National Institute of Health (NIH) funding levels, resources and burden of disease in the

United States. The researchers examined 29 common conditions to discover whether the

funding and resources allocated to each condition were correlated to their prevalence and

national burden. Gillum and colleagues found that some conditions received disproportionate

funding to their prevalence and burden; in particular, HIV/AIDS and Diabetes. The

researchers suggested that this is a result of ingrained condition discrimination, whereby

conditions are provided resources in relation to their 'attractiveness' and 'media profile'

The participants in the current study echoed these notions. The Group Leaders from

all of the support groups except cancer, expressed their frustrations with the 'invisibility' of

the LTHC they supported. Understandably, there was some palpable resentment or jealousy

from these Group Leaders towards cancer support groups and other groups that received

considerable funding from NGOs. However, participants generally directed their exasperation

towards the healthcare system; they believed did not prioritize support for a diverse array of

LTHC. Participants noted a general lack of recognition of the socio-emotional needs of

individuals with LTHC that fall outside of the 'Big 4' (WHO, 2015) and displayed

disparagement regarding the likelihood of this changing in the future.

Overall, the participants in the current study displayed a general dissatisfaction with

the engagement from health professionals in peer-led support. This related to the conception

that the psychosocial needs of patients with LTHC are not valued. Health Professionals are educated to address chronic illness with collaborative care models (Campbell & McGauley, 2005); however, it is clear that not all healthcare professionals understand the psychological impact of LTHC on individuals and their carers. Understandably, this disconnect is a considerable barrier to the development and maintenance of peer-led support groups.

Issues of Group Maintenance

Group Maintenance was an evident challenge faced by individuals involved in peer-led support groups for LTHC. Participants discussed the ways in which resource provision, sustainability and stagnation related to the maintenance, and consequent success of support groups. However, many participants appeared to be somewhat daunted by these issues and presented little conceptualization of how to overcome them.

Firstly, financial issues were one of the most prominent challenges faced by peer-led support groups. Fisher (in Peers for Progress, 2014) discussed the nature of peer-led support and outlined the implementations that can increase its effectiveness. Fisher suggests that peer-led support groups provided with government or charity funding are more beneficial to participants than those that are not. He infers that this is a result of the reduction of financial pressures on Group Leaders, allowing greater time to focus on group dynamics, activities and extra support of vulnerable members. Similarly, Murphy, Lindenau, Corrigan, Downes & Higgins (2016) outlined and evaluated the support services for mental illness in Ireland. The report suggested that financial instability was a major concern for peer-led support groups

and ultimately produced detrimental effects; these included inability to pay for group

expenses, leader stress and consumption of leader time.

Participants in the current study expressed concerns surrounding the sustainability of

peer-led support groups, particularly due to unstable and inadequate funding. Group

Participants discussed their concern over the lack of funding for their support groups,

suggesting it was a barrier to member attendance. Specifically, they stated that they were

unable to keep member costs low and as a result, individuals experiencing financial strife

could not attend. Further, participants in the current study were focused on the psychological

impact of fiscal issues on people involved in peer-led support. Group Leaders expressed their

anxiety and frustration over the lack of financial support from the MDHB and NGOs and the

uncertainty this lack of stable funding induced. As a result, many Group Leaders intimated

that they experienced some level of 'burn out' from the psychological strain of trying to

sustain a group with minimal funds.

Secondly, the absence of adequate educational resources for peer-led support groups

was addressed in the current study. This included the deficit of standardized guidelines for

how to develop and sustain groups. Ansell (2013) suggests that it is pertinent that peer-

leaders be provided with formal guidelines that prepare them for their role. Further, Ansell

inferred that leaders developing groups should be provided with educational tools to help

format the group and develop group goals. Analogously, Faulkner & Kalathil (2012)

prepared a report on peer-led support for patients with mental illness. The researchers

inferred that becoming a Group Leader is a difficult and daunting process; the lack of

available resources to support leaders can make the task of developing or taking over a group

unappealing. Faulkner & Kalathil suggested that peer-leaders do not have the same 'power,

resources or influence as professionals', often making it difficult for them to navigate the maintenance of a support group alone.

Participants in the current study also expressed concern surrounding the lack of educational resources for how to develop, run and maintain an effective peer-led support group. Group Leaders were the most concerned with this, however Health Professionals also noted that there was a lack of consistency in advice and training given to current and prospective peer-leaders. Both Group Leaders and Health Professionals suggested that standardized codes of practice for peer-led support groups would help to legitimize these services within the healthcare system. Group Participants, however, contradicted previous literature and the assertions of Group Leaders and Health Professionals. The majority of Group Participants believed their leaders were more knowledgeable than healthcare professionals; they suggested that they did not believe their group would benefit from external codes of practice. Understandably, Group Participants may not be aware of the struggles faced by leaders regarding group maintenance and development; they may also be concerned that any external influence or regulation may change the group dynamic.

Thirdly, group maintenance is intrinsically tied with the issues of sustainability and stagnation. In peer-led support groups for LTHC, leaders often report difficulties in keeping groups sustainable, avoiding stagnation and changing with the needs of members (Butow et al, 2005). Butow and colleagues conducted a study analysing the sustainability of cancer support groups. The researchers suggested that group sustainability was dependant upon leadership structure; external and internal pressures on the leader resulted in higher leader turnover, which negatively affected group maintenance. Similarly, Convey, Dickson-Gomez, Weeks & Li (2010) examined peer-led support for the intervention and prevention of HIV.

They conducted a longitudinal study of the effects of peer-led support over the course of almost 5 years. The researchers found that having committed, altruistic peer-leaders was a major factor in the sustainability of the group. However, keeping volunteer leaders for extended periods of time is a difficult task due to the lack of educational, social and financial support for such roles.

Several of the Group Leaders in the current study believed that their peer-led support group would not successfully continue without them. However, contrary to previous literature, the peer-led groups in the current study did not experience high leader turnover; many Group Leaders had held their role for several years, and planned to continue to lead the group for the foreseeable future. Despite this, participants in the current study iterated the need for greater resources to aid individuals involved in developing and sustaining support groups. Participants suggested that greater financial, educational and practical resources would increase leader's ability to sustain groups and ensure they remain effective for both existent and potential members.

The available literature on peer-led support group stagnation is sparse. It is clear that in order for a peer-led support group to be comprehensively effective, it must be flexible and evolve with the changing needs of members (Mead & McNeil, 2013). The current study found one considerably dated piece of literature that discussed the lack of evolution in self-help support groups. Kurtz's (1997) book on psychosocial support services presents the notion that groups that do not evolve to suit new members are unlikely to maximise benefits for participants. Kurtz infers that while sustainability and maintence are important group concerns, the failure to develop and grow can have detrimental effects.

Group stagnation was an issue that was addressed by several participants in the current study. Despite the relative absence of research on support group stagnation, Group Leaders and Group Participants expressed concern over the lack of growth in local peer-led support groups. Group Participants in particular believed that while support groups were beneficial to current members, they were considerably set in their ways. Group Participants surmised that it would be difficult for new members to enter these pre-existing groups and feel comfortable and accepted. Further, some of the Group Leaders discussed their experiences as participants in peer-led groups. Two Group Leaders in particularly suggested that they had attempted to join stagnant groups and found the, uninviting and ineffective. While group stagnation is not well-documented in psychological literature, it is an important factor to consider when analysing support group maintenance.

Maintaining successful peer-led support groups is a difficult task. Participants in the current study addressed the lack of financial and educational resources for groups; it was clear that these deficits made group sustainability and longevity challenging. As these issues were a prominent concern for participants in the current study, it would be a pertinent area for future research and intervention.

Challenges of Participant Attendance

Another prominent challenge faced by peer-led support groups was participant attendance. Issues with reaching potential participants and retaining existing members were addressed by the majority of participants in the current study. Understandably, developing

peer-led support groups that can maintain members is imperative to their growth and success within communities.

Previous literature has indicated that group attendance behaviours are underpinned by the practical and emotional barriers to participation. Kaiser, Franks & Smith (2011) examined support group attendance in individuals who had had gastric banding surgery. Kaiser and colleagues asked potential group participants what factors would influence their attendance. The majority of participants in the research suggested that time constraints and distance barriers would be the most substantial reasons for non-attendance. Ostensibly, creating support group sub-branches in local communities and increasing the frequency of meetings could address some of these challenges. However, as the researchers suggest, while these barriers are practically-oriented and conceivably simple to address, without adequate funding, they are difficult to resolve.

Personal cost to participants as a barrier to attendance has also been addressed in literature. Thom and colleagues (2013) conducted research on peer-led support groups for patients in the United States who had poorly controlled diabetes. The participants in the study were all from low socio-economic backgrounds; thus, the peer-led intervention was targeted towards self-management behaviours that were cost-effective. The researchers found that initial attendance costs were off-putting to potential participants. Furthermore, participants did not experience significant financial benefit from group attendance in the early phases of the support program. Understandably, for individuals with LTHC who are retired or unable to work, even the relatively minimal cost of peer-led support membership can deter them from attending.

Whittaker & Cowley (2010) examined participant's attitudes towards attendance to parenting support groups. The participants in this study indicated several reasons why they didn't attend, or would not attend in the future. The predominant reasons for non-attendance were program content, leadership style and other conflicting commitments. However, some participants suggested that religious, cultural and personal lifestyle clashes between the Group Leader and the participants, or between themselves and other participants were strong reasons for non-attendance. While the former barriers are practically-oriented, the latter are more emotionally-engrained; the researchers suggest that these emotional barriers are considerably harder to address.

The participants in the current study discussed both practical and emotional barriers to attendance. Similar to previous research, participants inferred that challenges of time and distance affected group attendance. The existent body of literature does not specifically focus on the personal cost of peer-led support as a major barrier to attendance; however, the cost of attendance was a prominent concern in the current study. All groups of participants- Group Leaders, Health Professionals and Group Participants were concerned that many individuals with LTHC struggled to cope financially; the additional cost of transport to support services, gold coin donations for meetings or payment for group activities were often difficult for members to afford. Perhaps, participants in the current study were focused on these issues because they are often apparent in their personal experiences with support groups. Further, participants may have believed that personal cost challenges were more surmountable than intrinsic, emotional barriers and that addressing them could potentially lead to tangible change.

Lastly, one of the most prominent barriers to attendance to peer-led support is the lack of diversity. Research has cited decreased attendance of ethnic minorities, young people and men to physical and mental health support groups. Marmot (2006) produced a report on the inequalities in health support for minority individuals. In his report, Marmot suggests that there are less support resources targeted to ethnic and cultural minorities, resulting in poorer physical and psychological outcomes for minority individuals dealing with health conditions. Marmot infers that this is the reason why many support services are dominated by Caucasian attendees. Further, the researcher suggests that the preponderance of non-minority individuals in support groups has resulted in minorities engaging in self-segregation; specially, because they feel as though their identity is not cohesive with other members of the group, resulting in discomfort and anxiety.

Participants in the current study were reluctant to directly address issues with ethnic diversity in the support groups they were involved in. Though the Focus Group Topic Guide provided prompts for participants to discuss concerns over ethnic minority attendance (in particular Māori attendance), participants generally stated that they felt it could be increased, but they were unsure how this could be accomplished. Furthermore, it was clear that Caucasian Group Leaders did not feel competent in their ability to cater to the needs of culturally diverse individuals. Many participants felt the support group they were involved in would be applicable for individuals from diverse backgrounds, provided they were not looking for culturally-specific advice or support. Such assertions reflect the need for greater involvement from minority individuals in group leadership. Further, there is a palpable need for support groups to be developed that specifically target cultural minorities and provide support oriented around the unique challenges minorities dealing with LTHC face.

Another challenge for peer-led support was its lack of applicability for young people. Sawyer and Aroni (2005) suggested that support resources for people under 30 dealing with chronic illness are not comprehensive. The researchers aimed to discover how self-management of chronic illness in adolescence could be increased through group support. Sawyer and Aroni's analyses revealed that traditional support services may not be applicable to young people, considering the difficult intersect between coping with illness and the unique challenges of adolescence. The researchers suggest that support services must focus on social development, self-management and involvement from parents in a way that doesn't compromise autonomy. Overall, the study infers that pre-existing support resources are minimally beneficial to young people, resulting in reduced attendance.

Overall, the participants in the current study were over 30 years of age; however, two of the Group Leaders were under 30. These Group Leaders expressed the most concern over the lack of young people attending support groups. One of the leaders decided to initiate a peer-led support group for LTHC for people under 25; this participant was adamant that the existing support resources were targeted to a much older population, and therefore did not provide the pertinent peer social interaction. However, some of the older participants in the study did not seem concerned with the limited attendance of young people to support groups. Further, a few Health Professionals suggested that young people were not a priority target group for peer-led support groups. Though the available literature displays a palpable need for greater support resources for young people, it is clear from the current study that not all people involved in peer-led support are aware that they are failing to cater to a large group of individuals.

The final issue of diversity relating to support group attendance is the imbalanced number of female to male members. There is limited research available detailing the differences between males and females in psychosocial support groups. However, Martinez-Hernàez, Carceller-Maicas, Giacomo & Artise (2016) examined gender differences in individuals' coping with depression. The researchers suggested that males were less likely to engage in healthy coping skills, ask for social support or attend support groups; this was explained by a decreased ability to emotionally communicate and greater levels of social isolation in males. Despite this, research has indicated that males require similar levels of psychosocial support to females (Vlasoff, 2007).

Generally, participants in the current study agreed that the lack of male attendance was an issue for support groups; however, they were relatively unsure of how to tackle this issue. This lack of assuredness with how to increase male attendance was likely affected by the fact that the majority of the Group Participants and Group Leader in the current study were females; however, this sample was reasonably indicative of the overall participation and leadership levels of males and females in peer-led support (Martinez-Hernàez, Carceller-Maicas, Giacomo & Artise, 2016). A few of the Group Leaders intimated that female leaders may not be able to provide the types of support that are most effective for males. One Group Leader suggested that activity-based support groups were more effective for males rather than discussion-oriented groups. However, other Group Leaders and Heath Professionals in the current study suggested that it was important to the group dynamic that support groups have a balance of males and females. Overall, it was clear that there was little consensus over how to engage with males affected by LTHC by participants in the current study; this only illuminates the need for greater educational resources for peer-leaders on how to appeal to, and be effective for males.

Attendance issues present a significant challenge to people involved in peer-led support. The participants in the current study recognized the importance of increasing attendance and providing resources that are applicable to a diverse range of individuals; however, they were often unsure of how to do so. The current study has illuminated the need for attendance issues to be addressed in order for peer-led support groups to be utilized to their full potential by the community.

5.3 Research Question 2: What are the functions and benefits of peer-led support groups for people with LTHC?

Many of the themes presented in the current study related to the difficulties faced by peer-led support groups. However, it was clear that participants also noted several positive functions of these groups. Overall, participants provided a unique look into the benefits of peer-led support from their own perspectives and allowed the current study to provide a much needed 'voice' to the community.

Inciting Self Efficacy (and Self-Management)

As presented in the initial chapters of the current study, Social Cognitive Theory (Bandura, 1977) informs many of the goals of peer-led support. Specifically, peer-led support groups aim to incite self-efficacy and condition self-management in participants. Individuals who are self-efficacious feel as though the are capable of effecting positive personal change

and growth. Ultimately, the unique emphasis on self-management in peer-led support group

has been a strong factor in the endorsement of its use in the healthcare system.

Previous literature clearly delineates the positive impact of self-efficacy and self-

management on psychological and physical wellbeing of people dealing with mental and

physical conditions. Motl, McAuley, Wynn, Sandroff & Suh (2012) examined self-efficacy

levels in patients with multiple sclerosis. The researchers found that individuals who tested

high for self-efficacy engaged in more proactive health behaviours- such as physical exercise,

healthy eating and medication adherence, Ultimately, this resulted in greater health outcomes

for patients, as well as the utilization of adaptive coping strategies in difficult times. Research

outlining the benefits of self-efficacy in patients has incited the development of wellness

programs oriented around self-management. Larsen (2014) examined the effects support

groups had on the wellbeing of patients with LTHC; it was suggested that support groups

focusing on encouraging self-management of health conditions decreased unplanned hospital

admissions for patients over time. Larsen infers that this is likely a result of positive

reinforcement from group members, increased condition knowledge, and group modelling of

proactive behaviours. Ultimately, by increasing patient self-efficacy, peer-led support can

decrease patient reliance on formal support services. As a result, patients gain self-confidence

in their ability to cope with and manage their condition.

Though the majority of participants in the current study did not necessarily mention

the term self-efficacy, it was clear that they perceived self-management and self-confidence

as principal benefits of support groups. Group Participants noted that they were better able to

manage their emotions and deal with negative circumstances since joining the group. Further,

several of the Group Participants felt that educational support provided by the support group

increased their confidence in caring for a partner with a LTHC. Many Group Leaders also

noted a correlation between group attendance and individuals engaging in positive, proactive

health behaviours. Such behaviours included doing physical exercise, following a healthy

diet, adopting positive hobbies or pastimes and adhering to medication. Further, Health

Professionals indicated that they noticed positive changes in individuals with LTHC who

attended peer-led support; namely that members exhibited increased self-confidence. One

Health Professional stated that participants that attended support groups frequented her clinic

less because they were better able to manage their treatment and symptoms autonomously.

The current study was consistent with previous literature in asserting that peer support

is instrumental in increasing patient self-efficacy. The benefits of increasing self-efficacy,

self-management and self-confidence for people with LTHC are widespread and illuminate

the unique positive influence peer-led support groups can have.

Shared Experience

Shared Experience was another recurrent theme expressed by participants. The notion

of shared experience relates to the development of a supportive social community within a

group and the emotional bonds formed from realizing one is not alone in their struggle

(Steffen, 1997). Arguably, the formation of shared experience is one of the most ubiquitous

functions of peer-led support groups; it is imperative in inciting meaning-making and in

generating a supportive social community (Arvaja, 2011).

The pre-existing literature on support groups suggests that the generation of shared experienced is one of it's most prominent functions (Davidson, Pennebaker & Dickerson, 2000). Davidson and colleagues examined support group participants for 20 disease categories across 4 cities in the United States. The researchers determined that support-seeking was high in diseases that were stigmatizing such as HIV/AIDS. They inferred that this was because support groups provided an environment that was emotionally safe, and where participants were understood. It is exceedingly beneficial for patients to have a supportive social community where they can express their concerns, frustrations, triumphs and sadness without fear of judgement.

Similarly, Ussher, Kirsten, Butow & Sandoval (2005) interviewed 93 patients who participated in one of 9 cancer support groups across Australia. The researchers were primarily focused on analysing the differences between support groups and other forms of social support for individuals with cancer. Ussher and colleagues suggested that the exchange of anecdotal experience provided comfort, eased cognitive dissonance and broke down emotional barriers for patients. The interviewees in the study expressed immense value of the shared-experience generated in the support group. Overall, the researchers found that participants perceived the main purpose of support groups as the provision of 'a unique sense of community, unconditional acceptance and valuable information and education'.

The importance of shared experience was elucidated by participants in the current study. Group Leaders, Group Participants and Health Professionals all stated that they believed one of the most prominent benefits of peer-led support was the collective social community that was formed. Group Leaders and Group Participants focused on the emotionally-oriented benefits of shared experience. Several Group Leaders suggested that

members reported feeling accepted and understood within the group; they believed that this was important in promoting communication and self-expression. Group Participants also conceptualized the peer-led group as a place where they could complain, cry, or express feelings of guilt or hopelessness without feeling judged. Health Professionals focused on slightly different benefits of shared experience for patients; namely, tangible benefits such as positive modelling, social interaction and self-management. Understandably, Health Professionals' focus on practical benefits may be related to the lack of firsthand experience of the emotional benefits of groups. Regardless, both emotional and practical benefits of shared experience in peer-led support are immensely beneficial to patients.

The generation of shared experience is a paramount function of peer-led support groups. The personal experience of the peer-leader increases group empathy and strengthens the collective social community of the group (Delman, Delman, Vezina & Piselli, 2014). Group Leaders and Group Participants in the current study better understood the emotional benefit of the development of a social community, compared to Health Professionals. Thus, it is clear that people affected by LTHC involved in peer-support groups are the ones who truly understand the unique emotional benefits these services have.

Education and Information

The provision of education and information was another benefit of peer-led support. Though this was not as prominent as the former two benefits, it illuminates the importance of practical functions of peer-led support. Though it is important that patients with LTHC continue to receive medical advice and intervention from healthcare professionals, peers and

peer-leaders can provide a unique perspective on treatment, side-effects, diet and lifestyle and emergent condition-related research.

Literature on support groups reiterates the importance of education and information functions. Campbell, Phaneuf & Deane (2003) examined cancer support groups to discern whether they were beneficial for patients. Campbell and colleagues suggested that it is important that support groups incorporate the provision of education to maximise member benefit. The researchers found it difficult to objectively evaluate the effectiveness of peer-led support; however, they found robust and significant benefits to participants from the informational components of groups, such as information on new treatments, lifestyle changes and anecdotal experience regarding how to cope with medical interventions.

Comparably, Shah and colleagues (2001) examined peer-led programs for asthma that were focused on the provision of health education, specifically for young people. The researchers utilized measures of quality of life, school absence and lung function after a three-step peer-led health education program. It was found that upon completion of the program, asthma sufferers had increased quality of life, decreased school absence and improved lung function. The researchers suggest that while the socio-emotional functions of peer-led support are important, these groups have the potential to provide beneficial health education. Ultimately, these educational programs are focused on increasing self-efficacy and self-management in participants; it is likely these interventions are successful because of the emotional safety and understanding of the peer group environment (Norris et al, 2002).

Several of the participants in the current study noted the importance of educational and informational functions of groups. Many of the Group Leaders stated that they

incorporated education into the peer-led support group; they believed that this allowed

participants to deal with both the emotional and practical aspects of LTHC. One Group

Leader suggested that the peer environment allowed for participants to ask personal or

embarrassing questions that they may not feel comfortable asking a healthcare professional.

Further, several of the Group Participants suggested that the Group Leader was an important

source of information on LTHC. Notably, participants inferred that the Leader was

exceedingly more accessible and contactable than healthcare professionals. Group

Participants also stated that the support group acted as a forum for discussing treatments,

medications, prognoses and providing practical advice (such as which stores were disability

accessible). While the educational and informational functions of peer-led support may not be

considered the foremost benefit, it is clear that they are a very important part of these

services.

Peer-led support also has other educational functions that are explored less often in

literature; such functions include advocacy, raising awareness and public lobbying. Dennis

(2003) examined peer-led support in a healthcare context; the study focused on providing

information to nurses regarding how to implement effective peer-led support for LTHC.

Dennis explicated some of the less obvious benefits of peer-led support, including medical

advocacy; this involves peer-to-peer provision of support in healthcare contexts- including

aiding in communication with medical professionals and ensuring autonomy in treatment

decision making. Dennis also suggests that many peer-led support groups engage in public

health campaigns and and fundraising. Similarly, Bhagwanjee & Steven (1999) suggested

that raising awareness of LTHC and inciting proactive and preventative action are important

forms of public education that peer-led support groups are often part of.

Finally, many support groups also have lobbying functions (Cornet, 2015); however, the think between peer-led support groups for LTHC and lobbying has been largely unexplored in literature. Cornet suggests that historically, mental health peer support groups are more engaged in political lobbying for greater resources and funding than LTHC groups. There is extensive potential for lobbying functions of support groups; this includes increasing the political and public awareness of the needs of people affected by LTHC. Overall, Cornet surmises that groups with fundraising, raising awareness and lobbying functions can increase the effectiveness of peer-led support; this can be attributed to the increase in self-efficacy and restoring autonomy, educational competence and internal locus of control. Furthermore, these functions allow for individuals affected by LTHC to utilize their difficult experiences to help others; as a result, they are likely to interpret these experiences as meaningful.

In the focus groups and interviews of the current study, participants were questioned about advocacy, fundraising and lobbying functions of support groups. While participants were able to provide examples of traditional education and information in their support groups, the majority did not recall instances where they engaged in other functions such as advocacy. This result was unsurprising, given the relative lack of qualitative research on peer-led support and advocacy, lobbying and fundraising. However, when participants were questioned as to whether they though these functions would be beneficial to members and to the public, many noted that they felt it would be a positive addition. A few of the Group Leaders noted that while they would love to engage more in these functions, the limited time and money provided to groups restricted their ability to do so.

Conclusion

Research on peer-led support has indicated that it has different functions for different individuals. (Docherty, 2003). Thus, it is imperative that these groups continue to have both practical and emotional benefits for members. The prominence of the theme of 'Group Purpose' in the current study reflects the notion that peer-led support is dynamic and goal-oriented; and while there are numerous challenges faced by peer-led support groups, it is clear that they provide many benefits. Peer-led support is unique in its ability to provide diverse benefits to members - from social friendships, to engagement in activities and educational programs, to participation in public initiatives. Ultimately, peer-led support gives meaning to the experiences of people affected by LTHC and provides them with an ongoing supportive community that allows them to thrive in the face of adversity.

5.4 Research Question 3: Does the role of the Facilitator have the potential to benefit peer-led support groups for LTHC in the future, and if so, how?

The themes highlighted in the results section of the current study illuminated distinct issues and challenges faced by peer-led support groups. Participants in the current study did not appear to have a clear conception of the role of the Facilitator or the ways in which this could be beneficial to their group. However, with greater time and investment from the MDHB, the Facilitator could address some of the issues that individuals involved in peer-led support explicated.

Attendance & Non-Referral

Low attendance to peer-led support groups is often influenced by the lack of referrals from healthcare professionals. Further, practical and emotional barriers also affected potential members' willingness to attend. Fundamentally, tackling issues of low attendance and non-referral would be beneficial to the growth and maintenance of support groups.

Psychological literature suggests that healthcare professionals may not refer to peer-led support groups because of a fundamental lack of understanding of the psychosocial support needs of individuals affected by LTHC (Beard, 2016). Beard suggests that limited institutional resources make it difficult for healthcare professionals to focus on the socio-emotional effects of LTHC on patients. Historically, healthcare professionals have experienced some apprehension over referring patients to groups led by lay people or paraprofessionals (Williamson, 1999). Williamson suggests that there are many misconceptions in the healthcare system regarding what a peer-leader is, Many healthcare professionals express concern regarding whether these peer-led groups will provide contradicting medical advice. Similarly, Ansell & Insley (2013) suggest that the popularization of peer-led support has resulted in significant changes in patient-centred care-including the reliance on these informal resources and the focus on patient autonomy. However, the positive effects of peer-led support are still somewhat unestablished in literature (Miyamoto & Sono, 2012); thus, it is understandable that healthcare professionals are sceptical of such resources.

Group Participants and Group Leaders in the current study suggested that the Facilitator could be helpful in developing greater relationships between healthcare professionals and individuals involved in peer-led support. Several Group Leaders in the

current study believed that gaining the approval and support from healthcare professionals

would make it easier for them to reach potential participants. Therefore, it would be

beneficial for the Facilitator to meet with healthcare professionals working with individuals

with LTHC and introduce them to the database of support groups. Further, the Facilitator

could initiate information evenings for healthcare professionals and Group Leaders to meet

one another. These meetings could be focused on developing rapport between people

involved in peer-led support and discussing the ways in which they could work together on

providing dynamic and comprehensive patient care. The Health Professionals in the current

study were enthusiastic about the emergence of more peer-led support groups, and about the

role of the Facilitator. Some Healthcare Professionals that were involved with support groups

suggested that they could be utilized as examples for how the healthcare system and

psychosocial support services could work together and benefit one another.

Additionally, many of the participants in the current study suggested that there were

other ways to increase attendance without relying on referrals from healthcare professionals.

Group Leaders suggested that it would be beneficial for the Facilitator to help them advertise

their group to a more diverse audience. The Facilitator could help group leaders to utilize

creative means to advertise their group, such as through social media or community

fundraisers. The Group Leaders and Group Participants also suggested that the Facilitator

may be able to help them reach minority individuals that don't attend support groups;

including Māori, immigrants, young people and in particular, individuals from low socio-

economic areas and backgrounds. The Facilitator could utilize their community connections

to put Group Leaders in touch with local Maraes, schools and churches, learning centres and

community centres in low socio-economic areas.

There are several issues when attempting to address personal practical and emotional barriers to support groups attendance. In order to overcome many practical barriers, there needs to be greater financial investment from DHBs and NGOs (Kaiser et al, 2011). Participants in the current study cited transport availability and costs as the largest practical barriers to attendance. Group Participants suggested that the Facilitator could help them to communicate the transport needs of their support group to the MDHB in the hopes that they might subsidize costs. However, Health Professionals in the current study suggested that this issue could be addressed by increasing the availability of support groups in rural communities; consequently, decreasing transport costs for individuals living outside of Palmerston North. As developing new peer-led support groups is part of the Facilitators role, they could work to create sub-groups in rural and isolated areas.

It was surprising that participants in the current study did not suggest that the Facilitator help in fundraising for member transport costs, as peer-led support groups are often reliant on fundraising and donations in order to continue to operate (Stevenson, Lyndon & Amir, 2010). However, it is suggested that the Facilitator could help organize single or inter-group fundraising initiatives within the MDHB and encourage the public to support local peer-led groups. As participants inferred that the transport costs of peer-led support groups in the MDHB were relatively low, it would not take an extensive amount of fundraising to gain enough money to finance transport costs, particularly for members who are financially struggling.

There is minimal research on how to address the emotional barriers to attendance. However, the International HIV/AIDS Alliance (2015) discussed group attendance to HIV & AIDS support groups and presented ideas on how to reduce emotional barriers. The

researchers suggest that having group 'open days' where potential participants can explore

the support group environment without feeling out of place or having to commit to attending,

are beneficial in encouraging group membership. Further the researchers suggest that these

'open days' should be activity-oriented and allow participants to bring family, friends or

partners. Additionally, Heisler (2010) examined peer-led support for Diabetes and the ways

in which it can be mobilized to increase patient participation. Heisler suggested that there

needs to be a balance between encouraging attendance and negative coercion; he infers that

group leaders must receive comprehensive education on how to find this balance and how to

appropriately reach out to potential members.

Participants in the current study did infer that there needed to be greater provision of

education for group leaders, particularly in regards to how to approach and obtain new

members. Several of the Group Leaders and Health Professionals thought that education

evenings or written codes of practice for people involved in peer-led support groups could

provide advice on how to tackle emotional barriers to attendance in potential participants.

Conceivably, it would be possible for the Facilitator to develop educational resources that

provided group leaders with this knowledge; particularly as the Facilitator has a strong

educational background in psychology.

Lack of Resources

As addressed, another large challenge faced by peer-led support groups is the lack of

resources. The Facilitator does not have the fiscal means to provide monetary support to

groups; however, they do have the experience and knowledge to provide individuals involved

in peer-led support with advice on how overcome some of the issues presented due to the lack of resources.

Heisler (2010) suggested that while peer-led support groups are relatively low-cost, they require some level of resource provision in order to be sustainable. Heisler inferred that peer-leaders should be provided with education and information on how to deliver effective support. Further, he suggests that leaders should be compensated for any group expenses and if possible, for their time. However, as Scott (2011) states in his report on peer-led support groups in New Zealand, that stable funding and updated educational resources are difficult to come by- particularly from government institutions. Despite the considerable importance of educational resources for peer-leaders, these is minimal psychological research focusing on this deficit.

Many of the participants in the current study were hopeful that the Facilitator could communicate the basic needs of peer-led groups to the MDHB. Ostensibly, providing feedback on support groups within the community to the MDHB is an important part of the Facilitator's role. Ideally, such feedback would result in greater financial investment in peer-led support groups; unfortunately, this is a lengthy process and doesn't necessarily result in long-term, stable funding. Understandably, many participants were pragmatic in assuming that receiving direct funding from the MDHB was improbable. Group Leaders suggested that the Facilitator could create a network for individuals involved in the running of peer-led support groups. Such a network could allow group members to exchange ideas on group maintenance, advertising and alternative funding sources and inexpensive venues and activities. Further, these network meetings would provide a platform for peer-led support

groups to garner volunteers to help in the running of groups, or donors who are interested in sponsoring local groups.

Issues with Diversity

The lack of diversity in peer-led support groups is a complex issue to tackle. As mentioned, the participants in the current study identified ethnic minorities, young people and men as groups that had markedly low attendance in support groups. Previous literature on diversity in support networks provides limited suggestions on how to increase the participation of these minorities. However, Gaertner & Dovidio (2014) examined the ways in which interpersonal differences among group members can be minimized. They suggest that racial, cultural, gender and age differences in groups can make it difficult for individuals who identify as a minority to feel comfortable and accepted. The researchers infer that groups focused on collaborative activities create temporary in-groups that negate the emphasis on potentially divisive differences in identities.

Further, Feely, Stubits, Todd & Young (2015) suggest that group settings that are not focused on face-to-face engagement may provide a positive introduction for minority individuals. Feely and colleagues suggested that information evenings or activity-based seminars can neutralize in-group and out-group dynamics. The researchers suggest that not having to engage directly with other participants or engaging in a collaborative, goal-based activity can decrease minority individuals' feelings of isolation within homogenous groups.

The peer-led support groups in the MDHB are relatively homogenous; they are generally comprised of Caucasian individuals over the age of 40. Furthermore, these groups

tend to have more females than males. Participants in the current study acknowledged the

lack of diversity in the groups they were involved in. Group Leaders suggested that the

Facilitator could help them to reach out to ethnic minorities with LTHC, by creating links of

communication between peer-led groups and places with considerable ethnic diversity such

as Maraes, Refugee services and community centres. The Facilitator could enact this by

visiting these locations and providing them information booklets on the available support

groups in the area. Furthermore, the Facilitator could make contact with community leaders,

local health providers, kaumatua, school principals, English-language teachers and volunteers

that work with ethnic minorities in areas of high ethnic diversity; in doing this the Facilitator

could promote peer-led groups and provide a point of contact if they come across individuals

with LTHC who could benefit from social support services.

Participants in the current study also noted that the existent services were not tailored

to young people. They suggested that it would be beneficial for the Facilitator to develop

groups specifically targeted at people under the age of 30. As mentioned, one Group Leader

was developing a support group for young people with a LTHC; this leader suggested that

they required the support of the Facilitator to reach potential participants, particularly as

young people are often reluctant to attend support groups (Sawyer and Aroni, 2005). Again, it

would be beneficial for the Facilitator to introduce themselves to leaders in schools, youth

centres and church youth groups and educate them on the importance of developing youth-

oriented peer-led support for LTHC. In doing so, the Facilitator may also encounter young

people who are interested in becoming peer-leaders or starting support groups.

Finally, the low number of males attending support groups was another issue of

diversity that was addressed by participants in the current study. Participants provided more

detailed ideas of how to increase male engagement in peer-led support than they did for

ethnic minorities and young people. This is surprising, given that the literature on diversity in

support groups is generally more focused on the latter two groups. Understandably, this may

be because the MDHB has a comparatively high Caucasian population to other areas in NZ

(Statistics New Zealand, 2013) and thus, participants may not have come into contact with a

large number of individuals from ethnic minorities with LTHC. Similarly, the likelihood of

developing a chronic condition increases significantly with age (Jetha, Besen & Smith,

2016); therefore, participants in the current study may have not had experience with young

people with LTHC. The focus group of Group Participants presented the greatest number of

ideas on how to increase male attendance. They inferred that men would benefit from less

emotionally-oriented support groups, such as workshop groups, or more casual groups, such

as meeting at the pub or a bowling club. Ostensibly, the Facilitator could help to guide the

development of male-only support groups and provide group leaders with information on

how to create environments that are conducive to the psychosocial support of males.

Furthermore, it would be pertinent for the Facilitator to gain a comprehensive

understanding of the informal support networks that ethnic minorities, young people and men

may utilize outside of support groups. In exploring these, the Facilitator could determine the

areas in which there is a legitimate lack of support resources. Furthermore, it would be

beneficial for the Facilitator to speak with minority individuals with LTHC and determine

whether the existent support groups would suit their needs, or whether new groups need to be

developed. Overall, increasing the diversity of peer-led support groups is an important step to

making effective social support services available and accessible to all who need them.

Prescription for The Role and Future Directions

While the past 18-months has been a challenging time for the establishment of the role of the Facilitator, it has also illuminated many palpable areas in which this role will be effective. The specific prescriptions for the progression of the role have been outlined in the Appendix (Appendix E) section of this report.

The role of the Facilitator has the potential to be of great benefit to people involved in peer-led support groups, and individuals with LTHC in the community. If the MDHB were to continue to fund the role of the Facilitator, it would present an opportunity for many of the issues of peer-led support groups to be tackled. Further, as the initial 18-month period of the role was primarily focused on discovering and evaluating support groups in the community, an extension of the role would allow for it to be adequately assessed by the MDHB. Though it is clear that the Facilitator will not be able to address all of the issues peer-led support groups face alone, the introduction of this role signals an important step in the movement towards a comprehensive system of patient care and greater synergy between support groups and the healthcare system.

5.5 Limitations

The current study is not without limitations. It is imperative that these are addressed to illuminate issues that future research could avoid. Further, while the current study was focused on providing an objective look at peer-led support for LTHC in the MDHB, it is not without biases.

The method of sampling in the current study provided a somewhat bias sample. Whilst an invitation to participate was sent to all Group Leaders and Health Professionals on the MDHB database, those who replied likely did so because they had the time and resources. The time constraints of the current study made it impossible for the researcher to pre-interview every participant and ensure they came from a variety of backgrounds. Understandably, this selection method may have missed out on people from low socio-economic communities or from groups that are under-resourced. Limitations like this are not unusual in qualitative research. Mfutso-Bengo, Masiye, Molyneux, Ndebele & Chilungo (2008) suggest that people from resource-poor areas are less inclined to participate in research. Based on this, the sample of the current study is not truly random, nor is it completely representative of people involved in peer-led support groups in the MDHB.

Comparably, the participant sample in the current study did not possess ethnic diversity that was representative of the demographics in the area. While the greater Manawatu area is predominantly Caucasian, there are still a considerable number of ethnic minorities in the MDHB (Statistics New Zealand, 2013). The participants in the current study were almost all Caucasian, and therefore it was difficult to get an accurate sense of the struggles faced by minorities with LTHC. Again, the time constraints of the current study made it difficult to specifically garner an ethnically balanced sample. In the context of New Zealand, Māori are less likely to participate in research (Sporle & Koea, 2004). Sporle and Koea suggest that in order to garner more Māori participants, research must be tailored to their cultural needs. However, the researcher did not feel competent enough in Maori history, culture and customs to set out to specifically examine Māori experience in peer-led support. Regardless, the limited ethnic diversity of the sample is a limitation to the current study's representativeness of people with LTHC in the MDHB.

Though qualitative research is not as focused on traditional concepts of reliability and validity of results as quantitative research (Golafshani, 2003), the current study did lack consistency in some aspects of data collection. Firstly, though it was planned that all groups of participants would engage in focus groups, the differing schedules of participants-particularly Health Professionals, resulted in several individual interviews being conducted. As reliability in qualitative research is grounded in consistency (Leung, 2015), the current study's mix of data collection method reduces the reliability of the research. Similarly, interviews and focus groups were conducted in different spaces and locations, based on what was convenient for participants. While this poses less of a concern to reliability, the variability in the setting of data collection may have influenced participant responses and affected results (Leung).

A final limitation of the current study was the narrow sample of Health Professionals. The current study set out to garner a broad sample of Health Professionals; namely, it was hoped that more doctors and nurses would reply to the invitation to participate. While doctors and nurses were contacted regarding their participation, other health professionals that were more involved in, or aware of peer-led support were likely more interested in engaging in the research. The time constraints of the current study, as well as the limited access to Health Professionals resulted in the researcher being unable to directly focus on acquiring doctors and nurses for the sample.

Though the aforementioned limitations must be considered when interpreting the results of the current study, they are not confounding. There are ways in which future research could improve upon the current study; particularly by gathering a larger more

representative sample. However, the research has presented a unique look in to the nature of

peer-led support and the role of the Facilitator in the MDHB from the perspectives of Group

Leaders, Group Participants and Health Professionals.

5.6 Implications & Applications

The current study has several implications and applications in a real world context.

While many of the issues, barriers and challenges of peer-led support, as well as the positive

functions and benefits were not novel, the current study presented these from the dynamic

perspectives of Group Leaders, Health Professionals and Group Participants. There is clearly

a deficit in comprehensive literature on peer-led support, and the current study provides a

diverse, community-grounded, in-depth examination that allows for a greater understanding

of the way in which peer-led support functions.

Firstly, the majority of research on peer-led support groups is focused on mental

illness. While this literature is important, it has resulted in a deficit in research on the

importance of support for individuals with LTHC. Furthermore, of the literature that does

focus on peer-led support for LTHC, the majority is oriented around popularized conditions;

namely, cancers, diabetes and HIV/AIDS. The current study examined support groups for a

variety of different conditions; this allowed for a stronger understanding of the universalities

in the functions and positive and negative aspects of peer-led support. The current research

aimed to deemphasise the differences between support groups and instead, focus on the

commonalities of experience and the ways in which disparate groups could work together to

mutual benefit. Overall, the novel implication of the current study is that while the resources

and structure of peer-led support groups for LTHC may differ between conditions, the

fundamental goals, needs, functions and experiences are remarkably similar.

As mentioned, an important aim of the current study was to provide a more

comprehensive look at peer-led support for LTHC than available in previous literature. Thus,

the current study interviewed Group Leaders, Health Professionals and Group Participants,

asking them similar questions about their experiences with peer-led support. The current

study proffers a unique comparison of these three groups, which has not been presented in

previous literature. Overall, it was clear that all three groups of participants believed that

peer-led support was a valuable resource. The implication of these results is that there are

fewer divisive difference between Group Leaders, Health Professionals and Group

Participants than previous literature has suggested. Ultimately, reducing the categorical

division between these groups and allowing greater collaboration and communication

regarding support services would generate more comprehensive, inclusive and effective

support groups.

The current study has also outlined 7 emergent themes regarding peer-led support that

were explicated by all three groups of participants. These results provide a distinct look at the

most prominent narratives surrounding peer-led support; the themes can be presented to the

MDHB, as well as other DHBs across New Zealand, to provide a summary of the nature of

peer-led support. It is hoped that these themes will provide a clear outline of the most

important areas of peer-led support for future intervention to focus on. Furthermore, each of

the themes illuminates an important area of peer-led support that future research could

expand upon. The future directions for research are presented in Chapter 6.

One of the most important aspects of the study is the potential future applications of the role of the Facilitator. The implementation of the community-based role is novel to health psychology research. The current study has provided information on the trajectory of the role; specifically, that an initial 18-month period is not substantial enough to enact significant change. Furthermore, it has illuminated the limitation of contact between the DHB and peer-led support services and the resulting isolation and lack of support for these groups. The participants in the current study were hopeful that the Facilitator would be able to help them overcome some of the challenges they experienced; however, they also were adamant that it was important the Facilitator did not manage or take over existing groups. It is clear that the role of the Facilitator would be beneficial to many support groups, including those outside the MDHB. The hope and promise that the potential of this role brought to people involved in peer-led support elucidates the distinct need for a support group Facilitator in the community.

5.7 Conclusion

This chapter aimed to discuss the results of the current study in relation to the research questions outlined in Chapter 2. It was found that participants expressed several issues faced by peer-led support groups; the most prominent of these included a lack of support from health professionals, issues of group maintenance and challenges to group attendance. Conversely, participants also expressed several functions of peer-led support; namely, inciting self-efficacy and self-management, the development of shared experience and the provision of education and information- including advocacy, public awareness and lobbying.

Importantly, many of the issues and challenges of peer-led support as outlined by

participants could be addressed by the Facilitator. Specifically, the present chapter outlined

the ways in which the Facilitator could address attendance and non-referral, lack of resources,

and lack of diversity if the role were to continue to be funded in the future. It is hoped that

this chapter proffered greater insight into the results presented in Chapter 4. It was important

that the current study provided a distinct 'voice' to people involved in peer-led support. This

chapter has allowed for these voices to be elaborated upon and express the importance of

listening to, and learning from the firsthand experiences of individuals involved in peer-led

support.

Chapter 6

Conclusions & Future Directions

6.0 Conclusions

The current study examined peer-led support groups for LTHC in the MCDHB and

the potential for the continuation of the role of a Facilitator to aid these groups. Participants

were Group Leaders, Health Professionals and Group Participants and engaged in focus

groups or individual interviews. Participants utilized their personal experiences to discuss the

functions and benefits of peer-led support, as well as the needs, barriers and challenges.

Seven distinct themes emerged from these discussions; and while some participants differed

marginally in their experiences of peer-led support, overall, there were a multitude of

similarities. Importantly, the emergent themes were discussed in relation to the development

of the role of the Facilitator in the MDHB. It was suggested that the Facilitator could aid in

addressing many of the challenges faced by peer-led support groups.

While the current research aimed to highlight the struggles of peer-led support, it was

also important that the positive functions were illuminated. Participants suggested that

limited group referrals, lack of resources, barriers to attendance, group sustainability,

diversity and condition discrimination were all prominent issues. Despite the extensive

struggles faced by peer-led support groups, it was clear from the discussions with participants

that it is an exceedingly valuable resource.

Peer-led support is unique in it's ability to incite the development of strong social

networks, united by collective experience. People involved in the running and maintenance of

peer-led support engage with groups that are often under-resourced, under-funded and under-appreciated by the healthcare system. Despite, this Group Leaders and Health Professionals involved in peer-led support for LTHC continue to provide ongoing, valuable community support. It is clear that peer-led support groups in the MDHB and across New Zealand would benefit immensely from greater government involvement and endorsement. Investing in peer-led support groups would increase the sustainability of groups, and allow them to continue to benefit people affected by LTHC.

6.1 Future Directions and Recommendations

The current study has illuminated seven themes surrounding peer-led support that would make for pertinent areas of research in the future. Whilst all of the themes could be reinterpreted into research questions, referrals from health professionals, issues of diversity and conditions discrimination present the most promising and unexplored areas for future research.

There is minimal research available on the reasons why Health Professionals are reluctant to refer to peer-led support groups. The current study was only able to locate one piece of literature that directly explored this; Farmer & Griffiths, 1992 examined some of the hesitations experienced by doctors regarding referring to peer-led mental health support groups. However, this publication is considerably outdated and does not focus on support groups for LTHC. Through discussing the experiences of non-referral from participants in the current study, it was clear that they felt there were palpable communication barriers between patients with LTHC and doctors. It is proposed that future research focusing on the reasons why GPs and Specialists fail to refer patients to peer-led support groups would be

exceedingly beneficial. The lack of referrals to peer-led support from doctors is an issue that

must be tackled if peer-led support is to thrive in the future. Greater research on these

tendencies may illuminate possible interventions to increase doctor's understanding of, and

confidence in peer-led support.

Secondly, it is apparent that greater research on issues with diversity in peer-led

support is required. Whilst there is a fair amount of literature surrounding the relative

homogeneity of support groups, literature has failed to delve into the underlying reasons as to

why existent peer-led support groups are not appealing to minorities. The current study has

illuminated some particularly problematic notions surrounding indigenous attendance to peer-

led support groups for LTHC. Several participants expressed their firsthand experiences in

observing institutionalized racism towards Māori in the New Zealand healthcare system.

Previous literature has analysed the psychosocial support needs of Māori dealing with

physical or mental illness (Medical Council of New Zealand, 2006); however, it would be

pertinent to examine the perspectives of healthcare professionals on Māori wellbeing and the

perceived adequacy of psychosocial support services for Māori dealing with illness. Future

research could go another step further and compare healthcare professionals' conceptions of

the psychosocial support needs of indigenous peoples with LTHC in disparate countries; for

instance, of Māori in New Zealand and Aboriginals in Australia.

Lastly, another pertinent area of future research derived from the current study

surrounds 'Condition Discrimination'. The inequalities in funding and resources for LTHC

outside of popularized conditions such as cancers, diabetes and HIV/AIDS have been detailed

in previous literature (Stuart & Soulsby, 2011). Despite this, it is clear that there are many

LTHC that are overlooked in research. In the context of peer-led support groups there may be

complex reasons surrounding why less popularized, more stigmatized and rarer LTHC are not

represented in groups. Future research on condition discrimination could speak with

individuals who have underrepresented LTHC. It would be beneficial for these individuals to

be asked whether or not they would feel comfortable leading, initiating or attending support

group. Such questions could help to illuminate whether peer-led support groups for

underrepresented conditions do not exist simply due to a lack of funding and resources or

because of deeper issues surrounding fear of judgement, embarrassment or feeling as though

their illness is not serious enough to require psychosocial support.

With regards to the role of a Facilitator, it would be beneficial for research to be

conducted on the development of this role in the future. If it were to be further funded by the

MDHB, a 12 or 18-month review on the role would be appropriate. Furthermore, research

could focus on adapting this role to other DHBs in New Zealand, and a more flexible model

for the application of a Facilitator in a variety of contexts could be developed.

Ultimately, any research that increases knowledge of peer-led support, its difficulties

and its benefits for people affected by LTHC is valuable. Peer-led support is considerably

under-researched, allowing ample opportunity to produce novel studies focused on

understanding this form of psychosocial support. It is hoped that the current study has

delineated the need for research on this topic and highlighted some of the most important

areas for future research. Peer-led support is a relatively inexpensive support resource and yet

it has many benefits for individuals affected by LTHC. Logically, increased research on peer-

led support will incite psychological and medical communities to recognize its importance

and to support the development of greater support resources for LTHC. After all, when it

comes to LTHC, the provision of ongoing, comprehensive, community support can be the

difference between an individual struggling to cope and an individual utilizing their

experience to increase self-efficacy, engage in meaning-making and become an advocate,

supporter and friend to others in the same position.

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Appendices

Appendix A

Focus Group Topic Guide

Focus Group Topic Guide

Emily Hughes & Sara Joice
Massey University, Palmerston North

Aim:

To examine peer-led support groups for long term health conditions (LTHC) and explore…

1. The perceived value/benefits of peer-led support for leaders, participants and health professionals
2. The possible barriers and catalysts for ethnic participation (especially for Maori participants)
3. The issues around developing new groups, sustainability and purpose
4. The potential of the role of a facilitator for peer-led support groups

Further, this study will provide the DHB with a report on the role of the facilitator to inform future development and funding.

Group 1: Peer-Leaders
Introduction Questions

1. Introduce yourself! What group do you belong to and what is your position in that group?
2. What do you understand the meaning of "peer-led support group" to be?
3. How would you describe the structure of the group you belong to? (ie- meets online, support for family, mainly sharing knowledge)
4. How did you find out about the group in the first place?
5. As you know, the MCDHB are piloting the role of a facilitator; what do you understand this role to be?

Main Questions

6. What do you think the values and benefits of support groups are?

7. Has being part of a support group helped you manage your own condition (or cope with the condition of a person close to you)?

8. If it did- how did it help and why do you think it has helped?

9. Do you think the support group you belong to helps participants?

10. In your experience, what do participants get out of the support group?

11. What are some of the most common problems your support group faces?

12. Do you think a facilitator could help with these issues?

13. How could the facilitator increase attendance, awareness and accessibility of your support group?

14. What are the most positive parts of your support group?

15. How much ethnic diversity is there in your support group?

16. Is there anything you think encourages or discourages ethnic participation in support groups?

17. What are the benefits of having an ethnically diverse support group?

18. Do you think a facilitator could help to increase ethnic participation in your support group? If so, how?

19. Are there any other issues with diversity in your support group (ie. not enough young members, not enough males)?

20. How sustainable do you think your support group is?

21. Could a facilitator help to increase future sustainability for the group?

22. How could the facilitator increase attendance, awareness and accessibility of your support group?

23. What are the biggest worries you have for the future of the support group? Could the facilitator help address these?

24. What do you think some barriers for starting a new support group are? Could the facilitator make this process easier?

25. Do you find it difficult to manage your illness (or the effects of someone else's illness on your life) and your position as a group leader?

26. What do you see as the potential for the role of the facilitator? Do you think this role will be effective?

27. What do you think the facilitator could do to aid your support group?

28. Do you have any other comments?

Group 2: Group Participants

Introduction Questions

1. Introduce yourself! What group(s) do you belong to and what brought you to this group?

2. What do you understand the meaning of "peer-led support group" to be?

3. How would you describe the structure of the group you belong to? (ie- meets online, support for family, mainly sharing knowledge)

4. How did you find out about the group in the first place?

5. As you know, the MCDHB are piloting the role of a facilitator; what do you understand this role to be?

Main Questions

6. What do you think the values and benefits of support groups are?

7. Has being part of a support group helped you manage your condition (or cope with the condition of a person close to you)?

8. If it did- how did it help and why do you think it has helped?

9. How much do you think the support group you belong to helps participants?

10. What do you think participants get out of the support group?

11. What are some of the problems you think your support group faces?

12. Do you think a facilitator could help with these issues?

13. How could the facilitator increase attendance, awareness and accessibility of your support group?

14. What are the most positive parts of your support group?

15. How much ethnic diversity is there in your support group?

16. Is there anything you think encourages or discourages ethnic participation in support groups?

17. What are the benefits of having an ethnically diverse support group?

18. Do you think a facilitator could help to increase ethnic participation in your support group? If so, how?

19. Are there any other issues with diversity in your support group (ie. not enough young members, not enough males)?

20. How sustainable do you think your support group is?

21. Could a facilitator help to increase future sustainability for the group?

22. How could the facilitator increase attendance, awareness and accessibility of your support group?

23. What are the biggest worries you have for the future of the support group? Could the facilitator help address these?

24. What do you think some barriers for starting a new support group are? Could the facilitator make this process easier?

25. What do you see as the potential for the role of the facilitator? Do you think this role will be effective?

26. What do you think the facilitator could do to aid your support group?

27. Do you have any other comments?

Group 3: Health Professionals

Introduction Questions

1. Introduce yourself! What is your occupation/position and how are you affiliated with peer-led support groups?

2. What do you understand the meaning of "peer-led support group" to be?

3. How would you describe your contact with support groups and patients involved in support groups?

4. As you know, the MCDHB are piloting the role of a facilitator; what do you understand this role to be?

Main Questions

5. What do you think the values and benefits of support groups are?

6. Do you think being part of a support group helps patients manage their condition (or cope with the condition of a person close to them)?

7. If it so- how do you think it helps and why?

8. In your experience, what do participants get out of support groups?

9. What are some of the most common problems you think support groups face?

10. Do you think a facilitator could help with these issues?

11. How could the facilitator increase attendance, awareness and accessibility of support groups?

12. What do you think the most positive parts of support groups are?

13. How much ethnic diversity is there in the support groups you are familiar with?

14. Is there anything you think encourages or discourages ethnic participation in support groups?

15. What are the benefits of having an ethnically diverse support group?

16. Do you think a facilitator could help to increase ethnic participation in support groups? If so, how?

17. Have you witnessed any other issues with diversity in support groups (ie. not enough young members, not enough males)?

18. How sustainable do you think support groups are? Are some more so than others?

19. Could a facilitator help to increase future sustainability for these groups?

20. How could the facilitator increase attendance, awareness and accessibility of support groups?

21. What are the biggest worries you have for the future of support groups? Could the facilitator help address these?

22. What do you think some barriers for starting a new support group are? Could the facilitator make this process easier?

23. Do you find it difficult to refer patients to support groups or to access information about these groups? If so, why do you think this is? How can it be improved?

24. What do you see as the potential for the role of the facilitator? Do you think this role will be effective?

25. What do you think the facilitator could do to aid support groups? Do you have any specific ideas?

26. Do you have any other comments?

Appendix B

Screenshot of Support Group Directory

Support Group Directory

2015/16

TABLE OF CONTENTS

Appendix C

Information Sheet

Participant Information Sheet

"Peer-led Support Groups for Long Term Health Conditions; exploring their value and the introduction of a designated facilitator"

Emily Hughes & Sara Joice
Massey University, Palmerston North

Introduction

This study will be conducted by Emily Hughes as part of her Masters of Science Degree in Health Psychology. The purpose of this research is to examine the experiences of people involved in peer-led support groups for long term health conditions (LTHC)

Summary

You have been asked to take part in this study as you are involved in peer-led support groups in some way. We know from literature on peer-led support that it is very effective- however we want to find out how these groups work and what makes them a positive resource! We will be speaking with groups of peer-leaders, group participants and health professionals to understand how these support groups function.

This research will also help the Mid-Central District Health Board (MCDHB) to evaluate the potential value of a facilitator for these groups. In this case, a facilitator is not someone who helps run any specific group, but acts as an external resource for support groups and provides an important link to the MCDHB. We want to know how you think peer-led support groups could benefit from having a facilitator involved.

What is involved?

As a participant, you will be part of a focus group where we will discuss:

1. Your involvement with support groups (such as being a leader, participant or referring patients)
2. The positive and negative aspects of support groups, including any issues or concerns you may have
3. Any feedback you have on the role of the facilitator and how you think this role could be helpful in the future

The focus group is likely to take 1-2 hours, with a break halfway through. If you are not comfortable taking part in the focus group, an alternative interview can be arranged. Please contact Emily.

What are the Benefits & Disadvantages of Taking Part?

The focus group will give you the opportunity to discuss any issues and ideas you have surrounding support groups and the role of the facilitator. The information we gain from these focus groups will be part of the feedback we give to the MCDHB. This will help to inform whether the role of the facilitator should be developed and aid us in understanding the functions, needs, and importance of peer-led support groups.

We don't anticipate any disadvantages of taking part in the research. The focus group setting will be similar to that of a support group, which we hope will encourage open discussion.

Decision to Participate:

Your decision to participate or not participate in this focus group will not affect your future involvement with/in support groups.

This is an invitation to participant in the current study. You are under no obligation to accept this invitation. Should you accept this invitation, you have the following rights:

1. The right to decline to answer any particular question
2. The right to withdraw from the study at any time
3. The right to ask questions about the research at any time
4. The right to confidentiality. Your name will be replaced by a pseudonym (fake name)
5. The right to a summary of research findings once the research is completed
6. The right to review **your** input in the focus group (on a written transcript)

The results of this study will be used in a research report for the MCDHB, and may be published later.

Contact Details

For any further questions or concerns please contact Emily or her supervisors:

Researcher: Emily Hughes

                (027) 253-4818

                emilyjoanh@gmail.com

Supervisors: Dr Sara Joice   Dr Don Baken
                (06) 356 9099 ext. 84969   (06) 356 9099 ext. 84975
                S.A.Joice@massey.ac.nz   D.M.Baken@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A,
Application 16/47. If you have any concerns about the conduct of this research, please contact Mr Jeremy

Hubbard, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63487, email humanethicsoutha@massey.ac.nz.

Appendix D

Consent Form

"Peer-led Support Groups for Long Term Health Conditions; exploring their value and the introduction of a designated facilitator"

FOCUS GROUP PARTICIPANT CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I acknowledge that my participation in this study is voluntary and I can leave at any time

I agree not to disclose anything discussed in the Focus Group.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: .... **Date:** ....

Full Name - printed ....

Appendix E

Prescription for the Role of the Facilitator

The current study supports the continuation of the role of the Facilitator for peer-led support groups within the MCDHB. The past 18-months of the role have been utilized to gain knowledge of the groups in the area, and introduce Group Leaders and Health Professionals to the role. Ostensibly, further engagement with the community is needed to begin to effect real change for these support groups. The continued investment in the role of the Facilitator would allow peer-led support services to feel valued by the MCDHB. Further, the continuation of this role would aid these groups in becoming more solidified within the community, sustainable, diverse and inclusive.

Through the 12-month process of this Masters Thesis, there have been many developments to the role of the Facilitator; numerous ideas have developed regarding how it should be conceptualized in the future. Based on discussions with people involved in peer-led support, the following job description for the Facilitator is recommended:

The Facilitator for peer-led support groups for people with LTHC should have the following duties

1. To be a point of contact for peer-leaders to come for advice and information
2. To develop a rapport with a variety of Group Leaders across the MCDHB
3. To develop a rapport with health professionals within the MCDHB, particularly those responsible for providing referrals

4. To help Group Leaders meet and communicate with relevant Health Professionals

5. To help existing groups with maintence, avoiding stagnation and increasing

   participation (through fundraising, advertising, etc.)

6. To help peer-leaders to start new support groups or break-off groups where they are

   needed

7. To be a communication link between peer- leaders, the MCDHB and health

   professionals

8. To create networks between people involved in peer-led support groups, particularly

   leaders

9. To organize and provide forums of advice for peer-leaders on how to run successful

   groups

10. To continue do develop online and print resources that list and advertise support

   groups across the MCDHB

The role of the Facilitator is by no means the answer to all of the problems experienced

by peer-led support across the MCDHB. However, it represents a starting point for increasing

support services for individuals with LTHC within the community. Through the process of

completing this study, the researcher has worked with the Facilitator on several initiatives to

aid support groups in the area; these are outlined below:

1) The researcher and the Facilitator have worked to develop a comprehensive list of

   free venues in the MCDHB area. This involved contacting café's and community

   centers in the Mid-Central area and asking whether they would be willing to have a

   support group convene at their venue and whether they were disability-accessible.

   Many of the places contacted were happy to permit this, provided members purchased

   a coffee or snack. These venues have been documented in a list that can be provided

to individuals who want to start a peer-led group and require an inexpensive venue or to existing support groups that would like to meet in less formal environments on occasion.

2) The researcher and the Facilitator have spent the last 12 months discussing the ways in which peer-led support groups could be effectively advertised. Initially, the idea of an 18-month calendar was suggested, advertising one support group per month. However, it was decided that a large poster advertising the support services for LTHC in the MCDHB and directing people to the online database would be more effective. There would have to be separate posters for different areas within the MCDHB to advertise area-specific groups. These posters could be displayed in hospitals, health clinics, GPs offices, Community Centers, English-Language Centers, schools, churches, iwi health services and WINZ offices.

3) Another topic that was discussed at length was the need for more activity-based support group resources in the area. The researcher and Facilitator proposed the idea of developing a bike track and augmenting several bikes to make then disability-accessible; this idea is based on UK models of 'Inclusive Cycling' such as that of 'We Are Cycling UK' and "Get Cycling UK'. Ostensibly, this would be a costly project and require a considerable amount of time to complete; however, the researcher and Facilitator have worked to find possible funding avenues. This idea will continue to be developed in the future.

4) The current study has illuminated the notion that some LTHC have no support services in the area The researcher has had experience running peer-led support

groups in the Auckland region for young women with fertility issues. Currently, no groups in the MCDHB exist that provide support to these women; therefore, the researcher has set out to develop a peer-led support group. This process will continue to allow the researcher to understand the issues that peer-leaders face when developing new groups.

5) Many participants in the current study discussed the need for the development of networks between peer-leaders, group leaders and health professionals involved in support groups. The researcher and Facilitator have addressed this, and decided that if the role is funded, open meetings for these individuals will be organized as a way of exchanging ideas and sharing resources. These meetings could also result in future opportunities for the Facilitator to run seminars on how to effectively lead a group, how to engage in fundraising and how to advertise to a wider demographic of potential members.

It is clear that many of these initiatives require the extension of the role of the Facilitator for the MCDHB. The 18-month period that the Facilitator has been funded for has been productive in building relationships with people involved in support services, and identifying areas of deficit. However, it has not been enough time to incite solid initiatives to work towards improving the services for people with LTHC. The Facilitator noted that this role requires significantly more hours per week to be truly effective. It is suggested that the role be funded for 30-40 hours per week, and that an administrator also be employed to reduce some of the clerical workload on the Facilitator. If these recommendations are followed, and the role of the Facilitator is funded, there is huge potential for support groups for LTHC in the MCDHB.

Furthermore, it is suggested that the role of the Facilitator could be applicable to other DHBs in New Zealand. Though each DHB presents its own set of needs and difficulties, it is believed that a Facilitator-type role would be universally beneficial. In order for peer-led support, and other forms of psychosocial support services to be prioritized and developed in New Zealand, the government needs to fund external roles to aid in this. The Facilitator would act as a means for support groups to communicate their needs to medical professionals and DHBs and help in bridging the gap between the medical and psychological communities.

End