

# Pulled from the streets: Quest narratives among young men with violently-acquired spinal cord injuries

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**Overarching Research Objective:** Examine day-to-day experiences for adolescents and young adults (AYAs) with a spinal cord injury (SCI) and their caregivers (CGs) to understand relationships among participation, identity, development, and wellness.

**Analytic Question:** What factors influence the experiences of AYAs who acquire SCIs through violence and their CGs as they transition to community life after injury?

## Research Design and Methods

**\*Phase I:** N = 17 (9 AYAs and 8 CGs)  
(Data collected Aug 2015 – Jan 2016)  
- Individual Narrative Interview (1 each)  
- Group Narrative Interviews (2 for AYAs; 2 for CGs)

**Phase II:** n=subset of 3-5 Phase I dyads  
(Data collection in progress)  
- Individual Interviews (2-4 per AYA; 1-3 per CG)  
- Activity Observation (1-2 per AYA)

**\*This preliminary analysis focuses on Phase I data.**

All interviews were audio recorded and transcribed verbatim for coding in Nvivo 11. Data were analyzed categorically, thematically, and narratively within- and across-cases to identify and unpack individual perspectives<sup>(1)</sup> emerging during life after a devastating injury. For participants with violently-acquired SCIs, coding and data interpretation were further organized to understand realities of being pulled from “street” life<sup>(2)</sup> into hospitals and homes after injuries in order to identify mediators of experiences.

## Analytic Background

**Background:** Acts of violence, primarily gunshots, are the third leading cause of SCIs in the United States<sup>(3)</sup>. While acute rehabilitation for SCIs from gunshots may not significantly differ from non-gunshot SCIs<sup>(4)</sup>, life after violently-acquired SCIs can present a range of unique challenges, including cultural changes and social isolation<sup>(5)</sup>. In this study involving AYAs with SCIs, participants’ injuries resulted from a range of causes, but data from AYAs with injuries from violence emerged as exceptionally complex. Narratives can shed light on ways life experiences are understood, futures are imagined, and actions are negotiated<sup>(1,6-7)</sup>. Therefore, this analysis uses a framework from Frank<sup>(8)</sup> to unpack narrative data from AYAs with violently-acquired SCIs in order to identify arcs of experience and influences on perspectives after SCI.

**Frank’s organizational framework for narratives:**<sup>(8)</sup>

<b>Restitution</b>	Dominant narrative form, focusing on treatment for eventual cure. Teller invokes a transience to illness, and he/she minimizes effects of illness on the self.	<b>Chaos</b>	Opposite of restitution. Narrative lacks order because teller is caught up in immediate needs or concerns; teller feels little control of storyline.	<b>Quest</b>	Teller assumes control over his/her story and uses control to make good or summon positive change, such as in cases where one pursues a new vocation.
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## Findings

AYA participants with violently-acquired SCIs (n=5) and their caregivers (n=4) were Black, Hispanic, or mixed-races and had varying ethnicities. They primarily lived in underserved communities within a large, metropolitan area of Southern California. At various points, data from these participants resembled each one of Frank’s narrative forms<sup>(8)</sup>, but quest narratives were dominant in 3 of the 5 cases.

### Influences on Narratives Arcs

**Knowledge:** Knowledge of opportunity was critical to the AYAs’ imaginations of possibilities, both present and future.

AYA4: “I like cooking. I used to say I wanted to be a chef. [But not anymore]; I don’t know too many chefs in a wheelchair.”

**Dynamics of Space:** Space invokes a variety of meanings, including physical, cultural, and social characteristics. Each of these was found to impact narrative arcs.

**Physical Space:** Immediately following a SCI, AYAs were separated from their homes and communities as they received necessary medical care/rehabilitation. Supportive, controlled environments, such as hospitals, promoted cultivation of quest narratives. Out in communities (often near where injuries occurred), quest narratives were still apparent but sometimes difficult to maintain.

AYA4: “[My PT] calls me the G.O.A.T. ...And he pushes me, and... like I don’t really even open up with people. And like I felt the connection with him... He knows how bad I want to succeed, and he helps me with it. So, he’s a good motivator.”

AYA1: “They make everything so difficult for you when you try to do it the right way.”

**Social and Cultural Spaces:** In vulnerable states of being after SCI, social communities had a significant effect on individual identities, actions, and hopes or goals. Many AYAs with violently-acquired SCIs found little consistent support among pre-existing friendships; this emerged as a significant difference in experiences of these participants from those with non-violent injuries and/or no history of street life. AYAs with violently-acquired SCIs also felt stigmatized and appeared to receive less support from their communities.

AYA5: “The friends that I have now... see that I’m still the same person. And some people just see me as like - I wouldn’t say like sorry for me, like they don’t want to see me this way or something. But just only a few people stayed down with me.”

AYA4: “I’m supposed to be your ‘brother,’ and you’re not even - like he didn’t even call me since I’ve been here [in the hospital].”

**Interpersonal Space:** Shifting plots between individual and group interviews revealed how audiences impact narratives. Witnessing peer narratives affected both the tone and arc of AYA stories in group interviews. In individual interviews, AYAs appeared to feel less social pressures and shared varied intimate details.

**Sense of Self:** Across cases, it was apparent that SCIs were drastically disrupting the AYAs’ senses of self. Many AYAs with violently-acquired SCIs reported feeling “humbled,” and this shaped narratives differently for each participant.

AYA1: “It was a very humbling feeling, you know? You feel very... weak, you know? You used to think you - I used to think I was superman, you know, and now it’s, like - like, there’s my kryptonite. It’s a humbling feeling. You look at everything different.”

### Narrative Arcs Revealed

<b>Restitution</b>	AYA3: “[The doctor told me], ‘most likely you’re not going to walk.’ ...I don’t believe it because so many people, they says they got shot in the neck, and... the doctor told them they’re not going to walk. They’re not going to feel with their hands. They’re not going to be nothing. I just saw that same person walking and standing like, ‘Damn! Get out of here with that bullshit. Don’t be saying shit like that.’ ... I feel like [God’s] going to give me back my legs as soon as He sees my heart changed.”	<b>Chaos</b>	AYA2: “This year [was] supposed to be graduating year for me, but nope, I’m still in the ninth grade... My situation...keeps me back from a lot of stuff. If something happens, I got to stay home. I have accidents at school, stuff like that. It would just never be a day where I could just be at school all day, like in peace. There’s always something happening, or something like that.”	<b>Quest</b>	AYA4: “Before this, I was just thinking money, and not the right way... I’m trying to better myself now... I was just living like, pssh, no care in the world... I deserve... better than what I was doing. So, why not go to school?... I know I’m smart. Shit, I know I can do the work. I know I could become something successful... I wasn’t doing any good [before], so I wouldn’t want to go back to that. So, I’m trying to move forward, go to school, become something.”
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## Implications

For these AYAs with violently-acquired SCIs, rehabilitation was a type of moral endeavor, complicated by functional abilities and social influences. Where some AYAs were previously “lost to the streets,” (-a CG speaking about her son before his SCI), these devastating injuries were sometimes understood to be a chance to start fresh, to re-create one’s identity, and in doing so, to live a safer and more meaningful life. Notably, within this small sample of AYAs with violently-acquired spinal cord injuries, there were strong patterns resembling quest narratives<sup>(8)</sup> impacted by embodied knowledge, social and physical spaces, and sense of self or identity. However, a lack of experience and support relating to future ambitions (e.g. self-care, work) and occurrence of these injuries in the midst of critical developmental periods left these AYAs with few resources to create or maintain changes to which they were oriented.

In narrative analysis, the arcs of a storyline can indicate how experiences are internalized and acted upon. Since SCIs often result in chronic disability<sup>(3)</sup>, restitution narratives may disrupt action and development, and chaos narratives exist in states of unrest. Therefore, considerations of how quest narratives are cultivated and supported can have important implications for application in care and community envornments. Quest narratives may be acted on to generate productive action towards desired purpose<sup>(8-9)</sup> and well-being. However, it is critical to consider the fluidity and fragility of storylines, particularly for individuals with limited resources.

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