A
Narrative
Literature
Review

of

Patient and Family Centred Care

in

Adult ICUs

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1

ICU nurses | Also ICU nurses

I don't even have time to tell you how wrong you are.

Actually, it's gonna bug me if I don't.

Sarah Friedman, MD
@sarah13friedman

It happened. My elderly patient thought my name was Dr. Patagonia

3:21 PM · 2021-11-10 from Queens, NY · Twitter for iPhone

475 Retweets 76 Quote Tweets 15.5K Likes

Natalie
@jbfan911

Unfortunately had to go to the hospital this morning. Nothing is wrong I just work here

Me: "you need any help?"

New grad: "no I'm good"
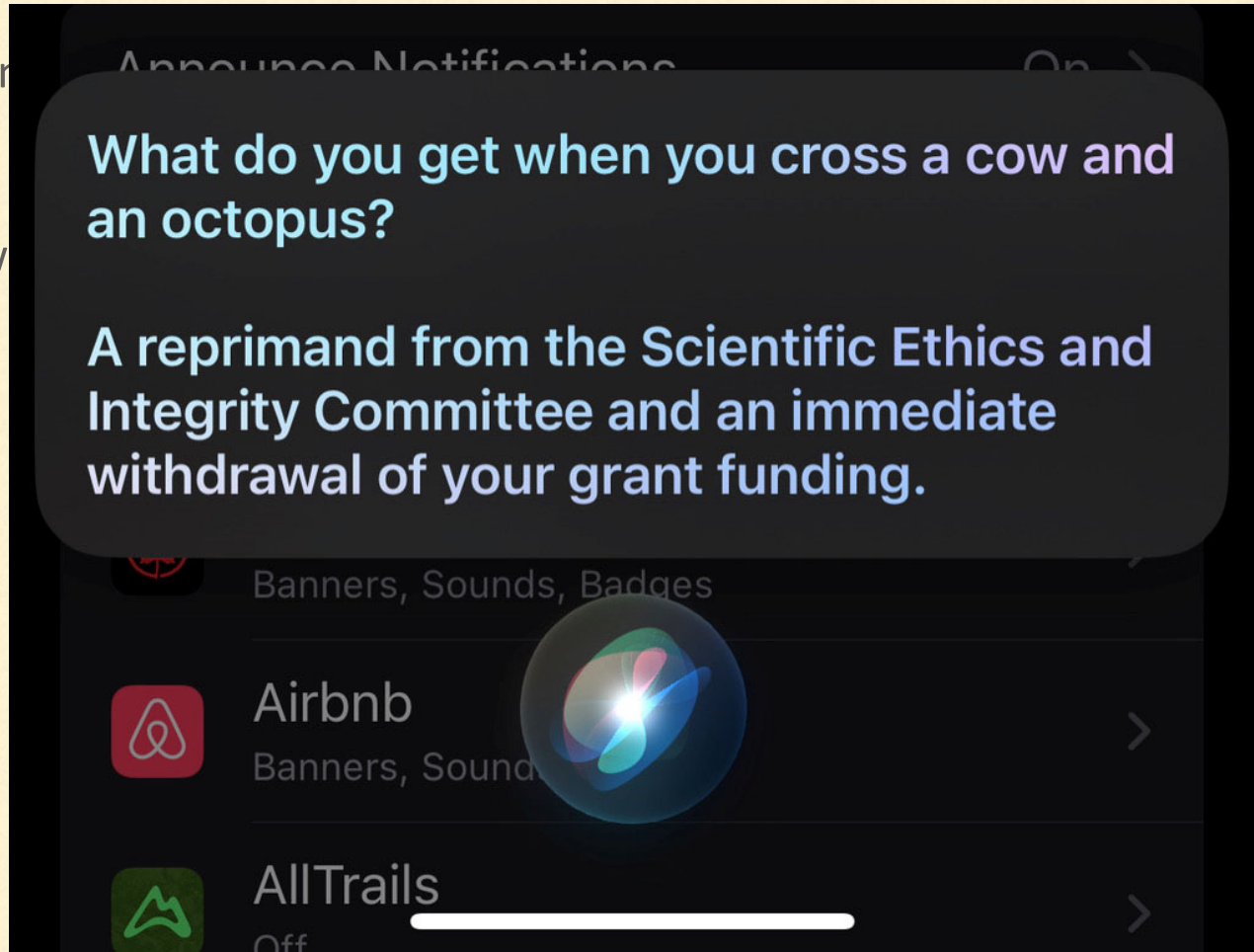
Their last six patients:

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- - I have no actual or poter[...] program/presentation
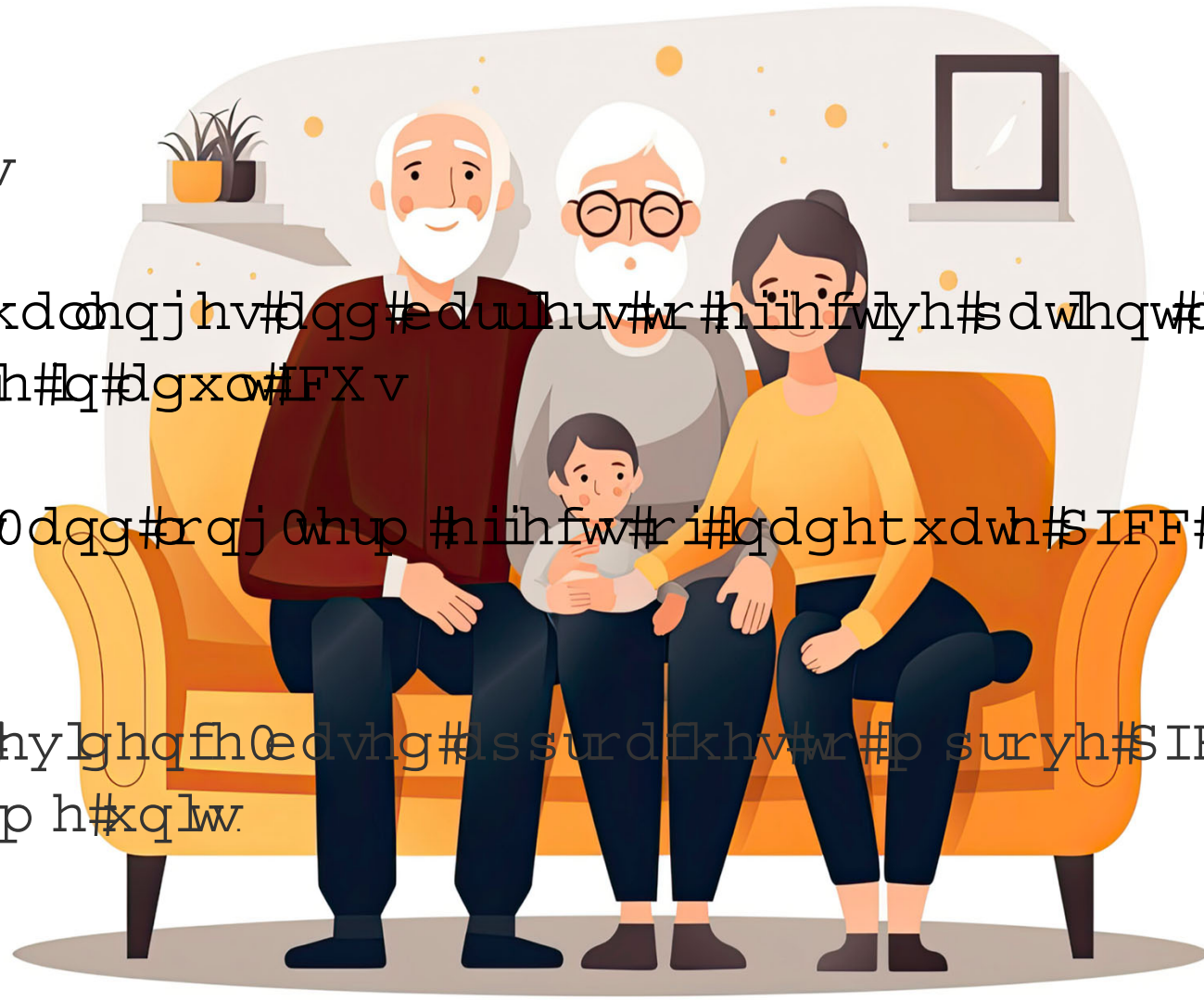
- - please talk to me afterw[...]

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Not

- **A Systematic review** — a massive, [c]
  and structured review

- **A Scoping/Integrative review** - [pr]
  broad research area

But

- **A Narrative review** - summary and
  research on a topic, to provide an [o]
 of the subject without following sp[...]
  structured criteria.

Table 1.1 Differences between the three common review types

	Narrative	Integrative	Systematic
Purpose	Provides an overview on a topic of inquiry for a research study, dissertation, or stand-alone review	Critical analysis of empirical, methodological, or theoretical literature, which draws attention to future research needs	Answers a single clinical question
Team member(s)	One or more reviewer	Two or more reviewers and librarian involvement recommended	Three or more reviewers includes librarian or information specialist and statistician if meta-analysis is performed.
A priori review protocol (plan)	No	No	Yes—protocol registration encouraged (PROSPERO, Cochrane Collaboration)
Review question	No	Broadly defined purpose and/or review question(s)	Single clinical question generally in the format of PICO P = population, I = intervention, C = comparison, O = outcomes
Established reporting guidelines	No	No	Yes (PRISMA reporting guidelines)
Timeline	2–6 months	6–12 months	12–24 months
Use of a systematic search methodology (allows for replication)	No	Yes	Yes
Sampling	Scholarly work on topic	Experimental/ nonexperimental research—may include theoretical and methodological literature	Experimental research
Eligibility (inclusion and exclusion)	No	Yes	Yes
Search flow diagram	No	Yes	Yes (PRISMA flow diagram)
Critical appraisal	No	Yes	Yes
Data extraction	No	Yes	Yes
Analysis and synthesis	Narrative analysis	Narrative and/or thematic analysis with descriptive and qualitative synthesis	Narrative analysis with descriptive and qualitative synthesis— may include quantitative synthesis (meta-analysis)
EBP Implications	No	Yes	Yes

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- Searched three databases PubMed, C[...]
  2000- Feb 2023
- Keywords used in the search:
  patient and family-cent(e)red car[...]
  patient-cent(e)red care
  adult
  intensive care unit*
  critical care*
  communication
  expectation*
  perception*
  satisfaction*
- Keywords were chosen based on research question to get the most relevant research
- Limited to full articles and English language

when you find a perfect article but only the abstract is available

All right, then. Keep your secrets.
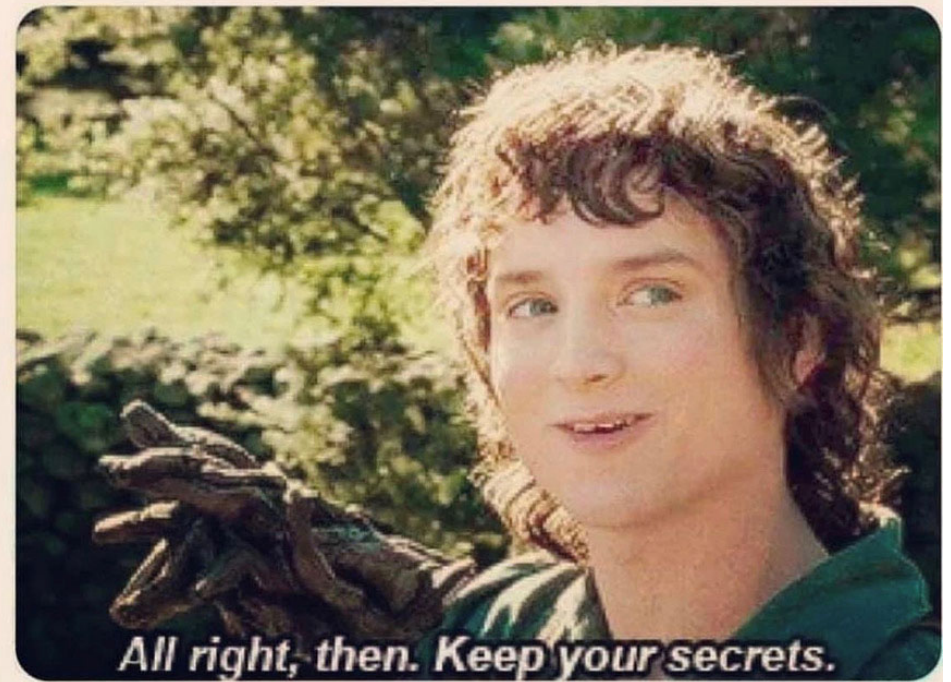
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- **Family:** Defined by the patient

- **Patient and Family Cent(e red Care (PFCC):** Approach to health care that is respectful of and responsive to individual families' needs and value

- **Communication:** All verbal, in person, telephone, formal and informal discussions as well as educational materials, printed and online

- **Satisfaction:** How well an individual or group's needs and expectations are met, when their needs and expectations are fully met, satisfaction tends to be high
  - FSICU, CCFSS

- **Healthcare Provider (HCP):** MD, RN, RRT, anyone working in the ICU unless specifically stated

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Key themes emerged

1. Barriers to PFCC Identified by Patients and Families
2 .Barriers to PFCC Identified by HCPs
3. Consequences/Outcomes of poor, ineffective PFCC
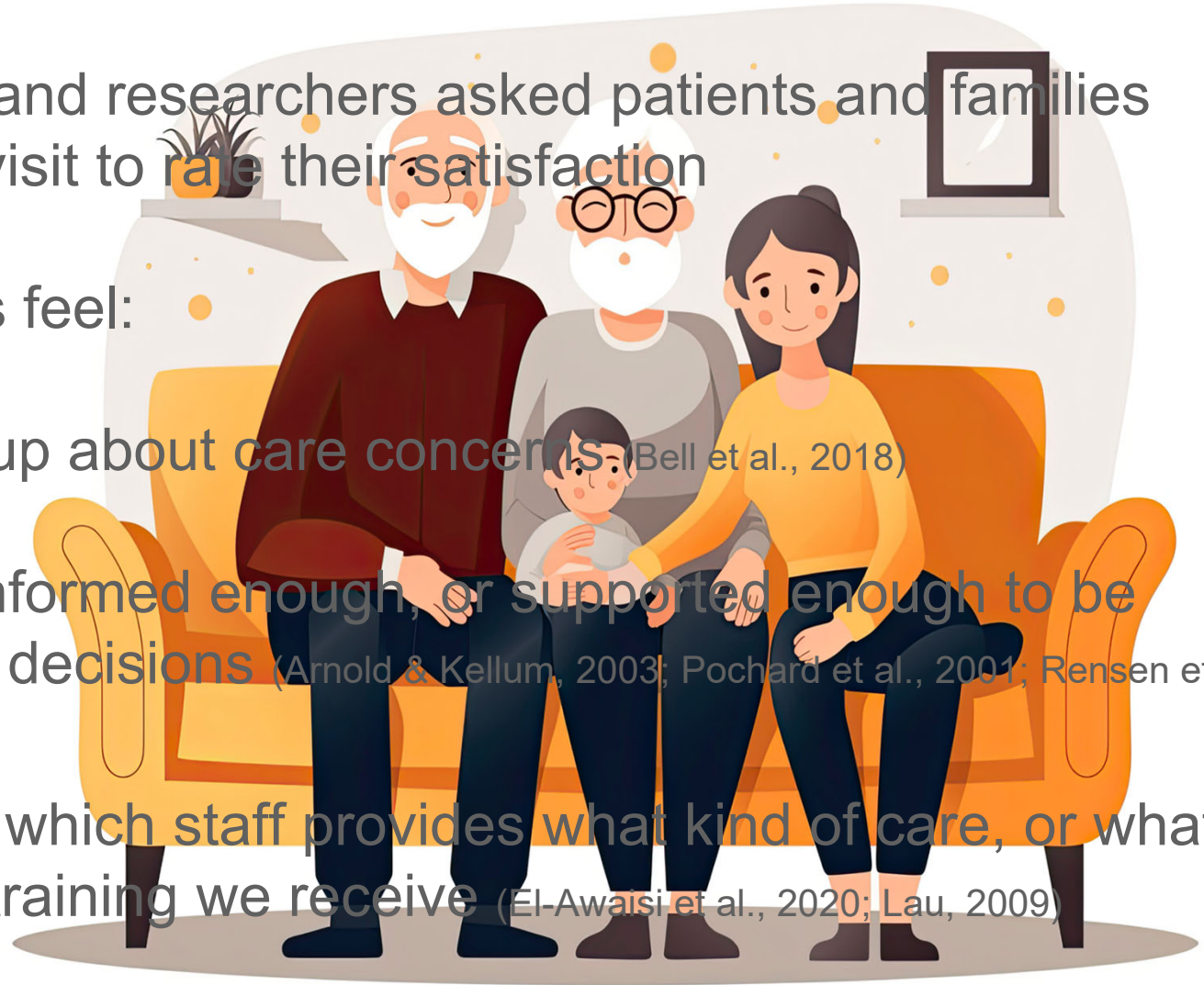4. Strategies to improve

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Many organizations and researchers asked patients and families during or after their visit to rate their satisfaction

Patients and families feel:

- They can't speak up about care concerns (Bell et al., 2018)

- They do not feel informed enough, or supported enough to be making significant decisions (Arnold & Kellum, 2003; Pochard et al., 2001; Rensen et al., 2017)

- They do not know which staff provides what kind of care, or what kind of education/training we receive (El-Awaisi et al., 2020; Lau, 2009)

- Their perspectives on their needs often differ from what HCPs provide (or think they need)(Scott et al., 2019)

Needs

Identifying by Patient and Families

TABLE 1 Studies of family needs

Author	Aim	Setting	Sample size	Method	Outcome
Auerbach et al. (2005)	To examine family members perceptions of whether their needs were met in a trauma ICU at both at admission and prior to discharge	One Trauma ICU in teaching hospital in the United States (USA)	Forty family members	Quantitative CCFNI	On Admission,most prominent of unmet needs were information, explanations and comfortable waiting area Discharge—tended to show all needs were being met
Bijttebier et al. (2001)	To investigate differences between perceptions of family members, physicians and nurses about the needs of relatives of critical care patients.	One general ICU of a University Hospital in Belgium	Two hundred family members, 38 physicians, 143 nurses	Quantitative CCFNI	Information emerged as being the most important factor across all three groups. Nurses and physicians underestimated this need.
Bond et al. (2003)	To describe the needs of families of patients with severe traumatic brain injury in a neurosurgical ICU	One neurological ICU in trauma centre USA	Seven family members	Qualitative-Exploratory interviews	Content analysis of the interviews identified 4 themes The need to know, The need for consistent information, The need for involvement The need to make sense of the experience
Fry and Warren (2007)	To describe the perceived needs of the ICU family members viewed from their own words	One General ICU in the USA	Fifteen family members	Qualitative-Contextual analysis using interviews	4 explicit needs were expressed by all participants. These needs were seeking information. Trusting the professionals. Being a part of the care and maintaining a positive outlook.
Hinkle et al. (2009)	To describe family members needs of ICU patients identified by family members and nurses.	Six ICU's (4 neurological and 2 surgical) in the USA	Hundred and one family members and nurses	Qualitative-descriptive approach	Hierarchical cluster analysis identified the 4 themes of Emotional resources and support Trust and facilitation of needs Treatment information Feelings Family members and nurses differed significantly on three of the four themes
Hinkle & Fitzgerald (2011)	Needs of American relatives of intensive care patients: Perceptions of nurses, physicians and relatives	Six ICU's (4 neurological and 2 surgical) in the USA	Hundred and one family members, 28 physicians and109 nurses	Quantitative CCFNI	The three most important needs were 1)To have questions answered honestly 2)To be assured that the best care possible is being given to the patient 3)To feel the hospital personnel care about the patient.
Keenan and Joseph (2010)	Identify the needs of family members of ICU patients who have sustained a severe traumatic brain	One neurological ICU in Canada	Twenty-five family members	Qualitative Semi-structured Interviews	Key themes identified were as follows: The need to talk about their experience. To receive information about the injury and prognosis. To be supported by professionals in becoming involved

Scott et al., 2019

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- Families cannot effectively or accurately understand the patients' condition or the severity (Curtis et al., 2014; Debaty et al., 2015; Peigne et al., 2011)

- Organizational barriers (Kleinpell et al., 2019)

- Individual barriers (Curtis et al., 2014, Kiwanuka et al., 2019, Visser et al., 2019)

- Interprofessional barriers (Kiwanuka et al., 2019, Visser et al., 2019)

  - "not my job"

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- Post intensive care syndrome - *family* (PICS-F)

  (Davidson et al., 2012; Zante et al., 2020)

- Anxiety and Depression

  - reported up to 70-97% of family members of ICU patients

    (Paparrigopoulos et al., 2006, Debaty et al., 2015; Pochard et al., 2001; Scott et al., 2019, (van Beusekom et al., 2016)

- Post Traumatic Stress Disorder (PTSD)

  - Over 50% of family display clinically significant symptoms of PTSD (Wendlandt et al., 2021)
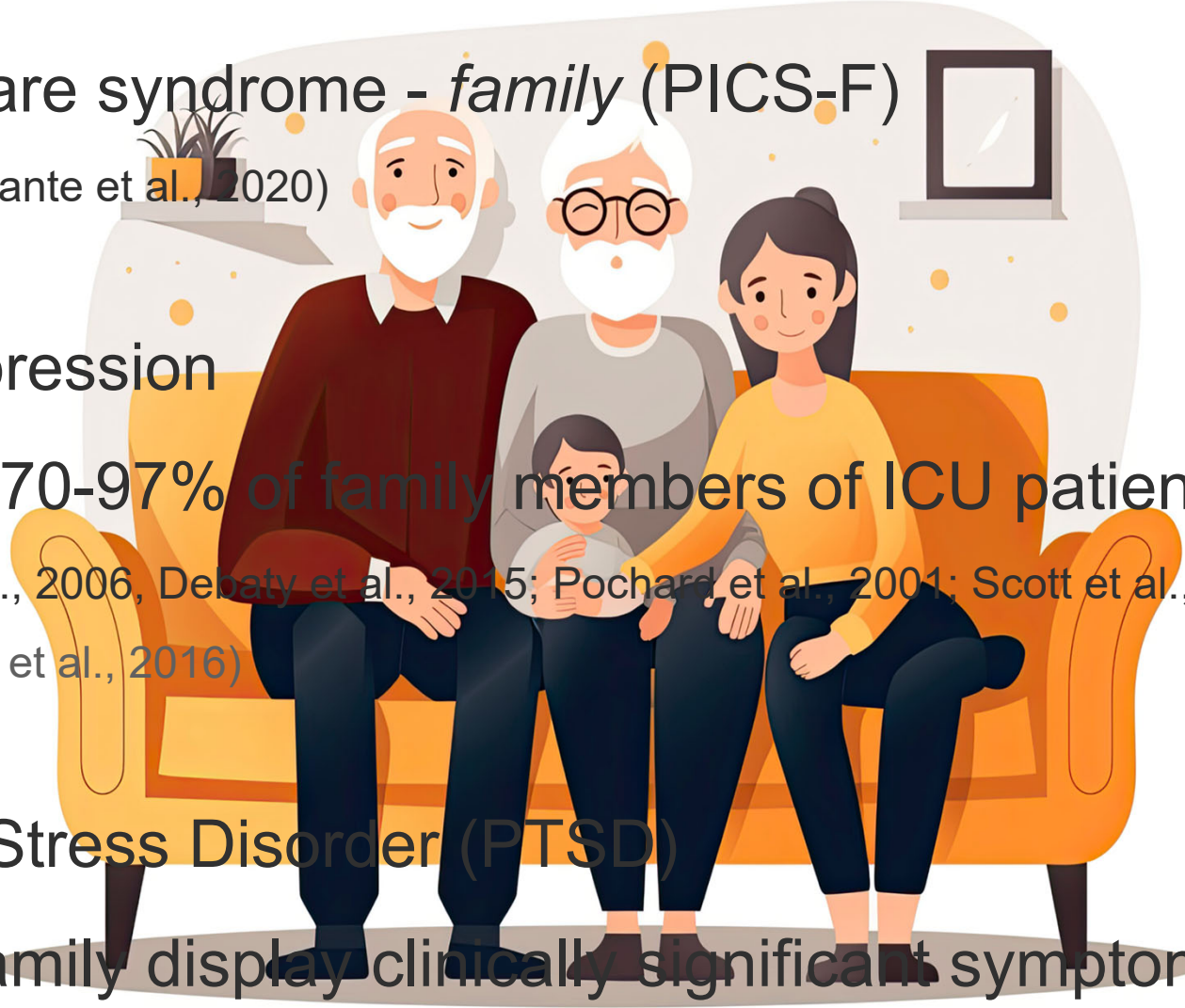
Table 3 Summary of main findings of the reported burden

Type of burden	Time of measurement	Reported outcomes
Anxiety[a]	During admission	42–80 %
	3 months	24–63 %
	6 months	15–24 %
Depression	During admission	16–90 %
	3 months	12–26 %
	6 months	5–36 %
	12 months	23–44 %
Post-traumatic stress disorder	During admission	57 %
	3 months	30–42 %
	6 months	35–57 %
	12 months	32–80 %
Employment status	Up to 50 % of the informal caregivers reduced their work hours, quit their job or were fired in order to provide informal care	
Health-related quality of life	Major decreases in mental health, limited changes in physical health	
Use of medication	Between 8 % and 32 % of informal caregivers started to use medications after the ICU admittance of their relative	
Lifestyle interference	Up to 12 months after discharge, almost 50 % of informal caregivers had to quit activities in order to take care of the patient	

[a]Anxiety was not assessed at 12 months after discharge

van Beusekom et al., 2016

13

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- Family navigators/CNS (Buhagiar et al., 2020; Curtis et al., 2016; Torke et al., 2016)

  - Facilitate needs-based education program for families (Chien et al., 2006)

- Pet therapy (Kleinpell et al., 2019)

- Staff education – specifically to Improve language (Curtis et al., 2014)

- Scheduled family tour (Lai et al., 2021)

- Structured communication tool, premade questions (Nelson et al., 2009; Peigne et al., 2011; Sviri et al., 2019; White et al., 2018)

  - Repeat and clarify goals of care on regular basis (Visser et al., 2014)

- Screening and support for mental health (van Beusekom et al., 2016)

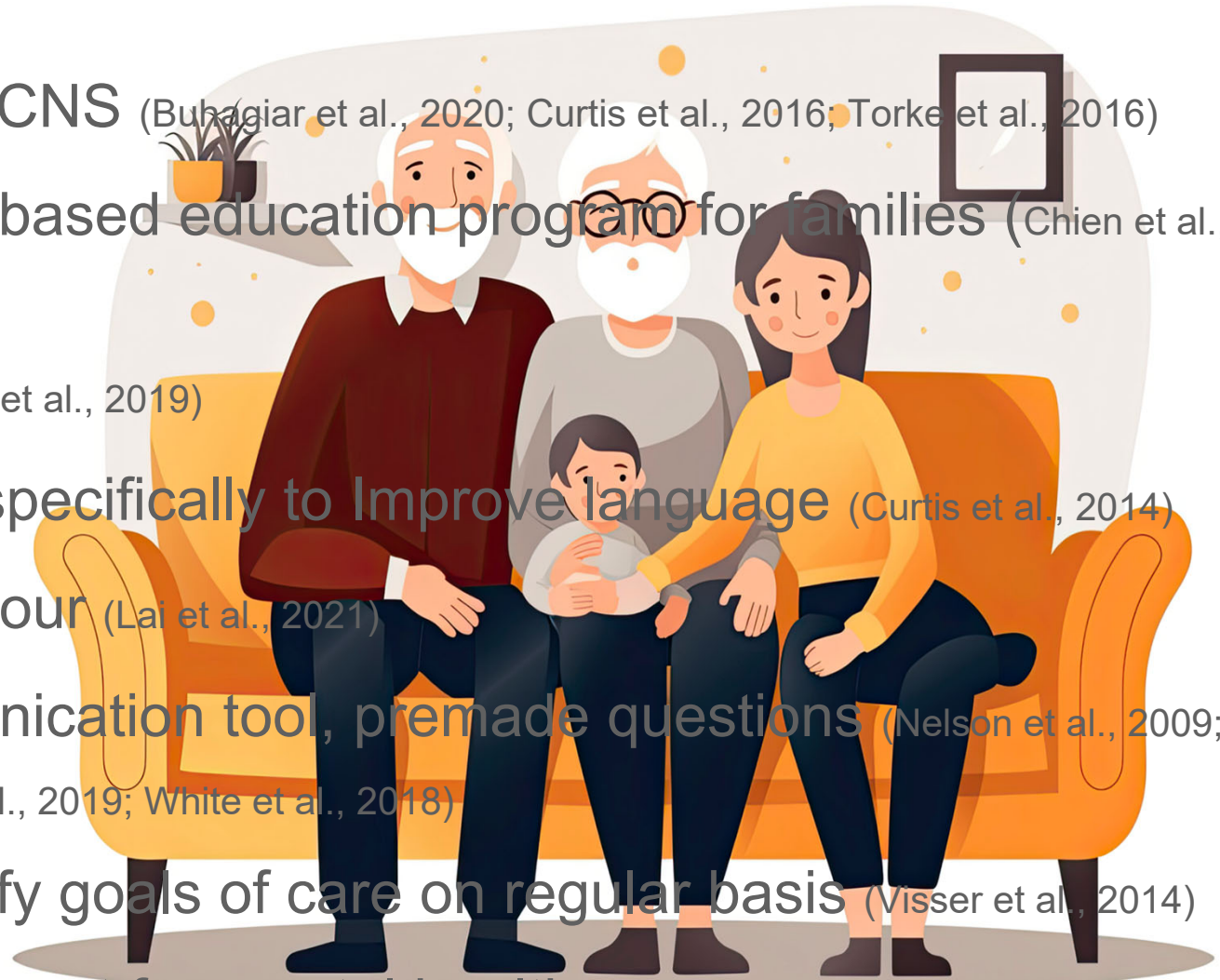 - Cognitive behavioural therapy for families (Chiang et al., 2016)

Table 2. List of the 10 most important family needs

Order	Family need	Dimension
1st	To have responses delivered sincerely	Assurance
2nd	To know the prognosis	Assurance
3rd	To sense that the healthcare staff is concerned about the patient	Assurance

Table 4. Order of the 10 least important needs

Order	Family necessity	Dimension
1st	Being notified of religious services available	Information
2nd	Being visited by a pastor	Support
3rd	Feeling that there is no problem in crying	Support
4th	Having good food in the hospital	Comfort
5th	Being alone at any moment	Support
6th	Being informed about someone who can help with family problems	Support
7th	Having a place to be alone while in the hospital	Support
8th	Having comfortable furniture in the waiting room	Comfort
9th	Being able to speak with someone about negative feelings like guilt or anger	Support
10th	Having a telephone near the waiting room	Comfort

Chien et al, 2006 &
Fortunatti, C 2014

Table 1 Words we should avoid in the ICU and some alternatives

| Phrases we should not use	Replacement	Rationale
Withholding or withdrawing care	Withholding or withdrawing life-sustaining measure	We never withhold or withdraw our "care"
There is nothing more we can do	We will focus our efforts on keeping the patient comfortable	There is always additional care and support we can provide, even if our care will not sustain life
Withholding and withdrawing life-sustaining measures are morally and ethically equivalent	Withholding and withdrawing life-sustaining measures are both ethically and morally permissible	These two acts (withholding and withdrawing) are not the same, but they overlap practically and they are both morally and ethically permissible in the right circumstances
Consider an end-of-life decision	Consider continuing, withholding, or withdrawing life-sustaining measure	An "end-of-life decision" is not specific and presumes only one outcome. If the decision is made to pursue ongoing life-sustaining measure, it is not an end-of-life decision
No escalation of treatment	Make decisions about whether additional specific therapies are indicated	"No escalation" of treatment as a plan of care can be confusing, especially to physicians receiving handoffs, since the specific definition of an "escalation" can be subjective and arbitrary. In addition, an escalation cannot be specified for many ICU therapies.

Curtis et al., 2014

16

Table 2. List of the 21 most important questions asked by family members of patients in the intensive care unit

Domain	Subdomain	Question
Diagnosis	Neurologic status	Why is he/she not fully conscious?
Diagnosis	Disease	What is wrong with him/her?
Diagnosis	Appearance	I am upset by the way he/she looks. Can you tell me why he/she looks different?
Treatment	What treatments?	What treatments and other care is he/she receiving?
Treatment	Weaning	When will he/she be able to breathe on his/her own?
Treatment	Tubes and machines	What is the purpose of the tubes and machines attached to him/her?
Prognosis	Recovery	Will he/she get better?
Prognosis	Probability	What are the chances that he/she recovers?
Prognosis	How and when families will know	How and when will we know what is going to happen?
Prognosis	Recent events	Is he/she better today?
Comfort	Psychological distress	Is he/she in psychological distress?
Comfort	Supplying comfort items	Is there anything I can do to make him/her more comfortable? (music, newspaper, food)
Comfort	Physical pain	Is he/she in pain?
Interaction	Hearing	Can he/she hear me when I speak to him/her?
Interaction	My participation	What can I do for him/her? (help with care, feeding, washing)
Communication	Being informed	Can I be sure I will be told if something happens?
Communication	News	Will I be informed regularly of changes and, if so, how?
Communication	Phone	Can I call to find out how he/she is doing?
Family	Decision-making	In a decision-making situation, what is expected of me?
Post-ICU	Length of stay	How long will he/she stay in the ICU?
Post-ICU	Sequelae	Will he/she have any after-effects?

ICU, intensive care unit.

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- Family presence
  - during rounds (Cypress, 2012; Jacobowski et al., 2010)
  - balance teaching medically (residents, students) with family
  - resuscitation
- Family support
  - Participation in skin/mouth care (Mitchell et al., 2009)
  - Peer to peer support
  - Informational brochures
  - Designated family to receive information (Visser et al., 2014)
  - Personal diaries
  - Decision support tools
- Communication
  - Routine/ Scheduled family conferences
  - Structured approach to conversations
- ICU HCPs receive training on family-centred communication

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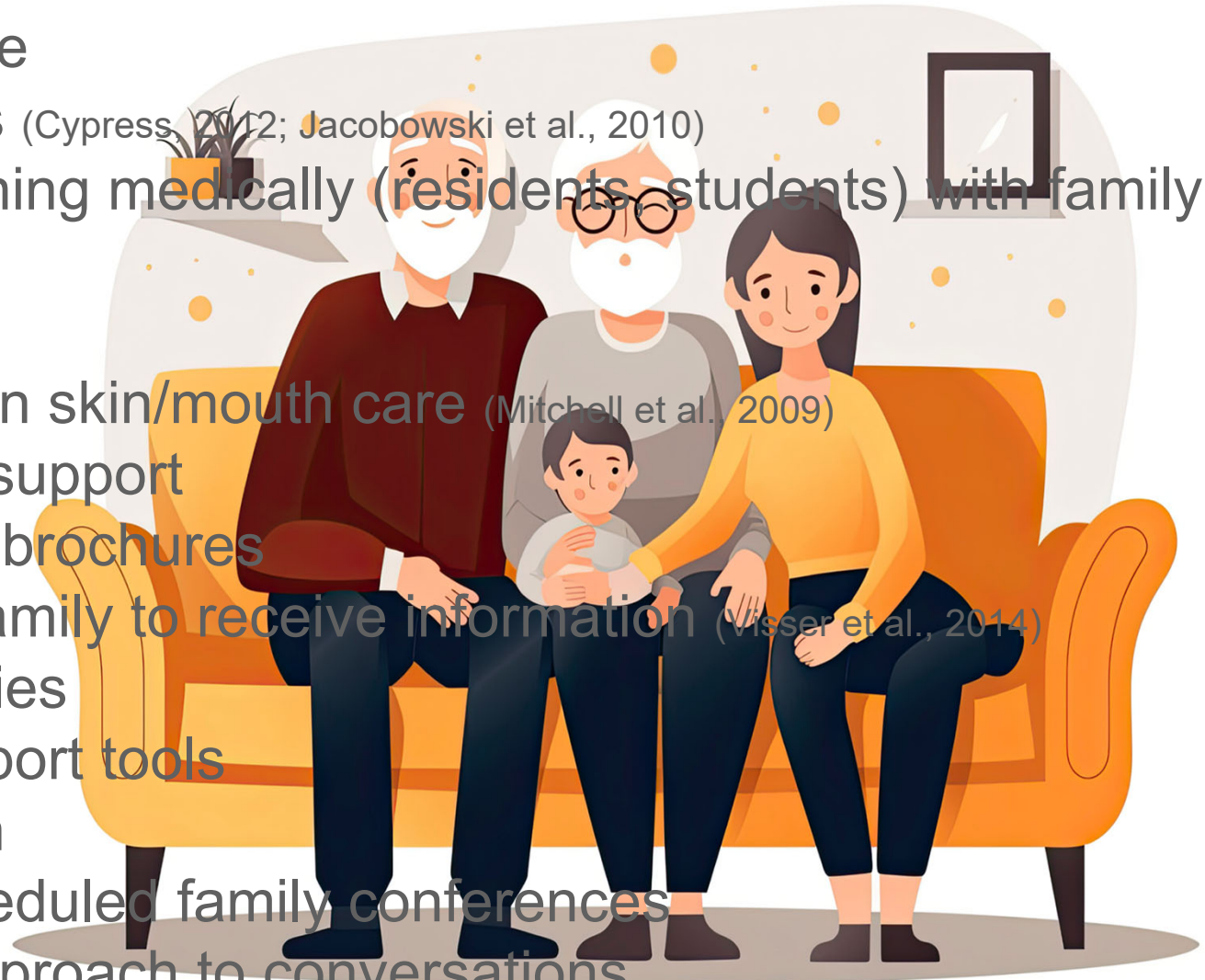
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- Use of specialty consultation services
  - Palliative care (Frontera et al., 2015)
  - Ethics consultation
  - Social work
  - Spiritual support
- Standardized use of sedation and analgesia during withdrawal of life support
- Nurses to be involved in decision-making about goals of care and trained to provide support
- Hospital promote/support PFCC initiatives
- Implement noise reduction strategies
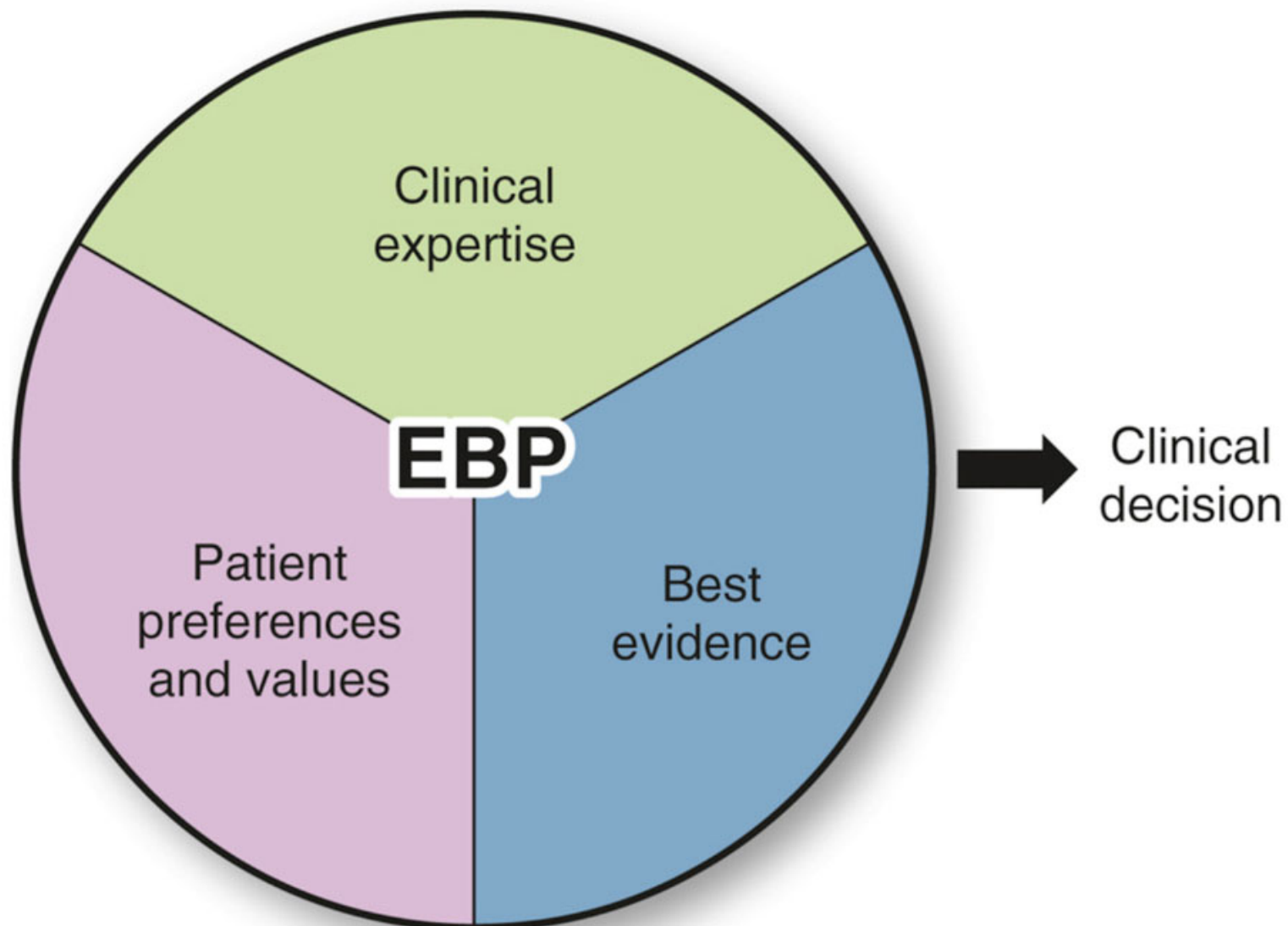- Promote family sleep

Now it is up to you…

FIGURE 2.1 Evidence-based practice components.

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caregiver uncertainty of illness and only reviewed the literature from healthcare discipline databases. Future research should incorporate

4.2 | Future research

There is a need for further empirical research to increase understanding of family needs and their perspective of whether their needs were met or not and the factors that militate against this.

sho PTSD trajectories in this population, with the ultimate

has an impact on outc analysis found a very high level of satisfaction with critical care

Since this scale was developed for the first time in an Asian only slightly country with Eastern culture, it is recommended to study and her focus on develop it in other nations in terms of cross-cultural adaptation. waiting room

Due to the critical conditions of patients in ICUs and increasing itcomes after

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What does the Public expect from us?

How can we meet or manage their expectations?

   - Do they expect daily phone calls from us? From MDs?

   - Is an update from an RN or RRT sufficient?

   - Do they expect 1:1 nursing?

How should we approach those first conversations?

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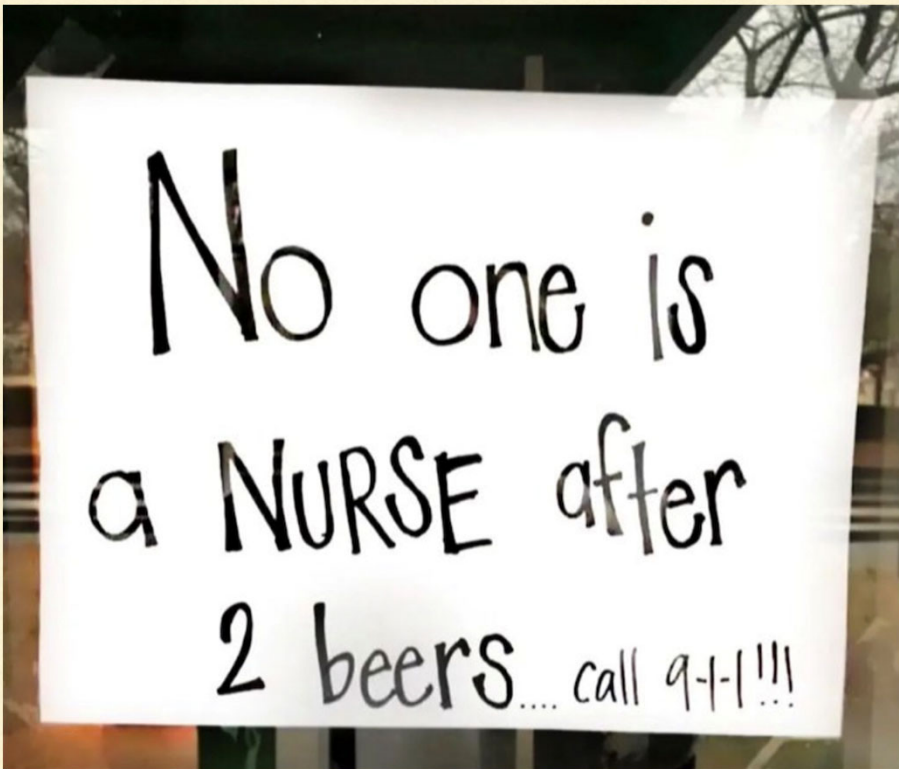
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Questions?

No one is a NURSE after 2 beers... call 9-1-1!!!

Friend: you better be in a good mood tonight

Me doing my best:

You guys ever think about dying?