

Evidence to Decision Frameworks: Quality of Life, Self-care and Education

Clinical question What are effective strategies for promoting quality of life for individuals with or at risk of pressure injuries?

Good Practice Statement 22.1

Assess the health-related quality of life, knowledge and self-care skills of individuals with or at risk of pressure injuries to facilitate the development of a pressure injury care plan and education program.

Background: Evaluation of patient consumer knowledge before and after education delivery provides an indication as to whether the intervention is successful. The pre-evaluation identifies education needs.

SUPPORTING EVIDENCE, WHEN AVAILABLE

Evidence to support the opinion (when available)

There is no evidence regarding the influence of assessments on pressure injury incidence or healing.

Tool psychometric properties

- In adults in a secondary care hospital setting,¹ the nine subscales of the revised version of Pressure Ulcer Quality of Life scale (the PUQOL-P), which measure HRQoL domains, had good to excellent internal consistency ($\alpha = 0.795$ to 0.97) (*Level 4*).
- In adults with SCI in community settings,² the Spinal Cord Injury Quality of Life Pressure Ulcer Scale (SCI-QOL), which measures HRQoL in 12 items, had good test-retest reliability (intraclass coefficient [ICC] = 0.79 , 95% confidence interval [CI] 0.74 to 0.84) (*Level 4*).
- In individuals with SCI with and without pressure injuries living in community,³ the 12-item Skin Management Needs Assessment Checklist, which measures knowledge and self-care skills, had excellent reliability (ICC = 0.899 , 95% CI 0.862 to 0.927). (*Level 4*)
- In hospitalized adults,⁴ the Patient Participation in Pressure injury prevention (PPPIP) scale, which measures self-care skills with 7 items, had excellent internal consistency ($\alpha = 0.86$). (*Level 4*)

Justification

Measuring HRQoL, knowledge and self-care skills provides insight into the individual's needs and is intrinsic to delivering holistic care. Tracking these outcomes over time provides an indication of the effectiveness and acceptability of treatment.⁵ Some tools have been tested for reliability and validity in individuals with or at high risk of pressure injuries.

Clinical question What are effective strategies for promoting quality of life for individuals with or at risk of pressure injuries?
 What are effective strategies for engaging individuals in pressure injury prevention and treatment?

Recommendation 22.2 Provide pressure injury education, skills training and psychosocial support to individuals with or at risk of pressure injuries.

Option: Providing education and lifestyle support
Comparison: No education or lifestyle support, or a comparator intervention

Background: The patient consumer has an important role in pressure ulcer prevention. Knowledge of pressure injuries and self-care skills required their prevention is important and requires a special emphasis for those at high risk.

	CRITERIA	JUDGEMENTS	RESEARCH EVIDENCE AND ADDITIONAL CONSIDERATIONS										
BENEFITS & HARMS OF THE PRACTICE	What is the overall certainty of the evidence?	<table border="1"> <tr> <td>No included studies</td> <td>Very low</td> <td>Low</td> <td>Moderate</td> <td>High</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	No included studies	Very low	Low	Moderate	High	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<p>Evidence for pressure injury incidence</p> <ul style="list-style-type: none"> In individuals with SCI in rehabilitation (n=47), individuals receiving a multi-faceted self-efficacy program that included education and skills training experienced fewer pressure injuries at eight weeks than a control group receiving written material (0 versus 1, p = not reported).⁶ (Level 1, high quality) In individuals with SCI (n=41) an enhanced education program was associated with a significantly lower incidence of pressure injury recurrence at 24 months compared to standard contact with health professionals and a group receiving limited contact (odds ratio [OR] 0.228, 95% CI 0.080 to 0.647, p=0.003).⁷ (Level 1, low quality) <p><i>No effect</i></p> <ul style="list-style-type: none"> In individuals with SCI in US (n=170), a multifaceted lifestyle skills program had no significant impact on rate of medical serious pressure injuries at 24 months (Rate ratio [RR] 1.14, 95% CI 0.72 to 1.82, p >0.05)⁸ (Level 1, high quality) In community-based individuals with SCI in US (n=142), rates of pressure injuries at 6 months were not statistically significantly different between a group receiving an automated telephone education and support service compared to usual care (p>0.05)^{9,10} (Level 1, moderate quality). <p>Evidence for improved pressure injury healing</p> <ul style="list-style-type: none"> In outpatients with SCI and pressure injuries (n=), individuals who did not smoke had superior healing outcomes compared to smokers (65.2% decrease in pressure injury size versus 33.3% decrease in size, p=0.03) More individuals who were exposure to a smoking cessation education and support program were non-smokers after 6 months compared to individuals not receiving the program (44% vs 21%, p=0.03).¹¹ (Level 3, low quality) In outpatients with SCI and pressure injuries (n=120), a telephone-based lifestyle skills program was associated with a significantly greater reduction in pressure injury size at 12 weeks compared with written education (mean between-group difference 2.3cm² favoring intervention group (95% CI -0.3 to 4.9, p=0.008).¹² (Level 1, moderate quality) <p><i>No effect</i></p> <ul style="list-style-type: none"> In individuals in US with SCI and Category/Stage III or IV pressure injuries (n = 143), an individualized, telephone-based skills training plus motivational interviewing program was associated with no significant difference in pressure injuries assessed as having a worsened state after six months compared to a group receiving standardized telephone support and a written education guide (12.7% vs 15.3%, p=0.86).¹³ (Level 1, moderate quality) <p>Evidence on knowledge levels</p> <ul style="list-style-type: none"> In individuals with SCI in rehabilitation (n=47), individuals receiving a multi-faceted self-efficacy program that included education and skills training showed significantly better improvements in knowledge at eight weeks compared to a control group receiving written material (18.83 ± 1.61 versus 15.78 ± 2.50, p = 0.004)⁶ (Level 1, high quality). In individuals with SCI (n=41) an enhanced education program was associated with a significant increase in knowledge at 24
	No included studies	Very low	Low	Moderate	High								
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	Is there important uncertainty about how much people value the main outcomes?	<table border="1"> <tr> <td>Important uncertainty or variability</td> <td>Possibly important uncertainty or variability</td> <td>Probably no important uncertainty or variability</td> <td>No important uncertainty or variability</td> <td>No known undesirable outcomes</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> </tr> </table>	Important uncertainty or variability	Possibly important uncertainty or variability	Probably no important uncertainty or variability	No important uncertainty or variability	No known undesirable outcomes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
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How substantial are the desirable anticipated effects?	<table border="1"> <tr> <td>Unclear</td> <td>Not substantial</td> <td>Probably not substantial</td> <td>Probably substantial</td> <td>Substantial</td> </tr> <tr> <td><input checked="" type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Unclear	Not substantial	Probably not substantial	Probably substantial	Substantial	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
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Do the desirable effects outweigh the undesirable effects?	<table border="1"> <tr> <td>No</td> <td>Probably No</td> <td>Uncertain</td> <td>Probably Yes</td> <td>Yes</td> <td>Varies</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	No	Probably No	Uncertain	Probably Yes	Yes	Varies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
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CRITERIA	JUDGEMENTS	RESEARCH EVIDENCE AND ADDITIONAL CONSIDERATIONS
		<p>months compared to a group receiving limited contact (20 versus 10 percentage points gained, $p < 0.003$).¹⁴ (<i>Level 1, low quality</i>)</p> <ul style="list-style-type: none"> In community-based individuals with SCI (n=14), a two-week e-learning program was associated with an increase in knowledge scores over time (mean 96 vs mean 107, $p < 0.005$, highest possible score 120)¹⁵ (<i>Indirect evidence</i>) <p><i>No effect</i></p> <ul style="list-style-type: none"> In individuals with SCI in US (n=170), a multifaceted lifestyle skills program was not associated with statistically significant improvements in pressure knowledge over 24 months ($p = 0.68$), with no significant difference to a usual care group ($p = 1.00$).⁸ (<i>Level 1, high quality</i>) <p>Evidence on self-care skills</p> <ul style="list-style-type: none"> In individuals with SCI in rehabilitation (n=47), individuals receiving a multi-faceted self-efficacy program that included education and skills training showed significantly better improvements in self-care skills at eight weeks compared to a control group receiving written material (92.29 ± 5.21 versus 77.1 ± 12.81, $p < 0.001$)⁶ (<i>Level 1, high quality</i>). In individuals with SCI in US (n=170), a multifaceted lifestyle skills program was associated with statistically significant improvements in performing preventive behaviors over 24 months ($p = 0.005$), which was also statistically significantly superior to a usual care group ($p = 0.001$).⁸ (<i>Level 1, high quality</i>) In outpatients with SCI and pressure injuries (n=120), a telephone-based lifestyle skills program was associated with a significantly greater improvements in confidence in managing pressure injuries at 12 weeks compared with written education (mean between-group difference 1.7 on a 10-point scale, 95% CI 1.0 to 2.3, $p < 0.001$).¹² (<i>Level 1, high quality</i>) In hospitalized individuals with SCI (n=10), a skills program that included written and practical training in positioning was associated with a significant increase in patient-initiated position changes compared to no intervention ($p = 0.016$).¹⁶ (<i>Level 1, low quality</i>) In hospitalized individuals (n=31), a written education resource was associated with 46% of individuals self-reported initiating self-care skills.¹⁷ (<i>Indirect evidence</i>) <p><i>No effect</i></p> <ul style="list-style-type: none"> In individuals in US with SCI and Category/Stage III or IV pressure injuries (n = 143), an individualized, telephone-based skills training plus motivational interviewing program was associated with no significant difference in self-reported skin care behaviors performed after six months compared to a group receiving standardized telephone support and a written education guide (% of items on a checklist being performed: mean 85.0 ± 15.2 vs 83.0 ± 14.6 $p = 0.41$).¹³ (<i>Level 1, moderate quality</i>) <p>Evidence on quality of life</p> <ul style="list-style-type: none"> In outpatients with SCI and pressure injuries (n=120), a telephone-based lifestyle skills program was associated with a significantly greater improvements in confidence in managing pressure injuries at 12 weeks compared with written education (mean between-group difference on EQ-5D VAS, 10.5, 95% CI 4.5 to 16.6; $p = 0.001$).¹² (<i>Level 1, high quality</i>) <p><i>No effect</i></p> <ul style="list-style-type: none"> In individuals with SCI in US (n=170), a multifaceted lifestyle skills program was associated with statistically significant improvements on scales of the SF36 over time at 24 months ($p < 0.05$); however the changes were not statistically significantly different from a group receiving usual care.⁸ (<i>Level 1, high quality</i>) <p>Adverse events None reported</p> <p>Strength of Evidence: C – Mixed findings</p>

	CRITERIA	JUDGEMENTS	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
RESOURCE USE	How substantial are the resource requirements?	<p>Not clear <input type="checkbox"/> Not substantial <input type="checkbox"/> Probably not substantial <input type="checkbox"/> Probably substantial <input type="checkbox"/> Substantial <input type="checkbox"/> Varies <input checked="" type="checkbox"/></p>	<ul style="list-style-type: none"> In individuals with SCI in US (n=170), a multifaceted lifestyle skills program, delivery of the program cost approximately \$5,200 (USD in 2015). The program included one-one education and lifestyle skills counseling delivered in the individual's home over 12 months, with additional support provided by telephone.⁸ 	
PRIORITY AND ACCEPTABILITY	Is the option acceptable to key stakeholders?	<p>No <input type="checkbox"/> Probably No <input type="checkbox"/> Uncertain <input checked="" type="checkbox"/> Probably Yes <input type="checkbox"/> Yes <input type="checkbox"/> Varies <input type="checkbox"/></p>	<ul style="list-style-type: none"> Individuals in US with SCI and Category/Stage III or IV pressure injuries (n = 143) receiving an individualized, telephone-based skills training plus motivational interviewing program, and those receiving a comparator intervention of standardized telephone support and a written education guide both had low levels of engagement with telephone support (36% and 22% respectively).¹³ (Level 1, moderate quality) Individuals in US with SCI (n=71) had 78% adherence to an automated telephone education and support service.^{9,10} (Level 1, moderate quality) Individuals in US with SCI (n=71) 70% rated an automated telephone education and support service as most useful compared to less than 10% rating a written book as useful.¹⁰ (Level 1, moderate quality) 	
	Is the option a priority for key stakeholders?	<p>No <input type="checkbox"/> Probably No <input type="checkbox"/> Uncertain <input type="checkbox"/> Probably Yes <input type="checkbox"/> Yes <input checked="" type="checkbox"/> Varies <input type="checkbox"/></p>	<ul style="list-style-type: none"> In an international consumer survey (n=1233) on importance of different education topics to patients consumers and informal caregivers, more than 80% of responses rated the majority of topics (14/16) as important or very important.^{18,19} (Indirect evidence) 	
FEASIBILITY	Is the option feasible to implement?	<p>No <input type="checkbox"/> Probably No <input type="checkbox"/> Uncertain <input type="checkbox"/> Probably Yes <input type="checkbox"/> Yes <input checked="" type="checkbox"/> Varies <input type="checkbox"/></p>	<ul style="list-style-type: none"> A telephone support and home visit program that was delivered in Bangladesh was delivered according to protocol 87% of the time for phone calls and 100% of the time for home visits²⁰ (Level 1, moderate quality). For SCI individuals in US (n=143), an individualized, telephone-based skills training plus motivational interviewing program was effectively delivered at minimum dose (at least 4 support calls) to 81% of participants. 86% of individuals in a control group receiving standardized education received the minimum dose of 4 calls.¹³ (Level 1, moderate quality). 	

Balance of consequences	Undesirable consequences <i>clearly outweigh</i> desirable consequences in most settings <input type="checkbox"/>	Undesirable consequences <i>probably outweigh</i> desirable consequences in most settings <input type="checkbox"/>	The balance between desirable and undesirable consequences <i>is closely balanced or uncertain</i> <input type="checkbox"/>	Desirable consequences <i>probably outweigh</i> undesirable consequences in most settings <input type="checkbox"/>	Desirable consequences <i>clearly outweigh</i> undesirable consequences in most settings <input checked="" type="checkbox"/>
Strength of recommendation	Strong negative recommendation: Definitely don't it <input type="checkbox"/>	Weak negative recommendation: Probably don't do it <input type="checkbox"/>	No specific recommendation <input type="checkbox"/>	Weak positive recommendation: Probably do it <input checked="" type="checkbox"/>	Strong positive recommendation: Definitely do it <input type="checkbox"/>
Justification	Two high quality, ^{6,8} one moderate quality ^{9,10} and one low quality ^{7,14} Level 1 studies reported the impact of patient consumer education and lifestyle programs on preventing pressure injuries. One of the studies ⁶ reported fewer pressure injuries developed compared to a group receiving written education, but the incidence rate was very low in both groups and follow-up was only eight weeks. A second study ^{7,14} found lower pressure injury recurrence rates at 24 months in a group of individuals who received an enhanced education program compared to groups receiving less or no education. Two studies ^{8,9,13} reported no significant reduction in pressure injuries associated with education interventions compared to usual care, at either six months ^{9,13} follow-up or at 24 months. ⁸ The findings from two moderate quality Level 1 studies ¹² and one low quality Level 3 study ¹¹ reporting the relationship between patient consumer education programs and healing of pressure injuries were also mixed. A high quality Level 1 study, ⁶ a low quality Level 1 study ^{7,14} and a Level 5 study ¹⁵ indicated that education programs have positive impacts on patient consumer knowledge levels in the short and long term. ^{6,15} Three high quality ^{6,8,12} and one low quality ¹⁶ Level 1 studies and indirect evidence ¹⁷ reported improvements in self-care skills following participation in education and lifestyle programs for up to 24 months. However, a study with six months' follow-up showed no effect on self-care skills for individualized compared to standardized telephone support. ¹³ Quality of life outcomes were reported less frequently, but findings were also mixed. One high quality Level 1 study ¹² reported HRQoL improvements associated with education ¹² and a second high quality Level 1 study ⁸ finding improvements over time, but these were not different to usual care. The mixed results reported in these studies could relate to the varied program delivery methods, content of the programs, duration and intensity of education and follow-up periods, outcome measurement methods or characteristics of the participants.				

References

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