

ORIGINAL ARTICLE

Residence and quality of life determinants for adults with tetraplegia of traumatic spinal cord injury etiology

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Study design: Cross-sectional analysis of individual interviews with a convenience sample of persons living with tetraplegia.

Objectives: To describe patterns of residence among persons living with tetraplegia following discharge from initial acute medical care after spinal cord injury, decision-making process for each residence move and quality of life determinants at different residence types.

Setting: California and Minnesota, United States.

Methods: A total of 22 adults with traumatic spinal cord injury tetraplegia were interviewed about their residence histories, the residence decision-making process for each move, and positive and negative features at each residence at which they had lived.

Results: Information, money, insurance, accessibility, intimate relationships and personal assistants had the strongest influence over residence location, with insufficient information and finances demonstrating particularly strong influences. Participants frequently viewed parents' homes as an 'only option,' 'place of refuge' or 'stunting' environment. They viewed own homes as 'only options' or ways to achieve quality of life improvements, and other institutions as 'only options' or 'stepping-stones' to independent living.

Conclusion: Further research is needed to examine decision-making across multiple moves over the course of the lives of persons living with tetraplegia, particularly examining the roles of inadequate information and finances as inhibitors of freedom of choice.

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Introduction

Between 22 500 and 288 000 people with spinal cord injuries (SCI) live in the United States, and 11 000 new injuries occur every year.¹ Traumatic spinal cord injuries (TSCI) resulting in tetraplegia have enormous health consequences. For people under 50 at the time of injury, average life expectancy ranges from 20.2 to 40.6 years post-injury, depending on high versus low tetraplegia and ventilator dependence.¹ Pneumonia was the leading cause of death for people with tetraplegia in the mid 1990s,² and pneumonia, septicemia and pulmonary emboli are the current leading causes of reduced life expectancy for people with SCI. Diseases of the skin and subcutaneous tissue are a leading cause of rehospitalization.³

Tetraplegia, which commonly predisposes to depression,⁴ was the second costliest condition treated in US hospitals in 2002.⁵

There are numerous avenues by which a person with tetraplegia's type of residence can affect his/her quality of life, such as opportunity for community integration, privacy, independence, safety, and access to family and friends. While no complete analysis of how these quality of life determinants vary across residence types and individuals, compelling evidence demonstrates that residence type is associated with quality of life. A retrospective study comparing quality of life between community dwelling and nursing home residents found that people living in the nursing home had a lower quality of life.⁶ Similarly, a qualitative study of people with SCI in nursing homes found that change in quality of life across time was at least partially explained by variation in the physical and social environments.⁷ Medicaid sponsorship,⁸ less education^{9,10} and

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unemployment,¹¹ which are associated with discharge from initial acute medical care to skilled nursing facilities (SNFs), are correlated with lower quality of life and health outcomes.

Opportunity for community integration shows a positive association with quality of life and conceivably differs among residence options. While causality cannot be inferred from these relationships, it may be significant that among people with SCI, those who view themselves as contributing to their communities experience less pain,¹² have fewer health problems and adjust better to their injuries.¹³ Internet use^{14,15} and employment are also positively associated with quality of life.¹¹ More frequent contact with friends and relatives, as well as organizational affiliations are associated with less frequent emergency room visits.¹⁶

Type of residence immediately after discharge from the initial acute hospital or rehabilitation facility stay is related to a variety of factors, including type of insurance, employment status and type of injury. About 88% of people with TSCI are discharged from their initial acute hospital stay or subsequent rehabilitation facility to their own or parents' homes, 6% are discharged to group homes and 5.3% are discharged to SNFs.¹ Discharge to SNFs or extended care units is associated with high lesion (C1–C4), ventilator dependence, older age, non-white race, unemployment at time of injury, Medicare or Medicaid sponsorship, being unmarried, having less than an eighth grade education, preexisting medical conditions, lack of worker's compensation and lack of social support.^{17,18} Patients with SCI on Medicaid receive fewer benefits and experience more distress than patients with other coverage.¹⁹ However, little is known about why people choose a certain residence, whether people change residences after discharge and what their motivations are for doing so.

Although where people with TSCI tetraplegia live is thought to have an enormous impact on quality of life, virtually nothing is known about the decision-making process that leads to one residence outcome over another. The qualitative approach of this research is intended to elucidate this decision-making process from the perspectives of people with tetraplegia and identify those influences that enable people to choose what would be best for them or limit their freedom. Furthermore, creating a more complete picture of positive and negative residence features by examining participants' reactions to living at different locations can inform people making residence decisions and help them address specific challenges to quality of life.

Methods

Participants

All procedures were approved by the appropriate institutional review board. A total of 22 persons with TSCI tetraplegia living in California and Minnesota participated. All participants were 18 years of age or older at the time of the study. Participants were recruited by advertisements distributed through organizations that have clients with tetraplegia. These organizations included independent living centers in the San Francisco Bay Area, Internet chat groups

with members in the Bay and a nonprofit care management organization in Minnesota.

After providing informed consent, participants were interviewed in-person or by telephone for 35–90 min in as private of an environment as each participant desired. All participants were offered \$50 in compensation. All interviews were audio recorded.

Eight participants lived in Minnesota at the time of the interview, and fourteen in California. Four interviews were conducted in-person and eighteen over the phone. Six of the participants were female and sixteen male. The mean age at injury was 29.2 years (range 17–49 years). The mean time elapsed since injury was 14.4 years (range 2–37 years). Level of injury ranged from cervical vertebra 1 (C1) to C7; the modal level was C5/C6.

Twenty participants lived in their own homes at the time of interview and two in group homes. Five participants had lived in an SNF at least once since leaving the hospital, and six participants had lived in rehabilitation, board and care or another type of non-SNF institution. Fifteen participants were insured at the time of interview by only Medicare, Medicaid or another government insurance program, such as Veterans Affairs insurance. Two participants received worker's compensation insurance at the time of interview, and five were insured privately.

Measures

Measures included open-ended interview questions developed for this study and refined through pilot testing that addressed the decision-making process for each residence move, the elements that increased or limited participants' freedom of choice, and positive and negative characteristics of their post-injury residences. Three subjects participated in the pilot testing and provided feedback on the appropriateness and clarity of the instrument. These participants gave the same consent and received the same compensation as the experimental participants.

Fifteen open-ended questions were asked about each residence at which a person had lived since injury. These 15 questions covered the reasons for moving to a residence and positive and negative factors at that residence. Typical questions included 'what factors at your home are positive for you?' and 'when you were considering leaving the nursing home, to what extent did you have appealing housing options available to you?'

Data analysis

The answers to the open-ended questions were transcribed. One of the authors (BAB) designed first round codes with little or no inference and coded each transcript using NVivo (qualitative analysis software). Determinants of participants' moves, as well as positive and negative residential descriptors, were grouped into categories of similar responses. Second round codes that required inference were then created to describe residential decisions. The first and second round codes were independently reviewed by the other two authors to ensure that the codes did not reflect one person's biases.

First round codes, which included 'Information,' 'Accessibility' and 'Money' among others, were applied whenever a participant used that word or a conceptual synonym. Second round codes, such as 'Parents' Home as Refuge' or 'Own Home as Only Option' were used when a participant described a situation that fit that code, for instance moving to her parents' home to save money or feeling that there was no option but to return to a preinjury residence, respectively. A residence was defined as a location considered by a participant to be his/her home for any amount of time after injury.

Statement on ethics

We certify that all applicable institutional and governmental regulations concerning the ethical use of human subjects were followed during the course of this research.

Results

Factors influencing residence decisions

Participants reported living or having lived in five kinds of locations, their own homes/friends' homes, parents' homes, group homes/transitional living centers/board and care, SNFs and rehabilitation facilities. Group homes, transitional living centers, and board and care are residences that provide caregiving by personal attendants and customarily have small numbers of residents. Independent living skills training is standard at transitional living centers, but varies at group homes and board and care. These types of residences are distinct from SNFs in their sizes, which are usually smaller, and in their focus on personal attendant care as contrasted with skilled nursing care.

Consideration of six potential resources exerted strong influences over the residence decision-making process and participants' quality of life across residence types: information, money, accessibility, insurance, intimate relationships and personal assistants/caregiving. These considerations varied in their importance and effects across participants and residences, but were consistently powerful determinants when present.

Information. Participants nearly always reported having insufficient information when leaving the hospital for the first time after injury, but were less likely to report lacking information in later moves. When participants did not have information on the range of options available, they moved to the location that they considered to be their 'only option,' whether that was a parent's home, own home or institution.

I didn't feel as if I had any [options] other than returning to my parents' home...As far as I knew there weren't any attendant care programs that could help a person. (P06)

Participants frequently reported having access to good housing information when leaving rehabilitation facilities, as the facilities often assisted in the housing search. Having access to a rehabilitation center's information for that one

move did not make it more likely that a participant would have access to specific information during future moves, though general knowledge of the types of residences that exist, such as SNFs and group homes, was of course retained.

Money. Financial considerations were omnipresent. Participants decided to move or stay based on cost and chose new residences based on affordability. Money also limited participants' abilities to renovate their homes to meet their accessibility needs.

[Money] was a factor because I'd used up my savings and you know it takes a while to get on disability and everything else that's following the injury. So I was fortunate enough that the hospital that I was in paid for the first year I was there. So money was a big factor in it. (P22)

Accessibility. Participants' housing options were limited by inaccessible design and otherwise preferable housing choices were ruled out on that account.

My first choice would have been to move back to my residence prior to my injury, but I was unable to do that. I was renting with some friends and the house was completely inaccessible [*sic*] and it would cost quite a bit to make it accessible. (P22)

Participants frequently had to settle for housing locations that were at least partially inaccessible, despite accessibility being a major consideration in their decision-making process. Nearly every participant described the accessibility of every residence at some point during the interview, usually as a characteristic that had a major impact on quality of life. Own homes and parents' homes were likely to have aspects that were accessible and parts that were not, while the other residence types were almost always accessible. The flatness of a neighborhood, the proximity and ease of 'wheeling' to local stores, the climate and public transportation affected participants' abilities to access the outside world.

Interviewer: What factors at your home are positive for you?

Participant: My roll-in shower in my bathroom...The town is flat with bike lanes and it also has a transit that comes to my door and takes me anywhere I go for a dollar. (P17)

Insurance. Insurance frequently influenced residence choice, particularly in the first two moves. Twenty participants were forced to leave the hospital because of insurance limits although they would have liked to stay longer.

Interviewer: Could you have stayed longer [at the hospital] if you had wanted to?

Participant: No. The insurance was by the state and so

they wanted me out of there. I would have loved to; I could've really used more time there because I had gotten sick. I had pneumonia. (P32)

After the initial move from the hospital, insurance continued to impact where participants lived, particularly for those who were living in institutions or in their parents' homes. Insurance also influenced the remodeling of houses, and therefore accessibility, and determined access to health care and assistive technologies.

Intimate relationships. Intimate relationships showed a complex interaction with residence decision-making. Overall, the existence of intimate partners made living in an own home more likely—nine participants moved to a home of their own to be with a significant other. As the partners primarily responsible for finding a home, most significant others did the majority of the home searching while participants typically became involved only at the final decision. Although significant others often made possible a move to an own home, they also limited the choice of residence, as their needs, such as proximity to work, competed with participants' needs, such as accessibility.

I had a companion at the time and she was moving down here for work. So we looked in San Jose for a house close to her work. And so that's how we did it. Now she did a lot of the pre-looking and then I did the final looking with her. And that's how we found this house. (P11)

Personal assistants/caregiving. Personal assistants and the caregiving environment frequently influenced decision-making and quality of life. Some participants in their own homes or parents' homes remained in a city because of assistant availability or moved because of assistant unavailability or inadequacy. Participants noted the negatives of abuse, negligence, strict schedules, lack of privacy and theft. Positives included assistance with activities of daily living and help in emergency situations, such as being stuck in the bathroom. These negatives and positives were present across residence types, though individual experiences varied enormously.

Every participant that used family members as assistants was dissatisfied with that arrangement and described worsened family relationships and a sense of being a burden as a result.

Interviewer: Was your parents' home your first choice of places to move?

Participant: No it was embarrassing. But I had no option. It was just a home base to figure things out. And then my sister at the time said, 'You know, I could really use the money and I'd like to go into nursing anyway, so I'll be your nurse for a bit.' And I thought, 'Oh shit. I'm the eldest, she's the second.' I have a younger sister who's six years younger and she's always been jealous of my position in the family. So you can

imagine what kind of position [I was in] when she has physical control over me. So that was the family dynamic. (P23)

Residence types and decisions

The average participant had made 3.3 residential moves since injury, corresponding to a move every 4.3 years. Participants reported common themes in their motivations for moving to each type of residence and found important differences in quality of life associated with these different residence types.

Parents' homes. Parents' homes had considerable disadvantages as well as benefits. They were used as residences soon after injury and, with one exception, only by persons 25 years or younger at injury. Participants moved back to their parents' homes primarily because they saw them as 'only options' and reported a lack of information about other types of residences that were available as well as an inability to afford other options.

[I had] no clue. Pretty much no clue. So the idea of being home was a pretty crazy change of plans. So I didn't really have much access then to what to expect or not expect...I didn't want it to be the only option, but realistically it was. (P24)

Living with parents was often perceived as 'stunting.' All participants who had lived at some point with their parents, regardless of the time since injury, reported that they did not gain independent living skills, responsibility or maturity while living with their parents.

I wish I hadn't. I really, really wish I had not gone back to my parents' after that!...I think it may have stunted my growth. (P11)

Furthermore, participants reported burdening their family members. The two participants who had attempted suicide subsequent to their injuries reported doing so because of experiencing feelings of worthlessness while living with their parents.

The only way I could get anybody's attention was my dad rigged up a bell for me, a buzzer to ring if I needed help. But my mother suffered from depression a lot and sometimes she wasn't in the best of moods. It was hard. She wouldn't respond to the bell if I needed something and some tensions got built up there after I while. I just ultimately, that's why I figured that I would try the suicide, because I just thought, well I can't keep staying here I don't want to go anywhere else. I'm just a burden anyway so that's why I did the suicide. (P25)

Living at home with family members as caretakers also compromised privacy, contributing to tensions within the family and stressful sibling dynamics.

At the same time, parents' homes provided a 'place of refuge' where participants could save money and receive daily support.

My wife and I were dating at the time. We became engaged and were starting to get ready for a wedding and stuff so it seemed more appropriate for me to try and save money and stay with my folks for a while. (P18)

Own homes. Own homes were the most common destination and leaving point for moves. Independence, freedom and privacy were the most prevalent motivations for moves from a different type of residence to an own home, while accessibility, environmental characteristics, such as neighbors, monetary considerations and familial or intimate partner relationships were the most frequent reasons for moves from one own home to another. Moves from own homes to parents' homes or institutions were made only out of necessity for monetary, logistical, psychological, intimate partner or health reasons.

Institutions. Participants lived in various care management institutions after their injuries, including SNFs, board and care, rehabilitation facilities and group homes. Participants viewed these institutions in two ways, sometimes simultaneously: as their 'only option' and as a 'stepping-stone' toward independent living. Participants who moved to SNFs or rehabilitation facilities from the initial hospital stay frequently did so because of a lack of information and saw an institution as an 'only option.'

Interviewer: Was the nursing home your first choice?

Participant: No. I didn't know what was out there...I didn't know anything. I had no information or anything. (P26)

Even though they perceived having no other options, many participants were excited to move to rehabilitation to improve independent living skills. Gaining independent living skills was usually a goal for moves to rehabilitation and was occasionally a goal for moves to SNFs. Participants reported many negative aspects of living in SNFs and other institutions, such as crowded living spaces, strict schedules, lack of freedom, poor social life and unsatisfactory personal assistance.

They gave you a specific time when they'd have people to put you down, you know. So at first I was having to go down at like seven o'clock! You know, I mean it was ridiculous, you know. I'm a forty four year old guy being told I have to go down to bed at seven o'clock! (P32)

Discussion

This is a small, qualitative study requiring recollection of experiences many years in the past and is not intended to be a definitive analysis of residence choice and quality of life

determinants. Instead, this work serves to illuminate a previously understudied yet vitally important facet of life for people with tetraplegia. In this capacity, the current study documents an enormous role for residence location in quality of life and provides findings suggesting directions for further research that may lead in the future to policy and care considerations.

Having insufficient information was ubiquitous and was most frequently reported in regard to one of the first two moves after injury. It is important to know the scope of this problem nationally. Enormous social and academic benefit could be derived from better understanding the influence of information about residence cost, accessibility (especially of bathrooms and kitchens), and location relative to shopping centers and medical and personal assistant services on freedom of choice, residence satisfaction and quality of life.

Yet even when adequate information was available, financial considerations often forced participants into unsatisfactory residences. How have existing support programs, such as Section Eight housing subsidies affected freedom of choice and residence satisfaction in practice? Investigation into the role of established and emerging financial assistance models is warranted.

Participants consistently reported that residence-specific characteristics, such as accessibility, privacy and freedom had major effects on their quality of life. With further research, understanding a person's motivation for moving could potentially help predict satisfaction at a residence. For example, an individual's response to an SNF may depend on whether he/she is obligated to move there due to a lack of options or is moving to get out of his/her parents' home. A person in the first situation might be frustrated by poor care, crowded rooms and an unstimulating social environment, while a person in the second may overlook those features because of his/her new independence. What are the most salient predictors of the best housing options for an individual with TSCI tetraplegia? Research is needed to explore the potential use of these preferences and could benefit quality of life for people with many types of disabilities.

This study also suggests an urgent need to understand the effects of living at parents' homes more deeply. Is moving to parents' homes associated with worse quality of life or even suicidal behavior for adults with TSCI tetraplegia, and are there influences that may moderate those outcomes? As returning to a preinjury parents' home is the default option for many young adults, the possibility that living with family tends to lead to poor psychological outcomes is worthy of immediate investigation.

Given the common, yet oftentimes contradictory, meanings of different types of residences for people with tetraplegia, individual residence decision-making is assuredly complex. Yet prospective longitudinal research investigating residence trajectories across the post-injury lifespan with attention to the influences that limit and enhance residential freedom and predict residence satisfaction could help to resolve this complexity. Such research would enable people with TSCI tetraplegia and their families to make more informed residence decisions and take greater

control over one of the most fundamentally important aspects of their lives: their choice of home.

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