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Toronto General Hospital Toronto Western Hospital Princess Margaret Hospital

The Boundaries of Patient Centred Care

Kyle Anstey, PhD
Linda Wright, MHSC
Mary Jane McNally, MN
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Outline

- Definitions of patient-centred care (PCC)
- Two popular misconceptions about PCC
- Reasons for and against these views
- Policy example of imposing limits on respect for patient preferences

How is Patient-Centred Care Defined?

- "an approach that consciously adopts the patient's perspective… about what matters."
  Through the Patient's Eyes (Gerteis, M. et al., 1993)

Misconception 1:

“Patient centred care means we have to do everything the patient wants”

Picker Institute- 8 Dimensions of PCC

1. Respect for patient's values, preferences and expressed needs;

2.Coordination and integration of care;

3.Information and education;

4.Physical comfort;

5.Emotional support and alleviation of fear and anxiety;

6.Providing accommodations for family and friends;

7.Continuity and transition

8.Access to care

SOURCE; NRC Picker. Accessed: Thursday, February 16, 2012 Available: http://www.nrcpicker.com/member-services/eight-dimensions-of-pcc/

Respecting Autonomy

- **Autonomy:** Respecting free and informed decisions made in view of the values, beliefs and goals that orient the individual's life plans

- **Health Care Consent Act (1996):**
  - Purpose "(c) to enhance the autonomy of persons for whom treatment is proposed...."
  - Means: Ensuring that no treatment is provided without consent of the capable patient or the incapable patient's SDM (except in emergencies)

Respecting Autonomy does NOT mean doing whatever the patient wants

- No right or fundamental freedom is absolute
- Freedom to choose among options is different from the freedom to determine them: **Patient-Centred vs Patient-Directed Care**
  - ➢ Not required to offer or provide treatments that are not standard of care or almost certainly of no benefit to the patient
    - – E.g. surgery without anesthesia
    - – E.g. CPR for some patients
- Not required to respect preferences that would have a high probability of seriously harming other patients

Misconception 2:

“We are patient
AND
family centred”

Frequently Asked Questions

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care.

Patient- and family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental support are integral components of health care. They promote the health and well-being of individuals and families and restore dignity and control to them.

Patient- and family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction.

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Why Patient AND Family?

- Grants that "family-centred" should not remove control from capable patients
  - Capable patient defines degree of family involvement
- "Patient-Centred" inadequate to:
  - Capture the need to support a relationship that benefits the majority
  - Combat social isolation

Source: Institute for Patient and Family Centred Care. Available: http://www.ipfcc.org/faq.html Accessed:3/7/2012

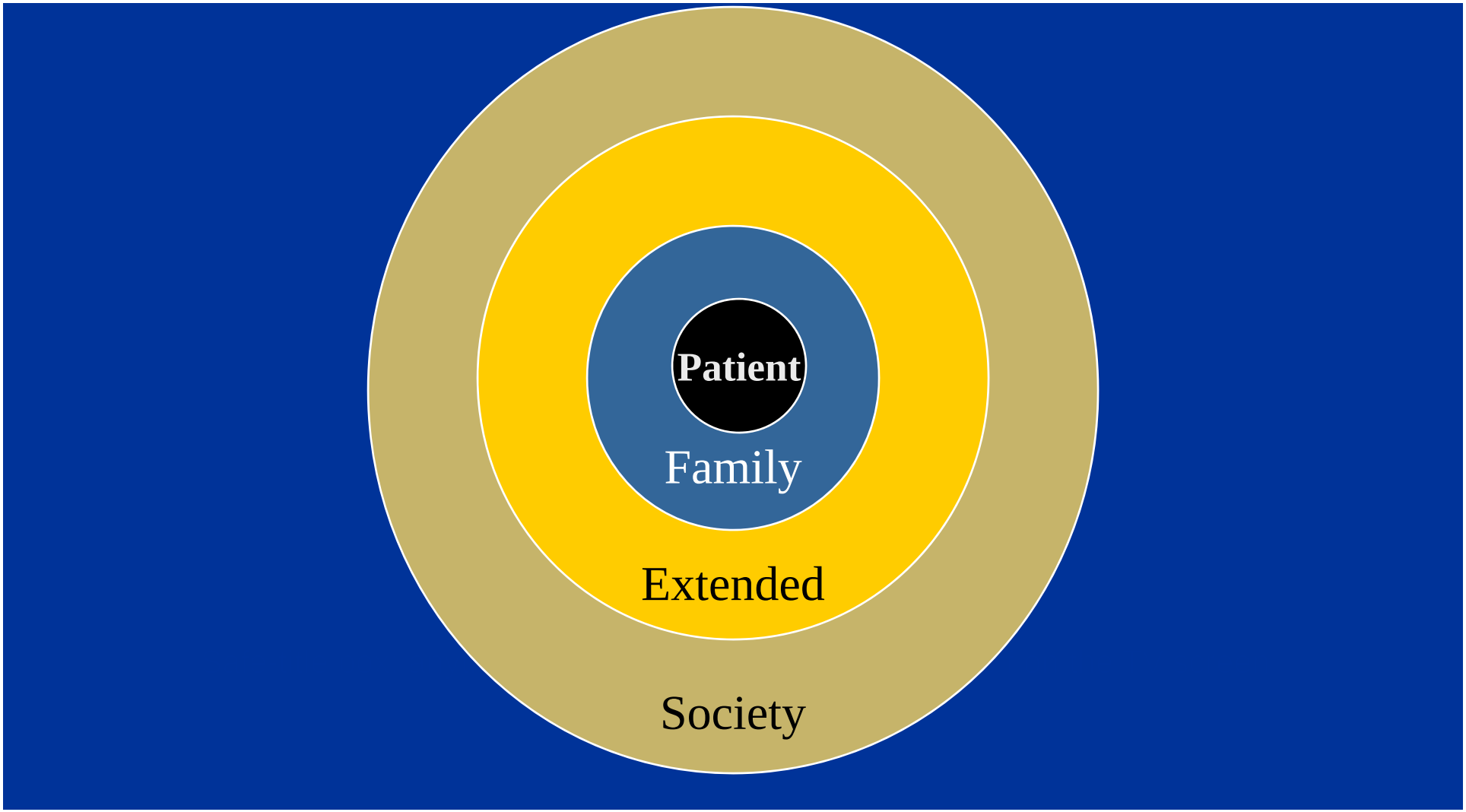
Why not Patient AND Family?

- Pediatric settings: Risks legitimizing family choices based on belief systems that remove or block their child's ability to later chose to remain in or exit that belief system
  - E.g. Jehovah's witness parent wants to deny their child a blood transfusion
- All settings: Encourages providers to place family in role conflicts
  - E.g. Use of family vs. professional interpretation

Why not patient AND family?

- **Health Care Consent Act recognizes and avoids the potential role conflict in substitute decision-making:**
  - Substitute Decision-Makers are supposed to tell us what the patient, not they, would want.
  - If they don't know it is still a matter of situating the patient's values, not their own, in the context of whether the treatment is likely to improve, stabilize or slow the deterioration of the patient's condition.

One Centre, Overlapping Roles and Obligations



UHN's *Caregiver Preference Guideline* as an example of a policy Defining Boundaries/Limits on patient preferences

Recent Case

- “I don’t want any Muslims looking after me”
- Identified one staff member as Muslim based on his beard
- Other staff members in the patient’s circle of care were also Muslim

Are there circumstances under which we should honour a patient or SDM request for treatment by a caregiver of a particular background (e.g. racial or ethnic)?

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Defining *Caregiver*

- Guideline uses this term broadly to cover:
  - Requests received by those who have contact with patients & families but do not provide direct care
  - E.g.. support staff, volunteers and administrators

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Ethical Considerations: Avoiding Harm

Staff	Avoidance of complicity in discrimination against staff
Patients & families expressing a caregiver preference	•Avoid compounding past traumatizing experiences or denying well-founded beliefs •Harm following from denial of care/abandonment
Other patients	Protection of other patients from discrimination or harassment
the institution	E.g. by bringing its delivery of care to particular groups into disrepute

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Ethical Considerations:
Respect for individual **autonomy**

- E.g. Parents' free and informed choices about the care of their children in view of values and beliefs that help orient and constitute parental life plans, and the place of children within them.

Contextual Demands

- **Organizational Policies**
  - E.g. Anti-discrimination, harassment, abandonment
- **Organizational Initiatives**
  - E.g. patient-centered care
- **Professional College Policies & Guidelines**
  - E.g. Anti-discrimination & Harassment Policies
- **Legislation:**
  - Provincial/State & Federal E.g. Human Rights Codes

Professional College & Association Policies and Statements

- Predominantly directed at interprofessional or professional-> patient discrimination.
  - ➢Focus on provider misconduct harms the safety and interests of the patient
    - Refusal of assignments
    - Abandonment of patients

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Nursing Legislation & College Requirements

- **Nursing Act 1991**

Discontinuation=misconduct, but not if requested by client, alternative services arranged or client is given the opportunity to do so

- **CNO Professional Standards**

•“Nurses have the right to refuse assignments that they believe will subject them or their clients to an unacceptable level of risk” (College of Nurses of Ontario, 2003, p. 9).

•Nurses in administrator roles should ensure that ”that mechanisms allow for staffing decisions that are in the best interest of clients and professional practice”

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Nursing Legislation & College Requirements

- **RNAO Policy Statement on Racism**

- Calls for protocols “to assist nurses in dealing with acts of racism related to client-specific and provider-specific situations”

- “Recognize and acknowledge that racism/discriminatory behaviour can have a tremendous impact on the individual”;

- “Validate perceptions/feelings and provide support. Do not attempt to justify the behaviour or minimize the impact”;

- “Determine if immediate intervention is needed. The decision should be based on the needs of the client, the needs of the nurse, and should recognize that the nurse-client relationship is critical to effective care”;

Recommendations of Existing Literature

- **Dialogue** with patients about the reasons behind their request
  - (Capozzi and Rhodes, 2006)
- Firmly **express any disagreement** with the patient's views if they are racist
  - (Selby, Gough, Easmon 1999)
- **Express repugnance**: not doing so can lead to **complicity** in the patient's oppression of the affected caregiver
  - (Gough, 1999)

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Other Q&A needed to Design a Process

- How do we **structure** our response?
- What is the **role** of managers/supervisors in responding to these requests?
- Does it matter whether fulfilling the request is **clinically feasible**?
- Should affected caregivers be **allowed/required to transfer care** to another caregiver?

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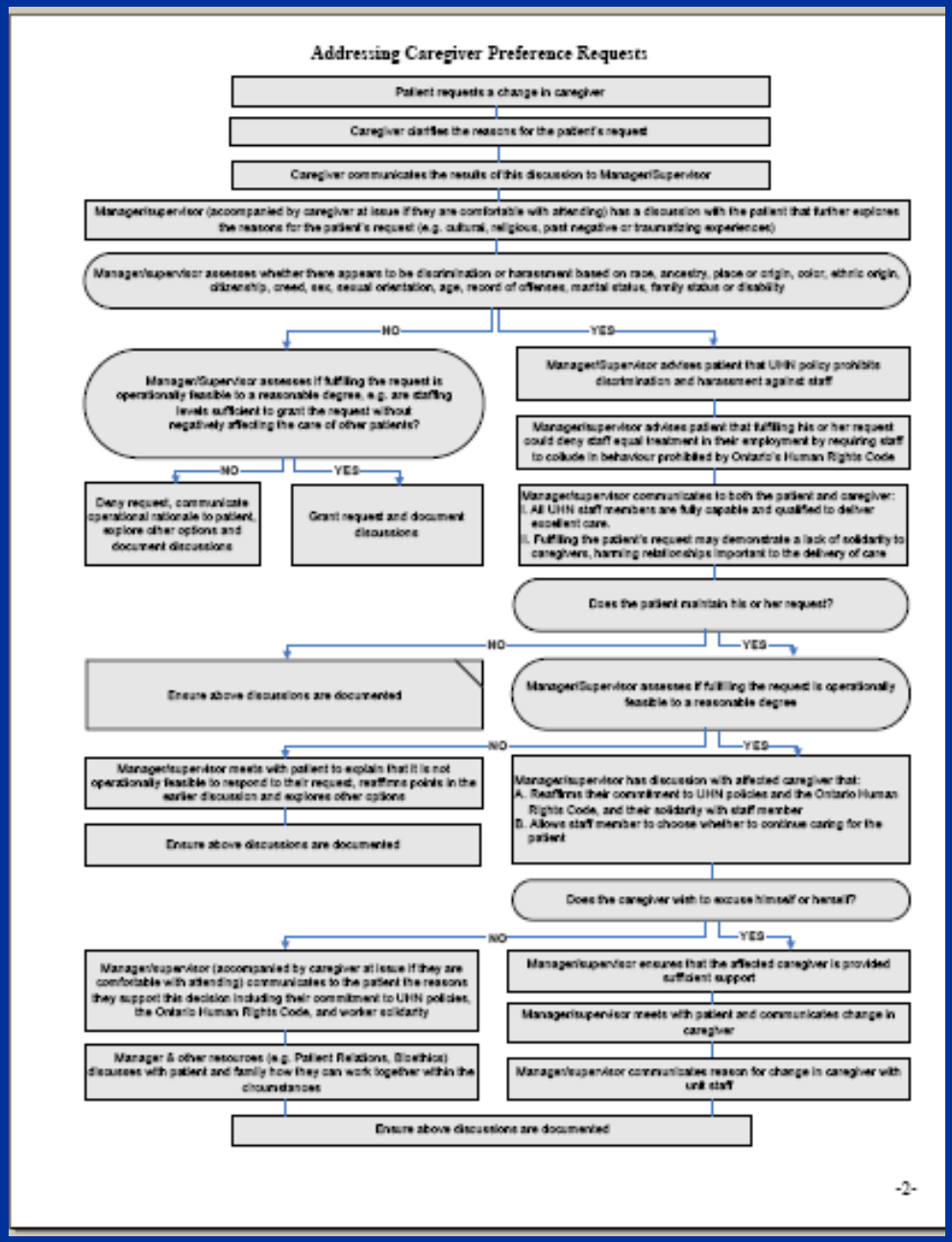
UHN Caregiver Preference Guideline



Addressing Caregiver Preference Requests

Patient requests a change in caregiver

Caregiver clarifies the reasons for the patient's request

Caregiver communicates the results of this discussion to Manager/Supervisor

Manager/supervisor (accompanied by caregiver at issue if they are comfortable with attending) has a discussion with the patient that further explores the reasons for the patient's request (e.g. cultural, religious, past negative or traumatizing experiences)

Manager/supervisor assesses whether there appears to be discrimination or harassment based on race, ancestry, place or origin, color, ethnic origin, citizenship, creed, sex, sexual orientation, age, record of offenses, marital status, family status or disability

NO

Manager/Supervisor assesses if fulfilling the request is operationally feasible to a reasonable degree, e.g. are staffing levels sufficient to grant the request without negatively affecting the care of other patients?

NO

Deny request, communicate operational rationale to patient, explore other options and document discussions

YES

Grant request and document discussions

YES

Manager/Supervisor advises patient that UHN policy prohibits discrimination and harassment against staff

Manager/supervisor advises patient that fulfilling his or her request could deny staff equal treatment in their employment by requiring staff to collude in behaviour prohibited by Ontario's Human Rights Code

Manager/supervisor communicates to both the patient and caregiver:
I. All UHN staff members are fully capable and qualified to deliver excellent care.
II. Fulfilling the patient's request may demonstrate a lack of solidarity to caregivers, harming relationships important to the delivery of care

Does the patient maintain his or her request?

NO

Ensure above discussions are documented

YES

Manager/Supervisor assesses if fulfilling the request is operationally feasible to a reasonable degree

NO

Manager/supervisor meets with patient to explain that it is not operationally feasible to respond to their request, reaffirms points in the earlier discussion and explores other options

Ensure above discussions are documented

YES

Manager/supervisor has discussion with affected caregiver that:
A. Reaffirms their commitment to UHN policies and the Ontario Human Rights Code, and their solidarity with staff member
B. Allows staff member to choose whether to continue caring for the patient

Does the caregiver wish to excuse himself or herself?

NO

Manager/supervisor (accompanied by caregiver at issue if they are comfortable with attending) communicates to the patient the reasons they support this decision including their commitment to UHN policies, the Ontario Human Rights Code, and worker solidarity

Manager & other resources (e.g. Patient Relations, Bioethics) discusses with patient and family how they can work together within the circumstances

YES

Manager/supervisor ensures that the affected caregiver is provided sufficient support

Manager/supervisor meets with patient and communicates change in caregiver

Manager/supervisor communicates reason for change in caregiver with unit staff

Ensure above discussions are documented

-2-

Flowchart to Address Requests for Different Caregivers

Decision-making tool that stresses:

- Dialogue with decision-makers to clarify their wishes
- Support for affected staff
- Compliance with Ontario's Human Rights legislation and hospital policies
- Documentation

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Flowchart
to Address Requests for Caregivers

Key decision points:

- Is request clearly discriminatory?
- Does the decision-maker maintain his or her request?
- Is fulfilling the request clinically feasible?
- Does the staff member wish to excuse themselves from caring for this patient?

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The Wrong Way…

Surprisingly, provided courtesy of
“Grey’s Anatomy”

" **Crash Into Me**: Part **1”**

(TV episode 2007)

Dialogue With the Patient to Clarify Wishes

Patient requests a change in caregiver

↓

Caregiver clarifies the reasons for the patient's request

↓

Caregiver communicates the results of this discussion to manager/supervisor

↓

Manager/supervisor (accompanied by caregiver at issue if they are comfortable with attending) has a discussion with the patient that further explores the reasons for the patient's request (e.g. cultural, religious, past negative or traumatizing experiences)

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Is the Request Clearly Discriminatory?

Manager/supervisor assesses whether there appears to be discrimination or harassment based on race, ancestry, place or origin, color, ethnic origin, citizenship, creed, sex, sexual orientation, age, record of offenses, marital status, family status or disability

No

Manager/supervisor assesses if fulfilling the request is clinically feasible to a reasonable degree, and clinically indicated
e.g are staffing levels sufficient to grant the request without negatively affecting the care of other patients?
Is granting the request likely to improve patient response to care and treatment?

No

Deny request, communicate Clinical rationale to patient and document discussions

Yes

Grant request and document discussions

Yes

Manager/supervisor advises patient that UHN policy prohibits discrimination and harassment against staff

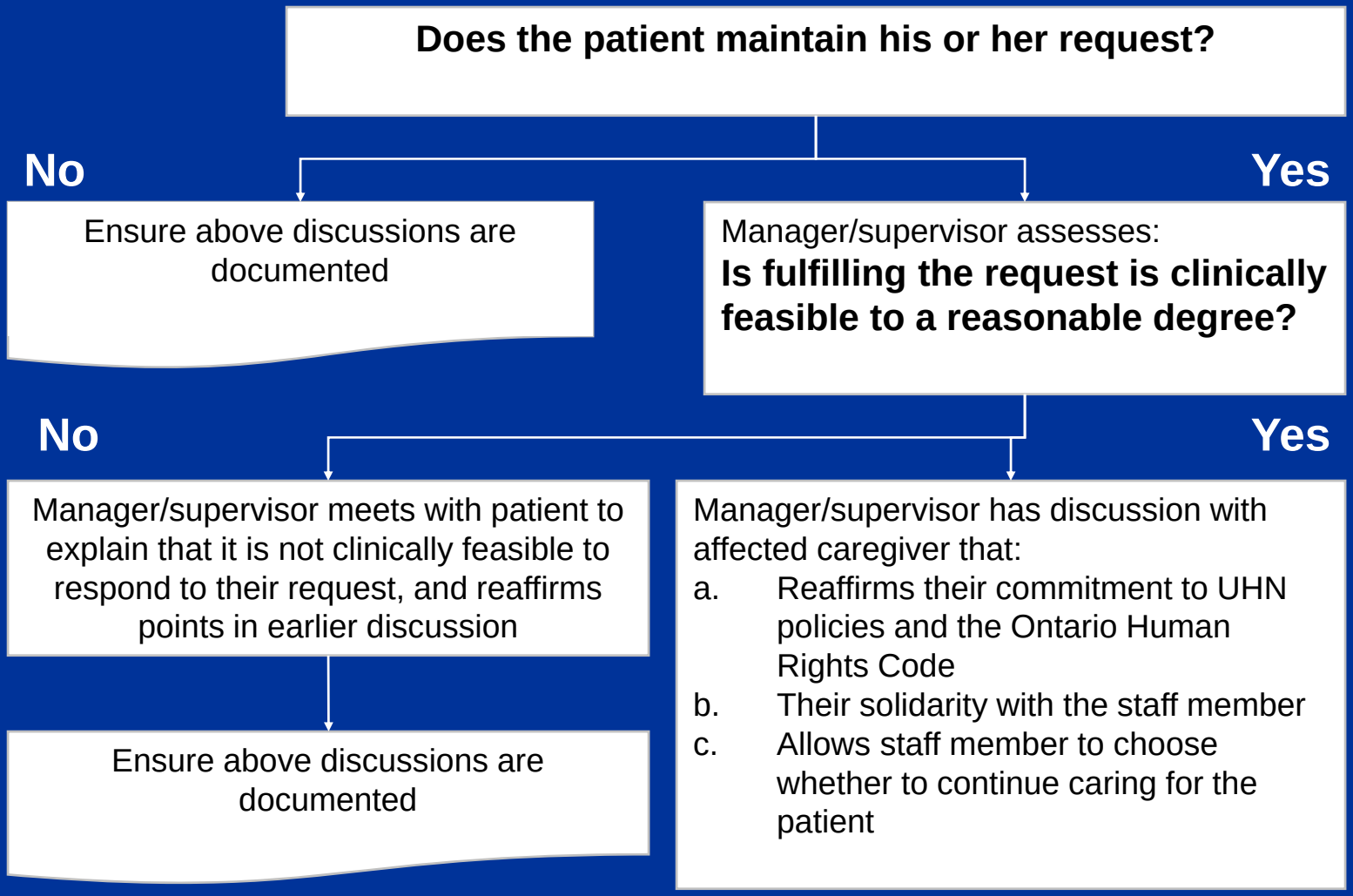
Manager/supervisor advises patient that fulfilling his or her request could deny staff equal treatment in their employment by requiring collusion in behaviour prohibited by Ontario's Human Rights Code

Manager/supervisor communicates to both the patient and caregiver that:

i. All UHN staff members are fully capable and qualified to deliver excellent care

ii. Fulfilling the patient's request may demonstrate a lack of solidarity to caregivers, harming relationships important to the delivery of care

Does the Patient Maintain Their Request? Is Fulfilling the Request Clinically Feasible?



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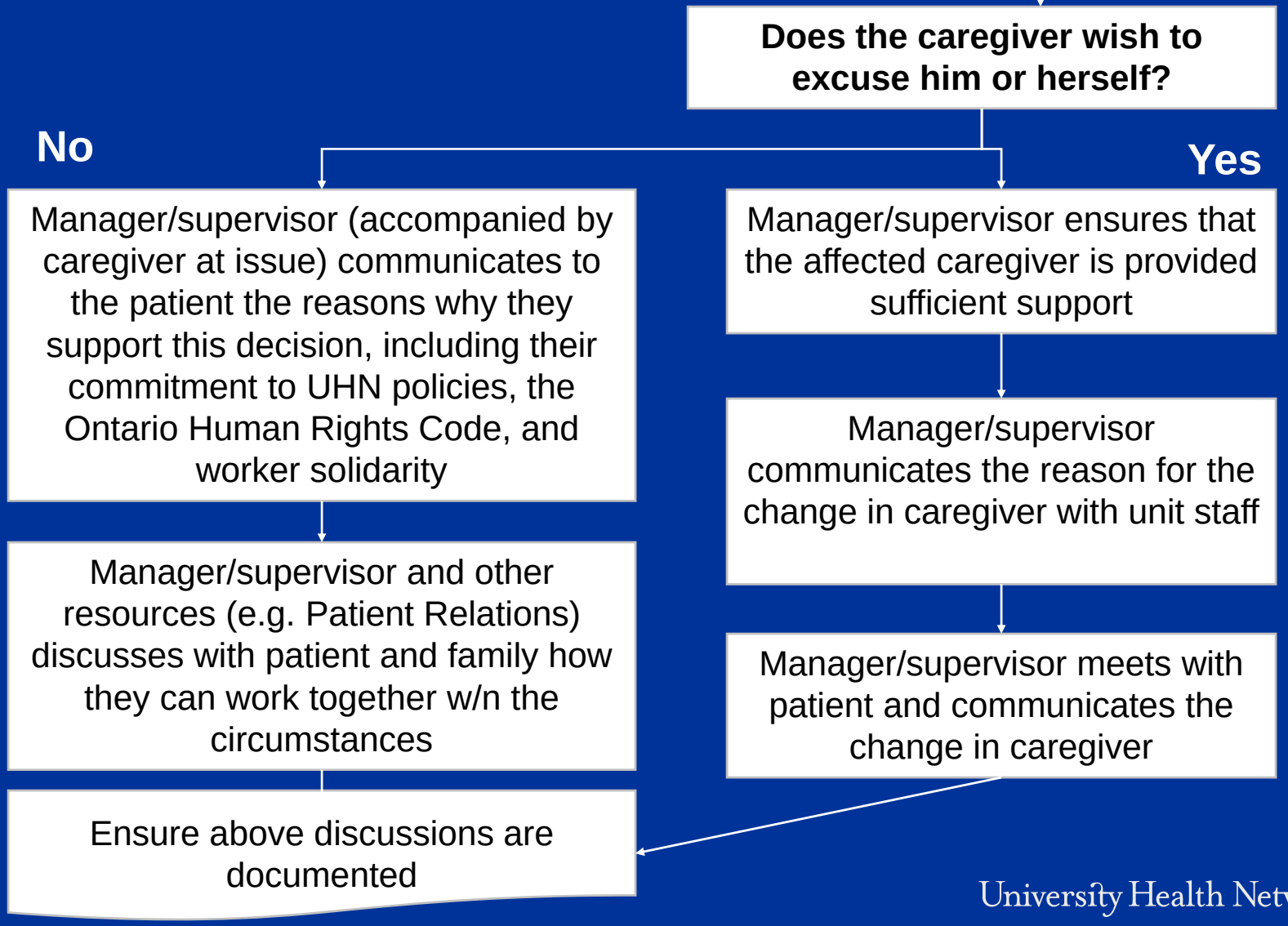
Does the Staff Member Wish to Excuse Themselves?



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Potential Difficulties

- *Inconsistent* preferences of
  - Substitute Decision-Makers and incapable patients
  - Parents and children: e.g. parents exhibit potentially discriminatory preferences for caregivers despite their children's disagreement with their views.
- Despite consistency in the quality of treatment, a change in providers might remove a provider the incapable patient/child has a good therapeutic relationship with.

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Conclusions

- Doing “whatever the patient wants” has negative implications that are particularly evident in the context of preferences for a particular caregiver
- Legislation, organizational & professional policy often impose reasonable limits on the extent to which we can honour patients’ preferences for care including those for certain caregivers.
- UHN’s Caregiver Preference Guideline provides a practical process for assessing and imposing these limits on a per case basis.

Conclusions

- **A process** for responding to these requests should stress
  - Dialogue with decision-makers to clarify their wishes
  - Support for affected staff
  - Compliance with legislation and alignment with organizational and professional policy
  - Documentation

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Conclusions

- **Key decisions** that need to be made by managers/supervisors include:
  - Is request clearly discriminatory?
  - Does the patient maintain his or her request?
  - Is fulfilling the request clinically feasible?
  - Does the staff member wish to excuse themselves from caring for this patient?

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We welcome your questions!

Further discussion:

- Kyle.anstey@uhn.ca
- Maryjane.mcnally@uhn.ca
- Linda.wright@uhn.ca