

Symbiosis by Persons with Disabilities: Perspectives from Interviews

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Abstract: This study reports on an interview perspective on symbiosis by persons with disabilities. A main theme, Elements of Symbiotic Collaboration, emerged from the data, along with several subthemes. Symbioses described by participants are closely related to the concepts of independence and interdependence in the Disability Studies literature.

Keywords: Symbiotic Collaboration, Independence, Interdependence

Introduction

As an occupational therapy practitioner, the first author occasionally observed instances in which clients assisted each other at various tasks in occupational therapy. For example, one client with mental illness and another with both cognitive and visual impairments collaborated and assisted each other on the respective craft projects each was doing. Informal observation suggested that the two clients were able to accomplish more on their projects via collaboration than if they worked on their projects individually. Moreover, they appeared to gain a sense of satisfaction from what they were to accomplish together. Finally, a sense of friendship emerged from their having worked together to attain a goal.

Instances such as this stimulated questions about the broader nature of collaboration by persons with disabilities and how they were manifested beyond the context of therapy. For example: when, why, where, and how do people with disabilities in the community collaborate with others in their lives? Is collaboration by persons with disabilities important to their lives, and, if so, why?

Consequently, the first author undertook a study of collaboration by persons with disabilities. During the data analysis for that larger study, the concept of symbiosis emerged, defined here as a mutually beneficial two-way interaction of giving and receiving wherein the contributions of one party matched needs on the part of the other, and vice versa. In order to

delve into the rich data around the concept of symbiosis, she decided to do a secondary analysis. The current, preliminary study represents an initial effort toward that end. We would like to first provide some background information from the literature regarding the important concept of symbiosis.

Literature Review

A dictionary definition of symbiosis is “1: The living together in more or less intimate association or close union of two dissimilar organisms...; esp[ecially]: MUTUALISM 2: A cooperative relationship (as between two persons or groups)...” (Merriam-Webster, 2005, p. 1266). The word “symbiosis” appears to readily apply when considering mutual, cooperative relationships between persons with disabilities and others in their lives, such as observed by the first author and described by her in the introduction, in which each partner to the symbiosis brings his/her different contributions as well as needs to the interaction. Nevertheless, the concept of symbiosis by persons with disabilities is minimally addressed in the occupational therapy literature or in health care literature in general. However, the phenomenon of symbiosis by persons with disabilities is directly relevant to a contemporary discussion of the concepts of independence and interdependence as they are discussed in the Disability Studies literature.

Independence

The concept of independence has long been addressed in the Disability Studies literature. Scholars argue that an antiquated definition of independence, stemming from the medical model of disability (Goggin, 2008; White, Simpson, Gonda, Ravesloot, & Coble, 2010), still prevails in rehabilitation and in society. This concept of independence focuses on whether a person can perform necessary self-care tasks and desired daily activities without the aid of another person. Conversely, persons with disabilities are considered dependent if they need assistance from another person throughout their day (DeJong, 1979; Nosek & Howland, 1993). Such dependence is considered undesirable and thus something to be avoided.

The Disability Rights movement and the Independent Living movement (White et al., 2010) revolutionized the definition of independence. Writers argue that instead of focusing on measures of functional ability, independence should focus on individuals being in control of their choices, their decisions, and their lives, thereby being self-determining (Longmore, 1995; Oliver, 1993; Parker, 1993; Scheer & Luborsky, 1991; Nosek, 1993). This is echoed by Milner and Kelly (2009), who report that “the most highly valued forms of participation were self-chosen activities that people undertook with a degree of autonomy” (p. 56). Nosek and Fuhrer (1992a, 1992b) provide a hierarchical model of independence with four progressive need stages of “basic survival, material well-being, productivity, and self-actualization” (1992a, p. 5) and developed a profile measuring independence based on the following four non-traditional components of independence: “perceived control over one’s life...psychological self-reliance...physical functioning, and...environmental resources (1992b, p. 3).

Interdependence

As the concept of symbiosis is synonymous with mutualism, defined as “1: the doctrine or practice of mutual dependence as the condition of individual or social welfare; 2: mutually beneficial association between different types of organisms” (Merriam-Webster, 2005, p. 820), symbiosis is a form of interdependence. According to Condeluci (2014), a disability advocate, interdependence “...implies interconnection, or an interrelationship between entities. It suggests a connection or partnership between the entities in an effort to maximize potential for both groups” (p. 8).

The concept of interdependence is flourishing among people with disabilities. According to Gill (1995), recognizing interdependence as a part of existence is a central value of the disability community. Longmore (1995) states that persons with disabilities have values which stem from their experience of interdependence, connection to, and affiliation with others. Jacobs (2002) views interdependence as having enormous value to empower people with disabilities because of increased connection and the resulting sharing of information and knowledge. White et al. (2010) discuss the interdependence model, which “stresses building social capital capacity among consumers to help them participate in their communities to the fullest extent they are able” (p. 237), while Condeluci (2014) discusses the interdependence paradigm as a major change from the medical model view of disability.

The Disability Studies literature provides a few examples of interdependence; each involves collaboration as a central component. For example, Scheer and Luborsky (1991, p. 1176) describe an elderly woman with disabilities who, upon her husband’s demise, “lost... a valuable disability ally who helped her maintain physical comfort and functional capacity”. French (1993a) discusses a case of interdependence between a social worker with blindness and his or her clients. Scheer and Groce (1988) discuss a community of persons with quadriplegia and paraplegia on Roosevelt Island, New York, which became an example of the value of interdependence among persons with disabilities. They provided “...each other support and informal counsel about various issues, from attendant care management, to advice about dating, to equipment repair and purchase” (Scheer & Groce, 1998, p. 35). Many of the residents in this community formed connections not only among themselves but with people outside the disability community as well. These examples suggest that a variety of forms of collaboration, including symbiosis, are involved in expressing the value of interdependence and point to the need to know more about the nature and impact of symbiotic collaboration.

Design and Method

The current study is a secondary analysis and employed a phenomenological, qualitative design to explore symbiosis by persons with disabilities. Phenomenology is often used in qualitative research as it provides an insider view on the particular experience being examined (Creswell, 2013; Patton, 2015). The study aimed to illuminate the perspectives of people with disabilities about their experience of symbiotic collaboration with others in interview data.

Participants

This study is a subset of a larger study of collaboration by persons with disabilities. The original, larger study had five participants. For the current study, a convenience sample comprised of three of the original five participants (two men and one woman) was used. All three of these participants were professional contacts suggested to the first author by a colleague who acted as a gatekeeper and initially contacted participants about the study and obtained permission for the first author to contact them about being in the study. The age range of participants was from 49 to 52 years. All of the participants had a physical disability; one had head injury, and two had quadriplegia. All of the participants were living in the community; two of them worked at jobs or professional careers and one participant was a hobbyist. Two of the participants had advanced degrees and one of the participants had received a high school education. Please refer to Table 1 for demographic information about the participants. Two of the participants were married; the third participant lived with friends. All of the participants were from the middle or upper socioeconomic class. All were involved with the disability movement during the 1970s in one form or another either through participation in demonstrations or by consciousness raising on their college campuses or in the community and some are still involved in the disability movement today. As such, the participants in this study were well aware of the Disability Studies' discussion of the concepts of independence and interdependence. In order to protect confidentiality in the reporting of participant data, the names of the participants for this study have been replaced with pseudonyms. Please refer again to Table 1 for pseudonyms for each participant.

Table 1. Participant Demographics

Name	Age	Gender	Disability	Education	Occupation
Brian	52	Male	Head Injury	High School	Hobbyist
Karen	49	Female	C1-C2 Quadriplegia	Advanced Degree	Attorney
Michael	52	Male	C4-C5 Quadriplegia	Advanced Degree	Manager

Alternate description - Table 1 provides participant demographics. Three participant's names are provided, their ages, gender, disability, education, and occupation.

Note: This study was approved by the Human Subjects Review Committee of the Institutional Review Board of Texas Woman's University, Houston.

Data Collection

For the parent study, data were collected through two in-depth, semi-structured interviews that explored instances and meaning of collaboration, as well as eleven participant observations, all of which were conducted by the first author. The first interview asked participants about their

past experiences with collaboration, and the second interview asked them about their current experiences with collaboration. Interviews consisted of open-ended questions and were audiotaped. The first author met with participants in their homes or in private and quiet locations at their workplace. For each participant, each interview was one to two hours in length. There was about a two-week time frame between interviews for each participant.

The current study reports only on the interview perspective on symbiosis. A future paper delineating the results regarding symbiosis from a secondary analysis of the participant observations, and comparing them to the results from interviews reported here, is anticipated. Therefore, for the purposes of the current study, excerpts which were relevant to symbiosis from only the interviews were then isolated and provided to four data analysts. The relevance to symbiosis for these excerpts from the initial interviews was determined via open coding by the first author when she coded the original parent study.

Data Analysis

Audio taped interviews were transcribed. As mentioned above, excerpts determined from the first author's original coding of the parent study to be relevant to symbiosis from these interviews were then independently subjected to open coding (Creswell, 2013) analysis by the third, fourth, sixth and seventh authors, who were students of the first author. Initially, the data analysts engaged in practice coding to ensure consistency. Then, during the formal coding process, the first author met separately and regularly with each student to help answer any questions they might have about the transcripts they were coding or about coding in general, and to clarify that they were coding for symbiosis. For the purposes of this study, the term symbiosis was used to describe a collaboration between two individuals or groups in which members of each side of the collaboration bring different needs, abilities and/or contributions to the collaboration. In a symbiotic collaboration, each member's differing needs, abilities, and/or contributions to the collaboration complement those of the other member, resulting in a mutually beneficial interaction and outcome. Codes and categories related to symbiosis were identified (Creswell, 2013) individually by each data analyst for one excerpt at a time, until all examples of symbiosis in each excerpt were identified and coded. The data analysts then met regularly as a group to compare codes and discuss and develop categories and themes from the coded data. The first author acted in the role of facilitator during this process. Working together excerpt by excerpt, the data analysts grouped similar codes into subcategories, then collapsed these subcategories into categories, and then collapsed the subcategories into one overarching theme. A piece of data was included in the final analysis of the coded data if at least three out of the four coders agreed that it reflected symbiosis as defined for the study. Any disagreements among the data analysts regarding subcategories, categories and themes were discussed and resolved by consensus among all four data analysts. An outside consultant then reviewed all of the results, including representative quotes, subcategories, categories, and themes for the coded data and made recommendations to the researchers, which were followed.

Verification of Data

The first author used spot member checking to assist with verifying data. Member checking is an approach used in qualitative research (Merriam, 2009) to help insure greater accuracy of results. One of the three participants in this study was involved in the member checking process and reviewed and made comments on a portion of his interview transcripts.

Findings

One main overarching theme emerged from the data: Elements of Symbiotic Collaboration. Please refer to Table 2 which displays this theme and its subthemes about symbiosis.

Table 2. Overarching Theme and Subthemes About Symbiosis

1. Elements of Symbiotic Collaboration
a. Cognitive/Cognitive Collaboration
- Inter-Institutional Work
- Inter-Personal Work
b. Physical/Cognitive Collaboration
- Family
- Attendant and Care Recipient
- Work
- Volunteer Work
c. Physical/Emotional Collaboration
- Family
- Work
d. Emotional/Emotional Collaboration
- Work

Alternate description - Table 2 describes the overarching theme and subthemes about symbiosis. These will be discussed below.

1. Elements of Symbiotic Collaboration

The overarching theme Elements of Collaboration has to do with the different components, structures, or aspects of symbiotic collaborations evidenced in the data. This theme contained four subthemes which represent the four general types of symbiosis which emerged: *Cognitive/cognitive collaboration; Physical/ cognitive collaboration; Physical/emotional collaboration; and Emotional/emotional collaboration;* to be reported below. Each subtheme (example: Physical/emotional) reflects the two elements that participants were bringing to the symbiotic collaboration. In turn, the sub-subthemes (example: Family) under each subtheme represent specific subtypes of these symbioses and reflect either the type of environment the symbiosis occurred in or the roles of those involved in the symbiosis.

1a. Cognitive/Cognitive Collaboration

This subtheme was reported by one participant and highlighted instances in which a cognitive symbiosis occurred between two parties. These cognitive symbioses occurred in the work environment or while the parties (either individual people or whole institutions) involved were engaged in an intellectual work task. They illustrated times when members of the collaboration brought their different knowledge and cognitive skills or abilities to the task at hand.

1a.1 Inter-institutional work.

A type of cognitive/cognitive symbiotic collaboration occurred at the inter-institutional level. Michael, a manager with C4 - C5 quadriplegia, spoke of how his workplace had collaborated symbiotically with the Better Business Bureau Consumer Education Foundation on providing technical assistance to businesses regarding disability rights:

“Now, the Consumer Education Foundation...in a general sense... has no particular expertise or skill in the area or knowledge of disability rights... by the same token, our work group, our institution has relatively little knowledge compared to the Better Business Bureau about...the way business works...the way business people think, the way small businesses in particular are organized, the resources they have, the interest they have, what motivates and drives them, and so on and so forth. So... we...from a public service, uh, health promotion, uh not-for-profit perspective, are collaborating with an organization that views things from a commercial for-profit, uh, business perspective, and together we are able to achieve something that neither one of us could achieve independently.”

This example illustrates how institutions championing the rights of persons with disabilities cognitively engage symbiotically by sharing their specific knowledge regarding important issues with other institutions in the community.

1a.2 Inter-personal work.

Michael also shared how he had worked with a colleague on a grant proposal for research on independent living, a topic of particular interest to persons with disabilities. Their work together consisted of a type of symbiosis in which they each brought their own cognitive talents to the project.

“Well, I mean, she’s a lot smarter than I ever thought about bein’ and she [was] a far better writer, so...the most intellectually challenging...written tasks...were ones that she...volunteered to do, and those more mundane...documentary tasks were ones which I...quite naturally volunteered to...write.... We often would go to conferences and congresses together and do both joint and individual presentations where we divided up... [the] materials- she would often talk about the demonstration itself where I would talk about some of the findings of the research we were doing.”

This example demonstrates two people, one with a physical disability [C4-C5 quadriplegia] and one without a physical disability, symbiotically collaborating on cognitive tasks for a research project. This cognitive/cognitive symbiosis was not based on needs resulting from disability, but rather on the differing cognitive skills and interests of the collaborators.

1b. Physical/Cognitive Collaboration

Three participants described themselves as engaging in physical/cognitive symbiotic collaborations as well. In a physical/cognitive symbiosis, one member of the symbiosis contributed his or her physical strength or abilities to the situation in order to meet the needs of the other party, while, in turn, the latter contributed his or her cognitive abilities in order to meet the needs of the first party. These types of symbioses occurred in a variety of life areas, such as while participants were interacting with family, attendants, or co-workers.

1b.1 Family.

Brian, a hobbyist who had a cognitive disability resulting from head injury, spoke about the physical/cognitive symbiosis he experienced at home with the family he lived with, which included some persons with physical disabilities. He discussed how the family members with physical disabilities might ask him to do a physical task for them, which they could not do, such as take out the trash. Because they were aware of his memory deficits, they supported him cognitively by consciously limiting the number of sequential tasks or steps in a task they would ask him to do so that he would not forget the later steps. His use of the term “symbiosis” here describes the give and take he experienced at home when he helped people with physical limitations and they adjusted for his cognitive limitations:

“They...are my helpers now. And I help them. That’s one of the things I’m calling symbiosis. ‘Cause of the...interaction we have. Where everybody helps each other. So I’m calling that a collaboration, or symbiosis, or I feel a lot of other adjectives that would describe it. But, the two current ones are symbiosis and/or collaboration.”

1b.2 Attendant and care recipient.

Another form of physical/cognitive symbiosis occurred during interactions between participants who were either providing attendant care for one member of the symbiosis or receiving care from the other. This form of physical/cognitive symbiosis was mentioned by two participants and was best explained by Brian, the hobbyist with a cognitive disability stemming from head injury, who enthusiastically described how a symbiotic attendant/attendee relationship with someone who had a physical disability, allowed them both to achieve autonomy that neither could attain without the other:

“Well... [A] is my memory, because I don't have...one that works well; I'm his arms and legs, is basically the way it works. And, because I've helped him with the physical assistance he needs, he's been able to... go a lot of places he couldn't go otherwise because he...couldn't get out of bed and into his clothes or into his wheelchair if [he] hadn't had my help. And by the same token, if he hadn't been helping me, I wouldn't have been able to...do a lot of the other things that I've done since I have been helping [A] because of the help I've gotten from him.... neither one of us could be as independent as we are without the help of the other. And that basically says it all... [A] couldn't put on his pants and get out of bed in the morning without my help, and I have troubles with my memory...so [I have] other kind of problems that I couldn't deal [with] without [A]'s help. Or someone like [A]. That's why I call it symbiosis. 'Cause of the fact that we do help each other in the way we do... neither of us could be as independent as we are without the help of the other, or someone like the other person.”

Here Brian describes a type of long-term give-and-take physical/cognitive symbiosis in which he was the personal attendant for someone with a physical disability where each contributed a remaining capacity to compensate for the other's impairment.

1b.3 Work.

Some physical/cognitive symbioses occurred while working together. Karen, an attorney who had C1-C2 quadriplegia, and (among other things) was unable to use her arms as a result, spoke about an enjoyable physical/cognitive symbiosis she experienced with a friend who did not have a disability:

“... We opened up a gift shop that we both...ran together. She would help do all the...inventory and I would kind of run the shop in terms of deciding what to purchase and where, maybe where and how to display it, and then she would help with just, you know, gathering the items and physically laying them out in the store.”

This is yet another example of a type of physical/cognitive symbiotic collaboration; in this case, the friend contributed her physical abilities while Karen contributed the intellectual skills involved in decision making and design.

1b.4 Volunteer work.

Brian also mentioned a symbiotic process occurring in his volunteer work, wherein he helped others and they, in turn, helped him out cognitively so he would stay on track.

“...If one of the volunteers asks me to help them with something I’d gladly do it.... [They might ask me to] go tell somebody something but I ask them for a note so I don’t forget...any of the details and what they want me to tell them....Somebody in the volunteer office might ask me to do something for them and I... gladly do it, ‘cause I’m not doing anything else at the moment. Or if I am...doing something else I ask them to remind me what I’m doing when I get back with...whatever [they] asked me to go and get for them...so I can complete the task.”

In this example, the individuals who asked Brian to do a task did not necessarily have a physical disability and may have been able to complete the task, but delegated tasks to Brian that he was physically capable of doing and that needed to be done so they could focus on other tasks. In return, they provided him the cognitive support he needed to do the task.

1c. Physical/Emotional Collaboration

Two participants mentioned physical/emotional symbiotic collaborations they engaged in with others in their lives. In these forms of symbiosis, one member contributed his or her physical abilities while having his or her emotional needs fulfilled in return. These forms of symbiosis occurred both with family members and at work and will be discussed below.

1c.1 Family.

Michael spoke about a physical/emotional symbiotic collaboration that occurred between him and a family member after he acquired his disability:

“...My mother...shortly after I was injured...became my primary caretaker, and through her I was able to do a lot of things that I would not have been able to do under other circumstances....And at that stage of her life...she was having a difficult time coping with her kids being gone, and she was dealing with her own predisposition towards alcoholism, and I think the fact that she found herself occupied caring for me...was...to her a kind of...distraction from the...addiction which she had...and a way of ...coping with that...addiction...and a consequential temptation...and she felt like she was really accomplishing something. Whereas, if she didn’t have that...sense of responsibility and duty to care for me right in front of her...more than likely, and I think she knew it...she would have...been harming herself and her family.”

In this example, Michael received from his mother the physical help and care he needed and was able to do things, and in turn this filled an emotional void for her and gave her a purpose.

1c.2 Work.

Karen discussed physical/emotional symbioses that she experienced in the work environment. One example of this type of symbiosis she provided was in her day-to-day work with her secretary:

“...I’m a strong believer that when a person comes to work, your home life doesn’t just go away. For example [B] must be available for her children, her husband, and her parents, so oftentimes she’ll get calls from her family...she knows I’ll read through my mail and I’ll just make gestures to her to turn a page but she might be... you know, on the phone taking care of some business....It will be a[n]...opportunity for me to go through magazine...publications that I just need to kind of skim through, and so, basically what she’s doing is turning pages. But she’s actually concentrating on something else.”

Due to her disability, Karen was unable to turn the pages, so her secretary physically turned the pages for her. Karen’s contribution to this symbiosis was to permit her secretary to make personal phone calls while doing this task, thereby fulfilling some of her secretary’s emotional needs regarding the well-being of her family. Through this physical/emotional symbiosis they were able to enfold their respective responsibilities together.

Another example provided by Karen of a physical/emotional symbiosis which occurred at work was in her work with her student:

“So rather than me making the phone call to another attorney or colleague...I’ll have them do that so they...can meet that person. And hopefully it’s a helpful experience for them as well.”

In speaking a little earlier in the interview regarding her interactions with her students:

“...When you’re in the role of someone who’s trying to help the person you’re with...learn about life in a different way, I find that to be particularly rewarding.”

Here, the student accomplished the task of making phone calls, which Karen would have needed physical assistance with in order to accomplish. In turn, working with the student was personally rewarding for the Karen, and the student possibly experienced interesting career opportunities.

Yet another example of a work-based physical/emotional symbiosis Karen provided was in her interactions with her care attendant. This interaction was very different from the traditional employer/employee relationship and different from any she had had in the past. This attendant was more like a family member to her, traveling with her, going on camping trips with her, and spending holidays with her and her family:

“I really believe that the kinds of things that she would do for me on a daily basis she would do because we liked each other, and we enjoyed being with each other. And she wasn’t doing it just that it was her job. Although it was her job. But, she wasn’t doing it for that reason alone. She was doing it for other reasons.”

In this case, the care attendant provided physical assistance for Karen. Both women enjoyed the interaction and the care attendant received more than just pay for taking care of the participant.

1d. Emotional/Emotional Collaboration

In this type of symbiosis, parties to the symbiosis meet each other’s emotional needs, and was mentioned by one participant as occurring in the workplace.

1d.1 Work.

This form of a symbiotic collaboration was described by Karen and involved again her interactions with her secretary:

“And, you know, we both anticipate each other’s, well maybe moods, or feelings for that day.”

In this form of symbiosis each was respectful of the other’s emotional needs by anticipating each other’s feelings in order to better work together.

Discussion

The results of this study indicate that persons with disabilities engage in a variety of symbiotic collaborations in a range of environments and relationships, including work and home. Some of them, such as when Brian discussed his unusual symbiosis with a person with a physical disability (reported under “Attendant and Care Recipient” under the subtheme “Physical/Cognitive”), were more specific to persons with disabilities, as opposed to persons without disabilities. Other forms of symbiosis, such as the one between a participant’s workplace and the Better Business Bureau Consumer Education foundation regarding disability rights (reported under “Inter-Institutional work” under “Cognitive/Cognitive”), is an example of a type of symbiosis that would be particularly valued by people in the disability community. However, it is also important to note that some of the symbioses that study participants engaged in were symbioses that someone with or without a disability could potentially engage in. An example of

this would be when Karen and her secretary anticipated each other's moods (reported under "Work" under the subtheme "Emotional/Emotional"). This highlights the notion that persons with disabilities are not necessarily different from the non-disabled population in the types of symbioses they do. This is a refreshing finding, as, traditionally, people with disabilities have been treated as "different" and socially and physically separated from non-disabled persons as a result (Dear, Wilton, Gaber, & Takahashi, 1997). This finding is potentially liberating for persons with disabilities, because if non-disabled persons can come to realize that persons with disabilities are not necessarily different from them, this might encourage more positive interactions (Dear et al.), and therefore more symbioses between persons with disabilities and their non-disabled counterparts. This would provide persons with disabilities with more social capital, which could improve their community involvement (White et al., 2010). Also, the notion that symbiosis can be engaged in by non-disabled and disabled persons alike underscores the idea of the universality of interdependence among human beings. To quote Robertson (2001):

“... all of us are much more dependent on others than we acknowledge, and yet we stridently, almost bizarrely, deny this reality and that of interdependence except then referring to *others*- young infants, disabled children and adults, and the elderly.” (p. 123)

The literature about persons with disabilities and friendship reflect some of the findings of this study, particularly in the realm of cognitive support, emotional support, and physical/emotional collaboration. For example, Pottie and Sumarah (2004) reported on friendships between persons with intellectual disabilities and persons without intellectual disability at a community known as L'Arche in Canada. While the non-disabled friends often provided cognitive support with activities such as reading a menu at a restaurant or telling time, the friends with intellectual disability contributed to the friendships by providing emotional support. Although not actually part of a category named in this study, this example would readily fall into one that could be called "cognitive/emotional collaboration". Fisher and Gallagher (1988) discuss how women with physical disabilities often try to provide emotional support for their non-disabled friends as an attempt to balance out the amount of physical help they receive from the friend (p.180). This example echoes elements of the physical/emotional collaboration found in this study between Karen and her secretary, but is in the realm of friendship instead of work.

Williams and Robinson (2001)^[A3] found that persons with intellectual disabilities, some of whom have "high support needs" (p. 61), often provide emotional support and do physical care or physical tasks around the home for their parents (some of whom are elderly or disabled) while the parents provide the support needed for their children with the intellectual disability. This reflects some of the aspects of physical/cognitive and physical/emotional collaboration found in the current study. However, Williams and Robinson found that such relationships were not often viewed as one of interdependence by the parent. They expressed that "understanding how to value and respect someone who nevertheless does need support, is a vital but unmet need in many families" (p. 61).

Many of the symbiotic collaborations described by the participants are closely related to the concepts of independence and interdependence in the Disability Studies literature. As the participants chose to engage in symbiotic collaborations, they further exemplify ways in which people with disabilities choose to be autonomous and in control of their lives. In this regard, some of these symbiotic collaborations allowed the participants to achieve the kind of independence envisioned by disability scholars (Brisenden, 1996; Condeluci, 2014; Longmore, 1995; Nosek, 1993; Oliver, 1993; Parker, 1993; Scheer & Luborsky, 1991). They are also example of situations in which people with disabilities were willing to ask for help and saw the positive aspects of interdependence with others, reflecting the value that members of the disability community place on interdependence.

They also exemplify values of community and connectedness that are espoused by disability activists. As French (1993b) states, "... giving and receiving help can greatly enrich human experience" (p. 47). The eagerness with which some participants spoke of their symbiotic experiences and the ability of such experiences to improve their lives in meaningful ways attest to that richness.

For some participants, symbiotic collaboration was an ongoing means to accomplish important life tasks and roles or achieve a level of independence that would not otherwise be possible. However, symbiotic collaboration had another equally important dimension of mutual benefit achieved by two people working together in close and constant proximity. Some involved in these symbiotic collaborations exchanged cognitive, physical and emotional support in remarkably reciprocal ways. There is also a form of intimacy in this relationship characterized by the unusual extent to which persons must share close physical space, orchestrate their respective actions, and share and be considerate of highly personal actions and information.

It is clear that some study participants felt overall that symbiosis was immensely beneficial to them. Through some of the symbiotic collaborations they discussed, participants were able to accomplish necessary and desired tasks they would normally not be able to, thereby achieving a better quality of life. As Condeluci (2014) mentions, "[Interdependence] suggests a fabric effect, where diverse people come together in a synergistic way to create an upward effect for all" (p. 8). In fact, Gooden-Ledbetter, Cole, Maher, and Condeluci (2007) found teaching interdependence to persons with disabilities in independent living programs to be a predictor of life satisfaction (p. 157). Williams and Robinson (2001) state: "...mutual caring [between persons with learning disabilities and their parents] is far more common than is recognized..." (p. 56). The current study suggests that symbiosis may be a phenomenon worth further exploration.

Interdependence is a complex issue. This notion is supported by Walmsley (1993), who found that receiving and giving care can simultaneously provide sustenance and frustration, and by The Roeher Institute (2001) who discuss the need for respectful interdependence between people with disabilities and providers of support. Also of particular note is the phenomenon of mutual caregiving between adults with disabilities and their young children and the consequent

impact on the children (Aldridge & Becker, 1999; Pakenham & Cox, 2012). Further investigation of these topics is warranted.

The original study from which the data for the current study was derived was not about symbiotic collaborations, but rather any types of collaborations by persons with disabilities in general. As such, it is important to note that the current study is a preliminary study and does not provide an exhaustive list of the types of symbiotic collaborations that persons with disabilities engage in. Also, as there were only three participants in this study, and the participants were quite articulate, the results of this study cannot be generalized to the population of persons with disabilities; particularly to persons with disabilities who may not be as articulate. The concept of symbiotic collaboration needs further exploration with a wider and more varied range of participants.

Conclusion

Occupational therapy has adopted the following definition of independence:

“[A] self-directed state of being characterized by an individual’s ability to participate in necessary and preferred [meaningful and purposeful activity] in a satisfying manner irrespective of the amount or kind of external assistance desired or required.” (American Occupational Therapy Association, 2002, p. 660)

The use of symbiosis could be viewed as a unique adaptive strategy for people with disabilities. As the participant Brian stated: “I’ve chosen to collaborate to achieve the goals I’ve set that I couldn’t have achieved without the collaboration of other people...” It is important for medical professionals, caregivers, and non-disabled persons to be aware of the value of symbiosis to persons with disabilities as a form of adaptation which can empower them in the attainment of meaningful life goals. Moreover, our own understanding of independence would benefit from a clearer underscoring of the tenets of autonomy and self-determination as well as the recognition that they often require a significant measure of symbiosis.

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References

- Aldridge, J., & Becker, S. (1999). Children as carers: The impact of parental illness and disability on children's caring roles. *Journal of Family Therapy*, 21, 303-320. Doi: 10.1111/1467-6427.00121
- American Occupational Therapy Association. (2002). Broadening the construct of independence [Position Paper]. *American Journal of Occupational Therapy*, 56, 660. <http://dx.doi.org/10.5014/ajot.56.6.660>
- Brisenden, S. (1986). Independent living and the medical model of disability. *Disability, Handicap, and Society*, 1, 173-178.
- Condeluci, A. (2014). Independence, inclusion, and self-determination. *Interaction*, 27, 8-13. Retrieved from <http://www.aiidd.org.au/interaction/27/3/273.pdf>
- Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed). Los Angeles: Sage.
- Dear, M., Wilton, R., Gaber, S.L., Takahashi, L. (1997). Seeing people differently: the sociospatial construction of disability. *Environment and Planning D: Society and Space*, 15, 455-480. doi:10.1068/d150455
- DeJong, G. (1979). Independent living: From social movement to analytic paradigm. *Archives of Physical Medicine and Rehabilitation*, 60, 435-446.
- Fisher, B., & Gallagher, R. (1988). Friendship and fairness: How disability affects friendship between women. In M. Fine, & A. Asch (Eds.), *Women with disabilities: Essays in psychology, culture, and politics* (pp.172-194). Philadelphia: Temple University Press.
- French, S. (1993a). Experiences of disabled health and caring professionals. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers- Enabling environments* (pp. 201-210). London: Sage.
- French, S. (1993b) What's so great about independence?. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers- Enabling environments* (pp. 44-48). London: Sage.
- Gill, C. S. (1995). A Psychological view of disability culture. *Disability Studies Quarterly*, 15, 16-19.
- Goggin, G. (2008). Innovation and disability. *M/C Journal*, 11. Retrieved from <http://journal.media-culture.org.au/index.php/mcjournal/article/viewArticle/56>

- Gooden-Ledbetter, M. J., Cole, M. T., Maher, J. K., & Condeluci, A. (2007). Self-efficacy and interdependence as predictors of life satisfaction for people with disabilities: Implications for independent living programs. *Journal of Vocational Rehabilitation, 27*, 153-161.
- Jacobs, P. G. (2002). Potential maximization: Toward a micro-sociological approach in disability studies. *Disability Studies Quarterly, 22*(1), 59-73. Retrieved from <http://dsq-sds.org/article/view/336/420>
- Longmore, P. K. (1995). The second phase: From disability rights to disability culture. *Disability Rag & Resource, 16*, 4-11. Retrieved from <http://www.independentliving.org/docs3/longm95.html>
- Merriam, S.B. (2009). *Qualitative research: A guide to design and implementation*. Los Angeles: Sage.
- Merriam-Webster. (2005). *Merriam-Webster's Collegiate Dictionary* (11th ed.). Springfield, MA: Author.
- Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society, 24*, 47-62. Doi: 10.1080/09687590802535410
- Nosek, M.A. (1993, April/May/June). A response of Kenneth R. Thomas' commentary: Some observations on the use of the word "consumer". *Journal of Rehabilitation, 59* (2), 9-10.
- Nosek, M.A., & Fuhrer, M. J. (1992a). Independence among people with disabilities: I. A heuristic model. *Rehabilitation Counseling Bulletin, 36* (1), 6-20.
- Nosek, M.A., & Fuhrer, M. J. (1992b). Independence among people with disabilities: II. Personal Independence Profile. *Rehabilitation Counseling Bulletin, 36* (1), 21-36.
- Nosek, M., & Howland, C.A. (1993). Personal assistance services: The hub of the policy wheel for community integration of people with severe disabilities. *Policy Studies Journal, 21*, 789-800. Doi: 10.1111/j.1541-0072.1993.tb02175.x
- Oliver, M. (1993). Disability and dependency: A creation of industrial societies. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers- Enabling environments* (pp. 249-256). London: Sage.

- Pakenham, K. I., & Cox, S. (2012). The nature of caregiving in children of a parent with multiple sclerosis from multiple sources and the associations between caregiving activities and youth adjustment over time. *Psychology and Health, 27*, 324-346.
Doi:10.1080/08870446.2011.563853
- Parker, G. (1993). *With this body: Caring and disability in marriage*. Philadelphia: Open University.
- Patton, M. Q. (2015). *Qualitative research and evaluation methods* (4th ed.). Los Angeles: CA: Sage.
- Pottie, C., & Sumarah, J. (2004). Friendships between persons with and without developmental disabilities. *Mental Retardation, 42*, 55-66.
doi: [http://dx.doi.org/10.1352/0047-6765\(2004\)42<55:FBPWAW>2.0.CO;2](http://dx.doi.org/10.1352/0047-6765(2004)42<55:FBPWAW>2.0.CO;2)
- Robertson, C. (2001). Autonomy and identity: The need for new dialogues in education and welfare. *Support for Learning, 16*, 122-127. Doi: 10.1111/1467-9604.00203
- Scheer, J., & Groce, N. (1988). Impairment as a human constant: Cross-cultural and historical perspectives on variation. *Journal of Social Issues, 44* (1), 23-37.
- Scheer, J., & Luborsky, M. L. (1991, November). Post-polio sequelae: The cultural context of polio biographies. *Orthopedics, 14* (11), 1173-1181. Doi: 10.3928/0147-7447-19911101-05
- The Roeher Institute. (2001, February). *Disability-related support arrangements, policy options and implications for women's equality*. Ottawa, ON: Research Directorate, Status of Women Canada. Retrieved from
<http://publications.gc.ca/collections/Collection/SW21-60-2000E.pdf>
- Walmsley, J. (1993). Contradictions in caring: Reciprocity and interdependence. *Disability, Handicap & Society, 8*, 129-141.
- White, G. W., Simpson, J. L., Gonda, C., Ravesloot, C., & Coble, Z. (2010). Moving from independence to interdependence: A conceptual model for better understanding community participation of centers for independent living. *Journal of Disability Policy Studies, 20*, 233-240. Doi: 10.1177/1044207309350561
- Williams, V., & Robinson, C. (2001). 'He will finish up caring for me': People with learning disabilities and mutual care. *British Journal of Learning Disabilities, 29*, 56-62. Doi: 10.1046/j.1468-3156.2001.00111.x