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Methodological Considerations
in Life Course Theory Research

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Abstract

Currently, disability studies is starting to apply a life course theory framework to some of its investigations. Given the strengths of each field, life course theory can greatly impact disability studies, and vice versa. For this cross-pollination to reach its maximum potential, disability studies researchers need to understand life course methodology and the types of results that arise from these methods, as well as the implications of these results for the field of disability studies. This paper reviews life course methods as they apply to the field of disability studies. More specifically, methodological issues are highlighted through a study of individuals with traumatic brain injuries. The article illustrates the utility of life course theory as a tool to investigate the total life experiences of persons with disabilities and the implications of integrating non-normative experiences into life course research.

Introduction

One of the strengths of disability studies has been its willingness to place the individual into his or her cultural context. This is also a strength of life course theory. Until recently, these fields existed independently. In 1991, Albrecht and Levy called for disability to be studied as part

of the life course, since disability affects the majority of individuals at some point in their lives. However, it was not until Priestley's (2001) volume that disability studies forged explicit links to life course research.

Since this combination of fields is so new, it is important to understand the methodological and theoretical implications of this mixture. First, this paper will briefly define life course theory. Second, linkages between life course theory and disability studies will be outlined. Next, one study will be highlighted to review both general life course methodological issues, as well as disability-specific issues in life course studies. Lastly, recommendations will be made for the future.

What is life course theory?

At their core, all life course theories posit that a dynamic exchange exists between individuals and their environments. This conceptualization yields four constructs: location, referring to the historical and geographical patterns of life; social ties, relating to social relationships; personal control, describing aspects of agency; and timing, pertaining to individual development (Giele and Elder, 1998). As such, any life can be examined through the unique interplay of historical patterns, social relationships, individual development, and situational control. This may lead to a deeper understanding of both the individual and the individual's environment.

The history of life course research is replete with studies of 'typical' if not 'privileged' development, dating back to Terman's (1947) study of gifted children and continuing through Vaillant's (1977) study of male, Harvard undergraduates. As such, these authors did not see disability as being a component of typical adult development. Similarly, this lack of focus on the life courses of individuals with disabilities is shown in Clausen's (1986) definition of expectable life course:

A normal, expectable life course includes a number of illnesses, major and minor, but some persons are born with or acquire impairments that make this expectable life course impossible... The courses of their lives are markedly influenced by their impairments, but to a considerable extent they are subject to the same general developmental processes as their unimpaired peers. (p5)

Here, Clausen does not explicitly describe which individuals with disabilities he perceives as being included in, or excluded from, typical life course processes. He also does not discuss how disability affects the life course. In addition, this quote reflects the medical model stance that most life course studies have taken in regard to illness, impairment, and disability. If these studies address health, they tend to examine impairment and physical limitations as

characteristics of the individual's body, without including socially constructed meanings of disability or disability identity.

What can life course theory bring
to disability studies?

While life course research tends to ignore the effects of illness and disability, this paradigm is often used to examine the effects of normative and non-normative experiences on the life course. As such, life course theory can function as an entry point for examining the impact of illness and disability. For example, one can focus on the aging population of the USA, in whom chronic illness or disability is likely to be viewed as a typical experience (Albrecht and Levy, 1991). In contrast, the developmental and social implications of chronic illness or disability may be quite different for children, adolescents, and young adults, because impairments are often perceived as non-normative in these age groups (Albrecht and Levy, 1991). Additionally, life course researchers who do not routinely focus on disability issues may find themselves questioning their assumptions about normative experiences, if they analyze the non-normative experiences of youth with disabilities.

Another thread that life course theory can provide to disability studies is a focus on total life experiences, not solely on disability experiences. As early as 1988, Fine and Asch commented that disability should be viewed as one variable, not necessarily the overriding variable. By taking a life course approach, disability can become a facet of life, not the focus. Assuming funding can be located, life course research can also bring to disability studies a history of large, longitudinal designs. Large studies can help disability studies reach beyond case studies, yielding a wider range of experiences and participants, while serving as a foundation for the growth of the field. Longitudinal designs can explore the interactions of the links between personal timing of impairment, social ties, location, and personal control.

What can disability studies
bring to life course theory?

As stated above, one commonality between disability studies and life course theory is both fields' reliance on placing the individual into his or her cultural context. However, disability studies can also make several unique contributions to life course theory. First, since culture is important to both fields, disability studies can introduce life course research to the concept of disability culture, in order to investigate how disability culture is or is not incorporated into individuals' lives. This may lead to heightened awareness about how these cultural concepts are communicated among individuals, which may lead to targeted

interventions to spread disability culture. Second, disability studies assumes that the temporarily able-bodied to disabled continuum is constantly in flux. Therefore, it can be argued that life course research needs to go beyond cataloging disease and impairment to investigating illness and disability, as a part of the life course of the majority.

Finally, disability studies can teach life course researchers the positives of centering the experience of disability (Linton, 1998). While on the surface, this sounds similar to the dichotomy in life course research between normative and non-normative experiences, there is an important difference. Equating disability with a non-normative experience tends to assume that disability is a negative, undesirable status. In contrast, centering disability can highlight the positives of disability culture and can question the assumptions of non-disabled culture.

To illustrate how the above issues affect research design, the remainder of this paper will discuss one project. We will show how non-normative experiences shed light on normative expectations, how the study of the experiences of people with disabilities should not be limited to their experience of disability, how disability culture does or does not appear in the life course, and how the 'expectable life course' interacts with the experience of disability.

Methods

In 1997, the first author collected pilot data for a life course study involving people with traumatic brain injuries (TBI); since 2000, this has grown into an on-going study of the life experiences of people with TBI, spinal cord injuries (SCI), or no known disabilities (NKD). This study is now beginning to explore the similarities and differences in the life course experiences of people from these three groups, as well as the portrayals of the similarities and differences in individuals' narratives. However, this paper will solely focus on the individuals with TBI and the methodological issues involved in conducting life course research with individuals with cognitive impairments.

Between the two studies, eleven participants with TBI were recruited through several routes, including participant lists from previous studies, support groups, other disability organizations, and snowballing. Their ages ranged from 20 to 43, four were female, and the group reflected the ethnic diversity of New York City. All their injuries resulted in a loss of consciousness of at least 24 hours, and occurred between the ages of 15 and 20. Therefore, these individuals were between two and 26 years post-injury. While a few individuals had speech that could be considered to be significantly affected by their injuries, all the participants were able to communicate at some level in English.

Interview procedures and instruments

The pilot interview had two parts, a self-structured life story section, and an interviewer-structured time-line section. Due to limitations found in the pilot, the full study has two additional parts: a linguistic section, and a follow-up phone conversation to administer questionnaires on identity and the participants' history of brain injury. The life story section is based upon the work of Rosenthal (1993). In her study, the author asked participants, in individual interviews, to describe how German socialism had affected their life experiences. She then let them speak, without interruption, until they were finished. Rosenthal felt that this technique minimized the possible contamination from her own ideas, perspectives, and questions. However, the author does mention that she made socially appropriate responses, when required.

The current study adopts Rosenthal's technique for these reasons, as well as reasons related to individuals' cognitive abilities. Some individuals with TBI may experience short-term memory loss or pragmatic difficulties with the two-way nature of communication. For these individuals, an unstructured interview without interruption may be most comfortable and productive. To clarify any narrative confusion, at the end of this section, the interviewer asks follow-up questions.

The second section of the interview, a co-construction of the individual's time-line, builds on other cognitive and linguistic abilities. In the pilot study, the time-line started out with markings for the individual's age and the year. Then, during the course of conversation, events were placed on the time-line. Most time-line events were very individualized and had stories attached to them, for example, the timing of a religious ceremony or the attainment of puberty. Some of these events had been mentioned in the first part of the interview, while others had not. During the pilot testing, one participant, who expressed concern over the spottiness of his memory for past life events, recorded several winners of the Super Bowl for American football, which captured his fan identity, while filling his time-line.

While all of these individualized events are important to participants' identities, it was decided, for data collection purposes, that the time-line section needed more structure beyond markings for age and year, since the narrative already allowed for individualization. Therefore, in the full study, a series of visual icons, based on those used by Bruckner and Mayer (1998), was constructed to collect specific information about eight areas of life: schooling, working/volunteering, housing, family relationships, significant romantic relationships, friendships, own or other's health, and significant life events. In order to standardize data, specific questions are associated with each icon, which may or may not lead to stories about the topic. These icons serve to lessen the reliance on the participant's pragmatic abilities, while providing visual prompts to facilitate memory recall.

From analyses of the pilot data, it became obvious that unexamined linguistic characteristics were influencing the

content and structure of the stories in the first two parts of the interview. Therefore, two linguistic tasks were added to the full study. The Controlled Oral Word Association Test (COWAT, Benton, Hamsher, & Sivan, 1994) is used to examine verbal ability. Also, the 'Cookie Theft Picture' from the Boston Diagnostic Aphasia Examination (Goodglass and Kaplan, 1983), is used to examine how various individuals tell a story when given the same stimuli.

As a result of a pilot participant's comment that the interview experience subsequently led her to continue reviewing her life on her own, a decision was made to contact participants a day or two after the initial interview, partly to verify that they do not experience harm from the initial interview. Therefore, in the full study, at the end of the linguistic section, participants schedule a follow-up phone call. The phone interview completes the study, by administering an identity questionnaire (Bolton and Brookings, 1998), and the Brain Injury Screening Questionnaire (RTC, 1997). These instruments are being administered last, so that they do not influence other sections of the interview.

The identity questionnaire will allow for triangulation with the identity information from the first three parts of the interview. This short questionnaire (64 questions) has four identity subscales: personal competence, group orientation, self-determination, and positive disability identity. The Brain Injury Screening Questionnaire delves into participants' histories of losses of consciousness from different sources, as well as collecting information about the problems experienced with a variety of cognitive tasks over the previous month.

Results

The results discussed here focus on issues that may influence design decisions in all life course studies, as well as issues that relate to the intersection of life course theory and disability studies.

Prospective versus retrospective design

The implications of prospective versus retrospective designs are often discussed in life course research. Some of this is reflected in the design of the life-story and narrative sections. Although prospective data collection is often seen as 'more accurate', because it is capturing events as they happen, it often lacks the distance in time for the participant to have achieved a sense of the events' long-term implications. While it is hoped that these 11 participants will form a core for a prospective, longitudinal study, the cross-sectional nature of their length of time post-injury started to address this difference. Due to the wide variation in years post-injury, some participants, who were more recently injured, mentioned issues in their life stories, like schooling and employment, which participants further along had resolved.

Also, the difference between prospective and retrospective data collection may be more salient when interviewing people with TBI, who may have more memory constraints than the average person. Therefore, with this population, prospective research may be more likely to capture 'accurate' facts about employment, housing, and other issues, as they unfold. However, narrative theory would take the stance that many, if not all, 'facts' are constructed, reconstructed, and remembered within the framework of the individual's current situation. As a result, the role of 'accuracy' is less important than the outcome of the individual's sense-making. In order to gain the advantages of both stances, the time-line section attempted to prompt individuals for 'facts', while accepting answers indicating a lack of memory for specifics, while the life story section privileged the sense-making behind the 'facts'. Especially with a population that is frequently silenced and not given the opportunity to express their own opinions of their experiences, this sense-making becomes more interesting than accuracy, and may eventually lead to interventions.

Participant-versus interviewer-structured life stories

This ability to structure their own life-stories allows participants to convey information that might not be gathered, otherwise. In addition to providing the participant with a voice, and relegating the interviewer to the status of recorder, their structuring may reveal issues about themselves and their experiences that would not be considered. For example, one participant, a college student, reviews her life from birth to her plans after college, and closes her narrative with, '...and somewhere in between, I was hit by a car and had a brain injury.' Although she had indicated, outside of the interview, that she saw herself as someone with a brain injury, by constructing her narrative in this way she bracketed her TBI as different from her other life experiences. She was willing to talk about her injury, but not as a narrative; she would only talk about it as a dyadic conversation, in the form of questions and answers.

In contrast, another participant, who was paid to provide outreach to the TBI community, talks about being practiced in telling her story, as well as mentioning that early on, since she had no memory of her accident, she memorized police reports, in order to be able to answer questions about her history. Perhaps these responses would have been camouflaged by an interviewer's question of, 'Please tell me what happened in your accident.' Since this question was not posed, the individuals were given the opportunity to fashion their own responses to their experiences.

Capturing normative versus non-normative experiences

During his life-story section, another participant discusses his recuperation, which sheds light on the ways in which non-normative experiences may shape understandings of normative experiences. He was injured at 16, and there are

threads of independence and normative expectations running through his recounting of his recuperation,

...I have a picture of the first time I got out of the wheelchair, with a cane, a quad cane, y'know. But, they took a picture of it. And, I've still got the picture, and I treasure it of course, cuz, y'know that's a big victory in my life.

When other 16 year-olds are experiencing independence through learning to drive, he is becoming independent by re-learning to walk. He continues his themes by describing his reaction to his rehabilitation center, which focused on community re-integration, 'We would go out all the time, y'know, we did almost every night, and y'know, it was cool'. For a teen who had never lived away from home, living away from his parents and going to restaurants nearly every night fits developmentally with his need for independence, and allowed him to be like other young people.

For several participants, the experience of TBI or their life after injury were not central, focal experiences of their lives. Parental divorce or other non-normative traumatic experiences were likely to shape individuals' stories. Having an injury does not insulate one from other traumas or life events. Since other aspects of his or her life will shape the individual's disability experiences, these other aspects need to be included in any analyses.

The 'expectable life course' is another area where the interaction of life course theory and disability can be explored. Although this study is only starting to explore this area, one topic that many participants identified as differing from the expectable life course was their lack of significant others. A few had experienced relationships; however, several did not even have opportunities to meet significant others. These participants were primarily in their twenties and most felt a sense of loss at this lack. One participant mentioned a parent's advice to not even look; others simply did not know where or how to meet other people similarly in search of relationships. Although some of these perceptions may reflect their cultures' and the participants' own sense of being inappropriate partners, much of their angst may be due to their own sense that they are of the appropriate age to be forming relationships. It is the expected outcome, and although parts of the culture may tell them that they may be considered less desirable as partners, other parts of the culture may be telling them that this is the appropriate developmental task for their age. So, it is not simply that they are, or are not, excluded from the expectable life course; the expectations exist, but the opportunities do not. Significant relationships are simply one of many areas that can be viewed as part of an expectable life course. Future studies will have to continue these investigations, to see how the tension between expectable life course and exemptions due to disability play out in individual lives.

Capturing disability culture

One of the strengths of life course theory has been its inclusion of many aspects of culture as objects of study. By wedding disability studies to life course theory, it becomes possible to make disability culture, and participants' construction of it, into a focus of study.

Although participants did not explicitly label or discuss 'disability culture', most had connections of various strengths to a sense of a disability community. This may have simply included knowledge of a few other people with TBI. Several participants had gone further to participate in research or support groups, to become members in the state or national brain injury association, or to become involved in outreach. Many participants saw support groups as meeting time-limited needs, like access to other people or support after a recent injury. For those who saw groups as having time-limited purposes, they talked about how their support groups catered to individuals who needed to talk about their own experiences, as opposed to supporting individuals in their daily lives in the community. Given these participants' experiences with support groups, an incorporation of a greater sense of community and culture may encourage support groups to grow with individuals.

Concluding thoughts

In the future, it can be hoped that there will be greater co-operation and collaboration between the disability community and the research community. Bringing life course theory into disability studies is one way to accomplish this. By centering the experience of disability, and exploring its ramifications across the life course, researchers may be better able to capture the experience of disability and to explore topics of importance to people with disabilities. Although the goals of the disability community and the research community have not always been compatible in the past, life course theory is one way to ensure a better fit, since life course theory privileges individual agency, whole life experiences, and participants' constructions of their experiences.

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