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All in the family: A descriptive analysis of family network change in families managing chronic illness

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Abstract

Background: Social networks can be a source of support, including informational support, in chronic illness management, but can change over time in response to health crises. However, little is known about how families leverage their support networks to manage chronic illness over time—and how these networks may change.

Methods: For 28 families managing either diabetes or HIV, we gathered survey-based social network data, including network size, exchanges of support, and tie strength, up to 5 times over 2 years. We then used descriptive analysis to examine changes in network size, structure and function (e.g., informational support).

Findings: Although family networks remained stable in terms of network size and transitivity, these networks experienced regular fluctuations in both tie-level variables (i.e., tie strength) and density of informational support exchanges.

Discussion: Observed changes in these measures indicate that even family support networks are susceptible to change over time, particularly at the tie-level, indicating a need to expand the way we think of network change beyond whole network measures when looking at small, family networks, especially examining how information exchanges fluctuate over time. Future research should explore tie-level measures and support exchange networks to understand *why* networks change over time.

KEYWORDS

chronic illness, family networks, informational support, social support

1 | INTRODUCTION

Chronic illnesses are complex long-term health issues with no cure that require self-management, including treatment regimens, dietary and exercise changes (National Centers for Chronic Disease Prevention and Health Promotion, 2016). These illnesses are the leading causes of death and disability in the United States, directly impacting 60% of US adults (National Centers for Chronic Disease Prevention and Health Promotion, 2019).

Due to their duration and evolving nature (Maes, Leventhal, & de Ridder, 1996), long-term treatment and illness management are needed (Schulman-Green et al., 2012). Illness management is "the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms,

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treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions" (Richard & Shea, 2011, p. 261). Unlike shorter-term, acute conditions, chronic illnesses are largely managed away from healthcare settings like doctors' offices. Instead, patients perform most illness-management at home (Schulman-Green et al., 2012). Home-based management happens within the context of patients' day-to-day lives and, frequently, in collaboration with members of their family networks (Mirzaei et al., 2013).

Patients and their family caregivers need access to resources like social support, which is "a flow of emotional concern, instrumental aid, information, and/or appraisal between people," (House, 1981, p. 26) in order to manage chronic illness (Sivan-Donin, Ben-Ezra, & Hamama-Raz,-2019). Such resources are accessed through social networks, or the relationships among social entities like people (Wasserman & Faust, 1994). Types of social networks include personal social networks (i.e., networks of relationships centered on a focal individual) and whole social networks (i.e., networks of relationships not centered on a particular individual, such as whole networks of families). Patients and their family members often have personal social networks that may assist with managing chronic illnesses through the provision of network-mediated resources like social support, including informational support (e.g., Knowlton, 2003; Mignone et al., 2015; Veinot, Kim, & Meadowbrooke, 2011).

Whole social networks are dynamic and evolve over time in difficult to predict ways (Kuehn, Martens, & Romero, 2014; Romero, Uzzi, & Kleinberg, 2019; Wrzus, Hänel, Wagner, & Neyer, 2013), although little prior work has considered whole family networks. Furthermore, little is known about how patients' personal social networks, or whole social networks that include patients, may change over time in the context of the long-term trajectories of chronic illness. Therefore, this study explores how family support networks involving chronic illness management change over time. This exploration was guided by the following research question: does the structure of family support networks change over time? If so, which aspects of family network structure change?

2 | BACKGROUND LITERATURE

2.1 | The value of social networks

Social networks are important to chronic illness management as they provide access to useful resources, including informational and other social supports. Three types of social support are particularly important: informational support, giving "information that the person can use in coping with personal and environmental problems"; tangible support, providing direct support such as help with practical tasks; and emotional support, "providing empathy, caring, love, and trust" (House, 1981, pp. 24–25). These forms of support can positively impact health outcomes including improved mental health (Harkness et al., 2010), decreased mortality (Zhang, Norris, Gregg, & Beckles, 2007), and higher overall quality of life and well-being (Wang, Wu, & Liu, 2009). However, differences in network structures including tie types (i.e., relationships) and network cohesion (i.e., amount of interconnectivity within a network) can impact how support is accessed.

Personal network ties with closer people, "strong ties," are connections that share more time, emotional intensity, intimacy, and reciprocity (Granovetter, 1973). Strong ties can be particularly important to how individuals access (Wiener, 1998), and perceive the availability of (Cheng, Meng, & Liu, 2018), emotional support. Strong ties can also be a critical component of accessing tangible support such as drives to healthcare appointments, as shown among people with HIV/AIDS (Veinot, 2008). Such tangible support from social networks can help patients manage the day-to-day work of managing chronic illness (Vassilev et al., 2013). Informational support, however, is associated more strongly with access to weak network ties (Granovetter, 1973) or healthcare providers (Pettigrew, 2000; Veinot, 2010a). For health information in particular, much searching behavior is completed on behalf of others, including ill family members and friends (Fox & Duggan, 2013). Personal social networks can provide health information and advice (Abrahamson, Fisher, Turner, Durrance, & Turner, 2008; Longo et al., 2010), but this information may not always be perceived by patients as supportive (Veinot et al., 2011). Some patients may even think it is harmful if they are avoiding health information (Brashers, Goldsmith, & Hsieh, 2002).

Notably, some work has shown that exchanges of support are more beneficial when they are perceived to be reciprocal, meaning support flows in both directions (Jaeckel, Seiger, Orth, & Wiese, 2011; Jung, 2010). This is more likely to occur in strong tie relationships or in ties between patient peers (Veinot, 2010b). Social support in families, in particular, has been credited as a source of improved outcomes such as increased life expectancy (Lipowicz, 2014). Family support has also been linked to higher psychosocial adaptation to illness (Trief, Himes, Orendorff, & Weinstock, 2001), increased self-efficacy, and intentions to conduct self-care activities (Wen, Shepherd, & Parchman, 2004).

In addition to ties between single individuals, much work links both personal and whole social networks to flows of information (i.e., Gruhl, Guha, Liben-Nowell, & Tomkins, 2004; Watts, 2002). Information flows at different rates through different whole network structures,

with highly cohesive networks tending toward fast flow of potentially redundant information and less cohesive networks flowing more slowly, but bringing more novel information (Weng, Menczer, & Ahn, 2013), especially when networks include weak ties across subgroups (Granovetter, 1973). Personal and whole networks that are more cohesive may also be experienced as more emotionally supportive (e.g., Sparrowe, Liden, Wayne, & Kraimer, 2001). Despite the importance of networks to accessing social support (e.g., Wiener, 1998), and the subsequent importance of these resources to health and well-being (e.g., Wang et al., 2009), little is known about how these resources are accessed via family support networks for those managing chronic illness.

2.2 | Social network change

Personal social networks frequently change over time, with much prior work relating to network size. Previous research has shown that personal social networks of particular individuals tend to decay over time due to difficulty maintaining ties across life phases (Roberts & Dunbar, 2011). Major transition phases, such as moving into adulthood (Degenne & LeBeaux, 2005), entering the labor market (Bidart & Lavenu, 2005), or other common major life events (e.g., marriage, divorce, or retirement) often lead to changes in personal network size and composition (Weng et al., 2013). These changes can also be linked to growing older (Weng et al., 2013), lack of meeting opportunities in a geographic area (Mollenhorst, Volker, & Flap, 2014), and decreases in contact frequency and joint activities after geographic relocation (Roberts & Dunbar, 2011).

As mentioned, personal and family networks can be a vital source of informational, emotional, and tangible support for chronic illness (Barbarin, Klasnja, & Veinot, 2016; Barbarin, Veinot, & Klasnja, 2015; Veinot, 2009). However, these networks may change in different ways than the aforementioned research on general personal network change since prior research has included voluntary (e.g., friends or neighbors) connections. Family network membership tends to be less voluntary by comparison; thus, there is potential for network change dynamics to differ.

A small body of research has begun to explore personal network change in relation to health, particularly after mental health diagnoses (Perry & Pescosolido, 2012) and stroke (e.g., Northcott, Hirani, & Hilari, 2017; Northcott, Marshall, & Hilari, 2016; Northcott, Moss, Harrison, & Hilari, 2016). This work has found that there is an "isolation effect" after these events such that patients experience decreases in personal network size after illness onset (Northcott, Marshall, & Hilari, 2016; Perry & Pescosolido, 2012). Additionally, mixed networks (i.e., networks containing both friends and family) are likely to unevenly decline in size after stroke such that friends leave the network, leaving primarily family members in the stroke survivor's network (Northcott et al., 2017). However, networks have other characteristics which may be sensitive to the frequent changes in patient health status (Maes et al., 1996). For instance, tie strength and network cohesion might change in response to health-related stressors. Moreover, such prior studies do not investigate the dynamics of information and other support networks. However, these support networks may change over time since chronic illness involves long-term management of evolving needs (Maes et al., 1996). Therefore, we evaluate family support networks over time using multiple measures, and specifically examine networks which involve informational, emotional, and tangible support.

3 | METHODS

3.1 | Data collection

Data were collected as part of a larger, mixed methods, longitudinal study which investigated the informational and other support needs and behaviors of families managing chronic illness. Families managing diabetes and HIV/AIDS were theoretically sampled to represent differing chronic illness experiences regarding stigmatization, treatment types, and communicability. Patients were recruited via: (a) flyers distributed by disease-specific non-governmental organizations; (b) in-person approach following appointments at a large Midwestern Veterans Affairs hospital; or (c) online via a large university-based participant recruitment service. Recruitment followed a quota sampling approach to obtain a sample of patients that was roughly balanced across the two disease groups and representative of the race and gender composition of the study state.

After their own recruitment, patients subsequently recruited family members for the study. By design, patients self-defined "family member," thus recruited individuals included blood relatives, spouses, partners, friends, neighbors, housemates, and co-workers. Although it was requested that family members be involved in the patient's illness management, this was left to patient discretion, leading to variation in family member involvement.

Data collection involved five contacts over approximately 2.5 years, with 5–6 months between contacts on average. All participants completed individual surveys with network questionnaires at each time-point in addition to either family group (T2–T4) or individual (T1 & T5) semi-structured interviews. Each observation in the data represented a single family at a single time-point, with a maximum of five observations per family. Thirty-eight families (97 individuals) were recruited for the study

at Time 1 (T1) and 23 families (66 individuals) remained at the conclusion of the study at T5 (68% retention rate).

Due to the current focus, only families that participated at more than one time-point were included in the analyses (n = 29). One family was removed from the dataset due to missing network data at T2 and T3 (n = 28). The final dataset consisted of 96 observations which represented 28 families from T2 up to T5. Patients in the 28 included families did not differ significantly ($P > .1$) in terms of disease type, sex, education level, age, or network size when compared to patients in the 10 excluded families.

3.1.1 | Self-reported network data

Self-reported network data were collected at each interview via combined survey and interview methods. At T1 individual interviews, all participants identified people who were involved in the patient's illness management. Additionally, participants were asked to indicate with which of these people they exchanged informational, emotional or tangible support, either receiving or providing these supports. These responses were used to generate support networks for the three types of support.

After identifying network members, participants populated a visual representation (*see* Figure 1*)* of their networks reflecting how close they felt to others in the network, using a paper-based name-generation technique (Hogan, Carrasco, & Wellman, 2007). Network elicitation was embedded in the interview process, and any ambiguities were discussed and clarified. Photographs of these diagrams were used to generate adjacency matrices for overall family relationship networks. After T1, participants were given follow-up network forms and asked to report on tie strength and support exchanges, as well as membership changes such as exiting/joining network members.

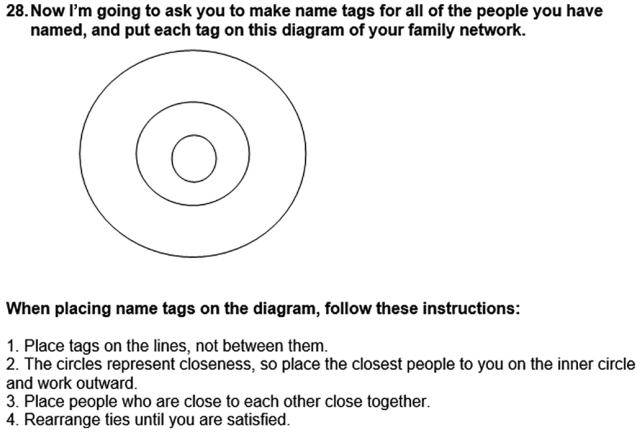

FIGURE 1 Network data collection format. Used only at T1

3.2 | Data analysis

3.2.1 | Relationship networks

Graphs, mathematical representations of network structures, for overall family relationship networks were generated using data on ties and their strength. These were undirected graphs; nodes (i.e., points for each entity in the network) represented individual people and edges (i.e., lines between network entities) represented a reported tie between those people. Any reported tie resulted in the creation of a single edge between a given pair of nodes (n_i, n_j). Edges were weighted by tie strength, with strong ties assigned the value, 3, and weak ties assigned the value, 1. Figure 2 shows a sample relationship network for a family dealing with diabetes at T1.

As described below, four measures were generated from overall family relationship networks; two tie-level variables and two network-level variables.

Relationship network measures

Tie-level variables. Tie-level variables are used to illuminate local patterns of network change by focusing on how the connections and patterns associated with each individual edge in a network changed over time. Changes in Jaccard distance and tie strength were calculated at the tie level.

Jaccard distance. Jaccard distance was selected to represent dissimilarity among connections, as dissimilar edges may be more able to access different forms of support, particularly informational support, from a network, given their diversity of connections relative to edges with higher similarity.

Measures of Jaccard distance (JD), which represented the dissimilarity between the respective ties of two nodes

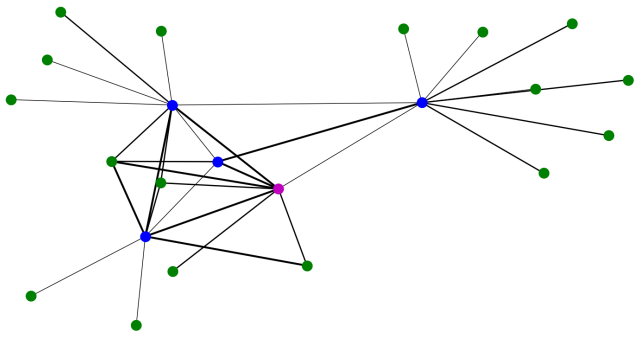

FIGURE 2 Example family relationship network. Patient represented as pink/purple node, study family members as blue nodes, other network members as green nodes. Edges indicate relationships between nodes and edge width indicates relationship strength

in a given edge, were calculated for each edge according to the formula, $JD(A,B) = 1 - \frac{A \cap B}{A \cup B}$ (Ciobanu, Reina, Dobre, Toral, & Johnson, 2014). Here (A,B) represented an edge between nodes A and B, A⋂B (intersection) was the number of nodes in the network which were connected to both A and B, and A⋃B (union) was the number of nodes in the network which were connected to A and/or B. JD is the intersection divided by the union, subtracted from one, with values ranging from 0 to 1 where dissimilarity increases moving toward 1.

For each edge in each network, change in JD over time was the current value of JD subtracted from this value at the previous time-point. Overall change was then calculated for each network as the average change in Jaccard distance experienced between the current and previous times. Positive values indicated increasing dissimilarity over time, and therefore decreasing cohesion. Conversely, negative values indicated decreasing dissimilarity over time, therefore, increasing cohesion.

Tie strength. Tie strength was initially determined by perceived closeness in the provided concentric circles diagram. Closest ties were placed on the first, innermost circle, the least close ties were placed on the third, outermost circle, and somewhat close ties were placed in the intermediate circle. In follow-up surveys, participants were asked to indicate how close they felt to each network member. These designations were then assigned values from 1 (weak) to 3 (strong), representing tie strength. Each tie was assessed for changes in tie strength from the current to previous time, and then change values were averaged for each network at each time to find the overall change in tie strength.

Whole network-level variables

Network size. Network size was the number of nodes in a given network at a given time.

Network transitivity. Network transitivity was another measure of network cohesion which measured the amount of overall interconnectedness of a network. High transitivity may be an indicator of a more clustered network with faster flows of resources between strong ties (such as tangible and emotional support) but decreased access to informational support via weak ties. Measures of network transitivity were calculated for the overall relationship networks using the standard formula for transitivity, $T = \frac{3 \, x \, number \, of \, triangles \, in \, the \, network}{number \, of \, connected \, triples \, of \, nodes \, in \, the \, network}$ (Newman, 2004).

3.2.2 | Support networks

Participants were asked for information on who provided them with social support. Using these data, three additional illness-related support networks, representing information, tangible, or emotional, were generated for each family at each time-point. These were represented as directed multigraphs, networks in which edges have a set direction, based on the direction of interaction, and multiple edges between a single pair of nodes are permitted. In these networks, for a given pair of nodes (n_i, n_j) an edge is drawn from n_i to n_j if n_i reported giving n_j the relevant type of support. An additional edge is drawn towards n_i if it was also reported that n_i also receives that type of support from n_j. Figure 3 shows an example informational support network, also for a family managing diabetes at T1. Sizes of support networks were identical to the relationship networks as all nodes included in these networks were also included in the support networks. However, the number of edges within the support networks generally differed as study members did not exchange these types of illness-related support with all individuals to whom they were connected.

Support network measures

Support network density (network-level variables). Measures were created to represent the density of connections within these support networks for each family at each time-point. Density was selected as it can be an indicator of increased interaction frequency, feelings of solidarity (Ten Kate, Haverkamp, Mahmood, & Feldberg, 2010), and network closeness (Wejnert, 2002). These measures reflected the function and calculation of network density, (i.e., the number of existing connections divided by the total number of possible connections in a network), but were operationalized

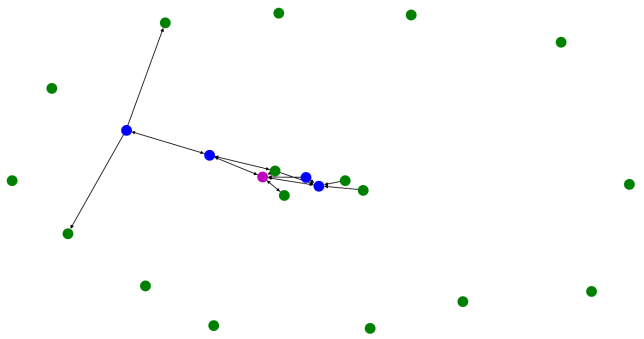

FIGURE 3 Example emotional support network. Patient represented as pink/purple node, study family members as blue nodes, other network members as green nodes. Edges indicate emotional support shared between nodes, arrows point to support receiver. Note that not all network members were involved in exchanging support, therefore there are nodes in the graph which are not connected to other network members via support edges

differently to fit the current dataset. Support network densities were calculated as the number of existing support connections across all nodes relative to the number of possible support connections (i.e., the existing connections in the overall family relationship networks). This differs from traditional density calculations as the denominator was derived from existing edges in the overall relationship network rather than all possible connections. This was necessary as individuals could not exchange support with someone to whom they are not connected.

Support reciprocity. Reciprocity can impact the benefits received from engaging in support (e.g., Jung, 2010); therefore, reciprocity is important to understand in relation to support networks. Reciprocity is calculated as the number of edges in a given support network through which support (informational, emotional, or tangible) is shared by both nodes in those edges divided by the total number of edges in that network (Borgatti, Everett, & Johnson, 2013).

3.3 | Descriptive analysis

The above measures were analyzed to develop a better understanding of how family support networks change over time. These analyses focus primarily on the distribution of change values for each time-point, as represented by descriptive statistics across time. Descriptive analyses were conducted by each time-point, rather than across the whole dataset, because the data were non-independent by design with time-points nested within family groups.

4 | RESULTS

4.1 | Participant demographics

Twenty-eight families were included, including 14 (50%) managing diabetes and 14 (50%) managing HIV (Table 1). Patients were roughly balanced by gender for all time-points. Of the 28 families included at Time 2 (T2), 19 remained in the study at T5.

TABLE 1 Included study participants and networks

	T2	T3	T4	T5
Total Family Groups	28	25	23	20
Total Individuals	70	63	57	55
Families Managing Diabetes	14	12	12	12
Families Managing HIV	14	12	10	7
Median Family Group Size (Minimum–Maximum)	2 (2–5)	2 (1[a]–5)	2 (1[a]–6)	2 (2–7)
Median Network Size (Minimum–Maximum)	12.5 (3–27)	13 (3–28)	12 (3–25)	13 (2–32)
Median Proportion of Strong Ties (IQR)	0.56 (0.40–0.76)	0.57 (0.43–0.70)	0.57 (0.43–0.70)	0.57 (0.41–0.70)
Median Network Average Jaccard Distance (IQR)	0.9995 (0.9987–0.9998)	0.9992 (0.9987–0.9998)	0.9997 (0.9987–0.9998)	0.9995 (0.9986–0.9999)
Median Informational Support Network Density (IQR)	0.34 (0.17–0.53)	0.35 (0.17–0.50)	0.25 (0.11–0.46)	0.25 (0.14–0.36)
Median Informational Support Reciprocity (IQR)	0.31 (0.05–0.78)	0.38 (0.00–0.60)	0.45 (0.00–0.58)	0.33 (0.00–0.50)
Median Tangible Support Network Density (IQR)	0.26 (0.09–0.44)	0.17 (0.08–0.38)	0.17 (0.04–0.27)	0.13 (0.04–0.17)
Median Tangible Support Reciprocity (IQR)	0.45 (0.00–0.75)	0.00 (0.00–0.50)	0.38 (0.00–0.67)	0.18 (0.00–0.56)
Median Emotional Support Network Density (IQR)	0.46 (0.24–0.68)	0.36 (0.25–0.56)	0.33 (0.21–0.50)	0.36 (0.21–0.45)
Median Emotional Support Reciprocity (IQR)	0.50 (0.29–0.71)	0.35 (0.14–0.67)	0.50 (0.36–0.67)	0.40 (0.23–0.63)

[a]Although recruiting family members was a requirement of participation in the study, one family with only 1 member in the study was allowed to remain at T3 and T4 after a falling out with the other member of his family in the study, as his experiences reflected a network change of interest.

As indicated in Table 1, family support networks were fairly small overall with the largest network size being 32 nodes. Family group size was relatively consistent, most were two individuals (one patient and one family member) with only a few larger families. Networks tended to have high proportions of strong ties (median values 0.56/0.57). Jaccard distance was consistently very high (>0.9992, with a maximum possible value of 1.0), indicating high dissimilarity of network ties between participants.

Support network density for the three types of support varied, with tangible support being lowest and emotional support being highest, indicating that more interconnected individuals may be relied upon for emotional than informational or tangible support. Networks tended to have some amount of reciprocal support exchanges, with the exception of tangible support at T3; median values for all three types of support across ranged from 0.18 to 0.50 (on a scale from 0, not reciprocal, to 1, fully reciprocal). Emotional support networks were slightly more reciprocal, on average, than informational and tangible support networks.

4.2 | RQ: Does the structure of family support networks change over time? If so, which aspects of family network structure change?

4.2.1 | Tie level measures: changes in overall family relationship networks over time

Overall family relationship networks were evaluated for changes in Jaccard distance and tie strength. Note that the Jaccard distance measure represented a change in a value which ranged from 0 to 1, therefore possible values ranged from −1 to 1. Similarly the tie strength measure represented the change in a value which ranged from 1 to 3, therefore possible change values range from −2 to 2.

Changes in Jaccard distance (dissimilarity)

Overall, tie-level changes in Jaccard distance averaged to 0 (no change) for most family networks at all time-points. At all times, approximately 50% of all families networks had an average Jaccard distance change of 0 or close to 0, with 25% of values at T2 indicating an increase of 0.02 or more, 25% at T3 indicating a decrease −0.01 or more and 25% at T4 indicating an increase of 0.02 or more.

However, as these values were calculated at the tie level and then averaged, 0 values could either indicate a lack of change within networks or a balance of ties increasing and decreasing (positive and negative) values. Notably, the majority of networks (>50%) had 0 ties experiencing an increase or a decrease in distance at T3 through T5. A majority of networks also had 0 ties experiencing a decrease in distance at T2, however 50% of networks had proportions of ties with increasing distance of 0.08 or higher. Across all time-points, at least 25% of all networks had ties experiencing changes in distance (increases and/or decreases) (see Table 2).

Changes in tie strength (tie-level)

Average change in tie strength for each network was slightly higher than that of Jaccard distance, with greater than 50% of networks having a non-zero average change (both increases and decreases) in tie strength across all ties, although these changes were still relatively small. T3 to T5 remain fairly consistent, with a median average change value of 0.00, 25th percentile's ranging from −0.13

TABLE 2 Changes in tie level variables over time

	T2 Median (IQR)	T3 Median (IQR)	T4 Median (IQR)	T5 Median (IQR)
Average Change in Jaccard Distance	0.00 (0.00 to 0.02)	0.00 (−0.01 to 0.00)	0.00 (−0.00 to 0.02)	0.00 (−0.00 to 0.00)
Proportion of Edges with Increasing Distance	0.08 (0.00 to 0.29)	0.00 (0.00 to 0.13)	0.00 (0.00 to 0.26)	0.00 (0.00 to 0.12)
Proportion of Edges with Decreasing Distance	0.00 (0.00 to 0.11)	0.00 (0.00 to 0.15)	0.00 (0.00 to 0.08)	0.00 (0.00 to 0.19)
Average Change in Tie Strength	0.17 (−0.08 to 0.41)	0.00 (−0.14 to 0.14)	0.00 (−0.05 to 0.14)	0.00 (−0.04 to 0.13)
Proportion of Edges with Increasing Tie Strength	0.34 (0.14 to 0.46)	0.07 (0.00 to 0.20)	0.07 (0.00 to 0.22)	0.06 (0.00 to 0.16)
Proportion of Edges with Decreasing Tie Strength	0.11 (0.00 to 0.26)	0.10 (0.00 to 0.18)	0.08 (0.00 to 0.14)	0.08 (0.00 to 0.14)

to −0.05, and 75th percentiles ranging from 0.11 to 0.17. Although the IQR at T2 was similar to other times (−0.08 to 0.41), T2 had a median value of 0.17 (see Table 2).

Similar to Jaccard Distance values, 0 values for average change in tie strength do not necessarily indicate no change, but could indicate a balance of increases and decreases. Therefore the proportion of ties experiencing increases or decreases in tie strength over time are also included in Table 2. In general, at least 50% of networks at all time-points had ties which experienced increases or decreases, with at least 75% of networks having ties experiencing increases in tie strength at T2.

4.2.2 | Whole network level measures: family relationship networks over time

Next, overall family relationship networks were evaluated for changes at the network level (i.e., changes in network average values from one time to the next) across three measures; (a) network size, (b) network transitivity. For network size, change is measured in number of nodes, so a value of 1 would indicate the addition of 1 individual to the network and a value of −1 would indicate the opposite. Network transitivity ranges from 0 to 1, so change values could range from −1 to 1.

Changes in network size

Network size remained fairly constant with the majority (50% or more) of networks at each time-point experience little to no change in network size, and the majority of changes at each time-point falling between 0 and 2 individuals added/removed. Increases in size were slightly more common than decreases, with 25% of networks at T4 and T5 in particular having a size increase of 2 or more individuals. Additionally, 25% of networks at T3 had seen a size increase of 1 or more, although 25% of networks also at T3 had seen a decrease of −1 or more. At T2, neither increases nor decreases were common, with at least 50% of networks experiencing no change in network size (see Table 3).

Changes in network transitivity

Changes in network transitivity remained relatively small throughout the study. Median values for all time-points were 0, indicating no change in network transitivity, and for T2, T3, and T5 the 25th and 75th percentiles were roughly close to 0 (no greater than 0.04). At T4, although the median value was 0, the 25th percentile was −0.12 indicating that at least 25% of networks had experienced a decrease in transitivity of 0.12 or more (see Table 3).

4.3 | Whole network level measures: Family support networks over time

Next, the three different support networks (informational, tangible, and emotional) were evaluated for changes in three support network density measures and three support reciprocity measures. Note that support network density and support reciprocity values range from 0 to 1, so change values can range from −1 to 1, with negative values indicating decreases in density or reciprocity and positive values indicating increases in density or reciprocity.

Changes in informational support networks

Informational support network density. For all time-points, a majority of families experienced a change (either increasing or decreasing) in informational support network density as compared to the previous time-point, with a roughly even split between increasing and decreasing values at each time-point. Twenty-five (89%), 22 (92%), 19 (86%) and 17 (89%) families had changing information support network density at each time-point respectively. Decreases in informational support network density across all time-points ranged from −0.01 to −0.50. These numbers can be interpreted as follows: a network decrease of −0.50 means that a network went from having 75% of possible support connections actively providing informational support to only 25% providing support. Increases can be interpreted inversely and, across all time-points, had a similar range with the lowest increase being 0.007 and the highest being 0.5 (See Table 4).

Informational support reciprocity. As Table 4 shows, most families experienced some fluctuation in informational support reciprocity across time-points, with changes roughly balanced in terms of both increasing and

TABLE 3 Changes in network-level variables over time

	T2	T3	T4	T5
Change in Network Size Median (IQR)	0 (0 to 0)	0 (−1 to 1)	0 (0 to 2)	1 (0 to 3)
Change in Network Transitivity Median (IQR)	−0.00 (−0.04 to 0.00)	0.00 (0.00 to 0.01)	0.00 (−0.12 to 0.00)	0.00 (−0.00 to 0.04)

TABLE 4 Informational support networks over time

	T2	T3	T4	T5
Change in Informational Support Network Density Median (IQR)	−0.00 (−0.12 to 0.13)	−0.07 (−0.12 to 0.06)	0.00 (−0.17 to 0.07)	0.00 (−0.20 to 0.12)
Change in Informational Support Reciprocity Median (IQR)	0.08 (0.00 to 0.30)	0.00 (−0.25 to 0.04)	0.00 (−0.16 to 0.24)	−0.06 (−0.33 to 0.33)

TABLE 5 Tangible support networks over time

	T2	T3	T4	T5
Change in Tangible Support Network Density Median (IQR)	0.02 (−0.07 to 0.20)	−0.02 (−0.23 to 0.05)	−0.05 (−0.25 to 0.08)	−0.00 (−0.04 to 0.07)
Change in Tangible Support Reciprocity Median (IQR)	0.23 (0.00 to 0.67)	−0.17 (−0.50 to 0.00)	0.00 (−0.40 to 0.50)	0.00 (−0.04 to 0.23)

TABLE 6 Emotional support networks over time

	T2	T3	T4	T5
Change in Emotional Support Network Density Median (IQR)	0.02 (−0.08 to 0.18)	−0.07 (−0.19 to 0.05)	0.03 (−0.11 to 0.11)	0.00 (−0.10 to 0.21)
Change in Emotional Support Reciprocity Median (IQR)	0.22 (−0.13 to 0.45)	−0.07 (−0.23 to 0.09)	0.09 (−0.17 to 0.50)	0.00 (−0.36 to 0.10)

decreasing reciprocity, with the exception of T2 when changes leaned towards increasing values with greater than 50% of networks experiencing an increase of 0.08 or higher (median = 0.08). At T5, overall, there was the greatest change in reciprocity, with 50% of networks experiencing a change in reciprocity greater than 0.33 (either increasing or decreasing) and greater than 50% experiencing a decrease in reciprocity of 0.06 or more. At T3, changes leaned slightly towards higher decreasing values (IQR = −0.28 to 0.06), although the median value was 0, indicating that less than 50% of networks saw either an increase or a decrease.

Changes in tangible support networks

Tangible support network density. Similar patterns occurred for changes in tangible support network density, although tangible these networks tended more towards decreasing values from one time to the next. Twenty-six (93%), 20 (83%), 22 (100%) and 16 (84%) families had changing tangible support network density at each time-point, respectively. Decreases in tangible support network density across all time-points ranged from −0.004 to 0.63. Increases, across all time-points, had a similar range with the lowest increase being 0.015 and the highest being 0.63. These distributions are shown in Table 5.

Tangible support reciprocity. Table 5 shows that tangible support reciprocity fluctuated in terms of direction of change across time periods, with some time-points indicating decreases in tangible support reciprocity and others indicating the opposite. In particular, at least 50% of networks at T2 experienced an increase of reciprocity of 0.23 or higher whereas, at T3, at least 50% of networks experienced a decrease of 0.17 or greater. At T4 and T5, changes were slightly more balanced, although results at T4 tended towards larger values, with 50% of networks exhibiting an increase or decrease in tangible support reciprocity greater than 0.40. At T5, there were the smallest changes generally, although there was a tendency towards somewhat larger increases than decreases (75th percentile = 0.23, compared to 25th percentile = −0.04).

Changes in emotional support networks

Emotional support network density. As in Table 6, emotional support network density tended more towards increasing from one time to the next, with the exception of T2 to T3 (median change = −0.07). Twenty-seven (96%), 22 (92%), 20 (91%) and 17 (89%) families had changing emotional support network density at each time-point respectively. Decreases in emotional support network density across all time-points ranged from −0.008 to −0.75. Increases, across all time-points, ranged from 0.028 to 0.667.

Emotional support reciprocity. Emotional support reciprocity exhibited similar patterns of change to

informational support reciprocity over time, with T2 changes being slightly higher than other time-points and change being roughly balanced across increases/decreases (although less so than informational support). At T2, at least 50% of networks saw an increase in emotional support reciprocity greater than 0.22, with 25% increasing by more than 0.45. At T3 and T5, emotional support reciprocity exhibited higher decreases than increases and, at T2 and T4, the opposite was true. These distributions are shown in Table 6.

5 | DISCUSSION

This study investigated family support network change over time in families managing chronic illness. Findings revealed that most tie-level and whole network measures changed over time, as did characteristics of network associated with three forms of support, including informational support. However, network size and transitivity remained relatively stable. Although more work is needed to fully explain these differences, it is possible that the less voluntary nature of family network membership leads to a more stable overall network structure, even if relationships and interactions shift over time as families deal with the stresses of chronic illness. Among all measures exhibiting change, changes were generally small, becoming smaller and less common as the study progressed.

Despite the importance of personal social networks to families managing chronic illness(e.g., Mignone et al., 2015) and the evolving nature of chronic illness over time (Maes et al., 1996), much previous social network-based information behavior work relies on cross-sectional interviews and surveys (Brewer, 1994). Using a longitudinal approach instead, this study showed that even family support networks can fluctuate over time along some measures, even if some measures are unchanging. Such changes may be caused by a variety of factors, such as changes in health status, decreased need for informational support over time (e.g., Chen, 2016), evolving relationships or life situations, or other factors which impact these family support networks. More work is needed to explain these observed changes.

The results of this work also indicate the value of investigating measures of change in network flows, specifically flows of informational, tangible and emotional support. Support measures, in general, exhibited more change than measures of network cohesion overall. This is in line with prior work showing that chronic illness management, and associated information and other support needs, evolve over time (Barbarin et al., 2016; Maes et al., 1996). However, more work is needed to understand what drives these changes.

Prior research has consistently shown that social networks change over time, including both personal networks and whole networks. However, much of this work focuses on networks with many weak ties, and non-familial relationships. In contrast, the current study demonstrates that there is also change over time in smaller, close-knit family networks, even though network size and transitivity remained relatively stable. These results indicate that although there may be a family core (e.g., Wrzus et al., 2013) with stable membership throughout time while managing illness, after the potentially disruptive moment of illness onset (e.g. Northcott et al., 2017), this stability does not necessarily mean that family networks are not experiencing other forms of instability such as changing patterns of informational support exchange and fluctuations in feelings of closeness. Findings presented here validate the need to explore a greater variety of network measures when evaluating change over time.

Furthermore, much of prior research on social network change examines network change after major transitions, such as the transition from youth to adulthood (Degenne & Lebeaux, 2005) or other major life events such as marriage/divorce (Bidart & Lavenu, 2005; Wrzus et al., 2013). In contrast, the networks in this study also exhibited change over time despite being centered on patients who were relatively settled in their lives as working adults throughout the entire study period. However, although patient's lives remained relatively stable, other factors may have been in flux, such as health information which is constantly changing, leading to fluctuations in network patterns. Therefore, more work is needed to understand network changes throughout periods of life which are thought to be relatively stable, again using a greater variety of measures to evaluate change.

Whole network measures were more stable, on average, than their local level counterparts. Even averaged values of tie-level variables changed less than measures accounting for the amount of ties which experienced changes (i.e., proportions). For instance, averaged or aggregate measures of changing cohesion (average Jaccard distance and network transitivity) showed minimal change over time although many networks had some proportion of ties experiencing changes. This is aligned with prior work on the value of local level patterns, also called "motifs," to understanding network dynamics (e.g., Wax, deChurch, & Contractor, 2017). However, much of this prior work has focused on motifs within very large networks, as opposed to smaller personal social networks. This indicates a need for studies looking at changes in family networks over time consider local level patterns, as whole network and averaged tie-level measures may obscure more nuanced changes, such as in

exchanges of information, even if network size is relatively small.

This study has limitations. Participants were recruited from one Midwestern state and networks in other regions may exhibit different dynamics. Also, the use of personal networks means that there is missing information where study participants did not speculate on ties between external members of the networks. This may impact measures sensitive to missing information, such as network transitivity. However, data were consistently missing as a product of intentional study design; hence, change values remain informative.

6 | CONCLUSION

This study of 28 families managing HIV/AIDS or diabetes showed that family networks experienced demonstrable change over a two-year period. Exchanges of support, including informational support, tended to be dynamic with patterns fluctuation over time. However, in terms of network structure, network size remained relatively stable, along with other network-level measures of change. Change was more apparent in local level measures, indicating that, even in small networks, overall network level variables can obscure nuances in the ways that networks change over time. Overall, findings suggest that family groups, although stable in some respects, experience changes throughout the duration of chronic illness whereas prior work has focused on before-after comparisons in which the onset of illness as the primary instigator of illness-associated network change. However, given the present study's limitations, there is a need for further research to illuminate how and why these family networks change, including how families interact to exchange needed resources, such as health information.

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