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A Framework from the Health and Social Sciences

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Economic and Health Outcomes of Unpaid Caregiving:

A Framework from the Health and Social Sciences

Unpaid caregiving performed by family members for dependents is often overlooked in research and policies on development processes and outcomes. This article presents a framework for understanding the determinants and effects of caregiving for caregivers, organized into three levels: at the micro-level, individual care recipient and caregiver characteristics and resources; at the meso-level social norms, social support, and community resources; and at the macro-level, caregiver support policies. Drawing on existing evidence from developed and developing nations, the article highlights gaps in knowledge regarding developing nations, proposes interdisciplinary questions for future research in developing nations, and points at policy and research implications within and between each analytical level.

The dominant model in international development focuses on fostering economic growth through macro-level policy mechanisms. Progress is typically charted by changes in macro-level data (e.g., average per capita income, gross domestic product, labor force participation rates). Changes in human development mechanisms that are reflected in these macro-level data are less understood, yet these mechanisms reflect patterns among individuals, families, and communities that have cumulative effects on development. Caregivers provide the link between family life and community engagement for their care recipients, enabling them to integrate into society and function to the highest degree possible, and seldom considered when development policies and programs are crafted (Benería, 2008). Caregivers are more likely to have poor health and economic outcomes than non-caregivers, yet development programs give little consideration to how caregiving affects individuals' participation in paid labor, erodes physical and mental health, inhibits educational and training opportunities, and contributes to gender inequality. We argue that caregiving not only erodes the health and economic stability of individual caregivers, but that poor health and financial vulnerability caused by caregiving can, in turn, also lead to greater needs for caregiving, potentially creating a cyclical pattern of poverty.

BACKGROUND

A common view in economics, and one that has been criticized by feminist scholars and activists, like Waring (1988), is that women's work, which often includes unpaid labor and caregiving, is not considered productive, a view exemplified by national income accounting systems' capturing only monetized labor for a nation's gross domestic product. Although there are efforts to modify national income accounting systems to include unpaid work (Stiglitz et al., 2009), the exclusion of this work underestimates a nation's true productivity and reinforces the social perception of what constitutes valuable work (Folbre, 2001). Progress in development is

often marked by changes in national accounts. A number of researchers, feminist economists in particular, have explored the implications of unpaid labor and caregiving for economic development. Marxist feminist economists, for example, have recognized the value of unpaid labor for reproducing and maintaining the working population (Gardiner, 2000). Folbre, for instance, argues that because raising children contributes to economic and human development, it constitutes a public good and a pivotal output of unpaid labor (1994, 2008). Emerging research is documenting the benefits for development of integrating unpaid labor into the economic system, in particular showing that individuals who provide unpaid care are less likely to be engaged in the paid labor force (Antonopoulos and Hirway, 2010). Researchers have also demonstrated that although economic development efforts such as export-promotion policies are increasingly targeting women by promoting their entry into the paid labor force (Caraway, 2007), such efforts wrongly assume an infinite supply of unpaid labor (Elson, 1991). Rarely do they consider the cascading effects that labor force participation has on the informal systems of care women provide.

Just as national accounting systems overlook the value of caregiving labor, national indicators of health also overlook the risks faced by caregivers who perform that labor. By using only the widely used indicators of a nation's health—average life expectancy, morbidity and mortality rates—policy makers concentrate their development efforts on maternal and child health (e.g., reducing pregnancy-related death, reducing child morbidity and mortality). Feminist scholars have criticized this de-contextualization of health to women's biological processes, arguing that by doing so, women are seen mainly as reproducers. Less attention is paid to gender-specific social and economic determinants of health (Inhorn and Whittle, 2001), keeping

women's non-reproductive health conditions, like those generated by their caregiving, hidden from view.

Because national resources available for human development are scarce, basing policy decisions on macro-economic and health indicators that ignore caregiving work leaves caregivers invisible and at risk of being trapped in poverty. Effectively targeting resources to address poverty traps and gender-based inequities requires identifying those caregivers who bear the greatest burden and experience the poorest economic and health outcomes, outcomes that impede the development of human capabilities. Here drawing from health, economics, and other social sciences, we define concepts and present methodological challenges of multidisciplinary research and then propose a multilevel framework to help conceptualize the determinants and effects of caregiving on caregivers and the possible causal pathways that can lead to poor economic and health outcomes. This framework can help researchers conceptualize the relationship between caregiving and human development and assist policy makers in understanding the impact that policy and direct public services has on caregiver outcomes. We then suggest directions for future interdisciplinary research and policy interventions to help target those most in need.

METHODOLOGICAL CONSIDERATIONS

Although both economics and health can affect human capabilities, research in these two fields is often conducted independently. We, therefore, present common definitions and discuss the potential challenges for conducting this cross-disciplinary research.

Definition of Caregiving

Himmelweit (2007, 581) defines *caregiving* as “the provision of personal services to meet the physical and mental needs that allow a person to function at a socially determined

acceptable level of capability, comfort, and safety.” We modify this definition to include *unpaid* services to *dependent* persons and include *emotional* as well as physical and mental needs. By *dependents*, we refer to all children (before they are legal adults); those with temporary or permanent physical and/or mental health conditions or disability; and the elderly with poor functional status.

The current development literature does not distinguish between unpaid *labor* and unpaid *caregiving*. We have argued elsewhere that a narrow definition of unpaid caregiving based upon the dependence of individuals allows researchers to distinguish between the developmental stages of various care recipients (baby, child, adolescent, adult, elderly) and their conditions (healthy, ill, chronically ill, disabled) (***) . It also offers the possibility of isolating the benefits to care recipients in developing economies, where home-based work and subsistence work are prevalent, allowing for the measurement of both direct and indirect forms of support for dependents and non-dependents.¹ In this sense, we understand unpaid caregiving of dependents to be a subset of the larger concept of "care work," which includes both dependents and non-dependents, and of "unpaid labor," which in turn incorporates unpaid labor force work, unpaid housework and care work.

Definition of Caregiver Burden

In health sciences, *caregiver burden* is the collective set of stressful exposures or “stressors” that caregivers face. Although caregiving has positive effects on caregivers, such as an improved sense of strength in the face of adversity, a sense of accomplishment, and emotional closeness to the care recipient (Balducci et al., 2008), the health sciences have focused more on those less-desired effects of caregiving that are amenable to intervention. In economics, the term most often used for this burden is *penalty*. We use the term *burden* because, as traditionally used

in the health field, as it includes both health and economic components. A multi-dimensional concept, *burden* incorporates the physical, cognitive, affective, and economic load that caregivers bear (Figure 1). *Burden* is considered dynamic, a process that changes over time as the caregiver's and the care recipient's circumstances change. It is measured by assessing the different objective and subjective stressors that caregivers often experience.

Objective burden includes the number of hours in a given period of time spent on caregiving and the tasks for which the care recipient needs support. These tasks are often categorized into *activities of daily living* (ADLs: hygiene, dressing, feeding, toileting, transfers, mobility) and *instrumental activities of daily living* (IADLs: driving, supervising, accompanying, paying bills, managing financial, legal, or medical issues). It also captures demands on caregiver time, such as coordinating paid labor, family life, and regular housework activities with caregiving; a lack of time for employment, social, leisure, and educational activities; and the economic (direct and indirect) and opportunity costs of caregiving, including paying for food, shelter, day care, education, and health-related expenses associated with providing and managing care.

Subjective burden includes the perceived demands that caregivers experience, including their emotional reactions to providing care, such as anger and embarrassment, feelings of entrapment, and a lack of control over one's life, time for leisure and socialization, and privacy.² Within the work-family balance field, subjective burden also captures the emotional reactions to role conflict, life imbalance, and overload that additional social roles create (Ferree, 1991, Malley and Stewart, 1988, Schooler et al., 1983).

Economist Maria Floro has proposed (1995) and tested (Floro and Pichetpongsa, 2010) a methodology for time-use studies that complements the scholarship on work-family balance by

capturing the more realistic experiences of caregivers, especially those in the Global South who may combine caregiving with formal or informal paid labor, including home-based work (e.g., selling vegetables and minding a child). She argues that stress results from simultaneous work tasks and long working hours. While the family/work balance scholarship has focused on the subjective, intra-personal reactions to being unable to do two tasks simultaneously (e.g., picking up a child from school and working for pay) and the measurement of stressors and strain that can result from this, Floro's scholarship on work intensity calculates objective measures of simultaneous workload, regardless of remuneration for work, based on an assumption that stress is generated by intense work. We argue that perspectives from both the health sciences and economics should be considered when attempting to understand objective and subjective caregiver burden.

Definition of Caregiver Outcomes

One challenge in bridging economic and health research is translating and defining outcomes across disciplinary silos. To that end, our proposed framework includes a set of caregiver outcomes that incorporates both health and economic indicators and can be measured via objective and subjective measures.

In sociology, industrial engineering, and the health sciences, including public health and health psychology caregiving is conceptualized using theories of stress and coping (Williamson et al., 2002, Gordon et al., 2006). *Strain* describes the harmful effects of burden and occurs when one is exposed to stressors that exceed an individual's efforts to manage the challenge. Subjective measures used include self-reported assessments of depression, anxiety, fatigue, insomnia, and of physical functioning. *Economic strain* refers to the consequences of economic burden when economic instability or uncertainty leaves an individual financially vulnerable.

Income loss from reductions in paid work or exit from the paid labor force, a lack of asset accumulation, or the depletion of assets is associated with economic burden.

Research Challenges

There are methodological challenges in conducting research that integrates economic and health science approaches for understanding the impact of caregiving on development. The primary challenge is modeling causality. Caregiving studies often assume a linear relationship between determinants and outcomes. But, as Vithayachockitikhun (2006) points out, in caregiving research, certain factors, such as burden, are often considered both determinants of an outcome (such as depression) and an outcome, albeit not in the same study. We argue that causality is difficult to assess because caregiving is often cyclical and can follow a recursive pattern: women who are confined to a caregiving role, while making it possible to improve the human capabilities of their care recipients, are also paradoxically limited in opportunities to develop their own capabilities and challenged to maintain existing capabilities. Understanding which factors precipitate this cycle and who is most vulnerable to falling into it is a methodological challenge, but critical for testing this hypothesis. We expect that these trajectories lead to poverty traps and limit productivity of individuals, social groups and nations as a whole. For example, caregivers without financial, social or personal resources may be more likely to experience stressors and have poor health and economic outcomes and, in turn, their care recipients may suffer, creating greater demand on resources and economic vulnerability. If financial strain reduces quality of life, it is also likely to have a negative effect on health, which in turn will create a greater need for health care and caregiving. Caregivers who can provide unpaid caregiving and participate in paid employment may face a different trajectory. They may be at risk for stress-related illness from the challenges of balancing caregiving and paid

employment (van Ryn et al., 2010), challenges that may then limit their ability to participate in paid labor and reduce their long-term earning potential and accumulation of assets.

Furthermore, we can expect difficulties escaping the cycle: a caregiver will eventually need care herself, possibly perpetuating the caregiving trap by becoming the care recipient of yet another female caregiver.

Testing causal pathways and their potential cyclical course will require longitudinal caregiving studies, which are generally rare in both the health sciences and economics. Few studies have evaluated caregiver interventions across the life-course. Methods to evaluate the impact of policies and programs to break this cycle could be adapted from the health sciences, where implementation and evaluation methods are more commonly used. In development, little has been done to institute policy and program evaluations, although calls for evidence-based development policy and for systematic reviews of the outcomes of human development policy outcomes have been made (Department for International Development, 2010).

Another methodological challenge in bridging health and economic sciences is that the outcomes are often considered theoretically different. We suggest that, in fact, they are complementary and should be considered simultaneously. Health sciences offers a substantial number of valid measures (e.g., ADLs, IADLs, mastery, family/work balance, depression, anxiety, self-esteem, family functioning) that can be adapted and validated for populations in the Global South and used in conjunction with time-use surveys and economic outcomes questions. Likewise, theoretical frameworks used in economics, such as the intra-household bargaining framework, can provide a new lens for examining how social influence affects health. Building interdisciplinary teams could help facilitate integration of these approaches. Incentives for

working across disciplinary silos, especially from funding agencies, could help foster innovative research and policy development.

CAREGIVER OUTCOMES

Although caregiving is beneficial for societies at large, its effects are borne by the individual. In the Global South, research on unpaid caregiving is limited, especially studies assessing economic and health outcomes. Consequently, our framework is necessarily based part on research conducted in the developed world to identify theoretical and methodological pathways for research and policy in developing nations.

Economic effects of Caregiving

There is no country-specific evidence on the number of caregivers in the Global South. In the United States, however, 21% of the adult population is estimated to provide unpaid caregiving at any one time (NAC 2010 Health economists have estimated opportunity costs in lost wages (Pfoh et al., 2008), lost promotions, career changes, career abandonment (Timmermans and Freidin, 2007), loss of pensions (Arno et al., 1999) as well as the indirect non-medical costs of caregiving incurred by individual caregivers (Martinón-Torres et al., 2008).

Employment is pivotal to understanding the short- and long-term outcomes of caregiving. Caregivers who leave the labor force or provide care for more than 10 hours a week are unlikely to re-enter paid employment at the same level (Lilly et al., 2007), possibly making them financially vulnerable in the future even if they were not already. Income decreases as caregiving time increases, and increases in caring responsibilities have a larger and more immediate effect on the earnings of women than men (Bittman et al., 2007). A systematic review of research conducted in the United States, Canada, and Europe suggests that caregivers in poor

health are at greatest risk for leaving the labor force, working reduced hours, and reducing their earnings (Lilly et al., 2007).

Little research has explored the economic effects of caregiving in the Global South. One of the few studies explored the ability of working parents in Vietnam to care for their children and found that 63% of parents, most of whom were women, lost income or promotions or had difficulty retaining jobs due to caregiving (Vo et al., 2007). In China, welfare reforms that reduced care services resulted in women increasing their time caring for elders, less time in paid labor and fewer earnings (Lan et al., 2010). These studies suggest that in developing nations caregivers, especially women, face lower income, fewer assets, and greater financial hardship. Comparative studies across functional status (ability to perform one's physical, cognitive, emotional roles) would help identify caregivers at higher risk of financial vulnerability.

Compared to developed countries, little information exists in the Global South on how caregiving affects rates of labor force participation and earnings lost by caregivers. One exception is a comparative study of dementia caregivers in 10 countries in Latin America, three in Asia, and one in Africa in which many caregivers cut back or stopped work for pay to provide care (The 10/66 Dementia Research Group, 2004). An important, yet unanswered question for both the Global North and South is the direction of causation between caregiving and participation in the paid labor force. Do people leave paid employment to assume caregiving (employment status as an outcome), or do they take on caregiving in the absence of employment opportunities or employment (employment status as a determinant)? Although some scholars working on caregiving in the Global North argue that caregiving is exogenous to the decision of working for pay (Carmichael and Charles, 2003), others have found that the unemployed (those looking for work) assume more caregiving responsibilities while people outside of the labor

force (those not looking for work) have no increased probability of becoming caregivers (Henz, 2006). Whether these patterns are consistent across the globe remains unanswered.

Health Effects of Caregiving

Overwhelming evidence shows that caregiving burden creates strain (Pearlin et al., 2005). While caregiving-related strain appears universal across health conditions, there is little knowledge on its cross-national, cross-cultural, or cross-class variability that might help develop appropriate policies and interventions to reduce strain and negative health outcomes in the global south. One of the few cross-cultural studies available reports that caregivers of individuals with Alzheimer's disease in Taiwan, Hong Kong and the United States had different levels of strain (Pang et al., 2002). Researchers hypothesize that Chinese caregivers may have lower levels of strain than U.S. caregivers because of the influence of Confucian ideas that might make Chinese caregivers more accepting of care recipients' symptoms. More research is necessary to determine whether caregiver health outcomes in the Global North and South are expressed in the same ways. A corollary need is to validate health measures to the cultural context.

Understanding which groups of caregivers are bearing most of the economic and health risks of caregiving and their magnitude is key to developing appropriate policies for specific groups. Yet the dearth of knowledge regarding nations in the Global South is staggering. Identifying which demographic subgroups of caregivers are most vulnerable to reductions in earnings, to depletion or non-accumulation of assets, and to poor physical and mental health outcomes is pivotal for policy making, interventions, and the development and maintenance of human capabilities.

FACTORS THAT DETERMINE CAREGIVER OUTCOMES

Care recipient, caregiver, and household characteristics may determine caregiver outcomes in the Global South as they do in the North. Understanding under what circumstances burden and outcomes vary would allow much of the knowledge already available in the North to be adapted to the South, thus providing a “short cut” for research, policy formulation, and service implementation and evaluation.

Shown in Figure 1, we have organized our conceptual framework for assessing the determinants of outcomes discussed above into three levels that capture different factors associated with caregiver burden and their hypothesized relationships to economic and health outcomes. At the micro-level, we include caregiver, care recipient, and family factors that with individual-level policies and interventions could improve human capabilities. The upward arrows indicate causal relationships between micro-level factors and caregiving burden; the downward arrows indicate that caregiver outcomes may, in turn, affect factors at the micro-level. Caregiver and care recipient characteristics are framed outside these factors, showing that they are important in understanding the relationships among variables, but not modifiable and therefore, not subject to intervention.

Meso-level factors include socio-cultural norms that are within the social realm and influence of the caregiver (e.g., choice to provide care, community resources, social support networks). We suggest these factors influence objective and subjective caregiver burden and, ultimately, outcomes.

Macro-level factors include transnational and national caregiver support policies (e.g., workplace, care services, and caregiver payments). They affect caregiver outcomes but are outside the scope of the caregiver’s influence.

Micro-Level Factors

Caregiver Demographics

Caregiver characteristics, such as gender, age, and kinship to the care recipient, have consistently been associated with strain. Strong evidence exists that among all caregivers in the United States and Europe, women have poorer physical and mental health outcomes than men. This is in part because women are more often the primary caregivers, provide more intensive care to care recipients across all levels of need, and are more likely to provide care to the sickest care recipients and those with the greatest needs, including those needing assistance with ADLs and IADLs. Women also have more challenges balancing caregiving, paid employment, and other household and family responsibilities than male caregivers (Navaie-Waliser et al., 2002, Torti et al, 2004). Caregivers and women have been shown to have lower earnings than non-caregivers and men who are caregivers (Carmichael et al., 2010). A British study found that women in higher managerial and occupational professions assumed caregiving at a lower rate (Henz, 2006). Kinship may also matter. Caregivers of individuals with traumatic brain injuries who are spouses or partners experience more stress and strain than parents (Thomsen, 1984).

One U.S. study showed that not only female caregivers but those older, less educated, married, in lower occupational strata, co-residing with care recipients, and have fewest skills experience larger reductions in earnings; even when caregiving stops, women have more difficulties recovering from the losses (Wakabayashi and Donato, 2005).

Care Recipient Demographics and Functional Status

In the Global North, care recipient characteristics, including their stage of life (infant, toddler, child, adolescent, adult, elder) and/or their condition, illness, or disease and its severity are the strongest predictors of poor health outcomes for caregivers. These factors are often

indicators of the time and physical, emotional, and cognitive labor that care recipients require and the kinds of material goods and services care recipients need. For this reason, the caregiving literature in the health sciences is often organized by the disease of the care recipient (e.g., infectious disease, chronic conditions, trauma, rehabilitation, disability) or the type of formal health care that care recipients require because of the stage of their condition or disease (e.g., prevention, in-patient care, outpatient care, nursing care, and terminal/palliative care). Although caregiving for individuals who need ADL support generates strain, caring for recipients with cognitive or mental health conditions (e.g., dementia) appears to generate even more strain than caring for those with a physical condition (e.g., cancer, asthma) (Vithayachockitikhun, 2006). Few studies have explored whether a caregiver's expectation of required caregiving length will affect their outcomes. We suggest that knowing the horizon of care is likely to help caregivers manage their role. For example, the intensity of caring for healthy children as they develop has a predictable time horizon marked by developmental milestones. Caring for chronically ill elders, however, is less predictable since their condition might change with time, and neither the death of the care recipient nor the end of caregiving is foreseeable. Studies in the area of critical care and of traumatic brain injury report that caregivers need clear information on prognosis to be able to deal with the uncertainty, but such studies are limited to acute care and do not extend to long-term care, let alone to unpaid caregiving (***)

Key questions remain on how caregiving affects human capabilities, including the relationship between participation in paid labor and caregiver strain, and how it varies by care recipient and caregiver characteristics. What is known is that the amount of time caregivers spend in that role determines both health and economic outcomes. Studies have shown that stress and strain among caregivers of people with brain injuries remains high even 10 to 15 years

post injury (Verhaeghe et al., 2005) and that income decreases as caregiving time increases, especially among women, as mentioned above (Bittman et al., 2007).

Caregiver Resources

In health sciences, intra-personal resources are often conceptualized and examined as a means of buffering the relationship between burden and outcomes. When caregivers have well-developed intra-personal resources, they can better manage stressors, reduce burden, and improve outcomes. Intra-personal resources often categorized as educational resources, such as health literacy or the ability to access adequate and accurate information, or as cognitive resources, such as mastery (the individual perception that one is able to master certain tasks) and self-efficacy (the confidence in being able to perform tasks) and often addressed by training caregivers in a timely and culturally appropriate way. In the United States, lessons from caregiving interventions for chronic conditions suggest that meeting the educational needs of caregivers can improve caregiver knowledge, and improving mastery and self-efficacy have been the most effective interventions for improving well-being among caregivers of dementia and elderly patients (Gilliam and Steffen, 2006, Rabinowitz et al., 2006).

Few studies on the economics of caregiving, however, take into account the social, cognitive, and emotional factors when studying the financial and economic decisions of caregivers, leaving gaps in our understanding of how intra-personal resources affect financial outcomes for caregivers.

Household Resources

Household characteristics also can play a role in poor outcomes. How a family functions or manages problems and challenges can affect how a caregiver reacts to burden and can influence the amount of resources a family designates to care (Sander et al., 2002). If families are

effective in managing problems, they can act as advocates, translating family norms to others, and help and support those who are primarily responsible for providing care. Reports of family strife and marital distress due to caregiving, however, are common. Families often disagree about how and how much care should be provided or the impact that providing care has on other family members or household responsibilities (Gwyther 1995). A number of U.S. studies have documented that among married patients with a traumatic brain injury, 30 to 50 percent of marriages had dissolved within a decade of the trauma (Verhaeghe et al., 2005), although other studies refute this finding and suggest that families may stay together despite a tragedy (Kreutzer, 2007). What remains clear is that strong family cooperation can promote better health outcomes for caregivers (Ergh et al., 2002), but that when families fracture because of caregiving, they leave caregivers and care recipients without the added resources families provide and thus vulnerable to poor outcomes.

Family conflict can stem from disagreements on balancing caregiving with other work. The majority of research on family/work balance has examined this from the worker's perspective, but not from how the family perceives the conflict or how family members bargain over the different aspects of care. In fact, only recently have scholars begun to disaggregate the "family" in family/work balance to caregiving/work balance. Scholars studying caregiving populations in the United States (van Ryn et al., 2010) and home-based workers conducting unpaid labor including caregiving in Thailand (Floro, 1995, Floro and Pichetpongsa, 2010) have found that additional role demands, such as having more than one dependent or one or more jobs, may be an additional sources of stress. Understanding the impact of multiple roles, such as being paid workers, parents to small children, caregivers of dependent adults, and single breadwinner,

can affect human development and what policies and programs could be implemented to reduce poor outcomes from juggling multiple roles is a wide-open field in the Global South.

Meso-Level Factors

In developing nations caring for dependents is considered women's work. Social norms about who is allowed or obligated to be a caregiver and on whose behalf likely vary by age and kinship. Examining social norms will help to identify how assignment rules affect caregiving outcomes and limit human development.

Social Norms: Why and How Caregiving Is Assigned to Women

Women's dominant role in caring for dependents has been explored at length by feminist economists, sociologists, and historians. Feminist economists have argued that the social norms of how caregivers are assigned their role reinforces female disadvantage, altruism, and rules of familial obligation (Badgett and Folbre, 1999), impairing any collective political and economic power women may have in choosing to become caregivers (Folbre, 1994), and undermining social change to persuade men to bear some of the work and costs of care (Badgett and Folbre, 1999). Health sciences scholarship, however, has largely viewed the analysis of caregiving motivations as gender-neutral. Some sociologists and family studies scholars have suggested a solidarity model by which strong familial ties determine an obvious "choice" in caregiver (Bengtson and Roberts, 1991), a model that has been critiqued for its over-emphasis on altruism and love and its views of the family as a consensual unit (Luescher and Pillemer, 1998). Others have suggested caregiving assignment is simply a function of individual ambivalent feelings of affection and resentment toward the care recipient and societal norms and resources regarding caregiving (Luescher and Pillemer, 1998).

Undoubtedly, some caregivers do care work out of love and familial obligation, yet over time some caregivers may become, what Folbre calls, prisoners of love (2001). Others may be captive from the start. Is it possible for women to challenge their cultural designation as caregivers based on economic necessity, or do social norms trump the need to work for pay? Does asset ownership, formal employment, or a steady stream of income allow women to negotiate with kin on who will do what for whom? Context-specific explanations of how caregivers come to provide care may help us understand who becomes a caregiver and for how long and on whose behalf. In addition, a caregiver's rationale may relate to her emotional response to the care work or the level of stress from her caregiving. As Folbre has stated, "Multiple structures of constraint describe a complex game board, but raise the question of how people play" (1994, 66). Finding out exactly how individuals come to be caregivers is a challenge because family life is a mixture of selfishness and altruism, making it hard to separate what individuals may want (which includes "why people care" due to social norms) from how they get what they want.

Most research on caregiving in developing nations focuses on child rearing and unpaid labor, and as previously stated, often makes no distinction between the two. The scholarship in the Global South does reveal the intricate maneuvers that women engage in to be able to work for pay while still fulfilling the social norm of keeping house and raising children. Naila Kabear's ethnography of women who enter paid employment, to give but one example, examines the strategies used to bypass notions of family honor in Bangladesh and language and cultural barriers to employment among Bangladeshi immigrants in London (2000). What remains a constant in the experiences of poor women is that they negotiate to work for pay but not about childcare responsibilities. In short, the burden and outcome implications of having or not having

a choice in providing care for children are moot for most mothers since few opt out of caring for their children, which is not the case for other types of caregiving, such as for a parent, siblings, or grandchildren.

Research conducted in the Global North has found that caregivers of relatives with dementia have poorer health outcomes if they had no choice over providing care (Burrige et al., 2007), although there is no specific information on their economic outcomes. A few studies on how such caregiving is assigned across cultures and within families in the Global South provide a glimpse of emerging patterns. A study in Mexico, for instance, reports that the selection of caregivers for parents is usually made by men, the oldest sibling, or the care recipient and that men are generally excluded as an option for caregiving, as women often are in the formal labor force (Robles, 2001). In Sub-Saharan Africa, researchers have found that although adult women are culturally designated as caregivers, the large number of adult deaths from the HIV/AIDS pandemic has increasingly led to girls' becoming full-time caregivers of surviving family members, forcing them to stop attending school and thus limiting their capabilities (Kipp et al., 2007). Clearly, who provides care, for whom, and how that is decided has consequences for the distribution of burden and the economic and health outcomes of caregivers. Our call to distinguish caregiving from other forms of unpaid labor suggests that a productive area for future research is understanding how care for recipients who are not young children is assigned and how the degree of choice afforded caregivers influences their objective and subjective burden.

Research has also shown that, under certain circumstances, individuals can negotiate or oppose cultural assignment of the caregiving. For instance, a recent study in Latin America finds that women in the formal labor market negotiate the distribution of filial care with female siblings (***) . Further research may find that around the world, women subject to the paid work

schedules may negotiate their way out of particular responsibilities, a strategy unavailable to those working in the informal, unpaid sector or in subsistence activities. But a potential caregiver with low emotional resources may also find it difficult to oppose caregiving than someone with good emotional health; and domestic violence may be used as a means of coercing an individual into caregiving; or relatives may use their assets in exchange for caregiving services (***)).

Additional knowledge about caregiving labor in the Global South could be developed by future research linking self-reported caregiver explanations of how they came to provide care to their burden and health and financial outcomes, including possible negotiations with other relatives regarding direct and indirect costs of caring. Combining findings and methods from the health sciences and economics can elucidate such links, the former providing measures that capture how caring affects family functioning and conflict and the latter the theoretical and methodological background to assess choice in the context of bargaining.

Resources and Support Available to Caregivers

Future research may also find that caregivers who have social and community resources (e.g., friends and extended family, non-profit organizations, and neighborhood associations) use them to distribute caregiving activities and as emotional support. Research in the Global North suggests that meeting the resource and social support needs of caregivers plays a positive role on caregiver health, as it can decrease their perceived burden and distress and increase life satisfaction (van Ryn et al., 2010, Upton and Reed, 2006). A study in Vietnam among parent caregivers of disabled children finds mothers' health strain is reduced by support from extended family and friends, while fathers' strain is reduced by professional support (specialized health and educational services) (Shin and McDonough, 2008). Studies on dementia show that

economic and social support resources have a positive effect on the health outcomes of caregivers (van Ryn et al., 2010). Yet, a multi-country study of dementia has found that the cultural stigma of conditions such as dementia can undermine social support and increase strain (The 10/66 Research Group, 2004). Community centers, formal social support groups, and educational campaigns regarding such conditions can be effective interventions. Future research in the Global South could examine the availability and use of social resources by different caregivers and their effect on caregiver outcomes.

Macro-Level Factors

Macro-level factors can be international, national, or local policies that unintentionally affect caregivers, such as the reduction in public service provisioning as a cost-cutting measure to balance national budgets which has transferred much of the care to families and increased caregiver economic burden (Akintola, 2008; Himmelweit and Land 2008). We focus exclusively on policies intentionally formulated to influence caregiving. Research in this area, however, is not well-developed, especially in regards to caregiving.

Conventions established by international organizations and then proposed, ratified, and legislated by nations can serve as a starting point for alleviating caregiving barriers to participation in the workforce, reducing the negative health consequences of caregiving, and distributing caregiving more evenly between men and women. Current research on the three main types of supportive policies for caregivers that nations can implement--workplace policies, caregiver services, and caregiver payments--has shown that although providing payments to caregivers allows them to remain at home with care recipients and is the strategy followed by countries most interested in reducing healthcare expenditures (Arksey, 2007), such payments provide an incentive for those with little income to leave the labor force and thus place

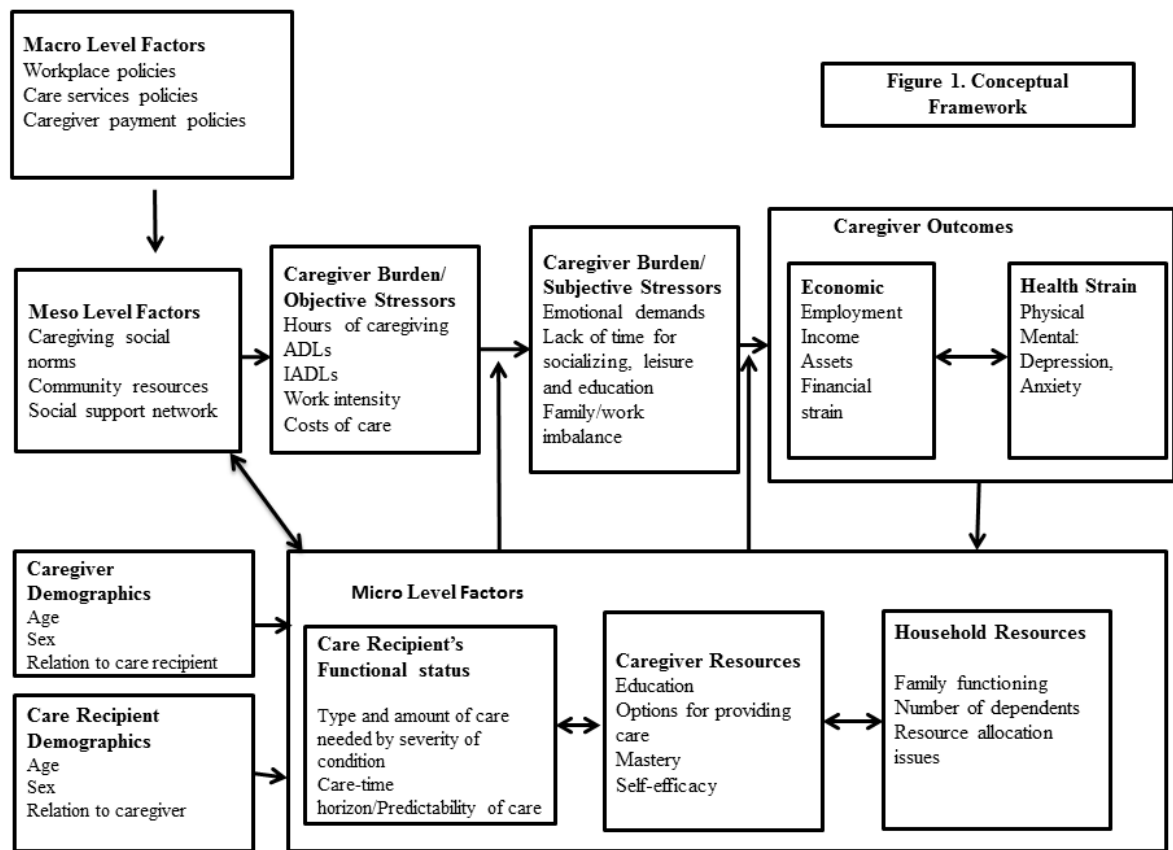
caregivers in further financial vulnerability when payments end (Lilly et al., 2007). Whether any of these policies or any combination of these policies reduce caregiver burden, strain, and financial penalties in cost-effective ways has been much less explored than micro-level determinants in either developed or developing nations.

How macro-level policies determine caregiver outcomes thus is a largely unexplored field for research in the Global South. Most studies focus on child care showing that unaffordable and/or poor-quality daycare for young children is a common reason why parents, most often mothers, decide to leave the labor force, as is the case in Vietnam (Vo et al., 2007). One of the few comparative multinational studies available exploring the effect of parental leave and child care provision in Canada, Italy, Germany, and Sweden found that while policies do facilitate paid work-force participation, differences in pay between men and women and context-specific social norms also influence the amount of time men and women spend providing care for their children, with women still providing more care than men (Pacholok and Gauthier, 2004). The study found that when parental leave is gender neutral--and even if it is generous--women are still more likely to use it because they are typically paid less. This underscores the need to develop and evaluate complementary policies, such as pay equity policies, that could minimize the financial incentives that affect how men and women distribute their time between work and caring. Similarly, wider implementation of effective and evidence-based policies, such as Sweden's non-transferable parental leave for mothers or fathers, can support broader changes in social norms.

EMERGING OVERARCHING RESEARCH AND POLICY NEEDS

Minimizing the negative economic and health consequences of caregiving for caregivers requires a multidisciplinary approach that integrates the tools of both economics and health

sciences to conduct research that informs the development, implementation, and evaluation of appropriate and effective social policy. In addition to the specific research discussed above, several interrelated, overarching research and policy needs are identified in Table 1, organized into micro-, meso-, and macro-levels.



Ideally, caregiving support policies would be universally available. However, widespread coverage is unaffordable in most developing nations. Therefore, determining which groups of caregivers have the heaviest burden and poorest outcomes is critical to providing social and health services to care recipients that alleviate negative caregiver outcomes. This requires two basic research efforts. The first, at the micro-level, is to gather information on the prevalence

of caregiving by care recipient condition. Prevalence data is scarce for many health conditions, including those that appear to be on the rise in the Global South and typically have a heavy caregiver burden, such as dementia (The 10/66 Dementia Research Group 2004), mental health and cognitive disabilities (Shin and McDonough, 2008), and conflict-related physical disabilities.

Table 1. Summary of Research, Policy, and Intervention Needs

Level	Research Needs	Policy and Intervention Needs
Micro	<ul style="list-style-type: none"> • Prevalence studies of <ul style="list-style-type: none"> ○ caregiving by care recipient ○ caregiver burden and outcomes by care recipient status • Needs assessment studies by <ul style="list-style-type: none"> ○ Care recipient needs ○ Caregiver needs ○ Service organizations needs ○ Workplace needs • Refinement of measurement tools to be context specific • Evidence on effectiveness of interventions on caregiver burden and outcomes 	<ul style="list-style-type: none"> • Design and allocation of services to fit high-need caregivers <ul style="list-style-type: none"> ○ Workplace policies including <ul style="list-style-type: none"> ▪ Gender equity ▪ Diversity in family structure ○ Social and health services for care recipients <ul style="list-style-type: none"> ▪ Health services ▪ Child day, adult, respite, nursing care ○ Social and health services for caregivers <ul style="list-style-type: none"> ▪ Education/training on managing care recipient's needs ▪ Education/ training on self-efficacy and mastery ▪ Education/training on professional services ○ Caregiver payments • Evidence-based policy implementation and service delivery
Meso	<ul style="list-style-type: none"> • Cultural context, social norms • Effect of social support on burden and outcomes <ul style="list-style-type: none"> ○ Stigma <ul style="list-style-type: none"> ▪ care recipient condition ▪ being a caregiver ○ Community resource needs 	<ul style="list-style-type: none"> • Culturally appropriate policies and interventions • Educational campaigns on conditions • Social support via community-based group
Macro	<ul style="list-style-type: none"> • Evaluation of provision of caregiver supportive policies <ul style="list-style-type: none"> ○ Workplace policies ○ Social and health services ○ Caregiver payments ○ Cost effectiveness 	<ul style="list-style-type: none"> • Ratify international conventions • Legislate caregiver supportive policies • Include men, diverse family structures, and caregiving situations • Evidence-based policy formulation

The second effort is to assess the burden and outcomes of caregivers by care recipient condition. These data could provide policy makers with information on the magnitude of caregiver support required and facilitate the identification of groups of caregivers most at risk of financial and health vulnerability. It would provide the basic information needed to determine the demand for caregiver support policies, including childcare, adult daycare, nursing homes for the elderly and disabled, and respite and hospice, which could be fully or partially provided or subsidized.

To design policies and intervention that fit the context-specific needs of care recipients and caregivers, especially considering the scant resources typically available, requires a thorough understanding of unmet caregiver and care recipient needs and of the processes and personnel in service organizations that could be put in place to meet these needs and improve outcomes.³ Training and education can provide caregivers with information about care recipients' short- and long-term outlook and resources for professional services (medical, legal, administrative) to help manage their responsibilities. Training can also help caregivers develop skills that can then improve their self-efficacy and mastery in their role.

Identifying the impact of caregiving on work sectors, in particular those with a high rate of female employees, such as export processing, can identify strategies that can accommodate the caregiving demands of employees and reduce costly high turnover rates, such as adequate paid and unpaid leave (***)). Needs assessments across these groups would allow more thorough planning so that material, financial, human capital, and time resources can be used more effectively and efficiently.

Interventions can be developed to reduce the caregiver health burden and improve health outcomes. In the health sciences, implementing and evaluating interventions is a well-developed

area that multidisciplinary studies can emulate. Developing pilot and demonstration programs can minimize costs and improve policy and service delivery and promotion of programs.

At the meso-level, facilitating social support via community resources (e.g., parks, community centers, social support groups) is another strategy known to improve outcomes. Using these resources to promote educational campaigns that can inform communities and different sectors in society on conditions may reduce stigma and improve the use of available services. Even so, programs can fail or not be effective if they are not culturally appropriate. Given the stigma of many conditions, culturally sensitive approaches, including an understanding of why a condition might be stigmatizing to the care recipient, the caregiver, and among specific social groups, are critical to developing appropriate policies and interventions. Investigating the cultural appropriateness of interventions can be done during the needs assessment or the evaluation phase of any intervention.

At a macro-level, little progress has been made in formulating and passing legislation addressing these three areas of policy. The majority of countries in Latin America and the Caribbean, for example, have not signed ILO convention 156, which mandates equal treatment for men and women with family responsibilities. Nor have they signed ILO convention or 183, which stipulates at least six weeks of paid maternity leave, even though between 1990 and 2008 women's participation in paid work in the region increased from 32 to 53 percent (ILO and UNDP 2009). The number of women who enter the work force will continue to increase, creating a greater demand for caregivers. Therefore, national policies are needed to alleviate individual caregiver burden and diminish national and employers' costs related to absenteeism, worker rotation, and training of new workers. Nations that have not ratified the conventions should do so. Nations that have ratified them should review their legislation to fit the ILO

framework (ILO and UNDP 2009). National legislation should be reviewed to include men and diverse family structures (heterosexual, homosexual, transgender, single parents, parents by adoption) to allow the same caregiving rights and convey the same caregiving obligations to all individuals. Such policy may be more effective with information and education campaigns that promote cultural changes to include men as caregivers, as previously called for (Folbre, 1994, 2001). In addition, nations should form anti-discrimination policies and educational campaigns to ensure that all individuals, regardless of gender, use the policies without social and work-related penalties. Last, policies should be formulated based on evidence of efficacy at a local and national level. Evaluations should assess, for example, if providing supportive workplace policies increases labor force participation, and if so, among which groups of caregivers. Likewise, national-level studies should be able to answer whether providing payments to caregivers diminishes participation in the labor force, and if so, among what groups. The adoption and dispersion of supportive policies for caregivers need to be widespread and evaluated to assess if their intended effects are indeed taking place.

CONCLUSION

The burden of being a caregiver traps individuals in poverty by limiting their capabilities. This article's attention to how caregiving affects the potential for developing the human capabilities of caregivers and care recipients alike parallels the World Bank's recent call to focus development efforts on social and health service provisioning for the poor at the village, town, and country level (WDR, 2004). Based on insights and tools provided by the health sciences and economics, we have provided a conceptual framework for identifying caregiver populations at risk of poor economic and health outcomes and delineating which determinants may be the most fruitful for targeting caregivers at greatest risk. In this way, the available scholarship on

caregiving provides multidisciplinary research pathways and policy interventions to diminish gender-based inequity in care in developing nations.

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¹ Hirway has argued (2010) the classification system of activities originally used in time-use surveys (TUS) by developed nations is not applicable to the needs of developing nations in which substantial segments of the population are dedicated to informal work activities. The new classification system is designed to meet the specific needs of developing nations. A drawback of TUS is their current lack of international harmonization of concepts and methods (Hirway 2010). Our definition can be implemented in the harmonization efforts by gathering sufficient background information on care recipients and other non-dependents. TUS can measure simultaneous activities; therefore, it is possible to know if a woman is performing childcare and subsistence agriculture, or if the water carried home is for care recipients who are dependents, independent, or both.

² The Zarit burden inventory is commonly used to assess subjective burden (Zarit, et al., 1980).

³ The authors recently conducted two needs assessment studies in the United States. The first assessed care recipient, caregiver, and service organizational needs (***) and was instrumental in guiding the development of a system of care incorporating family caregivers, specialty units within hospitals, outside service, and support organizations for US service members injured at war. This study was designed by adapting the techniques of rapid rural appraisal used by anthropologists in developing nations. The second study detailed caregiver burden and outcomes for family members caring for injured service members (***)