

Picture of Me: Life-Story Work Made Accessible

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Abstract

Aim: The goal of this project was to determine if a dementia-focused quality improvement (QI) project entitled Picture of Me (POM) could increase direct care providers' (DCPs) knowledge about individual residents and if this increase in knowledge would also improve their perceptions of personhood of the long-term care (LTC) resident with dementia.

Background: A key aspect in the delivery of quality dementia care is the person-centered care approach which is an approach that involves recognizing the person with dementia as a unique individual with a distinctive life story. Direct care providers report barriers to providing this care that include the inability to secure needed information, lack of mechanisms for communicating information, and lack of the time available to do either. Systems need to be created that support communication processes to facilitate the exchange of person-centered information to direct care providers and staff. The Picture of Me (POM) quality improvement (QI) project is designed as a cost-effective, concise, and accessible way to collect and display life story information about LTC residents with dementia.

Method: A convenience sample of 22 direct care providers who worked in the memory care unit of a long-term care facility in rural North Carolina were recruited to participate in this mixed-methods project conducted over a three-month period. The primary outcome measure was an increase in DCPs' knowledge about individual resident's life story. The secondary outcome measures were an improvement in perceptions of personhood in the care of LTC residents with dementia and an increase in staff satisfaction with caring for these residents.

Results: One hundred percent of the participants completed the all surveys, and the Picture of Me project increased DCPs' knowledge as well as changed perceptions and opinions of personhood in the care of LTC residents with dementia.

Conclusion: Picture of Me boards improved DCPs' knowledge of residents with dementia and their life story as well as improved DCPs perceptions of the residents by provoking thoughtful conversation, increasing convenience of information availability, facilitating the use of relevant calming techniques, and changing situational perspective in regard to everyday care practices.

Keywords: long-term care facility; life-story work; person-centered care; dementia; direct care providers

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Dementia is a syndrome, meaning it is a group of symptoms that have a number of different causes (Fazio et al., 2018). These symptoms include difficulties with problem solving, memory, language, and other cognitive skills affecting a person's ability to perform everyday activities (Alzheimer's Association [AA], 2017). Research is now proving the care of patients experiencing dementia must address the medical and the social aspects of their care. The unique personal stories of patients experiencing dementia are an important component of patient-centered care (O'Connor & McFadden, 2010). This view is centered on the idea of personhood, "a standing or status bestowed upon one human being by others, in the context of relationship and social being" (Kitwood, 1997).

There is an estimated 5.7 million Americans living with dementia (AA, 2018). By age 80, 75% of people with dementia are admitted to a nursing home (Arrighi et al., 2010). When a person is admitted to a nursing home or long-term care facility, the majority of their care is provided by direct care providers (DCPs). Direct care providers are the "hands-on" workers in long-term care and are identified specifically in this project as nurses, nursing assistants, and medication technicians (Gilster et al., 2018). The AA (2017) states the "single most important determinant of quality dementia care across all care settings is direct care staff." These caregivers play a vital role in the provision of long-term care (Graf et al., 2016), and the care they provide dramatically shapes the daily lives of persons with dementia (Squires et al., 2015).

A key aspect in the delivery of quality dementia care is the person-centered care (PCC) approach (AA, 2018). This approach involves recognizing the person with dementia as a unique individual with a distinctive life story (Gronhdal et al., 2017). Knowing life story information about a resident with dementia assists the DCP to view them as a whole person, not simply a task or a person with a chronic disease (Gronhdal et al., 2017). Obtaining and using this information involves working with a person and their family to find out about their life, recording that information in some way, and then using the information to improve the care they receive (McKeown et al., 2006). Studies have shown that DCPs want life story information in order to provide PCC (Gronhdal et al., 2017). However, staff report barriers

that include the inability to secure needed information, lack of mechanisms for communicating information, and lack of the time available to do either (Kolanowski et al., 2015).

Systems need to be created that support communication processes to facilitate the exchange of person-centered information to DCPs and staff (Gilster et al., 2018). The Picture of Me (POM) quality improvement (QI) project is designed as a cost-effective, concise, and accessible way to collect and display life story information about long-term care (LTC) residents with dementia (Fick et al., 2013). The utilization of POM boards can be used to overcome barriers to person centered care by providing concise ways to display life story information that is easily accessible in the busy care setting (Spazzapan et al., 2020). This is why the Picture of Me QI project, designed to make life story information more accessible and available for DCPs in LTC, is needed.

Purpose

This QI project targeted DCPs caring for residents with severe dementia in three units in a LTC facility in rural North Carolina. The aim is to demonstrate improvement in the knowledge level and perceptions of personhood among DCPs caring for LTC residents with dementia after implementation and utilization of POM boards in clinical practice.

Literature Review

A systematic review of the literature was performed to identify studies evaluating different interventions used to increase accessibility and utilization of life story information in LTC settings. This review focused specifically on studies that explored the effects these interventions had on direct care providers (Bakken et al., 2009; Buron, 2010; Cooney & O'Shea, 2019; Egan et al., 2007; Eritz et al., 2016; Ervin et al., 2013; Kellett et al., 2010; McKeown et al., 2010, 2015; Subramaniam et al., 2014). Each of the selected studies implemented a life-story intervention that addressed a person-centered care model and was based on prior research in the field. Although the studies differed in aims and methodologies, they all had at least one outcome measure that focused on the effects of life-story interventions on direct care providers (Doran et al., 2019). The differences in study designs, data collection methods, validation of tools, and analysis techniques resulted in varying overall outcomes.

Many of these studies were also included in Gridley et al.'s (2016) review, which concluded more robust research is required in this field.

The choice was made to focus on life story work in regard to its effects on direct care providers because, with respect to person-centered care models, literature on life-story interventions primarily focuses on the person being cared for instead of the person doing the caring (Barbosa et al., 2015). Despite their key role in caring for the person with dementia, the impact of life story work on staff is rarely evaluated (Subramaniam & Woods, 2012). Although most of the studies evaluated the impact of life story work on direct care staff as a secondary outcome, very few looked at this group as the primary focus of the study.

Outcome measures related specifically to DCPs were found to be perceptions of person-centered care and personhood (Buron, 2010; Eritz et al., 2016), empathy for the individual with dementia (Eritz et al., 2016), attitudes towards these individuals (Subramaniam et al., 2014), changes in the relationship with the individual and their family (Ervin et al., 2013; Kellett et al., 2010), knowledge and understanding of their life-story information (Buron, 2010; Subramaniam et al., 2014; Cooney & O'Shea, 2019), changes in the care they provide (Egan et al., 2007), and experiences they have of implementing LSW into clinical practice (Bakken et al., 2009). When assessing the components of these outcome measures, there seemed to be agreement that implementing life story work into the care of dementia residents can be an overall enjoyable experience for staff with the potential to lessen the gap between the conceptual and practical applications of person-centered care in clinical practice (Mckeown et al., 2010).

The studies referenced here resulted in many incongruent results (Kellett et al., 2010). For example, Kellett et al. (2010) reported life story work empowered staff to provide relationship-centered care as opposed to talk-oriented care. In contrast, Buron (2010) found that the introduction of life story work did increase staff's knowledge but did not significantly affect their perceptions of person-centered care. This incongruency could be a result of the different methods of collecting and analyzing data. Buron (2010) suggested perceptions of providing individualized care are consistent with the prevailing social value of the importance of patient centered care of residents with dementia; therefore, DCPs tend to rate

themselves favorably in perception areas during data collection. Doran (2019) suggests the lack of consistent, significant outcomes is due to the range of terminology used in the primary studies differing greatly, resulting in a lack of clarity about what life story work means in practice.

Another gap in the research was found to be the implications life story work has on persons with more severe levels of dementia (Eritz et al., 2016; Erin et al., 2013; Subramaniam et al., 2014). There were three studies acknowledging the fact that some persons with dementia are frequently unable to tell their stories or explicitly express their needs and preferences (Eritz et al., 2016; Erin et al., 2013; Subramaniam et al., 2014). Even so, a key area of uncertainty in this field relates to whether a life story work can be created for a person with dementia without the person's engagement in the life review process (Subramaniam et al., 2014). Subramaniam et al. (2014) hypothesized having access to residents' life storybooks would improve staff knowledge and also be associated with improved attitudes toward people with dementia, reflecting person-centered care, even if the person with dementia was not directly involved in the process. Ervin et al. (2013) posited that many times staff must rely on family members to provide information on persons with severe cognitive impairment due to dementia.

Gridley et al., (2016) proposes four models of life story work, with each model having distinguishing approaches to care of patients with dementia, including the narrative approach, the biographical approach, the care-focused approach, and the hybrid approach. The care-focused approach formats may vary, but this approach places emphasis on the 'product' or the outcome of life story work (Gridley et al., 2016). Persons with severe dementia that can no longer tell their own story still need their story told; thus, interventions that relate life stories are likely of the greatest benefit to those residents who suffer from severe cognitive impairments (Eritz et al., 2016).

In summary, all of the studies included in this review acknowledged the potential of life story work to increase the quality of care for persons with dementia. However, these studies did not agree on the most efficient, valuable, and sustainable way to implement these interventions into practice.

One reason for this disagreement was the differing ideas of purpose, focus, and process in each study which led to varying outcomes that are difficult to compare to one another. Very little emphasis was

placed on life story work for the person with severe cognitive impairment due to the severity of the disease process. More research is needed in respect to life story work as a care-focused intervention between staff and family members for the benefit of persons with dementia who can no longer tell their stories.

Methods

The principal investigator (PI) for this project developed a care-focused QI project called Picture of Me (POM). This project focused on the use of life story work for persons with severe dementia, and the effects access to life story information about residents had on DCPs. The project included the collection of life story information and creation of Picture of Me boards for residents with severe dementia, education on life story work and its usefulness in the clinical setting for DCPs, and dissemination of life stories for individual residents who were suffering from severe dementia. Key components include collaboration with DCPs and stakeholders and interdisciplinary consultation to brainstorm sustainability options. The primary outcome of the Picture of Me project was an increase in DCPs' knowledge about the life stories of individual residents. The secondary outcome was the improvement in DCP perceptions of personhood in the care of LTC residents with dementia. Process measures included a chart review to determine the residents' level of dementia severity and the collection of pertinent demographic information about DCP participants.

This was a three-month mixed-methods QI project that implemented the Picture of Me project in the context of a doctorally-prepared nurse practitioner student designed and managed project. The project setting was a long-term care unit in a continuing care retirement community in rural North Carolina.

Participants

A convenience sample of 22 direct care providers (DCPs) consisting of certified nursing assistants (CNAs), license practical nurses (LPNs), associate degree nurses (ADNs), and baccalaureate degree nurses (BSN) participated in the project. Eligibility required that DCPs had been employees of the facility for the duration of the project and that they work one of the three long-term memory care units at least once a week during project implementation. Inclusion criteria for the project were English-speaking

DCPs, and prior experience working on one of the three long-term memory care units. Exclusion criteria included no experience working on these units. Participating direct care provider demographic information was obtained before project implementation. Surveys were given to determine gender, ethnicity, age, years of experience working in long-term care, job title, and shift worked.

A convenience sample of seven residents was also a part of the project design but, once recruited, residents were considered passive participants since they functioned as a source of information for the Picture of Me boards. Residents were chosen with the help of facility administrators and staff and met the criteria if they had a diagnosis of severe dementia and a family member or proxy available who had known the resident more than 25% of the resident's life.

Measures

Demographic Data

The PI collected demographic information on the DCPs participating in the project (age, gender, ethnicity, years of experience in long-term care, job title, and shift that the participant primarily worked). This information was used to describe the DCP sample.

Clinical dementia rating (CDR) scale

The CDR was used to assess the severity of the person's dementia. The CDR scale is a clinician-rated dementia staging system that tracks the progression of cognitive and functional deterioration, from 0 (healthy) through 0.5 (questionable dementia), 1 (mild dementia), 2 (moderate dementia) to 3 (severe dementia) (Subramaniam et al., 2014). The CDR has been reported to have good concurrent validity with other measures, good test-retest reliability, and inter-rater reliability ($r = 0.89$) (Hughes et al., 1982). For this project, the CDR was rated after consulting the clinical records and feedback from staff and providers. Residents were chosen to be the participating subjects of POM boards if they had a CDR score of 3 (severe dementia).

Knowledge of persons with dementia assessment

Data on DCP's knowledge about the life story of each participating resident was collected using PI-developed pre-test and post-test self-administered assessments. The assessment was comprised of ten

questions asking DCPs to record life details regarding the participating patient such as his/her hobbies, favorite type of music, important family members' names, education, occupation, etc. Each item was scored as 'correct' (where the answer given was consistent with the information provided by the participant's relative), 'incorrect' (for an answer that was inconsistent with the information provided by the participant's relatives), or 'don't-know' (where no answer was given). Higher numbers of 'correct' and lower numbers of 'incorrect' or 'don't-know' answers indicated better knowledge of the resident's life story, with a range from 0% correct-100% correct.

Qualitative Data Collection: Perceptions of Personhood, Viewpoints, and Observations

A qualitative descriptive approach was used to explore DCPs' perceptions of personhood. This emergent design was chosen because of its ability to capture the realities and viewpoints of project participants, giving a more in-depth view of the phenomenon (Polit & Beck, 2017). Anonymous surveys created by the PI were used to collect data at the beginning of project implementation and after completion. The initial survey questions were created by the PI to explore DCP's perceptions of caring for residents with dementia. The second and final survey questions evolved after primary survey responses were analyzed and as themes emerged throughout the project.

Process Measures

Process measures included chart review to determine residents' level of dementia severity and pertinent demographic information collection about DCP participants.

Procedures

The PI was assisted by the administrative stakeholder from the long-term care facility and other support staff such as activities department employees, facility nurses, and certified nursing assistants. Collaboration between direct care providers, other members of the health care team (speech pathologist, activity directors, nurse practitioners, management), and family members were encouraged throughout the development and implementation of the QI project by understanding each individual's motivations, establishing open conversations to discuss process improvement, and respecting the culture of the facility as well as each employee and resident involved.

After reviewing the template created by the PI, the facility administrators collected information from the selected family members regarding the resident and their life story. Some specific items elicited from the outline included important family members' names, pets, education, occupation, hobbies, and nicknames. Family members were also encouraged to bring in pictures to be duplicated for the life story boards and then returned to family. With the help of support staff, all of the information was compiled into a decorative board format to hang in the resident's room, as well as a paper format that could be placed in the resident's chart.

While each Picture of Me board was being created, the PI began to recruit the direct care staff to take part in an anonymous pre-implementation survey to assess their perceptions of personhood and their viewpoints on caring for persons with dementia. During this stage of development, the PI also administered a knowledge survey to all participating direct care providers to assess their baseline knowledge about the residents. After initial surveys were complete, the PI conducted a brief "get to know me" session, providing DCPs the life story information collected from family members.

The boards were then shown to a family member for approval and placed in a conspicuous, direct view position in the residents' room. Four weeks after the life story boards were placed in individual resident rooms, a post-implementation survey to assess participating providers' knowledge of the resident was given once more, as well as a second post-implementation survey to assess staff viewpoints and observations on caring for residents with dementia.

Ethical Considerations

The project was approved by the Institutional Review Board at Lenoir Rhyne University, Hickory, North Carolina. A "No Signature" informed consent was provided to each project participant. Participation by the direct care providers was voluntary and participants had the right to withdraw at any time without consequence or prejudice. Family and resident participation was managed by facility administrators, who made the initial contact with the family members of the passive resident participants.

Data Analysis

Wilcoxon Matched-Pairs Signed Rank Test was used to determine the mean knowledge scores before and after the implementation of Picture of Me Boards. A Shapiro-Wilk test was conducted to determine the normality of the sample distribution, and the Wilcoxon Matched-Pairs Signed Rank Test was chosen over the Two-Tailed Paired Samples *t*-test due to the violation of the normality assumption (Razali & Wah, 2011). Descriptive statistics were also used to describe the participants' demographic information, including gender, age, ethnicity, and years of experience in long-term care, job title, and shift primarily worked by the participant. Nominal and ordinal variables were presented as percentages.

The qualitative data was transcribed and closely analyzed by the PI to identify themes. Once the survey responses were collected, the PI became familiar with the data, and codes were generated. Codes were then grouped into larger themes in order for the data to be described and summarized.

Results

Participants

All 22 DCP participants completed both knowledge assessments and perception opinion surveys. Among the 22 participants, all 22 (100%) were female. Eight (36.364%) participants were between the ages of 18-24, 5 (22.727%) were between the ages of 25-34, 5 (22.727%) were between the ages of 35-44, 2 (9.091%) were between the ages of 45-54, and 2 (9.091%) were between the ages of 55-64.

Seventeen (77.273%) of participants reported their ethnicity as white or Caucasian, 3 (13.636%) reported their ethnicity to be black or African American, and 2 (9.091%) reported their ethnicity to be Hispanic or Latino.

Three (13.636%) participants had been working in long-term care 0-11 months, 8 (36.364%) had been working in long-term care 1-5 years, 7 (31.818%) had been working in long-term care 6-10 years, and 4 (18.182%) had been working in long-term care 16-20 years. Nine (40.909%) participants were CNAs, 5 (22.727%) were LPNs, 5 (22.727%) were ADNs, and 3 (13.636%) were nurses with a bachelor's degree.

Twelve (54.545%) participants reported working primary ^{first} shift (7 am-3 pm), 6 (27.273%) reported working primarily ^{second} shift (3 pm-11 pm), and 4 (18.182%) reported working primarily ^{third} shift (11 pm-7 am). These frequencies and percentages are presented in Table 1.

Table 1

Frequency Table for Nominal and Ordinal Variables

Variable	<i>n</i>	<i>%</i>
Months-Years Working in Long Term Care		
0-11 months	3	13.64
1-5 years	8	36.36
6-10 years	7	31.82
11-15 years	0	0.00
16-20 years	4	18.18
21+ years	0	0.00
Missing	0	0.00
Ethnicity		
White or Caucasian	17	77.27
Black or African American	3	13.64
Hispanic or Latino	2	9.09
Missing	0	0.00
Job Title		
LPN	5	22.73
CAN	9	40.91
AND	5	22.73
BSN	3	13.64
Missing	0	0.00
Age		
18-24	8	36.36
25-34	5	22.73
35-44	5	22.73
45-54	2	9.09
55-64	2	9.09
65+	0	0.00
Missing	0	0.00
Gender		
Female	22	100.00
Missing	0	0.00
Shift		
1 st	12	54.55

2 nd	6	27.27
3 rd	4	18.18
Missing	0	0.00

Note. Due to rounding errors, percentages may not equal 100%.

DCP Knowledge

DCPs' knowledge about the life story of each resident participant improved significantly from pre-intervention surveys to post-intervention surveys ($p < 0.001$). The median score of pre-intervention knowledge surveys was significantly lower than the median score of post-intervention knowledge surveys.

Themes

Based on the pre-intervention and post-intervention perceptions and opinion surveys completed by the DCP participants, four themes emerged from the analysis.

Conversation

An increased opportunity to engage in meaningful conversation emerged as a theme among survey participants. Having information about the residents' lives in the rooms made it readily available when providing care. This enabled staff to initiate conversations that could divert the resident's attention from the care being provided and focus it on other things that are important to them. One DCP wrote, "while providing everyday care to the resident, I was able to look at the board and bring up questions or topics to talk to them about. I guess I felt like this type of conversation seemed to give the resident more dignity." Another participant recalled a time where she had to provide care to a resident after an incontinence episode, writing, "One of the residents had a toileting accident, and I had to help her change clothes. She was so embarrassed and kept apologizing. I looked on the board, and we started talking about her family, and that seemed to make her feel better."

Having life story information readily available also helped DCP's to find similarities in themselves and the resident for whom they were providing care. These similarities also began meaningful conversations among DCPs and residents, as one DCP described when writing, "I realized that the resident went to the same college that I go to! We talked about that for a while one day."

Convenience

Convenience and availability of information retrieval emerged as another common theme among survey responses. All participants agreed that having life story information in the rooms of residents made caring for the resident more time-efficient. Prior to the intervention, all of the residents' life story information was kept in a book in the nursing station. One participant wrote, "I know that we have information about the residents in a book in the nursing station, but it was really cool to be able to see that information in the room while I was taking care of her." Another participant had a similar response when writing, "Being able to look at her board saved me a lot of time. It was easier than going to the computer to find out information about her family."

The pictures on the boards of the resident and their family members was also a common response when writing on the convenience of the POM boards. One DCP stated, "I talk with her family members on the phone all of the time, but it was nice to be able to put a picture with a name. When COVID restrictions lift and she comes to visit, I will know who she is."

Calming

Knowing information that could help calm the resident during times of distress was a third theme that emerged during the analysis of survey responses. Over half of DCP participants commented on the appreciation they had for the "what calms me" section being included on the POM boards. One DCP provider wrote, "I loved the calming section on the board. Knowing strategies to calm a resident down when they are angry or upset was really helpful." Another participant wrote of an experience she had during a stressful situation: "One afternoon the resident was upset. I looked about the board and saw that she loved listening and singing gospel music. I played her some songs, and she began singing along. It was much easier to help her change clothes after that." The information on the boards also uncovered new opportunities to improve person-centered care practices that DCP staff had not thought of before. One DCP wrote, "I never realized that the resident's best friend also lived in the facility. After I saw this, I would let the resident call and talk to her when she was sad. This seemed to lift her mood some."

Perspective

The final emerging theme found during the analysis was the change of perspective life story information had on participating DCPs. Many participants commented on their experiences of learning about the residents and the effect it had on the care they provided. One participant wrote, "I was able to take more time with the resident once I knew about them before they got sick. Sometimes it's easy to forget they lived a whole life just like me before they got dementia." Another participant commented on the change that the board had on the care she provided, writing, "I noticed I had a lot more patience with the resident after we learned about their life."

This intervention was implemented during COVID-19, and the state and facility regulations did not allow visitors to come into the facility. Many participants commented on their change of perspective due to the boards during this difficult time. One participant wrote, "COVID-19 restrictions have been so hard on the residents. I really liked the information on the boards about their families. Since they can't see them right now, it was nice to be able to talk about them."

Discussion

A key aspect in the delivery of quality dementia care is the person-centered care (PCC) approach (AA, 2018). Providing PCC can be facilitated by gaining knowledge of life story information about a resident with dementia to help DCPs view them as a whole person, not simply a task or a person with a chronic disease (Gronhdal et al., 2017). Picture of Me boards can improve DCPs' knowledge of residents with dementia and their life story. The life story boards may improve DCPs perceptions of the residents by provoking thoughtful conversation, increasing convenience of information availability, facilitating the use of relevant calming techniques, and changing situational perspective in regard to everyday care practices.

The Picture of Me QI project created a cost-effective, concise, and accessible way to collect and display life story information about LTC residents with dementia. The POM boards were widely accepted and appreciated by staff and clinical stakeholders. Plans are also being made by facility staff to continue creating and utilizing these boards for other residents throughout the facility.

Because of the small sample size of DCP participants, findings may not be generalizable to all of the nursing staff as a whole. This project also focused on DCP staff that work with the residents on at least a weekly basis. Many DCPs who care for these residents with dementia are part-time employees that do not work on the selected units on a weekly basis; therefore, they were not included in this project. Future research is needed on the effects of POM boards in this DCP population.

Conclusion

This project showed life story information could be made available to care staff efficiently in a busy care setting. It also showed this information is appreciated by DCPs and can be utilized to improve communication between DCPs and residents. It is also important to note this project does not demonstrate that an increase in DCP knowledge and a change in perspective will always lead to a change in resident care outcomes. This project solely focuses on DCP outcomes; therefore, further projects are needed to determine if an increase in DCP knowledge can lead to an improvement in resident outcomes and quality of life.

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