

Diabetes Caregivers Needs Assessment Survey – Executive Summary

Conducted by

The Hormone Foundation

in collaboration with

The National Alliance for Caregiving



The program was supported by an educational grant from Eli Lilly and Company.

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PARTNERING ORGANIZATIONS



The Hormone Foundation (www.hormone.org)

Established in 1997, by The Endocrine Society as its non-profit public education affiliate, The Hormone Foundation serves as a resource for the public by promoting the prevention, treatment and cure of hormone-related conditions through outreach and education. Since its inception, the Foundation has reached over 350 million people with important health information on conditions such as diabetes, bone loss, menopause and thyroid disorders.



The National Alliance for Caregiving (www.caregiving.org)

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of 45 national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations. The Alliance conducts research, analyzes Federal policy, develops national programs to reach caregivers, works to increase public awareness of family caregiving issues, strengthens state and local caregiving coalitions, and represents the U.S. internationally. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.



The Endocrine Society (www.endo-society.org)

Founded in 1916, The Endocrine Society is the world's oldest, largest and most active organization devoted to research on hormones and the clinical practice of endocrinology. Today, The Endocrine Society's membership consists of more than 14,000 scientists, physicians, educators, nurses and students in more than 100 countries. Society members represent all basic, applied and clinical interests in endocrinology.

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INTRODUCTION AND BACKGROUND

In June 2007, The Hormone Foundation conducted an environmental scan of diabetes, aging and caregiving organizations and identified a gap in diabetes resources designed to meet the needs of caregivers of people with diabetes.

In 2008, The Hormone Foundation partnered with the National Alliance for Caregiving to implement a national study – three focus groups and a needs assessment survey – of informal (unpaid) caregivers of people with diabetes. The goals of the study were to identify critical issues that affect diabetes caregivers and to explore their diabetes-related information needs and resources, including both currently available sources and potential new ones.

Three focus groups were conducted in July 2008. Participants were recruited through several national caregiving organizations, including the National Alliance for Caregiving. The focus groups found that caregivers are providing key assistance to the people they care for such monitoring blood sugar, coordinating doctor visits, inspecting nails and feet, managing medications, preparing meals and other key functions in the management of diabetes.

The focus groups also found that diabetes caregivers are dealing with significant challenges. The key concern was the emotional impact on their loved ones and themselves, which often leads to anger and depression. Other challenges included compliance issues with diet and exercise, and finding it difficult to know what information about diabetes to believe.

The data from the focus groups was used to develop the national diabetes caregiver survey, which was implemented in April 2009. This report details what we have learned and, hopefully, provides information about opportunities to address the unmet needs of diabetes caregivers.

Overview of Methodology

Caregivers were recruited from the e-Rewards® Market Research Online Consumer Panel, which includes over two million members. Panel members are recruited from a diverse set of sources using a "by-invitation-only" approach. e-Rewards® uses a mix of both online methods (e.g., solo e-mail invitations and other targeted online modes) and offline methods (e.g., physical postcard invitations, direct mail inserts, etc.) to build a diverse panel that is geographically and demographically representative of the U.S. population. e-Rewards® Market Research has employed the same standardized member enrollment methods since 1999.

By using this approach, e-Rewards® has been able to control and manage the demographic make-up of their panel and invite only the types of individuals that fit the current normalization needs of the panel. This approach also reduces self-selection bias by recruiting those who ordinarily do not sign up for panels.

All panel establishment methodologies employed are fully compliant with CASRO (Council of American Survey Research Organization) guidelines.

After an individual responds to an invitation, he or she completes a 300+ item member profile, which collects information about demographics, interests, life events, health ailments, various product purchase intent data, and more.

A panel of 5,200 respondents was selected because they had already indicated that they provided care in some way. To qualify for the Diabetes Caregiver study, panel members were screened for the following:

- Currently provide unpaid care to a relative or friend 21+ years old to help take care of themselves
- Care recipient had to have diabetes
- Caregiver had to assist with least one ADL (bathing, dressing, etc.) or IADL (giving medicines, shopping, preparing meals, etc.)
- Caregiver had to say he/she provides some, most, or all of the recipient's diabetes care

Of those who attempted the survey, 19% qualified. This report is based on a survey of 1,002 caregivers of people with diabetes. Each caregiver completed a 20-minute online survey between April 6 and 20, 2009.

Study Limitations

Because the survey respondents were not drawn from a probability sample of all U.S. adults, estimates of sampling error are inappropriate. Additionally, because the sample is based on those who agreed to participate in the E-Rewards® panel, there may be some bias towards those who have ready access to and a comfort level using the Internet.

The respondents of the survey were 70% white, 6% Hispanic, 6% African American and 9% Asian American. Although we oversampled to broaden representation across ethnic and gender groups, generally speaking, minorities have less access to technology; therefore, the panel represents lower minority numbers. However, because a key objective of the study was an evaluation of online information sources, it was felt this was the most efficient way to reach the most likely users of such information.

GLOSSARY

Throughout this report, notable differences from overall results are given for certain subgroups, most of which do not require definition: caregiver's age, sex, race, education, household income, region of residence, employment status, relationship to care recipient, frequency of care visits, status as primary care provider or not, information-seeking (active or not); care recipient's age, number of medical conditions, main medical problem, history of requiring emergency care (yes or no). The following subgroups of caregivers, however, use terms that need definition in the context of this report.

Years caring for person with diabetes

- “Rookies”: Caregivers with 1 year or less caring for someone with diabetes. 12% in this survey were “rookies.”
- “Veterans”: Caregivers with 10 years or more caring for someone with diabetes. 11% in this survey were “veterans.”

Level of Caregiving Burden Index

- Measure of caregiving intensity scored from 1 (least burden) to 5 (highest burden).
- Based on the number and types of activities of daily living (ADLs; actions we normally perform for ourselves every day, such as feeding, bathing, dressing) and instrumental activities of daily living (IADLs; actions that allow us to live independently, such as housekeeping, preparing meals, taking medications, shopping, using the telephone) that the caregiver is responsible for, and the amount of time per week spent caring for the recipient.
- Level 1 caregivers perform no ADLs and devote relatively few hours per week providing care. Level 5 caregivers typically help with four ADLs and six IADLs and provide constant care.
- 17% of the diabetes caregivers were at burden level 1 and 17% were at burden level 5.

Diabetes Responsibility Index

- Measure based on whether diabetes is the care recipient's primary condition and on how much responsibility the caregiver has for diabetes care—“highest,” “higher,” “lower,” “lowest.”
- 10% of caregivers had highest diabetes responsibility (diabetes primary concern, provide all care).
- 32% had lowest diabetes responsibility (diabetes not primary concern, not responsible for all diabetes care).

KEY FINDINGS

NOTE: The key findings selected for inclusion in this list reflect two primary goals of the survey: to identify the challenges faced by diabetes caregivers and to explore their diabetes-related information needs and resources, including both currently available sources and potential new ones.

Profile of Diabetes Caregivers

- The 1,002 diabetes caregivers in this survey are mostly female (70%, 706 female vs. 296 male), white (77%), married (60%), and on average about 45.5 years of age.
- Most (59%) are caring for a parent who is on average about 70 years of age.
- 46% are living in the same household.
- 60% of diabetes caregivers have a college or graduate degree, and 64% are employed part- or full-time.
- 81% provide care more than once per week, and more than half (53%) have been providing care for 2-5 years.

Characteristics of the Caregiving Situation

- Nearly 9 in 10 caregivers reported some social and personal health sacrifices as a result of their caregiving. Demand on their time was the biggest concern. More than two thirds of the respondents said that they had less time for friends and other family members; 61% said they had to give up vacations, hobbies, or their own social activities; and over half reported less time for exercise.
- When asked how many hours per week they provided care, caregivers could respond “Less than 1 hour per week” or “I provide continuous round-the-clock care” (continuous care would amount to 168 hours per week) or they could give a specific number of hours. Calculated on the basis of these responses, the average amount of time spent on caregiving was 50.1 hours per week. Looking at the data another way, half of the respondents spent less than 20 hours per week and half spent more than 20 hours per week.
- Women were more likely than men to have their mental and physical health affected by the demands of caregiving: 39% of women versus 29% of men reported adverse effects on their personal mental health, and 35% of women versus 27% of men reported a negative impact on their physical health.
- Among the caregivers living in the same household with the care recipient, many more are non-spouses than spouses/partners (333 vs. 132). Compared with spouses/partners, non-spouses who live with the person in their care reported providing more different types of help and doing so more often. Typically, these non-spouses are caring for a parent and so are dealing with more health conditions and older-aged (by 12 years on

average) persons. Non-spouses living in the same household reported helping more with both ADLs and IADLs and considered themselves responsible for more of the diabetes-related care than did spouses. They reported a greater number of hours of care and were just as likely as spouses to say that they provided around the clock care.

- As expected, the number of hours per week spent providing care increased depending on the number of medical conditions present in the care recipient, the number of years providing care, the care recipient's age, and the share of the caregiving responsibility on the caregiver. The amount of time spent providing care was greater among caregivers with lower incomes than those with higher incomes.
- 90% of caregivers provide care at least 1-5 hours per week. As expected, the need for assistance increases with the age of the recipients, as well as with the number of co-morbidities present and the frequency of caregiver visits and share of diabetes care.
- A substantial proportion of caregivers assist with ADLs: getting in or out of beds/chairs (46%), getting dressed (43%), bathing or showering (38%), getting to/from the toilet (27%), dealing with incontinence (26%), feeding (26%); however, 34% said they helped with none of these.
- A greater percentage reported helping with IADLs: transportation (86%), grocery shopping (84%), housework (77%), managing finances (75%), preparing meals (71%), giving medicines, pills, or injections (68%), performing fingerstick to test blood glucose (48%), arranging or supervising services from an agency, such as nurses or aides (40%).

Scope of Diabetes Caregiving

- Caregivers have a wide range of diabetes-related responsibilities. 20% reported responsibility for "all" of the diabetes care, while 29% said "some."
- 92% reported dealing with conditions in addition to diabetes; 58% reported 4 or more conditions, with high blood pressure, arthritis, heart disease, and Alzheimer's/dementia leading the list.
- The survey defined four levels of diabetes care responsibility. *Highest* means diabetes is the primary condition and the caregiver provides all diabetes care; *higher*—diabetes is the primary condition but the caregiver does not provide all diabetes care; *lower*—diabetes is not the primary condition but the caregiver does provide all diabetes care; *lowest*—diabetes is not the primary condition and the caregiver does not provide all diabetes care. Alzheimer's disease and heart-related disease were the conditions most often listed as primary when diabetes was not.
- Across the four groups, caregivers were dealing with, on average, more than three conditions, and a large majority were assisting with multiple ADLs (averaging 1.6 to 3.4 out of 6) and IADLs (averaging 5.1 to 6.8 out of 8).

- For those with *highest* responsibility, 78% lived in the same household as the care recipient, whereas only 39% of those with *lowest* responsibility did so.
- Among caregivers with *highest* responsibility, 66% reported dealing with insulin, as compared with 38%, 36%, and 25% in the other three groups.
- 80% in the *highest* responsibility group reported dealing with diabetes complications, but a large percentage in each of the other groups did too: 71%, 65%, and 70%.
- A substantial percentage in each group reported that their care recipient had ever been hospitalized for a diabetes-related reason: 51%, 46%, 39%, and 35%.

Diabetes Caregiving Challenges

- Caregivers are faced with many different challenges. Diet-related difficulties (cooking, meal planning, and non-compliance) were mentioned slightly more often than providing other medical care.
- Caregivers reported great difficulty in managing diabetes in addition to other medical problems, with the difficulty rising along with the number of conditions.
- 49% of caregivers listed aspects of the medical management of diabetes as their biggest challenge, including monitoring sugar levels, controlling HbA1c, managing medications, and medical compliance issues.
- Two thirds of those whose care recipient takes insulin were responsible for ensuring proper doses.
- More than half of those whose care recipient takes oral medication portioned out the doses.
- 71% said they were dealing with at least one of the more serious complications of diabetes, such as mobility, heart-related problems, vision loss, wound care, hypoglycemia, kidney disease, loss of limb, and neuropathy, among others.

Self-reported Diabetes Knowledge and Information Resources

- 69% rated themselves “informed” about diabetes and its potential complications. However, when asked how informed they were when they first began dealing with the diabetes of the person under their care, only 25% called themselves informed.
- The survey divided respondents into two groups—rookies and veterans—depending on the number of years spent providing diabetes care. 12% were rookies with one year or less; 11% were veterans with 10 years or more. As expected, veterans were more likely and rookies less likely to rate themselves as “informed” about diabetes and its potential complications.

- Both rookies and veterans listed potentially valuable tools and information sources in the same order of preference, although the percentages differed between rookies and veterans: cooking/exercise tips (68% vs. 59%), food shopping checklist (60% vs. 44%), calendars/diaries for tracking medical information (46% vs. 40%), local resources (46% vs. 38%). When asked what tools would be valuable in their diabetes care, both rookies and veterans (63% of each group) named information you can read online or print out.
- Diet and exercise are topics about which many caregivers sought information. However, 25% of caregivers overall, and 35% of “veterans,” reported that there are no areas where they need more information.
- The physician is the top information source for caregivers, especially among older caregivers and those with lower diabetes responsibilities. The Internet is the second highest source of information (especially among younger caregivers, active information seekers, and those with highest diabetes responsibilities).
- 73% use the Internet for diabetes information. Those with the highest diabetes responsibilities and who are more Internet savvy (younger, college educated) are even more likely. 18% used to, but no longer search the Internet for diabetes information.
- WebMD and the American Diabetes Association (ADA) websites were the two most popular current sources. A significant number of caregivers also cited search engines.
- The biggest frustration in using the Web is not the amount of information, but deciding on the quality of it—63% cited trying to sort good information from bad. Those who no longer (or never did) search for information were more likely to be overwhelmed by too many websites.
- Caregivers said they want a website that’s easy to use and has tools that will be relevant to them. Information is the main reason they go to a website, and they want it to be thorough and up-to-date. Potential users recommended avoiding commercial messages on the site and monitoring the content.

Specific Diabetes Knowledge

- On a five-question diabetes knowledge quiz, 61% of caregivers had 4 or 5 correct answers and 39% had 3 or fewer. This grouping allowed analysis of caregivers most in need of diabetes information. The quiz revealed that across both groups many diabetes caregivers are unsure about the ADA-recommended HbA1c goal.

DETAILED FINDINGS

Diabetes caregivers are a part of larger community of caregivers who care for family and friends each day. Based on a 2004 survey of caregivers, the National Alliance for Caregiving estimates that there were 3.5 million caregivers of people with diabetes in the United States. Six years later, given the growing elderly population and increased rate of diabetes, this number is likely to be higher.

On average, caregivers of people with diabetes spend between 10.5 and 14 hours providing care each week. The more medications and complications involved in the care of a loved one, the higher the burden on the caregiver. Below are the detailed findings of the 2009 Diabetes Caregiver Survey.

General Caregiving Scope and Challenges

Characteristics of the Caregiving Situation

General Questions

Caregivers were asked general questions about the person they cared for, their relation, housing arrangements, and frequency of care visits.

- Age of care recipient (*Q8*)
 - 22-59 years—21%
 - 60-69 years—22%
 - 70-79 years—25%
 - 80 years and older—32%
- Relation of caregiver to care recipient (*Q9*)
 - 58% were looking after a parent or parent-in-law
 - 14% were caring for a spouse or partner
 - 28% were caring for someone other than a parent/parent-in-law or a spouse/partner.
- Living arrangements of care recipients (*Q11*)
 - 46% live in the same household as the caregiver
 - 37% live in a private home other than the caregiver's
 - 17% live in a care facility
- Frequency of care visits (*Q12*)
 - 81% of caregivers who don't live in the same home as the care recipient visited more than once a week.
 - 10% said they visited "about once a week"
 - 4% said "a few times a month"
 - The other 5% indicated monthly or less frequent visits.

Caregiver Challenges

Activities of Daily Living

Caregivers were asked about which activities of daily living (ADLs) they helped with (Q4, Figures 1 and 2). Their responses showed that:

- The need for ADL assistance increased with the age of the recipients.
- An increase was also associated with the number of medical conditions, the frequency of caregiver visits, and the claimed share of diabetes care.
- More men than women caregivers indicated helping with ADLs.

Figure 1. ADLs assisted with.

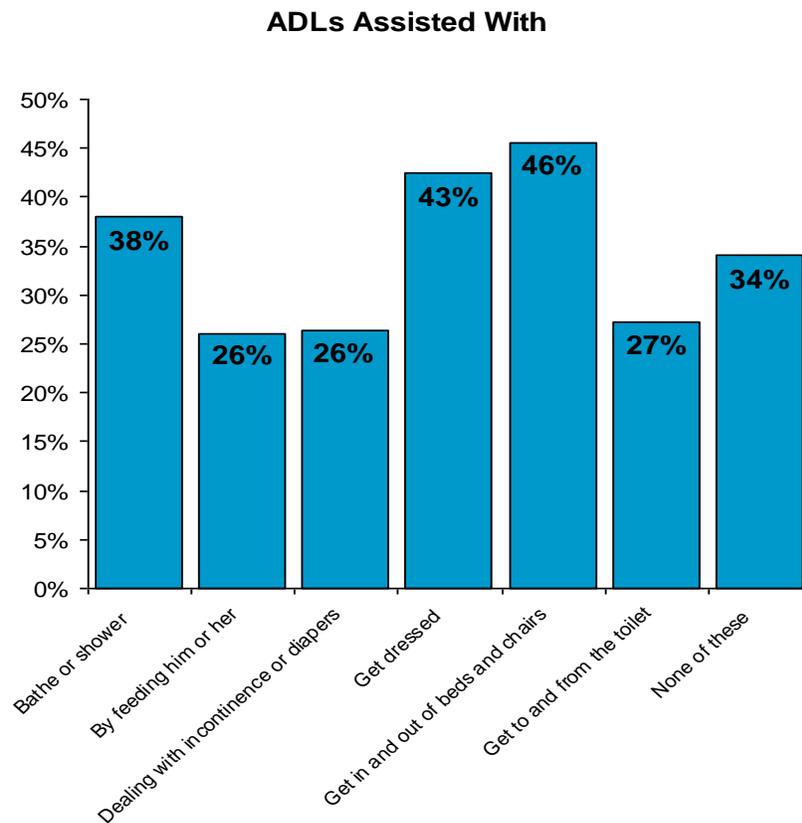
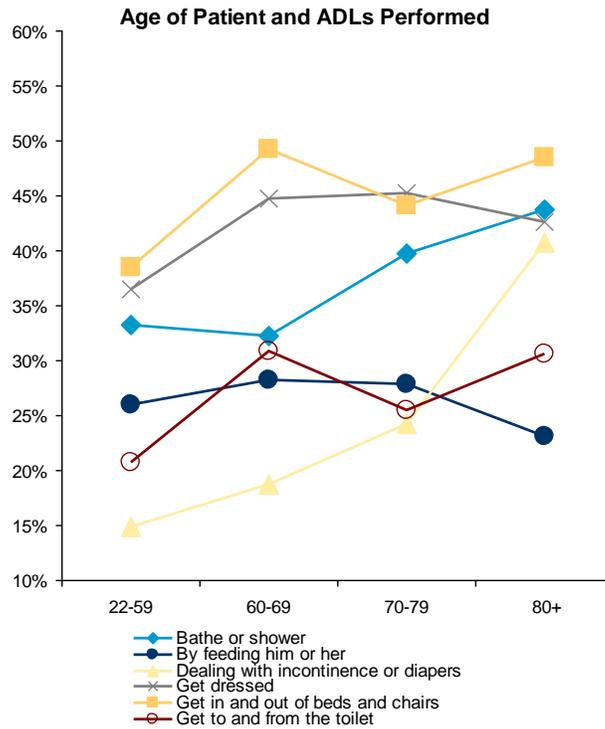


Figure 2. Age of patient and ADLs performed.

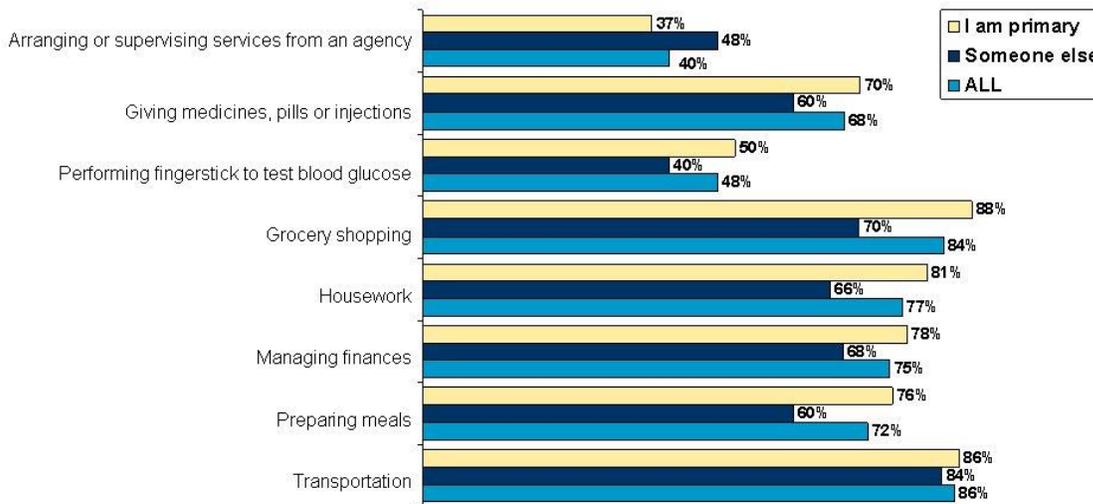


Instrumental Activities of Daily Living

Caregivers were also asked about which instrumental activities of daily living (IADLs) they helped with (*Q5, Figure 3*).

- Caregivers were most involved with grocery shopping and transportation.
- The number of IADLs assisted with increased with the number of medical conditions, frequency of visits, and claimed share of diabetes care.
- When someone else (paid or unpaid) provided most of the care, the respondent was more likely to arrange or supervise outside care, but the primary care provider was more likely to do the other IADLs.

Figure 3. IADLs assisted with.

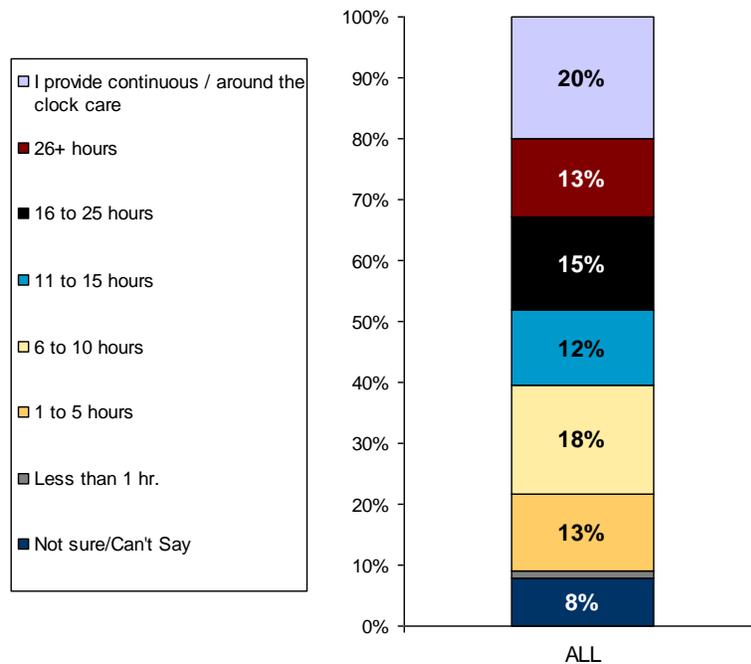


Time Spent on Caregiving

Caregivers were asked to think about all the things they do to help a care recipient and then to estimate the number of hours per week that they spend on those tasks (*Q7, Figure 4*).

- The number of hours devoted to caregiving increased with the
 - number of medical conditions
 - number of years providing care
 - caregiver's age
 - share of diabetes care
- More time is spent providing care in lower than in higher income households.
 - More than half of those in households earning under \$30,000 provide 26 or more hours per week.
 - Half of those in households earning over \$100,000 provide 10 or fewer hours per week.

Figure 4: Hours per week devoted to caregiving.



Impact of Caregiving on Caregivers

Caregivers were asked about specific ways in which providing care had affected their lives (Q20).

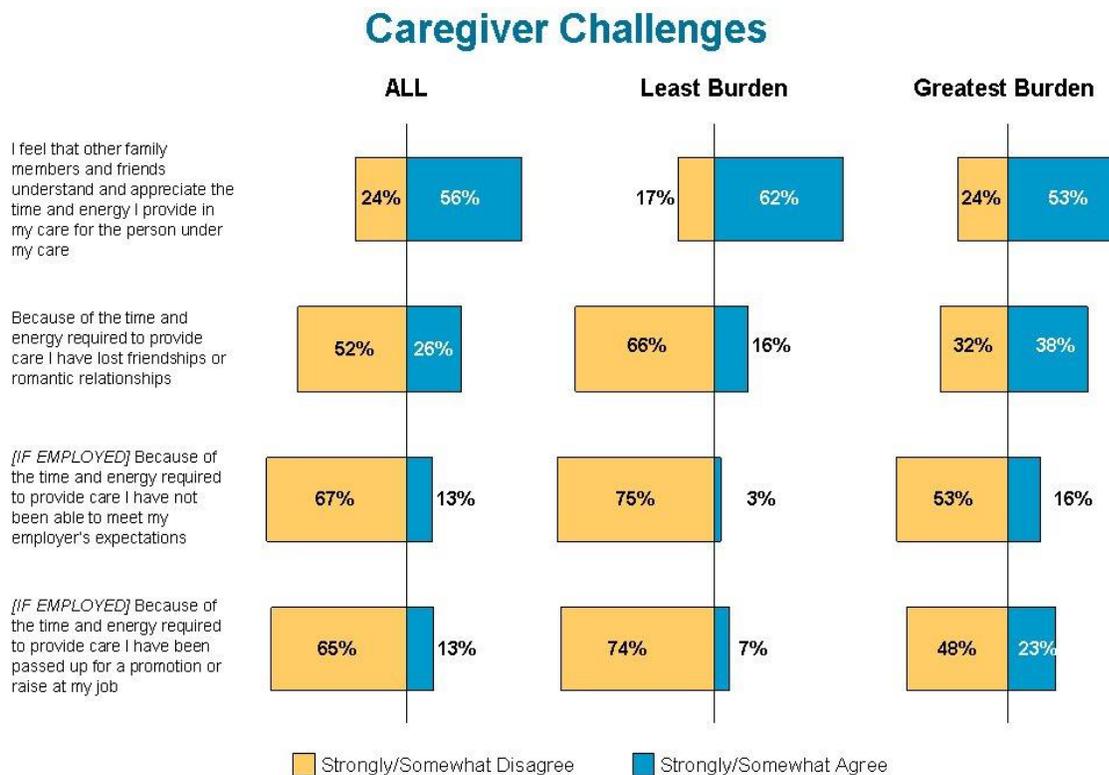
- Overall, nearly 9 in 10 caregivers reported social and personal health sacrifices as a result of their caregiving.
 - 68% said they had less time for friends or other family members than before.
 - 61% said they had to give up vacations, hobbies, or their own social activities.
 - 53% said they had less time for exercise.
 - 36% reported worse mental health.
 - 39% of females
 - 29% of males
 - 33% reported worse physical health.
 - 35% of females
 - 27% of males
 - Only 12% said they had experienced none of these sacrifices.
- Mentions of sacrifices increased with the
 - number of conditions
 - level of burden
 - age of the care recipient
 - frequency of visits
 - share of diabetes care

Caregivers were also asked how much they agreed or disagreed with four statements related to their feelings of appreciation and to the social and professional consequences of their caregiving responsibilities (Q19, Figure 5).

- Most agreed that they were appreciated for their caregiving.

- Most disagreed that they had lost friendships or suffered a negative impact on employment or career opportunities.
- Levels of agreement/disagreement differed between those with the least and those with the greatest caregiving burden.

Figure 5. Appreciation for and consequences of one’s caregiving, as perceived by caregivers overall and by those with “least” and those with “greatest” burden of responsibility.



Who Could Be Doing More

Caregivers were asked how much they agreed or disagreed with the following statements: *Others could be doing much more than they are* and *I could be doing much more than I am* (Q17).

- 47% agreed that others could be doing much more than they are, and that percentage rose as the number of conditions and overall burden increased.
- Caregiver “rookies” were more likely to say that others could be doing more.
- Only 18% agreed that they themselves could be doing much more.
- Those who thought they could be doing more tended to be employed full time, not provide the majority of the care, be caring for a parent or other loved one, and be men.

Scope of Diabetes Caregiving

Diabetes and Other Conditions

Reported Medical Conditions

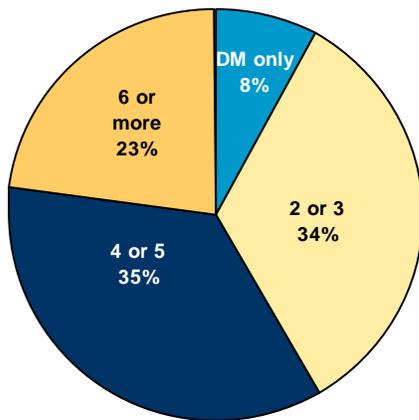
Caregivers were given a list of medical conditions and asked to check all those that the person in their care had (Q2, Table 1 and Figure 6).

- 92% of diabetes caregivers reported that the person being cared for had medical conditions in addition to diabetes.
- 58% reported four or more conditions.

Table 1. Medical conditions in care recipients

Medical condition	% Reporting
Diabetes	100
High blood pressure	59
Arthritis	43
Heart disease	38
Alzheimer's/dementia	30
Deafness/hearing loss	20
Blindness/low vision	19
Mental/emotional illness	17
Stroke	16
Kidney disease	14
Osteoporosis	13
Lung disease	12
Cancer	11
Amputee	4
Parkinson's	4
Mental retardation	2
AIDS	1
Other	10

Figure 6. Number of medical conditions the diabetes (DM) care recipient has.



Main Problem

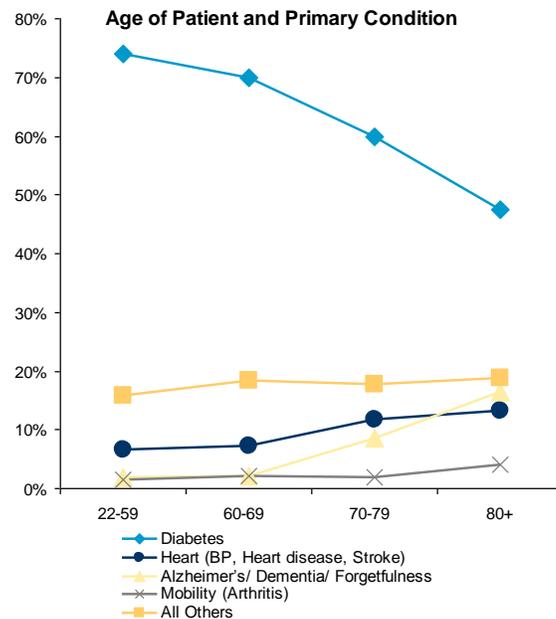
Caregivers were asked to name the main problem of the person in their care (Q3, Table 2).

- The care recipient’s age affected whether the caregiver named diabetes as the main problem. Specifically, more than 70% of caregivers of persons aged 22-59 named diabetes as the person’s main health problem, in contrast to about 60% of those caring for persons aged 70-79 and about 50% of those caring for persons aged 80 or older (Figure 7).
- Cardiovascular disease and dementia became the main problem in some elderly (age groups 60-69, 70-79, and 80+ years) care recipients.

Table 2. Care recipient’s main health problem

Main problem	% Reporting
Diabetes	61
Cardiac/vascular conditions	10
Alzheimer’s/dementia/forgetfulness	8
Mobility (arthritis)	3
All others	18

Figure 7. Age of patient and primary condition.



Diabetes Care Responsibility

Levels of Diabetes Care Responsibility

The survey defined four levels of diabetes care responsibility as follows:

Highest—Diabetes **is** the primary condition and the caregiver provides **all** diabetes care.

Higher—Diabetes **is** the primary condition, but the caregiver does **not** provide all diabetes care.

Lower—Diabetes **is not** the primary condition, but the caregiver provides **all** diabetes care.

Lowest—Diabetes **is not** the primary condition, and the caregiver does **not** provide all diabetes care.

Among the caregivers responding to the survey, their level of responsibility was associated with some clear differences in terms of the tasks they performed and the persons they cared for, as summarized in Table 3.

Table 3. Differences in caregiving duties and recipients, by level of caregiver responsibility

	Highest Responsibility (10% of caregivers)	Higher Responsibility (51% of caregivers)	Lower Responsibility (7% of caregivers)	Lowest Responsibility (32% of caregivers)
Primary condition	Diabetes	Diabetes	Other condition: 31% Alzheimer's, 21% heart-related	Other condition: 27% heart-related, 19% Alzheimer's
Diabetes responsibility	All	Most/some	All	Most/some
Average # of conditions recipient has	4.7	3.6	4.7	4.7
ADLs assisted with (avg. #)	3.4 out of 6 (19% none)	1.6 out of 6 (44% none)	2.8 out of 6 (21% none)	2.3 out of 6 (26% none)
IADLs assisted with (avg. #)	6.6 out of 8	5.1 out of 8	6.8 out of 8	5.4 out of 8
Hours per week of care	43% in this group provide continuous care, 42% provide 16+ hr per wk	13% continuous, 27% 16+	50% continuous, 30% 16+	18% continuous, 26% 16+
Care recipient age (avg.)	67 years old	68 years old	72 years old	75 years old
Care recipient relationship	23% spouse, 47% parent	13% spouse, 59% parent	22% spouse, 51% parent	10% spouse, 63% parent
Care recipient location	78% same HH, 16% other home, 7% facility	41% same HH, 29% other home, 17% facility	71% same HH, 21% other home, 8% facility	39% same HH, 42% other home, 19% facility
Years caring for person	13% Rookie, 15% Veteran	11% Rookie, 11% Veteran	13% Rookie, 14% Veteran	14% Rookie, 10% Veteran
Caregiver employed	57% full-time	56% full-time	32% full-time	53% full-time
Caregiver dealing with insulin	66%	38%	36%	25%
Caregiver dealing with diabetes complications	80% some complication	71% some complication	65% some complication	70% some complication
Recipient ever hospitalized for diabetes-related reason	51%	46%	39%	35%
Caregiver age (avg.)	44 years old	44 years old	50 years old	47 years old
Caregiver gender	71% female	70% female	74% female	70% female

ADLs, activities of daily living (e.g., walking, dressing, eating, bathing); IADL, instrumental activities of daily living (e.g., driving, preparing meals, managing medications, using the telephone); HH, household; Rookie = diabetes caregiver with no more than 1 year’s experience; Veteran = diabetes caregiver with more than 10 years’ experience.

Scope of Caregiving

Caregivers were asked several questions about how long they had provided diabetes care for the recipient, how much of his/her care fell to them, and who provides most of the care (*Q13, Q6, Q 16*).

- 75% said they were the person who provides most of the care.
- 25% said another person (either paid or unpaid) provides most of the care.
- 20% reported responsibility for **all** of the diabetes care (Figure 8). For those providing **all** care, they are more likely to
 - care for a spouse/partner
 - deal with Alzheimer’s as a primary concern
 - have care recipients with 6 or more medical conditions
 - have the highest level of diabetes responsibility
 - live in the same household as the care recipient
 - have a household income under \$50,000
 - have a high school (or less) education
 - tend to care recipients aged 22-59 years
- Equal numbers of caregivers are either very new (less than 2 years) or very experienced (more than 11 years) in their caregiving.
- The majority (52%) have been caregivers for 2 to 5 years (Figure 9).

Figure 8. Portion of diabetes-related care that falls to the caregiver.

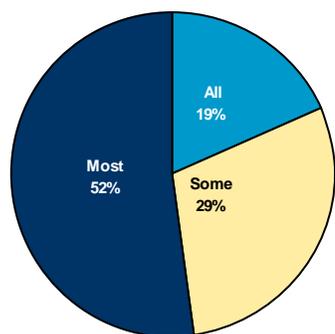
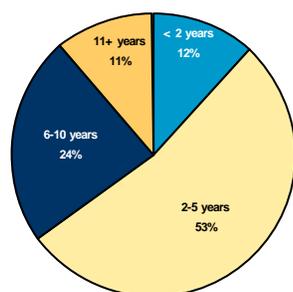


Figure 9. Length of time providing care.

Length of time providing care



Diabetes Caregiving Challenges

Issues and Challenges

Caregivers were asked to list the biggest issues and challenges they face in caring for someone with diabetes (Q21).

- Nearly half (49%) listed aspects of the medical management of diabetes as their biggest challenges, including:
 - Monitoring sugar levels
 - Controlling HbA1c
 - Managing medications
 - Medication compliance issues
 - Medical noncompliance
- More than half (54%) struggle with diet-related issues, including:
 - Eating right
 - Cooking and meal planning
 - Diet noncompliance
 - Exercise
 - Avoiding sweets/carbohydrates/bad foods
- Other issues and challenges were:
 - Patient interactions
 - Caregiver concerns (stress, mental/emotional health)
 - Disease-related complications

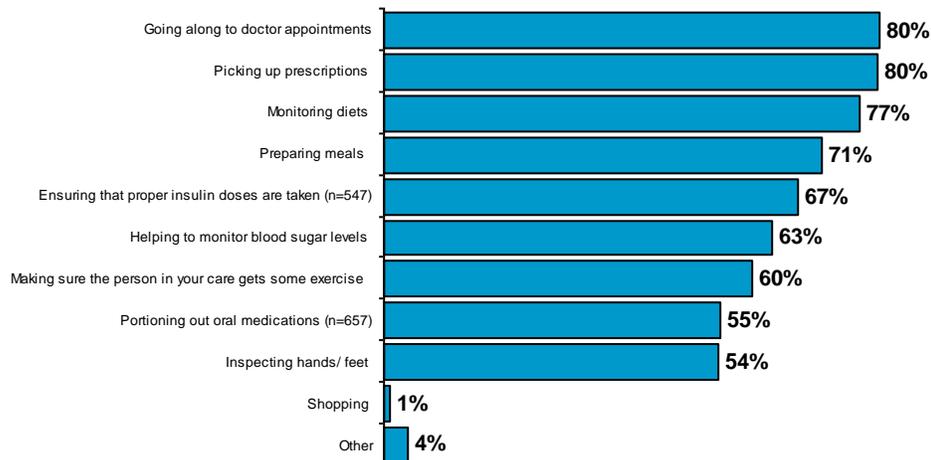
Specifics of Diabetes Care

Tasks

Caregivers were asked which areas of diabetes care they were personally involved in (Q23, Figure 10). Their responses show that they are responsible for many tasks:

- Medical appointments and prescriptions topped the list, along with monitoring diets and preparing meals.
- Two-thirds of those whose care recipient takes insulin were responsible for ensuring proper doses.
- More than half of those whose care recipient takes oral medication portioned out the doses.

Figure 10. Percentage of caregivers responsible for specific tasks.



Insulin and Other Medications

When asked which prescription medicines were taken by the person under their care (Q22), oral medication and insulin headed the list:

Pill(s)/oral med(s)	66%
Insulin	51%
Insulin pump	5%
Other injectable med	3%
Other/not sure	1%
Does not take med	4%

Caregivers of persons who need to take insulin face special challenges as they deal with more advanced diabetes and its complications:

- 69% have to ensure that proper insulin doses are taken.
- The persons under their care are more likely to be going to an endocrinologist.
- Insulin-taking patients are more likely to have other conditions, such as heart and kidney disease and blindness, and their caregivers are more likely to be assisting with diabetes complications like hypoglycemia, loss of vision, kidney disease, and related heart problems.
- 54% have had to bring the person under their care to the hospital for a diabetes-related problem (as compared with 30% of caregivers of diabetics not taking insulin).
- Patients under their care are much more likely to be frustrated and overwhelmed by their condition.
- As their biggest concern, these caregivers are more likely to mention administering medications as the top challenge, and less likely to mention diet issues. A majority struggle with maintaining consistent target blood sugar levels.
- However, these caregivers tend to feel more informed and more actively seek out information. They would like to see information related to complications and dealing with medical emergencies.

Complications

Caregivers were asked if they were assisting with care related to any of the more serious complications of diabetes (Q24).

- Overall, 71% said they were.
- Many caregivers selected more than one complication from the list provided:
 - Mobility 39%
 - Related heart problems 30%
 - Loss of vision 27%
 - Wound care 23%
 - Hypoglycemia 16%
 - Kidney disease 16%
 - Loss of limb 6%
 - Neuropathy 1%
 - Other 2%
- 29% they were dealing with “none” of the complications listed.
- Caregivers were more likely to respond “none of these” if:
 - They were caring for someone with no medical condition other than diabetes.

- They were caring for someone with Alzheimer’s as the primary condition.
- They were caregiving “rookies.”
- They had lower diabetes responsibility.
- Their care recipient was younger than age 60.

Significant Issues for Diabetes Care Recipients

Responding to a list of statements, caregivers indicated how big an issue each of them was for their care recipient (Q25).

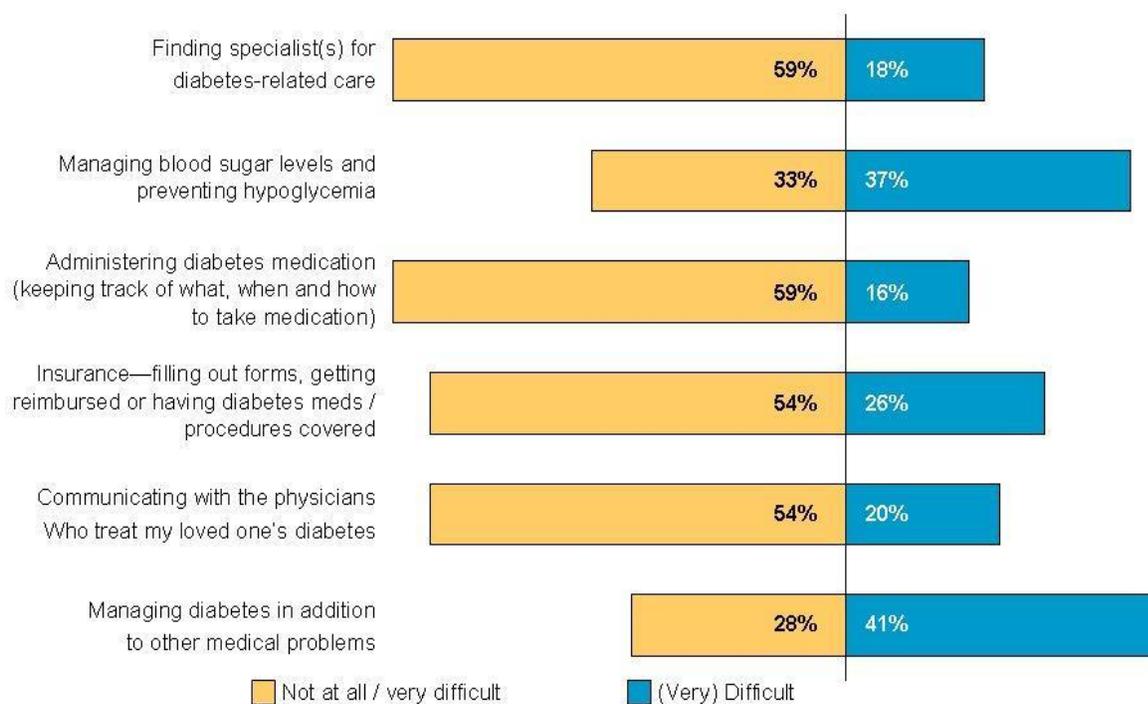
- Exercise and diet compliance were two “very significant” issues identified by at least half of the caregivers.
- Other issues said to be “very significant” for care recipients were depression, maintaining target sugar levels, and memory loss/confusion/Alzheimer’s disease.

Managing Diabetes Care

Caregivers indicated how difficult or challenging specific tasks were for them (Q26, Figure 11).

- Caregivers reported great difficulty in managing diabetes in addition to other medical problems, with the degree of difficulty growing as the number of medical conditions increased.
- Managing blood sugar levels is another area of difficulty for caregivers.
- Finding diabetes specialists and administering medications are far less difficult for caregivers, although both are more difficult for older caregivers than for younger ones.

Figure 11. Difficulty in managing specific caregiving tasks.

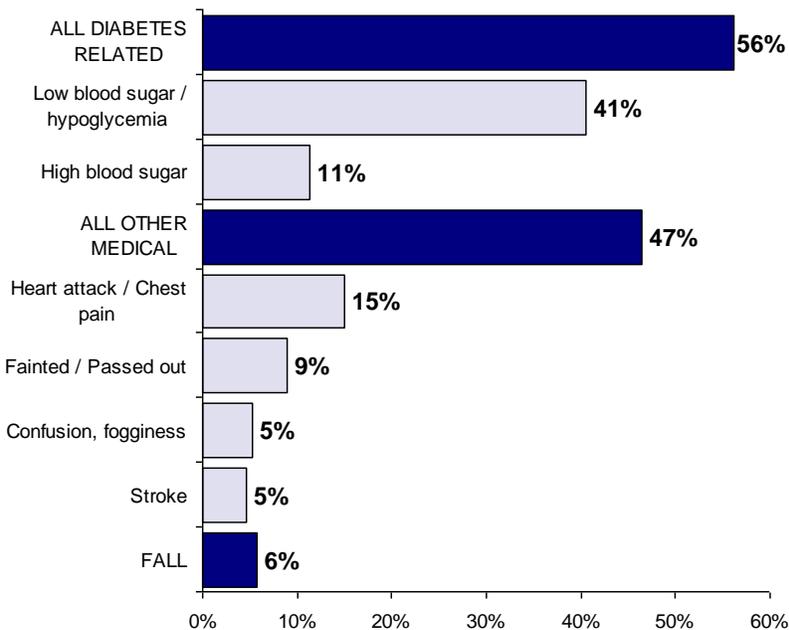


Dealing with Emergencies

Caregivers were asked whether they had ever had to deal with a diabetes-related emergency and, if so, what was the reason for rushing their care recipient to the hospital or calling an ambulance (*Q26NEW, Figure 12*).

- Caregivers with a longer time providing care, increased responsibility for diabetes care, and older persons under their care were more likely to have had to deal with an emergency.
- 42% of caregivers had to rush the person they care for to the hospital or call an ambulance because of a diabetes complication, such as dangerously low blood sugar or heart attack.
- More than half reported a blood sugar-related emergency, but other medical problems were also frequently mentioned.
- Falls were mentioned more often among caregivers of older patients.

Figure 12. Reasons for seeking emergency treatment.



Self-reported Diabetes Knowledge and Information Resources

Caregivers' Self-Assessment

Level of Diabetes Knowledge

Diabetes caregivers were asked to rate their knowledge about diabetes and its potential complications on a scale of 1 (“not at all informed”) to 5 (“completely informed”) (*Q27*). They were also asked how informed about diabetes they were when they started as diabetes caregivers (*Q29*).

- 69% rated themselves informed about diabetes and its potential complications.
- Caregivers were more likely to feel informed if they had high diabetes responsibility, were “veterans,” and cared for persons aged 55-65.
- They were less likely to feel informed if they had low diabetes responsibility, were “rookies,” and cared for persons aged 55 or younger.
- Only 26% said they were informed when they first began dealing with the diabetes of the person in their care.
- 48% of the most informed (those who gave themselves a 4 or 5 rating) said they were not informed starting out (gave themselves a 1 or 2).

Diabetes Information-Seeking Style

Caregivers were asked which of the following statements “best describes you today” (Q29A):

__I actively search out information about caring for someone with diabetes.

__If I see or hear something of interest related to caring for someone with diabetes, I read it or listen to it, but I don’t search it out.

__I am too busy or not interested in finding more information about caring for someone with diabetes.

Respondents were divided between those who actively seek information (54%) and those who wait for it to come to them (45%):

- Information seekers: Diabetes only or main problem, highest diabetes responsibility, care recipient under 70 years of age, spouse, see more frequently, employed, educated, women
- Wait for information: Other conditions (especially Alzheimer’s) are the primary concern, lower diabetes responsibility, care recipient older than 80 years, parent/other relationship, see less frequently, someone else primary caregiver, less educated
- There was no relationship between number of years caring for a person and whether the caregiver was an information seeker or not.

Diabetes Care Information Needs

Caregivers were asked to name areas where they need more information (Q28). More than anything else, caregivers are seeking information about diet and exercise.

- 26% of caregivers overall and 58% of those dealing with mobility problems said they need more information about diet and exercise.
- 25% of caregivers overall and 35% of “veterans” said there were no areas where they need more information.

In a separate question, respondents were given a list of 11 topics related to caring for someone with diabetes and asked how useful it would be to get additional information on each of those topics (Q30). For 10 of those 11, more respondents said such information would be *useful or very useful* than said it would be *not at all or not very useful*:

- Dealing with medical emergencies (e.g., hypoglycemia): 54% vs. 21%
- Preventing or dealing with the chronic complications of diabetes: 68% vs. 10%
- Managing limited mobility, both in public and at home: 44% vs. 31%
- Managing diabetes diet and nutrition, including monitoring, tracking, and testing blood sugar levels: 62% vs. 14%

- Administering, scheduling, and dosing insulin and other diabetes medications: 34% vs. 39%
- Helping with the emotional health of the person you care for: 61% vs. 16%
- Focusing on and maintaining your own physical and emotional health as a caregiver: 57% vs. 18%
- Finding caregiver support: 43% vs. 33%
- New developments in diabetes treatment: 76% vs. 7%
- Research into causes and cures for diabetes: 57% vs. 17%
- Dealing with diabetes alongside other chronic conditions: 64% vs. 13%

In response to a related question, more than two thirds said that information about the following complications would be useful to them:

- Heart disease 78%
- High blood pressure 78%
- Nerve pain in the limbs 74%
- Vision loss or blindness 72%
- Hypoglycemia 69%
- Kidney disease 68%
- Wound care 67%

Less than half (46%) said that information about amputations would be useful.

The Internet and Other Information Sources

Diabetes Care Information Sources

Caregivers were asked how much information about diabetes—*a lot, some, not much, or none*—they get from various sources (Q32). They were also asked to name their top three sources (Q34).

- Physicians
 - 55% of caregivers ranked physicians as their top source of information
 - 89% said they get *a lot* or *some* of their information from physicians.
 - Characteristics of caregivers most likely to name physicians as their top choice were “veterans,” male, in same household, care recipient aged 60-69, doesn’t search for information, care recipient is parent.
- Internet
 - 14% ranked the Internet as the top source.
 - 69% said they get *a lot* or *some* of their information from the Internet.
 - Several different subgroups of caregivers were most likely to name the Internet as their top choice: those whose care recipient was aged 22-59, “rookies,” those caring for persons with diabetes as their only condition, those who actively search for information, those whose care recipient is a spouse/partner, and caregivers aged 18-45.
- Other choices were much less often named as a top source of information: diabetes educator (8%), family or friends (7%), nurse or medical assistant (6%), newsletters or magazines about diabetes/caregiving (5%); an even smaller percentage named pharmacist, case manager/social worker, or “other.”

- Support groups were used more by those with highest diabetes responsibility.
- Use of diabetes educators was lowest in households with lower education, lower income, and oldest care recipients.

If caregivers said they use a physician for information *a lot* or *some*, they were asked which type of physician is their main source (Q33).

- 69% named primary care physicians. Characteristics of those most likely to name PCPs:
 - Household income under \$30,000
 - Lower or lowest diabetes responsibilities
 - Hispanic or Asian ethnicity
 - Caregiver's educational level less than a college degree
 - No diabetes-related hospitalization of care recipient
 - Doesn't search out information
 - Care recipient is parent
- 26% named endocrinologists. Subgroups most likely to name endocrinologists:
 - Care "veterans"
 - Diabetes primary condition
 - Diabetes only condition
 - Care recipient aged 22-59 years
 - Household income over \$100,000
 - Diabetes-related hospitalization of care recipient
 - Highest diabetes responsibilities
 - Actively searches for information
- 5% named other types of physicians.

Using the Internet for Diabetes Information

Caregivers were asked about their use of the Internet for diabetes information (Q31).

- Overall, 73% said they use it now, but several subgroups of caregivers were even more likely users, including those who:
 - actively search for information on the Internet, or
 - are younger (18-45) and have at least a college education, or
 - have the highest diabetes responsibilities, or
 - are care "veterans," or
 - are caring for a spouse, or
 - have a care recipient with more than 6 conditions
- 18% used to use it, but no longer do so. These caregivers are more likely to be in the subgroup that:
 - does not seek out information or
 - has no more than some college-level education
- 9% have never used the Internet. These caregivers are more likely to be in the subgroup that:
 - does not seek out information, or
 - has no more than a high school education, or
 - is aged 46-55, or
 - has the lowest diabetes responsibilities

Website Use

Those who said they used the Internet *some* or *a lot* were asked to name the three websites that they consult most often for information about diabetes, its potential complications, and all that is needed for diabetes caregiving (Q35).

1. WebMD was named by 56%. Caregivers listing this website were more likely to:
 - be “rookies” and to have lower diabetes responsibilities
 - have a household income under \$30,000
 - say a physician is their top source of information
 - be aged 46-55
2. American Diabetes Association (diabetes.org) was named by 38%. Caregivers listing this website were more likely to:
 - be “rookies” and have the least caregiving burden
 - caring for persons with diabetes as the primary condition
 - be college educated
3. Google/Yahoo/AOL/other search engines was named by 21%. Caregivers listing this website were more likely to:
 - be male
 - be aged 46-55
 - have at least a college education

Much smaller percentages of caregivers listed the Mayo Clinic website (9%), diabetes.com (8%), National Institutes of Health (6%), among others that received even fewer mentions.

Biggest Internet Frustrations

Caregivers were asked to name their biggest frustrations in using the Internet to find help with their caregiving (Q36).

- Trying to sort good information from bad was the biggest frustration for 63%.
- Wading through commercial content was a frustration for 49%.
- Being overwhelmed by too many websites or search results was a frustration for 37%, but more so for those who do not actively (or no longer) search for information.
- Having difficulty finding information specific to the caregiver’s needs was named by 33%.
- Poor quality information on the Internet was a frustration for 12%, and a lack of searching skills was the biggest concern for 10%.
- 14% reported no frustrations.

Potential New Resources for Caregivers

Valuable Tools and Information Sources

Caregivers were given a list of tools and information sources and asked to mark those that would be valuable to them in their diabetes care (Q37):

- 64% selected “Tips for cooking and exercising.”
- 53% selected “Food shopping checklists.”

- 45% selected “Calendars/diaries for tracking medication, appointments, and other medical information.”
- 44% selected “Tips for communicating with health care professionals.”
- 43% selected “Local resources, including clinic information, respite care, and supplies.”
- 31% selected “Tips for communicating with your care recipient.”
- 28% selected “Local events, including seminars and support groups.”
- 23% selected “Opportunities to connect with other caregivers.”
- 2% selected “Other.”
- 7% selected “None of these.”

Besides tools and information sources, caregivers were asked which **online** tools would be valuable (Q38):

- 65% picked “Information you can read online or print on a printer.”
- 53% picked “Periodic e-mail alerts about new developments in diabetes care.”
- 43% picked “Links to caregiving resources.”
- 36% picked “Personalized tools like calendars or calculators that you log in to access.”
- 31% picked “Online journals or blogs written by other caregivers that you can read or submit comments to.”
- 30% picked “Educational videos you can watch or listen to on your computer or portable video player (e.g., video clips like on YouTube).”
- 22% picked “Message boards or chat rooms where you can participate in an online discussion with other diabetes caregivers and experts.”
- 14% picked “Radio programs that you can listen to on your computer or portable audio player (e.g., podcasts).”
- 9% picked “None of these.”

Interest in New Website

Caregivers were asked to imagine a website that included the following:

- Information you can read online or print on a printer
- Message boards or chat rooms where you can participate in an online discussion with other diabetes caregivers and experts
- Online journals or blogs written by other caregivers that you can read or submit comments to
- Personalized tools like calendars or calculators that you log in to access
- Radio programs that you can listen to on your computer or portable audio player (e.g., podcasts)
- Educational videos you can watch or listen to on your computer or portable video player (e.g., video clips like on YouTube)
- Links to caregiving resources

Then they were asked about the likelihood of their regularly visiting such a site and why they would or wouldn't (Q39, 39B).

- Caregivers were largely positive about a new website.
 - 38% “Very likely” to visit
 - 34% “Likely” to visit
- Those with the highest diabetes responsibilities were the most interested.

- Those positive about the site described it as a central location, a “one-stop shop,” and said it would be useful or helpful to them.
- The single biggest reason for a negative mention was lack of time. Only 3% said that they don’t need more information.

Caregiver Advice for a Website

Caregivers were asked what advice they would give to an organization interested in developing a website that would be most helpful to caregivers of people with diabetes (Q40).

- Ease of use and relevant tools led the list of recommendations.
- The health of the caregiver, as well as the care recipient, should be included.
- Thorough and up-to-date information is essential.
- Avoiding commercial messages on the site and monitoring the content were other recommendations.

Specific Diabetes Knowledge

Test

At the end of the survey, caregivers were asked five specific questions about diabetes, its complications, and management:

1. What is the ideal level of HbA1c that a person with diabetes should maintain?
2. What causes diabetes?
3. What should caregivers know about a diabetes meal plan?
4. Having diabetes also increases the risk for having what?
5. What should you do if someone with diabetes has dangerously low blood sugar?

The questions were aimed at gaining an understanding of what caregivers know about diabetes, don’t know, or are unsure about. For this reason, they were asked not to guess if they didn’t know the answer.

Analysis of Test Results

The number of correct answers was counted for each respondent. The respondents were then grouped according to whether they had four or five correct answers or had three or fewer correct answers. This grouping made it possible to identify and focus on those most in need of information about diabetes caregiving. Of the 1,002 respondents, 39% answered three or fewer questions correctly.

To better understand this particular group of caregivers, the data analysts next looked for trends in subgroups. For example, 75% of these lower-scoring caregivers reported that they are not sure what diabetes medications their care recipient takes, and 75% say they are not at all informed about diabetes caregiving. Sixty-one percent say family and friends are their top source of information. More than half (58%) strongly agree with the statement “I could be doing much more than I am.” Half or more are of Hispanic origin (57%), don’t feel skilled enough to use the Internet for information (53%), don’t think information on new developments in diabetes treatments would be at all useful (52%), agree that “I have been passed up for a promotion or raise at my job” (52%), say a pharmacist is their top

information source (52%), are aged between 18 and 35 (50%), or care for someone with diabetes only (no comorbid conditions) (50%).

Generally, those with fewer correct answers are less involved in the daily work of caregiving, but experience confusion and frustration about the requirements of providing care. They don't know where to look to find reliable information. They feel pressure internally (they think they should be doing more) and externally (there are challenges they must face in relation to their employment).

In order to see what underserved populations might be experiencing as compared with more affluent whites, data analysts looked at two racial groups, white and nonwhite (people of color) and two income groups, higher ($\geq \$50,000$) and lower ($< \$50,000$). Highlighted in red are numbers for any racial/income category of caregiver that are notably different from those in other categories (Table 4).

Table 4. Comparison of caregivers' characteristics and information needs, by race and income level

	White & lower income (<\$50,000) (n=190)	White & higher income ($\geq \$50,000$) (n=465)	Nonwhite & lower income (<\$50,000) (n=52)	Nonwhite & higher income ($\geq \$50,000$) (n=142)
Worse personal physical health than before	42%	33%	21%	27%
Sought emergency medical care	39%	45%	52%	39%
When first started providing care, felt very/completely informed	24%	23%	48%	23%
Actively searches out information about diabetes caregiving	46%	57%	56%	60%
Useful online tool: information to read online or print	69%	64%	77%	62%
Useful online tool: blogs	29%	31%	44%	37%
Likely to visit website with those tools	72%	71%	87%	74%
Children in household	27%	34%	40%	54%
Age of caregiver	45	48	35	39
Caregiver is female	73%	66%	83%	70%
Caregiver is single, never married	27%	10%	40%	19%
Caregiver education is high school or less	16%	7%	13%	4%
Provides continuous / round-the-clock care	32%	16%	17%	14%
Mean age of person under care	69	71	64	68
Caring for spouse/partner	20%	14%	8%	7%
Employed full time	51%	68%	56%	75%
Retired, student, or homemaker	28%	18%	19%	8%
Mean number of knowledge questions correct	3.7	3.8	3.4	3.2

Table 4 shows that lower-income nonwhites tend to be younger, less educated, and female, and they are more likely to have sought emergency medical treatment for the person in their care. This group, much more than any of the other three groups, said that they felt very informed when they started providing care. Even so, for this group, the mean number of correct answers to the five diabetes knowledge questions was less than four. Interestingly, the

lower-income nonwhite group was the one most likely to declare readiness to visit a website with useful tools and to say printable information would be useful.

SUMMARY AND CONCLUSIONS

The most recent statistics provided by the U.S. Centers for Disease Control and Prevention show that an estimated 23.6 million Americans have diabetes and could climb to as many as 37 million by 2015. Currently, approximately 18.3% (8.6 million) of people with diabetes are age 60 and older. While many adults control their diabetes successfully and on their own, many others experience severe complications (e.g., stroke, blindness, amputation, dental disease, compromised immune system, etc.) and require help from family and friends to manage their disease.

As of 2004, 44.4 million people in the U.S. (or 21% of the population) served as unpaid caregivers to adult family members or friends. They are a diverse group and their experiences range from relatively easy tasks to some that are very challenging. About 8% of these caregivers (or 3.5 million) are caring for people with diabetes, providing care such as grocery shopping, bathing, planning and preparing meals, administering medications, providing transportation, and communicating with health care providers.

The Diabetes Caregiver Survey looked specifically at caregivers of people with diabetes. It identified challenges and opportunities for how we can begin to meet the needs of diabetes caregivers. By providing targeted tools and resources, we can ease the burden on caregivers and improve diabetes management outcomes in their care recipients. Here are some highlights.

- We learned that caregivers at different stages in the caregiving process have different needs for information. “Rookies” are more likely to need a lot of basic information to get up to speed, whereas “veterans” are more interested in the newest developments in the management of the disease. In general, even though caregivers were relatively knowledgeable about diabetes, educational programs and resources should reinforce the fundamental aspects of diabetes management: diet, exercise, managing blood sugar, and preventing hypoglycemia.
- We learned that physicians, especially primary care physicians, are a very important source of information for caregivers; this is particularly true for the older caregiver. It was also striking how underutilized diabetes educators and pharmacists are as sources of information. The survey shows several opportunities to reinforce the physician-caregiver relationship, and for physicians to partner with pharmacists and diabetes educators as part of the health care team that supports caregivers and patients with diabetes.
- We learned that for the majority of diabetes caregivers the Internet is an important source of information—second only to the physician—and that caregivers are experiencing some frustration discerning good information from bad, finding information that is specific to their needs, and wading through the commercial content. We also know that Internet use increases every year and that younger caregivers are already online. The Internet is a

cost-effective and accessible medium to deliver resources and information to many busy caregivers. Even so, face-to-face opportunities to support caregivers should not be disregarded, especially for older caregivers. Overall, resources should be practical and to the point, and address the day-to-day management of diabetes as well as tips for self-care. These should be developed by reputable organizations and experts that are knowledgeable about diabetes management and its complications to reassure caregivers that they are getting the best information.

- We learned that the majority of caregivers are positive about a new website that is targeted to meet their needs and that this should include a variety of tools to meet the diverse needs of caregivers. A website should include features such as downloadable fact sheets, videos, forums/chats where caregivers can connect with each other, and the ability to register for updates. While not appealing to most, these features do appeal to those with the most diabetes responsibilities.
- We learned that the more medications and complications there are to manage, the heavier the burden on the caregiver. This provides an opportunity to develop practical tools for caregivers to manage their time, such as calendars and checklists, and tips for how to facilitate communication between health care providers who often are not talking to each other.

APPENDIX: SURVEY AND FREQUENCY RESULTS

This needs assessment survey of diabetes caregivers was conducted by The Hormone Foundation in collaboration with the National Alliance for Caregiving. It was conducted on April 6- 20, 2009 and reflects the answers of 1,002 caregivers of people with diabetes ages 21 and older who qualified for the survey. In the section below, you will find the survey questions and the frequency of answers provided by respondents.

Q1. Do you currently provide unpaid care to a relative or friend over 21 years old to help them take care of themselves?

	TOTAL ASKED
TOTAL ASKED	1002
Yes	100%
No	0%

Q2. Please check the problems or illnesses the person in your care has.

	TOTAL ASKED
TOTAL ASKED	1002
AIDS	1%
Alzheimer's/ Dementia/ Forgetfulness	30%
Amputee	4%
Arthritis	43%
Blindness or Low Vision	19%
Blood Pressure/ Hypertension	59%
Cancer	11%
Deafness/Hearing Loss	20%
Diabetes	100%
Heart Disease	38%
Kidney disease	14%
Lung Disease (ex: Emphysema, Asthma)	12%
Mental Retardation	2%
Mental Illness, Emotional Illness, Depression	17%
Osteoporosis	13%
Parkinson's	4%
Stroke	16%
Other	10%

Q2ILLNESS. Number of problems or illnesses the person in your care has.

TOTAL

TOTAL ASKED	ASKED
	1002
1 (Diabetes Only)	8%
2,3	34%
4,5	35%
6+	23%

Q3. What would you say is the main problem or illness the person under your care has?

TOTAL ASKED	TOTAL ASKED
	1002
Diabetes	61%
Alzheimer's/ Dementia/ Forgetfulness	8%
Mobility (arthritis)	3%
NET: Heart (BP, Heart disease, Stroke)	10%
Blood Pressure/ Hypertension	1%
Heart Disease	5%
Stroke	3%
NET: Other	18%
AIDS	0%
Amputee	0%
Blindness or Low Vision	2%
Cancer	2%
Deafness/Hearing Loss	0%
Kidney disease	2%
Lung Disease (ex: Emphysema, Asthma)	2%
Mental Retardation	0%
Mental Illness, Emotional Illness, Depression	2%
Osteoporosis	0%
Parkinson's	1%
Other	4%
Don't Know	

Q4. Please select all the ways in which you help the person under your care.

TOTAL ASKED	TOTAL ASKED
	1002
Bathe or shower	38%
By feeding him or her	26%
Dealing with incontinence or diapers	26%
Get dressed	43%
Get in and out of beds and chairs	46%
Get to and from the toilet	27%
None of these	34%

Q5. Do you provide help for the person in your care with:

TOTAL ASKED

TOTAL ASKED	1002
Giving medicines, pills or injections	68%
Performing fingerstick to test blood glucose	48%
Arranging or supervising services from an agency, such as nurses or aides	40%
Grocery shopping	84%
Housework, such as doing dishes, laundry or straightening up	77%
Managing finances, such as paying bills or filling out insurance claims	75%
Preparing meals	71%
Transportation, either by driving him or her, or helping them get transportation	86%

**Q6. You mentioned that the person in your care has diabetes.
How much of their diabetes care falls to you?**

	TOTAL ASKED
TOTAL ASKED	1002
I am responsible for all of the diabetes related care for this person	19%
I am responsible for most of the diabetes related care	29%
I am responsible for some of the diabetes related care	52%
I am responsible for little of the diabetes related care	0%
I am responsible for none of the diabetes related care	0%

Q7. # of hours: Thinking now of all the kinds of help you provide for the person in your care, about how many hours do you spend in an average week doing these things?

	TOTAL ASKED
TOTAL ASKED	1002
Less than 1 hr.	1%
1-5	13%
6-10	18%
11-15	12%
16-25	15%
26+	13%
I provide continuous / around the clock care	20%
Not sure/Can't Say	8%

Q8AGE. How old is the person for whom you provide care?

	TOTAL ASKED
TOTAL ASKED	1002
22-59	21%
60-69	22%
70-79	25%
80+	32%
MEAN AGE	70.00

Q9. What is your relationship to that person? This person is my...

	TOTAL ASKED
TOTAL ASKED	1002

Spouse or Partner	14%
Parent (or Parent-in-law)	59%
NET:Other	28%
Son or daughter	7%
Brother or sister	2%
Grandparent (or Grandparent-in-law)	9%
Other relative	8%
Friend / Family friend	2%

Q11. Does the person you care for live in:

	TOTAL ASKED
TOTAL ASKED	1002
The same household as you	46%
NET:Other Home	37%
Someone else's home	24%
Their own home	13%
NET:Care Facility	16%
An independent living or retirement community	10%
An assisted living facility where some care may be provided	4%
A nursing home or facility	2%
Somewhere else	0%

Q12. On average, how often do you visit this person?

	TOTAL ASKED
TOTAL ASKED	540
More than once a week	81%
NET: Less frequently	19%
About once a week	10%
A few times a month	4%
About once a month	1%
A few times a year	2%
Less often than that	0%
Not Sure	1%

Q13CAREYRS. # of years - For how long have you been providing care for this person?

	TOTAL ASKED
TOTAL ASKED	1002
0,1 yrs	12%
2-5yrs	53%
6-10 yrs	24%
11+	11%

Q16. Who would you consider to be the person who provides most of the care for the person you care for?

**TOTAL
ASKED**

TOTAL ASKED	1002
You	75%
Someone else (paid or unpaid)	25%

Q17_1. Others could be doing much more than they are - How much do you agree or disagree with the following statements?

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	47%
BOTTOM TWO BOX	22%
MEAN	3.44
Strongly Disagree	12%
2	10%
3	22%
4	20%
Strongly Agree	27%
Not Applicable	9%

Q17A_1. I could be doing much more than I am -

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	18%
BOTTOM TWO BOX	56%
MEAN	2.38
Strongly Disagree	29%
2	26%
3	26%
4	14%
Strongly Agree	4%

Q18. Which one of the following best describes your employment status?

	TOTAL ASKED
TOTAL ASKED	1002
NET:Employed Full-Time/Self	63%
Employed full time	53%
Self-employed	9%
NET:Not Employed Full-time	37%
Employed part time	11%
Not employed, but looking for work	4%
Not employed and not looking for work	2%
Retired	9%
Student	4%
Homemaker	7%

Q19_1. I feel that other family members and friends understand and appreciate the time and energy I provide in

my care for the person under my care - Please tell us how much you agree or disagree with the following statements:

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	56%
BOTTOM TWO BOX	24%
MEAN	3.55
Strongly Disagree	9%
2	15%
3	19%
4	24%
Strongly Agree	32%
Not Applicable	1%

Q19_2. Because of the time and energy required to provide care I have lost friendships or romantic relationships - Please tell us how much you agree or disagree with the following statements:

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	26%
BOTTOM TWO BOX	52%
MEAN	2.51
Strongly Disagree	32%
2	21%
3	19%
4	16%
Strongly Agree	10%
Not Applicable	3%

Q19_3. Because of the time and energy required to provide care I have not been able to meet my employer's expectations - Please tell us how much you agree or disagree with the following statements:

	TOTAL ASKED
TOTAL ASKED	639
TOP TWO BOX	13%
BOTTOM TWO BOX	67%
MEAN	2.06
Strongly Disagree	42%
2	25%
3	19%
4	9%
Strongly Agree	4%
Not Applicable	2%

Q19_4. Because of the time and energy required to provide

care I have been passed up for a promotion or raise at my job - Please tell us how much you agree or disagree with the following statements:

	TOTAL ASKED
TOTAL ASKED	639
TOP TWO BOX	13%
BOTTOM TWO BOX	65%
MEAN	2.05
Strongly Disagree	44%
2	21%
3	18%
4	9%
Strongly Agree	5%
Not Applicable	4%

Q20. As a caregiver, do you have . . .

	TOTAL ASKED
TOTAL ASKED	1002
less time for your friends or other family members than before?	68%
to give up vacations, hobbies, or your own social activities?	61%
less time for exercise than before	53%
worse personal physical health than before?	33%
worse personal mental health?	36%
None of the above	12%

Q21. What are the biggest issues and challenges you face when it comes to being a caregiver of a person with diabetes?

	TOTAL ASKED
TOTAL ASKED	1001
DIABETES CARE ALL	49%
Diabetes medical care	5%
Monitoring sugar levels	14%
Controlling sugar / HbA1c	13%
Managing doc visits	3%
Managing medications	11%
Managing supplies	2%
Medical noncompliance	7%
Medication compliance issues	8%
DIET/FOOD ALL	54%
Diet / Eating right	29%
Avoiding sweets /carbs/ bad foods	6%
Cooking and meal planning	12%
Grocery shopping	1%
Diet noncompliance	10%
Educating patient about diet	4%
Exercise	7%

COMPLICATONS ALL	11%
Dealing with hypoglycemia	1%
Neuropathy	2%
Complications from diabetes	4%
Wound care / checking feet/hands	4%
Amputations	1%
Kidney disease	1%
Other complication	1%
Vision/eyesight loss/ blindness	2%
FINANCES ALL	5%
Money	2%
Cost of drugs/supplies	1%
Insurance and medicare hassles	1%
PATIENT INTERACTIONS	21%
Logistics	1%
Time to manage all care	8%
Coping with pt mental health	4%
Coping with Alzheimer's / dementia	1%
Mobility problems, falls, injury	3%
Communication problems w/ patient	1%
Bathing/hygiene/personal care	1%
Other medical conditions	2%
Educating patient on diabetes/seriousness of disease	1%
Dealing with incontinence	1%
CAREGIVER CONCERNS	12%
CG personal challenges	1%
Time to self / with other people	4%
CG physical health	2%
Stress / CG mental/emotional health	6%
Employment concerns	1%
Others don't understand what I do	1%
Other	7%
None / Don't Know	3%

Q22. Which prescription medication does the person under your care take for his/her diabetes?

	TOTAL ASKED
TOTAL ASKED	1002
Insulin (injectable shots or pen)	51%
Insulin pump	5%
Other injectable medication (e.g., Byetta)	3%
Pill(s) / Oral Medication(s)	66%
Other (Specify:)	1%
Does not take medication	4%
Not Sure	0%

Q23. Which of the following areas of diabetes care are you personally involved in:

TOTAL

	ASKED
TOTAL ASKED	1002
Ensuring that proper insulin doses are taken	37%
Going along to doctor appointments involving diabetes care	80%
Helping to monitor blood sugar levels (doing fingersticks and using meters)	63%
Inspecting hands/ feet	54%
Making sure the person in your care gets some exercise	60%
Monitoring diets	77%
Picking up prescriptions	80%
Portioning out oral medications	36%
Preparing meals	71%
Other	4%
Shopping	1%
None of these	0%

Q24. Are you assisting with care related to any of the more serious complications of diabetes?

	TOTAL ASKED
TOTAL ASKED	1002
Hypoglycemia	16%
Kidney disease	16%
Loss of vision	27%
Loss of limb	6%
Mobility	39%
Related heart problems	30%
Wound care	23%
Other	2%
Neuropathy	1%
None of these	29%

Q25_2. . . .doesn't want to change to or maintain a healthy diet - How big an issue is each with the person to whom you are giving care?

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	50%
BOTTOM TWO BOX	28%
MEAN	3.33
Not at all an issue	14%
2	14%
3	22%
4	25%
A very significant issue	25%

Q25_3. . . .doesn't want to / is unable to exercise - How big an issue is each with the person to whom you are giving care?

TOTAL

TOTAL ASKED	ASKED
	1002
TOP TWO BOX	59%
BOTTOM TWO BOX	20%
MEAN	3.63
Not at all an issue	9%
2	11%
3	21%
4	26%
A very significant issue	33%

Q25_4. . . .is frustrated and overwhelmed by his/her diabetes - How big an issue is each with the person to whom you are giving care?

	TOTAL ASKED
	1002
TOP TWO BOX	38%
BOTTOM TWO BOX	34%
MEAN	3.03
Not at all an issue	16%
2	17%
3	28%
4	22%
A very significant issue	15%

Q25_5. . . .has experienced side effects of diabetes medications - How big an issue is each with the person to whom you are giving care?

	TOTAL ASKED
	1002
TOP TWO BOX	25%
BOTTOM TWO BOX	51%
MEAN	2.54
Not at all an issue	29%
2	23%
3	24%
4	16%
A very significant issue	9%

Q25_6. . . .can't maintain consistent target blood sugar levels - How big an issue is each with the person to whom you are giving care?

	TOTAL ASKED
	1002
TOP TWO BOX	43%
BOTTOM TWO BOX	27%
MEAN	3.24

Not at all an issue	10%
2	17%
3	30%
4	24%
A very significant issue	19%

Q25_7. . . .is depressed - How big an issue is each with the person to whom you are giving care?

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	45%
BOTTOM TWO BOX	32%
MEAN	3.17
Not at all an issue	16%
2	16%
3	23%
4	25%
A very significant issue	20%

Q25_8. . . .experiences memory loss, confusion or has Alzheimer's Disease - How big an issue is each with the person to whom you are giving care?

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	40%
BOTTOM TWO BOX	44%
MEAN	2.87
Not at all an issue	28%
2	15%
3	17%
4	20%
A very significant issue	19%

Q25_9. . . .has experienced episodes of hypoglycemia (low blood sugar) that have required immediate action - How big an issue is each with the person to whom you are giving care?

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	43%
BOTTOM TWO BOX	39%
MEAN	3.01
Not at all an issue	23%
2	16%
3	18%
4	24%
A very significant issue	19%

Q25_10. . . . experiences stress or embarrassment in public situations due to their diabetes - How big an issue is each with the person to whom you are giving care?

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	19%
BOTTOM TWO BOX	62%
MEAN	2.26
Not at all an issue	39%
2	23%
3	19%
4	12%
A very significant issue	7%

Q26_1. Finding specialist(s) for diabetes-related care - How difficult or challenging do you find the following tasks?

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	18%
BOTTOM TWO BOX	59%
MEAN	2.28
Not at all difficult	36%
2	23%
3	22%
4	13%
Extremely difficult	5%

Q26_2. Managing blood sugar levels and preventing hypoglycemia - How difficult or challenging do you find the following tasks?

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	37%
BOTTOM TWO BOX	33%
MEAN	3.01
Not at all difficult	15%
2	18%
3	31%
4	25%
Extremely difficult	12%

Q26_3. Administering diabetes medication (keeping track of what, when and how to take medication) - How difficult or challenging do you find the following tasks?

TOTAL

TOTAL ASKED	ASKED
	1002
TOP TWO BOX	16%
BOTTOM TWO BOX	59%
MEAN	2.25
Not at all difficult	36%
2	23%
3	25%
4	12%
Extremely difficult	3%

Q26_4. Insurance—filling out forms, getting reimbursed or having diabetes meds / procedures covered - How difficult or challenging do you find the following tasks?

	TOTAL ASKED
	1002
TOP TWO BOX	26%
BOTTOM TWO BOX	54%
MEAN	2.50
Not at all difficult	34%
2	21%
3	19%
4	14%
Extremely difficult	12%

Q26_5. Communicating with the physicians who treat my loved one's diabetes - How difficult or challenging do you find the following tasks?

	TOTAL ASKED
	1002
TOP TWO BOX	20%
BOTTOM TWO BOX	54%
MEAN	2.36
Not at all difficult	36%
2	18%
3	26%
4	14%
Extremely difficult	6%

Q26_6. Managing diabetes in addition to other medical problems - How difficult or challenging do you find the following tasks?

	TOTAL ASKED
	1002
TOP TWO BOX	41%
BOTTOM TWO BOX	28%
MEAN	3.13

Not at all difficult	13%
2	14%
3	31%
4	27%
Extremely difficult	14%

Q26NEW. Since the person under your care has developed diabetes, have you ever had to rush them to the hospital or call an ambulance because of a diabetes complication—i.e. dangerously low blood sugar, diabetes coma, heart attack?

	TOTAL ASKED
TOTAL ASKED	1002
Yes	42%
No	58%

Q26A. What was the reason for the (most recent) emergency care?

	TOTAL ASKED
TOTAL ASKED	424
DIABETES/SUGAR RELATED	56%
Blood sugar	2%
Low blood sugar / hypoglycemia	41%
High blood sugar	11%
Diabetic coma	4%
OTHER MEDICAL	46%
Heart attack / Chest pain	7%
Heart attack	8%
Stroke	5%
Blood pressure	2%
Fainted / Passed out	9%
Kidney failure	1%
Seizure	2%
Dehydrated	2%
Heart palpitations	1%
Bleeding	1%
Infection	4%
Confusion, fogginess	5%
Edema	1%
Breathing problems	2%
Fall	6%
Side effect to medication	1%
Other	7%
None / Gave date only	1%

Q27_1. How informed do you feel about diabetes, its potential complications and what you need for diabetes caregiving?

TOTAL

	ASKED
TOTAL ASKED	1002
TOP TWO BOX	69%
BOTTOM TWO BOX	4%
MEAN	3.87
Not at all informed	0%
2	4%
3	26%
4	47%
Completely informed	22%

Q28. In which areas do you need more information?

	TOTAL ASKED
TOTAL ASKED	1002
ABOUT DIABETES	8%
General diabetes info	2%
Aging, diabetes in elderly	1%
Long-term effects	2%
Causes and function of disease	3%
BLOOD SUGAR	11%
Hypoglycemia	1%
Managing blood sugar levels	9%
Medical emergencies	2%
MEDICATIONS	12%
Side effects	2%
Insulin	3%
Available medications	3%
Dealing with medications and side effects	5%
New/alternative medications & research	10%
DIET/EXERCISE	26%
Diet	23%
Exercise	6%
Compliance	2%
ALL MEDICAL ISSUES	17%
Interactions with other conditions	3%
Mental health / Depression	2%
Dementia / Confusion / Alzheimer's	1%
Comorbid conditions	2%
SUBNET: COMPLICATIONS	12%
Complications from diabetes	7%
Wound / foot care	3%
Eyes and vision loss	2%
Kidney disease	1%
LOCAL RESOURCES	2%
Finding a specialist	1%
Support groups	1%
Respite care, in-home help	1%
HOW TO PAY	2%
Insurance / Medicare	2%

Financial assistance	1%
COMMUNICATION	3%
Communication with pt	3%
Communication with doc	1%
All areas	1%
Other	4%
None	24%
Don't Know	5%

Q29_1. How informed did you feel about diabetes, its complications and what you needed for diabetes caregiving when you first began dealing with the diabetes of the person under your care?

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	26%
BOTTOM TWO BOX	53%
MEAN	2.59
Not at all informed	24%
2	29%
3	21%
4	15%
Completely informed	10%

Q29A. Which of the following statements best describes you today?

	TOTAL ASKED
TOTAL ASKED	1002
I actively search out information about caring for someone with diabetes	54%
If I see or hear something of interest related to caring for someone with diabetes, I read it or listen to it, but I don't	45%
I am too busy, or not interested in finding more information	1%

Q30_1. Dealing with medical emergencies (e.g., hypoglycemia) - For each, please tell us how useful it would be to get additional information on that topic.

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	54%
BOTTOM TWO BOX	21%
MEAN	3.52
Not at all useful to me	10%
2	11%
3	25%
4	26%
Would be very useful	28%

Q30_2. Preventing or dealing with the chronic complications of diabetes, such as kidney disease, high blood pressure, vision loss/blindness, nerve pain in the limbs, wound care, amputations and heart disease

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	68%
BOTTOM TWO BOX	10%
MEAN	3.94
Not at all useful to me	4%
2	6%
3	22%
4	29%
Would be very useful	39%

Q30_3. Managing limited mobility, both in public and at home - For each, please tell us how useful it would be to get additional information on that topic.

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	44%
BOTTOM TWO BOX	31%
MEAN	3.19
Not at all useful to me	18%
2	13%
3	25%
4	22%
Would be very useful	23%

Q30_4. Managing diabetes diet and nutrition, including monitoring, tracking and testing blood sugar levels - For each, please tell us how useful it would be to get additional information on that topic.

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	62%
BOTTOM TWO BOX	14%
MEAN	3.76
Not at all useful to me	6%
2	8%
3	23%
4	28%
Would be very useful	34%

Q30_5. Administering, scheduling, and dosing insulin and other diabetes medications - For each, please tell us how useful it would be to get additional information on that

topic.

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	34%
BOTTOM TWO BOX	39%
MEAN	2.89
Not at all useful to me	22%
2	16%
3	27%
4	18%
Would be very useful	16%

Q30_6. Helping with the emotional health of the person you care for - For each, please tell us how useful it would be to get additional information on that topic.

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	61%
BOTTOM TWO BOX	16%
MEAN	3.70
Not at all useful to me	7%
2	9%
3	22%
4	29%
Would be very useful	32%

Q30_7. Focusing on and maintaining your own physical and emotional health as a caregiver - For each, please tell us how useful it would be to get additional information on that topic.

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	57%
BOTTOM TWO BOX	18%
MEAN	3.59
Not at all useful to me	10%
2	8%
3	25%
4	28%
Would be very useful	30%

Q30_8. Finding caregiver support, including respite care or a home health aide, social workers, and other community support services - For each, please tell us how useful it would be to get additional information on that topic.

TOTAL ASKED

TOTAL ASKED	1002
TOP TWO BOX	43%
BOTTOM TWO BOX	33%
MEAN	3.13
Not at all useful to me	18%
2	15%
3	24%
4	21%
Would be very useful	22%

Q30_9. New developments in diabetes treatment - For each, please tell us how useful it would be to get additional information on that topic.

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	76%
BOTTOM TWO BOX	7%
MEAN	4.13
Not at all useful to me	2%
2	4%
3	17%
4	29%
Would be very useful	47%

Q30_10. Research into causes and cures for diabetes - For each, please tell us how useful it would be to get additional information on that topic.

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	57%
BOTTOM TWO BOX	17%
MEAN	3.66
Not at all useful to me	7%
2	9%
3	27%
4	23%
Would be very useful	34%

Q30_11. Dealing with diabetes alongside other chronic conditions - For each, please tell us how useful it would be to get additional information on that topic.

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	64%
BOTTOM TWO BOX	13%
MEAN	3.80
Not at all useful to me	6%

2	7%
3	24%
4	29%
Would be very useful	35%

Q30B1_1. amputations - How useful would it be to have information about preventing or dealing with each of the following?

	TOTAL ASKED
TOTAL ASKED	684
TOP TWO BOX	46%
BOTTOM TWO BOX	35%
MEAN	3.20
Not at all useful to me	19%
2	16%
3	19%
4	18%
Would be very useful	28%

Q30B1_2. heart disease - How useful would it be to have information about preventing or dealing with each of the following?

	TOTAL ASKED
TOTAL ASKED	684
TOP TWO BOX	78%
BOTTOM TWO BOX	8%
MEAN	4.14
Not at all useful to me	3%
2	5%
3	14%
4	31%
Would be very useful	47%

Q30B1_3. high blood pressure - How useful would it be to have information about preventing or dealing with each of the following?

	TOTAL ASKED
TOTAL ASKED	684
TOP TWO BOX	78%
BOTTOM TWO BOX	7%
MEAN	4.15
Not at all useful to me	4%
2	4%
3	14%
4	30%
Would be very useful	48%

Q30B1_4. kidney disease - How useful would it be to have information about preventing or dealing with each of the following?

	TOTAL ASKED
TOTAL ASKED	684
TOP TWO BOX	68%
BOTTOM TWO BOX	14%
MEAN	3.88
Not at all useful to me	5%
2	8%
3	18%
4	29%
Would be very useful	39%

Q30B1_5. nerve pain in the limbs - How useful would it be to have information about preventing or dealing with each of the following?

	TOTAL ASKED
TOTAL ASKED	684
TOP TWO BOX	74%
BOTTOM TWO BOX	12%
MEAN	4.04
Not at all useful to me	5%
2	6%
3	14%
4	27%
Would be very useful	47%

Q30B1_6. vision loss or blindness - How useful would it be to have information about preventing or dealing with each of the following?

	TOTAL ASKED
TOTAL ASKED	684
TOP TWO BOX	72%
BOTTOM TWO BOX	12%
MEAN	4.01
Not at all useful to me	4%
2	7%
3	16%
4	28%
Would be very useful	44%

Q30B1_7. wound care - How useful would it be to have information about preventing or dealing with each of the following?

TOTAL ASKED

TOTAL ASKED	684
TOP TWO BOX	67%
BOTTOM TWO BOX	13%
MEAN	3.87
Not at all useful to me	5%
2	8%
3	20%
4	27%
Would be very useful	39%

Q30B1_8. hypoglycemia - How useful would it be to have information about preventing or dealing with each of the following?

	TOTAL ASKED
TOTAL ASKED	684
TOP TWO BOX	69%
BOTTOM TWO BOX	12%
MEAN	3.92
Not at all useful to me	6%
2	7%
3	19%
4	29%
Would be very useful	40%

Q31. Which of the following best describes your experience using the Internet to look for information about diabetes caregiving?

	TOTAL ASKED
TOTAL ASKED	1002
I've never tried to use the Internet for that	9%
I tried to use it to find information in the past, but no longer do so	18%
I use it now	73%

Q32_1. Case manager or social worker - How much information about caring for diabetes do you get from the following sources?

	TOTAL ASKED
TOTAL ASKED	1002
None	60%
Not much	20%
Some	16%
A lot	4%

Q32_2. Family or friends - How much information about caring for diabetes do you get from the following sources?

TOTAL ASKED

TOTAL ASKED	1002
None	20%
Not much	27%
Some	40%
A lot	12%

Q32_3. Nurse or medical assistant - How much information about caring for diabetes do you get from the following sources?

	TOTAL ASKED
TOTAL ASKED	1002
None	18%
Not much	22%
Some	40%
A lot	20%

Q32_4. Diabetes educator - How much information about caring for diabetes do you get from the following sources?

	TOTAL ASKED
TOTAL ASKED	1002
None	37%
Not much	19%
Some	29%
A lot	15%

Q32_5. Pharmacist - How much information about caring for diabetes do you get from the following sources?

	TOTAL ASKED
TOTAL ASKED	1002
None	23%
Not much	29%
Some	36%
A lot	11%

Q32_6. Physician - How much information about caring for diabetes do you get from the following sources?

	TOTAL ASKED
TOTAL ASKED	1002
None	2%
Not much	9%
Some	40%
A lot	49%

Q32_7. Support groups - How much information about caring for diabetes do you get from the following sources?

TOTAL

TOTAL ASKED	ASKED
	1002
None	73%
Not much	15%
Some	10%
A lot	2%

Q32_8. The Internet - How much information about caring for diabetes do you get from the following sources?

	TOTAL ASKED
	734
TOTAL ASKED	
None	1%
Not much	6%
Some	48%
A lot	46%

Q32_9. Newsletters or magazines about diabetes/ caregiving - How much information about caring for diabetes do you get from the following sources?

	TOTAL ASKED
	1002
TOTAL ASKED	
None	20%
Not much	23%
Some	40%
A lot	17%

Q32_11. Media - How much information about caring for diabetes do you get from the following sources?

	TOTAL ASKED
	1002
TOTAL ASKED	
None	20%
Not much	23%
Some	40%
A lot	17%

Q32_12. Internet - How much information about caring for diabetes do you get from the following sources?

	TOTAL ASKED
	1002
TOTAL ASKED	
None	20%
Not much	23%
Some	40%
A lot	17%

Q33. Which type of physician would you say is your primary source of information about caring for diabetes?

TOTAL ASKED	TOTAL ASKED
	890
General practitioner	69%
Endocrinologist	26%
Other	5%

Q34RANK. Rank Summary - TOP

TOTAL ASKED	TOTAL ASKED
	995
Case manager or social worker	1%
Family or friends	7%
Nurse or medical assistant	6%
Diabetes educator	8%
Pharmacist	3%
Physician	55%
Support groups	0%
The Internet	14%
Newsletters or magazines about diabetes/ caregiving	5%
Other	1%
Media	0%
None	0%

Q34_1. Case manager or social worker - RANK: Top information sources

TOTAL ASKED	TOTAL ASKED
	1002
NET Top Three	5%
TOP	1%
2nd	2%
3rd	2%

Q34_2. Family or friends - RANK: Top information sources

TOTAL ASKED	TOTAL ASKED
	1002
NET Top Three	30%
TOP	7%
2nd	10%
3rd	14%

Q34_3. Nurse or medical assistant - RANK: Top information sources

TOTAL ASKED	TOTAL ASKED
	1002
NET Top Three	36%
TOP	6%
2nd	18%
3rd	11%

Q34_4. Diabetes educator - RANK: Top information sources

	TOTAL ASKED
TOTAL ASKED	1002
NET Top Three	24%
TOP	8%
2nd	8%
3rd	7%

Q34_5. Pharmacist - RANK: Top information sources

	TOTAL ASKED
TOTAL ASKED	1002
NET Top Three	22%
TOP	2%
2nd	9%
3rd	11%

Q34_6. Physician - RANK: Top information sources

	TOTAL ASKED
TOTAL ASKED	1002
NET Top Three	83%
TOP	54%
2nd	19%
3rd	9%

Q34_7. Support groups - RANK: Top information sources

	TOTAL ASKED
TOTAL ASKED	1002
NET Top Three	1%
TOP	0%
2nd	0%
3rd	1%

Q34_8. The Internet - RANK: Top information sources

	TOTAL ASKED
TOTAL ASKED	1002
NET Top Three	52%
TOP	14%
2nd	20%
3rd	19%

**Q34_9. Newsletters or magazines about diabetes/ caregiving -
RANK**

**TOTAL
ASKED**

TOTAL ASKED	1002
NET Top Three	25%
TOP	4%
2nd	9%
3rd	12%

Q34_10. Other - RANK: Top information sources

	TOTAL ASKED
TOTAL ASKED	1002
NET Top Three	2%
TOP	1%
2nd	0%
3rd	1%

Q35. Please name three websites that you consult most often for information about diabetes, its potential complications and all that is needed for diabetes caregiving.

	TOTAL ASKED
TOTAL ASKED	688
WebMD	56%
American Diabetes Association (diabetes.org)	38%
Google, Yahoo, AOL, other search engines	20%
Mayo Clinic	9%
Diabetes.com	8%
National Institutes of Health (NIH & NLM)	6%
Wikipedia	3%
Centers for Disease Control and Prevention	2%
dLife	2%
md.com	2%
Juvenile Diabetes Research	2%
Don't know	4%
DID NOT COMPLETE	0%
N/A	2%
Not Specific	3%
None	1%
NET ALL OTHER (1% or less)	42%

Q36. What are your biggest frustrations in using the Internet to help you in your caregiving?

	TOTAL ASKED
TOTAL ASKED	910
Having difficulty finding information specific to my needs	33%
Not feeling skilled enough with search techniques and website navigation	10%
Poor quality information on the Internet	12%
Too many websites or search results	37%
Trying to sort good information from bad information	63%
Wading through commercial content	49%

Other frustrations	2%
Not enough time	1%
No frustrations	14%

Q37. Which of the tools and information sources below would be valuable in your diabetes care?

	TOTAL ASKED
TOTAL ASKED	1002
Calendars or diaries for tracking medication, appointments, and other medical information	45%
Tips for communicating with health care professionals	44%
Tips for communicating with your care recipient	31%
Opportunities to connect with other caregivers	23%
Local events, including seminars and support groups	28%
Local resources, including clinic information, respite care, and supplies	43%
Food shopping checklists	53%
Tips for cooking and exercising	64%
Other (specify)	2%
None of these	7%

Q38. Which of the following online tools would be valuable in your diabetes care?

	TOTAL ASKED
TOTAL ASKED	1002
Information you can read online or print on a printer	65%
Message boards or chat rooms where you can participate in an online discussion with other diabetes caregivers and experts	22%
Online journals or blogs written by other caregivers that you can read or submit comments to	31%
Personalized tools like calendars or calculators that you log in to access	36%
Radio programs that you can listen to on your computer or portable audio player (e.g., podcasts)	14%
Educational videos you can watch or listen to on your computer or portable video player (e.g., video clips like on YouTube)	30%
Links to caregiving resources	43%
Periodic e-mail alerts about new developments in diabetes care	53%
Other (specify)	1%
None of these	9%

Q39_1. How likely are you to regularly visit a site that included all of these tools?

	TOTAL ASKED
TOTAL ASKED	1002
TOP TWO BOX	72%
BOTTOM TWO BOX	8%
MEAN	3.99
Not at all likely	3%
2	5%
3	21%
4	34%

Very likely

38%

Q39A. Why do you say that?

	TOTAL ASKED
TOTAL ASKED	1002
ALL POSITIVE MENTIONS	72%
General positive	3%
Helpful, informative, useful	22%
Good use of my time	3%
One stop shop: Central, efficient, convenient, one place to look	23%
I always need more information	9%
LIKES: ALL	17%
Like: articles, printable resources	1%
Like the combination of tools	4%
Like: emotional support	2%
Like: personalizable	1%
Like: accurate information	3%
Like: research / data	2%
Like: info about diet/sugar	1%
Like: blogs	1%
Like: message boards	3%
Like: video	1%
Would involve loved-one	4%
Internet always available	2%
Other positive	5%
ALL NEUTRAL MENTIONS	14%
None / Non-answer	3%
Don't know	2%
Neutral factual, general	6%
Neutral factual: time	2%
ALL NEGATIVE MENTIONS	18%
Not interested	1%
No or limited time, not a good use of my time	8%
Don't need more info	3%
DISLIKES: ALL	3%
Tools don't appeal to me	1%
Don't like: blogs	2%
Don't like: message boards	1%
Rely on doc for information	1%
Don't have easy access to internet	1%
Other negative	1%

Q40. What advice would you give to an organization that would like to develop a website to help caregivers of people with diabetes?

	TOTAL ASKED
TOTAL ASKED	1002
General positive	5%

EASE OF USE	41%
Keep it simple	16%
User-friendly, easy to use	18%
Easy to understand	16%
Good search function	2%
INFORMATION GENERAL	23%
Keep up-to-date	4%
Thorough	3%
Provide info	7%
Provide basics	1%
Provide info for experienced caregivers	1%
News and news alerts	1%
Data / Research tools	1%
Expert / Physician answers	2%
Email newsletters	1%
Local groups / resources	2%
Tips about medication administration, compliance, education	3%
Info for patients	1%
FOOD, DIET, AND EXERCISE	7%
Diet / Food info	5%
Recipes	1%
Exercise	1%
PATIENT HEALTH	4%
Pt mental / emotional health	2%
Info about complications	2%
Info about comorbidities	1%
TOOLS REQUESTED	12%
Interactive tools	3%
Forums	1%
Chat	2%
Blogs	1%
Calendar	1%
Monitor/Track sugar levels	1%
Stories from other CGs	3%
Audio/Video tools	1%
CAREGIVER RESOURCES	6%
CG mental / emotional health	3%
Respite care	1%
Cost and insurance	1%
Communication with patient	1%
Advertise your site	1%
Natural / Alternative therapies	1%
No marketing	5%
Monitor content to ensure accuracy	4%
Provide opportunities for surveys and feedback	2%
Printable and mailed information	1%
Samples, coupons, freebies	1%
Make it attractive	1%
Other	3%
Other specific content	4%

None / Non-answer	5%
Don't know	4%
Neutral factual, general	1%

Q41. What is your ZIP code? (Region)

	TOTAL ASKED
TOTAL ASKED	1002
Northeast	24%
Midwest	26%
South	30%
West	20%

Q42_1. # of people in household: How many people, including yourself and any children, live in your household?

	TOTAL ASKED
TOTAL ASKED	1002
1	6%
2	34%
3-4	44%
5+	14%
Prefer not to answer	2%

Q43. Are there any children or grandchildren living in your household under 18 years of age?

	TOTAL ASKED
TOTAL ASKED	1002
Yes	35%
No	63%
Prefer not to answer	2%

Q44AGE. Caregiver Age:

	TOTAL ASKED
TOTAL ASKED	1001
18-35	24%
36-45	25%
46-55	30%
56-65	18%
66+	4%
MEAN AGE	45.51

Q45. Caregiver Sex:

	TOTAL ASKED
TOTAL ASKED	1002
Male	30%
Female	70%

Q46. Caregiver Marital Status:

	TOTAL ASKED
TOTAL ASKED	1002
Married	60%
Living with a partner	9%
Widowed	1%
Separated	1%
Divorced	10%
Single, never married	17%
Prefer not to answer	2%

Q47. What is the last grade of school you completed?

	TOTAL ASKED
TOTAL ASKED	1002
NET:High School/Less	8%
Less than high school	0%
High school degree or GED	8%
NET:Some College/ Tech	30%
Some college	24%
Technical school degree	6%
College degree	37%
Graduate degree	23%
Prefer not to answer	1%

Q49RACE. Caregiver Race:

	TOTAL ASKED
TOTAL ASKED	1002
White	77%
Black	6%
Hispanic	6%
Asian or Pacific Islander	9%
Other	4%

Q50INCOME. What is your total annual household income in 2008 from all sources, before taxes?

	TOTAL ASKED
TOTAL ASKED	1002
Under \$30K	10%
\$30-50K	15%
\$50-75K	23%
\$75-100K	16%
\$100K+	21%
Refused	15%

Q51. According to the American Diabetes Association, what

is the ideal level that a person with diabetes should maintain?

	TOTAL ASKED
TOTAL ASKED	1002
HbA1c levels of 9.0% or below	1%
HbA1c levels of 8.5% or below	1%
HbA1c levels of 8.0% or below	3%
HbA1c levels of 7.5% or below	4%
NET CORRECT	40%
HbA1c levels of 7.0% or below[CORRECT]	20%
HbA1c levels of 6.5% or below[CORRECT]	20%
Not sure	51%

Q52. Diabetes:

	TOTAL ASKED
TOTAL ASKED	1002
is caused by eating too much sugar and sweet foods	6%
is a condition in which the body cannot use food properly[CORRECT]	73%
results when the kidney cannot control sugar in the urine	14%
is caused by liver failure	0%
Not sure	7%

Q53. A diabetes meal plan:

	TOTAL ASKED
TOTAL ASKED	1002
must be individualized to meet a person's needs[CORRECT]	90%
is a diet that requires many special foods	5%
does not allow a person to have any starches	3%
allows a person to have sweets anytime they want	0%
Not sure	2%

Q54. A person with diabetes has a greater chance of having which of the following, compared to a person who does not have diabetes.

	TOTAL ASKED
TOTAL ASKED	1002
A heart attack	2%
Stroke	2%
Blindness	5%
Kidney disease	3%
All of the above[CORRECT]	85%
Not sure	2%

Q55. What should you do if someone with diabetes is suffering from dangerously low blood sugar?

TOTAL

TOTAL ASKED	ASKED
	1002
Call 911	14%
Pour the person a glass of water	0%
Have the person lie down	0%
Find the person's medications and give them to him/her right now	1%
Give the person a fast-acting sugar, such as fruit juice[CORRECT]	82%
NOT SURE	2%