

Negotiating Care: How Care is Negotiated between a Young Carer and a Parent Facing Mental Illness and Addiction

by

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Abstract

This study explores the negotiation of care between a young carer and a parent facing mental illness and addiction. The paradigm derived from the current research focuses mainly on issues faced by young carers, seeing them as a population at risk. With an overrepresentation of research exploring children's caring work, the highly complex relationships between disabled and/or ill parents and their children who care for them tend to be overlooked. Using action theory this study explores a case study of a young carer and parent to answer the question: how is care negotiated between the two? The results demonstrated the fluidity in the relationship in terms of how care was negotiated and that it was more reciprocal than that which is often presented in the literature. This reciprocity challenges the stigma and stereotypes often associated with young caring and parents with disability and/or illness and can help inform both future research and practice.

Preface

Ethical approval for this research project was obtained from the University of British Columbia Behavioral Research Ethics Board (BREB), certificate number H10-01484.

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Dedication

To my parents

1 Introduction

This study explores the negotiation of care between a young carer and a parent facing mental illness and addiction. The paradigm derived from current research focuses mainly on issues faced by young carers, seeing them as a population at risk (Banks et al., 2001). With the largest portion of research exploring children's caring work, the highly complex relationships between disabled and/or ill parents and their children who care for them tend to be overlooked (Aldridge, 2007). In an effort to fill this gap in the literature, this case study attempts to answer the question, how is care negotiated between a young carer and a parent receiving care?

The topic of young carers has been studied extensively with little consensus on a widely accepted definition. North American literature tended to use the term *parentification* to describe the young carer relationship (Barnett & Parker, 1998). Parentification occurs when a parent's disability and /or illness causes them to completely disregard the needs of the child which results in the child taking on the parenting role in the family (Barnet & Parker, 1998). Although parentified children are often young carers not all young carers are parentified (Charles, Stainton, & Marshall, 2008). Taking on the parenting role implies a role reversal and a distribution of power that is less than optimal for child development. That being said, socially acceptable levels of responsibility taken on by children are largely dependent on age, ethnicity, gender and social class (Charles et al., 2008) and for that reason a universal definition of who is considered a young carer does not exist (Aldridge & Becker, 1999). What we do know is that although some level of caring is encouraged throughout childhood as a healthy part of development; young carers tend to take on a more extreme level of

caring (Aldridge & Becker, 1999; Charles et al., 2008). The caring duties taken on by these children and adolescents vary depending on the parents' level of disability and/or illness (Aldridge, 2006), but many carers are involved in one or more of the following: emotional support, domestic work, personal care, healthcare treatments and/or financially assisting the family (Moore, 2005). The presence of disability and/or illness in a family does not automatically lead to children within the family taking on a caring role; rather, young caring is often triggered by a combination of a family member's onset or presence of disability and/or illness combined with a lack of adequate support from other family members and/or the community (Thomas et al., 2003). Although a number of studies have attempted to narrow in on the definition of young carer, more attention has historically been given to investigating the experiences and needs of either the young carer or the parent with little attention paid to their relationship.

Past young carer research reveals that early studies tended to focus on the experience of the disabled and/or ill parent and later evolved to mainly focus on the experience of the young carer (Aldridge & Becker, 1999). The parent and the young carer were explored largely in isolation of one another. A brief overview of the past perspectives regarding young caring will better help to illustrate the current need for a more relationship-orientated approach.

The early medical model, which emerged in the 1950's, focused on parental disability and ill health, examining the causes of family breakdown (Aldridge & Becker, 1999; Olsen, 1996). Children were rarely mentioned in this model and when they were it had little to do with their caring roles but rather their maladjustment and behavioral problems. The social model, which first emerged in the 1970's, focused its attention on

the needs and experience of disabled adults (Aldridge & Becker, 1999). Children were often mentioned in this perspective but it was in terms of being at risk of developing illness while the emotional impact on children's well-being was more or less ignored. Recent models use a rights based perspective in exploring young carers but still focus on either the parent or the child thereby overlooking the negotiation of care between the two.

The recent disability rights and child rights perspectives focus mainly on the rights of either the parent or the child (Thomas et al., 2003). The disability rights perspective believes that if disabled parents' rights are fully realized and their needs met, young caring would not exist and therefore see increased support for disabled parents as a main intervention for alleviating the burden on young carers (Aldridge & Becker, 1999). This perspective also suggests that supports put in place for young carers legitimize children's work and exploitation (Aldridge, 2008). In contrast, the child rights perspective emphasizes empowerment of children as they are considered competent individuals who may not be as vulnerable as previous research has indicated. As such, attention needs to be given to supporting young carers in the decisions they make (Thomas et. al., 2003). Although both perspectives present valid points, they do so largely in isolation of the other participant in the caring relationship and creating a debate between the idea of safeguarding young people versus supporting those who are already in caring roles (Bolas, Van Wersch, & Flynn, 2007). The dichotomy created by these perspectives, once again, largely ignores the rich diversity within caring relationships and how caring is negotiated. The family centered

approach most closely represents a model of thinking that includes both the young carer and parent receiving care.

The family-centered approach is a newer perspective that strives to simultaneously bring the rights and experiences of all involved in young caring together and support each family member according to their individual needs. Although exploring children's experiences and needs regarding being young carers is very important it is also critical to do so in the context of the *entire* family. Family centered approaches attempt to provide support for young carers (Grant, Repper, & Nolan, 2008) by working within the context of the family to move towards a more holistic approach (Butler & Astbury, 2005). It has been argued that ineffective interventions will remain so if they do not start addressing the needs of the entire family (Aldridge, 2006). This lack of family and relationship understanding can be seen in the literature regarding parental supports and young caring.

Interventions remain scarce in Canada; research dedicated to the topic has been conducted in the United Kingdom, Australia and America. The majority of the current interventions in these countries focus on the young carer and only a handful of supports are orientated towards disabled and/or ill parents. Looking at literature on current parent supports helps to illustrate the lack of understanding regarding negotiation of care between young carers and disabled and/or ill parents (for example, Grant, Repper, & Nolan, 2008). Similar to the lack of support available to young carers there is a lack of adequate services for parents experiencing disability and/or illness (Banks, et. al., 2002). The services that are available often rely on the assessment of parenting capacity which are rarely accurate and over-focus on parental deficits (Aldridge, 2006).

Such supports assume that disabled and/or ill parents are incapable of adequate parenting which results in children taking on the caring role in the relationship which thereby reinforces the view that the caring relationship is of one directional nature from parents to children. This assumption of parental inadequacy assumes there is little negotiation and children are often forced into the role. Parenting with a mental illness or disability is more complex than the implied simple carer-dependant relationship.

Disability and illness covers a wide range conditions including physical disabilities, mental illness and addiction and it is inaccurate to assume that these parents requiring help from their children are inadequate parents (Banks et al., 2001). Studies indicate that parents often continue to retain their parenting status (Aldridge, 2006) and continue to have control over their children while at the same time relying heavily on children to keep parents healthy and safe (Walmsley, 1993). Being a parent, in particular being a mother, is a largely accepted social role and for mothers with mental illness it can be a normalizing life experience (Nicholson, Sweeney, & Geller, 1998). Although many mothers with mental illness experience stress and difficulty dealing with both children's needs and managing their own illness (Nicholson et al., 1998) many mothers dealing with mental illness identified parenting as an expression for feelings of concern and care and fundamental to one's sense of self (Oyserman, Mowbray, Meares, & Firminger, 1999). It is important to note that while disability and/or illness may influence the parent-child relationship, certain aspects may manifest in a way that is considered 'normal' in typical parent-child relationships. Investigating the complexities of these relationships will enhance the ability to help support families.

Similar to research available on mental illness and parenting, the research available on drug addiction and parenting focuses largely on the negative effects on children and the problems faced by the parent (Barnard & McKeganey, 2004). Children are seen as being at risk for having problems developing healthy relationships, entering into care, and misusing substances themselves (Barnard & McKeganey, 2004; McKeganey, Barnard, & McIntosh, 2002). In regards to parents and addiction, studies have found that increased use of problematic substances by parents is associated with harsher forms of discipline, decreased supervision and less involvement in the children's lives (Kandel, 1990). This being said, it is important to note that addiction often occurs in cycles of recovery and relapse (Barnard & McKeganey, 2004), meaning the relationship between parent and child changes depending on where the parent is in the cycle. Care is negotiated and looks different in different periods of the cycle. Studying the negotiation of care may result in a better understanding of how care changes over time between parents and their children who provide care.

The image of inadequate parenting that is often associated with disability and/or illness can also be explained by looking at the social construction of what is considered to be 'normal' expectations of parenting and a 'proper' parent (Stables & Smith, 1999). Many of these parents cannot fit into the prescribed role. As such, it may be necessary to revisit the definitions and criteria socially accepted to be considered an acceptable parent (Stables & Smith, 1999). Understanding the negotiation of care between the young carer and a disabled and/or ill parent would help to draw a more accurate and inclusive picture of what can be included in a 'normal' framework of parenting.

Although it is inevitable that parental disability and/or illness can generate concerns regarding parenting (Kahng, Oyserman, Bybee, & Mowbray, 2008) the responsibilities of the parent and young carer are often blurred and shift depending on the needs and state of the parent (Walmsley, 1993). Disability and/or illness often result in episodic times of needing either more or less care and as a result the relationship between young carer and parent continues to be negotiated depending on the parent's current state (Oyserman et al., 1999). In a time of parental health-related difficulties a young carer may take on an excessive amount of caring work as opposed to when the parent is doing well and the young carer's role is minimal. Therefore, the relationship is fluid depending on the type of disability and/or illness and the parent's current state of need. It is this fluidity in the negotiation of care that is missing from current research. A greater understanding of this negotiation of care will not only help guide programs of support for families but also hopefully shed a more positive light on the caring relationship which currently is viewed as being negative in nature and comprised of static carer and dependant roles.

There is an overemphasis in the research on the young carer in isolation (Aldridge, 2007). The current research generally ignores the negotiation of care between the parent and child. Past research has largely overlooked parents' perspectives which are an integral part of the interpersonal relationship that is developed through the reciprocity of care (Cass, 2007). As mentioned, parenting and young carer responsibilities are constantly changing depending on the children's availability and parents' current state. Understanding the negotiation of care will help to inform more holistic support services. In order to advance our knowledge of the young

carer field, the interdependent and reciprocal nature of the caring relationship within the family needs to be acknowledged and explored in order to nurture and support these relationships in the form of services, procedures, and policies (Aldridge & Becker, 1999). It is for this reason that this study has chosen to explore the negotiation of care between a young carer and a parent. Action theory (Valach, Young & Lynam, 2002) has been used to analyze a mother experiencing mental illness and addiction and her daughter who is a young carer.

To better understand negotiation of care one needs to look at the power and roles that exist during the negotiation. Traditionally, parent-child relationships have been examined through single domain lenses such as attachment or socialization which has constrained the views of power in a relationship (Harach & Kuczynski, 2005; Kuczynski, 2003). A vertical distribution of power with parents holding power over children is typically seen in literature on parent-child relationships. However, more recent conceptualizations include both a vertical and a horizontal power distribution. A horizontal power distribution is often observed when the relationship is more reciprocal in nature (Harach & Kuczynski, 2005) such as during play (Russell, Pettit, & Mize, 1998).

The nature of young caring more likely involves fluctuation between vertical and horizontal power relationships depending on the parental state and the abilities of the child. Horizontal parent-child relationships are considered to be a healthy aspect of adolescent development (Russell et al., 1998), they are only considered unhealthy when the child takes on the role of the parent, or parentification. Typical parent-child relationships are often motivated by the parent's cognitions regarding the importance of

the child's autonomy and the belief in the rights of the child (Russell et al., 1998).

Although these values may influence disabled and/or ill parents, necessity for care will also be influential in shaping the power arrangements between parents and their children.

Another issue in assuming that horizontal power relationships imply parentification is that it ignores how young carer relationships can be reciprocal in nature. When a child provides care to a parent it does not mean that the relationship is one sided. Horizontal relationships can be reciprocal by either both participants simultaneously sharing power or alternating who is in control (Russell et al., 1998) as would likely be more common among young carer relationships. The parent and a young carer would alternatively take on more or less responsibility in the relationship depending on the family's current needs. Balancing relationships does not imply neutralizing of power. Each participant may still have control or power over the other (Emerson, 1962). In other words, although horizontal relationships may be present with the young carer holding some power, the parent does not necessarily lose their parenting status (Grant et al., 2008). It is also important to note that past research has viewed children of parents with disability and/or illness as passive recipients of change and that in more recent studies parents and children are viewed as being active agents in developing caring relationships which are now viewed as being bidirectional in nature (Byrne, 2003).

In summary, the current literature on young carers tends to paint a picture of a carer-dependent dichotomy when in reality young caring is part of an interdependent and reciprocal relationship (Aldridge & Becker, 1999). Several studies have begun to

highlight the importance of understanding caring work as a relationship of interdependence and reciprocity (Aldridge & Becker, 1999; Ely, 2004; Aldridge, 2006; Walmsley, 1993) and that the family needs to be considered as a whole for interventions and supports to be successful (Aldridge & Becker, 1999). Young carer relationships are likely more fluid and complex than the current young carer research implies. Using action theory to explore the negotiation of care in the young carer dyad will allow for an increase of knowledge regarding the negotiation of care which will help to inform future research exploring the young carer-parent relationships.

1.1 Theoretical and Methodological Approach

The theory used for this study is action theory which is largely based on the past work of von Cranach and colleagues (1982). Valach, Young, and Lynam (2002) describe action theory as a language used to explore the applied tasks which humans engage in during everyday life. This language is shared and used to describe what individuals are doing in a common environment (Valach et al., 2002).

Action theory views actions as goal-directed and intentional behaviors (Young et al., 2006). These actions have the ability to be cognitively manifested and verbally expressed but they are also often physically manifested which can enhance the understanding of the action (Valach et al., 2002). These behaviors are believed to be organized into three different levels: goal setting, strategies and operations (Valach et al., 2002). In the case of the young carer and parent dyad, a goal may be to keep the family intact with the strategy of having the child take on caring responsibilities. Operations refer to the ability to adapt to changes such as the parent's level of need.

Each of these levels can be explored in more depth to extract the finer details of what motivates the actions.

Joint action refers to the actions between two or more individuals. Within joint action the three levels of organization are present at both the individual and group level. The dyad may share the goal of keeping the family together but there may be different sub-goals and organizational steps for each participating individual. The behavior and regulation of the dyad is believed to be communicated between participants who organize actions and sub-goals to move towards the highest shared goal (Valach et al., 2002).

A key concept of the action theory method is that the actions observed between members of a dyad are the unit of analyses as opposed to the individuals themselves. Although individual actions are observed, this method emphasizes the importance of looking at the joint actions in the dyad, such as that of young carer and parent. In joint action, the actions of each participating individual intersect and are largely guided by the present environment (Valach et al., 2002). Young carers and parents can be seen engaging in joint actions over time which contributes to the construction of the parent-child relationship.

Furthermore, actions are believed to be 'energized' or set in motion by emotional processes. These processes are present throughout the progress of action (Valach et al., 2002). The child's and parent's emotional process of love and loyalty towards the family can be seen as motivation for involving a child in care taking responsibilities. Energizing of the action is mostly required at the beginning of action or when changes occurs (Valach et al., 2002).

As mentioned, action theory is also interested in action over time and the present case study took place over a six month time period which again allowed for the ability to see the change over time in action and how that related to the mother's different stages in the cycle of relapse and recovery as well as her mental health.

Action theory was chosen for this particular case study as it allowed for the identification of a parent's and child's goals and steps to reach those goals thus making it possible to identify the dyad's ability to negotiate care. Action theory was a useful way to collect, organize, and code the data and then a modified approach, using content analysis, was used to identify the negotiation of care.

2 Methods

Data collected from a previous study was reanalyzed using the same techniques as originally employed. In the data analysis of the previous study on career development, the research team identified one of the dyads being comprised of a parent being cared for by an adolescent. The mother self-identified as being addicted to illicit drugs and experiencing unipolar depression. In the initial interview the mother and child discuss how the child supports her mother during her recovery and depression reveals the child as a young carer.

This case was used to explore the negotiation of care between a young carer and parent. A case study need not on be a single person (Stake, 1995). In this instance the case is that of a mother-daughter dyad and those that support them. A within case analysis allowed for an in-depth study of the negotiation of care between a young carer and parent. Little is known of the present topic and a case study allowed for gaining an understanding of the complexity of a single case (Stake, 1995). Deep investigation into the dyad's data revealed information that might otherwise be missed in a larger cross-analysis of multiple dyads. Gaining an understanding of the negotiation of care is a beneficial first step before pursuing larger scale comparisons.

The following outlines how the data for the previous study, conducted by Marshall et al. (in press), were collected. It is from this sample that the data from a single dyad and their social supports were used for further analysis to explore the negotiation of care between a young carer and mother experiencing addiction to drugs and depression. The protocol for the original study was reviewed and approved by the University of British Columbia behavioral research ethics board.

The protocol for the original study involved four phases of data collection and analysis. The first phase consisted of observations of parent-adolescent conversations and video recall interviews. The second phase included member checks regarding initial analysis of the data from the first phase. The third phase consisted of brief bi-weekly telephone interviews for a period of approximately six months and the fourth phase was a talking circle interview with the parent-adolescent dyad and the identified supports they invited. Interviews were digitally recorded and then transcribed; transcriptions were checked against the recordings for accuracy.

2.1 Participants

Participants for the previous study were recruited via broad-based poster and newspaper advertising. Potential participants contacted the research team who then conducted a quick interview over the phone to determine if the interested family met the study's participation criteria. Participation criteria included dyads consisting of an adolescent between the age of 13 and 16 years and one legal parent or guardian. Parent-adolescent dyads were invited to bring up to four family members and/or social supports to the final interview. Participants were briefed about confidentiality and any risks involved in participating in the study before signing consent and assent forms. All participants were reimbursed for their travel expenses to and from the interview location and each participant received a \$25 honorarium for each interview attended.

2.2 Sample

The original sample was comprised of 11 parent-adolescent dyads ($n = 22$) and their social supports ($n = 17$). All but one adolescent ($n=1$) were attending school at the

time of the study; adolescents in school ranged from grade eight to ten. Parents were between the ages of 32 and 47 with varied marital statuses.

The dyad selected for the current study was a mother-daughter dyad. The daughter was 14 years of age and attending school. The mother was 34 years of age and experiencing depression and drug addiction. The daughter cared for her mother by providing emotional support when needed regarding using drugs and feeling depressed. Both the parent and the adolescent brought one person to the final interview. Certain aspects regarding the dyad and their supports are being excluded from the description of the participants to prevent revealing of their identities.

2.3 Data Collection and Analyses

Phase One. The first interview consisted of an orientation and rapport building period. In this interview dyads were guided in beginning to think about the adolescent entering adulthood and his or her future. Participants were then asked to converse, without the researchers present, about topics that had emerged in the first part of the interview until they felt the conversation had naturally ended. On average these conversations lasted 16.47 minutes. The conversation of the dyad described in this study was 14.02 minutes in length.

Directly after this conversation, each participant reviewed the video recording of the conversation with an interviewer without the other participant present. Participants were asked to recall thoughts and feelings they felt during each one-minute segment of the video-recorded conversation. Video recall interviews lasted an average of 34.69 minutes for parents and 32.03 minutes for adolescents. The video recall interviews of the mother and daughter in this study were 48.24 and 26.21 minutes long, respectively.

Data from Phase One was analyzed to develop two individual narratives and one joint narrative. The narratives were developed through analysis of the individual and joint goals that were identified by the research assistants at both the macro and micro level. The narratives summarized each participant's goals and the functional steps taken to move them towards those goals.

Phase Two. The second interview took place six to eight weeks after the first. Each participant of the dyad was interviewed separately and was presented their individual narratives and given a chance to discuss any changes they felt needed to be made. The dyad was then interviewed together to review the joint narrative to ensure that the identified joint career development project was in congruence with the dyad's views. At the end of the interview the participants were given instructions regarding the third phase of the study.

Phase Three. The following six months was a monitoring period with an interviewer phoning the adolescent and parent separately every two weeks. Participants were asked about changes in the family's joint project, if any activities relating to the project had occurred and if there were any feeling associated with those activities.

Phase Four. At the end of the monitoring period a talking circle interview was conducted for each dyad. Participants were invited to bring up to four individuals they identified as being supportive in the context of the project. The interview began with an overview of the narratives derived from Phase Two and the remainder of the interview was guided by the following questions: 1) Where did individuals feel the joint family project was going (continuing, already completed)?, 2) What roles did individuals feel

they played in the joint project?, 3) How involved did participants feel in this joint project? Coding for the analysis of the data from phase one was applied to the data from the talking circle interview. This final interview also provided a time for participants to be debriefed about the experience of being a part of the study.

Data collected from phase one, three, and four was used for the young carer dyad being analyzed for the current study. The first interview was coded using the original studies coding template and each participants goals and functional steps were determined for each minute of the dialoged. The same was done with the final interview which included the goals and functional steps of the supports brought in by the participants and the two talking circle facilitators. Unlike the original study the goals and functional steps were then used to conduct a content analysis to identify when and how care was being negotiated. The data from the six month monitoring period was used to gain a better understanding of the family's context and was not coded for in-depth analysis.

3 Findings

3.1 Initial Interview

In the initial joint conversation, parent and adolescent were asked to discuss the adolescent's career development and supports she receives during the process. In other words, care of the daughter was the topic of discussion. Minute by minute analysis of this conversation reveals the mother and daughter alternating the focus of discussion from the daughter's care, to care of the mother by the daughter. The dialogue began with the daughter taking charge of the conversation by asking "So mom, how was your last relapse?" The daughter's initial goal for the conversation was to discuss her mother's recent relapse. The mother answered her daughter's question with little hesitation and discussed her feelings and progress for a full minute before the subject was changed. This initial joint action demonstrates the daughter's ability to attain power within the relationship via controlling the conversation and requesting information about her mother.

The conversation transitioned from talking about the mother's progress since her last relapse to how to the two participants support each other. The information presented by both mother and daughter indicate the reciprocal nature of the relationship as both participants discussed examples of how each supports the other. Regarding how the mother supports her daughter:

Daughter: You get me...involved in extracurricular activities.

Mother: I um always know where you are now too.

The daughter expressed humor about the number of things her mother helps her become involved in. When asked what she does for her mother, she expressed anger

that her mother would assume she does little to support her and she gives the following examples:

Daughter: I come home when you need me and I'll talk to you if you're feeling depressed or feel like going to use yadayadayada. I work on my Steps [12 Steps] with you, I'll go out with you. I don't know yadayadayada (laughing) I basically I help you out when you tell me to help you out.

The daughter continued to take charge of the conversation by asking her mother what she would do if she (the daughter) would ever relapse. The mother used exaggerations (e.g. "I'd kill ya") to emphasize the fact that she would be upset which she then followed with a serious discussion about her daughter's future:

Mother: You have dreams. And you – you drugs can't be a part of those dreams. Drugs is for people who don't have dreams. You know ... drugs is for people who don't have a future. Right? They – they get high off of that instead of life. You know you - you can get high off of life. You have a future. Right? You have a good chance of really making something really big out of yourself.

The mother had now taken control of the conversation and the reciprocal nature of the relationship is once again revealed as she took on a clearly more powerful role. The mother's conversation with her daughter also demonstrated her ability to maintain her parenting status while simultaneously dealing with a mental illness and recovery from addiction. The daughter remained quiet while her mother talked.

The mother further demonstrated her parenting role in the relationship by discussing her daughter's personality and how it compares to her own. The daughter asked about what type of person she (herself) was and the mother used hand gestures to indicate they were both independent rather than conforming to others around them:

Mother: You're a lot like me. And you know [cough cough] so you know that [cough cough] – let me put it this way... I get you things to head in any direction you want. Right?

The dialogue transitioned into the mother explaining how drugs had negatively affected her life as a method to deter her daughter from doing the same. The daughter interrupted her mother to describe how it is the two support each other which reinforces the idea of both young caring and reciprocity:

Daughter: We support each other by always being there when one of us needs us.

While discussing how the mother supports her daughter the daughter mentioned her need for time alone. The conversation went back and forth with each participant presenting their case and it is evident that the mother sometimes needs the support of her daughter which may infringe on her daughter's time to herself which is often mentioned in the research as a negative side effect for young carers:

Daughter: I'm just sitting alone in my room and you come in there and I'm like – go away – You don't support me.

Mother: But I want to talk.

Daughter: I don't!

In the final portion of the dialog the mother initiated the topic of discussion regarding the daughter's career options and choices. The mother asked questions about her daughter's career choices and about hypothetical situations with the goal of helping her daughter gain a deeper understanding of the careers in which she has expressed an interest.

This initial conversation between mother and daughter contains evidence of both participants' acquired control of the conversation and caring for the other which demonstrates the relationship's reciprocal nature. Both participants took control of the conversation and what is said by each participant paints a picture of the mother and the daughter taking on a carer and dependant role at different times in their relationship.

3.2 Telephone Monitoring

Over the six month telephone monitoring period the daughter was telephoned every two weeks and was successfully contacted three different times and was asked a series of questions about her career development projects. Each telephone interview was conducted by a different research assistant. These interviews provided information about the family context in the period between the first and second interview. The daughter described development towards her career aspiration to have an acting/singing career in each of the interviews. When asked about how the mother and daughter had been moving towards the daughter's career goals, the daughter mentioned helping her mother:

Daughter: I try and help out as much as I can.

This statement may indicate the daughter taking on a caring role. Indication of the mother's caring role was also mentioned in the discussion of the daughter's birthday party which the mother was helping to organize. The daughter also started to write about her mother as an inspirational female in her life for a writing contest which reflects the feelings she has towards her mother. Although the data from the telephone interviews is not in-depth enough to draw substantial conclusions, it provides insight into the dyad's life of the way they care for one another.

3.3 Final Interview

The final interview's topic of discussion was again the daughter's career development but unlike the first interview each participant brought a support person with them. Two facilitators were also present. The final interview was in the form of a talking circle which began with a facilitator explaining how the talking circle worked followed by each participant introducing themselves.

The facilitator who opened the talking circle took the time to outline the purpose of the study and what it is the researchers were looking to discuss in the circle, which was how the daughter is supported by others in her career development. The support person that the mother brought to the circle started the talking circle by discussing how he had supported the mother in her recent relapse and his involvement in helping others around him.

The circle continued with the mother talking about her daughter but quickly digressed when she began to talk about her own relapse which occurred two weeks before the final interview. The mother's inability to talk about anything other than her own current situation as opposed to the care of her daughter paired with the information provided about her relapse and depression indicated a time of struggle with her mental illness and addiction. The daughter was silent while the mother spoke. At one point the daughter left the room saying she needed to use the washroom. After approximately ten minutes of talking about her own situation the facilitator attempted to bring the mother back to the subject of her daughter:

Facilitator 1: I haven't heard you mention [daughters name] in the last 5-10 minutes.

From this point the mother was able to discuss the daughter again but chose to focus on a story about the daughter not listening to her instead of discussing the topic of care and support. The facilitators then intervened in order to move on in the talking circle by suggesting they move on to the next participant, the support person the daughter brought to the circle.

The daughter's support person discussed how the daughter had supported her in her times of need and that the daughter calls her when things are not good at home as, for example, mother's recent relapse. The mother interrupted and said her daughter often helps others with their problems and how her daughter evolved into that role:

Mother: She was a leader for the longest time and she started to be a follower in the second semester of grade 7 and now since she's back in recovery she's taken on that leader role again...

This statement by the mother about her daughter demonstrates that even in her own state of high need regarding her mental illness and addiction recovery she has knowledge about her daughter's development and has the ability to describe it. The facilitator asked the mother about the support person the daughter had invited to the interview and the mother described her daughter's relationship with her friend and how she supports it:

Mother:[friends name] is at my house...[friends name] is a good kid and I know that she's not going to go the drug way so you know it's a positive relationship.

This, again, indicates her ability to assess her daughter's relationships with others and how to support her positive peer relationships. The facilitator asked the daughter's support person for more information about their relationship. After the

friend's response the mother discussed her daughter's singing career and her interest in interior design, once again demonstrating her ability to support and care for her daughter:

Mother: she also has an opportunity to make the demo, another demo but she hasn't wrote out a song or memorized a whole - a whole song and so I've been you know nailing her about that and for months...I've been telling her 'cause this is her dream right...

Initiated by the facilitator, the talking circle moved on to the daughter who had little to say about her own career development. She answered the facilitator's questions about the support person she brought to the interview and got into an argument with her mother when she was asked to stop digging in her bag. The mother and daughter argued about the bag with the mother gaining little ground and the daughter disregarding most of what the mother said.

Through the mother's initiative, the conversation turned to the topic of the daughter's self esteem which the daughter was reluctant to discuss. The members of the talking circle discussed the daughter's relationships with boys and although it was off topic it again demonstrated the mother's ability to show concern for her daughter:

Mother: She was saying in front of everybody 'I'm ugly' and I'm like '[daughters name] you're not ugly'...so she's really down on herself and you know it's - it's been hard for me to hear my daughter say that cause I think she's beautiful.

The conversation then veered off topic for several minutes until the facilitator redirected the focus to the topic of the supports persons the mother and daughter brought along to participate in the talking circle interview. Both mother and daughter discussed why they chose to bring their support persons with them to the interview.

The mother discussed how her support person has helped her in the past and what she was described very similar to what the daughter described in the initial interview as how she supported her mother. The parallel between the daughter and support person's caring responsibilities reinforces the idea of the daughter's caring role in the relationship:

Mother: me and [support's name] go to some functions or some meetings together.

Once again, the mother began to talk about her own situation. The facilitator acknowledged her story but redirected the focus to the daughter's social support when an opportunity arose. The daughter's social support discussed her family life and her own mother's situation and the talking circle ended with the mother interrupting and telling a story she had heard which she found comical.

Throughout this final interview the mother frequently steered the conversation towards herself and despite the facilitators' efforts to focus on the daughter's career development, the mother had great difficulty maintaining a discussion regarding care of her daughter. Compared to the initial interview where a more reciprocal relationship was seen between mother and daughter, the daughter said little during the conversation and the mother displayed her struggle with mental illness and addiction. The lack of knowledge regarding the daughter's silence makes it difficult to gain an understanding of how much care was being provided for the mother in her state of high need. However, the daughter's actions suggest a non-verbal form of negotiation with the daughter sending a message to her mother through her silence and leaving the room. There is no way to know what message the daughter was attempting to convey but the

act alone indicates a type of care negotiation. The mother was able to discuss her daughter's development and care occasionally throughout the interview but did not stay on this topic long and was often prompted to focus on the daughter by the facilitators.

The results demonstrate the mother's and daughter's ability to negotiate care and the reciprocal nature of their caring relationship. Although significantly varied, in both times of recovery and relapse the mother was able to maintain some form of parenting and care for her daughter. On the other hand the daughter discussed the care of her mother in her time of recovery but said little of the care in the mother's time of relapse again demonstrating the shifting amount of care and how it is negotiated.

4 Discussion

This study explored the negotiation of care between an adolescent young carer and her mother who experienced addiction to illicit drugs and depression. This approach to studying a young carer challenged the carer-dependant dichotomy which is more often portrayed in existing literature. Data from a previous study was reanalyzed looking at the joint actions between mother and daughter to gain a better understanding of how care is negotiated between the two. The findings are discussed in two sections, the first being how care was negotiated in the first interview and second how the two interviews compare to one another over time.

Although it was mentioned earlier that some level of care and responsibility is encouraged for healthy adolescent development, the emotional support present in this dyad can easily be considered a more extreme level of caring as stated in the definition presented by Charles and colleagues (2008). Emotional support is present in the form of the daughter being available for her mother when she (the mother) is feeling depressed or feeling like using drugs. The daughter's expression of her desire for time on her own is also consistent with reported negative effects of young caring, as many young carers report a lack of time to oneself (Cree, 2003). The daughter's caring role does not, however, fit the definition of a parentified child outlined by Barnet and Parker (1998), as the daughter does not take on a parenting role in the relationship, that role is maintained by the mother.

It is revealed in the initial interview that the mother-daughter relationship is quite reciprocal in nature which is in accordance the findings of Aldridge and Becker (1999) as the two participants each discuss the support they give one another. The daughter's

opening question at the beginning of the interview about her mother's relapse is a clear indicator of the daughter taking a powerful role in the relationship. This, combined with the mother's description of how she supports her daughter and the daughter's description of their mutual support, paints a clear picture of a reciprocal relationship that is in agreement with Byrne's (2003) idea that the caring relationship is bidirectional. Mother and daughter both receive and give care, this does not however infringe on the mother's ability to maintain her parenting status.

Walmsley's (1993) findings regarding parents with disabilities who still retain control over their children while relying on them for care, are seen in the findings of this case study. In this particular case the mother is still heavily involved in her daughter's life and organizing her extracurricular activities, while at the same time relying on the daughter's support to help in her own recovery. The daughter's examples of how she supports her mother include that she helps her mother when asked which demonstrates their negotiation of care outside of the interview setting. It is interesting to note that the mother asks for help whereas the daughter, according to the data, seems to be given support without request. This alludes to the difference of care provided by the mother and this young carer. This arrangement of care will be different for every young carer relationship but for this dyad it is an important difference in how the care is given and received.

Findings from both interviews challenge stereotypes of parenting inadequacy (Banks et al., 2001) that currently exist regarding parents with illness and/or disability. In the second interview, the mother expresses some of the difficulties she has parenting; she discusses the difficulty she has controlling her children and her need for

time to herself. Difficulty in parenting is inevitable (Kahng et al., 2008) but the mother also demonstrates, especially in the initial interview, her ability to care and support her children as well as negotiate that care with her daughter. These findings demonstrate the mother's ability to parent her child while in relapse and recovery and can help to move away from the stereotypes associated with young caring and parenting. These types of findings could possibly challenge the stigma that is currently often attached to people with a mental illness and/or addiction who parent.

A better understanding of a parent's abilities and the negotiation of the caring relationship could potentially help develop supports for families where young caring is occurring. The recommended family centered approach (Grant et al., 2008) could greatly benefit from this understanding. It could also help agencies develop family support programs that empower families to take control of the caring relationship. Control of the relationship and negotiation of care could potential make the caring relationship a more positive experience for all involved. As Aldridge (2006) argues, the entire family needs to be involved if supports are going to be effective. As mentioned earlier, many interventions and supports that are currently available for young carer assume the child is highly vulnerable and the parent is incapable of parenting. It is clear from looking at the findings of negotiation of care from this dyad that both mother and daughter have strengths and weaknesses. It is a combination of the two that makes it work for them. Focusing on just one side of the relationship would exclude an important aspect needed to properly support those involved in the caring relationship.

Parent-child relationships are typically viewed as being of vertical power distribution with the parent holding power over the child (Russell et al., 1998). The

findings from this dyad demonstrate that while power may be balanced and shared, power is not necessarily neutralized. This is consistent with the early findings of Emerson's (1962). During the negotiation of care the daughter has power when asking about her mother's relapse but this does not diminish the power the mother has over her daughter regarding things such as support and extracurricular activities. Power in the negotiation of care is being shared but not cancelled out as both participants retain power over the other. This, again, reinforces the idea that the caring relationship is more fluid and complex than it is represented in much of the young carer literature.

Since data were collected through separate interviews spaced several months apart, negotiation of care can be seen across time. In the first interview the mother was in a state of recovery from illicit drug use and in the second she had recently relapsed and displays a number of struggles, such as her difficulty in discussing the care of her daughter, compared to the initial interview. This fluctuation changes the level of care provided by the daughter. This can be seen in the final interview by the lack of discussion of how the daughter cares for her mother, as the mother dominated the conversation. In the initial interview it was the daughter who discussed how she supported her mother. In the second interview the daughter said little unless asked for information by others.

It is not possible to interpret the daughter's silence as many things were different in the two interviews but it is still important to note the daughter's different behavior in the two interviews. The change in behavior could be equated to the fact that that more participants were present creating a different environment opposed to the intimate setting of the first interview. Either way, there is a clear change in how care is

negotiated during recovery and relapse and understanding that the cyclical pattern of addiction and mental illness would be a great asset for interventions and support services hoping to assist families consisting of a young caring relationship.

In the initial interview the topic of discussion was the daughter. Although both the support of the mother and daughter was discussed, it was much more balanced than in the final interview. The mother dominated the conversation throughout the final interview although it is difficult to say whether she had the power in the conversation or a lack of power to control her own need to discuss her problems. That being said, one the facilitators regularly redirected her attention to the topic of discussion, and when prompted the mother was still able to discuss her daughter's care.

Regardless of the mother's tendency to veer off topic, she was able to discuss her daughter's career development and make observations about the daughter's behaviors. This finding supports the earlier reported finding that parents with a mental illness and /or addiction still retain some of their abilities to parent. Stigma is strong regarding parental mental illness and addiction. Comparing the initial and final interview for this dyad it is clear that the mother has increased difficulties in parenting when there are increased difficulties regarding mental illness and addiction, but can still discuss the care of her daughter.

The comparison of the two interviews captures the complexity of the young carer-parent relationship and demonstrates the need for supports. Researchers need be open to each unique family's situation, and that the relationship between young carer and parent is more than a carer-dependant dichotomy. In the initial interview care was negotiated in a balanced manner, giving insight into the reciprocal nature of the caring

relationship. In the second interview little care was negotiated between parent and child. This demonstrated the cyclical pattern of parenting with a mental illness and addiction. Therefore, care too would be different depending on the current state of the parent. This study has explored the negotiation of care in hopes of gaining a better understanding of the complex relationship between young carer and parent.

4.1 Limitations

The secondary data used for this study was originally used to study adolescent career development. Although career development is a form of parental support the topic of discussion was not specifically that of young carers. The young carer dyad happened to reveal itself to the researcher of the past study. The data might have been richer if the topic of discussion had been: how do you, as a young carer and a parent with a mental illness and disability, negotiate care? Nonetheless, the natural occurrence of the topic of care suggests that the dyad's actions are not forced to fit with the research question.

Although coding and findings were checked against a coding template from the original study, the data analysis is that of one person's work. It is possible that another researcher's analysis of the data could result in alternate findings.

This study was also limited by the fact that the second interview did not involve a video recall interview following the talking circle as was done in the initial interview. The video recall in the initial interview allowed for the participants to explain what they were thinking and feeling during each minute of dialog, making it possible to better understand the goals of each participant allowing for a better understanding of the negotiation of care.

The final interview did not involve a video recall interview because of its complexity with the large number of participants. As a result, it was more difficult to determine the goals of each participant as the only data were what was observed in the interview. The daughter's silence and her brief exit from the second interview could have been better understood if the researchers had an opportunity to ask what she was feeling and thinking during the interview. The goals coded for the participants during the second interview were more vague than in the first. A video recall interview would have allowed for richer information.

4.2 Implications

As this was a case study analysis, no generalizations can be made. These findings can rather be seen as a starting point for further research regarding young caring and negotiation of care. Previous to this study little was known regarding how care was negotiated between parents and young carers with the assumption that young carers passively took on the role. The findings from this study shed light on the fact that care is negotiated to determine what kind of care is given and received by both mother and young carer. This study reveals important information about the reciprocity of the young caring relationship as well as looking at the fluidity and complexity of the caring relationship over time. Studies comparing larger sample groups would be able to make more accurate generalizations, which would hopefully inform support services for families where young care relationships exist. Although generalization cannot be made from this case study analysis, the idea of being open and respectful of each family's unique relationship needs can hopefully be taken away.

5 Conclusion

Much of the current young carer literature explores the parent or child in isolation of one another thereby overlooking the highly complex relationship that exists between the two. This study used action theory to analyze two interviews of a young carer-parent dyad and explored their negotiation of care. Results showed the relationship was fluid in terms of how care was negotiated and more reciprocal in nature than the common carer-dependant dichotomy which is often portrayed in the literature. The reciprocal caring relationship allowed for challenging of the stereotypes and stigma often associated with parents living with disability and/or illness demonstrating that parents can retain power and control in the relationship with their children while at the same time relying on them for their care. The comparison of interviews over time demonstrated the cyclical nature of both mental illness and addiction, resulting in different levels of care provided by the child depending on the parent's current state. Findings from this study can be used to inform future research regarding young carers and negotiating care, which in turn could be used to greatly improve both understanding and supports for families and the young carer-parent relationships within them.

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in the parent-adolescent projects of families with and without challenges. *Journal of Vocational Behavior*, 68, 1-23.

Appendix A: Certificate of Approval



The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - MINIMAL RISK

PRINCIPAL INVESTIGATOR: Sheila Marshall	INSTITUTION / DEPARTMENT: UBC/Arts/Social Work	UBC BREB NUMBER: H10-01484
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
Institution		Site
UBC Other locations where the research will be conducted: N/A		Vancouver (excludes UBC Hospital)
CO-INVESTIGATOR(S): N/A		
SPONSORING AGENCIES: N/A		
PROJECT TITLE: Negotiating Care: the relationship dynamics between a young carer and a parent facing mental illness and addiction		

CERTIFICATE EXPIRY DATE: June 18, 2011

DOCUMENTS INCLUDED IN THIS APPROVAL:	DATE APPROVED: June 18, 2010	
Document Name	Version	Date
Protocol: Research Proposal	1	June 1, 2010
Consent Forms: Parent consent for youth	1	June 11, 2010
Parent consent for self	1	June 11, 2010
Assent Forms: Youth assent	1	June 11, 2010
The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.		
<i>Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:</i>		

Dr. M. Judith Lynam, Chair
Dr. Ken Craig, Chair
Dr. Jim Rupert, Associate Chair
Dr. Laurie Ford, Associate Chair
Dr. Anita Ho, Associate Chair