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Editor's Forum

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The authors in this issue of *Health Ethics Today* work in a wide variety of health related settings involving a broad scope of clinical practice and multiple disciplines. The need for ethical reflection in these various situations attests to ethics being an integral part of everyday work in health care. Ethics education has focused on teaching health care students and providers the necessary knowledge and skills to deal with complex and often esoteric patient related moral problems. While this is important, it is being increasingly recognized that the day to day work of health care providers involves many ordinary ethical dilemmas for which they have not been adequately prepared.

At the level of the single institution, the innovative development of the Royal Alexandra Hospital ethics internship is a good example of bringing the philosopher 'ethics expert' into the living world of clinical ethics. Likewise, Connolly and Chidwick (2005) have described another Canadian clinical ethics internship that provides opportunities to gain clinical ethics experience for upcoming ethicists. Frank (2004) suggests that we should think about ethics as an active relational process, think of it as "ethicsing", rather than an inert or passive substantive.

The papers by Blyth and Ryll, and Bailey and Russell are examples of active, relationally focused ethics dealing with care providers and

patients/clients. A shared model of decision-making, based on a mutually respectful conception of this relationship, is being taught to students in health sciences curricula. The future should bring interdisciplinary education in ethics to students in

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Medicine, Nursing, Pharmacy, other health science disciplines and Law, beginning at the undergraduate stage of the students' professional development.

Schrecker's paper reminds us how important 'up-stream' decisions involving resource allocation can have profound effects on patient care. Such decisions require careful ethical analysis as well as the customary focus on efficiency and cost effectiveness. The challenge is to identify societal values underpin-

ning cries for cost controls and to promote ethical reflection on those values. ■

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Learning About the Role of the Hospital Ethicist

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Five years ago, clinicians and ethics committee members at the Royal Alexandra Hospital (RAH), with financial support from the hospital's foundation, established a residency program in clinical ethics. The purpose of this year-long program is to bridge the divide between the academic and clinical worlds by providing individuals with academic training in bioethics the opportunity to apply theory learned in the classroom to real-life clinical situations. Through a variety of activities, including attending weekly unit meetings with members of the multi-disciplinary team (e.g., physicians, nurses, physiotherapists, occupational therapists, social workers, dieticians, pharmacists, etc.), shadowing health care team members to learn about their roles, serving on the hospital ethics committee, working alongside the hospital's ethicist, and engaging in ethics consultations, the resident gains an appreciation for the realities of an acute care teaching hospital and learns about the role of the clinical ethicist in that setting.

As the 2004 ethics resident at the RAH, I appreciated the wisdom behind the decision to create the residency program. As described by Polanyi (1962) and explored by Benner (1984), there is a difference between having a theoretical understanding of something, or knowing "that", and having practical knowledge about how something is done, or knowing "how". Reading about how to drive a car is quite different from actually getting behind the wheel and driving one. To use an example from the field of

bioethics, reading about the process of ethics consultation will provide you with theoretical knowledge, but practical knowledge of the process can only be gained through engaging in consultations. It is in the clinical setting that one comes to understand the complexity of ethical issues and the intensity of emotions at the bedside or in a family conference.

The cases brought to the attention of the Ethics Service at our hospital are rarely simple or straightforward. These situations not uncommonly involve a patient with questionable decision-making capacity and a level of uncertainty regarding the patient's prognosis, the patient's wishes, or the "good" in the situation. In some instances, there may also be an element of disagreement present as to how best to proceed. Imagine being asked by the health care team for assistance in working with an elderly woman who can no longer express her wishes as a result of dementia. The attending physician has suggested that the patient would benefit from a surgical procedure, but there are clear risks associated with the procedure. Family members have considered the options and disagree among themselves about whether or not to proceed with the surgery. It is one thing to puzzle over how one might theoretically proceed in this type of situation, quite another to meet with the people involved individually and listen to their stories, and then, as appropriate, to bring everyone together as a group to discuss the issue at hand. Skills are required to facilitate the process of



sorting through this type of complex situation, skills that cannot be learned solely in the classroom.

In the late 1990s, a task force of The Society for Health and Human Values and Society for Bioethics Consultation issued a report on the core competencies, that is to say the skills, knowledge, and character traits, required for ethics consultation (Aulisio, Arnold, & Youngner, 2000). It is suggested in the report that to “perform competently” (Aulisio et al., 2000, p. 61), consultants should possess: knowledge in nine different areas (e.g., knowledge of ethical theory and concepts, knowledge of the health care system, etc.); virtues such as compassion, courage, honesty, and integrity; and ethical assessment skills, process skills, and interpersonal skills. The authors of the report acknowledge that certain skills, particularly process skills (e.g., the skills of facilitating meetings, eliciting people’s moral viewpoints, resolving conflict, and building moral consensus), are best taught using “ ‘hands-on’ approaches” (Aulisio et al., 2000, p. 64). That is exactly what the ethics

residency at RAH provides the resident – a hands-on approach to learning about ethics consultations.

I am grateful for the opportunities this residency has offered me to develop skills in ethics consultation. At this point in time, Edmonton is one of very few cities in Canada where programs of this nature are in place. The wisdom and foresight of the program’s founders and sponsors are acknowledged. It is my hope that similar programs may emerge in other teaching hospitals in Canada in the near future. ■

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Why Wouldn't You Tell?

Telling donor-conceived children about their conception

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Research studies show that while an increasing number of parents of children conceived as a result of donor conception procedures appear to be telling - or planning to tell - their child about their conception (see Golombok et al., 2004; Brewaeys et al., 2005 for an overview), a large proportion of parents choose not to do so. Since the overwhelming majority of parents normally support truth-telling within their families, the decision to conceal the nature of the child's conception - and deception to maintain its concealment - requires explanation.

Factors that appear to influence parents' decisions include pragmatic reasons and the desire to protect the child, the parents and family relationships:

1. they are often advised by clinics not to tell;
2. in the case of donor insemination, disclosure reveals the father's potentially stigmatizing fertility difficulties;
3. disclosure may alienate the child and damage family relationships between the child and the non-genetically related parent, between the parents and between the family and the extended family;
4. disclosure may damage the child's self-image;
5. limited information about the donor means that parents are unable to answer any questions the child may have;
6. parents do not know how to tell their child;
7. if this information is disclosed to others, they may stigmatize the child and/or the whole family.

There is limited evidence that any of these fears are realized in practice. Indeed, the experience of many parents who have told their children is the converse, that telling strengthens family bonds. We believe that families are best served by children being told about their origins at a very early age. Keeping a secret such as this can itself become an unnecessary burden that may undermine family relationships - especially if the secret is divulged accidentally or inadvertently. Lack of information about the donor



certainly doesn't mean that children shouldn't be told anything. Donor-conceived children are clear about what they think they should be told, as evidenced by this nine-year old (personal communication):

"If you do not tell, you will no longer hold or gain your child's trust. However if you do tell, there is nothing to be afraid of. You are doing the right thing. In fact, I can't remember a time when I didn't know. Do not be afraid. You can't keep things a secret forever and if/when your child finds out they will want to know if you are hiding anything else."

One of the strongest reasons for telling is to ensure that the donor-conceived person has accurate information about his or her health history. If they are never told about their donor conception, they will incorrectly assume their family health history is accurate. Of course, this also means that information about donors and their health history needs to be more comprehensive than is often currently provided by fertility clinics and sperm banks. They need to respond to this challenge for the benefit of the families they are helping to create. ■

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Everyday Practice, Ethics and the Law¹

Capacity of a Minor to Consent

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Antonio, 12 years old, sits uncomfortably in the walk-in clinic's examining room with a bloody washcloth in his hand. With tear-stained cheeks, he whimpers softly while his mother gently rubs his back. Dr. Tollefson, a family physician, enters, clipboard in hand. "Hi, I'm Dr. Tollefson. You're.....Mrs. Bracco? And you're Antonio?" "Hello, Doctor," replies Mrs. B. Antonio nods shyly. "That's quite the split lip you have. Skateboarding, was it?" "Yes, he was trying to jump over something he had never tried before. He loves his skateboarding. But when I saw how big the cut was, I brought him here right away." "That's good. Antonio, did you hurt any of your teeth? Or maybe your tongue or inside your mouth?" "I don't think so..." he replies, waveringly. "Well, why don't you open your mouth for me so I can get a good look inside?"

Visual examination shows no damage to his teeth, tongue or oral tissue. "Right, your teeth are fine. So is your tongue and cheek. That's really, really good. It's just your lip that's hurt. Now...." "So you'll stitch it up?" asks his mother. "Yes, I could stitch it up; it'd take two, maybe three, little stitches. Or we could just leave it alone because it's already closed pretty nicely by itself." "Well, if that's all that's needed, go ahead and stitch up his lip." (Names are fictitious).

The lawyer: In Alberta, no age is specified in provincial legislation regarding when a healthcare practitioner must obtain consent to recommended treatment from a minor (i.e., someone under age 18) versus from his or her guardian (i.e., usually a parent). As a result, we look to the common law (that body of law created by the courts). In this case, it has developed the "mature minor" doctrine or principle. If a minor understands the nature of the treatment being proposed and the consequences of proceeding with, or refusing, that treatment, he or she is considered to be a mature minor with the capacity to agree to or refuse the treatment (Picard and Robertson, 1996). A practitioner providing services to a mature minor must look to that minor for consent and not to their guardian. If the patient does not qualify as a

mature minor, then the guardian's consent must be sought.²

How does a practitioner decide if a minor has capacity to consent to treatment or refuse treatment?³ From a legal perspective, the assessment is a functional one which must be made on a case by case basis. The ability to consent to treatment or refuse treatment depends on the particular minor's maturity relative to addressing the specific medical problem. The practitioner does not assess capacity to make all decisions, but only the ability to decide with respect to the treatment in question. The practitioner must determine whether the minor is able to understand what treatment and non-treatment entails, predicted benefits and risks, and the consequences that may affect his or her body, among other things. Factors to consider include the minor's age, seriousness of the medical condition (e.g., sprained finger or heart surgery), nature of the treatment, and ability to comprehend information that is relevant for making an informed decision.

While in most cases, a mature minor can consent or not to treatment decisions, the Child, Youth and Family Enhancement Act of Alberta (2000) can trump the above consent process. Under the Act, anyone "who has reasonable and probable grounds to believe that a child is in need of intervention" (s. 4) is legally obligated to report this to a director. If the treatment is essential for the minor and the minor or the guardian refuses it, a practitioner must report this (Child, Youth and Family Enhancement Act of Alberta, 2000, s. 2.1(b)). If a court deems the treatment essential and in the specific minor's best interests (as per several factors set out in the Act, s. 2), a judge may order treatment (s. 22.2).⁴ An example of this occurred in the case of *H.(B.) v. Alberta (Director of Child Welfare, 2002)*⁵ in which a 16-year old Jehovah's Witness with acute myeloid leukemia who was found to have capacity at the Court of Queen's Bench level refused chemotherapy accompanied by blood transfusions. The court stated that it was bound to make the decision that was in



her best interests, and her wishes were but one factor it was required to consider in reaching its decision.

The ethicist: Parental duties are not limited to their child's physical well-being, safety, education, and happiness. Parents also are responsible for developing the child's life skills and character. Included in important life skills is sound decision-making just as being responsible (acting in ways that demonstrate a holistic concern for others as well as oneself) and accountable (being answerable to other people and to oneself) are important character traits. Since health has an indisputably immense impact on one's life, it should be a primary area in which children and adolescents practice sound decision-making and develop personal responsibility and accountability.

When caring for children/adolescents, a pediatrician or other health practitioners' first duty is to the

individual patient. However recognizing a child is not only an individual but also a member of a family, pediatric practices and facilities customarily balance their duties to children with the role and needs of the family. Accordingly, practitioners honour their primary duty to the child by assisting parents in discharging their parental duties. Our society allows parents considerable latitude in raising their children. One justification for this latitude is the societal belief that parents, *prima facie*, are committed to and care about the child more than anyone else. A second, often unmentioned, reason is the societal belief that being a parent is itself a highly valued experience.⁶

Legal-ethical recommendations for practitioners: Dr. Tollefson needs to decide if Antonio sufficiently understands the nature of a split lip and the consequences of having versus not having sutures. If he concludes Antonio is a mature minor, then Antonio

should choose. Antonio probably does understand the nature of his injury: he can see it and he's likely had some "respectable" cuts as part of a healthy childhood of play and exploration. He should be able to understand Dr. T's explanation of having versus not having sutures if the doctor avoids medical-ese. The predictable risks of either option are very minor, assuming that Antonio has no complicating morbidities (e.g., hematological or immunological conditions). Moreover, Antonio has calmed down and is not in significant pain (fear or pain can be obstacles to sound decision-making for anyone).

But when taking his mother into account, Dr. T concedes that he has no prior experience with her in terms of her parenting approach. Past practitioners may have never involved the boy in his health-related decisions and so he and his mother could be surprised if Dr. T. bluntly said "Well, it's all up to Antonio." Surprises are undesirable in healthcare because they can erode trust in practitioners. Working from the idea that practitioners should help parents "grow" their children's abilities to make choices as well as be responsible and accountable, Dr. T. could say to Mrs. B, "I like these kinds of situations because parents and I get to work together on what the child wants done and what he learns from making such choices. Antonio's injury is luckily simple and I bet he'll understand when I explain to him about having stitches versus not having them. You've settled him down a lot already and he isn't having much pain anymore. So this seems to be a good opportunity to see what he wants done to his lip...."

Dr. T's statements to Mrs. B are neither confrontational nor condescending. Instead he adopts a collaborative approach, acknowledging the care Mrs. B. has already given her son. Using ordinary language, he has identified basic components of informed consent and patient autonomy: proportional level of understanding, no internal coercion (i.e., pain or fear), and the person's *prima facie* authority over the burdens that are endured and benefits that are sought. Furthermore since this is Dr. T's first visit with Mrs. B, a collaborative approach provides "room" in the discussion for her to identify cultural values that

may impact how the treatment/non-treatment decision is finally made.

But what if Antonio is 8 years old and the condition is a life-impacting ailment and/or the standard treatment recommended by Dr. Tollefson is not simple? From a legal perspective, his parents would most likely be the appropriate persons to look to for consent. An ethical perspective would recommend that Antonio still be involved in appropriate discussions wherein the guiding goal is that he won't be surprised or afraid by what will happen, he is able to have some personal input to the therapy plan (maybe to be hospitalized in a room with other children rather than alone), and that he has opportunities to get answers to *his* questions or worries.

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Notes

1. This information is not in any way intended to be legal advice and should not be relied on for such a purpose. If you have any doubt or questions about assessing capacity, or any other matters that potentially involve your obligations and the rights of minors and guardians, consult with your colleagues and, where appropriate, seek legal advice.
2. In either instance, consent must be informed and referable (proper disclosure must be made), and provided voluntarily.
3. For guidelines on the assessment of capacity, see College of Physicians and Surgeons of Alberta Guideline. (2002). *Competency Assessment and Surrogate Decision Making*. Retrieved from http://www.cpsa.ab.ca/publicationsresources/attachments_policies/competency%20assessment%20and%20surrogate%20decision%20making.pdf.
4. Where the child is subject to a guardianship order.
5. See also [2002]. A.J. No 568 (Alta C.A.) though it appears that the Court of Appeal misapprehended some of the findings of Justice Kent of the Court of Queen's Bench.
6. A helpful overview regarding practitioners' responsibilities for and to children and parents is Harrison et al. (1997). Bioethics for Clinicians: 9. Involving children in medical decisions. *Canadian Medical Association Journal*, 156(6), 825-828.

Interrogating Scarcity: The Challenge for Health Ethics

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When people working in health ethics discuss resource allocation, they are often thinking of cases in which a surgeon must choose between two candidates for a transplant, with different medical histories and prognoses, when only one donor organ is available. Or, they may be thinking about a situation in which an emergency room physician knows that an accident victim with serious brain injuries belongs in the Intensive Care Unit (ICU), but also knows that no beds are available, so the patient cannot be sent to ICU without shifting someone else to a less satisfactory setting (McKneally et al., 1997).

For purposes of policy analysis, these situations are quite different. The scarcity of suitable organs for transplantation is a 'natural' scarcity, given the current state of medical science and technology. (In the future, the ability to grow organs for transplantation *in vitro* may raise quite a different set of resource allocation issues.) On the other hand, the shortage of ICU beds exemplifies a more common set of circumstances, described by Calabresi and Bobbitt (1978, p. 22) in their remarkable book on *Tragic Choices*: "Scarcity is not the result of any absolute lack of a

resource but rather of the decision by society that it is not prepared to forgo other goods and benefits in a number sufficient to remove the scarcity."

Press reports suggest that such decisions have led (for instance) to preventable deaths from emergency care delays in Saskatoon, and to refusals of demonstrably effective pain relief for patients in Toronto (Haight, 2004; Papp, 2003). Media file clippings provide an imperfect basis for informed discussion about resource allocation, yet even as Canada spends more than \$84 billion in public funds annually on health care, solid descriptive research on how priorities are actually set at the institutional, regional and provincial level is extremely scarce.

It is therefore time to abandon deference to choices made by political elites and senior managers within the health care system. To quote Calabresi and Bobbitt (1978, p. 150-151) again: "We must determine where – if at all – in the history of a society's approach to the particular scarce resource a decision substantially within the control of that society was made as a result of which the resource was permit-

ted to remain scarce. Scarcity cannot simply be assumed as a given.”

So when (for example) there are not enough ICU beds or there is not enough money for palliative care, it is important to ask why not, and to challenge decisions that have generated or worsened scarcity. The Registered Nurses Association of Ontario provided a fine example in 2004, when they urged the newly elected Ontario government to: “Stop the tax-cut tail from wagging the [health care] rebuilding dog.”

Ritual invocations of resource scarcity are even more frequent, and less persuasive, in the global frame of reference. We’re solemnly told by political leaders like Prime Minister Martin that modest increases in development assistance for health-related programs, which could save literally millions of lives per year (UN Millennium Project, 2005) are unaffordable, although the price for the G7 industrialized countries would be equivalent to the value of 0.6-1.5 Big Macs per person, per week (Labonte, Schrecker & Sen Gupta, 2005) ... and the costs involved for Canada and the United States are dwarfed by the value of recent tax cuts.

The argument that health care ethics must engage directly with broader social choices about resource allocation is not new. Barry Hoffmaster pointed out in 1992 that examination of nontreatment decisions within neonatal ICUs must be combined with questions about social conditions (determinants of health) that contribute to the need for such units. What’s new is the urgency of that engagement, at a time of relentless domestic pressure to scale back publicly financed social provision and a parallel international retreat from acceptance of obligations across borders.

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Book Review

The Anatomy of Hope: How People Prevail in the Face of Illness

Author: Jerome Groopman, MD

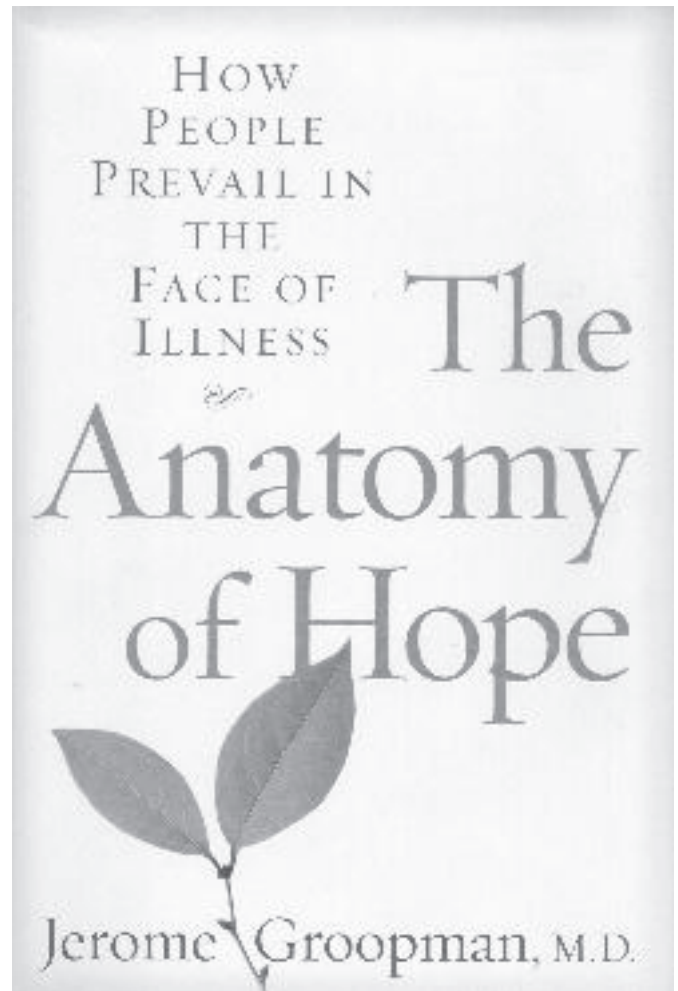
Publisher: New York: Random House, 2004

ISBN 0375506381 (also available in audio)

Seeing the title, it's likely that the author will be presumed to be someone working in palliative care or chaplaincy and thus discounted by medical researchers and physicians. However, Groopman is a hematologist-oncologist, the Chair of Medicine at Harvard Medical School and the Chief of Experimental Medicine at Beth Israel Deaconess Medical Center. He's co-authored approximately 200 clinical articles, authored two books about practice, and contributes regularly to *The New Yorker* magazine (see www.jeromegroopman.com). Groopman disputes modern healthcare's understanding of hope as being a concern only for pastoral care, a comforting platitude, or so idiosyncratic that a practitioner cannot bear any responsibility for it. Instead *The Anatomy of Hope's* raison d'être is to persuade practitioners that preserving hope may be as clinically desirable and attainable as increasing oxygen saturation rates, decreasing white cell counts, and maintaining fluid balance.

The Anatomy of Hope has two sections: the first section presents anecdotal evidence about hope's clinical efficacy while the second section presents empirical evidence. Early in the book, Groopman admits that he "mistook information for insight" during medical school at Columbia University (pp. 23). Now much wiser, he carefully examines a few telling patient cases, demonstrating what is often known in philosophical circles as the "ethics of attention". As is typical for how most of us learn or become open to new ways of thinking, the case of "someone like me" (i.e., a colleague who is diagnosed with a virtually-untreatable cancer) and the case of "me" (i.e., Groopman's own intractable back problems) provide particularly powerful insights for him. The result is gripping stories that have led the author to conclude that hope legitimately qualifies as a clinical concern.

The final two chapters present emerging clinical research evidence that hope has a significant connection with physiological recovery. The physiological effect comes from the relationship of endorphins and enkephalins to our emotional and cognitive states. These two chapters try to convince clinicians that hope warrants as much empirical investigation as do pharmaceutical or surgical options.



I recommend this book for three reasons. First, its topic is an avenue of therapy which a seasoned clinician believes is very promising. Second, practitioners should be comforted by Groopman's courage to admit that, despite years of experience and many accomplishments, some patients continue to haunt him. To his credit, he has let them teach him. And last, I found *The Anatomy of Hope* to be a particularly moving account of the competing, often conflicting, expectations of being a doctor.

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Upcoming Events

Dossetor Centre Health Ethics Seminars:

Please check the John Dossetor Health Ethics Centre website at www.ualberta.ca/BIOETHICS/ for an updated seminar schedule.

Bioethics Week 2006:

Theme: Organizational Ethics

Bioethics Week will take place from 6 – 12 March 2006.

UAH/SCH Clinical Ethics Committee: Grand Rounds

For the 2006 schedule, please check the John Dossetor Health Ethics Centre website at www.ualberta.ca/BIOETHICS/.



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