Meaningful Experiences of Community-Based Support Workers for Individuals With Acquired Brain Injury

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ABSTRACT

Support workers hold a variety of roles and responsibilities when supporting individuals with Acquired Brain Injuries (ABI), yet research on the experience and meaning of being a support worker for individuals with ABI in the community setting is scarce. The present study explored the first-hand accounts of community-based support workers and their meaningful experiences of providing support for individuals with ABI. The guiding research question was: *What is the experience of support workers who support youth and young adults with ABI in the community setting?* Five female support workers, ranging in age from 21 to 28 years, participated in individual semi-structured interviews. The data were transcribed and analyzed using Interpretive Phenomenological Analysis (Smith, Flowers & Larkin, 2009), revealing five themes: (i) *forming the relationship*; (ii) *personalizing support;* (iii) *making a difference*; (iv) *growing personally*; and (v) *becoming politically and socially aware.* The present study provided a valuable contribution to the limited literature on support workers' experiences supporting youth and young adults with ABI in the community setting by illuminating the many roles of a support worker and by providing insight into the qualities that give support work meaning. Implications for practice and suggestions for future research are discussed.

Keywords: Acquired Brain Injury (ABI), community-based, meaningful work, support worker roles, supported relationship

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER ONE: INTRODUCTION

Although community reintegration using supported relationships has demonstrated positive effects and helps increase the level of independence for individuals with brain injuries (Hibbard, Cantor, Charatz, Rosenthal, Ashman, Gundersen, … & Gartner, 2002; McCabe, Lippert, Weiser, Hilditch, Hartridge & Villamere, 2007), there is limited research examining services and programs that provide one-on-one support for individuals with Acquired Brain Injury (ABI) in the community setting. Although there are few studies that have explored the impact of one-on-one social peer mento

ring programs (Hibbard et al., 2002) and group community-based social and recreational programs (Gerber & Gargaro, 2015) for individuals with ABI, researchers have yet to explore the experience and meaning of being a support worker for individuals with ABI in the community setting. The present study adds to the existing literature by exploring the first-hand accounts of community-based support workers and their meaningful experiences of providing support for individuals with ABI.

Background and Significance of the Study

ABI can result in long-term or lifelong physical, cognitive, behavioural and emotional difficulties. Brain injuries are often referred to as a 'hidden' disability (Simpson, Simons & McFadyen, 2002), or an 'invisible epidemic' (Carter & Spencer, 2007) because ABI related symptoms are not always physical and are often cognitive, emotional and behavioural. It is common for research surrounding rehabilitation to focus on physical recovery, however, the long-term problems typically impact every aspect of the individual's life and are not limited to just physical abilities. There is a growing body of literature to suggest that most brain injuries are likely to impact an individual's emotional and social functioning (Anson & Ponsford, 2006; Yeates, Swift, Taylor, Wade, Drotar, Stancin & Minich, 2004) and cause feelings of social isolation (Johnson & Davis, 1998). Therefore, it is especially important to place greater effort into increasing the social participation of children, youth and young adults with ABI (Dumas, Bedell & Hamill, 2003). Having added support systems and relationships may promote the social and emotional wellbeing and the development of youth and young adults with ABI. Community-based support workers provide this opportunity and help to reintegrate and include individuals with ABI in the community.

Researcher Background

My own experiences give me personal insight to the experiences of support workers as well as ABI. I have volunteered and worked for several years within the human services field as a support worker, supporting youth and young adults with ABI within the community. This involvement allowed me to experience first-hand that being a support worker is challenging, but also highly rewarding. I learned how to adapt to various situations and discovered that there are many ways to connect and form relationships with individuals. I find great fulfilment when working with youth and young adults in the community setting. Further, I believe community involvement is an important aspect for individuals with ABI to pursue and reach their recovery goals.

I have found, generally, that families appreciate support not only for their child, but also for themselves, because it provides them temporary relief from their caring duties. I have been witness to some of the post-injury struggles that families experience and the many changes and transitions that occur. Working directly with families, as a support worker, has revealed the need for caregivers (i.e., parents or guardians) to have temporary relief from their caregiving responsibilities. Further, research demonstrates that many caregivers experience emotional distress (Harris, Godfrey, Partridge & Knight, 2001) and reduced personal health (Hibbard et al., 2006) when caring for children with ABI. Therefore, I believe that the support provided by support workers is important for both the supported individuals and their families and has a positive impact on their overall quality of life.

Overall, my personal experiences have directed my desire to explore the experiences that support workers find most meaningful within their work. While working within the human services field as a support worker, I have found that funding and accessibility to support services are lacking within the province of Saskatchewan. It is important to note that within this sector limited education and training are required to be hired and little professional development is provided once hired. Fewer people are working long-term in the job, which results in higher employee turn-over rates and staff shortages. Valuable employees and programs are lost due to budgetary constraints and high levels of employee burn-out. Investigating and understanding the meaningfulness and benefits of support work may help identify what attracts and keeps people in supporting roles, which is important because lasting support relationships and post-injury social integration have been shown to have positive outcomes for individuals with ABI (Grossman &

Rhodes, 2002; Rhodes et al., 2005). Moreover, research suggests that obtaining social supports post-injury is beneficial for individual and family functioning. Very little research, however, has examined the experiences and impact these support relationships have for support workers.

Through my experiences working as a support worker with ABI youth, I have come to understand that not only do the youth benefit from the relationship, but so do I. I believe that a supported relationship has a positive impact on both the support worker the supported individual. Based on previous literature (Grossman & Rhodes, 2002; Rhodes et al., 2005), I assume that a lasting support relationship will have the most positive impact, compared to a shorter relationship.

It is important to note that every support relationship is unique, wherein the benefits of each relationship differ and every lived experience can be interpreted differently. The belief that multiple interpretations of an experience exist is consistent with an interpretivist - constructivist paradigm (Haverkamp & Young, 2007). There is not just one single constructed reality of the relationships formed between support workers and individuals with ABI. This paradigm posits that meaning or knowledge is co-constructed through an interaction between participants and the researcher. The axiology of constructivism states that the researcher's values are assumed to influence the research process (Haverkamp & Young, 2007) and should not be excluded (Hays & Singh, 2012) from the research process.

Purpose of the Study

Given the importance yet invisibility of support work for people impacted by ABI, the purpose of the study is to advance the literature by using Interpretive Phenomenological Analysis (IPA) to explore the lived experience and meaning of being a support worker for individuals with ABI in the community setting.

Definition of Key Terms

The following terms have been defined as they are used in the current study:

Acquired brain injury. The terms *Acquired Brain Injury (ABI)* and *Traumatic Brain Injury (TBI)* are often used interchangeably in everyday language. There is some dispute among the brain injury community regarding the definition and interchangeability of these terms. For this study, the term ABI will be conceptualized as an "umbrella term" that encompasses all the specific brain injury subcategories. An ABI results from damage to the brain, occurring after birth, but is not related to a congenital or a degenerative disease (Brain Injury Network, 2016).

There are three levels of severity of brain injury: mild, moderate and severe (Brain Injury in Children, 2015). An ABI can be either traumatic (TBI), or non-traumatic (nTBI). These impairments may be temporary or permanent and cause partial or functional disability and psychosocial maladjustment (WHO, 1996). Based on these definitions of ABI and TBI, the two terms will not be used interchangeably throughout the document. Instead the term ABI will be used as an umbrella term that encompasses both TBI and nTBI and all levels of severity, as explained above.

Health and wellbeing. In everyday language, the terms *health* and *wellbeing* are often used interchangeably. The meanings of these terms have moved toward a more holistic perspective and define a broad spectrum of areas including physical, social, emotional, cognitive and even spiritual areas (Foster, 2007). In 1948, the World Health Organization (WHO) defined the term health as: "a state of complete, physical, mental and social wellbeing and not merely the absence of disease or infirmity" (p.100). The WHO's description of health encompasses three aspects of wellbeing: physical, social and emotional. This study considers these aspects of wellbeing as essential to the description of health. Similarly, the terms health and wellbeing will be used interchangeably throughout the document.

Paid care work, support work and respite. Different professional carers are often categorized under the generic term *paid care worker*, including personal care worker, attendant care worker, disability support worker and home care worker. For the purposes of this study the terms *support worker* and *paid carer* will be used interchangeably. The terms *support worker* and *supported individual,* will refer to the two individuals involved in the one-to-one support relationship. The term *support worker* will refer to adults over the age of 18, who partake in a support worker role and help supported individuals by promoting all aspects of wellbeing, resiliency, positive lifestyles, community involvement, as well as many other aspects in their daily lives (Mitchell, 2018). The term *supported individual* will refer to the individuals with ABI that are in a supportive one-to-one relationship with a support worker. The term *respite* refers to the use of an organized service that is developed to provide temporary relief for caregivers and their responsibilities associated with looking after an individual with a disability (Mitchell, 2018). Paid care and respite are often referred to as support services, and paid care and support work are often viewed as forms of respite provided by a support worker. Throughout this document, the terms support work, paid care and respite will be used interchangeably.

Quality of life. The term *Quality of life* is a broad ranging concept that is often used as a measurement of health. Quality of life is affected by a person's "physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to significant features of their environment" (WHOQOL, 1997, p.1). WHO defined the term quality of life as an "individual's perceptions of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHOQOL, 1997, p.1). Within this study quality of life will be considered integral to an individual's health and dependent on the subjective wellbeing across a whole range of areas.

Youth and young adult. The terms *youth* and *young adult* refer to the periods of transition from childhood to adulthood. Although youth and young adult are more fluid categories than other fixed-aged groups, the easiest way to define these groups is through age parameters. In 1981, the United Nations (UN) defined youth as "those persons between the ages of 15 and 24 years" (p. 1). Statistics Canada (2018) defined youth as individuals between the ages of 15 to 34, and young adults between the ages of 20 to 34. The term youth broadly encompasses individuals within the young adult period. For the purposes of this study the terms youth and young adult will be used interchangeably and will include individuals between the ages of 8 to 35 years, allowing for some flexibility on either end of the spectrum.

Thesis Organization

This thesis is organized into five chapters. Chapter One introduces the purpose of the current study, the researcher's background and definitions of key terms. Chapter Two reviews the current literature on the causes, impairments and impact of brain injuries, the support that is needed for an individual with ABI, the importance of community integration for individuals with ABI, as well as the job roles and training needs of support workers for individuals with ABI. Chapter Three describes the methodological approach of IPA, followed by the data collection and analysis procedures. Chapter Four introduces the support workers and presents the findings by reporting the resultant themes, utilizing quotes from the support workers to express their personal experiences of support work. Lastly, Chapter Five presents the results and integrates them with the existing body of literature and finally concludes with strengths and limitations of the study, as well as implications of the research and considerations for future research.

CHAPTER TWO: LITERATURE REVIEW

This chapter focuses on the literature informing the present study. Information on brain injury begins the chapter and is followed by a review of the literature on supporting individuals with Acquired Brain Injury (ABI).

Acquired Brain Injury

An ABI is a generic term referring to damage to the brain occurring after birth that is not related to a congenital or a degenerative disease (Brain Injury Network, 2016). An ABI can be the result of a traumatic (TBI), or non-traumatic (nTBI) event. A traumatic event may include physical injuries such as a sports accident or motor collision, whereas a non-traumatic event may include non-physical injuries such as infection, stroke, or tumour. In all cases, injury to the brain results from bleeding, bruising, tearing, or bleeding into soft brain tissues, or from interference to the oxygen supply to the brain (Acquired Brain Injury Working Group, 1995; Brain Injury Network, 2016). Both functional and medical effects of an ABI, can range from minor to severe (Paniccia, 2017) and in some cases can be fatal (NBIA, 2017).

A characteristic of ABI is that it is a 'hidden' disability (Simpson, Simons & McFadyen, 2002) because there are typically no physical distinctions that an individual has brain damage. However, the damage and lasting impact of brain injury remains. The impact of the brain injury depends on which part of the brain has been injured and the effects of damage can be classified as either mild, moderate, or severe (Brain Injury in Children, 2015). Moreover, the prognosis after brain injury ranges from complete recovery to severe disability. Based on data from several Saskatchewan hospitals, 2,200 individuals are injured each year within the province of Saskatchewan. Approximately 150 of those individuals require multiple services (e.g. medical care, rehabilitation) and a lifetime of support (Acquired Brain Injury Services, n.d.).

Long-term Impairments of Brain Injury

The impairments from brain injury may be temporary or permanent, range in severity and cause partial or functional disability as well as psychosocial maladjustment (WHO, 1996). Given the long-term nature of the effects of brain injuries, one could reasonably assume that there is a growing need for services. However, as there are no longitudinal studies available, it is difficult to estimate just how many individuals with residual effects from ABIs are currently residing in Saskatchewan (Froehlich, n.d).

The literature is replete with information on the potential and long-lasting impact of ABIs. In general, ABI can result in long-term or lifelong physical, cognitive, behavioural and emotional difficulties. Due to the variable presentation of brain injuries, ABI is often referred to as an 'invisible epidemic' (Carter & Spencer, 2007). This is because ABI related symptoms are not always physical and are often internal (i.e., cognitive, emotional, behavioural). It is common for research on reintegration and rehabilitation to focus on physical recovery, however, the long-term problems experienced by individuals with ABI are more complicated than that. That is, these problems impact every aspect of their lives and are not limited to just physical abilities.

In addition to physical impairments, individuals with ABIs often experience cognitive, emotional and behavioural problems, including depression, anxiety and reduced quality of life (Hibbard et al., 2002). As a result, an ABI is considered, by some, to be one of the most disabling injuries (Langlois, Rutland-Brown & Wald, 2006). In addition to disability, ABI can lead to an increased risk for other health concerns. The result is often a combination of physical (e.g., headache, fatigue), cognitive (e.g., difficulty concentrating), emotional (e.g., anxiety) and behavioural (e.g., irritability) consequences for all degrees of ABI severity (Hibbard et al., 2002; Paniccia, 2017). Although children and youth often maintain or regain pre-injury skills and abilities, they are at a higher risk of failure to acquire new skills at the same rate as their peers (Anderson & Catroppa, 2006). Consequently, children and youth with ABI demonstrate long-term difficulties that impact all areas of functioning (Anderson & Catroppa, 2006).

Several studies (e.g., Andrews, Rose & Johnson, 1998; Popernack, Gray & Rice, 2015; Taylor, Yeates, Wade, Drotar, Stancin & Minich, 2002) have shown that the severity and mechanism of the injury (e.g. trauma, infection) are associated with a child's functional outcome. Moreover, the functional impact of a brain injury for children and youth is different for adults because young brains are still developing. One of the greatest challenges that individuals face after a brain injury are impairments in judgement and reasoning, which impacts their ability to learn and develop socially appropriate behaviours (Canadian Institute of Health Information, 2006). Considering the assortment of problems that may result from a brain injury, a wide range of support services are necessary to meet these needs. It is important for individuals who provide these services to take into account issues not only related to the child's neurological impairment, but also to the fact that children, youth and young adults are still developing and changing post-injury due to the natural course of human development (CanChild, 2001).

Post-injury social outcomes. Several lines of research suggest that individuals with ABI are likely to demonstrate overall poorer social outcomes (Yeates et al., 2004), including declines in adaptive behaviour and lower academic achievement, especially among children with more severe injuries (Taylor et al., 2002). A study comparing 27 TBI children with 27 controls found that TBI children demonstrated significantly lower levels of self-esteem and adaptive behaviour and experienced higher levels of loneliness, maladaptive behaviour and aggressive/antisocial behaviour (Andrews, Rose & Johnson, 1998). Further, research suggests that individuals with ABI often find it much harder to cope with and manage stress. A study examining 33 adult individuals living with a TBI found that participants' coping style and the strategies used to manage stress were associated with the amount of emotional distress that participants with ABI experienced (Anson & Ponsford, 2006). This association suggests that emotional adjustment might be improved by the facilitation of more adaptive coping styles. It further suggests the possibility that teaching appropriate coping strategies may lower an individual's level of emotional distress and improve overall emotional adjustment. Overall, there is a growing body of literature to suggest that most brain injuries are likely to impact an individual's social functioning. Therefore, it is especially important to place greater effort into increasing the social participation of children, youth and young adults with ABI (Dumas, Bedell & Hamill, 2003).

Another consequence of the hidden disability is social isolation. A focus group study found that individuals with ABI expressed a need for human connectedness and social belonging to decrease feelings of social isolation (Leith, Phillips & Sample, 2004). A conceptually related study examined supported relationships as a means to decrease those feelings of social isolation. Johnson and Davis (1998) matched three adults with brain injuries with four community participants, who met once per week for four weeks to participate in leisure activities, in hopes to increase the integrated social contacts of the adults with brain injuries. For the purposes of the study, integrated social contact was defined as a 15-minute or more face-to-face interaction (e.g., going to a movie with a community participant, meeting a friend for dinner) between the individual with ABI and at least one other person (e.g., community participant, community member), but did not include contact with service professionals such as a sales clerk or coffee barista (Johnson & Davis, 1998). The study found the support relationships intervention to be effective in increasing the number of integrated social contacts experienced by the three individuals with ABI throughout the 4-week intervention period and afterwards. That is,

individuals continued to have contacts with their matched community participants. They also engaged in an increased number of community activities and interacted more and with a wider variety of people than they did prior to the intervention. In general, the supported relationships helped to reduce the social isolation experience by individuals with brain injuries.

Supporting an Individual with a Brain Injury

The increasing prevalence of ABI in Canadian youth has led researchers to examine the necessity and importance of support systems for youth and their families. Several studies have suggested that more resources and support services are needed for individuals with ABI (Ergh et al., 2002; Rivara et al., 1996), especially long-term community support (Gan, Gargaro, Brandys, Gerber & Boschen, 2010). In general, these types of services and supports can assist families that are feeling distressed and overwhelmed by the level of care that youth with ABI often need. Moreover, community-based support programs provide the opportunity to reintegrate individuals into the community. Further, having added support systems and relationships may promote the social and emotional wellbeing and development of youth with ABI. In general, community reintegration using supported relationships has demonstrated positive effects and helps increase the level independence for individuals with ABI (McCabe et al., 2007).

Social support and family functioning. Seeking and obtaining social support is important for family functioning and for the overall wellbeing of caregivers and families of individuals with ABI. Ergh, Rapport, Coleman and Hanks (2002) examined the predictors of family dysfunction and caregiver distress among 60 pairs of individuals with ABIs and their caregivers. Caregiver perceived social support was a moderator of caregiver wellbeing and was a strong predictor of family functioning. Specifically, caregivers without adequate social support were increasingly distressed as time elapsed post-injury, whereas caregivers with adequate social support were not (Ergh et al., 2002). Further, family functioning improved with increased social support (Ergh et al., 2002). Overall, this suggests that distress experienced by caregivers is substantive and meaningful. It is important to note, however, that social support may be an important influence in diffusing distress experienced by caregivers.

Further, research suggests that there is a high level of unmet need for respite and other support services resulting in higher burdens on caregivers. A study exploring 85 carers' perspectives on respite for persons with ABI found that (a) most of the caring was done by at least two persons, (b) almost half of the carers indicated that caring may prevent a carer from

obtaining employment and (c) more than half reported that they also relied on other family members to assist in the care (Chan, 2007). Further, the data indicated a continuing demand on carers with more than half of them accessing respite services. In particular, a majority of the carers reported that holiday arrangements are necessary for the individual with ABI, respite services outside the home and club activities. This suggests that given the high level of dependency reported by carers and their reliance on other family members to assist in the care, there is a high level of unmet need for formal respite and a need for increased respite funding for individuals with ABI (Chan, 2007). The most frequently reported needs included providing a wider range of services (e.g., holiday arrangements and activities) that are available during the week and increased availability and trained qualified staff so that carers can feel assured of the quality of care provided, thereby lessening the stress around arranging and locating quality respite. As indicated by the carers in Chan's (2007) study, incorporating the support needs of carers may be imperative to decreasing carer stress.

Community Integration and Inclusion for Individuals with ABI

It is important to place a greater effort into increasing the community participation of individuals with ABI in the community. Previous literature (Martelli, Zasler & Tiernan, 2012; Sander, Clark & Pappadis, 2010) suggests that the main rehabilitation goals after brain injury is community reintegration. However, more research is needed to better understand and expand effective community reintegration strategies post-injury. Individuals with ABI often face lifelong disabilities and experience difficulties with community reintegration (McCabe et al., 2007). In order for programs to support the participation of individuals in the community, it is necessary to understand what community integration means. Most research agrees that community integration is defined by three main areas: social activity, employment or other productive activity and independent living (Sander et al, 2010). The priority of these areas varies for different age groups (Sander et al., 2010); thus, to be successful support programs need to address each individual's priorities.

Although researchers can help to guide the definition of community integration, it is important to incorporate the viewpoints of individuals with ABI regarding what full participation in the community means for them. In a series of structured interviews conducted with 167 individuals with ABI, Sander and colleagues (2010) found that the type and quality of social relationships was common to the responses of all participants as important for feeling part of

their communities. McColl, Carlson, Johnston, Minnes, Shue, Davies and Karlovits (1997) ran a series of focus groups to gather the perspectives of community integration directly from individuals with ABI. They found "meeting new people and making new friends" was commonly cited by participants (p. 25). Thus, the need for social interaction and meaningful relationships are crucial aspects of community integration for individuals with ABI.

There is some evidence for the positive effects of community-based rehabilitation programs that utilize peer or support relationships; however, there is a lack of empirical evidence to support this and inconsistent results are reported (McCabe et al., 2007). What is known, however, is that many individuals with brain injuries require programs to support their opportunities for community participation. There is limited research examining services and programs that provide one-on-one support for individuals with ABI within the community. One investigated approach to improving community integration has been social peer mentoring programs. Studies have examined peer support programs for a variety of health care contexts for individuals with mental health/addictions challenges (Jacobson, Trojanowski & Dewa, 2012), cancer patients (Hoey, Ieropoli, White & Jefford, 2008), individuals with intellectual and developmental disabilities (Haring & Breen, 1992) and individuals with brain injuries (Hibbard et al., 2002).

One previous peer-support study (Hibbard et al., 2002) evaluated a community-based peer support program with individuals with brain injuries. They recruited "personally ready" (i.e., successful adjustment to the challenges of living with a brain injury, motivation to "be there for people who are where I was") individuals with ABI as mentors and matched them with an individual with ABI who was in need of peer support. In total, 20 individuals (11 individuals with ABI and 9 family members) participated in the peer support program for a one-year period. Participants in the program reported that the relationship not only increased their quality of life and general outlook, but also enhanced their ability to cope with their ABI and increased their knowledge of brain injuries. Further, family members reported some positive impact on their own happiness, their ability to cope with anxiety and sadness/depression and their sense of control over their lives (Hibbard et al., 2002). These results suggest that individual support programs have a positive impact for individuals with ABI and their family members.

Several studies examining community-based approaches to social integration describe the benefits of social-recreational activity for individuals with ABI. Although previous research

(Brown, Gordon & Spielman, 2003) has reported that individuals with ABI are significantly less active in social and recreational activities than are people with no disability, other research suggests that social-recreational activity is beneficial for individuals with brain injuries. In a series of interviews conducted with 240 individuals with ABI (64 exercisers, 176 non-exercisers), Gordon, Sliwinski, Echo, McLoughlin, Sheerer and Meili (1998) found the exercisers reported health status was better and were less depressed than their non-exercising counterparts.

Gerber and Gargaro (2015) evaluated a community day program for individuals with ABI. Individuals attended the program for two afternoons per week to participate in social and recreational activities. Participation in the program increased community integrationand individuals reported that participating in the program helped them to feel less socially isolated. Fraas, Balz and DeGrauw (2007) examined the effectiveness of a community-based approach in meeting the long-term needs of individuals with ABI. Through survey responses and focus group discussions, individuals with ABI rated that the community-based approach provided emotional and social support, a variety of recreational opportunities and helped to increase their overall quality of life. Overall, social and recreational programming for individuals with ABI encourages them to participate in a variety of activities that increase community integration and quality of life.

Barriers to Community Integration and Inclusion for Individuals with Disabilities

Due to the mostly invisible nature of ABI, children, youth and young adults are often met with hesitation from the community when they receive accommodations in school, work and the community (Langlois et al., 2006). Within the literature, it has been established that participation in play and recreational activities has a major influence on child development (Waters, Goldfeld & Hopkins, 2002), however, participation in out-of-school activities is more limited for children with physical disabilities than those without disabilities (Law, Petrenchik, King & Hurley, 2007). These barriers appear to increase with age, as there is less parental assistance and more independent participation is expected. This makes participation particularly difficult and the perceived barriers higher and more significant, for children and youth with limited ability to perform tasks independently (Law et al., 2007).

Several studies (e.g., Bedell & Dumas, 2004; Law et al., 2007) have explored potential school, recreational and community barriers to participation. They found that peoples' attitudes

in the community, lack of community support and a lack of available programs and services within the community were all environmental barriers experienced by children and youth with ABI and physical disabilities (Bedell & Dumas, 2004; Law et al., 2007). Bedell and Dumas (2004) found that participation was most restricted for children and youth with ABI in structured community events or activities and in social and play activities with peers at school and the community. In another similar study (Galvin, Froude & McAleer, 2010), children with ABI were reported to participate at age-expected levels within their own homes, but had significantly more difficulties in both structured and unstructured activities in school or in the community. Previous research (e.g., Leith, Phillips & Sample, 2004) has identified access to transportation as a barrier to community access for individuals with ABI. Further, individuals in Fraas et al.'s (2007) study reported that community education of the general public about the impact of ABI is necessary in order to improve understanding, funding and support for brain injury rehabilitation services. Overall, these results suggest that lack of support programming and transportation, people's attitudes, community education and community support are factors that have an impact on ABI individuals' experiences and their participation within the community.

Job Roles and Responsibilities of Support Workers

A support worker, also often called direct support professionals (Friedman, 2018) or paid carer (or many other job titles, McCluskey, 2000) provide assistance to supported individuals (e.g., individuals with disabilities, older adults, individuals with brain injuries) by helping them to live their lives as independently as possible and supporting them to reach their potential (Mitchell, 2018). Support workers can work independently and as part of a team and in a variety of settings, such as in the supported individual's home, a care home, a day center or out in the community. A support worker's job roles and responsibilities vary depending on the individuals they support. Just as there are many different job titles for a support worker, there are many different types of support workers including, but not limited to, family support workers, mental health support workers, vocational support workers and community support workers.

Support workers provide a variety of services, including helping supported individuals with aspects of day-to-day living, promoting physical and emotional wellbeing and helping them to live a fulfilled life (Friedman, 2018; Mitchell, 2018). The community support worker's role is to 'support' the individual in structured and unstructured activities. Examples of support in the community include assisting the individual to participate in social and recreational activities,

teaching the individual personal management skills (e.g., time management, money management, decision-making skills, organization skills), helping the individual to build and maintain different coping strategies and encouraging overall community inclusion.

Several studies to date have explored different aspects of support work. Topics which have been documented include the qualities that are valued in direct care workers by the individuals with ID that they support (Dodevska & Vassos, 2013); the emotional needs of support staff including work stress and burnout of direct support workers for individual with ID (Devereux, Hastings & Noone, 2009; Gray-Stanley, Muramatsu, Heller, Hughes, Johnson & Ramirez-Valles, 2010; Skirrow & Hatton, 2006); the effects of coping and support on the relationship between perceived work demands and burnout in support staff (Devereux, Hasting, Noone, Firth & Totsika, 2009); the training needs of direct support staff (Test, Flowers, Hewitt & Solow, 2004); and the experiences of support workers in relation to the mental health needs of individuals with intellectual disabilities, the barriers they face to accessing services and their training needs (Thiemann, 2017). A majority of studies typically focus on the perspective of individuals with intellectual or physical disabilities receiving support, or the demanding nature of support work and the resultant support staff stress or burnout. Within the literature there is very little focus on the support workers that work with individuals with brain injury, or the support workers' experience of the work that they do.

One study (McCluskey, 2000) focused on paid carers for individuals with ABI and found that they hold important roles which contribute to the lives of individuals with brain injury. McCluskey (2000) explored the job role expectations and responsibilities of five individuals with severe brain injury and their five paid attendant carers in Australia. McCluskey identified five major roles of the paid carers (see Table 2-1), which can help to understand the spectrum of support that may be required.

Table 2-1

Summary of McCluskey's (2000) Paid Carer Roles

Role	Key Features and Examples
Attendant – 'Helping with tasks'	- Assisting with personal care - Money management - Organizing schedules - Planning recreational outings
Coach – 'Teaching and Motivating'	- Motivating and pushing client to participate in activities - Skill development - Challenging the client to progress in activities - Use reward system to motivate client
Companion – 'Forming a friendship'	- Reciprocity - Trust - Listening and talking - Socializing outside of work hours - Confiding in carer
Negotiator – 'Mediating and setting boundaries'	- Setting limits and rules for the client - Mediating with client's family and others - Negotiating with upset/angry client
Protector – 'Maintaining safety'	- Stopping client from injuring themselves or others - Allowing client to participate and try activities independently

Training Needs of Support Workers

In the community, support workers often work in isolation with a client and might have to deal with unpredictable and, at times, stressful situations. A task or activity that may appear straightforward can actually be quite complex. For example, when accompanying an individual to the swimming pool, the support worker continually observes their environment and the individual within the environment. The support worker may need to monitor the individual's behaviour, front-loading the individual with information (i.e., providing the individual with verbal prompts or directions in advance), while maintaining a close proximity and ensuring the individual's safety. Redhead (2010) accurately suggests that without an understanding of the

individual's more hidden social and emotional difficulties, the support worker may be unsure of how to respond to an individual's behaviour and can find themselves in challenging situations. With brain injury training, Redhead explains that, support workers can learn alternative strategies.

Although those who support individuals with ABI have particular training needs, currently there are limited options for training in brain injury. In 2001, a United Kingdom based organization developed a customized program for support workers of individuals with ABI (Redhead, 2010). This five-day program delivered over a ten-week span is designed to cover two main areas: *role of the support worker* (as defined by McCluskey, 2000) and *understanding brain injury*. The main aim of the program is to increase the personal effectiveness of support workers already working the community with individuals who have an ABI (Redhead, 2010). Further, the program utilizes an experiential learning approach and enables support workers to build on their current knowledge, skills and experience through sharing ideas with each other.

Redhead (2010) posits that completing the training program provides several benefits for support workers and the individuals they support. The benefits for the support workers include sharing and working with other support workers, developing ongoing peer support, creating increased confidence for individuals who have not completed any formal training and preparing individuals to cope with the challenges of working with unpredictable situations (Redhead, 2010). The benefits of support worker training for the individuals with ABI includes being able to provide more consistent supports and a more skilled support worker who is better prepared to understand the individual's needs.

The Current Study

Several key points are evident from the literature. Limited information is available about the work of support workers, particularly in relation to individuals with a brain injury. Although support workers are reported to hold a variety of roles and responsibilities when supporting individuals with brain injuries, their perspective on the work has not been well documented. The nature of their lived experience as support workers and how support workers talk about and understand their relationships with the individuals they support is unclear. Also missing from the literature is an understanding about the perceived positive personal impact of the work for support workers. Given the current gaps in the literature described above, the present study was designed with the intent of using qualitative research to explore the lived experience and

meaning of being a support worker for individuals with ABI in the community setting. Reflecting these interests, the research question was:

What is the experience of support workers who support youth and young adults with ABI in the community setting?

CHAPTER THREE: METHODOLOGY

The methodology chapter begins with an outline of qualitative inquiry, followed by a description of interpretive phenomenological analysis (IPA). Next, the study's data generation, participant recruitment criteria and a description of the data analysis procedure are presented. Lastly, the chapter concludes with several ethical considerations.

Qualitative Inquiry

Qualitative inquiry is a holistic, interpretative, naturalistic approach that focuses on subjective experiences and meanings to achieve an in-depth understanding of experiences within their natural setting (Hays & Singh, 2012; Nelson, 2007). The focus of qualitative research is to understand how people make sense of their world and provides both the researcher and participants with a 'discovering' experience (Creswell, 2007). There are numerous and varying methodological traditions that belong to qualitative inquiry (e.g., case study, grounded theory, ethnography or phenomenology) that are used to explore a problem (Creswell, 2007). Each have distinct methodologies and derive from specific philosophical foundations (Nelson, 2007). Qualitative inquiry is a suitable method when an in-depth account of a phenomenon is needed (Cresswell, 2007). By using qualitative methods, I collected detailed data, which allowed deep insight into support workers meaningful lived experience of supporting individuals with Acquired Brain Injury (ABI) in the community setting.

Interpretative Phenomenological Analysis

Interpretive phenomenological analysis (IPA) was the methodology selected to explore the lived experience and meaning of being a support worker for individuals with ABI in the community setting. According to Smith (2004) there are three characteristic features of IPA: (i) idiographic, (ii) inductive and (iii) interrogative. First, IPA is idiographic in that it starts with the analysis of one case and when some degree of closure has been made, it moves onto the detailed analysis of the second case and so on throughout the rest of the cases. Afterwards, a detailed cross-case analysis is conducted. Smith (2004) posits that this detailed analysis is only possible with a small sample (i.e., 5 - 10 participants). Detailed case studies allow in-depth learning about a particular person but leave enough space to see connections between the different aspects of participants' description (Smith, 2004). Next, IPA is inductive in nature and the data collection techniques are flexible. IPA allows researchers to construct broad research questions which lead

to the collection of expansive data, allowing room for unanticipated topics or themes to emerge during analysis. Lastly, IPA is interrogative as one of its aims is to make a contribution to psychology through "interrogating or illuminating" existing research (Smith, 2004, p. 43). In other words, the results of analysis are not stand-alone, but rather are discussed in relation to existing psychological literature (Smith, 2004).

IPA is a form of interpretive phenomenology that explores participants' personal lived experience and how participants make sense of that lived experience (Smith, 2004). IPA focuses on providing in-depth, detailed qualitative inquiry (Smith, 2004), rather than the traditional method of testing a predetermined hypothesis set by the researcher (Smith & Osborn, 2004). IPA highlights 'how' individuals perceive specific situations and make sense of their personal and social world (Smith & Osborn, 2004).

That is, IPA is concerned with trying to understand what a particular phenomenon is like, from the point of view of the participant (Smith & Osborn, 2007). IPA draws on key concepts from three different philosophies of knowledge: phenomenology, hermeneutics and ideography (Smith, Flowers & Larkin, 2009).

Phenomenology. Phenomenology is the study of lived experience. It focuses on describing what all participants have in common as they experience a phenomenon (Creswell, 2007). The basic purpose of phenomenology is to form a description of how individuals examine and comprehend a lived experience (Creswell, 2007; Smith et al., 2009). This description consists of 'what' they experienced and 'how' they experienced it (Creswell, 2007).

The phenomenological aspects of IPA were drawn heavily from the writings of four philosophers: Husserl, Heidegger, Merleau-Ponty and Sartre (Smith et al., 2009). Husserl believed that experience should be examined in the way it occurs and in order to do so, an individual must disengage from the activity and attend to the experience (Smith et al., 2009). In that way, when an individual is consciously reflecting on an experience they are being phenomenological. Husserl believed to achieve this *phenomenological attitude* we need to *bracket* or "put away" the assumptions we hold and not allow them to shape the data collection process. Heidegger, Merleu-Ponty and Sartre developed Husserl's work further. They contributed to the view of a person as immersed in a world of objects, relationships, languages, cultures, projects and concerns (Smith et al., 2009). Also, they focused more on understanding

personal perspectives of one's involvement and relationships in the world and towards others (Smith et al., 2009).

The four philosophers' ideas and developments led to the realization that the complex understanding of 'experience' calls upon a lived process which is unique to every individual's relationship to one another and the world (Smith et al., 2009). Their ideas developed the major goal of IPA: to interpret others relationship to the world as they relate to and create meaning from their everyday activities and experiences (Smith et al., 2009). The idea of interpretation lead to the second major influence of IPA, hermeneutics.

Hermeneutics. Hermeneutics focuses on the matter of interpretation. Hermeneutic theorists were concerned with the methods and purposes of interpreting text and determining if it was possible to uncover the original meanings or intentions of the author and the relation between the texts production or past and its interpretation or present context (Smith et al., 2009). Following the work of Heidegger, a hermeneutic theorist, the IPA research process examines how a phenomenon appears and make sense of this appearance (Smith et al., 2009).

IPA is connected to the interpretative or hermeneutic tradition because it is recognized that the researcher has a central role in making sense of that personal experience (Smith, 2004). IPA, as indicated by its name, involves an interpretation process. One of the most significant ideas in hermeneutic theory is that of the hermeneutic circle, which describes the analytical process of interpretation and using a non-linear method of thinking. It focuses on the dynamic relationship between the part and the whole, wherein "to understand any given part, you must look at the whole; and to understand the whole, you must look at the parts" (Smith et al., 2009, p.33). The use of interpretation means that the written document cannot be a presentation of the individual's experiences but rather is what is referred to as a *double hermeneutic* (Smith, 2004). 'Double' refers to the two-stage interpretation process (Pringle, Drummond, McLafferty & Hendry, 2011). The first is the participant trying making sense of their world and the second is the researcher interpreting or making sense of the participant's interpretation. Although the intent of the researcher is to present and interpret an accurate representation of the participant's experiences; it is important to acknowledge that it still just that, an interpretation of the participant's perspective.

Idiography. Idiography is concerned with the particular. IPA operates as idiographic on two-levels. First, IPA is concerned with the depth of the analysis and commitment to detail.

Second, IPA focuses on understanding how a specific experience, event, or relationship is understood from the perspective of a person or group, within a particular context (Smith et al., 2009). This knowledge helps explain why small, purposively selected samples are recommended for IPA research. Taken together, IPA suggests that detailed experience can be understood by examining the meaning people place on their experience.

The focus of IPA on an individual's lived experiences and the commitment to exploring how people make sense of those experiences aligns with the purpose of the study (Smith et al., 2009). IPA provided many ideas about how to examine and interpret the lived experiences of support workers for individuals with ABI. Further, IPA provides a detailed framework to guide the researcher through analysis, which was helpful for me as a novice researcher because it provided structure and direction throughout the entire research process.

Data Collection

Participants. Five support workers were recruited to participate in this study. IPA studies are often conducted using small sample sizes. Several researchers (Smith, 2004; Smith & Osborn, 2004) posit that three to five participants is a reasonable sample size for IPA. Smaller sample sizes allow for detailed examination of similarity and difference, as well as convergence and divergence, of individual cases. This range of participant numbers allow for more in-depth analysis to address the gap in the literature while not too many as to produce an overwhelming amount of data (Smith, 2004).

The selection criteria for inclusion required (a) participants had worked for a minimum of six months as support workers providing community-based support to youth and young adults (ages 8 – 30) with ABI and (b) they identified this work as personally meaningful. The participants' experience of support work that they considered meaningful was subjective, that is, it was not the experience itself that determined its meaningfulness but rather each individual's interpretation of the experience.

Participants were recruited using a recruitment poster (see Appendix A) emailed by a third-party individual to individuals they knew were likely to fit the study's recruitment criteria. Those receiving the invitation emailed the student researcher directly if they were interested in participating in the study. Five people emailed interest in the study, however, only three could make the time to commit to an interview. A further two participants were recruited as a result of emailing a letter of invitation to two support workers who I knew had experience working with

the ABI population. After screening, a total of five individuals met selection criteria and were recruited.

   Semi-structured interviews. In-depth individual semi-structured interviews were conducted to collect data from participants (Smith et al., 2009). The interviews included open-ended questions relating to the research questions with opportunity for responsive follow-up questions; this style of interviewing gave participants the flexibility to share their stories and personal experiences. Examining in detail how participants perceive and make sense of things which are happening to them requires a flexible data collection instrument (Smith & Osborn, 2004).

   An interview guide (see Appendix B) was used to facilitate the interview process. This style of interviewing allowed participants to engage in dialogue and the questions could be modified or prompted depending on their responses (Smith, 2004). The interview began with the consent process and basic demographic questions such as age of the participant and the years of experience as a support worker. The interview questions were based on the purpose of the research. Therefore, the questions were aimed to reveal the experiences that participants found most meaningful while providing support for individuals with brain injuries.

   The interview took place at a safe and private location of the participant's choice (e.g., coffee shop, library). The interviews were audio recorded and later fully transcribed by the researcher. Permission to audio-record the interviews was collected during the consent process. The consent form was discussed prior to the interview. The consent process provided details regarding purpose of the research, confidentiality and expectations. All information was kept completely confidential and data was reported in a manner to protect the identity of participants and the individuals they support. Therefore, all identifying information, such as names and organizational affiliations were removed. After the interview, the researcher gave participants the option to choose a pseudonym and review their transcripts. One participant accepted this opportunity, but made no comments for change or clarification.

Data Analysis

   The current study used IPA to explore the lived experience and meaning of being a support worker for individuals with ABI in the community setting. The data generated through interviews included detailed information regarding each support worker's experiences and what those experiences were like for that individual. Interpretation of the meanings made by

participants, therefore, involved a two-stage interpretation process (Smith, 2004), as the researcher attempted to make sense of the meaning created by participants. IPA assumes that researchers have their own pre-existing conceptions and assumptions.

In general, the IPA analysis process has three characteristic features: idiographic, inductive and interrogative (Smith, 2004). First, IPA is idiographic or individual in nature, wherein the researcher looks at each individual on a case-by-case basis. Next, the researcher attempts to conduct a cross-case analysis by examining the convergence and divergence of the themes for each individual. Congruent with qualitative methodology there is an inductive emphasis in IPA, which allows for flexibility during data collection and analysis when unexpected themes or topics arise (Smith, 2004). IPA allows for broader research questions which leads to the collection of extensive data (Smith, 2004). Finally, IPA aims to contribute to psychology through strengthening existing research (Smith, 2004). Specifically, the results of the in-depth analysis are discussed in relation to pre-existing literature. IPA does not have a single proposed method for analyzing data, but instead is characterized by a set of common practices and principles that encompass the above three characteristic features of IPA (Smith et al., 2009).

For the data analysis, I followed the six-step process recommended by Smith et al. (2009) for IPA: (1) reading and re-reading, (2) initial noting, (3) developing themes, (4) searching for connections across themes, (5) moving to the next case and (6) looking for patterns across cases.

The first step involved immersing myself in the data. This is the process of listening to the audio-recording, transcribing the data into text and then reading and re-reading the transcripts (Smith et al., 2009). Each transcript was read multiple times, in order to immerse myself into the participant's world and to begin to locate the detailed portions of the transcripts.

The second step included an initial noting of the content and language used within the transcripts. As I explored the content of the transcript, detailed commentary was created for each interview. The comments were descriptive in nature and my aim was to stay as close to the participant's explicit meaning as possible (Smith et al., 2009). Three categories of comments were recorded: (i) descriptive comments that described what the participant said, (ii) linguistic comments that explored the participant's specific use of language and (iii) conceptual comments that were more inquisitive and abstract in nature (Smith et al., 2009).

The third step involved developing emergent themes. This involves primarily working with the notes rather than the transcript itself, by analysing the exploratory comments to identify

emergent themes. This also involved grouping portions of the transcript into emergent theme groups, accompanied by their exploratory comments.

The fourth step included searching for connections across the emergent themes. I looked for connections by printing the list of emergent themes, cutting up the list so each theme was on a separate piece of paper and then moving the themes around to group the related ones together. I used several strategies to identify the connections and patterns among themes including abstraction, subsumption, polarization, contextualization and numeration. Abstraction involved putting similar themes together and developing a new name (i.e., super-ordinate theme) for the group. Subsumption is similar to abstraction, but uses the identified themes as the super-ordinate theme for the group. Polarization involves grouping opposing themes together. Contextualization involves connecting themes and a particular context or narrative moment in the transcript. Numeration reflects the frequency of which a theme occurs throughout the transcript and helps to uncover major themes.

The fifth step involved moving from the first transcript to the next and so on, until all five transcripts were analyzed using all four steps. Steps one through four were completed for one transcript prior to moving onto the next. This allowed for bracketing by limiting the influence of themes from one transcript to the next.

The final step involved looking for patterns across cases. I grouped recurring or similar themes across the five transcripts to create super-ordinate themes and created a master table of themes and sub-themes. Afterwards, when necessary, I adjusted the locations of the sub-themes to improve coherency and changed the wording of the super-ordinate themes to better reflect the groupings. The analysis was then written up to give an overall account of the data and to offer my interpretations of the data by representing each participant's experiences to the best of my ability. The analysis is presented in the results section followed by a discussion that links the themes to current literature.

Ethical Considerations

Research in this field of study must allow for ethical considerations which include informed consent, confidentiality and multiple relationships. In accordance with the University of Saskatchewan research requirements, an ethics application was submitted to the Behavioural Ethics Review Board (Beh-REB) and approved on July 20, 2018 (BEH approval # 147). Participants read and signed a consent form that covered the studies purpose, confidentiality and

storage of data, right to withdraw and potential risks and benefits of the study. There were no known risks to participating in the study. This ensured that individuals understood that their participation was voluntary and that they have the right to withdraw from the study at any point in time. It is important to ensure that individuals have the capacity and comprehension to understand their rights and choices. Further, maintaining confidentiality is connected to the informed consent process and ensures participants right to privacy. To ensure confidentiality, all identifying information was altered and pseudonyms were used for participants. Lastly multiple relationships occurred because I did know most of the participants prior to the study, or someone closely associated to them, due to my pre-existing role as a support worker. I believe that for the purposes of this study, multiple relationships did not cause impairment or harm to any one individual. All information regarding to and provided by the participants remained confidential and anonymous.

CHAPTER FOUR: FINDINGS

Results are presented in this chapter. After an introduction of each of the participants, thematic findings are described in terms of super-ordinate themes and sub-themes illustrated with direct quotes from the transcripts. The passages from the transcripts were slightly altered to make comprehension easier for the reader. This included removing repeated words and *filler* words such as yeah, like, um, or uh. Another alteration included using ellipses (…) to represent omitted words or dialogue that did not relate to the phenomenon and using square brackets ([]) to enclose words that I have used to clarify or explain context. To maintain confidentiality, any information that could be used to identify participants was altered and pseudonyms were created. The individuals being supported are referred to as the supported individual and any identifiable details regarding the supported individuals have been slightly altered to maintain anonymity.

Introduction to the Support Workers

The five women who participated in this study – Grace, Anna, Tina, Sue, Mary – work as community support workers for individuals with brain injuries. They ranged in age from 21 to 28 years old. All the participants lived in a prairie province and worked in a mid-sized city. The five participants worked part-time every week for several hours in the evening and/or during the weekend and had provided individuals with Acquired Brain Injury (ABI) support in the community for one to six years. All the supported individuals are between eight to 30 years of age and had moderate to severe brain injuries. One of the supported individuals had a concurrent diagnosis of Autism Spectrum Disorder.

As community-based support workers, participants provided supported individuals with the opportunity to participate in recreational and social activities in the community. The level of support they provided varied depending on the individual's interests and abilities. The non-direct support responsibilities included but were not limited to, helping the individual to choose activities and set goals and communicating with the individual's parents/guardians or home staff to schedule outings and relay how the outings went. Typically, post-outing, support workers employed through an agency completed paperwork to summarize activities and report any incidents that occurred. Wages and reimbursements depended on the employer and available funding (see Table 4-1). The direct support responsibilities included, but were not limited to: (i) transportation: wherein all participant's hold a valid driver's license and have a reliable vehicle

to drive the individual to and from the activities; (ii) participation: taking part in the recreational and social activities with the individual; and (iii) provision of companionship: talking with and listening to the individual.

Table 4-1

Description of Support Worker Wages and Reimbursements

	Employed Directly by Family	Employed by a Non-profit Community Organization
Wages and Reimbursements	▪ Wage is dependent on the provincial and federal funding the supported individual applies for and receives and the family's financial situation. Typically paid at an hourly rate.	▪ Wage is dependent on the non-profits allotted provincial and federal funding and grants. Typically paid at an hourly rate.
	▪ Mileage is typically reimbursed. Reimbursement is based on the provincially set rate for private vehicle usage.	▪ Mileage is typically reimbursed. Reimbursement is based on the provincially set rate for private vehicle usage.
	▪ Support worker pays up front for activities, meals, etc. and is reimbursed later by family.	▪ Support worker pays up front for activities, meals, etc. and is reimbursed later by organization.

Grace. Grace was a 28-year-old full-time Direct Support Worker for adults with Intellectual Disabilities, in the process of transitioning out of her full-time job into becoming a full-time university student. She aspired to continue working in the human services field but in a different occupation. Grace started working as a community-based support worker when she completed an undergraduate degree. She worked part-time in the evenings and weekends with two young men over the span of two years, typically meeting with each of the young men one-on-one weekly for three hours, although on occasion they would pair-up and she would take them on an outing together.

Anna. Anna was a 21-year-old undergraduate university student with aspirations to work in the medical field. Anna first started working with the ABI population as a volunteer in a

recreational program for individuals with ABI. She explained that she heard about the program from her sibling who was already involved in the program. Through that program, Anna applied to a non-profit organization to be a community-based support worker for individuals with ABI. Anna supported the same individual for approximately one year in the evenings and on weekends. They met once a week in the community with a focus on participating in physical and social activities.

Tina. Tina was a 25-year-old university graduate student with aspirations to work in the field of public health. Tina coordinated a once-a-week recreational group program for individuals with ABI for the past three years and had previously worked full-time throughout the summer months providing one-on-one support to individuals with ABI out in the community. Tina emphasized that although her current part-time position was in a group setting, there have been many opportunities to support the individuals in a one-on-one format.

Sue. Sue was a 24-year-old who worked full-time in addition to part-time support work. She recently earned a university undergraduate degree and is in the process of applying for a graduate program. Sue was a community-based support worker for the past one-and-a-half years. Sue first started working with individuals with ABI as a volunteer for a recreational program for individuals with ABI. Through that program, Sue applied to a non-profit organization to be a full-time community support worker for individuals with ABI throughout the summer months for individuals with ABI. After the summer, Sue continued working with two individuals part-time during evenings and weekends.

Mary. Mary was a 27-year-old full-time Direct Support Worker for adults with Intellectual Disabilities. She also worked part-time providing community support for an individual with a dual diagnosis of ABI and Autism Spectrum Disorder. Mary was employed directly by the individual's family and for the past six years she has consistently worked one evening per week and occasionally on weekends. Mary described their relationship as "Really close. It is like I'm her sister. It is that kind of bond and that kind of trust." During the interview, Mary shared that if it were not for meeting the individual she might not be in her current field of work.

The Nature of Support Work

Being a support worker is an umbrella term that includes many different titles and functions. Ultimately, however, a support worker's job is to provide support. In general, a

community support workers' job is to provide individuals with the opportunity to go out into the community to participate in social and recreational activities together. Sue described these outings as an opportunity for the supported individual, "… to kind of forget that they have [a] brain injury for an hour and a half," and support workers "just get to have fun and [the supported individuals] get to make new friends."

It is necessary for support workers to get to know the supported individuals interests and abilities so they can provide them with the best possible support. At the beginning of a relationship, support workers often meet with parents and guardians, as well as other important members in the supported individual's life, to acquire this information. Grace described this process as, "you kinda just yah know get matched up with your support person, they [the agency or the supported individual's parents] give you the quick run-down of who the [supported individual] is. But I mean, that only helps so much."

The support worker assists the supported individual to develop a description of their preferred types of activities and individual goals. This description is based on the individual's capabilities and preferences. This personalized plan forms the foundation of the support worker's work.

Community outings typically involve activities that are social and recreational in nature and are often a fun opportunity for both support worker and the supported individual. Participants listed some of the supported individuals preferred community-based activities; these activities included bowling, mini-golfing, swimming, going for lunch, as well as driving around looking at cars or houses. Sue described the outings as, "an opportunity to get them [the supported individual] out of the house." Similarly, Tina described the outings as, "a lot of the time it is respite for their family, but I think it's respite for them [the supported individual] more so, so that they get to have a break from their families too and they get to have a fun social [outing]. Further, participants explained that they partake in the activities alongside the individual they are supporting. A part of being a support worker, Sue shared, is to help the individuals by participating alongside them and being supportive of them.

A term used frequently by participants was "go with the flow." Tina explained how "going with the flow" applied to being a "good support worker" and how learning this also benefitted her outside of work:

…you need to be the type of person that's really relaxed with how things turn out and you can't be too like 'it needs to go this way.' You need to be really relaxed and kind of go with the flow. Yeah and I feel like it's kind of taught me how to do that in social settings a little bit more… so, I think that's really benefited me.

The notion of "go with the flow" that participants spoke of is a mindset that in community-based support work is helpful to develop because support workers must be versatile and make "on the spot" decisions while also being responsible for the safety and wellbeing of the supported individual.

Support work was found to be mutually beneficial. That is, the relationship was enjoyable for both the support worker and the individual. Anna described her "own happiness" as "… instant once you are there [with the supported individual] … doing stuff with them and you're seeing how they are having a good time too." She further explained that as a support worker, "you make it enjoyable for them and by that it will be enjoyable for you."

Participants described the growth they saw in the supported individual and their own growth, from the support relationship. Mary described this bi-directional aspect of support work, "I think … actually seeing that we started out not knowing each other and then seeing [the supported individual] develop and [that] I'm actually teaching stuff and she's growing as a person because I can actually help her and teach her…and I think she's taught me a lot of insight" into working with individuals with varying abilities. Similarity, Sue revealed that "I really like seeing [the supported individual] have fun and I like seeing their improvements...even if it's not a physical improvement, if it's a social improvement…I think it's really great to see that, that makes [the work] worth it."

How Community Support Workers Experience Supporting Individuals with ABI

Using IPA as a means to illuminate the experience of community support workers allows for in-depth exploration into the participants' unique experiences and insights. IPA is a dynamic process, wherein the researcher is trying to understand and interpret each participant's account of the experience (Smith, Jarman & Osborn, 1999). Following the IPA model, I analyzed and interpreted the support workers' transcripts and identified several recurrent themes. After completing a further analysis of these emergent themes, they were clustered, merged and incorporated into sub-themes. The analysis process resulted in five super-ordinate themes and six sub-themes. The themes were generated based on the relevance of the passage and the

prevalence within the data. This means that not every participant's experience contributed to each of the themes identified, but each occurred for a minimum of two participants. Figure 4-1 provides a graphic representation of the themes and subthemes.
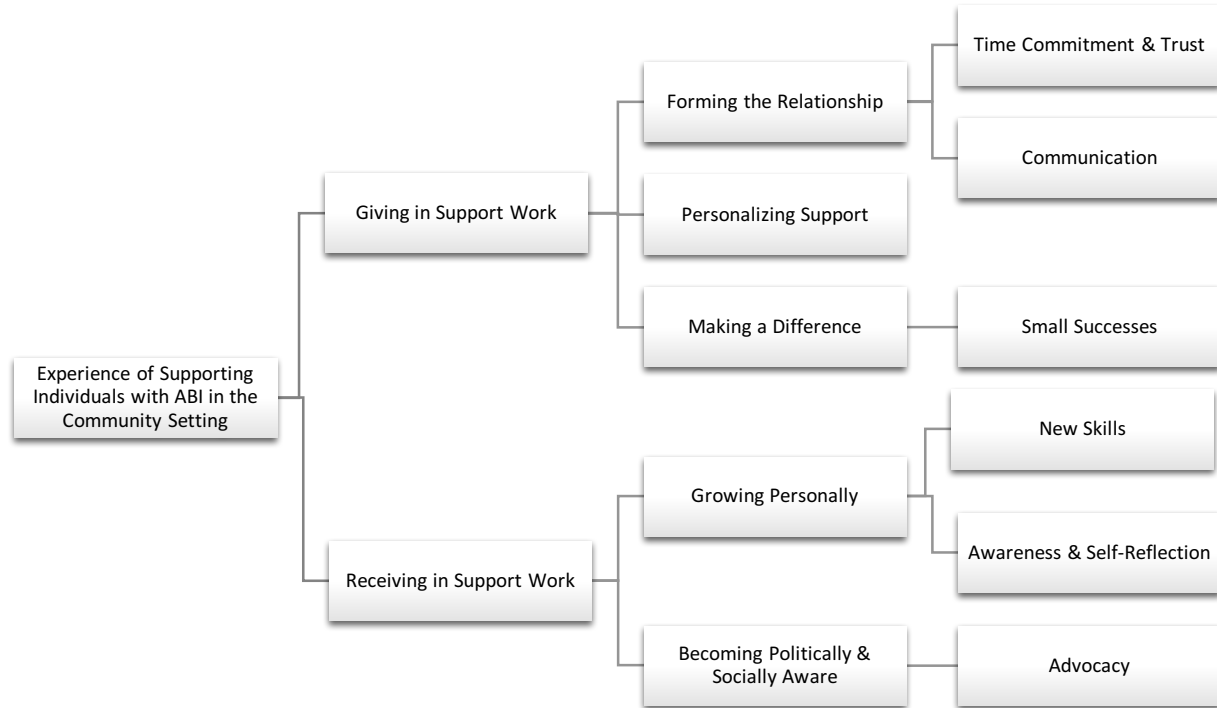
Figure 4-1. Experience of Supporting Individuals with ABI: Summary of Themes and Sub-Themes

The themes describe two overarching aspects of the support workers experience supporting individuals with ABI. Based on the support workers' meaningful experiences, five super-ordinate themes and six sub-themes were identified. The first being, how they experienced giving in support work, which included three themes (a) *forming the relationship* (time commitment, trust and communication); (b) *personalizing support;* and (c) *making a difference* (small successes). The second being, how they experienced receiving in support work, with two major themes (a) *Growing personally* (new skills and awareness and self-reflection); and (b) *becoming politically and socially aware* (advocacy). The following sections elaborate on each theme and sub-theme and provide my interpretations of their meaning.

Support Workers' Experience of Giving

A Community Support Worker has many job roles and responsibilities that are built on several core elements. The participants described three core elements of being a support worker as: (i) *forming the relationship*, (ii) *personalizing support* and (iii) *making a difference.*

Forming the relationship. The relationship between the support worker and supported individual is the basis on which community support is provided. The participants discussed time commitment, building trust and successful communication as foundational elements to the support relationship.

Time commitment and trust. Throughout the interviews, participants discussed their relationship with supported individuals relative to commitment of time. The participants described the understandable need to spend time with the individual, in order to get to know them, make connections, build trust and ultimately form a relationship. The amount of time it takes to get to know an individual was unique to every relationship. Grace stated that "it definitely took two or three hangout sessions…," Tina explained that "it took a few weeks for me to get to know them and I was new with working with people with acquired brain injuries as well," and Mary commented "…it took a lot of years to get to this spot. It takes a lot of time and years to develop routine and formality."

As with any relationship, the participants found that their relationship developed as they spent more time with the supported individuals. For example, Sue shared "it was just like the longer we stay together, I just think like the more solid we were." When Mary committed to working with the individual she supported she knew that it was going to be a relationship that took time and was long-term. Mary explained, "I told myself this isn't going to be short-term, it's long-term because I can't do that to her and even [when I] talk about, 'oh, I am going to go somewhere, [I think] no, I have to consider her now too,' and it is just kind of a part of me, she is a part of me." Sue and Mary indicated that as a support worker you must be prepared to commit time to working with the individual, otherwise you will not build a relationship.

Time was also associated with trust, another integral component of support work. With time, workers discovered and supported individuals interests and preferences. For example, Mary found out that one supported individual loves the candy Skittles: "I know she loves them and so I'll bring her Skittles or something that she likes, so that she knows, 'I pay attention to you

and I know what you like.'" Mary does this because "I want to make her happy." In this way, Mary believes that the supported individual is happy but also feels known, seen and cared for. Similarly, Sue expressed that it is easier to get to know the supported individual when they found "common ground or an interest that [the individual] had." Sue builds rapport by talking about her own interests and then asking about theirs. Sue explained that eventually, "as time goes on and [we] get to know one another" she will then "delve into more personal or specific questions about current things going on in [the individual's] life."

Tina and Grace mentioned making time to "check-in" every outing, asking the supported individual about what is going on in their life or how their day was and about things that were of interest to the individual. For example, Grace depicted the beginning stages of the relationship and her efforts to create conversation with the individual:

When we first started working together I was just working on [them] actually talking to me. But once we got past that hurdle, you get to know them… He loved sports… I would ask 'what do you like, what are your favourite teams?... 'what do you play? What is your favourite subject in school?' Eventually he started telling me these things and then I would just keep asking about them because I knew that's what he would talk about.

Likewise, Tina described that to build those one-on-one kinds of relationships, she started "by talking to them about what's going on at home or how they are doing" and built-up to asking them more personal questions such as "how's school going or how's work going?". Grace found that she could tell that a supported individual trusted her more based on the type of information they shared over time, the information went from "small talk" to more "personal" in nature. When asked if she felt like she was able to help the individual through more personal matters, Grace stated, "I think… it is always nice to have a different perspective." The "different perspective" that Grace spoke of is the notion that often individuals with ABI have difficulty with social communication skills, resulting in feelings of social isolation; however, the support worker is often one of the few avenues for individuals with ABI to practice their social communication skills. That is, support workers provide the supported individual with someone who will listen to them, but will not tell them what to do and will guide them by offering alternative solutions or strategies for situations.

Conversely, Tina took a more direct approach by explaining to the individual that she was there to help if they had an issue and that she is there to listen to them and support them.

While giving individuals the choice to divulge information at their own pace is important, it is equally important to let them know that, as a support worker, you are there to listen to themand provide them with emotional support, if needed.

It was evident that to get to know the supported individuals and build relationships, participants had to find ways to genuinely connect. Tina expressed the importance of "not forcing the relationship," allowing supported individuals to decide when they are comfortable and when they feel rapport has been built. Mary shared that when she first started, things were "hectic" and the supported individual would "have so many meltdowns" because "[the individual] needed to build trust and a bond." Mary explained that over time their outings together became more comfortable and how at first the supported individual "…doesn't like to be touched. She touches you if she likes and trusts you…" and "…now, six years later, it is basically like I'm her sister…she shows more of her emotions towards me, now she'll want to hug me [whereas] before it was 'don't touch me'…and now she hugs me and cuddles me." Throughout the interview, Mary referred to herself as someone the individual's family considers to be a "family member, sister, or best friend."

The level of comfort and length of time to feel comfortable with a new person depended on the individual. Grace found that one supported individual took a long time to feel any level of comfort with her. Grace laughed while sharing a story about one of their first outings:

> The first time we ever hung out together…I bought him a drink afterwards and he wouldn't even sit at the same table as me. He went and sat two tables away and I [thought to myself], 'oh, this is going really well, this is a great start.' There was not much talking that first time.

Grace clarified that later in their relationship the supported individual sat with her at the same table. Another similar experience Grace described occurred while driving to their outing, wherein "[the individual] wouldn't even sit in the front seat, he sat in the back seat." Grace further explained that she would offer the supported individual the option to sit in the front passenger seat but would ultimately let him make the decision. She allowed the space he needed to feel comfortable and found that "towards the end, he did sit in the front seat a couple of times. But most of the time he still sat in the backseat."

In comparison, Anna told the story of one supported individual who divulged an intensely personal experience within one week of meeting each other "… it was probably the week after I

started with her she tried to overdose on Tylenol in her room and she felt comfortable coming to me with that… so I would say it was pretty soon, [when] she was quite comfortable with me." Anna went on to describe how she listened to the individual and offered the supported individual guidance:

> I think that day she got in a fight with [a sibling]. [They] don't get along at all and I think there… might have been something with school too. I think she acted very spontaneously and I talked to her after and… she [appeared] very frustrated, angry, [but] not depressed or anything like that but I said [to her] 'next time you know there are better ways to take your frustration out and better way to deal with these feelings and to talk about it.'"

Anna was present during a very serious time in the individual's life, but she demonstrated her care by offering the individual a safe space to talk about what happened. Further, the behaviour Anna modelled was a way of showing the supported individual that she mattered. Afterwards, she presented the supported individual with alternative possibilities to deal with future situations and emphasized that she was always there if the individual needed to talk. Based on the range of participants' responses, it was apparent that it takes time to become comfortable with one another and as support workers, it was especially important to allow the supported individuals to decide their level of comfort and readiness to divulge personal information.

Communication. Communication was the third integral component associated with forming the relationship and it was evident that communication experiences were unique to each supported individual. Grace, for example, shared two contrasting communication experiences that she encountered. The first supported individual she explained was "the most social creature," somebody who would always have something to talk about and often gave too much information. This supported "social" individual was eager to talk to Grace about things going on in his life. Although they were able to communicate, the supported individual was not always able to understand where Grace was coming from or what she was trying to convey. Grace described a specific example of this:

> When he is telling me the issues that he feels is happening. [For example] the thing he talked about a lot was that he felt his… [parent] didn't love him. So, it was heartbreaking. I would try and help him realize that he is very different from you [and] just because he doesn't say it, doesn't mean he doesn't feel it… That was a challenge for me because a lot of the times he just wouldn't understand where I was trying to come from.

Grace expressed the importance of helping the supported individual come to a potential solution or to see other sides to a situation by introducing the idea that there could be other alternatives. Understanding this is especially important for supporting individuals with ABI because a brain injury can affect an individual's ability to relate in an appropriate way to other people (Kahn & Cohen, 2014).

In contrast, Grace described another supported individual as "painfully shy." This quieter individual did not talk very often and when he did, it was prompted. Grace was always the one to initiate any conversation between the two of them and had to ask a lot of questions and do more than her share of "the work" to keep the conversation going. As has been depicted in an earlier excerpt, during the first outing with the quieter individual when Grace sat down at a table, the quieter individual chose to sit two tables away from her. Grace laughed when describing how she started gain the quieter individual's trust and build rapport with them: "when we first started working together I was just working on him actually talking to me. But once we got past that hurdle, um, you get to know them, right?" Through perseverance and patience, Grace gained the trust of the supported individual. Through this trust and comfort, the individual became less shy around Grace. Eventually the quieter individual talked and had conversations with Grace and he made a conscious choice to sit at the same table.

Some of the participants found that before getting to know an individual, they had to learn different language and communication styles. For example, Mary reflected on working with a supported individual who is semi-verbal:

> In the beginning, I let her sit in the back seat because I didn't know her that well. She sat in the back seat so that she could see me and I could see her and [there] was no communication in the vehicle. I [would] turn the radio on and basically it was just silence until we got to where we were going. Then I let her do her own thing and then observe and then I got to know how far to push her and what to do. If [someone] pushed her too far and she didn't want to do something then she would start screaming. But now if she sings a certain song then I know, 'okay she is frustrated.' If she says certain words, [then] 'I'm like, okay, she's going to have a meltdown.' Little hints like that she gives me now.

Through close and repeated observation, Mary has learnt how this supported individual communicates and how particular words or songs or behaviors are associated with different emotions or feelings, such as feelings of distress.

Semi-verbal individuals have difficulties with verbal communication even when they trust the person they are communicating with. Thus, they often communicate through non-verbal actions. Mary described a situation wherein the supported individual's non-verbal gestures gradually evolved over time:

[The supported individual] would never ever let me finish. When we first started, I would have to wolf down my meal before she even got finished. Then I started not ordering anything and I'd be super hungry, because she would stand up and throw out her garbage and then be ready to go… Now [the supported individual] will wait until I'm done … she will sit quietly and she will watch me eat … now she respects that I need to eat too.

Tina also worked with an individual who is semi-verbal. It took time to become comfortable and to develop a system of communication and it required persistence. Tina said, "I was really nervous about it when I first started" and she recalled thinking "I cannot understand this person at all. I feel bad." But with time, they developed their own way of communicating. Tina shared, "I think once I was able to kind of get the hang of like interacting with him, that made it a lot better because then it's like you're actually speaking to each other and listening to each other and it's more of a conversation…." Together they used hand motions and spelled out words, which made Tina "…feel better like, 'okay the longer you spend time with this person, you really get to know them and you feel comfortable and you can make it work.'" Furthermore, "our way of communicating made it seem more special, like we got each other." Tina went on to say, "so I think that made us closer too because he saw that [I was] taking the time to stick with him, even though it's going to take [him] ten minutes to get a sentence out." Taking the time to communicate with the individual fostered something special between them and demonstrated her commitment to understanding the individual. Tina's persistence and dedication led to them being able to communicate together and the process of learning together helped to build the rapport between them.

Personalizing support. *Personalizing support* means adopting a planning process that is choice-driven and encourages individuals to make independent decisions. Brain injury results in a wide array of problems, which means that supports must be personalized to each individual. As explained by Tina, "Everyone's different…it's a different approach for every single person who has a brain injury. That's what I like about [individuals with] brain injuries. It's never the same." Similarly, Sue explained:

It's one of my favourite jobs I've ever had. It's been challenging in some parts, but I also feel like it's been really rewarding in other parts … The trickiest part of it is no one is the same or how you might get along with someone or little ways that you make someone's day fun …It's completely different with everyone…I think what makes it the most interesting is getting to know everyone separately and then just trying to make every session tailored to their interests and their life and their personality.

All the participants' accounts revealed that support relationships were guided by the supported individual. Anna laughed when explaining the supported individual's typical decision-making process for deciding where they wanted to eat:

It's quite funny because no matter what [the supported individual] decided the week before we always end up going and getting her chicken fingers … and [one week] I had planned and texted her mom and I said I will take her out for a nice dinner, I won't make her choose now because I know she will change her mind. [Then] I get there and I am like 'alright girl, where do you wanna go for dinner?' And [she replied] 'chicken fingers.'

Support involves providing outings that are personalized to focus on supported individuals' specific preferences and strengths, to foster their hopes and to correspond with their goals. The support worker and supported individual work together to encourage independence and choice for the supported individual. For example, Anna starts each outing by giving the supported individual time to talk about what is going in their life and the chance to direct the conversation as they wish. One supported individual talked with Anna about her "hopes and dreams", so Anna sought ways to support these dreams and help supported individuals to realize their abilities. Anna found herself helping to motivate them to pursue their dreams and supporting them towards realizing their potential:

…They [individuals with ABI] have been told probably many times that they cannot do something or they shouldn't and if you are that person that shows them they can then maybe that one thing that you showed them, they'll be able to take that further and realize it themselves next time they come across something like that.

During our conversation, I expressed to Anna that it sounded like the work had helped her to realize her own potential as a supportive and caring individual and she happily agreed.

Providing the individual with opportunities to make decisions was another topic that was common across the interviews. Each participant shared that an integral part of their job was to

provide supported individuals with the opportunity to plan their own activities and to empower them to choose what they want to do through supported decision making. Facilitating the supported individuals' right to choose gives individuals control to make their own decisions. Sue explained the delicate balance between empowering a supported individual to choose the outing activity, but at the same time trying to encourage the individual to pursue their goals:

> *Sue*: I like to ask [the individual] right off the get-go if they had anything that they wanted to do today, instead of me planning it. Because I think it's good for [the individual] to plan their own activities and say things that they enjoy… If it's something they want to do the session goes by better … I would [also] try to incorporate … something that we had set as a goal for them … the beginning [of the support relationship] I asked them if they had goals or if there was something that they were wanting to accomplish. For example, say I went to go play pool with someone but they said that their goal was to exercise more. [During] the second half of the session [we would] go for a walk outside … so have something fun, but then also incorporate what they're trying to work on.
>
> *Interviewer*: You're helping them meet their goals?
>
> *Sue*: Exactly. Lots of those things they wouldn't do at home with their family. So, it's an opportunity for them to get out of the house and do it with someone [who will] push them through it or help them get it done.

Participants described the importance of providing the supported individuals with choices and opportunities to make decisions; however, Sue found it equally important to encourage and "support [the individuals in making] healthy choices and stuff like that."

Supporting independent decision making also helps supported individuals regulate their emotions and avoid outbursts. According to Anna, "when they [the individual] have control of what they want to do and their choices, you don't really run into that [outbursts] as much." And as Sue explains, when outbursts are minimized, interactions and communication improve, "…when they're doing something that they're enjoying, that's when you get more out of them too. They will open-up to you more and feel comfortable around you because they are having a fun time and doing something they like." It was evident that in those moments, the supported individual was more likely to feel comfortable and talk about things that, in turn, can be used to help best support them.

It was apparent that forming a relationship and personalizing an individual's supports were interconnected. That is, trust and communication appeared to be core elements to forming the support relationship; and without the core elements, support workers would not be successful in helping the supported individuals navigate difficulties with interpersonal relations, in guiding the individuals to improve their social communication skills, or in teaching the individuals to make independent decisions.

Making a difference. Having an impact by being a positive person and making a difference in the supported individuals' lives were also described as central to support work. Sue shared a spontaneous conversation with a supported individual who told her that, 'I want you to go on a trip [anywhere in the world] with me because I am super thankful for you.' Sue described this expression of genuine gratitude and thoughtfulness as "so sweet" and "just melted my heart a little bit." Another situation that let Sue know how important these support work relationships are arose when there was a death in the family of a supported individual:

> My [supported individual's parent] died and he just asked for me to be at the funeral. So, I mean that's a big moment in your life and so the fact that they recognize that 'oh, this is a support system for me. I'd like them to be there in a difficult time.' Like obviously it's horrible, but it did make me feel like 'Okay - that's nice that they trust me enough to be in that type of situation with them or to go through that with them.' So yeah, so little things like that.

Sue believed that being a positive influence in someone's life and being someone they want to spend time with was extremely meaningful and she explained that "those are the sweet moments … I guess like what I keep saying, to know that I am a positive in someone's life is super meaningful to me." The participants described having an impact on the supported individuals in terms of the small successes that they helped them to achieve.

Small successes. The participants recognized that the simple, small successes they had with the individuals they support were the most meaningful. Grace made this clear when she described a small success she had with the quieter individual, "There would come a time eventually in our relationship that the super shy guy would actually ask me questions and that was such a huge thing." Grace recalled that this small success, "it just put such a big smile on my face." The significance of the positive impact the participants believed that had on the individuals they support was made evident by Grace when she shared:

I definitely feel like I've had a positive impact on someone's life. To quote my mom, one thing she always says is - even if I had a bad day, like 'uh I really screwed up, I should have done this better or this' - my mom always says: 'you are just a drop in the bucket.' Even if it wasn't a big drop, you still had a positive impact and then you just keep building on it.

The "drop in the bucket" that Grace spoke of is the notion that a support worker is only a small part of all the people and things that make a difference in the supported individual's life. Although it may not appear significant at the time, the impact the support worker has on the individual is valuable. Although a support worker is "one drop," it is important not to diminish the importance adding up all the "single drops in the bucket." That is, the impact of one individual is an important and valuable contribution to a larger collective impact made by multiple individuals. It was evident that Grace felt a sense of pride in knowing that she had made a positive impact on the individuals she supports.

Anna was mindful of the "progress" that the supported individuals made with her support and explained the success as "completely positive and so rewarding" for her. During our conversation, Tina reflected on the notion that there will be "hard weeks, but there will be easier weeks" and expressed that the "successes with the individuals make [the work] all worth it." Sue shared her rewarding experience of helping an individual to be successful by modifying a sports activity:

There was one person that would show up but was in and out of the wheelchair, had trouble with balance and clearly didn't have the most fun playing sports because it was very difficult for them. We were playing badminton and it was like they weren't really involved because they were just standing there but couldn't move fast enough to go forward and back and didn't really have the coordination to hit it, so they were just on the court. Then they were serving and they couldn't serve. I noticed this … and so I was like why don't we try it this way. [Then] I got him to hold the badminton racquet, balance the birdie on there and just fling it over. [Afterwards] he was like 'oh this game is so fun.' Then the next week … we played volleyball. I asked him if he wanted to try and then I got him to serve, [but] he could only use one arm and so … I would throw it up for him and he would hit it over.

Sue went on to explain that the individual was usually "very stoic," and often chose not to participate in the activities. After some assistance, however, he was successful at the activity, "he got over it and smiled … It was so good to see [him] smile. Not a huge thing but, it's just nice to see [them] having fun, [they] feel included and feel like [they are] good at something." Sue continued to share her amazement in her supported individual and herself when she shared, "so the fact that I got through to someone, that they can [participate]. That was nice to see."

There appeared to be many successful moments throughout Mary's narrative that she described as "huge milestones" for the supported individual. These moments consisted of witnessing the supported individual do things they had never done before and getting them to feel comfortable enough to try new things. Mary shared an experience that she considered a milestone moment:

Last weekend [the supported individual] came to my house and she didn't scream and she always screams. As soon as she walks in the door she screams. I don't know if she is more comfortable with me or her mom already [*sic*] conditioned her [by saying] 'you're going there and you're doing this and this'. I don't know what it was, but to me it was a milestone, a pretty important thing….

Mary also exuberantly shared her feelings towards those moments when she said, "It was kind of like it was my own child [reaching] a milestone – like walking for the first time – really is what it seemed like. It was that much excitement and that emotional. It was crazy." Such successes helped Mary appreciate that they had to learn from each other to make those milestone moments possible.

Support Workers Experience of Receiving

When supported individuals recognized and appreciated their support worker, the impact was personal and meaningful. As support workers, they valued these and other pivotal moments in their relationships with supported individuals. Many participants appreciated being a part of the supported individual's life because it personally transformed them. The following sections (i) *Growing Personally* and (ii) *Becoming Politically and Socially Aware* discuss how the participants have been personally impacted by the individuals they support.

Growing personally. A deep appreciation for the opportunity to be a support worker and the personal growth that resulted from the work, was evident across the participants' accounts. All participants felt gratitude towards being a supportive person in the individuals' lives and the

opportunity to positively influence others was described as a rewarding aspect of their work. Anna shared how she felt this work was rewarding when she stated, "… [the individuals] eagerness to come to you, I think is a really good feeling. Knowing they choose you as someone to look up to and learn from." Grace explained, "This kid [one individual she supported] was always grateful. He was always like 'thank you so much for taking me out.' So, to be honest, he made me feel special." After hearing those types of compliments, Grace stated that it made her think, "yah okay, I could do this [work] again." Having the individual thank her and convey appreciation encouraged Grace to stay in this line of work.

Participants experienced personal growth throughout their work supporting individuals with ABI. For example, Mary discovered that the work has encouraged her to be more empathetic towards others. Mary expressed that because of support work, "…I think I have a little bit more compassion and sympathy …I think just being with [the supported individual] I am more sympathetic working with her and more empathetic." Further, Tina expressed that through the work she found herself more comfortable around people with disabilities. She also found supporting individuals with ABI improved her ability to "go with the flow" at work and in other social settings. Sue believed that just getting the experience of working with people of different backgrounds and abilities is "applicable in life and super important," and that everyone should take the opportunity to work with individuals of varying abilities. Two sub-themes were identified for *Growing Personally*: (i) new skills and (ii) awareness and self-reflection that are described below.

New skills. As the interviews progressed it was evident that several of the participants had discovered an increased awareness of their own abilities through their job as a support worker. Prior to being a support worker Anna said she had been described as "life-stupid:"

> "My [sibling] used to joke that I was very life stupid and that I wouldn't be able to carry a conversation. I was pretty introverted and I kept to myself. So being with these people [individuals with ABI] who … could care less who they are talking to as long as you are there for them and they'll look up to you. So, they definitely helped me open up and become more comfortable with that. I learned what I was actually capable of, [that] I could help someone out [and] I can speak to people. But definitely their no judgment policy helped me a lot…

Although Anna did not think she was capable of taking care of someone or being a role model to them, she found that support work changed her perspective on herself. Anna expressed, "…I feel like I have definitely grown a lot through this experience and I think that is why I am still here, because I am still growing." Anna believed that she was learning from the supported individuals. Anna found that, "They [the supported individuals] teach me something new every time I see them.…no negative impact, all positive" and they remind her to "be more patient, just general things like that." Through this work, Anna found herself constantly learning. Figuring out what worked and what did not and how to adapt her response to work better next time a similar situation occurs.

The participants' narratives conveyed the challenges of this work and the many opportunities that resulted from the challenges they faced. Participants described experiences where they learned how to navigate new situations, developed competencies from these situations (i.e., learning to be assertive when necessary) and gained new insights into situations that were complex. For example, Sue described a challenging experience with a supported individual:

[After the summer] there was like a little bit of time in between where I stopped working with the client and then I went back to start visiting them one-on-one [at their care facility]. It was my first time coming back… and there was another [person] that I think was blind or had a visual impairment. This person kept asking 'who's there, who's there?' …and I think [the supported individual] was thrown off by it, [as] it was the first time I've seen them be very paranoid and irritated with someone. I think that's what triggered it [the incident described below] is they were just confused as to why they [the other person] was there and didn't know what was going on… Finally [the person] went on their way. [But] when we went back to the main area the same person… was there… and all of a sudden [the supported individual] grabbed this person and went to go bite him… and I had no idea what to do… But I didn't want to get in between of the two of them. They both started biting each other. So, I went down to ear level to get [the supported individual] to listen to me or hear me that 'I'm here and I think you need to stop what you're doing. This is not okay.'

After reflecting on the situation, Sue recommended that, "support workers should get more training if this is the type of situations they will be in" … but she also recognized that, "I

think in situations like that, it's not like [the support worker] can plan for it and I feel like [they] will always be thrown off no matter what."

Another challenging situation, discussed by both Sue and Anna, was learning how to navigate sexual commentary made by supported individuals. Anna described her experience learning to deal with sexual comments: "[Sexual comments] came up a lot with a couple of boys and just knowing how to deal with that. I was so thrown off the first couple of times, [but] I know what to do now." Anna described that she used a consistent approach with every supported individual and would say, "'no, please do not say that again, you can apologize, that was not respectful.'" Sue approached the situation a little differently and explained that, "if [the supported individual] said sexual comments or inappropriate comments … to just completely ignore it." This type of situation prompted the support workers to learn how to appropriately respond to sexual commentary and as a result developed assertive skills that they can utilize in future situations.

Anna shared a serious situation where one of the supported individuals she supports divulged to her during an outing that they had been sexually assaulted and, "that [the supported individual's] family didn't know about it. Anna explained, "I was the first adult to know about that and I relayed the information to the family." Anna continued to share that, "when [the supported individual] first mentioned the overdose and rape it took me by surprise. I was like, 'I've not had to deal with this before. And so she has definitely helped me grow. I know how to handle a lot more situations now … and I've definitely become more … comfortable with not knowing what's happening, [and] not knowing what's going to happen." It was evident that although there were challenging aspects of support work, the participants managed to find many opportunities for learning from those situations.

Awareness and self-reflection. Many of the participants experienced a change in perspective and outlook about others as a result of their work. Anna described it eloquently when she said:

> … This work has made me expand what I what I think about and what I recognize…You
> definitely start thinking differently than you did before and have a more inclusive outlook
> on life for sure and you … notice things that you didn't before and I definitely feel more
> comfortable approaching other people, [from] all walks of life. I feel like I am better able
> to handle myself in all kinds of situations. Honestly, the things I've learned from this

experience I can take on, [and] use for the rest of my life and just apply them slightly differently in so many different aspects. I think this definitely changed my life and I was a completely different person before I got involved.

Tina shared that working with individuals with ABI has helped her to expand her awareness to the notion that everyone is different. She believes that often individuals with disabilities are thought of as "all the same." However, her work has helped her to see everyone is "just a little bit different." Tina found herself learning about people's differences and now she doesn't "lump them all together:"

I feel like that's benefited me to know that everyone's coming to me where they're at and [that] they're all at a different stage in their life and all at a different stage in their brain injury and 'how can I help them at that stage?' It's good to know…I like that I know now how different everyone is.

Tina's understanding and awareness has developed from her relationships with the individuals she supported and as a result she has realized the importance of being responsive and creative as she supported each individual uniquely and individually. Gaining this insight changed the way she approached supporting individuals with disabilities, as well as people in general.

Being exposed to a diverse group of individuals and learning about the lives and stories of the supported individual has provided perspective for the participants' own challenges. For example, Mary shared that working with these individuals makes you "appreciate the little things more, … [I can] go home and I can live on my own. I can make supper. I can get groceries. I can fill my car with gas and [the individual she supports] will never get to do that. So, it makes you appreciate everything." Sue expressed a similar awareness when she said:

I guess I find [working with people] more rewarding, like when you can tell that you're making a positive impact on someone or just getting those little things like 'oh we clicked today' or 'I got through to someone today.' I find that much more rewarding than other jobs I've had and so yeah, that's just definitely something that makes you want to keep doing it … working with people, especially with different stories, [and] different backgrounds. It's very interesting and it kind of makes [me] reflect on you know, how many different people are out there and how [I] treat people.

Sue continued to reflect on her changed perspective when she shared, "getting everyone's stories and what they've been through and what [I] can still be appreciative of and what [I] can

still work on or help someone with …[The work] has been interesting for me that way, to get other perspectives and kind of refreshing.

A clear sense of self-reflection emerged from the participants' narratives. Looking at situations retrospectively helped Anna decide whether: "'I could have handled that differently' or 'wow, I think I handled that pretty good.'" Similarly, Grace shared her thoughts about self-reflection and bettering herself:

I definitely think it makes me more introspective, if that makes sense …[Afterwards] I am like 'Okay, I definitely could have handled that better' or 'I should have said this or whatever.' It kind of just makes you pause and [think], 'what is it about me that I reacted this way.' So I honestly think it helps me be more patient… But also [reflect on] how I handle certain things and how I should handle them.

The "introspection" that Grace described is her ability examine her thoughts, feelings and reactions to situations that she encounters with individuals. By reflecting on their experience the support workers became more aware of themselves and how they could improve their relationship with the supported individual. It was apparent that the participants experienced personal growth (i.e., expanded view of others and themselves) through their work supporting individuals with ABI.

Becoming politically and socially aware. The participants have all been changed by their experience supporting individuals with ABI. Many of the participants spoke about their expanded awareness of others and themselves as a result of their work. The theme *Becoming Politically and Socially Aware* emerged from the support workers' descriptions of how support work led them to advocate for the basic rights of the individuals that they support.

Advocacy. Several participants shared that working with the individuals they support influenced them to become an advocate for individuals with ABI in order to break down barriers and misunderstanding. During the interview when I asked Anna, "as a support worker you are there to…?" She replied, "to break down those walls." Through their role Anna, Sue and Mary shared that they hoped to increase community members' understanding of individuals with varying abilities and knowledge about their role as a support worker out in the community by advocating for the individuals they support and the service that they provide.

Anna described her emotional reaction to a recent classroom assignment in which she and her classmates read and wrote a response to an article based on interviews with children who

were judgmental and wanted to exclude people with disabilities. Anna expressed her discontent and passionately shared:

> I've seen what they [individuals with disabilities] can do and what they are capable of. We [as a society] have to look at it differently. We have to change our environment, make things more accessible to them and change our attitudes towards them … I am forever just in that mindset now. I'll relate back to them without even knowing.

Anna believes witnessing the strength and capability of the individuals she has supported gives her a deeper understanding, appreciation and compassion that extends to all other people with varying abilities. Anna expressed that she always advocates for people to be more involved with programs that support individuals with disabilities. She wished people would change the way they think by changing their outlook about the abilities of people with any form of disability. Towards the end of the interview Anna remarked "they are great people and I wish more people got the opportunity to see that."

As has been discussed earlier, Sue had trouble communicating with the individual she supported but once they found a way to communicate and understand each other she was able to help this person in a way she did not expect. The supported individual would ask Sue to interpret for him and advocate for him by becoming his voice when other people did not understand him. Sue explained "people wouldn't understand and then he would get me ...He's like, 'oh she knows' and so just being a voice for him was nice and like he trusts you to get it out."

Mary has had several difficult experiences where she has taken on an advocacy role; advocating for the rights and acceptance of the supported individual in the community. Mary described her experience with members of the community making negative comments towards the supported individual's self-stimulatory behaviour, called "stimming" for short (i.e., repetitive physical movements, sounds or words):

> [The supported individual] will be stimming at the lights and they [parents talking to their children] will be like, 'oh, get out of her road, she is dangerous'. Then I [respond with], 'no she is not dangerous, you're okay.' I reassure them that she is just human … I confront a lot of people or kind of acknowledge that I heard them and then they feel bad because I've heard them.

When asked if her response to the situation would have been the same when she first started, Mary replied "Probably not. I think it's more of a comfort and relationship thing because before

we had no relationship, it was just me doing my job and now it's more so 'oh is that your sister?' Or 'is that your best friend?' And I am like yeah we're hanging out…so it's no longer work." Throughout the interview, Mary described herself as an advocate for individuals with differing abilities who takes every opportunity she can to educate others. Mary further explained why she advocates, "I have a bigger appreciation for [the supported individual]. And what she's going through in her life because she cannot help any of it. And [as a result] I have a bigger passion for Autism and brain injury because I work with someone [diagnosed] with that. Now I'm kind of like an advocate."

Summary

This chapter described and interpreted the lived experiences of five female community support workers for individuals with ABI. The data was collected through semi-structured interviews and analyzed using Interpretative Phenomenological Analysis (IPA). The use of IPA as a qualitative methodology provided detailed descriptions of support worker experiences supporting individuals with ABI in the community. While I cannot guarantee that I completely represented the experiences of the support workers, I did strive to interpret their experiences to and find commonalities across their accounts to the best of my ability in order to provide useful insights into the support worker experience. In general, the insight at the individual level can lead to insight into the whole (Smith et al., 2009).

The commonalities across participants' experiences formed the following themes and sub-themes: *forming the relationship (*time commitment, trust and communication*), personalizing support, making a difference* (small successes), *growing personally* (new skills and awareness and self-reflection) and *becoming politically and socially aware* (advocacy).

The participants expressed that the basis of support work was around *forming the relationship* with the supported individual. The support workers viewed *time commitment, trust and communication* as foundational to their relationship with the individual. The support workers recognized the necessity of *personalizing support* for every individual. The supports provided were centred around the individual and their role in empowering the individual to choose and make their own decisions. In forming a relationship with the supported individual, the support workers found themselves *having an impact* on the individual. They recognized the *small successes* by finding value in the small successful moments that they had with the individuals. The support workers found that through support work they were *growing personally*. It was

evident that participants learned *new skills* and displayed an overall sense of expanded *awareness and self-reflection*. Support work was influential to the support workers *becoming politically and socially aware* and working with the supported individuals influenced them to take on an *advocacy* role.

  These themes provide a valuable perspective on how support workers experience supporting individuals with ABI, as well as the qualities that give support work meaning. The findings illuminate the many roles of a support worker, the varying nature of support work and provide insight into the different aspects of support work that greatly impact the support workers.

CHAPTER FIVE: DISCUSSION

Chapter Five begins with a summary of the present study followed by an analysis of findings in terms of the current literature. Then strengths and limitations of the study are identified. The chapter concludes with implications and recommendations for future research.

Summary of the Present Study

The purpose of this research was to explore the lived experience and meaning of being a support worker for individuals with Acquired Brain Injury (ABI) in the community setting. A review of the literature revealed that researchers have reported on the positive impact that community involvement (McCabe et al., 2007) and supported relationships (Hibbard et al., 2002; McCluskey, 2000; Redhead, 2010) have for individuals with ABI; however, there is a lack of exploration into the experience and impact of supported relationships for the support worker. Therefore, the purpose of this study was to hear from the individuals who provide support and explore their meaningful experiences supporting youth and adults with ABI in various recreational and social activities out in the community.

Findings of the current study demonstrated that the meaningfulness of doing support work was not based exclusively on positive or happy moments. Although participants reported the special moments of success associated with finding an enjoyable activity (e.g., driving around looking at cars or houses) or helping someone acquire a new skill (e.g., modifying a sports activity), there were also special moments associated with challenges, crises and loss (e.g., being there at a funeral, hearing a story of sexual assault). Similarly, previous research revealed that people found their work most meaningful in moments that were considered challenging but resulted in a sense of accomplishment (Bailey & Madden, 2016).

Two areas of meaningful experience were identified and explored in the present study. The first area was how the support workers *experienced giving in the supporting role,* which included three super-ordinate themes and three sub-themes. The first theme, *forming the relationship*, focused on *time commitment, trust and communication*, the elements that the support workers viewed as foundational to their relationship with the individual. The second theme, *personalizing supports* for the individual*,* explored how the support workers recognized the support they provided to be centred around the individual and their role in empowering the individual to be autonomous and make their own choices. The third theme, *making a difference*,

focused on recognizing the *small successes,* wherein participants recognized the value in the small successful moments that they had with the individuals.

The second area explored how the support workers *experienced receiving in the supporting role,* which included two super-ordinate themes and three sub-themes. In the first theme, *growing personally*, it was evident that participants learned *new skills* and displayed an overall sense of expanded *awareness and self-reflection*. The second theme, *becoming politically and socially aware,* described how working with supported individuals influenced the participants into taking an *advocacy* role for individuals with brain injuries. The following chapter provides a review of the findings and integrates them with current literature. This is followed by the strengths and limitations of the current study and concludes with the implications and directions for future research.

Meaningful Experiences That Give Work Meaning

The literature suggests that meaning is something many individuals strive for in their work and meaningfulness is often associated with a sense of pride and achievement. Previous research (Bailey & Madden, 2016) examined and revealed five qualities that gave work meaning. Bailey and Madden interviewed 135 people working in 10 different occupations in the United Kingdom (i.e., retail assistants, priests, artists, lawyers, academics, entrepreneurs, nurses, soldiers, stonemasons and garbage collectors) regarding incidents and times when they found their work to be meaningful. After reviewing the literature, they defined meaningful work as occurring "when an individual perceives an authentic connection between work and a broader transcendent life purpose beyond the self" (p. 55). In the current study, the participant's narratives coincided with Bailey and Madden's (2016) Five Qualities of Meaningful Work. The five features of meaningful work were labelled as self-transcendent, poignant, episodic, reflective and personal (p. 54-55).

In the present study, findings suggested that participants' experience of work were *self-transcendent*, *poignant, episodic, reflective and personal*. Bailey and Madden (2016) discovered that individuals experienced their work as meaningful when it mattered to others more than just to themselves. Thus, they described meaningful work as *self-transcendent*. Similarly, when talking about meaningful experiences, the participants focused on the impact of their work for the supported individuals and their families. For example, participants described empowering the

supported individuals to make independent decisions by planning their own activities and as a result the individuals enjoyed themselves more when they made the choice.

The participants also experienced the work as *poignant* because as noted earlier, meaningful moments did not only elicit positive feelings, but sometimes bittersweet or painful feelings. The meaningful experiences that stood out the most were ones where participants: (i) navigated situations that fell outside their existing zone of comfort (e.g., navigating inappropriate sexual comments by supported individuals or negativity by community members); (ii) listened to heart-wrenching experiences and managed challenging situations (e.g., being the first adult to hear about a sexual assault or an attempted overdose); or (iii) supported individuals through traumatic life events (e.g., being asked to attend a family member's funeral).

Throughout their interviews participants alluded to the notion that meaning occurred *episodically* throughout their work. All the participants took their time reflecting back on their relationship with the individual and were then able to recall meaningful moments that were scattered sporadically over the time spent with the supported individual. Similar to the participants in Bailey and Madden's study, the awareness that work was meaningful developed at "peak times" (p. 55) or pivotal moments the individuals had with the individuals they supported. That is, the experiences made enough of an impact on the participants that they were memorable and easy to recall during the interview. For example, one participant described that they found their work meaningful when they assisted a supported individual to modify a sports activity, a tangible sign of how their support helped the supported individual to succeed.

It is important to note that the awareness of the meaningful experiences often comes about through *reflective* thought because according to Bailey and Madden, it is only when participants were asked to describe a meaningful experience that they developed a conscious awareness of the significance of those experiences. Similarly, the participants in the current study found meaningfulness was not often experienced in the moment, but rather in retrospect. One of the participants pointed out that support work has made them more introspective; that is, she reflects on situations and identifies how she handled it and whether she can improve. Finally, the moments of meaningfulness were *personal* and frequently occurred when the experiences converged with recognition and expressed appreciation (e.g., hearing 'thank-you') from the supported individual.

Key Features of the Supporting Role

The participants' narratives provided a deeper understanding of their role as support workers and its varied nature. Very much like the findings reported by McCluskey (2000), who conducted an exploratory study with a group of paid carers supporting people with brain injury. Five major roles were identified: Attendant, Coach, Companion, Negotiator and Protector. McCluskey's framework gives a full understanding of the supports that are required and helps to provide an understanding of the wide and dynamic range of skills and qualities that support workers need to utilize (Redhead, 2010).

Within the parameters of the current study, the key features of the attendant role identified by participants included driving and planning recreational and social activities together. Next, the key features of the coach role included teaching the individual social skills (e.g., encouraging socially appropriate communication), motivating and "pushing" the individual by encouraging and challenging them to participant and progress in activities (e.g., modifying a sports activity). The role of companion included the establishment of reciprocity, trust and consistency between the individual and worker (e.g., asking and remembering supported individual's interests, being consistent with scheduled outings). Further, the key features of negotiator included advocating for the individual, setting limits and boundaries with the individual, mediating with the individual's family or guardian on their behalf and negotiating with the individual during an emotional moment or temper outburst (e.g., talking to the supported individual about the problem and reminding them that the support worker is there to help). Lastly, the role of protector described by the participants included maintaining physical and emotional safety by implementing strategies to maintain client safety in the community and preventing clients from injuring themselves (e.g., modifying an activity, being pro-active and giving choices to minimize outbursts).

The responsibilities and characteristics of the paid carers identified in McCluskey's study closely resembled those described by the participants in the current study. However, findings of the present study suggest a sixth role category of *role model*. The key features of this role include (a) being an active listener rather than passive (i.e., listening, concentrating, understanding, responding and recalling what was said), (b) empowering the supported individual to make decisions and be independent, (c) encouraging the supported individual to set and pursue goals, (d) helping the supported individual to problem solve, (e) offering the supported individual other

perspectives, (f) advising the supported individuals with problems and (g) boosting the supported individuals self-confidence and supporting them to make positive life-style decisions. Figure 5-1 provides a graphic representation and summary of support worker roles and the key features of each role organized according to McCluskey's roles plus the addition of a sixth role.

Attendant
- Coordinating weekly session
- Organizing recreational & social activities
- Driving to activities

Role Model
- *Actively listening*
- *Helping individual to set & pursue goals*
- *Problem solving*
- *Offering other perspectives*
- *Offering advice*
- *Supporting (+) life-style choices*

Coach
- Teaching social skills
- Being a motivator
- Encouraging & challenging individual to participate & progress in activities

Support Worker

Protector
- Maintaining physical & emotional safety of the individual
- Implementing strategies to stay safe in the community
- Preventing self-injurious behaviours

Companion
- Listening & talking (chatting)
- Forming trust & rapport
- Reciprocity
- Maintaining consistency

Negotiator
- Advocating
- Setting limits & boundaries
- Mediating with family members
- Negotiating with individual during a temper outburst

Figure 5-1. Summary of Support Worker Roles

    Forming the relationship: Time commitment and trust. The participants expressed that committing time each week to spend with the individual was necessary element to building a relationship. Over time they made connections, built rapport and formed a relationship with the supported individual. Langaard and Toverud (2009) asked forty-six students aged 16 - 22 years to reflect on support they had been given during stressful situations and the students all highlighted the importance of someone who *cared* about them. They found that the supporting person was perceived as a person who cares because they actively approached the young person

in personal ways. Similarly, participants reported that part of forming trust with the supported individual was paying close attention to the supported individual's specific interests and preferences and actively making them feel attended to and cared for (e.g., remembering that an individual loves skittles and bringing them a treat).

All the participants reported being in their support relationships for over a year and consistently met with their supported individuals once per week for several hours. Consistent with previous literature (Redhead, 2010), participants found that taking a consistent, non-intrusive approach that allowed the individual to determine when they felt comfortable to divulge information was important. The results of the current study supported Redhead's (2010) notion that individuals with brain injuries benefit from a consistent approach and effective relationships are built on trust and understanding with the same worker. Rhodes et al. (2005) posit that longer relationships are more beneficial because it takes a close and trusting relationship to foster change and growth in an individual. Likewise, the current study found that by forming a close and trusting relationship the supported individual was more open to having the support worker listen to their personal problems and offer a different perspective or advice.

Alexander and Charles (2009) conducted a study examining social workers' experiences of receiving care from their clients. Participants described how the relationship between participants and clients is dynamic. In general, participants noticed that every relationship changes over time and the client also directs the relationship. That is, the client also influences the amount of closeness between worker and client, the choice of activities they participate in together and when the relationship changes or ends. However, whether a more personal relationship developed was dependent on both the worker and client. Similar to the current study, it was both the workers and supported individuals that influenced the closeness and mutuality of the relationship.

Forming the relationship: Communication. Some of the themes that have been discussed thus far, such as time commitment, rapport building and trust are universal for the foundations of any kind of working relationship. Building a relationship with individuals with brain injuries is unique, however, because of the specific challenge of finding ways to communicate with each individual. This includes not only learning how to communicate appropriately with the individual, but how to best facilitate interactions between the support worker and individual, as well as with others in the community.

Communication involves the use of verbal and non-verbal language in social contexts and individuals with brain injuries often have a difficult time with their social communication skills. Previous research indicates that in order to improve social communication skills it is beneficial to practice in real-life situations (Dahlberg, Cusick, Hawley, Newman, Morey, Harrison-Felix & Whiteneck, 2007). The participants expressed that communication with some individuals was challenging at first but was vital component to building their relationship. Some of the participants described their experiences figuring out effective ways to communicate with semi-verbal individuals, such as learning the individual's non-verbal language cues and persevering to understand individuals who have difficulties with trying to state what they want to say. Further, one of the participants described helping to facilitate interactions between a semi-verbal individual and others in the community. It was evident that communication was an integral component to forming a relationship and inversely getting to know the individual and their oral language skills and preferences were necessary to communicating with them.

Previous research (Jacobson et al., 2012) examining the job roles of paid peer support workers in a hospital-setting found that one of the main types of direct work was related to relationship building with clients. The participants suggested relationship building included the work of initiating, establishing and maintaining relationships with clients. Similar to the current study, throughout the relationship building process the peer support workers developed trust and rapport with clients by conversing with the client and giving advice when needed, or simply listening to what the client had to say.

Personalizing supports. Participants explained that it was essential to personalize the supports for each individual. Consistent with previous literature that describes the diverse nature and wide array of problems associated with brain injuries, findings of the current study demonstrated that the type and level of support was different for each supported individual. Redhead (2010) depicted this accurately when she described the role of the support worker as open-ended. Likewise, the participants described providing an array of supports ranging from teaching social skills to participating in a game of badminton or accompanying the client for lunch.

Services for individuals with disabilities are promoting a more person-centred culture. This culture is based on beliefs, values and behaviours wherein people direct their own lives (Saskatchewan Social Services, 2019). Person-centred approaches acknowledge the rights of

individuals to make informed choices and take responsibility for those choices (Person Centered Thinking Training Collaborative, 2015). Likewise, the participants in the current study provided support that was personalized and focused on the strengths, skills and goals of the individual with ABI. Consistent with other person-centred approaches the participants in the current study treated the individuals with respect and empowered them to set and reach their own personal goals and make their own decisions. The participants in the current study supported the individuals in planning their own activities and provided them with opportunities to make informed decisions. I believe when an individual is happy and enjoying what they are doing they are most receptive. It is in those moments when trust and rapport develop which was reflected in the transcripts when participants shared that they found it easier to connect with individuals when the individuals enjoyed the activity.

As previously mentioned, Jacobson and colleagues (2012) examined the job roles of paid peer support worker's in a hospital-setting. Consistent with the present study, they found that another one of the main types of peer support work was related to skill-building, mentoring nd goal setting. In addition, some of the specific activities that made up this type of work intersected with the current study, including one-on-one conversations in which the peers and support workers provided advice and encouragement to the individuals they supported. For example, one participant told the story of a supported individual who divulged that they had attempted to overdose. The participant discussed the situation with the supported individual, the feelings that led to the situation and better ways to handle future situations that involve similar feelings.

McCabe and colleagues (2007) examined community reintegration after an ABI and found independence and social integration facilitated post-injury recovery. Likewise, Brown, Gordon and Spielman (2003) report that social participation is often impacted post-brain injury due to the cognitive and behavioural challenges that the individuals face. In addition, Gordon and colleagues (1998) posit that recreational activity is beneficial to individuals with brain injury, but is often ignored due to the challenges of integrating individuals with physical or other types of disabilities. The participants in the current study demonstrated that they assist individuals with ABI socially integrate into the community by helping them to participate in recreational and social activities, while fostering their independence at the same time.

McColl and colleagues (1997) conducted a qualitative study that sought to establish a clearer definition of community integration by asking people with brain injuries their own

perspectives on community integration. One of the indicators that participants described was independence and how sometimes they experienced staff supervision to be a hindrance towards their efforts to be independent. The researchers proposed that there may be ways of structuring supervision that are less intrusive and more self-directed by the individual and hopefully as a result the individuals will perceive it as being supported rather than supervised. Further, they note that perhaps supervision is provided in the interest of safety, however, this still may undermine the individual's efforts to be more independent and self-determining. In the current study, support workers noted their efforts to allow the activities to be self-directed by the individual and the importance of empowering the individual to be more autonomous decision makers. Participants in the current study provided the supported individuals with opportunities for supported decision making by encouraging the supported individuals to choose the activities they wanted to participate in.

Making a difference: Small successes. The participants expressed their appreciation for the support relationship and the opportunity to make an impact on the individual. Further, the participants described how they knew the client appreciated them. Consistent with previous literature (Alexander & Charles, 2009), the participants described overt and subtle gestures that made them aware of the supported individual's care for them. As previously mentioned, Alexander and Charles' (2009) study explored social workers' experiences of receiving care from clients. The social workers reported awareness of care from overt actions including hugs or invitations to special events and subtle gestures including friendliness, personal inquiries, or shared laughter. In the current study participants described overt gestures of care from their participants including hugs, smiles, invitations to special events and direct verbal gratitude or positive acknowledgement. The subtle gestures of care that participants described included friendliness, sitting together, advice-seeking, personal inquiries, or shared laughter. It was apparent that participants felt appreciated when they thought about the positive feelings generated when they and the individual spend time together.

Johnson and Davis (1998) applied a supported relationships intervention to increase the integrated social contacts of three individuals with brain injury. Each individual was matched with four community participants, meeting once per week for four weeks to participate in leisure activities. Similar to the present study, naturally occurring reinforcement helped to maintain the supported relationship. Johnson and Davis found that the community participants rated their

experience better when the individuals they were paired with demonstrated appreciation by thanking them and verbalizing how much they enjoyed their company. Two participants, Grace and Sue, expressed that hearing the individuals thank them reinforced the notion that they were not only appreciated by the individual, but that that their role as a support worker was impactful. Therefore, the more reinforcing the contact for the participant the greater the possibility that the support worker feels their work is making a difference and the more they want to stay in the supporting role.

The participants described the value in the smaller successful moments that they had with the individuals and acknowledged their positive influence in helping the individuals to progress. Amabile and Kramer (2011) explored the concept 'the progress principle' and found that people are more productive when their inner work lives are positive. They found that participants were happy when they were intrinsically motivated by the work itself. They also examined what events could evoke emotions, motivations and perceptions. When comparing participants' worst and best days, they found that the most common event to trigger a 'best day' was any progress in the work made by the individual or the team. They also found that actions that support work (e.g., help from a person) and events such as words of encouragement and acknowledgement were events that triggered a best day for participants. In general, when participants were motivated and happy by the end of the workday, it was because they had made some progress with their work. Likewise, participants in current study reported small events that they deemed successful elicited a positive reaction and emotion afterwards. These small events included watching an individual become successful by helping them to modify a sports activity, or witnessing the individual try new things, such as calmly entering a new environment.

The current study supported Amabile and Kramer's (2011) findings that even small wins can boost inner work life. In their study, the progress events that participants reported were only small steps forward, nonetheless, the small achievements evoked positive reactions. Even the small events that often go unnoticed increased engagement, happiness and are important to the overall performance of organizations. Likewise, participants in the current study found that the small, incremental achievements they made with individuals were important to the overall success and progress of the individual.

Growing Personally: New skills. It was evident that participants developed new skills through their job as a support worker. One of the participants talked about how she came to

realize her potential as a caring individual and found that the work changed her perspective of herself. In that way, participants found themselves learning from the challenges they faced throughout their work. Participants learned to navigate new situations and developed skills from those situations. See Table 5-1 for example situations and learned skills.

Table 5-1

Example Situations and Learned Skills

New Situation	Learned Skills
▪ Witnessing the supported individual fighting with or trying to harm another person or themselves	▪ Deescalating the situation and preventing the individual from hurting themselves or others
▪ Inappropriate sexual comments made by supported individuals	▪ Learning how to respond
▪ A supported individual divulges serious information (e.g., sexual assault, overdose)	▪ Actively listening ▪ Engaging with the individual to encourage them to tell their story ▪ Strategizing - Suggesting alternative strategies for future situations
▪ Community members making uninformed comments	▪ Learning how to be assertive when necessary and verbally advocating for supported individual
▪ A supported individual has difficulties with the physical aspects of an activity	▪ Being resourceful and adaptive ▪ Being a motivator
▪ Communicating with individuals who have difficulty with verbal communication	▪ Being patient, understanding and dedicated

Growing personally: Awareness and self-reflection. The current study found that participants reported a changed perspective and social outlook about others based on their work supporting individuals with ABI. Previous research found that quality contact between children (Armstrong, Morris, Abraham & Tarrant, 2017) and adults (Keith, Bennetto & Rogge, 2015) from the mainstream population and individuals with intellectual disabilities can lead to more positive attitudes and lower levels of negative attitudes and prejudice towards disability. Consistent with the present study, higher levels of quality of contact were related to participants supporting the inclusion, autonomy and empowerment of individuals with disabilities. Further,

participants that had higher levels of quality contact found it easier to connect disability with something positive and valuable.

In addition to having an increased awareness of individuals with ABI and their abilities, the participants had an increased awareness of themselves and their own abilities. The participants found that the development of meaningful relationships required refining relational skills and reflective practice. The majority of participants found themselves reflecting on their feelings, perspectives, responses and reactions to situations with the individual in order to adjust or modify for the future.

Becoming politically and socially aware: Advocacy. As participants continued to work with the supported individuals, they found themselves advocating for the individuals they support and for the service that they provide as support workers. Being out in the community with the supported individuals made participants aware of the stigma that the individuals face (e.g., community members expressing that the supported individual was a dangerous person), but also the strength and capabilities of the supported individuals. Participants expressed that these personal experiences encouraged them to develop advocacy skills. Previous research (Fraas et al., 2007) found that there is an unmet need for community education regarding the impact of ABI and the needs of survivors. Consistent with the current study, participants felt that misconceptions and lack of knowledge has an impact on community members' perceptions and interactions with the individuals with ABI.

Participant's described the work they did to promote community understanding of individuals with ABI and to increase community knowledge about support workers in general. This is consistent with previous literature (Jacobson et al. 2012) that found advocacy encompassed both the work that the participants did to fight for the rights of their clients and the work that they did to provide clients with the means to fight for themselves. Consistent with previous studies (Jacobson et al. 2012), the current study found that participants perceived themselves to be involved in advocacy work when they did things like providing information to individuals and community members and working with supported individuals to build-up their self-confidence.

Strengths of the Study

There are several strengths in this study. The findings of this study added to the limited literature surrounding the meaning of support work for the individuals doing the supporting and

the experiences of this work for support workers of individuals with ABI. The current study explored the personal experience of meaningful work, the supporting role and the impact of supporting relationships for community support workers of individuals with ABI.

The second strength of the current study was the data collection method. Semi-structured interviews allowed participants the opportunity to share, in their own words and reflect in-depth on their experience without the limitations of a strict interview schedule (Smith et al., 2009). This form of in-depth interviewing prompts participants to recount stories, thoughts and feelings about their experience. Further, one-on-one interviews allowed for the development of rapport with participants, gave participants the opportunity to share their stories at their own pace and allowed the researcher and participants to engage in a detailed, purposeful dialogue (Smith et al., 2009).

The third strength was the use of IPA as the specific qualitative approach as a means of exploring how support workers experience supporting individuals with ABI in community settings. Utilizing IPA, participants were able to offer an in-depth, first-person description of their experiences. Further, the idiographic and phenomenological nature of IPA allowed for detailed engagement with a small homogenous sample of participants and a rich examination of experiences from multiple perspectives (Smith et al., 2009). This involved an in-depth data collection and analysis processes, wherein participants' transcripts were examined on a case by case basis to find themes. The structure also allows for examination of themes across cases to explore connections among the cases. In the current study, IPA provided detailed descriptions and interpretations of the participants lived experiences as support workers (Alase, 2017). In general, an advantage of qualitative methodology is that they involve interactions between the researcher and participants and this open dialogue makes it less likely for misinterpretation of the participants' responses (Alase, 2017). Further, the use of semi-structured interviews allowed the participants to provide more in-depth narratives and recount their experiences in their own ways.

A fourth strength was the use of a small, homogenous sample which allowed for detailed examination of convergence and divergence among cases (Alase, 2017). Further, the homogeneity of the research participants and the small sample size created a rich and detailed analytical process (Smith et al., 2009).

The final strength of the study was the impact of the research process on the support workers. Throughout the interviews the participants appeared eager to share their experiences. Several participants expressed that they were excited for the opportunity to share their insights and express their thoughts regarding their work and the individuals they work with. At the end of the interview, several participants expressed that they found the process affirming. Being able to share their thoughts and feelings with someone who wanted to listen and was understanding and empathic to their situation, was confirming for them. The interviews also reinforced to me (the researcher) that there are other support workers who think and feel in similar ways and their experiences overlap and are congruent with my own. Overall, the interviews were a positive experience for both the participants and the researcher.

Limitations and Delimitations of the Research

Limitations are elements of the study that are beyond the control of the researcher, but are inevitable due to constraints of the methodology and design (Simon & Goes, 2013). A limitation of the study was that the research was conducted by a novice qualitative researcher. As a novice researcher, I found the task of learning the intricacies of qualitative research and writing this thesis, to be complex and demanding on top of my other responsibilities. Other limitations include the time commitment to participate and the time constraints of gathering the research data. There may have been individuals who met the criteria for the study but were too busy to commit to the two-hours needed to participate. The data gathering stage of the research was conducted within a short time frame for a masters-level thesis and a longer time frame may have allowed participants to find the time to commit to an interview.

Delimitations arise from limitations in the scope of the study and the decisions made by the researcher during the development of the research design (Simon & Goes, 2013). A delimitation of the study was the specific nature of support work being explored (i.e., community support work for individuals with ABI). The experiences of support workers in the present study may be restricted to experiences supporting individuals with moderate to severe brain injuries. Generalizations to other forms of support work, or to support workers working with other disability populations (e.g., intellectual disability, severe brain injury), should be made carefully. Finally, all the support workers were women and were identified through my own work connections. As a support worker myself, I had pre-existing connections or work

relationships with the participants. The above factors may limit the generalizability and transferability of the findings to other support workers.

Implications of the Research

The results of the current study provide insight into the lived experiences of support workers and the support role they provide in the community for individuals with ABI. This is especially important because there is a lack of exploration and research into the experience and impact that supported relationships have for the individual providing the support. The current study provided findings based on personal accounts that detailed support workers' meaningful experiences supporting individuals with ABI in various recreational and social activities out in the community. These results may be of interest to a variety of audiences.

Results may benefit new and on-going support workers who work in the community with the brain injury population. The narratives within the present study may provide validation for other support workers, in that they may be able to relate to the stories and know there are others who understand their experiences. The findings may serve to inform and prepare individuals who are new to support work by giving them a glimpse into the experiences of existing support workers. Further, the findings may provide valuable knowledge to on-going support workers so that they can be better prepared to provide quality support.

The results may benefit organizations that employ community support workers for individuals with ABI. The findings provide insight into the need for support agencies to spend more time and money training new staff for this type of work. Complex interpersonal skills were required by all support workers. Specifically, the support workers needed be creative, determined and resourceful to figure out ways to communicate with individuals, to negotiate and resolve conflicts, to establish boundaries and to be assertive. Further, a deeper understanding of ABI is required. For support workers to understand the range of difficulties that can be experienced by individuals with ABI, including the less visible cognitive and emotional changes, more education and training is needed prior to supporting the individual. Previous research (Redhead, 2010) suggests that individuals with ABI benefit from a consistent approach and an effective relationship built on trust and understanding with the same workers. Overall, support workers who have training cope with demands better and are more likely to stay in their position.

Considerations for Future Research

There is a need for more research, qualitative and quantitative, about support workers' experiences and the meaningfulness of their work supporting individuals with ABI in the community. The current study provided understanding into how support workers experience supporting individuals with ABI and the support worker role in the community. This was the first study, to my knowledge, that examined the meaning and impact of this work for the support worker. Therefore, future research is warranted to further examine support work in the community and the meaning and impact of support relationships on support workers, the individuals they support and other stakeholders. The current study specifically explored the support workers' experiences of support work in the community. One further question that arises is, how do others observe support workers out in the community? Also, how can other individuals, such as employers, job coaches, recreational therapists and other helpers interact with each other to achieve the best outcome in providing the individual with opportunities for community recreational and social activities?

Given the findings of the current study, specifically that the support workers felt their work impacted both themselves and the individual they supported, it would be worth examining how individuals with ABI experience community support and the impact this support has on them. Further, previous research has found that involvement in community-based programs for individuals with brain injuries has been associated with an increased level of met needs (e.g., increased quality of life, emotional and social support; Hibbard et al., 2002; Fraas et al., 2007), improved family functioning (Ergh et al., 2002; Hibbard et al., 2002) and decreased feelings of social isolation (Johnson & Davis, 1998; Leith, Phillips & Sample, 2004). However, there remains a need to examine the impact of community-based support programs on family members. Further, it would also be worthwhile to explore the meaningful experiences of community support workers for individuals with different types of disabilities and contrast that with the current study's findings.

Lastly, future research could focus on service provision for individuals with ABI. There are a limited number of programs that provide recreational and social supports for youth and young adults with ABI. Moreover, during the interviews, participants expressed frustration with the state of the current community climate regarding community support for individuals with disabilities. It was evident that there is limited community knowledge regarding the roles of a

66

support worker and the community services they provide. A challenge I encountered while conducting this research was the ambiguity of terminology used for this type of support. Within the literature, I came across many different names given to the individuals providing the support (e.g., paid care provider, respite worker, support professional), the service they provide (e.g., community integration, mentoring, respite) and the names used to describe the individuals they support (e.g., client, participant, mentee). This area needs more attention to gain a better understanding and conceptualization of the roles and contributions that support services and workers offer these individuals, as well as the terminology used to describe it.

Researcher Self-Reflection

Due to my own personal experiences, there were several occasions throughout the research study where I tried not to lead the participant being interviewed to the conclusion that I assumed they were making, based upon my own experiences. In reflection, there may have been instances where I could have asked participants for more elaboration or clarification, but may not have because I thought I fully understood what they were saying. This was something I had anticipated prior to the interviews however, so I tried my best to be cognizant of it throughout each interview.

The experiences of participants all felt very familiar to me, but that did not surprise me. Although participants' perspectives did not really surprise me, I found it quite reassuring and confirming to know that others shared my experiences and perspectives of supporting individuals with ABI in the community. Several participants also expressed to me after their interview that they appreciated the chance to be heard, and that getting to share their experiences was very validating. This helped me to realize the importance of sharing workplace experiences, especially so in one-on-one work environments. Sharing experiences with co-workers may help to ensure that community-based support workers for individuals with ABI understand and acknowledge that they are not alone. It also allows for experiential learning from others, and gives them the means to reflect on situations, gather feedback, and learn how others respond to situations. It gave me a great sense of reassurance and optimism that participants were doing the best they could with the resources that they had been given.

Conclusion

The purpose of this research was to explore the experience of support workers and what they found most meaningful about supporting individuals with ABI in the community setting. The literature revealed a lack of exploration into the experience and impact that supported relationships have on the individual providing the support. Therefore, to fill this gap the current study explored five support workers' lived experiences supporting youth and adults with ABI in various recreational and social activities out in the community.

Based on the support workers' meaningful experiences that were explored utilizing IPA, five super-ordinate themes and six sub-themes emerged: (1) how they experienced giving in support work, with three themes of (a) *forming the relationship* (time commitment, trust and communication), (b) *personalizing support and* (c) *making a difference* (small successes). (2) how they experienced receiving in support work, with two major themes (a) *Growing personally* (new skills and awareness and self-reflection); and (b) *becoming politically and socially aware* (advocacy). The themes provided insight into how and why community support work is meaningful to the support workers and the experience of giving and receiving in support work.

Through the individual interviews, participants shared personal experiences that gave their work meaning. Findings aligned with many of Bailey and Madden's (2016) core qualities that give work meaning. Participants displayed a deep understanding for the impact of their work on themselves and the individuals they support. Additionally, participants revealed several key elements that were foundational to their supporting role. When the key elements were interpreted alongside McCluskey's (2000) five major roles of a paid carer, it was found that all five roles (*Attendant, Coach, Companion, Negotiator and Protector*) were identified. The results revealed additional key features that support a sixth role category which fit that of a *Role Model*. The findings of this study provide an improved understanding of the qualities that give support work meaning and brings to light the aspects of support work that greatly impact the individuals that provide the support. My hope is that the identified core roles help to provide a better understanding of the scope of support that is required, the challenging nature of the work and the range of skills and qualities that support workers use to understand every individuals' unique needs in order to provide them with tailored supports.

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Department of Educational Psychology and Special Education
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Do you provide support for individuals with Acquired Brain Injuries?
Do you find this work meaningful?
Would you be willing to talk about your experiences in a 1-1 interview?

We are looking for volunteers to take part in a study of **support workers** who provide **community-based support** (e.g., outreach, respite, mentoring) to **youth and young adults** (ages 10 – 25) **with Acquired Brain Injuries (ABI)**.

To participate, you must
- Have worked for at least **6 months** supporting youth and/or adults from the ages of 10 – 25 with ABI out in the community.
- Have provided consistent **one-to-one support** (e.g., once a week for 2+ hours) in structured or unstructured activities.
- Find the work of supporting individuals with ABI to be personally **meaningful**.
- Have **approximately 45 – 90 minutes** to meet and discuss your experiences as a community-based support worker.

If you are interested, please contact Bethan Weeding by email:
bethan.weeding@usask.ca

This project was reviewed and approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board (BEH#147) on July 20, 2018. To thank-you for your participation, each participant will be entered into a draw to win a $30 gift card.

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Appendix B: Semi-Structured Interview Guide

1. Demographics:
   - Gender: M or F or Other
   - Age:
   - Where do you work:
   - What age of individuals do you support?
   - Years of experience:
   - Mailing address or Email (Request Final Transcript):

2. Introduction to the Research:
   - The purpose of this conversation is to learn about your experiences as a support work for individuals with acquired brain injury and in particular, how this work is meaningful and positively impacts you.
   - There are no wrong answers to the questions that I ask and you can talk freely as we consider the topic and discover new insights and understanding together.
   - Again, please talk freely about your experience as a support worker.

3. Let's begin by having you tell me about your experiences doing support work with individual(s) with ABI. Starting from the beginning, tell me how you got involved, what it's been like and where you are now.
   Prompts:
   - How did you get involved with supporting individual(s) with ABI?
   - How long have you been doing this work?
   - Could you take me step by step through a typical day or outing?
     - Describe what you do together and your role.
     - Could you describe a recent typical outing?
   - Could you give me some examples of recreational/social activities you do?
   - What about the work appeals to you?
   - In what ways, do you make connections/ build a relationship with the individual you work with?
   - Have there been any changes in your relationship since you first met?
   - Have there been any challenges associated with support work?

4. Please think about a meaningful experience you had supporting an individual with ABI that stands out for you. Then tell me about it, from beginning to end.
   Prompts:
   - What did you see? Hear? Smell? Do?
   - How did you feel?
   - Who else was involved? what were they doing?
   - Where were you? what space were you in?

5. Please think of another meaningful experience, maybe different in some way than the first story you told me. Again, then tell me about it, from beginning to end.
   Prompts:
   - What did you see? Hear? Smell? Do?
   - How did you feel?

- Who else was involved? what were they doing?
- Where were you? what space were you in?

6. Please tell me how support work has impacted you
      Prompts:
- What, if any, are some significant circumstances or events that stand out [have impacted] your relationship?
- How would you describe the meaningfulness of this work?
- How does this work positively affect you? personal benefits?
- What would you say is the biggest motivator [for you &/or others] for staying in this line of work?
- In your experience is there anything about this work that can be improved?

7. What advice would you give someone thinking about doing this work?

8. Is there anything we haven't talked about/discussed that you would like me to know about supporting individuals with ABI?

Appendix C: Consent Form

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College of Education

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Support Workers' Experiences of Supporting Youth with Acquired Brain Injury

REB# 147

You are invited to participate in a research study titled *Support Workers' Experiences of Supporting Youth with Acquired Brain Injury*. Please read this form carefully and feel free to ask me any questions you may have about the study.

Researcher(s): Bethan Weeding, B.A. (Hons)., Department of Educational Psychology and Special Education, University of Saskatchewan, Email: bethan.weeding@usask.ca

Supervisor: Jennifer Nicol, Ph.D., R.D.Psych., M.T.A., Department of Educational Psychology and Special Education, University of Saskatchewan, Phone: (306) 966-5261, Email: jennifer.nicol@usask.ca

Purpose and Procedure: The purpose of this study is to understand the experience of supporting youth with Acquired Brain Injuries (ABI) in the community. Once you express interest to participate in the study, you will receive an email to set up an interview. The interviews will take place at your convenience and preferred location. The interviews will be audio recorded and transcribed. The interview will be approximately 60 to 90 minutes long and will ask questions related to the participants experiences as a support worker out in the community. The interviews will then be transcribed and analyzed for content and themes. Data within the thesis will be either summarized form or direct quotations, however, no identifying information will be used.

Potential Risks: There are no known risks that will result from participating in this study.

Potential Benefits: By taking part in this study you will help us to better understand how support workers are positively impacted by their experiences of supporting individuals with ABI in the community. We hope our findings will contribute to ways in which we can best assist and support individuals in supporting roles. You may also find it helpful and enjoyable to reflect on and share your experiences with the student researcher.

Confidentiality and Storage of Data: At all times, no personally identifying information will be used and a pseudonym will be used to describe any data related to the participants. Further, all audio recordings will be kept confidential and all information provided for this project will only be shared with members of the project team. The data will be stored separately from the consent forms in a secure office assigned to Dr. Jennifer Nicol at the University of Saskatchewan. Data from these interviews will be used for Bethan Weeding's master's thesis and may be presented in journal articles and/or professional conference presentations.

Right to Withdraw: Your participation is voluntary and you may withdraw from the research project for any reason, at any time, without penalty of any sort. You have the right to refuse any questions at any time. If you choose to withdraw from the project, any information that has been contributed will not be used and will be destroyed. Furthermore, you will still be entitled to an entry into the gift card draw for

your time. Your right to withdraw data from the study will apply until November 30, 2018. After this date, it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data.

Questions and Follow-up: If you have any questions concerning the research study or if you wish to receive a copy of the final report, please feel free to ask the researchers (Bethan Weeding or Dr. Jennifer Nicol) using the contact information provided at the top of page 1.

This research project was reviewed and approved on ethical grounds by the University of Saskatchewan Research Ethics Board on July 20, 2018. Any questions regarding your rights as a participant may be addressed to the Research Ethics Office at 306-966-2975 or ethics.office@usask.ca. Out of town participants may call toll free at 1-888-966-2975.

Consent to Participate: Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project. I understand that I may withdraw my consent at any time. A copy of this Consent Form has been given to me for my records.

Signature of Participant	*Date*

Student Researcher's Signature	*Date*

Bethan Weeding, B.A. (Hons), M.Ed Candidate
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