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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 included person-centered health education, advocacy for the safe return home of individuals with intellectual or developmental disabilities, support for staff to understand that health issues can lead to behavior changes of individuals with intellectual or developmental disabilities, and enabling their 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

The American Association on Intellectual and Developmental Disabilities defines an intellectual disability 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 to 19 years in the 1930s. With the exception of individuals with severe I/DD and Down Syndrome (DS), the life expectancy of individuals with I/DD is

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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 & Diggins, 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 & Diggins, 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 intellectual disability 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: (a) why did this community outreach nursing program (CONP) for people with I/DD emerge, and (b) 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?

Methods

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 is 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 about how this program supports and improves the situations of individuals with intellectual disabilities. 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 US 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 18–70 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.

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). 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).

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 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 be able to recognize that.

According to a clinical nurse who collaborated with the community outreach nurses, another issue emerged because 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 technical 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 to 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 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 like 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 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 of 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 improves 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 pre-existing 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 (Office of the Surgeon General, 2002;

Ouellette-Kuntz et al., 2005; Department of Health, 2001; 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 APN 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 UK, students can become registered learning disability nurses; in Scotland, there are registered intellectual disability nurses. While nurses in the United States can become certified intellectual and developmental disability (IDD) 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 & Diggins, 1999; Nehring, 2003).

In this paper, 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 to 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.

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Figure 1.

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

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.

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

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 (“ <i>your eyes</i> ”)
Potential themes (phase 3)	Creating awareness Person-centered education Prevention
Final theme (phase 4)	Providing person-centered health education
Theme description (phase 5)	See below in the results section under: Providing person-centered health education