

Patient Centered Care Ethics Analysis Model for Rehabilitation PCEAM-R¹

- I. Identify the ethical issue(s) to address: *What is at stake and for whom?*
 - a. What is/are the ethical issue(s) (question, problem, decision) we are facing? What is at stake and for whom?
 - b. How do those involved define/describe the issue(s)? If there are different descriptions, can we account for these differences?
 - c. What are the initial impressions of those involved about the values and ethical principles that are relevant to the issue?
 - d. Do values or ethical principles appear to be in tension/opposition?
 - e. When does a decision need to be made and by whom?

- II. Collect information: *What do we need to know to be able to evaluate the issue(s)?*
 - a. **Medical history and impairments of bodily functions and structures**
 - What are the patient's medical history, diagnosis and prognosis? What is the anticipated trajectory of rehabilitation?
 - What impairments of bodily functions (physiological functions of bodily systems) or bodily structures (anatomical parts of the body) does the patient experience?

 - b. **Activity and participation**
 - What is the patient's current level of activity (individual level of functioning) and prospect of change? What activity limitations does he or she experience and why?
 - What is the patient's level of participation (social level of functioning) and in what domains?
 - What prospects are there for change and what barriers to participation exist?

¹ For more information about the model and a discussion of its application please see Hunt, Matthew R and Carolyn Ells (2013). A patient-centered ethics analysis model for rehabilitation. *American Journal of Physical Medicine and Rehabilitation*. 92 (9): 818-27.

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Work on this model was initiated in collaboration with the Clinical Ethics Committee of the Jewish Rehabilitation Hospital, Laval, QC.

A French translation of the model is also available.

c. Environmental factors

- Are there relevant socioeconomic factors (e.g. insurance)?
- Are there architectural or design features that contribute to the issue (e.g. accessibility)?
- What environment might the patient go to at discharge? What supports and resources (practical, clinical, social, emotional) are likely to be required?
- Are there staffing or institutional issues that might influence the situation (e.g. program design, administrative structures, resource availability and allocation, etc)?
- What are the legal, policy, and regulatory considerations relevant to the ethical issue (e.g. institutional, professional, other)?
- Are there any conflicts of interest? If so, how are they being managed?

d. Preferences and decision-making

- What are the patient's aspirations, expectations and life goals?
- Has disability or disease caused the patient to reevaluate their life plans or goals? Are these plans or goals currently in flux?
- What has the patient expressed about preferences for their rehabilitation care?
- Does the patient have particular fears or concerns that contribute to the issue at hand?
- Does the patient have sufficient capacity to make decisions related to healthcare and/or other life domains? What is the trajectory of the patient's capacity to make such decisions (stable, fluctuating, trending upward or downward)? How can the patient's capacity be re-established, optimized or supported? If the patient has capacity, does the patient consent to the current or proposed management?
- If a surrogate decision-maker is involved, what role should the patient have in decisions (e.g. identify or explain preferences, assent)? If a surrogate is involved, is the surrogate acting in ways that are congruent with relevant legal standards?

e. Treatment plans, goals

- What are the short-term and long-term goals of rehabilitation? Is there consensus on these goals?
- Is there an accepted standard of care for the patient's condition?
- What is the treatment plan?
- Is the patient unwilling or unable to cooperate with rehabilitation? If so, why? Are there behaviour concerns?
- Are there secondary gains that the patient may or may not recognize?
- What physical, mental, functional and social deficits is the patient likely to experience if rehabilitation goals are or are not met?

- What are the prospects, with or without treatment, for a return to the patient's prior life (social, vocational, recreational, independence)?
- What are the plans if rehabilitation goals are not met?
- What are the plans for discharge?

f. **Relationships**

- Are there family considerations that influence the ethical issue?
- What is the impact of this situation on family members and caregivers?
- Do past experiences of people close to the patient influence the patient's understanding of the situation?
- Do religious, cultural or language factors influence the current situation?
- How do relationship dynamics between the team and patient, or within the treatment team, influence the ethical issue?
- Are there barriers to collaboration between the patient and team?
- Has the patient experienced stigma? Is the situation influenced by discriminatory perceptions of disability?
- What are the power dynamics in patient-clinician relationships, in the family, or amongst the team that influence the ethical issue? Is there potential for marginalization or discrimination (i.e. concerns of justice or fairness)?

III. Review and analyze: *Do we need to reformulate the issue(s) and what can help us better understand it?*

- a. Are there features of the situation that are unclear at this time or that we may have overlooked?
- b. In what ways might we have imposed our own viewpoint or values?
- c. Have we involved all the people who should be part of the process?
- d. Have there been similar cases within the institution? What can we learn from them?
- e. What legal and institutional policy considerations are applicable?
- f. What ethical resources should we draw upon to guide our analysis (e.g. hospital and professional codes of ethics, institutional mission statements, ethics principles and approaches, patient-centered care commitments)? Should we seek input from Clinical Ethics Committee, clinical ethics consultant, expert clinicians, or moral role models?
- g. Does this review and analysis lead us to reformulate the ethical issue(s) identified in step I?

- IV. Identify and weigh options: *What are our options and what rationales support them?*
- a. What actions or options are possible to respond to this issue?
 - b. What ethical values support each option?
 - c. What ethical values oppose each option?
 - d. What consequences might result from each option (including potential for negative fallout) and for whom?
 - e. How do options relate to (professional, institutional, personal) obligations and duties?
 - f. Can consequences, values and obligations be reconciled? What might be lost if particular options are selected?
- V. Make decision(s): *What is the best option and how should we implement it?*
- a. Which options are ethically permissible?
 - b. Which option(s) is/are supported by the strongest rationale(s)?
 - c. Can a “best” option be identified by consensus?
 - d. Where a consensus cannot be reached, whose perspective(s) have priority?
 - e. If there seems to be no “best” option, what ethically permissible option is most acceptable?
 - f. How will the chosen option be implemented? How will “success” or the quality/acceptability of the outcome be measured?
 - g. After the option is implemented, how can we offer support to those who require it?
 - h. Document decision, rationale and action plan.
- VI. Evaluate and follow-up: *What was the outcome and how can we learn from it?*
- a. Has the process led to an anticipated outcome? If not, what might account for this situation?
 - b. How is the outcome characterized by those involved?
 - c. Do those involved judge the process and outcome to be ethically acceptable? If there are different views, how can these differences be accounted for?
 - d. What helped or hindered the process?
 - e. Is there a need for further follow-up?
 - f. What can we learn from this process?
 - g. Does this process suggest that policies or procedures should be reassessed?