"Be Grateful You Don't Have a Real Disease": Understanding Rare Disease Relationships

Haley MacLeod, Grace Bastin, Leslie S. Liu, Katie Siek, Kay Connelly
School of Informatics & Computing
Indiana University
Bloomington, IN, USA
{hemacleo, gkbastin, lsliu, ksiek, connelly}@indiana.edu

ABSTRACT

We characterize how people with rare diseases consider their support needs as being met or neglected by different sources. After a 22-week study with 11 participants, we found that people with rare diseases identify strongly with their conditions but demonstrate a range of outlooks on their condition (positive, negative, and accepting). We found that participants think of themselves as being in a separate "Rare World" from the "normal" people in their lives and that relationships with friends and family members are strained. On the other hand, online communities were described as valuable sources of many forms of support, but do not adequately compensate for the lack of *tangible* support in offline relationships. We propose an approach to facilitating tangible support that leverages existing research on social matching, towards facilitating support among people with *different* rare diseases to overcome geographic and symptomatic challenges of coordinating support between people with the *same* rare disease.

ACM Classification Keywords

H.5.m. Information Interfaces and Presentation (e.g. HCI): Miscellaneous; J.3 Life and Medical Sciences: Health

Author Keywords

Rare disease; chronic illness; online health communities; timebanking; social matching; social support.

INTRODUCTION

HCI researchers have explored challenges and solutions in many different health domains, focusing on health concerns on social media sites [13, 30, 42, 72], patient communities [45, 59, 64], mobile technology [8, 31, 38, 57], and other platforms. This research has focused primarily on common health concerns impacting a large number of people. Those conditions have very specific sets of symptoms that are generally well understood in medical literature, making it possible to design tailored solutions for maximum effectiveness.

CHI 2017, May 06–11, 2017, Denver, CO, USA

ACM 978-1-4503-4655-9/17/05…$15.00
DOI: http://dx.doi.org/10.1145/3025453.3025796

Rare diseases have not been as widely studied in HCI, and there is an opportunity here to better support the experiences of this unique population. Rare diseases are conditions that, by definition, impact an extremely small number of people. In the US, rare diseases are those that impact less than 200,000 people (or 0.06% of the population) [78]. While each individual disease is rare, it is estimated that 10% of people world wide have one of the approximately 7,000 different known rare diseases [78]. These conditions can be very challenging to diagnose – it takes an average of five (in the UK) to seven (in the US) years to receive a diagnosis, and patients are misdiagnosed an average of two or three times before receiving a final diagnosis [78]. This process requires visits to many different primary care physicians and specialists. There is also a heavy emotional toll of living with a rare disease; people with rare diseases have reported experiencing depression (75%), anxiety (86%), isolation from friends/family (65%), and less interaction with friends/family (70%) [78].

Although rare diseases have not been widely studied in HCI, our previous work [61, 62] examined the needs of people with rare diseases, and how they are similar to or different from the needs of people with common chronic illnesses (i.e., diseases like diabetes, asthma, or arthritis that impact large numbers of people). We found that people with rare diseases face a unique set of challenges because they have diseases that few have even heard of, let alone understand.

In [61] we described the experiences of people with rare diseases; here we build on this work by focusing specifically on *relationships* between people with rare diseases and their friends and family. We invited people with rare diseases to join a private Facebook group and provided the 11 participants with 10 activities over 22 weeks. We identified ways in which people with rare diseases felt that their support needs were being met or neglected. In this work we describe:

1. The perspective of people with rare diseases on family and friend relationships.
2. An approach to reducing reliance on external support, in favor of support between people with rare diseases.
3. A proposal to encourage support between people with *different* rare diseases, focusing on the experience of "rarity" rather than the symptoms, and leveraging different skills and abilities for supportive matching.

RELATED WORK

Our work towards understanding the support needs and relationships of people with rare diseases draws from several different areas of prior work. First, we discuss types of social support and their presence in online health communities and other sociotechnical interventions. Understanding these types of support allows us to examine if/how the support needs of people with rare diseases are met (or not). In our study, we are interested in the sources of support (i.e., from friends and family vs. from other people with rare diseases and online communities) and the areas where support is lacking. Second, we discuss theories of help seeking and expectations of support in different types of relationships. This helps to understand barriers to seeking and providing support to explain some of those areas where social support is lacking. Understanding how those norms vary by relationship is helpful to better contextualize the differences in sources of different types of support. Finally, our related work concludes with a discussion of the differences in providing support voluntarily or through a caregiving obligation. We draw from work suggesting a shift towards peer support (and away from traditional caregiving models) which we suggest is a valuable lens for thinking about support for people with rare diseases.

Social Support

Social support is defined as *"verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationships, and functions to enhance a perception of personal control in one's experience"* [2]. Social support can be beneficial when used appropriately, but when misused, or provided in the wrong context, it can have a negative impact [56] depending on the nature of the relationship between the provider and recipient [27, 43], the timing of the support [48], the personality of the recipient [43, 55], the nature of the stress [21, 26], and the spontaneity of the support [27, 32, 36, 54].

While several authors have suggested taxonomies of support behaviors, in this paper we rely on Cutrona and Suhr's five categories of social support [28]:

- **Informational support:** *"advice ('I think you should tell your supervisor'); factual input ('If you don't treat the infection quickly, it will get worse'); and feedback on actions ('You shouldn't have told her so bluntly')."*
- **Emotional support:** *"expressions of caring ('I love you'), concern ('Are you feeling better?'), empathy ('You must have been really hurt by his coldness'), and sympathy ('I'm so sorry you're upset')."*
- **Network support:** *"a sense of belonging among people with similar interests and concerns ('We'd like you to join our support group')."*
- **Esteem support:** *"expressions of regard for one's skills, abilities ('I know you'll do a good job') and intrinsic value ('Losing your job doesn't mean you're worthless')."*
- **Tangible aid:** *"offers to provide needed goods (e.g., money, food, books) and services (e.g., baby-sitting, transportation, housework)."*

Cutrona and Suhr [28] classify these support types into two categories: ***action-facilitating support*** (informational, tangible) and ***nurturant support*** (emotional, network, esteem). Action-facilitating is intended to eliminate a problem, whereas nurturant support focuses on comforting or consoling without directly addressing the problem.

In the case of rare diseases, where people are geographically dispersed, online health communities and social networks are valuable sources of support [3, 5, 24, 33, 40, 61, 75, 78]. This is particularly true for informational support; Braithwaite et al. [10] hypothesize that the asynchronous nature of online communities make it easier to provide informational support, because supporters can take time to look up information instead of having to respond immediately off the top of their head. Posting a request for information online also means it will be read by a larger audience than just one person, thereby increasing the likelihood of a useful response.

Online communities are also known as places for a high volumes of emotional support, especially for people with rare diseases [3, 5, 33, 40, 75]. This is somewhat intuitive, as these communities represent a place where people can connect with people who might better understand what they are going through (because they are going through similar things).

Esteem, network and tangible support have not been the object of support messages on online communities to the same extent [1, 10, 24]. Of particular interest to our study is tangible support; the low volume of tangible support messages in studies of online health communities is to be expected, as most of these behaviors require collocation between partners. In many cases, this support need is attended to by collocated family and friends (as in [80]). Our findings here have shown that this support is not provided in the same way to people with rare diseases, and we suggest there is an important opportunity to better facilitate tangible support.

Support Relationships and Help Seeking

Clark and Mills have extensively studied expectations of support and norms around seeking support in different kinds of relationsips [16, 17, 18, 19, 20]. They draw a distinction between two different types of relationships:

The first are ***exchange relationships***, where support is given *"with the expectation of receiving a comparable benefit (or benefits) in return"* [17]. Receiving support from an exchange partner incurs an obligation to provide an equivalent benefit in return. People keep track of how much they owe and are owed [18], and even conduct a brief cost-benefit analysis before choosing to enter into the relationship [34]. These tend to be relationships between acquaintances or strangers.

The second is a ***communal relationship***, typically found in close friends, family members, or romantic partners (with some exceptions). In these relationships, support is given without any expectation of repayment. The support recipient may still feel motivated to similarly provide support in the future should the opportunity arise, and the support provider may still *"hope that the recipient will be similarly responsive to his or her needs as they arise"* [17], but there is no expectation that these benefits come with a price tag.

In both kinds of relationships, people prefer support that is offered spontaneously over having to ask for it explicitly, and struggle to ask for help when they need it. In communal relationships [27], if a person does not provide support until asked, this causes their partner to doubt the quality of the relationship. If help is provided unsolicited, this reinforces perceptions of the helper as attentive to the needs of their partner and strengthens the intimacy of the relationship. Spontaneous support is also preferred in exchange relationships because support seekers feel embarrassed or inadequate when asking for help [32, 54, 85], underestimate the willingness of others to comply with requests for help [36], feel they are imposing on their exchange partner [36], and worry about incurring a debt they might not be able to repay [17, 27, 32].

This suggests that communal relationships are filled with challenging dynamics at the best of times if people do not ask for support when they need it but expect people to provide support without being asked. Our study shows this is certainly the case for people with rare diseases, who do not feel their support needs are being met by their communal partners. While there3 may be opportunities to overcome these barriers in communal relationships, in this work we turn to exchange relationships as an alternative source of support and focus on ways of reducing barriers to support in exchange contexts.

Prosocial Behavior vs. Caregiver Burden

There is a substantial difference between obligatory and voluntary support. Voluntarily engaging in prosocial behaviors (via volunteering or peer support groups) provides positive benefits to the support provider [6, 12, 68, 76, 50]. Cialdini et al. [15] propose that adults are more likely to help others when they feel bad, as a way of improving their mood [7]. This has been validated numerous times: Wilson et al. [50] found volunteering is beneficial for one's health, Schwartz et al. [76] found quality of life increased when people provided emotional support to others, and Brown et al. [12] found reduced mortality from providing instrumental support.

On the other hand, when caregiving is an obligation (e.g., caring for an ailing family member) the literature describes both objective (practical consequences) and especially subjective (emotional) burdens [14, 39, 70]. Unfortunately, caregivers deal with these burdens largely in isolation; they feel they cannot vent to someone more vulnerable (i.e., the person they are caring for) [14], especially if expressing their frustrations may exacerbate symptoms (as in depression [86]). Caregivers often lose their own social connections through the caring process [86], and develop depression and anxiety; the strongest predictors of depression/anxiety in caregivers are subjective and objective burdens [39]. There have been a few sociotechnical approaches to addressing this issue of caregiver burden:

1) Supporting Caregivers with Technology: There are a few examples of technology designed for caregivers, and often these are centered around communication, coordination, or providing information [29, 57, 74, 82]. For example, the Estrellita system [57, 82] aims to make things easier for parents of high risk infants by facilitating communication between parents and the medical team. Chen et al. [14] argue against these kind of systems, because they may unintentionally increase the burden on caregivers by making it easier to do even more work. Hwang et al. [47] similarly found that caregivers were concerned that these systems would add to their burden because they would additionally have to manage the technology on top of existing caregiving tasks. Instead, Chen et al. [14] and Tixier et al. [84] both suggest that systems for caregivers should include room for personal tasks to bring more balance to the caregiver's life. Fuentes et al. [37] designed the Ohana Bear, which focuses more on the emotion work and reflection necessary for caregivers.

2) Expanding the Care Network: Chen et al. [14] noted that caregivers often felt that others did not appreciate the volume of work they were doing. One approach to reducing this burden is to expand what Consolvo et al. [23] call the care network, distributing the volume of work across more caregivers. Hong et al. [44] leverage this idea in SocialMirror, a device for young adults with autism that allows them to seek advice from a trusted network. Similarly, Consolvo et al.'s [23] CareNet prototype, Paganelli et al.'s [74] ERMHAN system, and Skeels et al.'s Helping Quilt [80] all aim to coordinate care between network members. Chen et al. [14] propose a system that maps out the entire workload a caregiver routinely undertakes and allows other people to offer help, as a way of increasing the visibility of the workload and reducing it.

3) Shifting Towards Peer Support: Arreola et al.'s [4] older adult participants relied more heavily on their peer group for support (e.g., running errands) and hesitated to ask their adult children for help. The authors argue for a shift from the one-caregiver-to-one-older-adult model to a peer support model where older adults help care for each other: *"By replacing the individual caregiver with a peer group, each older adult has more eyes watching for them in case there is a problem. There is also less social stigma associated with asking about the day-to-day business of peers. This allows for less friction in terms of communication and may enhance activity within a community."* [4]

Stroomer et al.'s study found this shift towards peer support to be a successful strategy, stating *"people may be willing to provide support within their community, proving the barriers are lowered in asking for support. The field trial demonstrated that a social network service could be used to lower barriers towards asking for help."* [81]

Research around supporting caregivers or expanding the care network provides thoughtful solutions in cases where there is one or more overburdened caregiver. Our findings here have shown that people with rare diseases currently face so much isolation that a prerequisite step (prior to adapting those solutions for this context) would be determining ways of repairing those relationships or preventing them from breaking down in the first place. Thus, in the interim, we propose that the shift away from a caregiving model towards a peer support model makes sense for people with rare diseases as a way of more urgently addressing their unmet support needs. Participants in our study speak much more positively about the emotional and informational support they receive from online health communities; we suggest a way of extending this peer support model to also include tangible support.

Disease Name	Description
Avascular Necrosis (AVN) (aka Osteonecrosis)	AVN is the death of bone tissue due to a lack of blood supply. Pain can be mild or severe and develops gradually.
Ehlers Danlos Syndrome (EDS)	EDS affects connective tissue, primarily the skin, joints, and blood vessel walls. Symptoms include overly flexible joints that can dislocate, and skin that's translucent, elastic, and bruises easily. In some cases, there may be dilation and even rupture of major blood vessels.
Hereditary Angioedema (HAE)	HAE causes episodes of extremely painful swelling that often inhibits normal routines. Gastrointestinal attacks involve excruciating pain, nausea, vomiting, and diarrhea. Some patients undergo unnecessary surgery during abdominal attacks because the symptoms mimic a surgical emergency. Laryngeal swelling can close the airway and cause death.
Inclusion Body Myositis (IBM)	IBM is a progressive weakness in the muscles of the wrists and fingers and those at the front of the thigh. Trouble with gripping, such as a shopping bag or briefcase, and frequent stumbles are common. About a third of people with IBM have some weakness of the swallowing muscles. Most people with IBM remain able to walk, although some require a wheelchair full time.
Kallmann Syndrome (KS)	KS is characterized by a failure to go through puberty. People with KS have no sense of smell or very weak ability to smell. Males have undescended testes, a small penis, and simultaneous movement of both hands. Menstruation never starts in women.

Table 1: Rare Disease Descriptions

METHOD

We used the Asynchronous Remote Communities (ARC) method [1] [60] to understand the needs and experiences of people with rare diseases with a particular focus on relationships and support needs. We invited participants to join a private Facebook group specific to the study and provided participants with 10 activities over the course of 22 weeks. These activities were:

1. **Diary.** Participants tracked interactions with others about their disease and documented who they talked to, how they communicated, what they discussed, and how they felt.
2. **Circles.** Participants used small objects to illustrate their comfort level sharing information with different people by drawing circles with themselves at the center and placing people at different distances from the center.
3. **Questions.** Participants made a list of questions they wished their friends/family would ask about their disease.
4. **Problems.** Participants ranked a list of problems generated from their previous posts in order of how much each was a problem for them personally.
5. **Solutions.** Participants discussed strategies or solutions they used to address these problems.
6. **Photo Elicitation.** Participants took photos around a theme and commented on each other's photos.
7. **Mad Lib.** Participants created a mad lib, detailing the more humorous aspects of conversations they have surrounding their conditions.
8. **Movie Script.** Participants wrote scripts for the movie of their life.
9. **Rant Line.** Participants called, texted, or sent photos to a "Rant Line," a Google Voice number, anytime they needed or wanted to rant about something.
10. **Personas.** Participants critiqued two personas and discussed how representative they were of their own lives.

In addition to these activities, participants independently started new conversations amongst themselves - these posts are included in our analysis. This study was approved by our Institutional Review Board (IRB).

Participants

We recruited adults with a rare disease from Facebook support groups, since Facebook is actively used by people with rare diseases as a way of connecting with each other [61] and providing a sense of support. We did not recruit from other sources because we did not want to create additional privacy risks by encouraging people to share their data on Facebook who were not already doing so.

There were 11 active participants in our study. These participants had one of five different rare diseases (Table 1). We relied on the National Institutes of Health's list of rare diseases [2] to determine inclusion criteria. Participants ranged in age from 32–68 (mean=48.9). Ten participants identified as female and one as male. All participants were from the US, except one from Australia. Two participants were employed full time, while the rest were either unemployed, receiving disability payments, or retired at the time of the study. They were each offered a $50 honorarium for their participation in the study, regardless of their level of activity.

[1] We developed the ARC method specifically for this study so we could conduct group-based research with this dispersed population. We have reported in detail on the method, the data collected in each activity, and the response rates over the course of the study in [60] and encourage readers with additional questions about the methods used in this study to consult that paper.

[2] https://rarediseases.info.nih.gov/gard

Code Name	# of Participants	Total Instances
Outlook & Self-Image		
Identity - Acceptance	7	16
Identity - Positive	9	20
Identity - Negative	7	17
Mourning One's Old Life	4	11
Adjusting Expectations*	4	6
Expectations to Feel a Certain Way*	4	6
Jealousy*	3	4
Relationships Outside Rare World		
Absence of Relationship	6	23
Emotional Distance from Others	9	34
Belief/Validation	8	43
Listening	9	25
Passive Disinterest	8	28
Active Denial	6	22
Unhelpful Comments	9	32
Practical Support	7	28
Recognizing Limitations	8	16
Guilt/Burden*	4	4
Wanting an Apology*	2	2
Relationships Within Rare World		
Support from Other Groups	7	15
Comments about Other Participants	5	8

Table 2: Summary of codes used in analysis. Number of participants refers to participants who made at least one comment during the study that was classified as that code. Total instances is the number of comments classified as that code. Codes with asterisks (*) are not discussed in this paper.

Analysis

We iteratively coded all data from the study. Three researchers participated in the coding process, ultimately converging on an inter-rater reliability (Cohen's Kappa) score of 0.72. A summary of our codes are provided in Table 2. In this paper, we do not discuss codes with low prevalence (i.e., where they were only discussed by a small number of participants) or where there was a heavy skew towards a single participant (i.e., where a topic was discussed extensively by one participant, but rarely by others).

Because of the highly sensitive nature of this research topic and the high re-identification risks associated with rare diseases, we have removed any potentially identifying information from quotes included in this paper, including disease names (a summary of the diseases present in this study are provided in Table 1). Additionally, all participants were given the chance to review this paper before publication to ensure they were comfortable with the content.

Limitations

We did not recruit any participants' friends or family members as part of our study. Although it would have been interesting to study these relationships from both perspectives, many of the relationships of people in our study had broken down, resulting in estrangement or divorce. We focus our analysis on the perspective of people with rare diseases, rather than on the perspectives of their loved ones.

Additionally, we made the choice to recruit participants solely from rare disease Facebook support groups so that we would not expose participants to additional privacy risks by encouraging them to share information about their condition on Facebook if they were not already doing so. We recognize that this means that our findings may not be representative of people who are less engaged, or do not have access to online rare diseases support communities (either because none exist for their conditions or because they do not have access to the necessary technology).

FINDINGS

Our previous work [61] broadly described the experiences of people with rare diseases and a phenomenon called "Rare World." People with rare diseases face additional challenges as a result of a rare disease diagnosis, which influences their perspective on the world around them. We found this concept pervasive in our data in this study as well. We define "Rare World" as meaning that people with rare diseases compare themselves to the "normal" people in their lives (i.e., healthy people or people with common chronic illnesses), leaving them with a feeling of isolation or inadequate support.

We begin with a brief description of the outlook and self-image of participants from our study (bolstering findings from [61]). We then extend this work to focus specifically on people with rare diseases' perspectives on their relationships with people outside of "Rare World". Finally, we discuss the relationships people build and the support they receive from within Rare World (from others with a rare disease).

Outlook & Self-Image

We found that having a rare disease was a significant part of a participant's identity. They made comments like *"I told [my son] we [the participant and another family member with the same condition] were sharing about a main feature in our lives and something we were proud of"*(P8). This echoes findings from [61] that people with rare diseases think of themselves *"as ambassadors, as if they could not be understood apart from their medical conditions."* Given the work that goes into living with a rare disease (navigating the medical system, staying up to date with research, raising awareness of the condition, advocacy initiatives, etc.) as well as the severity and persistence of some of these conditions, it is understandable that it becomes an easy thing upon which to fixate. Participants even agreed with this characterization, and wished it was not the case:

> *"I tried not talking about my disease at all or how I feel or what's happening to me medically, because when I respond to their questions of "how are you doing?" with honesty, their next comment is always that I am dwelling on my illness and I need more activities in my life. To which I always agree. And feel discounted every time it happens"*(P7).

Even within this sense of identifying with the condition, we saw variance in the *valence* of participants' outlooks on their conditions. Although previous research found that people with chronic illnesses have different needs and outlooks based on their illness trajectory [35], participants in our study did not fall into a particular mindset based on the progression of their disease (i.e., someone who had been diagnosed with a disease for years did not necessarily feel more accepting of it than someone who was newly diagnosed). They even shifted between these mindsets over the course of the 22 week study; of the 11 participants who were active throughout the entire study, we observed a range of outlooks in all them (see codes for positive, negative, and accepting identities in Table 2).

We observed some participants who managed to reach a stable point in their lives, maintaining an attitude of doing the best that they could and acknowledging their limitations without being defined by them. When faced with insulting or unhelpful comments, accepting participants laughed it off and made a joke of it. They were not necessarily "proud" of their condition, but had learned to deal with it and accept it.

Other participants demonstrated a more positive mindset, not only accepting that they were dealing with a new normal, but also wanting to go beyond acceptance by helping others who were struggling, raising awareness or advocating for the condition, conducting research about the condition, and engaging in other proactive and positive behaviours.

Finally, we saw that some participants saw their disease as a factor that isolated them from the rest of their family and friends, and saw the disease as having *"pretty much destroyed my whole world"*(P4). These participants seemed to adjust poorly to the limitations their disease now placed on their daily activities, as they were sometimes jealous of those who were healthy and often mourned the loss of their old life:

> *"I used to have all the nice crap. I owned a condo full of antiques, I drove a brand new BMW, I had amazing jobs, a million friends, NOW, 3 years later, I had to declare bankruptcy, my parents are kicking me out of their basement after this surgery"*(P1).

Relationships Outside of Rare World

Some participants had family members that were supportive, especially in cases of hereditary conditions where a participant's parent also had the condition (e.g., *"[My friends and family] have been good. Though they kind of understand that Dad passed this to me :("*(P5)). For the most part however, participants described wanting support out of those relationships and did not feel those support needs were being met.

In many cases, participants' relationships had broken down and many participants attributed this to the rare disease experience. They commented, *"I've been abandoned by most of my friends. Nobody comes visit, nobody calls me. It gets very lonely and very depressing"* (P10) or *"Being sick all the time has ruined family relationships, friendships, and put a severe strain on my marriage"* (P8). Sometimes this isolation was something participants did to themselves, stating, *"I have gone through times where I have insulated and isolated myself because I have felt so different from others"* (P9).

Nurturant Support

Participants discussed a lack of emotional, esteem, and network support. They regularly felt people simply did not care about them, lamenting, *"How about someone in my family actually asking and remembering the name of my disease? And how about just one of them wants to know what it is, how it affects me, what it's trajectory is, what is likely to happen to me, and is it hereditary? None of those questions have ever been asked of me the past 11 years"*(P8).

One participant theorized that their friends or family members found it hard to face these health concerns, explaining that *"'Normal' people don't really want to hear about sad things and from people who have a health problem because it makes them feel 'down' or guilty that they are well."*(P8)

Other times, participants attributed this lack of support to a lack of understanding, feeling that people generally wanted to be helpful but sometimes made comments that may have been intended as caring and supportive, but came across as minimizing or unhelpful. Participants described how family and friends would suggest, *"Let go and let God."*(P10) or *"try eating healthier, acupuncture etc"*(P3). Participants found these comments to be minimizing, lamenting, *"...face palm. 'Friends' and I air quote because they are proving themselves to be less and less, downsize it and say things like they never heard of it and it can't be thaatttt badd. Omg if I hear that one more time!"*(P3).

Comparisons to cancer were especially common (e.g., *"You ought to be grateful you don't have a real disease like cancer"*(P7)). Participants expressed frustration with these comparisons, stating *"It's minimizing, [t]hose kind of comments, especially the first, 'at least you do not have something serious, like cancer.' [Cancer], not minimizing it at all, is not the only financially, emotionally, physically, mentally devastating disease. But it is the only [one] [t]hat many have heard of. It has a face."* (P2) Some participants went as far as wishing they *did* have cancer stating, *"actually I think I would have a better chance of survival with some forms of cancer"* (P7) or *"If I shaved my head I would bet they wouldn't think twice about asking me"* (P10).

Participants felt others did not believe they were sick, believed they were sick but not with a rare disease, or thought they were exaggerating their symptoms (*"my mom is in denial and tells me I am not disabled"*(P1)). Participants regularly commented that doctors, friends, and family members alike all accused them of being hypochondriacs (*"I get treated as if I'm a know it all and a hypochondriac sometimes too"*(P3)). Additionally, they heard accusations of making up the disease to get attention (*"If I had a nickel for every time that I over heard people saying that I was just seeking attention (that one really hurts)"*(P2)). Others expressed that their family members felt that because the disease was rare, the participant probably didn't have it: *"It's a very rare disease so you can not have it...Why [don't you] go to another doctor and find out what's really wrong with you?"*(P7).

Participants sought to combat this disinterest or lack of understanding with education; they were very active in seeking

out and distributing information about their condition to their friends and family members. One participant described how they *"TRIED to send email links about [disease name], [disease name], etc., I have TRIED to send letters from DOCTORS stating that [disease name] is HEREDITARY and the risks and how they should be tested, I HAVE TRIED to personally educate, I have TRIED to take people to dinners and Dr appointments, NONE OF IT HAS HELPED."*(P8)

Some participants sent articles to friends and family members that were more detailed (*"I have sent medical journal articles to my relatives to read that talk about the disease in some detail"*(P7)), while others looked for materials that were easier to understand (*"I've searched the internet and tried to find easy info for my family to read and research."*(P1)). Regardless of how the information was presented, it did not appear to make a difference to the reception of the information (*"but that seems to have had really no effect at all"*(P7) and *"Not sure if they don't want to face it, or if they are scared, which leads to them not wanting to believe me"*(P1)).

Action Facilitating Support

Participants also wished friends and family members would be more understanding of their physical limitations (e.g., trouble gripping objects or moving around) or other sorts of tangible support needs (e.g., needing a place to live or financial support). When we asked participants what kinds of questions they wished their family and friends would ask, many of these were centered around practical, instrumental support:

- *"Are there any projects you could use help on?...Could I pick up anything for you at the store?"*(P8)
- *"What kind of routine household chores do you need help with?"*(P2)
- *"What kind of limitations does XXX cause you? What can I do to help you with those limitations?"*(P11)

This tangible support was generally not present. Participants provided anecdotes like their parents kicking them out of the house or a relative refusing to come inside when picking up his daughter from the participant's house. Participants had to adjust their practical need expectations based on what they could and could not get done in a given day. One participant said, *"I prioritize what I must get done today over what I'd like to get done, because I might not have the energy for both"* (P8). Definitions of "busy" or "getting a lot done" had to change: *"I had a 'busy day' today. I was able to shower and go to the grocery store with my mom."* (P1)

In our study, participants did not discuss informational support as being something they expected or wanted from friends and family members. This type of support is something they generally expected more of from other sources (e.g., medical professionals, "Dr. Google", or other patients).

Relationships within Rare World

People with rare diseases connect with each other via support groups [61, 75]. In cases of other kinds of chronic conditions, research has shown that supporting each other may alleviate some of the need for outside help and even act as a form of self-therapy [58].

We observed that if there is support needed that is not currently being provided by friends and family members, people with rare diseases turn to each other for support. Participants reported that this was the case for the Facebook groups they were a part of (*"the [online] support groups are where I find the best support"*(P5)), and even within our study group we observed participants engaging in discussions with each other outside of the formal study activities. Often, these discussions involved a participant describing some experience or challenge they were going through while other participants offered empathy or emotional support. Participants regularly posted updates on their life, such as recent or upcoming medical visits. Sometimes these were topics not directly related to their medical condition, but around notable things going on they wanted to share. They regularly exchanged resources or information with one another. One participant shared a link to their blog and other participants were curious about how to start one, so they began exchanging instructions. Similarly, a participant experiencing financial stress received suggestions about applying for disability insurance and where to find an appropriate lawyer. An international participant asked about health insurance while travelling in the US.

Most participants were either retired, unemployed, or receiving disability payments and some even considered managing their disease as being their job now: *"I am on disability so I spend my time learning and keeping up on research for my disease so I can keep my doc informed. Sad isn't it? lol"* (P5). They discussed how they contributed to their other groups and communities (i.e., not our study group but the Facebook groups we recruited from) by sharing research they found. *"I subscribe to Google scholar for research on [disease name] as soon as it's published. I don't always understand the biochem information, but I share the research paper with Facebook [disease name] group and there is usually someone who can put the information into understandable English for me LOL"*(P7).

In this work, we created a group for participants with *different* rare diseases to come together. We found that they were interested in learning from one another and were curious about each other's conditions. Although there was a certain amount of clustering by disease, participants expressed empathy towards each other and were appreciative of the support they received. Despite the difference in symptoms, the shared experience of living in "Rare World" provided much common ground. *"I am glad that I got to be a part of this experience. I learned a lot about other people and their conditions, and that we are ALL basically fighting the same battles..."*. They expressed an appreciation for the support they received from each other,

> *"PUT ON YOUR PARTY HATS AND GET OUT THE NOISEMAKERS, MY HUSBAND GOT A JOB!! Let me tell you, after years of disappointments and tears and fears, learning how to feel again is different. I'm numb...The thing is, that most of you didn't know that you supported us; BUT YOU DID! Thank you all."*(P2)

Participants even expressed that that this diversity of diseases gave them a different perspective on their own experience, *"I*

came to the conclusion from being in this group that most of you are far worse off than people with [my condition]"(P8).

IMPLICATIONS FOR DESIGN

We saw that people with rare diseases often do not feel they are getting the support they need from their friends and family members. There may be opportunities for designers and HCI researchers to support the relationships between people with rare diseases and their friends and family, but further study of these challenges from the perspective of these friends and family members would be necessary to properly understand the barriers.

Instead, we suggest there are opportunities for people with rare diseases to support *each other*, instead of relying as much on people outside of Rare World. While existing rare disease support groups excel at providing informational, emotional, network, and esteem support, there are barriers to facilitating tangible support within these communities. We propose overcoming these barriers using social matching to facilitate support among people with *different* rare diseases. We conclude by providing three example scenarios of this *networked peer support* approach.

Peer Support

People in our study described receiving better support from similar others [53, 69] (i.e., people who also had a rare disease who were more familiar with their experiences and better able to empathize). Arreola et al.'s [4] argument for shifting away from a caregiving model towards a peer support model allows people to tap into much richer, more diverse ecosystems for support and reduce the burden on a traditional informal caregivers. Adopting a similar mindset of empowering people with rare diseases to support *each other* may reduce some of the reliance on friends and family members.

Helping each other would not only address gaps in the support needs of people with rare diseases, but could also serve as a useful distraction from the challenges of living with a rare disease, or self-reported "dwelling" on one's illness. Being empathetic and helping someone else with a rare disease would allow people to continue to live in "Rare World" without as much negativity. As was the case in our study, this might also provide some perspective on what others may be experiencing. This idea is also supported by previous work in psychology and sociology, showing that individuals derive a number of mental and physical health benefits from helping others [7, 12, 15, 49, 50, 68, 73, 76].

Support Between People with Different Rare Diseases

Peer support between people with rare diseases already happens to a certain extent within disease-specific support groups, especially for informational, emotional, network, and esteem support. These groups provide people with a sense of community and belonging they do not feel they are getting elsewhere.

An interesting new opportunity for HCI designers and researchers is to consider how we might extend work on social matching [51, 65, 66, 83] towards more *tangible* forms of support. The low prevalence of specific rare diseases makes any sort of in-person practical or tangible support currently challenging to coordinate (i.e., if there is no one with the same condition in an individual's geographic area). Additionally, some of the tasks participants described needing help with are things that would be challenging for someone with the same condition to provide; if a person requires help with groceries because their condition makes lifting the grocery bags challenging, it is likely that someone with the same disease might have similar support needs, rather than being able to help out.

We propose extending research on social matching by focusing on abilities, skills, and expertise instead of (or in addition to) demographic characterstics, interests, and preferences. We distinguish between abilities, skills, and expertise as follows: *abilities* are tied to physiological capabilities or symptomatic limitations (e.g., being able to see, hear, walk, lift something); *skills* are acquired abilities, learned through experience or through study (e.g., cooking, programming, knowing a different language); *expertise* is acquired through formal education, certification, or regulated professional experience (e.g., practicing law, real estate, skilled trade)

We suggest that approaches to matching based on abilities, skills, and expertise be applied to help a person with a rare disease connect with people with *different* rare diseases. Mayer et al. [67] introduce the concept of *match moderators* in social matching, which help determine which simliarities are most useful in matching people. They suggest that the *rarity* of a similarity, or how many other individuals have the same attribute in either the local or broader social context, is an important match moderator. Our research here reinforces findings [61, 62] that despite the differences in diseases and symptoms, there are many experiences, challenges, and perspectives in common between people with different rare diseases and that these are unique from people with common chronic illnesses or no health afflictions at all. We hypothesize that these common social experiences of rarity may serve as appropriate common ground, while coordinating support among *different* rare diseases may help overcome the symptomatic and geographic limitations of trying to coordinate tangible support between people with the same condition.

Networked Peer Support in Rare World

Although it might be possible to facilitate one-on-one exchanges of tangible support, we suggest this would be more effectively achieved using a pay-it-forward mentality. Research on timebanking [9, 22, 41, 52, 77] uses the idea of "time dollars." We suggest that a person with a rare disease would gain time dollars for help they provide to others that they could then redeem for help with their own needs.

Here we provide three example scenarios of how social matching based on skills, abilities, and expertise might facilitate this type of cross-disease support. In all scenarios, we will refer to the "support provider" and the "support recipient" for clarity, but we note that people with rare diseases would shift between these two roles at various times, earning and spending time dollars as they go.

It is also possible a "support provider" in a given scenario could be a friend or family member, in a case where there

are friends or family members that want to be supportive and helpful. This would be particularly useful in a case where the friend or family member does not live near the person with the rare disease, but still wants to be helpful. The support provider could bank time for their remote friend or family member while helping someone locally.

Scenario 1: Coordinating Support by Abilities

Several participants had conditions with severe physical symptoms. For example, the primary symptom of IBM is progressive muscle weakening. For other conditions, the physical limitations might not be persistent, but rather temporary debilitating flareups, such as in the swelling episodes associated with HAE.

One task participants specifically mentioned as an example was carrying groceries. Although there are an increasing number of grocery delivery services available, these do not take care of the tasks of gripping the bags, carrying the heavy items into the house, and lifting them into the fridge or cupboards. We imagine that if a support provider in the neighbourhood was going grocery shopping, they could take the support recipient with them, helping them bring the groceries inside at the end of the trip. Alternatively, if the support recipient is not up for the trip to the store, they could give the support provider a shopping list to be filled independently.

To facilitate this kind of match, it would be ideal to know information about the location and grocery habits (schedule, location, mode of transport, etc.) of both parties. Speaking more generally about matching based on abilities, it may be possible to infer various abilities (or the lack of these abilities as exclusion criteria) from online behaviour. For example, Morris et al. [71] found that it was possible to identify accounts on Twitter belonging to blind users, even if there was no explicit mention of blindness. While Morris et al. [71] discuss this primarily as a potential privacy risk, there might be value in being able to detect different kinds of abilities towards facilitating matches.

Scenario 2: Coordinating Support by Skills

One conversation that took place in our study was around how to start a blog. This was something that one participant mentioned doing as a way of sharing their experiences and educating the public about the condition. Other participants in the study found this interesting and considered starting their own, but had questions about how to do so.

We imagine that a support provider who is comfortable with technology, familiar with blogging platforms, or maybe skilled with web programming could help a support recipient who is less skilled in this way to put together and/or maintain their own blog.

Notably, this scenario relies on skills that might be picked up formally (e.g., through some computing education program), but could also be self-taught (e.g., having taught oneself to put together a personal blog). This example also does not require geographic proximity. To facilitate this kind of match, it would be useful to know details about the skill set of the support provider. Where these skills are related to education programs, employment, or hobbies, there may be clues in one's online profile from which skill sets can be inferred.

Scenario 3: Coordinating Support by Expertise

Another conversation that took place in our study group was around the process for a claim for disability payments. One participant was experiencing financial hardship, and another participant described their experience through the process and provided advice on how to find a lawyer to help them.

We propose extending this informational support scenario even further to the tangible next step: What if the support provider *was* a disability lawyer? While it may initially seem like an infrequent combination to find a disability lawyer who also has a rare disease, research suggests that people often choose a career path to which they have some personal connection, especially when it comes to health topics [11, 25].

As a second example, it is possible that someone with a strong background in certain sciences or medicine could help interpret or explain the medical jargon often used in research papers that are of interest to a support recipient.

In this kind of matching scenario, it would be important to know not only the support provider's area of expertise (as in Scenario 2), but also their credentials and qualifications. This is a critical step in preventing bad legal advice or incorrect medical advice (as discussed in [46, 63]). This is especially important because potential support providers might not always be aware of their own limitations. For example, Siek et al. [79] described how people with end-stage renal disease had a sense of being smarter than others, even when they were describing information that was incorrect. Our previous research [61] similarly found that people with rare diseases were quick to point out whatever experience they *did* have with medicine or research, listing everything from a past career in phlebotomy, working as a nurse, or teaching professional development to science teachers. They felt that these experiences made them better equipped than an average person to understand medical information.

CONCLUSION

In this work, we provided insight into the support needs of people with rare diseases and their perspective on their relationships with friends and family with respect to these needs. We saw that people with rare diseases live in a separate world from their non-rare disease counterparts, and experience numerous challenges and barriers to receiving support from outside of this Rare World bubble.

We proposed not only matching people with rare diseases for the sake of facilitating peer support within Rare World, but in particular matching people with *different* rare diseases to help overcome geographic and symptomatic barriers to tangible support that may exist within disease specific communities. Where existing research on social matching aims to match people with similar demographic characteristics or interests, we propose additionally considering people's complimentary abilities, skills, and expertise.

This notion of networked support has shown some initial success in older adult communities (e.g., [4]), but has not yet

been explored as a way of facilitating support between people with *different* chronic conditions. We see this approach as having potential benefits for rare disease communities, for whom tangible support is limited and difficult to coordinate.

The possibility of extending this approach to more common chronic conditions as well is an interesting area of future study; while these conditions might not have the same barriers to receiving support, existing research on caregiver burden [86] suggests that there may still be value in expanding the care network [23] and reducing demands on existing caregivers by empowering people with chronic illnesses to support each other.

ACKNOWLEDGMENTS

This work is supported by CLEAR Health Information and by the Center of Excellence for Women in Technology (CEWIT). We also thank Kim Oakes for her help in moderating the study, and Prianka Rayamajhi and Katie Spoon for their help with analysis. Finally, we thank the participants of this study for their time and contributions.

REFERENCES

1. Phil Adams, Eric PS Baumer, and Geri Gay. 2014. Staccato Social Support in Mobile Health Applications. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '14)*. ACM, New York, NY, USA, 653–662. DOI: http://dx.doi.org/10.1145/2556288.2557297
2. Terrance L. Albrecht and Mara B. Adelman. 1987. *Communicating social support*. Sage Publications, Newbury Park, California.
3. Tawfiq Ammari and Sarita Schoenebeck. 2015. Networked Empowerment on Facebook Groups for Parents of Children with Special Needs. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15)*. ACM, New York, NY, USA, 2805–2814. DOI: http://dx.doi.org/10.1145/2702123.2702324
4. Ingrid Arreola, Zan Morris, Matthew Francisco, Kay Connelly, Kelly Caine, and Ginger White. 2014. From Checking on to Checking in: Designing for Low Socio-economic Status Older Adults. In *Proceedings of the 32Nd Annual ACM Conference on Human Factors in Computing Systems (CHI '14)*. ACM, New York, NY, USA, 1933–1936. DOI: http://dx.doi.org/10.1145/2556288.2557084
5. Ségolène Aymé, Anna Kole, and Stephen Groft. 2008. Empowerment of patients: lessons from the rare diseases community. *The Lancet* 371, 9629 (June 2008), 2048–2051. DOI: http://dx.doi.org/10.1016/S0140-6736(08)60875-2
6. C. Daniel Batson and Adam A. Powell. 2003a. Altruism and Prosocial Behavior. In *Handbook of Psychology*, Irving B. Weiner (Ed.). John Wiley & Sons, Inc., Hoboken, NJ, USA. DOI: http://dx.doi.org/10.1002/0471264385.wei0519
7. C. Daniel Batson and Adam A. Powell. 2003b. Altruism and Prosocial Behavior. In *Handbook of Psychology*, Irving B. Weiner (Ed.). John Wiley & Sons, Inc., Hoboken, NJ, USA. http://doi.wiley.com/10.1002/0471264385.wei0519
8. Eric P.S. Baumer, Sherri Jean Katz, Jill E. Freeman, Phil Adams, Amy L. Gonzales, John Pollak, Daniela Retelny, Jeff Niederdeppe, Christine M. Olson, and Geri K. Gay. 2012. Prescriptive Persuasion and Open-ended Social Awareness: Expanding the Design Space of Mobile Health. In *Proceedings of the ACM 2012 Conference on Computer Supported Cooperative Work (CSCW '12)*. ACM, New York, NY, USA, 475–484. DOI: http://dx.doi.org/10.1145/2145204.2145279
9. Victoria M.E. Bellotti, Sara Cambridge, Karen Hoy, Patrick C. Shih, Lisa Renery Handalian, Kyungsik Han, and John M. Carroll. 2014. Towards Community-centered Support for Peer-to-peer Service Exchange: Rethinking the Timebanking Metaphor. In *Proceedings of the 32Nd Annual ACM Conference on Human Factors in Computing Systems (CHI '14)*. ACM, New York, NY, USA, 2975–2984. DOI: http://dx.doi.org/10.1145/2556288.2557061
10. Dawn O. Braithwaite, Vincent R. Waldron, and Jerry Finn. 1999. Communication of Social Support in Computer-Mediated Groups for People With Disabilities. *Health Communication* 11, 2 (April 1999), 123–151. DOI: http://dx.doi.org/10.1207/s15327027hc1102_2
11. Alyssa T. Brooks, Shakira Washington, Bradley O. Boekeloo, Brian Gilchrist, and Min Qi Wang. 2013. Relationship of Personal Health Experiences with Interest in Health Careers Among Youth from an Underserved Area. *Journal of allied health* 42, 3 (Fall 2013), 135–40.
12. Stephanie L. Brown, Randolph M. Nesse, Amiram D. Vinokur, and Dylan M. Smith. 2003. Providing Social Support May Be More Beneficial Than Receiving It: Results From a Prospective Study of Mortality. *Psychological Science* 14, 4 (July 2003), 320–327. DOI: http://dx.doi.org/10.1111/1467-9280.14461
13. Stevie Chancellor, Zhiyuan Lin, Erica L. Goodman, Stephanie Zerwas, and Munmun De Choudhury. 2016. Quantifying and Predicting Mental Illness Severity in Online Pro-Eating Disorder Communities. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '16)*. ACM, New York, NY, USA, 1171–1184. DOI: http://dx.doi.org/10.1145/2818048.2819973
14. Yunan Chen, Victor Ngo, and Sun Young Park. 2013. Caring for Caregivers: Designing for Integrality. In *Proceedings of the 2013 Conference on Computer Supported Cooperative Work (CSCW '13)*. ACM, New York, NY, USA, 91–102. DOI: http://dx.doi.org/10.1145/2441776.2441789

15. Robert B. Cialdini, Betty Lee Darby, and Joyce E. Vincent. 1973. Transgression and altruism: A case for hedonism. *Journal of Experimental Social Psychology* 9, 6 (Nov. 1973), 502–516. DOI: http://dx.doi.org/10.1016/0022-1031(73)90031-0

16. Margaret S. Clark and Judson R. Mills. 1979. Interpersonal attraction in exchange and communal relationships. *Journal of Personality and Social Psychology* 37, 1 (1979), 12–24. DOI: http://dx.doi.org/10.1037/0022-3514.37.1.12

17. Margaret S. Clark and Judson R. Mills. 2011. A Theory of Communal (and Exchange) Relationships. In *Handbook of Theories of Social Psychology: Volume Two*, Paul A. M. Van Lange, Arie W. Kruglanski, and E. Tory Higgins (Eds.). SAGE.

18. Margaret S. Clark, Judson R. Mills, and David M. Corcoran. 1989. Keeping Track of Needs and Inputs of Friends and Strangers. *Personality and Social Psychology Bulletin* 15, 4 (Dec. 1989), 533–542. DOI: http://dx.doi.org/10.1177/0146167289154007

19. Margaret S. Clark, Judson R. Mills, and Martha C. Powell. 1986. Keeping track of needs in communal and exchange relationships. *Journal of Personality and Social Psychology* 51, 2 (1986), 333–338. DOI: http://dx.doi.org/10.1037/0022-3514.51.2.333

20. Margaret S. Clark and Carolyn Taraban. 1991. Reactions to and willingness to express emotion in communal and exchange relationships. *Journal of Experimental Social Psychology* 27, 4 (July 1991), 324–336. DOI: http://dx.doi.org/10.1016/0022-1031(91)90029-6

21. Sheldon Cohen and Thomas A. Wills. 1985. Stress, social support, and the buffering hypothesis. *Psychological Bulletin* 98, 2 (1985), 310–357. DOI: http://dx.doi.org/10.1037/0033-2909.98.2.310

22. Ed Collom. 2008. Engagement of the Elderly in Time Banking: The Potential for Social Capital Generation in an Aging Society. *Journal of Aging & Social Policy* 20, 4 (2008), 414–436.

23. Sunny Consolvo, Peter. Roessler, Brett E. Shelton, Anthony LaMarca, Bill. Schilit, and Sara Bly. 2004. Technology for care networks of elders. *IEEE Pervasive Computing* 3, 2 (April 2004), 22–29. DOI: http://dx.doi.org/10.1109/MPRV.2004.1316814

24. Neil S. Coulson, Heather Buchanan, and Aimee Aubeeluck. 2007. Social support in cyberspace: A content analysis of communication within a Huntington's disease online support group. *Patient Education and Counseling* 68, 2 (2007), 173–178. DOI: http://dx.doi.org/10.1016/j.pec.2007.06.002

25. H. L. Crimlisk and I. C. Mcanus. 1987. The effect of personal illness experience on career preference in medical students. *Medical Education* 21, 6 (Nov. 1987), 464–467. DOI: http://dx.doi.org/10.1111/j.1365-2923.1987.tb01403.x

26. Carolyn E. Cutrona. 1990. Stress and Social Support in Search of Optimal Matching. *Journal of Social and Clinical Psychology* 9, 1 (March 1990), 3–14. DOI: http://dx.doi.org/10.1521/jscp.1990.9.1.3

27. Carolyn E. Cutrona, B. Beth Cohen, and Surria Igram. 1990. Contextual Determinants of the Perceived Supportiveness of Helping Behaviors. *Journal of Social and Personal Relationships* 7, 4 (Nov. 1990), 553–562. DOI: http://dx.doi.org/10.1177/0265407590074011

28. Carolyn E. Cutrona and Julie A. Suhr. 1992. Controllability of Stressful Events and Satisfaction With Spouse Support Behaviors. *Communication Research* 19, 2 (1992), 154–174.

29. Sara J. Czaja and Mark P. Rubert. 2002. Telecommunications Technology as an Aid to Family Caregivers of Persons With Dementia:. *Psychosomatic Medicine* 64, 3 (May 2002), 469–476. DOI: http://dx.doi.org/10.1097/00006842-200205000-00011

30. Munmun De Choudhury, Scott Counts, Eric J. Horvitz, and Aaron Hoff. 2014. Characterizing and Predicting Postpartum Depression from Shared Facebook Data. In *Proceedings of the 17th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '14)*. ACM, New York, NY, USA, 626–638. DOI: http://dx.doi.org/10.1145/2531602.2531675

31. Mary Beth Deline, Eric P.S. Baumer, and Geri Gay. 2012. Normative Communication Processes and Associated Emotion in Mobile Health Groups. In *Proceedings of the ACM 2012 Conference on Computer Supported Cooperative Work Companion (CSCW '12)*. ACM, New York, NY, USA, 75–78. DOI: http://dx.doi.org/10.1145/2141512.2141546

32. Bella M. DePaulo, Gregory L. Brittingham, and Mary K. Kaiser. 1983. Receiving competence-relevant help: Effects on reciprocity, affect, and sensitivity to the helper's nonverbally expressed needs. *Journal of Personality and Social Psychology* 45, 5 (1983), 1045–1060. DOI: http://dx.doi.org/10.1037/0022-3514.45.5.1045

33. Maya Doyle. 2015. Peer Support and Mentorship in a US Rare Disease Community: Findings from the Cystinosis in Emerging Adulthood Study. *The Patient - Patient-Centered Outcomes Research* 8, 1 (Feb. 2015), 65–73. DOI: http://dx.doi.org/10.1007/s40271-014-0085-9

34. Richard M. Emerson. 1976. Social Exchange Theory. *Annual Review of Sociology* 2 (1976), 335–362.

35. Jordan Eschler, Zakariya Dehlawi, and Wanda Pratt. 2015. Self-characterized illness phase and information needs of participants in an online cancer forum *(AAAI Conference on Web and Social Media)*. 101–109.

36. Francis J. Flynn and Vaness K. Lake. 2008. If you need help, just ask: underestimating compliance with direct requests for help. *Journal of personality and social psychology* 95 (2008), 128.

37. Carolina Fuentes, Valeria Herskovic, Jurgen Heysen, and Monica Tentori. 2013. Towards a Technology for Caregivers' Emotional Expression and Self-reflection. In *Ubiquitous Computing and Ambient Intelligence. Context-Awareness and Context-Driven Interaction*, Gabriel Urzaiz, Sergio F. Ochoa, José Bravo, Liming Luke Chen, and Jonice Oliveira (Eds.). Lecture Notes in Computer Science, Vol. 8276. Springer, 143–150.

38. Andrea Grimes, Martin Bednar, Jay David Bolter, and Rebecca E. Grinter. 2008. EatWell: Sharing Nutrition-related Memories in a Low-income Community. In *Proceedings of the 2008 ACM Conference on Computer Supported Cooperative Work (CSCW '08)*. ACM, New York, NY, USA, 87–96. DOI: http://dx.doi.org/10.1145/1460563.1460579

39. Eva Grunfeld, Doug Coyle, Timothy Whelan, Jennifer Clinch, Leonard Reyno, Craig C. Earle, Andrew Willan, Raymond Viola, Marjorie Coristine, Teresa Janz, and Robert Glossop. 2004. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal* 170, 12 (June 2004), 1795–1801. DOI: http://dx.doi.org/10.1503/cmaj.1031205

40. Tonje Gundersen. 2011. 'One wants to know what a chromosome is': the internet as a coping resource when adjusting to life parenting a child with a rare genetic disorder: Parenting children with a rare genetic disorder. *Sociology of Health & Illness* 33, 1 (Jan. 2011), 81–95. DOI: http://dx.doi.org/10.1111/j.1467-9566.2010.01277.x

41. Kyungsik Han, Patrick C. Shih, Victoria Bellotti, and John M. Carroll. 2015. It's Time There Was an App for That Too: A Usability Study of Mobile Timebanking. *Int. J. Mob. Hum. Comput. Interact.* 7, 2 (April 2015), 1–22. DOI: http://dx.doi.org/10.4018/ijmhci.2015040101

42. Andrea L Hartzler, Megan N Taylor, Albert Park, Troy Griffiths, Uba Backonja, David W McDonald, Sam Wahbeh, Cory Brown, and Wanda Pratt. 2016. Leveraging cues from person-generated health data for peer matching in online communities. *Journal of the American Medical Informatics Association* (2016).

43. Stevan E. Hobfoll, Arie Nadler, and Joseph Leiberman. 1986. Satisfaction with social support during crisis: Intimacy and self-esteem as critical determinants. *Journal of Personality and Social Psychology* 51, 2 (1986), 296–304. DOI: http://dx.doi.org/10.1037/0022-3514.51.2.296

44. Hwajung Hong, Jennifer G. Kim, Gregory D. Abowd, and Rosa I. Arriaga. 2012. Designing a Social Network to Support the Independence of Young Adults with Autism. In *Proceedings of the ACM 2012 Conference on Computer Supported Cooperative Work (CSCW '12)*. ACM, New York, NY, USA, 627–636. DOI: http://dx.doi.org/10.1145/2145204.2145300

45. Jina Huh. 2015. Clinical Questions in Online Health Communities: The Case of "See Your Doctor" Threads. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '15)*. ACM, New York, NY, USA, 1488–1499. DOI: http://dx.doi.org/10.1145/2675133.2675259

46. Jina Huh and Wanda Pratt. 2014. Weaving Clinical Expertise in Online Health Communities. In *Proceedings of the 32Nd Annual ACM Conference on Human Factors in Computing Systems (CHI '14)*. ACM, New York, NY, USA, 1355–1364. DOI: http://dx.doi.org/10.1145/2556288.2557293

47. Amy Hwang, Khai Truong, and Alex Mihailidis. 2012. Using participatory design to determine the needs of informal caregivers for smart home user interfaces. In *Pervasive Computing Technologies for Healthcare (PervasiveHealth), 2012 6th International Conference on*. IEEE. DOI: http://dx.doi.org/10.4108/icst.pervasivehealth.2012.248671

48. David E. Jacobson. 1986. Types and Timing of Social Support. *Journal of Health and Social Behavior* 27, 3 (1986), 250–264.

49. R. Jay Turner John Taylor. 2001. A Longitudinal Study of the Role and Significance of Mattering to Others for Depressive Symptoms. *Journal of Health and Social Behavior* 42, 3 (2001), 310–325. http://www.jstor.org/stable/3090217

50. Marc Musick John Wilson. 1999. The Effects of Volunteering on the Volunteer. *Law and Contemporary Problems* 62, 4 (1999), 141–168. http://www.jstor.org/stable/1192270

51. Hyunggu Jung, Victoria Bellotti, Afsaneh Doryab, Dean Leitersdorf, Jiawei Chen, Benjamin V. Hanrahan, Sooyeon Lee, Dan Turner, Anind K. Dey, and John M. Carroll. 2016. 'MASTerful' Matchmaking in Service Transactions: Inferred Abilities, Needs and Interests Versus Activity Histories. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA, 1644–1655. DOI: http://dx.doi.org/10.1145/2858036.2858263

52. Judith Lasker, Ed Collom, Tara Bealer, Erin Niclaus, Jessica Young Keefe, Zane Kratzer, Lauren Baldasari, Ethan Kramer, Rachel Mandeville, Julia Schulman, Danielle Suchow, Abby Letcher, Anne Rogers, and Kathy Perlow. 2011. Time Banking and Health: The Role of a Community Currency Organization in Enhancing Well-Being. *Health promotion practice* 12, 1 (2011), 102–115.

53. Paul F. Lazarsfeld, Robert K. Merton, and others. 1954. Friendship as a social process: A substantive and methodological analysis. *Freedom and control in modern society* 18, 1 (1954), 18–66.

54. Fiona Lee. 1997. When the Going Gets Tough, Do the Tough Ask for Help? Help Seeking and Power Motivation in Organizations. *Organizational Behavior and Human Decision Processes* 72, 3 (Dec. 1997), 336–363. DOI: http://dx.doi.org/10.1006/obhd.1997.2746

55. Herbert M. Lefcourt, Rod A. Martin, and Wendy E. Saleh. 1984. Locus of control and social support: Interactive moderators of stress. *Journal of Personality and Social Psychology* 47, 2 (1984), 378–389. DOI: http://dx.doi.org/10.1037/0022-3514.47.2.378

56. Darrin R. Lehman, John H. Ellard, and Camille B. Wortman. 1986. Social support for the bereaved: Recipients' and providers' perspectives on what is helpful. *Journal of Consulting and Clinical Psychology* 54, 4 (1986), 438–446. DOI: http://dx.doi.org/10.1037/0022-006X.54.4.438

57. Leslie S. Liu, Sen H. Hirano, Monica Tentori, Karen G. Cheng, Sheba George, Sun Young Park, and Gillian R. Hayes. 2011. Improving Communication and Social Support for Caregivers of High-risk Infants Through Mobile Technologies. In *Proceedings of the ACM 2011 Conference on Computer Supported Cooperative Work (CSCW '11)*. ACM, New York, NY, USA, 475–484. DOI: http://dx.doi.org/10.1145/1958824.1958897

58. Leslie S. Liu, Jina Huh, Tina Neogi, Kori Inkpen, and Wanda Pratt. 2013. Health Vlogger-viewer Interaction in Chronic Illness Management. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '13)*. ACM, New York, NY, USA, 49–58. DOI: http://dx.doi.org/10.1145/2470654.2470663

59. Diana MacLean, Sonal Gupta, Anna Lembke, Christopher Manning, and Jeffrey Heer. 2015. Forum77: An Analysis of an Online Health Forum Dedicated to Addiction Recovery. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '15)*. ACM, New York, NY, USA, 1511–1526. DOI: http://dx.doi.org/10.1145/2675133.2675146

60. Haley MacLeod, Ben Jelen, Annu Prabhakar, Lora Oehlberg, Katie Siek, and Kay Connelly. 2016. Asynchronous Remote Communities (ARC) for Researching Distributed Populations. In *10th EAI International Conference on Pervasive Computing Technologies for Healthcare*. ACM. DOI: http://dx.doi.org/10.4108/eai.16-5-2016.2263322

61. Haley MacLeod, Kim Oakes, Danika Geisler, Kay Connelly, and Katie Siek. 2015. Rare World: Towards Technology for Rare Diseases. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15)*. ACM, New York, NY, USA, 1145–1154. DOI: http://dx.doi.org/10.1145/2702123.2702494

62. Haley MacLeod, Shuo Yang, Kim Oakes, Kay Connelly, and Sriraam Natarajan. 2016. Identifying Rare Diseases from Behavioural Data: A Machine Learning Approach. In *Connected Health: Applications, Systems and Engineering Technologies (CHASE), 2016 IEEE First International Conference on*. IEEE. DOI: http://dx.doi.org/10.1109/CHASE.2016.7

63. Lena Mamykina, Elizabeth D. Mynatt, and David R. Kaufman. 2006. Investigating Health Management Practices of Individuals with Diabetes. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '06)*. ACM, New York, NY, USA, 927–936. DOI: http://dx.doi.org/10.1145/1124772.1124910

64. Michael Massimi, Jackie L. Bender, Holly O. Witteman, and Osman H. Ahmed. 2014. Life Transitions and Online Health Communities: Reflecting on Adoption, Use, and Disengagement. In *Proceedings of the 17th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '14)*. ACM, New York, NY, USA, 1491–1501. DOI: http://dx.doi.org/10.1145/2531602.2531622

65. Julia M. Mayer, Starr Roxanne Hiltz, Louise Barkhuus, Kaisa Väänänen, and Quentin Jones. 2016. Supporting Opportunities for Context-Aware Social Matching: An Experience Sampling Study. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA, 2430–2441. DOI: http://dx.doi.org/10.1145/2858036.2858175

66. Julia M. Mayer, Starr Roxanne Hiltz, and Quentin Jones. 2015. Making Social Matching Context-Aware: Design Concepts and Open Challenges. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15)*. ACM, New York, NY, USA, 545–554. DOI: http://dx.doi.org/10.1145/2702123.2702343

67. Julia M. Mayer, Sara Motahari, Richard P. Schuler, and Quentin Jones. 2010. Common Attributes in an Unusual Context: Predicting the Desirability of a Social Match. In *Proceedings of the Fourth ACM Conference on Recommender Systems (RecSys '10)*. ACM, New York, NY, USA, 337–340. DOI: http://dx.doi.org/10.1145/1864708.1864781

68. Elizabeth Midlarsky. 1991. Helping as Coping. In *Prosocial behavior*, Margaret Clark (Ed.). US: Sage Publications, Inc., Thousand Oaks, CA, 238–264.

69. James M. Cook Miller McPherson, Lynn Smith-Lovin. 2001. Birds of a Feather: Homophily in Social Networks. *Annual Review of Sociology* 27 (2001), 415–444. http://www.jstor.org/stable/2678628

70. R. J. V. Montgomery, J. G. Gonyea, and N. R. Hooyman. 1985. Caregiving and the Experience of Subjective and Objective Burden. *Family Relations* 34, 1 (Jan. 1985), 19. DOI: http://dx.doi.org/10.2307/583753

71. Meredith Ringel Morris, Annuska Zolyomi, Catherine Yao, Sina Bahram, Jeffrey P. Bigham, and Shaun K. Kane. 2016. "With Most of It Being Pictures Now, I Rarely Use It": Understanding Twitter's Evolving Accessibility to Blind Users. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA, 5506–5516. DOI: http://dx.doi.org/10.1145/2858036.2858116

72. Mark W. Newman, Debra Lauterbach, Sean A. Munson, Paul Resnick, and Margaret E. Morris. 2011. It's Not That I Don't Have Problems, I'm Just Not Putting Them on Facebook: Challenges and Opportunities in Using Online Social Networks for Health. In *Proceedings of the ACM 2011 Conference on Computer Supported Cooperative Work (CSCW '11)*. ACM, New York, NY, USA, 341–350. DOI: http://dx.doi.org/10.1145/1958824.1958876

73. Allen M. Omoto and Mark Snyder. 1995. Sustained helping without obligation: Motivation, longevity of service, and perceived attitude change among AIDS volunteers. *Journal of Personality and Social Psychology* 68, 4 (1995), 671–686. DOI: http://dx.doi.org/10.1037/0022-3514.68.4.671

74. Federica Paganelli, Emilio Spinicci, and Dino Giuli. 2008. ERMHAN: A Context-aware Service Platform to Support Continuous Care Networks for Home-based Assistance. *Int. J. Telemedicine Appl.* 2008 (Jan. 2008), 4:1–4:13. DOI: http://dx.doi.org/10.1155/2008/867639

75. Naveen Pemmaraju, Vikas Gupta, Ruben Mesa, and Michael A. Thompson. 2015. Social Media and Myeloproliferative Neoplasms (MPN)—Focus on Twitter and the Development of a Disease-specific Community: #MPNSM. *Current Hematologic Malignancy Reports* 10, 4 (2015), 413–420.

76. Carolyn E Schwartz and Rabbi Meir Sendor. 1999. Helping others helps oneself: response shift effects in peer support. *Social Science & Medicine* 48, 11 (June 1999), 1563–1575. DOI: http://dx.doi.org/10.1016/S0277-9536(99)00049-0

77. Patrick C. Shih, Victoria Bellotti, Kyungsik Han, and John M. Carroll. 2015. Unequal Time for Unequal Value: Implications of Differing Motivations for Participation in Timebanking. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15)*. ACM, New York, NY, USA, 1075–1084. DOI: http://dx.doi.org/10.1145/2702123.2702560

78. Shire Human Genetic Therapies. 2013. *Rare Disease Impact Report: Insights from patients and the medical community*. Technical Report. Shire Human Genetic Therapies.

79. Katie A. Siek, Kay H. Connelly, and Yvonne Rogers. 2006. Pride and Prejudice: Learning How Chronically Ill People Think About Food. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '06)*. ACM, New York, NY, USA, 947–950. DOI: http://dx.doi.org/10.1145/1124772.1124912

80. Meredith M. Skeels, Kenton T. Unruh, Christopher Powell, and Wanda Pratt. 2010. Catalyzing Social Support for Breast Cancer Patients. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '10)*. ACM, New York, NY, USA, 173–182. DOI: http://dx.doi.org/10.1145/1753326.1753353

81. Bas Stroomer, Martijn H. Vastenburg, and David V. Keyson. 2011. *CommunityNet: Mediating Care at the Local Community Level*. Springer Berlin Heidelberg, Berlin, Heidelberg, 275–284. DOI: http://dx.doi.org/10.1007/978-3-642-25167-2_37

82. Karen Tang, Sen Hirano, Karen Cheng, and Gillian Hayes. 2012. Balancing Caregiver and Clinician Needs in a Mobile Health Informatics Tool for Preterm Infants. In *Pervasive Computing Technologies for Healthcare (PervasiveHealth), 2012 6th International Conference on*. IEEE. DOI: http://dx.doi.org/10.4108/icst.pervasivehealth.2012.248716

83. Loren Terveen and David W. McDonald. 2005. Social Matching: A Framework and Research Agenda. *ACM Trans. Comput.-Hum. Interact.* 12, 3 (Sept. 2005), 401–434. DOI: http://dx.doi.org/10.1145/1096737.1096740

84. Matthieu Tixier and Myriam Lewkowicz. 2016. "Counting on the Group": Reconciling Online and Offline Social Support Among Older Informal Caregivers. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA, 3545–3558. DOI: http://dx.doi.org/10.1145/2858036.2858477

85. Karen B. Williams and Kipling D. Williams. 1983. Social inhibition and asking for help: The effects of number, strength, and immediacy of potential help givers. *Journal of Personality and Social Psychology* 44, 1 (1983), 67–77. DOI: http://dx.doi.org/10.1037/0022-3514.44.1.67

86. Naomi Yamashita, Hideaki Kuzuoka, Keiji Hirata, and Takashi Kudo. 2013. Understanding the Conflicting Demands of Family Caregivers Caring for Depressed Family Members. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '13)*. ACM, New York, NY, USA, 2637–2646. DOI: http://dx.doi.org/10.1145/2470654.2481365