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Social Workers' Perceptions on Quality Hospital Care for Individuals with Intellectual Disabilities

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with Intellectual Disabilities

By

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Abstract

People with intellectual disabilities (ID) are not experiencing the quality care they deserve from healthcare professionals when hospitalized. A qualitative exploratory study was conducted using questionnaires and Grounded Theory to examine the perceptions social workers have in regards to the quality care people with ID receive in the hospital. From the data analysis, five themes emerged: (a) a lack of understanding, (b) a need for medical professionals to have specific education for treating people with ID, (c) person-centered care, (d) advocating for people with ID, and (e) barriers to quality care. Social workers can apply these findings toward a better understanding of how to help educated healthcare professionals to be culturally sensitive when working with patients' with ID.

Keywords: intellectual disability, social workers, quality care, hospitals

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Social Workers' Perceptions on Quality Hospital Care for Individuals

with Intellectual Disabilities

People with intellectual disabilities are a significant part of the American

population, but their needs are frequently unnoticed by the general population. In the U.S.

there are approximately 4.5 million people that have either an intellectual or

developmental disability (ID; The Arc, 2011). Individuals with ID commonly struggle

with health conditions, such as asthma, gastrointestinal symptoms, skin allergies,

migraines, headaches, and consequently seek help from healthcare professionals on a

regular basis and often experience discrepancies in the care they receive.

Healthcare professionals lack experience and education on how to work with

patients with ID. Admittance into the hospital can put a lot of stress on individuals with

ID as well as their caregivers, and the healthcare professionals involved. Individuals with

ID often face communicatory difficulties and the need for special ambulatory assistance

when seeking medical care. These factors are contributing stressors when an individual

must trust an unknown healthcare professional who does not understand how to

respectfully and effectively work with individuals with ID (Dinsmore, 2011; Hemsley,

Baladin & Worrall, 2011a; Iacano, 2003).

The inadequate quality of care individuals with ID represents a legitimate public

health concern (Wisdom, McGee & Horner-Johnson et al. 2010). However, there are

many parties involved who are in a position to make a difference. For instance, The

Surgeon General (United States Department of Health and Human Services, 2005) has set

goals to improve the quality of care for these individuals and has addressed the lack of

knowledge and understanding of how to treat this particular population by providing

adequate training to healthcare professionals (Dinsmore, 2011; Hemsley et al., 2011; Iacano, 2003; Stein, 2008).

Caregivers have become a critical component of the medical model that healthcare professionals can utilize when trying to effectively communicate with patients with ID (e.g. how to detect pain and the likes and dislikes of a patient; Helmsley et al., 2011; Iacano, 2003; Dinsmore, 2011[verify citation format]). Caregivers are often with the patient to ensure quality treatment is being provided, and their expertise is valuable in understanding the unique communication style of the patient.

As the medical model has changed over time, social workers have become an integral part of the team. Social workers identify and support patients' needs in the hospitals. Licensed independent clinical social workers (LICSW) work particularly close with healthcare providers. LICSW's are in a position where they can advocate for patients when adequate care is not being provided (Ward, Nicholas & Freedman, 2010). Balancing the needs of individuals with ID is a challenge for many disciplines throughout the hospital due to multiple factors have led to years of social oppression, institutional discrimination and attitudinal barriers. Different disciplines in the hospital should be made aware of the need to be sensitive to historical issues regarding the treatment of people with ID and become mindful of the quality of care they people with ID deserve (Brasher, 2006).

The purpose of the following study is to examine LICSW's and Licensed Social Workers' (LSW) perceptions related to the quality of care persons with intellectual disabilities receive in a hospital setting. A qualitative study was conducted to understand those perceptions of social workers. Thus, the following research question will be

examined: What are social workers' perceptions of the quality of care people with ID

receive in the hospital?

Literature Review

To address the concerns for quality of care provided to intellectually disabled

individuals in our medical system, as well as, develop a method of improving this quality

of care through the utilization of social work, it is essential to develop a fundamental

understanding of the medical system. This literature review will investigate the medical

system as a whole, and how it provides treatment to the intellectually disabled

population. The literature review will concentrate on key individuals within the medical

system and document their experience working with this population. The interactions in

this study between the intellectually disabled, their families, doctors, nurses, and social

workers will provide an appropriate foundation of knowledge from which the issue can

be addressed.

Definition of People with Intellectual Disability and Developmental Disability

"Mental retardation" is no longer a politically correct term when referring to

people with an intellectual or developmental disability (American Association on

Intellectual Disabilities, 2010). Today the medical profession uses the term intellectual

disability (ID). An intellectual disability is an umbrela term that incorporates individuals

that have different diagnoses with developmental and intellectual disabilities. These two

terms ID and DD are not interchangeable terms and have two separate definitions that are

discussed below.

People with ID have significant limitations in both intellectual functioning and

behavioral adaptation when developing social and practical skills. To be considered

intellectually disabled, a person's disability must have originated before the age of 18

(e.g. Down syndrome, fragile X syndrome; The Arc, 2011). In comparison, the term

developmental disability (DD) describes a severe chronic disability that can be attributed

to physical or mental impairment. DD results in substantial limitations in how the

individual functions (The Arc, 2011). Not all individuals who are diagnosed with an

intellectual disability have a form of developmental disability. To be considered

developmentally disabled, the disorder must have had to before the age of 22 (The Arc,

2011). Other disorders, such as cerebral palsy, epilepsy, autism spectrum disorder, can

onset in a child's development before the age of 18.

　　　　For the duration of the study, the term ID will be used to stay consistent with the

medical profession terminology. This study will include both types of disabilities (ID and

DD) when discussing the perceptions of social worker's quality hospital care for the ID

population.

Supports in the Community for People with Intellectual Disabilities

　　　　Persons with ID make up 3% of the general American population, which equates

to nearly 30 million individuals (AAID, 2010). Many of these individuals are not

independent and need assistance throughout their lives, and that often means depending

on family. One out of ten families is directly affected by the needs of individuals with ID

(AIDD, 2010), but they cannot provide full support alone. Their constant dependence on

external support puts the ID population into a vulnerable position. A support system

needs to be established to ensure the safety and equality for an individual with ID.

　　　　A support system is often a combination of family members and caregivers. To

afford support, some families apply for additional funding through a waiver program

called Home and Community Based Services (HCBS; Segal & Jacobs, 2014). HCBS

waivers provide support for more than 700,000 older persons with ID (Segal & Jacobs,

2014). A key benefit of the waiver program is that it provides support such as caregiving

and housing for individuals with ID without removing them from the community. Since

2008, 95% of the residential settings serving the ID community have been group homes.

On average, these group homes house between one and six individuals (Segal & Jacobs,

2014). Most of these group homes are run by non-state operated facilities. This shift from

state-run to non-state operated facilities has reflected the recent move towards smaller

privatized placements (Segal & Jacobs, 2014). HCBS has provided opportunities for

people with ID to be integral members of the community. As result, integration has

helped change the community's perceptions of people with ID.

The Role of Caregivers

A caregiver can either be a family member or a worker paid through an outside

agency. The relationship that is between the caregiver and an individual with ID plays a

critical role in the hospitalization experience (Iacano, 2003). The intimate knowledge of

the disability that the caregiver holds is vital for effective planning and provision of the

individual's hospital care (Dinsmore, 2011).

Caregivers face a multitude of challenges. Hemsley et al. (2011a), wanted to

understand the role that paid caregivers play in supporting adults with ID that have

complex communication needs. A study was conducted with 15 paid caregivers, 15 adults

with ID and 15 hospital nurses (Hemsley et al. 2011a). Obtaining the views of all parties

in the triadic interaction between the patient, the paid caregiver and the hospital staff was

necessary to understanding key issues that arise within the hospital. Narrative analysis

was utilized to organize the data collected (Hemsley et al., 2011a). The study found that paid caregivers often feel they walk the grey line of being a professional and being the individual's friend (Hemsley, et al., 2011a). The paid caregiver spends time with the individual and builds an emotional connection to the individual with ID overtime (Hemsley et al., 2011a). Because of this relationship, the individuals prefer the paid caregiver to be present at all times when they are admitted into the hospital (Hemsley et al., 2011a). The caregiver, whether they are a family member or a paid individual, is then put in a position where they need to build a working relationship with the nurses (Hemsley et al., 2011a). Overlap can occur when the nurse and the caregiver have ill-defined roles on who provides care to the individual. This overlap in roles often causes confusion and the individual with ID becomes discontent (Hemsley et al., 2011a). Caregivers reported frustration when they felt that their expertise on the individual was not valued (Hemsley et al., 2011a).

In the study performed by Hemsley et al., caregivers made comments that providers lack experience working with individuals with ID. They expressed mistrust in the physician's judgment when executing examinations (Ward, Nichols, & Freeman, 2010). Caregivers encourage physicians to build rapport with the patient before and during treatment, and they highly rate physicians who keep up with the new aspects of care, and are sensitive to the particular needs of the individual (Liptak et al., 2006). Unfamiliarity can lead to inappropriate labeling or misdiagnosing for the individual if a caregiver is not present (Ward, Nichols, & Freeman 2010).

Liptak et al. (2006) sent a survey to families who had a child that received services for physical disabilities (e.g. cerebral palsy or spina bifida) and developmental

disabilities (e.g. autism or intellectual disability). The survey consisted of three parts: (a) demographic information, (b) the Multidimensional Assessment of Parental Satisfaction (MAPS) for children with special needs, and (c) general questions. MAPS evaluated care coordination, developmentally appropriate care; family-centered care, interpersonal competence and technical competence. The general questions assessed baseline attitudes toward physicians in general. Findings suggested that families who had children with autism were more likely to disagree with how a physician managed their child's medical condition (Liptik et al. 2006). With this negative opinion, caregivers have developed a self-management role to help individuals instead of relying on physicians for resources to help with the specific medical condition (Liptik et al., 2006).

Struggling to trust physicians, caregivers are often hesitant to leave the individual with ID alone with healthcare providers (Iacono & Davis, 2003). Caregivers understand the communication style of the individual and can provide tips to help the hospital staff. This sense of responsibility places an undue burden upon caregivers (Iacono & Davis 2003). Caregivers feel that they are not able to leave the person's bedside in fear that the individual will not receive proper care. Phillips (2012) found how the establishment of the roles and responsibility of the caregiver aided in the support required for a person with ID upon admission to the hospital stay (as cited Welsh Assembly Government 2011). Establishing the roles of responsibility pertaining to the aid of the individual with ID helps eliminate assumptions that the caregiver is always around, thus eliminating some of the stress from unpredictable circumstances.

Social Work

Social workers are another support system for people with ID. Medical social workers have a skill set in understanding behavior; lending empathy and helping people overcome issues that hinder quality of life for people with ID (Clarke & Davidson, 1990). Social workers recognize that families and other strong support systems play a vital role in the continuous care and support needed for the client. Promoting strong support systems helps social workers maintain control and direction throughout a crisis (Davidson & Clarke, 1990). Social work not only works with the individuals and their families, but also collaborates with nurses, physicians, and other professionals who make-up the different healthcare disciplines (Clarke & Davidson, 1990).

Health Care for Individuals with Intellectual Disabilities

Historically, people with ID have had low life expectancy, but with the advancements in technology and medical research, people with ID are living longer (HHS, 2005). Today people with ID are expected to live well into adulthood (HHS, 2005). In parallel, with the advancement in the medical profession, societal attitudes towards people with ID have significantly changed (Haslam & Milner, 1992). Haslam & Milner (1992) surveyed the attitudes that pediatricians, child neurologists and pediatric surgeons have towards Down syndrome. The study found that physicians and neurologists have become more aggressive in persuading parents to choose life-saving surgery when individuals with Down syndrome are babies (Haslam & Milner). In 1990, 38% of surgeons attempted to persuade parents to sign consent for surgery compared to 17% in 1975 (Haslam & Milner, 1992). Although there have been societal strides, people with ID are still not seen as equals to "normal" people, especially when it comes to

healthcare (Roscigno, 2013). People with ID have complex medical needs and making

preventive care is important when working to improve their quality of life. However,

there are times when acute care overshadows preventative care (James & Shireman,

2010).

The discrimination and oppression of people with ID is directly correlated with

the lack of quality of care this population receives in the healthcare system (Wisdom,

McGee, Horner-Johnson, et al., 2010). For example, one contributing factor to these

disparities is the presumption that people with ID are less likely to engage in health-

promoting behaviors. People with ID who have poor health conditions increase their

need for healthcare service, and as a result increases health care costs (Wisdom et al.,

2010). Even though people with ID use health care more often, these individuals struggle

to receive quality care (Phillips, 2011). Individuals with ID tend to stay with their

pediatricians beyond childhood because the pediatrician understands the individual's

complex medical needs (Krauss, Gulley, Sciegaj & Wells, 2003). This causes concern

because a pediatrician may struggle to provide appropriate care when the patient reaches

adulthood (HHS, 2005). When an individual with ID does find an adult specialist,

scheduling an appointment may take several months, which makes it difficult to keep up

with the individual's ever-present medical needs (Ward et al., 2010).

Another factor limiting the availability of quality care is the physician's

reluctance to accept Medicaid patients (Levy, 2003). Medicaid sets a benchmark of

monthly assigned federal-state expenditure, and if a patient with high medical needs goes

beyond that benchmark the physician may be facing out-of- pocket costs (Levy, 2003).

Physicians have to feasibly consider the amount of Medicaid patients they can accept in

order to earn money in their practice (Levy, 2003). Individuals with ID require an

increased time commitment from the physician. Compensation for this additional time

allotted to the patients is not given to the physician (Hall, Wood, Hou & Zhang, 2007).

Beyond the time commitment and financial risk, many health care professionals are

unsure of how to adequately help patients with ID. Individuals who are nonverbal are

being labeled as "difficult." At times it is determined that an individual does not require

service based on the apparent behavioral problems (Ward et al., 2010). The labels

patients with ID carry encourage stereotyping, and creates biases that are inherent to the

healthcare organization and influence the quality of care they receive. Providers need to

have unbiased information regarding treatment options for patients with ID (Liptik et al.

2006). Providers cannot properly care for these individuals when preconceived notions

and stereotypes are present.

       Hospital experiences. Admittance into the hospital can be an anxiety provoking

and stressful experience. Webber, Bowers and Bigby (2010) looked into the hospital

experiences of older adults with ID living in group homes over a three-year period. The

participants in the study included family members, group home, staff, group home

managers, and residents. To collect the data, the researcher conducted telephone

interviews as well as in-person interviews. Webber et al. (2010) used Grounded Theory

to guide the data analysis. Sub-themes that emerged from the caregivers' perceptions of

hospital experiences were the perceptions of hospital staff attitudes, knowledge about ID,

predictable routines, pain management and hospital staff communication. They found that

feelings of frustration, distress and anger when dealing with patients who have ID

contribute to the perception that the nurses lack experience and knowledge in how to care for individuals with ID (Webber et al., 2010).

The results of the research showed that the ID population experiences multiple interactions with various health care professionals in various clinical settings, yet they often feel that their insight and experience is blatantly ignored (Roscigno, 2013). The hospital staff are unfamiliar with the individual, and often struggle to effectively communicate with someone with ID. Understanding an appropriate communication style is difficult when a communication style is unique to each person. Hemsley, Balandin and Worrall (2012) conducted a qualitative study discussing communication needs in the hospital. Detecting the level of pain an individual was experiencing was a high priority in measuring the individual's communication abilities. Hemsley et al. (2012) found nurses used a scaled response system that was made up of a scaled response system asking a series of yes or no questions. The resulting answers helped interpret nonverbal facial expressions or body signals in response to a stimulus or action to relieve pain. If the system did not work, the nurse utilized a caregiver to help the patient report pain.

Even individuals that are capable of communicating feel they receive unequal treatment in the hospital (Iacono, 2003). Dinsmore (2011) used purposive sampling to interview participants with a learning disability who had a hospital visit after March 2007, as well as caregivers of a person who had been to the hospital within the same time frame. The study found that patients expressed a desire to have a more proactive process in admission include a more thorough inquiries about pain expression, complex dietary needs and what communication style would be most effective with the individual (Dinsmore, 2011). Communication is an increasing challenge when individuals are by

themselves and unable to accurately portray their needs (Hemsley et al., 2011b).

Caregivers assisting with communication can significantly improve the amount of

negative interactions experienced in the hospital (Hemsley et al., 2011b). Fortunately,

many people with ID have caregivers that help advocate on their behalf when at the

hospital.

Experiences between Health Care Professionals and Persons with ID

   Nurses. Nurses are the most utilized staff members in the hospital when

providing care for individuals with ID. In comparison to other healthcare professionals

who have minimal contact (Liptak et al. 2006). Nurses are the face of healthcare services,

acting as a bridge between the caregiver and the physicians (Bornman, Alan & Lloyd

2007). Yet, nurses, too, struggle to provide quality care for individuals with ID (Philips,

2012). Philips (2012) systematically reviewed prior qualitative research that examined

individuals with learning disabilities in a secondary care setting. The collaboration of

articles found that nursing staff had poor attitudes about working with individuals with

ID, and were admittedly less confident in working with them. When nurses are not

comfortable working with individuals with ID the quality of care can be negatively

affected (Phillips, 2012). Nurses' own discomforts need to be managed to ensure that an

individual with ID are equally valued (Hemsley et al., 2011b).

   Nurses and other professionals need to put personal beliefs and cultural attitudes

aside when working with patients with ID. Nurses' inability to separate personal beliefs

and attitudes towards people with ID explains the insensitive encounters people with ID

may experience (Roscigno 2013). Roscigno's (2013) purpose was to gain an

understanding of the negative interactions between a person with ID and healthcare

professionals. Roscigno hoped the information collected could inform healthcare

professionals about how to provide culturally sensitive care.

Nurses feel that there is not enough time allotted in the schedule to adequately

help individuals with ID (Hemsley et al., 2011b). A component to this barrier is when

caregivers are present; nurses utilize the caregiver to help with the individual's needs.

Nurses expect caregivers will help with communication and provide personal care for the

individual with ID. When delegating the work to the caregiver, nurses are still

responsible for overseeing all treatment that is undertaken (Hemsley et al., 2011a).

Nurses often assume the individual has poor communication abilities and

automatically direct conversations towards the caregiver (Ward et al., 2010). This is

unfair to the patient and could be alleviated if nurses had adequate training and

equipment to provide effective communication when working with individuals with ID.

In the hospital, there is a scarceness of available tools for communicating with the patient

(Bornman et. al, 2007). The caregiver could bring a personal communication device for

the individual such as a white board or an electronic device; however, if nurses have had

no prior training on how to use the device, this avenue of communication is ineffective.

Nurses feel spending the time to learn how to use the device seems daunting and an

efficient use of their time when a caregiver will most likely be there to help.

Hemsley et al. (2012) interviewed nurses in an effort to understand their view on

the concept of time when communicating with patients with ID and other situations with

complex communication needs in the hospital. Nurses reported that they were able to

maintain their patience when they had elected a particular method of communication, and

the person with ID felt the nurses were more approachable and friendlier. This tactic

averted the frustrations of both the nurse and the patient (Hemsley et al., 2012). The time

spent utilizing the communication board for direct communication saved time in the

nurses'routine (Hemsley et al., 2012). Nurses that were able to employ a range of

adaptive communication strategies experienced increased patient compliance to care and

procedures that were necessary for quality care (Hemsley et al., 2012). A patient who is

unable to speak for him or herself is a major obstacle when a nurse needs to assess the

patient with ID for pain. People with ID experience pain in many different ways. Without

knowing the individual, a nurse would have a hard time understanding the nonverbal cues

(Stein, 2008).

       Walsh et al. (2000) surveyed over 500 nurses in New Jersey about the education

and training received in helping individuals with ID. Ten percent of the nurses reported

that they had received formal training with people with ID. Most nurses reported that the

only training received was strictly related to work experiences or time spent with a family

member with a disability. Nurses are aware they are in need of training and 75% of them

believe that information about ID should be integrated into the educational coursework

(Walsh et al., 2000).

       The knowledge relevant to work with ID individuals has increased over time. As

this knowledge base continues to grow along with nurses' experiences and confidence the

quality of care will improve (Broman et al., 2007).

       Physicians. Physicians function primarily under the medical model which

upholds the idea that a disability resides within the individual. This model focuses on the

pathology and ailments of the individual and the inherent belief that there is always a

defining reason that something is wrong with the person. For individuals with ID, they

can accumulate multiple diagnoses and ailments over their lifetime. These ailments

eventually limit the value of the person and their humanity is degraded based on the

medical model (Brashler, 2006). Using the medical model as a standard has also resulted

in a deficiency in care. The medical model is inadequately constructed to assist with the

health care needs of the ID population. Hall, Wood, Hou & Zang, (2007) analyzed the

health and health-related services for people with ID in the state of Florida. The study

found that the utilization rate of health services for people with ID was lower than

expected. Predictions are that this low number could stem from the lack of relevant

education physicians receive in medical school. Individuals with ID are reluctant to see a

physician that is inexperienced managing their disability.

　　　　Wilkinson, Dreyfus, Cerreto & Bokhour (2012) sought to understand the

educational needs of family physicians that provide care to adults with ID. Physicians felt

that they were operating "without a map"; they had discomfort with the patient, and were

unfamiliar with the community of people ID. Sharma, Lalinde and Brosco (2006)

understood that physicians feel a sense of discomfort and sent students completing their

residency to homes of individuals with ID. The residents met with the parents who had

children with ID. The parents educated the residents about what it is like to have a family

member with ID. Based on this interaction, the residents stated that the medical

profession should be aware of barriers that patients with ID experience when anticipating

medical procedures. Residents also declared that the provider should attempt to eliminate

barriers prior to the exam to help decrease anxiety and fearful emotions for individuals

with ID. The time spent within the families changed the residents' perspectives on the

struggles faced by people with ID and their families. This study supports the work of

Haslam and Milner (1992) who found that physicians who have years of experience

working with ID individuals are more likely to engage the individual in their health care

decisions instead of directing conversation towards the individual's caregiver. Exposing

physicians to the ID population during their schooling better equips the physicians to

work with patients with ID in the future.

The attitudes physicians have towards people with ID are shaped by personal

experiences. These experiences can be through educational programs or role models in

their career (Haslam & Milner, 1992). Haslam and Milner (1992) suggest continuing the

emphasis on patients with ID in undergraduate programs would be highly beneficial with

the younger generation. Younger physicians should become well informed on the

specifics of handling individuals with ID.

Licensed Clinical Social Workers within the Hospital

LICSW's are also known as medical social workers in the hospital, are a

secondary support system within a hospital setting. The presence of medical social

workers has proven to be a vital component in ensuring there is proper care for all

individuals. The role of medical social workers is to help coordinate care between

families and other medical professions in order to simplify transitions (Levy, 2003).

Improving cooperation between professionals allows for a more cohesive

interdisciplinary team and ultimately improves the quality of life for the patient.

Families' concerns are also taken into consideration when caring for a patient.

Social workers spend time coaching, counseling and educating the families about the

patient's condition (Ward et al., 2010). Providing direct services to patients and families,

LICSWs seek to strengthen individual's coping skills and social functioning to militate

against the effects of troubling illness and taxing situations (Davidson & Clarke 1990). LICSW's aims to reinforce the families' abilities to utilize the necessary resources and service that are provided to the family. LICSW's constantly watching out for the emotional wellbeing of the individual served.

However, like physicians and nurses, medical social workers are not always well educated or experienced working with the ID population. When Lippman (1997) had participants rank professionals that were equipped to handle ID patients, social workers did not score high on the scale. The negative connotations that are associated with social work may have contributed to the low score (Lippman, 1997). Individuals and their families lack enthusiasm for professional social services, and there is a mistrust of information regarding the role of social work. Social workers themselves need specific training for health conditions and the specific needs of individuals with ID. Social workers and other professionals need to realize that they carry preconceived notions about what life with a disability is like and how those beliefs impact their work (Brashler, 2006).

Strategic placement of social workers in the medical setting helps promote better healthcare for all individuals. Social workers are trained to recognize inequalities and inequities experienced by individuals (Ward et al., 2010). Even though they still lack sufficient training, social workers are better equipped to handle all different types of people than the other roles in the healthcare system. Social workers advocate for patients' needs which in turn help prevent unequal conditions and strive to eliminate healthcare barriers (Ward et al., 2010).

Case Managers

People with ID need continuous care throughout their lives. Case managers, who

can be licensed social workers (LSW), are assigned to individuals with the purpose of

coordinating care for the individual with ID. They provide a collaborative process of

assessment, planning, and facilitation that presents options and services to meet complex

needs of the individual. Case managers know how to navigate the system to ensure that

the necessary supports are in place and to promote an optimal quality of life (National

Association of Social Work, 2005). Individuals that receive the HCBS waivers receive a

case manager that can coordinate and integrate social and medical services to maintain

independent living. By providing the necessary medical supports, individuals with ID can

maintain and increase independent functioning (James & Shireman, 2010).

James and Shireman (2010) described the perspectives of case managers who

provided health promotion services. Case managers went through intervention trainings

with the purpose to provide appropriate resources to intervene effectively and to improve

the quality of care for persons with ID. A baseline survey was given to participants before

completing the intervention. The study revealed that case managers had low confidence

in their abilities to handle the complex medical conditions and suggested that more

knowledge is needed to handle these situations appropriately. The social work

background that case managers have specifically helps when coordinating healthcare for

individuals with ID.

Improvements

To meet the medical needs of patients with ID, care needs to focus on the person

and not the disability. The patient's unique preferences and values need to be emphasized

for the care to be optimized. Health care professionals might want to consider the effect

of increasing their time commitment when treating patients with communication

disabilities. They can then focus on areas of treatment that impede equal access to the

healthcare services provided. The current rules and regulations should be modified to

encourage these actions (Wisdom, McGee, Horner- Johnson et. al).

Problem

There is a shortage of training provided to health care professionals that leave

them unprepared when treating individuals with ID. Professionals with limited exposure

and limited experience with the needs of patients with ID create an uncomfortable

situation for both the patient and the healthcare professional. However, social workers'

education focuses on the whole individual and not one specific aspect in their life.

Medical social workers find ways to improve the quality of life for patients and their

families with effective interventions. Their effectiveness in working with this population

would make social workers key advocates in the fight for equality and quality care for

individuals with ID. This leads to the question: what are the social workers perceptions

on the quality of care people with ID receive in the hospital?

Conclusion

Upon reviewing the current state of the field of medicine, as well as the individual

experiences of those in the medical profession, it is clear that changes are necessary if

equivalent quality of care is to be provided to persons with ID. Doctors, nurses, and

social work professionals stated that they feel uneducated and ill prepared when it comes

to treating an individual with ID. Difficulties with communication and preconceived

judgments and stereotypes of people with intellectual disabilities can drastically hinder

the quality of care that is provided. Social workers are optimally positioned to improve

communication and performance of these cross-functional teams of medical

professionals. Before improvements can take place, the societal viewpoints and

preconceived notions regarding individuals with ID need to be altered. Repeatedly,

professionals in the medical field have stated that they feel a lack of confidence and lack

of preparation when treating persons with ID. Based on the articles reviewed above,

promoting increased education and training would improve social workers and other

healthcare professionals and work towards narrowing the gap for quality of care people

with ID receive in the hospital.

Conceptual Framework

In this section, the researcher will explain the conceptual framework that guides

the understanding of the problem. Various theories and perspectives shape social work

and facilitate interactions between a person and the various systems within society. This

research study views the problem through the ecosystems theory and incorporates

concepts from both the systems theory and the ecological perspective (Zastrow &

Ashman, 2008).

Person-in-environment is a perspective within the ecosystem theory that has

become an influential reference point and has helped define social workers' role when

working with an individual (Zastrow & Ashman, 2008); for it provides guidance on ways

to appropriately and effectively intervene when working in a hospital setting with people

with ID.

Systems theory breaks the ecosystem into separate components for analysis. One

of these components is a social system, the system of people affecting people. In this

study, the researcher applies system theory to social interactions within the hospital

system between healthcare providers and people with ID. Additionally the concept of

boundaries will be approached within the research. Boundaries are the borders or margins

that separate one entity from another (Zastrow & Ashman, 2008). Clinical social workers

within the hospital collaborate with physicians as well as work with the patient. This

requires them to have an understanding the values of both parties. Homeostasis is another

concept that creates the tendency for a system to maintain a relatively stable, constant

balance (Zastrow & Ashman, 2008). Making sure everything flows within a hospital is

important, and adapting to the needs of an individual with ID can cause disarray within a

unit. The concept of role is culturally established social behavior and conduct expected

of a person in any designated interpersonal relationship (Zastrow & Ashman, 2008). The

concept of role plays an essential function in the study. People with ID constantly

struggle with receiving equal treatment in society. The purpose of social work is to make

sure all persons in the community have access to social justice. Social workers strive to

help vulnerable populations that experience oppression within society. Relationship is

another fundamental concept that is reciprocal, dynamic, and interpersonal connection

characterized by patterns of emotional exchange, communication and behavioral

interaction (Zastrow & Ashman, 2008). Relationships become established between the

caregiver, the nurse, the physician and the individual. Input in relationships involves the

information or communication received from other systems (Zastrow & Ashman, 2008).

Output in relationships is the response of the system after receiving and processing input.

When input and output work together it creates cohesion within other systems in the

environment (Zastrow & Ashman, 2008). The interface is the point that which two

systems come in contact with each other or communicate (Zastrow & Ashman, 2008).

The research project to be conducted analyzes the communication between nurses,

caregivers, physicians, and people with ID. The final key concept of systems theory

interrelates to ecosystems theory; this is the concept of equifinality. This term refers to

the fact that there are many different means to the same outcome (Zastrow & Ashman,

2008). Social workers provide a variety of resources to guide individuals in a direction

that ultimately improves the individual's situation. An individual's social environment

affects the circumstances and interactions that surround their life (Zastrow & Ashman,

2008). The key concepts described in systems theory contribute to the understanding of

ecosystems theory.

In addition to systems theory, concepts from the ecological perspective can be

integrated within the ecosystems theory. The first key concept is a social environment in

which there are conditions and circumstances where human interactions encompass

human beings. (Zastrow & Ashman, 2008). Individuals with ID that are patients within

the hospital must have effective interactions within the hospital environments in order to

feel that they are safe and supported (Zastrow & Ashman, 2008). The idea of transaction

is another major concept within systems theory. A transaction is defined as an active

dynamic of people communicating and interacting with each other in the social system

(Zastrow & Ashman, 2008). Transaction may be positive or negative depending on the

environment (Zastrow & Ashman, 2008). Adaptation is a concept that refers to the

capacity to adjust to the surrounding environment (Zastrow & Ashman, 2008). Energy,

the natural power of active involvement between people and their environment, is another

concept (Zastrow & Ashman, 2008). Interdependence is the mutual reliance of each

person on every other person. People with ID are a vulnerable population that depends on

other people for help within society (Zastrow & Ashman, 2008). The last concept that

interrelates to the ecosystems theory is coping. Coping is a form of adaptation that

implies a struggle to overcome problems (Zastrow & Ashman, 2008). There are many

dynamic factors that occur in an individual's social environment. An individual's response

to a social situation varies depending on the coping skills the person has developed. The

integrative concepts of systems theory and ecological perspective within the ecosystems

theory navigate the social worker through troublesome interactions.

Ecosystems theory is the foundation for understanding the problem evaluated

within this research study: individuals with ID struggle to receive high quality care when

admitted into the hospital. The social work profession is heavily influenced by the

person-in-environment theory, the ecological perspective and systems theory. These

theories will guide the researcher to understand the perceptions of the LICSW's working

within the medical system, and the LSW case managers working with individuals with

ID.

Methods

Study Design

In this section, the researcher will describe the methods used for this qualitative

study. The researcher sought to understand social workers' perceptions of the quality of

hospital care received by individuals with ID. To execute the research, the researcher

used Grounded Theory as the qualitative design. Grounded theory is a method that allows

the theory to emerge from the data (Monette et al., 2014).

Sample and Sample Recruitment

Participants in this study were either an LSW or an LICSW. Participants were recruited using the criterion sampling technique. Criterion sampling identifies characteristics of a population by asking knowledgeable persons to name and select eligible participants based on the study's criteria. To recruit LICSWs for the study, a mailing list was obtained from the State of Minnesota Board of Social Work (BOSW). LICSW were recruited through a flyer that the researcher emailed to potential participants to invite them to participate in the study (see Appendix A). An information sheet was also attached to each email with a description for the purpose of the study and the option to skip questions or withdraw from the study (see Appendix B). If potential participants responded to the email, the researcher provided a more detailed explanation of the study as well as the interview questions and the consent form.

The researcher enlisted Hammer Residence Inc., a Minnesota non-profit serving children and adults who have developmental disabilities, to apply the criterion sampling method and identify case managers and care coordinators with an LSW to participate in the study. Hammer signed a letter of cooperation (see Appendix C) to acknowledge that they agreed to recruit employees to partake in the study, and a Hammer director distributed flyers to potential participants. Interested participants were instructed to contact the researcher via email, the researcher responded with information about the nature of the study and how it was to be conducted. The researcher also clarified to the participants that, by completing the questionnaire, participants were consenting to be part of the study. Participants received the questionnaire, information sheet, and consent form all in one email.

With the information gathered from the participants' questionnaires, the

researcher hoped that this study would help social workers and service providers

understand the experiences of people with ID in the hospital and their barriers to quality

care. From the findings, the researcher also hoped to develop better ways to support

individuals with ID and their families when admitted and discharged from the hospital.

Protection of Human Subjects

The participants were informed in the consent form of how the researcher planned

to maintain confidentiality. The researcher did not ask identifying information regarding

the organization or where the participant was employed from the participants that are

selected from the BOSW list. The information sheet (see Appendix B) described how the

questionnaires were stored as well as how the information was going to be used for

publication. Electronically submitted questionnaires were saved in on the researcher's

computer as well as printed. Any emails that were exchanged for the purpose of the

study were stored on a computer that required a personal pass code. Printed copies were

kept in a locked file cabinet at the researcher's residence, and all copies were locked up

when not in use by the researcher or the research assistant. The printed copies were put

into a folder and placed in a locked file cabinet in the researcher's residence. Only the

researcher, the researcher's chair, and researcher's assistant had access to the

questionnaires. The research assistant signed a confidentiality agreement (see appendix

E) prior to assisting the researcher in coding the data to ensure the privacy of the

participants. The researcher and research assistant coded the data. After the data was

coded, the data was destroyed. All documents were kept until May 31, 2015. At that time,

the researcher ensured all emails were permanently deleted from the computer.

Data Collection

Qualitative questionnaires allowed the researcher to explore the experiences of

social workers and their interactions with hospital professionals who were treating people

with ID. A qualitative questionnaire was the chosen method of data collection, because

participants who fill out a qualitative questionnaire via email are more likely to provide

substantial responses to qualitative questions and do not demonstrate evidence of

evaluative bias (Thyer, 2010 pg. 134).

The questions used in this study were designed to help guide and systematize

relevant information (Barker, 2003). The researcher included both close-ended and open-

ended questions in order to understand the history of the participant and the perceptions

of the social workers. The open-ended questions allowed the participant space to give in-

depth answers, and were focused on the themes outlined in the literature review. The

close-ended questions asked for specific information without detail or opinion (Barker,

2003).

Through the use of the questionnaire (see Appendix F), the researcher explored

the perceptions of social workers. The questions started with basic demographic

information (e. g., the level of licensure, and the number of years worked with individuals

with ID). The questions funneled down to more specific questions regarding issues in a

hospital setting (e.g., *In your work experience, describe what barriers you have witnessed*

with people with intellectual disabilities when they are admitted into the hospital?; If you

could change one thing in the hospital setting that benefits people with ID, what would

you change?). Some of the questions would not be relevant to all participants due to

varying levels of work experience. The researcher was aware that uninformed answers

could create a statistical bias.

The researcher estimated that the questionnaires would take thirty minutes

allowing time for the participants to read over the informed consent and to thoughtfully

answer as many questions as possible. Participants were told in the informed consent

(Appendix D) that by completing the questionnaire they were consenting to be a

participant. Once the researcher received a completed questionnaire and if the participant

provided a mailing address the researcher mailed a $10 gift card to Caribou Coffee, as

compensation for their participation.

Forty-three questionnaires were sent out to interested participants, and six

participants completed the questionnaire. Four participants were LICSW and two

participants were LSW. Though participants had the option to not to answer a question or

discontinue filling out the questionnaire at any time, all the participants answered every

question in the questionnaire.

Data Analysis

Content analysis was used to identify codes and themes in the completed

questionnaires. Content analysis was a method used to transform the symbolic content of

the document, from a qualitative unsystematic form to a quantitative systematic form

(Monette et al., 2014). The different categories of data were developed from coding

which identified the themes in the data (Monette et al., 2014). The questionnaire was

structured to tease out themes related to ecosystems theory with the components of the

person-in-environment perspective, systems theory and the ecological perspective. The

researcher used different units of data analysis, including themes, single-word and

context analysis (Monette et al., 2014). Theme analysis refers to the overall subject

matter of the questionnaires. Single-word unit of analysis is used to identify the presence

of key words in the questionnaires (Monette et al., 2014). Content analysis is used with

single-word analysis to discover the context on which each single word was found

(Monette et al., 2014). The combination of the unit analyses provided for a better

understanding of the data.

Participants' responses guided the researcher to move from concrete observations

to abstract theories in order to explain the findings. The researcher used open coding to

begin looking for common themes among participant responses. In this way, the data

guided the application of theory and meaning to unfold as themes emerged in the

questionnaires.

After completing open coding, the researcher used Grounded Theory to group

similar concepts into themes. A code that appeared three or more times in multiple

questionnaires was considered a theme (L. Peterson, personal communication, June

2014).

Validity and Reliability of Data

Validity in content analysis refers to whether or not the identified themes and

aspects of the coded content are meaningful indicators of what the research intends to

measure. Content validity is a measuring device that covers a range of interpretations. To

strengthen the content validity, the researcher used reliability checks. Data is considered

reliable if there are consistent results each time the data is used (Barker, 2003). For this

study, the researcher and the research assistant performed a reliability check on the

themes identified in the data analysis.

Strengths and Limitation of Study

One of the strengths to this study was that it added to the literature available to the public on the quality of care people with ID receive in a hospital. Existing literature goes into depth about the perceptions of physicians and nurses, however, social workers' perceptions had not been analyzed in this context until now.

A limitation to this study was its small sample size of six social workers. With such a small sample size, the researcher is less confident that the findings can be generalized for the population as a whole. Another possible impact was the researcher's personal experience working with individuals with ID and assisting them with their health care needs. The experience of the researcher may have contributed a bias. However, the reliability checks performed by the research assistant proved that, if there was any personal bias, it did not affect the outcome of the research.

Perhaps the most unfortunate limitation was the researcher's inability to interview individuals with ID due to Individual Review Board limitations. Individuals with ID are vulnerable adults, and interviewing them about their experiences would have been difficult. Interviewing social workers without including people with ID limited what the researcher learned in regards to the perceptions of quality hospital care.

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Findings

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This research study was designed to gain a better understanding of the perceptions of social workers in relation to quality care in hospital settings for persons with intellectual disabilities. The researcher distributed 150 emails to recruit LICSW to offer their perceptions of quality care for people with intellectual disabilities. The researcher also partnered with Hammer Residences Inc., to have LSW case managers offer their

perceptions to the study. Forty-three potentials responded back to the researcher with

their interest. Of the 43 questionnaires distributed, six people sent a completed

questionnaire back to the researcher. The respondents consisted of three LICSW and

three LSW. Two LICSW had 6-10 years of experience working with people with

intellectual disabilities, and the LICSW had over 11 years of experience working with

people with intellectual disabilities. All three LSW had 6-10 years of experience working

with people with ID.

After the questionnaires were collected, the researcher consolidated all responses

to one document and separated their responses into each question category. Once the

responses had been placed on a single document, certain words or phrases were

highlighted that appeared to follow general themes throughout the research. Each of these

words or phrases was placed into sub-categories for a more detailed theme analysis, and

five themes emerged. These themes consisted of the following: (a) a lack of

understanding, (b) health care professionals need to have training on how to specifically

work with ID patients, (c) person-centered care, (d) advocating for people with ID, (e)

barriers to quality care. Throughout this paper, the researcher will highlight certain words

or phrases that each participant used. To ensure full anonymity, respondents will be

referred to as "Participant 1," "Participant 2," etc..

Lack of Understanding

Participants' responses acknowledged that health care professionals demonstrate a

clear lack of understanding of how to work with someone with an intellectual disability.

Participant 4 claimed, "…people just don't understand the overall population and are

uncomfortable to associate with them. It is not mean, but when [they] don't understand

something people tend to shy away, because it is just easier."

Participant 5 stated, "[There is a] mutual lack of understanding between

individuals and most providers. Many individuals don't understand what is going on

when admitted to the hospital, and often providers do not know how to best support the

individual." Participant 5 also commented the following, "Hospital staff do not know

how to best support someone with [a] cognitive limitation."

Participant 6 commented, "[There is a lack] of knowledge, other staff gets

inhibited by their personal rigid beliefs that rules are not flexible and can be modified to

help people succeed. Participant 6 also said, "Minimal amount of staffing recognize cues

that ID individuals have, [and] therefore, do not make any necessary accommodations."

Participant 1 wrote in frustration about the lack of awareness on how to help

individuals with ID by stating, "Professionals need more empathy! Many people do not

understand this population and simply call them 'retardad.'" Health care professionals'

lack of knowledge was a significant theme throughout the findings and many participants

responded to the issue by suggesting additional training or education is needed to

appropriately work with the ID population.

Health Care Professionals Need to Have Training on How to Specifically Work

With ID Patients

In the questionnaire the researcher asked a specific question to allow participants

to share what type of education is needed for physicians and nurses. However, education

was discussed in other responses in the questionnaire. Participant 5 first responded with,

"Hospitals seem to be under trained on how to work with this population [. . . it's]

important to educate hospital providers that individuals with ID/DD often have the ability

to make their own healthcare decisions." Participant 5 explained how education would be

beneficial:

> I think that it is just getting the professional to really understand how their
>
> decisions and services they provide impact the individual; [. . .] So many times it
>
> seems like a doctor orders a medication or suggests an intervention that is
>
> impossible given the persons situations. Providers don't always take into account
>
> that a person may not be able to follow certain important discharge instructions
>
> given their situations.

In regards to the type of training health professionals need, Participant 5

suggested, "Any person-centered training or any training that really emphasizes the fact

that every patient is in a different situation regardless of their diagnoses or medical

condition." Participant 2 stated, "More education about what ID really is, how it

manifests in the lives of the people it affects and how, on a day-to-day basis, they can

best care for these patients." Participant 1 and 6 both made comments on educating about

specific medications/treatments for individuals with ID. Participant 1 responded, "More

education for [physicians] on medication options for this population to help control

aggression/violent behaviors. Participant 6 stated, "…having awareness to different types

of treatment interventions to help this population succeed…" Participant 6 also

commented, "…more in-depth training is needed to recognize signs an individual may

have ID… as well as a training focused on helping them understand the barriers the client

experiences as this allows them to become more open minded…" Participants'

suggestions for additional training align with the person-centered theme. Specific

trainings on how to work with individuals would allow the hospital staff to adapt

individuals with ID and their specific needs.

Person-Centered Care

Throughout the responses from participants, person-centered care emerged as a

common theme. Participant 5 referred to person-centered care in almost all of her

responses. Participant 3 and 4 made statements that fit under this theme as

well. Participant 5 began by stating, "The person-centered approach in providing

healthcare to patients does not always seem to work as it should when providing care to

individuals with ID/DD. [. . .] Involving them [individuals with ID] in their own care is

really important [. . .] as they have the ability to make their own healthcare decisions."

Participant 5 elaborated how care should be unique to all individuals:

> All patients should be treated as if their healthcare needs are unique and their plan
>
> of care should reflect this idea. For example an individual whose daily routine
>
> consists of watching The Tonight Show every night at 10:30pm and will not go to
>
> bed unless they watch it, will not be served well by having to take medication that
>
> causes drowsiness at 8pm.

Participant 5 described another situation that was directed towards a person-centered

approach:

> The hospital staff didn't seem to put much effort into informing the individual
>
> what was going on or being done to the individual, which would have gone a long
>
> way towards reducing the individual's anxiety and creating an overall better
>
> hospital experience.

Participant 3 provides a supportive example of being person-centered in a hospital

setting:

> We had a patient who wasn't able to articulate why she didn't want surgery due to
>
> her disability. The medical team became frustrated with her because in their eyes
>
> there wasn't a question as to why she wouldn't want the surgery. She didn't know
>
> what it all meant and needed it to be very simply laid out. It ended up being a
>
> nurse that was able to explain what the surgery entailed before she really
>
> understood it and after understanding it, she eagerly agreed to have it.

Participant 5 suggested how she would "encourage hospital staff to meet the individual

where they are, as difficult as that might be…work with family support system…to

develop a plan that can be most beneficial to the individual in addressing whatever the

health issue might be." Participant 4 suggested, "Hospital staff need to learn to relate to

the individuals with ID to not make them feel 'different.' I feel like you need to work

with the population for a while to get a feel, how to relate and grow comfortable."

The person-centered approach described by the participants requires hospital staff

to adjust their routine and skills to meet the specific needs for patients with ID. At times,

caregivers and social workers may need to draw attention to situations where individuals

are not receiving person-centered care.

Advocating for People with ID

Participants were asked how they advocate for individuals with ID. Among the

responses participants discussed advocacy issues relating to guardianship, caregiving and

patients' rights. Participant 3 provided reasons for advocacy:

> Advocacy is very important! Being able to provide the history of the client's
>
> diagnoses, health, behaviors, likes/dislikes, allergies, etc. is crucial to help the
>
> client receive quality care and to be as comfortable as possible when in an
>
> unfamiliar place or with unfamiliar people. [. . .] Many clients with ID are not
>
> their own guardian and therefore cannot advocate for their needs or provide an
>
> accurate history of their health so it is extremely important to have staff or
>
> guardian present when admitted to provide that history for the client.

The other participants felt similarly and gave examples of how they advocate for people

with ID. Participant 4 said, "I help individuals to try and stay out of the hospital and SNF

[skilled nursing facility] setting. Helping make referrals for services that can help keep

them at home and safe as long last possible." Participant 5 wrote, "Advocacy on behalf of

individuals with DD/ID is important on all levels but I think it is paramount in hospital

settings…" Participant 6 shared thoughts on how to improve the system going forward:

> I advocate that we modify the treatment expectations that we have for the client to
>
> ensure he can meet his identified treatment plan goals….advocate for more
>
> neuropsychological evaluations to help identify what specifically is the
>
> impairment and what modifications are recommended to help this client be
>
> successful."

It was not just the social workers who demonstrated a desire to advocate for people with

ID. Caregivers are also active advocates, and their involvement was a strong sub-theme

within this study.

Caregivers in the Hospital. Participants were asked how caregivers should be

utilized in the hospital. From their responses, the participants revealed that the utilization

of caregivers is necessary to effectively advocate for individual with ID's personal rights in the hospital and to ensure that the individual's voice is heard. Participant 2 believed "[Caregivers should be] treated like the next of kin…should help advocate for the patient…be part of as much of the care plan as the patient would like." Participant 3 agreed:

> [It] should be mandatory for staff to check in with the client's support system [caregivers] to get the background of the client in order to provide quality care and make the client as comfortable as possible . . . I had a behavioral client with ID and I felt the hospital should've contacted team members [caregivers] to find out good ways to interact with the client to diffuse the situation to help make the client comfortable when receiving care.

Participant 4 stressed that caregivers, "know the [individual with ID] best out of everyone. [Caregivers] can answer specific questions about what [the individual] enjoys and what will make them most comfortable."

The experiences of each of these participants emphasizes the importance of caregivers in the decision making process when individuals with ID are hospitalized. Participant 1, 5 and 6 agreed that caregivers are vital when an individual is in the hospital, but they also believe that all of the decisions should still be made or consulted by the patient to the best of his or her ability. Participant 1 said, "[Caregivers should be] respected and supported in whatever the best decision is for the patient." Participant 5 added,

> I think caregivers should be the main contact for best practices for supporting the individual in the hospital. Relying on caregivers or people who the individual

knows or trusts to be present and reinstate some routine is high. Caregivers help

explain the situation to the individual can help provide some stability and

normalcy to the situation.

Participant 6 believes that the involvement of the caregiver varies, "I think caregivers are

vital in a client's care and they should be involved as the client wants in their own

treatment."

Participants perceive that it is critical for social workers and caregivers to

advocate for individuals with ID. However, the next section identifies the barriers that the

participants believe make it difficult for them to effectively advocate for individuals with

ID.

Barriers to Quality Care

Participants were asked to describe barriers that they have witnessed with the ID

population when being in the hospital, and two sub themes emerged: a lack of resources

and an individual's behavior.

Lack of Adequate Resources. Three of the participants believe that there are

limited and inadequate resources available to fully support people with ID. Participant 1

explained:

I work in the ER and many people with MR or cognitive impairment are turned

away from the hospital as they are too low functioning cognitively to be able to

participate in the programming on the inpatient psych unit…. [it is] hard to

advocate for the population when I do not have any placement options for them.

[There are not] enough services for this population, group home or respite

services to place individuals [. . .] I'd love to have access to group home setting or

some type of respite care for this population for placements directly from the ER.

Participant 2 supported these beliefs by saying, "The largest struggle I see them having

are accessing resources [and experiencing] limitations to resources." Participant 4 pointed

out that, "money is a barrier and sometimes there is no housing [available for the

individuals]…a member of mine was admitted into the hospital and then placed in a

skilled nursing facility because he had no other housing options." The lack of resources

inhibits individuals with ID to be placed in the most appropriate setting.

Behaviors. Participants 1 and 3 made comments in regards to situations where

persons with ID's behaviors impacted the quality of care that the individual received in

this hospital and the continued care that was needed after the hospital. Participant 3

observed how difficult providing care can be when hospital staff have a hard time reading

nonverbal behaviors. Participant 1 described a situation that prevented an individual from

receiving the necessary care:

A teenager with moderate-severe MR was violent at home; his parents brought

him in to be hospitalized. He was out of control in the ER and actually bit his

mother, causing a bruise. We tried to admit him but the inpatient psych MD

would not accept him due to his cognitive ability. We had to discharge him back

with his parents who were crying because they didn't have any other options.

Participant 1 sympathized with the situation, "I often understand the bind [the caregivers

are in] and why [their loved ones with ID] can't return home, but it is hard for the

hospital to manage as well."

It is evident in these responses that the participants perceive problematic behaviors as a barrier to individuals with ID's ability to receive proper care and to find appropriate community placements and resources.

Conclusion

Six participants with experience working with individuals with ID filled out a questionnaire to share their perceptions of the quality of care individuals with ID receive when hospitalized. From their responses, the researcher identified five themes. The themes included (a) a lack of understanding, (b) a necessity for medical professionals to have specific education for how to treat people with ID, (c) person-centered care, (d) advocating for people with ID, and (e) barriers to quality hospital care. Eliminating barriers that hinder the hospital experiences and inhibit community placement would improve quality care for individuals with ID. The next section will discuss how these findings compare to the findings of other related studies in the literature.

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Discussion

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Analysis of this study revealed themes that correlate to the studies highlighted in the literature review. However, the researcher found that some of the findings in this study are underrepresented in the current literature, such as the barriers that inhibit quality of care for an individual with ID as well as the need for person-centered care. The study was primarily exploratory, and more research is needed to identify how to support individuals with ID in the hospital. The researcher hopes that this study can inform future research studies and serve as a framework for social worker policies and procedures.

Correlation to Literature

      Lack of Understanding and Education. There are two perceptions that

significantly correlate with previous findings in the literature: healthcare professionals do

not know how to work with patients with ID due to the need for better education and

training on how to effectively work with patients with ID.

      Participant 1 cited times when professionals lacked empathy when caring for

people with ID and how it negatively impacted the individual's perceived quality of care.

Dinsmore's (2011) findings suggested that many of his participants believed that the

hospital staffs' attitudes and communicative habits were paramount in the hospital

experiences for people with ID. If hospital staff learned how to empathize with this

population and how much they can influence the overall experience, they may assume a

more conscientious demeanor when engaging with patients with ID.

      Roscigno's (2013) findings contributed to the perception that professionals lack

an understanding or lack of empathy due to the attitudinal barriers that have been

acquired from society overtime. "Healthcare providers inadvertently detach ("they are not

like me") and focus more on their disciplinary knowledge (i.e., objectivity and evidence

based medicine) and assume a greater expertise of living with an ID" (Roscigno, pg.

34).

      Ward et al. (2010) and Iacano & Davis (2003) found that healthcare professionals

lack sufficient training and exposure to individuals with ID. More specifically,

participants in Iacano and Davis's study felt that hospital staff needed to know more

about how health problems can be manifested in people with various types of disabilities.

This opinion was shared by Participant 1 who suggested specialty training on medications

and different interventions to tailor the needs of people with ID.

     Advocating for people with ID. The perception that there is a need of advocacy

for individuals with ID was a reoccurring theme in the participants' comments throughout

the questionnaire, not just in response to the specific question about advocacy. Most of

the participants agreed that people with ID are vulnerable adults and need persons who

can advocate for their needs. Social workers advocate in the hospital and for placement

options beyond the hospital; however there has not been a significant amount of research

that analyzes how social workers work with individuals with ID in the hospital setting.

Most research and literature on hospital care is primarily focused on physicians and

nurses.

     Caregivers in the hospital. Previous studies have evaluated whether or not

caregivers should be included in the hospital experience for individuals with ID. The

perception of the participants in this study was that caregivers are needed to help with

communication. This perception was supported by the literature that cited caregivers as a

valuable asset to healthcare professionals who provide care to patients with ID

(Dinsmore, 2011; Iacano & Davis, 2003; Levy, 2003; Phillips 2012; Swaine et al., 2013;

Ward et al., 2010). Evidence seems to show that caregivers are essential for eliminating

the gap of communication between the individual and the hospital staff. Without

caregivers, people with ID would have very different experiences while in the hospital.

     Person-Centered Care. The LSW participants commented on the significance of

person-centered care and person-centered training for healthcare professionals.

Participant 5 suggested health professionals could benefit from person-centered training

that emphasizes how every patient is in a different situation regardless of their diagnoses or medical condition.

The perception that individuals with ID deserve person-centered care was not exclusively mentioned in previous studies. The researcher believes that this theme may have been influenced by the amendment of the Minnesota Home and Community-Based Services statute of 2014 that requires case managers to practice with a person-centered approach (Minn. Stat. § 245D.07, 2014).

Other studies did not use the term "person-centered care," although, Iacano & Davis (2003) and Hemsley et al. (2011) described situations that alluded to the use of person-centered care. Examples of the findings are hospital staff adapting routines to better serve a patient going to the bathroom and adjusting their communication style to meet the needs of the individuals.

Barriers to quality care. The participants described situations where patients with ID were unable to receive appropriate care due to extreme behaviors and the limitations of their mental capacity. The perception of the participants in this study was that behaviors limit placement options not only in the hospital but also in permanent placements in the community. One participant spoke of a patient who was denied inpatient psychological treatment due to his extreme behaviors and his level of cognition. Hall et al. (2007) had also found that behavioral and communication difficulties limit access to care. Hall et al.'s findings did not describe specifics of the limitations for individuals with ID. Understanding the barriers that people with ID have in and outside the hospital is important for determining how the medical system can better accommodate for care for these individuals.

Conclusion

   The perceptions of social workers that were identified in this study have

implications for health professionals who work in hospital settings and who encounter

patients with ID. The findings provided insight into what is needed to improve the quality

of care persons with ID receive in the hospital. The study revealed perceptions that health

professionals lack an understanding, education, and training for how to treat individuals

with ID, and that there is a need for person-centered care and advocates who can help

overcome barriers to quality care. The researcher concludes that the findings in this study

will benefit healthcare professionals. If health professionals are provided with more

education on how to treat individuals with ID, they will be able to all patients' equitable

care. By educating healthcare professionals about the caregiver role, they will have a

better understanding of when to take advantage of the caregivers' knowledge and

influence to meet the unique needs of each individual with ID.

Strengths and Limitations

   One strength, of this research study was that social workers perceptions have not

been analyzed regarding the quality of care for people with ID in a hospital. Studies in

the literature significantly address the perceptions of physicians and nurses but not with

social workers. The findings in this study added one more professional perspective to the

literature: social work. Another strength, to this study was the findings identified specific

barriers persons with ID experience in a hospital setting. The researcher was able to

provide more in-depth understanding of the problem and why individuals with ID do not

receive the same quality care as other patients in a hospital setting. This information

could help inform policy makers who are intending to address issues in the healthcare

system.

Before beginning the research, the researcher knew that a small sample size of

social workers would not be sufficient to generalize perceptions in the population as a

whole. The researcher was only able to recruit six participants to fill out the

questionnaire. The researcher obtained a list of 1,000 email addresses belonging to

LICSW in Ramsey County from the Minnesota BOSW. The researcher first emailed 20

participants that had email address associated with a medical system (i.e. HealthPartners,

Fairview, HealthEast. etc.). The researcher did not receive any responses the first week.

The researcher followed up with another email to the same 20 people requesting

their participation and added a time limit for completing the questionnaire. The

researcher received two questionnaires. The researcher proceeded to send another 80

emails to a randomly selected group from the BOSW list. The researcher received

responses from ten people who said they would participate in the study, but when the

researcher sent the questionnaire to the participants the researcher received only one

completed questionnaire. The researcher followed up with an email to the other nine

people but did not receive any response.

The researcher contacted social workers that worked in hospitals to disperse the

flyer advertising the study to their colleagues. The researcher did not receive any

responses from the flyer being dispersed.

The researcher's last effort to recruit participants was sending out another 50

emails randomly selected from the BOSW list. The researcher did not receive any

responses but followed up with another email one week later in one last attempt to

receive more participants. No responses came from the second email.

The researcher attempted to recruit LSW participants through Hammer Residence

Inc. The researcher received one response expressing interest to fill out the questionnaire

after the flyer had been available at Hammer for one week. The researcher contacted the

director and requested that the flyer be distributed again and to encourage employees to

participate. The researcher received two more completed the questionnaires. Recruitment

of participants did not go as well as the researcher had hoped. However, the responses

that were received from participants provided valuable data that enriched the research.

An additional limitation to the research is the researcher has experience working

with individuals with ID and assisting them with their healthcare needs. The experience

of the researcher may have contributed to a bias but with the reliability checks from the

research assistant, the bias did not affect the outcome of the research.

Another limitation was the researcher was not able to interview individuals with

ID due to IRB limitations. Individuals with ID are vulnerable adults and interviewing

them about their experiences would be difficult. Not including people with ID limited the

researcher's findings to the perceptions of quality hospital care.

Implications for Social Work Practice

The care for individuals with ID needs to be addressed on the micro-level but also

on a macro-level. It is important to advocate for changes within the hospital setting.

Social workers should advocate for the needs of patients with ID as well as the hospital

staff to eliminate as many barriers as possible for both the giving and receiving ends of

hospital care for people with ID. Levy (2003) stated in his analysis that medical social

workers are a secondary support system within a hospital's primary medical setting. Levy

(2003) also expressed that "medical social workers relationship with the patient helps

express the psychosocial sensitivity, understanding and the effective clinical adjustment

to the ID, paving the way for mutuality, compliance and participations between increased

quality of care and cooperation between medical professionals" (pg.23). This statement

could also hold true for LSWs who are case managers for people with ID. If LSWs and

medical social workers (LICSWs) collaborated with hospital care, they could improve the

continuity of care with individuals with ID.

Implications for Policy

Research that has been conducted to analyze hospitals experiences of people with

ID has been limited to questionnaires and small groups of participants (Davis, & Iacono,

2003). More research needs to be done to determine which trainings and classes are the

most pertinent for hospital staff to learn about how to work with people with ID. It would

be wise to involve people with ID when developing these educational courses for hospital

staff, for it would provide a better understanding and help participants develop empathy

towards individuals with ID (Phillips, 2012). As more education is offered to hospital

staff, the competency levels will increase, thus providing a better hospital experience for

individuals with ID.

Implications for Future Research

The research assessing quality of care for people with ID has been primarily

focused on physicians and nurses. More research is needed to analyze the interactions of

social workers in the hospital and to evaluate how they impact the quality of care people

with ID receive in the hospital. Research is also needed to analyze case managers and

LSW in order to get a sense of the experience individuals with ID have when

transitioning from hospital to permanent placements.

   Lack of education was a major component to the research. Research should be

conducted to develop an effective training that helps physicians, nurses and social

workers understand intellectual disabilities. Once trainings have been completed an

evaluation should be conducted to ensure trainings are effective.

Conclusion

   People with ID make up 4.5 million people in the U.S., and many of those

individuals experience complex health conditions causing them to go become admitted

into the hospital (The Arc, 2011). This study revealed that healthcare professionals are

not well equipped to properly handle individuals with ID, resulting in poor quality of care

in hospital settings. Many steps need to occur to improve this issue. More research and

education needs to be put in place to address concerns of inequality care experienced by

individuals with ID in hospital settings. Additionally, a focus on providing education

among healthcare providers needs to be evaluated. Social workers who specialize in

working with persons with ID can help train the hospital staff to work with this

population. Social workers' perceptions helped inform this study and can be a valuable

asset to policy makers who are addressing the issues in the U.S. healthcare system.

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APPENDIX A: Flyer

Looking for LSW's and LICSW's!

Who have experience working in a hospital
or
have experiencing working with individuals with intellectual disabilities!

STUDY PURPOSE: to understand social workers perceptions on the quality care received by individuals with intellectual disabilities in a hospital.

Criteria for participation:
LSW
LICSW

Commitment: at most 1 hour of your time

Receive a $10.00 gift card to Caribou Coffee if you fill out the questionnaire.

Please email or call Mallory Clark at XXX@stthomas.edu or XXX-XXX-XXXX if interested in filling out the questionnaire or have questions regarding the study!

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through St. Catherine University at
(651) 690-7739

APPENDIX B: Information Sheet

INFORMATION SHEET FOR THE STUDY

My name is Mallory Clark and I am a masters of social work student under the direction of Professor Catherine Marrs Fuchsel, PhD., LICSW, LCSW in the School of Social Work, St. Catherine University and University of St. Thomas. I am conducting a research study to explore the perceptions of social workers and the quality of care given to individuals with intellectual disabilities. I am interested in learning the perceptions of social workers to understand quality of care and how to make improvements working with intellectually disabled individuals. I hope that what I learn from this study will help social workers and service providers understand the hospital experiences so healthcare professionals will know how to better support individuals with ID and their families. I would like for social workers with their LSW or LICSW who have experience either working in a hospital or have experience supporting individuals with ID will take the time to fill out the questionnaire.

If you agree to participate, I will ask you to read the information letter and the informed consent before completion of the questionnaire, to allow time for you to ask any questions you may have, and if you agree to take part in the interview. Once you have completed the questionnaire you will send the questionnaire via email or placing the questionnaire in the self-addressed envelope and sending the questionnaire to the researcher. This study is voluntary and you may choose to stop participating at any time. You may also choose not to answer any question.

The questions in the questionnaire pertain to your experiences in working with individuals with ID. I will ask you to tell me how you define quality of life and how those impacts on the advocacy you do on behalf working with your clients/ individuals with ID. I will ask you about barriers you see within a hospital for people with ID and identify what you would change in the hospital for people with ID

One incentive to you for participating in this study is you will receive a $10 gift card for your time and commitment. This study may help other people understand the quality of care for individuals with ID in the hospital setting. The information from this study will be published in my thesis and may be published in social science journals. Your name will not be used to identify you and information will be recorded anonymously.

The questionnaires will not be kept in a locked cabinet at my place of residence as well as on my computer that requires a passcode to access. Only Dr. Catherine Marrs Fuchsel and I will have access to the confidential information.

The data will be kept until May 31, 2015 and all reports and notes will be shredded or deleted from the computer. The emails will be permanently deleted after the questionnaires have been coded.
Contact information:
Mallory Clark
Cell phone: XXX-XXX-XXX E-mail: XXX@stthomas.edu

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through St. Catherine University at (651) 690-7739

APPENDIX C: Letter of Cooperation

Letter of Cooperation for Research Project

Institutional Review Board
St. Catherine University
St. Paul Campus
2004 Randolph Avenue
St. Paul, MN. 55105
RE: Social workers perceptions on quality hospital care for individuals with intellectual disabilities

Lead Investigator: Mallory Clark, BSW, LSW
                     MSW Student
                     St. Catherine University and the University of St. Thomas
                     School of Social Work; Joint Program
               Chair: Catherine L. Marrs Fuschel, PhD, LICSW, LCSW
                     St. Catherine University Fotbonne Hall 204a
                     phone: 651-690-6140
                     fax: 651-690-8821
                     email: clmarrsfuschel@stkate.edu
To whom it may concern:

        We have agreed to assist Mallory Clark in recruiting participants for her research project. Mallory Clark's research project will be a qualitative research project about the perceptions of social workers related to the quality of care received in a hospital for people with intellectual disabilities. We will allow Mallory Clark to send an email to the case mangers that have an LSW to recruit potential participants. We will allow Mallory Clark the opportunity to ask questions that pertain to the perceptions of the quality of care people with intellectual disabilities receive in the hospital.

        Mallory Clark will make it clear to potential participants that their responses will be coded to identify the common themes of social workers. These questions will be emailed to Mallory Clark; and no person will have access to these emails except for Mallory Clark and her research assistant and they will be immediately destroyed after completion of the research project.

         Mallory Clark will make it clear to potential participants that they are free to refuse to participate in Mallory Clark's research project and that there will be no identifying information presented in the study. Upon completion of this research project, Mallory will share the findings of this research project with Hammer Residences Inc. The information reported, will be shared in aggregate form only without individual identifiers. If you have any questions, please feel free to contact me at:

_____

Sincerely,

_____   _____

Signature and Title   Date

APPENDIX D: Informed Consent Form

**Social Workers Perceptions on Quality Hospital Care for Individuals
with Intellectual Disabilities**

INFORMATION AND CONSENT FORM

Introduction:
You are invited to participate in a research study investigating the perceptions of social workers
on the quality of care received by individuals with intellectual disabilities in a hospital setting.
This study is being conducted by Mallory Clark, a graduate student at St. Catherine University
under the supervision of Dr. Catherine Marrs Fuchsel PhD. LICSW, LCSW, and a faculty
member in the Department of School of social work.   You were selected as a possible participant
in this research because you are an LSW or an LICSW who has experience working either in a
hospital or has worked with individuals with intellectual disabilities. Please read this form and
ask questions before you agree to be in the study.

Background Information:
The purpose of this study is to evaluate the perceptions social workers have regarding the quality
care people with intellectual disabilities receive in the hospital. Approximately 15-20 people are
expected to participate in this research.

Procedures:
If you decide to participate, you will be asked to thoughtfully complete the questionnaire
regarding questions related to your perceptions on the quality of care people with intellectual
disabilities receive in the hospital. The questionnaire will be emailed or mailed to you. Once you
receive the questionnaire you will have 2 weeks to fill out the questionnaire and send back to me.
This questionnaire will take approximately 30-60 minutes to complete. I will ask you to read
the information letter and the informed consent before completion of the questionnaire, to
allow time for you to ask any questions you may have, and if you agree to take part in the
interview. Once you have completed the questionnaire you will send the questionnaire
via email or placing the questionnaire in the self-addressed envelope and sending the
questionnaire to the researcher. This study is voluntary and you may choose to stop
participating at any time. You may also choose not to answer any question.

Risks and Benefits of being in the study:
The study involves no risks.
There are no direct benefits to you for participating in this research.

Compensation:
If you participate, you will receive a $10 gift card to Caribou. In order to receive the gift card the
participant will provide the researcher with a mailing address at the end of the questionnaire.
Once the questionnaire is received the researchers will send the participant the gift card.

Confidentiality:
Any information obtained in connection with this research study that can be identified with you
will be disclosed only with your permission; your results will be kept confidential. In any written
reports or publications, no one will be identified or identifiable and only group data will be
presented.

I will keep the research results in a locked file cabinet at my place of residence and on my computer that requires a pass code and only my advisor and I will have access to the records while I work on this project. I will finish analyzing the data by May 31, 2015. I will then destroy all original reports and identifying information that can be linked back to you.

Voluntary nature of the study:
Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with Hammer Residences Inc. or St. Catherine University in any way. If you decide to participate, you are free to stop at any time without affecting these relationships.

Contacts and questions:
If you have any questions, please feel free to contact me, Mallory Clark at XXX-XXX-XXXX. You may ask questions now, or if you have any additional questions later, the faculty advisor, Dr. Catherine Marrs Fuchsel, PhD., LICSW, LCSW at XXX-XXX-XXXX, will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or jsschmitt@stkate.edu.

You may keep a copy of this form for your records.

Statement of Consent:
You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study.
_____

I consent to participate in the study.

_____
Signature of Participant   Date

_____
Signature of Parent, Legal Guardian, or Witness   Date
(If applicable, otherwise delete this line)

_____
Signature of Researcher   Date

APPENDIX E: Research Assistant Confidentiality Agreement

**Social Workers Perceptions on Quality Hospital Care for Individuals
With Intellectual Disabilities**

I am conducting a study about the perceptions social workers have about the quality care people with intellectual disabilities receive in a hospital.

This study is being conducted by: Mallory Clark under the advisement of my chair, Dr. Catherine L. Marrs Fuchsel Ph.D., LICSW, LCSW, St. Catherine University and University of St. Thomas.

Confidentiality:

Confidential information includes all data, materials, products, technology, computer programs and electronic versions of files saved to portable storage devices. Questionnaires will be filled out by participants and either mailed or emailed to the researcher. The completed questionnaires will be hand delivered to you by the researcher to assist with coding. No personally identifying information will be attached to the questionnaire. Any notes or electronic files produced by you will not include information that will make it possible to personally identify participants in any way. All questionnaires are to be kept in a locked file or on the researchers locked computer. No one else will have access to the records. No one else will have access to the computer on which the questionnaires are saved. All coded questionnaires along with your notes will be returned in their entirety to the researcher. Once coding has been completed and all notes and questionnaires compiled, you will contact the researcher who will then personally pick them up. You will receive a payment of $10 gift card to Caribou coffee for coding assistance.

Contacts and Questions

My name is Mallory Clark. If you have questions, you may contact me at XXX-XXX-XXXX or my research chair, Dr. Catherine L. Marrs Fuchsel, PHD. LICSW, LSW at XXX-XXX-XXXX.

You may also contact the St. Catherine's University Institutional Review Board at 651-690-7739 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Agreement of Confidentiality:

I, _____, have read the above information and agree to confidentiality as stipulated above. I further agree not to disclose, publish or otherwise reveal any of the confidential information received from the researcher or interview participants.

Appendix F: Questionnaire

1. What is your social work licensure? LSW or LICSW

2. How many years have you worked with people with intellectual disabilities or worked in a hospital setting?

3. In your work experience describe what barriers you have witnessed with people with intellectual disabilities when they are admitted into the hospital.

4. Based on your definition of quality of how does that impact the advocacy you do on behalf of working with individuals with ID in the hospital?

5. When working with other health care professionals to coordinate care for people with intellectual disabilities what serves as the biggest barrier?

6. If you could change one thing in the hospital setting to benefit people with ID, what would you change?

7. Describe an experience where you felt your client/patient could have received better quality care.

8. The literature has stated that physicians and nurses go through very little training on working with people with intellectual disabilities. Which type of training do you feel physicians and nurses most likely need?

9. Caregivers are a key support system for people with ID. How do you feel they should be utilized within a hospital?

If you would like to receive a $10 gift card to Caribou Coffee please write your name and address below