

International consumer engagement in pressure injury/ulcer guideline development:

Global survey of patient care goals and information needs

Abstract

European Pressure Ulcer Advisory Panel (EPUAP), National Pressure Ulcer Advisory Panel (NPUAP), and Pan-Pacific Pressure Injury Alliance (PPPIA) are revising the **International Pressure Injury/Ulcer Clinical Guideline** in collaboration with associate wound care organizations. An international survey of patients and informal caregivers was conducted to identify their care goals and information needs. Responses from 1,233 individuals in 27 countries indicated that patients and caregivers have similar care goals. Preventing pressure injury and reducing the size of a pressure injury were identified by patients (68.9% and 46.5%, respectively) and informal caregivers (65.2% and 46.8% respectively) as a care goal. A greater proportion of patients (46.5%) included pain management as a goal than did caregivers (35.9%). The project highlights the importance of engaging w patients and caregivers in guideline development.

Purpose

This project sought to determine patient/informal caregiver information needs and care goals related to pressure injuries to inform recommendations in the guideline. The study sought to promote patient and informal caregiver contribution to guideline development.

Method

A web-based survey containing Likert scales and multiple choice questions was developed based on consumer engagement recommendations.[1-2] The survey was promoted to patients and informal caregivers by peak wound care bodies, consumer organisations and clinical members of the guideline team in 30 countries. The survey was open from 24 April 2018 to 30 October 2018. Descriptive statistics were conducted on the results. Categorical data were summarized using frequencies and percentages. Ethics clearance was attained from Australian National University and Review Boards granted waivers in USA and Japan.

Results

1,233 people completed the survey, of which 383 had or were at risk of a pressure injury and 850 were an informal caregiver. 86.5% of respondents were in Asia and 4.8% in the USA and the majority of respondents were aged between 31-50 years (Table 1). Of patients, 34.5% had experienced a pressure injury and 62.4% had been told they were at risk. Of those who had experienced a pressure injury, 23.5% currently had a pressure injury and 26.5% had experienced a pressure injury in the past 12 months.

Patients and caregivers nominated 3 main care goals. Preventing a pressure injury was the most common care goal for both groups (68.9% patients and 65.2% caregivers). Patients who had experienced a pressure injury were significantly more likely than patients who had never had a pressure injury to have care goals of preventing any

pressure injury ($p < 0.0001$), healing a pressure injury ($p < 0.001$), managing pain ($p < 0.001$) and having another care goal ($p = 0.001$). Significantly more patients than caregivers nominated managing pain as a care goal (46.5% versus 35.9%, $p < 0.001$) (Figure 2).

For all 16 information topics presented, over 75% of both patient and caregivers rated the item as being either important or very important to receive information on. Information needs were similar between patients and caregivers (Figure 1).

Table 1: Survey respondents

GEOGRAPHIC REGION	All respondents		Patients		Caregivers	
	n	%	n	%	n	%
No response	49	3.97	2	0.52	47	5.53
Oceania	18	1.46	6	1.57	12	1.41
Asia	1067	86.54	348	90.86	719	84.59
Americas	59	4.79	16	4.18	43	5.06
Europe	40	3.24	11	2.87	29	3.41
Total	1233	100	383	100	850	100
AGE						
No response	55	4.46	0	0	55	6.7
< 18 years	5	0.41	3	0.78	2	0.24
19-30 years	325	26.36	66	17.23	259	30.47
31-50 years	587	47.61	172	44.91	415	48.82
> 50 years	261	21.17	142	37.08	119	14
Total	1233	100	383	100	850	100

Discussion and conclusions

Patients and informal caregivers have similar care goals related to pressure injury prevention and treatment, although patients are more likely to have goals of managing pain. Patients who have experienced a pressure injury are significantly more likely to nominate all pressure injury care goals than people at risk but who have never had a pressure injury. Patients and informal caregivers indicated that receiving information on all pressure injury related topics was important or very important.

Discussing care goals and providing information is important in the care of patients with or at risk of pressure injuries, and should include informal caregivers.



Figure 1: Care goals of patients and informal caregivers

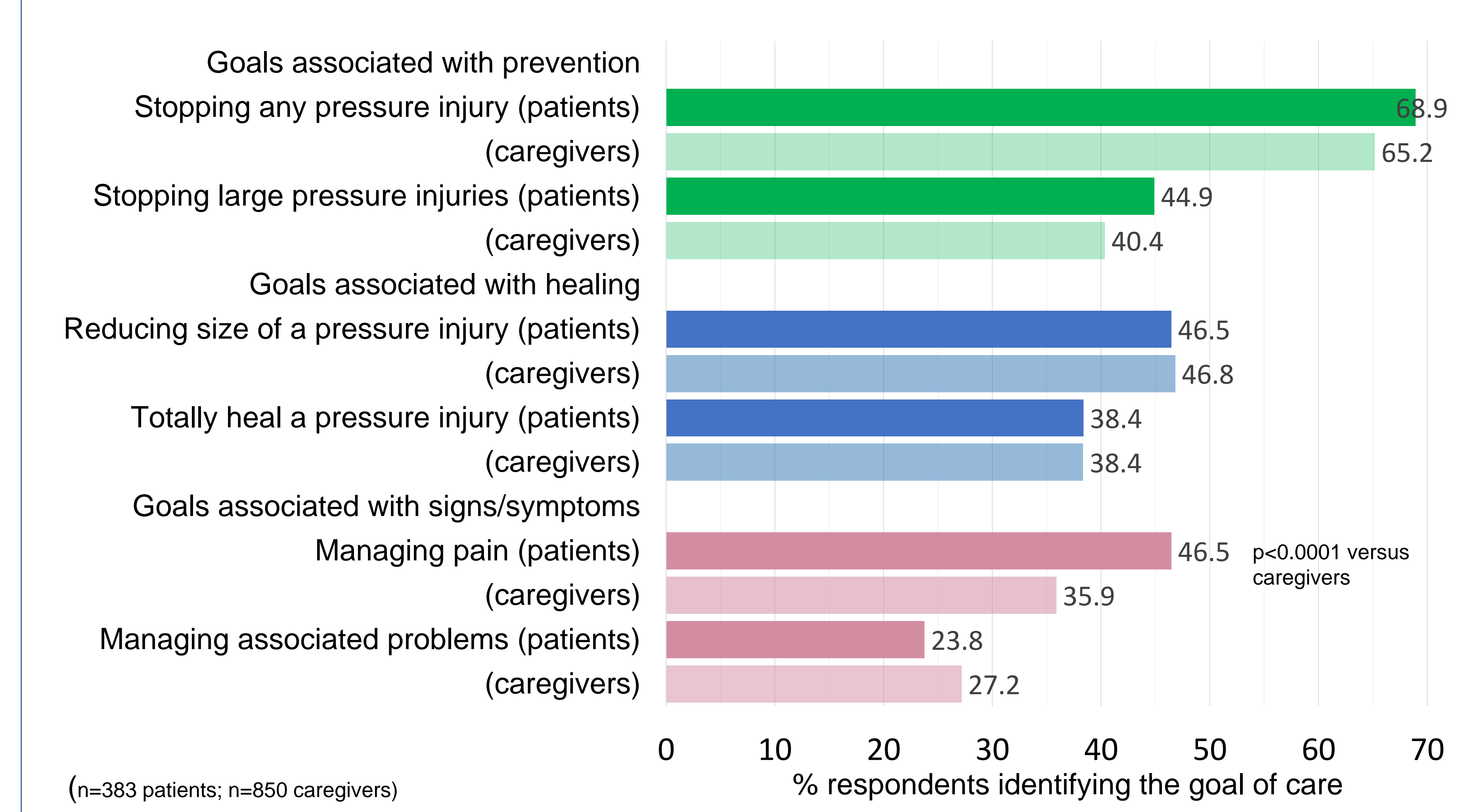
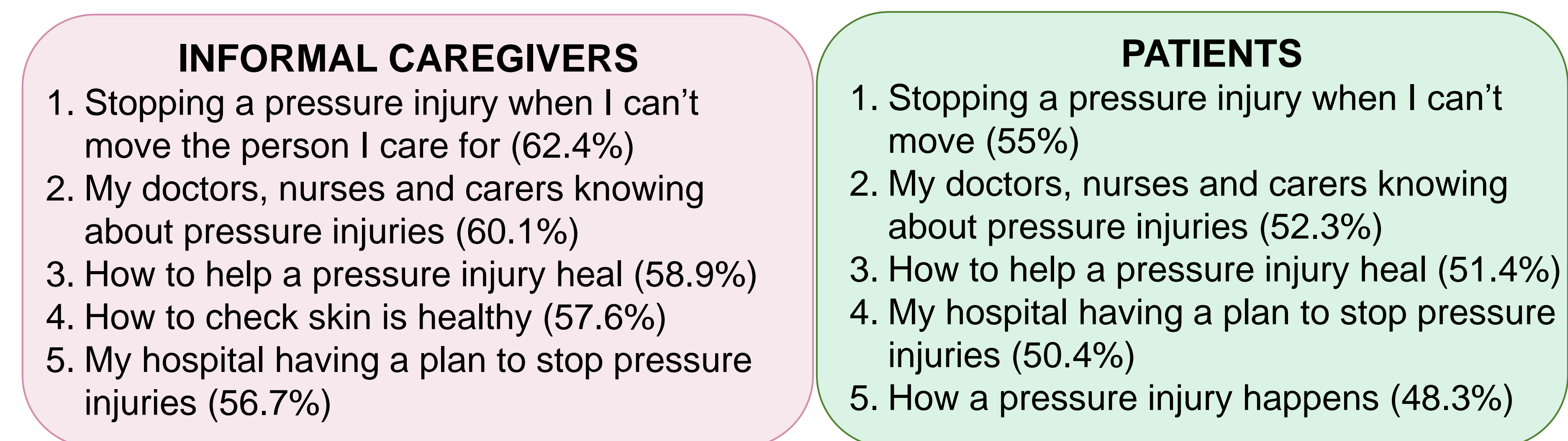


Figure 2: Topics most often rated as a most important information need



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References

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