RECEIPT OF BEHAVIORAL HEALTH CARE IN CHILDREN WITH CHRONIC ILLNESS: RELATIONSHIP AMONG TYPE OF PSYCHOSOCIAL PROBLEM, COMMUNICATION, AND DISEASE

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Degree of Master of Arts

by

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Introduction

Chronic illness affects between 6.5-25% of children in the United States (Compas, Jaser, Dunn, & Rodriguez, 2012; Bilfield, Wildman, & Karazsia, 2006; Wallander & Varni, 1998). Estimates vary depending on the strictness of definition applied, and are contingent upon the types of chronic illnesses included. No matter the definition used, the effects of chronic illness impact multiple areas of a child’s life, including their social interactions, school attendance, and/or the number of activities or sports they are able to participate in (Newacheck & Halfon, 2000; Sturge, Garralda, Boissin, Dore, & Woo 1997). Enduring effects resulting from chronic illness include pain and negative side effects from treatments, which can include physical limitations (Sandstrom & Schanberg, 2004). Often, after the chronic illness is diagnosed and experienced, parents of these children tend to become protective, or they tend to be anxious about their child relapsing or being susceptible to other illnesses. This reaction by parents is commonly known as “vulnerable child syndrome” and it can affect the way parents interact with their children (Leslie & Boyce, 1996). Often, these maladaptive interactions between the parents and children result in children responding negatively to novel situations, and may lead to comorbid child emotional and behavioral issues (Anthony, Gil, & Schanberg, 2003).

Not surprisingly, with chronically ill children being affected in multiple areas of their lives, they have been shown to be at twice the risk for psychosocial problems when compared to their peers without chronic illness (Drotar, 1999; Cadman, Boyle, & Offord, 1988). Psychosocial problems are defined as a variety of issues within the domains of
social, emotional, behavioral and educational functioning (Bikson, McGuire, Blue-Howells, & Seldin-Sommer, 2009). Children with these issues are often anxious, withdrawn, and depressed, or they exhibit aggressive, delinquent, or inattentive behaviors (Fritzsche et al., 2010). Among the barriers that impede identification of these psychosocial problems and referral for treatment are difficulties with patient-physician communication and problems associated with the typical structure of pediatric appointments. Along with these barriers, there appear to be many factors that can influence rates of identification and referrals, such as different types of psychosocial problems or chronic illnesses. Even with increased prevalence rates of psychosocial problems among children with chronically illnesses, their comorbid psychosocial difficulties do not always receive the attention or the behavioral health treatment they require.

When children are diagnosed with chronic illnesses, typically pediatricians manage their care and are one of the few health professionals who see children on a somewhat regular basis. In the literature, the term pediatrician includes both specialists and, most frequently, the child’s Primary Care Physician (PCP) (Wildman, Stancin, Golden, & Yerkey, 2004). PCPs are often the first round of care that a chronically ill child receives and consistently continue to see this child throughout their chronic illness. Therefore, these physicians are placed in the crucial role of being able to identify and manage their psychosocial problems. PCPs typically maintain this contact throughout the child’s chronic illness treatment, and thus, have the opportunity to recognize changes in the child. However, while PCPs are in an ideal position to help identify psychosocial
problems in children with chronic illnesses, little literature has examined identification of psychosocial problems in children with chronic illnesses specifically.

Despite the lack of research with children with chronic illnesses, there has been more research conducted using healthy peers, or children without chronic illnesses. In this healthy population, the number of children presenting with psychosocial problems in primary care has risen and, since these same children do not frequently seek out mental health services, pediatricians are in the roles of both medical and behavioral health providers (Gardner et al., 2000; Costello et al., 1988). In fact, about 75% of children with psychiatric difficulties are managed in the primary care setting, and roughly half of all pediatric visits are related to emotional or behavior difficulties (Bernal, 2003). Despite having physicians in a role that allows them to address children’s psychosocial problems, as little as one in five children without chronic illnesses needing mental health treatment are actually referred by their PCP to behavioral health providers (Brugman, Reijneveld, Verhulst, & Verloove-Vanhorick, 2001). Similarly, 20% of the school age child population without chronic illnesses requires mental health treatment, but only 2% are typically seen by mental health professionals (Williams, Klinepeter, Palmes, Pulley, & Foy, 2004). Overall, there is a disconnect between the current rate of children needing behavioral health help and those actually receiving care, as identified in research using healthy peers. However, this is true for children with chronic illnesses as well, and it can have an even larger impact on these children, as they endure psychosocial problems at higher rates (Bilfield, Wildman, & Karazsia, 2006) than their healthy peers. Additionally, within all children, we know that those who are left untreated are affected in terms of
their daily functioning and they have been shown to utilize medical services more frequently (Stancin & Palermo, 1997), signaling a strong need for identification of psychosocial problems within children with and without chronic illness.

The PCP is in a prime position to identify and refer children with psychosocial problems due to being the first round of care for and having relatively consistent contact with these chronically ill children. However, there are many barriers that PCPs face in terms of identification of and referral for these psychosocial problems in children without chronic illness, including time available in appointments, financial concerns spurring need for quick appointments, and feeling adequately trained in identification and referral for psychosocial concerns (Brown, Wissow, & Riley, 2007; Rhoades, McFarland, Finch, & Johnson, 2001). Often there is a lack of time in appointments, or at least a perception of lack of time by the physicians, which can limit discussion of psychosocial concerns (Cooper, Valleley, Polaha, Begeny, & Evans, 2006; Rhoades, McFarland, Finch, & Johnson, 2001; van Dulmen & Holl, 2000). A typical PCP appointment lasts about 15 minutes, limiting physician-patient contact (Wildman, Stancin, Golden, & Yerkey, 2004). During this restricted time, it is unlikely that children will exhibit behavioral or emotional issues that would signify to a physician that they should be referred. Additionally, when PCPs work with children with chronic illnesses, they are further constrained on time. For example, research examining treatment of chronic illness and time constraints within adults in primary care have suggested that with current time limits of appointments, it is not possible for PCPs to adequately treat patients with chronic illness (Ostbye et al., 2005). Additionally, as physicians often have to address parent concerns about physical
aspects of their child’s treatment (Cheng, Savageau, DeWitt, Bigelow, & Charney, 1996),
this further limits time available to identify psychosocial concerns. Also, when working
with healthy peers, it is also unlikely, given the limited time available, for the parents to
actually be able to disclose or feel comfortable enough to disclose their concerns.
However, even when parents disclose concerns to their children’s pediatricians, only
about 50% have been shown to receive mental health treatment (Briggs-Gowan, Horwitz,
Schwab-Stone, Leventhal, & Leaf, 2000). Taking into account these obstacles to
identification of psychosocial concerns, it is imperative that an environment within the
PCP office is created, in which disclosure can occur more frequently or physicians can
gather more information to inform their decisions. This environment is particularly
important when working with children with chronic illness, as time restrictions (Ostbye et
al., 2005) and a parent focus on physical concerns (Cheng, Savageau, DeWitt, Bigelow,
& Charney, 1996) can further limit opportunities for parent disclosure or physician
discussion. Overall, one way this environment can be created is by focusing on
communication within the PCP appointment.

Within physician-patient communication, however, there are several problems
that typically emerge. Rhoades, McFarland, Finch, & Johnson (2001) found that
physicians interrupt patients after an average of 12 seconds and interrupt 25% of adult
patients. Additionally, 43% of parent-physician discussions have been identified as
including a “discouraging” response from the physician (Hart, Kelleher, Drotar, &
Scholle, 2007) and doctors often take little time to check in about patient understanding
(Dugdale, Epstein, & Pantilat, 1999). When parents are trying to discuss psychosocial
problems with the physician, parents often negatively interpret being interrupted by the physician. For example, interruptions can convey a lack of willingness to listen to parent concerns (West & Zimmerman, 1983) and can decrease overall patient satisfaction (Rhoades, McFarland, Finch, & Johnson, 2001). In sum, the structure of PCP visits can affect the amount of time available for communication regarding mental health concerns and, it can help shape an environment that either facilitates or discourages discussion of psychosocial concerns. This environment of good communication, in turn, can affect the rates of identification and referral of psychosocial problems during such visits—and eventually, can affect the reception of mental health treatment.

Communication about psychosocial concerns involves both the facilitation of discussion by physicians, as well as the formation of a relationship between physicians and parents. Robinson and Roter (1999) determined that 57% of referrals occur based on parental disclosure, and maternal disclosure is the largest predictor of identification. However, the proportion of parents who have concerns is much larger than those who actually disclose and disclosure has only been shown to occur when the mother becomes distressed enough about her child’s problems (Wildman, Stancin, Golden, & Yerkey, 2004). Physicians have been shown to be able to increase disclosures by having multiple discussions of psychosocial concerns, as well as by building a “familiar” relationship with the patients (Larson, et al. 2015; Robinson & Roter, 1999). However, in contrast to mothers with well-children who report that they are more interested in psychosocial concerns, most parents of children with chronic illnesses put a higher priority on discussion of physical concerns during PCP visits (Cheng, Savageau, DeWitt, Bigelow,
& Charney, 1996). Therefore, either, often these psychosocial problems are not considered a high-priority, or these concerns are not adequately communicated by the parents (Horwitz, Leaf, & Leventhal. 1998). If concerns are not discussed, naturally, identification, referral, and reception of care rates are negatively affected.

Clearly, the physician-parent relationship appears to be an important precursor to children receiving mental health care. However, good communication between doctors and patients also helps in other ways, such as building a relationship, improving outcomes, and improving overall patient satisfaction in children and adults. For example, good communication has been shown to help ensure accurate diagnosis and improves patient satisfaction with care in children without chronic illnesses (McAlinden, 2014). In the adult literature, perception of high-quality communication is associated with higher satisfaction with both physician care and the overall quality of the care received (Deledda, Moretti, Rimondini, & Zimmermann, 2013) and aids in developing an environment in which disclosure is encouraged. Adults who reported feeling very satisfied with care, stated that they were asked for their ideas or included in the treatment process (Deledda, Moretti, Rimondini, & Zimmermann, 2013). Having a clear understanding between doctors and patients has also been reported as being vital in determining patient satisfaction in the adult literature (Deledda, Moretti, Rimondini, & Zimmerman, 2013). Finally, in the adult literature, research has suggested that having culturally competent and sensitive communication also leads to better patient outcomes (Perloff, Bonder, Ray, Ray, & Siminoff, 2006). Therefore, a further benefit of improved communication is better overall adult patient adherence. This finding of a positive
relationship between communication and patient adherence bodes well for treatment success (Zolnierek & DiMatteo, 2009) and has been linked with better adult patient health outcomes (Hojat et al., 2011; Rakel et al., 2011). Even though the literature has not examined the connection of communication and patient outcomes in children with chronic illnesses specifically, the adult literature cited suggests that parent perception of this communication could have a similar impact on their satisfaction with communication and overall treatment.

As suggested by the literature linking communication and patient satisfaction, there are also several specific aspects of physician-patient communication that have emerged as increasing the likelihood of parent disclosure. Showing empathy and concern helps strengthen the working alliance between physicians, parents, and patients (Bellet & Maloney, 1991), and honesty and respect has been linked to higher adolescent patient satisfaction with care in specialty clinics (Britto et al., 2004). Additionally, it is important to note that 36% of adults in the U.S. have low health literacy (White, Chen, & Atchison, 2008). Therefore, it is necessary for physicians to use plain-clear communication when discussing concerns with parents (Howard, Jacobson, & Kripalani, 2013). Research also indicates that parents value the physician listening to and understanding them more than they value understanding the information the physician is giving back to them (Hart, Kelleher, Drotar, & Scholle, 2007). Overall, there is limited research connecting improved communication and increased reception of mental health care rates for psychosocial problems in chronically ill children. However, there is evidence to suggest that improving communication, providing more time for psychosocial disclosure, and
building the physician-patient relationship, might aid in better identification, referral, and reception of care rates in children (Braeken et al., 2013). However, this same research has not been conducted to examine how improving communication impacts physician-parent relationships specifically, suggesting there needs to be more research in this area. More specifically, there is need for identification of individual aspects or factors of communication that physicians should focus on in these relationships and if these factors are related to reception of care. Multiple aspects have been suggested, but there is a need for identification of the specific communication items valued by parents to be identified by physicians and focused on within physician-parent interactions.

Apart from communication, rates of identification and reception of care can also differ by type of psychosocial problem. Parents have been shown to disclose externalizing disorders at higher rates than internalizing disorders in children with chronic illnesses (Hysing, Elgen, Gillberg, & Lundervold, 2009)—despite the fact that chronically ill children suffer from internalizing disorders at high rates. In fact, when children had internalizing disorders, physicians were unlikely to identify or refer these problems (Sharp, Pantell, Murphy, & Lewis, 1992). When sampling of children without chronic illnesses, when psychosocial problems were addressed and chronic illness was controlled for, physicians differed in identification rates depending on severity of the psychosocial problem (Brugman, Reijneveld, Verhulst, & Verloove-Vanhorick, 2001). Additionally, in a study of children assessed using the Child Behavior Checklist, physicians were four times more likely to identify children in the clinical range as compared to children not meeting clinical criteria (Brugman, Reijneveld, Verhulst, &
Verloove-Vanhorick, 2001). Similarly, rates of disclosure have been shown to increase and be dependent upon the seriousness of the patient’s psychosocial problems within the primary care setting (Robinson & Roter, 1999). Therefore, those with more serious psychopathology and those with externalizing disorders are more often identified; those with less severe pathology or internalizing disorders are left untreated (Robinson & Roter, 1999). However, Robinson and Roter’s (1999) sample, only included those in primary care, did not address those with chronic illness, and included both children and adults. Therefore, there is still a need for more research to be conducted examining reception of care factors within children with chronic illnesses.

Similarly, identification, referral, and reception of treatment rates may differ by chronic illness type. When comorbid psychosocial problems exist, less is known about rates of treatment for children with various types of chronic illnesses (Bilfield, Wildman, & Karazsia, 2006). Research indicates that many of these comorbid psychosocial problems show up consistently in certain types of chronic illnesses. For example, in neurological disorders, such as epilepsy and cerebral palsy, children tend to suffer emotionally, have difficulty adjusting, and have frequent troubles socially interacting with their peers (Glazebrook, Hollis, Heussler, Goodman, & Coates, 2003); in adolescents with diabetes, problems with depression, anxiety, and disruptive behavioral disorders were found to limit glycemic control (Hood, Peterson, Rohan, & Drotar, 2009; Northam, Matthews, Anderson, Cameron, & Werther, 2005). What has yet to be determined is if psychosocial problems in specific types of chronic illnesses are more readily identified and more frequently receive treatment. Past research suggests that there
are not specific types of diseases and comorbid psychosocial problems that are more or less likely to be referred for treatment, but more research is needed on potential disease-specific barriers.

**Current study**

The purpose of this study was to examine whether parent perception of physician communication is related to parent report of their child receiving treatment for behavioral and emotional concerns, above and beyond the presence of a psychosocial problem. We expect that communication will be aligned with past research and will be a stronger predictor of parent report of reception of mental health care than the reported presence of a psychosocial problem alone. Due to the importance the literature suggests communication has on reception of mental health care, we hypothesize that communication will be a significant predictor of report of reception of treatment.

Secondly, our study also examines, within parent report, whether, in our sample, there are specific communication factors used by the physicians. We hypothesize parent report of certain physician communication factors, such as empathy, understanding, respect, and cultural competence within typical doctor-patient communication. Finally, the current study also evaluated if parent report of reception of treatment rates differ depending on disease or psychosocial problem type. We predict that externalizing problems will be referred for and receive treatment more frequently in all disease types.
Method

Participants

Participants were parents who responded to the National Survey for Children with Special Health Care Needs (NS-CSHCN, 2009-2010). This nationally representative telephone survey consists of 40,242 families with children with special health care needs ages 0-17. Of these 40,242 families, only 10,620 responded that their child needed mental health treatment, and thus represents the total sample that was examined. Participants were mostly Caucasian (69%), and the average participant had more than high-school level education (77%), whereas only 6% had less than a high-school education. The majority of children were from a two-parent, biological or adoptive household, and the highest percentage (27%) were 400% above the poverty level. Descriptive statistics for the overall sample are listed in Table 1, and percentages of Chronic Illness Type and Psychosocial Problem Type are listed in Table 2.
<table>
<thead>
<tr>
<th>Table 1</th>
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<tbody>
<tr>
<td><strong>Descriptive Characteristics of Full Sample, EFA Sample, and CFA Sample</strong></td>
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<td></td>
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<tr>
<td><strong>Child Characteristics</strong></td>
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<tr>
<td>Age</td>
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<tr>
<td>Biological Sex</td>
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<tr>
<td>Male</td>
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<tr>
<td>Female</td>
</tr>
<tr>
<td>Race</td>
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<tr>
<td>Hispanic</td>
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<tr>
<td>White, Non-Hispanic</td>
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<tr>
<td>Black, Non-Hispanic</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td><strong>Parent &amp; Family Characteristics</strong></td>
</tr>
<tr>
<td>Education (Highest level attained)</td>
</tr>
<tr>
<td>Less than high school</td>
</tr>
<tr>
<td>High School</td>
</tr>
<tr>
<td>Graduate</td>
</tr>
<tr>
<td>More than high school</td>
</tr>
<tr>
<td>Family Structure</td>
</tr>
<tr>
<td>Two Parent Biological/Adopted</td>
</tr>
<tr>
<td>Two Parent Stepfamily</td>
</tr>
<tr>
<td>Single Mother/No Father</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Poverty Level (PL)</td>
</tr>
<tr>
<td>At or below 50% of PL</td>
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<tr>
<td>Above 50% to at or below 100% PL</td>
</tr>
<tr>
<td>Above 100% to at or below 133% PL</td>
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<tr>
<td>Above 133% to at or below 150% PL</td>
</tr>
<tr>
<td>Above 150% to at or below 185% PL</td>
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</tbody>
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Note: All percentages may not equate to 100 due to rounding, as well as answers of “Don’t Know” or “Refused to Answer were excluded.

SD = standard deviation; M = sample mean

<table>
<thead>
<tr>
<th>Disease Type</th>
<th>Prevalence (%)</th>
</tr>
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<tbody>
<tr>
<td>Asthma</td>
<td>21.8%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1.2%</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>3.0%</td>
</tr>
<tr>
<td>Frequent Headaches/Migraines</td>
<td>13.6%</td>
</tr>
<tr>
<td>Heart Problems</td>
<td>2.4%</td>
</tr>
<tr>
<td>Blood Problems</td>
<td>1.1%</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>0.2%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>1.2%</td>
</tr>
<tr>
<td>Muscular Dystrophy</td>
<td>0.2%</td>
</tr>
<tr>
<td>Arthritis/Joint Problems</td>
<td>3.9%</td>
</tr>
<tr>
<td>Internalizing Psychosocial Problem</td>
<td>54.3%</td>
</tr>
<tr>
<td>Externalizing Psychosocial Problem</td>
<td>32.9%</td>
</tr>
</tbody>
</table>

Methods

The National Survey for Children with Special Health Care Needs (NS-CSHCN, 2009-2010) is a national study conducted by the National Center for Health Statistics within the Centers for Disease Control and Prevention, and is funded by the following sources: the U.S. Department of Health and Human Services, Health Resources and Services Administration, and the Maternal and Child Health Bureau. The survey was first
used in 2001, and has been repeated every four years since. A separate survey, the National Survey for Children’s Health will absorb this survey in its next iteration, expected in 2017.

Families were surveyed by assigning randomly generated telephone numbers to either the main or referent sample (NS-CSHCN, 2009-2010). An algorithm was used to pinpoint households and cell-phone numbers that included children, and once contacted for the main sample, the families were screened for both number of children in the household and for having a child with special health care needs. Only one child with special health care needs from each household was targeted, and parents provided their survey information.

Our study was approved in August 2014, as a Level 1 Exempt research study by the Kent State Institutional Review Board. Permission was also gained by the Child and Adolescent Health Measurement Initiative, who allows access to the data.

**Measures**

**National Survey for Children with Special Health Care Needs (NS-CSHCN, 2009-2010).** The National Opinion Research Center (NORC) within the University of Chicago was contracted for data collection of the NS-CSHCN, and thus, trained its employees in both locations where data collection occurred: Chicago, Illinois and Las Vegas, Nevada (Bramlett et al., 2014). Training included extensive mock survey administration and training in strategies to acquire complete interviews when participants refused to begin or did not want to finish the interview. To decrease nonresponse, a letter was sent to the families before calling them, which explained the purpose and importance
of the survey. Additionally, the survey was available in English and Spanish, in an attempt to reach a larger demographic.

Within the interview, parents responded to questions concerning their child’s health care needs, issues or limitations they face as a result of their conditions, and general demographic information, such as the child’s age, sex, race/ethnicity, and number of children in the household. Most importantly for the present study, the parents responded to questions about whether or not a doctor had recommended that their child receive treatment or counseling for emotional, developmental, or behavioral problems. Parents were also asked whether or not their child received all the mental health care that was needed following these recommendations. Overall, the mean length of time for the interview was 28 minutes, but varied by individual (Bramlett et al., 2014). The completion rate for the interview was “83.6% in the landline sample, 76.6% in the cell-phone sample, and 80.8% overall” (Bramlett et al., 2014). Full information on the NS-CSHCN can be found at the following website, within the Data Resource Center for Child and Adolescent Health: http://childhealthdata.org/learn/NSCH.

**Coding and Missing Data**

Considering the size and complexity of the CSHCN dataset, the authors had to appropriately determine how to code specific variables of interest, as well as handle missing data resulting from the procedure used for data collection. This process is described below for key variables.

Two separate types of psychosocial problems could be identified: internalizing (i.e. depression and anxiety) and externalizing (i.e. Behavioral or Conduct Problems). For
these two psychosocial areas, the parents were specifically asked, “Has a doctor or other health care provider ever told you that your child has the [condition], even if they do not have it now?” (i.e. 0 = No and 1 = Yes, Don’t Know = 6, and Refused to Answer = 7), and then, if they responded “Yes” to this initial question, parents were asked “Has a doctor or other health care provider told you that your child currently has the [condition]?” (e.g., coded identically to the previous question). Due to our interest in current reception of care for these issues, our analyses only included the responses to the latter question. The “Externalizing Psychosocial Problem” variable included in the analyses represents those parents who responded “Yes” to the presence of a “Behavioral or Conduct” condition. For the internalizing variable, if parents responded “Yes” to the presence of either the “Anxiety” or “Depression” condition currently, they were included in the “Internalizing Psychosocial Problem” group. For the “Internalizing Psychosocial Problem” variable, both variables were combined, and the variable was coded: 0 = presence of neither “Anxiety” or “Depression”, and 1 = presence of either “Depression” or “Anxiety”, or the presence of both.

If parents responded “Don’t Know”, “Refused to Answer”, or were “Missing” for the presence of any of the psychosocial problems, they were coded as 0 (e.g., 0=No). For the purposes of our analyses it was assumed that if they did not know how to respond, their child did not have a psychosocial problem. If the data were missing, according to how the survey was coded by the NORC data collection team (Bramlett et al., 2014), parents responded “No” to the question asked about “ever” having the condition. Since
this means that the parents are reporting that their child has never had this psychosocial problem, they were coded as 0 in our analyses (e.g. coded as not having the problem).

A similar approach was taken when coding specific disease type. The following variables were included in the initial analyses: asthma, diabetes, epilepsy, migraines or frequent headaches, heart problems, blood problems (i.e. sickle cell, anemia, and hemophilia), cystic fibrosis, muscular dystrophy, and arthritis. Parents were asked specifically if their children ever had the [condition], (even if they do not have it now), and then if they currently had the [condition] (i.e. 0 = No and 1 = Yes, Don’t Know = 6, and Refused to Answer = 7). If parents responded “Don’t Know”, “Refused to Answer”, or “Missing” it was assumed that these children did not have this disease type, and thus, they were coded as 0 (e.g., 0 = No). The same approach was taken for the “Missing” data, as in the psychosocial problem type.

Similarly, the “Communication” construct was assessed using the following ten communication questions, and were rated on a scale of 1=Never, 2=Sometimes, 3=Usually and 4=Always:

1. How often did your child’s doctors and other health care providers spend enough time with [him/her]?

2. How often did your child’s doctors and other health care providers listen carefully to you?

3. How often were your child’s doctors and other health care providers sensitive to your family’s values and customs?

4. How often did you get the specific information you needed from your child’s doctors and other health care providers?

5. How often did your child’s doctors and other health care providers help you feel
like a partner in [his/her] care?

6. How often did your child’s doctors or other health care providers discuss with you the range of options to consider for [his/her] health care or treatment?

7. How often did they encourage you to ask questions or raise concerns?

8. How often did they make it easy for you to ask questions or raise concerns?

9. How often did they consider and respect what health care treatment choices you thought would work best for your child?

10. How often does your child’s doctors or other health care providers encourage [him/her] responsibility for [his/her] health care needs?

Within the CSHCN dataset, these questions were only asked if parents responded “Yes” to the following question: “Did your child visit any doctors or other health care providers in the past 12 months?” If they responded yes, they answered questions 1-9, before proceeding to question 10 (seen in the list above). However, if they answered “No”, “Don’t Know”, or “Refused to Answer”, they were only asked question 10. When parents responded “No” or “Don’t Know” to the initial question, they were skipped to question 10; therefore, these 84 total participants were excluded from analyses.

Additionally, question 10 was only asked of parents of children age 5 or above; therefore, there were 382 total parent responses that were set to “Missing” and were excluded when a “Total Communication” variable was created. For this variable, a mean score was created using all ten communication variables. This mean “Total Communication” variable was used for all regression analyses; however, within both the Exploratory Factor Analysis and Confirmatory Factor Analysis, each of the individual ten communication items was examined.

Finally, when examining reception of mental health care treatment, parents were first
asked the following question: “During the past 12 months, was there any time when your child needed mental health care or counseling?” For those parents who responded, “Yes” to needing mental health care, they were asked: “Did your child receive all the mental health care or counseling that he/she needed?” Parents who responded “No”, “Don’t Know”, or “Refused to Answer” to needing mental health care or counseling were not asked about reception of care; however, these parents were coded as “Missing” by the CSHCN survey and were excluded from all analyses.

**Psychometric Properties**

The CSHCN questionnaire has been shown to have good internal psychometric properties. Carle, Blumberg, and Poblenz (2011) reported a Cronbach’s alpha of .76, in addition to reporting that the screener included “minimal random measurement error”. They arrived at the conclusion that the NS-CSHCN dataset is reliable and an adequate measure of what chronically ill children experience.

**Analysis Plan**

**Logistic Regression.** In order to test our first hypothesis, that communication improves the likelihood of parent report of reception of treatment for psychosocial problems above and beyond the presence of a psychosocial problem, a binary logistic regression was conducted. Both Psychosocial Problem Type variables (e.g. “Internalizing Psychosocial Problem Type” and “Externalizing Psychosocial Problem Type”) were entered into the first step of the regression as two separate covariates, the “Total Communication” variable was entered into the second step also as a covariate, and
“Reception of Care” was entered as the outcome variable. “Internalizing Psychosocial Problem Type” and “Externalizing Psychosocial Problem Type” were specified as categorical covariates. We predict that communication will have a significant positive effect on predicting reception of care, above and beyond psychosocial problem type.

**Exploratory Factor Analysis and Confirmatory Factor Analysis.** To examine our first hypothesis regarding physician communication and whether specific communication factors exist within our sample, a split-half of the sample was used to conduct both an exploratory factor analysis (EFA) and a confirmatory factor analysis (CFA) to allow for validation of the factor structure. Using SPSS, participants were randomly assigned to one of the two sub-samples. Approximately half of the participants were assigned to the first sub-sample, which was used for the EFA procedure (N=5,332), and the second half to the CFA procedure (N=5,288). The EFA procedure was used to examine the underlying factor structure of the communication variables, and the CFA procedure was then used to confirm this identified factor structure. There were no significant differences between the participants in the EFA and CFA sub-samples on key demographic variables (e.g. gender and age of child). Full descriptive tables are found for both split-half samples (for both EFA and CFA) in Table 1.

The EFA was conducted using Principle Axis Factoring with Promax rotation. This type of rotation has been supported by past research, as it allows for the variables being examined to be correlated, which is true of the “Communication” variables in the dataset (Reise, Waller, & Comrey, 2000). Additionally, parallel analysis was conducted to determine the appropriate number of factors to extract from the data (Reise, Waller, &
Comrey, 2000). A parallel analysis is a procedure that allows the number of factors suggested for extraction to be compared to an analysis of a random data set with the same number of items and people. It allowed us to avoid extracting a factor that explains less variance than a factor that emerges from this random data (Reise, Waller, & Comrey 2000). Previous research summarizing best practices in factor extraction suggests that parallel analysis is the most accurate procedure, as compared to other methods, including the “eigenvalues greater than 1” method and scree plot examination (Henson & Roberts, 2006).

A CFA was also conducted using MPlus software (Muthen & Muthen, 2012). Past research has suggested the $\chi^2$ statistic as a poor test of model fit for CFA, especially with larger sample sizes (Kline, 2011). Therefore, alternative model fit statistics were used to test model fit, including the standardized root mean square residual (SRMR), the comparative fit index (CFI) and the root mean square error of approximation (RMSEA), the use of which is supported by past research (Hu & Bentler, 1999). According to Hu and Bentler (1999), cut-off SRMR values $<.10$ and RMSEA values $\leq .05$ are most acceptable, and indicate goodness of fit. Finally, CFI values $\geq .95$ further demonstrates goodness of fit (Browne & Cudeck, 1993).

**Preliminary Reliability and Validity.** To determine internal consistency of the Communication scale, alpha coefficients were calculated for each item of the Communication scale and the total scale.

**Linear Regressions.** To test our third hypothesis, that reports of reception of treatment rates differ depending on disease or psychosocial problem type, we ran separate
linear regressions for each disease type. In these linear regressions, each specific disease type was entered as predictors, and “Reception of Care” was entered as the outcome variable. We predict that reports of having an externalizing psychosocial problem type will result in reports of higher rates of reception of care, in comparison to internalizing type.
Results

Exploratory Factor Analysis

Using the first subsample (N=5,332), a preliminary EFA was conducted using Principle Axis Factoring and Promax rotation to examine the ten items. Using parallel analysis, one factor emerged. Additionally, when a second EFA was run, in which the data was constrained to one factor, the results were identical. Therefore, only one factor was retained, and the one-factor solution accounted for 57.1% of the variance. Please refer to Table 3 for the factor loadings.

Confirmatory Factor Analysis

Using the second subsample (N=5,288), an initial CFA was conducted on the 10 items to cross-validate the one-factor solution that emerged from the EFA. On the EFA, all items had a standardized loading of at least .4 on their respective factor, thus all ten items were retained for the CFA. The chi-squared value for the overall model was $X^2 (35) = 853.16, p < .001$, suggesting a goodness of fit for the model tested. In addition, when examining alternative fit indices, it showed a good fit of the model using CFI = 0.993 and SRMR = 0.002, and an acceptable fit of the model using RMSEA = 0.066. Standardized factor loadings are reported in Table 3. Several of the factor loadings were close to 1 (e.g. factor loadings 0.977 or above), indicating that there is little variability between the different items on this scale. Therefore, it is likely that items or questions are essentially the same, or very similar, and represent one overall communication construct. Means and standard deviations for all communication items are reported in Table 4 and correlations between items are reported in Table 5.
Table 3  
*Factor Loadings – Parent reports of presence of specific communication factors*

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
<th>EFA ($N = 5.332$)</th>
<th>CFA ($N = 5,228$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.</td>
<td>How often did they make it easy for you to ask questions or raise concerns?</td>
<td>0.823*</td>
<td>0.772**</td>
</tr>
<tr>
<td>9.</td>
<td>How often did they consider and respect what health care treatment choices you thought would work best for your child?</td>
<td>0.802*</td>
<td>0.827**</td>
</tr>
<tr>
<td>5.</td>
<td>How often did your child’s doctor and other health care providers help you feel like a partner in his or her care?</td>
<td>0.785*</td>
<td>0.692**</td>
</tr>
<tr>
<td>6.</td>
<td>How often did your child’s doctors or health care providers discuss with you the range of options to consider for his or her care?</td>
<td>0.777*</td>
<td>0.773**</td>
</tr>
<tr>
<td>7.</td>
<td>How often did they encourage you to raise questions or concerns?</td>
<td>0.758*</td>
<td>0.784**</td>
</tr>
<tr>
<td>2.</td>
<td>How often did your child’s doctors and other health care providers listen carefully to you?</td>
<td>0.752*</td>
<td>0.619**</td>
</tr>
<tr>
<td>4.</td>
<td>How often did you get the specific information you needed from your child’s doctors and other health care providers?</td>
<td>0.699*</td>
<td>0.729**</td>
</tr>
<tr>
<td>3.</td>
<td>How often were your child’s doctors and other health care providers sensitive to your family’s values and customs?</td>
<td>0.675*</td>
<td>0.532**</td>
</tr>
<tr>
<td>1.</td>
<td>How often did your child’s doctors and other health care providers spend enough time with him or her?</td>
<td>0.638*</td>
<td>0.515**</td>
</tr>
<tr>
<td>10.</td>
<td>How often does your child’s doctors or other health care providers encourage him or her to take responsibility for his or her health care needs?</td>
<td>0.483*</td>
<td>0.805**</td>
</tr>
</tbody>
</table>

*Note: Items with factor loadings of .4 or higher and exhibiting specificity (having a >.40 loading on the one factor) were considered “good items” and were retained.*

(*) = Item was retained for the one factor in the Exploratory Factor Analysis  
(**) = Item was retained for the one factor in the Confirmatory Factor Analysis
Table 4  
*Description of Communication Items*

<table>
<thead>
<tr>
<th>Communication Items</th>
<th>Mean; SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How often did your child’s doctors and other health care providers spend enough time with [him/her]?</td>
<td>3.21; 0.90</td>
</tr>
<tr>
<td>2. How often did your child’s doctors and other health care providers listen carefully to you?</td>
<td>3.38; 0.80</td>
</tr>
<tr>
<td>3. How often were your child’s doctors and other health care providers sensitive to your family’s values and customs?</td>
<td>3.46; 0.80</td>
</tr>
<tr>
<td>4. How often did you get the specific information you needed from your child’s doctors and other health care providers?</td>
<td>3.17; 0.92</td>
</tr>
<tr>
<td>5. How often did your child’s doctors and other health care providers help you feel like a partner in [his/her] care?</td>
<td>3.39; 0.85</td>
</tr>
<tr>
<td>6. How often did your child’s doctors or other health care providers discuss with you the range of options to consider for [his/her] health care or treatment?</td>
<td>3.28; 0.92</td>
</tr>
<tr>
<td>7. How often did they encourage you to ask questions or raise concerns?</td>
<td>3.30; 0.99</td>
</tr>
<tr>
<td>8. How often did they make it easy for you to ask questions or raise concerns?</td>
<td>3.41; 0.87</td>
</tr>
<tr>
<td>9. How often did they consider and respect what health care treatment choices you thought would work best for your child?</td>
<td>3.32; 0.89</td>
</tr>
<tr>
<td>10. How often does your child’s doctors or other health care providers encourage [him/her] responsibility for [his/her] health care needs?</td>
<td>2.95; 1.09</td>
</tr>
</tbody>
</table>
Table 5
Correlations Between Communication Items

<table>
<thead>
<tr>
<th>Variables</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Spend Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Listen Carefully</td>
<td>0.59*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Sensitive to Values/Customs</td>
<td>0.46*</td>
<td>0.57*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Specific Information Needed</td>
<td>0.46*</td>
<td>0.51*</td>
<td>0.48*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Partner in Care</td>
<td>0.49*</td>
<td>0.59*</td>
<td>0.55*</td>
<td>0.58*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Discuss Range of Options</td>
<td>0.47*</td>
<td>0.55*</td>
<td>0.47*</td>
<td>0.57*</td>
<td>0.62*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Encourage Questions</td>
<td>0.43*</td>
<td>0.52*</td>
<td>0.47*</td>
<td>0.51*</td>
<td>0.57*</td>
<td>0.63*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Make Easy to Ask Questions</td>
<td>0.48*</td>
<td>0.60*</td>
<td>0.54*</td>
<td>0.54*</td>
<td>0.63*</td>
<td>0.63*</td>
<td>0.71*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Consider/Respect Parent Options</td>
<td>0.47*</td>
<td>0.60*</td>
<td>0.53*</td>
<td>0.54*</td>
<td>0.62*</td>
<td>0.63*</td>
<td>0.62*</td>
<td>0.69*</td>
<td></td>
</tr>
<tr>
<td>10. Encourage Child</td>
<td>0.31*</td>
<td>0.33*</td>
<td>0.29*</td>
<td>0.37*</td>
<td>0.37*</td>
<td>0.41*</td>
<td>0.39*</td>
<td>0.39*</td>
<td>0.40*</td>
</tr>
</tbody>
</table>

*p<.01

Preliminary Reliability and Validity

Preliminary reliability. Nunally & Bernstein (1994) recommend coefficients of .7 or greater, which all items exceeded. For the communication items, alpha reliability of the total scale was also good (α = .910).

Logistic Regression

A logistic regression analysis was conducted to investigate whether reported communication, over and beyond reported presence of a psychosocial problem, predicted
reported reception of mental health care. Results showed that the proposed model represented the data well, \( \chi^2 (3) = 871.990, p<.001 \). The reported presence of a psychosocial problem increased the odds of reporting receiving care by a factor of 1.18 [95% CI = (1.06, 1.31)] for “Internalizing Psychosocial Problem Type” and by 1.16 [95% CI = (1.04, 1.30)] for “Externalizing Psychosocial Problem Type”. However, “Total Communication” exceeded this, as the odds of reporting receiving care increased by a factor of 2.86 [95% CI = (2.67, 3.08)], with every one-point increase in communication (4-point scale). Results are presented in Table 6.

Table 6
Logistic Regression Analysis Results Predicting Reception of Care from Communication, Above and Beyond Presence of Psychosocial Problem (N=10,620)

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE B</th>
<th>SE ( \beta )</th>
<th>e^b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internalizing</td>
<td>.162**</td>
<td>.055</td>
<td>1.18</td>
<td></td>
</tr>
<tr>
<td>Externalizing</td>
<td>.150**</td>
<td>.057</td>
<td>1.16</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>1.05**</td>
<td>.036</td>
<td>1.42</td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-1.95</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>( \chi^2 )</td>
<td>871.990</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>df</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Not Receiving All Care Needed</td>
<td>18.0</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p<.05, **p<.01

Linear Regressions

Separate linear regressions were conducted for each reported disease type, in terms of their prediction of reported reception of mental health care. There is a significant negative relationship between reported presence of two disease types and reported reception of mental health care, such that when migraines or arthritis were reported, parents reported that their children were less likely to receive treatment.
[Migraine/Frequent Headache ($\beta = -0.058$, $R^2 = 0.003$, $p < 0.001$), and Arthritis/Joint Problems ($\beta = -0.045$, $R^2 = 0.002$, $p < 0.001$)].

Due to running twelve separate regressions, as well as being cognizant of large sample size, a Bonferroni correction was calculated. The Bonferroni correction suggested only accepting as significant values <0.004. Therefore, two disease types [blood problems, such as anemia or sickle cell disease ($\beta = -0.022$, $p < 0.05$); and cerebral palsy ($\beta = 0.23$, $p < 0.05$)] that were significant at the .05 level, but were greater than .004, were not reported. Results are presented in Tables 7-8. For all other disease types, the relationship between reported disease type and reported reception of care was not significant ($p > 0.05$).

Table 7

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>$\beta$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>.828</td>
<td>.004</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Migraine/Headache</td>
<td>-.065</td>
<td>.011</td>
<td>-.058</td>
<td>.000</td>
</tr>
</tbody>
</table>

Note: $R^2 = 0.003$. 
Table 8  
Relationship between “Arthritis and Joint problems” Disease Type and Reception of Care (N = 10,620)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>.823</td>
<td>.004</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arthritis/Joint Problems</td>
<td>-.089</td>
<td>.019</td>
<td>-</td>
<td>.000</td>
</tr>
</tbody>
</table>

Note: $R^2 = .002$. 
Discussion

Our findings suggest that parent report of use of specific types of physician communication (e.g. making it easy or encouraging parents to ask questions or discuss concerns, respecting parental choices, and making the parent feel like a partner in the child’s care) results in increased likelihood that parents will report reception of care. Specifically, our analyses highlighted that, above and beyond the reported presence of a psychosocial problem in a child, reports of physician communication that facilitates a positive relationship with parents (e.g. where parents feel like a partner in their child’s care, and that their choices are respected and heard) significantly predicts parent report of reception of care. Past research has highlighted several aspects of communication between physicians and parents that might lead to the formation of this positive relationship between parents and physicians, including respect, understanding, and time spent with the parents and child (Deledda, Moretti, Rimondini, & Zimmermann, 2013; Hart et al., 2007). However, while previous research has examined the relationship between use of these critical communication factors and better relationship with parents and patient satisfaction (Hart, Kelleher, Drotar, & Scholle, 2007), it has not examined the relationship between communication and reception of care. The results of this study extend the literature by highlighting the importance of parent perception of physician communication, as well as the effects this perception of communication has on reports of reception of mental health care treatment for the children.

While past research has not studied the relationship between communication and reception of care, we hypothesized that many of the aspects of communication linked to
patient satisfaction (e.g. understanding, warmth, empathy, and honesty) (Hart, Kelleher, Drotar, & Scholle, 2007; Bellet & Maloney, 1991) would predict reports of reception of care. However, interestingly, our findings suggest that there is likely one overall factor of communication related to report of reception of care. Additionally, our findings make intuitive sense, in that having an internalizing and/or externalizing psychosocial problem increases the odds of receiving mental health care. However, our results also suggest that the increased odds of receiving care are similar in both psychosocial types.

**Parent Perception**

The current study examined all key variables (e.g., reception of care, presence of psychosocial problem and disease type, and perception of communication) through parent report. Therefore, it is important to note that all reports are based on parental perception of these variables, including their perception and verbal report of presence of psychosocial problems, as well as reception of care. However, as past research has identified, physician identification of psychosocial problems is largely dependent on parent report (Robinson & Roter, 1999), and parents are more likely to disclose when they are distressed by these problems (Wildman, Stancin, Golden, & Yerkey, 2004). Essentially, parents are the driving force behind identification of problems and reception of psychosocial treatment, and are an important population to survey. However, we know that not all parents disclose concerns, and when they do, disclosure still does not guarantee identification and reception of treatment. Therefore, our study allowed us to examine how parents perceive and report on the psychosocial problems that they believe their children are experiencing, as well as how fully they think these mental health
concerns were addressed. In the current study, 10,620 parents reported that their children needed psychosocial treatment (e.g., 26% of the sample). Parents generally reported that their children received all the psychosocial treatment they needed (e.g., 81.9% of the sample), however, another portion of parents reported that their child did not (e.g., 18.1% of the sample).

Our study’s percentage of children needing care is lower than past data has suggested (e.g., 38% of children with chronic illness) (Bilfield, Wildman, & Karazsia, 2006), whereas the number of parents reporting reception of all the mental care their children needed, far exceeded past reports (Williams, Klinepeter, Palmes, Pulley, & Foy, 2004). This discrepancy is likely due to rates being reported by parents, which is a limitation discussed later in more detail. Parent perception of mental health care can be skewed for various reasons, and thus, may not be the most method to assess reception of care. First, for the reports on needing care, the parents in our study could have been unaware that their child needed mental health treatment due to not identifying it themselves, or physicians not identifying it in their child. Additionally, it is possible that, with the stigma surrounding mental health care, parents preferred to not seek out mental health treatment, even if told to do so by their child’s physician. Next, because only parents acknowledging that their child needed care were then asked about reception of care, it is likely that the number of those receiving care is skewed. Additionally, it is possible that parents within our sample were not aware of what mental health treatment should look like, and parents inaccurately reported receiving all the care that they needed. Furthermore, as the sample is of a predominantly high socioeconomic status (SES), it is
likely that these parents were able to attain adequate mental health care for their children, and our skewed sample does not represent all SES groups. Finally, as past research summarizing patient surveys has suggested, respondents are typically reluctant to make negative comments about their health care providers. This is usually due to social desirability by how much they like their child’s health care provider (e.g., the “halo effect”) (Fitzpatrick, 1991). Overall, the percentages within our study of parents reporting that their child needed and received all the mental health they desired should be interpreted with caution. However, they are likely to reflect parent opinion and influence which children will actually receive behavioral health care.

Communication

Our findings suggest that there is only one doctor-patient communication factor that is predictive of reception of care, which includes the physician making the parent feel heard, encouraging questions, making the parent feel like a partner in their child’s care, and respecting the parent’s choices. Of the communication questions asked of parents, this one communication factor emerged. The finding of one factor suggests that these items are strongly related, and are likely tapping into one construct of communication, which appears to be related to the formation of rapport and a positive relationship between parents and physicians. Past research has identified aspects of communication as important to parents, such as willingness to listen, understand, and respect the parent and child (Deledda, Moretti, Rimondini, & Zimmermann, 2013; Hart et al., 2007; Rhoades, McFarland, Finch, & Johnson, 2001). However, our one-factor communication construct suggests that physicians should be less concerned about using
or addressing all aspects of communication supported by past research, but rather focusing on communication that leads to the development of this relationship centered around respect and understanding. Additionally, as the “halo effect” suggests, it is also likely that use of good communication might also add to the likeability of the physician, resulting in parents perceiving this communication as better, purely because they like the physician more (Fitzpatrick, 1991).

According to parent report, our study identified that when parents perceive a higher frequency of positive physician communication, they are more likely to be receptive to receiving psychosocial treatment. Additionally, communication had a stronger influence on reception of care than presence of a psychosocial problem, which highlights the importance of good physician-patient communication, and the importance of positive parent perception of this communication for reception of care. Our finding that parent perception of communication is critical suggests that physicians’ communication is an integral factor in terms of child reception of treatment, and should be a major focus within all primary care appointments. However, from past research, we know that several barriers to identification of psychosocial problems have been suggested, such as lack of physician time during appointments to discuss psychosocial concerns and reimbursement pressures to see more children (Cooper, Valleley, Polaha, Begeny, & Evans, 2006; Rhoades et al., 2001; Van Dulmen & Holl, 2000). This lack of time within appointments likely adds to difficulties identifying psychosocial problems, and likely reduces rates of eventual reception of care.

Though there is time pressure within PCP appointments, statistics support large
rates of psychosocial problems seen within a primary care setting, pointing to the need for Primary Care Physicians (PCPs) to prioritize these discussions (Bernal, 2003). Additionally, because we know that children with chronic illnesses are at increased risk for development of psychosocial problems (Drotar, 1999; Cadman, Boyle, & Offord, 1988) and we know that physical concerns are often the main focus of physician appointments within this sample (Cheng, Savageau, DeWitt, Bigelow, & Charney, 1996), it is critical that physicians find ways to assess and discuss psychosocial concerns. This discussion should be employed using the type of communication we identified in our study, and should be prioritized along with the discussion of physical concerns.

**Psychosocial Problem and Disease Type**

The current study found that having both internalizing and externalizing psychosocial problems increases the odds of reception of mental health care. The increased odds are similar for internalizing and externalizing problems. These findings differ from past research that reported that externalizing disorders more likely to result in reception of care (Hysing, Elgen, Gillberg, & Lundervold, 2009) than internalizing problems. Externalizing disorders, especially those that parents reported as more severe on measures such as the Child Behavior Checklist (Brugman et al., 2001), are more noticeable. Often, these children are also more outwardly distressing to parents, resulting in higher identification of these problems. However, as supported by our sample, there is a higher incidence of internalizing problems (19.1% of children with special health care needs) than externalizing problems (11.5%), which might have affected reported reception of care rates in this sample of children with chronic illnesses. As the difference
suggested by our study is not large, our results suggest the need for future research to parse apart the relationship between psychosocial problem type and reception of care.

Additionally, children with specific chronic illnesses, including arthritis or joint problems and frequent headaches or migraines, were less likely to receive mental health care overall. These two disorders have a large pain component, which has been linked to increased risk for internalizing disorders, such as anxiety and depression (Pitrou et al., 2010; Schanberg et al., 2003). This connection between both of these diseases and internalizing disorders fits with past research that has suggested that children with internalizing disorders are less likely to identified and receive mental health care (Hysing, Elgen, Gillberg, & Lundervold, 2009). However, as other diseases that were analyzed also have a pain component, more research is needed to study the link between these two specific diseases and perceived reception of care. Additionally, as mentioned previously, there is a paucity of research linking all disease types and reception of mental health care. Therefore, as our findings suggest a very small connection between these specific disease types and reception of care, future research is needed in this area to further study the link between these two diseases—as well as all disease types—and reception of care. It is also likely that the combination of having a chronic illness and a psychosocial problem is too much for parents to deal with. Therefore, mental health care might not have been a priority at the time these parents were interviewed. Future research should also examine parent and child barriers to obtaining mental health treatment, such as time and desire for services taking into account the relationship between disease type and reception of care.

Overall, our findings on the relationship between psychosocial problems and disease type
also support past research highlighting the need for physicians, as well as other medical professionals, to spend more time attempting to identify both internalizing and externalizing problems in children with special health care needs (Bilfield, Wildman, & Karazsia, 2006).

**Clinical Implications**

The results of the current study have important clinical implications for Primary Care Physicians (PCPs). Bernal (2003) highlighted the fact that roughly 50% of children seen by PCPs are seen for consultation of behavioral or emotional difficulties, but past research consistently shows that many of the children who need mental health care, don’t receive it (Williams, Klinepeter, Palms, Pulley, & Foy, 2004). One possible reason for this disconnect between need and reception of care is that physicians often refer to mental health care professionals outside of their practice. However, rates for referral completion are low (Rushton, Bruckman, & Kelleher, 2002) as parents often do not follow-up with the recommendation, and physicians often do not check back in regard to their reception of care. For example, 60% of children referred for mental health care fail to attend an appointment within six months of referral, and of children who attend a first appointment, only 15-20% will actually attend a second appointment (Kelleher et al., 2000); overall rates of follow-through on a PCP’s referral for children with psychosocial problems are low (Rushton, Bruckman, & Kelleher, 2002; Riekert et al., 1999; Kanoy & Schroeder, 1985). Parental attitudes toward and perception of treatment is one of the most salient factors in choosing to consider and eventually attend psychosocial treatment (Power et al., 2005). Therefore, it is imperative that PCPs assess how best to communicate with
parents by checking in with the parents frequently, as well as allowing parents to ask any questions about potential treatment. As we know parent disclosures are strongly related to reception of care (Robinson & Roter, 1999); our findings specifically highlight the need for rapport to be developed between physicians and parents of children with chronic health conditions. Since these children are at increased risk for psychosocial problems (Drotar, 1999; Cadman, Boyle, & Offord, 1988), physicians should focus more on building rapport with parents. Our results suggest that physicians should build this rapport by focusing on communication throughout their appointment, especially during discussion of referral options. Communication within these appointments should focus on the one-factor structure of communication identified within our study, which includes building rapport with parents by making them feel heard, respected, and a key player in the treatment of their child.

Limitations

The findings of the current study should be interpreted in the context of several limitations. First, this study relied solely on parent report, and thus, relied on parent perception of our main hypotheses. Because parents are self-identifying presence of psychosocial problems, disease type, and reception of care, it is possible that we are missing parents and children who have a psychosocial problem and either are not aware of these difficulties or don’t believe or remember what a physician has told them previously. Additionally, it is possible that our study includes false positives, or parents that inaccurately report that their child has a psychosocial problem. Of the 40,242 families polled, 10,620 parents of children with special health care needs (26.4% of the
sample) reported that their child needed mental health treatment. Of the roughly 30,000 parents who reported no need of mental health treatment, it is possible that we are missing children who have a psychosocial problem, and need treatment for it (Williams, Klinepeter, Palms, Pulley, & Foy, 2004). The fact that we could be missing children who do need mental health treatment could be due to multiple reasons, including parents not being aware that their child needs mental health treatment or preferring to not seek out mental health treatment. Therefore, our study is limited by the accuracy of these reports, as well as if our reception of care and communication variables are being asked of all parents and children who presently have mental health concerns. Future research should examine this same construct with more objective measures, such as physician diagnosis and parent screeners, or by adding in the perspective of more key players in this interaction, such as the physicians themselves.

Secondly, in addition to parent report, our study is limited by the utilization of an existing dataset. Specifically, our examination of the key variables of interest (e.g. presence of a psychosocial problem/disease type, communication, and needing/receiving mental health care) was limited by the language and content of the survey. Specifically, the present study asked the following questions about reception to care: “During the past 12 months, was there any time when your child needed mental health care or counseling?”, and “Did your child receive all the mental health care or counseling that he/she needed?”. The wording of the questions and structure of the questionnaire limited our findings, as we were only able to examine reception of care for those parents who identified need of mental health care. Similar to other questions on the survey, parents
were only asked about reception of care if they acknowledged needing care in the first place. From past research, we know that not all parents are aware of presence of a psychosocial problem and physicians under-diagnose and under-refer these problems in children (Steele, Lochrie, & Roberts, 2010; Williams, Klinepeter, Palms, Pulley, & Foy, 2004). Therefore, it is likely that we are missing children within our sample due to the language used and structure of the survey. Additionally, with the language of “all the mental health care needed”, we are limited in knowing many of the following aspects of their mental health treatment: actual reception of treatment, attendance at treatment, the length of services that a parent perceives as adequate, or possible early termination. Factors such as these are limited both by the language used and structure of the survey, as well as by only collecting parent report.

Additionally, due to the structure of the survey, several parents reported “Don’t Know” or “Refused to Answer”, and thus were excluded from analyses or coded as not having the psychosocial problem or disease type. With these parents, it is hard to identify if we accurately excluded or included these people. Future research with more objective measures and additional perspectives should attempt to accurately distinguish between those needing care and those who do not.

Finally, this sample includes a large proportion of parents who have more than a high school degree (77%), are reporting on male rather than female children (62%), and are 400% above the poverty level (27%). This sample is not representative of the U.S. population, which should be a focus in the next iteration of this nationally representative survey collection in 2017.
Summary and Conclusions

In summary, our study found that, above and beyond the presence of a psychosocial problem, parent perception of the physician’s communication is imperative in reception of mental health care among children with chronic health conditions. We identified that there is likely one communication factor or construct that parents perceive as important, which includes aspects of communication such as making it easy for the parent to ask questions, respecting parent choices, and making the parent feel like a partner in their child’s care. Our findings highlight the need for physicians to be aware of this factor of communication throughout their encounters with parents, and check in with parents regarding the parents’ perception of this communication. Our results suggest a strong connection between parent perception of communication and reception of care, and supports future research on this relationship. It is possible that when physicians demonstrate specific communication skills, that parents are more likely to disclose psychosocial concerns, which would likely result in increased rates of reception of care. However, future research is needed to parse the factors involved in this relationship.

Additionally, future research is needed to better understand the relationship between psychosocial or disease type and reception of care. Our findings suggest that when children have specific disease types (e.g., frequent headaches or migraines and arthritis or joint problems), they are less likely to receive the mental health care their parents think they need. Our findings did not allow us to understand why these children did not receive the care their parents thought they needed, or how communication played a role in this relationship. Therefore, more research is needed on the factors at play in this relationship.
relationship and, specifically, research needs to identify why and what barriers to care exist for these children.

The combination of psychosocial problems and a chronic illness can cause significant difficulties for families but, when these families do not receive the mental health care they need, additional problems are present for the child and parent. Our findings highlight the need for physicians to focus on using good communication with parents and children with chronic illnesses. This communication should be used to build rapport with parents, and include aspects of communication, such that they make parents feel respected, heard, and included in the care process.
References


Appendix A. List of Survey Questions Used in the Current Study

**Disease and Psychosocial Problem Type:**
For the following list of conditions, has a doctor or other health care provider ever told you that [CHILD'S NAME] had the condition, even if [he/she] does not have the condition now? If yes, does [CHILD'S NAME] currently have the condition?

- Depression (Internalizing)
- Anxiety problems (Internalizing)
- Behavioral or Conduct Problems (Externalizing)
- Asthma
- Diabetes
- Epilepsy or Seizure Disorder
- Migraine or Frequent Headaches
- Heart problem, including congenital heart disease
- Blood Problems, such as anemia or sickle cell disease
- Cystic Fibrosis
- Cerebral Palsy
- Muscular Dystrophy
- Arthritis or Other Joint Problems

**Reception of Care:**
During the past 12 months, was there any time when [CHILD’S NAME] needed mental health care?

- Did they receive all needed care?

**Communication:**

- How often did [CHILD’S NAME]’s doctors and other health care providers spend enough time with [him/her]?
- How often did [CHILD’S NAME]’s doctors and other health care providers listen
carefully to you?

• How often were [CHILD’S NAME]’s doctors and other health care providers sensitive to your family’s values and customs?
• How often did you get the specific information you needed from [CHILD’S NAME]’s doctors and other health care providers?
• How often did [CHILD’S NAME]’s doctors and other health care providers help you feel like a partner in [his/her] care?
• How often did [CHILD’S NAME]’s doctors or other health care providers discuss with you the range of options to consider for [his/her] health care or treatment?
• How often did they encourage you to ask questions or raise concerns?
• How often did they make it easy for you to ask questions or raise concerns?
• How often did they consider and respect what health care treatment choices you thought would work best for [CHILD’S NAME]?
• How often do [CHILD’S NAME]’s doctors or other health care providers encourage [him/her] responsibility for [his/her] health care needs?