ABSTRACT. Paternalism in the medical care of children is appropriate and ethically justifiable. However, dilemmatic disagreement by paternalistic agents as to which clinical choice is in the child’s best interest may occur because of the underlying conflict between two rival standards for the moral value of life: longevity versus quality. Neither standard is unreasonable. Either could be the basis for choice of medical care by the parents or by the pediatrician. Having the child choose between options disputed by his parents and the pediatrician is unlikely to resolve their conflict. Exercise of informed consent by the adolescent requires agreement by his parents to relinquish their paternalistic veto. The probable best-interest choice by the child when he has matured could be reasonably made from either standard. Therefore, the longevity/quality of life question ought not ordinarily to be foreclosed by paternalistic authority which opts for one standard to the exclusion of the other. Medical interventions, paternalistically determined, are justified in the face of deteriorating quality, but only as long as the interventions themselves do not cause deterioration. Application of this limitation of paternalism to the zone of agreement between the rival life standards is made to clinical case examples. Multiple extrinsic criteria may measure the quality of life. Three quality factors, sensation of pain, capacity to communicate and physical functioning are considered. The extent of the zone of agreement between the two life standards varies because quality of life is a relative good, contingent both upon which extrinsic criteria are selected to assess it and upon the priorities which are set among these criteria.

Key words: Autonomy, Paternalism, Consent, Life, Pediatrics.

0. INTRODUCTION

Paternalism is inevitably present in medicine. To a greater or lesser extent, the victim of illness or trauma not only needs help but is helpless. An asymmetry characterizes the physician-patient relationship with the heavier weight of responsibility falling upon the physician. The patient’s goal is only to get well for his own sake, whereas the physician’s goal is to help to heal him, for the patient’s sake [3]. Although contemporary culture appears quite ambivalent about paternalism in medical care, alternating between condemnation and praise [7], we see it rather as a factor present in medicine which needs to operate within ethically justifiable limits. In Pediatrics the exercise of paternalism can be most justifiable. However, its application and particularly its limitation pose some of the most acute problems of medical practice.

Our paper is in two parts. In Section 1 we present moral criteria for clinical best-interest judgments which limit paternalism. We develop the principle that paternalism ought to be limited to the zone of agreement between rival standards for the moral value of life. In Section 2 we discuss application of this limiting principle to pediatric cases involving three quality of life factors: sensation of physical pain, capacity for communication and for physical functioning.

1. MORAL CRITERIA FOR CLINICAL BEST-INTEREST JUDGMENTS LIMITING PATERNALISM

The essential purpose of paternalism is beneficence. Beauchamp’s statement of ‘the paternalistic principle’ expresses this essential intent well: “... limiting a person’s liberty is justified if through his own actions he would produce serious harm to himself or would fail to secure an important benefit” [2]. Protecting from harm and providing for well-being (that offers a benefit as well as requires its acceptance) provide the combination of restriction and coercion which characterize paternalism.

1.1. Life

In the hierarchy of value standards by which protection from harm and provision of benefit are assessed, the position of the moral value of life is the most critical. Indeed, that position will indicate the definition of the moral value of life being used. When the locus of worth is essentially intrinsic, life as a moral value moves to the top of the list. Such other values as freedom, justice, excellence, trust will be subordinate to life, which approaches an ultimate and absolute value. Variously expressed as, ‘living longer is morally right’, this vitalist definition generates clinical imperatives whose success is measured by longevity. Conservatively interpreted Judeo-Christian religious teaching maintains that the character of the Creator-creature relationship requires not only ascribing high intrinsic value to life, but also calls for love and obedience, so that life does not become idolatrous, an end itself [5]. Hence the phrase ‘sanctity of life’ is not synonymous with an absolute vitalism, but the very high intrinsic worth of life from this position may place longevity in extremely high (if not highest) priority [11].

In direct contrast, the locus of the worth of life may be found extrinsically, relative to other values, which, in turn, require definition. The value of life then may be expressed as, ‘better quality of living is morally right’. While optimizing quality of living may be the goal, other value standards may rise higher on the priority scale to assess its achievement. Longevity is therefore only a contingent value. As a relative good, quality of life is subject to continuous reassessment by the array of values which determine it. Both the various value standards used and the priorities set among them to assess the quality of life, are as variable as the individuals who make those judgments. Attempts have been made to develop criteria by which to assess ‘humanness’ [6] in order to make judgments of ‘human existence’ rather than ‘mere biological existence’. The need for objective criteria defining ‘humanness’ arises in those situations, such as irreversible coma in the vegetative patient, when ‘quality of life’ may be below a minimum