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# Table of Contents

**Volume 6    Number 8**

**August 2016**

## **Expectations and Perspectives of Users with the Screening Program for Cervical Cancer**

G. E. S. Olimpia, G. H. Darío, M. M. R. Adriana, G. G. Verónica, T. F. Yolanda.....565

## **The Application of Scales in the Diagnosis of Perceived Needs in the Elderly with Mild Cognitive Impairment**

J. B. S. Ferreira, S. P. C. Sa, L. K. Rezende, R. M. de Sant'Anna, A. M. Domingos, R. F. Santana.....573

## **Exploring the Implementation of Individual Care Plans in Relation to Characteristics of Staff**

A. Condelius, U. Jakobsson, S. Karlsson.....582

## **Nurses' Experiences of Using the Liverpool Care Pathway Plan in Hospitalized Patients with Heart Failure in the End-of-Life Stage: A Qualitative Content Analysis**

R. Hove, N. Fållun, B. Fridlund.....591

## **Utilized Theories by Nursing in the Care of People with an Ostomy: Integrative Review**

L. P. de Medeiros, M. D. M. Melo, B. C. Enders, S. S. de Mesquita Xavier, J. F. de Sena,  
G. de Sousa Martins Melo, J. M. M. de Assis, I. K. F. C. Assunção.....600

## **Care Technologies in Nursing for People with Colorectal Neoplasia: Integrative Review**

A. R. A. de Araújo, A. R. Feijão, L. P. de Medeiros, M. B. C. Medeiros, A. L. C. Maia,  
A. L. B. de Carvalho Lira, I. K. F. C. Assunção.....610

## **Using Gene Expression Analysis to Examine Changes in Loneliness, Depression and Systemic Inflammation in Lonely Chronically Ill Older Adults**

L. A. Theeke, J. A. Mallow, J. Moore, A. McBurney, R. VanGilder, T. Barr, E. Theeke,  
S. Rellick, A. Petrone.....620

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# Expectations and Perspectives of Users with the Screening Program for Cervical Cancer

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## Abstract

**Objective:** Evaluate user satisfaction before and after taking the Pap. **Methodology:** Observational and prospective study. It was carried out in two health centers in San Luis Potosí, Mexico in 93 users which attended for a Pap test from February to June 2015. The satisfaction was assessed using multidimensional scaling SERVQUAL with 5 dimensions to evaluate the quality of services in an organization: reliability, responsibility, security, empathy and touchable and materials goods (tangible elements). This scaling was obtained internal consistency by Cronbach's alpha coefficient with a value of 0.74. For data analysis, nonparametric test Wilcoxon for related samples was used. **Results:** In all cases, perspective was less than expectancy where the means of the scores before attention (expectation) and after care (perspective) there was a statistically significant difference ( $p = 0.000$ ). Before receiving care users had an expectation of 192.96 points, after care perspective score dropped to 184.49 points indicating that the care provided was not what they expected. The difference in scores was 8.47 points ( $p = 0.004$ ). **Conclusions:** Users of the screening program for cervical cancer were unsatisfied because the attention was not what they expected. In most of the indicators studied, a high percentage of dissatisfaction was obtained.

## Keywords

Cervical Cancer, Pap Smears, Prevention and Control, SERVQUAL

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## 1. Introduction

The appreciation of users is essential to improve all health programs. In this 21st century, the global competition among service providers is to render qualitative services to satisfy the desires of customers [1]. The quality of

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\*Corresponding author.

care is a judgment that is made by the customer after receiving the service and comparing their expectations with the received service [2]. Most of the organizations, for improving customer's satisfaction and, consequently, their own survival, are willing to evaluate the strategies of their service quality, and so, the customer is considered the key indicator in this evaluation [3]. Expectations are customer's demands, meaning that what they feel a service provider must present and perceptions are customer's experiences [4] with the service received and the difference between customer's expectations and perceptions is called service quality gap [5].

Researchers of service marketing have developed nineteen service quality models during the period 1984-2003 [6]. The service quality model "SERVQUAL" ranks as the most important of these models. By determining the gap between customer's perceptions and expectations of the quality of provided services, the process of service provision could be improved and customer's satisfaction, as a very sensitive element in today's field of competition, could be provided [7].

In order to determine the gap of the service quality in hospitals and health care centers, the SERVQUAL approach has been used in many studies. This service conceptual model was introduced in 1985 by Parasuraman *et al.* This tool measures the patients' perceptions and expectations of services in 5 different dimensions, including physical or concrete dimensions, reliability, responsiveness, assurance, and empathy [8]. In fact, customer-centered organizations set their activities based on the expectations and preferences of their customers and are to satisfy the needs and expectations of customers and considering their expectations as service quality standards is of essence [9].

Quality in the field of health services has a special place because the critical duty and mission of protecting the health and lives of the society is the responsibility of this part and any mistake could be irreparable; on the other hand, health services are related to a vast part of the society [10]. Different studies have been conducted to evaluate customer's satisfaction for improving the quality of provided services using SERVQUAL model in different areas from higher education [11] to health services [12], but a little attention has been paid to evaluation of service quality in different sections of primary health care of health centers [13], including service timely detection of cervical cancer. It is in this sense that the aim of the present study was to evaluate the perspectives of users of the cervical cancer detection service in two health centers of a Mexican province.

## 2. Patients and Methods

### 2.1. Data Source

Quantitative, observational, prospective and longitudinal study. It was conducted in two health centers in San Luis Potosi, Mexico. The work was conducted with a total of 93 users (49 health center called for this study as 1, and 44 health center labeled 2), which they received attention for taking cervical cytology (Pap) by nurses in the period from February to June 2015. Satisfaction was measured using the multidimensional SERVQUAL model.

This survey was designed by Parasuraman *et al.* in 1985 for validation and reliability [14]. In Mexico the survey was validated in 2011 at the General Hospital of Celaya, Guanajuato, obtained an internal consistency by Cronbach's alpha coefficient of 0.74 in full scale and factor analysis that was detected in the five dimensions of the scale 0.82 for expectations and perceptions to 0.66 for ; showing that it is valid and reliable [15].

Multidimensional SERVQUAL model measured and related customer perception and expectations regarding the quality of service. The 5 dimensions contained to the evaluation, in this case of a health service are:

- 1) Reliability. Ability to develop the service as promised, agreed and accurately.
- 2) Liability (answer's capacity). Willingness to help customers and provide prompt service.
- 3) Security. Knowledge of employees about what they do, their courtesy and their ability to convey trust.
- 4) Empathy. Ability to provide care and personal attention to their customers.
- 5) Tangibles. Related to the appearance of physical facilities, equipment, personnel and communication materials. They are the physical aspects in the organization that the customer perceives [14].

For the development of research scale it was modified and used prior review by experts for validation. It was applying in two-phase: Before the consultation (Pap) for determining the expectation of the users and after of consultation for determining perceptions. To determine the degree of satisfaction of users were compared Perspectives (P) and Expectations (E), and it analyzed according to the numerical ratings assigned to each element of the 21 that make up the survey divided into 5 dimensions. To qualify, a numerical scale 1 - 7 was used, whereas 1 is the lowest value and 7 the highest [16]. The satisfaction of users is handled as shown in the following table:

VALUE	MEANING
Difference between P and E = 0	Satisfied user
Difference between P and E = a positive number	Very satisfied user
Difference between P and E = between -1 y -3	Little satisfied user
Difference between P and E = between -4 y -7	Unsatisfied user

## 2.2. Data Analysis

Descriptive statistics were applied as percentages and frequencies, confidence intervals were estimated at 95%, the normality of the data was validated with the Kolmogorov-Smirnov test and based on the results of this test, nonparametric Wilcoxon test was applied to compare the scores of perspectives and expectations.

## 2.3. Ethical Considerations

The research protocol was reviewed and approved by the Ethics Committee of the School of Nursing of the Autonomous University of San Luis Potosí which assigned a registration number CEIFE-2015-118. Discretionary criteria were taken into account as the Declaration of Helsinki brand and general health law of Mexico, article 17. All participants signed a letter of informed consent.

## 3. Results

In this study, 93 users from San Luis Potosí, México were selected and some of its characteristics were analyzed, which indicate, from **Table 1**, that most of them are between 31 and 35 (52.7%), 21.5% between 21 and 30 years and 25.8% are in the range of 36 to 40 years. in relation to level education, the highest percentage (44.1%) have baccalaureate education and the lowest (12.9%) have high school education. As for marital status, most are married (82.8%). Regarding health services they have, 76.3% it affiliated to the Mexican Social Security Institute, 19.4% to Publicly Provided Health Insurance and 4.3% to Services Institute of Social Security for State Workers.

By measuring expectations and prospects in each dimension of scale SERVQUAL model, it was found that in all averages the scores before the attention (expectations) and after this (perspectives) there is a difference statistically significant ( $p = 0.000$ ). In all cases, prospects were below expectations, which it means that users expected better care that they received (**Table 2**).

Degree of user satisfaction by dimension (as after care) was obtained as a percentage. Intangibles (the physical aspects that the customer perceives of the organization), 53.8% of them was unsatisfied and 3.2% very satisfied. Regarding reliability (ability to develop the service as promised as agreed and accurately), 54.8% of them was satisfied and 3.2% unsatisfied. On the other hand, responsibility (willingness to help customers and provide service fast), 51.6% of them was little satisfied and anyone was very satisfied. With regard to security dimension (knowledge of employees about what they do, their courtesy and their ability to convey trust), 52.6 % of them was little satisfied and anyone was unsatisfied. In the dimension empathy (ability to provide care and personal attention to their customers), 59.1% of them was little satisfied and anyone was unsatisfied about the service. It is important to note that the satisfaction's degree "very satisfied" never obtained the highest percentage and that the degree "satisfied" only responsibility dimension occupied the highest percentage (**Figure 1**).

Before receiving care users had an expectation of 192.96 points. Considering that the highest score that can be obtained by applying the scale SERVQUAL is 196 points, we can assume that the expectation was high. However, after receiving the service perspective score was 184.49 points, indicating that the care provided was not that they expected. Difference between scores was 8.47 points ( $p = 0.004$ ) (**Figure 2**).

## 4. Discussion

In this century, global competition among service providers is to provide quality care to meet the customer's wishes. This has been increasingly important in developing countries, allowing service providers to provide greater value, competitiveness, opportunities, services growth and increased customer satisfaction. The role of service quality as a key factor in user satisfaction and organizational performance is widely recognized in developed countries [1]. Although the quality of health services has been a topic widely discussed in the literature

**Table 1.** Socio-demographic data of users who came to take pap.

Socio-demographic data		Frequency	%
<b>Edge</b>	21 a 30	20	21.5
	31 a 35	49	52.7
	36 a 40	24	25.8
Total		<b>93</b>	<b>100.0</b>
<b>Education level</b>	High school	12	12.9
	baccalaureate	41	44.1
	Technical education	25	26.9
	College	15	16.1
Total		<b>93</b>	<b>100.0</b>
<b>Civil status</b>	Single	9	9.7
	Married	77	82.8
	Free union	6	6.5
	Divorcee	1	1.0
Total		<b>93</b>	<b>100.0</b>
<b>Health service has</b>	*IMSS	71	76.3
	*SP	4	4.3
	*ISSSTE	18	19.4
Total		<b>93</b>	<b>100.0</b>

Source: Multidimensional SERVQUAL scale. \*IMSS: Mexican Social Security Institute, \*SP: Publicly Provided Health Insurance, \*ISSSTE: Services Institute of Social Security for State Workers.

**Table 2.** Expectations and perspectives of users by scale dimensions of SERVQUAL.

Dimension	Indicator	Average	S.D.	D.B.A.	L.L.	U.L.	<i>p</i> *
<b>Tangibles</b>	E	54.84	1.035	3.312	2.959	3.665	0.000
	P	51.53	1.646				
<b>Responsibility</b>	E	20.76	0.427	0.462	0.260	0.665	0.000
	P	20.30	0.918				
<b>Capacity</b>	E	62.04	1.122	3.097	2.686	3.508	0.000
	P	58.95	1.964				
<b>Security</b>	E	27.51	0.670	0.613	0.333	0.893	0.000
	P	26.89	1.118				
<b>Empathy</b>	E	27.68	0.514	0.849	0.629	1.070	0.000
	P	26.83	0.904				

Source: multidimensional SERVQUAL scale. E = Expectations; P = Perspectives; D.E. = Standard deviation, D.B.A. = difference between the average; L.L. = Lower Limit; U.L. = Upper limit. \*Wilcoxon.

for over 40 years, its definition, interpretation and assessment rating remains controversial and complex because of the multiple factors involving construction, [17] plus it has been interpreted in different ways. The satisfaction of external users, expressing individual value judgments and subjective, is the key in the definition and assessment of quality.

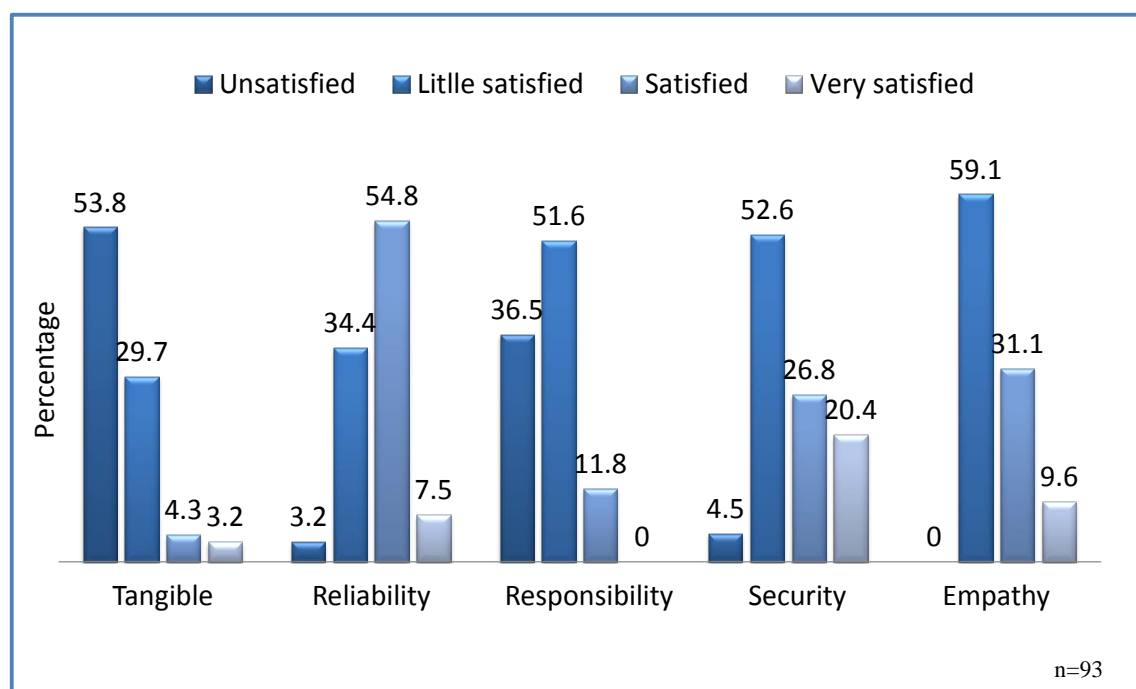


Figure 1. Degree of user satisfaction by dimension of SERVQUAL model.

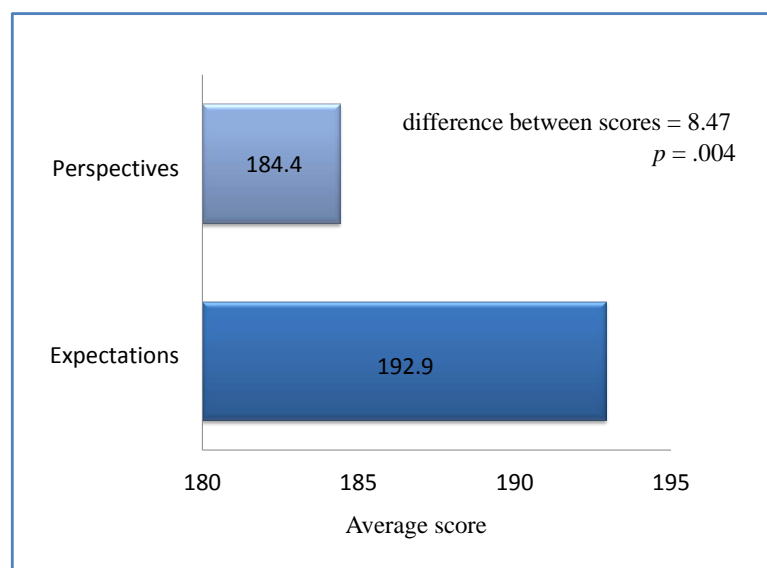


Figure 2. Degree of user satisfaction by dimension of SERVQUAL model. Nonparametric Wilcoxon test.

This is most often used to assess the quality of care in health services and measurement indicator is expressed in levels of user satisfaction [18]. The survey for validity and reliability is the most widely accepted to measure the quality of care in multidimensional tool business services [19]. Babakus and Mangold validated a new SERVQUAL construct to hospital [19] and in Mexico were validated in 2011 in a Celaya Guanajuato hospital [15].

The incidence of cervical cancer has decreased substantially in developed countries due to the widespread success of Pap smears programs, however, these results have not been obtained in developing countries [20] [21]. Recognizing the limited effectiveness of the program in Mexico [22], different strategies have been implemented, but the assessment of the prospects of the users of it is very important and little or nothing has been

explored, marking the aim of this research using multidimensional SERVQUAL scale. In other countries like in Iran, was studied the customer's perceptions and expectations of primary healthcare services quality in health centers of Bandar Abbas in this paper the authors found that the majority of participants (64%) assessed the services quality moderate and that the best dimension of service quality was assurance, followed by reliability, responsiveness and tangibles with empathy being the worst [23]. In our study, users had higher expectations that perspectives on the care provided, indicating low satisfaction. Furthermore, in this study it was found that the dimension was more dissatisfaction was tangible, which include material, equipment, facilities and staff health. About, program quality and patient safety at Children's Hospital of Mexico "Federico Gómez", mentions that amenities include elements such as degree of comfort achieved, hotel services provided, the information system and situation of intimacy in which the patient is attending among others. This specifies that the quality is the application of science and medical technology in a way that maximizes their health benefits without increasing proportionately their risks [24].

Thus, in our study we found that most users are dissatisfied with the elements related to the institution, which is important for future research are analyzed factors concerning the organization and specifically concerning the service provided by nurses, the qualitative aspects and everything that influences so that patients come to perform or not Pap using new indicators. Health institutions in the public sector in Mexico, nursing staff is responsible for taking the cervical smear tests and the main contact with users of the program since one of its functions, in addition to providing care, is to provide the necessary information to women so they can achieve greater attachment to the early detection program. Such personnel must hear from women attending the screening on their expectations and experiences regarding the care in order to detect areas of opportunity later to become improvement strategies that increase the quality of this priority health program. In this sense, we have identified the main problems perceived by users, which lie in long waiting periods, conditions of inadequate physical spaces, lack of respect for privacy and lack of continuous and appropriate monitoring causing dissatisfaction with the service [25].

The authorities of public organizations have realized that their achievements as the targets are not associated with the appreciation that management makes citizens. Political discourse and theoretical approaches are not always compatible with the operation of programs that impact poorly on the reality of the people they are intended. In this context, studies seeking to approach people and understand their complex reality of incorporating multidimensional aspects, are relevant to narrowing the gap between public policy planners and those who receive benefits [26].

On the other hand, users have certain needs or desires which sometimes are not even concerning the care and can be obtained by the organization to design and deliver a service that no longer satisfied. Some systems are available to identify the real needs of customers, while others allow only perceive the needs of which the user is aware. Both perspectives are used to improve service quality and tend to greater satisfaction of people who receive it [16].

In conducting this study there were different limitations, including the small influx of women who demand service and large span of time (45 minutes) to do this, which meant not being able to have a larger sample.

Finally, it should be mentioned that studies as performed by this research group and characteristics that were addressed are important to improve a program, in this case the timely detection of cervical cancer. Users' opinion of the program is critical because they are the recipients of care and can provide useful information for decision makers' information. For future research is suggested to address the point of view of health personnel regarding some variables analyzed in this study for comparison of the experiences of the major players in the program of cervical cancer screening. It should be mentioned that there are few studies on the quality of health care and user opinion, and much less those related to the service responsible for the early detection of cervical cancer.

## 5. Conclusion

Users of the program for early detection of cervical cancer were dissatisfied with it because attention was not what they expected. In most indicators addressed, a high percentage of dissatisfaction was obtained.

## Acknowledgements

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# The Application of Scales in the Diagnosis of Perceived Needs in the Elderly with Mild Cognitive Impairment

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## Abstract

The study evaluated the use of the Mini-Mental State Examination scale (MMSE), Tinetti scale, and Motor Scale for the Elderly (EMTI) to assist in the diagnosis of potential needs observed in elderly with Mild Cognitive Impairment. This was a quasi-experimental research, conducted in a Basic Health Unit in the city of Rio de Janeiro in 2014. The sample population consisted of 22 elderly aged 64 to 88 years and 86.36% females. The SAS statistical software (version 9.3.1) and Kruskal-Wallis test were used at a 95% confidence interval and a significance level of 0.05 and demonstrated significant differences in the evaluations performed before and after the intervention. The detected diagnoses were: impaired memory, the risk of falls, and willingness to improve relationships, among others. The evaluations showed MMSE results that were suggestive of cognitive impairment in 22.73% of the elderly; the Tinetti scale showed a high risk of falls in 31.82% of the elderly; and EMTI with 88.36 points, which was equivalent to the normal low classification. The intervention took place through ten weekly activity sessions after the initial evaluations. In the second evaluation, the Tinetti showed 59.09% of the elderly with a moderate risk of falls and the EMTI as the normal average classification with 90.32 points. It was concluded that the scales offered diagnostic possibilities, which allowed for the implementation of necessary interventions according to the detected problems.

## Keywords

Nursing Diagnosis, Mild Cognitive Impairment, Sensory-Motor Performance, Postural Balance, Elderly

## 1. Introduction

Increasing longevity is a worldwide phenomenon. The proportion of elderlies is growing rapidly in Brazil and in many countries, with demographic projections suggesting that the age group above 65 years should increase from 14.9 million (7.4% of total) in 2013 to 58.4 million (26.7% of total) in 2060 [1]. Although longer life expectancy may be considered an achievement, it is associated with an increased incidence of chronic degenerative diseases, which leads to a significant growth in demand for health services. Many elderlies maintain high levels of cognitive functioning throughout life [2], however, many present some decline in some cognitive abilities. The increasing number of elderly patients with dementia using public health services deserves special attention, especially if the progression trend continues and this chronic degenerative disease assumes epidemic proportions. Because there are few alternative therapies and treatments with the early diagnosis are more effective, it is essential to identify cases that present a high risk of progression to dementia [3]. A program of activities implemented by a multidisciplinary team can contribute significantly to life's structure and cognitive function in the elderly population [4].

The concept of Mild Cognitive Impairment (MCI) can be defined as impairment revealed in changes in memory, a situation which does not imply dementia. Tests such as the Mini-Mental State Examination (MMSE) are used to diagnose MCI. Criteria for this diagnosis include normal general cognitive functions and socio-occupational activities and a minimum score of 24 points (performance in about 1.5 standard deviation below the mean of normal controls of same age and education level) [3] [5] [6].

The assessment of functional capacity is necessary to know the degree of dependence/independence in the elderly [7], which represents the independence an individual has to perform physical and mental activities necessary to maintain basic and useful activities [8]. Longevity, when associated with non-transmissible chronic diseases, can affect the functional capacity of elderlies and thereby prevent them from performing independent activities and fostering dependence on another person [9].

Therefore, early screening of cognitive and functional conditions in the elderly is key to improving life structure and cognitive function in the elderly population.

Nurses play an important role in promoting health and preventing disease in the elderly population, especially in the context of cognitive health. Therefore, it is essential that nursing evaluations are used to determine appropriate interventions.

Hence, NANDA International [10] offers proposals for specific nursing diagnoses as well as interventions commonly associated with those diagnoses. These interventions correspond to activities necessary for the determination and implementation of the assistance required for each client and may be used in different contexts.

Nursing evaluations using specific scales for the elderly, as is the case in this study, are important in relating a diagnosis with the appropriate intervention(s). Nursing evaluations provide a systematic and dynamic method of providing humanized care, which is oriented to obtain the best results [11].

This study used the Mini-Mental State Examination (MMSE), Motor Scale for the Elderly (EMTI), and Tinetti scale to assist in the diagnosis of perceived needs in elderly patients with mild cognitive impairment to achieve care goals.

## 2. Methods

This quasi-experimental study was conducted over four months. Twenty-two male and female elderlies over 60 years of age who were located in Rio de Janeiro and users of a Basic Health Unit (BHU) participated. The study was conducted in the outpatient clinic of the institution; the participants attended the Memory Workshop.

Medical records of elderly participants indicated mild cognitive impairment as defined by the researcher. Diagnosis of cognitive impairment was based on examinations such as magnetic resonance, computerized tomography, and laboratory tests among others. Referrals made by the institution's geriatric assessment were also considered.

Inclusion criteria were: males and females over 60 years of age with Mild Cognitive Impairment (MCI) and a score above 24 on the Mini-Mental State Examination for individuals with higher education, at least 18 for individuals with high school education, or above 14 for the illiterate. Exclusion criteria were individuals who missed 25% of the psychomotor stimulation activities, had severe vision deficit, presented recent bone injuries, had prosthetic lower limbs, had a surgical procedure in the last 6 months, were affected with labyrinthitis, and who

had hemodynamically unstable cardiovascular disease.

As the number of elderly, in principle, to obtain a significant number a survey was conducted in this institution. According to surveys conducted in the clinic of the Municipal Hospital of Geriatrics and Gerontology of Rio de Janeiro Health (Brazil) in the period from September to November 2013 were attended 679 elderly. Patients with Mild Cognitive Deficit are directed to cognitive stimulation, already existing in service 57 elderly.

Using this information, and a significance level of 0.05, standard error of 0.15 percent, it has to be for this institution the sample is at least 13 elderly in order to have a significant sample. These are the minimum values to make the sample representative for the institution and so there is the possibility of evaluating these elderly and perform interventions in time for the research. A total of 34 elderlies were initially evaluated: 12 (35.3%) were excluded through the exclusion criteria and 22 (64.7%) participated were included in the study outcomes, which were also considered a significant sample number based on an initial study survey.

Instruments used included: the Mini-Mental State Examination-MMSE [12] [13]; Tinetti Scale [14]; and Motor Scale for the Elderly-EMTI [15]. They were used to determine psychomotor activities after diagnosis; activities were designed to promote balance and functional capacity. Group activities were conducted for ten weekly sessions. The Tinetti [14] and EMTI [15] scales were applied at the beginning of the study and at the end of the performed psychomotor stimulation program.

The Mini-Mental State Examination [12] [13], which is a cognitive impairment screening mechanism was used in this study only the first step to evaluate the cognition of the participants. In this case, considering the scale EMTI complete by cover all psychomotor factors, the good results on this scale corresponds also to improvement in cognition in the elderly.

This instrument was developed by Folstein and McHugh [12] and translated by Bertolucci *et al.* [13] to assess specific cognitive functions: time orientation (5 points), location orientation (5 points), three-word record (3 points), attention and calculation (5 points), recall of the three words (3 points), language (8 points), and visual-constructive capacity (1 point). The scoring system ranges from zero to 30. In this study, the validated version used the following cutoff points: 13 for illiterates, 18 for medium and low education levels, and 26 for higher education level [13]. The Tinetti [14] and EMTI [15] Scales were used for diagnostic evaluation before and after the intervention.

The validated version of the Tinetti scale is an instrument that utilizes the Mary Tinetti protocol [14]. This protocol predicts the risk of falls by detecting changes in gait and diagnoses and quantifies the severity of impairment. According to this instrument, the lower the score is, the greater the problem is. A score lower than 19 indicates five times higher risk of falls. Thus, individuals who presented scores below 19 points present a high risk of falls; those between 19 and 24 a moderate risk; and those over 24 do not present a risk of falls.

The Tinetti index consists of two scales: balance with a total of 16 points and gait with a total of 12 points (total points: 28). The balance component consists of 9 items: sitting balance, rising from a chair, attempts to rise, balance after rising (first 5 seconds), standing balance, the three times tests, eyes closed, balance while turning 360 degrees, and balance while sitting. In the tasks requiring the use of a chair, the patient starts the evaluation in a rigid chair without armrests and with his back in the upright position [14].

The gait has seven items: gait start, length and height of steps, steps' symmetry, continuity of steps, direction, trunk, and ankles' distance. In the tasks/maneuvers in which the use of a chair is needed, the patient starts the evaluation in a rigid chair without armrests, and with his back in the upright position [14].

The Motor Scale for the Elderly-EMTI [15] is an innovative, validated instrument [16], which provides new opportunities for evaluation and intervention in the elderly population. Evaluation using motor tests allows verification of the progressive stages of physical function and detection of the decline in physical parameters and, in turn, provides for the planning of effective intervention strategies. This is an exploration method that evaluates specific areas of human motricity (body stability and proprioception movements).

Each test has different degrees of difficulty that are presented in an increasingly progressive order. The scores obtained in the evaluation allow the classification of motor parameters in levels: very high (130 or above), high (120 - 129), normal high (110 - 119), normal average (90 - 109), normal low (80 - 89), low (70 - 79), and very low (<70).

Interventions: elderlies could miss only two out of the ten sessions. Stimulating cognitive and psychomotor activities to improve psychomotor quality through an exercise program were developed according to NANDA-I [10] after diagnosis. Scales were used and followed-up by the researcher. Dynamics suggested by Rosa Neto [15] were used with supplemental music and videos according to the theme. Ten weekly group exercising activities were conducted for a period of four months. The participants were re-evaluated with the Tinetti and EMTI scales at the end of these sessions.

SAS statistical software version 9.3.1 was used for data analysis. Data were divided into initial and final evaluations, *i.e.*, before the start of activities and after the end of activities. The initial descriptive analysis included all 22 elderlies.

The Shapiro-Wilks normality test was used. Because variables were not normally distributed, the signal non-parametric test was applied. The Kruskal-Wallis test was used with a 0.05 significance level to verify differences between measurements. A significant difference with 95% confidence interval was observed between the scores obtained in the initial and final evaluations that used the Tinetti [14] and EMTI [15] scales.

The study was approved by the Ethics Committee in Research including Human Beings from the School of Medicine of the Fluminense Federal University/FM/UFF/HUAP under number 531.807 in 2014. The ethical principles of voluntary and informed participation were respected.

### 3. Results

**Table 1** shows results from the normality Shapiro-Wilkstest performed to verify the presence of normal distribution and determine the best statistical test to be used.

Because no variable other than the General Motor Ability (GMA) presented normal distribution, the nonparametric test signal was applied. All variables showed differences through the equality test with 95% confidence interval and 0.05 significance: that is, differences were observed between initial and final evaluation scores. These tests were not used for the MMSE evaluation because it was only conducted in the initial evaluation of cognitive impairment.

**Table 2** shows the sociodemographic data and MMSE scores. The average age was 74.36 years, and the

**Table 1.** Normality and average similarity tests in the study variables. Rio de Janeiro, 2014.

Variable	Normality test	Average similarity test
MF1 (fine motricity)	0.0001	0.0001
MF2 (global motricity)	0.0004	0.0106
MF3 (balance)	0.0015	0.0001
MF4 (body scheme/agility)	0.0001	0.0001
MF5 (spatial organization)	0.0001	0.0001
MF6 (temporal organization)	0.0001	0.0001
GMF (general motor fitness)	0.3042	0.0001
Tinetti (balance and gait)	0.0001	0.0001

Source: Study data from 2014. MF = Motor Fitness.

**Table 2.** Distribution of elderlies according to gender, age, and MEEM scores. Rio de Janeiro, 2014.

Variável		n	%		
Gender	Female	19	86.36		
	Male	3	13.64		
Age	60 - 69	5	22.73		
	70 - 79	12	54.54		
	80 - 89	5	22.73		
	Suggestive of cognitive deficit (23 points or less)	5	22.73		
MEEM	Doubtful or alterations not suggestive of deficit (24 - 26 points)	8	36.36		
	Preservedcognitivefunctions (27 - 30 points)	9	40.91		
Variable	Average	Standard Deviation	Minimum	Maximum	Amplitude
MEEM	25.72	2.27	22	30	8
Age	74.36	6.75	64	88	24

Source: Study data from 2014.

standard deviation was 6.75. The ages ranged from 88 to 64 years old.

MMSE results averaged 25.72 points, ranging from 22 to 30 points. We observed 59.09% of participants with some cognitive deficit; 22.73% with a suggestive cognitive deficit, and 36.36% with alterations that were not suggestive of cognitive deficit. A total of 40.91% was observed with preserved cognitive functions. All selected participants remained in the study because they had been referred by geriatricians to the cognitive workshop due to memory shortage complaints.

**Table 3** shows the results of the two evaluations using the Tinetti balance and gait scale.

According to **Table 3**, 31.82% of the elderly initially presented a high risk of falls, with 36.36% presenting a moderate risk of falls. After the intervention, only 9.09% presented a high risk of falls evaluation, with the majority, 59.09%, presenting a moderate risk of falls. According to the Tinetti scale, 31.82% of the elderly did not present a risk of falls in both evaluations.

**Table 4** presents the results of the initial and final evaluations using the Motor Scale for the Elderly (EMTI). Fine Motricity (FM1) showed an average of 105 points in the initial evaluation, and 105.81 points in the final evaluation, both equivalent to the average normal classification.

Global Motricity (GM2) averaged 38.72 points in the initial evaluation, and 38.73 points in the final evaluation, corresponding to the extreme low classification.

**Table 3.** Distribution of elderly according to scores obtained in the Tinetti Scale and results using the Kruskal-Wallis test. Rio de Janeiro, 2014.

First evaluation					Second evaluation			
n	%	Average	SD	Tinetti scale	n	%	Average	SD
7	31.82	17.42	1.14	High risk of falls (<19)	2	9.09	17.5	0.70
8	36.36	21.75	1.28	Moderate risk (19 - 24)	13	59.09	21.30	2.14
7	31.82	26.86	1.46	No risk of falls (>24)	7	31.82	26.86	1.46

Source: Study data from 2014.

**Table 4.** Distribution of variables according to motor areas and classification of scores in the EMTI scale, and results using the Kruskal-Wallis test. Rio de Janeiro, 2014.

First evaluation				Seconde valuation				
Average	SD	P value		EMTI scale	Average	SD	Pvalue	
105	13.57	0.001		Fine motricity (MF1)	105.81	12.40	0.002	
38.72	14.78	0.0483		Global motricity (MF2)	38.73	14.78	0.005	
89.18	26.72	0.0317		Balance (MF3)	92.73	22.66	0.009	
77.45	19.14	0.0001		Body scheme/agility (MF4)	82.91	16.93	0.0001	
109.63	19.95	0.0014		Spatial organization (MF5)	111	17.83	0.0006	
110.18	20.49	0.0003		Temporal organization (MF6)	110.72	19.91	0.0003	
88.36	10.26	0.0017		General motorability (MFA)	90.32	9.48	0.0007	

First evaluation				Second evaluation				
MF3		MFG		EMTI scale	MF3		MFG	
n	%	n	%	Classification	n	%	n	%
7	31.82	1	4.54	Very low (<69)	1	4.54	0	0
1	4.54	2	9.09	Low (70 - 79)	7	31.82	1	4.54
4	18.18	12	54.54	Normal low (80 - 89)	4	18.18	9	40.90
5	22.73	6	27.27	Normal medium (90 - 109)	5	22.73	11	50
0	0	1	4.54	Normal high (110 - 119)	0	0	1	4.54
2	9.09	0	0	High (120 - 129)	2	9.09	0	0
3	13.63	0	0	Very high (>130)	3	13.63	0	0

Source: Study data. SD—Standard deviation.

An average of 89.18 points was observed in the initial evaluation of balance (MF3), equivalent to the normal low classification. An average of 92.73 points was observed in the final evaluation.

The Body Scheme/agility (MF4) averaged 77.45 points in the initial evaluation. The final evaluation averaged 82.91 points, corresponding to classifications of low and normal low, respectively.

The Spatial Organization averaged 109.63 points in the initial evaluation, equivalent to the normal average classification. The final evaluation averaged 111 points corresponding to the normal high classification.

The Temporal Organization averaged 110.18 points, equivalent to the normal high evaluation. The final evaluation averaged 110.72 points, corresponding to the normal high classification.

**Table 4** shows General Motor Fitness (GMF) results, an average obtained from the sum of all motor areas in the EMTI scale. Most elderlies (54.55%) obtained scores below 89 and were initially classified as normal low. Six elderlies (27.27%) were classified in the normal average classification with scores between 90 and 109; two elderlies (9.09%) with scores lower than 79 were classified as low. One elderly with scores lower than 69 was classified as very low. One elderly scored between 110 and 119 and was classified as normal high. The average GMF in the first evaluation was 88.36 points.

The analysis using the Kruskal-Wallis test with 95% confidence interval and 0.05 level of significance showed that all motor fitness (MF), except Global Kinetics and Motricity (MF2), which presented 95.45% of elderlies in the classification of very low and 4.55% as low, were significantly different between the initial and final evaluations.

## 4. Discussion

The predominance of women in the study (86.36%) is similar to that reported in other studies and may be related to male higher mortality rates. [16] The increased demand for health services by women mainly due to gender factors and related to culture [17] may also be a contributing factor. A total of 54.54% of participants were aged between 70 and 79 years old.

The Mini-Mental State Examination results (**Table 1**) show that the vast majority (59.09%) of elderlies presented some type of cognitive impairment, 22.73% demonstrated signs suggestive of cognitive impairment with scores ranging from 22 to 23 points, and 36.36% exhibited either questionable changes or no suggestive cognitive deficit. This result is supported by another study in the elderly population where 34.1% shows cognitive impairment [18].

The MMSE evaluation shows the diagnosis of impaired memory, which is understood as the inability to remember or retrieve information or behavioral skills [10]. Participants were advised about the benefits of an early diagnosis and the importance of participating in psychomotor activities.

Psychomotor activities were organized as either individual or joint participation. A willingness to increased communication [10] was observed as the elderlies interacted well not only with the professional guiding the activities but also with each other. Participants gave and received suggestions, and exchanged information in order to reach goals, demonstrating a willingness to increased decision-making [10]. It is important to promote the elderlies' input to demonstrate that their needs are valued and to prevent evasion.

The risk of falls [10] was observed in the diagnosis of Perception/Control of health in the initial evaluation assessing balance and gait using the Tinetti scale and the balance parameter (MF3) using the EMTI scale. In the results from the Tinetti scale, 68.18% of the elderlies showed some changes in balance and aspects related to difficulty in gait, such as the length and height of steps, trunk position, and distance between ankles. Some of the elderlies reported tripping over their feet, which indicated the need for interventions; 31.82% showed a 17.42 point average, which corresponds to a high risk of falls, and 36.36% showed the moderate risk of falls with an average of 21.75 points.

The comparison of balance and gait using the Tinetti scale with the motor balance parameter (MF3) using the EMTI scale showed that 31.82% of the elderlies presented scores lower than 69 points in the EMTI scale, corresponding to the classification of very low in the first evaluation. The average obtained in this parameter by the studied participants was 89.18 points and were classified as normal low in the first evaluation.

The results using the Tinetti scale in the final evaluation showed that 22.73% of the elderlies were able to improve balance and gait, and 59.09% moved from high to moderate risk of falls. Despite continuing at moderate risk of falls, 36.36% of participants showed an increase in their scores. However, 31.82% of the elderlies maintained an average of 26.86 points, suggesting no risk of falls in either evaluation. A total of 27.27% of the elder-



lies obtained improved scores in the balance parameter (MF3) in the final evaluation, improving their classification from very low to low. The average of participants was 92.73 points, and their classification changed to normal average in the EMTI scale.

The score increase in balance and gait in the Tinetti scale supports this result because the results from the two scales used in the second evaluation showed satisfactory improvement in balance. Balance is formed by a set of static and dynamic skills including postural control and development of motor fitness; it is considered as the primary basis for all differentiated action of the body and is central to coordination [15].

The diagnostic evaluation using the Motor Scale for the Elderly-EMTI, which features six motor parameters (Table 4), shows Fine Motricity (MF1) scores between 90 and 109 with an average of 105 points, classified as normal average in the first evaluation; the average for the second evaluation was 105.81 points. Despite the unchanged fine motricity, the average increased. The precentral cortex corresponding to the fine motricity skills plays a key role in the control of isolated movements of hands and fingers. The cortico-sensorial motor areas of hands and fingers are relevant because they emphasize the finesse of tactile and motor controls [16].

Although numerical scores modestly increased in the second evaluation, twenty-one elderlies (95.45%) presented final classification as very low in the EMTI scale for global motricity (MF2). Most of the motor parameter test proves difficult for those who do not practice physical activities because they include climbing on a bench, jumping over a rope, jumping in place, jumping at 20 cm height, walking on a straight line, doing the “soft foot” jump at 40 cm height, jumping in the air, doing the “soft foot” with a box of matches, and jumping over a chair [15].

Therefore, the diagnoses according to NANDA [11] show sedentary lifestyle and deficient recreational activities. Elderlies who do not attend a gym or establishments that provide physical fitness do not feel safe to carry out such tests; it is understood that with the aging process and progressive decrease in muscle strength, muscle tone also decreases [4].

The comparison of results from fine motricity, global motricity, and balance showed that fine motricity presented the most satisfactory results because the obtained scores classified the elderlies as normal average. The global motricity parameter (MF2) showed the highest degree of difficulty out of all evaluated motor areas and was classified as very low in both evaluations. This is because this area is responsible for regulating balance and the individual’s attitude, playing an important role in the improvement of nerve commands and refining of perceptions and feelings [15].

The comparison between the motor parameters of body scheme (MF4), spatial organization (MF5), and temporal organization (MF6) showed that spatial organization (MF5) was the criterion that received the highest scores in the final evaluation; it was classified as normal high as opposed to normal average in the initial evaluation. The elderlies were classified as normal high in both evaluations of temporal organization (MF6). They showed the lowest scores in body scheme (MF4); however in the second evaluation, they showed improved scores and moved from the classification of low to normal low. These increased scores indicated an improvement in these parameters.

The movements considered most difficult for the elderly are those of body dissociation, lateral domain, coordination of upper and lower limbs, speed, agility, breath, proprioception, rhythm, and body memory [16]. Such movements are primarily associated with the natural aging process as well as physical exercise, motivation, and quality of life [4].

The Motor Scale for the Elderly (EMTI) presented the General Motor Fitness (GMF) measurements according to the scores obtained in the initial and final evaluation and showed the effectiveness of activities and satisfactory improvement in the evaluated motor parameters.

It is important to diagnose perceived needs early and, from there, guide the elderly in a continuous and effective way, including benefits provided by regular physical exercises, to prevent and treat functional declines associated with the aging process.

## 5. Conclusions

The use of the MMSE, Tinetti, and EMTI Scales allowed the diagnoses of psychomotor deficits, which were observed among perceived needs. The results from the use of the Tinetti scale showed that 68.18% of the elderlies were associated with risk of falls, 31.82% were at high risk of falls, and 36.36% at moderate risk of falls. The results from the use of the EMTI scale showed low scores in the parameters of global motricity, balance,

and body scheme/speed in the initial evaluation, and increased scores in the final evaluation. The identified diagnoses were a risk of falls, sedentary lifestyle, and deficient recreational activities.

The elderly showed improved performance in the temporal organization, spatial organization, and fine motoricity areas. The EMTI scores were 83.11 points (normal low classification), and 90.72 points (normal average classification) in the first and second evaluations, respectively. This result demonstrates the satisfactory effect of interventions.

The results from the use of MMSE showed that 59.09% of the elderly had some cognitive impairment, and 22.73% had signs suggestive of cognitive impairment and diagnosis of impaired memory. Elderly who participated in the activities demonstrated increased communication, enhanced decision making, and improved relations.

This study contributes significantly to the development of strategies to care for the elderly with mild cognitive impairment by improving functional capacity.

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# Exploring the Implementation of Individual Care Plans in Relation to Characteristics of Staff

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## Abstract

The aim was to explore the implementation of individual care plans in municipal elderly care in relation to characteristics of staff. Data regarding characteristics of staff were derived through a questionnaire distributed to all staff working in the care for older people, (N = 908, n = 245) in four municipalities in Sweden. The number of care plans established during a one-year period was collected through a contact person in each municipality. In total 47 individual care plans were established during the study year. Significantly more staff in the municipality that had the most number of established individual care plans agreed that there had been sufficient education (p = 0.017), sufficient time (p = 0.002) and routines established regarding individual care plans (p = 0.014) and had a significantly better job satisfaction (p = 0.001), compared to staff in the other municipalities. Implementation leaders may need to take the working conditions and the perception of available resources among staff into consideration in the on-going process of implementing individual care plans.

## Keywords

Aged/Aged 80 and Over, Patient Care Planning, Health Plan Implementation

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## 1. Introduction

In Sweden, as in other countries, lack of coordination and cooperation between various providers of care poses

problems in terms of continuity and quality of care, in particular among older people with more complex care needs. To find a remedy for this problem in Sweden, a new paragraph was inaugurated in the Health and Medical Services Act [1] and in the Social Services Act [2] in January 2010. The paragraph makes clear that the county councils and the municipalities shall collaborate and establish an individual care plan (ICP) for persons in need of both social services and healthcare. A successful implementation and use of ICP may contribute to improved inter-professional collaboration and better continuity in care for older people. However, to transform a policy into action is rarely a straightforward process and the attitudes and behaviour among frontline staff should not be underestimated [3]. To fully understand organisational change, it is necessary to understand changes among the individuals involved [4]. Thus, the influence of staff on the process of implementing ICP in elderly care needs further exploration.

## Theoretical Framework

The Consolidated Framework for Implementation Research (CFIR) [5] provides an overarching typology for implementation research and has been used as guidance in the design of this study. The framework was developed through a review of published theories about constructs that influence implementation. The framework is composed of five overarching domains; of which two are analysed in this study, *i.e.* “Process” and “Characteristics of individuals”. The domain “Process” may be evaluated by the actual execution *i.e.* the actual use and spread of the intervention in the organisation [5], in this case the use of ICP.

The domain “Characteristics of individuals” [5] emphasises that organisational change and the implementation of new routines is influenced by the individuals involved. Two constructs in this domain are analysed in this study and are classified as “Knowledge and beliefs” and “Individuals’ identification with organisation” [5]. The construct “Knowledge and beliefs” refers to the individuals’ knowledge, thought and opinions about the intervention. The actual use of ICP among professionals (the outcome, execution) can be regarded as a human behaviour. As such it may be predicted by the perceived usefulness and ease of use among the intended users [6]. Yu, Li and Gagnos [7] performed a study about the acceptance of Health IT in long-term care facilities and found a significant relation between perceived usefulness, perceived ease of use and the intention to use Health IT among the caregivers. Thus, it may be hypothesised that the acceptance of ICP among staff as a useful and valuable tool in the collaboration with professionals in other organisations and in the care of older people may impact their behaviour in using it. However, their use of ICP may also be related to their belief that they have access to the appropriate skills, resources and support [6]. Since ICP is regulated by law it can be regarded as an externally developed intervention not originating from those who are expected to use it. This puts demand on a well performed dissemination process [8] where staff receives the education, information and resources they need to use ICP in daily practise. Fernandes [9] conducted a study about the process of implementing advanced care plans in aged care facilities. The results showed that the provision of education to staff enhanced their knowledge to take part in advanced care planning and that a more formalised procedure for data collection and documentation improved the number, as well as the quality of the plans that were established. Thus, the acceptance of ICP among staff and their perception of organisational support in terms of education and availability of resources may influence the actual spread and use of ICP. However, this relationship has not been investigated and needs further exploration.

The construct “Individuals’ identification with organisation” [5] emphasise that the relationship the individuals have to the organisation they work in may affect their attitudes regarding using an intervention and thus their willingness to engage in a changing process. An increased workload has been reported among staff in elderly care with stress, fatigue and job strain common problems cited by employees in these organisations [10] [11]. Emotional exhaustion has been shown to impact work attitudes and job performance among staff [12] and low job-satisfaction has been shown to be related to the intention to leave the elderly care work sector [13]. Considering that successful implementation is greatly influenced by the engagement among the individuals involved [14], job satisfaction among staff can be expected to influence the process of change and the use of ICP. However, so far this relationship has not been explored, particularly not in relation to the implementation of ICP in elderly care.

The aim of this study was to explore the implementation of individual care plans in municipal elderly care in relation to characteristics of staff.

## 2. Method

### 2.1. Sample

The study was conducted in four municipalities in southern Sweden. All staff working in nursing homes, or with home nursing care for older people, were included ( $N = 908$ ). All working places were operated by the municipalities except for three nursing homes and one staff group providing home-help services to older people that were operated by private agencies.

### 2.2. Data and Data Collection

#### 2.2.1. Process

The concept “Process” was operationalised through the actual use of individual care plans and thus the number of established individual care plans in each municipality in collaboration with the county council was collected during a one-year period (November 2013 through December 2014). This was done through a form filled in by contact persons in the municipalities and the private agencies. The form was filled in continuously by the contact persons regarding the date and the organisations involved in the establishment of each individual care plan.

#### 2.2.2. Characteristics of Staff

Data regarding “Characteristics of individuals/staff” was derived through a questionnaire and distributed to staff at baseline in November 2013. The questionnaires were distributed by a contact person at each working place and were returned to the research group in preaddressed envelopes after they were completed. The contact persons were also responsible for reminding the staff to fill in and return the questionnaire. Thus, the research group did not know the names of those who received the questionnaires and was not in control of how and when staff was reminded. This procedure made the respondents anonymous to the research group. The respondent gave their consent to participate in the study by ticking in a box in the questionnaire and by returning the completed questionnaire. The questionnaire took approximately 30 minutes to complete.

The construct “Knowledge and beliefs about the intervention” was operationalised through seven statements constructed for this study. The statements were intended to capture the subjective opinions and beliefs among staff regarding access to resources and support in terms of own knowledge and received education (statement 1 - 2), presence of routines and time (statement 3 - 4) and their overall acceptance of ICP as an effective and useful tool (statement 5 - 7). The statements were scored on a four-point scale ranging from 1 = disagree completely to 4 = agree completely.

The construct of “Individual identification with organisation” was operationalised through The Psychosocial Aspects of Job Satisfaction questionnaire [13]. The questionnaire contains 49 questions measuring eight factors (4 - 11 questions/factor); Workload, Criticism, Cooperation, Expectations and demands, Personal development, Internal motivation, External motivation and Position in the group. The questions are scored on a five-point scale ranging from 0 = never to 4 = very often. Total scores are transformed to 0 - 100 for each factor by summing and dividing raw scores by the highest possible score in each factor and multiplied by 100. This makes it possible to compare factor scores even if they contain various numbers of items [13]. Higher scores indicate a more desirable state. The psychometric properties of the instrument have been shown to be acceptable [13].

### 2.3. Data Analyses

To explore variation in the process of implementing ICP in relation to characteristics of staff the sample was divided into two groups. The division was based on the variation in the process outcome *i.e.* the number of established ICP in the municipalities during the study year. The municipality that had the most number of established ICP (municipality I) was compared to those that had fewer and more similar number of established plans (municipalities II-V) regarding the beliefs about individual care plans and job satisfaction among staff. Comparisons were performed using Mann-Whitney U-test for ordinal data and Student’s t-test for numeric data. A p-value below 0.05 was regarded as significant.

A total of 46 out of 49 items in the Satisfaction with Work Questionnaire had less than 5% missing values. The question “cooperation with colleagues” had 5.7% missing values and the question “cooperation with staff in other units” had 7.8% missing values. These missing values were replaced with the median value of the group (*i.e.* municipality with most individual care plans and municipalities with fewer). The items with more missing

values were: “criticism from subordinates” (33.3%) and “praise from subordinates” (33.9%). Due to the high number of missing values these two questions were excluded in the calculation of total scores for the factors they belonged to, *i.e.* Criticism or Position in the group, and in the calculation of total score for job satisfaction.

The Regional Ethical Review Board in Lund approved the study (Dnr 2013/549).

### 3. Results

In total 245 staff returned the questionnaire giving an overall response rate of 26.9%. Fifty-two persons declined participation by returning a form stating that they didn’t want to participate. The reasons given for not wanting to participate were not having the time ( $n = 8$ ), newly employed ( $n = 2$ ), not interested ( $n = 4$ ) and not relevant questions ( $n = 1$ ). A total of 76.3% of the respondents were assistant or auxiliary nurses, 13.1% were registered nurses, 5.7% were occupational therapists and 4.1% were physiotherapists. Five percent of the respondents had nine-year compulsory school education, 62% had upper secondary school education and 32% had university education. Ninety-five percent were women and the mean time working at the present working site were 10 years (range 0 - 38 years). There were no significant differences between the four municipalities regarding the proportion of each profession that responded to the questionnaire.

#### 3.1. Process

In total 47 individual care plans were established in the four municipalities during the study period. Of these, 31 were established in municipality I, three in municipality II, seven in municipality III and six in municipality IV (**Table 1**). A total of 39 were established in collaboration with primary healthcare and eight in collaboration with specialised hospital care.

#### 3.2. Characteristics of Staff in Relation to Process

Overall it was found high agreement and no significant differences between groups in the statements regarding knowledge about which information that should be written in a individual care plan (90.2% stating partly agree or agree completely); that an individual care plan is an effective tool to provide high quality care and service (91.9%); that an individual care plan is useful in collaboration with professionals in other organisations (90.1%) and that there should be more individual care plans established than at present (65.5%) (**Table 2**). A significantly larger proportion of staff in the municipality that had the most number of established individual care plans agreed that there had been a satisfactory amount of education about how to establish individual care plans (80.4% vs 63.8%), that there is sufficient time to establish them (58.9% vs 39.1%) and that there are routines in the organisation about how to establish the plans (73.2% vs 67.8%).

Overall the staff rated the highest value for internal motivation (mean 78.7) and the lowest for external motivation (mean 47.3) (**Table 3**). Staff working in the municipality that had the most number of established plans had a significantly higher (better) mean value compared to staff in the other municipalities regarding personal development (mean 71.1 vs 65.9), workload (mean 63.8 vs 56.5), expectations and demands (mean 65.7 vs 61.1), cooperation (mean 76.9 vs 70.1), position in the group (mean 66.4 vs 61.3) and total job satisfaction (mean 67.8 vs 62.5). There were no significant differences in the factors: criticism, internal motivation or external motivation.

**Table 1.** Inhabitants, number of established Individual Care Plans (ICP) and the number of respondents in the four municipalities.

	Inhabitants n/% aged 65+	Established ICP n	Staff N/n respondents
Municipality I	20 248/17.3	31	250/73
Municipality II (including one private nursing home)	17 211/17.9	3	283/72
Municipality III (including one private provider of social care and two private nursing homes)	22 994/18.9	7	181/37
Municipality IV	13 460/18.8	6	194/63

**Table 2.** Beliefs about Individual Care Plans (ICP) among staff in the total sample and comparisons of the municipality with the most established ICP and those with fewer.

	Total sample n = 245	Municipality I n = 73	Other municipalities (II-IV) n = 172	p-value*
It is clear to me which information that should be written in an ICP (%) (n = 174)				0.154
Disagree completely	2.9	0	4.2	
Partly disagree	6.9	3.6	8.5	
Partly agree	47.1	44.6	48.3	
Agree completely	43.1	51.8	39.0	
There has been a satisfactory amount of education about how to establish ICP (%) (n = 172)				0.017
Disagree completely	9.9	0	14.7	
Partly disagree	20.9	19.6	21.6	
Partly agree	47.1	51.8	44.8	
Agree completely	22.1	28.6	19.0	
There is sufficient time to establish ICP (%) (n = 171)				0.002
Disagree completely	12.3	0	18.3	
Partly disagree	42.1	41.1	42.6	
Partly agree	36.8	44.6	33.0	
Agree completely	8.8	14.3	6.1	
There are routines in the organisation about how to establish ICP (%) (n = 174)				0.014
Disagree completely	7.5	0	11.0	
Partly disagree	23.0	26.8	21.2	
Partly agree	45.4	39.3	48.3	
Agree completely	24.1	33.9	19.5	
ICP is an effective tool to provide high quality care and services (%) (n = 174)				0.668
Disagree completely	1.1	0	1.7	
Partly disagree	6.9	5.4	7.6	
Partly agree	42.5	41.1	43.2	
Agree completely	49.4	53.6	47.5	
ICP is useful in collaboration with professionals in other organisations (%) (n = 172)				0.106
Disagree completely	1.7	0	2.6	
Partly disagree	8.1	5.3	9.6	
Partly agree	45.9	38.6	49.6	
Agree completely	44.2	56.1	38.3	
There should be more ICP established than at present (%) (n = 170)				0.768
Disagree completely	12.4	8.9	14.0	
Partly disagree	22.4	25.0	21.1	
Partly agree	36.5	35.7	36.8	
Agree completely	28.8	30.4	28.1	

\*Mann-Whitney U-Test.

**Table 3.** Psychosocial aspects of job-satisfaction in the total sample and comparison between the municipality that had the most established ICP and those with fewer.

Factor	Total sample Mean (SD)	Municipality I Mean (SD)	Other municipalities (II-IV) Mean (SD)	p-value*
Personal development (n = 231)	67.5 (17.6)	71.1 (16.1)	65.9 (18.0)	0.039
Workload (n = 233)	58.7 (16.1)	63.8 (12.4)	56.5 (16.9)	0.001
Criticism (n = 232)	68.2 (14.5)	67.8 (14.1)	68.4 (14.7)	0.076
Expectations and demands (n = 239)	65.7 (12.2)	65.7 (14.1)	61.6 (16.5)	0.033
Cooperation (n = 228)	72.2 (15.2)	76.9 (11.0)	70.1 (16.3)	0.001
Internal motivation (n = 238)	78.7 (14.6)	79.6 (14.6)	78.3 (14.1)	0.514
External motivation (n = 234)	47.3 (18.0)	50.0 (15.2)	46.1 (19.1)	0.104
Position in the group (n = 238)	62.9 (15.2)	66.4 (12.6)	61.3 (16.0)	0.010
Total job satisfaction (n = 212)	64.2 (11.9)	67.8 (8.9)	62.5 (12.7)	0.001

\*Student's t-test.

#### 4. Discussion

The process of implementing ICP in municipal elderly care appears to be slow and varies between municipalities. Despite that ICP has been regulated since 2010. The results show a rather great disparity in the number of plans established, with one municipality having 31 and the other 3 - 7 (**Table 1**). According to the regulations an individual care plan should be established when a person has a need for both social services and healthcare, which means the majority of the elderly people who receive social services in the municipalities. Research has shown that 75% of elderly people who receive social services also have contact with outpatient care and 58% have contact with specialist care [15]. Thus, one could expect a higher number of established plans than demonstrated in the result. The problem, however, is that the regulation also states; *“The plan shall be established if the municipality or the county council determines that it is necessary for the individual to get their needs met”* [1] [2]. This wording leaves it open for interpretation regarding when an ICP should be established. Thus, the organisations that intend to implement the legislation are also expected to formulate the policy, *i.e.* they are policy makers and policy implementers at the same time [16]. The advantage of this is that the intervention or the policy can be adapted to fit the organisation and thus be easier to implement [14]. The management has a key role in the interpretation and the development of a clear policy adapted to each organisation. However, the problem is that there is a risk for disagreements regarding how to define the targeted population between the numerous organisations and providers involved in the establishment of ICP. Furthermore, it becomes difficult to evaluate the accuracy in the demonstrated number of established plans. The variation in the number of established ICP in this study might partly be explained by this problem. This has, however, not been investigated in this study and thus needs further exploration.

In general, staff within elderly care seemed to have positive attitudes about ICP with the majority in agreement that it was clear what information should be written in an care plan; the establishment of ICP is a useful document in the collaboration with other care providers; an individual care plan is an efficient tool in providing good quality in care and that they should be established more often (**Table 2**). These findings are encouraging since an acceptance of the intervention among staff increases motivation and the chances of successful implementation and use of an intervention. However, the variations in the process outcome *i.e.* the use of ICP between municipalities seems not to be explained by beliefs about the plans among staff, since there were no significant differences in the questions between the municipality that had the most established care plans and those with the fewest. The variation in the process seems rather to be influenced by differences in their perception of availability of resources *i.e.* the education of staff, staff time and the establishment of routines. The municipality that had the most established care plans had a significantly larger proportion of staff stating that there had been sufficient education and that there was a sufficient amount of time and routines regarding how to establish ICP (**Table 2**). This result is in line with previous research showing that organisational investments in terms of education [9] [17], time and staff [18] [19] are important in the implementation processes and cannot be ignored. However, the results in this study indicate that it might be necessary for managers and implementation leaders to pay at-



tention to the opinion about these investments among staff and not only to the investments per se. This knowledge is of value for future research as well as for managers involved in the ongoing process of implementing ICP in Sweden. However, due to the low response rate these findings should be interpreted with caution and more research is needed to confirm these results.

The construct in the theoretical framework referred to as “Individuals’ identification with organisation” seems to influence the implementation of individual care plans in municipal elderly care. The municipality that had the most established care plans had a significantly higher degree of general job satisfaction among staff and a higher mean value in six out of nine factors compared to the other municipalities (Table 3). According to the constructors a mean value above 75 is desirable [13] and this was found in the total sample in the factor “Internal motivation” and in the municipality that had the most established care plans in the factor “cooperation”. The mean values shown in this study do not differ from previous studies about job satisfaction among staff within elderly care [20] [21]. Previous studies have found that the caring climate, working environment and the leadership all have an impact on job satisfaction [21] [22]. Consequently, interventions improving the caring, working climate and leadership may have a positive impact on job-satisfaction and also the process of implementing individual care plans.

### Methodological Consideration

There are methodological issues that need to be addressed. The study does not include the characteristics of managers or staff working in the county council and thus does not cover all those involved in the process of implementing ICP in the care of older people. This limits the generalisations of the results and the conclusions that can be made regarding the influence of staff during the implementation process. The low response rate also constitutes a threat to the external validity in this study and limits the conclusions that can be made from the results. The low response rate may be explained by the facts that contact persons and not members of the research group were used to distribute the questionnaires and to inform and remind the staff about the study. For an increased control, the research group could have distributed the reminder to fill in the questionnaires to the staff. The low response rate may also be explained by the high workload and the lack of time among staff indicated in the results. Having more time available for responding to the questionnaire might have solved this problem. This has implications for future studies where questionnaires are used for data collections among staff working under pressure. However, despite the low response rate this study adds with valuable knowledge about a process that has not been explored previously, that is ongoing and involves large parts of the health-and social care sector in Sweden. Thus, the results are of significance for future research about this process as well as for policymakers and managers with responsibility for implementing ICP who might need to take the working conditions as well as the attitudes among staff into consideration.

A high degree of missing values were found in the items “criticism from subordinates” (33.3%) and “praise from subordinates” (33.9%) in the instrument Job Satisfaction Questionnaire, as were found in another study [23]. This could be due to the many items of the instrument but it is more likely that these questions were not applicable in this sample. The sample was comprised mostly of frontline staff, assistant or auxiliary nurses (76.3%), without any subordinates. For further research within this context it is suggested to take out these questions and further develop the instrument.

The Consolidated Framework for Implementation Research (CFIR) [5] provided this study with a pragmatic structure for organising the results and their influence on implementation of individual care plans in elderly care. The CFIR was shown to be useful and can serve as a guide to explore factors that influence the implementation of care plans. Such a framework promotes comparisons of the results with other contexts and studies over time.

### 5. Conclusion

The implementation of individual care plans remains a slow process with disparities between municipalities. Since it is up to each authority to determine when it is appropriate to establish an individual care plan, it is impossible to evaluate whether the established number of care plans is appropriate or not. In general, staff within elderly care seems to have a positive attitude towards individual care plans. The variation in the process of implementing the plans in municipal elderly care seems to be influenced by the perception of available resources and job satisfaction among staff. This study is explorative and the low response rate limits the conclusions that can be made. However, the results indicate that the working conditions and the prerequisite to establish ICP



among staff need to be taken into consideration in research and in the ongoing process of implementing ICP in municipal elderly care. Since ICP is regulated by law and a successful implementation may contribute to improved continuity and quality in care, this process is of great importance and needs further investigation.

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# Nurses' Experiences of Using the Liverpool Care Pathway Plan in Hospitalized Patients with Heart Failure in the End-of-Life Stage: A Qualitative Content Analysis

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## Abstract

**Background:** The introduction of care pathway plans for end-of-life cares such as the Liverpool Care Pathway (LCP) reveals a unique possibility for inter professional collaboration. Knowledge of symptom relief and how to meet the patients' needs at the last stage of the palliative phase are essential for the nurses' approach and care actions, but the documentation of such implementations is still rare and sometimes criticized. **Aim:** To explore and describe nurses' experiences of using the LCP plan with patients hospitalized with heart failure at the end-of-life stage. An explorative design was applied, using qualitative content analysis of 20 interviews with nurses practicing the LCP plan in two district hospitals in Norway. **Results:** The nurses found the LCP plan as quality assurance for treatment and care in patients with heart failure in the last hours and days of life. The use of the LCP plan implied: 1) individualized adjustment, 2) symptom relief and 3) a holistic approach. **Conclusion:** Nurses experienced that using the LCP plan as a comprehensive action plan contributed in the decision making process and improved inter professional communication. Using the LCP plan should be seen as a tool to practice individualized and holistic nursing to patients at the end-of-life and their families, as well as a purposeful relief of symptoms associated with heart failure.

## Keywords

End-of-Life Care, Heart Failure, Nursing, Palliative Care, Qualitative Method

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## 1. Introduction

Palliative care involves the active treatment and care of patients with incurable diseases and a short life expectancy. This end-of-life care aims to strengthen patients' possibility to accept death and prepare families for grief and bereavement [1]. Thus, its goal is to offer the best possible quality of life for both patients and their families. This ambition is also reflected in WHO's definition [2] of palliative care that can be seen, among others, in the hospice philosophy (Box 1). Effective palliative care at the outset can contribute to a positive clinical outcome as symptom alleviation and it improves patients' satisfaction with care [3]. Yet, even for experienced nurses, communication with patients and close relatives about death might be stressful, and emotional and existential reactions from patients and families might be difficult to handle [4] [5]. A coherent and clear theoretical framework for communication in palliative care is thus of utmost importance for nurses working in this area [6] [7]. Basic prerequisites for optimal palliative care are that nurses have the necessary professional expertise in knowledge, skills and attitudes [8] [11]. The introduction of care pathways plans for end-of-life care also reveals an unique possibility for interprofessional collaboration [12] [13].

### Box 1: The WHO definition of palliative care.

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual." ([2], p. 10)

The Liverpool Care Pathway (LCP) [14] is a care plan for patients in their last hours and days of life. The LCP plan is based on the hospice philosophy and was developed in England in the early 1990s. Today, it is internationally recognized as a model for support and care in patients at the end-of-life [4] [12], but not without criticism stating it is impossible for nurses and physicians to predict when death is imminent, why the decision to set a patient on the pathway is at worst self-fulfilling [15] [16]. Regardless, the LCP provides evidence-based guidance in relation to various aspects of end-of-life care such as recommended prescription of medication and discontinuation of unnecessary medication, psychological support, spiritual care, and not the least care of families [17] [18]. The LCP discontinues if the patients' condition improves, but resumes if deterioration recurs.

Heart failure is a progressive and irreversible clinical syndrome caused by different cardiac dysfunctions [1]. Advances in healthcare and reduction of mortality help explain the high prevalence of heart failure, as there is an ageing of the population and prolonged survival of patients suffering from ischemic heart disease, hypertension and a trial fibrillation [19]–[21]. Patients with heart failure are mainly treated with medication, but before end-of-life care, devices and interventions such as the implantable cardioverter defibrillator (CRT-D), ventricular assist device (LVAD) or heart transplantation might be appropriate [22].

Despite both bio-medical and existential needs at the end-of-life, individual care plans for patients with heart failure are seldom implemented [1] [23] [24]. This might be due to the often unpredictable prognosis of heart failure, making the "right time" for the decision on end-of-life care challenging [5] [25]. Nevertheless, knowledge of symptom relief and how to meet the patients' needs at the last stage of the palliative phase are important for the nurses' approach and care actions [17] [19] [25]. Nurses' experiences of using a palliative care plan such as the LCP plan are essential, but the documentation of such implementations is rare and sometimes contradictable. Therefore, the aim of this study was to explore and describe nurses' experiences of using the LCP plan in hospitalized patients with heart failure at the end-of-life stage.

## 2. Methods

### 2.1. Design, Setting and Method Description

The study used an explorative design based on qualitative content analysis, to provide knowledge and understanding of nurses' experiences of using the LCP plan. The study was carried out in two district hospitals in southwestern Norway. Qualitative content analysis was chosen, as it can be applied to analyze individual experiences. Using both manifest and latent content analyses provides more insightful and meaningful findings than using only one approach. Manifest analysis focuses on the visible and literal components in the text, while latent analysis aims to reflect the underlying meaning of what the text talks about [26].

## 2.2. Participants and Criteria

The inclusion criterion was nurses who had experience with using the LCP plan with a minimum of three patients with heart failure at the end-of-life. The exclusion criterion was nurses who did not master the Norwegian language. Both the inclusion and exclusion criteria were set to assure the quality of the interviews. To ensure a broad sample with maximum variation, a strategic sampling [27] of 20 nurses was carried out, where participants varied in terms of age, sex, educational level, years of nursing experience and geographical area (Table 1).

## 2.3. Interviews

The three authors, all with experience on the subject and methods, developed an open interview guide based on the three elements of the LCP plan [28]. Two pilot interviews with nurses well-experienced in using the LCP plan were conducted by the first author to test the interview guide and process. These pilot interviews are excluded in the study and did not result in any adjustments. The interviews were conducted by the first author, who aimed to establish a relation to the participants. The opening question was: “What are your experiences with using the LCP plan in relation to patients suffering from heart failure?” Follow-up questions to explore the experiences with each of the three parts of the LCP plan were; “What was the most challenging topic while using the LCP plan?”, “What area was the most challenging for the patient?”, “How well did the collaboration with the physicians work out?”, “How were families taken care of?” The participants were encouraged to provide more in-depth information, for example by being asked to elaborate answers with concrete examples [27].

## 2.4. Data Collection

Participants were contacted through their head nurse and asked if they were willing to participate in the study. The 20- to 60-minute long tape-recorded interviews took place from December 2013 to January 2014 in an undisturbed place at their own departments.

**Table 1.** Socio-demographic and clinical characteristics of the nurses using the Liverpool Care Pathway plan in hospitalized patients with heart failure in the end-of-life stage.

Nurses	20
Age (years)	
-29	4
30 - 39	4
40 - 49	6
50 - 59	5
60-	1
Sex	
Male	6
Female	14
Geographic area	
Urban area	8
Rural area	12
Educational level	
Bachelor	9
Specialist education	11
Years of nursing experience	
-3	1
3 - 9	5
10 - 19	6
20 - 29	5
30-	3

## 2.5. Data Analysis

Data analysis was carried out stepwise according to Graneheim & Lundman's [26] six steps of qualitative content analysis. The interviews were analyzed and transcribed verbatim by the first author. An awareness of pre-understanding supported the authors to bracket the data [27]. In the analysis process, the intention was to remain true to the text and preserve contextual meanings in both the manifest and the latent content. The text was both listened to and read repeatedly by the authors to obtain a sense of the whole. Significant meaning units that matched the aim of the study were identified, condensed and coded. Differences and similarities among various codes were compared in order to sort out sub-categories and categories (Table 2). The codes were grouped into 38 subcategories which were abstracted into three categories. These categories reflected the central message and constituted the manifest content, *i.e.* what the text says. These categories were then tied together and further abstracted into a theme reflecting the underlying meaning, *i.e.* the latent content (Table 3). To ensure strength and trustworthiness of the results, the text and selected segments were examined repeatedly. The authors critically examined and discussed until consensus was reached [26] [27].

## 2.6. Ethical Considerations

The study conformed to the principles outlined in the Declaration of Helsinki and obtained ethical approval from the Norwegian Social Science Data service (36313/2013). The director and the head nurses of the departments gave their written consent before each participant was approached. Verbal and written information was given to each participant to obtain informed consent, and they were also reassured that they could withdraw from the study at any time. Confidentiality was ensured in the study by storing the interview material according to current data regulations

## 2.7. Findings

The emerging theme emphasized LCP plan as a form of quality assurance for treatment and care for patients with heart failure in the last hours and days of life. The LCP appeared to be helpful in assuring quality of treatment and nursing care in the end-of-life in patients suffering from heart failure. The LCP was a clear and necessary action plan for patients with heart failure at the end-of-life stage where the objective was to improve the care in the last days and hours of life. Moreover, the transition from usual care to the LCP plan was thoroughly evaluated by an interprofessional team of nurses and physicians, and all reversible causes for deterioration had to be considered. In using the LCP plan, the importance of being a well-educated nurse to make correct assessments about timing was central. The assessments and conversations between nurses and physicians before the transition to the LCP plan were, according to the participants, essential when evaluating the patient's physical and mental health.

**Table 2.** An example of the data analysis procedure regarding the emerged abstraction levels in nurses' experiences of using LCP plan to patients with heart failure in the end-of-life stage.

Meaning units	Condensed meaning units	Sub-category	Category
"Great variation in the need of information both for patients and relatives...some are very well prepared"	Great variation in need of information	Adapted information	Adapted individually
"Inform about priest available—do not need to be a Christian to have a meeting with the priest"	Offer a meeting with the priest	Take care of spiritual and existential needs	Adapted individually
"LCP ensures that the evaluation of deactivation of CRT-D is done"	Deactivation of CRT-D	Avoid electro shock	Symptom relief
"Give furosemide through the last few days to avoid dyspnea to dying patients with heart failure"	Furosemide important medication	Adapted symptom relief	Symptom relief
"LCP contributes to a new focus for everyone involved...more calmness"	Changes focus from curation to palliation	Acceptance of the last stage	Holistic approach
"Primary nursing is the better—to get to know each other"	Make continuation	Security and stability	Holistic approach

**Table 3.** Overview of quotations, condensed meaning units, sub-categories, categories and theme regarding the emerged abstraction levels in nurses' experiences of using LCP plan to patients with heart failure in the end-of-life stage.

Quotations	Sub-categories	Categories	Theme
I will continue with exercise training not only during the rehabilitation programme but also when I come home, and thereby attempt to delay another MI.	Motivated to change	Individualized adjustment	LCP plan as quality assurance for treatment and care for patients with heart failure in the last hours and days of life.
I have decided that this will be a new life. Friends and colleagues will be there for me if I need them.	Having a new life		
You need an inner strength to achieve goals. Many people give up, but you can do one thing at the time. You don't have to do it all at the same time.	Learning a lesson		
I tell my husband that we shall do what we want to do. The day will appear soon enough when it's too late.	Seeing the bright side of life	Symptom relief	
The positive effect of this acute heart attack is that you get a kick in your ass. If I just keep on going, I'm sure I will end up here at the hospital again.	Changing attitude towards life		
I have a country house, where I spend the whole summer season. I always long to travel up there and I look very much forward to go there again, if I still keep healthy.	Having future plans	Holistic approach	
I work too much. I don't know if it matters, but I had a particularly stressful day when I was diagnosed with my MI.	Searching for precipitating causes		
Sometimes I feel discouraged. But I have a wife, children, and grandchildren...and I want to be there for them, just not sit in a chair for the rest of my life.	Feeling discouraged		
If I have to leave hospital in my present condition, both my relatives and I will be seriously anxious. Both my angina and my breathing problems concern me a lot.	Feeling ill and anxious		

## 2.8. Individualized Adjustment

The LCP plan was experienced by participants as increasing their awareness of the aspects of end-of-life. To meet the patients' unique experiences and needs, nurses had to make individual adjustments: "*The wife and daughters were concerned about how he (the patient) would accept that the treatment did not have any effect this time, ...he could not come home anymore..., they were not yet ready to let the physician tell the patient....This was done the next day, and then they were ready....*". The nurses confirmed that the individualized adjustments contributed to better understanding and cooperation between them and the patients. The consultations with patients and families, which were well-prepared and conducted in a good atmosphere and with both the nurse and the physician present, were regarded as highly important. The communication should be reciprocal to avoid misunderstandings.

## 2.9. Symptom Relief

A high level of competence both in palliative care and cardiac nursing was of importance to relieve symptoms. When starting the LCP plan, deactivation of the CRT-D had to be discussed, but dyspnea was graded as the main problem: "*It seemed so tiring...she struggled with heavy breathing...she gurgled actually...it came so suddenly...my colleague nurse had just been there...but they (the family) had to call us. I came back... late...they thought...looking at their mom...she was given both furosemide and morphine...it only took a few minutes before her breathing improved...after she had received furosemide more frequently...*". The nurses experienced that it was challenging to titrate Furosemide for optimal symptom relief. They needed to know the medications well, both its effects and side effects. In cooperation with patients and families, it was easier to make a good evaluation and obtain symptom relief.

## 2.10. Holistic Approach

A holistic approach was necessary to see patients in their context and to understand the interaction within fami-



lies. Creating an environment of patients with heart failure at the end-of-life stage, where all unnecessary equipment are removed to provide a “human atmosphere” was of utmost importance, especially for symptom reliefs of all types. The introduction of the LCP plan changed the focus from curing and life-prolonging treatment to optimal and immediate pain relief: *“It was very special...when it was decided...everyone was suddenly more peaceful...everything changed...for the better...Now it was more quiet...And now they wanted the minister present...and they sat and dined and talked together...I think the patient felt a kind of calmness...he was more peaceful too...not struggling...everyone was more peaceful...”*. The nurses revealed the importance of education in the use of the LCP plan, both for themselves and physicians, to be able to make “the right decisions” on when to include the patient on the LCP plan. A common assessment based on good communication and knowledge about the patient was important, but the complexity of the situation sometimes caused delays in applying the action plan.

### 3. Discussion

#### 3.1. Results Considerations

The nurses in our study graded the LCP plan as important for improving the quality of support and care in the last days and hours for patients with heart failure at the end-of-life stage. To succeed in the implementation of the LCP plan, a good training program was needed. The nurses expressed that common training and education together with physicians in the use of the LCP plan was necessary. Such improvement tools are supportive for nurses and physicians to predict when death is imminent, and thereby make the correct decision to set a patient on the pathway. These results reinforce the conclusions from recent studies [7] [15]–[17], that there are differences in opportunities for good quality of care in a palliative care unit compared to an internal medicine ward. A holistic approach, *i.e.* meeting the patients’ total needs, is of utmost importance as individualized and tailored nursing is essential for patients, but also their families.

#### 3.2. Individualized Adjustment

The LCP plan is documented in such a way that all information is written by the nurses on a printed form. The nurses regretted that the space for writing information was too limited. The strict rules for translation, due to copyright reasons, also made the content confusing and could lead to misunderstandings when filling up the form. This supports the importance of regular training and mentorship to assure the quality of care when using the LCP [15]–[17]. The nurses confirmed the challenge of finding the right time to introduce the LCP plan, an experience they shared with the physicians. There are patients suffering from many symptoms, but often experience a relief with correct treatments. The time it takes for patients to feel the benefits of treatment is however difficult to establish, which thus may result in delay in the start of the LCP plan. Also, Dee and Endacott [6] in their interviews with nurses and physicians found that “the right time” to initiate the LCP plan was problematic, independent of the patient’s diagnosis. Accordingly, end-of-life care has to be individually adjusted.

The results of our study also found the LCP plan to be significant in securing quality of care as well as quality assurance in this individualized adjustment. Several studies describe that good communication skills are important to succeed in using the LCP plan [12] [19] [27]. In line with Veerbeek *et al.* [11], the nurses in our study experienced that the LCP plan was important for a more individualized and tailored communication. In line with Di Leo *et al.* [29] and O’Hara [21] our study calls attention to the importance of using the interprofessional approach, with physicians and nurses doing the assessments together. Designing a plan together contributed to a continual assessment for individualized and tailored adjustment, leading to coordinated and coherent information not only for patients but also for their families. When the information was understood and nurses were able to give individualized adjustments, this constituted the backbone to sufficient relief, a conclusion also shared by Hanks *et al.* [2].

#### 3.3. Symptom Relief

Dyspnea was pointed out as the most crucial symptom to relieve, and the use of furosemide as the standard medication in the LCP plan was therefore an important finding in the study. Accordingly, the nurses had years of experience in titrating furosemide to relieve symptoms for patients with heart failure at the end-of-life stage. There were patients who had continuous infusions of furosemide until the decision was made to introduce the



LCP plan. This infusion had small effect on urinal production, and only a partial effect on dyspnea, which is in line with Hanks *et al.* [2]. Nurses in our study found that dry mouth was relieved by regular oral hygiene and small mouthfuls of water, ice or fruit cubes, as long as patients were able to swallow. In the Srivastava and Ting study [30] where patients had been denied drinking from the time the LCP plan started, the authors underline this grave misunderstanding and the importance of education in palliative care. Ordination of medication as a separate point in the LCP plan results to a quicker response to symptoms, as nurses could administer the medications on indication following the algorithms [28]. Our study implies that nurses need to be able to show empathy and understanding, and use individualized adjustments to take care of patients' primary needs.

### 3.4. Holistic Approach

Our study found that when the quest for effective treatment was finished and the transition to the LCP care was accepted, the focus changed for all parties involved. The nurses experienced more tranquility and a peaceful atmosphere around patients. The last days of life are characterized by sorrow, as well as crisis when patients have a sudden change in prognosis and patients and families are not prepared. The holistic approach thus has to focus on the patients' and families' total needs through the end-of-life. In line with Hanks *et al.* [2], the nurses in our study valued open, honest and coordinated communication as essential meeting all those needs. Further, when patients' conditions worsened making them unable to communicate, a close partnership with families was necessary [9] [15]–[17]. This underlines the nurses' conviction on the necessity of a holistic approach, *i.e.* the ability to grasp the condition as a contextual whole. Accordingly, the fundamentals in human existence demand a substantial competence from nurses [1].

### 3.5. Methodological Considerations

In a qualitative content analysis, the credibility, dependability, conformability and transferability should be discussed in relation to the trustworthiness of the study [26] [27]. In both the data collection and analysis, *credibility* was strengthened by the use of an open interview guide, which encouraged nurses to reflect on the phenomenon of using the LCP plan in hospitalized patients with heart failure at the end-of-life stage. In addition, follow-up questions were posed in order to avoid misunderstanding and to explain personal understanding in more detail, strengthening credibility. The interview guide guaranteed that the same open-ended questions were posed to all nurses. Each experience was described by several nurses augmenting a sufficient credibility. And finally, the authors' familiarity with the phenomenon and the fact that two pilot interviews were carried out also contributes to credibility. *Dependability* was strengthened by the fact that the data analysis sought to "identify" nurses' experiences of using the LCP plan in hospitalized patients with heart failure at the end-of-life. In the analysis, the authors attempted to be open to all experiences that corresponded to the aim. Dependability was increased by the fact that the co-authors were familiar with the methods, and interpretations were compared and revised until a negotiating consensus was reached between authors. *Confirmability* is considered relevant due to the way the data was systematically and carefully handled, using repeated readings, identification and reflection on the experiences. Furthermore, that the interviews were performed and transcribed by the main author and all six steps of the analysis was conscientiously used and reported, support confirmability. Experiences are described in as much detail as possible considering text limitations and quotations were used to strengthen and elucidate their content. An awareness of pre-understandings helped the authors to bracket the data. This means being aware of one's own attitudes and being attentive to how these might affect their own interpretations. *Transferability* was strengthened by the method and recruitment process, which were intended to provide maximum information. Qualitative content analysis is a method with high applicability for exploring human experiences of a phenomenon [27]. With regards to applicability of the study, it is a strength that two hospitals using the LCP plan were included in the study and that the selection took account of nurses' socio-demographic and clinical variables, such as age, sex, and length of experience. Accordingly, 20 nurses were found sufficient as this data was manageable and provided variation in experiences, thereby making our findings relevant for a national outlook from a qualitative method perspective.

### 3.6. Conclusion and Implications for Practice

This study highlights the need for a holistic approach when caring for patients with heart failure at the end-of-

life ensuring true patient and family involvements. Nursing organization and practice, the nurse role and expertise as well as individual needs and perspectives have to be integrated in the nurses' use of a care plan such as the LCP plan, for patients in their last hours and days of life. The social environment, a professional approach and value-adding measures are particularly relevant for optimal care offered by nurses in the hospital setting. Understanding the complexity of the situation of patients at the end-of-life stage, a palliative care plan such as the LCP plan is essential for reducing patients' symptoms and their families' burden. Therefore, it is substantial to incorporate the present findings in both clinical practice and in healthcare education deciding when to set patients on the pathway. More research is needed to establish strategies for individual and family tailored care needs, which is a fundamental condition for holistic nursing care.

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# Utilized Theories by Nursing in the Care of People with an Ostomy: Integrative Review

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## Abstract

**Objective:** To identify in the literature the theories used by nursing professionals in the care of people with an ostomy. **Method:** It's about an integrative review of the literature used in the LILACS, BDENF, PubMed Central, CINAHL, *Web of Science* and SCOPUS database. **Results:** The sample was made of 18 publications. Most of them were studies published in the last five years (44.4%), international publications (72.2%), published in international periodicals (66.7%), with level IV of evidence (83.3%). It was identified in the articles that the nursing theories were shown as the most used by the nurses in the care of people with an ostomy (55.5%), followed by the theories borrowed from psychology (38.9%) and, finally, the theories borrowed from pedagogy (22.2%). **Conclusion:** The nurses are using the assistance nursing models with a higher frequency to subsidize their surveys, as well as borrowed theories, mostly being performed and published internationally and with a low evidence level, highlighting the need of studies with a higher stringent methodology and, beyond this, analysis research of the used theories.

## Keywords

Ostomy, Nursing Cares, Nursing Theory, Nursing Models

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## 1. Introduction

The theories are made of a set of concepts and suppositions that show a global and systemic view of a determined phenomenon. They are used to explain, prescribe, describe and diagnose actions and can be applied in the

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practical, teaching, management and research field [1].

The importance to adopt the theoretical triad, research and clinical practice is clear as we perceive that the inter-relation between these concepts promotes the ongoing search in understanding the determinants of health problems to solve the needs of the individuals that are requiring an intervention to improve their health condition [1] [2].

However, the complexity in providing care to the population, demands from the nurse, a solidified knowledge and he must make good use of the used instruments in order to offer certainty in the assistance and to make a path to structure the nursing as a science. The nursing theories are an example of this kind of scientific tool.

In the nursing, the use of theories reflects the structure of self-sufficiency and the search to make a body of self-knowledge that meets the singularities of the profession and the social context [3]. To build this body of knowledge, the nursing professionals have identified representative phenomenon and acted upon them with specific views that innovate the know-how [4].

Some specific groups require a special attention from the professionals in reason of all the provoked nuances and the people with an ostomy are a part of those groups. Patients submitted to such procedure have their body image changed in a bad way by the stool evacuation in the ostomy pouch in the abdominal region [5].

The impact due to the making of an ostomy, brings various changes/difficulties to the individual that reflect in a modification of the life perspective, in the biological, psychological, social and spiritual aspects, contributing to reduction of his quality of life [6].

Faced by this situation, it's most important that the nurses use the nursing theories to support their experience and provide a quality assistance to these people. However, by learning about the used theories in nursing, it's important to remember that it evolves a lot during the last decades and that their knowledge foundation is a compilation of numerous different disciplines [7] and because of that, the nursing theories are not the only ones used in the practical assistance of the nurses.

In this overview, it's possible to see the need to extend and solidify the nursing knowledge by their body of self-knowledge, surpassing the technical barrier that is imposed to them in order to advance as a science. Because of that, it's necessary to evaluate the actual context of how and which theories are being used by nursing professionals in the care of people with an ostomy, through the execution of an integrative review of the literature for being a useful instrument and wide in the set of summary materials and data analysis, with a structured and clear methodology in order to establish a guidance and scientific base for the health workers to be applied in the health services [8].

Based on what has been exposed, the study had as purpose, to identify in the literature, the theories used by nursing professionals in the care of people with an ostomy.

## 2. Method

It's about an integrative review of the literature, which allows to make an actual source of knowledge about a determined problem and to summarize the available studies, to conduct the experience based on scientific knowledge [9].

To the development of this study, the following steps were used: theme identification and making of the research question, establishment of the conditions to include and exclude the studies, definition of the data that will be obtained from the selected studies, categorization of the studies, evaluation of the chosen studies, interpretation of the results and exhibition of the summary of information [10].

The step of data gathering occurred in December 2015, upon online search of the articles that answered the following guiding question: what are the theories that are being used by nursing in the care of patients with an ostomy?

The database used were from the Latin American Literature and Caribbean health sciences (LILACS), BNDEF—nursing accessed by the virtual library in health—BVS, PubMed Central, *Cumulative Index to Nursing and Allied Health Literature* (CINAHL), *Web of Science* and *SciVerseScopus* (SCOPUS).

During the investigation of the publications, non-controlled descriptors from the *Medical Subject Heading* (MeSH) were used, in the English Language: “Ostomy”; “Nursing Care” “Theory”. The linking of those descriptors upon the use of the Boolean operator AND.

To select the articles, the following conditions of inclusion were established: complete available articles in the database named above, no time and language restriction and that had submitted on their results at least one

theory used in the care of people with an ostomy. The studies were counted only one time in the database, excluding the ones in editorial form, letter to the editor and literature review. The search for the articles in the databases flowchart and the acquiring of the selected articles is shown on **Table 1**.

To analyze the level of evidence, it was used as parameter the Joanna Briggs Institute—JBI that classifies the studies on the four levels of scientific evidence [11].

In relation to the analysis and data extraction, instruments with the purpose to incorporate the acquiring of the theories that shape the research were used. The instruments were adapted from the models available by the JBI and referred to the initial evaluation to determine if the studies met the inclusion conditions and if the theory was or not described, critical appreciation to evaluate the study and methodological aspects and description of the characteristics of the studies to make the data analysis easier [8].

Finally, after a detailed reading of the selected articles at the previous step, it was defined the 18 articles that integrated the final sample of this integrative review of the literature. About the ethical aspects of the studies, the authorship of the studied articles was respected.

### 3. Results

From the 18 articles selected on the sample, 8 (44.4%) were published in the last five years, 13 (72.2%) are international researches, 12 (66.7%) published in international periodicals and 16 (88.9%) presented level IV of evidence. **Table 2** shows more information about this data.

The nursing theories were presented as the most used by the nurses in the care of people with an ostomy 10 (55.5%), followed by the theories borrowed from psychology 7 (38.9%) and, finally, the theories borrowed from pedagogy 4 (22.2%). **Table 3** and **Table 4** present the details of the information regarding the use of these theories in the nursing care [12]–[24].

Most of the selected studies to the sample, 9 (50%) used these theories applying them as theoretical references to analyze the data gathered. Others 6 (33.3%) used the theory to guide dissertation texts about determined themes related to the ostomy. The rest, 3 (16.7%) applied the theory directly to the person with an ostomy, performing the process and proposed steps by the theory and/or assistance model.

Those last ones [25]–[30] were not analyzed using the utilized instrument in this study, bearing in mind that they did not answered a lot of questions from the use of the instrument. However, they were not excluded in reason of being considered as a part of the available scientific literature about the study object in question, and, therefore, important in the characterization of the theories used in the researches performed by nurses about the care of the person with an ostomy.

### 4. Discussion

The nursing theories represent the formal expression of the empirical pattern of the knowledge of this science, and form the base of the progressive attribution of meaning to the Nursing on the basis of the preparation and

**Table 1.** Number of located studies (L), potentially relevant studies (R), excluded studies for being duplicated (D), selected for complete reading (S) and final sample (A) by linking the descriptors *ostomy*, *nursing care* and *theory* on the researched databases.

<i>Ostomy and nursing care and theory</i>					
Bases	L	R	D	S	A
Lilacs	7	7	0	7	4
Bdenf	2	2	0	1	1
Cinahl	44	17	3	12	10
Pubmed	86	3	0	3	3
Scopus	19	6	5	0	0
Web of science	3	3	3	0	0
<b>Total</b>	161	38	11	23	18



**Table 2.** Characterization of the studies about the place of publication, year of publication, methodological aspects and level of scientific evidence.

Place of publication	Year of publication	Methodological aspects	Level of evidence
Brazil	2014	Transversal, descriptive and qualitative	IV
Brazil	2013	Transversal, descriptive and qualitative	IV
Brazil	2008	Case study	IV
Brazil	2013	Transversal, descriptive, quantitative and qualitative	IV
USA	2005	Case study	IV
USA	1997	Case study	IV
USA	2008	Transversal, analytical e quantitativeandqualitative	III.2
USA	2002	Transversal, analytical and quantitative	IV
USA	1999	Transversal, analytical and quantitative	IV
USA	2011	Transversal, descriptive and qualitative	IV
USA	2015	Longitudinal, descriptive and quantitative	III.3
USA	2014	Transversal, descriptive and qualitative	IV
Brazil	2007	Bibliographic research	IV
USA	2012	Bibliographic research	IV
USA	2015	Bibliographic research	IV
USA	1999	Bibliographic research	IV
USA	1996	Bibliographic research	IV
USA	2003	Bibliographic research	IV

**Table 3.** Distribution of the studies from the step of critical appreciation of the theories.

ID	The theory was described?	The theoretical model used is based in one single or multiple theory?	The chosen methodology is consistent with what the theory implies?	The theory is being applied, tested, created or discussed?	The limits and potentials of the theories were evaluated?
12	Yes	Single theory	Yes	Yes	No
13	Yes	Single theory	Yes	Yes	No
14	Yes	Single theory	No	Yes	No
15	Yes	Single theory	Yes	Yes	No
16	Yes	Single theory	Yes	Yes	No
17	Yes	Single theory	Yes	Yes	No
18	Yes	Single theory	No	Yes	No
19	Yes	Single theory	Yes	Yes	No
20	Yes	Multiple	Yes	Yes	No
21	Yes	Single theory	Yes	Yes	No
22	Yes	Single theory	No	Yes	No
23	Yes	Single theory	No	Yes	No

communication of a specific body of knowledge that subsidize the professional experience. This way, the theories are presented to the Nursing as a fundamental instrument to make it possible the external recognition of the profession and self-sufficiency, making the theoretical bases that support the research, teaching and experience clear [4].

The evaluation process of the nursing theories is an essential component in the development of the nursing knowledge and show a critical element in the construction of the discipline. The evaluation of a theory can help

**Table 4.** Distribution of the studies from the step of the extraction of the data from the theories.

ID	Used theory	Author(s)	Study objective	Theory (applied, tested, created or discussed?)
12	Transitions theory	Afaf Meleis	Know the facilitators of the transition process of the dependency to the self-care of a person with an ostomy.	Applied
13	Self-care theory	Dorothea E. Orem	Identify the constraint factors to the self-care in patients with an ostomy and verify knowledge and experience about the care with an ostomy.	Applied
14	Self-care theory	Dorothea E. Orem	Apply the Self-care Theory of Orem in the assistance of the patient with an ostomy.	Applied
15	Basic human needs theory	Wanda Horta	Describe the daily problems lived by patients with Urinary Diversion and relate them with the Basic Human Needs Theory of Wanda Horta.	Applied
16	Self-care theory	Dorothea E. Orem	Describe the interventions made to promote the self-care of and elder with intestinal ostomy.	Applied
17	Cultural diversity and universal theory	Madeleine Leininger	Describe a theory of nursing that support the meaning of culture as an essential concept of the nursing experience.	Applied
18	Transpersonal care theory	Jean Watson	Analyze the spiritual quality of life of the seniors with intestinal ostomy.	Applied
19	Family system theory	Von Bertalanffy	Investigate the relation between the familiar dynamics and control locus of health in families that had a member with an ostomy.	Applied
20	Adaptation model and stress theory	Callista Roy e Lazarus & Folkman	Identify which factors contribute to the post-surgery adjustment of patients that had been submitted to a surgery of permanent colostomy.	Applied
21	Ecological social theory	M. Powell Lawton	Identify the factors that hinder or ease the detection and treatment of an ostomy and skin issues.	Applied
22	Self-care theory of orem	Dorothea E. Orem	Investigate the assistance of perioperative nursing and methods to improve the quality of life.	Applied
23	Stress theory	Lazarus & Folkman	Describe the strategies developed by the patients with digestive ostomy to deal with their situation.	Applied

determine which model and/or theory is more appropriated to determined practical and research situations, as well as help in the comparison and explication of a same nursing phenomenon [30].

Despite the importance of this process, the study's results show the gap in this aspect of the production analysis, bearing in mind that none of the articles that compose the sample have the goal of analyzing any theory. Even so, some studies used theoretical references, of both Nursing and borrowed, to support the care of people with an ostomy, a step that could be justified and credited after the analysis of those theories in this specific population.

The 18 articles of the sample from this study show that the quantitative of the production referring the use of the nursing theories, or borrowed, used by nurses in the care of people with an ostomy, is still small, when compared to the numbers of publications about the theme, of both national and international scope [31].

This way, the knowledge and use of nursing theories must be each time more included to the nursing actions, because they surround and give visibility to the know-how of the profession, differentiating them from the others health classes. The college education that reflects directly in the knowledge of the nurses about the theories has the mission to foster and stimulate the improvement of the use of the theories in the most diverse areas of nursing [32].

Despite this, the nursing experience is, a lot of times, based by a mental model that each nurse, or group of nurses, adopt to substantiate their actions from the clinical practice and personal experiences, resulting in a shared knowledge that use, or do not use, the theoretical foundations that can be clearly defined, recognizing the importance of this definition during the professional formation [33].

Beyond this, some studies show the deficit on the knowledge of the professionals about the theoretical device of the nurses, highlighting the difficulties in the choice of a theoretical positioning that permeate the experience and supply of a nursing teaching with quality that support and bring closer the theoretical scientific know-how of the assistance and professional practical action. Such results reflect negatively in the self-sufficiency production of the assistance and scientific care of nursing [34] [35].

It is possible to see that most 11 (61.1%) of the results of this revision is composed by studies that used theoretical reference borrowed to subsidize the research about the nursing care to people with an ostomy, being the theories of psychology and pedagogy the ones most quoted.

The use of borrowed theories was occurring as the nursing care identified the multiplicity of determinant aspects and constraints of the health-disease process. Thereby, to supply integral care, or build a wide theoretical model, it's required of the nurses to consider factors like physical, behavior, social, economics, psychological, among others, that are involved in the health assistance of people with intestinal ostomy [7].

The study of those elements that permeate the care, and their incorporation of them to the planning, execution and evaluation of the nursing care, form the use of borrowed theories. This way, the psychology shows concepts and theories that are clearly needed as a technical support in the health assistance of this population. The body image is one of them, being one of the main aspects that interfere in the quality of life and adaptation of the person with an ostomy [7] [18] [36] [37].

The stress, approached by the psychologists Lazarus and Strauss, also show a well explored field by nurses that study the adaptive process of the person with an intestinal ostomy. The adaptive and self-care needs, body image disorder, depression, social isolation, changes in the sexual functions and reduction of the independency are some of the factors frequently found in the literature that substantiate the care of those people [37]-[40].

Other theory from psychology that subsidize the care of people with an ostomy is the System Family Theory, present in all the sample studies. The family must be totally inserted in all the stages of the care of the person with an ostomy, bearing in mind that in the first months the adaptive demand and the care with the pouch generally require family support [41].

The person's family also receive a high emotional load that is present since the health-disease process that gave origin to the ostomy, stage of rehabilitation, treatment and stays during all the adaptive curse of the person with an ostomy. Some family reports reflect the high physical and psychological demands that permeate the care, or even the aid, to the person with an ostomy, that requires an acquisition of new abilities, time availability, emotional and financial support [42].

The theories from pedagogy represent 4 (22.2%) of the total of the studies that are part of the sample. This amount shows the importance of the knowledge related to the educative process to the person with an ostomy, as well as revealing this function of the nurse in the care to those people. The education in health is shown as one of the most remarkable interventions of nursing in the promotion of self-care, reflecting directly in the quality of life and adaptation of the individuals with an ostomy [43] [44].

There are various strategies of teaching to people with an ostomy, which use a theoretical device from pedagogy and nursing, coating itself with innovative technologies, to provide the professional of nursing the maximum of pedagogical options to attend the educational needs of the greatest number of people with an ostomy and their relatives [43].

The nursing theories represent the majority of the studies that form the sample 10 (55.5%) being 8 (80%) assistance models. The assistance models present themselves as the first theoretical concepts and denote a more abstract and wide level of knowledge of nursing, show from the global point of view, are not specific, present abstract and non-operational defined concepts and generally are not possible to test. The use of assistance models can direct the professional experience of the nurse providing him with the guidelines to the planning, execution and evaluation of the nursing care, being possible to analyze them in the perspective of various situations and populations [7] [45].

On the other hand, 5 (50%) of the studies that were about the nursing theories used the Theory of Orem. The General Theory of Orem is formed by three theoretical constructors: The Self-care, the deficiencies of the self-care and the nursing systems, making the emphasis on the theoretical model in the promotion of self-care aiming the improvement of the quality of life, health and well-fare of the patients clearer. The majority of the studies made using this model has elected as target audience individuals with chronic needs, explored the theory in its entirety and had as a goal to improve the process of care [46].

After the preparation, the person with an ostomy needs to acquire knowledge and abilities in order to take care, observe and protect the ostomy in the best way possible. The orientations referent to this must be realized as soon as possible, still during the internment, however, as this is not granted, the associations of people with an ostomy present themselves as a system of support and education to promote the know-how and the experience needed to the care of the ostomy. This way, the Theory of Orem provides subsidies to direct the nursing experience in the care of the person with an ostomy aiming the self-care and consequently improves adaptation in the quality of life [13].

Another model of nursing present in the sample of this study is the Basic Human Needs Theory of Wanda Horta. It's about a Brazilian theory that nowadays has been the foundation of the preparation and implementation of the nursing process in six stages in various institutions, being, therefore, another option of theoretical contribution to subsidize the assistance provision of nursing directed and systematized [47] [48].

However, it's possible to see that, although recognizing the importance of the Systematization of the nursing assistance, the knowledge referent to this process still needs to be learned by the professionals, since a lot of them don't know even the theory that it supports [47].

To close, only two studies [12] [21] used the theories of medium range, transitions theory and transpersonal care theory, which are lesser wide than the big theories, they present a medium view of reality, therefore, are more specific than the assistance model, or big theory, have a limited amount of concepts relatively precise and operationally defined, distinctly declared propositions, can generate hypothesis that are possible to test and can evolve from the assistance models [7].

This possibility of testing in practice gives advantages to the results referent to the theories of medium range identified in this studies, being them the Cultural Diversity and Universal Theory of Leiniger and the Transitions Theory of Meleis. The purpose of the first is to generate knowledge related to the nursing care of people that value their cultural heritage and their way of life, having as a goal to provide the care culturally coherent to individuals of various cultures. On the other hand, the last one, is about the process of transition in a patient after the changes in his life and disease patterns.

Both theories are clearly visualized as possibilities of choice to be applied during the practice of the nursing assistance to people with an ostomy, bearing in mind that the adaptive process and the impact of the ostomy in the lives of the people can change in relation to the understanding of the health-disease process in determined cultures, as well as demands in the care during the transition process after this condition are various and are subject to changes considering the determinants and constraints of health [7].

This being said, the use of assistance models, the nursing and borrowed theories are presented in the literature as possibilities of the theoretical device capable of subsidizing the professionals experience in the care of the person with an ostomy and their relatives. Furthermore, it's clear that the theories borrowed presents a fundamental part in the construction of nursing knowledge, bearing in mind that the subsidy provided that ends in a vision of the nursing of a determined phenomenon.

## 5. Conclusions

After the realization of this study, it is possible to conclude that the nurses have been using the nursing theories with a higher frequency in comparison to the borrowed theories, followed by the borrowed theories from psychology and pedagogy.

It's possible to see the increase in the scientific productions that clearly shows the use of one theory in the last five years, being most of the studies made and published in international territory and with level IV of evidence, in other words, it is needed that the studies with higher level of evidence should be used in order to provide reliable and safe subsidy to the science of nursing to lay the foundation of the professional experience and the researches in this field.

It's also possible to understand a gap in the literature referring to the analysis of the used theories in the care of people with an ostomy, especially about the assistance models of nursing. It's also necessary to point the need of studies with a higher level of evidence, which could be foundations to the practice of nursing in a safer and more efficient way.

This study provides to the nurses that aid people with an ostomy, and their relatives, various options of theories and assistance models that have already been used to support researches related to this theme, which can be tested and applied in individuals with an ostomy in other territories, as well as the analysis of them, which strengthen and enrich the specific knowledge of nursing, fortifying it as a health science.

To close, this study demonstrates the scientific production aiming the direction to its praxis, considering the important need to bring the theory, which is clearly defined, closer to the practice, ending in the immersion of the being in the signification of his attitudes as a nurse.

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# Care Technologies in Nursing for People with Colorectal Neoplasia: Integrative Review

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## Abstract

**Objective:** Identifying in the literature the care technologies used by nurses for people with colorectal neoplasia on Nietzsche's conceptual perspective. **Method:** It consists in an integrative review of the literature held in the database: Latin-American Literature and Caribbean in medical health sciences Literature Analysis and Retrieval System Online, Database in Nursing, US National Library of Medicine, Cumulative Index to Nursing & Allied Health Literature, Scopus Info Site and Web of Science in December 2015. **Results:** 28 articles were selected to compose the final sample of this review, which were analyzed and categorized in management technology (86.20%), assistance technology (20.68%) and educational technology (10.34%). Studies published in the last five years have predominated (62.06%), in international territory (82.75%) and with evidence level IV (44.82%). **Conclusion:** Today the growth on the production about this theme has been highlighted, but there is an important discrepancy between the researches with high and low level of scientific evidence, showing the need of more studies about technologies that strengthen the experience of nursing.

## Keywords

Nursing, Colorectal Neoplasia, Technology, Oncological Nursing

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## 1. Introduction

Nursing has achieved, in the last decades, a growth and transformation of its work process. This way, it led to an

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incorporation of new technologies and expansion of the possibilities on the fields of work. This process is complex and leads to new demands for the job, that generates the need of constant theoretical-practical update on the part of the nurses [1].

Working with nursing involves the constant use of technologies from the specific knowledge of the profession. Such technologies are a result of a process made from the daily experience and results of researches, seeking the development of scientific expertise to the idealization of material products, or not, that generates interventions in a determined practical situation [1] [2].

According to Nietzsche, the concept of Technology is understood as a result of implemented cases from the daily experience and research, to the development of a scientific knowledge set for the creation of material products, or not, with the goal to provoke interventions on a determined practical situation. All this process must be systematically evaluated and controlled [3].

Care technologies are classified by Nietzsche in educational: “systematic set of scientific expertise that make it possible the planning, execution, control and monitoring involving all the educational process”, assistance: “construction of a technical-scientific knowledge that is a result of investigations, application of theories and the daily experience of the professional and the clientele, constituting, therefore, in a set of systematic, processual and instrumental actions to the delivery of a qualified assistance to the human being in all dimensions”; and, finally, managerial: “systematic process and documented theoretical-practical actions (planning, execution and evaluation), used in the management of the assistance and health services, to intervene on the professional practical context, seeking an improvement of its quality” [3].

According to global estimates, the colorectal cancer is the third most common type among men, and the second among women, being those the ones that affect some portion of the large intestine and the rectum. In Brazil, it is estimated that between 2016 and 2017 it will appear approximately 34,280 thousands new cases of this type of cancer.

Among the risk factors to the development of this tumor stand out the age above 50 years, familial history, obesity, low consumption of calcium, sedentary lifestyle, inadequate food habits, especially the excessive consumption of meat, and inflammatory diseases of the intestine [4] [5].

The treatment of colorectal cancer encompasses chemotherapy and/or surgery and brings consequences to the psychological, social and physical domains of the individual, in addition to affecting his quality of life due to changes on the lifestyle, the confrontation of the stigma around the cancer. These are factors which require from the nursing a specialized care to this clientele [6] [7].

In this meantime, it's indispensable that the nursing develops proper technologies directed to the individual with colorectal cancer that approach all the complexity of the care that he needs since the diagnostic of the disease, passing through all his treatment, until the post-treatment interventions [8] [9].

From what is exposed, the objective of this study was to identify in the literature the care technologies used by nurses, from the Nietzsche's theoretical reference to people with colorectal neoplasia [2].

## 2. Methodology

It consists in an integrative review of the literature, method that makes it possible a broad understanding about a determined subject and to identify the gaps of knowledge [10]. As the guiding question the study had: “What are the nursing technologies used in the care of people with colorectal neoplasia?”

To carry out this research, the following stages were made: identification of the problem, establishment of conditions to inclusion and exclusion of studies (sample selection), definition of the data that will be acquired from the selected studies, analysis of the selected studies, interpretation of the results and display of the review [11].

The data gathering was performed during the month of January 2016, covering articles in complete text format. The inclusion condition taken was: electronically complete available articles, about the studied theme; Portuguese, Spanish and English published articles. The excluded ones were editorials, reflection articles, letters, opinion articles, book chapters, theses, dissertations, sneak preview notes and manuals.

The search was made based on the following database: Latin-American and Caribbean in medical health sciences Literature (LILACS) Medical Literature Analysis and Retrieval System Online (Medline), database on nursing (BDENF), US National Library of Medicine (PUBMED), Cumulative Index to Nursing & Allied Health Literature (CINAHL), Scopus Info Site (SCOPUS) and Web of Science, using Desc/MeSH descriptors. **Chart 1** quantitatively details the steps of the study to acquire the final sample.

**Chart 1.** Strategy of search and number of articles found in the database.

Database	Strategy of Search	Found Articles
LILACS	(Colorectal neoplasia) AND (tw: (("Nursing Care" OR "Oncological Nursing")))	11
MEDLINE	(Colorectal neoplasia) AND (tw: (("Nursing Care" OR "Oncological Nursing")))	47
BDENF	(Colorectal neoplasia) AND (tw: (("Nursing Care" OR "Oncological Nursing")))	3
PUBMED	(Colorectal neoplasia) AND (tw: (("Nursing Care" OR "Oncological Nursing")))	12
CINAHL	(Colorectal neoplasia) AND (tw: (("Nursing Care" OR "Oncological Nursing")))	34
SCOPUS	(Colorectal neoplasia) AND (("nursing care" OR "oncological nursing")) AND (LIMIT-TO (EXACTSRCTITLE, "Cancer Nursing")) AND (LIMIT-TO (DOCTYPE, "ar")) AND (LIMIT-TO (SUBJAREA, "NURS")) AND (LIMIT-TO (SRCTYPE, "j"))	99
Web of Science	(colorectal neoplasia) AND (tw: (("Nursing Care" OR "Oncological Nursing")))	0

Source: Data from the research, 2016.

The search on the database was performed separately, by two researchers, being the disagreements between the results solved by common understanding among them.

To the selection of the studies, the PRISMA recommendations were used as shown in [Figure 1 \[12\]](#). During the data collection there were excluded studies because they did not gave the proper answer to the guiding question and the ones duplicated in the database were also excluded.

During the evaluation and categorization of the studies, the authors created an instrument, to obtain the information of the studies. This had: identification of the articles, objectives of the study, methodological design, participants, results, difficulties/limitations, conclusions and implications to the Nursing pointed out by the researchers, and the technology in Nursing used.

To analyze the level of evidence, the Institute Joanna Briggs parameter was used, which classifies the studies in four levels of scientific evidence, being: "Level I: Randomized evidence; Level II: Evidence obtained from at least one controlled randomized clinical trial; Level III.1: Evidence obtained from well-planned controlled clinical trials, without randomization; Level III.2: Evidence obtained from well-planned cohort studies or case-control, analytical studies, preferably of one more center or research group; Level III.3: Evidence obtained from multiple temporal series, with or without intervention and dramatic results in non-controlled experiments; Level IV: Statement of respected authorities, based on the clinical conditions and experience, descriptive studies or reports of a committee of experts [13].

The descriptive presentation was chosen along with its discussions, seeking a better appreciation.

### 3. Results and Discussion

Among the 28 selected articles to the sample that had technologies about the care in nursing, 10 were selected in the database MEDLINE, 5 in the LILACS, nine in the CINAHL and four in the PUBMED.

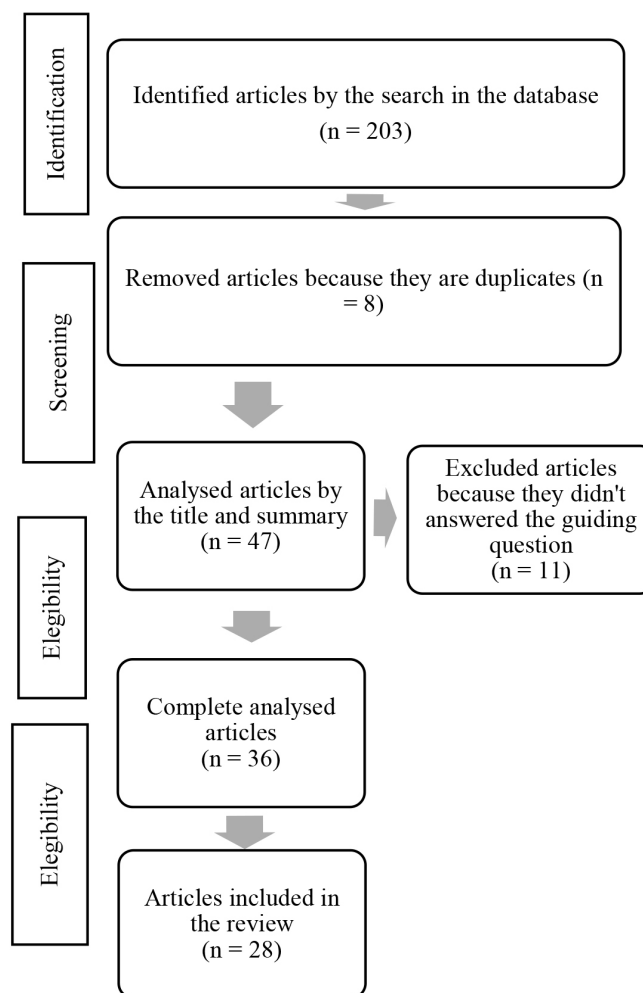
About the year of publication, it's possible to see that most of the publications were between 2011 and 2015 (62.06%). It's possible to see that most of the analyzed studies (82.75%) were published in international journals and 57.1% in journal of the Nursing field.

Although there were studies found in Brazil (17.5%), being those in the South and Southwest regions of the country, the studies included countries of the American, Asiatic, European and Oceania continents, reflex of the globalization of the disease and relevance in its study.

About the level of evidence, 44.82% of the studies, being descriptive studies or with a qualitative approach, were classified with level IV; 24.13% for representing the well-planned cohort studies or case-control, and analytical studies were classified with level of evidence III.2. And 20.68% as it's about randomized clinical trials were classified with level of evidence II [14].

The results of the studies were grouped in three categories based on the approached technology. Most of the studies (86.20%) were about the management technologies; followed by the researches that were about the assistance technologies (20.68%); and just three articles (10.34%) came as a result of researchin the educational care technologies.

It's important to highlight that one technology can be used to the analysis or improvement of another



**Figure 1.** Flowchart of the selection of the articles for the integrative review of the literature, made from the PRISMA recommendations [12].

technology and they complement each other. The analysis of the technologies was made considering the planning of the studies and their results, which are shown in **Table 1**.

Technologies are taken as a “set of systematized theoretical-practical actions used on the management of the care and health services” [1] [2]. The studies that approached this kind of technology investigated the ways of evaluation of the care, the perception of the individuals about the disease, the health services and other aspects to generate information that led to an improvement to the care and the services performed for them.

Five studies measured the quality of life of the patient with colorectal cancer, some approaching the treatment or the specific outcome of the disease, with the goal of planning and management of the assistance performed to the patients in a way to increase their quality of life, in addition to promote better post advising [14]–[17].

Studies about the quality of life are becoming common between the nurses all around the world and it's because most part of the clients assisted by the nursing team suffers from chronical affections or long treatment, where the cure is not always a possibility, but a healthy quality of life must be sought and developed. Nurses of Hong Kong highlight studies of this kind, which map the degrees of quality of life, help the professionals to identify people at risk of suffering a reduction on the quality of life and projection and also to plan interventions of appropriate care to improve their quality of life [18].

In addition, one of the main surgical treatments of colorectal neoplasia is undergoing an intestinal ostomy, a procedure that brings countless physical and psychological consequences, like a shift in the elimination of stool, body image disorder, sexual dysfunction, depression, social isolation, among other factors that affect directly on

**Table 1.** Distribution of the studies in relation to the management technologies used on the care of the people with colorectal neoplasia.

ID	Used Technology
A.M. O'MARA AND A.M. DENICOFF. 2010	Measurement of the quality of life of the people with colorectal neoplasia used to plan and manage the health assistance.
K. BEAVER <i>ET AL.</i> 2011	Evaluation of the satisfaction of the clients with colorectal neoplasia from tracking over telephone.
B. MCCARTHY. 2014	Exploration of the perception of the people with colorectal neoplasia and their relatives, about their relation with the health professionals that rendered assistance during the chemotherapeutic treatment.
A. S. ANDERSON <i>ET AL.</i> 2013	Evaluation of the knowledge of medics and nurses about the risks and benefits of the weight management in patients with colorectal neoplasia to identify the barriers noticed when giving advices about the life style of those clients.
SIERKO, E. <i>ET AL.</i> 2011	Identification of the physical, psychological and social needs of the patients with colorectal neoplasia with an advanced diagnostic of the disease.
JONSSON <i>ET AL.</i> 2011	Description of the immediate post-surgery experience after the operation of colorectal neoplasia.
MAHTICONA BENAVENTE SB, SANTOS MONTEIRO EM, SIQUEIRA COSTA AL. 2015	Evaluation of the socio-cultural and gender factors in the Afro-American population in relation to the decision about the tracking of the colorectal neoplasia.
FAUL <i>ET AL.</i> 2012	Evaluation of the benefits of the assistance plans to the survivors of colorectal neoplasia.
M. G. A. NORWOOD <i>ET AL.</i> 2011	Comparison of the costs and labor needs of the Nursing on the open surgical and laparoscopic approaches on the treatment of colorectal neoplasia.
BUETTO LS, ZAGO MMF. 2015	Interpretation of the meanings attributed to the quality of life of patients with colorectal neoplasia in chemotherapy.
UCHIMURA TT. 2008	Identify the profile of people with colostomy registered in the Attention Program of people with colostomy of Paraná.
MICHELONE APC, SANTOS VLCG. 2004	Comparison of the quality of life of the patients with colorectal neoplasia with and without intestinal ostomy.
TICONA BENAVENTE SB, SANTOS MONTEIRO EM, SIQUEIRA COSTA AL. 2015	Exploration of the differences of gender on the stress and confrontation strategies in people with colorectal neoplasia.
CHAVES PL, GORINI MIPC. 2011	Evaluation of the quality of life of people with colorectal neoplasia.
GROCOTT, P <i>ET AL.</i> 2001 PART. 1	Refinement of the validity of the matter of an auditing tool that defines and measures the best practices in nursing to the patient with colorectal cancer and identify fields to the development of this field.
GROCOTT, P <i>ET AL.</i> 2001 PART. 2	Refinement of the validity of the matter of an auditing tool that defines and measures the best practices in nursing to the patient with colorectal cancer and identify fields to the development of this field.
C.J.H. VAN DE VELDE <i>ET AL.</i> 2013	Multidisciplinary consensus of experts, using the Delphi technique, with the goal of defining core treatment strategies and development of a structured European auditing, to improve the quality of the care to all patients with cancer in the colon and rectum.
C.J.H. VAN DE VELDE <i>ET AL.</i> 2014	Multidisciplinary consensus of experts, using the Delphi technique, with the goal of defining core treatment strategies and development of a structured European auditing, to improve the quality of the care to all patients with cancer in the colon and rectum.
MAHON <i>ET AL.</i> 2000	Establishment of strategies of screening to detect early colorectal neoplasia, to implement educational activities and clinical protocols.
MAZANEC SR, FLOCKE SA, DALY BJ. 2015	Investigation about the feelings and habits of life of patients with colorectal neoplasia and their relatives, to subsidize posterior interventions of the nursing team.
LIN WL, <i>ET AL.</i> 2014	Evaluation of the satisfaction of the patients with colorectal neoplasia in relation to the telephone advising service realized by nurses.
JEFFORD M. <i>ET AL.</i> 2013	Evaluation of the impact of an educative intervention realized from on-site visits and phone calls.
GREEN BB. 2010	Determination of the effectiveness and cost-effectiveness relation of the phased increases in support systems to increase the colorectal neoplasia tracking and the follow-up after a positive screening test.
JESSICA T. DEFRANK, 2007	Evaluation of the perception of the body image of people with colorectal neoplasia to subsidize the psychological needs of the care of nursing of those people.



the quality of life of those people. The Nursing acts intervening at different stages of this process, taking care to improve the quality of life and self-care [18].

Four studies brought evaluations of the satisfaction of patients in relation to the health services, their perceptions about the relationship with the professionals and the monitoring over phone made by nurses to the patients that are not in outpatient/hospital treatment anymore [19]-[22]. The satisfaction of the patient is shown as an indicator of the quality of the health assistance performed by the institution and receives positive influence of factors like the absence of lucrative intention of the hospital, localization in urban environment, teaching hospital, more numbers of nurses, lower readmission and mortality perioperative rates [23].

As it was said, the nurses have an essential role on the health services relative to the management of the services and the care of the nursing team, studies about the evaluation of the satisfaction in these cares are relevant to direct and propose changes in a way to strengthen the reach of the results [24].

One study evaluated the knowledge of the professionals about the risks and benefits of the weight management in patients with colorectal neoplasia. Studies of systematic review with meta-analysis including data of countries from North America, Europe and Oceania reinforce the association between the weight gain in adult, young or advanced ages, to both genders on the development of the colorectal cancer [25].

Four studies traced the profile of the patients, being the investigation about the physical, psychological and social needs of this clientele, in addition to the feeling and life habits of patients with colorectal neoplasia and their relatives related to the stages experienced during the diagnostic and treatment, with the objective of supporting subsequent interventions of the nursing team [26]-[29].

Unfavorable socioeconomic characteristics like low income, non-ideal residence, exposure to atmospheric pollution in heavily industrialized fields, normally are connected to risky behavior like unbalanced diets, use of alcohol and tobacco, sedentary lifestyle. Beyond that, these populations are normally inserted in the informal labor market or in unhealthy conditions, which ends bringing higher occupational risks (accidents, professional diseases) and precarious home conditions. Associated to all these aggravating circumstances, there is also the difficulty to access health services. All of those factors increase the risk of developing diseases and makes it difficult the detection and appropriate treatment of them [30]-[32].

One study evaluated the influence of the socio-cultural and gender factors and their extension at the decision about the tracking of colorectal neoplasia [33]. The tracking program, or patient navigation program, seems to have a positive effect over time by accelerating the diagnostic after four months of follow-up, being, therefore, an important strategy in the early care of this type of cancer [34].

One study developed a strategy of screening to detect an early colorectal cancer for subsequent implementation of clinical protocols and educative activities [35]. And five studies approached an evaluation of measure instruments, assistance plans and care strategies to this clientele. One study even compared two different surgical approaches in relation to the costs of the nursing assistance to the bearer of colorectal cancer [36]-[41]. The preparation and implementation of these protocols involves the use of high quality scientific evidence, as well as the use of pointers to evaluate them, which involve the complete diagnostic of the colorectal neoplasia, determination of the carcinoembryonic antigen (CEA) serum in the post-operative period, lymph nodes exams, daily cleanse of the operative wound, reference to the oncologist, use of chemotherapy adjuvants after 8 weeks of the surgery and evaluation of the obstruction from the colonoscopy. Beyond that, the evaluation of the hospital costs forms a factor to determine the patient satisfaction [42] [43].

Consequently, studies that approach assistance technologies used in the care to the people with colorectal neoplasia were also identified. They are demonstrated in **Table 2**.

The assistance technologies involve “the construction of a self-technical-scientific know-how and procedures and techniques used for the care” [2], therefore, it involves an application of an intervention on the other by part of the nursing team.

Few studies brought as research results the use of assistance care technologies in nursing, yet, showed new approaches of nursing interventions. One of them approaches an intervention that make records of the patients that must be tracked, with the goal to ensure the referral process to the treatment and preparation of the patients to a complete the diagnostic test [44].

A second study describes the use and benefits of the acupuncture in the recovery of patients with colorectal neoplasia submitted to surgical treatment [45]. And the last study found is about the nursing assistance made by professionals that received specific treatment about time commitment, maximum number of clients for each nurse and approaching to the patient with colorectal neoplasia in psychological suffering during the treatment

**Table 2.** Distribution of the studies in relation to the assistance technologies used in the care of the people with colorectal neoplasia.

ID	Used Technology
GREEN <i>ET AL.</i> 2010	Intervention of nursing that makes records of the patients that must be tracked, ensure the process of referral of the treatment and prepare the patients to complete the diagnostic test.
CHAO, H <i>ET AL.</i> 2013	Use of acupuncture on the recovery of patients with colorectal neoplasia that were submitted to surgical treatment.
WAGNER <i>ET AL.</i> ,y 2014	Assistance of differentiated nursing made by professionals that received specific training about time commitment, maximum number of clients to each nurse and an approach to the patient with colorectal neoplasia in psychological suffering during the treatment.
SARAH K. ROSENBLOOM, 2007	Execution of periodic evaluations of quality of life of the patients with colorectal neoplasia, followed by structured interviews to advice and discussion about the clinical condition of the client.

and the benefits of a different approach [46].

This amount of results shows a gap in the literature in what refers to the study of nursing intervention, with high level of evidence, being this type of research fundamental to the progress of science in this job, subsidizing, with a larger safety, the nursing techniques on the care to the people with colorectal neoplasia [47]. This way, it's important to highlight the importance of the promotion of the nursing interventions, to supply a wide array of even larger options to professionals aiming to obtain the appropriate technology, in other words, the one that attend to the needs and expectations of a determined population, bearing in mind that the nursing techniques and technologies that form the nursing know-how used by the ones that execute it to the improvement of their praxis [48].

As it follows, there are the educational technologies used in the care to the people with colorectal neoplasia, which are shown in **Table 3**.

Educational technology used in the care refers to a “systematic set of knowledge that makes it possible the planning, execution, control and follow-up of an educational process” [2], where it is needed an educator/facilitator and the pupil that in nursing corresponds respectively to the nurse and the clientele. The present study identified three studies with educational technologies as results of the nursing range of activity.

Two of them implemented and evaluated education programs and evaluated the impact of this intervention on patients with colorectal cancer in of after treatment [21]-[49]. A third study after evaluating the quality of life of the clients conducted counseling and discussion about their clinical condition [50].

A study made in Australia evaluated the quality of the communication skills of the nurse in his interaction with the clients highlighting the clinical knowledge, the need to establish a close and trustworthy relationship with the client, have the sensibility to identify the needs of the client and readiness to listen to his information, in addition to the capacity to adapt the form of supplying information to each client individually, are characteristics considered fundamental so that the nurse can develop a good role as a health educator [51].

The needs of self-care of the patient with colorectal neoplasia are various, especially after the surgical approach of intestinal resection. The nursing has been building methods of teaching to the patient so he can comprehend the disease and the precautions needed during the treatment, like the manipulation of the ostomy pouch, that includes traditional instructions, use of DVD's, interaction group and feedback over phone [52]-[54].

From what has been exposed, it's important to highlight that the use of the nursing know-how as technology has an emancipating nature to the science and the job, used as an instrument to overcome obstacles and restrictions that submit the labor process of the nurse. So, the construction of self-knowledge of the nursing helps to build the critical conscience of the nurses, and the population, in the pursuit for freedom and autonomy of nursing to supply the specific cares for the people with colorectal neoplasia [48].

## 4. Conclusion

From Nietzsche's theoretical reference, it was possible to identify the technologies used by the nurses in the care of people with colorectal neoplasia, being most of them classified as management technology (86.20%), followed by the assistance technology (20.68%) and lastly, educational technology (10.34%). Studies published in the last five years have predominated (62.06%), in international territory (82.75%) and with level of evidence IV (44.82%).

**Table 3.** Distribution of the studies in relation to the educational technologies used in the care to the people with colorectal neoplasia.

ID	Used technology
G. KNOWLES ET AL. 2008	Implementation of an education program based on the evidences and evaluation of the impact of these interventions from the perception of changes in the professional experience of the nurses.
JEFFORD M. ET AL. 2013	Preparation, implementation and evaluation of an individualized educative plan to the patients after the treatment of colorectal neoplasia.

Currently, it's possible to see an increase in nursing scientific production about care technologies for people with colorectal neoplasia, but, most of the studies have limited themselves to describe a few important aspects to the managing activity of nursing, highlighting that the know-how, as an emancipatory technology, remains at the exploratory stage of the aspects involved in the health assistance of these individuals.

Therefore, it becomes evident that the scientific gap in the productions with high level of evidence forms the self-sufficient knowledge about the care and nursing interventions that may subsidize the professional technique more efficiently in relation to the safety and positive results on the population at issue.

Thus, this study shows itself as a type of technology available to subsidize the knowledge of the nurses related to the actual overview of the publications about the care technologies for people with colorectal neoplasia, as well as provides contributions to the advance of nursing science using as theoretical background a nurse with PhD at the theme, emphasizing and expanding the technological know-how of this job.

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# Using Gene Expression Analysis to Examine Changes in Loneliness, Depression and Systemic Inflammation in Lonely Chronically Ill Older Adults\*

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## Abstract

**Purpose:** The purpose of this study was to evaluate the effectiveness of LISTEN (Loneliness Intervention) on loneliness, depression, physical health, systemic inflammation, and genomic expression in a sample of lonely, chronically ill, older adults. **Methods:** This was a prospective, longitudinal randomized trial of LISTEN, a novel intervention based on theories of narrative and cognitive restructuring to target specific aspects of loneliness. Twenty-three older, lonely, chronically ill adults were recruited from a family medicine clinic in West Virginia. Participants were randomized to two groups, 13 in LISTEN group (Loneliness Intervention) and 10 in attention control (healthy aging education). Participants attended an enrollment session where they completed consent, survey data (including sociodemographics and chronic illness diagnoses), baseline physical measures, and blood sampling for gene expression analysis. After completing the 5 weekly sessions, all participants attended a 12 week post data collection meeting (17 weeks post-baseline) for survey completion, physical measures and blood sampling. **Results:** The results of this study show that the LISTEN intervention improves measures of physical and psychosocial health. Specifically, subjects enrolled in LISTEN showed reductions in systolic blood pressure, as well as decreased feelings of loneliness and depression. These changes may be due, in part, to a reduction in systemic inflammation, as measured by interleukin-2. **Conclusion:** This study provides support for the use of LISTEN in reducing loneliness in chronically ill, older adults. Further, while some of our results are inconclusive, it provides rationale to expand our study population to evaluate the relationship between loneliness and systemic inflammation. In the future, enhancing knowledge about

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**the relationships among loneliness, chronic illness, systemic inflammation, and gene expression of these particular targets, and how these relationships may change over time with intervention will inform translation of findings to clinical settings.**

## Keywords

**Loneliness, Depression, Gene Expression, Inflammation**

## 1. Introduction

Loneliness is a biopsychosocial stressor that elicits a neuroimmunological stress response that has been consistently associated with multiple cardiovascular morbidities like hypertension [1]-[3] and coronary artery disease [4] [5], immunosuppression [6]-[8], elevated blood glucose [9], and depression [10] [11]. The exact mechanism by which loneliness affects physical health is unclear but it is thought to be mediated through immune [12]-[14] and inflammatory regulation over time [1] [4] [15]. Recent studies indicate that socially stressed persons are at increased risk for other chronic inflammation-related illnesses like neurodegenerative diseases [16] [17] and some cancers [18] [19].

Interleukin-2 (IL-2) and interleukin 6 (IL-6) are two commonly used markers of inflammation, and increased expression of both IL-2 and IL-6 has been shown in cardiovascular disease [20], COPD [21] [22], loneliness [23]-[25] and depression [26] [27]. Pro-inflammatory cytokines, such as IL-2 and IL-6, act on the brain by activating the hypothalamic-pituitary-adrenal (HPA) axis. HPA axis activation ultimately leads to a secretion of glucocorticoids from the adrenal cortex, mainly cortisol, leading to inhibition of pro-inflammatory signaling pathways [16] [18]. The dynamics between inflammation, HPA-axis activation, and loneliness are quite complex. The majority of studies suggest that loneliness is associated with both increase inflammation and increased cortisol secretion, but given the negative feedback regulation of cortisol on pro-inflammatory signaling, these findings together may seem contradictory [28]. As such, there is still much to be known about the dynamics of inflammation and HPA-axis activity, especially in regards to loneliness.

Understanding the role of IL-6 in the inflammatory process is difficult since decreases in IL-6 may actually be a sign of failing to self-regulate an inflammatory process [29]. One gene expression study of 25 participants in the top quartile of the UCLA Loneliness scale scores over a 3 year period, controlled for age, gender, race/ethnicity, marital status, income, and BMI, reports that 98 genes show a  $\geq 15\%$  difference in average expression in high-lonely individuals when compared to low lonely people. In this study, highly lonely people have a repressive effect on leukocyte activation and it is important to note in this study that the high lonely people have a mean score of 46.5 on the UCLA loneliness scale (scale range 20 - 80) [8].

The purpose of this study was to evaluate the effectiveness of LISTEN (Loneliness Intervention) on loneliness, depression, physical health, systemic inflammation, and genomic expression in a sample of lonely, chronically ill, older adults. The study had three aims: 1) to describe the relationship between chronic illness burden and loneliness; 2) to describe the changes in loneliness, depression, blood pressure, and BMI over time in chronically ill lonely older adults who have participated in a randomized trial of an intervention for loneliness, and 3) to describe differences in the systemic inflammation and gene expression between participants of LISTEN and attention-control groups.

## 2. Methods

### 2.1. Human Subjects Protection

This study was approved by the WVU Institutional Review Board. Written informed consent was obtained from all subjects or their authorized representatives prior to performing study procedures.

### 2.2. Design, Sample, and Setting

This was a prospective, longitudinal randomized trial of LISTEN, a novel intervention designed to target specific aspects of loneliness. LISTEN is based on theories of narrative and principles of cognitive restructuring. The

development of LISTEN and initial feasibility and acceptability has been previously published in OJN [30] [31]. Twenty-three older, lonely, chronically ill adults were recruited from a primary care center at a university based family medicine clinic in West Virginia between September 2013 and September 2015. To be included, participants had to be aged 65 years or older, living in the community, chronically ill, able to interact in a group intervention setting (minimum mini-mental status score of 23), and moderately lonely (a minimum score of 40 on the revised UCLA Loneliness Scale) [32]. Participants were randomized to two groups, 13 in LISTEN group (Loneliness Intervention) and 10 in attention control (AC) (healthy aging education). Participants of LISTEN attended sessions that focused on belongingness, relationships, socialization in community, challenges of loneliness, and meaning of loneliness. Participants of the attention control groups received educational lectures on physical changes associated with aging, healthy diet, aging health, prevention of stroke, and routine preventive healthcare. All participants attended 5 sequential weekly 2 hour sessions in the same building at the same times on the same days to ensure fidelity. After completing the 5 weekly sessions, all participants attended a 12 week post data collection meeting (17 weeks post-baseline) for survey completion, physical measures and blood sampling (Figure 1). All sessions were audio and video recorded.

Participants attended an enrollment session where they completed consent, survey data (including sociodemographics and chronic illness diagnoses), baseline physical measures, and blood sampling. Sociodemographic information collected included age, gender, marital status, highest level of education completed, household income, and employment status. Physical measurements included height, weight, blood pressure, salivary cortisol, and number of chronic illness diagnoses. Psychosocial measures included depression via the 5 item Geriatric Depression Scale (GDS) [33] and loneliness via the revised UCLA Loneliness scale [32]. The development of the 5-item GDS was based on the diagnostic criteria from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition. Scores on this scale range from 0 - 5 and the scale has a reported sensitivity of 0.94 and a specificity of 0.81 [33]. The UCLA Loneliness scale scores range from 20 - 80, with 80 indicating very high loneliness.

### 2.3. Measuring Salivary Cortisol Levels

Salivary cortisol concentrations were measured using the Adrenocortex Stress Profile kit (Genova Diagnostics). Per the kit manufacturer instructions, saliva was collected at four time points to allow for circadian patterns of cortisol release: morning within one hour of waking, midday (11 am - 1 pm), afternoon (3 pm - 5 pm), and evening (10 pm - 12 pm).

### 2.4. Blood Sample Collection

Whole blood samples were drawn into PAXgene tubes during standard phlebotomy. PAXgene tubes were immediately inverted 8 - 10 times to ensure red blood cell lysis, de-identified and stored for future analysis. The PAXgene blood RNA tubes contain a reagent that prevents RNA degradation and preserves the RNA expression

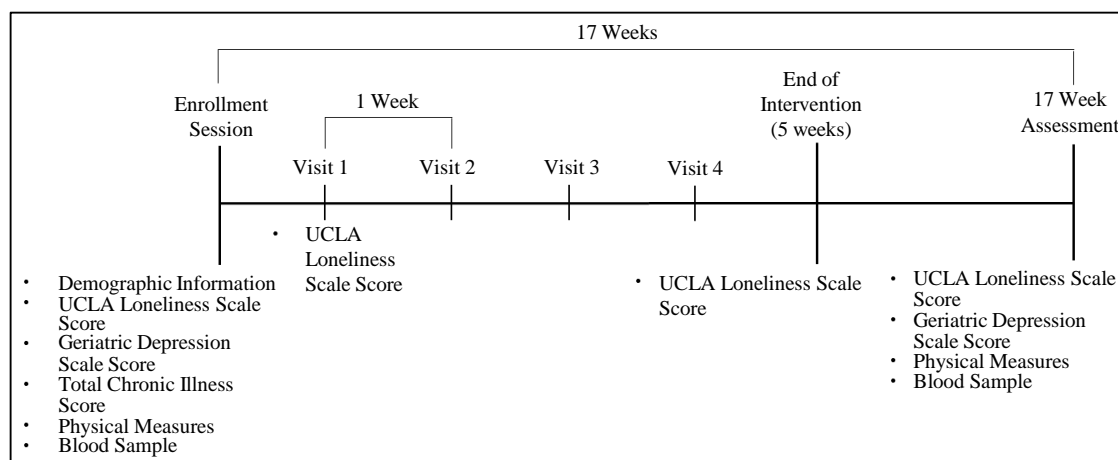


Figure 1. LISTEN trial study design.

profile. The stored specimens were assigned a number that is unrelated to any patient identifiers. The blood samples were stored in a  $-80^{\circ}\text{C}$  freezer until the analysis was conducted.

## 2.5. RNA Extraction

PAXgene® Blood RNA tubes were thawed overnight (16 - 20 h) at room temperature prior to RNA extraction. The PAXgene Blood RNA kit (Pre-Analytix) was used to purify/extract intracellular RNA, per manufacturer's instructions. RNA concentration and quality was determined by absorbance using a Take3 Trio Microplate (BioTek®) read on a Syntek Hybrid Plate Reader and analyzed using Gen5 (BioTek®) software. A260/A280 values between 1.8 and 2.2 were considered acceptable RNA quality.

## 2.6. Gene Expression Analysis

RNA was converted to complementary DNA (cDNA) using the High-Capacity Reverse Transcription Kit (Applied Biosystems). cDNA (10 ng) was used for quantitative real-time polymerase chain reaction (PCR) amplification using Taqman® gene expression probes (Applied Biosystems) on the Step One Real-Time PCR system (Applied Biosystems). Taqman® probes for *IL-2* and *IL-6* were used to detect gene expression samples, and relative expression of *IL-2* and *IL-6* was normalized to the expression of the reference gene, Beta-Actin. Fold change differences between groups for *IL-2* and *IL-6* were calculated by the  $\Delta\Delta\text{CT}$  method [34].

## 2.7. Data Analysis

All statistical analyses were performed using IBM SPSS Statistics (Version 24). Statistical significance was taken at the 5% alpha level ( $p < 0.05$ ). Fisher's exact test to compare AC and LISTEN groups for categorical variables, such as gender, marital status, education, and household income.

### *Analysis of Aim 1*

Spearman rank correlation was used to measure the association between chronic illness burden, UCLA loneliness scale score, and GDS. Mann-Whitney U test was used to compare UCLA loneliness scale score and GDS between AC and LISTEN groups.

### *Analysis of Aim 2*

Spearman rank correlation was used to measure the association between physical measurements, such as blood pressure and BMI. Mann-Whitney U test was used to compare physical measurements between AC and LISTEN groups.

### *Analysis of Aim 3*

Mann-Whitney U test was used to measure differences in *IL2* and *IL6* expression between AC and LISTEN groups. Fold changes were calculated using the  $\Delta\Delta\text{CT}$  method as described above, and standard deviation of fold changes was calculated using  $\Delta\text{CT}$  values. Mann-Whitney U test was also used to measure differences in salivary cortisol concentrations between AC and LISTEN groups.

## 3. Results

A total of 23 participants completed this study ( $N = 10$  AC,  $N = 13$  LISTEN). The baseline characteristics of participants by group are summarized in **Table 1**. There were no significant differences between groups for demographics, physical measurements, or psychosocial assessments at baseline.

### 3.1. The Relationship between Chronic Illness, Loneliness, and Depression

There is a positive correlation between total chronic illness score and scores on the UCLA loneliness scale at baseline ( $r = 0.51$ ,  $p = 0.013$ , supporting the premise that subjects with a higher burden of chronic illness tend to be more lonely (**Figure 2(a)**). Further, there is a positive correlation between scores on the UCLA loneliness scale and Geriatric Depression Scale at baseline ( $r = 0.507$ ,  $p = 0.014$ ) (**Figure 2(b)**), and at 17 weeks ( $r = 0.453$ ,  $p = 0.03$ ) (not shown).

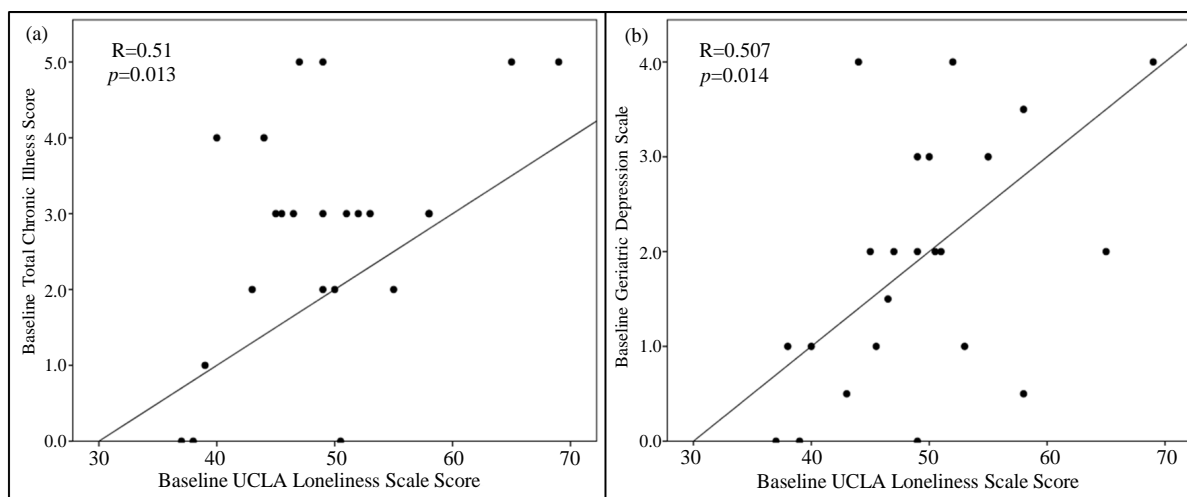
### 3.2. The Effect of LISTEN on Loneliness and Depression

While subjects enrolled in the LISTEN group appeared to have a greater decrease in UCLA loneliness scores

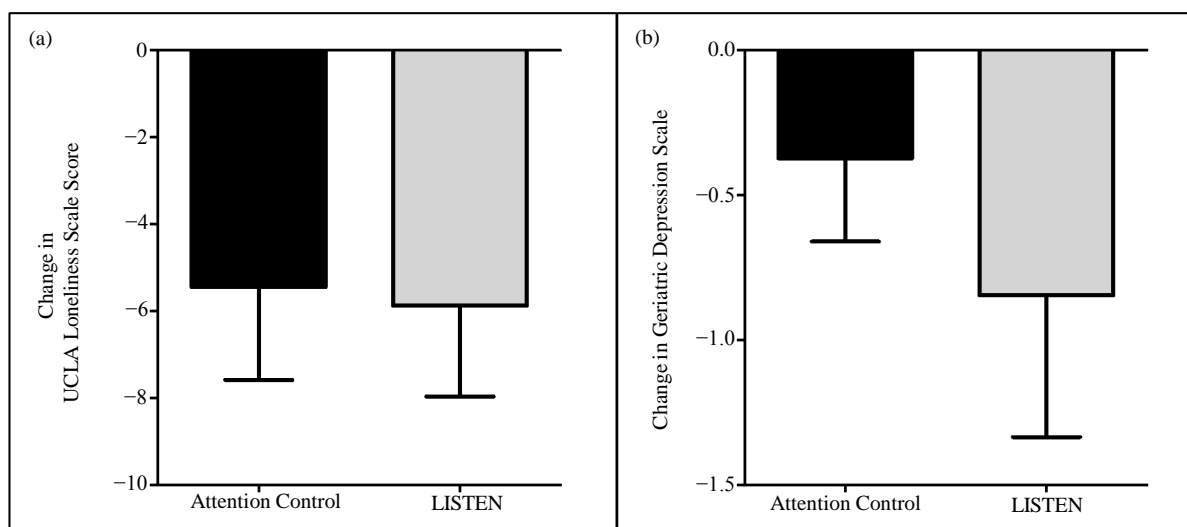
**Table 1.** Baseline demographic, physical, and psychosocial characteristics of study participants (N = 23).

Characteristic	LISTEN Group (N = 13)	Attention Control (N = 10)	Difference Statistic
<b>Demographic</b>			
Age (mean $\pm$ SD years)	75 $\pm$ 7.5	75 $\pm$ 8.8	$t = 0.015$ , $p = 0.98$
Gender (% female)	85%	100%	$\chi^2 = 1.69$ , $p = 0.19$
Marital Status (% married)	38%	20%	$\chi^2 = 2.58$ , $p = 0.46$
Highest Education Completed (N (%))			$\chi^2 = 4.35$ , $p = 0.50$
High School or Less	2 (15)	4 (40)	
Some College	6 (46)	2 (20)	
Undergraduate Degree	3 (23)	1 (10)	
Graduate Degree	2 (15)	3 (30)	
Household Income (N (%))			$\chi^2 = 8.9$ , $p = 0.26$
Less than \$20,000	3 (23)	6 (60)	
\$20,001 - \$30,000	4 (31)	2 (20)	
Over \$30,000	6 (46)	2 (20)	
Employment Status (N (%))			$\chi^2 = 0.21$ , $p = 0.90$
Retired and Not Working	10 (77)	7 (70)	
Working Part-Time	3 (23)	3 (30)	
<b>Physical</b>			
Body Mass Index (mean $\pm$ SD kg/m <sup>2</sup> )	31 $\pm$ 8.1	28 $\pm$ 7.5	$t = -0.654$ , $p = 0.52$
Systolic Blood Pressure (mean $\pm$ SD mmHg)	140 $\pm$ 11	128 $\pm$ 16	$t = -2.04$ , $p = 0.07$
Diastolic Blood Pressure (mean $\pm$ SD mmHg)	79 $\pm$ 7	75 $\pm$ 11	$t = -1.16$ , $p = 0.29$
Total Chronic Illnesses (mean $\pm$ SD), (N (%))	3.1 $\pm$ 1.5	2.4 $\pm$ 1.6	$t = -1.05$ , $p = 0.31$
Arthritis	8 (62)	7 (70)	
Cancer	3 (23)	3 (30)	
Diabetes	5 (38)	4 (40)	
Heart Disease	5 (38)	1 (10)	
Hypertension	10 (77)	3 (30)	
Lung Disease	5 (38)	4 (40)	
Stroke	1 (8)	0 (0)	
<b>Psychosocial</b>			
UCLA Loneliness Scale Score (mean $\pm$ SD)	48.5 $\pm$ 7.8	50.3 $\pm$ 8.7	$t = 0.49$ , $p = 0.625$
Geriatric Depression Scale Score (mean $\pm$ SD)	2.04 $\pm$ 1.3	1.65 $\pm$ 1.4	$t = -0.70$ , $p = 0.493$

across 17 weeks compared to subjects in the AC group, this reduction was not statistically significant (AC =  $-4.9 \pm 6.3$ , LISTEN =  $-5.4 \pm 7.15$ ,  $p = 0.856$ ) (**Figure 3(a)**). There was also a decrease in Geriatric Depression Scale Score in both the AC and the LISTEN group; however, this decrease was not statistically significant within either group (AC- $p = 0.229$ , LISTEN- $p = 0.109$ ), nor between groups ( $p = 0.448$ ) (**Figure 3(b)**). Interestingly, while the change in UCLA loneliness scores from baseline to 17 weeks did not differ dramatically between groups, the change in UCLA loneliness scores from 6 weeks (end of intervention) to 17 weeks were more significant. Specifically, there was an increase in loneliness in the AC group (mean change =  $3 \pm 7.33$ ), whereas loneliness continued to decrease from 6 to 17 weeks in the LISTEN group (mean change =  $-0.25 \pm 6.39$ ) ( $p = 0.067$ ) (**Figure 4**). We observed no significant changes in neither daily average salivary cortisol levels nor



**Figure 2.** The relationship between chronic illness, loneliness, and depression. (a) There is a positive correlation between total chronic illness score and scores on the UCLA loneliness scale at baseline ( $r = 0.51$ ,  $p = 0.013$ ). (b) There is a positive correlation between scores on the UCLA loneliness scale and Geriatric Depression Scale at baseline ( $r = 0.507$ ,  $p = 0.014$ ).

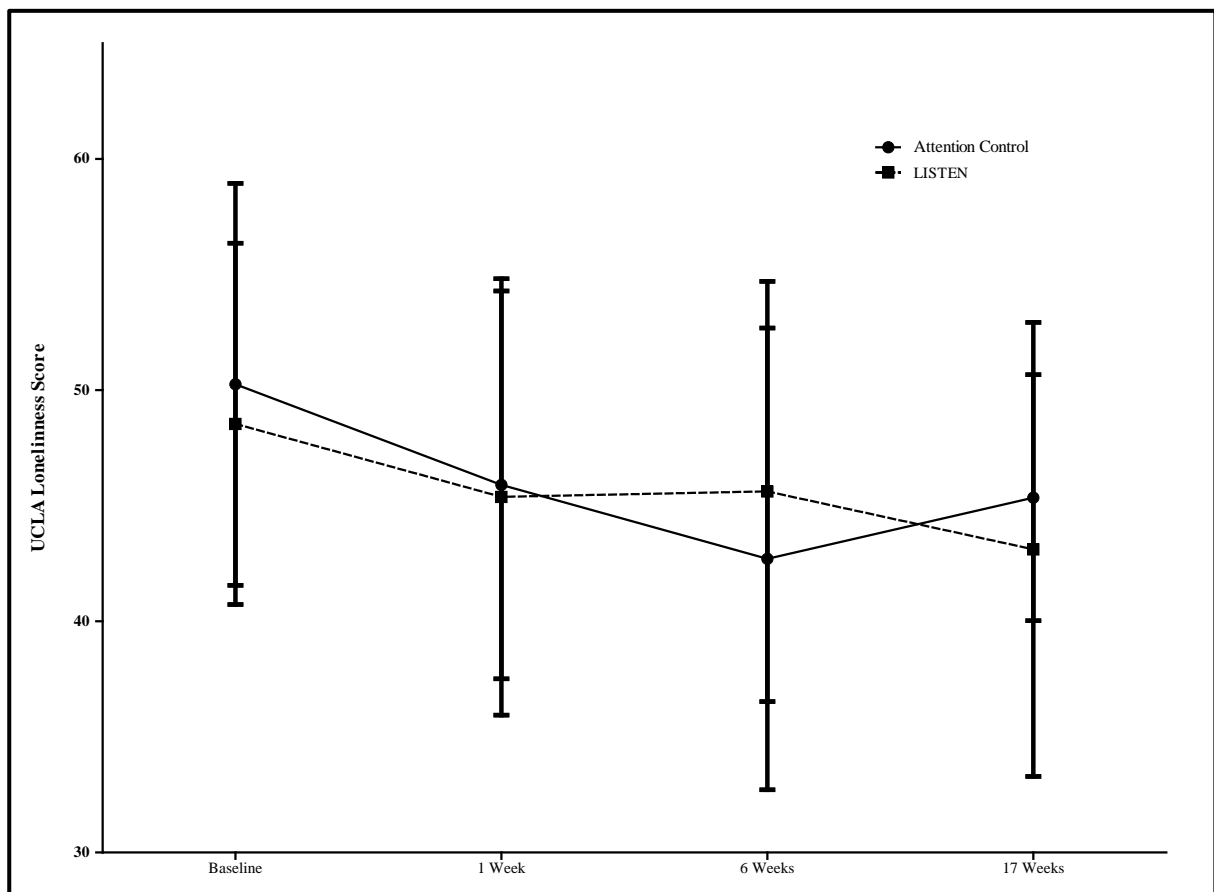


**Figure 3.** The effect of listen on loneliness, and depression. (a) UCLA Loneliness Scale Score was more greatly reduced in the LISTEN compared to attention control (AC =  $-4.9 \pm 6.3$ , LISTEN =  $-5.4 \pm 7.15$ ,  $p = 0.856$ ). (b) Geriatric Depression Scale Score was more greatly reduced in the LISTEN compared to attention control; however, this reduction did not reach statistical significance ( $p = 0.448$ ).

diurnal decline in salivary cortisol between the AC and LISTEN groups at any time point, nor within each of the groups from baseline to 17 weeks. **Table 2** summarizes the salivary cortisol concentrations at each time point for the groups.

### 3.3. The Impact of LISTEN on Physical Health Measures

There was a considerable reduction in systolic blood pressure in the LISTEN group compared to the AC group at 17 weeks (no intervention =  $-1.4 \pm 12.5$ , LISTEN =  $-11.1 \pm 13.8$ ,  $p = 0.013$ ) (**Figure 5**). There were no significant changes in diastolic blood pressure in either group. Further, this decrease in systolic blood pressure was correlated with a decrease in BMI ( $r = 0.552$ ,  $p = 0.008$ ) (not shown). While subjects in both the AC and the LISTEN group showed a decrease in BMI, this decrease was not statistically significant in either group (AC- $p = 0.251$ , LISTEN- $p = 0.498$ ), nor between groups ( $p = 0.396$ ) (not shown).



**Figure 4.** The effect of LISTEN on loneliness across study period (UCLA Loneliness Scale Score at each time point compared between attention control and LISTEN group). There was an increase in loneliness in the AC group (mean change =  $3 \pm 7.33$ ), whereas loneliness continued to decrease from 6 to 17 weeks in the LISTEN group (mean change =  $-0.25 \pm 6.39$ ) ( $p = 0.067$ ).

**Table 2.** Salivary cortisol levels in attention control versus LISTEN participants (mean  $\pm$  SD ug/dL).

	Wake (7 am - 9 am)	11 am - 1 pm	3 pm - 5 pm	Bedtime (10 pm - 12 am)	Diurnal Slope
<b>AC</b>					
Baseline	0.7 $\pm$ 0.4	0.3 $\pm$ 0.1	0.3 $\pm$ 0.2	0.1 $\pm$ 0.05	-0.6 $\pm$ 0.4
12 Weeks	0.5 $\pm$ 0.2	0.4 $\pm$ 0.3	0.3 $\pm$ 0.1	0.2 $\pm$ 0.1	-0.4 $\pm$ 0.2
<b>LISTEN</b>					
Baseline	0.7 $\pm$ 0.5	0.2 $\pm$ 0.1	0.3 $\pm$ 0.08	0.1 $\pm$ 0.05	-0.6 $\pm$ 0.5
12 Weeks	0.7 $\pm$ 0.6	0.3 $\pm$ 0.3	0.2 $\pm$ 0.2	0.2 $\pm$ 0.3	-0.5 $\pm$ 0.7

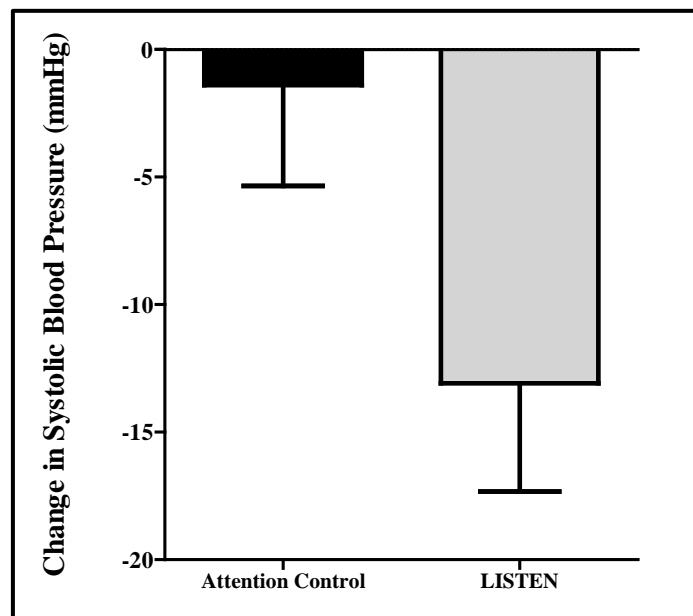
### 3.4. The Effect of LISTEN on *IL2* and *IL6* Expression

Subjects enrolled in the LISTEN group had a greater decrease in *IL2* expression at 17 weeks compared to subjects who attended attention control group sessions but this reduction was not statistically significant (AC *IL2* Fold Change =  $0.8 \pm 1.8$ , LISTEN *IL2* Fold Change =  $0.7 \pm 1.2$ ,  $p = 0.585$ ) (Figure 6). Neither subjects enrolled in LISTEN groups nor attention control showed a change in *IL6* expression at 17 weeks (AC *IL6* Fold Change =  $1.2 \pm 1.3$ , LISTEN *IL2* Fold Change =  $1.3 \pm 1.1$ ,  $p = 0.731$ ) (not shown).

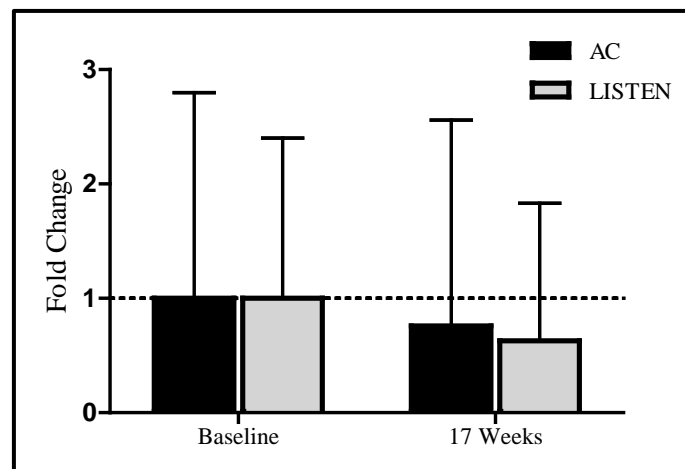
## 4. Discussion

The findings of this study on older adults who are living in Appalachia are similar to findings reported from





**Figure 5.** The effect of LISTEN on systolic blood pressure (systolic blood pressure at 17 weeks compared between attention control and LISTEN group). There was a considerable reduction in systolic blood pressure in the LISTEN group compared to the AC group at 17 weeks (no intervention =  $-1.4 \pm 12.5$ , LISTEN =  $-11.1 \pm 13.8$ ,  $p = 0.013$ ).



**Figure 6.** The effect of LISTEN on interleukin-2 mRNA expression (interleukin-2 mRNA expression fold changes from baseline to 17 weeks compared between attention control and LISTEN group). Subjects enrolled in the LISTEN group had a greater decrease in IL2 expression at 17 weeks compared to subjects who attended attention control group sessions but this reduction was not statistically significant (AC IL2 Fold Change =  $0.8 \pm 1.8$ , LISTEN IL2 Fold Change =  $0.7 \pm 1.2$ ,  $p = 0.585$ ).

national data [35] and prior studies on the relationship between loneliness and chronic illness [36]. Our pilot data previously revealed that, in a sample of 60 rural older adults, none were screened for loneliness but 33% were moderately lonely with prevalent multiple chronic conditions. National data analyses indicate that a higher total number of chronic illnesses are predictive of loneliness [37]. The finding that loneliness scores are correlated with depressive symptoms is consistent with the health and social science literature which identifies loneliness

to be a unique predictor of depression [38].

Loneliness has been identified as an independent predictor of hypertension [39] through the physiological stress response. Logically leading to the conclusion that diminishing loneliness may diminish psychosocial stress and lead to diminished blood pressure. This is clinically important because controlling blood pressure decreases the likelihood of poor health outcomes such as stroke, heart disease, and metabolic syndrome [40].

Findings from this study indicated that both LISTEN and attention control groups decreased in weight and BMI. While not statistically significant, this is a short trial which makes the findings clinically important. It has been reported that lonely adults in varied populations experience obesity [41] and metabolic syndrome [42]. Poor health consequences of obesity and metabolic syndrome include multiple chronic conditions that are well-documented and very costly to the healthcare system. Thereby, understanding how psychosocial problems like loneliness relate to these conditions is imperative.

When considering the findings regarding systemic inflammation and gene expression, the findings are inconclusive. It was interesting that participants who did NOT receive LISTEN had a decrease in IL2 expression which could be interpreted to indicate diminished immunity over time as they continued to be lonely. Diminished immunity has been associated with a chronic lonely state [8]. However, since both groups did diminish in loneliness over the relatively short study and the LISTEN group also decreased in IL2 expression, the results were not definitive. Though IL6 trended up for both groups, this increase in IL-6 with intervention could be interpreted in multiple ways. Again, since both groups diminished in their loneliness scores, it could be that less lonely persons were better able to moderate inflammation. This would be consistent with recent studies reporting that higher loneliness is related to higher inflammation on measures such as C-reactive protein [43].

#### 4.1. Future Research Implications

A better research approach should include a comprehensive assessment of the various arms of the immune system, not just single markers, across genomic and proteomic expression. This approach would require significant blood sampling/processing and a larger sample size than what we have studied here. The power of the techniques used for gene expression in this study lies in multiple sampling analyses and comparing the data over time amongst individuals. Future studies should be designed to optimize the technique as well as the biomarkers to be studied.

#### 4.2. Conclusion

Loneliness is a prevalent problem that contributes to multiple chronic conditions, functional decline [44], and mortality [45] in older adults. Further, loneliness negatively impacts the healthcare system as lonely older adults are more likely to enter a nursing home [46], more frequently access primary care [47], have increased emergency care visits [48], and report increased use of formal support services [49]; making loneliness a priority for study in this population. Although our results are not significant, we do observe trends that will inform future studies to further assess the inflammatory/immune patterns associated with loneliness. In the future, enhancing knowledge about the relationships among loneliness, chronic illness, systemic inflammation, and gene expression of these particular targets, and how these relationships may change over time with intervention will inform translation of findings to clinical settings.

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