Information Quality, Uncertainty, and Quality of Care in Long-Distance Caregiving

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Approximately 13% of Americans who provide care for an ailing family member do so from a distance, making long-distance caregiving a relevant health communication topic to study. A self-report online survey examined the quality of information provided by care recipient to distant caregiver, uncertainty about care recipient health, and perceived quality of care from the distant caregivers’ perspective. Information quality, uncertainty, and perceived quality of care were significantly related as predicted. How these findings offer new insight into the complex nature of distant caregiving communication is discussed.

Keywords: Caregiving; Information Quality; Long-Distance Communication; Quality of Care; Uncertainty

A caregiver “provides unpaid help, or arranges for help, to a relative or friend because they have an illness or disability” (Donelan et al., 1998, p. 223). Approximately 13% of the estimated 65.7 million Americans who provide care do so from a distance.
(National Alliance for Caregiving [NAC], 2009). As life expectancy and geographic mobility both increase, long-distance caregiving (LDC) is important. Thus, we focus here on the links between quality of information from care recipients, uncertainty about care recipients’ health and care, and perceived quality of distant care.

Information Quality and Uncertainty

Older adults withhold health information details from family members (Cicirelli, 1990), and distance can exacerbate this information deficiency (Bevan & Sparks, in press). Indeed, distant adult children felt uninformed about their mothers’ care (Schoonover, Brody, Hoffman, & Kleban, 1988), and distant caregivers accessed less information and were more dissatisfied with that information than proximal caregivers (Thompsell & Lovestone, 2002). Thus, of interest here is the quality of health information from care recipient to distant caregiver, which involves accuracy, comprehensiveness, currency, and usefulness (Eysenbach & Köhler, 2002).

Uncertainty exists when details “are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general” (Brashers, 2001, p. 478), and has been suggested in LDC (e.g., Baldock, 1999; Watari et al., 2006). Uncertainty is also frequently linked with information and health (e.g., Rosen & Knauper, 2009). For example, patients felt uncertain when they perceived the health information given from their doctor was inadequate (Gilje, Soderland, & Malterud, 2008). Thus, we expect that when care recipients offer better quality health information to their distant caregivers, distant caregiver uncertainty will decrease. The first hypothesis states the following:

H1: Quality of information between care recipient and distant caregiver will be negatively related to distant caregiver uncertainty about the care recipient’s care.

Perceived Quality of Care

Caregivers’ knowledge of the caregiving situation is important in providing care that is accurate and supportive (Clark et al., 2007; Thompsell & Lovestone, 2002). Furthermore, both caregiving (Lim & Zebrack, 2004) and uncertainty (Rosen & Knauper, 2009) can increase stress and anxiety, which could subsequently compromise quality care provision. Therefore, the second hypothesis predicts that the extent to which distant caregivers perceive that they can provide beneficial, satisfactory, and personal care is positively linked to information quality between care recipient and distant caregiver and negatively linked to distant caregiver uncertainty:

H2: Distant caregivers’ perceived quality of care will be positively related to (a) quality of information between care recipient and distant caregiver and (b) negatively related to distant caregiver uncertainty.
Method

Participants and General Procedures

Participants (N = 137) met three conditions to complete our self-report online survey: (a) be 18 years or older, (b) provide care for someone age 55 or older in the past year, and (c) consider the caregiving situation to be distant (i.e., consistent with Sahlstein’s, 2004, 2006, subjective view of distance). The sample was predominantly female (n = 95; male, n = 10), White (n = 94; African American, n = 4; Hispanic, n = 3; Asian, n = 1; and Native American, n = 1), and averaged 49.4 years of age (SD = 10.58; range = 26–70). The average distance between caregiver and care recipient was 811 miles (SD = 1,234.80; range = 8–10,000). The average length of time providing distant care was 4.5 years (M = 54.00 months, SD = 46.39; range = 3–240), and most were current distant caregivers (n = 104; no longer providing care, n = 29; and do not know, n = 2).

Recruitment took place through e-mail, Facebook®, LinkedIn®, and postings on multiple caregiving message boards, listservs, and Web sites such as www.SilverPlanet.com. Permission to post was obtained when requested. The survey took approximately 20 to 30 min to complete, and those providing their e-mail addresses were compensated with a $10 Amazon.com gift card.

Measures

Information quality. Ten Likert-type cancer information quality items were adapted from the 2003 Health Information National Trends Survey (HINTS); the scale ranged from 1 (strongly disagree) to 7 (strongly agree). An exploratory principal component analysis with varimax rotation revealed two factors: (a) information quality (e.g., You trusted the information from the care recipient; eigenvalue = 4.83; 48.3% of the variance explained; M = 4.04, SD = 1.57; α = .87), and (b) information barriers (You wanted more information from the care recipient, but did not know how to get it; eigenvalue = 1.14; 11.4% of the variance explained; M = 3.58, SD = 1.69; α = .63).

Uncertainty. Six Likert-type items adapted from Douglas’s (1990) and Clatterbuck’s (1979) scales measured how confident distant caregivers were about their care recipient’s health and caregiving situation; the scale ranged from 1 (strongly disagree) to 7 (strongly agree) (e.g., I know what my attitude toward the care recipient is; M = 5.83, SD = 1.87; α = .87).

Perceived quality of care. Richmond, Smith, Heisel, and McCroskey’s (1998) six-item Perceived Quality of Medical Care (PQMC) scale measured distant caregivers’ perceived quality of care; the scale ranged from 1 (not beneficial) to 7 (very beneficial) (M = 5.54, SD = 1.20; α = .90).

Results

Because age can be related to health, caregiver age was included in the correlation analyses. In support of H1, the relationships between uncertainty and both
information quality (partial $r = .21, p < .05$) and barriers (partial $r = -.29, p < .01$) were statistically significant. Consistent with $H2a$ and $H2b$, quality of care is significantly and positively related to both information quality (partial $r = .26, p < .01$) and uncertainty (partial $r = .36, p < .001$). Recall that higher scores on the uncertainty measure indicate lower levels of uncertainty. In addition, the correlation between information barriers and quality of care was statistically significant and negative (partial $r = -.40, p < .001$).

Discussion

This study took a preliminary step toward understanding how LDC communication is related to perceived quality of care. Our findings and their implications are discussed.

Information Quality and Uncertainty

For $H1$, individuals who accessed quality LDC information and possessed fewer information barriers experienced lower LDC uncertainty. This is logical, as LDC barriers (e.g., lack of nonverbal cues and fewer interaction opportunities) could be linked to greater uncertainty about the care recipient. Further, although information quality is typically a unidimensional measure, our adaptation of the 2003 HINTS cancer information quality items to the LDC context suggested that this variable may be more nuanced than previously believed. $H1$’s findings, thus, tentatively suggest that information-seeking alone may not be sufficient for understanding uncertainty in health contexts, and that information quality should be considered as well.

Perceived Quality of Care

Quality of care research, which mainly focuses on providers’ medical care, finds that as training continues, higher quality of care is expected (Tishelman et al., 2008). $H2$’s results extend these findings to LDC and also align with the finding that as caregiving burden decreased (here, in the form of decreased information quality), patient care would improve (Thompsell & Lovestone, 2002). Richmond et al.’s (1998) PQMC measure was also extended to perceived quality of LDC care and the caregiver’s perspective.

Identifying specific LDC burdens such as reduced information quality, information barriers, and uncertainty about care is integral to improving LDC provision. An important next step is for caregiver support organizations to target those who are facing an uncertain LDC situation to improve the perceived quality of their care provision. Such knowledge can be crucial for distant caregivers’ perceptions of quality, satisfactory, and beneficial care for their loved ones.

Limitations and Conclusion

One limitation is the lack of participant racial and gender diversity. However, American caregivers are typically White (72%) and female (66%; NAC, 2009), which
suggests that our sample may reflect the LDC population. Further, the lower reliability ($\alpha = .63$) of the information barriers scale means our findings for this variable should be interpreted with caution.

Our study took a step toward understanding LDC communication by identifying relationships between distant caregivers’ perceptions of uncertainty, which is related to stress and worry (e.g., Rosen & Knauper, 2009), information quality, and perceived quality of care. Future LDC research should examine quality of care and other competence measures in relation to topic avoidance and conflict, and from theoretical perspectives such as Communication Accommodation Theory (e.g., Harwood & Giles, 2005). Further exploration of the multiple dimensions of information quality is also suggested.

Notes

[1] A substantial number of participants did not complete the demographic and relationship items, which were at the end of the survey.


References


