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Introduction

Written memoirs of people who have aphasia offer a rich, accessible source of insights into their lived experience. In the tradition of narrative medicine, aphasiologists seek to “recognize, absorb, interpret, and be moved by” stories of people with aphasia, equipping us to be “more humane, more ethical” in our clinical practice and research (Charon, 2006, p. vii). Memoirs capture, in perpetuity, the natural evolution of stories following traumatic onset of stroke and aphasia, as they intersect with selfhood: from Chaos to Restitution to Quest (Frank, 1995). In initial chaos, “the suffering is too great for a self to be told.” Later, in restitution, “the active player is the remedy (intervention) ... they are self-stories only by default.” Finally, quest stories “accept illness and seek to *use* it,” given the self’s belief that “something is to be gained through the experience” (Frank, 1995, p. 115). Frank notes, “most published illness stories are quest stories” (p. 115).

A study of oral stories of American World War II veterans (Ulatowska et al., 2020), discerned central themes in stories of quest and reconciliation: gratitude for survival; sharing of lessons, as legacy; and the key role of identity. In aphasiology, thematic analysis of quest stories is a relatively new approach to narratology (Ulatowska 2010, 2014). Traditionally, the field has focused on linguistic deficits in elicited oral narratives; early studies of memoirs, too, focused on linguistic impairments (Ulatowska et al., 1979). The present study examines content of memoirs of authors with aphasia, as shaped by each author’s identity. One of the earliest, substantial memoir contributions (Luria, 1972) is included in the sample.

Methods

Sample: twenty-seven books and six articles, memoir genre, authored by people impacted by aphasia; all in English or English translation; most authored or co-authored by people with aphasia, and a few by an intimate. Authorship included representation from American, British, Polish, Swedish, Australian, and Russian cultures. Most authors were well educated. Some were professional writers pre-morbidly. **Content analysis:** 1) metacommentary on the pragmatic purpose and process of writing; 2) quest-oriented content; 3) reflections of identity and culture on quest-oriented lessons.

Results

Both professional and non-professional writers commented on the pragmatic need to write their stories, despite the difficulty of the writing process. Quest-oriented content included: gratitude for survival, acceptance of limits on recovery, and implicit and explicit lessons for the readership. Lesson content suggested identity- and culture-specific influences in the recovery

process, including religion/spirituality, professional identity, gender, and (re-)connection with intimates.

Conclusions

Content analysis of memoirs of authors with aphasia provides a unique window into their lived experience, legacy, identity, and culture. This pragmatic focus on communicative competence (Olness & Ulatowska, 2020) complements traditional linguistic narratology. The method may exclude representation of cultures in which written personal stories are inappropriate. Yet, memoir writing, which allows unfettered time for composition, may be ideally suited as a timeless contribution in human legacy. As one memoir author with aphasia notes (Luria, 1972), 'writing is exhausting, a titanic effort, which confirms one's humanity.'

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