Discussion #1 (ARTICLE ATTACHED IS PROMOTING HEALTHY AGING OF INDIVIDUALS WITH DEVELOPMENTALDISABILITIES. For this discussion, refer to the qualitative *case study* or *ethnography* research study you found in the Capella library. Use the Article Analysis Worksheet to prepare for this discussion. Briefly summarize the article (1–2 paragraphs). Discuss the following aspects of the study:

- How large was the sample and what were their characteristics?
- How was the data collected?
- How was the data analyzed?
- What were the results and how can they be utilized?
- How does this qualitative study differ from a quantitative study?

Discussion #2.(ARTICLE ATTACHED INCREASING AND DECREASING FACTORS OF HOPE IN INFERTILE WOMEN WITH FAILURE IN INFERTILITY TREATMENT: For this discussion, refer to the qualitative *phenomenology* or *grounded theory* research study you found in the Capella library. Use the Article Analysis Worksheet to prepare for this discussion. Briefly summarize the article (1–2 paragraphs). Discuss the following aspects of the study:

- How large was the sample and what were their characteristics?
- How was the data collected?
- How was the data analyzed?
- What were the results and how can they be utilized?
- How does this qualitative study differ from a quantitative study?

DISCUSSION #1

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Promoting Healthy Aging of Individuals With Developmental Disabilities: A Qualitative Case Study

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Abstract

This qualitative case study sought to examine an innovative community outreach nursing program designed to promote healthy aging for more than 250 individuals with intellectual or developmental disabilities living in the community. We analyzed 10 in-depth interviews, one focus group, and various documents using thematic analysis. We researched why the program emerged and found the reasons to be improving the communication with primary care providers, providing person-centered health care, and building on and contributing to existing community-based programs. Findings on what the daily work of community outreach nurses with individuals with intellectual or developmental disabilities entailed, included person-centered health education, advocacy for the safe return home, support for staff to understand that health issues can lead to behavior changes, and enabling social participation. This case study may inspire further research or help others develop similar programs.

Keywords

intellectual and developmental disabilities, health promotion, community nursing, person-centered health care

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The American Association on Intellectual and Developmental Disabilities defines an intellectual disability (ID) as "a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18" (Schalock et al., 2010, p. 3). While the life expectancy of individuals with intellectual and developmental disabilities (I/DD) is still lower than that of the general population, it has risen rapidly in recent decades (Coppus, 2013). Janicki, Dalton, Henderson, and Davidson (1999) arrived at an average age of death of 66.1 years, compared with 19 years in the 1930s. With the exception of individuals with severe I/DD and Down's syndrome (DS), the life expectancy of individuals with I/DD is approaching that of the general population (Coppus, 2013). For persons with DS, the mean age at death was 56 years in the 1990s (Bittles & Glasson, 2004). Despite their increased life expectancy, individuals with I/DD suffer from poorer health (Cooper, Melville, & Morrison, 2004; Krahn, Hammond, & Turner, 2006). They are particularly vulnerable to certain health issues, including epilepsy, mobility issues, sensory problems, and Alzheimer's disease (van Schrojenstein Lantman-de Valk & Walsh, 2008). Currently, the vast majority of adults with I/DD live in the community rather than in institutions. Whereas in 1970 approximately 170,000 individuals with ID lived in institutions in the United States, only about 35,000 lived in such institutions in 2010 (Larson, Ryan, Salmi, Smith, & Wuorio, 2012). The literature has widely acknowledged the importance of community outreach programs, but the role of nurses in community outreach seems to be almost invisible in the current body of research. Therefore, this qualitative case study aimed to describe and analyze one innovative community nursing outreach program developed in response to the recognized health problems and unmet needs of people with I/DD living in the community.

Health and Living Situation of Individuals With I/DD

The deinstitutionalization movement brought with it several challenges (Beadle-Brown, Mansell, & Kozma, 2007). Generally, it is difficult for people with I/DD in the United States to find primary care providers because of limited provider training, social stigma, and insurance issues (Benassi, 2011; Lennox & Diggens, 1999; Marks, Sisirak, & Hsieh, 2008). Health professionals feel unprepared when faced with caring for a person with ID/DD (Phillips, Morrison, & Davis, 2004; Sowney & Barr, 2006), perhaps due to the minimal curricular content offered in nursing and medical schools (Lennox & Diggens, 1999; Nehring, 2003). The health needs of individuals with I/DD are often not recognized or met because primary care providers

may overlook their health problems, including mental issues. Diagnostic overshadowing can lead to attributing symptoms to a person's ID rather than seeking treatable causes; such dismissal may have potentially negative consequences (Mason & Scior, 2004).

While approximately 72% of the estimated 4.9 million individuals with I/DD in the United States live with a family member, many also use other residential services, such as supported living (Braddock et al., 2011). Assisted by residential agencies, "supported living" is a common option to help these individuals live in the community (Braddock et al., 2011). Unfortunately, such support staff members often lack general training regarding health issues, particularly aging and age-related illnesses (Beadle-Brown & Forrester-Jones, 2003). Support staff may interpret symptoms of significant illness as "just getting older," failing to recognize signs of serious health problems that can result in behavior changes; in turn, these undiagnosed illnesses can lead to early institutionalization for individuals with I/DD (Bowers, Webber, & Bigby, 2014).

Role of Nurses in the Community

Until the late 1950s, nurses primarily cared for people with I/DD in institutional settings (Nehring, 2003). Following the deinstitutionalization movement, nurses today serve as consultants or play administrative and supervisory roles, either in group homes or in supported living environments (Nehring, 2003). While nurses have always held important roles in community and public health care, the literature has overlooked community nurses in the United States when it comes to caring for people with I/DD (Nehring, 2003). The scant research related to this topic focuses on the role of nurses in specific health promotion initiatives for people with I/DD (Cooper et al., 2006; Marks, Sisirak, & Chang, 2013), prevention services offered by advanced practice nurses (Hahn & Aronow, 2005), and guideline development for the implementation of community-based health promotion for individuals with I/DD (Drum et al., 2009). However, we still lack knowledge about the daily work of community nurses aiming to promote the healthy aging of individuals with I/DD living in the community.

Purpose

This qualitative case study sought to describe and analyze one innovative community nursing outreach program that emerged in 2009 in response to the observed health disparities and unmet health needs of people with I/DD. Two research questions guided the case study:

Research Question 1: Why did this community outreach nursing program (CONP) for people with I/DD emerge?
Research Question 2: What is the daily work of the community outreach nurses in this program with the goal of promoting healthy aging of individuals with I/DD in the community?

Method

Design

For this research, we used a single instrumental case study design (Stake, 2005). Appropriate for our research, the qualitative instrumental case study design allowed us to focus on a single program while permitting the detailed collection of information about individuals in this particular context. The purpose of an instrumental case study was to analyze the effects of a person or program on others (Stake, 2005).

In our case, we sought to gather comprehensive data about the rationale for the program's development as well as the daily work of nurses working for this CONP. We also sought information regarding how this program supports and improves the situations of individuals with ID. Ultimately, this case study aims to provide a detailed analysis and description of a particular program to inspire further research and to help others develop a similar program (Stake, 2005).

Case Description and Case Selection

Located in a Midwestern county in the United States, this CONP is an innovative program within a University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) in Wisconsin. UCEDDs, embedded in universities in every U.S. state and territory, provide services for individuals with disabilities, their families, and their support team. These centers, which provide training, offer information, and conduct research, focus on sustaining all citizens in their communities. The specific services that they provide vary. This CONP is one program within such a center in Wisconsin. Developed in 2009, this CONP is responsible for one county in Wisconsin and serves around 250 individuals with I/DD. Individuals with I/DD receiving support from this program range in age from 18 to 70 years. The community outreach nurses have the objective of maintaining the health and wellness of individuals with I/DD living in the community. To reach this goal, the nurses offer health assessments, health planning services, health interventions, and health evaluations. More

specifically, the community outreach nurses provide support in behavior, mental illness, medication, and diabetes management. We selected this particular case for this study because it represents one of the few nursing programs that offers care in the community while following the social model, rather than the medical model, of disability. Whereas the medical model of disability is primarily concerned with an individual's physical and/or psychological limitations, the social model of disability focuses on how the immediate environment of a person with I/DD can be organized in a way that reduces existing barriers (Palmer & Harley, 2012).

This CONP accepts referrals for individuals with I/DD who are registered with a county-based program for supported living from residential support agencies, case managers, and families. Individuals with I/DD who are registered with the county-based program can also contact the CONP themselves.

Data Collection

We conducted this study in three steps: First, we interviewed all three nurses currently working for this CONP. During these interviews, in-depth descriptions of their daily work emerged. In the second step, we conducted a focus group with the same three nurses to confirm and discuss the preliminary themes identified in the analysis of individual nurse interviews. This focus group session aimed to ascertain whether our preliminary findings correctly reflected how the community outreach nurses viewed their work. During the session, we also asked the nurses to nominate other people for interviews who were involved in establishing the CONP or who collaborated with it. In the third step, we interviewed seven people nominated as initiators of or who were collaborators with the program. The purpose of these interviews was to understand the rationale behind developing this CONP, particularly in terms of the needs underlying its formation. We adapted the interview questions to each specific group. Table 1 provides examples of interview questions for each group. Altogether, we conducted 10 interviews and one focus group (see Table 2). In addition to these data, we analyzed prior health care guidelines and the CONP funding proposal.

We obtained consent before conducting each interview. Each one-on-one interview occurred in a private room and was audio recorded with the participant's permission. The recordings were transcribed verbatim. The participating Institutional Review Board approved the study. We determined the data collection process to be complete after interviewing all nurses who worked for the program, and all individuals nominated as important resources for this CONP. Table 2 provides an overview of the education, position, and role of the interview partners.

Table 1. Examples of Interview Questions.

Specific Group	Interview Question
Community outreach nurses	Can you tell me what a workday looks like?
Focus group with nurses from the community outreach program	Based on our interview, I identified four areas of work. [Introduce the areas.] Do you think something is missing? If so, what is it?
Experts recommended by the community outreach nurses	Please tell me about the history of this program.

Data Analysis

Data analysis followed Braun's and Clarke's (2006) phases of the thematic analysis approach. After familiarization with the data (Phase 1), we generated initial codes (Phase 2) by summarizing the texts on a more abstract level; we then identified potential themes (Phase 3) by sorting the initial codes to determine if they fit under any overarching theme. We next began the process of reviewing and finalizing our data. In this phase, the researchers checked whether the text excerpts aligned with the final themes (Phase 4). The last phase consisted of describing the themes (Phase 5; Braun & Clarke, 2006; see Table 3). Following these phases, we also analyzed the funding proposal of the CONP and the health guidelines. To reduce the likelihood of misinterpretation, we triangulated data from different sources (Stake, 2005), such as the interviews with the community outreach nurses, with the initiators of the program, and with collaborators, and we included the documents. Involved in several phases of thematic analysis, the research group consisted of a team of five nurse researchers and a medical doctor, each with different fields of clinical expertise. Only the first and second author had expertise in providing care for people with I/DD, but all members of the research team were well versed in conducting qualitative research. These diverse backgrounds helped the research team reflect on the data; they also allowed the first and second author to reflect on their own experiences and involvement in the preliminary themes in terms of their interpretations of the transcript excerpts. When the first author arrived at the final themes, the group discussed those themes, including all of the transcript excerpts on which they were based. The research group checked and questioned whether the excerpts fit under the overarching themes. If the team disagreed on a suggested theme, we began the analytical process of building themes from Phase 3 (searching for potential themes).

Table 2. Education, Position, and Role of the Interview Partners.

Interview Partner	Education	Role in or Relationship With the CONP
1	RN, BSN	CONP nurse
2	RN, BSN	CONP nurse
3	RN	CONP nurse
4	RN	Clinical nurse, worked on the guidelines
5	MS	Initiator of the program
6	MS	Initiator of the program
7	MA	Collaborates with the program
8	RN, BSN	Collaborates with the program
9	RN, BSN, CPN	Nurse consultant
10	NP	Nurse, collaborates with the program

Note. CONP = community outreach nursing program.

Results

Research Question 1: Why Did the Program Emerge?

In 2000, the county's Department of Human Services initiated a working group to develop guidelines for maintaining the health of individuals with I/DD in the community. The group consisted of nurses who had worked with people with I/DD in varying capacities in training centers, I/DD associations, and residential agencies. These guidelines represented the starting point of a collaboration between the Department of Human Services and a key group of nurses experienced in working with people with I/DD in the community. This cooperation eventually led to the establishment of the CONP in 2009. Based on the thematic analysis of the interviews, the original guidelines, and the proposal for the establishment of this CONP, we identified three main themes guiding initial development: (a) improving communication with primary care providers, (b) providing person-centered health care, and (c) building on and contributing to existing community-based programs for people with I/DD.

Theme 1: Improving communication with primary care providers. Effective communication between patients and primary care providers is essential for adequate health care. However, county officials and health professionals who had worked with people with I/DD realized that communication tended to be problematic between people with I/DD and both their support teams and primary care providers. On one hand, individuals with I/DD were not always able to communicate their health problems in easily understandable ways. On

Table 3. Example for the Development of the "Person-Centered Health Education" Theme.

Process	Examples
Familiarizing (Phase 1)	"I have pictures—color pictures—of what can happen to your eyes. Really, it's very simple like diabetes can affect your eyes and then a picture of what normal vision looks like. And then a picture of what you would see if your eyes are affected by diabetes—and then a picture of a wound on the foot. So diabetes can affect your feet. I mean, very simple and that's the kind of thing."
Initial coding (Phase 2)	Pictures of body parts
	Visualization
	Effects of disease
	Personalized messages ("*your* eyes")
Potential themes (Phase 3)	Creating awareness
	Person-centered education
	Prevention
Final theme (Phase 4)	Providing person-centered health education
Theme description (Phase 5)	See "Providing person-centered health education" in the "Results" section

the other hand, primary care providers often did not understand or seriously consider what the person with I/DD was saying. People with I/DD and their support team members often found physicians difficult to understand because of their use of medical language. According to the community outreach nurses, this lack of understanding from both sides often led to diagnostic failures and untreated conditions. An initiator of the program explained this lack of understanding as follows:

> [Primary care providers] think the old people with developmental disabilities; they don't really feel pain, a lot of that old-fashioned thinking. So it was difficult sometimes to even get doctors to take things seriously, and also that because of a person's disability, they may present in a way that it's hard to understand what's going on with the person. And if you are not familiar, you may not able to recognize that.

According to a clinical nurse who collaborated with the community outreach nurses, another issue emerged as people with I/DD sometimes displayed behaviors that primary care providers failed to recognize as expressions of a health problem. The interviewee said,

> Often [members of the medical community] don't understand and just say, "Well, bring that person back when they'll behave." Well, [people with I/DD] might not be behaving because there's something internally happening that causes problems.

The Department of Human Services and the working group of nurses realized that health care professionals, especially nurses with experience working with people with I/DD, could facilitate more effective communication between people with I/DD and their support teams and primary care providers. In turn, better communication would translate into better professional health care while allowing people with I/DD to continue living in the community.

Theme 2: Providing person-centered health care. The county's Department of Human Services contracts with the residential agencies that provide services for individuals with I/DD. Some agencies provide nursing services, whereas others do not. However, in 2007 an evaluation of services offered by these agencies illustrated a mismatch between the department's community-living philosophy and the agency nurses' actual work. One initiator of the program explained this as follows:

> [We] realized that the nurses at the agencies were doing a lot of treatment things that could be done by clinics or other nurses; that really wasn't what we wanted to be buying. What we wanted to buy was that advocacy, that in between the technical work with teams [support teams for people with I/DD in the community] and the guardians.

In this sense, the emergence of this CONP was a response to agency nursing services following a rather medical model. The medical model of disability views people as needing extra help and services due to their disabilities instead of focusing on how to include individuals in the services provided to the general population. The medical model of disability has been dominant in the institutional care of people with I/DD (Shakespeare, 2006). Committed to the community-living philosophy of people with I/DD, the department wanted to avoid this medical model of disability. One person who was involved in getting the program off the ground explained the department's thoughts on this model as follows:

> And, of course, those of us that are not doing medical model kind of community-based stuff are saying, "No, no, no, no, no." None of us has a personal nurse. We use our doctor's nurse. We want people with developmental disabilities to do the same thing. They have a triage line at their clinic. They need to use it.

Making professional health care accessible for people with I/DD who live in the community without creating specialized health services represents a major challenge. The CONP was created to address people's health care needs in a person-centered model rather than a clinic-oriented one.

Theme 3: Building on and contributing to existing community-based programs. In this particular county, the CONP did not emerge in isolation, rather, it was based on previously existing community-based programs for people with I/DD. Three programs had been operating since 1986 to support individuals with I/DD living in the community. The first program began in 1986 to address the psychological, emotional, and behavioral challenges for people with I/DD and their caregivers. This program works with behavioral consultants who go into community settings with a support team to address behaviors in people with I/DD that caregivers find challenging, thus helping them avoid institutionalization. Established 15 years later, the second program sought to promote environmental safety with sensor-technology monitoring. The third and most recent program is the CONP. All three programs share the goal of enabling people with I/DD to stay in the community for as long as possible, avoiding institutionalization. The department was clear that it wanted this CONP to be another component in this community-living model for people with I/DD (see Figure 1), stating explicitly in the CONP funding proposal that the program "should not be a 'clinic' model, but rather a community-engaged model, where supports are provided wherever is deemed appropriate by the individual support team."

In 2009, the CONP was established, meeting a high demand from inception. As one initiator pointed out, "We hired three nurses and they immediately were needed; they have a large caseload and a large waiting list."

Research Question 2: What Is the Daily Work of Community Outreach Nurses in This Program?

The second research question considered the daily work of a community outreach nurse. Through data analysis, we developed four themes related to the daily work of a community outreach nurse: person-centered health education, advocacy for the safe return home of individuals with I/DD, the necessity of helping individuals with I/DD understand that health issues lead to behavior changes, and the importance of enabling social participation.

Theme 1: Person-centered health education. Much of the community outreach nurses' work involves educating individuals with I/DD about health issues of

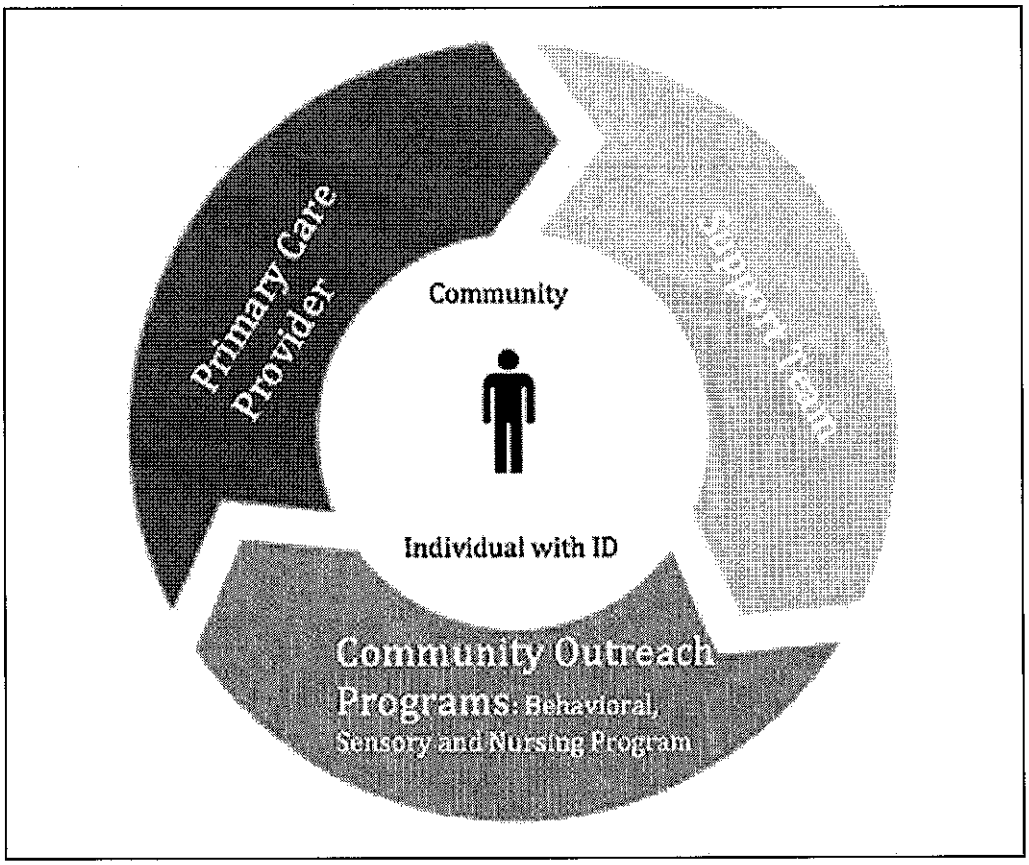

Figure 1. Illustration of the theme: Building on and contributing to existing community-based programs.
Source. Author.

particular relevance to them. Nurses described the goal of person-centered health education as having individuals with I/DD gain more knowledge about their health condition to communicate their needs, problems, and symptoms; thus empowering them to reach out for health services when necessary. In their interviews, nurses described the major health issues for individuals with I/DD, including constipation and diabetes management. Publicly available information about health issues such as diabetes is often not provided in an easily understandable form accessible to people with I/DD. Therefore, the nurses create their own informational material using plain language and pictures to make the information more easily comprehensible. The nurses also regularly offer training units for support staff, including management of diabetes, pain, constipation, and skin. Often, these training units are also offered for home managers and for individuals with I/DD in a more personalized fashion. The community outreach nurses aim to help everyone understand the

material and to prevent health problems such as making better eating choices. One CONP nurse reflected on this work as follows:

> I got pictures—color pictures—of what can happen to your eyes. Really, it's very simple, like diabetes can affect your eyes and then a picture of what normal vision looks like. And then a picture of what you would see if your eyes are affected by diabetes—and then a picture of a wound on the foot. So diabetes can affect your feet. I mean, very simple and that's the kind of thing.

Theme 2: Advocating for the safe return home of individuals with I/DD. When individuals go to the hospital and receive a community nurse visit, the nurses often seek to ensure that hospital staff members recognize where the person with I/DD lives and will return. The community outreach nurses often address misunderstandings and misjudgments regarding the living situations of individuals with I/DD. Staff members in the hospital often think that individuals return to an environment where nursing care is provided, such as skilled nursing facilities. Staff members in the hospital do not communicate with the support staff because they regard the support staff as less educated, or they believe that they cannot speak to them because of confidentiality issues. However, the community outreach nurses believe that support staff should be involved in decision making because they spend the most time with the individual with I/DD, and they often know how to communicate with the person with I/DD. In these kinds of situations, the outreach nurses often act as a bridge between hospital staff and support staff. As a registered nurse, an outreach reflected on being regarded as more qualified than support staff and others in the eyes of many hospital staff members: "They [hospital staff will] listen to me, and it's only because I have an RN after my name. And this direct care staff might have worked with this person for a long time."

Another reason for advocating for individuals with I/DD in the hospital is that decisions about their discharges are often made too early. The community outreach nurses take on the responsibility of advocating for a longer stay in the hospital for individuals with I/DD or for additional support staff in their homes before they return. This advocacy work is apparent in a comment made by a CONP nurse:

> Hospital staff often assumes that these patients are going home to some kind of medical care. They think there is a nurse there or there is a CNA there. So, we [community program nurses] have to be really clear with hospital staff. Nope, there's no medical staff at home, so you can't send them home with a catheter.

Theme 3: Helping to understand that health issues lead to behavior changes. Individuals with I/DD feel pain like anyone else, but sometimes they have

difficulties expressing how they feel (Scheepers et al., 2005). They might not say that they are in pain and instead exhibit behavioral or mood changes that suggest something is awry (Krahn et al., 2006). This subtlety of expression can lead to unrecognized and undiagnosed health conditions, and can even be life-threatening for individuals with I/DD. People with I/DD rely heavily on their support staff and other people around them to read their moods and behaviors, ask appropriate questions, and take action. However, many support staff members lack the knowledge and training needed to work effectively with individuals with I/DD who are aging and have certain health needs. The community outreach nurses frequently talk to support staff to help make them aware of the connection between behaviors and illness symptoms that may be difficult to identify. They teach support staff to read these subtle symptoms, to ask appropriate questions, and to determine whether the person should see a primary care provider. In an interview, a CONP nurse described how she worked with the support team for an individual with I/DD to help them understand possible health and medical issues behind this person's behavior and mood changes: "She doesn't have language, she's fairly low functioning; there was a lot of dysregulation of behavior, a lot of problems; then we found out that she was extremely constipated, which could not have been anything but painful."

Theme 4: Enabling social participation. Living in the community does not necessarily mean that individuals with I/DD have a high quality of life and good health, or are able to participate fully in their community. The community outreach nurses frequently described helping individuals and their teams participate in social activities outside of their homes and sometimes outside of their communities. Such activities are important because they provide memorable experiences and high points in social existence that enhance the quality of life. Feeling included in society and participating in community activities improve well-being (Abbott & Mcconkey, 2006; Simplican, Leader, Kosciulek, & Leahy, 2015). Below, a community outreach nurse talks about how a support person called her for advice on going to a football game with an individual, "Ben," with I/DD. The support person told the nurse that Ben had developed two bedsores. Ben really wanted to see the football game, but his support staff was concerned that sitting in the wheelchair for many hours during transport and the game would worsen these ulcers. One CONP nurse explained how this issue was addressed, so that Ben could go to the game: "When [Ben] gets [to the football game], get him off. Tilt him right away 10 to 15 minutes and then every two hours while he's at the game." Without this advice from the community outreach nurses, the support staff might not have even considered taking Ben to the game.

Discussion

This study's findings indicate that the program emerged to improve communication between individuals with I/DD and primary care providers, to provide person-centered health care, and to supplement preexisting community-based programs for people with I/DD. The role of nurses and their promotion of healthy aging for individuals with I/DD has included providing person-centered health education, advocating for the safe return home of individuals with I/DD, helping support staff understand that certain health issues lead to behavior changes, and enabling social participation for individuals with I/DD. National reports from many countries have acknowledged the need to address the health problems of individuals with I/DD on a community level (Department of Health, 2001; Office of the Surgeon General, 2002; Ouellette-Kuntz et al., 2005; Scottish Government, 2002). For example, in 2002, the U.S. Surgeon General published "Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation," which focused on health care delivery in the community, particularly how to "integrate health care services for individuals into diverse community programs" (p. 3). Krahn et al. (2006) noted the "cascade of disparities" and summarized recommendations from different national reports for future health care actions for people with I/DD. These recommendations include recognizing and improving self-determination, reducing associated health problems, empowering family members and caregivers to address the relevant health needs, and promoting healthy behaviors for individuals with I/DD.

Researchers in the field have also recognized the urgent need for community-based programs. Marks et al. (2013) commented that health promotion programs in community-based organizations represent the first steps in addressing the health disparities faced by individuals with I/DD. For example, based on their review of intervention studies on community-based physical activity and exercise programs, Heller, McCubbin, Drum, and Peterson (2011) concluded that community-based programs can effectively promote the health of individuals with I/DD. Various intervention studies have shown that nurses can play a crucial role in promoting the health of individuals with I/DD. For example, Cooper et al. (2006) did a health screening intervention with a team of nurses that included a comprehensive health assessment. Hahn and Aronow (2005) used a comprehensive geriatric assessment completed at the homes of individuals with I/DD by an advanced practice nurse and found a reduction in their health risks.

While the importance of community programs has been widely acknowledged, analysis of existing community outreach programs and the role of nurses in these programs has been largely absent, especially in the United States. One

reason for the lack of research and analysis is that the United States does not offer specialty training in disability for nurses, which would allow them to become registered nurses in disabilities. In the United Kingdom, students can become registered learning disability nurses; in Scotland, there are registered ID nurses. While nurses in the United States can become certified I/DD nurses, commissioned by the Developmental Disabilities Nurses Association (DDNA), general training and education in I/DD remains minimal in both nursing and medicine (Benassi, 2011; Lennox & Diggens, 1999; Nehring, 2003).

In this article, we attempted to address the need to systematically describe and conceptualize the functions and contributions of nurses in the community and to make visible the work of community outreach nurses and their impact on individuals with I/DD. Community nursing programs help avoid institutionalization while empowering individuals with I/DD through advocacy and health improvements. Through this evaluation, we hope to inspire further study as well as the implementation of similar CONPs promoting healthy aging of individuals with I/DD.

Authors' Note

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health (NIH).

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DISCUSSION #2

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Increasing and decreasing factors of hope in infertile women with failure in infertility treatment: A phenomenology study

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Abstract

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Abstract

Background: Assisted reproductive technology (ART) provide the hope of pregnancy for infertile women, but do not always turn this hope into reality.

Objective: The purpose of this study was to explore the lived experience of infertile women from increasing and decreasing factors of hope in infertile women with failure in infertility treatment.

Materials and Methods: Using a qualitative research design (Phenomenology study), 23 subjects were selected who had experienced infertility failure visited by gynecologist (Rasekh Infertility center) in 2012. The data were collected through semi structured interviews and analyzed using interpretive research strategies of phenomenology by Collizi's seven-stage method.

Results: Totally 96 codes were identified. The data arranged in two categories. The factors decreasing and increasing hope in infertility treatments. Totally 5 themes and 20 sub themes were extracted. The increasing factors which emerged from the data contain "spiritual source", "family interaction and support" and "information through the media", and decreasing factors contain "nature of treatments" and "negatively oriented mind".

Key words: Assisted reproductive technology, Infertility, Hope, Qualitative research, Phenomenology.

Introduction

Infertility is one of the important disorders and diseases in the human community. Fertility is highly valued in most cultures (1). Infertility is defined as lack of fertility after one year of intercourse without using any kind of contraceptives (2). Statistically, 25% of the women undergo some kinds of infertility in their lives. In most participants, frequency of treated and untreated infertility is 13-19% in which untreated portion possesses 2.4-5.9% (3). Studies carried out in Iran also revealed that the prevalence of infertility in rural and urban areas was 5.3% and 6.8% respectively (4). For many women the effect of infertility and notably of medical therapy is a considerable emotional stress (5). Also it was shown that, infertile women undergo more tension, anxiety, depression, self-reproach, and suicide temptations (6).

Losing hope to bear a child which is symbolically significant for the women carries a lot of sorrow which is intensified seeing mothers with their children (7). Hope is one of the vital psychological needs. In other words, hope makes self-confidence, internal positive feeling toward a particular thing or event. Materializing a purpose is impossible without hope and conversely, it makes people believe that darkest scenario would not happen to them (8). Hope predicts physical and mental health as determined by various indicators such as self-reporting health, positive response to medical interventions, mental health, positive mood, effective coping, reassessment, problem solving, avoiding stressful event, seeking support, and health promoting behavior (9).

Applying Schneider theory regarding hope, it has been discussed even in the death process and the final stages of diseases. According to this strategy, maintaining and even increasing hope in medical interventions for dying patients is considerably beneficial (10). This strategy is seeking to assist workers to formulate their purposes and make several passes to reach them, stimulate themselves to follow the purposes and reframe up hindrances as challenges to overcome and hope as a sort of treatment (11).

Some others know it to have a significant role in people's attitudes toward their lives (8). Compared to false hope (pessimism), hope (real hope) is associated with positive health, and decreasing hope has poor results (12). Hope in infertility treatment is one of the most important factors in In vitro fertilization (IVF) achievement (13). In other word positivists, in comparison to pessimists, are less likely to suffer from poor physical health or depression and disappointment or committing suicide (14). During and after long and sometimes unsuccessful treatments impulsive behavior, anger, depression, helplessness, worthlessness, inadequacy, anxiety and negative beliefs may occur (15).

Fertility attempts require tedious and expensive medical procedures thus, doubt and despair during treatment could threaten a couple (7). In study by Brendes et al the major reasons of discontinuation of treatment by IVF have been mental and affective problems (22.3%), weak prognosis of treatment (fear and hope to success in treatments (18.8%) and failure in infertility treatment (17.2%) (16). In a systematic review carried out by Gameiro et al the reasons of treatment discontinuation consisted of: prolong process of treatments (39.18%), unknown (19.17%), physical and mental factors (19.07%), conflict with others (16.67%), personal reasons (9.27%), communication problems (8.83%), refusal of treatment (13.23%), organizational (11.68%) and health care service (7.71%) (17).

As mentioned before, hope creates motivation and enthusiasm in individuals to reach their goals and overcome their difficulties. Studies which encompass all aspects and dimensions of the challenges associated with the infertility treatments are few in Iran. Most of information is received from sources and media, and this is the expert view of points. There are few studies that can cover this topic and investigate them thoroughly (18).

Also there is a qualitative study that examines the experience of infertility as a problem however, infertility treatments are not considered in any research (19-20). Due to the importance of hope as a unique experience in this type of treatment, this study is designed to investigate perceptions and experiences of infertile women with a history of failure in treatment procedure. Recognizing increasing and decreasing factors of hope in infertile women, particularly from live experiences and the viewpoints of people who deal with them can lead to present appropriate strategies in infertility treatment because they play an important role in designing treatment programs in infertile couples.

Materials and methods

This study was a qualitative study with a phenomenological approach (Husserl Ian descriptive phenomenology) carried out on infertile women attended to Rasekh Infertility Clinic in Jahrom in 2012 (21). Phenomenology study was used in this study. "Phenomenology study is the natural affinities to access the person's live experience "a phenomenological study is one that focused on descriptions of what people experience and how it is that they experience what they experience" (22). Purposeful sampling was conducted on a group of women who failed in assisted-infertile treatments.

Data collection

Inclusion criteria in this study were included: being native Persian, infertility diagnosed by gynecologist, referring to infertility clinic in Jahrom in 2012 with a history of at least one failure in treatment procedure, no record of chronic diseases, as well as physical and psychiatric diseases. Participants had primary infertility and were willing to participate in the interview. Sampling began purposefully by semi-structured interview. The interview lasted about 35 min for each participant ranging from 30-45 min. The questions were made by applying the statement about "when talking about infertility treatments, what is associated in your mind? What is promising for you in these infertility treatments? What factors decreases hope in you in these treatments? Further clarification regarding construction of the final questions expanded through the use of a pilot study. All available tapes would be copied and kept for further use according to data protection. In this study the researcher would applied pilot methods including confidence making in speaking, evaluating the room appropriateness, checking all equipment's such as audio recording and so on.

Data analysis

All of conversations were recorded, if not, they were rewritten word by word. The main question of this study was hope increasing and decreasing factors in individuals receiving assisted-fertile treatments. The seven-steps Colaizzi's method of data analysis was used in this study. Colaizzi's seven-step-method was employed to present a profound description of the structure of the women experience Colaizzi (1978). Colaizzi's method has some advantages (23). This method includes:

· Reading and rereading descriptions

· Refer to the narratives frequently and extract significant statements.

· Formulating meanings (to illuminate meaning hidden in various context of the phenomena)

· Categorizing into clusters of themes and validating.

· Describing

· Returning

Incorporating any changes based on the informants' (22).

Methodological rigor

Criteria for judging the rigor of such research include "credibility", "transferability", "dependability", and "conformability" which are determined in resent research (24). To provide credible research, we adhered to guideline of being professional with integrity, intellectual rigor and a methodological capability (25). Transferability refers to whether findings of a study can be applied to in different context (26). We provided a rich description of experiences of participating in ART and related factor to change hope in following treatment program .Dependent ability considers whether findings of a study would be similar if the study was to be replicated (25).

All the interviews transcript personality and to ensure that they did not contain mistakes, also we included contributions from peer debriefing (three experts in qualitative research) during the data analysis. Conformability suggests data, interpretation and findings of the research are not the creation of the research and that the data as well as the interpretations can be related to its source (27-28). After code reviewing and reaching agreement they were used. Recording all stages of the study makes it possible to transfer to the researchers. Ethical considerations in this study were content of the participants, granting permission to record interviews, respect to preservation of confidentiality and anonymity.

During interview an attempt was made to provide privacy and convenience of the participants, and participants' personal information was kept confidential, and they were assured that sound file would be removed after use. All of the participants were satisfied with the project and there was no coercion to participate in research. Proposal extracted from this paper confirmed by ethical committee in Jahrom University of Medical Sciences.

Results

Of all 96 codes were identified. 23 participants were selected. Participants' age mean was reported (28±2.6) years old. Most of participants with 66.7% had women infertility reasons and the rest had men reasons. The mean treatment duration was (7±1.6) maximally. Totally 2 had middle school education, twelve high school diploma, 5 associated degrees, and 4 had bachelor's degrees. Eleven had undergone at least once IUI and 5 IVF treatments and others used medicine therapy to solve their infertility problems.

All 96 extracted codes of data were investigated in two groups of hope decreasing and increasing factors which were led to categorization of themes into three increasing and two decreasing factors. The first main identified theme contains increasing factors (spiritual resources, family interaction and support and media) and the second main identified theme contains decreasing factors (nature of treatments & negatively oriented mind). Increasing factors was allocated to spiritual resources which were revealed such as:

Saying prayer to God

Prayers are demonstrated in the experiences of these people in various dimensions so that coming close to God can facilitate life hidden good intentions and provide motivation to follow the treatments. Another person who failed IUI says: "I resort to God then doctors. Saying prayers escalates hope in me, more than doctor's words. A motive is created suddenly, but prayer in really effective." Some believe that visiting holy shrines and even seeing them keep hope alive so that a person who had 3 unsuccessful IVF treatments finds donation and charity as a key to increase hope and believes: "I try to do some good works and by doing so, I feel others' prayers give me self-satisfaction."

Shrines

Shrines are situations used by people as a spiritual resource and increasing feel of hope in people. A person who failed IVF treatment says: "Some days ago it accidentally happened to me to visit Imam Reza shrine and I told myself Imam Reza would fulfill my wish since he has invited me".

Family prays

According to sayings, family prayer is rich spiritual source that gives people hope and a good sense of the aspirations." I have a grandmother who always prays for me and says: I just pray for you to bear a child. Sincere pray of family keeps hope alive that eventually the work". The second theme contain family interaction and support is the support and sympathy of others which is really effective in creating hope, attachment, and motive in treatment from the viewpoints of infertile women, and allocates subthemes such as couples' interaction ,and sympathy.

Couples' interaction

Positive interaction between couples is a source of hope in many women. Woman who failed treatment and her husband is addicted says: "my husband is the source of hope for me, he is addicted. The love between us gives me hope. Although he is addicted, he loves me and it gives me hope." Another woman who has experienced IVF cycle says: "My husband keeps telling me don't worry; you can bear a nice girl."

Sympathy

In most participants, family role is emphasized and individuals stress the role of their families particularly mothers and husbands and their promising roles. A woman who has failed IUI cycle states: "I do IUI again, it gives me hope, my mother is so influential in my life since she gives me hope, thus, I visit my mother frequently, but I must be the source of hope to my husband and sympathizes him because he has the problem."

Media

Informing properly and suitably through media has a great impact on promising to treat infertility and raise knowledge to keep on treatment. A woman with 14-year history of treatment and several failures states: "when I am so distress and depressed hearing some words on T.V or reading a book gives me hope. The information is really effective; for example, it says there is no infertility anymore, all are cured, etc." Investigating hope decreasing factors, two main themes were observed; one nature of treatments, and the other one negatively oriented mind. These include other subthemes which are pointed out:

Negatively oriented mind

Degradation of wishes and desires

Most people with infertility problem have negative perspectives, considering all their wills and wishes are lost. Some find negative imaginations and thoughts in frustration so that one of these people says: "I just make myself frustrate by grieving and telling myself that I cannot bear a child. I mean my thoughts make me frustrate, puzzle, and get enough of world. Sometimes I wish I was not born to suffer such pains."

Rough road

Hardness and toughness in the course of treatment hinder the continuity of treatment. Suffer and roughness as nightmares suppresses and devastates wishes and desires. The effects of these issues are observed in everyday life and performing daily routines so that one expresses that: "as soon as I understood I am infertile, I have less motivation, think more, think about the result of my work, and do not like to do my chores, and I pay attention to my husband less, I found that I have a hard and rugged road ahead,..."

Life troubles and difficulties

A woman with the history of failure says; "I'm absolutely frustrated right now, however, I'm still going on. It's a hard life, an uncertain future ...."

Fear and hope

People who have failed in the treatment of infertility in the range of feelings hopes and fears are gone. It feels a mutual sense of excitement that always threatens their lives." We live in constant fear, we live in hopes and fears that mean trembling of treatment failure"

Nature of treatments

Nature of treatment is considered another cause of frustration, and treatment continuity theme in a lot of expressed experiences and themes such as Difficult and painful treatments, Lack of facilities and Expensive treatments have also been named. Treatment effects on physical injuries resulting from it have been observed in the experiences of a lot of people so that the toughness of these treatments and failure in treatment procedure make the people frustrate. Low rate of treatment success, high cost, numerous treatments are also nature of infertility treatments that in many participants it is implicitly referenced.

Difficult and painful treatments

One who has a record of failure in IUI treatment mentions: "I don't visit doctor if IUI doesn't work this time. Some months ago I took color photo of my uterus and learned that my oviduct is closed; I took a lot of troubles. I pain overnight, I cannot sleep because of ..."

Lack of facilities

Lack of medical facilities has also been mentioned by some others. "Experienced doctors are few in this field; there aren't expiries in small city. I was told to visit a doctor, but it didn't work...."

Expensive treatments

Mostly treatment is one of the challenging issues. High cost of medicine on one hand, and failure in treatment procedure on the other hand, decrease the hope in individuals. While crying, another woman states: "I took IUI three times and IVF twice, my husband is a worker, we were told I cannot bear a child, we sold everything for treatment cost, etc."

Discussion

Aim of this study was live experiences of people from increasing and decreasing factors of hope in infertility treatments. The results of this study revealed that there are three effective factors to increase hope in infertile women as spiritual resources, media, and family sympathy and supports. Hope for infertility treatment is mentioned as one of the effective factors in IVF success (13). This is more important than being pessimist may be negatively affect infertility treatments outcomes (29). Similar to our study, a study conducted by Dafei et al demonstrated that 89.4% of the infertile women resort to prayer also remarkable number of them do obligatory or recommended acts and charitable works. Evidence has demonstrated that psychological factors are really important sign and better predictor of biological answers to the treatment than any individual predictors (30). Considering infertility, people who were more decisive in performing religious obligatory acts applied more active coping (28).

Some studies verify our results considering the effect of increasing hope factors from infertility treatment. The results of present study also revealed that relative supports and close relationship with them are led to increasing hope and motivation to keep on the treatment. Individuals can fight stressors by positive understandings from social supports and high hope which is led to mental health and this psychological well-being is a reaction to facilitation and following the future direction (29). Based on our study, the

interaction of family and spouse is effective factor in hope, however, the study of Vassard et al demonstrated that social relations were effective in making decision to terminate the fertility (31).

On one hand, communication difficulties with their partner for men and frequent challenge with their partner for women on the other hand reduced fertility treatment (32). In the identified themes in the present study, media had a remarkable role in promoting hope through informing individuals. It also has been pointed that consultation to infertile women should include both negative and positive aspects, assessment of response to treatment and assisting recognizing the future. It seems that Su has concentrated more on consultation (13). Our study showed that three factors decrease hope in treatment process. These factors contained "Degradation of wishes and desires, rough road, and life troubles and difficulties". In the line with our results, Peddie et al reported that women encountered difficulty to accept the fact that their infertility would not be solved (32).

The success of the treatment at the beginning of infertility treatments were under the pressure of the media and the society. These findings are identical to two subthemes of our study about the treatment of the infertility effects on the complexities of life and their affliction from the treatments Behbahani et al demonstrated that women underwent different negative emotional feelings such as loneliness, feeling guilty, depression, and isolation through infertility treatments (33). Another study carried out on the couples who experienced infertility treatment which showed underwent feeling of insufficiency, disappointment, and frustration (34). These results are agreed with our results, are evoke the difficulties of living in infertile couples' life. Fear and hope are factors in decreasing hope in these women.

In agreement with this result, Imeson and Mc murray showed that couples who underwent ART experienced emotional feeling as an alternative feeling of hope and disappointment inside powerlessness, hope-disappointment cycle and social isolation through life (35). Domar et al pointed out that the most typical cause of interruption of treatment is stress (39%) and the basic cause of this stress is the fear of treatment failure. These results agree with our results about decreasing hope in ART (36).

In the present study negatively oriented mind is a factor that decreases hope in patients with ART. In line with the obtained results, Miles, clarified that 42% of the participants underwent high level of general distress through cognitive appraisal (37). Other studies reported that more that 20% of women demonstrate some types of subclinical anxiety or depression six month after the unsuccessful treatment at the follow up. Determinant factors on the course of emotional factors include personality features, definition of fertility complexes, and social supports (38).

Lack of facilities, in the present study, was one of the most important factors that decreases hope in couples undergoing ART. Agree with our study, it was shown that the notion should be elaborated to two more aspects to obtain true high quality ART: timeliness, and patient-centered (39). Regarding patients' viewpoints over fertility care in a qualitative study, it was demonstrated that fertile patients required medical skills, veneration, coordination, getting acquired about the problem and the treatment, easiness, support, engagement of the partner in the process with positive viewpoint, appropriate relationship with the clinic staff, and ease of access to service (40). According to patients, others believe that insufficient patient-centered was a weak point in fertility care (41).

Other factors decreasing hope in current study were lack of facilities, difficult and painful treatments, and expensive treatments. In the line with our study, another study capitalized on the mental barriers including financial problems, physical problems, participants' age, insufficient experience of the health stuff, and treatment cost (1). Overall, infertile patients with infertility treatments need for medical skills, respect, coordination, accessibility, information, comfort, support, partner involvement and a good attitude of and relationship with fertility clinic staff (42). Research limitations were entering to privacy of patients with failure in infertility treatments, need to self-disclosure and express negative feelings. However all of the participants attended to participate in the study and there was no compulsion to participate in the interviews. What is particularly important is recognizing the factors which can provide increase or decrease of individuals' hope from infertility treatments. This important issue may be help to Policymakers with a comprehensive plan on making optimal use of all the medical facilities for users.

Conclusion

Applying supportive interventions for the relatives of infertile couples make them change their attitudes toward infertile issue and also sustain their positive relationship with the infertile couples. In this condition, it is expected that their encouragements make the couples keep on the treatment procedure. On the other hand, the role of consultant should not be neglected since the appropriate and systematic consultation helps them to be hopeful and people who are never able to bear a child are led in a direction to accept the current situation to be protected from devastating psychological effects of this problem.

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Conflict of interest

None.

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Discussion #1. For this discussion, refer to the qualitative *case study* or *ethnography* research study you found in the Capella library. Use the Article Analysis Worksheet to prepare for this discussion. Briefly summarize the article (1–2 paragraphs). Discuss the following aspects of the study:

- How large was the sample and what were their characteristics?
- How was the data collected?
- How was the data analyzed?
- What were the results and how can they be utilized?
- How does this qualitative study differ from a quantitative study?

Discussion #2. For this discussion, refer to the qualitative *phenomenology* or *grounded theory* research study you found in the Capella library. Use the Article Analysis Worksheet to prepare for this discussion. Briefly summarize the article (1–2 paragraphs). Discuss the following aspects of the study:

- How large was the sample and what were their characteristics?
- How was the data collected?
- How was the data analyzed?
- What were the results and how can they be utilized?
- How does this qualitative study differ from a quantitative study?

Use this worksheet to better understand the articles you review.

APA reference of article or source: Author last name, initials of first and middle names (if provided), (year of publication). *Source, (volume)*, issue, pages.

_____
_____
_____

The research problem is . . . [Determine the main problem identified in the introduction that sparked the research effort.]

_____
_____
_____

The previous research that has been done on this topic has found . . . [Identify the previous research the author uses to support his/her problem in the literature review.]

_____
_____
_____

The research question is . . . [Identify the main research question that has stemmed from the research problem and review of the literature.]

_____
_____
_____

The hypothesis (hypotheses) for this study is (are) . . . [Identify the hypotheses the researcher tests in the study (quantitative studies only).]

_____
_____
_____

How many participants were in the study? _____

How were the participants chosen or recruited?

_____
_____
_____

Were the participants separated into groups?

__ Yes.

__No.

How did the researcher collect data from the participants?

__ Interviews (qualitative).

__ Open-ended questionnaires (qualitative).

__ Behavioral observations (qualitative and quantitative).

__ Surveys (quantitative).

__ Archival data from records (educational, medical, census, et cetera) (quantitative).

__ Paper-and-pencil tests or measures (quantitative).

__ Physical tests or measures (quantitative).

__ Others (describe):

_____

_____

_____

How did the researcher prepare the data to be analyzed? (Check all that apply)

__ Coding of participants' words, either oral or written (qualitative).

__ Providing a rich description of observed behaviors (qualitative).

__ Tabulating and summarizing behaviors observed (quantitative).

__ Summing points assigned to each response, either behavioral or on a measure (quantitative).

__ Calculating scores on a measure (quantitative).

__ Calculating and entering test responses (quantitative).

__Other:

_____

_____

_____

How did the researcher analyze the data?

__ Performed thematic analysis of coded phrases and words (qualitative).

__ Searched for meaning in common responses (qualitative).

__ Determined meaning of observed behaviors (qualitative).

__Used statistical or mathematical analyses to compare or relate scores or measures (quantitative).

__Other:

_____
_____
_____

The results of the study were . . . [How was the research question answered? Were the hypotheses supported?]

_____
_____
_____

Implications of this research are . . . [What do the results mean in the real world to real people?]

_____
_____
_____

Future research should be focused on . . . [What did the researcher suggest as the next step for research in this field?]

_____
_____
_____