# Skin Changes at Life's End (SCALE) Annotated Reference List

September 1, 2008

Alvarez OM, Kalinski C, Nusbaum J, Hernandez L, Pappous E, Kyriannis C, Parker R, Chrzanowski G, Comfort CP. Incorporating wound healing strategies to improve palliation (symptom management) in patients with chronic wounds. *J Palliat Med*. 2007;10(5):1161-89.
Overview of S-P-E-C-I-A-L approach to palliative wound care incorporating clinical experience with evidence from curative literature, including rationale and principles of wound care, prioritizing strategies for symptomatic relief and improved outcomes.

Aminoff BZ, Adunsky A. Dying demenia patients: too much suffering, too little palliation. *Am J Hosp Palliat Care*. 2005;22(5):344-8.
Prospective study of pathological syndrome of suffering among terminal dementia patients in geriatric hospital ward, with follow up to discharge or death. Results showed 70.4% suffered pressure ulcers (PrUs) during last week of life.

Bale S, Finlay I, Harding KG. Pressure sore prevention in a hospice. *J Wound Care*. 1995;4(10):465-8.
Two phase prospective study to evaluate incidence of PrUs in hospice patients as related to use of modified Norton risk assessment alone and in association with three levels of pressure redistribution support surfaces.

Bansal C, Scott R, Stewart D, Cockerell CJ. Decubitus ulcers: a review of the literature. *Int J Dermatology*. 2005;44:805-10.
Literature review of PrUs incorporating evidence on pathogenesis, morphology, histopathology, treatment, outcomes and complications.

Berlowitz D, Wilkins SVB. The short-term outcome of pressure sores. *JAGS*. 1990;38(7):748-52.
Retrospective medical records audit using statistical analysis to evaluate short term outcomes of patients with PrUs in a long term care hospital. Only being bed or chair bound was a significant independent predictor of failure to progress toward healing.

Bourdel-Marchasson I, Barateau M, Sourgen C, Pinganaud G, Salle-Montaudon N, Richard-Harston S, Reignier B, Rainfray M, Emeriau JP. Prospective audits of quality of PEM recognition and nutritional support in critically ill elderly patients. *Clin Nutr*. 1999;18(4):233-40.
Report of two consecutive, prospective audits to investigate the quality of malnutrition recognition and nutritional support and outcomes in immobilized critically ill elderly patients. Improvement of malnutrition recognition and nutrition support was not followed by decrease in adverse outcome rate.

Brandeis GH, Berlowitz DR, Katz P. Are pressure ulcers preventable? a survey of the experts. *Adv Skin & Wound*. 2001;14(5):244, 245-8.
Report of a survey sent to convenience sample of experts in field of PrUs, ranking items using Likert Scale to determine opinion regarding preventability of PrUs in nursing homes, the availability of resources and the role of lawsuits in PrU care.

Brink P, Smith TF, Linkewich B. Factors associated with pressure ulcers in palliative home care. *J Palliat Med*. 2006;9(6):1369-75.
Retrospective exploratory study to identify factors associated with PrUs among palliative home care clients with terminal cancer and a prognosis of greater than 6 weeks. Information gathered using the interRAI instrument for palliative care.

Brown G. Long-term outcomes of full-thickness pressure ulcers: healing and mortality. *Ostomy/ Wound Management*. 2003;49(10):42-50.
Non-experimental retrospective quality analysis of nosocomial PrU data within the VAMC, among patients in acute care, intensive care and long term care. Comparison of time to death outcomes between two groups; those who died before 180 days of PrU onset and those who lived beyond 180 days of onset.

Cain JM. Practical aspects of hospice care at home. *Best Pract Res Clin Obstet Gynaecol*. 2001;15(2):305-11.
Review of practical recommendations for what the author terms *transmural* care; care that crosses between home and hospital settings to facilitate a seamless environment.

Cassel EJ. The nature of suffering and the goals of medicine. *NEJM*. 1982;306(11):639-45.
Thoughtful commentary on the nature of suffering and its relation to organic manifestation of disease with the purpose of attempting to understand the meaning of suffering as a phenomenon experienced by a person.

Chaplin J. Pressure sore risk assessment in palliative care. *J Tissue Viability*. 2000;10(1):27-31.
Description of a PrU risk assessment tool for palliative care patients developed by a multiprofessional group resulting in a hybrid tool through comparative analysis of scores achieved using professional judgment of experienced palliative care nurses.

Crown L. Pressure sores and end of life considerations. *Tenn Med*. 2006;99(6):9, 11.
Commentary on the complex interplay of factors related to skin breakdown at the end of life with consideration given to the skin as a visible organ and PrUs as markers of overall deterioration and their potential as high profile targets for litigation.

Dunne K, Coates VE. Care study: providing effective care in palliative nursing. *Br J Nurs*. 1999;8(21):1428-34.
Case study demonstrating use of evidence within palliative care setting to support nursing interventions, with recognition that empirical knowledge has limits and other forms of knowledge need to be taken into account to provide individualized care.

Eisenberger A, Zeleznik J. Pressure ulcer prevention and treatment in hospices: a qualitative analysis. *J Palliat Care*. 2003;19(1):9-14.
Qualitative analysis of interviews with hospice clinical directors and direct care nurses that demonstrated an emergent theme of balancing patient comfort with PrU prevention and treatment.

Ennis WJ. Healing: can we? must we? should we? *Ostomy/Wound Management*. 2001;47(9):6-8.
Editorial comment on the meaning of palliative care with illustration of concepts through case studies.

Ennis W, Meneses P. Palliative care and wound care: 2 emerging fields with similar needs for outcomes data. *WOUNDS*. 2005;17(4):99-104.
Prospective outcome study within a subacute wound unit incorporating an intent-to-treat approach to calculate healing rates and to establish surrogate end points.

Ferris FD, Al Khateib AA, Fromantin I, Hoplamazian L, Hurd T, Krasner D, Maida V, Price P, Rich-Vanderbij L. Palliative wound care: managing chronic wounds across life's continuum: a consensus statement from the international palliative wound care initiative. *J Palliat Med*. 2007;10(1):37-39.
Consensus statement by the International Palliative Wound Care Initiative, a global group of professionals in palliative care, wound care and education. Statement includes definition of problem, mission, vision, goals and future challenges.

Fitzsimons D, Mullan D, Wilson JS, Conway B, Corcoran B, Dempster M, Gamble J, Stewart C, Rafferty S, McMahon M, MacMahon J, Mulholland P, Stockdale P, Chew E, Hanna L, Brown J, Ferguson G, Fogarty D. The challenge of patients' unmet palliative care needs in the final stages of chronic illness. *Palliat Med*. 2007;21(4):313-22.
Study using mixed qualitative and quantitative methodologies to explore the palliative care needs of patients with non-cancer diagnosis, from the perspective of the patient, the significant other and the clinical team.

Galvin J. An audit of pressure ulcer incidence in a palliative care setting. *Int J Palliat Nurs*. 2002;8(5):214-21.
Retrospective audit of PrU prevalence and incidence in an inpatient palliative care unit over two year period, showing results of 12% incidence, with ulcers mainly developing during the last days of life.

Hampton S. Case study: the treatment or palliative care of pressure ulcers. *Br J Nurs*. 2000;9(6 Suppl):S32-4.
Case study of a palliative care patient with PrUs who after admission to a nursing home was able to progress to wound healing with an individualized plan of care.

Hanson DS, Langemo D, Olson B, Hunter S, Burd C. Evaluation of pressure ulcer prevalence rates for hospice patients post-implementation of pressure ulcer protocols. *Am J Hosp Palliat Care*. 1994;11(6):14-9.
Descriptive study that examines the quarterly prevalence of PrUs in a hospital based hospice following the implementation of PrU prevention and treatment protocols.

Hanson D, Langemo D, Olson B, Hunter S, Sauvage TR, Burd C, Cathcart-Silberberg T. The prevalence and incidence of pressure ulcers in the hospice setting: analysis of two methodologies. *Am J Palliat Care*. 1991;8(5):18-22.
Descriptive 2 phased study of PrU prevalence and incidence in a hospice, using both prospective and retrospective methods. The most common location of PrUs was the sacrum, while 62% of PrUs that developed did so in the last two weeks of life.

Henoch I, Gustafsson M. Pressure ulcers in palliative care: development of a hospice pressure ulcer risk assessment scale. *Int J Palliat Nurs*. 2003;9(11):474-84.
Swedish study to construct a PrU risk assessment scale for use in palliative care. Reliability and validity testing using a modification of Norton Scale and nine new scales, found one scale to be superior, The Hospice PrU Risk Assessment Scale (HoRT).

Hockley JM, Dunlop R, Davies RJ. Survey of distressing symptoms in dying patients and their families in hospital and the response to a symptom control team. *Br Med J (Clin Res Ed)*. 1988;296(6638):1715-7.
Qualitative study using mixed methodologies to identify symptoms and psychosocial aspects of care as experienced by dying patients and their families. As a result, a multidisciplinary team was formed to address symptoms and offer supportive care.

Hoffman R, Lile JL, Mace K, Pase M. Standards of care for hospice patients with pressure ulcers. *Decubitus*. 1991;4(4):19-24.
A deficit in standard protocols as identified by the primary investigator in a previous survey of hospice agencies in the southwest, led to the development of standards of care for hospice patients which stress care and comfort rather than cure of PrUs.

Hughes RG, Bakos AD, O'Mara A, Kovner CT. Palliative wound care at the end of life. Article originally published in *Home Health Care Management & Practice*. 2005;17(3):196-202. Copyright 2005 by Sage Publications. Agency for Healthcare Research and Quality, Rockville MD. http://www.ahrq.gov/about/nursing/palliative.htm
Overview of palliative wound care as it impacts quality at end of life. Addresses issues of palliative vs wound healing, ethical obligations and transition to end of life care.

Kennedy KL. The prevalence of pressure ulcers in an intermediate care facility. *Decubitus*. 1989;2(2):44-45.

Description of PrU surveillance in a nursing home population. Retrospective review of prevalence data provided a basis for investigation of how long people lived after onset of PrUs. Terminal PrU described and identified as Kennedy Terminal Ulcer.

Landi F, Onder AR, Bernabei R. Pressure ulcer and mortality in frail elderly people living in community. *Arch Gerontol.* 2007;(Geriatr Suppl. 1):217-223.
Observational cohort study to ascertain prevalence of PrUs and to explore the relationship between PrUs and the risk of 1 year all-cause mortality in a population of frail elderly living in the community.

Langemo D. When the goal is palliative care. *Adv Skin Wound Care.* 2006;19(3):148-54.
Analysis of literature on palliative care of patients with wounds, with a focus on quality of life related to PrU risk assessment, prevention and treatment.

Langemo D, Brown G. Skin fails too: acute, chronic, and end-stage skin failure. *Adv Skin Wound Care.* 2006;19(4):206-11.
Systematic review of literature to determine what has been published on skin failure. Based on the review it was concluded that minimal literature exists. Term defined and skin failure categorized as acute, chronic or end stage.

Lile JL, Pase MN, Hoffman RG, Mace MK. The neuman systems model as applied to the terminally ill client with pressure ulcers. *Adv Skin Wound Care.* 1994;7(4):44-8.
Description of systems approach to patients with multifaceted health problems. The Neuman Systems Model, based on stress and reaction to stress, provides a framework for holistic nursing care of terminally ill patients with PrUs.

Lishinsky ES. A philosophy of care: pressure sores in hospice patients. *Todays OR Nurse.* 1988;10(4):20-3.
Description of a philosophy of care for quality of life in hospice patients, with a focus on their risk for impairment of skin integrity while paying special attention to comfort and dignity.

Lorenz KA, Lynn J, Dy SM, Shugaman LR, Wilkinson A, Mularski RA, Morton SC, Hughes RG, Hilton LK, Maglione M, Rhodes SI, Rolon C, Sun VC, Shekelle PG. Evidence for improving palliative care at the end of life: a systematic review. *Annals of Int Med.* 2008;148(2):147-159.
Systematic literature review to address questions posed by subcommittee of the American College of Physicians to address "end of life" issues and intervention studies. Data shows strong evidence to support intervention at end of life and concludes that many critical issues lack high quality evidence.

Lyder CH. Pressure ulcer prevention and management. *JAMA.* 2003;289(2):223-6.

Overview of literature on PrUs as major health problem. Addresses statement of problem, risk identification, methods for prevention and treatment, with a call for research and physician involvement as integral to resolution of problem.

MacLean DS. Preventing and managing pressure sores. *Caring for the Ages*. 2003;4(3):34-5.
Overview of PrUs in the nursing home population including statement of problem, the issue of whether or not PrUs are preventable and principles for prevention and treatment, compiled by a Medical Director.

Maida V, Corbo M, Dolzhykov M, Ennis, Irani S, Trozzolo L. Wounds in advanced illness: a prevalence and incidence study based on a prospective case series. *Int Wound J*. 2008;5(2):305-14.
Prospective observational sequential case series to ascertain inventory of various wound types, their point prevalence and incidence rates and the anatomic locations in patients with advanced illness. Data stratified between patients with malignant and nonmalignant disorders.

Maklebust J. Pressure ulcers the great insult. *Nurs Clin N Am*. 2005;40(2):365-89.
Broad overview of PrUs that resembles textbook format and encompasses problem statement with demographics, risk assessment, issue of whether or not PrUs are preventable and/or healable, extent of provider knowledge, concluding with quality improvement.

McDonald A, Lesage P. Palliative management of pressure ulcers and malignant wounds in patients with advanced illness. *J Palliat Med*. 2006;9(2):285-95.
Review of literature on palliative approach to prevention and treatment of PrUs and malignant wounds in patients with advanced illness, also included are textbooks and online resources.

Meehan M. Prevalence of wounds among the frail elderly: a look at its value. *WOUNDS*. 2005;17(4):80-83.
Review of prevalence of wounds in the frail elderly. Call to consider moving beyond the epidemiological data to broaden the definition of outcomes management in wound healing to encompass quality of life issues.

Meehan M, Ferris F, Alvarez O, Ennis WJ. Wound care options: establishing management priorities for long term wards. *J Palliat Med*. 2005;8(1):203.
Speaker abstract of presentation on F.R.A.I.L. (for Recognition of the Adult Immobilized Life), for which the goal is to establish practical guidelines for clinicians seeking management options for people with chronic wounds.

Meehan M, Hill WM. Pressure ulcers in nursing homes: does negligence litigation exceed available evidence? *Ostomy/Wound Management*. 2002;48(3):46-54.

Topical review of PrU occurrence within the nursing home population with regard to quality of care with a focused discussion on the effects of this phenomenon, specifically the legal ramifications.

Mitchell SL, Kiely DK, Hamel MB. Dying with advanced dementia in the nursing home. *Arch Intern Med*. 2004;164(3):321-6.
Retrospective study comparing end of life experiences in 2 groups of persons with advanced dementia and terminal cancer, using data from the Minimum Data Set. Statistical analyses showed nonpalliative interventions were common as were PrUs.

Monteleoni C, Clark E. Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia: before and after study. *BMJ*. 2004;329(7464):491-4.
Retrospective chart review of patients receiving tube feedings, with comparative analysis of before and after implementation of quality improvement interventions that consisted of palliative care consulting service and educational programs.

Ogle KS, Hopper K. End-of-life care for older adults. *Prim Care Clin Off Pract*. 2005;32(3):811-28.
Overview of care at end of life from the perspective that it may be an opportunity for physicians to have a meaningful impact on the lives of their patients. Addresses care goals, communication, symptom management including skin care and the process of dying and grieving.

Qaseem A, Snow V, Shekelle P, Casey DE, Cross JT, Owens DK. Evidence – based interventions to improve the palliative care of pain, dyspnea and depression at the end of life: a clinical practice guideline from the American college of physicians. *Ann Int Med*. 2008;148(2):141-6.
Clinical guideline developed by the American College of Physicians, comprised of recommendations for evidence based interventions to improve palliative care of patients with pain, dyspnea and depression.

Reifsnyder J, Hoplamazian LM, Maxwell TL. Preventing and treating pressure ulcers in hospice patients. *Caring*. 2004;23(11):30-7.
Comparison study of prevalence and incidence of PrUs in 4 hospice sites. Based on the results, evidence based guidelines for hospice were developed with the goal of patient comfort as the priority for an approach to prevention and management.

Reifsnyder J, Magee HS. Development of pressure ulcers in patients receiving home hospice care. *WOUNDS*. 2005;17(4):74-9.
Study to examine PrU prevention and incidence in 4 home hospices and to test algorithms for prevention and management of patients with PrUs. Data collection included scores on Karnofsky or Palliative Performance Scale and the Braden Scale.

Sachs GA. Research at the interface of palliative care and geriatrics. *J Palliat Care*. 2003;19(1):5-6.

Editorial commentary that highlights the unintended consequences of efforts to improve PrU management and the need for hospice to heed the call to research. Proposal that management of PrUs, referred to as a geriatric syndrome, must be reconsidered in light of individual goals of care.

Schoonhoven L, Bousema MT, Buskens E, prePURSE-sudy group. The prevalence and incidence of pressure ulcers in hospitalised patients in the Netherlands: a prospective inception cohort study. *Int J Nurs Stud*. 2007;44(6):927-35.
Prospective inception cohort study set in 2 hospitals in the Netherlands. Weekly follow up until PrU occurrence, discharge or LOS greater than 12 weeks. Outcome measure was occurrence of nosocomial Grade 2 PrU or worse.

Sloss EM, Solomon DH, Shekelle PG, Young RT, Saliba D, MacLean CH, Rubenstein LZ, Schnelle JF, Kamberg CJ, Wenger NS. Selecting target conditions for quality of care improvement in vulnerable older adults. *J Am Geriatr Soc*. 2000;48(4):363-9.
Description of process, to identify a set of geriatric conditions as optimal targets for quality improvement, to be used in a quality measurement system for vulnerable older adults. PrUs and end of life were among the 21 conditions selected.

Sopata M, Luczak J, Glocwacka A. Managing pressure sores in palliative care. *J Wound Care*. 1997;6(1):10-1.
Description of actions taken within University of Medical Sciences in Pozman, Poland, to improve prevention and treatment of PrUs among patients with terminal illness.

Sullivan JM, Mackey DM. Pressure ulcer care for a terminally ill patient being cared for at home. *J WOCN*. 1995;22(3):153-5.
Descriptive case study of a terminally ill patient with PrU being cared for at home. Illustrates the importance of addressing prevention and considering outcome goals other than wound closure.

Thomas DR. Are all pressure ulcers avoidable? *JAMDA*. 2003;4(2 Suppl):S43-8.
Evidence based debate on whether or not PrUs are avoidable. Addresses recent trends on incidence, identification of modifiable and nonmodifiable risk factors and the efficacy of intervention strategies. Well documented case that when PrUs are not preventable by interventions, they cannot be used as a quality indicator.

Tice MA. Wound care in the face of life-limiting illness. *Home Healthc Nurse*. 2006;24(2):115-8.
Evidence based testimony on palliative care approach by a home health nurse using a case study to illustrate management of PrU at end of life.

Truog RD, Campbell ML, Curtis JR, Haas CE, Luce JM, Rubenfeld GD, Rushton CH, Kaufman DC. Recommendations for end-of-life care in the

intensive care unit: a consensus statement by the american academy of critical care medicine. *Crit Care Med*. 2008;36(3):953-63.
Consensus statement on recommendations for end of life care in the intensive care unit. Statement builds upon previously published recommendations (2003) and is based on ethical and legal principles.

Walding M, Andrews C. Preventing and managing pressure sores in palliative care. *Prof Nurse*. 1995;11(1):33-4, 37-8.
Description of systematic approach to wound care in patients with PrUs, being care for in a palliative care unit. Outcomes resulted in a decrease in PrU rates in this hospice.

Witkowski JA, Parish LC> The decubitus ulcer: skin failure and destructive behavior. *International J Dermatology*. 2000;39(12):894-95.
Evidence based commentary on what the authors term the 'permissable PrU.' They propose that deterioration of the skin as a terminal event is understated and under estimated and they use the term skin failure.