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Patient and Family Centered Actionable Processes of Care and Performance Measures for Persistent and Chronic Critical Illness: A Systematic Review

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Objectives: To identify actionable processes of care, quality indicators, or performance measures and their evidence base relevant to patients with persistent or chronic critical illness and their family members including themes relating to patient/family experience.

Data Sources: Two authors independently searched electronic, systemic review, and trial registration databases (inception to November 2016).

Study Selection: We included studies with an ICU length of stay of greater than or equal to 7 days as an inclusion criterion and reported actionable processes of care; quality improvement indicators, measures, or tools; or patient/family experience. We excluded case series/reports of less than 10 patients.

Data Extraction: Paired authors independently extracted data and performed risk of bias assessment.

Data Synthesis: We screened 13,130 references identifying 114 primary studies and 102 relevant reviews. Primary studies reported data on 24,252 participants; median (interquartile range) sample size of 70 (32–182). We identified 42 distinct actionable processes of care, the most commonly investigated related to categories of 1) weaning methods (21 studies; 27 reviews); 2) rehabilitation, mobilization, and physiotherapy (20 studies; 40 reviews); and 3) provision of information, prognosis, and family communication (14 studies; 11 reviews).

Processes with limited evidence were generally more patient-centered categories such as communication, promotion of sleep, symptom management, or family support. Of the 21 randomized controlled trials, only two were considered at low risk of bias across all six domains, whereas just two cohort studies and one qualitative study were considered of high quality.

Conclusions: We identified 42 distinct actionable processes of care relevant to patients with persistent or chronic critical illness and their families, with most frequently studied processes relating to weaning, rehabilitation/mobilization, and family communication. Qualitative studies highlighted the need to address psychologic needs and distressing symptoms as well as enabling patient communication. Our findings are informative for clinicians and decision-makers when planning high-quality patient and family-focused care.

Key Words: chronic critical illness; intensive care; persistent critical illness; process of care; quality indicator

Within ICUs in developed countries, 5–10% of critically ill adults transition from acute critical illness to a state of persistent and in some cases chronic critical illness (1–4). Persistent critical illness is characterized by some degree of clinical instability associated with persistent low-intensity inflammation and organ failure (5) that may not be directly attributable to the original reason for ICU admission (6). Patients with chronic critical illness continue to require prolonged ICU stays and, in most cases, a prolonged need for mechanical ventilation (7–9). Incidence rates are increasing, costs to the healthcare budget are estimated to be \$25 billion annually in the United States alone (10), and hospital mortality remains high for these patients (11). With an uncertain disease trajectory, extreme symptom load and profound physical, neuropsychologic, and cognitive deficits, patient burden is substantial (8, 12). Family members also experience significant emotional and physical caregiving and financial burden (13, 14).

Patients with persistent or chronic critical illness require adaptation of their clinical management plan and overall goals of care to a focus on rehabilitation, symptom relief, discharge planning, and in some cases, ventilation discontinuation, or end-of-life care (15). Realization of these goals requires development and implementation of strategies focused on actionable processes of care (i.e., those processes over which clinicians and decision-makers have direct control and are able to take action on) that will improve patient and family experience and clinical outcomes (5, 16). However, strategies such as weaning and mobilization protocols, which can be considered actionable processes of care, infrequently include guidance specific to patients with persistent or chronic critical illness (17). Daily checklists, which reinforce delivery of actionable processes of care, are focused entirely on acutely ill patients and thus may not include items likely to be considered important to patients experiencing long ICU stays, such as communication aids, family meetings, and symptom management (18).

Therefore, to inform the development of quality improvement tools for patients with persistent or chronic critical illness and family, we sought to identify actionable processes of care, performance measures, and quality indicators including reports of patient and

family experience specific to the management of persistent and chronic critical illness described in the current evidence base.

METHODS

We conducted this review according to the Preferred Reporting Items for Systematic Review and Meta-Analyses Protocol (PRISMA-P) guidelines (19) and completed a PRISMA-P checklist. We registered the protocol on the International Prospective Register of Systematic Reviews (PROSPERO) Centre for Reviews and Dissemination: 42016052715 and previously published our protocol (20).

Study Identification

Using an iteratively developed search strategy (**supplementary material**, Supplemental Digital Content 1, <http://links.lww.com/CCX/A4>) informed by an experienced information specialist, we searched (March 1980 to November 2016): MEDLINE, CINAHL, EMBASE, Web of Science, Cochrane Library, PROSPERO, and the Joanna Briggs Institute. We searched major guideline sites (e.g., Canadian Medical Association Infobase, National Guideline Clearinghouse) for clinical practice guidelines and policy documents, websites of relevant professional societies for practice recommendations relevant to our population of interest, and examined reference lists of relevant studies/reviews. We searched <http://apps.who.int/trialsearch> website for unpublished and ongoing trials.

Inclusion Criteria

Eligible studies had to report on actionable or modifiable processes of care, performance indicators, quality improvement measures or tools, or patient/family experience specific to adults described as persistent critical illness, chronic critical illness, prolonged mechanical ventilation or a study population admitted to a specialized weaning facility, long-term acute care hospital (LTACH), or respiratory high dependency unit. Due to recognized variability in definitions (21), we included only those studies using an ICU length of stay of greater than or equal to 7 days as a study inclusion criterion to reflect the consensus definition used by Medicare and Medicaid in the United States (22). Studies were eligible regardless of study design with the exception of case series/reports of less than 10 patients. We included observational cohorts that reported on presence of conditions such as polyneuropathy, hypothyroidism, or depression as we considered the need to assess for such conditions would comprise an initial step of an actionable care process. We excluded animal-only studies, opinion pieces (e.g., editorials, letters) and for practical reasons, non-English language studies.

Objectives

Our primary objective was to develop a list of evidence-based actionable processes of care to be considered by clinicians and decision-makers for delivery of quality care in daily practice for patients experiencing persistent or chronic critical illness and their family members. Secondary objectives were to identify quality improvement tools, quality indicators, or performance measures relevant to our population of interest; qualitatively derived themes related to patient and family experience.

Study Selection and Data Extraction

Two authors (L.R., L.I.) independently screened abstracts for eligibility. When necessary, a third reviewer (L.A. or B.C.) arbitrated consensus. Two authors independently extracted data using a standardized form; a third author (L.R.) checked all extraction for accuracy. We extracted data on country, care venue type and characteristics, patient characteristics, descriptions of actionable care processes or study interventions dependent on study design, and descriptions of quality indicators and performance measures. We extracted quantitative and qualitative study results including qualitative themes related to patient and family experience. Two investigators (L.R., L.I.) independently reviewed the extracted actionable care processes/interventions to develop a list of categories and independently assigned primary studies to categories. The study team then reviewed and confirmed agreement. We reviewed relevant narrative and systematic reviews and determined actionable processes of care described in these reviews.

Study Quality Assessment

For randomized and quasi-randomized studies, two investigators independently assessed risk of bias using the Cochrane Risk of Bias tool (23). The Scottish Intercollegiate Guidelines Network checklists (24) were used for cohort and case-control studies. We

used a modified 2014 Critical Appraisal Skills Programme quality assessment tool for qualitative studies (25) and, as this tool does not consider the more conceptual or theoretical aspects of qualitative studies, we also assessed additional criteria outlined by Popay et al (26).

Data Analysis

We summarized study and patient participant characteristics reported as categorical variables using counts and proportions and continuous variables as medians with interquartile ranges (IQRs). We calculated counts and proportions of categories of actionable processes identified in primary studies and relevant reviews. Due to a priori anticipated heterogeneity in study design, processes of care, interventions, quality indicators, and measures, we did not perform meta-analyses, subgroup or sensitivity analyses, or examine publication bias. For qualitative studies, we generated a table of author reported themes, and subthemes and undertook content analysis of these themes (27, 28) to quantify common categories and themes within these categories leading to identification of additional actionable processes of care. We categorized data using the conceptual framework of structure, process, and outcomes developed by Donabedian (29).

RESULTS

We screened 13,130 references, excluded 12,820 and included 114 primary studies, 102 reviews, and 94 abstracts (71 subsequently published as full manuscripts). Search results are presented using a PRISMA study flow diagram (30) (Fig. 1).

Study and Participant Characteristics

The 114 primary studies (for bibliography, see **Supplementary Table 1**, Supplemental Digital Content 1, <http://links.lww.com/CCX/A4>) reported data on 24,251 participants with a median (IQR) sample size of 70 (32–182). Most studies were from North America (48%), were conducted in ICUs (54%) as opposed to other care environments such as LTACHs or specialized weaning centers, were single-center studies (70%), and used a cohort design without a comparator group (37%) (**Table 1**). We identified nine qualitative or mixed methods studies reporting themes relating to patient and family experience.

Of the 99 studies including only patient participants, the reported mean (SD) age ranged from 40 (31) to 79 (32) years, with a median (IQR) of 60% (53–68%) male participants, and a median (IQR) of 75% (57–100%) admitted to the participating unit for medical reasons. Of the 42 studies reporting Acute Physiology and Chronic Health Evaluation II (33) scores at admission, mean (SD) scores ranged from 12 (4) to 27 (7). (Supplementary Table 1 [Supplemental Digital Content 1, <http://links.lww.com/CCX/A4>] provides unit characteristics/descriptors of individual studies).

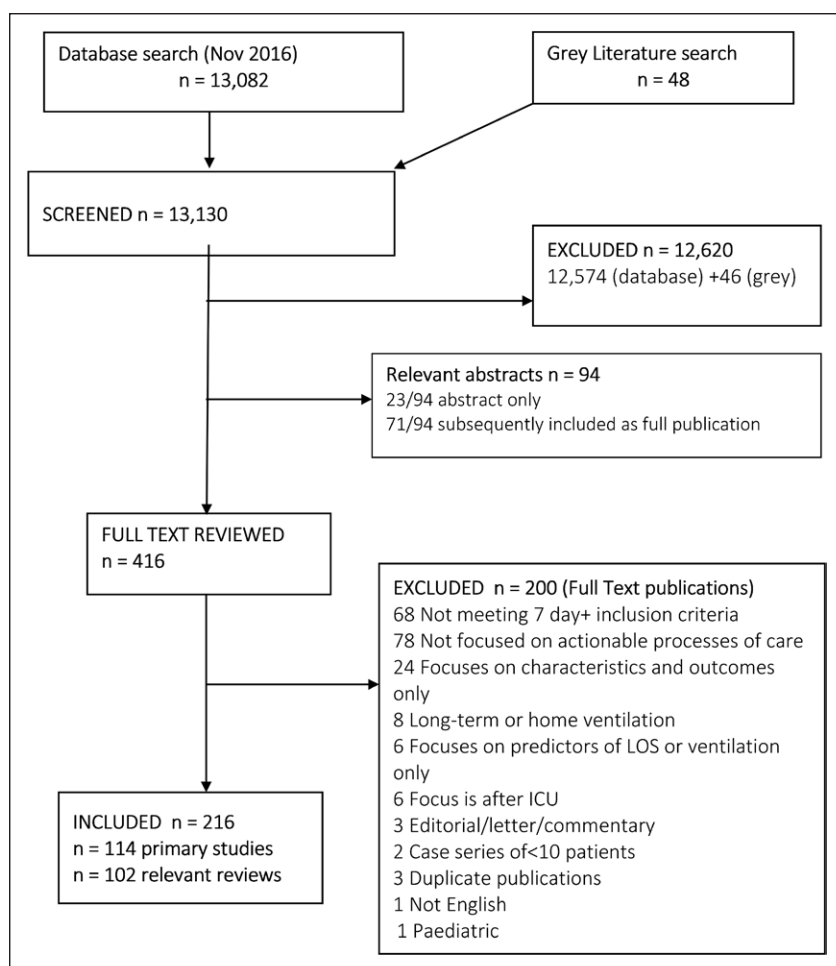


Figure 1. Citation screening and study selection: Preferred Reporting Items for Systematic Review and Meta-Analyses flow diagram. LOS = length of stay.

Actionable Processes of Care

We identified 42 distinct categories of actionable processes of care of relevance to the delivery of care for patients with persistent or chronic critical illness. These comprised 37 from the 114 primary studies, including three identified through content analysis of patient and family experience. Five additional categories were reported in narrative reviews only (**Table 2**; and **Supplementary Table 2** [Supplemental Digital Content 1, <http://links.lww.com/CCX/A4>] for actionable process categories and description of processes from individual studies). Most commonly occurring categories from studies using quantitative methods were: 1) weaning methods; 2) rehabilitation, mobilization, and physiotherapy strategies; and 3) providing information, prognosis, and family communication. Within these three categories, interventions demonstrated to have a positive effect on patient or family outcomes included individualized weaning plans, and respiratory therapist-led weaning protocols including a protocol of tracheostomy collar weaning; exercise training and neuromuscular electrical stimulation; and use of a decision aid for substitute decision-makers (**Table 3**). Other categories reflected clinical features of chronic critical illness including deranged neuroendocrine function, altered brain function and neuropsychiatric disorders, malnutrition, skin breakdown, and increased vulnerability to infection (49). (See **Supplementary Table 3** [Supplemental Digital Content 1, <http://links.lww.com/CCX/A4>] for the intervention or exposure, primary outcomes and main findings for other categories from studies with a control group; **Supplementary Table 4** [Supplemental Digital Content 1, <http://links.lww.com/CCX/A4>] the 56 studies without a comparator group).

Actionable Processes of Care Arising From Patient and Family Experience

Using content analysis, from the nine qualitative studies (**Table 4**) reporting themes relating to patient and family experience, we found 14 actionable processes of care categories. The most common categories were addressing: 1) psychologic needs; 2) promoting interprofessional communication/decision-making; 3) enabling patient communication; and 4) symptom management. Three themes not found in quantitative studies for clinicians and decision-makers to consider as actionable processes were: 1) promoting patient coping skills through enabling of hope and optimism as well as regain of control; 2) addressing reduced quality of life; and 3) care planning that includes strategies as to how to address unanticipated reversal in clinical recovery. Categories that converged across studies and reviews of interventions and those from qualitative exploration of patient and family experience related to improving communication with family, enabling patient communication, and management of psychologic and symptom distress.

Risk of Bias and Quality Assessment

Of the 21 randomized controlled trials (RCTs) including three secondary analyses of data relating to long-stay ICU patients from primary trials and the one nonrandomized intervention study, two RCTs were considered low risk across all domains (**Supplementary Fig. 1**, Supplemental Digital Content 2, <http://links.lww.com/CCX/A5>; **legend**, Supplemental Digital Content 1, <http://links.lww.com/CCX/A4>). We considered 14 (63%) to be at low risk of bias for sequence generation, six (27%) as unclear and

TABLE 1. Study Characteristics

<i>n</i> = 114	<i>n</i> (%)
Country	
United States and Canada	54 (47.4)
Europe	33 (28.9)
Asia	13 (11.4)
Australia	6 (5.3)
South America	4 (3.5)
Middle East	3 (2.6)
Multiple countries	1 (0.9)
Unit type	
ICU	61 (53.5)
Long-term acute care hospital	15 (13.2)
Specialized weaning center	15 (13.3)
High dependency unit	11 (9.6)
Respiratory ICU	7 (6.1)
Other ^a	5 (4.4)
Unit number ^b	
Single unit	79 (69.3)
Multiple units	34 (29.8)
Study design	
Cohort with no control	43 (37.7)
Cohort with control including before and after studies	33 (28.9)
Randomized control trial	21 (18.4)
Qualitative	9 (7.9)
Mixed methods	3 (2.6)
Other ^c	5 (4.9)
Participant type	
Patients only	99 (86.8)
Patients and family	4 (3.5)
Family	3 (2.6)
Clinicians	3 (2.6)
Patients, family, and clinicians	3 (2.6)
Patients and clinicians	2 (2.6)

^aOther unit types include two studies reporting data from ICU and high dependency unit, two reporting data from ICU and a specialized weaning center, and one study recruiting ICU survivors from the community.

^bNot reported for one study.

^cOther designs include randomized cross over, interrupted time series, nonrandomized clinical trial, survey, and quality improvement.

links.lww.com/CCX/A5; **legend**, Supplemental Digital Content 1, <http://links.lww.com/CCX/A4>). We considered 14 (63%) to be at low risk of bias for sequence generation, six (27%) as unclear and

TABLE 2. Actionable Processes of Care

Actionable Process of Care	Primary Studies, n = 114, n (%)	Relevant Reviews, n = 102, n (%)
Weaning—methods	21 (11.6)	27 (10.2)
Rehabilitation, mobilization, physiotherapy	20 (11.0)	40 (15.0)
Provide information/prognosis/family communication	14 (7.7)	11 (4.1)
Endocrine dysfunction (assess/treat) including hyperglycemia, hypothyroidism, adrenal insufficiency, metabolic bone disease	11 (6.1)	9 (3.4)
Manage psychologic issues	10 (6.3)	14 (5.3)
Nutrition and metabolic support	9 (5.5)	33 (12.4)
Assess/treat symptoms (e.g., dyspnea, pain, fatigue)	9 (5.5)	8 (3.0)
Promote speech/communication	7 (4.2)	4 (1.5)
Delirium and other cognitive dysfunction (screen/prevent/treat)	6 (3.9)	8 (3.0)
Consider tracheostomy	6 (3.9)	7 (2.6)
Swallowing (assess/treat)	6 (3.9)	2 (0.8)
Determine decannulation/extubation readiness	6 (3.9)	5 (1.9)
ICU acquired weakness (assess/prevent/treat)	5 (2.8)	14 (5.3)
Weaning—diaphragm/respiratory muscle dysfunction (assess/treat)	5 (2.8)	6 (2.3)
Discharge planning/timely transfer	5 (2.8)	2 (0.8)
Promote interprofessional communication/decision-making	4 (2.2)	—
Palliative care involvement	4 (2.2)	8 (3.0)
Promote sleep, day/night cycles	3 (1.7)	8 (3.0)
Withdrawal of care	3 (1.7)	—
Patient-centered care, nurse-led rounds, interprofessional meetings	2 (1.1)	1 (0.4)
Support for family	2 (1.1)	6 (2.3)
Minimize sedation	2 (1.1)	10 (3.8)
Tracheostomy management	2 (1.1)	4 (1.5)
Restoring normalcy	2 (1.1)	3 (1.1)
Family presence/visiting	2 (1.1)	3 (1.1)
Airway clearance	2 (1.1)	2 (0.8)

(Continued)

TABLE 2. (Continued). Actionable Processes of Care

Actionable Process of Care	Primary Studies, n = 114, n (%)	Relevant Reviews, n = 102, n (%)
Case management	2 (1.1)	—
Limit physiologic monitoring	2 (1.1)	—
Infection control/treatment, ventilator-associated pneumonia prevention	1 (0.6)	10 (3.8)
Pressure ulcer prevention/management and skin/wound care	1 (0.6)	8 (3.8)
Other (< 1% of primary studies or reviews)	7 (6.1)	4 (3.9)
Spiritual support	1 (0.6)	3 (1.1)
Monitor fluid and electrolyte imbalance	—	4 (1.5)
Optimize cardiac function	—	2 (0.8)
Total	181	266

Other: bowel health: constipation/diarrhea (prevent/treat); deep vein thrombosis screening and prophylaxis; prevent anemia/limit RBC transfusion; assess for ocular disorders; sleep-disordered breathing (assess for); and weaning—monitoring.

Percentage is calculated for total number of actionable processes of care identified. Excludes three actionable processes of care identified through analysis of themes from studies reporting patient and family experience.

Dashes represent no reviews with the category.

two (9%) as at high risk of bias. Eleven studies (50%) were considered at low risk of bias due to allocation concealment, nine (41%) unclear and two (9%) at high risk. Blinding of personnel or participants was only feasible in six trials (27%), one trial (5%) was considered unclear risk; 11 trials (50%) blinded outcome assessors, three (14%) did not blind, the remainder were assessed as at unclear risk of bias. All but one trial were considered at low risk of incomplete outcomes, 10 (45%) at low risk of selective reporting, and 17 (77%) free from other sources of bias.

Of the 33 cohort studies with controls, two (6%) were considered to be of high quality, 15 (45%) of acceptable quality, and 16 (48%) of unacceptable quality. Thirteen (39%) were considered to have clear evidence of an association between exposure and outcome, 17 (52%) were considered to have unclear evidence, and three (9%) no evidence of an association between exposure and outcome (**Supplementary Table 5**, Supplemental Digital Content 1, <http://links.lww.com/CCX/A4>). We did not perform quality assessment of the 43 studies without a control group. All nine qualitative studies were assessed as having a logical fit between aims and methods, seven (78%) reported appropriate recruitment methods and presented clear and detailed statements of findings, six (67%) described audio-recording and transcription processes as well as inter-rater discussion. Only two studies (22%) considered disconfirming findings or demonstrated reflexive concern. Four studies (44%) demonstrated

TABLE 3. Primary Results for Studies With a Comparator Group Grouped According to Actionable Process Category

References	Intervention/ Exposure	Comparator	Primary Outcome(s)	Outcome Intervention	Comparator Outcome
Weaning methods					
Duan et al (34) ^a	Noninvasive ventilation weaning	Usual care	MV duration, d ^b	10 (4–21) ^c	37 (16–51) ^c
Henneman et al (35)	Collaborative weaning plan	Usual care	MV duration, d ^b	11 (8–19) ^c	16 (10–26) ^c
Jubran et al (36) ^a	Tracheostomy collar weaning	Pressure support ventilation	Weaning duration, d ^b	15 (8–25) ^c	19 (12–31) ^c
Rudy et al (37) ^d	Case management	Usual care	Unit LOS ^e	49 (30) ^f	51 (33) ^f
Scheinhorn et al (38)	Respiratory therapist-led weaning protocol	Usual care	Time to wean, d ^b	17 ^g	29 ^g
Rehabilitation, mobilization, physiotherapy					
Burtin et al (39) ^a	Bedside ergometer	Usual care	6-minute walk test at hospital discharge ^b	196 (126–329) ^c	143 (37–226) ^c
Chen et al (32) ^a	6-wk supervised physio training	Usual care	Change in total FIM score ^b	Baseline: 34 (30–38) ^c 1 yr: 78 (62–126) ^c	31 (24–37) ^c 31 (21–50) ^c
Chen et al (40) ^a	Exercise training	Usual care	Change in FIM ^b and Barthel Index ^e	FIM: 16.5 (16.5) ^f Barthel: NR	4.6 (7.9) ^f NR
Chiang et al (41) ^a	6 wk physical training	Standard care	Change in FIM ^b and Barthel Index ^b	6W FIM: 49 (45–66) ^c 6W Barthel: 35 (20–55) ^c +4.8 ^h	26 (20–36) ^c 0 (0–9) ^c –3.2 ^h
Gruther et al (42) ^a	Neuromuscular electrical stimulation	Sham stimulation	Knee extensor muscle layer thickness ^b	+4.8 ^h	–3.2 ^h
Montagnani et al (43)	Standardized mobilization program	Chronic obstructive pulmonary disease for pulmonary rehabilitation	FIM at baseline and program discharge ⁱ	Baseline: 48 (23) ^f Discharge: 63 (30) ^f	97 (23) ^f 103 (26) ^f
Reames et al (44)	Mobility protocol	Usual care	Daily mobility episodes/patient ⁱ	1.4 ⁱ	4.7 ⁱ
Provide information/prognosis/family communication (also includes category of palliative care involvement)					
Braus et al (45) ^d	Palliative care rounding	Usual care	Documented family meeting ^b	55 (53) ^k	35 (35) ^k
			ICU LOS, d ^e	5 (3–11.5) ^c	4 (2–10) ^c
Carson et al (46) ^{a,d}	Booklet + palliative care led family meeting	No palliative care	90 d Hospital Anxiety Depression Score (family members) ^e	Total: 12 (8) ^f Anxiety: 7 (5) ^f Depression: 5 (4) ^f	11 (9) ^f 6 (5) ^f 5 (5) ^f
Cox et al (47)	Substitute decision-maker decision aid	Usual care	Physician-surrogate discordance scores for expected 1-yr survival ^b	7 (10) ^f	43 (21) ^f

(Continued)

TABLE 3. (Continued). Primary Results for Studies With a Comparator Group Grouped According to Actionable Process Category

References	Intervention/ Exposure	Comparator	Primary Outcome(s)	Outcome Intervention	Comparator Outcome
Daly et al (48) ^{a,d}	Case management and family involvement: step-down unit	Traditional ICU	Family satisfaction	NR	NR
			Unit mortality ⁱ	5 (33) ^k	3 (30) ^k
Douglas et al (49) ^{a,d}	Case management and family involvement: step-down unit	Traditional ICU	Mortality ^e	Hospital: 35 (35) ^k	24 (46) ^k
				After discharge: 23 (35) ^k	9 (32) ^k

FIM = Functional Independence Measure, LOS = length of stay, MV = mechanical ventilation, NR = not reported.

^aRandomized controlled trials.

^bStatistically significant difference between groups.

^cMedian (interquartile range).

^dStudies assigned more than one actionable process of care.

^eNo statistically significant difference between groups.

^fMean (SD).

^gMedian.

^hMean change.

ⁱDifference between groups not reported.

^jAverage.

^k*n* (%).

interpretation of findings at a conceptual and theoretical level (**Supplementary Table 6**, Supplemental Digital Content 1, <http://links.lww.com/CCX/A4>).

DISCUSSION

This systematic review identified 42 distinct categories of actionable processes of care for clinicians and decision-makers to consider when providing care to patients experiencing persistent or chronic critical illness and their family members. The most common categories were: 1) weaning—methods; 2) rehabilitation, mobilization, and physiotherapy; and 3) provision of information, prognosis, and family communication. Categories that converged across study designs types related to improving family communication, enabling patients to communicate, and management of psychologic and symptom distress. We did not identify any quality indicators, measures, or tools to evaluate quality of care or patient/family member experience of care. Only two (61, 62) RCTs were considered at low risk of bias, whereas only two (63, 64) cohort studies and one qualitative study (58) were considered of high quality.

Based on the numbers of studies within categories in the existing evidence base, implementation of processes of care that focus on weaning, rehabilitation/mobilization, and information sharing/family communication should be considered by clinicians and decision-makers as processes to optimize to enable provision of high-quality care. Likewise, those that converged across study designs should be prioritized; particularly provision of timely, frequent and empathetic communication with families, and alleviation of symptom burden.

Most patients with persistent or chronic critical illness will experience prolonged weaning from ventilation. Weaning protocols are effective for reducing ventilation duration in the broader ICU patient population (65). In this review, we found some evidence of effectiveness for patients with prolonged need for mechanical ventilation. Studies in this review reporting on patient and family experience highlight the need to address the distressing symptoms and psychologic impact of weaning failure, which should be considered when designing interventions to facilitate weaning in this patient population. Similarly, most if not all persistently or chronically critically ill patients will require physical rehabilitation strategies, due to profound weakness and muscle atrophy associated with myopathy, neuropathy, and alterations in body composition (5), benefits of which are likely best achieved when commenced early (66).

When comparing our results to the number of studies reporting efficacious or effective actionable processes of care during acute critical illness (11), the 21 RCTs identified in our systematic review highlights the paucity of high-level evidence for patients with persistent or chronic critical illness. Although reasons for the current lack of an evidence-base are likely multifactorial, the common strategy of single-center research identified in our review limits the number of potential study participants. It can also lead to a lengthy recruitment period, such as in a landmark trial of tracheostomy collar weaning at a LTACH, which took 10 years to accrue 316 participants (36). Of concern is the relatively limited evidence within each category, particularly in patient-centered categories such as communication, promotion of sleep and day/night routines, psychologic and social functioning, symptom management, or family support. Furthermore, studies did not reflect person-centered care approaches and the lack of qualitative

TABLE 4. Themes From Qualitative Studies

References	Structure	Exposure	Process/ Methodology	Thematic Outcomes
Arslanian-Engoren and Scott (51)	One university-affiliated trauma center (United States)	PMV and successful liberation	Patient lived experience (phenomenology)	1) endures a traumatic experience; 2) relies on self-determination; 3) credits family support and devotion; 4) finds comfort through religion and prayer; 5) praises healthcare providers; and 6) derives reassurance from angelic encounters
Azimi et al (52)	One university-affiliated trauma center (Iran)	Prolonged hospitalization and ICU delirium	Patient and family perspectives (qualitative description)	1) life-saving experience; 2) relieving bodily experience; 3) relieving bodily sensations; 4) life-threatening experiences; 5) jeopardizing bodily experiences; and 6) annoying and distressful bodily experiences
Johnson (53) and Johnson et al (54)	Three acute care hospitals (Australia)	Long-term ventilation in ICU	Patient lived experience (phenomenology)	1) being thrown into an un-everyday world; 2) existing in an un-everyday world; 3) reclaiming the everyday world; and 4) reframing the experience
Lamas et al (55)	One long-term acute care hospital (United States)	Tracheostomy for PMV	Quality of life, expectations, and planning for setbacks (mixed methods—qualitative description)	1) poor quality of life for patients; 2) surrogate stress and anxiety; 3) optimistic health expectations; 4) poor planning for medical setbacks; and 5) disruptive care transitions
Leung et al (56)	One university-affiliated hospital (Canada)	CCI	Nurses' experiences of patients with CCI and their families (interpretive description)	Internal tension-generated through participants' knowledge of patients' anticipated and protracted dying, while wanting to shield families from suffering
Nelson et al (57)	One university-affiliated trauma center (United States)	CCI	Relevant and important information for communication about CCI (qualitative description)	1) nature of illness/treatments; 2) prognosis; 3) impact of treatment; 4) potential complications; 5) expected care needs after hospitalization; and 6) alternatives to continuation of treatment
O'Shea (58)	Two suburban counties (United States)	PMV	Meaning of PMV from perspective of chronic obstructive pulmonary disease patients (phenomenology)	1) sinking into the blackness; 2) taking control; and 3) redefining myself
Roulin and Spirig (59)	One university-affiliated hospital (Switzerland)	Nurses providing care to CCI patients	To identify ways to improve care of CCI patients (action research)	Nursing focused patient history at admission and weekly nursing rounds; focus on communication, physical care, and understanding the patient beyond hospitalization, operationalized as a patient diary
Tosun et al (60)	One university-affiliated military hospital (Turkey)	PMV	Experiences related to mechanical ventilation and ICU environment (phenomenology)	1) physical and psychologic effects of endotracheal tube; 2) communication experiences; 3) upsetting experiences in ICU; 4) effects of nurses on experiences; and 5) coping

CCI = chronic critical illness, PMV = prolonged mechanical ventilation.

observational inquiry limits understanding of the influence of the organizational context on care processes and outcomes.

We identified 42 distinct categories of actionable processes of care, which is indicative of the extent of the needs of these patients and their families, and arises from the range of clinical features of persistent or chronic critical illness. However, this presents challenges for clinicians and decision-makers in terms of which

processes to prioritize. Furthermore, published studies designed by researchers may not reflect priorities of care of greatest importance from a patient/family member perspective. The lack of quality indicators, measures, or tools to evaluate quality of care or patient/family member experience, developed specifically for patients with persistent or chronic critical illness, may contribute to poor patient/family experience and adverse outcomes. Such

strategies are needed to embed actionable processes into routine clinical practice. Rounding or daily goal checklists are strategies shown to improve adherence to evidence-based practices enabling a systematic approach to care yet individualizing set goals (18, 67). Tools are needed that address those actionable processes of care most relevant to the needs of patients with persistent critical illness and their families. Subsequent phases of our research program aim to address these gaps.

Informed by experience based co-design methods (68), a rigorous quality improvement method that involves lived experience, expertise, and knowledge of those using and providing a service (69), we will conduct interviews with survivors of persistent or chronic critical illness, family members, and clinicians to establish important actionable processes of care from their perspectives. We will develop a short touch-point video using patient and family interview data to inform clinician interviews. To inform development of quality improvement tools including a daily goals checklist, we will gain consensus as to the most important actionable processes of care, using a two-round Delphi process (70) and modified nominal group technique involving clinicians, ICU survivors, and family (71).

This is the first systematic review of actionable care processes for patients with persistent or chronic critical illness to our knowledge. We used rigorous methods including two authors independent citation screening, data extraction, and coding as well as validated tools to assess risk of bias and evidence quality. There are also limitations. First, due to disparate study interventions, designs, and small numbers of studies with a control group evaluating a similar intervention, we were unable to perform meta-analyses or appraise the certainty of evidence, that is, apply the Grading of Recommendations, Assessment, Development, and Evaluation approach (72) or assess publication bias. Additionally, by limiting studies to those that used greater than or equal to 7 days as an inclusion criterion, it is possible we excluded some studies of potential relevance. However, given our inclusion of 216 studies, it is unlikely we missed other categories of actionable processes of care. Last, our exclusion of non-English language studies could limit generalizability.

CONCLUSIONS

In this systematic review, we identified 42 distinct actionable processes of care relevant to patients with persistent or chronic critical illness and their families. Most frequently studied processes related to weaning, rehabilitation/mobilization, and communication with family. Reports of patient and family experience highlighted the need to address psychologic needs and distressing symptoms as well as enabling patient communication. Clinicians and decision-makers should consider our findings to plan high-quality patient and family-focused care. However, we did not identify relevant quality indicators, measures, or tools to evaluate or facilitate high quality of care or patient/family member experience of care highlighting the pressing need for such tools and metrics. Our findings also highlight the need for a stronger evidence base for those actionable processes of care deemed most important to improve outcomes and experience of persistent or chronically critically ill patients and their family.

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