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RESEARCH ARTICLE

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Sustainability of personal social networks of people with Down syndrome

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Abstract

Research continues to demonstrate that the characteristics of one's social network could have an impact on the development of Alzheimer's disease. Given the predisposition of people with Down syndrome to develop Alzheimer's disease, analysis of their social networks has become an emerging focus. Previous pilot research demonstrated that the personal networks of people with DS could be quantitatively analyzed, with no difference between self-report and parent-proxy report. This manuscript focuses on a 12-month follow-up period with the same original participants (24 adults with Down syndrome). Their social networks demonstrated sustainability, but not improvement, as reported by people with DS (mean network size: 8.88; mean density: 0.73; mean constraint: 0.44; mean effective size: 3.58; mean max degree: 6.04; mean degree: 4.78) and their proxies (mean network size: 7.90; mean density: 0.82; mean constraint: 53.13; mean effective size: 2.87; mean max degree: 5.19; mean degree: 4.30). Intentional and continued efforts are likely needed in order to improve the social network measures of people with Down syndrome.

KEYWORDS
Alzheimer's disease, dementia, Down syndrome, personal networks, social networks, trisomy 21

1 | INTRODUCTION

Since an estimated 40%–80% of adults with Down syndrome (DS) will develop Alzheimer's disease (AD) (Salehi et al., 2016), prevention and treatment have remained a pressing concern for this population. Previous studies in the neurotypical population have demonstrated that larger personal networks could have a protective effect against AD (Crooks et al., 2008; Fratiglioni et al., 2004; Kotwal et al., 2016; Wilson et al., 2007). The science of sociograms continues to expand (Dhand et al., 2022), and the promise of pro-connection interventions is being explored (HHS, 2023). Personal networks are the persons around an individual who provide support, circulate information, and influence health behaviors (Dhand et al., 2016). In our previous research, we demonstrated that the personal networks of people with DS could be quantitatively analyzed, with no difference between self-report and parent-proxy report (Skotko et al., 2023).

An open question remained: how sustainable are the personal networks of people with DS? Our original study was conducted during the COVID-19 pandemic, a period of immense social change. During this time, when quarantine measures were in place, many people with DS had limited social interactions as day programs were mostly closed, athletic programming such as Special Olympics was canceled, and employment opportunities were put on hold (Wong et al., 2022). All of these changes could have consequently reduced social connections. Now that the pandemic has subsided and people with DS have largely resumed their daily routines, we sought to re-measure their personal networks. With these follow-up analyses, we hypothesized that the personal networks for individuals with DS

would have increased given the re-openings of their community-based programs and activities.

2 | PATIENTS AND METHODS

2.1 | Patients

All participants with DS and their study partners who participated in our original study were invited to participate in this one-year follow-up study (Skotko et al., 2023). All participants with DS were aged 25 or older and recruited from our Massachusetts General Hospital Down Syndrome Program, a multidisciplinary clinic geared toward the care of individuals with DS across their lifespan. Individuals with DS had to be proficient in English. Each participant was required to participate with an English-proficient study partner, who was at least 18 years of age and spent at least 10 hours/week with the participant with DS. Additional characteristics of our participants and study partners are previously described (Skotko et al., 2023).

Written consent was not needed, based on an exemption from the Massachusetts General Brigham Institutional Review Board. If the participant identified as their own legal guardian, informed, implied verbal consent was obtained from the participant and the study partner. In cases where the participant had a legal guardian, informed, implied verbal consent was obtained from the legal guardian and study partner of the individual with DS. Assent was then obtained from the individual with DS. If at any point the individual with DS either verbally or nonverbal expressed dissent, the study was stopped.

2.2 | Survey

Our survey for both the study partners and people with DS was adapted from the PERSNET personal networks instrument (Dhand et al., 2016, 2018; Prust et al., 2021) and is previously described (Skotko et al., 2023). In short, the survey elicited the names of people with whom the person with DS "discussed important stuff with," "hung out with," and sought help from when they felt sick (please see Supplementary Materials of Skotko et al., 2023, for a copy of the survey). Names were then unduplicated. The closeness of the social ties was then established, and sociodemographic traits were obtained.

2.3 | Study procedures

Approximately 1 year after their baseline survey, the same study partners were asked to complete our survey via Research Electronic Data Capture (REDCap) hosted at Massachusetts General Hospital (Harris et al., 2009, 2019). Study partners were instructed that the survey would take about 15–20 minutes and were asked to respond from their perspective. To ensure study partners are not responding from their loved one's perspective, the directions stated, "Please respond as to what you feel are the right answers NOT how you anticipate your loved one will respond to the same question." Once that was completed, our research team scheduled a co-visit over Zoom with the individual with DS and the study partner. First, our research team asked the questions directly to the participants with DS and entered their responses directly into REDCap. Afterward, the study partners were invited to join the session to support the individual with DS, help un-duplicate names, and provide perspective on the participant's social network, as previously described (Skotko et al., 2023).

2.4 | Analyses

Detailed analyses have been previously described (Skotko et al., 2023). In Table 1, we provide an abbreviated summary of analytic terms utilized within this current study.

We used Wilcoxon's signed rank test, a nonparametric paired test, to compare the network metrics between time points for both

TABLE 1 Abbreviated summary of analytic terms utilized within this current study.

Term	Description
Network size	Unbounded value identifying the number of individuals in the participant's personal network. This value does not include the participants themselves, but includes individuals within the direct network and any additional name listed in response to any of the survey questions.
Constraint	Measure of how closely the members in the participants' networks are connected to the network itself. Using a statistic derived from Burt's Aggregated Constraint value,[a] values can range from 0 to 125, with 0 indicating that the network is "open" or "bridging," and 125 indicating a fully "closed" or "constrained" network.
Density	Measuring how close the individuals in the participant's network are to each other. Density can range from 0 to 1, as the value is calculated by taking the number of ties between individuals in the network outside the participant over the total number of possible ties. A value of 1 would represent a perfectly "dense" network where all individuals outside of the participant have ties to each other.
Effective size	Measuring the amount of different groups and voices within a network. Ranging from final values 0 to the network size value, the statistic is calculated by subtracting total strength of the tie to the proband and from the average strength of the tie to each member. Larger effective sizes come from networks where individuals do not know each other, while smaller effective sizes come from networks where everyone knows each other.
Max degree	Looks at the greatest number of ties any individual, outside of the proband, has in the network.
Mean degree	Average number of ties for all network members, outside of the proband.

[a]Burt, R. S. Network items and the general social survey. Soc. Networks 6, 293–339 (1984).

TABLE 2 Demographics of participants with DS, as reported by study partners and the participants with DS.

	As reported by study partner ($N = 31$)		As reported by participant with DS ($N = 24$)		
Variable	***N***	**% [95% CI]**	***N***	**% [95% CI]**	***p* value**
Sex					
Male	15	51.6 [33.1, 69.8]	12	50.0 [29.1, 70.9]	n/a[a]
Female	16	48.4 [30.2, 66.9]	12	50.0 [29.1, 70.9]	
Other	0	0.0	0	0.0	
Race					
Black or African American	0	0.0	0	0.0	0.317
White	30	96.8 [83.3, 99.9]	23	95.8 [78.9, 99.9]	
American Indian/American Native	0	0.0	0	0.0	
Asian	1	3.2 [0.1, 16.7]	0	0.0	
Native Hawaiian or other Pacific Islander	0	0.0	0	0.0	
Other	0	0.0	0	0.0	
Blank/Skip Question	0	0.0	1	4.2 [0.1, 21.1]	
Ethnicity					
Hispanic	1	3.2 [0.1, 16.7]	1	4.2 [0.1, 21.1]	0.801
Not Hispanic	27	87.1[70.2, 96.4]	22	91.7 [73.0, 99.9]	
Unknown	0	0.0	1	4.2 [0.1, 21.1]	
Blank	3	9.7 [2.0, 25.8]	0	0.0	
Educational Level					
Some high school or less	8	25.8 [11.9, 44.6]	2	8.3 [1.0, 27.0]	0.815
High school graduate	18	58.1 [39.1, 75.5]	15	62.5 [40.6, 81.2]	
Some college	3	9.7 [2.0, 25.8]	3	12.5 [2.7, 32.4]	
Associate's degree	1	3.2 [0.1, 16.7]	2	8.3 [1.0, 27.0]	
Bachelor's degree	0	0	1	4.2 [0.1, 21.1]	
Prefer not to answer	1	3.2 [0.1, 16.7]	1	4.2 [0.1, 21.1]	
Blank	0	0.0	0	0.0	
Currently dating someone					
Yes	6	19.4 [7.5, 37.5]	9	37.5 [18.8, 59.4]	0.083
No	23	74.2 [55.4, 88.1]	15	62.5 [40.6, 81.2]	
Blank	2	6.5 [0.8, 21.4]	0	0.0	
Living status					
Living alone	5	16.1 [5.5, 33.7]	5	20.8 [7.1, 42.2]	0.157
Not living alone	26	83.9 [66.3, 94.5]	19	79.2 [57.8, 92.9]	

[a]There is perfect agreement on sex between the 24 participant-study partner pairs; as such, it is not possible to calculate a p value from McNemar's test when there is perfect agreement.

the study partners and persons with DS. Missing responses were excluded from analyses. We used McNemar's test to assess whether there is a significant difference between responses from participants with DS and their study partners ($N = 24$ with paired responses).

3 | RESULTS

3.1 | Participants

Of the 43 study partners and 38 people with DS who participated in our original study, 31 study partners and 24 participants with DS chose to participate in this follow-up study (Table 2). There were 12 dyads lost to follow-up; no participant and/or study partner expressed dissent. An equal number of men and women with DS participated. The majority identified as non-Hispanic white were not living independently and were high school graduates (Table 2).

3.2 | Personal network characteristics

There were no statistically significant differences for any social network summary *metrics* between baseline and follow-up measures, for either the study partners or the participants with DS (Table 3). At

TABLE 3 Comparison of network structure metrics, as reported by study partners ($N = 31$) and participants with Down syndrome ($N = 24$) at baseline and follow-up.

Respondent	Variable	Time point	Median	25th percentile	75th percentile	*p* value
Study partner	Network size	Baseline	8.00	6.00	11.00	0.1094
		Follow-up	8.00	6.00	9.00	
	Density	Baseline	0.87	0.67	1.00	0.7536
		Follow-up	0.90	0.61	1.00	
	Constraint	Baseline	54.87	40.19	62.37	0.6501
		Follow-up	56.02	44.28	64.80	
	Effective size	Baseline	2.50	1.60	4.29	0.9534
		Follow-up	2.80	2.00	3.86	
	Max degree	Baseline	5.00	4.00	7.00	0.2964
		Follow-up	5.00	4.00	6.00	
	Mean degree	Baseline	4.33	3.43	5.20	0.3294
		Follow-up	4.00	3.43	5.00	
Person with Down syndrome	Network size	Baseline	9.50	6.50	12.50	0.6249
		Follow-up	8.00	6.00	10.50	
	Density	Baseline	0.82	0.61	1.00	0.2341
		Follow-up	0.74	0.59	1.00	
	Constraint	Baseline	43.87	34.89	52.07	0.7911
		Follow-up	43.14	35.73	49.13	
	Effective size	Baseline	3.74	1.67	4.67	0.2448
		Follow-up	3.54	2.10	5.00	
	Max degree	Baseline	6.00	5.00	8.00	0.9832
		Follow-up	6.00	5.00	7.50	
	Mean degree	Baseline	5.06	3.88	5.33	0.9765
		Follow-up	4.94	3.55	6.00	

TABLE 4 Comparison of paired responses at follow-up ($N = 24$).

Variable	Respondent	Median	25th percentile	75% percentile	*p* value
Network size	Study partner	7.50	5.50	9.00	0.4466
	Person with DS	8.00	6.00	10.50	
Density	Study partner	0.90	0.68	1.00	0.0182
	Person with DS	0.74	0.59	1.00	
Constraint	Study partner	56.12	43.28	63.05	0.0013
	Person with DS	43.14	35.73	49.13	
Effective Size	Study partner	2.80	2.07	3.58	0.0132
	Person with DS	3.54	2.10	5.00	
Max degree	Study partner	4.50	4.00	6.00	0.0528
	Person with DS	6.00	5.00	7.50	
Mean degree	Study partner	4.00	3.43	4.67	0.3115
	Person with DS	4.94	3.55	6.00	

follow-up, there were some statistically significant differences in *metrics* between people with DS and their study partners: lower density (0.74 vs. 0.90, $p = 0.018$) and greater effective size (3.54 vs. 2.80, $p = 0.013$) (Table 4). There were also no statistically significant differences for any of the social network *characteristics* as reported solely by study partners between baseline and follow-up (Table 5).

Per their self-report, participants with DS had, on average, 8.88 individuals in their personal network at this follow-up time point (Table 4). Participants with DS reported that people in their personal network remained close (0.73 on a scale of 0–1), and relatively constrained (44 on a scale of 0–125). The networks mostly consisted of people who knew each other, as the average effective

TABLE 5 Comparison of network metric characteristics of social network members, as reported by study partners at baseline ($N = 31$) and follow-up ($N = 31$).

	Baseline ($N = 31$) Median [interquartile range]	Follow-up ($N = 31$) Median [interquartile range]	p value[a]
Proportion of network members who are kin	0.50 [0.40, 0.60]	0.50 [0.40, 0.60]	0.417
Standard deviation of network members' ages	16.46 [15.01, 19.15]	15.69 [13.29, 17.90]	0.164
Diversity of men and women in the network (0, all one sex; 1, equally balanced men and women)	0.94 [0.71, 0.98]	0.96 [0.67, 0.99]	0.542
Diversity of different races in the network (0, all one race; 1, equally balanced across all races)	0.00 [0.00, 0.29]	0.00 [0.00, 0.27]	0.826
Diversity of different ethnicities in the network (0, all one ethnicity; 1, equally balanced across all ethnicities)	0.00 [0.00, 0.00]	0.00 [0.00, 0.00]	0.477
Proportion of network members who have disability	0.20 [0.00, 0.38]	0.17 [0.00, 0.40]	0.502
Proportion of network members who exercise 3–4 times a week	0.58 [0.40, 0.80]	0.57 [0.32, 0.80]	0.431
Proportion of network members who eat a healthy diet regularly	0.80 [0.64, 0.97]	0.78 [0.43, 1.00]	0.273
Proportion of network members who are in contact daily or weekly	0.46 [0.38, 0.62]	0.53 [0.40, 0.72]	0.520
Proportion of network members who have been known for more than 6 years	0.80 [0.72, 0.89]	0.80 [0.68, 1.00]	0.558
Proportion of network members who live in the same house or within 15 miles	0.80 [0.64, 0.98]	0.80 [0.57, 0.85]	0.394
Proportion of network members who have a barrier in spending time with focal individual with DS	0.30 [0.00, 0.50]	0.15 [0.00, 0.58]	0.758

[a]Wilcoxon signed rank test with continuity correction comparing Baseline to Follow-up Values for all cases with complete data ($N = 31$).

size remained low (3.58). The greatest number of ties an individual in the network had to other people in the network (not including the individual with DS) was on average 6.04. Meanwhile, there were, on average, 4.78 ties that any given member outside of the participant with DS held with each other within a network. The diverse sociograms also captured the large standard deviations among participants (Figure 1).

4 | DISCUSSION

The social networks for our cohort of adults with DS demonstrated sustainability, but not improvement, over 12 months, as reported by people with DS and their proxies. The durability of our participants' social networks must be assessed against the changing backdrop of the COVID-19 pandemic. Massachusetts declared a State of Emergency in March 2020 due to COVID-19 (Markos, 2021), and our baseline study began in July 2020. Although there were phases and rollbacks for COVID-19 restrictions, the relaxation of restrictions officially began in January 2021 as vaccinations became more commonplace. The governor of Massachusetts ended the State of Emergency on June 15, 2021 (Mass.gov, n.d.). The earliest follow-up survey for this research was conducted in August of 2021, with the majority of other follow-up surveys being conducted in late 2021 through 2022. In short, our baseline study uniquely analyzed social networks during a time of heavy external restrictions, and our follow-up study captured a time of minimal to no external restrictions.

Despite these broad environmental differences, the social networks of people with DS remained unchanged and did not improve after the pandemic ended. This might indicate that individuals with DS maintain consistent relationships within their social networks. Unlike neurotypical individuals, who might have multiple social opportunities to form novel connections (e.g., book clubs, sports groups, and social activities), individuals with DS and other intellectual disabilities often have transportation barriers (Friedman & Rizzolo, 2016) and expressive language challenges (Grieco et al., 2015; Kristensen et al., 2022), which limit such occurrences. If this explanation holds true, the implication would be that intentional and sustained effort might be needed to improve access to social settings for people with DS.

An additional explanation could relate to housing settings for individuals with DS. Many adults with DS live in group home settings that are able to accommodate independent living with support as needed. Personal social networks for individuals with DS in these settings could rely on housemates, which remained relatively unchanged, and even inflexible, during state quarantine requirements (Hegedus, 2020). This was similar to many MA seniors who lived in nursing homes or other congregate living settings (Giri et al., 2021).

Another explanation could be that insufficient time had transpired from the end of pandemic restrictions. Even after the state of

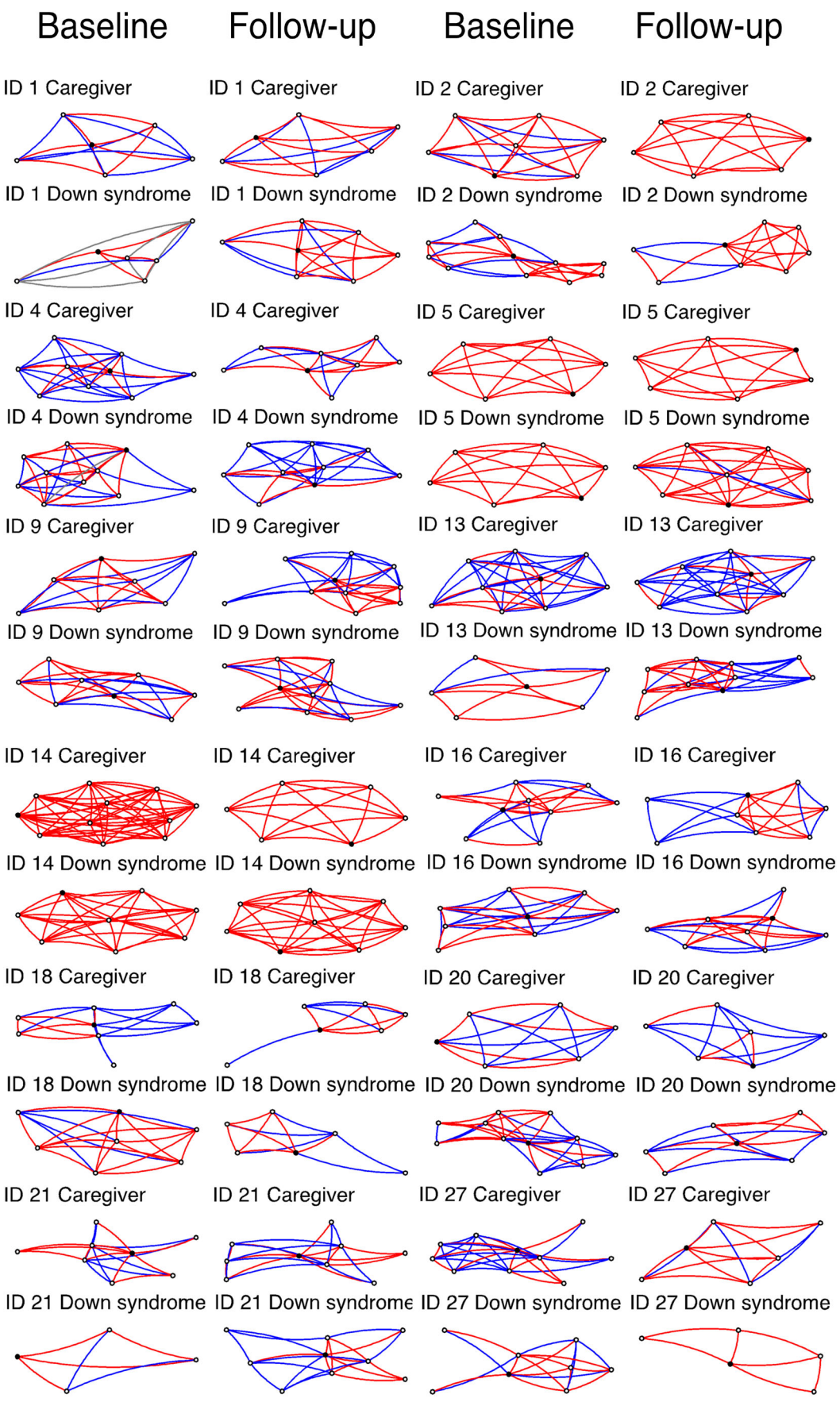

FIGURE 1 Personal networks of people with Down syndrome, as reported by participants with DS and caregivers. A solid black dot represents the participants with DS, open dots are other social connections. Blue lines represent weak social ties, while red bands represent strong social ties.

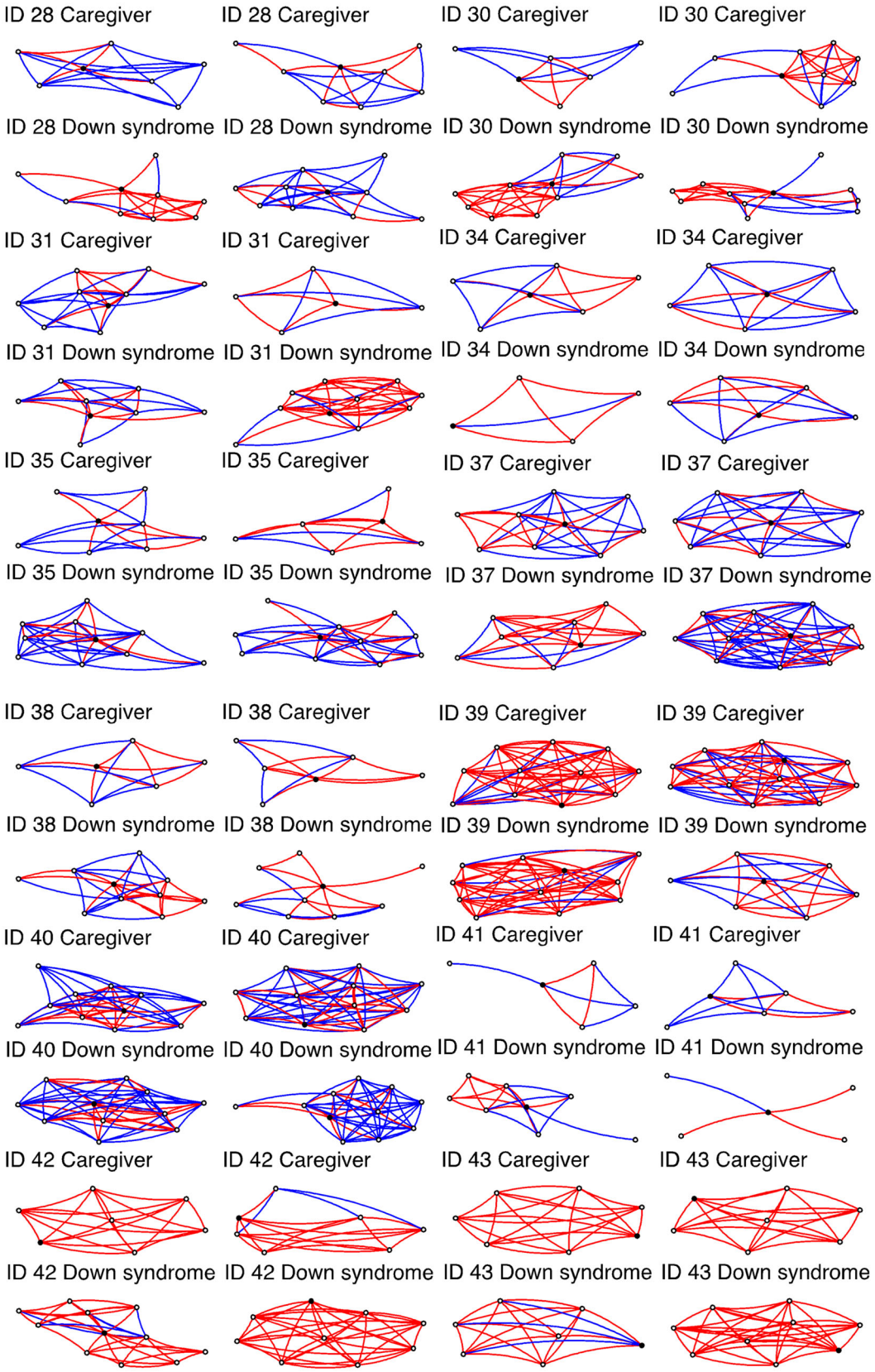

FIGURE 1 (Continued)

emergency was ended in Massachusetts, many of the day programs, jobs, and social activities remained limited for people with DS due to widespread staffing shortages. Thus, the follow-up survey results might continue to reflect more socially restricted environments. Additionally, a combination of these explanations might have contributed to the durability of the social networks in people with DS.

Previous research demonstrated that self-reported assessments of social networks matched proxy-reported assessments (Skotko et al., 2023). At this follow-up time point, this was the case for most—but not all—measures. In comparison to study partners, people with DS reported more groupings within their network (effective size) and less connections between those in their network (density). This suggests that both reports from adults with DS and caregiver proxies may be needed in future research to capture their full social dynamics.

Our study was not without limitations. The size of this pilot study was small and from one specific clinic; as such the results might not be generalizable to the larger population of people with DS. The majority of our participants were also non-Hispanic white (96.8%), meaning that the results might not be generalizable to other racial and ethnic groups. While the study was open to families of all races and ethnicities, future efforts must look toward addressing systemic structural barriers to research participation (Chung et al., 2023; Krell et al., 2023). Future studies could also replicate this study in other clinic and community settings to capture a wider range of perspectives. Additionally, future studies could incorporate in-person interviews. Often, due to living situations, the study partner would be sitting next to or near the individual with DS even for the part of the survey meant only for the individual with DS. A possibility remains that this impacted answers and/or led to the individual with DS seeking prompting from their study partner. Although the team encouraged the individual with DS to answer the questions without guidance, nonverbal guidance might have occurred. In-person separate interviews could further mitigate this possibility.

In conclusion, the science of social networks can be used for and with people with DS. For this cohort study, their social networks were sustained, although not improved, over a one-year period after the end of the COVID-19 pandemic. Social therapeutics hold promise for addressing Alzheimer's disease in the future (Perry et al., 2022), including those with DS. Since quantitative analyses on social networks can be performed in people with DS, such measures can now be introduced into clinical trials aimed at improving or enriching their personal connections. An open question remains: if the social networks of people with DS can be improved, could their incidence of Alzheimer's disease be reduced?

AUTHOR CONTRIBUTIONS

Conceptualization: Brian G. Skotko, Amar Dhand; Data curation: Brian G. Skotko; Formal analysis: Brian G. Skotko, Amar Dhand, Ayesha Harisinghani; Funding Acquisition: Brian G. Skotko; Investigation: Brian G. Skotko, Ayesha Harisinghani, Ellen Hollands Steffensen; Amar Dhand; Methodology: Brian G. Skotko, Ayesha Harisinghani, Ellen Hollands Steffensen; Amar Dhand; Project Administration: Ayesha Harisinghani, Ellen Hollands Steffensen; Resources: Brian G. Skotko, Amar Dhand; Software: Amar Dhand; Supervision: Brian G. Skotko, Amar Dhand; Validation: Amar Dhand; Visualization: Amar Dhand; Writing-original draft: Brian G. Skotko, Ayesha Harisinghani, Amar Dhand; Writing-review & editing: Brian G. Skotko, Ayesha Harisinghani, Ellen Hollands Steffensen; Amar Dhand.

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CONFLICT OF INTEREST STATEMENT

Dr. Skotko occasionally consults on the topic of Down syndrome through the Gerson Lehrman Group. He receives remuneration from Down syndrome non-profit organizations for speaking engagements and associated travel expenses. In the past 2 years, Dr. Skotko received annual royalties from Woodbine House, Inc., for the publication of his book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*. Within the past 2 years, he has received research funding from F. Hoffmann-La Roche, Inc., AC Immune, and LuMind Research Down Syndrome Foundation to conduct clinical trials for people with Down syndrome. Dr. Skotko is occasionally asked to serve as an expert witness for legal cases where Down syndrome is discussed. Dr. Skotko serves in a non-paid capacity on the Honorary Board of Directors for the Massachusetts Down Syndrome Congress and the Professional Advisory Committee for the National Center for Prenatal and Postnatal Down Syndrome Resources. Dr. Skotko has a sister with Down syndrome.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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REFERENCES

Chung, J., Krell, K., Pless, A., Michael, C., Torres, A., Baker, S., Blake, J. M., Caughman, K., Cullen, S., Gallagher, M., Hoke-Chandler, R., Maina, J., McLuckie, D., O'Neill, K., Peña, A., Royal, D., Slape, M., Spinazzi, N. A., Torres, C. G., & Skotko, B. G. (2023). Healthcare experiences of patients with Down syndrome from primarily Spanish-speaking households. *American Journal of Medical Genetics. Part A*, *191*(8), 2132–2141. https://doi.org/10.1002/ajmg.a.63250

Crooks, V. C., Lubben, J., Petitti, D. B., Little, D., & Chiu, V. (2008). Social network, cognitive function, and dementia incidence among elderly women. *American Journal of Public Health*, *98*(7), 1156–1333. https://doi.org/10.2105/AJPH.2007.115923

Dhand, A., Luke, D. A., Lang, C. E., & Lee, J.-M. (2016). Social networks and neurological illness. *Nature Reviews Neurology*, *12*(10), 605–612. https://doi.org/10.1038/nrneurol.2016.119

Dhand, A., White, C. C., Johnson, C., Xia, Z., & De Jager, P. L. (2018). A scalable online tool for quantitative social network assessment reveals potentially modifiable social environmental risks. *Nature Communications*, *9*(1), 3930. https://doi.org/10.1038/s41467-018-06408-6

Dhand, A., Podury, A., Choudhry, N., Narayanan, S., Shin, M., & Mehl, M. R. (2022). Leveraging social networks for the assessment and management of neurological patients. *Seminars in Neurology*, *42*(2), 136–148. https://doi.org/10.1055/s-0042-1744532

Fratiglioni, L., Paillard-Borg, S., & Winblad, B. (2004). An active and socially integrated lifestyle in late life might protect against dementia. *The Lancet Neurology*, *3*(6), 343–353. https://doi.org/10.1016/S1474-4422(04)00767-7

Friedman, C., & Rizzolo, M. C. (2016). The state of transportation for people with intellectual and developmental disabilities in medicaid home and community-based services 1915(c) waivers. *Journal of Disability Policy Studies*, *27*(3), 168–177. https://doi.org/10.1177/1044207316644413

Giri, S., Chenn, L. M., & Romero-Ortuno, R. (2021). Nursing homes during the COVID-19 pandemic: A scoping review of challenges and responses. *European Geriatric Medicine*, *12*(6), 1127–1136. https://doi.org/10.1007/s41999-021-00531-2

Grieco, J., Pulsifer, M., Seligsohn, K., Skotko, B., & Schwartz, A. (2015). Down syndrome: Cognitive and behavioral functioning across the lifespan. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, *169*(2), 135–149. https://doi.org/10.1002/ajmg.c.31439

Harris, P. A., Taylor, R., Minor, B. L., Elliott, V., Fernandez, M., O'Neal, L., McLeod, L., Delacqua, G., Delacqua, F., Kirby, J., & Duda, S. N. (2019). The REDCap consortium: Building an international community of software platform partners. *Journal of Biomedical Informatics*, *95*, 103208. https://doi.org/10.1016/j.jbi.2019.103208

Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, *42*(2), 377–381. https://doi.org/10.1016/j.jbi.2008.08.010

Hegedus, H. (2020). Group homes for those with disabilities hit hard by coronavirus. Boston 25 News. https://www.boston25news.com/news/local/group-homes-those-with-disabilities-hit-hard-by-coronavirus/A7R6HWS5VFBRJHVUIXSIPG7C24/

HHS. (2023). Our epidemic of loneliness and isolation. Retrieved August 2, 2023, from https://www.hhs.gov/sites/default/files/surgeon-general-social-connection-advisory.pdf

Kotwal, A. A., Kim, J., Waite, L., & Dale, W. (2016). Social function and cognitive status: Results from a US nationally representative survey of older adults. *Journal of General Internal Medicine*, *31*(8), 854–862. https://doi.org/10.1007/s11606-016-3696-0

Krell, K., Pless, A., Michael, C., Torres, A., Chung, J., Baker, S., Blake, J. M., Caughman, K., Cullen, S., Gallagher, M., Hoke-Chandler, R., Maina, J., McLuckie, D., O'Neill, K., Peña, A., Royal, D., Slape, M., Spinazzi, N. A., Torres, C. G., & Skotko, B. G. (2023). Healthcare experiences of patients with Down syndrome who are Black, African American, of African descent, or of mixed race. *American Journal of Medical Genetics. Part A*, *191*(3), 742–752. https://doi.org/10.1002/ajmg.a.63069

Kristensen, K., Lorenz, K. M., Zhou, X., Piro-Gambetti, B., Hartley, S. L., Godar, S. P., Diel, S., Neubauer, E., & Litovsky, R. Y. (2022). Language and executive functioning in young adults with Down syndrome. *Journal of Intellectual Disability Research*, *66*(1–2), 151–161. https://doi.org/10.1111/jir.12868

Markos, M. (2021). *Life in lockdown: A timeline of the COVID shutdown in Massachusetts*. NBC Boston https://www.nbcboston.com/life-in-lockdown/life-in-lockdown-a-timeline-of-the-covid-shutdown-in-massachusetts/2320541/

Mass.gov. (n.d.). COVID-19 state of emergency. Retrieved July 25, 2023 from: https://www.mass.gov/info-details/covid-19-state-of-emergency

Perry, B. L., Roth, A. R., Peng, S., Risacher, S. L., Saykin, A. J., & Apostolova, L. G. (2022). Social networks and cognitive reserve: Network structure moderates the association between amygdalar volume and cognitive outcomes. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *77*(8), 1490–1500. https://doi.org/10.1093/geronb/gbab192

Prust, M., Halm, A., Nedelcu, S., Nieves, A., & Dhand, A. (2021). Head-to-head comparison of social network assessments in stroke survivors. *The Neurohospitalist*, *11*(1), 5–94. https://doi.org/10.1177/1941874420945889

Salehi, A., Ashford, J. W., & Mufson, E. J. (2016). The link between Alzheimer's disease and Down syndrome. *A Historical Perspective. Current Alzheimer Research*, *13*(1), 2–6.

Skotko, B. G., Krell, K., Haugen, K., Torres, A., Nieves, A., & Dhand, A. (2023). Personal social networks of people with Down syndrome. *American Journal of Medical Genetics Part A*, *191*(3), 690–698. https://doi.org/10.1002/ajmg.a.63059

Wilson, R. S., Krueger, K. R., Arnold, S. E., Schneider, J. A., Kelly, J. F., Barnes, L. L., Tang, Y., & Bennett, D. A. (2007). Loneliness and risk of Alzheimer disease. *Archives of General Psychiatry*, *64*(2), 234–240. https://doi.org/10.1001/archpsyc.64.2.234

Wong, J., Ezeife, N., Kudla, A., Crown, D., Trierweiler, R., Capraro, P., Tomazin, S., Su, H., Pham, T., & Heinemann, A. W. (2022). Employment Consequences of COVID-19 for People with Disabilities and Employers. *Journal of Occupational Rehabilitation*, *32*(3), 464–472. https://doi.org/10.1007/s10926-021-10012-9

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