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A Medium of Inquiry for Students,
Faculty & Other Practitioners
Advocating for Health through
Occupational Studies

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OCCUPATION: A Medium of Inquiry for Students, Faculty & Other Practitioners Advocating for Health through Occupational Studies

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The occupational experiences of lesbian, gay, bisexual and transgender (LGBT) individuals during the coming out process: An analysis of self-acceptance, disclosure, and occupational change by Lee Meach

Abstract:

Human occupation is an intensely individual process that is colored by the cultural and life experiences of the individual who is engaged in an activity. The experiences of gender and sexual minorities typically defined as Lesbian, Gay, Bisexual, and Transgender (LGBT) individuals are different in many ways from the rest of the population. One occupation unique to this community is the process of “coming out” in which the individual discloses their minority sexual orientation or gender identity to others. The coming out process is complex and multi-faceted, involving both the internal reflective process of first self-accepting one’s orientation and identity and then the process of sharing it with others. Because of the stigmatized nature of LGBT orientations and identities this occupation often precipitates a great deal of occupational change involving occupational deprivation, marginalization, adaptation and gain.

Key Words: Self-Acceptance, Disclosure, Occupational Changes, LGBT

The occupational experiences of lesbian, gay, bisexual and transgender (LGBT) individuals during the coming out process: An analysis of self-acceptance, disclosure, and occupational change by Lee Meach

Occupational science as a discipline seeks to identify the ways humans experience their lives as occupational beings (Christensen, & Townsend, 2010). In doing this it is important to recognize different lived experiences and identities individuals have and how those factors shape their occupational choices and experiences. One area of particular relevance is the experiences of gender and sexual minorities, most commonly referred to as member of the lesbian, gay, bisexual and transgender (LGBT) community. Traditionally, literature within occupational science and occupational therapy has been dismissive of the multi-faceted ways that sexual orientation affects occupational experience by only focusing on the occupations of sexual expression and relationships (Jackson, 1995). Jackson (1995) argued that the experiences of being a sexual minority influence a wide variety of beliefs and convictions as a result of life experiences that in turn influence which occupations are accessible and chosen. When it comes to literature within occupational science on sexual minorities the focus is only on the experiences of gay and lesbian individuals or lesbian, gay and bisexual (LGB) individuals as one entity without exploring the specific occupational experiences of bisexuals. Literature outside of occupational science that focuses on unique experiences of bisexuals is still limited but suggests unique experiences that are very different from that of lesbian and gay individuals (Balsam, & Moore, 2007; Ross, Dobinson, & Eady, 2010). Occupational science literature has only just begun to explore the occupational experiences of transgender individuals which is very different compared to LGB individuals due to their identification with a gender outside the one assigned to them at birth (Beagan, et al., 2012). For all LGBT minorities the occupation of ‘coming out’ where individuals disclose their sexual orientation or gender identity is a common experience that warrants study both as an occupation within itself and as an experience that predates a great deal of occupational change in the lives of gender and sexual minorities. In this paper the occupational experiences of lesbian, gay, bisexual and transgender individuals with regards to the “coming out” process and the occupational changes brought on as a result of this process will be explored. These include self-acceptance, self-disclosure and occupational changes. Consideration of the way these experiences differ for people of different orientations will also be examined.

Methodology

For this literature review articles were found using the Google Scholar database as well as looking through the archives of the American Journal of Occupational Therapy, Canadian Journal of Occupational Therapy, Journal of Occupational Science, and British Journal of Occupational Therapy. Search terms used included: “coming out LGBT”, “coming out bisexual”, “coming out transgender”, “transgender”, “homosexuality”, “bisexuality”, and “occupation coming out”. Potential articles for review were identified based on title and abstract. Articles were analyzed according to which aspects of the coming out process they reviewed and what sexual and gender identities they focused on.

LGBT Identity and Relation to Occupation

Individual factors such as one’s sexual orientation can contribute to themes of meaning that affect ones actions and occupational choices (Jackson, 1995). Occupational scientists should seek to understand the ways that sexual orientation affects one’s experience as an occupational being such as coping with stigma, societal perceptions, disclosing their orientation and the effects that has on

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occupational experiences (Jackson, 1995). Occupations may be used by LGBT individuals as a way to portray and affirm their identities to others (Beagan, et al., 2012). Because gender and sexual minorities often face marginalization their experiences with stigma tend to affect occupational choice because they may be barred from certain activities or afraid to engage in certain activities that identify them as a member of the LGBT community (Zimmerman, 2009). For this reason the occupation of “coming out” provides a rich area of study for the unique ways that an LGBT identity can affect occupational choices and experiences.

Coming Out to Oneself

While traditionally coming out is seen as a process in which an individual discloses their sexual orientation or gender identity to others it is actually a process with multiple stages that starts with process of self-identification and acceptance of one’s identity internally (Bergan-Gander, & von Kurthy, 2006; Rhoads, 1995). This process relates to the occupational concept of “being” as described by Hitch, Pepin, and Stagnitti (2014) since “being” involves one’s individual understanding of who they are. As an individual learns to accept their gender identity or sexual orientation their sense of being changes and they in turn become more aware of who they are and at peace with their identity (Rhoads, 1995). This section will examine this process with regards to experiences of the lesbian, gay and bisexual community, and the more unique experiences of bisexual and transgender individuals.

Accepting an LGB Identity

Because all people regardless of sexual orientation grow up in a society of assumed heterosexism or “heteronormativity”, it is common for LGB individuals to develop negative attitudes about homosexuality which they then direct towards themselves when they begin to experience same sex attractions (Balsam, & Mohr, 2007; Bergan-Gander, von Kurthy, 2006; Cox, Dewaele, van Houtte, & Vincke, 2011). These negative views expressed towards themselves and other LGB individuals are commonly referred to as “internalized homophobia” (Bergan-Gander, von Kurthy, 2006). Internalized homophobia can have many emotional consequences such as internalized shame and self-doubt and denial of one’s homosexual desires, or even severe consequences such as self-hatred and self-destructive behavior including suicide (Cox, Dewaele, van Houtte, & Vincke, 2011). Coming to terms with these feelings and learning to accept one’s sexual orientation can be difficult due to the lack of LGB role models and peers for many individuals (Balsam, & Mohr, 2007).

The ways in which stigma and internalized homophobia affect the process of self-acceptance can be demonstrated in the way that the process of coming out to oneself has changed as homosexuality has become more accepted in American culture in recent decades. In one study of sexual orientation identity development, it was found that the process of LGB self-acceptance varied greatly between participants in an older cohort versus a younger cohort (Floyd, & Bakeman, 2006). LGB individuals in the older cohort tended to reach self-acceptance at later ages, have had more experience with heterosexual relationships before accepting an LGB identity, and tended to have same sex sexual experiences prior to publicly adopting an LGB identity (Floyd, & Bakeman, 2006). In contrast younger LGB individuals tended to adopt a lesbian, gay, or bisexual identity prior to having any same sex experience and reach self-acceptance at younger ages. This study illustrates the role of cultural context in promoting self-acceptance.

Accepting a Bisexual Identity

Despite growing cultural acceptance of lesbian and gay individuals, bisexual individuals continue to face greater stigma and barriers to self-acceptance (Balsam, & Mohr, 2007; Ross, Dobinson, & Eady, 2010). While homosexuality continues to be stigmatized it is at least

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acknowledged whereas bisexuality is often treated as an illegitimate orientation (Balsam, & Mohr, 2007; Ross, Dobinson, & Eady, 2010). Pressure to conform not only to heterosexuality but the dichotomy of hetero and homosexuality makes self-acceptance much more confusing to bisexuals. A study by Balsam, and Mohr (2007) found significantly greater identity confusion in bisexual participants in comparison to lesbian and gay participants. In another study on the mental health of bisexual individuals, Ross, Dobinson, and Eady (2010), found that bisexuals were often unaware that bisexuality existed as an orientation while they were young and that these participants struggled not only with internalized homophobia but internalized monosexuality, the assumption that individuals can only be attracted to one gender. This identity confusion and the intersection of multiple forms of internalized shame leads to significant mental health challenges among bisexual individuals and makes the process of self-acceptance much more difficult (Ross, Dobinson, & Eady, 2010).

Accepting a Transgender Identity

Because transgender individuals make up only a small proportion of the population and research about the trans community is fairly new, the majority of the available research on transgender individuals and their occupations involves a small sample size and qualitative research processes (Beagan et al., 2010). For the sake of this literature review the term “transgender” will be used to refer to trans individuals who identify within the binary as either male or female and have an identity that is opposite of the sex they were assigned at birth. While there are many transgender individuals who identify somewhere outside of the gender binary there is currently very little published research on individuals who do not identify with a discrete gender of either male or female. In a qualitative study of the occupational experiences of transgender individuals Beagan, et al. (2012) found that the participants generally knew from very young that their gender identities did not match the sex of their bodies. Despite early realization that something was different about them many transgender individuals experienced denial about their identity or tried to suppress it because they did not see role models of transgender people that depicted transition as a viable option (Zimmerman, 2009). One common occupation associated with the process of self-acceptance of gender identity was cross dressing. Cross dressing was often done in private while individuals engaged in gender-normative occupations publically as a way to explore and come to grips with their gender identity (Beagan, et al., 2010). For many individuals cross dressing was a difficult experience because it was an incomplete version of the acceptance they needed leading to further questioning of gender identity. The process of “becoming” as described by Hitch, Pepin, and Stagnitti (2014) involves a transition between occupations as one grows and develops. For transgender people, cross dressing is an occupation of becoming that is used as part of the process of developing acceptance of the necessity of physical and social transition.

Coming Out to Others**Coming out as LGB**

The occupation of coming out is an interesting lens through which to study the occupations of sexual minorities because it intersects with experiences of both discrimination and stigma but also has the potential to open up more authentic communication with others. There are many positive and negative responses to coming out and the burdens and benefits of coming out will vary for each individual depending on the cultural context they live in. Coming out has many benefits one of the biggest being that it enables an LGB person access to a the LGB community and social support from others who identify similarly which has a strongly positive affect on mental health (Cox, Dewaele, van Houtte, & Vincke, 2011). In studies of the experiences of LGB individuals, coming out to others was an important way to let go of some of the internalized homophobia, and the negative emotions associated with the stressful process of emotional suppression (Cox, Dewaele, van Houtte, & Vincke, 2011; Rhoads, 1995). Coming out can also be a way for someone to gain

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control over how others perceive them by preventing the consequences of being accidentally “outed” by others (Corrigan, & Matthews, 2003). Politically having more “out” and visible LGB individuals helps to reduce assumptions of heterosexuality and stigma for the LGB community as a whole (Bergan-Gander, & von Kurthy; Corrigan, & Matthews, 2003).

Negative responses to coming out were also noted in the literature typically connected to experiences of discrimination and marginalization. In one study by Corrigan and Matthews (2003) some reasons identified for nondisclosure included: the threat of violence, the feeling that disclosure was not appropriate to the situation, the desire not to upset a significant other, a lack of social support to shield against negative responses, and a fear of a person in power using the information against them. Many individuals feared harassment and exclusion (Rhoads, 1995). Individuals in highly controlling environments at home, work or socially were very unlikely to come out for fear of facing occupational loss including loss of social support from friends or family, or employment discrimination (Legate, & Molineux, 2012). This has especially strong consequences for younger LGB individuals who are reliant on their families for support. Research has shown that LGB individuals living with families who have strong religious beliefs, strong adherence to traditional gender roles and conservative political beliefs are less likely to disclose sexual orientation (Walder & Magruder, 2008). LGB individuals who have strong relationships with their families also tend to avoid coming out for fear of losing or harming their relationships with their families even if their families had not demonstrated negative views regarding homosexuality (Waldner, & Magruder, 2008).

Coming out as bisexual

Coming out as bisexual is much more complicated than coming out as gay or lesbian, so bisexuals tend to be far less “out” to others compared to lesbian and gay individuals (Balsam, & Mohr, 2007). Bisexuality tends to be dismissed and discouraged on a societal level which often means that the individual has to first explain and convince the other person that bisexuality exists (Balsam, & Mohr, 2007; Ross, Dobinson, & Eady, 2010). Coming out as bisexual is also more complicated because it cannot be revealed by stating the gender of one’s romantic partner since bisexuals in differently-sexed relationships are assumed straight and bisexuals in same-sexed relationships are assumed to be gay (Balsam, & Mohr, 2007; Ross, Dobinson, & Eady, 2010). For bisexuals this makes the process of coming out far more awkward and less likely to be taken seriously. For bisexuals who are monogamous, this is complicated since bisexuality is often not taken seriously unless the individual is sexually active with both genders (Ross, Dobinson, & Eady, 2010). Bisexuality is often accompanied by different stigmas which are hard to navigate such as being “slutty” or “hypersexual” which are not often present for people who identify as lesbian or gay (Ross, Dobinson, & Eady, 2010). Because bisexuality is often accepted by neither the straight or gay community, bisexuals may not feel safe coming out to lesbian and gay individuals because their identity is not taken seriously (Ross, Dobinson, & Eady, 2010). Being bisexual is a lot like having two closets because they have to come out both to gay and straight populations and are not often accepted by either community.

Coming out as transgender

The process of coming out as transgender is very different from coming out as LGB. While lesbian, gay and bisexual refers to sexual orientations, transgender refers to a gender orientation which is a far more overt and public than one’s sexual orientation. Because transgender people emphasize their identity as the gender of “man” or “woman”, rather than “transgender”, coming out is a very different process (Zimmerman, 2009). Zimmerman (2009) defines two parts to discussing a transgender identity; one of “declaration” where one first announces to themselves and others as

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identifying with a gender different from the one they were assigned at birth, and “disclosure” where one reveals a transgender history after having completed transition and having adopted the social role of one’s declared gender. “Declaration” for transgender individuals is more similar to the process of “coming out” for LGB individuals in that the person declaring their gender identity is revealing a fundamental truth about themselves (Zimmerman, 2009). On the other hand disclosure is not treated this way because a transwoman, for example, doesn’t see herself as a “trans” woman but rather just a woman and being forced to reveal one’s transgender status after transition may lead to others not taking that individual’s gender identity seriously (Zimmerman, 2009). For this reason, many transgender individuals choose to remain “stealth” and not reveal their transgender status after transition but just live openly as their identified gender. From a political standpoint this is somewhat complicated because disclosing transgender status helps to fight the stigma faced by transgender individuals still in the process of self-acceptance and declaration, but it may come at a cost to the people revealing their transgender status (Zimmerman, 2009). In interviews of transgender individuals regarding this issue many of them indicated that they felt disclosure was a personal choice that every person should be free to make for themselves (Zimmerman, 2009).

Another complication that makes both declaration and disclosure of transgender identity difficult for transgender people is the fear of facing violence and harassment (Beagan, et al., 2012; Zimmerman, 2009). While this fear is present for all individuals in the LGBT community it is especially prevalent for transgender individuals who have a very visible identity if they appear androgynous. In this past year alone in the United States 20 transgender women have been murdered (Kellaway, & Brydum, 2015). Additionally, transgender people have a lot less control in managing disclosure because their identity can be revealed by their legal name, people in past relationships, or their legal identifiers. When dealing with any form of bureaucracy there is potential to be “outed” if those legal identifiers have not been changed which requires a large amount of energy and planning (Beagan, et al., 2012). Due to the public nature of gender expression, transgender individuals spend a very large amount of time engaged in occupations related to social presentation such as dressing, grooming, and self-care (Beagan, et al., 2012). For transgender individuals who have not yet begun the process of physical transition their gender identity is often not accepted by others because they still appear to look like the gender they were assigned at birth (Zimmerman, 2009). Physical traits related to their birth gender such as pitch of voice, hairlines, body hair, height, and other physical traits can make it harder for someone to be accepted as their identified gender and may complicate the process of coming out (Zimmerman, 2009).

Coping with Stigma/Discrimination

The two main forms of discrimination noted in the literature facing LGB individuals are homophobia and heterosexism (Beagan, Carswell, Merritt, & Trentham, 2000). Homophobia is a fear or intense dislike of LGB individuals and tends to be expressed as outright intolerance and discrimination of LGB individuals. A more pervasive and less explicit form of stigma involves heterosexism which is ignoring the existence of non-heterosexual orientations or same-sex relationships and their experiences (Beagan, Carswell, Merritt, & Trentham, 2000). Heterosexism, unlike homophobia is often unconscious and unintended (2000). For transgender people transphobia is usually used to describe the same kind of outright intolerance towards transgender people that the term homophobia applies towards LGB identified individuals.

For all individuals in the LGBT community involvement whether online/virtual or in person in the LGBT community has been found to provide a significant buffer against stigma (Balsam & Mohr, 2007; Beagan, et al., 2012). Cow, Dewaele, van Houtte, and Vincke (2011) found that community involvement is significantly correlated with a reduction in internalized homonegativity among LGB individuals. For the bisexual community in particular access to other bisexual people

is essential because they are more likely to face alienation from both the straight and gay communities (Ross, Dobinson, & Eady, 2010).

Occupational Loss/Deprivation as a Result of Coming Out

Occupational Loss as a Result of Coming out LGB

Coming out can often be a difficult occupation simply because it can present so much risk for occupational loss. Corrigan and Matthews (2003) identified four main categories of risks individuals faced when coming out including: physical harm, social avoidance, social disapproval, and self-consciousness. These various reactions affect occupation participation in a variety of ways.

Social participation is one of the biggest areas of occupational loss for LGB individuals who come out. Individuals who come out identified that it had a major effect on relationships with friends and family including the loss of these relationships (Bergan-Gander, & von Kurthy, 2006). In a study of the experiences of gay college students several of them expressed losing friendships and roommates who did not want to face discrimination for being associated with an out gay man (Rhoads, 1995). Participation in social and leisure occupations was significantly affected by sexual orientation because LGB individuals tended to avoid people and places in which their sexual orientation would not be accepted (Bergan-Gander, & von Kurthy, 2006). Fear of harassment and violence also prevented LGB individuals from engaging in various social and leisure occupations (Began-Gander, & von Kurthy, 2006; Rhoads, 1995).

Aside from social occupations the occupations most affected including school and work. In a study of gay college students many of the students expressed feeling excluded and marginalized in class discussion by negative comments from classmates (Rhoads, 1995). In the work situation this marginalization is often present in the form of heterosexism among work policies where language is often gendered and excludes same-sex partners (Twinley, 2014). In many workplace situations individuals are encouraged to avoid talking about their partners or weekend experiences if they imply a non-heterosexual sexuality (Ward, & Winstanley, 2005). Oftentimes individuals justify this silence about LGB experiences by claiming that “bedroom identities” should not be discussed at work. Beagan et al. (2000) argue that this kind of silence does not simply render sexual lives invisible but entire lives invisible because one’s sexual identity plays a role in many formative life experiences outside of one’s romantic and sexual relationships. Asking LGB individuals to maintain this “double life” in which they are not allowed to express themselves at work affects their occupational participation in work activities because they spend a disproportionate amount of time engaged in developing and maintaining coping strategies for dealing with this marginalization (Ward, & Winstanley, 2005).

Workplace marginalization does not simply have social and relational consequences but plays an impact on career advancement and ultimately on financial stability. In one study by Bergan-Gander and von Kurthy (2006) one of the participants stated that after coming out to his manager his manager warned him that his orientation would limit his ability to receive promotions. In some workplaces coworkers may explicitly refuse to work with “out” LGB individuals and may ask to be accommodated for their prejudices. This kind of atmosphere creates a hostile working environment for someone who is LGB and was found to influence LGB people to actually leave their desired career (Twinley, 2014). Hostile attitudes are not the only form of discrimination related to employment that LGB individuals may face; in the U.S. in 29 states there are no legal protections to prevent employers from firing LGB individuals based on their sexual orientation (American Civil Liberties Union, 2015). Overall, the above forms of occupational deprivation and loss experienced by LGB individuals who are out in social, leisure, educational and work situations illustrate a form of occupational injustice (Bergan-Gander, & von Kurthy, 2006).

Occupational Loss as a Result of Being Bisexual

While the above forms of discrimination are often experienced by bisexuals, particularly individuals who are in same sex relationships and are therefore perceived as gay, there are some forms of occupational loss and deprivation that are unique to individuals who identify as bisexual. Most of these occupational losses and deprivations are related to the relative lack of community support for the bisexual community (Balsam, & Mohr, 2007). Because bisexuals often face stigma from both the straight and lesbian and gay community they often do not have access to a supportive community to mitigate the effects of stigma in the straight community (Balsam, & Mohr, 2007; Ross, Dobinson, & Eady, 2010). Bisexuals also tended to face more conflicts within their romantic relationships because their partners often misunderstood their sexual orientation (Ross, Dobinson, & Eady, 2010). Overall, bisexuals face similar forms of stigmas to lesbian and gay individuals with additional difficulties in social occupations related to having less emotional support and their orientations being less understood.

Occupational Loss as a Result of Being Transgender

Because gender identity is something that is often displayed publicly and plays a big role in how one is treated it affects occupation much differently than sexual orientation. In a study by Beagan et al. (2012), many of the transgender women interviewed stated that they felt deprived of the ability to engage in gendered activities that were not considered socially appropriate when growing up. Social norms were enforced strictly and if any of these individuals broke the norms they faced bullying and teasing in school which reinforced the occupational deprivation by discouraging them from participating in desired occupations (Beagan et al., 2012). Over time many of these individuals were forced to take up gender-normative occupations and roles that they did not desire such as the roles of husband and father in order to hide their true identities (Beagan, et al., 2012). In many ways this loss of desired roles and occupations is a strong example of occupational deprivation. Additionally, many transgender individuals experience significant loss when coming out and beginning transition. It is common for transgender individuals to lose relationships with friends, family, religious community and even professional relationships and jobs (Beagan et al., 2012). Because of the loss of social relationships, transgender individuals experience significant difficulty with occupational marginalization.

Occupational Gain/Adaptation

Occupational Adaptation for LGB Individuals

While coming out can be a cause for occupational loss and deprivation, it can also be a cause for the gain of new occupations and roles for LGB individuals. In a study by Corrigan and Matthews (2003), it was found that individuals who came out experienced reduced stress, were less likely to participate in risky behaviors, and experienced closer interpersonal connections in their remaining relationships. While 'belonging' is often a challenge since being openly LGB may lead to loss of some relationships, there is evidence that this honesty strengthens the relationships that survive the coming out process because it allows both people involved to know one another better (Rhoads, 1995). Individuals who came out expressed feeling an immense sense of relief, and greater confidence after coming out and some people say the process helped them to become more courageous in general (Rhoads, 1995). While the narrative of the unaccepting family is a common one, it is evident that many families are able to move past heteronormative social values and respond to their LGB family member in an accepting and nurturing way. In a study of families that are accepting of a family member coming out there were many narratives of families being untroubled

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by the announcement (Gorman-Murray, 2008). This was particularly common among the siblings of LGB individuals and as society is becoming more accepting in general (2008). Many parents in the Gorman-Murray (2008) study saw the coming out process as a positive thing and a chance to connect better with their child. One parent in the study had seen the pain that a sexuality related-suicide had brought to another family and used that as motivation behind his own acceptance of his daughter because he did not want her to experience that kind of pain (Gorman-Murray, 2008). This study showed that coming out can lead to occupational gain in the form of stronger familial relationships and bonds (2008). In another study of LGB college students it was found that after coming out many individuals found that they took up brand new occupations (Rhoads, 1995). After coming out many college students got involved in LGB community events, frequented LGB-owned bars and restaurants, and became much more involved in political activism (Rhoads, 1995). In work relationships coming out also seemed to foster more authentic relationships between coworkers (Ward, & Winstanley, 2005). Because so many closeted LGB people edit their descriptions of their lives in discussions at work in order to manage their identity being open about one's identity can allow for more honest communication and social connection (Ward, & Winstanley, 2005).

Occupational Adaptation for Bisexuals

Because coming out is much more complicated for bisexuals due to lack of social awareness and acceptance, many bisexuals will adapt how they come out and how they identify themselves based on the gender of their romantic partner at the time (Balsam, & Mohr, 2007). It is very common for bisexuals in same-sex relationships to call themselves gay or lesbian as a way of avoiding discrimination faced within the LGB community. Because bisexuals are less likely to have community support they were more likely to foster a wide range of self-care occupations such as exercise, meditation, and art to use as a source of pride and self-esteem and to provide an escape from the stress associated with dealing with stigma (Ross, Dobinson, & Eady, 2010). Much like out LGB individuals in general, many bisexuals are likely to take up occupations related to political and social activism as a way of challenging the social stigmas bisexuals face and making it easier for other bisexual individuals to reach the state of self-acceptance (Ross, Dobinson, & Eady, 2010). In this sense, the state of *becoming*, related to attaining self-acceptance of a stigmatized identity, is also related to helping others become comfortable with their own stigmatized sexual orientations.

Occupational Adaptation for Transgender Individuals

For transgender individuals, occupations associated with transitioning after declaring a transgender identity were numerous and accompanied a far greater range of occupations than those that were gained for LGB individuals. Of all the occupations related to transition the most common one was that of seeking information (Beagan, et al., 2012). The virtual context was especially important because it was the easiest way to access information and communities of other transgender people to learn about their experiences. The actual process of medical and social transition included a variety of occupations related to grooming, voice training, and securing access to medical interventions such as hormone therapy and surgical intervention (Beagan, et al., 2012). Because of the monetary expenses associated with medical transition, transgender individuals spend a lot of time engaged in occupations related to securing the money necessary for surgery or hormones. In many cases individuals would stay in jobs they did not necessarily enjoy or would change jobs in order to ensure they had medical coverage (Beagan et al., 2012). In general, it was found that securing health care services was exhausting. Because most medical professionals did not have much knowledge about transgender individuals, many transgender people end up engaging in the occupation of educating their doctors and other health care workers (Beagan et al., 2012). As part of the process of transition, individuals spent a lot of time navigating through bureaucracy while

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they looked into changing their identification cards, birth certificates, and dealt with navigating the legal system while their identifiers did not match their gender identity (Beagan, et al., 2012). The process of transition as a whole can be seen as an aspect of “becoming” in that it is a goal-oriented approach to changing appearance, legal identification, and social perceptions to gain widespread recognition of their gender identity (Hitch, Pepin, & Stagnitti, 2014).

In everyday occupations the occupations of dressing and grooming were hugely important for transgender individuals because it gave them the opportunity to “play” with gender expression through dress. Grooming activities such as finding a wig, styling hair and undergoing facial electrolysis were very important to transgender women hoping to be recognized as female in public (Beagan et al., 2012). Getting to finally participate in occupations associated with their gender identity, such as makeup for example, was an exciting experience for many transgender people who felt they were unable to engage in these occupations when they were still in the closet (Beagan, et al., 2012).

One new occupation that was adopted by many transgender individuals was that of educating others about the needs, challenges, and language of the transgender community (Beagan, et al., 2012). Many transgender individuals interviewed discussed participating in online communities and even going to national and international conferences for transgender people. Many transgender individuals expressed a strong need to give back to the transgender community and help others through the process of transition and associated occupations related to transition including disclosing at work, getting medical treatment, and dealing with bureaucracy (Beagan, et al., 2012). In this way many transgender individuals use their own process of becoming as part of transition to help others in their own process of becoming and belonging (Hitch, Pepin, & Stagnitti, 2014).

Conclusion

While this is not an exhaustive review of the literature it may be concluded that overall, the occupation of “coming out” is complex and holds a variety of meanings and struggles including the nuances of self-acceptance, social relationships and occupational changes. “Coming out” affects participation in a variety of occupations and community engagement. The process is very different depending on the social and cultural environment that surrounds the individual involved and the orientation of that individual. The occupation of “coming out” shows many facets of the processes of doing, being, becoming, and belonging since it involves action, reflection, change and adaption, and ultimately greatly affects social relationships with others in both positive and negative ways (Hitch, Pepin, & Stagnitti, 2014). Understanding the meaning behind these occupations can offer occupational therapists insight into this occupational process and offer greater help for working with LGBT clients (Jackson, 1995). The unique experiences of LGBT individuals related to learning self-acceptance, coming out to others, and adapting to occupational loss as well as the gain of new occupations color their experiences of all occupations (Jackson, 1995).

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Without Warning? What Occupational Challenges Cause Suicide Among Minority Young Adults? A Literature Review by Yazmin Walker

Abstract

Suicide is a major public health concern within the United States. Suicide is the tenth leading cause of death for all age groups and the second leading cause of death among young adults aged 15-35. This literature review examines the increase of suicide death rates in young adults age 15-35, specifically young adult minority groups. African American, American Indian, Asian American and Hispanic American have unique occupational challenges that led to the act of suicide. In this review various protective and risk factors are examined to determine the best intervention and prevention measures required to address the epidemic of young adult minorities committing suicide. When healthcare professionals embrace a *doing, being, becoming, and belonging* frame of reference, utilize an occupational lens and implement the principles of Occupational Perspectives of Health (OPH), suicides can be averted. Creating interventions that emphasize the diversity of risk factors across young adult minority groups can help dispel the myth that suicides occur without warning.

Key words: suicide, occupational challenges, minorities, young adults

Without Warning? What Occupational Challenges Cause Suicide Among Minority Young Adults? A Literature Review by Yazmin Walker

According to the Centers for Disease Control (CDC), suicide is the second leading cause of death among persons aged 15- 35 years of age (2015). Amongst this age group the rise of ethnic minorities committing suicide has increased drastically. The ethnic minorities represented in these statistics are African Americans, American Indians, Asian, and Hispanics. Among American Indians/Alaska Native Americans aged 10 to 34 years of age, suicide is the second leading cause of death, which is 1.5 times higher than the national average (CDC, 2015). Hispanic students had a higher percentage of suicide attempts than white and black students. The percentage of minority young adults aged eighteen or older having suicidal thoughts in a twelve-month period were as follows: 2.9% among blacks, 3.3 % among Asians, 3.6 % among Hispanics, 4.8% among American Indians/Alaska Natives, and 7.9% among adults reporting two or more races (CDC, 2015). The purpose of this literature review is to address these alarming statistics of an increase in suicide ideation, attempts, and acts of suicide amongst minorities, and to explore the occupational barriers that lead to the cause of suicide amongst young adult minorities. This literature review will explore the Joiner (2005) Interpersonal-Psychological Theory of Suicide, differences amongst minority subgroups, young adult transitions and occupations, and common themes across these ethnic minority young adults. By examining occupational challenges that increase suicides amongst young adults, the myth of suicides occur without warning will be demystified. Research suggests individuals provide warning signs eight out of ten times and nearly all attempters have reported suicide ideation or plans before the attempt (Leenaars, 1997; Jalongo, et al., 2002). Discovering the warning signs and risk factors of minority suicides will assist healthcare professionals to provide targeted intervention techniques to minority populations to decrease the number of suicides. By becoming aware of these risk factors displayed differently in these minority groups, healthcare professionals can effectively create measures to divert minority young adults who are contemplating suicide.

Methodology

This literature review was completed to determine what occupational challenges occur leading up to the act of suicide amongst minority young adults. The majority of the articles originated from the Health Professions Division Library at Nova Southeastern University (NSU) through an advanced systematic search of electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed. Articles also found through Google Scholar, The American Journal of Occupational Therapy (AJOT), British Journal of Occupational Therapy (BJOT), American Journal of Orthopsychiatry, and Suicide and Life-Threatening Behavior. Research articles that were obtained from NSU's Health Professions Division Library, AJOT, BJOT, American Journal of Orthopsychiatry and Suicide and Life-Threatening Behavior were obtained through general search criterion and were further filter utilizing databases such as CINAHL. Keywords for search criteria included: *suicide*, *minorities*, and *young adults*. In total there were 60 articles that met the following inclusion criteria: a) publishing dates within the past 20 years (1995-2015), b) studies published in full text and in English language, c) studies that related to main topic, as well as the subtopics of young adult minority suicide, Joiners Interpersonal-Psychological Theory of Suicide, differences amongst minority subgroups, protective factors, life transitions, and acculturation and lastly, d) studies that related to occupational challenges in relation to suicide, occupational therapy and occupational science. The exclusionary criteria included: a) the studies were irrelevant to the main topic of research or did not pertain to the subtopics, b) the studies were not available in full text, or were systematic reviews or research proposals and lastly, c) were not relevant to occupational challenges, occupational therapy or occupational science.

Young Adult Life Transitions and Occupational Roles

Throughout this literature review, young adulthood will be defined during the ages of 15-34 thirty years of age. “Young adulthood includes unique biological, psychological, cultural, and sociological issues” (Leenars, 1997, p.16; Erikson, 1980; Fitzpatrick, Piko & Miller, 2008). Erikson (1963, 1980) defined the young adult psychological stage from the ages 18 to 40 years of age. This stage is called Intimacy vs. Isolation. During this stage, humans will find love or be alone. During this period, we explore relationships and define intimacy in our lives. If during this stage we avoid intimacy, fear commitment and relationship this can lead to isolation, loneliness, and depression. In order to find love and define relationships, one must determine who they are as a person before they can appreciate the uniqueness of another individual to complete the cycle of this stage and find love. If the identity crisis with one self is not resolved, then relationships during this stage in life will be avoided and often become narcissistic in nature (Leenars, 1997).

During young adulthood, there are typical occupations and roles that young adults engage in such as, visiting with friends, college student, employee, a member of a club or sports teams, shopping for pleasure, dining out, gardening, movies etc. (Lobo, 1999). Transitions are constantly occurring during young adulthood (Blair, 2000). Transitions in life that may occur during this adulthood period are stressful life events and instability in relationships (Joe, Canetto, & Romer, 2008; Joiner, 2005). Such life transitions may occur from school to workplace, or from the family of origin to the family of proliferation. The transition from adolescence to young adulthood represents the period of highest risk for the occurrence of new mental disorders, risky behaviors, self-injurious behaviors, which leads to an increase in suicide rates (Ialongo, et. al, 2002, Whitlock & Knox, 2007).

The Interpersonal-Psychological Theory of Suicide

A common theoretical framework of The Interpersonal-Psychological Theory of Suicide (Joiner, 2005) served as the basis research studies included in this literature review. Joiner (2005) proposed three aspects of risks that lead a person to suicide: (1) a sense of perceived burdensomeness toward others; (2) feelings of thwarted belongingness; and (3) an acquired capability to self-injure. Human beings are social entities, and require social interactions with others (Davidson, Wingate et al. 2009). The inborn nature of all human beings is survival and existing (Christiansen & Townsend, 2010), why then do some humans, specifically, minority young adults seek to permanently terminate all social interactions and revoke their survival intuition. Joiner’s (2005) theory provides constructs that support this baffling question. One hypothesis is that during the time period of the ages of 15-34 years, many minority populations may experience, extreme inconsistencies, perceived inability to meet parental demands, peak onset of depression along with life transitions. These combinations of stressors are the perfect storm to create an internal struggle for survival. Therefore, if an individual perceives themselves as a burden on others, this may impede the basic human need to contribute and belong in a social group. Consequently, then, the idea of suicide may be entertained as a manner in which to relieve the perceived burdensomeness on others, and lack of belonging to a group or family (Garza & Pettit, 2010).

Minority Subgroups

A. African Americans

African Americans have experienced generations of prejudice, discrimination, poverty, social and cultural isolation and lack of community resources. Despite these cultural impediments, rates of suicide among African Americans have remained relatively low (Gibbs, 1997; Lincoln, Taylor,

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Chatter & Joe, 2012; Stansfeld, 2012; Walker & Bishop, 2005). This phenomenon has baffled researchers due to the apparent disadvantage status of African Americans and their uncommon use of suicide as a resolution to their tribulations (Gibbs, 1997). The statistics on African American suicide may be slighted due to cultural attitudes and the reporting of questionable and accidental deaths (Gibbs, 1997; Lincoln et al., 2012). Recent research has suggested that there has been a steady increase in African American suicide particularly, African American men (CDC, 2013; CDC, 2015; Gibbs, 1997; Joe & Kaplan, 2001).

Statistically, African Americans commit suicide much less frequently than whites, but they do so at much earlier ages (Garlow, Purselle & Heninger, 2005). African American suicides typically occur between ages 20 and 45, and virtually none above this age. In comparison to their white counterpart, suicide is high in young adulthood and peaks between ages 75-84 (Garlow, Purselle & Heninger, 2005; Gibbs, 1997, Ialongo, 2002). Within this age group of 15-24 in comparison to other racial groups, suicide is the third leading cause of death for African American men (National Center for Health Statistics [NCHS], 201). Willis, Coombs, Drentea, & Cockerham (2003) created a racial summary of African Americans who typically commit suicide. A few of the risk factors include: Occur more often under age 35, are likely to occur in the Midwest, Southeast, and Northwest, are likely to be young, male, single and never married, are less likely to occur in rural areas with less than a high school education, and firearm access in the home. (p. 425).

Previous literature has focused on protective factors that have seemed to shield this minority group from the tragedy of suicide as compared to their white counterparts. African American protective factors from suicide are religiosity, old age, living in a southern region and social support. Attending church has been associated with lower rates of suicide. Suicide rates within the African American community tend to decline with age, suicide rates tend to be lower in southern regions and in particularly in areas with less racial segregation, and lastly, social support has protected African Americans from suicide (Fitzpatrick, Piko, & Miller, 2008; Gibbs, 1997; Harris & Molock, 2010; Joe & Kaplan, 2001; Lincoln et al., 2012; Merchanr, Kramer, Joe, Venkataraman, & King, 2009; Molock, Matlin, Barksdale, Puri & Lyles, 2008; Walker, 2007, Walker & Bishop, 2005).

As African American individuals increase their association with mainstream culture they are at risk for losing cultural protective factors such as family cohesion and support due to increased family conflicts. As more African Americans begin to associate with mainstream culture there is a documented increase in attitudes of acceptance towards suicide. This acceptance of suicide is the result of experiencing hopelessness in their quality of life, which increase risks of suicidal behaviors. (Joe, Romer, Jameison, 2007; Walker, 2007).

African Americans have endorsed a “value for endurance, resilience, and persistence in the face of adversity” (Gibbs, 1997, p.74). This belief in hope, endurance and perseverance over obstacles through hard work and determination in the African American community has been labeled “John Henryism” (Willis, Coombs, Drentea, & Cockerham, 2003; Davidson, Wingate, Slish & Rasmussen, 2010). This John Henryism has also been an unstated protective factor within the African American community. This viewpoint of resilience in handling life challenges views suicide as an unacceptable solution (Davidson et al., 2010; Gibbs, 1997; Willis, et al., 2003).

Prevention and intervention techniques within the African American community should focus on social supports. These social supports safeguard against suicidal behaviors in African American young adults (Harris & Molock, 2000). Early intervention social supports are paramount to reducing young adult suicides. These social supports should include access to life options for African American youth. Life options include school-based intervention to increase high school graduation rates, job training, and training in skilled and technical occupations (Gibbs, 1997). Along with life options, early intervention programs should provide young adults with coping and stress management techniques that focus on cultural identification and unity (Joe & Kaplan, 2001). A vital

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aspect of social supports is the increased sense of belonging within the African American community. This feeling of belonging can be obtained from involvement in activities and groups with similar interests (Davidson et al., 2010).

The African American church is a social support that is central to African Americans. The church provides emotional and spiritual needs to the community. Molock et al., (2008) suggest the African American church has advantages to providing suicide prevention programs to the community. A model for this suicide prevention program is Helping Alleviate Valley Experiences Now (HAVEN). Key components of this program are key helpers, gatekeepers, a mental health resource directory, and community education curriculum. Access to firearms within the African American community has been attributed to increased suicide incidences in the community (Willis et al., 2003). Parents and family members can decrease the availability of firearms in the home especially in the residences of individuals with a history of depressive and suicidal tendencies. Health professionals can also screen young adults who have exhibited depressive and suicidal symptoms about the presence of firearms within the home (Joe & Kaplan, 2001).

Lastly, the public health community should emphasize encouraging African American communities and families to engage in “mental wellness promotion and mental illness prevention efforts, including suicide prevention” (Joe & Kaplan, 2001, p.117). Medical practitioners who treat African American young adults should routinely screen for suicidal ideations and make appropriate referrals, specifically those with a history of mental or substance abuse disorders (Ialongo et al., 2002). Without collaborative efforts to develop comprehensive public policies to address this public health concern of African American suicide, these rates will increase as the risk factors will inevitably outweigh the protective factors (Gibbs, 1997). Therefore, suicide prevention for African American young adults should focus on social supports, the feeling of belongingness, suicide intervention programs within the African American church, restricted access to firearms, coping and stress management skills, medical professional awareness and public policies.

American Indian

Suicide is a critical well-being and public health concern for American Indian adolescents and young adults (CDC, 2013; CDC, 2015; Freedenthal & Stiffman, 2004; Joiner, 2005; Lipschitz, 1995; Novins, Beals, Roberts & Manson, 1999; O’Keefe et al., 2013). The peak for death by suicide in American Indian is in young adulthood (Joiner, 2005). Suicide is the second leading cause of death for American Indians aged 15-24 and is 2.5 times that national rate (Center For Native American Youth, 2014). Non-Hispanic American Indian/Alaska Natives accounted for the highest suicide deaths among all race/ethnic groups (16.5 per 100,000 population) (Parks et al., 2014). There are 566 federally recognized tribes in 35 states in the United States. In 2011, it was estimated 22 percent of American Indians/Alaska Natives lived on reservations or other US Census-defined tribal areas and 60 percent of American Indians/Alaska Natives lived in metropolitan areas (Center for Native American Youth, 2011). Due to the diversity of environments in which American Indians live, forecasting the epidemic of American Indian suicide rates can be challenging, due to reservation or urban/city living. Freedenthal & Stiffman (2004) found lower rates of suicidal behavior in rural, off-reservation American Indian adolescents than rates reported for reservation reared American Indians. A hypothesis for these lower rates of suicides of adolescents living off reservations is urban-reared adolescents are more psychologically healthy because they had more opportunities for education and employment. These lower rates still do not account for the similar rate of suicide attempts of urban reared youth to reservation-reared youth. Therefore, urban-reared youth may not have an advantage, overall, in comparison to reservation- reared youth.

Furthermore, there is variation of suicide rates across tribal communities within American Indian tribes. Due to the diversity among the 566 federally recognized tribes there are differences in

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languages, social structure, emphasis on individuality, and gender roles (Novins et al., 1999). While the general rates of suicide of American Indians are high, suicide and suicide attempts rates vary across tribes. Novins et al., (1999) compared three American Indian regional tribes of Pueblo, Southwest, and Northern Plains. They found the Pueblo tribe had the most tightly-knit communities with strong social networks. This population was influenced the most when a friend committed suicide or engaged in suicidal behavior. These suicides within the Pueblo community often occurred due to feelings of being unsupported by family and friends and depressive symptoms.

The Southwest tribes were characterized by strong family, community and peer ties similarity to Pueblo American Indians. Southwest tribes have strong cultural prohibitions against thinking about death and suicidal ideation. Suicide ideation and attempts occurred in this community in homes without both biological parents. Lastly, the Northern Plains tribe highlighted individual achievement and a more ego-centered conception of self. Among the youth of this tribe, suicide ideation was associated with low self-esteem and higher levels of depressed affect and higher rates of suicide in comparison to the other two tribes in this research study. It can be hypothesized the higher rates of suicide amongst Northern Plains tribes is due to the lack of belongingness due to the focus on individualized achievement and ego-centered conception of self. These higher rates are seen when comparing the Apache tribe to the Navajo or Pueblo people; the latter tribes have greater focus on social integration (Joiner, 2005).

General protective factors identified within the American Indian community are: discussing problems with friends and family members, emotional health, cultural and spiritual orientation, and perceived connectedness to family (Borowsky, Resnick, Ireland & Blum, 1999; Garrouette et al., 2003; Hill 2006; Hill 2009). A surprising protective factor that was found by Scheel, Prieto & Biermann (2011) states American Indian college students have reduced incidences of suicide. This low number of suicidal ideation within American Indian college students may be due to the theory of hope; further research is warranted to support this protective factor of college enrollment in the American Indian culture.

Suicide risk factors vary across tribal communities within the American Indian population. General risk factors are depression, unintentional injury and violence behaviors, higher rates of poverty, sexual risk behaviors, isolation, tobacco, alcohol and other drug use, sociodemographic factors, loss of friend or family member to suicide and poor parent-child communication (Borowsky, et al., 1999; Freedenthal & Stiffman, 2004; Garrouette et al., 2003; Hill, 2006; Hill, 2009; Novins et al., 1999; Pharris, Resnick & Blum, 1999; Shaughnessy, Doshi & Jones, 2014).

Suicide prevention and screening programs within the American Indian population may be difficult to transfer from one American Indian tribal community to the other due to the vast amount of diversity. Prevention strategies within the American Indian community should be global and not generalized to specific a specific tribal community (Novins et al., 1999). Prevention strategies within the American Indian community should center on developing positive self-identities in young adults and environmental improvements that create safe neighborhoods that do not allow poverty, separation, illness, or alcoholism to impact positive role models and images within the American Indian community (Lipschitz, 1995). Intervention measures should include tribal health programs, and address discussing problems with friends or family, emotional health and cultural spiritual connections (Borowsky et. al, 2007; Garrouette et al., 2003).

Asian Americans

There has been a steady increase in Asian American suicides between the ages of 15-24. Within this age group Asian young adult men suicide rates rose from 10.9 deaths per 100,000 in 2010 to 11.9 deaths per 100,000 in 2013. Asian young adult women in this age group suicide rates accounted for 3.5 deaths per 100,000 in 2010 and 3.6 deaths per 100,000 in 2013. Among the 15-24-

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year old age group in 2013, Asian men and women had the second highest suicide rate for all racial groups preceded only by American Indian or Alaska Native men (NCHS, 2013). Overall suicide is the ninth leading cause of death for Asian Americans (Heron, 2015).

Family cohesiveness is a centrality to Asian Americans. Among Asian American college and university students living with a family member or partner has been notated as a protective factor. Especially, among Asian American young adults family relationships and group orientation are important values in Asian cultures (Wong, 2011a; Wong, 2011b; Wong, 2011c; Wong, 2012). Three main protective factors for Asian Americans are ethnic group identification, family cohesion and support (Asian American Psychological Association Leadership Fellows Program, Hijioka & Wong, 2012). These protective factors are seen predominately in Asian American young adult college students who are under cultural pressure to perform academically (Wong, 2011a; Wong, 2011b; Wong, 2011c; Wong, 2012).

Suicidal ideation, attempts and suicides within the Asian racial group have been associated with certain risk factors, such as mental illness, history of lifetime psychiatric illness, social factors, chronic medical conditions, born in the United States, high levels of family conflict, perfectionism, academic pressures, high levels of discrimination, and acculturative stress (Asian American Psychological Association Leadership Fellows Program, Hijioka & Wong, 2012; Duldulao, Takeuchi & Hong, 2009; Hahm, Jang, Vu, Alexander, Driscoli, & Lungren, 2013; Kuroki & Tilley, 2012; Leong, Leach & Chou, 2007; Shang, Li, Li, Wang & Siegrist, 2014; Wong, 2011a; Wong, 2011b; Wong, 2011c; Wong, 2012). There are also racial differences within Asian American groups; Japanese Americans had higher suicide rates than Chinese Americans and Filipino Americans (Chu, Hsieh & Tokars, 2011; Leong, Leach, Yeh & Chou, 2007; Lester, 1994). Chinese Americans were more likely to report suicidal ideation in comparison to Vietnamese and Filipino Americans (Cheng et al., 2010). Kim & Kim (2008) found among Korean youth who attempted suicide certain risk factors, such as lack of family cohesiveness, parent-child conflict, intra-familial sexual abuse, psychotic disorders, depression, chronic disease, and alcoholism among family members.

Outreach efforts to prevent Asian American suicide should include cultural norms and cultural practices when developing intervention programs. Interventions addressing Asian Americans should address help-seeking behaviors within this racial group (Chu, Hsieh & Tokars, 2011). Clinicians should focus on key cultural factors when addressing suicide with Asian Americans such as acculturation, the need for academic perfectionism, family generational issues, religious and spiritual background (Leong et al., 2007). Intervention efforts should also focus on the academic balance of heavy workload and competition. Poor academic performance has been found to impair self-esteem within the Asian culture (Shang et al., 2014). Mental health counselors and therapists at colleges and universities should focus on the assessment of family, academic, financial problems within Asian American populations, and family connectedness (Wong, 2011a; Wong, 2011b; Wong, 2011c; Wong, 2012).

Hispanics

According to the U.S. Census Bureau (2015) Hispanics are the largest minority group in the United States, they represent 17 percent of the nation's total population and are projected to constitute 31 percent of the nation's population by the year 2060 (U.S. Census Bureau, 2014). Current literature on suicide has suggested that there has been a steady increase of suicide in the Hispanic population (Canino & Roberts, 2001; CDC, 2015; Garza & Petit, 2010; Humensky, Gil, Coronel, Cifre, Mazzula & Lewis-Gernandez, 2013; Joiner, 2005; Olvera, 2001; Roberts, Roberts, & Xing, 2007; Zayas, Lester, Canassa, & Fortuna, 2005; Zayas & Pilat, 2008). Particularly there has been a rise in suicide amongst Hispanic women. Documented risk factors in Hispanic suicides are

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familial conflict, acculturative stress, female gender, fatalism, sociocultural stress, minority stress, and psychological/depressive symptoms (Garza & Petit, 2010; Olvera, 2001).

Hispanic familism emphasizes upholding of family cohesion, obligation and intense attachment to relatives. Family is central to the individual's self-identity and social world (Zayas, Lester, Cabassa & Fortuna, 2005, p.278). The concept of familism has been thought to be a strong protective factor to safeguard Hispanic women against suicide (Garza & Pettit, 2010; Humensky, Gil, Coronel, Cifre, Mazzula & Lewis-Gernandez, 2013; Zayas, Lester, Cabassa & Fortuna, 2005). Researchers have suggested that the family unit is stronger than the individual themselves and is the most influential aspect in a Hispanic woman's life (Garza & Pettit, 2010).

During the developing adolescent years, Hispanic women may feel the challenge of maintaining cultural traditions and traditional gender roles, and integration into mainstream social norms and customs (Garza & Pettit, 2010; Zayas, Lester, Cabassa & Fortuna, 2005). This internal conflict is characterized as connection versus separation or relatedness versus autonomy (Garza & Pettit, 2010). Hispanic women are torn between the obligations to family and responding to the internal sense of autonomy that is developing during the adolescent years. The notion of accountability and responsibility toward the Hispanic family causes strain and psychological challenges in the developing adolescent Hispanic woman. The protective factor of familism then becomes a gateway to suicidal ideation among Hispanic women believing a breach in family uprightness has occurred due to the process of discovering who they are as an individual separate from their cultural background, in particular the adolescent-parental conflict, once parent and child are unable to (Garza & Pettit, 2010; Zayas & Pilat, 2008; Zayas, Lester, Cabassa & Fortuna, 2005).

These suicidal ideation and thoughts occur when Hispanic parents and children cannot reconcile their acculturative differences (Zayas & Pilat, 2008). Acculturative stress occurs due to the Hispanic adolescent wanting to adapt and embrace the new culture, which represents greater autonomy of young girls compared to their traditional Hispanic roles in which the adolescent girl is expected to live in a restrictive and authoritative environment (Zayas & Pilat, 2008; Zayas, Lester, Cabassa & Fortuna, 2005). Consequently, the feeling a perceived burdensomeness is then entertained, identifying "oneself as a drain on others thwarts a basic human need to contribute to and be valued in a social group... Burdensomeness toward loved ones is a strong predictor of suicidal ideation, regardless of one's sense of obligation toward family" (Garza & Petit, 2010, p. 569-570). Joiner (2005) refers to this adolescent feeling of burdensomeness to family, as a perceived inability to meet parental demands known as the "expandable child" theory. "Individuals who perceive themselves as not measuring up and being a burden are prone to suicidal behavior" (Joiner, 2005, p. 111).

Interventions for Hispanic young adult women who are contemplating suicide should focus on coping skills and family (Canino & Roberts, 2001; Humensky et al., 2013; Zayas & Pilat, 2008; Zayas, Lester, Cabassa, & Fortuna, 2005). Coping skill interventions should include focus on the transition from adolescence to young adulthood and responding to the demands of meeting parent expectations and the need to find autonomy amongst mainstream culture. Interventions should be designed specifically to address coping skills to confront the psychological and psychosocial issues that arise during the life transition from adolescence to adulthood in Hispanic women. More importantly, the center of intervention with Hispanic women should include the family. Moreover, familism is an important role within the Hispanic community. Including family members in treatment for Hispanic women is important due to family being central to the Hispanic culture (Canino & Roberts, 2001; Humensky et al., 2013; Zayas & Pilat, 2008).

Summary and Similarities Across Minority Groups

Belonging

Evaluating suicidal ideation, suicide attempts, and suicide across minority groups two prominent themes emerged as factors involved in minority suicide, which were the sense of belonging and acceleration. Maslow (1970) identified belonging as a universal characteristic of human beings and is a basic need. "Belonging is multidimensional and reflects the psychological, sociological, physical, and spirituality connections of individuals, families, or communities (Hill, 2009, p. 66). As stated previously, Joiner (2005) identified belongingness as a key component to suicidal ideation. Literature has shown that belongingness is a protective factor amongst members of minority groups (Asian American Psychological Association Leadership Fellows Program, Hijioka & Wong, 2012; Borowsky, Resnick, Ireland & Blum, 1999; Garrouette et al., 2003; Garza & Pettit, 2010; Gibbs, 1997; Harris & Molock, 2010; Hill 2006; Hill 2009; Humensky, Gil, Coronel, Cifre, Mazzula & Lewis-Gernandez, 2013; Fitzpatrick, Piko, & Miller, 2008; Joe & Kaplan, 2001; Lincoln et al., 2012; Merchanr, Kramer, Joe, Venkataraman, & King, 2009; Molock, Matlin, Barksdale, Puri & Lyles, 2008; Walker, 2007, Walker & Bishop, 2005; Wong, 2011a; Wong, 2011b; Wong, 2011c; Wong, 2012 & Zayas, Lester, Cabassa & Fortuna, 2005) individuals who perceive themselves as members of a community or group are less likely to have suicidal ideations. Once there is a disconnect from these social connections individuals feel as though they do not belong and there is a disconnection between these groups the concept of belongingness becomes thwarted (Joiner, 2005). The sense of belonging can be health promoting, in communities that offer social support (Hill, 2006).

Acculturation

Acculturation is the process in which an individual adapts to a new culture and begins to adopt a new culture and adopts values, transitions, beliefs and behaviors of the new culture while maintaining components of the culture of derivation (Cabassa, 2003). The process of acculturation can become stressful in minority groups when there is pressure to maintain the culture of origin values and tradition while adapting to the new culture (Zayas & Pilat, 2008). This difficult transition of adapting is defined as acculturative stress. Acculturative stress is related to the procedure of adapting to the beliefs, practices, and values of a dominant culture (Gomez, Miranda & Polanco, 2011). Stressors within minority groups are prejudice, discrimination, poverty, inadequate housing and dysfunctional families (Canino & Roberts, 2001). Acculturative stress is associated with predictors of suicidal behavior, including depression and suicidal ideation, among adolescents and emerging adults (Gomez, et al., 2011; Roberts et al., 2007).

When surveying groups independently Gomez, Miranda & Polanco (2011) found familial acculturative stress was associated with previous suicide attempts in Asian and Black populations but not within Hispanic populations. Asian and African American young adults reported more ethnic discrimination in contrast to other ethnic minority groups. Asian-American young adults reported higher levels of acculturative stress, compared to other racial/ethnic groups (Gomez, Miranda & Polanco, 2011; Leong et al., 2007; Wong, 2011b; Wong, 2011c; Wong, 2012). In comparison, Hispanic individuals expressed more social acculturative stress; specifically perceived discrimination was linked to previous suicide attempt history. This perceived discrimination is associated with lower personal control, psychological distress, hopelessness, and sensation seeking is considered higher risk for suicide (Joe, Romer, & Jamieson, 2007). When connecting acculturative stress and belongingness, it can be theorized discrimination leads adolescents and emerging young adults to discover the meaning of belonging to an ethnic group (Cheng, et al., & Gomez, et al., 2011).

Discussion

Occupation and Suicide

The term occupation originates from Latin, which means “to occupy or to seize” (Christiansen & Townsend, 2010). To be occupied is to be engaged in meaningful and purposeful activities. When viewing humanity through an occupational framework, an understanding must be reached that occupation is “what people are doing, or want and need to do to survive, be healthy, and live well” (Christiansen & Townsend, 2010, p. 2). It can be speculated that individuals who commit suicide lost the meaning and purposefulness of their life and the need to “occupy” was absent or removed from them. Once an individual is unable to engage in the occupation of their choice suicide may then become an option. Davidson et al., (2009) established male professional athletes have higher suicide rates than the general population, and that along with psychosocial factors, injuries are the most commonly linked element to suicide among athletes. It can be inferred that once the male athletes’ occupation of engagement in sports is taken due to injuries there is a sense of meaningfulness lost in their life.

Occupational deprivation

Depression and mental illness is a key risk factor for suicidal ideations and suicide among racial groups. Depression and psychological disorders were risk factors for all racial groups presented in this literature review (Asian American Psychological Association Leadership Fellows Program, Hijioka & Wong, 2012; Borowsky, Resnick, Ireland & Blum, 1999; Garrouette et al., 2003; Garza & Pettit, 2010; Gibbs, 1997; Harris & Molock, 2010; Hill 2006; Hill 2009; Humensky, Gil, Coronel, Cifre, Mazzula & Lewis-Gernandez, 2013; Fitzpatrick, Piko, & Miller, 2008; Joe & Kaplan, 2001; Lincoln et al., 2012; Merchanr, Kramer, Joe, Venkataraman, & King, 2009; Molock, Matlin, Barksdale, Puri & Lyles, 2008; Walker, 2007, Walker & Bishop, 2005; Wong, 2011a; Wong, 2011b; Wong, 2011c; Wong, 2012 Zayas, Lester, Cabassa & Fortuna, 2005). Occupational deprivation involves someone or something external to the individual is doing to depriving. The state of deprivation arises not as a result of boundaries distinctive within the individual, but due to forces outside his or her control (Whiteford, 2000; 2010). Social environment enables or constrains individuals with psychosocial disorders, for example in the case of individuals with schizophrenia, the mental illness does not create the occupational deprivation but the social exclusions faced by people with schizophrenia because of the stigma of mental illness contributes to the experience of occupational deprivation (Whiteford, 2000; 2010). Therefore, in regards to individuals with suicidal ideation that have a history of mental illness their sense of belongingness and engagement in occupation could be deprived not by their own omission but due to societal restraints and stigmas against individuals who have mental illness.

Occupational balance/imbalance

The extent to which an individual is able to organize and participate in occupation in a manner congruent with their aspirations and values is referred to as occupational balance. Occupational balance is an individual perception; it is not the equal distribution of time spent and engagement in occupations but pertains to an agreeable arrangement of occupations that lead to a sense of well being (Blackman, 2010). In comparison occupational imbalance is described as excessive time spent in one area of life at the expense of other areas, or the lack of congruence across one’s occupations and values. As seen in Asian Americans pursuit for academic achievement and perfection there is an occupational imbalance, an inability to balance life and academic pursuits which has been researched to be a risk factor for suicide in Asian Americans (Wong, 2011a; Wong, 2011 b; Wong, 2011c; Wong, 2012). Occupational imbalance can also cause role overload and role strain, engagement in valued roles “with a need to live up to external expectations, contribute to a perception of imbalance (Blackman, 2010, p. 239). This role overload and perception of imbalance has been notated in all

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racial groups in regards to acculturation and living up to external expectations to assimilate into the new culture (Cabassa, 2003; Gomez, Miranda & Polanco, 2011; Zayas & Pilat, 2008). Specifically, research has shown Hispanic women have tremendous amount of role strain and imbalance in regards to familial roles. Hispanic women with suicidal ideation have the perception of the inability to meet cultural and parental standards may cause occupational imbalance and role strain thus leading to suicide (Garza & Pettit, 2010; Humensky, Gil, Coronel, Cifre, Mazzula & Lewis-Gernandez, 2013; Zayas, Lester, Cabassa & Fortuna, 2005).

Doing, Being, Becoming, and Belonging

The field of occupational science provides occupational therapy with this scientific foundation by studying how humans engage in meaningful occupations (Pierce, 2014). A theory that has emerged from the study of occupation is Wilcock's (1998) Occupational Perspective of Health (OPH), this theory addresses the concepts of *doing, being, becoming and belonging*. Wilcock proposed as occupational therapist the profession has a unique perspective on understanding of occupation, which embraces the concept of "the things people do, the relationship of what they do to who they are as human beings, and that through occupation they are in a constant of becoming different (Wilcock, 1998, p. 255).

Leufstadius, Erlandsson, Bjorkman & Eklund (2008) completed a research study reviewing the use of meaningfulness in daily occupations between individuals with mental illness. The findings of this study show that the use of meaningful occupations as interventions with individual's mental illness was proven effective. By engaging in meaningful occupations these individuals felt a connection with others, the society and culture around them i.e. *belonging*. Engaging in meaningful occupations provides individuals with mental illness with a sense of self-identity and purpose, it provides a role within a group or community and occupies time by something that is meaningful which provides a sense of achievement which reflects someone as they are *Doing, being, becoming and belonging* (Harvey & Pentland, 2010; Hitch, Leufstadius, Erlandsson, Bjorkman & Eklund, 2008; Pepin & Stagnitii, 2014a; Hitch, Pepin & Stagnitii, 2014b; Wilcock, 1998).

In relation to mental illness and suicide OPH can be used as intervention measures to assist these individuals. Utilizing OPH occupational scientist can begin to research occupational risk factors, such as occupational imbalance, deprivation and alienation that lead an individual to commit suicide. In turn occupational therapist can utilize the research from occupational scientist to create prevention programs to engage individuals with suicidal ideation in meaningful occupations and debunk the myth suicide occur without warning (Fieldhouse, 2000; Custer & Wassink, 1990).

Conclusion

This literature review has reviewed the epidemic of suicide within the young adult minority population. The time period of young adult years has been shown to be a vital period of transitions, self-identity and the attempt to discover love and partnership. If this time period is filled with turmoil, grief and strife it can have detrimental affects on an individual's psyche and lead to suicidal ideations (Erikson, 1963; Erikson, 1980; Fitzpatrick, Piko & Miller, 2008; Joe, Canetto, & Romer, 2008; Joiner, 2005; Leenars, 1997). During young adulthood there are typical occupations that occur, if occupational risks occur during this time period this may interrupt the engagement in meaningful activities (Ialongo, et. al, 2002; Whitlock & Knox, 2007).

The Interpersonal-Psychological Theory of Suicide (Joiner, 2005) provides insight on examining suicide across minority groups. This theory states that in order for an individual to complete a suicidal act there must be (1) a sense of perceived burdensomeness toward others; (2) feelings of thwarted belongingness; and (3) an acquired capability to self-injure. When looking across minority groups there are distinct differences and similarities in the act of suicide. African Americans

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have until recently had low rates of suicide but due to the lack of awareness of mental health services within communities, the concept of John Henryism, and lack of public health policies has propelled the acts of suicide within this community. In regards to American Indians the cultural deprivations of residing on reservations, poverty, drug and alcohol abuse and depression has led to American Indians having the highest rate of suicide among all minority groups. Asian Americans suicides have steadily been on the incline in recent years due to cultural norms of obtaining academic perfection among young adults. Lastly, Hispanic women are committing suicide at alarming rates after self-perceptions of not meeting cultural demands.

Although, each minority group has different intentions for committing suicide there are similarities across racial groups, belongingness and acculturative stress have been found as risks factors for all minority groups. Occupational scientist and occupational therapist can assist in being effective in addressing this epidemic in minority groups. By researching occupational factors that lead an individual to suicidal ideation, effective interventions can be created to divert these individuals from suicidal acts. Utilizing OPH and determining an individual means to *doing*, *being*, *becoming* and *belonging*, occupational practitioners can dispel the myths attached to committing suicide and begin to restore occupational balance into an individual's life.

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A Review of Occupation and Impairment Based Assessments Used in Occupational Therapy

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Abstract

Objective: The objective of this paper was to analyze the psychometrics, efficacy, and usefulness of assessments to measure occupational performance and occupation-based outcomes.

Methodology: Eight Doctor of Occupational Therapy Students at Nova Southeastern University, along with their professor, analyzed and appraised 46 commonly used assessments to discover and explore the assessments' purposes, theory-bases, psychometric properties, and usefulness as outcome measures.

Results: We found that many high quality assessments exist and meet the standards for validity and reliability. Although some assessments are client-centered and useful, some still require additional research to strengthen their psychometric properties.

Conclusion: Some widely used assessments are better for assessing occupation-based outcomes while others are better for assessing specific client factors. Despite their lack of psychometric information, some of the assessments we analyzed may still be useful in practice.

Keywords: occupational therapy, assessments, evaluation, client factors, theory base, psychometrics, measurements, outcomes

A Review of Occupation and Impairment Based Assessments Used in Occupational Therapy

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Evaluation is an essential part of the occupational therapy process. Through observation and assessment, the occupational therapy practitioner is able to plan interventions, justify service for reimbursement, determine whether or not to continue services, evaluate intervention outcomes, and determine program effectiveness.

In the field of occupational therapy, evaluation usually consists of multiple assessment measures including client and/or caregiver interview and observation. There are many assessments used by occupational therapists, so how does the therapist choose the best assessments for use with specific clients? There are many factors that go into a therapist's choice of assessment tools -- theory, cost, what needs to be measured, work environment, availability, client needs, context, etc. The decision can be overwhelming for any occupational therapist, but it can be even more intimidating for the new graduate who has only been exposed to a small fraction of assessment tools on the market.

In their third year of occupational therapy school, entry-level Doctor of Occupational Therapy students at Nova Southeastern University elected to take the course *Applying Measurement Theory to Evaluation*. The course was designed to provide the students with a deeper understanding of the theoretical foundations of measurement and to offer the students the opportunity to refine their abilities to appraise and select assessment tools for both individuals and programs. As an ongoing project of the course, the students collaborated to produce this article, which summarizes their findings of evidence supporting the use of assessments that measure occupational performance and occupation-based outcomes.

The purpose of this review was to analyze psychometrics, efficacy, and usefulness of assessments to measure occupational performance and occupation-based outcomes. We also discuss the evidence supporting the use of these assessments.

Methodology

Along with their professor, the students selected assessments commonly used in practice and evaluated them using the Outcome Measures Rating Form and Guidelines from the CANCHILD Center for Disability Research Institute of Applied Health Sciences, McMaster University (Law, 1994). The selected assessments were reviewed through a process that included reading the assessment manual, using the rating form and guidelines (Law, 1994), and looking for supportive articles that provided current evidence on the assessment tools. The specific focus of the review centered on the strength and availability of psychometric information found in the assessment manual as well as other sources including the overall utility and practicality of the assessment based on in-class practice and demonstration of selected tests. The selected assessments cut across populations from infants and youth to elderly, well population to populations with a variety of conditions and abilities. Selected assessments included:

- Ages & Stages Questionnaire (ASQ-3)
- The Assessment of Communication and Interaction Skills (ACIS)
- The Assessment of Motor and Process Skills (AMPS)
- Bay Area Functional Performance Evaluation (BaFPE)
- The Beery-Buktenica Developmental Test of Visual Motor Integration (Beery VMI)
- Birth to Three Assessment and Intervention System - Second Edition (BTAIS-2)

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- Burks Behavior Rating Scales (BBRS-2) 2nd Ed.
- Canadian Occupational Performance Measure (COPM)
- Child Occupational Self-Assessment (COSA)
- Children's Assessment of Participation and Enjoyment (CAPE) & Preferences for Activities for Children (PAC)
- Clinical Observations of Motor and Postural Skills (COMPS) 2nd Ed.
- The Cognitive Assessment of Minnesota (CAM)
- Craig Handicap Assessment and Reporting Technique (CHART)
- Craig Hospital Inventory of Environmental Factors (CHIEF)
- Disabilities of the Arm, Shoulder, and Hand (DASH)
- Dynamometer
- The Early Coping Inventory (ECI)
- Evaluation Tool of Children's Handwriting Manuscript (ETCH)
- Hawaii Early Learning Profile (HELP) 3-6
- Home Falls and Accident Screening Tool (HOME FAST)
- Kitchen Task Assessment (KTA)
- Life Stressors & Social Resources Inventory - A (LISRES-A)
- Melville-Nelson Self Care Assessment (SCA)
- Model of Human Occupation Screening Tool (MOHOST)
- Occupational Circumstances Assessment Interview, Version 4 (OCAIRS, Version 4)
- Occupational Performance History Interview, 2nd Edition (OPHI-II)
- Occupational Self-Assessment (OSA)
- Occupational Therapy Driver Off-Road Assessment (OT-DORA)
- The Pediatric Evaluation of Disability Inventory (PEDI)
- The Pediatric Volitional Questionnaire (PVQ)
- Pinch Meter
- The Quick Neurological Screening Test 2nd Revised Edition (QNST-II)
- Safety Assessment of Function and the Environment for Rehabilitation (SAFER Tool)
- Safety Assessment of Function and the Environment for Rehabilitation Health Outcome Measurement & Evaluation (SAFER Home)
- School Setting Interview (SSI)
- Sensory Profile Questionnaire (SP)
- The School Function Assessment (SFA)
- The School Setting Interview (SSI)
- The Self-Discovery Tapestry
- Short Child Occupational Profile (SCOPE)
- Test of Handwriting Skills - Revised (THS-R)
- Test of Sensory Functions in Infants (TFSI)
- Tinetti Falls Efficacy Scale (FES)
- The Volitional Questionnaire 4.1 (VQ)
- The Work Environment Impact Scale (WEIS)
- Worker Role Interview (WRI)

Results

Forty-six assessments were reviewed. Some were based on specific theoretical models while others were not specific to theory but to function, performance, or impairment. The following chart includes the name, theory base, purpose, quality of psychometrics, usefulness as an outcome measure, and recommendations of the assessments reviewed.

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Assessment tool	Theory based	Purpose	Quality of Psychometrics	Usefulness as an outcome measure	Recommendations
Ages & Stages Questionnaire (ASQ-3)	Developmental	To screen children ages 2-60 months for developmental delays (Squires & Bricker, 2015)	Excellent reliability and validity (Squires, Potter, Bricker, & Lamorey, 1998; Hornman, Kerstiens, de Winter, Bos, & Reijneveld, 2013; Veldhuizen, Clinton, Rodriguez, Wade, & Cairney, 2014; Schonhaut, Armijo, Schonstedt, Alvarez, & Cordero, 2013).	Useful as a quick screening tool; has excellent psychometrics and is easy to use	Consider writing versions that account for different cultures
The Assessment of Communication and Interaction Skills (ACIS)	Model of Human Occupation (MOHO)	ACIS is an assessment for the adult population that measures the impact of dysfunction on a person's communication and interaction skills while engaging in an occupation (Forsyth, Salamy, Simon & Kielhofner, 1998).	Very little psychometrics of reliability and validity. Simon (1989) found that 2 out of 22 items had low reliability and 16 items had low to moderate range ($r > +.17$ and $< +.76$) for single item stability (as cited in Forsyth, Salamy, Simon & Kielhofner 1998).	Not useful as an outcome measure due to lack of psychometrics and the subjectivity of the scoring.	Even though there is no training required to administer the ACIS, the administrator has to use their personal social competence in order to rate the individual's performance (Forsyth, Salamy, Simon & Kielhofner 1998).
Assessment of Motor and Processing	Occupation based.	Observational assessment tool for clients age 2	Excellent psychometric properties across	Useful for outcomes measures. It	None.

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<p>Skills (AMPS)</p>	<p>Motor planning and cognitive function.</p>	<p>years and older with almost any diagnosis (Fisher and Jones, 2011).</p>	<p>the board with extensive validity studies with over 200K participants (Center for Innovative Solutions, 2015).</p>	<p>can be used to track improvement in performance over time. The scoring software keeps previous score reports in the database for comparison and additional reports can be run within the software system.</p>	
<p>Bay Area Functional Performance Evaluation (BaFPE)</p>	<p>Neurological and developmental</p>	<p>Used to evaluate cognition in patients with psychological impairments, specifically with schizophrenia (Williams & Bloomer, 1987).</p>	<p>Excellent inter-rater reliability (0.9) and excellent concurrent validity (Williams & Bloomer, 1987).</p>	<p>Useful tool for outcome measure.</p>	<p>Yes, excellent tool that addresses emotional, social, and cognitive components. It is comprised of 5 sub tasks including sorting shells, money, and marketing, home drawing, block design, and kinetic person drawing (Williams & Bloomer, 1987).</p>

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<p>The Beery-Buktenica Developmental Test of Visual Motor Integration (Beery VMI)</p>	<p>Developmental based</p>	<p>The Beery-VMI evaluates clients' ability to utilize their visual motor abilities, and can also be used to identify learning difficulties children may experience at a young age (Brown & Jackel, 2007).</p>	<p>According to Brown & Jackel (2007), "Rasch analysis demonstrated the total group item separation at 1.00 and total group person separation at 0.96" (p. 357). "Internal consistency, based on Cronbach's alpha for the Beery VMI-5, the visual perception test, and the motor coordination subtest were 0.82, 0.81, and 0.82 respectively" (Brown & Jackel, 2007, p.357).</p>	<p>Useful as an outcome measure</p>	<p>The Beery-VMI is useful and it takes clients 10 – 15 minutes to complete the full form and subtests, then an additional 10 minutes for the administrator to score (Brown & Jackel, 2007).</p>
<p>Birth to Three Assessment and Intervention System - 2nd Edition (BTAIS-2)</p>	<p>Developmental</p>	<p>Measures global development in children between the ages of 0 and 36 months (Ammer & Bangs, 2002).</p>	<p>Lacks information on reliability and validity (Ammer & Bangs, 2002).</p>	<p>Useful, easy to score checklist of performance skills</p> <p>Scores from subtests are plotted on a graph that shows performance age in months.</p>	<p>Revise user manual to make more clear</p> <p>Perform psychometric research</p>

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<p>Burks Behavior Rating Scales - 2nd Edition (BBRS-2)</p>	<p>Psychosocial Theory Base</p>	<p>Assists in the diagnosis and treatment of children and youth with behavioral problems (Burks, 2006)</p>	<p>Multiple studies confirming excellent reliability and internal consistency of alpha co-efficients above 0.85 as well as validity of the tool (Burks, 2006).</p>	<p>Very thorough and useful tool. 100 items scored on 4 point Likert Scale. Scoring can be tedious due to wordy user manual.</p>	<p>Revise user manual to make more user friendly and scoring easier to complete and interpret.</p>
<p>Canadian Occupational Performance Measure (COPM)</p>	<p>Canadian Model of Occupational Performance</p>	<p>Identifies the client's self-perception of performance in self-care, productivity, and leisure activities for client-centered care (Eyssen, Steultjens, Oud, Bolt, Maasdam, & Dekker, 2011).</p>	<p>Reliability ranging from adequate-excellent and excellent validity (McColl, Paterson, Davies, Doubt, & Law, M. 2000).</p>	<p>Useful as an outcome measure tool.</p>	<p>This semi-structured interview format permits the client to share what is important to them, allowing for client-centered care. This tool is a sensitive to changes in the client's perspective and therefore a great tool in measuring outcomes.</p>
<p>Child Occupational Self-Assessment (COSA)</p>	<p>Model of Human Occupation</p>	<p>The COSA is an occupation-focused tool designed to allow the child the opportunity to identify their occupational performance in meaningful activities (Kramer,</p>	<p>The COSA lacks credibility in the psychometric properties. According to Kramer, Kielhofner, and Smith (2010), evidence for validity and reliability is inadequate due to</p>	<p>Not designed to be used as an outcome measure.</p>	<p>Although, the COSA is client-centered and occupation-focused, more research needs to be conducted in order to determine its clinical usefulness.</p>

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		Kielhofner, and Smith, 2010).	large variations of client population and assessment administration variables. As a result, more research is currently being conducted to strengthen this area.		
Children’s Assessment of Participation and Enjoyment (CAPE) & Preferences for Activities of Children (PAC)	Developmental	Combined assessment used to evaluate a child’s participation in daily activities outside of the school (King et al., 2004).	Adequate internal consistency reliability (0.6-0.77), adequate to excellent test-retest (0.64-0.86), and adequate content validity (King et al., 2004).	Useful as an outcome measure that focuses on the child’s participation, diversity, intensity, with whom, where, and overall enjoyment King et al., 2004).	Yes, it is easy to administer, 55-item interview that takes about 30-35 minutes to complete the CAPE and 15-20 minutes for the PAC (King et al., 2004).
Clinical Observations of Motor and Postural Skills, 2nd Edition (COMPS-2)	A. Jean Ayres Classic Sensory Integration	Developed to have a standardized clinical observational tool for practitioners working with children and youth ages 5-15.11 years who have problems with motor coordination (Wilson, Kaplan, Pollock, and Law, 2000).	Very good test-retest scores but low inter-rater reliability and lack of validity testing (Wilson, Kaplan, Pollock, and Law, 2000).	Not useful as an outcome measure.	Look at revising the tool to have better inter-rater reliability and conduct more studies to confirm validity of this tool.
The Cognitive	Neurological	Used to evaluate patients with brain	Excellent test retest (0.96) and	Useful as an outcome	Yes, this tool easy to

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<p>Assessment of Minnesota (CAM)</p>		<p>injury (anoxia, traumatic brain injury, cerebral vascular, etc.) (Rustard et al., 1993).</p>	<p>inter-rater (0.94) reliability (Rustard et al., 1993). Excellent concurrent validity after being evaluated with the Porteus Maze test and Mini Mental Status Exam (The University of Utah, n.d.)</p>	<p>measure tool.</p>	<p>administer, low in cost, and easy to score. It assesses mental functions focusing on attention, memory, though, calculations, and sensory functions, specifically assessing for visual neglect (Rustard et al., 1993).</p>
<p>Craig Handicap Assessment and Reporting Technique (CHART)</p>	<p>World Health Organization (WHO) model.</p>	<p>“Measures the level of handicap experienced by an individual in a community setting” (Connolly, Law, & MacGuire, 2005, p. 270).</p>	<p>Excellent test-retest reliability (0.80 to 0.95) (Dijkers, 1991). Adequate to excellent criterion validity (Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992).</p>	<p>Useful as an outcome measure tool.</p>	<p>Yes, this tool is easy to use, free, and assesses areas of orientation, physical independence, mobility, occupation, social integration, and economic self-sufficiency (Whiteneck et al., 1992).</p>

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<p>Craig Hospital Inventory of Environmental Factors (CHIEF)</p>	<p>World Health Organization (WHO) model of disability and the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) Environmental Factors</p>	<p>Evaluates how environment influences the ability of the client to perform daily tasks and fulfill social roles</p> <p>Intended for use with clients who have physical or sensory disorders (Harrison-Felix, 2001).</p>	<p>Excellent test-retest reliability (ICC = 0.926)</p> <p>Ongoing psychometric studies to determine additional validity and inter-rater reliability (COMBI, 2012).</p>	<p>Not useful as an outcome measurement.</p>	<p>Include information about environmental facilitators</p> <p>Get a clearer view of the magnitude of the problem (not just “big” or “small” problem)</p> <p>Clarify what questions pertain to which subscale</p> <p>Add scoring instructions to the manual</p>
<p>Disabilities of the Arm, Shoulder, and Hand (DASH)</p>	<p>Biomechanical</p>	<p>A 30-item questionnaire, used for assessing individuals with injuries to the upper extremity. Questions ask about the individuals’ symptoms as well as their ability to perform certain activities (Institute for Work and Health, 2006).</p>	<p>More than five studies on the DASH indicated that its ICC had values between 0.91 and 0.96 which means that the DASH is a reliable tool for clinical decision-making (Kolber, Salamh, Hanney, Cheng, 2014). Internal consistency was found to have a Chronbach’s alpha between</p>	<p>Overall the review of the literature shows the DASH to be a quick, valid, reliable, and an effective tool to use on patients with upper extremity injuries.</p>	<p>This questionnaire can be self-administered or administered by the therapist. The DASH can be completed in 6-30 minutes (Rehabilitation Institute of Chicago, 2010). No training is needed and the DASH questionnaire can be obtained online for free</p>

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			<p>0.96 and 0.97 (Beaton, Katz, Fossell, Wrights, Tarasuk, & Bombardier, 2001). The results from Gummesson, Atroshi, and Ekdahl's 2003 study allowed them to confirm that the DASH is capable of detecting both minute and large changes in function in their post-surgical participants with various upper extremity injuries. Construct validity was shown when the DASH was compared with several functional measures (Kolber, Salamh, Hanney, & Cheng, 2014). This same study by Kobler, Salamh, Hanney, and Cheng, 2014, validated the high sensitivity of the DASH indicating that this tool can effectively measure outcomes and improvements in function or lack there of. After</p>		<p>(Institute for Work and Health, 2006).</p> <p>Overall the review of the literature shows the DASH to be a quick, valid, reliable, and an effective tool to use on patients with upper extremity injuries.</p>
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			conducting their 2014 study on the DASH, Kolber, Salamh, Hanney, and Cheng concluded that the DASH is an assessment that is “reliable, valid, and responsive” (p.172).		
Dynamometer	Biomechanical	Used to assess upper extremity (UE) grip strength typically after 8-12 weeks of an injury (Kasch & Walsh, 2013).	Excellent intrarater reliability (0.86-0.93) (Toeman, Dalton, & Sandford, 2011). Excellent concurrent validity (Bellace, Healy, Besser, Byron, & Hohman, 2000).	Useful as an outcome measure tool.	This tool is easy to use and takes about 5-10 minutes to conduct. Can also assess healthy adults, older adults, upper extremity injuries, and chronic injuries such as stroke, osteoarthritis, and muscle myopathy (Bertrand, Mercier, Bourbonnais, Desrosiers, & Gravel, 2007; Kasch & Walsh, 2013; Van Den Beld, Van Der Sanden, Sengers, Verbeek, & Gabreels, 2006; Ziv, Patish, & Zeevi, 2008).
The Early Coping	Developmental	Aims to measure coping behaviors	Interrater reliability, test-retest reliability,	Can be useful when used in	Based on observation, so can be

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<p>Inventory (ECI)</p>		<p>in children 4-36 months old</p> <p>Based on observation</p> <p>Test items divided into three broad coping-related categories: sensorimotor organization, reactive behavior, and self-initiated behavior (Zeitlin, Williamson, & Szczepanski, 1988)</p>	<p>and construct validity are good (Zeitlin, Williamson, & Szczepanski, 1988)</p>	<p>addition to other assessments to create a more detailed profile of the child and to help in intervention planning</p>	<p>subjective; but highly recommended to supplement other assessments when completing an overall evaluation</p>
<p>Evaluation Tool of Children's Handwriting Manuscript (ETCH)</p>	<p>Biomechanical and developmental</p>	<p>ETCH is a criterion-referenced, standardized assessment designed to evaluate manuscript and cursive handwriting for children in grades one through six. The main focus of this assessment is to determine if a child's handwriting skills are equivalent to the required standards for that particular age group or classroom that they reside in</p>	<p>In the category of total word, ETCH reported an intra-rater score of .80, an inter-rater score of .62, and a test-retest score of .60 (Duff & Goyen, 2010).</p>	<p>Useful as an outcome measure.</p>	<p>ETCH is a fair assessment to determine a child's handwriting ability, but additional research must be conducted in order for this tool to be more widely accepted.</p>

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		(Duff & Goyen, 2010).			
Hawaii Early Learning Profile (HELP) 3-6	Developmental	The Hawaii Early Learning Profile (HELP) 3-6 is a non-standardized assessment for children between the ages of three and six with or at risk for developmental delays (Teaford, Wheat, & Baker, 2010). The Help 3-6 assesses five areas of development including cognition, language, gross motor, fine motor, social-emotional, and self-help (Teaford, Wheat, & Baker, 2010).	The questions on the HELP 3-6 were derived from both standardized tests and trusted scales of development (Simon, 2014). Documented reliability of the HELP 3-6 is minimal and although it has been tested in the field, data is not available (Simon, 2014). Both content and face validity were obtained via literature review to support the HELP 0-3 which is an alternate version administered to younger children however no validity studies have been conducted specifically on the HELP 3-6 (Teaford, Wheat, & Baker, 2010).	The HELP 3-6 is useful as an outcome tool.	The HELP 3-6 is affordable at around \$57.00 and \$3.50 per score sheet (VORT Corporation, 2015).
Home Falls and Accidents Screening Tool	None Identified	The HOME FAST is used to identify an older adults fall risk, identify the need for a thorough falls	Overall good reliability with inter-rater reliability at 0.82 with a 95% confidence	Useful as a quick screening tool; has good psychometri	Further recommendatio n on additional research regarding validity with a

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(HOME FAST)		assessment, and to help guide interventions related to fall risk (Mackenzie, 2009).	interval (CI), and test-retest reliability at 0.77 with a 95% CI (Vu and Mackenzie, 2012). According to expert panels, content validity was greater than 0.8. Construct validity found that the HOME FAST was useful in identifying hazards in the home with a 95% CI (Mackenzie, Bytes, and Higginbotham, 2002b).	c properties and is simple to administer; access at no cost	larger sample size.
Kitchen Task Assessment (KTA)	Cognition and motor planning	It is a functional measure that allows the practitioner to records the level of cognitive support the client needs, while completing a cooking activity (Baum & Edwards, 1993).	The inter-rater reliability was 0.853 for the total score (Furphy, 2014). The construct validity was based on correlations with cognitive and dementia tests as well as there were a high correlation coefficient 0.72 to 0.84 (Furphy, 2014).	The KTA can be used as an outcome measure.	Publish additional studies that utilize the kitchen task assessment.
Life Stressors & Social Resources Inventory - Adult form (LISRES-A)	None Identified	Examines the relationship between life stressors and social resources during evaluation of their impact on	The test retest reliability for males was 0.12 to 0.60, while for females it was 0.16 to 0.69, with a 12-15 month	Useful as an outcome measure	No spirituality items are included and this should be considered for

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		health and well-being for clients (Gitlow, 2007)	interval (Gitmo, 2007). No information regarding convergent validity is available, but content validity consisted of indices created from original literature search and research with two pilot studies with client who were healthy, depressed, and alcoholic and had arthritis (Rigby, Cooper, Letts, Stewart, & Strong, 2005).		future LISRES revisions.
Melville-Nelson Self Care Assessment	Performance-specific	To objectively measure performance and support for seven ADLs for clients in sub acute and SNF settings (Nelson & Melville, 2001)	Concurrent validity with FIM is -.85 and Klein-Bell is -0.86. Good predictive validity for caregiving time. Inter-rater reliability is 0.94 and test-retest is not reported. (Nelson et al., 2002)	One page, easy-to-score checklist that can be especially useful for those who must complete the Minimum Data Set (MDS)	Additional research on psychometrics to further support assessment Modify way of documenting “Support Needed” so that needed support can be specified for each component of the task
Model of Human Occupation Screening	Model of Human	The Model of Human Occupation Screening Tool	In the study of Kielhofner et al, 2010, the reliability ranged	Useful as an outcome measure	Could benefit from additional research to strengthen its

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<p>Tool (MOHOST)</p>	<p>Occupation</p>	<p>(MOHOST) is an assessment that is created to document progress achieved through occupational therapy intervention and a screening tool to determine if occupational therapy services are needed (Parkinson, Forsyth, & Kielhofner, 2006).</p>	<p>from .81 to .89. Discriminate validity was analyzed using ANOVA analyses, in which all subscales achieved a level of significance smaller than the concerned p value (Parkinson et al., 2006).</p>		<p>psychometric properties. Otherwise, it is a good assessment to utilize.</p>
<p>Occupational Circumstances Assessment Interview, Version 4 (OCAIRS, Version 4)</p>	<p>Model of Human Occupation</p>	<p>The OCAIRS is an interview used to determine how intrinsic and extrinsic barriers interfere with an individual's ability to perform chosen occupations. It can be used with clients from adolescent to adult age with a wide range of physical or cognitive disabilities (as long as the client is able to understand the questions and answer appropriately (Forsyth, Deshpande, Kielhofner, Henriksson, Haglund, Olsen,</p>	<p>There is limited psychometric information for reliability and validity (Forsyth, Deshpande, Kielhofner, Henriksson, Haglund, Olsen, Skinner, Kulkarni, 2005).</p>	<p>The OCAIRS is not useful as an outcome measure. It can only measure potential barriers to performance .</p>	<p>Additional psychometric testing is recommended.</p>

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		Skinner, and Kulkarni, 2005).			
Occupational Performance History Interview, 2nd edition (OPHI-II)	Model of Human Occupation (MOHO)	The OPHI-II is an interview tool used to assess a client's life history and occupational identity while taking into account environment (Schultz-Krohn, 2014).	Test-Retest Reliability is not available. There is only observable validity. Rasch analysis indicated that OPHI-II is valid in detecting occupational performance (Schultz-Krohn, 2014).	Useful for identify occupational identity and detailed life history (Schultz-Krohn, 2014).	Assessment is lengthy, it takes about total 2 hours for interview and scoring (Schultz-Krohn, 2014).
Occupational Self-Assessment (OSA)	Model of Human Occupation	The Occupational Self-Assessment (OSA) is used with clients age 12 and older, who are able to evaluate and provide information regarding their occupational competence, occupational functioning importance, as well as environmental adaptation (Schultz-Krohn, 2007).	Rasch analysis was utilized and no item misfits were identified, which indicates that all scales have internal validity (McColl & Pollock, 2005).	Useful as an outcome measure	Additional research is needed for the reliability aspect of OSA
Occupational Therapy Driver Off-Road Assessment (OT-DORA)	None Identified	The OT-DORA is an impairment-based assessment made up of multiple test that will allow efficient	Inadequate. Reliability Inter-rater – 3-5 practitioners rating 4 clients. .8	Not designed to be an outcome measure, only a	Further research needs to be conducted, before this assessment can

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		evaluation of an individual's cognitive, perceptual, behavioral, physical, and sensory skills and abilities that are related to driving, prior to an on-road assessment (Unsworth, Pallant, Russell, & Odell 2011).	to 1.00 (perfect agreement); Sensitivity & Specificity for the Heel Pivot component: Sensitivity 29.03%, Specificity 89.60% (Unsworth, Pallant, Russell, & Odell 2011).	recommendation tool.	be widely accepted.
The Pediatric Evaluation of Disability Inventory (PEDI)	Developmental	The PEDI is a standardized comprehensive occupation based standardized assessment that evaluates the functional skills and level of independence for 6 month-7.5 year old children with a variety of physical and cognitive disabilities (Haley, Coster, Ludlow, Haltiwanger & Andrellos, 1992)	The PEDI has excellent inter-rater reliability with an intraclass correlation coefficient (ICC) of 0.67 to 1.00 for functional skill scales and 0.68 to 0.90 for caregiver assistance scales (Haley et al., 1992). The PEDI also has excellent internal consistency of 0.95 and 0.99 for all six scales using Cronbach's alpha (Haley et al., 1992). More than two studies were conducted to prove the PEDI had convergent and construct validity (Letts & Bosch, 2005). The PEDI's test-retest	Useful for assessing the child's functional skills, level of caregiver assistance, and environmental modifications needed to perform tasks in the areas of self-care, mobility, and social function (Haley et al., 1992)	

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			ICC was more than 0.95 for total scores and above 0.80 for the three domains (Wright and Boschen, 1993). Its convergent validity was determined by comparing it to other developmental instruments such as the Battelle Developmental Inventory Screening Test with results of 0.62 to 0.97 and the WeeFIM with results from 0.80 to 0.97 (Nichols and Case-Smith, 1996).		
The Pediatric Volitional Questionnaire (PVQ)	Model of Human Occupation (MOHO)	The PVQ is an observational assessment for children 2-7 years old that determines a child's inner motivation and examines how the environment strengthens or weakens their volition (Basu, Kafkes, Schatz, Kiraly & Kielhofner, 2008).	Adequate validity was determined using Rasch analysis and the PVQ outcomes correlated with the Test of Playfulness ($r=0.47$) (Bundy, 2005).	It is useful for determining how much support the child requires in order to increase the child's active participation in therapeutic activities. This should be taken into consideration	The manual recommends observing the child during different parts of the day and in various environments (Basu, Kafkes, Schatz, Kiraly & Kielhofner, 2008). Needs further research on reliability and validity.

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				n when developing goals for the child (Basu, Kafkes, Schatz, Kiraly & Kielhofner, 2008).	
Pinch Meter	Biomechanical	The Pinch Meter or Pinch Gauge is a device used to measure pinch strength during a hand strength evaluation and is commonly used by Occupational Therapists. The pinch meter assesses three types of pinch strength including palmer pinch, key pinch, and tip pinch strengths (Mathiowetz et al., 1985).	Reliability and validity studies for the Pinch Meter are limited and outdated. Adequate test-retest reliability was best attained when practitioners found the mean of three trials (Mathiowetz, Weber, Volland, & Kashman, 1984). Intraclass consistency was excellent when comparing the results of various Pinch Meter brands including Jamar ®, B & L Engineering, JTech, and NK brands	Very useful for tracking progress and overall strength of an individual.	In their 1985 study, Mathiowetz et al. recommended several techniques that practitioners can use to optimize the validity and reliability when using the Pinch Meter. These techniques include proper positioning of client, finding the mean of three trials per measurement, using the same pinch meter for evaluation and re-evaluations, and regular calibration of

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			(MacDermid, Evenhuis, & Louzon, 2001). MacDermid, Evenhuis, & Louzon, (2001) also found that there is poor interclass correlation coefficients (ICCs) when comparing the classic Jamar® hydraulic Pinch Meter with the more modern electronic Jamar® Pinch Meter indicating the importance of consistently using the same type of meter when assessing and re-assessing a client.		the Pinch Meter (Mathiowetz et al., 1985).
The Quick Neurological Screening Test 2nd Revised Edition (QNST-II)	Development, age appropriate, neurological and neuropsychological theory and framework (Mutti, Martin, Sterling & Spalding, 1998)	QNST-II is a performance based standardized screening that screens for learning disabilities .It tests for soft or subtle signs of impairments that could impact the skills needed to engage in the occupation of school (Mutti et al., 1998).	Adequate to excellent psychometrics. The screening has excellent test retest reliability in that the coefficient was 0.81, and adequate interrater reliability of experienced administrators was 0.71 and 0.69 for new administrators (Mutti et al.,	Useful as a screening, but the QNST-II alone can't be used to diagnose someone with a learning disability (Mutti et al., 1998).	It is highly suggested that someone receives training before administering this screening (Mutti et al., 1998). There is a Quick Neurological Screening Test 3rd Edition (QNST-3).

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			1998). Validity for the QNST-II was excellent because there were more than two studies to test its construct and concurrent validity. It was determined that the QNST-II has moderate to strong construct, content, and criterion related validity (Mutti et al., 1998).		
Safety Assessment of Function and the Environment for Rehabilitation (SAFER Tool)	None identified	Identify the safety issues that geriatric populations have in their natural environment (Rigsby, Cooper, Letts, Stewart & Strong, 2005).	Adequate-Excellent validity and reliability (Rigsby, Cooper, Letts, Stewart & Strong, 2005).	Not a useful tool as an outcome measure.	This tool would be helpful in creating a treatment plan that is client-centered.
Safety Assessment of Function and the Environment for Rehabilitation Health Outcome Measurement and Evaluation (SAFER HOME)	None identified	Measures change in safety of geriatric patients in their natural setting over time (Rigsby, Cooper, Letts, Stewart & Strong, 2005).	Adequate, needs further support (Rigsby, Cooper, Letts, Stewart & Strong, 2005).	A useful tool in outcome measure.	This is a comprehensive tool to measure change in safety for the geriatric population that have physical disabilities and/or mental illness in their natural environment (Rigsby, Cooper, Letts, Stewart & Strong, 2005).

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School Setting Interview	Model of Human Occupation (MOHO)	Used to determine the degree of fit between the environment and student. Intended to be used with children 10 years and older who have physical disabilities (Hemmingson, Egilson, Hoffman, & Kielhofner, 2005).	Construct and content validity are good, and inter-rater reliability is good (90%) for most content areas (Hemmingson, Egilson, Hoffman, & Kielhofner, 2005).	Useful for determining what aspects of the environment /person should be adapted or modified in order to improve school performance	Highly recommended for use with the intended population Expand for use with children who are younger and with children who have other disabilities
Sensory Profile Questionnaire (SP)	Sensory Integration	The Sensory Profile is a norm-referenced assessment designed to identify possible contributions of sensory processing to the client's daily performance patterns (Haynes, 2014).	Adequate. According to Haynes (2014), internal consistency for every section varied from 0.57 to 0.93, while test-retest reliability was reported at 0.83 to 0.97 (Haynes, 2014, p. 417). Lastly, interrater reliability was reported at 0.49 to 0.89 for children and 0.53 to 0.90 for school age adolescents (Haynes, 2014)	A useful tool as an outcome measure	This tool will be useful to determine baseline measures when treating clients with sensory processing disorders.
The School Function Assessment (SFA)	Model of Human Occupation	Identifies the child's strengths and weaknesses in completing typical functional tasks in	Excellent. (Coster, Mancini, & Ludlow, 1999).	A useful tool in outcome measure.	Not valid for clients that have sustained a traumatic brain injury, and high interrater reliability

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		an academic setting (Coster, Mancini, & Ludlow, 1999).			(Davies, Soon, Young, & Clausen--Yamaki, 2004).
The Self-Discovery Tapestry	None.	Allows for self-reflection and visualization of how life events affect daily occupations (Meltzer, 2011).	None.	Not useful as an outcomes measure.	Helpful for clients that are transitioning into a new phase in life, providing a safe environment to self-reflect and raise self-awareness. Also beneficial in future planning with clients.
Short Child Occupational Profile (SCOPE)	Model of Human Occupation (MOHO)	Observational tool to assess how intrinsic and extrinsic factors affect the performance of children with a variety of physical and mental disability diagnoses (Bowyer et al., 2008).	No evidence available for any psychometric properties (Bowyer et al., 2008).	Not useful as an outcome measure due to lack of test-retest psychometric properties.	Conduct psychometric testing to establish reliability and validity.
Test of Handwriting Skills - Revised (THS-R)	Impairment based	The Test of Handwriting Skills – Revised (THS-R) was developed by Dr. Morrison Gardner to assess the handwriting skills of students in either manuscript or cursive. This assessment it is impairment based,	Coefficient alpha and Spearman-Brown reliability coefficients were calculated by participants’ age group and the coefficients showed moderate to high, with medians of 0.61 to 0.85 for the manuscript	Useful as an outcomes measure.	Occupational therapists can administer the THS-R, as well as psychologists, resource specialists, special education teachers, and affiliated

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		and evaluates neurosensory integration problems that are manifested in the handwriting of students, which is useful for planning interventions (Milone, 2007).	format, and 0.65 to 0.92 for the cursive format, with majority of the subtest reliability coefficients exceeding 0.80 (Milone, 2007). For interrater reliability, agreement among the raters was high and ranged from 0.59 to 1.00 with typical correspondence ranging from 0.75 to 0.90 (Milone, 2007).		professionals (Milone, 2007).
Test of Sensory Functions in Infants (TFSI)	Jane Ayres Classic Sensory Integration	This tool is designed to test for possible sensory processing or developmental delays in infants from 4 - 18 months of age (DeGangi and Greenspan, 1989).	Excellent reliability scores and multiple validity studies showing strong correlation to gold standard tools in sensory function (DeGangi and Greenspan, 1989).	Not useful as an outcome measure. Only screens for potential delays.	None. Advanced review and practice with administration is recommended.
Tinetti Falls Efficacy Scale (FES)	International Classification of Functioning, Disability and Health (ICF): activity	Evaluates one's perceived efficacy or self-confidence with their balance and stability during non-hazardous ADLs. It also evaluates fear of falling in the adult population	Adequate to excellent test-retest reliability as proved by two different studies. Adequate to excellent criterion and convergent validity with two different studies	Useful as an outcome measure.	Would recommend using the latest versions of the FES, which are the Modified FES and the Falls Efficacy Scale International as these include community and

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	and Participation ("Rehab Measures-Tinetti Falls Efficacy Scale," n.d.)	(Tinetti, Richman & Powell, 1990).	conducted for each (Hotchkiss, Fisher, Robertson, Rutencutter, Schuffert & Barker, 2004; Powell & Myers, 1995; Tinetti, Richman & Powell, 1990).		social activities respectively (Helbostad, Taraldsen, Grandbo, Yardley, Todd & Sletvold, 2010). Also the score is less subjective in these two versions.
The Volitional Questionnaire 4.1 (VQ)	Model of Human Occupation (MOHO)	The Volitional Questionnaire is a quick and easy way to assess an individual's motivation and inner drive. This assessment is unique as it evaluates how the environment affects an individual's volition (Jen-Suh, Kielhofner, Gloria de las Heras, and Magalhaes, 1996).	Only inter-rater reliability is available. Inter-rater reliability was found to be excellent at >0.90 (Jen-Suh, Kielhofner, Gloria de las Heras, and Magalhaes, 1996).	The Volitional Questionnaire 4.1 is useful to evaluate volition in individuals.	The Volitional Questionnaire 4.1 is cheap (\$40), easy to use and takes only minutes to administer.
The Work Environment Impact Scale (WEIS)	Model of Human Occupation (MOHO)	(WEIS) Version 2.0 is an occupation-based assessment that assesses 17 environmental factors that impact the worker's performance, gratification and well being. The WEIS can be used	Very little psychometrics. Corner, Kielhofner and Lin (1997) used fit statistics; including mean squared standardized residual (MNSQ) and the standardized	Not useful as an outcome measure.	

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		for adults with physical and/or psychosocial disabilities. (Moore-Corner, Kielhofner & Olson, 1998).	mean square (λ) to determine construct validity (Corner, Kielhofner & Lin, 1997). In general “the person and item separation index is low at 1.63 and 1.57 respectively” (Corner, Kielhofner & Lin, 1997, p.26), meaning that the items aren’t very good at separating people into different skill levels (Corner, Kielhofner & Lin, 1997). The reliability of these approximations is adequate at 0.73 and 0.71 (Corner, Kielhofner & Lin, 1997)		
Worker Role Interview (WRI)	Model of Human Occupation (MOHO)	For workers that are injured or disabled in identifying the environmental and psychosocial factors of their jobs that dictate when they can return to work (Reed, 2014).	Excellent validity and reliability scores (Reed, 2014).	Not recommended as a tool to measure outcomes.	Helpful when used with other physical capacity evaluation assessments in determining the client’s ability and needs in preparation for returning to work.

In reviewing these assessments we identified those assessments that were effective for occupation-based outcome measurement and those that were more focused on client factors that contributed to occupational performance. Based on the findings of this review, the occupation based

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outcome measures that the authors recommend for use are: AMPS, BaFPE, COPM, CAPE/PAC, CHART, DASH, ETCH, KTA, OPHI-II, PEDI, SFA, THS-R, WRI.

While on the other hand, the assessments that were found to have more emphasis placed on client factors that support occupational performance were: ASQ-3, ACIS, AMPS, BaFPE, Beery VMI, BTAIS-2, BBRIS-2, COMPS-2, CAM, dynamometer, ECI, HELP 3-6, MOHOST, pinch meter, QNST-2, SSI, SP, TSFI.

As identified in the results section of this paper, it is evident that not all of the assessments studied have attained strong psychometric support. Several of these studies have the potential to be great evidence-based resources for occupational therapy practitioners, but require more research to confirm that they have multiple forms of validity and reliability. Assessments that would benefit from further research because the psychometric support is less than excellent or lacking entirely include: CHIEF, COSA, HOME FAST, LISRES-A, Melville Nelson SCA, OCAIRS-4, OSA, OT-DORA, PVQ, SAFER Home, SAFER Tool, SCOPE, Tinetti FES, VQ, WEIS.

Discussion

Implications for practice

The measurement tools discussed above can be used in a variety of settings with a number of populations. Obviously some tools are better in one particular setting or population than others. As occupational therapy practitioners, it is crucial to understand the strengths and weaknesses of each measurement tool as well as the appropriate setting, population, and specific situation in which to use each one during the occupational therapy process. It is the hope of the authors that this article will assist with the identification of the measurement tool for each clinical situation. Ultimately the selection of assessment or screening tool will result in quality information being gathered so that practitioners are able to create effective, client-centered, occupation-based treatment plans. Additionally, quality outcomes will enhance the practitioners' ability to obtain successful reimbursement for services provided, and it may ideally expand the list of services for which we can be reimbursed. Occupational therapy can then continue to grow as a profession, and more people will be able to benefit from the services we offer.

Implications for education

In order for new practitioners entering the field of occupational therapy to be prepared to provide best practice, educational programs must be equipped to select and provide students with access to a variety of psychometrically supported measurement tools. While some of the measurement tools discussed above presented with psychometric concerns, it is still important for students to also study these tools from an analytical perspective so they are prepared upon entering the workforce to critically review the assessments and screening tools they are using on a daily basis. By reviewing measurement tools on a broad spectrum of psychometric ratings, students will be more prepared to evaluate tools upon entering the workforce and affect change in the clinical setting.

Implications for research

Occupational therapists not only need to appraise and improve the available assessments. In addition, they need to spend time developing assessments with quality psychometrics that measure occupational performance outcomes.

Limitations

This is not a comprehensive list of all of the available assessments used in occupational therapy practice and research. This review may contain the authors' subjective perspectives of the assessments.

Conclusion

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In order for an occupational therapy practitioner to develop an evidence-based intervention plan, a valid measurement process known as the evaluation must take place (Law, Baum, & Dunn, 2012). As previously mentioned, the evaluation is an essential part, as it not only determines the baseline of a client's occupational performance, but it also helps provide evidence of the effectiveness and proficiency of the occupational therapy intervention. Although every practitioner is aware of the importance of the measurement process, actually implementing this vital component in daily practice can be quite challenging. Some of the barriers new and seasoned practitioners face include but are not limited to: lack of time, determining what to measure, using the results to make clinical decisions, and most importantly finding the right assessment tool (Law, Baum, & Dunn, 2012).

As a result, the purpose of this review was to analyze and discuss the evidence supporting the use of assessments to measure occupational performance and occupation-based outcomes. Forty-six assessments that are commonly used in today's practice were evaluated using the Outcome Measures Rating Form and Guidelines from the CANCHILD Center for Disability Research Institute of Applied Health Sciences, McMaster University (Law, 1994). Hopefully, this review will promote further systematic reviews on outcome measurements, assist with the identification of the appropriate measurement tool for each clinical situation, and help reduce some of the barriers practitioners may face when trying to implement occupational performance and occupation-based measurements into their practice. We recommend continued review and refinement on the psychometric properties of all assessments used by occupational therapy practitioners.

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**What happens after the NICU?
Parents Experience of Caring for their Premature Infants at Home
Amanda Pignon**

Abstract

This paper reviews the literature on what happens after the NICU with premature babies and their families and provides perspective of a lived experience. There have been numerous studies conducted on the traumatic experience of the NICU, however there is limited research involving the parenting process and experience following the NICU and caring for a high risk infant at home. Articles were searched through two databases, CINAHL and Pubmed, yielding 15 articles in which three specific themes were outlined; psychological distress of parents, perceptions of parents and linking family to resources. While there are programs available for families, not all families are provided access to these programs or other resources. It seems that further research should be conducted on parent's experiences and finding out which services would be helpful after their stay in the NICU.

Keywords: NICU, Parenting, Premature Infants

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Prematurity is currently the leading contributor of infant death in the United States (Centers for Disease Control and Prevention, 2015). One out of every ten babies are born premature and prematurity continues to be the leading cause of neurological deficits in children (CDC, 2015). A premature baby is typically admitted to the neonatal intensive care unit (NICU) following birth. Depending on their gestational age babies can spend weeks or months in the hospital with the threat of having long term issues such as intellectual disabilities, cerebral palsy, breathing or respiratory issues, visual problems, loss of hearing, and feeding or digestive issues (CDC, 2015).

Parents undergo a tremendous amount of emotional and physical distress during their child's stay in the NICU. Stress is somewhat alleviated by having a skilled multidisciplinary team that provides around the clock care for their child. Parents have that little bit of comfort knowing that if something were to go wrong, their child is in the best place they can possibly be. There is a vast amount of research concerning the NICU journey and the traumatic experiences that occur during the hospitalization. However the consequences of having a baby born premature linger for a lifetime for both the baby and their family (Stokowski, 2004). This is why looking past the NICU when parents are finally at home for the first time with their premature baby should be considered another popular topic of interest. The statistics alone on developmental outcomes for premature babies can be very anxiety driven for parents. It's not uncommon for parents to exhibit psychological distress following their baby's hospitalization. Due to the possible threat of developmental issues or neurological disabilities, psychological distress can exacerbate and persist at home while caring for a premature baby. It is important that parents are provided the necessary amount of support, education, and available services needed to ensure they are able to properly care for a baby that is consider at risk for hospital readmission, disabilities, and deficits. In this paper I will discuss the literature and relate the literature to my lived experience.

Methodology

A literature review on preparing for the steps after the NICU, stressors that accompany caring for a preterm baby, and programs available for parents were searched and analyzed for the purpose of this scholarly reflection paper. Two databases were utilized in the search; CINAHL and PubMed using the keywords: 'psychological stress after discharge the NICU', 'parent's experience of premature infants', and 'parenting programs for premature babies' yielding a result of 17 articles that were analyzed in the final literature search. Articles that were excluded were articles with parents and babies still in the hospital. Articles that were included were involving families at home with their premature child following the NICU at varying times in the children's early lives. Three specific themes emerged that will be discussed. These included psychological distress of parents, perceptions of parents, and linking families to resources.

The Literature

Psychological distress of parents

Having a premature baby is a significant stressor and challenge to parents (Thomas, Renaud, DePaul 2004; Eiser, Eiser, Mayhew, Gibson, 2005). A premature baby poses a high biological risk, and parent's emotional health become strong indicators of infant developmental outcomes (Thomas et al., 2004). Mothers need to face that they could be parenting a very sick and disabled child. Infants born with an extremely low birth weight can have multiple health care conditions which result in parenting stress (Zerach, Elsayag,

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Shefer, & Gabis, 2013). The emotional well-being of the parents starts in the NICU as the discharge date approaches. Mothers were shown to experience an elevation in depression, stress, anxiety, and post-traumatic stress symptoms while in the NICU, that may continue on for months, and even years following discharge from the hospital (Holditch-Davis, Miles, Weaver, Black, Beeper, Thoyre, 2009; Holditch-Davis, Santos, Levy, White-Traut, O'Shea, Geraldo, & David, 2015).

At home parents have to be vigilant and acknowledge that their child has a vulnerability. Additionally, parents have to provide a positive and nurturing environment in which the baby is able to thrive, meet age appropriate milestones, and become independent (Eiser et al., 2005). This can create internal and external stressors for parents. They feel that they are faced with more challenges than they can handle, and their own health and well-being is implicated with the angst their baby's survival (Eiser et al., 2005). Families of very premature babies reported poorer family functioning, and higher family burden compared to families of a full term baby. Parents who had a mental health problem reported even higher parental stress (Treyvaud, Doyle, Lee, Roberts, Cheong, Inder, & Anderson, 2011). Another study looked at the mother's psychological adjustment of their very low birth weight baby in the second half of their first year of life, showing that the biological risk of their child increased parenting distress (Halpern, Brand, & Malone, 2001).

Many factors aside from the child's difficulties can cause internal and external stressors. The results of one study showed the parenting stress was significantly higher in mothers of premature babies compared to full term mothers at one year of age corrected (Gray, Edwards, O'Callaghan, Cuskelly, Gibbons 2013). The mother's symptoms of depression paired with the child's temperament were factors of parenting stress based off a study using the Parenting Stress Index (PSI) tool (2013). The parent's well-being was impacted since they felt that their child was dealing with a higher rate of difficulties and therefore became a form of parenting stress (Eiser et al., 2005).

Caring for a child with vulnerabilities can lead to maternal mental health issues such as Post Traumatic Stress Disorder (PTSD), anxiety and depression. Parental depression was reported the highest during the first three months, and symptoms continued to exist between both mothers and fathers at varying levels during their child's first year of life (Doucette & Pinelli, 2004). Resources along with family functioning declined for mother's and families following the NICU, and at the three-month assessment, which correlated with higher rates of depression at that time period (Doucette & Pinelli, 2004). The psychological distress that parents may exhibit while caring for their premature baby can have effects on the parenting process through the eyes of the parents and how sick their child becomes.

Perceptions of Parents

The day of discharge from the NICU brings mixed feelings for parents. The discharge date is both a joyous and stressful transition to home for families whom are now assuming care for their premature baby who required around the clock care by a skilled multidisciplinary team until that date (Bakewell-Sachs & Gennaro, 2004). Premature babies continue to require some kind of specialized care due to their central nervous system immaturity and higher risk for readmission to the hospital during the first year of life (Bakewell-Sachs & Gennaro, 2004). This can be very concerning for parents and can create undue stress while at home. According to Thomas et al. (2004) parenting distress alters both how competent parents feel and their interactions with the baby. Infant characteristics such as pain, sadness, fear and distress continue on after date of discharge, and has the ability to impact parental perceptions (Raines, 2013).

Parental perceptions were seen in the literature as to have negative connotations in the child's life. One study suggested that parents adopt a more prevention based parenting style that can ultimately lead to negative implications to the infant's quality of life. This was due to their perceptions about their infant's vulnerability of prematurity (Eiser et al., 2005). Another study suggested that mothers whom are caring for a premature child can have negative impacts on maternal mental health in that they see their child having more difficulties and could provoke even more problems than they actually have (Eiser et al., 2005).

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Although these perceptions are sometimes not warranted, parenting a premature baby is considered to be somewhat different to a full term baby according to some research. Premature babies do not respond as predictably, and their responses are organized in a different fashion as compared to full term babies (Bakewell-Sachs & Gennaro, 2004). The care required for a premature baby varies in term of how sick or how much care they need. Caring for a premature baby with a neurodevelopmental disability has shown an increased burden on family finances, planning, and parenting all at once (Treyvaud et al., 2011). The burden that families face could somewhat be alleviated with proper support and adequate resources in the community.

Linking families to resources

Services and supports provided to families following discharge can help with long term stress, anxiety, and coping with a sick or at risk baby. Practitioners need to reassure parents that they are not being left alone after discharge, and clarify issues that are best discussed with the NICU or the new community providers that assume the care following discharge (Garfield, Lee & Kim, 2014). Families who receive information about community providers prior to discharge can facilitate greater engagement in parenting strategies, and early intervention can ease the stress level for parents. A quick postnatal screen by NICU staff can help pinpoint problems or distress that can occur after discharge. Understanding the factors that influence a parent's stress before discharge from the NICU can help nurses develop interventional strategies that address those exact stressors for a smoother transition to home (Raines, 2013). Interventions should facilitate a normal environment with typical interactions between the child and their family and peers (Eiser et al., 2005).

Early intervention (EI) is a program that delivers neurodevelopmental evaluation and therapy as an option after NICU discharge to help with transition to home and with the community (Garcia & Gephart, 2013). These programs have been found to alleviate parental stress with fewer behavioral and regulation problems following the intervention. It is recommended that very premature and very low birth weight babies could benefit from EI services. However, these referrals have the ability to help all babies and their families (Garcia & Gephart).

Creating Opportunities for Parent Empowerment (COPE) is an intervention tool for young mothers. It provides infant behavior education, shows how mothers can be active in their child's care, enhances interactions, and help with their child's development. It has been found to reduce anxiety and health disparities also (Oswalt, McClain, & Melnyk, 2013). Primary Care Triple P is a short one-on-one parenting intervention program that consists of four sessions that involve strategies for parents of children with mild to moderate emotional or behavioral problems (Triple P, 2016). However, in one study researchers found that this program was not effective in reducing any problem behavior of children that graduated from the NICU when they were infants (Schappin, Wijnroks, Venema, Wijnberg-Williams, Veenstra, Koopman-Esseboom, et al, 2013). Shaw, et.al, (2014) were the first to examine the long-term effects of a trauma based Cognitive Behavioral Therapy (CBT) program that incorporates psychoeducation, cognitive restructuring, and exposure to trauma. The results concluded the need for this program since mothers were still exhibiting traumatic stress symptoms at 6 month follow up. They found this program was effective in reducing traumatic symptoms of the preterm birth and NICU experience (Shaw et al., 2014).

Perspective and Reflection

The NICU

On September 13, 2015 my son was born 7 weeks and 5 days premature. Due to his prematurity his birth was somewhat unconventional when compared to a full term infant birth. Immediately following his birth he was rushed to the NICU and I was not able to see or hold him for seven long and stressful hours. I

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was not provided a status on him and I had no idea how he was doing. During this time for parents of full term infants, they are immediately able to hold them and initiate a infant-mother bond. I was transported to the mother and baby unit where I was not able to have my child in the same room while I could see and hear other families being able to have that special time with their newborn baby.

I was unable to go to the NICU until later on that evening. Thankfully during the days following up to birth I had received two doses of steroids prior to his birth to help with lung development, and as a result he did not require any breathing support. He was four pounds and 15 ounces, which was considered a good size for his gestational age. He was stable and the nurse that was taking care of him allowed me to have some kangaroo care time with him. Upon examining him he had an IV coming out of his left hand as well as a feeding tube and probes to monitor his heart rate, respiratory rate and oxygen rate. He seemed to be peaceful and I was very excited to finally be able to hold and touch him. When he was placed into my arms I could tell immediately he knew whom I was. He was very alert and moved in the direction of the sound of my voice. The moment was perfect, however fleeting since 20 minutes later he was taken from my arms and placed back into his incubator. Due to the inability to regulate his temperature he was required to spend some time in one. I remember feeling so guilty and empty every time I had to leave him in the NICU. I remember feeling as though his suffering was my fault since I was not able to carry him full-term even though I did everything right in regards to proper prenatal care. I kept feeling as though this was very unfair, even though the rational side of me knew that he was in the best place he could be, and that in time I would be able to take him home.

The next 22 days were spent in the NICU. To say it was traumatic would be an understatement. It was a roller-coaster ride that I will never forget. Most days you went one-step forward just to go three steps backward the next day. Nolan did not have major complications, although he had some jaundice issues and had to be placed under a phototherapy light for multiple days during his stay. During these times I was not allowed to hold him or touch him. I understood the implications surrounding the jaundice and that if untreated possible brain damage could occur. It didn't matter though, because to me I was not able to feel a bond with my child during that time, and I saw him being very uncomfortable since he had to have goggles over his eyes during that time as well. Just think how uncomfortable you would be after 24 hours straight of something over your eyes with limited relief. Some nurses would give him breaks and others wouldn't bother giving him a break. The inconsistency of care was something that I will never be able to understand. Nolan probably had up to ten different nurses during his stay. The nurses all had different ways of care and very different personalities, which did promote stress with my husband and me, since we were told different things each day. I remember feeling that I had to advocate some days for my child, and that was very stressful since you hoped that in the NICU that would not have to occur.

Preparing for going home

I remember feeling as though the date of discharge would never come, though when it was time for him to go home I had a rush of anxiety and distress. My first thought was that I am neither equipped nor capable to care for a premature baby. He was having episodes of apnea and in order for him to be discharged he had to be sent home on an apnea monitor. This monitored his breathing and heart rate 24 hours of the day. My husband and I received a half-hour training on this machine through a representative of the company that provided the monitor and we had to show the nurses how to use the machine properly. He was prescribed a small dose of caffeine daily. We were not given any information on administering the caffeine. We were extremely intimidated, and told the NICU staff multiple times that we were not sure we are competent with the care of the monitor. Their only response was that we would be fine.

Home

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Fast forward to being home for the first night. My son woke more than ten times that night. This continued on for the first six weeks. Following discharge he was put on formula due to lack of breast milk supply, and this elicited painful screams and crying most of the day due to stomach discomfort. Not once during my stay in the NICU did the staff go over techniques that I could do to help ease his discomfort or swaddling techniques to help with “back-to-sleep” since they placed him on his stomach most of his NICU stay. Thankfully, I had previous knowledge of the importance of kangaroo care, infant massage and bicycle kicks, and I would apply them frequently. After seven long weeks of discomfort, crying days and sleepless nights, on our fifth formula we were able to settle into a routine where he finally seemed to be comfortable in his home. I have a great support system with my spouse and family and my knowledge with occupational therapy were my saving graces during those first seven weeks at home. Not one staff member called to follow-up from the NICU. Not one person thought to ask me in the NICU if I was interested in any referrals or support groups that were offered for parents of premature babies. Just as the research indicates, the care and parenting is very different from a full term baby especially in the first year of life, and having adequate resources would have been most useful.

I think that mothers of premature infants are sometimes at a disadvantage when they are trying to find their niche in motherhood. The infant mother bond is very different, and can be impeded by many obstacles that begin in the NICU, and can carry on at home as well. While in the NICU sometimes parents feel that they share a parenting responsibility with the nurses since they are providing the around the clock medical care. This is both stressful and hard on parents especially, if they don't feel they are getting proper bonding time with their infant. However challenging, you continue to be there every day. You continue to do everything in your power to ensure your child is getting the best possible care they can, and you cherish the small amount of time you get to hold them every day. The more time you get with your child the stronger that bond gets and the more empowered you feel as a mother, especially when you know your child can sense you are their mother.

At home you are finally able to be the one providing the care and nurturing. This is where the doing, being and becoming really starts to happen since you are not dealing with the internal and external stressors, and obstacles that existed in the hospital. Providing care and nurturing can be intimidating since there is no manual that is sent home with you on how to care for your premature infant. However, you face similar challenges that full term parents face, and you start to feel a sense that while every child is different you feel a sense of belonging to the parenting community. The more time that you have with your infant the more you feel you are doing, being and becoming a family., However, this did not come easy, and I believe parents of premature infants could really benefit from having services in the home that promote this notion, and help to empower parents at the same time.

Recommendations and Reality

There are some key points from the literature review to be discussed. Due to the high stress of having a very premature baby, it's suggested that the mothers should be screened for possible postnatal depression in order to implement appropriate intervention as needed (Gray et al., 2013). A postnatal screen would be a very valuable tool, and this tool could be taught and administered by multiple staff members in the NICU. There were times when I could have used someone to talk to, other than my spouse and family members, and a screen could have indicated a need to link me to a support group or the social worker. The most that the NICU staff emphasized were discharge instructions, which were general and not client specific. I do understand the importance of discharge instructions for the safety of the baby, however implementing some coping strategies or parenting techniques would have been very helpful when being at home for the first time with my premature baby. Parenting evokes stress, and teaching proper techniques to manage that stress is just as equally important as learning how to administer medications for proper care of the infant (Raines, 2013).

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Many studies focused on either the mother or the mother and father as a family unit. Though one study tried to examine them separately. Gender differences should be taken into consideration since men and women use alternate methods of coping when compared to one another (Doucette & Pinelli, 2004). Men and women cope differently and this should be a consideration when performing a postnatal screen, fathers are just as important as mothers in parenting premature infants. I would suggest meeting with the parents together and separately to ensure they understand the implications that exist while caring for their premature baby at home.

A very interesting topic that surfaced during the literature review was parental perceptions having an impact on child rearing. Practitioners need to be aware that parents could restrict their child's behavior and quality of life just by their perceptions of their vulnerability (Eiser et al., 2005). While in the NICU we were told numerous times that we should not bring our child around large crowds of people especially during their first year of life. We were told that they have a higher incidence of contracting illnesses, and these illnesses can have severe and detrimental effects due to the child's prematurity. I could see some parents taking this notion to the extreme and not allowing any contact with the outside world. It's important for the parents to have a support system and to maintain balance. For this to occur, there will be times that parents need to take their child out in public. Instead practitioners could offer practical alternatives to these parents who perceive their baby as being sicker than they actually are, because this could prevent children from actively engaging in play with their peers later on when they are older.

The strain on a family can have unfavorable impacts on the family dynamics from caring for a premature child. Finances can be very strained from very expensive hospital bills. An average NICU stay is around 3,000 dollars per day, totaling to 40,000 to 80,000 if the stay is longer than four days (Managed Care, 2010). Finances are not the only strains that families face. Families reported having a moderate level of family strains, and utilizing fewer resources, and more coping strategies at 18 to 24 months post hospital discharge (Doucette & Pinelli, 2004). More importantly families that are identified as having limited access to resources should be targeted early on to enable more successful engagement in appropriate services and programs (Doucette & Pinelli, 2004). It's safe to say that the longer out from hospital discharge the fewer resources are being used even though parents are continuing to need service referrals and interventions geared towards parenting and coping with internal and external stressors.

The last key point that will be discussed is finding the right intervention for families of premature babies following their discharge from the NICU. All families regardless of demographics and socioeconomic status could benefit from a program that is designed to help families make the transition from the NICU to home. The Parenting Preemies Program is a creative approach to providing post NICU support and education (Willis, 2008). The purpose of Parenting Preemies is to help with the transition from the NICU to home through individualized home visits and peer support groups through team members that include a clinical social worker, occupational therapist (OT), registered dietitian, certified lactation educator, and infant massage instructor, all with training in neonatal care (2008). This program is similar to having the skilled multidisciplinary team in the NICU, except you get to do the program from the comfort of your home in the child's natural environment. The skills and confidence that parents can build through this intervention can be more valuable than anything that was provided in the NICU. It's an occupation-based intervention that is family centered approach focused on the parents and their child. Further studies should be conducted utilizing occupation-based interventions, which can ultimately help with making the transition to home from the hospital, and gives parents some help and guidance along the way.

Conclusion

Prematurity continues to be a global issue, though thanks to modern medical technology and advances, outcomes have changed and babies born at 22 and 23 weeks gestation are beating the odds and surviving. The NICU will continue to be a very traumatic experience for some if not all parents. It's important that a postnatal screen is set up to identify any distress or concerns associated with caring for a

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premature baby after their NICU stay. Premature babies require different and more specialized care than full term babies, who can have an altering effect on family dynamics and parenting. By providing families with appropriate and adequate resources at discharge, they can become involved in helpful interventions to ease the parenting strain that can exist with a high-risk baby. Occupation-based interventions or interventions that provide family centered care can provide the most support for families since these interventions are performed in the child's natural home environment.

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