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Hematological Cancer Patient-Caregiver Dyadic Communication: A longitudinal examination of cancer communication concordance

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Abstract

Objective: Informal caregivers play a fundamental role in care and decision making with hematological cancer patients. Concordant patient-caregiver communication is a critical antecedent to high quality decision making. Little is known about patterns of dyadic communication throughout the cancer treatment continuum. The objective of this study was to assess patterns of cancer communication concordance regarding treatment and care among hematological cancer patients undergoing active treatment and their informal caregivers and test whether patterns were associated with participant characteristics.

Methods: A case series of hematological cancer patient-caregiver dyads (n=171) were recruited from oncology clinics in Virginia and Pennsylvania and followed for 2 years. Latent Class Growth Models (LCGM) were used to analyze longitudinal data captured using Cancer Communication Assessment Tool for Patients and Families (CCAT-PF) and the association with participant characteristics.

Results: White patient-caregiver dyads demonstrated decreased communication concordance and African American dyads demonstrated increased communication concordance over time. Lower communication concordance was found among dyads with lower levels of education and income, and cancers diagnosed at more advanced stages; these relationships were stable over time. Modeling identified the presence of three distinct communication groups (Stable Concordant (57.4%), Fluctuating Medium Concordant (37.8%), High Discordant (5.4%)) that differed by

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baseline level of communication concordance, patterns of concordance over time, race, income and the dyad relationship.

Conclusions: Patient-caregiver cancer communication concordance was not static overtime. Results suggest the presence of a new dyadic cancer communication typology that could help preemptively identify dyads at risk for communication difficulties that impede treatment decision making.

Keywords

cancer; cancer communication concordance; CCAT-PF; caregivers; hematological cancer; oncology; Psycho-Oncology

BACKGROUND

Hematological cancers are expected to account for 170,040 cases or nine percent of all new cancer diagnoses in 2019.¹ The non-Hodgkin's lymphomas (NHL) comprise about 50% of hematological cancers and is 7th most common cancer diagnosis.² Treatment advances among hematological cancers have increased survival; 5-year survival rates are over seventy percent.² Shifts in the way newer treatments are delivered and improved patient tolerance³ have led to an increased reliance on informal caregivers, usually family or friends, to provide a wide range of caregiving tasks in the home.⁴ Informal caregivers are increasingly involved in many aspects of care and decision making,^{5, 6} including attendance at clinical appointments and interactions with clinicians. Effective communication between patients and caregivers is essential for optimal patient outcomes,^{7, 8} yet communication research among hematological cancer patients and caregivers remains sparse.

Communication provides the primary medium for the expression of values, goals, needs, and other information supporting joint decision making, coping and the ability to implement care plans. Moreover, cancer patient-caregiver communication has been shown to affect communication with clinicians and satisfaction with treatment decision making.^{7, 8} Successful, effective communication, or concordant communication, is characterized by a shared understanding of treatment risks, benefits and long- and short-term care goals.⁹ Concordant communication does not mean that patients and caregivers agree about everything, only that they are able to communicate effectively and openly with each other. Indeed, a mutual understanding of disagreements can indicate concordant communication. Studies have demonstrated that open, effective communication between cancer patient-caregiver dyads reduces decisional conflict and increases QOL¹⁰ and greater relationship functioning.¹¹ However, the majority of these studies have used cross sectional or qualitative designs^{12, 13} that cannot explore whether communication patterns change overtime.¹⁴⁻¹⁶ Given the extended treatment trajectory, chronicity, risk of recurrence and the lack of psychosocial research among hematological cancer patients, longitudinal periods of observation are needed to identify whether fluctuations in communication patterns exist, and how and when changes occur. The extent to which caregivers are involved in patient care and their corresponding communication needs are likely fluctuate with patient functional status, changes in treatment, demographic characteristics and the dyads' coping response at successive time points along the care continuum. Understanding which dyads may

be experiencing communication difficulties that could negatively influence their ability to communicate with clinicians, participate meaningfully in decision making or execute care plans is currently missing from the clinical cancer treatment literature. Therefore, the objective of this paper was to assess patterns of cancer communication concordance among patients with hematological cancer and caregivers for 24 months following initiation of systemic treatment to determine levels of communication concordance over time and to determine whether concordance patterns were associated with patient and caregiver characteristics.

METHODS

Participants

A total of 171 patients with cancer were recruited to this longitudinal study. Study participants were adults (> 18 years) who were diagnosed with 1 of 3 hematological cancers (multiple myeloma [MM], Non-Hodgkin's Lymphoma [NHL], or chronic lymphocytic leukemia [CLL]) at any stage of disease, were in active treatment and had begun initial systemic treatment within the previous six months, were employed immediately before their diagnosis, and could identify an informal (unpaid) caregiver who also could participate. A complete case series of patients were identified who fit the study parameters for disease and treatment status within the study recruitment phase. A telephone screen was conducted to screen for employment and caregiver parameters for final eligibility. Patients were excluded if they had not been employed or actively searching for employment immediately prior to diagnosis, did not have an informal caregiver, had cognitive impairments, were receiving hospice care, or spoke a language other than English. Caregivers had to be adults (>18 years), cognitively able to participate and not being paid to provide patient care. Approval from the institutional review board for human subjects research was obtained from the IRB's at the participating institutions (IRB # HM13074).

Recruitment

Patients with cancer were recruited from 8 oncology clinics (both academic and community clinics) located in Pennsylvania or Virginia. Patients were identified using electronic medical records. Preliminary eligibility was confirmed by clinic staff (cancer diagnosis, no cognitive impairment or hospice care) and these patients were mailed invitation letters followed by a telephone call from research staff. Interested patients provided contact information for an informal caregiver and baseline interviews were scheduled once eligibility was determined. Of the 818 individuals contacted, approximately 21% declined participation, 57% were ineligible (primarily due to unemployment or the absence of a caregiver), and 21% provided informed consent. The final sample size was 171 patient-caregiver dyads (total of 342 individuals).

Interviews

Patients and caregivers were interviewed separately every 6-months for 2 years (a total of five interviews). Between 2013 and 2018, semi-structured interviews were conducted either in the participants' home or in a private room at the cancer center. A small number of follow-up interviews were completed over the phone, for example for dyads who moved

during the study period. Standardized scales were used to collect demographic information and cancer communication concordance. Consent was obtained to extract cancer diagnosis, stage and treatment dates from the patient's medical record. Baseline interviews were approximately 90 minutes and follow-up interviews lasted 30-60 minutes. Interviews were audio recorded and performed by trained graduate-level research staff, however standardized scales were self-administered (i.e., completed by the participant). Participants were provided a \$50.00 honorarium per interview. The current analysis is based on all five waves of data.

Measures

Demographics included patient and caregiver age, sex, race, education, annual household income, marital status and caregiver relationship (spouse, parent, offspring/sibling, friend). Cancer stage, cancer type and date of first systemic treatment were extracted from the patient medical record.

Cancer Communication Concordance was measured using the Cancer Communication Assessment Tool for Patients and Families (CCAT-PF).⁹ This measure was developed for use with patients with cancer and their informal caregiver to assess the level of communication concordance or discordance regarding cancer treatment and care decisions. It is composed of two subscales, the CCAT Patient and CCAT Family. The CCAT-P is an 18-item instrument completed by the patient about their preferences, values and experiences in making treatment and care decisions, with an emphasis on how family caregivers fit into this process. The CCAT-F is an 18-item instrument completed by the family that is exactly analogous to the CCAT-P. Maximum range of scores for either the patient-specific or the caregiver-specific scale is from 18 to 108. Together they make up the CCAT-PF. The CCAT-PF was scored according to published protocol and calculates a final absolute difference score (range of 0 to 90) with higher scores indicating greater communication discordance. Questions were modified to reflect the dyad relationship (i.e., referring to friend vs. family member).

Statistical Analysis

Descriptive information on demographic characteristics is presented for patients and caregivers on age, sex race, education, income and marital status. Cancer communication concordance (CCAT-PF) was examined by sociodemographic characteristics and for the overall sample at each wave. Latent Class Growth Models (LCGM) using the cancer communication concordance data were then completed. LCGM is a semi-parametric statistical technique used to analyze longitudinal data when the data follows a pattern of change in which both the strength and the direction of the relationship between the independent and dependent variables may differ across cases. The analysis sought to identify subgroups of dyads whose communication congruence followed a distinct pattern of change over time including stability, linear and quadratic change. The linear change parameter captures a constant increase or decrease over time (straight line); a quadratic parameter captures change that is not strictly linear but rather may change in one direction (e.g., increase) and then another (e.g., decrease) over time. Classes are presented with 95% confidence intervals. Confidence intervals that do not overlap indicate that the identified groups are more likely to be meaningfully distinct. LCGM was re-estimated

with a risk adjustment for patient deaths during the study to determine if this alters group membership. Once the LCGM groups were established, potential differences between groups by sociodemographic characteristics were examined (caregiver characteristics are used in the models).

RESULTS

Descriptive Analyses.

Table 1 presents descriptive statistics for the sample. Both patients and caregivers were 54 years on average, and the majority were married (75% and 83% respectively) and white (73%). Patients were primarily male and caregivers were primarily female. Most of the patients and caregivers had a high school diploma or some college and were in the higher income bracket. The most common diagnosis was NHL (63.7%) followed by MM (24.6%) and CLL (11.7%). Twenty-one (12.9%) patients died over the course of this study. Evaluation of communication concordance over time by sociodemographic characteristics (see last column in Table 1.) identified differences by race, education and income. African American patient-caregiver dyad communication concordance scores were higher at baseline, indicating poorer communication concordance, as compared to white dyads ($F(14, 1431) = 43.4, p < .0001$). The interaction of race and time was significant ($F(9, 1436) = 2.67, p < .03$); examination of the means revealed that communication concordance among African American dyads improved over time while communication concordance among white dyads worsened over time. Lower communication concordance was found among dyads with lower levels of education ($F(9, 1431) = 14.5, p < .0001$) and income ($F(14, 1431) = 8.40, p < .0002$) and these scores remained relatively constant over time. Earlier cancer stage diagnoses had greater communication concordance as compared to later stages ($F(14, 1431) = 3.29, p < .006$) and these scores were stable.

Latent Class Growth Models.

Graph 1 depicts the LCGM analysis revealing three distinct communication groups. The solid lines represent the average CCAT-PF score for the group over time; the dashed lines are the 95% CI. As the CI do not overlap for the three groups, we confirm that the groups are distinct. Note that the LCGM were also run with a risk adjustment for patient death during the study and death was not significant (data not shown). Higher scores on the CCAT-PF indicate greater communication discordance. The Stable Concordant Communication group (red line on Graph 1) represented just over half the sample 57.4% ($n=97$) and reported the greatest communication concordance overall. Moreover, this group revealed no significant linear or quadratic component and is thus presented as a stability model. The second largest group (green line Graph 1.), Fluctuating Medium Discordant Communication, represented 37.8% of the sample ($n = 65$) and revealed higher baseline communication discordance, compared to the Stable Concordant Communication group, had a significant negative linear component and a positive quadratic component. This suggests that communication discordance initially decreased and then began to rise again in latter waves of the study. The final group, representing 5.4% ($n = 9$) were named the High Discordant Communication group (blue line Graph 1) as they reported the lowest level of communication concordance at baseline, had a pattern of worsening communication overtime (significant positive linear

effect), followed by a return to baseline levels of communication discordance by the final time point (significant quadratic effect).

The three communication groups identified by the LCGM differed on several demographic variables. Compared to the High Discordant group, both the Stable Concordant and Fluctuating Medium Communication groups were more likely to have white participants and a spouse caregiver. Differences in income were also detected with the Fluctuating Medium Discordant group having the largest percentage of participants in the higher income range followed by Stable Concordant group. No other differences between the groups were detected for sociodemographic characteristics; no differences for type and stage of cancer were detected.

DISCUSSION

This study found that cancer communication congruence was not static over time for almost half of the dyads in this sample. This represents a significant proportion of hematological cancer patient-caregiver dyads who may have trouble communicating about cancer at some point along the cancer treatment trajectory. A novel observation was the finding that African American dyads initially reported greater levels of discordant communication compared to white dyads, but that over time their communication improved compared to white dyads, whose communication concordance worsened. To our knowledge, this relationship has not been previously reported. African American cancer caregivers have been shown to have lower levels of caregiver burden, depression and distress as compared to white caregivers¹⁷ and dysfunctional communication patterns are linked to poorer dyadic coping.¹⁸ After the initial adjustment to the cancer diagnosis, as communication improves overtime, it is plausible that perceptions of caregiver burden and psychological burden also improve. Future work is needed to explore potential mechanisms driving these differences in communication patterns and their effects on health outcomes.

Latent Class Growth Modeling identified the presence of three distinct communication groups: Stable Concordant, Fluctuating Medium Discordant and High Discordant communication. These groups differed by baseline level of dyadic communication concordance, patterns of concordance over time and demographics of race, income and the relationship of the dyad (i.e. spouse vs. friend). We propose that these three groups represent a new dyadic cancer communication typology that could be leveraged to identify dyads at risk for communication difficulties that may be identified and intervened upon at different points along the cancer treatment continuum.

A New Communication Typology

Just over half of the sample (57.4%) reported good communication congruence that was stable over time. Members of the Stable Concordant Communication group were also more likely to report higher annual household income compared to dyads in the High Discordant group. Higher income likely helps to buffer these dyads from financial stressors common to cancer patients and caregivers, which is a significant source of communication difficulty.^{19, 20} Communication concordance was not static over time for many dyads. Almost 1/3 experienced a temporary improvement in communication followed by a return

to baseline communication by 24 –30 months. In contrast, 5% of the sample (High Discordant Communication group) experienced a worsening of communication followed by an eventual recovery of baseline communication by 24-30 months. Contextual factors including prior relationship quality and patterns of communication effect coping and adjustment during cancer treatment.^{21, 22} For example, dyads with constructive, open communication experience improved relationship functioning¹¹ but dyads with pre-existing negative communication patterns may experience an amplification of communication difficulties due to the stress of cancer treatment.²³ This may explain the differences seen in the communication patterns between the Fluctuating Medium Discordant and High Discordant Communication groups.

Patterns of communication may also be influenced by the relationship between members of the dyads (e.g., caregiver was a relative or a friend). Relationship type may lend itself to ambiguities in role clarity and weaker interpersonal connections that influence expectations for caregiver participation in decision making and performance of care tasks when patient-caregiver dyads are friends rather than relatives or spouses. Caregivers in the High Discordant group were more likely to be friends of the patient. Caregivers who are not related to the patient represent a small but different caregiver group with unique communication patterns that may not be as open, a known predictor of the quality of dyadic communication.^{11, 24} For example, cancer patient-spousal caregiver dyads often engage in protection behaviors in which partners abstain from discussion of certain topics to try to mitigate distress.^{25, 26} This may not happen among patient-friend caregiver dyads. It is important to recognize the existence caregivers who are friends as these may represent an especially vulnerable group of patients who have no existing familial ties on which to depend but who, like all cancer patients, need assistance with caregiving. Further work is needed to better understand how communication concordance and the achievement of open communication can be enhanced and supported among all dyads.

Family communication and family functioning typologies exist²⁷ and have been applied to cancer patient-caregiver communication, including one specifically developed for use among cancer caregivers.^{27, 28} These typologies often use audience segmentation approaches to create caregiver types, describing distinct ways caregivers communicate and interact with patients as they cope with cancer care and decision making. For example, the Caregiver Communication Typology identifies four types of caregiver styles (i.e., Manager, Carrier, Partner or Lone caregivers).^{27, 28} Our new proposed typology differs from these in that it directly measures effective dyadic communication as represented by concordance or shared viewpoints. Dyads rather than individuals are considered the unit of reference, with higher dyadic communication concordance representing greater communication effectiveness and fewer misunderstandings about partner viewpoints regarding cancer treatment and care decision making. Moreover, our results used data collected at 5 separate timepoints over 24 months, thus enabling analysis of change in dyadic communication concordance over a longer period of treatment trajectory, as compared to existing studies.¹⁴ The explicit inclusion of the caregiver in the evaluation of communication is significant; indeed while shared decision making has long been an accepted model for joint patient-oncologist communication and decision making,²⁹⁻³¹ it does not include caregivers in the communication and decision making process. This is despite both clinician and caregiver

decision support being important predictors of patient satisfaction with decisions.⁷ This new typology specifically includes the cancer caregiver, demonstrating distinct patterns that dyadic communication may take. It could be used to identify common patterns of dyadic communication at different points throughout the cancer care trajectory that may be indicative of increased risk or vulnerability to communication difficulties, leading to less than optimal participation in treatment decision making, dissatisfaction with treatment decisions and poorer patient and caregiver health outcomes.

Study Limitations

This was one of the first large sample, longitudinal studies (24 months) of hematological cancer patient-caregiver communication. While we achieved a large sample of dyads, they were primarily white (73.5%) which limits our ability to state with assurance that the race-based differences observed are generalizable. To robustly tease apart the potential racial differences identified between the three communication groups a more representative sample of non-white cancer patient-caregiver dyads is required. Moreover, the number of dyads represented in the High Discordant Communication group was small; results should be interpreted with caution. We also do not know the nature of the dyad's pre-diagnosis communication patterns and therefore it is unclear to what extent the baseline communication scores reflect stress due to the cancer diagnosis and treatment initiation.

Clinical Implications

Clinicians can utilize the proposed typologies to identify patient-caregiver dyads that may be at increased risk or vulnerability to communication difficulties. Once identified, additional support resources, for example interventions focused on problem solving or communication skill building to facilitate difficult conversations, can be deployed to mitigate disagreements and enhance decision-making, care and ultimately outcomes.

Conclusions

This longitudinal study of cancer-patient-caregiver communication demonstrated that communication concordance fluctuates for a significant proportion of dyads following cancer treatment initiation. Importantly this study extends what is known about caregiving and communication among caregivers who are adult children or friends of the patient, indicating that these dyads are likely to be the most vulnerable and in need of support interventions different from dyads with spouse/partner caregivers. Further work is needed to better understand the triggers for these fluctuations in communication congruence to allow for identification of dyads at increased risk or vulnerability and interpersonal problems that might affect quality of life, ability of patients and caregivers to work or function within the family, and care outcomes.

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Data Availability Statement:

Data available on request due to privacy/ethical restrictions. The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Figure 1. Group 1: Stable concordant (mean) (confidence interval). Group 2: Fluctuating medium discordant (mean) (confidence interval). Group 3: High discordant (mean) (confidence interval)

Table 1.

Demographics: Total Sample and Communication Groups Identified by Latent Class Growth Model

	Total Sample N=171	Stable Concordant N = 97	Fluctuating Medium Discordant N = 65	High Discordant N = 9	F (p)
Patient Age (M (sd))	54.2 (12.1)	54.5 (13.0)	55.1 (10.8)	56.0 (16.4)	.08 (.92)
Caregiver Age (M (sd))	54.2 (12.9)	54.1 (13.7)	54.2 (12.2)	55.3 (14.9)	.04 (.62)
					Chi-sq (p)
Sex	N (%)	N (%)	N (%)	N (%)	
Patient Male	108 (63.2)	61 (63.0)	42 (64.6)	5 (55.6)	0.29 (.86)
Caregiver Male	44 (25.7)	25 (25.8)	17 (26.1)	2 (22.2)	.06 (.96)
Race					
Patient Race					
African American	37 (21.6)	14 (14.4)	19 (29.2)	4 (44.4)	12.1 (.01)
Caucasian	123 (72.0)	76 (78.3)	44 (67.7)	3 (33.3)	
Other	11 (6.4)	7 (7.2)	2 (3.0)	2 (22.2)	
Caregiver Race					
African American	39 (22.9)	15 (15.6)	19 (29.2)	5 (55.6)	12.6 (.01)
Caucasian	125 (73.5)	77 (80.2)	45 (69.2)	3 (33.3)	
Other	6 (3.5)	4(4.2)	1 (1.5)	1 (11.1)	
Education					
Patient Education					
< HS /HS/GED	35 (20.5)	15 (15.0)	16 (25.0)	4 (44.0)	8.4 (.08)
Some college	59 (34.5)	32 (33.0)	24 (37.0)	3 (33.0)	
Bachelors degree or higher	77 (45.0)	52 (54.0)	23 (35.0)	2 (22.0)	
Caregiver Education					
< HS /HS/GED	41 (29.8)	25 (25.8)	20 (20.8)	6 (66.7)	7.4 (.11)
Some college	52 (30.4)	29 (29.9)	21 (32.3)	2 (22.2)	
Bachelors degree or higher	68 (39.1)	43 (44.3)	24 (36.9)	1 (11.1)	
Income					
Patient Income					
<15-29,999	23 (13.4)	9 (9.0)	9 (14.0)	5 (56.0)	16.7 (.02)
30-59,999	20 (11.7)	10 (10.0)	9 (14.0)	1 (11.0)	
60-100,000+	118 (69.0)	74 (76.0)	41 (63.0)	3 (33.0)	
Missing	10 (5.8)	5 (5.0)	4 (6.0)	1 (11.0)	
CG Income					
<15-29,999	20 (11.7)	8 (8.25)	9 (13.8)	3 (33.3)	17.8 (.007)
30-59,999	21 (12.3)	12 (12.4)	7 (10.8)	2 (22.2)	
60-100,000+	119 (69.6)	68 (70.1)	49 (75.4)	2 (22.2)	
Missing	11 (6.4)	9 (9.3)	0 (0.03)	2 (22.2)	

	Total Sample N=171	Stable Concordant N = 97	Fluctuating Medium Discordant N = 65	High Discordant N = 9	F (p)
Marital Status					
Patient Married	129 (75.4)	78 (80.4)	45 (69.2)	6 (66.6)	1.4 (.50)
Caregiver Married	142 (83.0)	82 (84.5)	52 (80.0)	8 (88.9)	2.9 (.81)
Relationship					
Spouse/partner	126 (73.7)	71 (73.2)	51 (78.5)	4 (44.4)	20.2 (.003)
Parent	15 (8.8)	9 (9.3)	6 (9.2)	0 (0.0)	
Adult child/Sibling	22 (12.9)	13 (13.4)	7 (10.8)	2 (22.2)	
Friend/Other	8 (4.7)	4.12 (3.0)	1 (1.5)	3 (33.3)	
Diagnosis					
NHL	109 (63.7)	70 (72.2)	33 (50.8)	6 (66.7)	5.1 (.07) [†]
NHL Stage					
0	9	8	1		
1-2	33	19	13	1	
3-4	50	33	12	5	
Unknown/Unclassified	17	10	7		
CLL	20 (11.7)	8 (8.25)	12 (18.5)	0 (0)	
CLL Stage					
0	3	1	2		
1-2	6	3	3		
3-4	5	2	3		
Unknown/Unclassified	6	2	4		
MM	42 (24.6)	19 (19.6)	20 (30.8)	3 (33.3)	
MM Stage					
0	2	2	0		
1-2	10	4	5	1	
3-4	19	7	12		
Unknown/Unclassified	11	6	3	2	

[†]This is the p-value for diagnosis contrast; stage was also not significant.