

Knowledge and practice of Informal Caregivers on Pressure Injury Prevention and Treatment among Patients Need Palliative Care: A Cross-Sectional Study

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Abstract

Background: Pressure injuries represent an important problem in palliative care. Lack of knowledge and skills among informal caregivers on pressure ulcer prevention and management contributes significantly to the happening or deterioration of pressure injuries.

Aim: The aims of this study were to: (1) determine the level of knowledge and practices of informal caregivers on pressure ulcer prevention and treatment. (2) explore the socio-demographic characteristics of informal caregivers that influence pressure ulcer prevention and treatment among patients who need palliative care.

Methods: the quantitative cross-sectional descriptive design was used to collect data conveniently from 146 informal caregivers, and a valid and reliable questionnaire was used.

Results: One hundred and forty-six informal caregivers completed the study. Most participants had a relatively low level of pressure ulcer prevention, treatment knowledge, and practice. Participants older than 28 years, government workers, and married had significantly better knowledge and practice of PU prevention and treatment than other participants.

Conclusion information for informal caregivers in different settings about pressure ulcer prevention and treatment is needed by focusing on young married ones. Informal caregivers need to acquire more professional practices and knowledge to improve the quality of patient care.

Introduction

Patients receiving palliative care often have prolonged periods of immobility, which is associated strongly with pressure injury [1, 2]. Pressure injury (PI) is considered a significant and complex problem in all healthcare settings, mainly in patients who need palliative care [3]. The prevalence of PI ranged from 22–60% in acute care settings of palliative care, while in-home care settings, it has been reported between 10.7% and 26.9% [4]. The consequences of PI are known as; enormous impacts, including increased patient suffering and pain, social isolation, reduced quality of life, and increased health care services costs [5–9]. Studies have shown that patients who are disabled, elderly, and with chronic conditions receiving palliative care are considered high-risk patients for PI [10].

Hence palliative care also considers the contribution of the family in providing patient care; it is essential to consider the valuable assistance of informal caregivers to patients' health conditions at the end of life [4]. Informal caregivers require special knowledge and skills regarding implementing specific healthcare services; however, they are often unprepared to provide care at home [11, 12]. Acquisition of knowledge and skills empowers informal caregivers to provide competent care with the least possible negative consequences [13]. Hence, the lack of informal caregivers' knowledge regarding PI prevention and management resulted in consecutive crises throughout the overall process of caregiving [14, 15].

Caring for terminally ill patients with PI at home imposes a burden on informal caregivers due to poor knowledge of predicting the development of PI before it occurs or correctly using the risk assessment scales [16]. Thus, education about PI prevention and management options for family caregivers is required [15]; to increase their knowledge and improve their competence in providing care for patients, as well as their self-confidence [17].

Research on the knowledge and skills of informal caregivers providing care for people with PI has received little attention in the international context, much less at national or regional levels. Instead, research has focused more on caregivers of people with other chronic conditions [18, 19]. For that, the authors decided to conduct the current study, which is the first of its manner at the national level and in the Arab world. It provides an opportunity to evaluate the level of knowledge of informal caregivers on PI prevention and treatment, in addition to identifying factors that are associated with PI prevention and treatment among informal caregivers of patients who need palliative care in Jordan to explore the extent of the problem and to handle this issue in the future. Therefore, the aims of this study were to: (1) determine the level of knowledge of informal caregivers on pressure injury prevention and treatment. (2) explore the socio-demographic characteristics of informal caregivers associated with pressure injury prevention and treatment among patients who need palliative care.

Methods And Materials

Design

A self-reported cross-sectional survey was used to collect data from informal caregivers who provided care for patients needing palliative care with PI between February to July 2018. This study was approved by the Research and Ethics Committee/Institutional Review Board at the School of Nursing at the University of Jordan.

Sample/Participants

About 160 family caregivers showed interest in participating in this study. Of them, 14 participants were excluded due to medical-related academic backgrounds, illiterate participants, or cognitively impaired. Therefore, 146 participants, 18 years or older, who were caregivers of patients with PI, were recruited by convenience sampling for the current study.

Instrument

A questionnaire was used to collect data about informal caregivers' knowledge of pressure injury prevention and treatment. The questionnaire was developed to assess the knowledge among nurses with well-established validity and reliability (Cronbach's Alpha of .78 or more) [19]. This questionnaire had a good reliability coefficient [19]. The questionnaire was translated into the Arabic language based on WHO guidelines for the process of translation and adaptation of instruments. The questionnaire was divided into two parts; the first one was about socio-demographic characteristics, including (age, gender, marital status, education level, employment status, number of years experience in providing PI care for patients

who need palliative care, scientific qualification, type of work, number of family members, monthly income level, and the previous background on dealing with patients PU).

The second part of the questionnaire inquired about the knowledge regarding the interventions used for PI prevention (16 items), and PI treatment based and practice questions (29 items) [19]. Each item has three responses; “Yes”, “No”, and “I Don’t know”. The scoring system varied from 0 to 1; score 0 = for No, and 1 for Yes. The questions were answered by “I Don’t Know” scored as zero. The total score was normalized to 100. Participants with a total score of < 50, 50–69, or > 70 were considered low, moderate, and high knowledge about PI, respectively.

A pilot study was conducted using the adapted and translated questionnaire among a sample of twenty-five participants; 15 informal caregivers agreed to participate after convening the inclusion criteria. The selected participants were not included in the main study sample. The same methodology for the main study has been followed without modifications on the items of the tools.

Data collection procedure

Each participant was approached in person and asked to enter the study by the hospital’s medical staff and primary investigator. The participants who agreed to participate in this study were contacted individually by interviewing each and asked to sign the consent form. After obtaining verbal and written consent, the study’s questionnaire was distributed to participants. At the front of each questionnaire was a cover letter explaining the nature of the study, aims, way of completion, and return. Then, the researcher collected the questionnaire from participants considering that the time needed to fill out the questionnaire was 15 minutes. Self-completed questionnaires were then handed in an envelope in batches to the researchers; after that, they were kept locked in file cabinets in the office until the completion of the research study. All information was dealt with confidentiality.

Data analysis

The SPSS (V. 22.0) with a significance level of 0.05 was used. Descriptive analysis was used to describe the continuous variables and determine the level of knowledge and practices of informal caregivers on PI prevention and treatment. The knowledge score of PI prevention and treatment was summed up in total scores (normalized to a varied of 0 to 100). Dependent variables, knowledge, and practice toward PI prevention and treatment were operationalized as sums of the items (after negative items were reversed) relevant to the questionnaire. Univariate statistics were used to determine factors associated with informal caregivers’ knowledge of PI prevention and treatment. The knowledge scores were roughly negatively skewed by visual inspection using histograms and value of skewness; for that, non-parametric tests were used, namely Mann Whitney for two groups and Kruskal Wallis for more than two groups.

Results

Description of participants

Altogether, 146 participants aged from 19 to 36 years were included in the analysis (Table 1). Most participants were unmarried 119 (81.5%), and more than half had a diploma degree (n = 76, 52.1%). In addition, most participants (n = 109, 74.7%) reported that two caregivers provided care for their patients with PU, with a mean of 2.11 (SD = 0.51). Healthcare providers were considered as sources of information about PI only by 4 participants.

Table 1
Demographic data and clinical characteristic (N = 146)

Variables	N (%)
Age	76 (52.1%)
≤ 30 years	70 (47.9%)
> 30 years	
Gender	37 (25.3%)
Male	109 (74.7%)
Female	
Marital status	119 (81.5%)
Unmarried	27 (18.5%)
Married	
Educational level	11 (7.5%)
Primary & Secondary school level	76 (52.1%)
Diploma level	59 (40.4%)
Bachelor level	
Occupation	65 (44.5%)
Governmental jobs	38 (26%)
Private jobs & Business	43 (29.5%)
Unemployed	
Monthly income	80 (54.8%)
300–500	53 (36.3%)
501–700	13 (8.9%)
701–1500	
Number of family member	22 (15.1%)
1–4	124 (84.9%)
5–8	
Do you have background/ experience in caring PI patient (n, %)	3 (2.1%)
Yes	143 (97.9%)
No	

Variables	N (%)
Age	76 (52.1%)
≤ 30 years	70 (47.9%)
> 30 years	
Gender	37 (25.3%)
Male	109 (74.7%)
Female	
Number of caregivers provided care for their patients with PU	37 (25.3%)
One	109 (74.7%)
Two	
Do you live with PI patient after discharge (n, %)?	121 (82.9%)
Yes	25 (17.1%)
No	

Informal Caregivers' Knowledge of PI Prevention and Treatment

The level of knowledge for PI prevention and treatment is presented in Table 2. The overall average of informal caregivers' knowledge of PI prevention is 40.5 (SD = 23.4), which is higher than PI treatment at 38.3 (SD = 22.5). Regarding the low level of knowledge, the informal caregivers who had insufficient knowledge of PI treatment were more those who knew about PI prevention. Also, 14.4% (n = 21) of informal caregivers had a high level of knowledge about the prevention of PI than treatment 10.3% (n = 15).

Table 2

Descriptive Statistics and Classification of Knowledge Levels toward Pressure Injury Prevention & Treatment (N = 146).

	Mean ± SD	Min-Max	Low level	Moderate level	High level
Knowledge prevention	40.5 ± 23.4	0–78.6	86 (58.9%)	39 (26.7%)	21(14.4%)
Knowledge treatment	38.3 ± 22.5	0–73.3	93 (63.7%)	38 (26%)	15(10.3%)

Overall responses of participants indicate poor knowledge of PI prevention. Many questions were also answered with "I Don't Know" for most items considered zero, reflecting poor knowledge, moreover, regarding the knowledge and skills of PI treatment. The items with the best correct answers were the reversed questions, which gives a hint of knowledge toward PI treatment, but the worst answered items were many. The remaining worse answered items were mainly related to the PI using assessment scales

or dressing techniques. Table 3 shows the five best responses to the informal caregiver's knowledge of PI prevention and treatment questions.

Table 3
Best Five Responses of Informal Caregiver about PI Prevention Questions (N = 146).

Knowledge on PI prevention	Yes N (%)	No N (%)	I Don't know N (%)
Avoid excessive friction (rubbing) and/ or friction over bony prominences in patient's movements	86 (58.9%)	14 (9.6%)	46 (31.5%)
Use pillows, foam wedges to relieve pressure over bony prominences such as knees, or heels	84 (57.5%)	14 (9.6%)	48 (32.9%)
Avoid excessive moisture due to incontinence, perspiration wound drainage and maintain skin clean and dry.	83 (56.8%)	12 (8.2%)	51 (34.9%)
Use skin barrier creams to protect reddened Skin *	63 (43.2%)	14 (9.6%)	69 (47.3%)
Reposition those patients at risk frequently and on regular basis (if it is safe to do so)	80 (54.8%)	17(11.6%)	49 (33.6%)
Knowledge on PI Treatment	Yes N (%)	No N (%)	I Don't know N (%)
Leave the necrotic (dead) tissues with no debridement on ulcers without signs of infection *	23(15.8%)	18(12.3%)	105 (71.9%)
Use topical antibiotics on PI with signs of Infection*	48 (32.9%)	16 (11%)	82 (56.2%)
Antibiotics are prescribed according to the results of swab culture in an infected PI *	51 (34.9%)	5 (3.4%)	90 (61.6%)
Use alternative methods in PI treatment such as (Honey, Heat, or other preparations) *	46 (31.5%)	17(11.6%)	83 (56.8%)
Using antiseptics frequently to clean PI wound such as Iodine providing, H ₂ O ₂ , Chlorohexidine *	50 (34.2%)	18(12.3%)	78 (53.4%)
Note: * reverse question.			

Factors associated with informal caregiver's knowledge of PI prevention and treatment in terms of selected socio-demographic characteristic

A statistically significant difference in informal caregivers' knowledge of PI prevention according to the occupation status (Kruskal-Wallis = 24.49; DF = 4, $p = 0.001$) (Table 4). Further examination with LSD post hoc test revealed that the knowledge of PI prevention among participants with a governmental job was

higher than among unemployed and free business working caregivers. Moreover, the marital status of informal caregivers is significantly different in their knowledge (Kruskal-Wallis = 157.9; DF = 2, $p = 0.001$). The results of Tukey HSD revealed that married participants have higher knowledge than unmarried participants. Also, this study found that participants aged more than 30 had significantly higher knowledge of PI prevention than those under 30 (MW = 1805.5, $p = .001$).

Table 4
 university analysis for informal caregiver's knowledge of PI prevention and treatment (n = 146).

Knowledge on PI prevention		N	Mean (SD)	Df	Test statistic	P value
Age	≤ 30 years	76	31.4 (19.2)		1805.5 ¹	.001**
	> 30 years	70	45.8 (23.5)			
Gender	Male	37	41.3 (25.2)	2	1942.5 ¹	.738
	Female	109	40.3 (22.9)			
Monthly income	300–500	80	39.9 (23.5)	2	0.367 ²	.832
	501–700	53	40.6 (23.1)			
	701–1500	13	44.1 (25.6)			
Occupation	Governmental jobs	65	44.5 (18.8)	4	24.49 ²	.001**
	Private jobs & business	38	26 (23.4)			
	Unemployed	43	29.5 (26.8)			
Marital status	Unmarried	119	37.1(22.9)	2	157.9 ³	.001**
	Married	27	55.1 (19.9)			
Educational level	School	11	36.4 (24.3)	3	5.105 ²	0.164
	Diploma	76	43.5 (22.8)			
	Bachelor	59	37.3 (23.7)			
Family size	1–4	22	51.8 (18.6)	1	0.098 ¹	0.238
	5–8	124	38.5 (23.7)			
Knowledge on PI treatment		N	Mean (SD)	Df	Test statistic	P value
Age	≤ 30 years	76	31.4 (19.2)	1	1689.5 ¹	.001**
	> 30 years	70	45.8 (23.5)			
Gender	Male	37	40.8 (24.3)	2	185 ¹	.456
	Female	109	37.5 (21.9)			

Note: * P < 0.05, ** P < 0.01, (1): Mann-Whitney test, (2): Kruskal-Wallis test

Knowledge on PI prevention		N	Mean (SD)		Df	Test statistic	P value
Monthly income	300–500	80	36.1	(23.5)	2	2.24 ²	.327
	501–700	53	41.1	(20.9)			
	701–1500	13	40.9	(22.4)			
Occupation	Governmental	8	58.9	(18.1)	4	18.09 ²	.001**
	Private job & Business	9	51.2	(26)			
	Unemployed	22	42.0	(25.9)			
Marital status	Unmarried	119	35.7	(21.1)	2	157.9 ²	.001**
	Married	27	50.3	(25.6)			
Educational level	School	11	34.7	(25.8)	3	4.171 ²	.244
	Diploma	76	40.6	(22.4)			
	Bachelor	59	35.9	(21.6)			
Family size	1–4	22	47.6	(23.3)	1	923.0 ¹	.015*
	5–8	124	36.7	(22.1)			
Note: * P < 0.05, ** P < 0.01, (1): Mann-Whitney test, (2): Kruskal-Wallis test							

Similar to PI prevention, marital status, age, and occupation significantly differed in caregivers' knowledge of PI treatment. Furthermore, the participants' family size significantly differed in their knowledge of PI treatment; the participants with small family size had a significantly higher knowledge than large family size (MW = 923.0, $p = .015$). However, the other variables, such as gender, education, and monthly income, were not significantly different in the informal caregivers, knowledge, and practice toward both PI prevention and treatment.

Further multiple regression analysis was run to predict informal caregivers' knowledge about PI prevention based on participants' age, marital status, and occupation status. A significant regression equation was found $F(9, 136) = 3.243$, $p = .001$, with an $R^2 = .177$, but all these variables did not add any statistical significance to the prediction, $p > .05$. On another hand, the informal caregivers' knowledge about PI treatment based on participants' age, marital status, occupation status, and family size revealed that the participants who worked in governmental jobs have ten times more knowledge about PI treatment than other occupations. Small family members were also more likely to know about PI treatment than large family members. Both governmental jobs and small family size were significant

predictors of knowledge about PI treatment, which added more support for our results related to PI treatment. However, the factors significantly different based on PI prevention knowledge were not considered predictors for knowledge.

Discussion

One of the remarkable findings in this study was that more than half of the participants have a low level of knowledge about PI prevention and treatment, which may indicate insufficient informal caregiver ability to care for PI appropriately. These findings are consistent with various studies [13, 20–24]. Similar findings were cited in Egypt, Bangladesh, and Jordan, which revealed inadequate nurse knowledge about PI prevention and scarcity of training resources [25]; this may be considered a reasonable cause of poor knowledge about PI prevention and treatment among family caregivers in our study. Conversely, some studies revealed a good level of knowledge about PI prevention among healthcare providers in general and nurses in a specific manner, either in the Arab world [26] or internationally [27, 28].

Adequate PI knowledge about prevention is crucial for the health care provided to these patients with PI [26]. Our study found that few participants have received knowledge directly from healthcare providers or other sources like posters and the internet; also, most of them lived with PI patients after discharge at home as they are unemployed, which could give them a chance to have good knowledge about PI prevention and treatment. However, most participants did not receive any previous education or information about PI. This could be the significant reason for poor knowledge about PI prevention and treatment that enhance stress among patients and caregivers, leading to worsening patients' quality of life, as confirmed by another study [30, 31]. From the causal viewpoint, the negative impact of informal caregiving on caregiver employment was reported as the care is time-consuming, so providing care in addition to other work is difficult and may lead to decreasing the work hours or even giving up their job [29]. In addition, those caregivers who have more free time to care for their patients because they are unemployed or part-time working are more likely to become caregivers [29]. In this regard, the rituals in the Arab world mainly proposed that the unemployed and unmarried family caregivers should care more about their patients than those who spend many hours in their job. This may explain the converse findings between the informal caregiver's knowledge about PI prevention and treatment and occupation types; besides, the patients mainly were cared for by more than one family caregiver, and this shifting between caregivers could limit their awareness of holistic patient status, which gives a chance to have not all needed information about PI prevention and treatment among family caregivers.

Moreover, most participants were unmarried, younger, and had or still continue their university education; they have a lack of educational resources about PI care; this could be considered as a reason for the lack of informal caregivers' knowledge about PI prevention and treatment. In this regard, poor knowledge of predicting the progress of PI among caregivers was considered the biggest barrier to preventing PI before it occurs [16]. Thus, the informal caregivers who provide care for patients with PI need to gain knowledge and skills to provide specific care to patients with PI [13, 14]. Whereas, the knowledge of caregivers for palliative patients without PI, such as delirium, was poor, but it improved after receiving information

leaflets or booklets along with routine discussions with a clinician [32–34]; similarly, among caregivers of advanced heart failure patients [35]; and advanced chronic obstructive pulmonary disease [36].

In this study, gender was not considered a significant factor influencing informal caregivers' knowledge of a patient with PU. In contrast, a study [19] reported that gender had influenced the knowledge of caregivers regarding the prevention of PI and treatment, and the male gender was associated with better knowledge about PI prevention and management. Surprisingly enough, in this study, the education level was not associated with informal caregivers' knowledge of PI prevention and treatment, while education for informal caregivers has an important role in clinically improving patient status [37]. The other distinguished result is that caregiver age in many studies is not associated with good care providers' knowledge at home [25, 38]; this is incongruent with our results.

Low informal caregivers' knowledge, and practices give a hint that there is a need for more intention toward teaching PI caring and implementation of PI care guidelines as recommended in different studies [24, 39–40]. Therefore, there is a need to emphasize that palliative care is not only appropriate for people living with a life-threatening condition but also for those who are at risk of developing a life-threatening illness in the near future.

Important implications and recommendations of this study include enhancing the informal caregivers' knowledge about PI to promote preventive skills and appropriate management of PU. Subsequently, further studies are required to explore the teaching needs of informal caregivers and how to utilize these needs to enhance their knowledge. In hospitals, coordinators and educators need to educate informal caregivers on the importance of routine assessment and preventive skills, especially among patients who are at risk. Also, more attention should be directed toward older and married caregivers who can acquire knowledge better than others; all of these points could improve the patient quality of care.

Limitations

This study has some limitations. Firstly, the convenience and a small sample. Secondly, the informal caregivers were also enrolled from only one site in Northern Jordan, and the selection of family caregivers for patients with PI without focusing on other patients who need palliative care; the findings could not be generalized. Thirdly, there is a lack of published studies on this topic. Fourthly, a few participants answered PI prevention and treatment knowledge questions with "I don't know," which decreased the high knowledge score. Finally, the risk of bias may have increased due to the self-reported questionnaires.

Conclusion

Physicians, nurses, educators, and researchers can assist in providing information for caregivers in different sitting about PI prevention by focusing on young married ones. A high level of knowledge about PI prevention and treatment can help informal caregivers acquire professional practices and attitudes that will facilitate them to improve the quality of patient care.

Declarations

Ethics approval and consent to participate

The study was granted ethical approval to conduct the study by the Institutional Review Board (IRB) at the University of Jordan. Informed consent was obtained from all participants. All methods were carried out in accordance with Declaration of Helsinki.

Consent for publication

Not applicable.

Availability of data and materials

All data generated or analysed during this study are included in this published article.

Competing interests

The authors have no conflicts of interest to disclose.

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Authors Contributions

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