

Part VI
Connecting to Dynamics:
The Health and Illness Career

Chapter 23

Life Course Approaches to Health, Illness and Healing

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The life course perspective provides a theoretical framework, concepts, and analytical tools for examining how individual lives unfold in historical and institutional contexts. Nearly a half century ago, C. Wright Mills described the task and promise of the sociological imagination as the ability to “grasp history and biography and the relations between the two” (Mills 1959: 6). In the intervening decades since Mills’ plea for the sociological imagination, life course scholars have illuminated both the challenge and promise of this endeavor, focusing on the importance of a dynamic view of individuals and their social contexts. The growth of a wide array of large, longitudinal data collections and the increasing availability of a wide range of statistical tools for longitudinal analysis have made attention to the dynamics of lives in context increasingly possible. In turn, interest in innovative methodologies and the availability of large, national data sets that focus on particular life stages, such as adolescence, midlife, or later life, have encouraged more scholars to incorporate elements of life course perspective in their research.

In many respects, scholars interested in health, illness, and healing are at the forefront of these endeavors as they increasingly frame research questions about health within the context of particular life stages, examine effects of early life events on later health outcomes, and explore dynamic pathways of health and health correlates across the life course. The rapid growth in attention to life course concepts in health research has moved from being a specialized perspective applied to a specific set of topics to a core framework that defines a wide range of research questions.¹

While health scholars have embraced and enlightened many aspects of the life course perspective, there are other dimensions of this perspective that have remained underutilized in framing questions about health, illness, and healing. We contend that these neglected areas of the life course perspective can raise new questions and offer new insights into enduring questions about health, illness, and healing. In this chapter, we discuss two areas central to the life course perspective that have been underdeveloped in health research and explore some of the unique contributions that these dimensions of the life course perspective can bring to our understanding of health illness and healing. The first neglected area we will discuss is the life course perspective’s emphasis on indi-

¹For example, comparing the content of articles published in the *Journal of Health and Social Behavior* from 1986 to 2006, in 1986 none of the 28 articles published referred to the life course in the title or abstract and only four referred to life course concepts in either the title or the abstract. In contrast, 4 of the 28 articles published in 2006 mentioned the life course perspective explicitly in the title or abstract, and 11 (or nearly 40%) invoked key life course concepts such as timing, sequencing, life transitions, age/cohort analyses, or specific life stages.

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vidual agency within constraints. The second neglected area is attention to intersections between historical and institutional change with life trajectories.

Before turning to these neglected areas of study, we first review key elements of the life course perspective, including attention to variation in North American and European approaches to the life course (Marshall and Mueller 2003). Next we review several emerging areas where attention to the life course perspective is already broadening our understanding of health and illness. We then turn to neglected areas and suggest the types of questions that might be raised when these elements of the life course perspective are taken seriously. We close with discussion of the challenges of taking these issues seriously and ways that health researchers might overcome these challenges.

Basic Principles of the Life Course Perspective

The life course perspective has been informed by a wide range of disciplines ranging from sociology and demography to history and human development. As scholars from these disparate perspectives have elaborated various life course themes, it has, at times, been difficult to clearly identify what is, or is not, within the domain of this perspective. In response to this growing interest in the life course, Glen Elder (Elder et al. 2003) has specified a systematic set of life course principles that are central to the study of social change and individual lives. Elder has developed these principles from his long and influential program of research on the life course. As noted by Marshall and Mueller (2003), Elder's approach reflects a North American approach to the life course. While there is substantial overlap, Western European approaches to the life course perspective tend to differ from those in North America, and these differences are instructive. We thus begin by discussing each of Elder's principles and then consider differences between North American and Western European uses of the life course perspective.

Principle #1: Human Development and Aging are Life-Long Processes

While individuals face unique challenges and opportunities at different points in the life course, one of the major contributions of the life course perspective has been to shift attention to connections and pathways across the life course. For health researchers, the recognition that biological, intellectual, and social developments are not just occurring in childhood and that experiences in later life are shaped by a life time of opportunities and constraints has generated a wide range of new questions about patterns and pathways across the life course, which life course patterns are most salient for health, and the mechanisms underlying the unfolding of those patterns.

Recent research documenting the connections between early and later life health (Blackwell et al. 2001; Hayward and Gorman 2004) and the impact of poverty or mental health problems on educational attainment and the transition to adulthood (Guo 1998; McLeod and Kaiser 2004) illustrates the importance of looking beyond temporally proximate influences to consider more distal processes. Likewise, questions about when advantage and disadvantage accumulate and when disparities are stable or decline across the life course offer new insights into the production of health disparities (DiPrete and Eirich 2006; Dupre 2007; Guo 1998; McLeod and Kaiser 2004; Willson et al. 2007).

Principle #2: The Antecedents and Consequences of Life Transitions, Events Vary According to Their Timing in a Person's Life

A natural extension of attention to dynamic processes is the recognition that the meaning of an event differs depending on when it falls within the life course. The timing of an event may be important because of where it falls relative to biological or psychological development, because it affects other age-graded roles (such as school completion, or retirement), or because of normative expectations about the correct time for events to occur. For example, the optimal age to become a parent in the USA falls roughly in the 20s (Mirowsky 2002). Those becoming parents earlier than this optimal age face interruptions in schooling and restricted investment in career development while those who become parents after this optimal age face greater risks of physical health problems. Norms about the correct timing for parenthood and other life events also exist to varying degrees across different racial/ethnic groups and persons may experience negative consequences if they violate these norms (Jackson 2004; Neugarten et al. 1965).

Principle #3: Lives are Lived Interdependently and Sociohistorical Influences are Expressed Through This Network of Shared Relationships

The life course perspective is not alone in its emphasis on the interdependence of each person's life with others, but it does offer unique insights into the dynamic interplay between the lives of significant others. For example, attention to the coupling of careers illustrates how career patterns and decisions such as retirement are often coordinated between spouses or partners and are often contingent on earlier work and family trajectories. Women's decisions about retirement are particularly likely to be shaped by the timing of the spouse's retirement as well as prior history of combining work and family (Han and Moen 1999; Henretta et al. 1993).

Health events clearly illustrate the interconnectedness of lives, the ways that an event in one person's life impacts others, and how these interconnections may play out over time. For example, when an individual has a serious health event they may need to leave the labor force or stop working for a period of time but the effects of that health event also spill over to the work decisions of other family members. Women, in particular, are likely to assume care of ill or disabled family members and are at increased risk of leaving the labor force and experiencing their own health decline when they do so (Dentinger and Clarkberg 2002; Pavalko and Artis 1997; Pavalko and Woodbury 2000). The effects of caregiving extend far beyond the period of time when care is provided, increasing the risk of poverty in later life (Kingson and O'Grady-LeShane 1993; Wakabayashi and Donato 2006), thus also increasing risk of future health problems.

Principle #4: The Life Course of Individuals is Embedded in and Shaped by the Historical Times and Places They Experience over Their Lifetime

Each birth cohort experiences historical events at a distinct point in their life course, thus creating unique experiences for each cohort that differ from those in other cohorts. This basic demographic fact provides a powerful engine of social change, because it means the same historical events will be experienced differently by different birth cohorts and that each cohort will experience a unique

combination of events in their life time (Ryder 1965). Cohort differences will be particularly sharp when timing effects are strongest. For example, attitudes are malleable in late adolescence and young adulthood and then stabilize as individuals settle into work and family roles (Alwin et al. 1991; Alwin and McCammon 2003). This impressionable period in the life course can create unique cohort perspectives because each cohort encounters influential historical events at different points in their life course.

Given the rapid and widespread change in health care institutions, ranging from the current scaling back of national health insurance in Great Britain (Armstrong 1998), the rise of managed care (Scott et al. 2000; Wholey and Burns 2000), and the transformation of mental health care from institution to community (Grob 1994; Mechanic 1989), there are numerous ways that our understanding of health, illness, and healing may be better informed by attention to the ways that historical and institutional change. We will return to elaborate this issue later.

Principle #5: Individuals Construct Their Own Life Course Through the Choices and Actions They Take Within the Opportunities and Constraints of History and Social Circumstance

Given that the emphasis of many life course studies is on transitions and trajectories across individual lives, it is surprising that there is not greater attention to the choices, decisions and motivations behind these paths (but see Clausen 1993; Hagan 2001). However, an even greater challenge is simultaneously illuminating these choices and decisions and their boundedness within social structures, or what some refer to as agency within constraints. The life course perspective offers two avenues for incorporating agency within constraints into our understanding of health, illness, and healing. Instead of framing questions in terms of causation *or* selection, the life course perspective focuses our attention on the dynamic interplay of the two (George 2007). Second, attention to lives in historical and institutional contexts focuses our attention on variation, not only in outcomes but also in opportunities and constraints surrounding the choices individuals have available to them. We will further elaborate these potential contributions below.

Insights from European Approaches to the Life Course

Although the North American approach to the life course recognizes the importance of institutional structures in the life course, European models have tended to give more explicit attention to the role of institutions and structures in the life course (Leisering and Schumann 2003; Marshall and Mueller 2003). Marshall and Mueller (2003) argue that one reason for this difference may be the tendency for North American life course scholars to take a structural–functionalist approach defining structure by status positions and roles, while many European scholars invoke a more concrete and institutionally based concept of structure. The prominent role of the welfare state in many European nations and the dramatic change in state structures in countries such as Germany may also have contributed to the greater attention to the state and institutions in European life course research (Leisering and Schumann 2003). Regardless of the reasons for the difference, European theorizing and research on the life course provides numerous examples of the ways institutions regulate individual lives (e.g., Heinz and Marshall 2003; Leisering and Schumann 2003; Mayer and Schoepflin 1989; Schaeper and Falk 2003).

Medical institutions and the state play a key role in the regulation of health at all stages of the life course. In addition to defining who does or does not have access to care, institutions define what

is or is not an illness (Conrad 1992), which problems have the highest priority for treatment and research, and how inequities that serve as fundamental causes of disease are tackled. Our understanding of these types of connections between institutions and individual health has been limited, but as we argue below, it is a critical area for future research for health scholars wishing to take the life course seriously. Before elaborating on this point below, we now review several areas of research where the life course is expanding our understanding of health, illness, and healing.

Emerging Life Course Contributions to Health, Illness, and Healing

In this section, we review examples of the current and emerging approaches to studying health from a life course perspective. Our review of this burgeoning field is by no means comprehensive or exhaustive, but it does reflect a core theme running through much of the current work in this area – attention to dynamic health processes across the life course. In particular, recent life course studies of health share a focus on the long-term processes that affect health over the life course and attention to changing circumstances over the life cycle. Much of this work seeks to understand the emergence of physical and mental health disparities, and as a result places a strong emphasis on the dynamic interplay of health with status characteristics such as socioeconomic status, gender, and race/ethnicity (McDonough and Berglund 2003).

Emerging research on health from a life course perspective is demanding methodologically and has been aided by recent statistical innovations and data collections. Research in this area is generally quantitative, data intensive, and technically sophisticated. The life course perspective's emphasis on long-term patterns, combined with the availability of longitudinal data sets that now cover substantial portions of the life course and advances in methodological techniques, has led to a proliferation of studies examining trajectories of dynamics such as individual change over time and important inter-individual differences in change over the life course. For example, growth curve models allow researchers to examine how factors such as the experience of long-term economic advantage or disadvantage, as well as individual characteristics such as race/ethnicity and gender, affect health and well-being. In one of the earliest examples of growth curve modeling in health research, Maddox and Clark (1992) examined age-related trajectories of functional impairment in a cohort of employed older adults just prior to retirement, finding variation in functional impairment and differences in both initial levels of impairment and subsequent trajectories of impairment. Patterns varied considerably by age, sex, economic status, and educational attainment, and their research pointed to the limitations in making broad generalizations about the degree and trajectories of impairment among older adults. In a recent examination of age growth trajectories in depression among older adults, Yang (2007) found that increases in depression with age were explained by life course events such as health decline, widowhood, economic hardship, and negative life events, demonstrating the importance of distinguishing between age and cohort effects in understanding depression. Yang's research advances the literature on age and depression through its focus on disentangling the confounding effects of age changes and cohort differences.

The life course perspective draws attention to cumulative processes that create variation in life trajectories such as health and economic status, and the majority of studies on health from a life course perspective in some way addresses this process. Cumulative advantage/disadvantage theory (CAD) explains a process through which early advantages and disadvantages become compounded over the life course, leading to greater intracohort inequality at the oldest ages (Dannefer 1987, 2003; Merton 1968; O'Rand and Hamil-Luker 2005). Within the CAD framework, inequality grows with age as the result of the accumulation of social and personal resources, human capital, and economic returns to education in the form of income and wealth (DiPrete and Eirich 2006; O'Rand 2001). In sum, in its most basic form, cumulative advantage suggests that early advantage continues

to grow over time, conceptualized in terms of increasing returns to resources, such as education, and increases in intracohort inequality.

Used initially to explain variation in scientific careers and then later labor market inequalities by age (e.g., Dannefer 1987, 1988; Kerckhoff 1993; Merton 1968; O'Rand 1996), more recently researchers have begun using this theory to address the accumulating effects of socioeconomic and other resources over time on later life health. Although much of the literature can be characterized as motivated by CAD questions, studies take several different approaches. In a recent review of the CAD literature, DiPrete and Eirich (2006) identified a number of conceptual distinctions regarding cumulative advantage as a mechanism generating inequality across the life course. Although most studies address some combination of concepts, these distinctions can be identified in the health literature.

One strand of CAD research specifies a process whereby a prior state influences one's current state and has both direct and indirect long-term consequences (DiPrete and Eirich 2006). These studies link early life conditions to later life health and well-being, typically the relationship of early childhood diseases or hardships associated with low SES to mid- and later life outcomes. Numerous studies have demonstrated enduring effects of early life experiences on later life outcomes through both direct and indirect mechanisms that link childhood conditions to the health of adults, as well as direct effects of adult conditions. For example, Hayward and Gorman (2004) examine the effects of social conditions in early life on later life mortality and find that early disadvantage sets in motion are a series of "cascading socioeconomic and lifestyle events" that have negative long-term consequences for adult health. Using retrospective data on childhood economic hardship experienced by respondents now in old age, Kahn and Pearlin (2006) find that chronic economic strains have effects that are independent of current financial strain and income, and that the duration of strains is more important to well-being than their timing. And in their research on pathways between early environment and heart attack risk across the life course, O'Rand and Hamil-Luker (2005) find that early disadvantage leads to later disadvantage and an increasing difficulty managing and responding to new insults to health. These studies demonstrate that histories of hardship have enduring effects on well-being over time and the importance recognizing continuity and change in the dynamic relationship between social circumstances and health.

Other studies in this vein focus on the life course concept of *duration* to model the direct effects that long-term exposure to a particular status or state, such as the persistence and duration of poverty, may have on the rate of the accumulation process. The long-term processes examined in this conceptualization of CAD create extensive data requirements, and therefore relatively little empirical attention has been given to this area. One of the few examples is Kelley-Moore and Ferraro's (2004) analysis of the cumulative disadvantage of obesity across the life course from which they conclude that long-term obesity accelerates health decline. Their findings also point to the importance of considering compensatory mechanisms (in this case, exercise) in tempering the effects of early disadvantage. A second example is McDonough and Berglund's (2003) examination of the effect of poverty history on trajectories of health. From almost 30 years of longitudinal data, they observed that persistent poverty early in life predicted health disparities, but that cumulative exposure to poverty was not related to over-time change in health trajectories; initial differences in health remained constant over time (also see McDonough et al. 2005). Overall, our understanding of the cumulative effects of the duration of time spent in an advantaged or disadvantaged state as a mechanism generating health inequality across the life course is limited.

A second variation of cumulative advantage processes focuses on between-group inequality that results from the persisting direct effects of a status variable or as the result of variation across groups in rates of return to initial resources (DiPrete and Eirich 2006). Despite a growing body of research examining cumulative advantage as a mechanism generating life course inequality, little empirical attention has been given to whether cumulative advantage processes operate the same across groups over time (George 2005). Existing research has demonstrated that racial disparities in health result

from a long-term and cumulative process of disadvantage that begins in early life (Hayward et al. 2000; Warner and Hayward 2006). Studies in this area attempt to disentangle complex relationships between race, socioeconomic status, and health, such as Kelley-Moore and Ferraro's (2004) research which finds that black–white trajectories of disability diverge until controlling for changes in social and health factors, which eliminates the racial gap in health. This is an area of research receiving increasing attention. For example, a special issue of *Research on Aging* is devoted to research on race, socioeconomic status, and health from a life course perspective, with a focus on age, cohort, and period.

A third line of research models cumulative advantage as a process that produces growing rates of return to socioeconomic status with age and examines the extent to which trajectories of health diverge and health inequality based on socioeconomic status increases over the life course. This cumulative process is typically specified through the estimation of growth curve models that include interaction terms between age and socioeconomic status, and a significant and positive interaction coefficient is interpreted as support for cumulative advantage. Studies of this type have produced the most inconclusive evidence. A key question still under debate is whether cumulative advantage implies a process that continues indefinitely, or whether it slows upon reaching a particular critical age. Some longitudinal studies find that the SES gap in health diverges throughout most of life and then converges in the oldest old, or in other words, that the health advantages of socioeconomic resources diminish upon reaching a critical age value, evidenced by converging trajectories in later life (Beckett 2000; Deaton and Paxson 1998; Herd 2006). This slowing of the cumulative advantage process is framed as the age-as-leveler hypothesis and is often presented in competition with cumulative advantage as a mechanism of change in levels of health, inequality across the life course. Other studies have found support for a process of status maintenance, whereby intracohort levels of inequality remain stable over the life course. For example, McDonough and Berglund (2003) observed that persistent poverty earlier in life predicted initial levels of health, but did not affect change in health as people age. In contrast, there also is evidence that the SES gap in health continues to grow into old age (Dupre 2007; Lynch 2003, 2006; Willson et al. 2007). For example, Lynch (2003) found that the relationship of education and health strengthens with age and is becoming stronger across cohorts. Importantly, Lynch demonstrates that without accounting for both age and cohort in the analysis, the patterns would not have been detected. Dupre's (2007) use of hazard models to predict the effect of education on disease onset suggests that, with age, less-educated persons experience increases in the incidence of disease at a higher rate than the well-educated. And Willson et al. (2007) find evidence of a slow process of accumulation of advantage and disadvantage that, over long periods of time, produces sizable disparities in health.

The inconsistent evidence produced by these studies stems from several factors. First, data sets cover different spans of time. In contrast to the research reviewed above, conclusions from early studies were based primarily on cross-sectional or longitudinal data covering very short periods of time (e.g., House et al. 1990, 1994; Miech and Shanahan 2000; Ross and Wu 1996). The inconsistent results produced by this body of research on cumulative advantage have been attributed in part to the confounding of the effects of age and cohort that occurs with the use of cross-sectional data. The issue of disentangling age, period, and cohort remains a challenge to life course research and is related to choice of methodology and model specification.

But perhaps most important is the debate around the impact of selective mortality and attrition, which has the potential to produce biased estimates, another potential source of conflicting results. The strong association between low SES and mortality at younger ages and across the life course leads to an increasingly nonrepresentative group of hardy survivors among the disadvantaged group. As a result, their health at older ages does not differ greatly from that of the advantaged group, producing health trajectories that begin to converge at older ages (Beckett 2000; Lauderdale 2001). The difficulty of assessing selective mortality has led to much discussion and concern but few empirical assessments regarding its influence. Studies that have incorporated corrections for

selection bias into their analyses find evidence that selective attrition results in biased estimates (Ferraro and Kelley-Moore 2003; Willson et al. 2007). However, Beckett's (2000) lack of support for selective mortality as an explanation for converging health trajectories in later life has been the subject of debate (Lynch 2003; Noymer 2001). The disproportionate attrition of those with low SES contributes to the apparent convergence in health outcomes and affects conclusions regarding mechanisms of inequality across life course processes (Willson et al. 2007). Disentangling these methodological and conceptual issues will no doubt continue to generate innovative research with the potential to contribute to the conclusions we draw about inequality and age more generally.

Neglected Areas of the Life Course Perspective in Health, Illness, and Healing

While medical sociologists are increasingly using the life course perspective to ask new questions and gain new insights into health, illness, and healing, this focus on CAD processes draws primarily from the view of human development as a life-long, dynamic process that dominates much North American life course research. In the remainder of this chapter, we explore two additional ways that the life course perspective may offer new insights into health, illness, and healing. First, we discuss the role of individual agency in shaping the life course and discuss how life course concepts may contribute to our understanding of health. Second we turn to insights from both North American and European life course approaches that address the importance of historical and institutional change for shaping the life course and discuss how these might be applicable to questions of health, illness, and healing.

Agency Within Constraints: Applications to Health, Illness, and Healing

Social psychologists have recently called for greater attention to selection processes, and more broadly, to the importance of individual agency in understanding relationships between social structure and health (George 2007; McLeod and Lively 2007; Thoits 2006; Thoits and Hewitt 2001). The life course perspective's interest in agency within constraint is consistent with this call and offers several useful tools for this endeavor. As described by Peggy Thoits (2006), personal agency is "evidence that people make choices or decisions, acted intentionally or deliberately, formulated and followed plans of action, or set goals and pursued them (Bandura 2001)." Thoits (2006) also notes that not all selection processes reflect the same degree of agency, and she introduces the useful distinction between social selection and self-selection. While social selection processes reflect structural influences that define the opportunities available, self-selection reflects the choices and actions individuals take. We suspect that most selection processes do not fall neatly into one category or the other but rather fall somewhere on a continuum between the two. Nevertheless, when discussing agency and selection, Thoits' point that we are primarily interested in self-selection is an important one. There is growing evidence that attention to self-selection is important for understanding the health consequences of an event (Thoits 2006; Thoits and Hewitt 2001; Wheaton 1990).

Recent attention to agency and self-selection contrasts sharply to the traditional stress process model (Pearlin 1989, 1999), which frames much of the research examining the effect of social structures and inequalities on mental and physical health (Link 2003; Thoits 2006). In order to clarify the impact of social structures on health and well-being, causal effects of social structures on health have been separated from the influence of health and well-being on the roles and statuses

people hold. The latter are isolated from the causal processes of interest and ruled out as either inconsequential or statistically controlled.

Attention to causal order is an important step, but by framing these processes solely in terms of “selection” and viewing them as nuisances to be controlled and ruled out, we have not given attention to ways that individuals actively construct their lives and enact the resources they have to avoid or deal with adversity, and how those decisions may interact with social structures. While we want to avoid “blaming the victim,” we do not want to ignore the power individuals have and use in shaping their own lives but must also consider the role social processes play in shaping the extent of this power. The life course perspective embraces the role of agency in structuring the life course, while also recognizing that resources and constraints create wide variation in the degree of agency individuals hold. However, a concrete understanding of the ways that individual agency and social structures interact and relate to health and well-being remains in its infancy (Marshall and Mueller 2003).

One way that the life course can contribute to this broader interest in agency is through closer attention to the temporal unfolding of processes, including attention to trajectories and sequences of events. As noted by Linda George (2007), life course theorists rarely think in either or terms of causation and selection, focusing instead on the temporal unfolding of social processes and illness. “The pathways or trajectories often include lagged effects, reciprocal effects, and/or cyclical effects – temporal patterns that cannot be easily categorized as selection or causation effects” (George 2007: 191). The life course view of lives as cumulative and dynamic forces us to consider, not just where people are now and how that affects their health and well-being, but also where they have come from and how they got to this point.

Research investigating the effects of employment on health and well-being provides one example of both how research questions have typically been framed and how attention to this reciprocal, dynamic interplay can improve our understanding of health. A key interest in research on employment and health has been to identify the components of work, and more recently, work and family, promoting or endangering health. Just as work environments that require work with heavy machinery, fumes and other hazards place workers at greater risk of physical harm, and job stress also poses health risks. While a number of job stressors such as heavy demands and low control (Karasek and Theorell 1990) have been identified as risk factors for mental health problems and cardiovascular disease, researchers have increasingly recognized that health also selects persons into and out of the labor force and into and out of certain types of jobs, a process often referred to as the “healthy worker effect.” The “healthy worker hypothesis” is often presented as an alternative to the primary theoretical interest in causal effects of work environments on health (Khlat et al. 2000; Klumb and Lampert 2004; Pavalko and Smith 1999; Ross and Mirowsky 1995; Waldron and Jacobs 1988).

Attending to health selection is an important first step, but it is limited because it frames selection and causation as competing, independent processes. There is growing evidence that these processes are not fully independent from one another but instead that the work–health relationship is reciprocal. In other words, health plays a role in whether and where people work, but health is also affected by those jobs (Link et al. 1993; Pavalko and Smith 1999). Rather than trying to isolate these independent influences, attention to the dynamic, reciprocal nature of these influences may improve our understanding of the work–health relationship. Job transitions and statuses are imbedded in a work history that includes an accumulation of work experiences and, in many cases, prior transitions. For example, a life course approach might raise the following questions: how do the job histories and cumulative work experiences of those who change jobs or leave the labor force because of health problems compare with those who have health crises but do not make job changes as well as with those who do not have health crises? Are those whose job histories include extensive work in high demand and low control jobs at greater risk of leaving the labor force because of health problems? Does longer duration or more recent work in a high demand and/or low control job put one at greater risk of a health-related job exit than more distant work experiences?

While each of the questions above focuses on the work career, they also offer a unique perspective on questions of causation and selection from that provided by traditional approaches. Rather than defining transitions out of the labor force because of poor health as independent of work structures and job decisions, they question whether these “selection” processes may themselves be influenced by previous work structures. By viewing work and work transitions as imbedded with a broader career, we thus gain greater tools for exploring the interdependence of work and health.

Historical and Organizational Change and Illness Careers

A second neglected contribution of the life course perspective in the study of health, illness, and healing is the focus on how lives unfold within organizational and historical contexts. While much of the growth in life course research has emphasized dynamics across individual lives, a recurrent theme has been the impact of historical context and change on life paths (Elder 1974/1999; Haraven 1982; Pavalko and Elder 1990). International research on the life course has emphasized the effects of the state or organizational structures on the life course (Heinz and Marshall 2003; Mayer and Schoepflin 1989; Titma et al. 2003; Zhao and Hou 1999).

The organization, financing, and delivery of health services have undergone dramatic change over the past half century, and these structural changes have consequences for individual health, access to care, doctor–patient relationships, and the power and autonomy of the healing professions. While scholars have documented and analyzed these organizational changes (e.g., Quadagno 2004; Scott et al. 2000; Wholey and Burns 2000) and an extensive body of research on health services has assessed how health service use and treatment effectiveness is altered by program changes, we lack a broad understanding of how the organization of health care shapes the illness experiences of those needing services (but see Pescosolido 1991, 1992, 2006; Rogers et al. 1999). The life course perspective’s focus on historical and institutional change can provide valuable concepts and tools for addressing the intersection of health care organizations and illness experiences.

The illness career concept is particularly valuable for exploring the intersection of medical institutions and individual illness experiences. The initial development of the illness career concept stemmed from the early ethnographic studies of the Chicago School (Barley 1989; Goffman 1961; Hughes 1937). As defined by Hughes and others, the illness career was dual-sided. The illness career reflects, on one side, one’s personal experience of the career and on the other side, institutional positions. While careers are experienced by individuals, those experiences only take shape as individuals move through positions and enact the roles associated with those positions (Barley 1989). Just as occupational careers take shape within occupations, illness careers take on form and meaning as an individual moves through formal and informal treatment systems (Clausen and Yarrow 1955; Pescosolido 1991, 1992, 2006). The dual-sided concept of illness career thus provides a potentially valuable tool for exploring how individual health is shaped by the organization of healing and health care.

The example of mental illness careers is illustrative of this dual-sided nature of the career. At the individual level, various life course concepts are useful for understanding patterns of treatment as people move into, out of, and through the mental health treatment system. For example, Fig. 23.1 highlights broad patterns of exit after a first hospitalization contrasting those who have a steady decline or improvement from those who have a more fluctuating course of care (Pavalko 1997). For purposes of illustration, we organize our example around the critical event of the first hospitalization, and focus on variation in paths after this key turning point. The bottom path indicates a pattern of recovery and independent living, while the top represents a course of steady disability requiring long-term residential care. While indicating very different outcomes, these two contrasting pathways reflect persons who remain relatively stable after initial treatment or hospitalization.

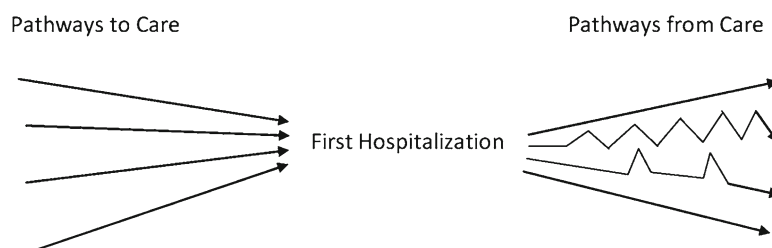


Fig. 23.1 Illustration of illness career patterns [source: Pavalko (1997)]

In contrast to these stable paths, the two middle paths represent fluctuating courses of care, for patients who either move back and forth between the hospital and the community (i.e., a revolving door model) or remain living independently in the community with only one or two short episodes of rehospitalization. The value added by focusing on the patterns of care, rather than just a snapshot of how people are doing at a single point in time, becomes more clear when we compare the bottom two lines on the right-hand side of the figure. If viewed at one point in time, persons following these two paths may look like they had similar levels of recovery, despite the fact that they reflect two very different courses of illness experience.

Beyond general patterns, the life course perspective offers a variety of additional concepts that may be useful for distinguishing different dynamic elements of the individual's movement through treatment and recovery. For example, turning points in the illness career, the sequence of movement between hospital, residential facilities, the criminal justice system, and independent living, and the pace of movement between any or all of these institutions all provide different types of information about the individual's treatment experience (Pavalko 1997).

However, mental illness careers do not just unfold across the individual's life course. They also take shape in a rapidly changing institutional context that in the USA included not only a move away from institutional care but also a complete transformation in the system of care as well as treatment philosophies. In the first half of the twentieth century, the mental hospital *was* the mental health system, but by the late twentieth century, a complex system of care including acute and long-term hospitals, day treatment, treatment teams, group homes, nursing homes and community mental health centers was in place to treat persons diagnosed with mental disorders (Pavalko et al. 2007). Because they unfold across both personal and historical time, illness careers thus reflect both individual and institutional dynamics.

In a recent study we took a first step toward following individual patients over time as they move into, out of and through the mental health system during a period of rapid institutional change to better understand how the organization of mental health care affects treatment experiences and outcomes (Pavalko et al. 2007). Sociologists have long questioned the extent to which treatment, or societal reaction to treatment, exacerbates or even creates mental disorder (Goffman 1961; Scheff 1966). In life course terms, this is a question of accumulation – whether there is an increasing intensity of illness or duration in treatment episodes as one accumulates more treatment experience, or what labeling theorists referred to as a downward spiral of care (Scheff 1966). Of even greater concern is whether this downward spiral is caused by the treatment rather than a natural progression of the illness but distinguishing these influences is difficult because they are so intertwined with one another. However, by assessing the extent of accumulation in the same patients before and after institutional reform we gain some leverage in addressing these questions. For example, we found that, prior to deinstitutionalization, there was strong evidence of accumulation, with length of prior hospitalization becoming an increasingly strong predictor of later hospitalizations, while illness characteristics a decreasing impact (Pavalko et al. 2007). However, after institutional reform the illness career was redirected, with prior hospitalizations no longer predicting risk of rehospitalization,

but illness characteristics such as diagnosis and severity of the illness becoming more predictive of rehospitalization.

The transformation of the mental health system in the USA and other countries has been followed by equally important changes in the organization and financing of medical care, including the growth of managed care systems in the USA or the restructuring of the National Health Service in Great Britain. There is little question that these changes have altered how and when people seek medical care, their use of both formal and informal care, and their experiences of that care, but specific information on the experience of illness as people move into, out of, and through these various organizations of care remain largely unknown (but see Pescosolido 1996; Pescosolido and Rubin 2000). While the specific types of questions will vary depending on the substantive example, attention to individual illness careers as persons move through a changing health care system offers medical sociologists powerful tools for conceptualizing and measuring the intersection of health care institutions and health care consumers.

Conclusions

In the 1960s and 1970s, the emerging life course perspective challenged researchers from a variety of disciplines to study lives “the long way” encouraging attention to how lives take shape and change through childhood, adulthood, and old age, while also considering how historical context and social change shaped those lives (Elder et al. 2003; Marshall and Mueller 2003). While sociologists, particularly from the Chicago School, had long studied careers and longitudinal paths across lives (e.g., Goffman 1961; Hughes 1937; Thomas and Znaniecki 1918/1920), attention to dynamic processes was viewed as the domain of qualitative research. In contrast, the emerging multidisciplinary field of life course studies viewed the study of aging processes, life course transitions and trajectories as critical in both qualitative and quantitative research and in samples both large and small. The challenge of studying lives over time was great, particularly since most large-scale surveys at that time were cross-sectional and statistical tools for analyzing these data were designed to assess variation across, rather than within, cases.

The progress in data and methods available for the dynamic study of the life course in the span of just a few short decades has been remarkable. Beginning with the investment in the 1960s in national longitudinal studies such as the Panel Study of Income Dynamics and the National Longitudinal Surveys, we now have numerous longitudinal data collections focusing on specific birth cohorts, life stages, and substantive areas. The growth in statistical methodologies to analyze longitudinal data has been equally impressive, and as a result, life course researchers have ample tools available for the dynamic study of change within and across lives including identifying trajectories and detailed analysis of the timing of specific events.

Research focusing on health, illness, and healing has been central to many of these endeavors. Just as health research has been broadened by the life course perspective, studies of health and health professions have contributed to the empirical and conceptual bases of life course studies. The emerging interest in CAD reviewed in this chapter is just one of many examples of this synchrony between health and life course. While we have made significant progress in understanding health dynamics, the life course perspective has much more to offer to health researchers. We have highlighted a few critical but understudied areas in health research, particularly the dynamics of selection processes and the intersection of organizational change and illness experience, that we feel can be better understood with conceptual and methodological tools offered by the life course perspective.

Even with the wide array of tools available to life course researchers today, including advances in data collection and statistical techniques, the task of fully engaging the life course perspective

presents several challenges. Data requirements for long-term longitudinal analysis are extensive. Despite major improvements in longitudinal data collection, researchers wishing to study paths across long periods of the life course are limited to available data collected during the time period of interest. In most cases, state-of-the-art measures and sampling procedures in place 30 or 40 years ago are out of date by today's standards, and one is restricted to the measures collected during that prior era (Elder et al. 1993). In other cases, longitudinal archives have updated or discontinued measures that are no longer in vogue, thus making it difficult to separate real change from measurement change in longitudinal designs. Thus, long-term longitudinal analyses are limited to the available data, but we contend that there is much that can be learned from longitudinal analyses of imperfect measures.

Advances in statistical techniques such as latent growth curve modeling, hierarchical linear modeling, latent class analysis, sequence analysis, and event history analysis all offer life course researchers powerful tools for temporal analysis of continuity and change. With this exciting array of tools, the greatest analytical challenge may be to retain life course theory and concepts as the driving force rather than having the newest methodology guiding research design.

However, probably the greatest challenge for life course researchers is presented by a core tension inherent in the life course perspective itself. Life course goals that emphasize understanding systematic patterns across lives and at the same time that attend to contextual variation create an inherent tension in life course research. For example, the process of identifying a manageable set of career paths in a particular domain, be it work, family, or health, requires that we obscure some of the complexity of people's lives. We might ignore key transitions or assume that those transitions mean the same thing for all persons following an identified trajectory. However, closer attention to the variation in the timing, meaning, or consequences stemming from a single transition risks losing sight of the broader trajectory in which that transition is imbedded. The strength of the life course perspective comes from the combination of these two dynamic elements, particularly when guided by a strong theoretical foundation, such as we have in research on health, illness, and healing.

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Chapter 24

The Complexities of Help-Seeking: Exploring Challenges Through a Social Network Perspective

Normand Carpentier and Paul Bernard

Complex Models in Health Sociology

By the end of the 1970s, the movement toward deinstitutionalizing mental health services had uncovered the complexity of developing a social model of care that would supplement, if not supplant, the traditional institutional model. The difficulties associated with the complexity of the social model of care are no less present today: some 30 years after the movement began, providing the right mix of community services and institutional care remains a delicate task (Thornicroft and Tansella 2004). Despite problems with the social model, however, the wave of deinstitutionalization of the psychiatric population in the 1970s was soon followed by an increase in community services for a second group: the growing population of elderly people. Ambulatory services for a great number of health problems were becoming less the exception than the norm and as time passed, it became evident that new treatments for chronic illnesses (serious psychiatric disabilities, cancer, Alzheimer-type dementia, etc.) and the emergence of a new biopsychosocial paradigm were leading researchers to consider several dimensions jointly rather than independently as they had done in the past. At the same time, the number of illnesses requiring long-term care was on the rise, and researchers began to analyze the help-seeking process more thoroughly, exploring such notions as community, networks of reciprocal obligations, and changes in values between successive generations (Mechanic 1989; Taylor and Bury 2007). This process led to the discovery of a serious mismatch: the public was reluctant to use the resources furnished by the medical community. This disparity between available resources and real needs was a major stumbling block in the attempt to create a social model of care. As a result, researchers came to question whether traditional healthcare models could cope with the changing reality of caring for chronic illness and whether they had sufficient explanatory power to bring new knowledge to a changing society (Pescosolido 1992; Silverstein et al. 2003). The response has been largely negative, making it necessary to develop complex models that consider such features of modern society as an ageing population, changing family structures, and the emergence of new kinds of solidarity, all of which have caused the State to redefine its role on an ongoing basis, especially in the light of globalization and fiscal pressures.

The new complex models of healthcare research thus developed have emerged in a number of fields, including population health (Berkman and Glass 2000; House et al. 1988), mental health (Pescosolido 1991, 1992, 1996; Rogler and Cortes 1993) and social gerontology (Litwak 1985; Messeri et al. 1993). While theoretical development is at different stages in different models, all

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consider the concept of social networks to be fundamental. For this reason, we have chosen to focus on networks as a means to examine the four central dimensions of complex models: structure, culture, multilevel effects, and temporality. In her presentation of a new complex model, Pescosolido asks an intriguing question: *Is there, in fact, a discernable set of patterns, combinations of options, or strategies that individuals use during an illness episode? And, if so, are these patterns socially organized* (Pescosolido 1992, p. 1115). This striking hypothesis evokes individuals' decision-making capacities, the concept of agency, and the idea that social behaviour can be attributed to various organizational structures, all of which are central issues in social network theory.

Working from this perspective, this chapter has two objectives. First, we discuss why the architects of complex models accord such great significance to the concept of networks and how researchers can address networks in a systematic manner. We recognize that network analysis is an inductive process founded on observations from the field. Accordingly, researchers who wish to work with the network approach must be careful to obtain empirical data that match the requirements for complex models, a far from simple task. For this reason, our second objective is to suggest relevant methods and identify the resources that scholars might use to answer the greater issue raised in this Handbook, with respect to our specific concern here: what if the sociology of health took social networks seriously? Our fundamental concern is how researchers can capitalize on the wealth of ideas and data offered by the network approach in order to better grasp social realities and develop innovative interventions and policies adapted to a social model of care. Because to take social networks seriously, we must pay attention to both conceptual and methodological considerations.

The first element to be considered in this endeavour might well be the relevance of social networks at the conceptual level. The growing complexity of modern society and the recent proliferation of different kinds of lifestyles have made it increasingly difficult to describe the social fabric in terms of traditional categories (Pescosolido and Rubin 2000; White 2008). In many circumstances, individual attributes are simply too imprecise to reflect today's empirical reality. While variable-centred studies can generate important information that helps to frame the subject under study, network tools are essential to defining the social and relational context, especially when individuals and families find unprecedented ways to cope with emerging health problems and to seek help. A network perspective, for example, helps modulate the personal characteristics of "divorced individuals" so as to reflect the process as well as the end result. Take the following examples: separated parents who maintain close ties in order to take care of a sick child; former spouses who form new families and develop extended supportive networks; previously married persons who experience social exclusion after they divorce. These examples show that questioning an individual on his or her marital status alone can only produce limited data. Previously rare arrangements have become more common and cannot be inferred from an individual's personal characteristics. Rather than asking yes/no questions, the conscientious researcher must determine the unique web of relationships for each actor and social group. While it is possible (and might be well-advised) to introduce measurements from population studies and network analyses into statistical equations, to truly take the idea of social networks seriously is to subscribe to a formalist paradigm (Simmel 1971); that is, a relational sociology in which the social world consists primarily of dynamic unfolding relationships (Emirbayer 1997).

If we take networks seriously at a conceptual level, we must take them seriously at the methodological level as well. This implies adopting procedures and research frameworks that sometimes diverge from conventional approaches. In this context, the network approach, which cannot be considered a theory proper, becomes an amalgam of tools and strategies that allows the researcher to take fuller account of the interactions, negotiations, and conflicts that occur between actors, both individually and collectively. Determining this web of relationships is far from simple (Marin and Hampton 2007). The identity of network actors, the cartography of

their relationships, and details of the links between network members cannot be ascertained with a few standard questions. The task is further complicated by the fact that it is difficult to evaluate the amount of time necessary to build a network, because this varies according to each actor's perception of the extent and dynamics of his or her network. Nonetheless, reconstructing the network is essential: the research community is presently moving from traditional models that seek to identify the factors that predict the use of services to complex models that aim to analyze the processes that lead to care pathways and determine their impact on health (Allen et al. 2004; Jones et al. 2009; Morgan et al. 2004). Social relations play a central role in this analysis.

The production of knowledge at this scale is admittedly still in the early stages and much research remains exploratory. Inspired by a few lead authors, however, the academic community has demonstrated considerable enthusiasm for projects that use a network perspective, and numerous researchers continue to apply themselves to perfecting indicators and developing theory (Degenne and Forsé 2004; Scott 2000; Wasserman and Faust 1994; Snijders and Doreian 2010). But development in this domain has been uneven so far, and scholars who work on indicators or try to explain social phenomena have frequently used easy-to-reach samples and populations far removed from the normal challenges of daily life. The development of "whole network" techniques (i.e., networks with closed boundaries that more easily fit mathematical procedures) is thus further advanced than that of "egocentric network" techniques. In addition, a large body of work has been conducted on themes in which subjects' actions can be explained by instrumental or rational motivations, reflecting the assumption that actors are utility maximizers: this had led researchers away from in-depth analysis of the relationship between social structure, agency, and culture (Emirbayer and Goodwin 1994, p. 1428). As a result, social network research has largely ignored a number of challenging fields, including health care (among exceptions, see Jippes et al. 2010; Levy and Pescosolido 2002; Lewis et al. 2008). And indeed, problems with the field of health care can be daunting. Addressing the question of service use in a chronic care setting requires dealing with populations that are difficult to recruit. It also means using techniques adapted to egocentric networks and approaching networks of people living in intense situations in which social relationships can quickly become complicated.

If, despite these obstacles, we persist in taking the notion of networks seriously and giving life to the complex models recently proposed, we must agree to study social relationships in crisis situations where networks are often composed of ambiguous relationships that contain the seeds of both conflict and support. While some of these relationships may be stable, others must be frequently renegotiated. We must also recognize the omnipresence of symbolic dimensions (social representations) and the constant human and social dilemmas that families face, making it difficult for them to set clear objectives. Furthermore, we must arm ourselves with tools and concepts that allow us to understand change. Finally, we must remember that the network approach was developed through a close relationship between theoretical advances and empirical analysis; consequently, the feasibility of data gathering must be a key consideration in the research process. Later in this chapter, we illustrate possible analytical avenues in relation to this last point, using one of the current projects of our research team as an example. In this project, begun in 2003, we formed a cohort of 60 caregivers of persons with Alzheimer's disease, with whom we met at 18-month intervals. Basing our analyses on the social network approach, social representation theory, and life history techniques applied within a multilevel and temporal framework, we sought to bring a new perspective to a field that continues to be largely dominated by individualistic models and the logic of rational choice.

In the sections that follow, we address three dimensions of the complex model of health seeking, namely the notions of structure, culture, and temporality. The first section addresses the notion of network structure, including the egocentric notion of networks and multilevel effects. We then move to the representation approach before discussing the sequential action approach.

Network Structures: Linking Individuals and Organizations

From the social network perspective, social structure can be defined as the linkages between individual and collective social actors as summed through an empirically established regularity of transactions (Emirbayer 1997; Erickson 2004). This understanding of social structure contrasts markedly with the definition of Marx, Parsons, or Weber (see Smelser 1988).

At first glance, it might seem relatively simple to reconstruct the network of an individual, a group, or an organization. A number of name generators with precisely this function have been developed over the course of the last few years. But each generator provides only one view of social structure. While some generators are designed to identify extended linkages (active and/or potential, direct and/or indirect, weak and/or strong, formal and/or informal), others aim to recreate an individual's primary network, the smaller and more stable environment in which self-confidence and identity grow. From the very beginning then, the study of relationships confronts the researcher with a crucial decision: which questions and research direction will allow him/her to construct a network that reveals the greatest possible number of facets of the object of analysis? An individual's description of his/her networks can only generate an incomplete image of interactions: under no circumstances can we expect to obtain all the data needed to account for the infinite subtleties of an individual's links and social relationships, especially when s/he is under the trying circumstances of chronic illness.

For our research programme, "Social Networks, Social Representation Project" (SNSR), we chose to use a name generator based on supportive relationships. Six questions allowed us to identify actors likely to provide our respondents, the caregivers, with emotional, instrumental, counseling, or companionship support. Our experience with this option leads us to make two observations. First, we must begin the data-gathering process by establishing a relationship with our respondent, especially if we hope to follow him or her over several years. The interview must be enjoyable and it is unrealistic to expect to obtain extensive network measurements, especially if certain aspects of our questions make respondents uncomfortable. We have, for example, frequently found respondents unable to discuss reciprocity, conflict, or intensity in the relationships among network members identified by the name generator. And a respondent who is made uncomfortable during an interview will be little disposed to see us again, especially if the illness has progressed and if his or her anxiety has grown since our last meeting. For this reason, we must sometimes reconstruct the nature of a respondent's relationships less formally, for example, by using material from his or her narratives. Our second observation is that supportive relationships are more complex than they seem. Some degree of simple classification is possible – one actor provides emotional support while another provides advice – but support can also be symbolic, invisible, stigmatizing, or pathological (Martuccelli 2002). If we are to exploit the notion of networks more fully, we must not only identify the functions of each link described by the name generator, but also attempt to discern the dynamics of the various elements working together as well as any differences between cases, differences that stem from respondents' subjectivity.

In addition to reconstructing an actor's relationships, network analysis allows us to move from one level to another by applying principles of extending and superimposing links and aggregates. For instance, Markovsky (1987) made propositions to theoretically integrate processes that operate at different levels. Without repressing individual actors or robbing them of their unique characteristics, we aim to imbed them within groupings that interact with other groupings also composed of individuals. Historically, the network approach has found fertile ground in organizational studies, and several classical network studies have analyzed political agencies (see Knoke 2004). In the field of health care, a number of concepts related to governance, integrated services, and network policy have originated in variations of the network perspective. Nonetheless, Dowding (1995) has shown that most research either continues to use

networks metaphorically or makes only partial use of data that would allow for structural analysis (but see Lewis et al. 2008 for innovative works). This difficulty in taking networks seriously is understandable and can be explained by the complexity of the methodology. The very first step, mapping the links between actors, is already complex. Following this step, however, researchers must also obtain information such as the frequency and means of contact, the methods used to transfer information, and the sinuous paths of decision-making; to do so, they must investigate the medical practices of individuals who are not used to divulging the information requested and have little interest in doing so (i.e., highly qualified medical staff). Furthermore, to the extent that these research procedures are used to generate reports of staff activities, it is not inconceivable that network analysis could jeopardize participants' confidentiality or even lead to management reprisals against staff. Several ethical obstacles to the study of organizations must therefore be overcome before we can expect participants to lower their resistance (Borgatti and Molina 2005).

Ethical issues aside, the very number of organizations now on hand to help the victims of chronic illness poses another challenge. The network approach is obviously a powerful means to understanding the internal logic of groups and the possible links between organizations with different ideologies and diverse practical orientations. But this field is as yet unexplored, especially when it comes to the interface between family, professional, community, and private systems. And yet, critical issues such as the balance between the supply and demand of services and the continuity of care hinge on the ways that those systems connect.

Drawing on Pescosolido's *Multi-Level Network Model* (1996) and Martuccelli's work on social roles and the notion of respect (2002), we undertook an exploratory study of the social care interface in early-stage dementia (Carpentier et al. 2008b). The aim of our study was to understand the linkage process and the interaction between formal and informal systems of care as seen through four dimensions: professionals' care practices, the relationships between health professionals and caregivers and internal and external environments (the team's network and the organization's network, respectively). Our rationale was that individual health trajectories are complex and undoubtedly influenced by the nature and configuration of health services available in the community (Allen et al. 2004). But here again, difficulties quickly arose. We found it difficult to interpret the links between formal and informal networks: one respondent might feel strongly connected to the network with only a few contacts per year (but with attentive listening by a professional), while another might be in frequent contact with professionals and still feel abandoned. Apart from strongly institutionalized links, it was, in general, difficult to ascertain with any precision the nature and strength of links between any two actors, especially when tension or incompatible values jostled for place with norms of solidarity and obligation. These findings explain our conviction that links are complex and cannot be summarized using sundry measurements of frequency, duration, or intensity as perceived by the parties at play.

In summary, the fundamental idea behind the network approach is to consider several elements simultaneously: nodes (the actors), lines (the relationships), direct effects (breaking a link), secondary effects (a change in the status of a network member), and multilevel effects (a health organization moves to a location nearby). Considering several elements at the same time allows us to first graph actors' positions and then use inductive methods to glean how relationships are structured, how groupings occur, and whether actors are positioned so as to take advantage of certain resources or turn to alternative strategies. Completion of this analysis puts us in the position to identify social inequalities and understand the processes that lead to social exclusion. The data generated by these kinds of studies is thus invaluable to deepening our understanding of the help-seeking process and the care trajectory as complex models aspire to do. But much creativity in the field of health care remains to be developed before we can hope to exploit the concept of networks to its full potential.

Network Content: Actors' Social Representations

In the early days of network theory, theorists floated the idea that structure alone could explain the behaviour of groups or individuals (Brint 1992; Fuhse 2009). Since then, this hypothesis has been largely discarded, and scholars now agree that social phenomena like help-seeking processes are best explained when the symbolic and discursive dimensions of networks are taken into account. We should note that concepts related to symbolic dimensions have historically had little place in traditional service use models, principally because of the lack of explanatory power of cultural variables in multivariate analyses (Kasper 2000). Today's researchers must therefore look for ways to integrate the notion of culture into studies on service use in the spirit of a relational sociology that fits the network perspective put forward by the authors of complex models.

Three conditions appear necessary for this venture to succeed. First, instead of considering network content to consist of individual values and attitudes, we must conceptualize it as an ensemble of normatively driven communications, relationships, and transactions that may head in different directions at the same time (Emirbayer 1997). For this reason, under ideal conditions, one would meet several respondents for each network; if only one respondent is available, however, it would be essential to solicit his or her perceptions of the positions of the other network members. The second condition addresses the fact that the form and the content of networks seem to follow a double-edged principle. The first is the principle of relative autonomy between current structure and content, meaning that an individual's identity, values, and beliefs are based on his or her life experiences, events, and past relationships. The symbolic universe is much broader than the structure described by an actor at any given point in time. At the same time, it is not completely alien: hence, the second principle of the continuous and dynamic nature of the interaction between network structure and network content. According to this last principle, network links allow information and symbols to circulate and uphold an individual's cultural universe. Members of a dense and coherent network with defined objectives, for example, share a common culture because messages conveyed by strong links encounter few obstacles and reinforce group values. While the prevalence of this kind of network in contemporary society is open to debate, networks inarguably experience great difficulty when a network member becomes subject to chronic illness and must be cared for at home: numerous studies have demonstrated how networks become destabilized and tensions grow when network structures undergo change and families are confronted by different systems and alien values. A final condition for the successful integration of culture into studies on formal services use lies in the creation of a methodology that captures network change: it must distinguish the form of relationships from their content, while recognizing that these dimensions interact and influence each other over time.

Keeping these three conditions in mind, our team developed a strategy that uses a qualitative approach to capture the symbolic content of networks (Carpentier et al. 2008a). A qualitative approach is useful for uncovering meaning, grasping the extent of changes, and exploring the interplay between individual and collective dimensions. Our work takes place within a sociology of action framework: we hold that social phenomena result from direct interactions between social actors. This framework can be made to converge with the logic of social network analysis, even though some versions of the sociology of action view social norms as a main driver of action and structure as a secondary aspect. The norm-based approach is not without problems, not least because of the discrepancy between the norms expressed by social actors and their actual behaviour. In other words, it appears that action contexts are part of a complex universe that cannot be reduced to a few normative parameters; norms are actuated in constraining contexts.

It is in this context that we chose the social representation approach as a means to plumb the depths of network content. Our strategy composed four steps. The first was to construct a databank of concepts that covered some of the many elements that help form social representations. Because

the literature on barriers to care covers a wide range of dimensions that could account for symbolic elements, we used an inventory of writings to identify 50 barriers to access to care: structural barriers (e.g., lack of access to trained physicians), relational barriers (e.g., conflict or lack of trust with professionals), cognitive barriers (e.g., normalization, denial), and cultural barriers (e.g., belief, norms, acculturation). Our second step was to identify the presence of those 50 barriers in the discourse of our interviewees, using content analysis. Our third step was to develop a conceptual model. As illustrated in Figure 24.1, our model is made up of six general concepts that comprise the 50 barriers referred to above. These 50 barriers cover the many facets that help form a respondent's social representations. In our study, the respondent is the caregiver of a person with chronic degenerative illness and is located at the centre of the model. The caregiver suggests a possible normative orientation for his or her network (which we could classify as collectivist, familiarist, or individualist), but content analysis reveals numerous other dimensions that influence the respondent's representation and impact his or her behaviour.

In the upper portion of our diagram, two dimensions refer to past experiences. *Social history* attests the quality of the relationship between the caregiver and his or her relative prior to the onset of disease. We consider a difficult or negative relationship to be a barrier to the use of services because relationship problems reduce interactions and negotiations between parties. The second dimension referring to past experiences consists in the caregiver's *experiences with assistance* in health problem situations. This concept is composed of three subgroups of elements: caregiver's past experiences with illness and health, his or her relationship with institutions (that is, his or her ideas about the responsibilities of institutions and attitude towards the healthcare system), and his or her perception of filial responsibilities and family values. At the centre of the model lie the *caregiver* and two categories of actors with whom the caregiver is in direct interaction. Caregivers report barriers such as acceptance or rejection of the disease by peers and tensions in relationships within the *informal system*, and facilitators such as medical referrals (each barrier has an opposite, that is to say, a facilitator). The next concept represented in the diagram is that of the *formal system's* response to the needs expressed by the caregiver. Here, the different positions held by formal and informal actors help shape and transform the caregiver's representations. Finally, the *social context* shapes the larger process and environment in which the family is embedded.

Guided by this model of social representations, by our command of the literature, and by Pescosolido's model of service use (1992), we turned to the final step of our strategy, namely the interpretation of the influence of representations on the actor's behaviour. We wanted to accumulate sufficient information to construct what Geertz has termed a "thick" description of situations

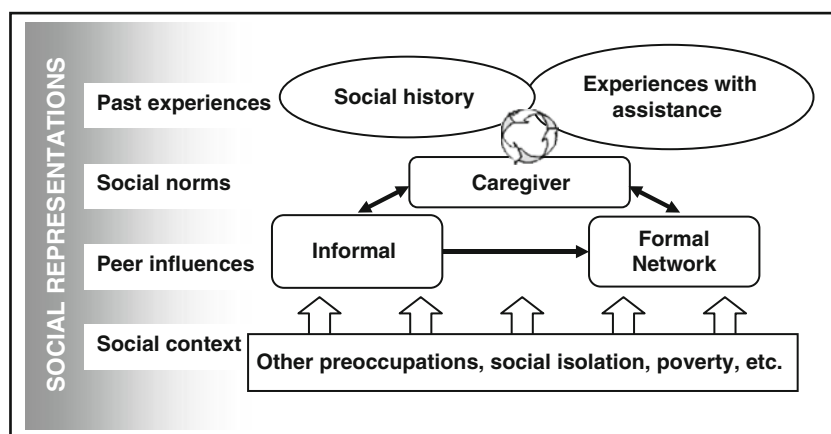


Fig. 24.1 Conceptual model of social representations

(1973), the best means of demonstrating the role of culture in social life. The structural approach of social representation theory allows the researcher to draw conclusions based on the frequency of occurrence of barriers as determined from the narrative material. Accordingly, we inserted all 50 barriers into a quadrant according to their frequency of occurrence, and in so doing produced a central system and three peripheral zones. Abric (1994) summed up the hypothesis of a central system as follows: “The organization of a representation presents a specific, particular modality: not only are the elements of the representation hierarchized but, what’s more, all representations are organized around a central core comprising elements that give the representation its meaning” (p. 19). Accordingly, the central system presents the dimensions most frequently identified in the discourse and gives us an indication of recurring, common themes shared by the majority. The first zone of the peripheral system presents a starker contrast in elements and may provide the basis for inter-group differentiation. The second and third peripheral zones present dimensions that could relate to the past, could play a role in future, or could serve to personify life histories and provide an idea of singularities.

This approach is a promising way to account for network content because it fulfils all three conditions mentioned above: (1) acknowledgment of the different positions of network actors who interact with the respondent; (2) the principle of autonomy/dependence between structure and content; and (3) concern for the ever-changing nature of the symbolic universe. The model proposed here (Fig. 24.1) systematically identifies sources of influence that might help form an actor’s social representations by acknowledging the importance of social actors who no longer belong to the network and by recognizing the daily, tangible links that influence an individual’s representations and ultimately affect his or her behaviour. Performed for each wave of interviews, this analytical process not only reveals changes in barriers but also demonstrates how respondents’ perceptions of the importance of those barriers change at different points in the care trajectory. Finally, with its use of central and peripheral zones, the model sheds light on the current debate on how individual status fits into culture. Let’s take one example: the supposed uniformity of values among members of a given ethnic community. While a given ethnic group might have a certain degree of collective identity, different ethnic communities have similar values and attitudes. The central zone thus captures the fundamental representation to which all actors ascribe, regardless of ethnic status, social class, gender, or the structure of the social network. In contrast, the peripheral zones can capture differences that do not necessarily correspond to predefined social categories (we are currently examining this possibility). According to network theory, social representations vary according to structural parameters, even though individual characteristics like age, gender, and social class will always bear weight.

Sequence Analysis: Exploring Social Processes

Like structure and the symbolic universe, temporality is a fundamental dimension of complex models. In our examination of these dimensions thus far, we have made only indirect reference to the dynamics of situation. In order to meet theorists’ ambitions, however, we must scrutinize the determinants of care pathways in greater detail, and this is where the researcher must choose an *action model* (Coleman 1986). Weber and Pareto are at the origins of the groundswell that produced one such model, the theory of rational choice. This theory has influenced traditional service use models to the extent that the “decision to seek care – and the choice of a specific provider – is often modelled using standard economic models such as those based on individuals maximizing their expected utility” (Shengelia et al. 2005, p. 98). According to this thinking, an individual instrumentally calculates the advantages and disadvantages of any given course of action and acts accordingly. She/he carefully sifts through available information and chooses the option that best meets his or her needs.

Rational choice holds that an individual's choice of alliances is strategic and opportunistic: people nurture relationships likely to further their interests.

Despite its popularity, the concept of rational choice has been contested by many social scientists. It seems particularly inappropriate in the case of chronic illness. As we have shown, the backdrop for decision-making in situations of chronic illness is largely made up of the interplay between network participants. Numerous cognitive, relational, and cultural barriers converge to create a complex system that constrains the actors' access to care. Far from witnessing rational actors working to maximize their profit, we observe mechanisms of decision-making in a context of multidimensional uncertainty. The unpredictable paths of chronic illness confront actors with a moral and emotional dilemma about the best course to follow: they are torn between the possibilities and frequently hesitate. Certain phases of the trajectory lend themselves well to rational choice, or even demand, but there is often no clear-cut best way to understand and handle the illness: actors must choose among a range of options that rest on contradictory assumptions. In these circumstances, any action or attempt at action impacts other players who subsequently reposition themselves in unforeseeable configurations because the lives of those involved are not insular but indeed interrelated. Furthermore, chronic illness often produces situations where precise objectives cannot be defined, where a single action can have multiple results, and where the serious nature of the consequences of many decisions requires the input of both central and peripheral care participants. Even after a decision has been made, uncontrollable events can call a chosen course of action into question at any time. In circumstances of chronic illness then, decisions can rarely be made on grounds of rationality: opposition and unforeseeable events are only too rife.

Once we reject rational action theory or at least question its relevance, the value of direct analysis of the process whereby an individual adapts his or her actions to the environment becomes apparent (Martuccelli 2005, p. 91). Over the past few years, studies have tended to address temporality with the concepts of careers, trajectories, or pathways, either by describing how an illness evolves through various stages or by enumerating the support resources sought at given points in time. Less frequent are studies that have looked at the social dynamics of the negotiations an actor must undertake in order to respond to the myriad phenomena encountered (Sørensen 1998).

A few researchers have nonetheless undertaken ambitious projects that attempt to evaluate the dynamics of change, for example, through narrative positivism (Abbott 1992), the creation of a "syntax" of social life (Abell 1987), or a formal approach for event sequence analyses (Heise 1991). This "return to the narrative" in the social sciences is part of a greater backlash against established analytical models and the purely quantitative treatment of data (see Bernard 1993, on causality). The new procedures use mixed methods and focus on the numerous challenges that face actors embedded within networks of relationships. The result has been a number of original studies (Stevenson and Greenberg 2000; Wiggins et al. 2007), many in the field of health care (Uehara 2001). Our team drew on these studies to develop a procedure to analyze action sequences (Carpentier and Ducharme 2005; Carpentier et al. 2010). Using a narrative approach and focusing our analysis on the concept of networks, we have attempted to identify the life events, negotiations, crisis episodes, and relationship structures that guide or hamper individuals in their search for and decisions to use formal, informal, or community care resources.

Figure 24.2 illustrates how narrative co-construction between the researcher and the narrator allows us to interpret action dynamics by looking at two networks at different points on the trajectory. Each interview solicits an "illness history" that allows us to analyze how the context of relationships has evolved since the last interview. Our first step is to evaluate the narrator's reflexive capacities. Symbolic interactionism holds that reflexivity is the process that accompanies action to the extent that actors can analyze the origins, procedures, and consequences of their actions. As Martuccelli has pointed out (2005), individuals constantly confront growing numbers of previously unencountered challenges and develop their reflexive abilities in consequence.

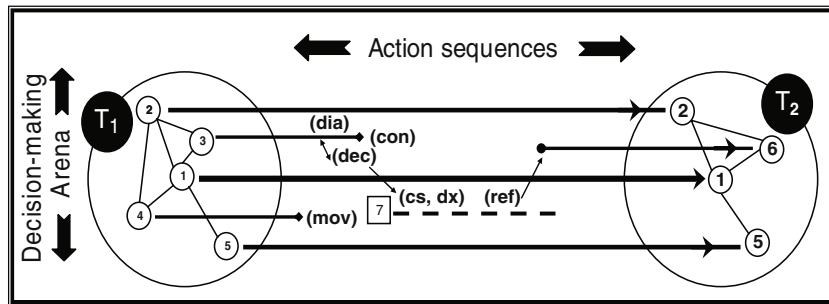


Fig. 24.2 Network transformation and action sequences

In affording us a personal interpretation of his or her life history, the narrator introduces us to the actors whom she/he considers to have participated in his or her decision-making process, either by blocking decisions or by facilitating them. Our diagram shows that five actors are active at T_1 and four are active at T_2 and that one of the actors at T_2 is new (two of the actors at T_1 having left the network). At this point, our goal is to explain the phenomenon of network change. This is not a novel endeavour: there exists a substantial body of literature on the structural principles that underlie transformation phenomena. Dense, closed networks, for example, are known to delay individual access to services, so that links with professionals do not emerge until later in the trajectory. There is also an extensive literature on symbolic elements: individualistic normative systems, for example, tend to cause families to disengage from their ill relative and delegate care to professional service providers, causing the network to include mostly nonfamily members. Our longitudinal procedure, however, uses the narrative approach and more direct observation to explore the general principles of network transformation. This allows us to be more precise in pinpointing mechanisms previously identified in the literature (and later to nuance them). Above all, it facilitates our simultaneous consideration of the structural (network) and cultural (social representation) dimensions of respondents' actions.

Figure 24.2 summarizes the action sequences thus: following a discussion (dia) with Actor 3, Narrator 1 decides (dec) to consult (cs) Doctor 7. This doctor makes a diagnosis (dx) before referring the family (ref) to Medical Specialist 6. During the same period, Actor 3 leaves the network because of conflict (con) over the narrator's interpretation of the illness and decisions about care. Actor 2, who was identified by the name generator as someone who provides emotional and instrumental support, does not participate in decisions during this period. Actor 4, who has been described as someone who provides companionship, moves (mov) to a new neighbourhood and the relationship ends. Actor 5 is a childhood friend and close confidant who is present at both T_1 and T_2 . The narrator has informed us that Doctor 7, who had been consulted in the past, is present for some time but that ties are cut after the family is referred to a specialist. This illustration of action sequences is somewhat simpler than those we usually encounter. More frequent are sequences involving many kinds of actors, both those identified by the name generator and those who do not provide support but are named in the narrative. Sequence analysis also commonly reveals subgroupings of action sequences.

Our tool analyzes actions sequentially in order to show how events can influence a life course within the observation period. Our coding system for "action-sequence trajectories" uses over 120 kinds of events to create a "syntax," which, among other things, situates the first signs of dementia, the beginning of the caregiver role, the creation of new social relationships, the end of relationships, the assistance-seeking process, the breadth of family resources, conflict resolution, and other life events (suicide, hospitalization, loss of employment, etc.).

Our diagram starts by reducing the complexity of social life to the principal events identified by the narrator, and then allows us to analyze the help-seeking trajectory from two perspectives.

The first perspective focuses on the sequential nature of actions: the sometimes simultaneous succession of occurrences such as meetings with professionals, changes in states of being (deteriorating health, for example), and associated decisions and experiences. Successive interviews reveal actors disengaging, sometimes to return; families attempting again and again to obtain professional help; and periods of great tension that leave a mark on the mental and physical health of those providing care. Studying sequences of these events reveals the cumulative effect of the many dimensions that mould the course of the care trajectory. The second perspective we use to analyze the help-seeking process focuses on the “decision-making arena” (see Fig. 24.2), that is, the pool of actors among whom the action takes place. This arena can be limited to members of the respondent’s support network but sometimes expands to include other actors and consequently accommodate new solutions that emerge as the illness evolves. The decision-making arena angle provides another view of trajectories and perhaps also a means of capturing weak ties. Weak ties are a central concept in network theory and theories of help-seeking processes. They are a singularly effective means of accessing other networks and they help to diversify information and increase the use of resources (Granovetter 1983). Identifying weak ties is a long and complicated process that has little place in interviews with actors grappling with serious, chronic difficulties, but life histories can be used to overcome these obstacles. Take, for example, the storey of a cousin who works in a hospital and informs the family about a specialized clinic, or the brief chat with a social worker at a neighbourhood party that starts the caregiver on a vast help-seeking mission. Both encounters provide useful information about the social elements that underlie the strategies of actors and their ability to interact with public organizations. Our preliminary results suggest that a range of weak ties is important to the first steps of the help-seeking process, but that a minimum of supportive actors is also necessary to retain links to formal resources. We suspect that while links with the outside world are never easy, continued dialogue with the informal network could be the factor that helps actors adjust their expectations and values so that a satisfactory relationship with formal resources can take place. It is interesting that in our study of caregivers to people with Alzheimer’s disease, few support actors seemed to take part in important decision-making; it is as if caregivers seek to protect the inner core of their networks, perhaps in anticipation of difficulties to come.

To summarize, we believe that care trajectories for chronic illnesses are a social construction that involves a large number of players; these actors observe each other and either create forums for constructive decision-making or elect not to cooperate. Because the information available to actors at any given point in time is always fragmented and open to interpretation, frequent misunderstandings, disagreements, and missed appointments are inevitable. In circumstances where actors have multiple goals, and especially in cases where the consequences of an action will not be known until years later, the model of the rational actor who assesses his or her choices and acts accordingly does not fit a complex and evolving reality.

Conclusion

The main goal of this chapter has been to present the contribution of a network approach to the construction of complex models of help-seeking in cases of serious degenerative illness. Our approach follows the tenets of relational sociology (Emirbayer 1997; White 2008), which, while little used, seems singularly apt at providing insight into care trajectories. Much of today’s research is dominated by surveys or experimental methods that abide by the biomedical paradigm or the framework of evidence-based medicine (Bond and Corner 2001; Dean 2004; Mykhalovskiy and Weir 2004). The network approach differs significantly from these methods by drawing on the teachings of the social sciences, stressing complexity, and attempting to integrate elements as disparate as individual subjectivity and wider contexts. By examining the dynamics of social actors

with different statuses and a plurality of interests, this approach can be uncomfortable to elites whose interests tend to lie with the status quo (Learmonth 2003).

This chapter has attempted to ascertain the challenges inherent in this research approach and suggest ways of meeting them. Our examples draw largely on our own experiences; other teams have adopted other solutions. Using social networks as their main concept, authors have launched a range of innovative studies. Some examine the linkage process between clients and healthcare organizations (Jinnett et al. 2002) or evaluate community-based healthcare coalitions using game theory (Ford et al. 2004); others assess neighbourhood effects on health interventions (Chiu and West 2007), propose new ways for programmes evaluation (Eisenberg and Swanson 1996), or seek to deepen our understanding of governance (Maturro 2004). This growing body of research nonetheless frequently neglects to draw on a comprehensive conceptual model, and complex models have led to only a small number of research programmes so far. It is our hope that complex models will not remain mere references for a few specialized projects, but will instead inspire a new generation of researchers to initiate original studies bringing fresh solutions to complex social situations.

Current interest in the direct observation of social relationships, whether performed on a small or a large scale, is making it more possible than ever to see how interactions affect the care trajectory. By moving away from a purely metaphorical interpretation of the concepts of trajectories, support networks, and the interface between services, complex models can provide us with a new perspective on interventions and on the links to and between organizations. That this perspective has become invaluable is evidenced by the growth in the number of assistance services with sometimes contradictory ideologies and practices and the concomitant threat of a scramble for resources offered by community, private, and public organizations. While individual variables are not sufficient to explain the phenomena at hand, it is clear that social status will always be a key factor. Even then, network analysis discerns the compensatory strategies adopted by disadvantaged families and identifies means of entry into social networks that are closed or resistant to outside assistance. In other words, it is entirely possible that careful observation of the social practices and solutions adopted by actors within their particular social and cultural context can lead to more appropriate interventions.

We must nonetheless proceed prudently in our interpretation of trajectories, for the three angles of analysis presented here (structure, culture, and dynamics) have a number of limitations. With respect to networks, for example, we can never be sure of the validity of the construct that results from the use of a given name generator. When we ask someone about his or her support ties, what do we actually obtain? How does the respondent treat complexity, particularly when a tie involves elements of tension or conflict? How does she/he regard new acquaintances, broken friendships, hasty reconstitutions, or separations, be they temporary or caused by profound disagreement? Is the respondent capable of identifying latent support ties that can be mobilized if needed? Can we hope to obtain valid data in line with theoretical expectations? Our analyses so far have demonstrated good validity for our network constructs (Carpentier and Ducharme 2007), but we cannot deny that reported social relations are never more than a reflection of an actor's representations at a given point on the trajectory. Our treatment of social representations also raises questions. To what extent, for example, do representations guide respondents' behaviours? Representations are likely to provide orientation, but only to the extent that they precede behaviour and guide future action. To complete the picture, representations can have other functions as well (Abric 1994): an identity-forming function, where respondents identify with a group or a culture, or a justificatory function, where actors use representations *a posteriori* to justify their choices and maintain consistency between their actions and their words. And finally, what about action sequences? Much of the material that we use to build trajectories relies on respondents' recollection: we can never be sure that the histories thus reconstructed will really reflect the facts. The actual number of doctor's visits, the true impact of a certain discussion with a friend, whether or not a conflict was the real cause for the end of a relationship: these are examples of questions that will always remain. Still, after analyzing

network data, social representations, and sequences of events in depth and over a long period of time, we think that we can draw a global portrait that, while imperfect, provides us with a relatively consistent image of the trajectories analyzed.

But the network concept is more than a powerful approach for the exploration of notions of structure, culture, and temporality: it also promotes the integration of theory and empirical research. Despite the jargon about interaction and social relationships and the resulting emphasis on collaboration, network theorists and researchers have tended to work in silos. This is regrettable, because the separation of the theoretical and empirical worlds does nothing to help the social sciences flourish in the field of health care. In fact, the more coherent, concrete, and action-oriented focus of the biomedical paradigm helps explain that paradigm's popularity. At the same time, however, the research programme of the biomedical model has increasingly engaged in quasi-routine activities that use standardized instruments and rote statistical procedures and may well hamper innovation. In contrast, the social science approach proposes an innovative analysis of social actors (both individual and collective) and leaves room for a range of research methods, promising a wealth of discovery in the process.

In closing, we may ask ourselves whether the procedures laid out in this chapter have brought us any closer to meeting the goals of the theorists of complex models and answering Pescosolido's (1992) question about the socially organized patterns that undergird the help-seeking process. But we can only answer after completing research programmes that cover the entire trajectory of care, use different research frameworks, and study various kinds of populations. At the very least, the network approach complements the data generated by traditional approaches and allows us to diversify our research questions. And a new look at service use problems is nothing short of essential, for two reasons. First, families are evolving and new kinds of solidarity have surfaced that we do not yet comprehend. Second, the healthcare system is straining to resolve a host of problems: the lack of compassion in the provision of care, an outdated technocracy, management techniques that are out of step with the social model of care, and an inability to control costs (Pescosolido and Kronenfeld 1995). A new generation of research will have to address emerging dilemmas in contemporary societies: individuals are both more autonomous and more vulnerable than they were in the past, and the environment in which they live is more difficult to master. New research programmes will have to generate plausible and original explanations about social phenomena and create new guidelines for interventions and the elaboration of social policy in the field of health care. The network project, if taken seriously, can help us reach this goal.

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