DYING WELL AGAINST THE ODDS

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Cultural and Religious Horizons

Phyllis Chesler is known for her startling claims about the social pressures that drive women to madness. In *With Child*, she turns the same scathing light on childbearing. When she becomes a mother late in her professional life, she declares:

Under patriarchy, pregnancy and childbirth are savage “tests” of your ability to survive the wilderness alone. And to keep quiet about what you’ve seen. Whether you’re accepted back depends on your ability, your willingness to live without any confirmation that you’ve undergone a rite of passage...You must keep quiet and pretend to return to life as usual.¹

While Chesler unfairly puts all the blame on patriarchy, these words still suggest a great deal not only about motherhood in white, middle-class North America but about rites of passage in our contemporary society in general, including the prospects of dying well—against the odds. Much happens in the passages to birth and death about...
which people do not talk. Those who come close to such rites of passage must keep quiet about what they have seen and must return to life as normal. The wilderness of silence that surrounds these experiences makes birthing well and dying well especially difficult.

For me, teaching a course on “Death and Dying” through the thick haze of the final trimester of a second pregnancy marked a major turning point when my intellectual passions took a leap from issues of illness and dying to the activities of birthing and raising children. I could never quite get into the course material. At the time, I blamed the larger size of the class, its unusual reticence, the tedium of teaching the same course several years in a row, the sun blaring in the window; I dimly suspected my expanding belly had something to do with it.

Now I see a little more clearly: I had already stepped off into the liminal space, the betwixt and between, the out-of-time-and-place of the embodied process of pregnancy and birth. I remember the moment an unusual realization came unbidden into my mind: bringing to birth means bringing to death, for the one to whom I give birth must, like the rest of us, face death. Age-old resistance swelled from deep within me: NO! How unfair and absurd it seemed! In a paradoxical way, I was so close to life and death that the sheer protruding shape of my distended front not only made it hard to sit behind the classroom table but also forbade direct engagement with finitude.

With my first child, I had survived the wilderness of silence that often surrounds the struggles of motherhood, but I was less willing to keep quiet about what I saw the second time around. The complications of caring for a helpless new being without relying upon conventional breadwinner-homemaker roles within our family had made it impossible to return to “life as usual” anyway. So began my project of advocacy for the mother and for motherhood as a powerful source for theological reflection, a project that I saw as “literally born along with my children, almost as inevitable, and yet as precarious as their lives.” The resulting book, Also a Mother, hardly survived the children, as they barely survived its unforeseen demands.

This essay affords the opportunity to name some unexamined connections between my reflections on the opposite ends of the life cycle. There are some curious ways in which previous efforts to lift up the moral and religious context of
death in *Death, Sin and the Moral Life* and more recent attempts to break silences that surround the other end of life’s spectrum are related. Although I never saw these two projects on death and birth as disconnected, I have never before attempted to identify the connections.

At the most general level, these two projects are connected by a deep commitment to gaining insight into weighty, sweeping subthemes—living well and dying well. With some distance, three more specific amplifications of this commitment to wisdom about living well and dying well come to mind: the relentless tensions between an abundant life and finitude, the disturbing disregard for caregivers and dependents, and the critical need for awareness of the cultural assumptions that often distort our living and dying. In each case, there are important connections between reflections on birthing and reflections on dying well. Careful attention to these three considerations is absolutely essential to enhancing our care of the dying and to creating the possibility of living and dying well. Yet in many cases, these are matters about which many people have kept silent. An expansive wilderness of unexplored territory awaits examination.

**GENERATIVITY AND FINITUDE**

In an effort to reshape contemporary ideas about work and family, in *Also A Mother* I use the concept of *generativity* first articulated by life cycle theorist Erik Erikson. Although this term is less familiar to those outside the discipline of academic psychology, I found generativity to be the only term that captures the pursuit of good work and the desire for good love particular to the life cycle stage of human adulthood. Generativity is the challenge in adulthood of finding meaningful avenues of productivity, creativity, and procreativity. In theological terms, generativity entails the idea of meaningful vocation and fruitful procreation.

Like Erikson, I use this term to underscore the integral connections between love and work. To ponder “work” or “love” or “family” in isolation, as we are often tempted to do, misses the essential interconnection of economics, culture, and family life. Distinct from Erikson, I use the term normatively and theologically to explore the roles of women and men in the spheres of work and family. Most importantly, I use it to name current generative challenges. How might the church and the general public counter the premises of a society that continues to
relegate the tasks of real “work” to men and the chores of genuine “love” to women? How can we bridge the gap between the spheres of public paid employment and private family life? How can we contest social mores that prize material productivity and discount the nonmaterial, hidden structures of caring labor upon which all human productivity rests?

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What does all this have to do with finitude and dying well? As with each life cycle stage, generativity in adulthood has its downside. When generativity fails, “stagnation”—to use Erikson’s term—and regression to previous life stages results. So important is generativity, Erikson asserts, that its denial has repercussions as severe as the “denial of sexuality.” Denial of generativity is, he claims, “as severe a source of inner tension.” Oddly enough, today we tend to take sexual frustration seriously but seldom concern ourselves with the problems of “generative frustration.” Moreover, to find problems of “generative frustration” discussed in any depth in relationship to dying well, one has to go beyond psychology, medicine, and relative concerns about psychological and physical health to religious reflections.

Religion in general and Christianity in particular reveal that human efforts to be generative finally are rendered inept in the face of death. Death “always comes too soon,” or in some cases of increasing dementia and personal decline, too late. No matter how long life is prolonged, no matter how well people care for others, no matter how much people pontificate on dying well, we cannot ultimately bring about death’s consummation in any completely satisfactory way. In the face of death, human beings are called to account and inevitably come up short. The completion of “unfinished business,” as Elisabeth Kübler-Ross liked to say, in order to achieve a “peaceful” death is, in the end, something of a sham. In theological understandings of human nature, failure, and tragedy in human generativity are mourned as “inevitable yet not necessary” to harken back to the most apt phrase of Reinhold
Niebuhr for the precarious, vulnerable nature of human sinfulness. To use words theologian Paul Tillich preached, despite ourselves we turn away from “participation in the divine Ground from which we come and to which we go.” Moreover, in Christian views of salvation, human frailty and limits require human intervention in the form of acts of justice, kindness, and mercy and ultimately, divine intervention in the form of God’s redemption.

Psychologists and some medical practitioners sense this tension between human hopes about generativity and finitude, but they do not have the traditions or the language, the rituals or the protocol, to articulate or honor these recognitions. Erikson knows that attempts at ego integrity—that is, recognizing one’s generativity in the final stage of life and adapting to the “triumphs and disappointments adherent to being”—are bound to lead to despair. Ideally, the psychologically healthy achieve a greater balance of integrity over despair, as the wisdom of living teaches them to perceive their lives as part of a greater, interconnected whole. Nonetheless, in face of death’s finality, even Erikson resorts to what he identifies as “great philosophical and religious systems”: to brace ourselves against despair and transcend the limitations of our identity we must turn to “ultimate concerns,” he says, quoting Tillich.12

Although death and even fear of death belong to the natural order or the created order of being “quite apart from estrangement and sin,” human alienation adds to the natural anxiety the “feeling of standing under judgment,” according to Tillich’s theological assessment.13 As a result, the natural fear of finitude becomes the “horror of death.” Death as a final mark of human limits becomes a “structure of destruction” or a “mark of evil.”14

Medicine tends to perpetuate a myth about the human ability to control suffering. There is a reality gap between suffering as depicted in pain management literature and suffering as confronted by health care professionals. Medical literature sometimes gives the false impression that suffering can be adequately managed if only the physician improves palliative skills, takes another course, reads widely, and so forth. For many patients the real success of palliation is limited. Not only is pain difficult to manage, other forms of suffering, including the existential afflictions of the soul, almost always baffle the caregiver.
This raises an important and increasingly familiar question: has American society set up physicians to fight finitude for all the rest of us? If so, when we ask physicians to control suffering and even to control death, we have set them up to do our dirty work, to carry the burdens of society, and, ultimately, to fail. Society, not wanting to face reality and having put religion to one side, demands that physicians arrange the last terms of dying well when indeed this is finally an impossible task for medicine alone. Are inflated salaries actually an attempt to assuage guilt for placing such burdens upon physicians? And deflated salaries a punishment for failure?

For many women and men today, the difficult antithesis that impedes living well and dying well is not the “generativity vs. self-absorption and stagnation” that Erikson identified thirty to forty years ago. For many people, especially those in midlife, the challenge has shifted. The prime crisis and task of contemporary adulthood in the United States is not so much “generativity vs. stagnation,” but more often “generativity vs. fragmentation” or “generativity vs. overextension and exhaustion.” In contrast to the problems of self-indulgence and self-absorption that Erikson postulates, the problem is self-loss, self-depletion, and the inability to establish just and appropriate limits to human desire.

In some ways, the cliché, of “having it all” is a phrase analogous to that of “doing everything you can” in medical decisions about tests and treatment. Just as North American society has denied death, the penchant to “have it all” refuses to acknowledge finitude. The temptation is to refuse to let go of what cannot be, to step beyond obvious human limits, to seek more than can be humanly cared for, or in more religious terms, to want to become “like God” in “having it all” or in “doing all we can.” In this sense, no one can or should “have it all” or “do everything.” These are, at heart, misleading modern premises. From a Christian perspective, the failure to recognize human limits is part of human sinfulness.

However, the desires to “have it all” and to “do everything we can” are not wrong or evil in and of themselves. Women and men who want to participate actively in both private and public spheres have also glimpsed fresh ways for abundant life. On some level, they have seen that to work and to love is the essence of human creation and creativity. Similarly, those who work hard to
heal and save lives have glimpsed the awe, beauty, and gift of life. Hence, the real challenge faced by ethicists, theologians, philosophers, health care professionals, and all the rest of us is determining when generativity and desire are fitting and good and when they have gone awry. To assure living and dying well, people need greater support in discerning the limits of desire and generativity both in work and family and in illness and dying.

Ultimately children, like the dying, reinforce a message that Christian theology has tried to convey and that American culture continues to deny, even after the 1970s heyday of the death and dying movement and current Kevorkian-related debates: in the end all generative adults must contend with human limits and failure. The potential and realities of children make readily apparent that people must choose among life’s many possibilities and then live well enough within the fixed parameters of these choices. There is, as Jean Bethke Elshtain points out, an important moral distinction between, “say, polishing one’s Porsche and sitting up all night with a sick child.” Potential parents must consider their limits and the limits of life and let some aspirations go while claiming others instead. The dying, it could be argued, provoke a similar moral and religious assessment. Children and the dying can help us recognize “moral limits and constraints” in the face of “human frailty, mortality, and finitude.” Even if only in fleeting moments, both children and the dying ask us to view and judge our living well and dying well from a much broader angle, or in Christian terms, from the angle of eternity.

DISREGARD FOR CAREGIVERS AND DEPENDENTS

Another dynamic besides tensions between abundant life and finitude impedes dying well. Many crucial activities of generativity—of caring for whom and what we have generated—are delegated to the most marginalized, the least valued, the most exploited people and classes. The real caregivers are often women. The dirtiest tasks—whether changing diapers of infants and aged, toilet training, feeding, washing sweaty bodies and soiled clothing, disposing of waste—are often left for mothers of all classes and colors, for the poorer class, for those of color, and generally for those unable to move up in the world to better paid and respected positions.

Virginia Woolf acknowledges the strain of those who “hold up half the
sky.” In *A Room of One’s Own*, tongue firmly in cheek, she reprimands women for their lesser achievements. What, she inquires, is your excuse for lacking the normally recognized accomplishments of sonnets, battles, and empire building? Her women reply:

We have borne and bred and washed and taught perhaps to the age of six or seven years, the one thousand six hundred and twenty-three million human beings who are, according to statistics, at present in existence, and that, allowing that some had help, takes time.\(^\text{18}\)

For the most part, this underside of caregiving remains hidden from view because the possibility of speculating about the demands of care for the living and the dying usually requires what most poor people and most mothers lack: space, time, energy, money, permission, circumstances, choice, education, travel, varied experience, and two other critical ingredients indispensable to full creativity—unrestrained solitude and the “essential angel.” The “essential angel” is Tillie Olsen’s term for the woman who is thanked on dedication pages of the books of men for assuring what Joseph Conrad terms a “daily life made easy and noiseless...by a silent, watchful, tireless affection.”\(^\text{19}\)

Ironically, those closest to such acts of caring labor know life’s most valuable lessons. Although it must never become an excuse for exploitation and domination, the one who serves is ultimately the blessed one. The one who comes last is first. The needy, the dependent, the child, and the ill remind the caregiver, as Jesus himself asserts when he calls the children to come to him, of the relativity of all human power and of our ultimate vulnerability before life’s whims. All are finite and, in the end, no one takes with him or her anything he or she has produced or acquired.

Yet, despite all that is gained by caring for the dying and the young, America has never liked the dependencies of caregiving. Admired, yes; valued, no. In *Blessed Are the Poor? Women’s Poverty, Family Policy, and Practical Theology*, practical theologian Pamela Couture reveals destructive consequences of this disdain. In the 1980s, when American politicians addressed the problems of a growing underclass of children and women, the thought was to “eliminate ‘dependency’ rather than to eliminate poverty” using the American tradition of self-sufficiency.\(^\text{20}\) The problem with self-sufficiency as a norm, asserts Couture, is that,

it conceals the interconnections between individuals, families, social institutions,
and government which are essential for human flourishing. Theologically, no human being is self-sufficient; all are dependent upon God, one another, and the world. These interdependencies are not just theological niceties but constitute the real social fabric which supports people’s survival.21

In public policy and in treatment of the dying, people prize what has been labeled self-sufficiency. But doctrines of self-sufficiency lead us to overlook the necessity of securing and respecting what Couture describes as the “frequently invisible supports which anchor the flourishing of both children and adults.”22

To temper and qualify the American obsession with independence, dependency must be appreciated and respected as an essential ingredient of dying well. In the care of others in need, an intricate dance between self-denial and self-survival occurs for the mother as she cares for her child and for caregivers as they care for the dying.23 To care for others often requires a decentering of oneself; one must often set aside immediate needs in order to assess and respond adequately to the needs of others. Yet such self-denial, self-giving, and even at its extreme, self-sacrifice must never be practiced in the vacuum in which many self-sacrificing women practice it. As I wrote in Also a Mother, “self-giving love never rests on its own, alone, unaided, uninterrupted. It must be alleviated and countered by contrasting moments of self-gratification, within the broader network of dependencies that make up human community.”24 The care of others that is essential for dying and living well requires other people and institutions standing by. A parent cannot give to a less adept and dependent child who cannot yet fully reciprocate, unless that giving is refreshed by the supportive attentions of another, whether spouse, neighbor, friend, relative, or church member.

Failure to appreciate the complexities of dependency distorts even the most enlightened analysis of “family values” and decisions in the face of death.25 Families are relational configurations in which traditionally most mothers and women, to a far greater extent than most fathers and men, have borne directly the vulnerabilities created by a child’s dependency or by the dependency of the sick, the dying, and the otherwise disabled. To understand the complications of care for the young as well as the ill and dying, we must consider not only the child’s dependency on
the parents and the sick person's dependency on the caregiver, but the caregiver's dependency on others, on community and social structures, and in some cases, on government.

In families, we do not just have "adults and dependent children who slowly acquire capacities for independence" as Bethke Elshtain argues.26 We have fathers, dependents (children and otherwise), and temporarily dependent caregivers, who are more often than not, mothers. Philosophers and theologians alike have yet to solve the problem of how to integrate the dependency of the child, the ill, and the dying and the dependency of primary caregivers into democracy and a capitalist economy. In other words, children and the dying, the old and the ill, create an intersubjective dependency that has not yet been valued and integrated into our understandings of living well and dying well.

This intersubjective dependency is, of course, idealized, romanticized, and appreciated by politicians and family theorists alike. But the reality of this dependency is far more troubling. As political theorist Susan Moller Okin observes, many women become vulnerable before, during, and after marriage. They become vulnerable at at least three points: before marriage, by sacrificing education and vocational pursuits in their anticipation of marriage and children; during marriage, by dedicating themselves to caregiving while husbands control the family wealth; and after marriage, because of lack of financial security or because of their custody of children, unequal property settlements, and default of child payments by husbands.27 There is a disturbing parallel in health care. The closer a health care provider gets to hands-on involvement in providing chronic care, the less he or she is paid and valued, the more vulnerable they become.

Children test the limits of a religious ethic of mutual love and a civic policy of equality. Likewise, the unexpectedly dependent, the ill, and the dying test the limits even further. They force the question of how best to secure the care of those most dependent upon our care and least able to reciprocate. Dying well is possible only when social
structures and ideals support temporary dependencies by caring adequately not only for the dying, but also for the caregivers themselves.

**ANALYSIS OF NORMATIVE AND CULTURAL ASSUMPTIONS**

Dying well in postmodern society ultimately requires careful reconsideration of the hidden and sometimes distorted values and assumptions that define our lives. When considering the way in which my two projects on death and birth intersect, I immediately identified the common task in both enterprises as critical analysis of the implicit normative and cultural assumptions that shape and often distort our living and dying. In investigating psychological and medical approaches to dying, I was determined to understand, for example, the impact of pressures in psychology to reach a final stage of acceptance of death and attempts to achieve in medicine technological, physiological definitions of death. Both phenomena limit the ability of people to face adequately the complexities of dying as human beings with more than psychological and physical desires. Analogously, with work and family, I identified the ways in which psychological and theological understandings of human fulfillment consistently lead to a disregard for the voices of mothers and children as sources of knowledge and to a failure to grasp the complex demands of caring labor in today's society. In other words, without a moral and religious analysis of prominent cultural assumptions, responses to end-of-life dilemmas and resource allocation debates remain limited. Problems such as high divorce rates, conflicts between work and family time, and poverty among children and mothers require more than an adjustment in divorce laws, leave policies, and welfare programs. None of these problems can be resolved purely on a policy level.

In one sense, identification of assumptions that shape living and dying has been a subtheme in the first two sections. But the responsibility of the practical theologian to be a participant in public discourse in medicine and family public policy is clear. The practical theologian also has a responsibility to speak as a committed member of a community of religious practice, scriptures, and traditions, which, in the case of Christianity, stands against many cultural practices in its prophetic advocacy for justice, truth, and mercy.

An intriguing study of mother love and child death in rural northeast Brazil illustrates the necessity for vigilance in
understanding cultural norms. In her fieldwork and writing, anthropologist Nancy Scepter-Hughes sought to explain what she names “death without weeping”—the virtual absence of parental and community grief amidst the multiple deaths of Brazilian infants. Instead, mothers proudly tabulate each “little angel-baby” as a sign of special blessings accumulating in the afterlife. Do these mothers genuinely feel nonchalant or have they simply covered over deeper sorrows?

In contrast to cultural judgments conditioned by North American psychological and biomedical wisdom that explain the absence of grief as denial, displacement, or delayed mourning, Scheper-Hughes “takes the women at their word.”28 One mother she interviews is not sad or sleepless the day after the death of her three-month-old—her loss of appetite is simply due to her dislike of that day’s commeal. Scheper-Hughes does not detect the hidden, repressed sorrow or longing for the deceased children that many would suppose. Searching for the moral vision that guides the actions of women who do not cry or mourn, she discovers neither the Kantian universalistic thinking that reasons from blind justice nor the relational, context-specific reasoning of Carol Gilligan, but a different kind of moral rationale. The women employ a “lifeboat ethics” that must discern who among the sick and ailing can be saved when saving all would spell certain disaster. As in the United States, the emotional work, including the love work and the grief work, is almost completely relegated to women. Since the burden of child survival and the distribution of insufficient familial resources falls “unfairly on the shoulders of Alto women,” perhaps the least distorted response is to take these women at their word and to resist the demand that they conform to our ideal of “appropriate” maternal sentiment.

Neither Scheper-Hughes nor I commend the posture of a lifeboat ethic as an example of “dying well.” The important point is this: Scheper-Hughes stresses the import and success of culture in fashioning fitting human reactions to material and social oppression. First, in detailing the influence of culture, Scheper-Hughes observes the “awesome power of...early ‘primal scenes’” in routinizing later adult responses. She observes the lack of interest in dolls, bred by the close association between lifeless dolls and lifeless siblings. She watches the steady stream of funeral processions, composed most-
ly of children, winding their way through the backstreets, delivering a small deceased bundle to its grave. In addition, contrary to North American fears about the dangers of repressed emotion, in Brazilian culture emotional outbursts are seen as a dangerous source of misery, suffering, and personal and cultural dissipation.

Religion plays an equally powerful role. In folk piety, it is believed that a mother’s tears keep the baby from rising to heaven while her joy assures a safe passage, hence the pressure against a mother’s mourning the death of a child. Schepers-Hughes is less content with the social embarrassment and bureaucratic indifference of the Roman Catholic Church that keeps a safe distance from these practices. The church has ceased to mark the graves of children with prayers or priestly presence because these deaths strike such a “glaring contradiction with the hierarchy’s prolife and pronatalist teachings.”

Although Schepers-Hughes stops short of sufficient religious analysis, her work underscores my final point. Western science tends to view religious belief as an add-on, a superficial or separate feature of human experience, and strives to uncover the “real” emotions and physical forces through secular psychology and medicine. In contrast, Schepers-Hughes recognizes religious belief as a “powerful force that penetrates and constitutes the person.” Biology is not the base and culture, the veneer; rather, emotions are constructed and produced in culture. They “cannot be understood outside the cultures that produce them,” she argues. More radically still, “without our cultures, we simply would not know how to feel.”

While I do not believe that all emotional reactions are determined by the cultural context, I do agree that religion occupies a powerful cultural position. This premise cautions against narrow biological or psychological explanations of proper bereavement or of maternal attachment or abandonment of children. Not only do cultural and symbolic anthropologists have as important a place as biomedical and psychoanalytic anthropologists, theologians and philosophers who make cultures and symbols a central focus have an equally distinct contribution to make. In rural northeast Brazil, the mothers feel no grief, and culture and religion have played a significant role in this phenomenon. Maternal indifference and resignation are culturally reasonable responses to the unreasonable conditions of deprivation and hardship.
In our own society, where prenatal and postnatal care is subordinated to high-tech transplants and heart surgery, where basic needs remain unmet while huge medical edifices complete new additions, where inner-city mothers abandon children while government cuts back on daycare and food programs, one also has to wonder about the cultural and religious ideas that have made the abnormal seem so utterly normal, the lesser response seem the only viable one, analogous to the situation in Brazil. Confronting the injustice and blight of everyday life in Brazil reminds us that many people in wholly inhospitable contexts are forced into moral decisions that no one should have to make. In our own country, the same can be said of the poor and disenfranchised as well as of the hospitalized and the dying.

If cultural context and socialization powerfully shapes human attitudes toward mothering and toward dying, the kind of normative and theological investigation suggested in this essay plays an important role in helping shape possibilities of dying well in the twentieth century against the odds. In this task, we must pay close attention to what informants themselves tell us, breaking silences in the wildernesses of life's most difficult challenges. We must make room for what Schepers-Hughes calls the "often unanticipated 'force' and intensity of emotions" in both human living and in human dying.32

NOTES

8. Ibid., 132.


22. Ibid., 10.


24. Ibid., 167.


26. Ibid., 126.


29. Ibid., 51.

30. Ibid., 50.

31. Ibid., 57.

32. Ibid., 58.