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An exploration of the perspectives of individuals and their caregivers on pressure ulcer/injury prevention and management to inform the development of a clinical guideline

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Abstract

Background

Consumer engagement is a requirement of high quality clinical guidelines. Developing strategies to engage consumers and incorporate the perspectives of individuals with or at risk of pressure ulcers/injuries and their informal caregivers was one priority in the recent update of the EPUAP/NPIAP/PPPIA's *Prevention and Treatment of Pressure Ulcers/Injuries: Clinical Practice Guideline*.

Aims

The aims were to determine the goals of individuals and caregivers for pressure ulcer/injury care, priorities for pressure ulcer/injury education and biggest problems related to pressure ulcers/injuries.

Methods

An online, anonymous, international 10-item survey, accessible in nine languages was provided to individuals and their caregivers from April to October, 2018. Descriptive statistics were used for quantitative data and a thematic analysis approach was used to analyse qualitative data.

Results

There were 1,233 individuals from 27 countries who completed the survey. Overall, individuals and caregivers had similar goals of care. Reducing the size of pressure ulcer/injury was selected more often as a care goal than complete healing. Individuals, compared to caregivers, considered managing pain more important. Qualitative data analysis identified five themes including knowledge, attitudes, and skills; risk factors for pressure ulcer/injury; accessing pressure ulcer/injury care; quality of life for patients and caregivers; and the pressure ulcer/injury.

Conclusions

The consumer survey provided consumer engagement and perspective that was incorporated into guideline development, including consideration during evaluation of the relevance and acceptability of recommendations, and assignment of recommendation strength ratings.

Keywords

Pressure ulcer, pressure injury, consumer engagement, consumer perspective, clinical guideline, survey

An exploration of the perspectives of individuals and their caregivers on pressure ulcer/injury prevention and management to inform the development of a clinical guideline

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1. Introduction

Consumer engagement is increasingly being recognized as a requirement for high quality, international clinical guidelines [1-5]. Engaging consumers in the development process for clinical guidelines endeavors to achieve numerous aims, including facilitating the development of recommendations and content more relevant to individuals, responding to the education needs of individuals and their informal caregivers, and promoting consumer awareness of the clinical guideline [3]. Most importantly, when consumer engagement is a focus of a clinical guideline, the values and preferences of individuals are more likely to be considered in the development of recommendations, and the needs of specific populations receive greater acknowledgement [3, 6]. Inclusion of the preferences of those affected with the condition/issue in clinical guidelines acknowledges that they are experienced in regards to their own care

needs. This not only increases the relevance to the populations for which the guideline seeks to guide care, but also increases the confidence that both health professionals and consumers have that the guideline will meet the needs of individuals dealing with the condition.

Despite the recognized benefits of engaging consumers in the development of clinical guidelines, the process of engagement is complex and presents numerous challenges to guideline development teams. The literature identifies a wide range of barriers to consumer engagement, including discrepancies between health professional experts and consumers regarding topics of interest, difficulty integrating consumer opinion into clinical recommendation development, consumer recruitment and retention issues, limitations in consumer understanding of technical terminology, time and financial constraints, resistance to change, and cultural (e.g. language), health (e.g. sensory impairment) and physical (e.g. lack of internet) barriers [1, 3, 4].

In 2017, a Guideline Governance Group (GGG) commenced the development of a third edition of *Prevention and Treatment of Pressure Ulcers/Injuries: Clinical Practice Guideline* (referred to as the 2019 International Guideline) [7]. This clinical practice guideline provides evidence-based recommendations for health professionals, informal caregivers and care recipients on pressure injury prevention and treatment in the healthcare settings worldwide. This guideline is developed by the European Pressure Ulcer Advisory Panel (EPUAP), National Pressure Injury Advisory Panel (NPIAP) and the Pan Pacific Pressure Injury Alliance (PPPIA), in conjunction with wound organizations from 14 other countries. Recognizing the importance of consumer contribution to the development of clinical guidelines, the GGG overseeing the development of the third edition sought to develop and implement methodology that would capture the perspectives of consumers in the updated guideline. A key component of the strategy to engage consumers in the 2019 International Guideline [7] update was to undertake a consumer survey. In the context of this project, the term consumer was used to refer to individuals with or at risk of a pressure injury[#] (referred to as ‘individuals’) and their informal caregiver (i.e. family, friends or someone in the community providing care).

This manuscript builds on our prior works describing methodology [8] and classification of pressure injuries, [9] used in the 2019 International Guideline by providing a more detailed description of the methods used to collect consumer perspectives and incorporate the data into the guideline development process.

[#] Pressure ulcer and pressure injury are used synonymously in this text.

2. Purpose and aims

The purpose of the consumer survey was to increase engagement of individuals and their informal caregivers in the development of the 2019 International Guideline [7], and to collect their perspectives in order to increase the relevance of the guideline and its associated resources to those individuals. The specific aims of the survey were to establish the goals of individuals with or at risk of a pressure injury and their informal caregivers for pressure injury care, to determine pressure injury related topics of priority to consumers, and to explore the biggest problem related to pressure injuries that consumers experience. Collecting and analysing this data was undertaken with the aims of ensuring the clinical questions addressed in the guideline covered topics of importance to consumers and identifying topics for potential companion consumer education resources.

3. Methods

The study was undertaken using a convergent mixed methods design that consisted of collection of quantitative and qualitative data from consumers, independent analysis of the two datasets and then interpretation and comparison of the findings from the two datasets [10-13]. The main outcomes of interest were care goals and information needs of consumers, and problems they experience related to pressure injuries. The quantitative data collection focused on establishing the frequency and priority of different care goals and information needs. The qualitative data provided insight into the problems that consumers experience in receiving care for and information about pressure injuries and living with or at risk of pressure injuries.

3.1 Data collection

Data collection was undertaken using a mixed method survey of individuals with or at risk of a pressure injury and their informal caregivers (see Appendix 1). The research received ethical approval from the Australian National University Human Research Ethics Committee (Protocol 2018/66) and a waiver from the Institutional Review Board, Bedford Veterans Affairs Hospital, Bedford, USA. Information related to the main study interests was collected primarily through 10 multiple choice questions (MCQs) which were established through a comprehensive literature review and research team expert agreement and consensus. Demographic information was collected and included geographic location, age and history related to pressure injuries (Q1 – Q6). Additional survey items related to goals of pressure injury care (MCQ8; select a maximum of three care goals) and how important survey respondents felt it was to learn more

about specific pressure injury topics (Q9; ranked on a five-point Likert scale) were collected. These items were ranked on a Likert scale. The survey also included an open-ended question relating to the respondent's biggest problem related to pressure injuries (Q7) and provided opportunity for respondents to expand on their experience (Q10; note: this question received insufficient responses for analysis and is not reported in the results).

Because the guideline was intended to address global and international prevention and treatment of pressure injuries, the survey was developed with consideration to the diverse cultures, education level and experience of the target participant groups, and was prepared to English language proficiency Level 5 [14]. The survey was reviewed by the full Guideline Governance Group research team for face validity before being translated into nine languages. Translation was undertaken using the documented procedure for translation used by teams translating the 2019 International Guideline. This included requirements for involvement of at least four independent health professionals who are fluent in both languages to undertake translation and back translation [15].

3.2 Target population and recruitment

The consumer survey was accessible to anyone with or at risk of a pressure injury, or an informal caregiver, with internet access. It was voluntary and anonymous and was distributed as a web-based survey hosted on the guideline website (www.internationalguideline.com), accessible from 01 April 2018 to 31 October 2018. The landing page of the survey included a Participant Information Sheet and consent to participate. Consent to participate was assumed by completion of the survey; signed consent forms were not required to preserve anonymity.

The consumer survey was promoted by EPUAP, NPIAP, PPPIA and associate wound organisations via social media, newsletters, and websites. The Guideline Governance Group promoted the survey through academic publications [16] and conference presentations. All clinicians involved in the guideline development were encouraged to invite anyone with or at risk of a pressure injury and informal caregivers in their clinical setting to complete the survey either online or using a paper-based copy. In some regions, professional consumer representative organisations promoted the survey to their subscriber bases.

3.3 Data analysis

Data was downloaded from the consumer survey platform into Excel spreadsheets. The quantitative data was analysed using IBM® SPSS® Statistics 26 software using descriptive statistics. Continuous data were summarised using means and standard deviations, and categorical data were summarised using frequencies and percentages.

The qualitative data from the open-ended question were analysed using a thematic analysis approach [17]. First, members of the Guideline Governance Group translated the responses into English. Because the answers were short (generally 5 to 10 word responses), back translation was not used. One multi-lingual researcher translated responses and a second researcher confirmed the translation (SL; YYC). Next, the responses were reviewed by three members of the research team. One researcher (EH) searched the data for initial themes and grouped responses according to the themes generated. Next, the data for each main theme was re-evaluated searching for categories. Responses were reviewed a third time searching for any sub-categories. Two other members of the research team (JP; JC) reviewed the data and its coding to confirm the interpretation and increase the credibility of the thematic structure. The analysis team undertook discussion to reach agreement on the meaning of data and the themes, categories and sub-categories that were used to describe it. Finally, the qualitative and quantitative data were integrated through a comparison of the two datasets to gain a more complete understanding of consumer perspectives [10].

4. Results

There were 1,233 respondents to the survey, of which 383 identified as individuals who had experienced or had been assessed as having a risk of pressure injuries and 850 identified as an informal caregiver. Of the individuals who had experienced a pressure injury (n = 132), 23% had a pressure injury at the time they responded to the survey, 27% had experienced a pressure injury in the previous 12 months, 26% had a pressure injury between two and five years prior to responding and 24% had a pressure injury more than five years before completing the survey.

Responses were received from 27 countries. The majority of respondents were from Asian countries (86.5%), with 4.8% from the Americas, 3.2% from Europe, 1.5% from Oceania, and 4% providing no location (See Table 1). Respondents were primarily aged over 30 years (68.68%); however, only 21.17% of all respondents were aged over 50 years. Approximately

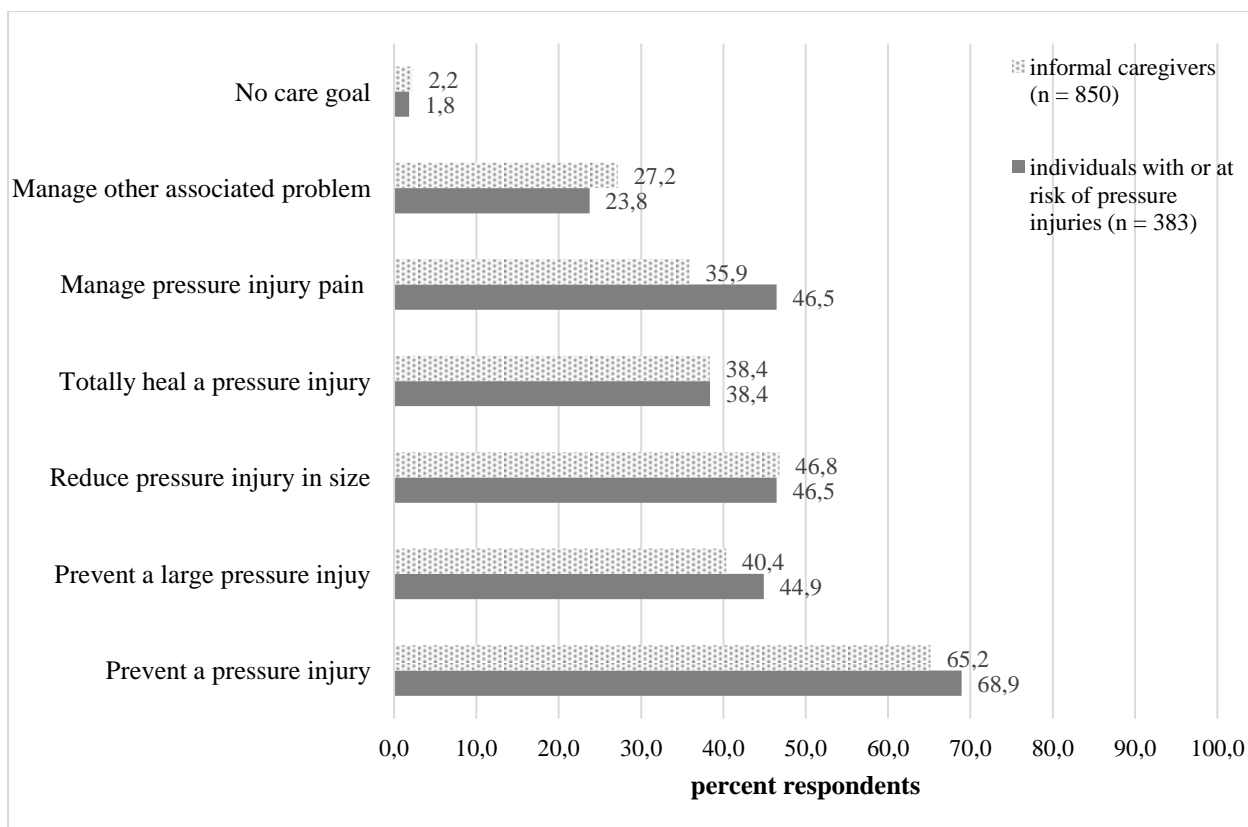
37% of individual respondents and 14% of informal caregiver respondents were aged over 50 years (See Table 1).

	All responses		Responses from individuals with or at risk of pressure injuries		Responses from caregivers	
	n	%	n	%	n	%
Geographic location						
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
Oceania	18	1.46	6	1.57	12	1.41
no response	49	3.97	2	0.52	47	5.53
Age						
< 18 years	5	0.40	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
no response	55	4.46	0	0	55	6.7
TOTAL	1233	100	383	100.00	850	100.00

Table 1: Respondent demographics

4.1 Care goals identified by individuals and their informal caregivers

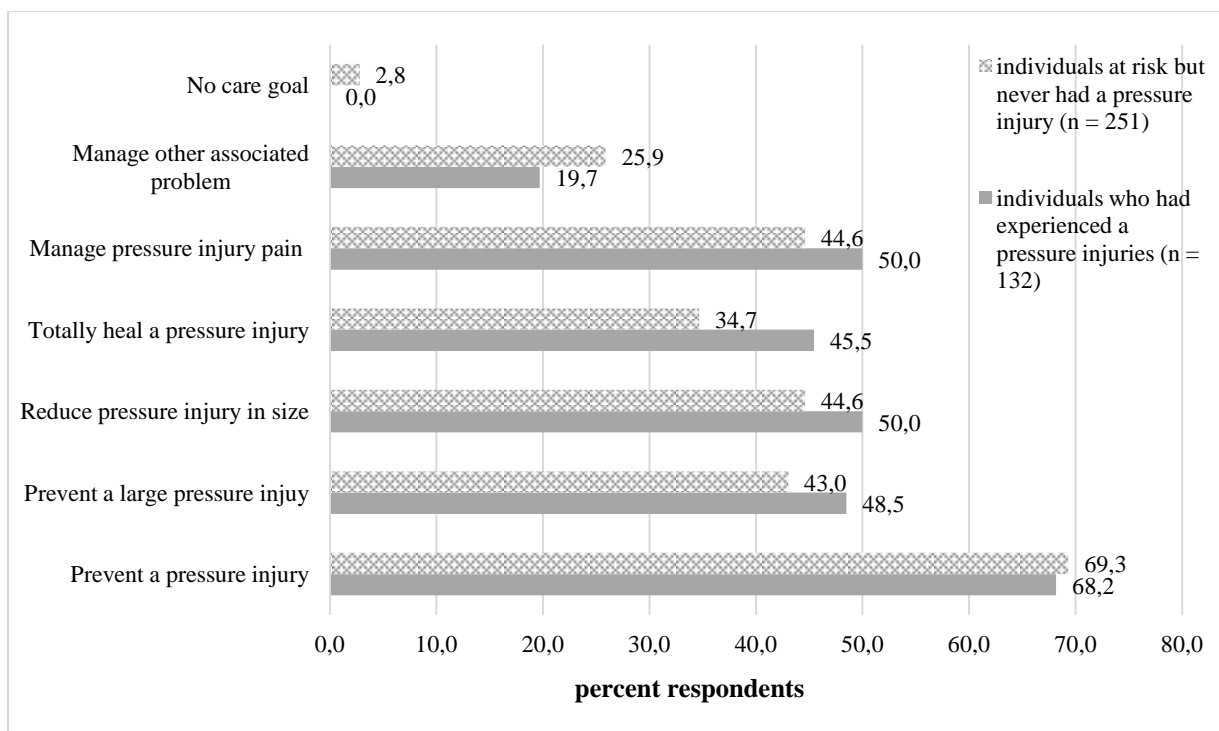
Figure 1 reports the maximum of three care goals that participants considered most important for themselves or the person for whom they were providing care. ‘Preventing any pressure injury’ was the most selected care goal for both individuals (65.2%) and their informal caregivers (68.9%). ‘Stopping a large pressure injury’ was also a goal for a large proportion of individuals (40.4%) and informal caregivers (44.9%). ‘Reducing the size of a pressure injury’ was selected more often as a care goal than ‘totally healing a pressure injury’ by both individuals (46.5% versus 38.4%) and caregivers (46.8% versus 38.4%). ‘Managing pain’ was selected as a care goal by 46.5% of individuals and 35.9% of caregivers. Although most care goals were similar between individuals and their caregivers, notably fewer caregivers selected pain management as a care goal than did individuals with or at risk of a pressure injury. Only around 2% of both individuals and informal caregivers identified that they did not have any specific pressure injury prevention or treatment goals.



Respondents were asked to identify their most important care goal(s) for a maximum of three goals.

Figure 1: Goals of care for individual consumers and informal caregivers[#]

Figure 2 compares care goal responses between individuals who had ever experienced a pressure injury (n = 132) and individuals who were assessed as being at risk but had never had a pressure injury (including those who were uncertain, n = 251). Preventing a pressure injury was selected as an important care goal by the majority of both individuals who had experienced a pressure injury (68.2%) and those who were at risk (69.3%). Not unexpectedly, people who had experienced a pressure injury more often reported totally healing a pressure injury (45.5% versus 34.7%), reducing the size of a pressure injury (50% versus 44.6%) and managing pressure injury pain (50% versus 44.6%) as important goals of care.



Respondents were asked to identify their most important care goal(s) for a maximum of three goals.

Figure 2: Goals of care for individuals who had experienced a pressure injury and those identifying as being at risk of a pressure injury#

4.2 Information needs identified by individuals and their informal caregivers

Participants considered that most of the topics presented in the survey were either important or very important to their information needs (see Table 2). Education topics that were rated by most individuals with or at risk of a pressure injury as important or very important were: caregivers (both formal and formal) being knowledgeable about pressure injuries (82.51%), preventing a pressure injury during immobility (79.90%), skin care (79.37%), facility-based pressure injury prevention plans (78.85%) and pressure injury healing strategies (77.54 %). Topics least likely to be ranked as important or very important were pressure injuries associated with medical devices and pressure injury support surfaces.

	Very important or important (%)	Neutral (%)	Not important or not at all important (%)	No response (%)	Median (IQR) [±]
Immobility [€]	79.9	3.7	7.1	9.4	5 (1)
Skin care	79.4	3.1	5.5	12.0	5 (1)

Carers knowing about pressure injuries	82.5	1.6	6.3	9.7	5 (1)
How to help pressure injuries heal	77.5	5.0	5.7	11.8	5 (1)
Hospital plans to prevent pressure injuries	78.9	4.4	6.3	10.4	5 (1)
Risk factors	77.0	6.5	6.5	9.9	4 (1)
How pressure injury happens	77.0	5.5	7.8	9.7	4 (1)
Positioning	76.2	6.0	7.8	9.9	4 (1)
Pain management	74.4	7.6	6.8	11.2	4 (1)
Assessing pressure injuries	76.2	6.3	6.3	11.2	4 (1)
Dressings	72.1	8.6	6.3	13.1	4 (1)
Skin assessment/skin checks	72.6	8.9	6.8	11.8	4 (1)
Diet	71.8	10.7	7.1	10.4	4 (1)
Where to get more information	71.5	8.9	7.3	12.3	4 (1)
Medical devices	66.8	9.1	8.9	15.1	4 (1)
Beds and chairs	68.7	11.2	8.1	12.0	4 (1)

∅ Refer to Appendix 1 for the full wording of items included on the consumer survey.

± Median ratings and the interquartile range (IQR) were calculated using Likert scale values not at all important = 1, not important = 2, neutral = 3, not important = 4, very important = 5, individuals who selected “no response” were not considered in this analysis.

Table 2: Ratings from individual with or at risk of a pressure injury regarding the of importance of learning about specific pressure injury topics (n = 383)

Informal caregivers also placed high importance on the majority of topics for education (see Table 3). Education topics that were rated by most caregivers as important or very important were: how pressure injuries occur (73.3%), preventing a pressure injury during immobility (72.36%), pressure injury risk factors (72.11%), facility-based pressure injury prevention plans (71.53%), skin care (70.95%) caregivers (both formal and formal) being knowledgeable about pressure injuries (70.82%) and pressure injury healing strategies (70.82 %). Caregivers were least interested in learning more about pressure injury support surfaces, diet and pressure injuries associated with medical devices.

Median ratings of importance of education topics were similar between informal caregivers and individual with or at risk of pressure injuries (see Figure 3, individuals selecting “no response” were not considered in this analysis). Median ratings by caregivers were higher than those of individuals with or at risk of pressure injuries for facility-based pressure injury prevention

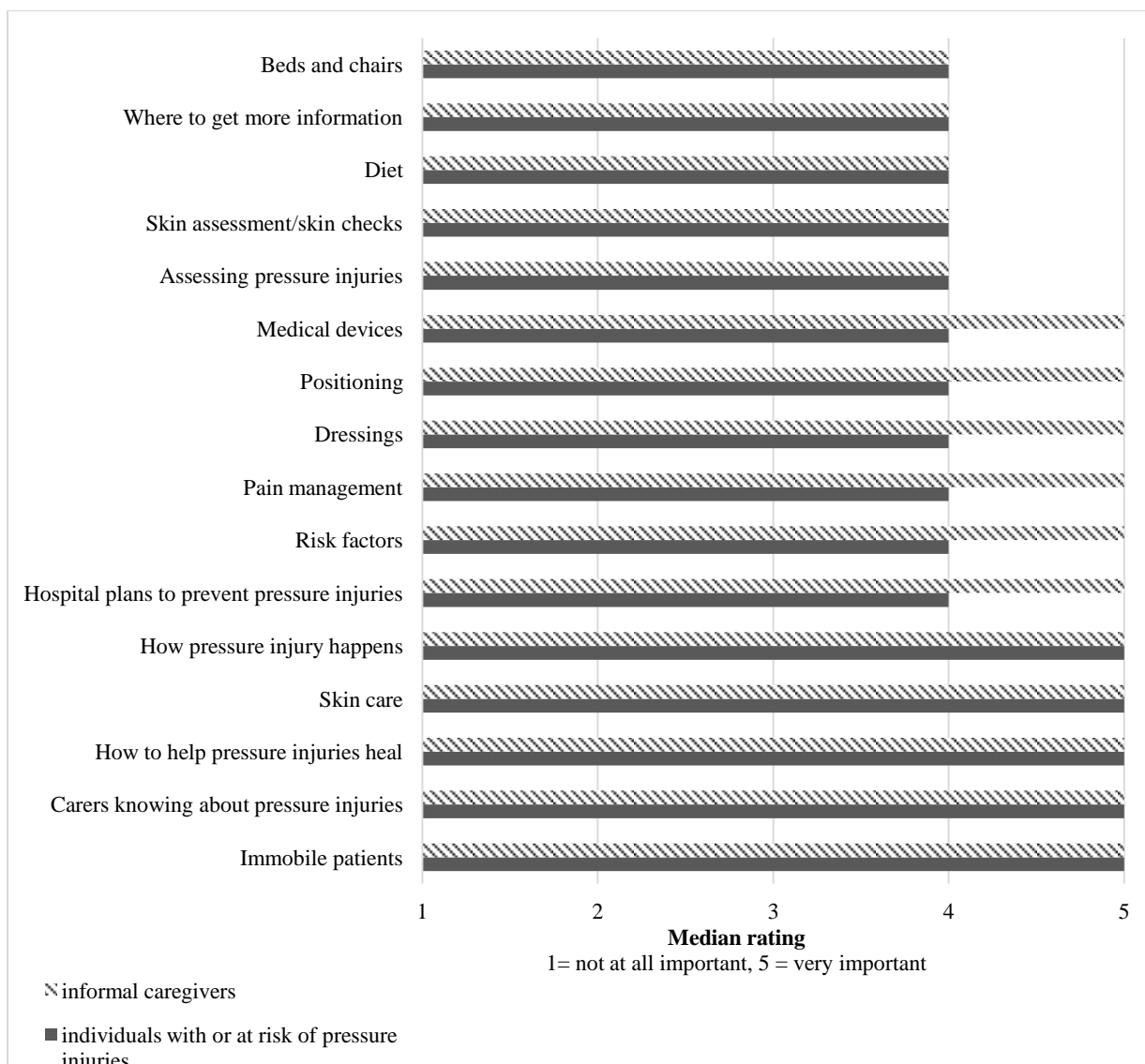
plans, risk factors, pain management, dressings, positioning and pressure injuries associated with medical devices.

	Very important or important (%)	Neutral (%)	Not important or not at all important (%)	No response (%)	Median (IQR) [±]
Immobile patients ^ç	72.4	2.1	6.8	18.7	5 (1)
Carers knowing about pressure injuries	70.8	4.0	6.4	18.8	5 (1)
How to help pressure injuries heal	70.8	3.3	6.4	19.5	5 (1)
Skin care	71.0	3.3	6.8	18.9	5 (1)
How pressure injury happens	73.3	4.1	7.4	15.2	5 (1)
Hospital plans to prevent pressure injuries	71.5	4.0	6.6	17.9	5 (1)
Risk factors	72.1	3.4	7.1	17.4	5 (1)
Pain management	68.2	4.9	6.1	20.7	5 (1)
Dressings	67.3	5.9	6.5	20.4	5 (1)
Positioning	69.8	5.7	6.9	17.7	5 (1)
Medical devices	65.2	6.6	7.3	20.9	5 (1)
Assessing pressure injuries	67.4	5.8	6.4	20.5	4 (1)
Skin assessment/skin checks	67.5	6.4	6.7	19.4	4 (1)
Diet	64.0	10.0	7.1	18.9	4 (1)
Where to get more information	66.1	8.1	7.5	18.2	4 (1)
Beds and chairs	61.5	10.0	8.1	20.4	4 (1)

ç Refer to Appendix 1 for the full wording of items included on the consumer survey.

± Median ratings and the interquartile range (IQR) were calculated using Likert scale values not at all important = 1, not important = 2, neutral = 3, not important = 4, very important = 5, individuals who selected “no response” was not considered in this analysis.

Table 3: Caregiver ratings of importance of learning about pressure injury topics (n = 850)



¥ Median ratings calculated using Likert scale values not at all important = 1, not important = 2, neutral = 3, not important = 4, very important = 5, individuals who selected “no response” was not considered in this analysis.

Figure 3: Median ratings of importance of learning about pressure injury topics[¥]

4.3 Biggest problems faced by individuals and their informal caregivers

A thematic analysis was undertaken on the survey’s open response question collecting qualitative data related to the biggest problem individuals and their informal caregivers experience with respect to pressure injuries. The thematic analysis identified five themes, 11 categories and 28 sub-categories (See Table 4). The first theme, ‘knowledge, attitudes and skills’, describes problems of individuals, informal caregivers and health professionals, with respect to having appropriate knowledge and skills to address pressure injury prevention and treatment, and the attitudes of these groups. The second theme, ‘risk factors for pressure injury

and other comorbidities’, combines the risk factors that individuals and informal caregivers identified as causing significant problems, as well as the individual’s clinical condition, that was reported by some respondents as leading to problems with preventing and treating pressure injuries. The third theme, ‘accessing pressure injury care’, describes both access to caregivers and appropriate equipment, as well as the financial burden of pressure injury care. The fourth theme describes the impact of pressure injuries on the quality of life, including pain, psychological distress and other physical and social manifestations. This theme also included the impact on informal caregivers, which was often reported as burdensome. The fifth theme, ‘the pressure injury’ included difficulties in achieving healing and preventing recurrence, complications such as infection and the challenge of performing pressure injury care.

An overarching issue that crossed many of the themes was the problem of immobility. Responses included in the first theme referred to inadequate knowledge and skills to move and reposition individuals, as well as attitudes of individuals that reduced their adherence to regular repositioning during periods of immobility. In theme two, immobility was a frequently cited risk factor, often related to surgery, age or general clinical condition. With respect to theme three, responses noted the challenge of accessing caregivers with skills to reposition the individual and the lack of appropriate repositioning equipment in home settings. In theme four, responses identified that pain sometimes prevented the individuals’ repositioning, or increasing their immobility.

4.4 Data convergence

Qualitative data generally converged with, and supported the quantitative data, while providing a richer understanding and a more focused perspective of the most important problems facing individuals and caregivers. For example, managing pain was selected as a care goal by 46.5% of individuals and 35.9% of caregivers (Figure 1) and identified as an important education topic by both individuals and their caregivers (Figure 4). Pain was identified as a sub-category within the theme ‘quality of life for patients and their caregivers’ (Table 4). Here responses from individuals expanded on the pain experience, with comments including “long period of suffering”, “suffering greatly”, “causing pain over whole body” and “pain restricted patient change [of] position”. In another example of convergence, the quantitative dataset indicated that all the presented topics were a priority information need for individuals and their caregivers (Table 3). The category ‘knowledge, attitudes and skills of patients and their caregivers’ within the first theme comprised qualitative responses that augmented the

quantitative data on importance of pressure-injury specific education topics, all of which were rated as important by both individuals and caregivers. The qualitative comments demonstrating education needs included “once [a pressure injury] happens, how to prevent and treat it?”, “lack of necessary understanding” and “I do not know what is the consequence [of a pressure injury]”.

Theme [T]	Category [C]	Sub-category [SC] and “indicative response”	
[T1] Knowledge, attitudes and skills	[C1] Knowledge, attitudes and skills of health professionals	[SC1] Knowledge of staff <i>“Doctors and nurses need increased awareness and to use preventive measures.”</i> [SC2] The health professional’s attitude <i>“Sensitizing professionals to the problem of pressure.”</i> [SC3] The way health professionals practise (skills) <i>“Professionals do not execute the pressure care as they should.”</i>	
	[C2] Knowledge, attitudes and skills of patients and their caregivers	[SC4] Knowledge of patients <i>“That you as a patient are not advised of it can it be treated? Not knowing.”</i>	
		[SC5] Knowledge of informal caregivers <i>“Knowing exactly what to do or what not to do.”</i>	
		[SC6] Patient attitudes to engaging in care <i>“Patient [does] not cooperate, do not want to change position, do not understand pressure injury.”</i>	
		[SC7] Caregiver attitudes <i>“Lack of value in prevention of pressure injury by relatives and carer.”</i>	
		[SC8] Lack of informal caregiver skills <i>“Family care not appropriate because do not change position promptly.”</i>	
		[SC9] Lack of self-care ability and skills <i>“Cannot self-care when lying in bed for long period.”</i>	
	[T2] Risk factors for pressure injury and other comorbidities	[C3] Patient risk factors for pressure injuries	[SC10] Nutrition <i>“Very thin, rubbing of bones.”</i>
			[SC11] Musculoskeletal concerns <i>“I believe having osteoporosis is the direct cause...”</i>
[SC12] Circulatory and perception disorders <i>“Poor blood circulation.”</i>			
[SC13] Age <i>“Old age.”</i>			
[SC14] Condition of the skin <i>“Irritation by urine, faeces and sweats.”</i>			
[SC15] Immobility <i>“Long duration of no body movement.”</i>			
[C4] Patient clinical condition		[SC16] General illness/comorbidities	

		<i>"Because of personal health reason and external factors."</i>
[T3] Accessing pressure injury care	[C5] Accessing pressure injury care	[SC17] Access to caregivers <i>"Elderly at home cannot access medical help easily."</i>
		[SC18] Access to equipment <i>"Bed at home is not appropriate to care patient."</i>
	[C6] Financial costs of accessing care	[SC19] Financial costs <i>"Dressing material too expensive, patient cannot afford."</i>
[T4] Quality of life for patients and their caregivers	[C7] Impact on individuals with or at risk of pressure injury	[SC20] Pain <i>"The pain and complications."</i>
		[SC21] Psychological distress <i>"Fear to have pressure injury."</i>
		[SC22] Impact on physical and social quality of life <i>"Can't sleep, situation occur when sleep for long period."</i>
	[C8] Impact on informal caregivers	[SC23] Impact on informal caregivers <i>"Not convenient to care."</i>
[T5] The pressure injury	[C9] Healing the pressure injury	[SC24] Difficulties with healing <i>"Difficult to heal, wound size increase gradually."</i>
		[SC25] Pressure injury recurrence <i>"Repeatedly get one, not easy to heal."</i>
	[C10] Pressure injury complications	[SC26] Infection <i>"Severe infection may endanger life."</i>
		[SC27] Exudate and Odor <i>"Wound with foul odor."</i>
	[C11] Caring for the pressure injury	[SC28] Performing wound care <i>"Correct choice of wound dressings."</i>

Table 4: Themes, categories and sub-categories established in the qualitative data

5. Discussion

To the knowledge of the researchers, this survey represents the largest study of the goals, needs and problems of individuals with or at risk of a pressure injury and their informal caregivers. The study provides data from over 1,200 respondents from 27 countries and highlights some universal experiences of pressure injuries across many cultures, with a notably high response from individuals located in Asian countries. The consumer survey results provided substantial insight into the perspectives of consumers and informed the development of the 2019 International Guideline [7].

Engagement of individuals and their informal caregivers in guideline development is still in its infancy. [18, 19] Further, inclusion of consumer preferences in guidelines is an emerging component of best practice in guideline development. A recent cross-sectional survey of guideline developers (n = 52) from around the world identified that only 48% reported a policy on consumer engagement, 53.8% utilized self-reported surveys to collect individual preferences and 55.8% reported consumer preference data in their guideline [18]. Despite these relatively low numbers, these findings represent a recent increase in the undertaking of new research to evaluate consumer perspectives and preferences as a part of guideline development. As recently as 2017, a systematic review of 56 clinical guidelines reported only 25% of guidelines included consumer preferences [19]. Given the current status of consumer engagement in guideline development, the methods used by the Guideline Governance Group to establish consumer goals, needs and problems are notable. More exceptionally, this project sought to engage individuals with or at risk of a pressure injury and their informal caregivers across more than 40 countries in which the 2019 International Guideline [7] is used, which appears to be a unique endeavor in clinical guideline development [18].

In developing the recommendations on prevention and treatment of pressure injuries that are included in the 2019 International Guideline [7], the development team undertook a comprehensive review of evidence underpinning each recommendation. The full methodology for the guideline has been previously reported [20, 21]. As a part of the guideline development, evidence-to-decision (EtD) frameworks, a tool developed as a part of the Grading of Recommendations Assessment, Development and Evaluation (GRADE) methodology, were used to summarize and evaluate the evidence [22, 23] and reach decisions on appropriate clinical practice recommendations. The EtD framework criteria for consideration in making recommendations includes an evaluation of the importance to individuals of potential clinical outcomes that a recommendation may achieve, as well as the acceptability and feasibility of recommendations for individuals, health professionals and health systems [22, 23]. However, evidence on the priorities of people with or at risk of pressure injuries and acceptability of various interventions is infrequently reported in traditional pressure injury research. By undertaking this global consumer survey, the GGG sought to better understand the impact of pressure injuries on individuals and their informal caregivers in order to inform the process of recommendation development.

The data from the consumer survey was used to provide evidence on whether specific interventions recommended in the guideline were feasible and acceptable to consumers, and whether there is variability in how much consumers value the primary outcomes of interventions being recommended. These data were used to determine the Strength of Recommendation given to recommendations. Thus, the consumer survey data provided perspectives from individuals with or at risk of a pressure injury and informal caregivers on most of the recommendations in the guideline, and directly influenced the recommendation ratings.

Patient-centered care, which is a gold standard care model, includes delivering care that is consistent with the individual's preferences, needs and care goals [24]. However, there is only limited research on the goals of care that are prioritized by people with or at risk of pressure injuries. Very few respondents to this survey did not have a goal of care, highlighting the importance of health professionals working with the individual and their informal caregivers to determine needs and values, and to align care goals. A surprising finding in this survey was the proportion of individuals for whom a care goal was pressure injury size reduction. The concept of chronic, non-healing wounds is discussed throughout the literature focused on wound treatment in the palliative care setting, [25-27] and to a lesser extent in aged care, [28, 29] but is less frequently acknowledged in other clinical settings. The clinical setting and health status of respondents to this survey was unknown, therefore the relevance and generalizability of this finding is unknown; however, most respondents were aged under 50 years (i.e., less likely to be or have been in a palliative or aged care setting). Regardless, the findings highlight the importance of working with individuals to deliver care consistent with their needs, goals and expectations. To this end, the 2019 International Guideline [7] includes the following Good Practice Statement (GPS):

Set treatment goals consistent with the value and goals of the individual, with input from the individual's informal caregivers, and develop a treatment plan that supports these values and goals (GPS 10.2).

The education needs of individuals and their informal caregivers in this survey were wide ranging, with almost every pressure injury-related topic presented in the survey ranked as either important or very important. These data supported the evidence-based recommendation within the 2019 International Guideline [7] to:

Provide pressure injury education, skills, training and psychosocial support to individuals with or at risk of pressure injuries (Strength of evidence = C, Strength of Recommendation = ↑, Recommendation 22.2)

Of note was the high priority both individuals and caregivers placed on items related to continuous quality improvement within the facility (i.e., hospital pressure injury prevention plans and caregiver education). This finding is significant given the recent focus on engaging consumers in facility-based safety initiatives [30, 31], including pressure injury prevention bundles [32, 33]. The importance consumers placed on receiving information about such initiatives indicates a potential receptiveness to future engagement in facility-level patient-centered preventive care strategies. Previous research indicates that inclusion of effective individual and caregiver education components may be critical to the success of such initiatives [32], and this survey indicates that individuals and their informal caregivers are likely conducive to receiving such education.

The major problems associated with pressure injuries that are described in this study concur with previously reported consumer and informal caregiver experiences. In an earlier study in which interviews conducted with nine family caregivers, Rodrigues et. al. (2015) [34] highlighted the impact of caregiving on the quality of life of the caregiver. As in the current study, Rodrigues et. al. (2015) [34] noted that caregivers had a need for more knowledge and skills, and that caregivers are often not prepared to undertake the caregiving role. This was similarly identified as a problem for some of the informal caregivers responding to this survey who noted that the caregiver role was “burdensome” and “inconvenient”. Other studies also support the notion that providing care for a person with or at risk of pressure injury has a negative influence on the informal caregiver’s quality of life [35]. The participants in the study by Rodrigues et. al. (2015) [34] also noted that the many negative emotions that caregivers experience, such as rage and intolerance, are often experienced concurrently with positive emotions, such as love and patience. The survey undertaken as a part of the development of the 2019 International Guideline [7] did not explore positive experiences of individuals with or at risk of a pressure injury and informal caregivers, and this is an area that deserves further investigation.

The evaluation and reporting of outcome measures considered important by pressure injury patients has received increasing attention as a component of both clinical practice and research [36-38] in parallel to the emerging evolution of a stronger consumer focus in clinical guidelines

[1-5]. In the development of a conceptual framework that identified significant domains describing health-related quality of life for individuals with a pressure injury, Gorecki et. al. (2010) [36] identified the need for an assessment tool for patient-reported outcomes. Gorecki et. al. (2010) [36] followed this with the development of a standardized assessment tool for clinical and research use to collect quality of life focused outcome measures. This tool included similar concepts as identified by consumers in this current survey (e.g., emotional well-being, sleep and pain). [38] In their recent work identifying and classifying outcome measures relevant to pressure injury research, Lechner et. al. (2020) [37] also identified a number of similar outcomes, including emotional (e.g., wellbeing) and delivery of care (e.g. satisfaction and acceptability with intervention), that are significant to individuals at pressure injury risk and also align with issues identified by consumers responding to our survey.

The survey has numerous limitations. First, although the survey was tested for face validity and designed to maximize accessibility, formal reliability and validity testing was not undertaken. Although respondents from around the world completed the survey, approximately 86% were in China. The large response from Asian participants is likely due to both the high population in this geographic region, as well as the high digital connectivity many individuals and informal caregivers have in these regions, increasing the ease at which the survey could be passed from health professionals to their clients. Although older people are generally at higher risk of pressure injuries, only around 37% of individual respondents were aged over 50 years, reducing the generalizability of results. The researchers suggest that the lower than expected response from older individuals may relate to the internet-based nature of this survey. Survey respondents self-selected to participate, potentially creating a level of bias toward participants who have greater interest in and/or knowledge of pressure injuries. Self-selection and self-reporting have been cited as fundamental sources of bias in survey data collection. [39]. Other researchers have proposed that anonymity, as was afforded in this study by the online data collection method, can increase honesty in self-report [40, 41] and decrease social desirability bias [39, 42]. However, this effect may relate to the change in types of participants recruited to voluntary, anonymous surveys rather than increased disclosure [41]. The anonymous nature of the survey also meant that it was possible that people who were not eligible to complete the survey may have responded. However, given the access information for the survey was primarily distributed by health professionals and through professional networks, we consider it unlikely that that this limitation would have significantly influenced the findings. More

research on the influence of data collection methods in attaining accurate, valid and rich consumer perspectives is warranted.

In the current study, the use of a mixed methods design provided additional opportunity to validate responses, [10] although many of the respondents chose to make short comments when responding to open-ended questions. Exploring the issues in greater depth through interviews is likely to elicit richer data and allow exploration of themes in greater detail. This was beyond the scope of this current consumer survey that sought to collect data from a large, global sample of consumers. Additionally, due to the survey methods used to collect the data, we were unable to use data saturation as the point at which we ceased qualitative data collection. However, the large volume of survey responses addressing similar themes suggested that redundancy was likely to have been reached. Ongoing exploration of the experiences of individuals with or at risk of pressure injuries and their informal caregivers using methods designed to understand these topics in even greater depth is an imperative.

6. Conclusion

Engagement of individuals and their informal caregivers in guideline development is a rapidly evolving component of guideline methodology. This project has demonstrated strategies that can be used to incorporate the perspectives of individuals and their informal caregivers into the development of guidelines in both a meaningful and transparent way. The findings of this survey not only provided the guideline developers with insight into outcome measures, clinical questions and general topics of relevance to individuals with or at risk of a pressure injury, but also provides valuable information for health professionals. The survey indicated that the care goals of individuals with or at risk of pressure injuries are variable and the problems they face are wide-ranging. This emphasizes that health professionals should establish the personal goals and support needs of individuals with or at risk of a pressure injury and their caregivers when developing care plans. Individuals with or at risk of a pressure injury and their informal caregivers also have significant education needs and appear likely to require information on a range of pressure injury topics, suggesting a strong need for consumer-focused education tools.

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8. Conflicts of interest

The authors have no conflicts of interest to declare.

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