DERMATOLOGY

Review

Quality of life of patients with pressure ulcers: a systematic review

Erofili Roussou, Georgia Fasoi, Areti Stavropoulou, Martha Kelesi, Georgios Vasilopoulos, Georgia Gerogianni, Victoria Alikari

Postgraduate Program “Treatment and care of wounds and ulcers”, Department of Nursing, University of West Attica, Athens, Greece

Abstract

Introduction. Patients suffering from pressure ulcers experience low quality of life, in every dimension of daily living.

Aim. The aim of this systematic review was to investigate the impact of pressure ulcers on the patients’ quality of life involving mental/emotional, spiritual, physical, social, cognitive dimensions, and pain.

Methods. A systematic literature search of published articles in the English language during the past 15 years was conducted. Articles were identified in the electronic databases of Google Scholar, PubMed, and PsycINFO using the keywords: pressure ulcers, quality of life, emotional dimension, social dimension, physical dimension. The inclusion criteria were: articles relevant to the study topic, written in English, and published between 2004 and 2019. Articles that were secondary studies, such as reviews and meta-analyses, case studies, and articles written in a language other than English, were excluded from the study. The PRISMA method was applied.

Results. Fourteen studies were included in this systematic review. Eight were quantitative studies (six cross-sectional, one longitudinal, one multicenter cohort, and one pilot study) and six qualitative (one was based on grounded theory, one pilot study, one case study of mixed methods, one phenomenological study, and one comparative study). The emerging themes were related to the mental/emotional, spiritual, physical, social, cognitive dimensions, and pain.

Conclusions. Pressure ulcers have a negative impact on the patients’ quality of life, especially at a psychological level. Patients’ life is severely affected as they are fully dependent on their supportive environment and health services.

Keywords: pressure ulcers, quality of life, emotional dimension, social dimension, physical dimension

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Address for correspondence:
Victoria Alikari
vicalikari@uniwa.gr

Introduction

A pressure ulcer (PU) is an injury on the surface of the skin or the underlying tissue, usually over a bone prominence caused by prolonged pressure or shearing [1]. PUs can occur on the areas of the coccyx, the heels, the foot, the hips, the shoulders, the knees, the ankles, the elbows, and the ear flaps [2,3]. PUs are caused by three factors a) prolonged pressure over bone prominence, which leads to tissue ischemia and necrosis, b) a combination of shear and friction, when the patient is lying in bed, leading to capillary damage and local hypoxia and c) prolonged moisture, which leads to maceration and tissue distraction [3,4]. In the international literature, PUs can also be found with the terms: pressure sore, bedsores, and decubitus ulcers underlying the fact that these injuries usually occur in patients who stay in bed [5].

In most studies that have been conducted regarding the quality of life (QoL) and chronic ulcers, the results demonstrate that the patients have poor quality of life due to pain and the poor physical condition that the patients experience [6-9]. In addition, the cost of the treatment is high, both for the patients treated at home and for those who are hospitalized. Indirect costs, resulting from the fact that patients are unable to work are also considered as an additional burden [10]. A vicious circle is created, where expenses are constantly increasing, whereas there is no source of income [8,11-13].

In addition, the patients' dependence on their family caregivers can be increased as pain deteriorate their activities and affect them psychologically [11]. PUs, as a complication of a disease, may delay patients' recovery. At the same time, PUs lead to patients' inability to participate in social activities because of exudation, emotional factors, and the lack of independence [12].

Moreover, patients experience psychological fluctuations, as well as low self-esteem, and often they state that support from their family is of great importance. In relevant research, anxiety and depression are referred to as the most common psychological disorders as they both contribute to further physical and mental decline, eating and sleep disorders, resulting thus in even lower self-esteem, negative self-image, and, finally, poor health outcomes [8]. The above-mentioned emotions are hard to express. In a study by Spilsbury et al. [12], patients referred to three causes of the development of pressure ulcers a) chronic illness, poor health and loss of appetite and weight, b) poor management by medical staff in terms of medical interventions, and particularly, insufficient skin care [8].

Finally, research evidence demonstrates that patients with dark skin are subjected to racist behavior in the hospitals where they are treated, as they acquire more frequently pressure ulcers in institutions, compared to patients with white skin [14-16]. Similarly, people belonging to lower social strata and with insufficient financial resources tend to develop pressure ulcers more often, due to the lack of education and their incapacity to cover the cost of care [17,18]. Moreover, economic constraints may result in the patients' inability to visit the doctor and this may result in poor healing outcomes [16].

Aim

The present systematic review aimed to investigate the impact of PUs on patients' QoL. In particular, the impact of PUs on mental/emotional, spiritual, physical, social, cognitive dimensions, and pain is studied.

Methods

To investigate the impact of PUs on QoL, a systematic review of published qualitative and quantitative studies was performed. The search included articles from the electronic databases PubMed, Google Scholar, and PsycINFO. The keywords used were: pressure ulcers, quality of life, impact, physical health, mental health, social health, and combinations of these words. The PRISMA method (Preferred Reporting Items for Systematic Reviews and Meta-Analyzes) was applied. Duplicate articles were removed, and alsothose with titles not relevant to the purpose of the systematic review. After reading the titles and the abstracts, articles that were not compatible with the topic under investigation were rejected. The full text of the remaining articles was then read and those that were not relevant to the present study were removed.

The eligibility criteria for including the articles in the study were: English-written articles; years of publication: 2004-2019; keywords contained in the articles that match the research question. The exclusion criteria were: studies concerning the ways of assessing and staging the ulcers; studies analyzing interventions for ulcer cure; studies analyzing the cost of treating pressure ulcers; the population is not adult patients; patients being treated in the intensive care unit; research protocols; systematic reviews.

Results

From the initial search, a total of 256,580 studies emerged mostly from Google Scholar and PubMed databases. As shown in figure, 14 studies met the criteria and were finally included in the systematic review.

The studies included in the systematic review, concerning the population, methodology, and results are presented below (Table I).

The studies originated from different countries: four from Brazil, one from Canada, six from the UK, two from the U.S.A, and one from Spain. Regarding the study design, six were qualitative [19-24] and eight were quantitative studies [25-32]. Of the qualitative studies, one was qualitative research based on grounded theory [19], one was pilot study [21], one was a case study of mixed methods [22], one was a phenomenological study [23], and finally, one was a comparative study [24]. Data from the latter six studies were all collected via interviews. Concerning the quantitative studies, six were cross-sectional studies [25,27,29-32], whilst one study was longitudinal [25] and one was multicenter cohort and pilot study [28].

The thematic analysis of the results can be analyzed in seven sections: a) mental / emotional dimension, b) spiritual dimension, c) physical dimension, d) social dimension, e) cognitive dimension, f) effect of pain, g) HRQoL score.

A. Mental/emotional dimension

Eleven studies have shown results for this dimension, where patients have been found to have negative emotions. Specifically, increased feelings of insecurity, decreased feelings of dignity, feelings of frustration, despair and being helpless, lack of confidence, anxiety, worry, and shock were reported [19-22,24-26,27-29,31].

B. Spiritual dimension

From a total of four studies, it appeared that the spiritual dimension of patients was reduced [20,24,27,31]. It is noteworthy that spirituality is a broad concept with basic characteristics of "Meaning of Life", "Hope", "Peace" and reflects faith in a higher being or in a God [33].

C. Physical dimension

In the eight studies of this thematic unit, it was found that the patients had reduced physical condition and functionality. In particular, they reported a decrease in the performance of their activities, a frequent need for help from the medical staff, reduced physical activity even after their recovery, and, finally, fatigue due to sleep disorders [20,21,24,25,27-29,32].

D. Social dimension

The results of four studies served this topic. It was found that there was reduced social activity due to the treatment of ulcers, bed rest, pain, and symptoms of PUs such as exudate and odor [20-21,24,27].

E. Cognitive dimension

In one study it was found that patients had low scores in the dimension of cognitive status [27]. Cognitive impairment is associated with impaired mental functions, such as impaired concentration and attention, and easy memory loss and impaired memory retrieval [27].

F. Effect of pain

Results were obtained from 9 studies on this topic, where it appeared that there was a negative correlation between pain and the performance of activities. More specifically, pain causes fatigue and it is the main feature in the presence, development, and treatment of PUs. Also, pain is not perceived and not measured by medical and nursing staff. Its duration is continuous, it is not easy to put the intensity under control, it is not related to the stage of the ulcer, may be inflammatory or neuropathic; the latter being greater in lower extremity ulcers and hospitalized patients having lower scores in the pain section [19,21-25,27,28,30].

G. Health-related QoL score

Four of the five studies related to the quality of life reported low scores [19,26,27,31,32].

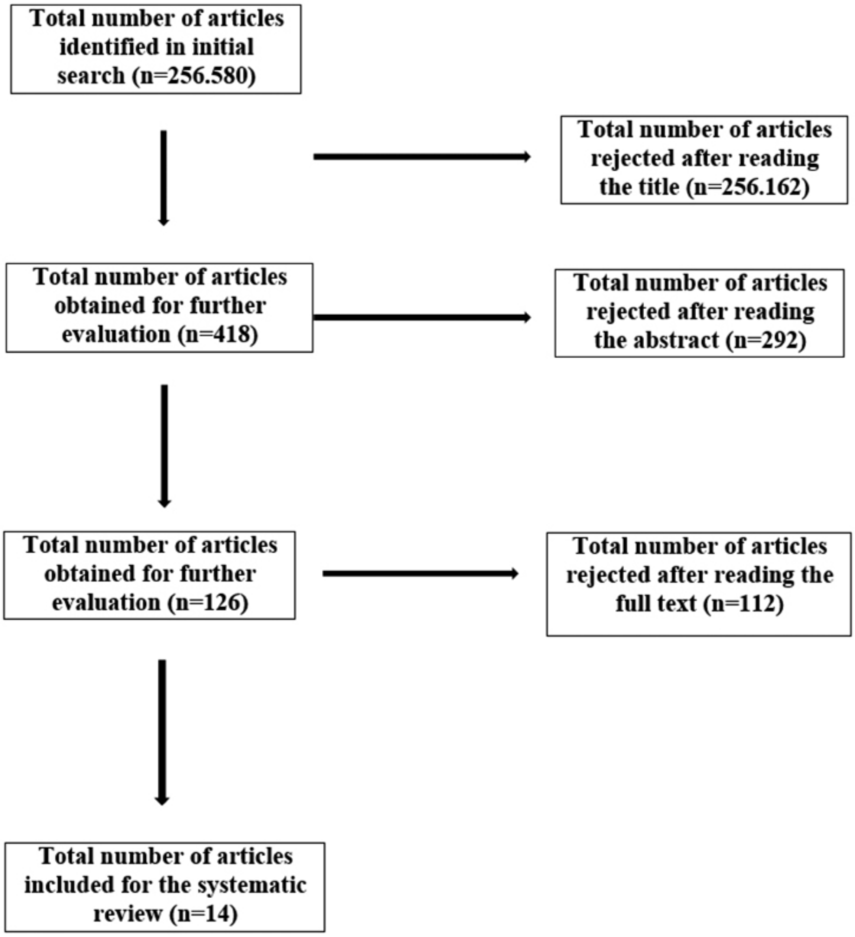

Figure 1. Flow diagram of the selection process of studies for the systematic review.

Table I. Summary of findings of the 14 studies reviewed.

Authors, Years, Country	Title	Purpose	Study Design	Study Population	Data Collection	Analysis	Study Outcome
García-Sánchez, Martínez-Vizcaíno and Rodríguez-Martín, 2019, Spain	Conceptualisations on home care for pressure ulcers in Spain: perspectives of patients and their caregivers	Investigating the perceptions of patients and their caregivers about pressure ulcers.	Qualitative research based on grounded theory.	n = 10 patients with pressure ulcers or had had an ulcer in the past and n=15 caregivers of people with pressure ulcers.	Interview.	Inductive statistics.	The ulcer is an inevitable lesion due to the lack of knowledge of caregivers. It is painful and the pain leads to despair.
Esson, 2007, UK.	Inpatients felt that pressure ulcers had emotional, mental, physical, and social effects on their quality of life because nurses did not adequately treat or manage their pain or discomfort.	Investigating the effect of pressure ulcers and their treatments on physical health, functional capacity, psychological well-being, and social relationships.	Qualitative research.	Proportional sample of patients from 23 hospitals, aged between 33-and 92 years old who had pressure ulcers.	Interview.	Descriptive statistics.	Patients feel dependent on the nursing staff, stressed, suffering, and in pain. Impact on emotional, mental, social, and physical dimensions.
Hopkins et al., 2006, UK.	Patient stories of living with a pressure ulcer.	Investigating the experience of elderly patients with pressure ulcers.	Pilot study.	n = 8 patients over 65 years with IV and V grade pressure ulcers.	Interview with the method of the phenomeno-logical-Heideggerian approach.	Inductive statistics.	The pain is unbearable, it is constant, and the means used to alleviate it are not enough. It makes movement difficult, reduces activity and the impact of ulcers also affects the family environment.
Jackson et al., 2017, UK.	Pain associated with pressure injury: A qualitative study of community-based, home-dwelling individuals	The presence of pain felt by patients with pressure ulcers living at home.	Case study of mixed methods.	n = 12 adult patients at home who have a pressure ulcer.	Interview.	Descriptive statistics.	Pain has negative effects on the activities of daily living, mobility, and sleep.
Rastinehad, 2006, U.S.A.	Pressure ulcer pain.	The description and interpretation of pain experienced by patients with pressure ulcers.	Phenomeno-logical study.	n = 10 patients aged 30-90 years old who are hospitalized in acute units.	Interview.	Descriptive statistics.	The pain is constant and affects their sleep and activities, medicine and technology fail to provide care and comfort. Feelings of hopelessness, unhappiness, anxiety, and urgency prevail.
McGinnis et al., 2015, UK.	What is different for people with MS who have pressure ulcers: A reflective study of the impact on people's quality of life?	Examining the views of patients with MS and pressure ulcers compared to the the general population of patients with pressure ulcers.	Comparative study	n = 30 patients who belonged to the general population and n=6 patients with MS who have a pressure ulcer aged 48-61 years old.	Interview.	Descriptive statistics.	Ulcers affect the lives of MS patients socially, psychologically, and physically. They cause bed rest and as a consequence, abstinence from their activities, while they cause pain and suffering.
Degenholtz et al., 2008 U.S.A.	The association between changes in health status and nursing home resident quality of life.	The study of the relationship between the change of QoL2 and the clinical factors of the residents in nursing homes with pressure ulcers.	Longitudinal study.	n = 931 patients, women aged 65 years and older.	Interview using a multi-dimensional QoL tool and data from Minimum. DataSet.	Descriptive statistics.	Patients with one or more grade II or larger pressure ulcers report a reduction in their autonomy, safety, and mental well-being.
Galhardo et al., 2010, Brazil.	Health-related quality of life and depression in older patients with pressure ulcers	Evaluation of HRQoL3 and depression in elderly patients with pressure ulcers.	Cross-sectional analytical study.	n = 42 outpatients aged 60 years and older, without cognitive deficits living in the communities, divided into 2 groups: 21 with pressure ulcers and 21 without pressure ulcers.	Analytical study.	Statistical data analysis using the Pearson chi-squared test, The Mann-Whitney test, and The Spearman correlation coefficient.	Patients with pressure ulcers had significantly lower HRQoL compared to the other group of patients and lower scores on the SF-36 in terms of physical function and emotional. 17 of the patients with pressure ulcers had depression.

Table I. Summary of findings of the 14 studies reviewed (continuation).

Authors, Years, Country	Title	Purpose	Study Design	Study Population	Data Collection	Analysis	Study Outcome
Sebba Tosta de Souza et al., 2015, Brazil.	Health-related quality of life in elderly patients with pressure ulcers in different care settings.	The measurement and comparison of HRQoL3 in elderly patients with pressure ulcers, in acute care units, home, and long-term care units.	Comparative cross-sectional study.	n = 110 patients. 54 (38 with and 16 without pressure ulcers) were hospitalized, 31 (11 with and 20 without pressure ulcers) living in long-term care facilities, and 25 (9 with and 16 without pressure ulcers living at home.	Comparative cross-sectional study.	Statistical analysis using the Statistical Package for the Social Sciences 18.0 (SPSS Inc, Chicago, Illinois), of the chi-squared test.	A lower score on the SF-36, in the physical, social and emotional dimensions for those who were hospitalized.
Essex et al., 2009, UK.	Health-related quality of life in hospital inpatients with pressure ulceration: assessment using generic health-related quality of life measures.	Determining the impact of pressure ulcers on HRQOL3 in elderly patients.	Multicenter cohort study and pilot study.	n = 218 people with pressure ulcers compared to 2289 people without ulcers for the cohort study and 6 patients with pressure ulcers compared with 16 patients without for the pilot study over 65 years.	Polycentric cohort study using SF-36 and pilot study using EQ-5D and use of pain Visual Analogue Scale.	Statistical analysis using SPSS version 14.0.	In the multicenter study: low scores in the areas of physical and mental health. In the pilot study, patients with pressure ulcers had lower scores on the SF-36. Similarly with the use of EQ-5D.
Lala et al., 2014 Canada.	Impact of pressure ulcers on individuals living with a spinal cord injury.	The description of the impact of pressure ulcers in terms of participation in daily and social activities, the use of health resources, and the overall QoL of people with S.C. injury.	Cross-sectional study.	n = 1137 patients with S.C. injury, over 18 years of age who had been traumatized for more than 1 year before and lived in the communities, of whom 381 had a pressure ulcer last 12 months.	National cross-sectional study.	Statistical analysis using SPSS version 21.0.	65.3% of patients report a decrease in activity.
McGinnis et al., 2014, England.	Pressure ulcer-related pain in community populations: a prevalence survey.	Estimating the prevalence of pressure ulcers in patients in the community.	Cross-sectional study.	n = 287 adult patients with pressure ulcers from two communities.	Cross-sectional study.	Statistical analysis using SAS software and descriptive Statistical analysis using SAS software and descriptive.	133 patients reported pain (75.6%). The degree of pain was not related to the severity of the pressure ulcer. The pain was of neuropathic and inflammatory type.
Lourenco et al., 2014, Brazil.	Quality of life and self-esteem in patients with paraplegia and pressure ulcers: a controlled cross-sectional study.	Evaluation of HRQoL and self-esteem of patients with S.C. injury and pressure ulcers.	Controlled cross-sectional study.	n = 60 patients divided into two groups: a) control group with a mean age of 30.23 ± 9.52 years and b) study group 38.17 ± 9.08 years.	Cross-sectional study using SF-36.	Statistical analysis using the chi-square test, Fisher's exact test, and Students t-test.	Patients in the control group had lower scores on the SF-36, in all categories except general health. While patients with pressure ulcers from the control group had lower self-esteem compared to those in the study.
De Fátima Rodrigues dos Santos et al., 2016, Brazil.	Quality of life of people with chronic ulcers.	The evaluation of QoL and the analysis of personal and health characteristics of patients with pressure ulcers.	Cross-sectional study.	n=200 patients with ulcers of various etiologies, of which n=14 with pressure ulcers aged 60-79 years	Cross-sectional study, using Ferrans and Power Quality of Life Index – Wound Version.	Statistical analysis using SAS version 9.2.4.	The overall score in QoL was 21.6, with the lowest scores in terms of health and functionality, with the latter having the worst score of 19.7.

MS: Multiple Sclerosis; QoL: Quality of Life; HRQoL: Health-Related Quality of Life; S.C: Spinal Cord.

Discussion

This study aimed to investigate the effect of PUs on the QoL of patients through a systematic review of articles published in the last 15 years. This study is of great importance for understanding the side effects on the patients' life dimensions.

Results regarding the patients' quality of life from qualitative studies

Regarding the results from qualitative studies, PUs were considered to be "inevitable injuries and painful wounds". The pain was the main feature of the presence, treatment, and development of the ulcer that led to feelings of frustration, despair, and the feeling that patients were "helpless" [19]. It appears that patients with PUs had a strong dependence on family members or social services for their activities. In addition, patients expressed the view that their ulcer affected the emotional, social, spiritual, and functional dimensions and many were biased while calling the PUs "problem", and "annoying", which caused depression and lack of self-confidence [20].

About the pain, patients characterized it as "endless, with constant presence" and in some cases stated that it was not recognized by the doctors and it was difficult for them to move. The result of pain was a life with limitations and restrictions concerning their social life and general activities. As a result, the patients' anxiety about their family environment, who assisted them, and about the burden they would have on their lives had increased [21]. In addition to the previous findings concerning the pain, patients found it difficult to control it, since it lasted a long time, it was intense, and got worse every time they performed activities. At the same time, the patients' attempts to reduce and control the pain did not have the desired results. The treatment of ulcers aggravated the condition and increased the intensity of pain. It also affected every area of their lives, with its presence even during sleep, when the pain was able to cause discomfort to the point that patients were interrupted from sleep and painkillers did not have the desired results. Finally, the patients reported that they had uncertainty about the future, as the healing of the ulcer was slow, they felt frustrated and anxious [22]. Moreover, the pain was characterized in different ways depending on the feeling it caused, the appreciation patients gave it, and the feeling it created. Thus, characteristics such as "caustic, unpleasant, anger" emerged, it was constant and affected their activities.

In addition, medical technology and care were found to be insufficient to soothe it and give patients the care and comfort they needed. Finally, for the patients, the characterization "unpleasant" was not sufficient to describe the feelings of misery, despair, agony, and urgency they experienced [23].

Patients experienced problems in the area of functionality, with limited mobility and reduced activities, and had difficulty in sleeping due to pain and change of posture that caused fatigue. Moreover, they were unable to participate in their social activities due to their bed rest and treatment. Patients from the general population avoided social contact due to pain, odor, and ulcer exudate. At the same time, the psychological state of both groups was poor, as they both had negative emotions, such as stress and shock [24].

Results regarding the patients' quality of life from quantitative studies

Patients who had one or more stage II PUs, over two consecutive periods had reduced autonomy, increased sense of insecurity, and decreased mental well-being. There had been a decrease in the sense of dignity that resulted from physical disability. High depression scores were found, which were associated with comfort, and enjoyment of food and activities, while pain resulted in a decrease in functional capacity. Finally, patients who had recovered from stage II or higher stage PUs continued to have reduced physical activity [25]. In another research, patients with PUs had lower health-related QoL scores, while 80.9% of patients were found to be depressed [26]. Respectively to the previous survey, it was found that geriatric patients with PUs had lower scores on the SF-36 questionnaire in terms of functionality, physical condition, social functionality as well as emotional [27]. SF-36 is a popular survey consisting of 36 items measuring eight dimensions of the HRQoL: vitality, physical functioning, bodily pain, general health, social functioning, role physical, role emotional, role physical, and mental health with excellent reliability and validity [34]. Moreover, in a mixed survey where both cohort and pilot studies were performed, the cohort study found that patients with PUs had low scores in the dimensions of physical and mental health while in the pilot study authors found that patients with PUs had lower scores on the SF-36, in terms of physical function and vitality, as well as limitations due to physical problems. Finally, patients with PUs felt more pain [28]. In the previous study the EuroQol-5Dimension (EQ-5D) survey was, also, used which explores five dimensions of the generic QoL: Usual Activities, Pain/Discomfort, Mobility, Self-Care, and Anxiety/Depression [28]. In another survey, it was found that 65.3% of the patients had reduced activity. At the same time, 32% of patients with one or two PUs appeared to have a greatly reduced activity or lack of activity, respectively, compared to 53% of patients with stage III ulcers and above. At the same time, people with PUs were more dissatisfiedneeded help from medical staff more often [29]. Concerning the degree of pain, it was not found to be related to the severity of the pressure ulcer, while patients reported both neuropathic and inflammatory-type pain while the neuropathic was greater in lower extremity PUs [30]. In a survey where patients were grouped into two groups, it was found that patients in the control group had lower scores on SF-36 compared to patients in the study group, in all categories except general health, while patients with PUs from the control group had lower self-esteem compared to those in the study group [31]. Finally, concerning QoL, in a survey among patients with ulcers of various etiologies, of which 14 with PUs, it was found that the lowest scores occurred in the dimensions of health and functionality, with the latter having the worst score [32].

Conclusions

PUs represent a complication that greatly affects the QoL of patients. Although they are not a disease, they complicate the general condition and health of the sufferers. As the results showed, the highest negative effect of PUs is on the emotional dimension of the lives of patients, as well as their caregivers. At the same time, the lives of patients are affected both socially and in the field of activities, based on their testimonies, since the treatment and the symptoms of ulcers, lead to "disability", making them completely dependent on their supportive environment and health services. In addition, regarding the dependence on health and hospital care facilities, it seems that the two components are directly dependent since the treatment of ulcers requires medical examination and access. We could say that the results of the research were expected in most cases, , based on the existing literature. However, the new data that emerged lead to the conclusion that further and more thorough research should be done on the correlation of PUs with QoL and health-related QoL. At the same time, perhaps, because the existing measurement tools used are not always suitable enough to cover all the dimensions and capture the overall impact of PUs on patients' QoL, it is necessary to try to create and use new tools that would illustrate more accurately and overall the research question being studied.

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