

Clinical evaluation with long-term follow-up of patients with pressure ulcers in one Swedish county

Objective: To conduct a screening, skin examination and risk assessment of patients with pressure ulcers (PUs) in one Swedish county (inpatient, primary and community care) with follow-up after six months to investigate ulcer healing, frequency of amputation and mortality rate linked to preventive measures.

Method: The methodology recommended by the European Pressure Ulcer Advisory Panel was used. Screening, risk assessment and skin examination were performed during March 2017. The modified Norton scale was used to assess PU risk, with a score of ≤ 20 indicating presence of risk. A research questionnaire was used to document prevention and treatment. Follow-up was performed after six months, during September 2017. The same research questionnaire was used to capture the current situation of the patients, including ulcer healing, frequency of amputation, and mortality rate.

Results: Screening covered 464 patients: 303 hospitalised, 68 in community care, and 93 in primary care. A total of 110 patients—55 at risk of PU and 55 with PUs, the majority of which were category 2–4 PUs—were included in the study. At follow-up, 67% were treated in community care, 32% in primary care, and 1% in hospital. Mortality rate for patients with PUs was 44%. Of the remaining 31 patients, 17 had unhealed PUs, 10 had healed PUs, two had undergone amputation, and complete follow-up data was missing in the remaining two patients.

Conclusion: These results reflect the complex situation of an aged and frail patient group, including a lack of preventive measures and follow-up routines in community and primary care.

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hard-to-heal ulcer • modified Norton scale • mortality • pressure ulcer • pressure ulcer prevention • ulcer healing

Patients with hard-to-heal ulcers have long been considered a neglected patient population. Many are treated without diagnosis and so receive suboptimal ulcer care.¹ Shortcomings in follow-up and continuity of care have crucial implications for these patients who are older, fragile, and often with comorbidities such as diabetes, arterial and venous insufficiency, heart and lung diseases, and rheumatoid arthritis.^{2,3}

Pressure ulcers (PUs) represent a subgroup within hard-to-heal ulcers and account for approximately 20% of all ulcer diagnoses.³ PUs are defined as 'localised injury to the skin and/or underlying tissue usually over a bony prominence, as a result of pressure, or pressure in combination with shear'.⁴ The modified Norton scale is used widely in Sweden to assess PU risk, covering general condition, mental health status, physical activity, mobility, incontinence, and food and fluid intake.^{5,6}

The Swedish agency for health technology assessment and assessment of social services reports that organisation of wound treatment with regard to specialised wound care clinics and care processes differs greatly between different regions in Sweden.⁷ Moreover, there are shortcomings in the procedures, documentation, and communication between different caregivers. Reforms of the Swedish healthcare system have led to lack of continuity of care, and more and diverse healthcare providers. This is especially true for the care of patients with PUs.⁷

PUs are among the most common healthcare injuries impacting on suffering, illness, or death that could have been avoided if appropriate measures had been taken during contact with the relevant healthcare provider.⁸ They have been identified by the Swedish Association of Local Authorities and Regions (SALAR) as one of six focus areas for improvement of patient safety.⁹

There is a widespread lack of documentation and follow-up of PU patients, especially for patients treated in community care; in addition, the quality of care of PU patients appears to depend on staffing levels and skills.⁷ Systematic reviews have found that PU patients experience lower quality of life (QoL), partly due to feeling ignored by the healthcare system.^{10,11} Patients with PUs are especially vulnerable where access to qualified wound management is limited.^{7,12}

The reported prevalence of PUs in Canada varies from 15.1% to 29.9% in different settings.¹³ In Sweden, the overall prevalence of category 1–4 PUs was found to be

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14.4–16.1% in hospitals and 11.8–14.5% in nursing homes.¹⁴ Attempts to capture current prevalence data for hospitalised PU patients and patients treated within community care have been made by both SALAR¹⁵ and the Swedish national quality registry, Senior Alert.¹⁶ However, prevalence data on PU patients treated in primary care are still lacking.

Wound management entails considerable costs for healthcare systems throughout the world, accounting for roughly 2–4% of the total healthcare budget in industrialised countries.⁷ A study showed that the cost of treating a PU in the UK varied from £1214 (category 1 PU) to £14,108 (category 4 PU),¹⁷ whereas another study reported that the cost per patient per day of PU prevention and PU treatment varied from €2.65 to €87.57 and from €1.71 to €470.49, respectively, across different settings.¹⁸

There is still a lack of research concerning the organisation of prevention and treatment of patients with PUs, leading to a situation that is difficult to manage, particularly in community care.⁷ Furthermore, structured working processes and follow-up are unusual, making it difficult to form a clear national picture.

Aim

The purpose of this project was to conduct screening combined with skin examination of patients with PUs and/or at risk of PUs in one Swedish county (inpatient, primary and community care) with follow-up after six months to investigate ulcer healing, frequency of amputation, and mortality rate linked to preventive measures.

Methods

Healthcare in the county of Blekinge (population 159,838 as of September 2018) is provided by two county hospitals, five municipalities, 21 primary care centres, and one specialist centre (Blekinge Wound Healing Centre, BWHC) where ulcer care is carried out in cooperation with staff from the hospitals, municipalities, and primary healthcare centres.

Caregivers from hospital, community, and primary care in Blekinge county were invited to screen patients with PUs and/or at risk of developing PUs. To avoid the risk of registering a patient more than once, the researchers scrutinised the material in joint sessions in order to reduce the risk of double registration.

Screening, risk assessment, and skin examination

The methodology recommended by the European Pressure Ulcer Advisory Panel was used.⁴ Screening, risk assessment and skin examination of patients with category 1–4 PUs were performed during 6–10 March 2017 in primary and community care and during one day (8 March 2017, starting at 07.00 am) in hospital care. Patients were included in the study after giving their informed consent.

The modified Norton scale was used to assess PU risk, with a score of ≤ 20 indicating the presence of risk.^{5,6}

Skin examination was performed on the body sites where PUs usually occur, such as the sacrum, ischial tuberosities, scapula, hips, heels, ears, elbows, ankles and scalp. Sacrum and ischial tuberosities were considered as one location for practical reasons.

A research questionnaire was used, similar to an established and validated survey that has been used annually in the county of Blekinge since 1987 for registration of patients with hard-to-heal ulcers, including PUs, to map ulcer incidence and treatment as well as staff workload during one week.¹⁹ The survey in this study was complemented with questions about PU location, treatment strategies and preventive measures, including turning regimen and the use of sliding sheets, heel protection, pressure-relieving or pressure-equalising mattresses, and arginine-enriched nutritional supplementation.^{5,7} Inclusion criteria were slightly adjusted to fit each specific caregiver; included in primary care were patients with category 2–4 PUs and in hospital and community care patients with category 1–4 PUs were included.

Inpatient care

For hospitalised patients, screening was performed in all clinical departments by 25 nurses supervised by five nurses belonging to the nurse director's staff and specially trained in PU classification, risk assessment and prevention. Hospitalised patients were treated for a variety of acute illness; PUs were never the primary diagnosis, as the Blekinge hospitals lack inpatient beds for PU patients.

Community care

The head nurses of the five municipalities in Blekinge were approached and invited to participate in the study. Screening, risk assessment and skin examination were performed in 12 larger nursing homes and within five home healthcare districts by 25 community nurses.

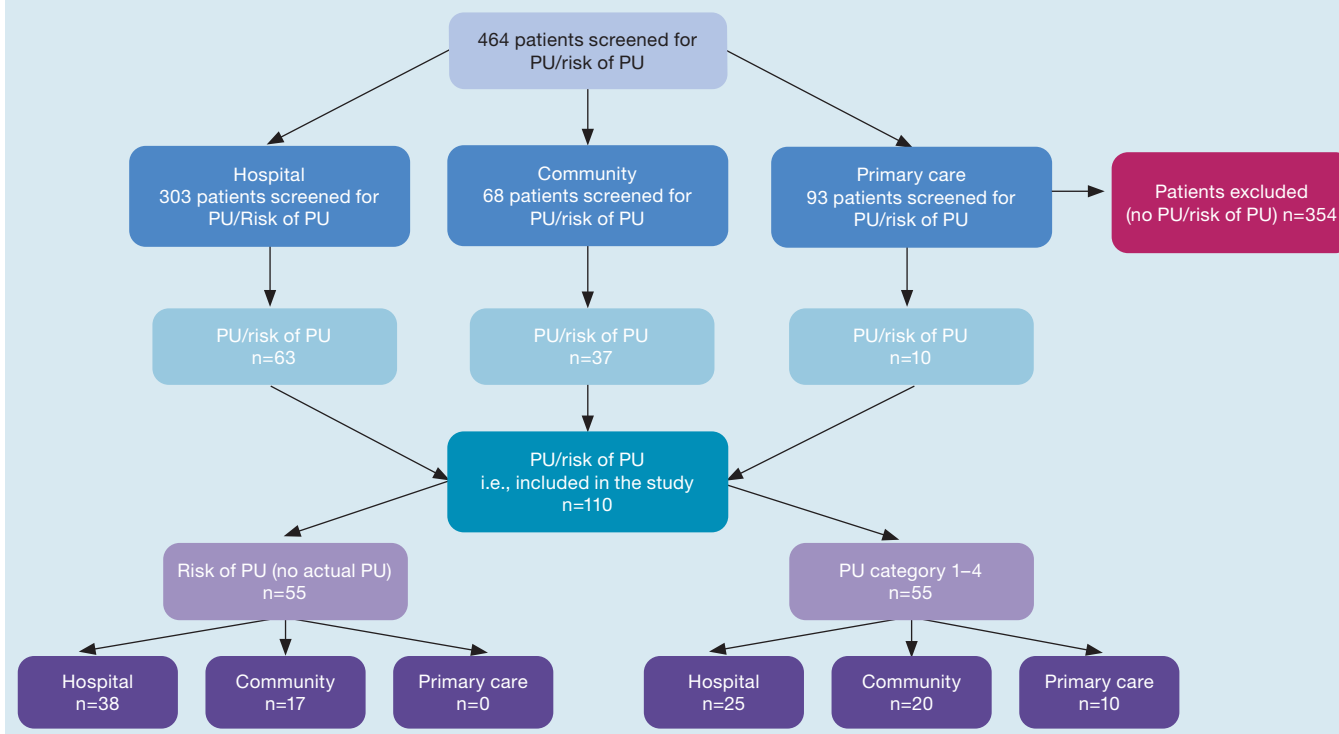
Primary care

District nurses and assisting nurses were asked to screen every patient who came to the healthcare centre for dressing changes or to seek professional help for an open wound. Screening, risk assessment and skin examination were performed in 14 different healthcare centres by 22 district nurses/assistant nurses. The nurses were, in many cases, registrars in the Swedish National Quality Registry for Ulcer Treatment (RUT/RiksSår), as documentation in this registry is mandatory in primary care in Blekinge county. Detailed information about registering in RUT and research data from the registry can be found elsewhere.¹

Follow-up after six months

The follow-up was performed during 4–8 September 2017, including screening, risk assessment and skin examination of patients with PUs. The same research questionnaire was used to capture the current situation of the patients, as well as questions on ulcer healing

Fig 1. Screening of patients with pressure ulcers (PUs) and/or at risk of PUs treated in hospital, community, and primary care in Blekinge County in March 2017



and whether the patient had developed a new PU, had undergone amputation or was deceased.

The researchers traced the patients to their present caregiver, where the responsible nurse performed a risk assessment, examined the patient's skin, classified potential PUs and reported the patient's prescribed measures for prevention/treatment of the PUs. If the patient had returned home and no longer needed medical care, the district nurse responsible for home healthcare conducted and documented the results of the risk assessment and skin examination. Patients who were included when hospitalised and later discharged from hospital were followed up by specially trained nurses responsible for inpatient care.

Statistical analysis

Statistical analysis was performed using IBM SPSS Statistics version 24. Normally-distributed data on the interval level (age) were expressed as mean and standard deviations (SD) and compared using Student's t-test. Age was also presented with median values and ranges in parentheses. Non-normally distributed data on the interval level (Norton scores) were expressed as median and ranges, and compared using the Mann-Whitney U-test. Data on the nominal level (gender, ulcer category, antidecubitus mattress, sliding sheet, turning regimen, heel-relieving aids, nutritional supplementation) were compared between patient groups using Pearson's chi-square test. A p-value of <0.05 was considered to indicate statistical significance.

Ethics approval

Ethics approval was obtained from the Regional Ethical Review Board of Lund, Sweden (2016/1067). Patients were included in the study after giving their informed consent. Patients could withdraw from the study at any time.

Results

Screening of patients treated in hospital, community, and primary care

The screening covered a total of 464 patients, of whom 303 were hospitalised, 68 were treated in community care and 93 were treated in primary care. Of the five included municipalities, one did not participate in the study due to lack of staff, time and interest.

The majority of the examined patients (76%, n=354) did not have PUs and were not at risk of developing one. We thus included a total of 110 patients with PUs and/or at risk of PUs (Fig 1). Of these, 57% (n=63) were treated in hospital, 44% (n=37) in community care and 9% (n=10) in primary care. The mean age was 79 years (SD: 9.8, median: 80 years, range: 52–96 years) and 55% were women. Median Norton score was 18 (range: 9–28).

Patients at risk of PUs (modified Norton score ≤20)

Of the 110 patients included, 50% (n=55) were at risk of developing PUs but had no present PUs. The mean age in this group was 83 years (SD: 9.8, median: 84 years, range: 52–96 years), and 53% were women. The patients were found within hospital care (69%, n=38)

and community care (31%, n=17), but not in primary care. Their median Norton score was 17 (range: 9–20).

The majority of patients were treated with preventive measures, such as pressure-relieving or pressure-equalising mattresses (58%), while 27% had heel protection, 49% had sliding sheets, 42% had turning regimens and 35% had sitting restrictions.

Patients with category 1–4 PUs

The mean age of the 55 patients with PUs was 76 years (SD: 8.7, median: 76 years, range: 53–96 years), and 53% (n=29) were women. Of these patients, 46% (n=25) were hospitalised, 36% (n=20) were treated in community care, and 18% (n=10) were treated in primary care. Most (35/55) had category 2–4 PUs, while 18/55 had category 1 PUs. No category was reported for the remaining two patients. Median Norton score was 19 (range: 9–28). Mean age was significantly lower than for patients at risk but without PUs ($p<0.001$) and median Norton score was significantly higher ($p=0.03$).

Regarding PU location, 20 patients had PUs on their heels; these were mainly category 2–4 PUs (n=12), while seven were category 1 and no category was reported for the remaining one patient.

PUs located on the sacrum or ischial tuberosities were identified in 16 patients, with most being category 1 (n=9) and the rest category 2 (n=7). The remaining 19 PUs (35%) were on the ears, scapula, hip or ankle (Table 1).

Follow-up

At the six-month follow-up, the majority of the 110 patients with PUs and/or risk of PUs (67%) were treated in community care, 32% were treated in primary care, and 1% hospitalised. Mortality rate was 40% (n=44) in the total group. There were incomplete follow-up data for 10 patients despite repeated reminders by mail, telephone and check-ups of medical records. Median Norton score was 22 (range: 16–28).

Patients at risk of PUs with no actual PUs

Among the 55 patients with PU risk but no actual PUs at screening, complete follow-up data were found for 71% (n=39) (Fig 2). The majority of these patients (74%, n=29) were followed up by staff in community care, 23% (n=9) in primary care, and one patient in hospital. The median Norton score was 22 (range: 16–28), and the mortality rate was 36% (n=20). There were 10 women and 10 men among the deceased patients and the mean age was 83 years (SD: 10.2, median 84 years, range: 58–95 years). Mean time for inclusion in the study until death was 41 days (median: 16 days, range: 0–176 days), including one woman who died just after being included in the study. Cancer-related disease was the cause of death in seven patients, for five patients the cause of death was related to cardiovascular diseases, four patients died of neurological diseases, one of lung disease, one patient died of old age and one of liver cirrhosis. For one patient the cause of death was not

Table 1. Pressure ulcer location, patient characteristics and preventive measures at initial screening

	Location		
	Scrum/ischial tuberosities (n=16)	Heel (n=20)	Other (n=19)
Patient characteristics			
Female, %	50	70	53
Age, years, mean (standard deviation)	77 (6.8)	77 (1.7)	74 (2.5)
Modified Norton median (range)	17 (9–24)	20 (9–28)	21 (15–28)
Category 1 PU, %	56	35	11
Categories 2–4 PU, %	44	60	84
Category of PU unknown, %	0	5	5
Preventive measures			
Antedecubitus mattress:			
Pressure-equalising, %	69	40	26
Pressure-relieving, %	25	40	32
Not used, %	6	20	42
Sliding sheet, %	38	55	42
Turning regimen, %	69	40	32
Heel-relieving aids, %	44	85	16
Arginine-enriched nutritional supplementation %	44	40	26

available. In all cases, there were no notes in the death certificates of a link to a PU causing death.

A PU developed in three patients; their mean age was 83 years and their median Norton score was 16, two were women, and all had been treated with pressure-equalising/pressure-relieving mattresses.

Patients with category 1–4 PUs

Among the 55 patients with PUs at screening, complete follow-up data were available for 37. The majority of these patients (59%, n=22) were followed up in community care, 41% in primary care, and none in hospital. The median Norton score was 22 (range: 17–28), and the mortality rate was 44% (n=24).

Follow-up mortality data for 14 women and eight men was available, showing a mean age of 76 years (SD: 9.5, median: 75 years, range: 61–93 years). Mean time for inclusion in the study until death was 74 days (median: 66 days, range: 5–170 days). For 11 patients (50%), cause of death was related to cardiovascular diseases, four patients died of cancer, three of lung diseases, two of chronic kidney disease, one of a neurological disease and one patient of infection (Candida sepsis). In all cases there were no notes in the death certificates of a link to a PU causing death.

For deceased patients, there was a difference in age,

cause of death and time from inclusion to death when comparing patients at risk of PUs with patients with 1–4 PUs. Patients at risk of PUs had a median age of 84 years compared with 75 years for patients with PU category 1–4 and median time from inclusion to death was 16 days and 66 days respectively.

Cause of death was mainly cancer (37%), cardiovascular diseases (26%) and neurological diseases (21%) for patients at risk for PUs compared with cardiovascular diseases (50%), cancer (18%) and lung disease (14%) for patients with category 1–4 PUs. Mortality rate did not differ significantly from the group with PU risk but no actual PUs at screening ($p=0.512$). In terms of healing after six months, 31% of patients ($n=17$) had unhealed PUs, 18% ($n=10$) had healed PUs, two had undergone amputation, and complete follow-up data were missing for the remaining two (Fig 3).

Among the 10 patients whose PUs had healed, five had healed category 1 PUs and the remaining five had healed category 2–4 PUs. Most of these PUs ($n=5$) were located on heels, two were located on the sacrum/ischial tuberosities and the remaining three were in other locations. The mean age of these patients was 84 years (SD: 8.0, median: 84 years, range: 73–96 years), 60% ($n=6$) were women, their median Norton score was 19 (range: 16–22), and half ($n=5$) had received arginine-enriched nutritional supplementation.

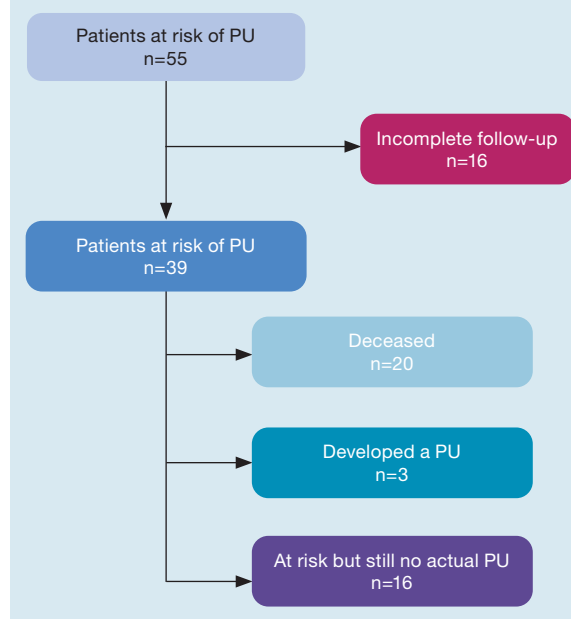
Patients with PUs on the heels had received heel protection, while only one patient with a PU on the sacrum/ischial tuberosities had access to a pressure-equalising mattress, sliding sheet and turning regimen.

Discussion

The findings of this study of PU patients in hospital, community, and primary care showed that 50% of the patients had open PUs and 50% were at risk of developing PUs, according to the modified Norton scale. Mortality rate among the 110 patients in the total group was high, with 40% ($n=44$) having died by the time of the six-month follow-up. Even if this is not in accordance with previous research, reporting a 66% death rate at follow-up after 12 weeks,²⁰ it indicates that patients with PUs belong to a frail patient group with high median age (84 years) and with higher mortality rate than the expected 20% for persons aged >80 years in Sweden.²¹ Mortality did not differ significantly between patients with PUs at screening (44%) and patients at risk but with no actual PUs at screening (36%).

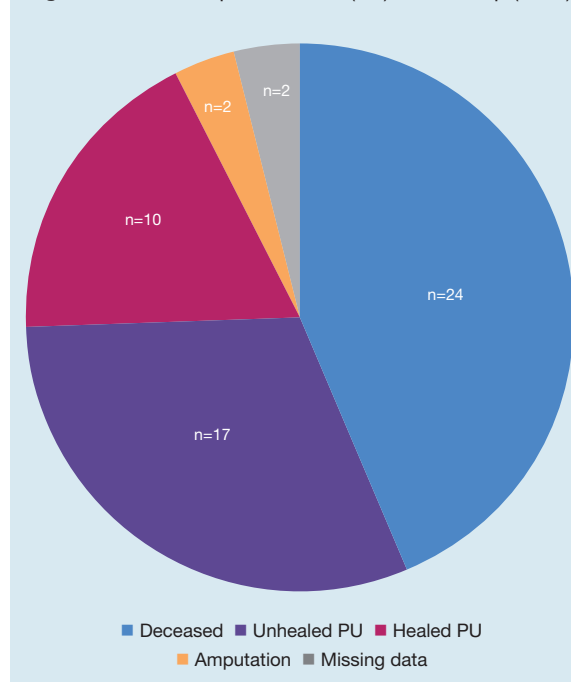
However, there were some notable differences between the two groups showing higher age and shorter time from inclusion to death for patients at risk of PUs compared with patients with category 1–4 PUs. An explanation could be the difference in causes of death, showing cancer as the main cause for patients at risk of PUs compared with cardiovascular diseases for patients with PUs category 1–4. Screening further showed that the majority of patients with PUs and/or at risk of PUs were hospitalised, but the primary diagnosis was not related to PU. As most patients died in hospital, we

Fig 2. Follow-up of patients at risk of pressure ulcers (PU) (modified Norton score ≤ 20) but no actual PUs at screening



could not confirm what earlier researchers have reported on nursing home residence to be an independent predictor of mortality in older patients with PUs.²⁰ Screening for PU is performed regularly, both in Swedish hospitals and in community care, and screening routines have improved continuously both in Blekinge

Fig 3. Patients with pressure ulcer (PU) at follow up ($n=55$)



and nationally. However, our results suggest that this measure is not sufficient to reflect the whole complex situation of patients with PUs. That patients with PUs and/or risk of PUs are mainly treated (and for a longer time) within community care reflects the fact that these patients are older, frail and have complicating comorbidities.⁷ Of the patients included in the study, nine were followed up in primary care, which seems to be an untapped resource to find and refer these patients to adequate community care.¹⁹

Patients with PUs had a significantly higher median Norton score (19) than patients at risk of a PU (17) ($p=0.03$), which raises the question of whether the modified Norton scale is sufficiently sensitive and captures the right patients. Other PU risk assessment instruments, such as the Waterlow Score, the Braden Scale and the PURPOSE-T (Pressure Ulcer Research Programme) are used in other healthcare settings.²² However, we found, in accordance with earlier researchers,⁶ that the modified Norton scale was sufficient for assessing patients at risk of PUs, since this scale is used regularly in daily practice in Swedish hospitals and community care. Conversely, in primary care the modified Norton scale was unknown, even to very experienced district nurses, which illustrates a competence gap in primary care concerning patients with PUs and/or at risk of PUs.

An interesting result was that the median Norton score was higher at follow-up (22) than during screening (18), which might reflect the fact that many of the screened patients were hospitalised due to acute illness and had recovered by the time of follow-up. Another intriguing result was that patients with a modified Norton score of <20 and no PUs at screening were significantly older (mean: 83 years) than patients with a PU at screening (mean: 76 years) ($p<0.001$). This finding might be explained by PU patients having other comorbidities (mainly cardiovascular diseases) than patients without PUs (cancer) but this result was not further investigated in our study.

At screening, the majority (64%) of patients with PUs had category 2–4 PUs on the heel, and those PUs located on the sacrum were mainly category 1. This is in contrast with earlier research showing the majority of PUs to be category 1.²³ A plausible explanation for this could be that we did not include patients with PU category 1 in primary care; a larger patient population would possibly have clarified the situation. Patients with PUs located on the sacrum or ischial tuberosities had a lower median Norton score (17) than patients with PUs located on the heels (20), but due to the small number of patients no convincing conclusions could be drawn.

Almost one-third (31%) of the patients with PUs located on the sacrum or ischial tuberosities were not treated with an antidecubitus mattress or turning

regimen, which should be prescribed for every patient with a PU or at risk of PUs. Furthermore, only 44% of these patients were prescribed arginine-enriched nutritional supplementation. An explanation for this failure to follow actual guidelines for patients with PUs might be that this patient group is frail, dependent on others and the health problem has low medical priority, which has been reported elsewhere.^{7,24}

At the six-month follow-up, 10/55 patients had a healed ulcer. This is a low healing frequency compared with previous research showing complete healing for 56.7% of patients with category 2 PUs; however, in that study patients transferred to other units were not included in the follow-up.²⁵ We also noted that more of the PUs that were healed at follow-up were located on the heel ($n=5$) than on the sacrum ($n=2$), which might indicate that patients with PUs on the sacrum did not get the right preventive measures, such as a turning regimen or the right mattress. The three patients who acquired a new PU belonged to the oldest patient group, with a mean age of 83 years, and had the lowest median Norton score (16). Once again, this reflects the vulnerability of this aged patient group.

Follow-up raised many questions, such as what the healing frequency and mortality rate would be if every patient was prescribed adequate preventive measures. Our study reflects a medical field with room for improvement; one of the main findings was that the patients whose PU had healed at follow-up had been given the same pressure-relieving equipment at baseline and at follow-up. Preventive measures should follow patients with PUs through the whole healing process.

To our knowledge, this study is the first to screen and examine patients with PUs treated by different caregivers and with follow-up after six months. Our choice to cover a whole county pinpointed the difficulties of following PU patients over the boundaries of different caregivers.

Limitations

The largest obstacle was the shortfall of documentation at follow-up, which has been noted in several earlier studies showing high levels of missing data.²⁶

The failure to obtain solid follow-up data might reflect the lack of time that staff feel they can devote to PU patients, and possibly also a lack of competence in wound management. It could also be explained by non-adherence to existing routines and guidelines for following the patient's healing process.⁷

Conclusion

Despite the small study group and the shortcomings in follow-up data, this study could be clinically valuable in reflecting the true situation of an aged and frail patient group with PUs. **JWC**

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Reflective questions

- How is treatment of patients with PUs in your unit organised?
- How does communication regarding patients with PUs work between staff in primary care, community care and different hospital wards in your region?
- What kind of follow up do you have for checking preventive measures and their impact on patients with PUs?

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