

Lupus: A Survey Among SLE Patients, Physicians, and Supporters

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1 About the Survey

About This Survey

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GfK Roper Public Affairs & Corporate Communications conducted a survey among patients with systemic lupus erythematosus (SLE), as well as supporters who care for patients with SLE, and rheumatologists who treat patients with SLE, to provide insights about patients' experiences with the condition. The specific goals of this survey were to:

- Understand the perceived health and overall well-being of patients
- Assess the effect lupus has had on the relationships of patients and the supporters who care for them
- Evaluate the effect lupus has had on patients' careers
- Understand where gaps in communication and understanding exist between patients and the supporters and doctors who care for them

The survey was conducted from July through September 2011. It involved 502 people who self reported that they had received a diagnosis of lupus, 204 supporters of people with lupus and 251 rheumatologists (physicians who specialize in treating lupus).

The survey was funded and developed by Human Genome Sciences and GlaxoSmithKline.

About This Survey (continued)

The patient and supporter portion of the survey was conducted online from July 28 to August 26, 2011. Sample was provided by online panels of Americans who have previously agreed to participate in surveys and self-identified themselves as SLE sufferers/caregivers. Several panels were used in order to better represent the target audience within the public at large and to collect a sufficient number of patient and caregiver respondents. In total, 502 patients and 204 supporters participated.

The physician survey was conducted via telephone from July 28 to September 9, 2011. The sampling frame for the surveyed rheumatologists was the American Medical Association Directory, screened for those who presently diagnose and treat SLE patients. A national sample of rheumatologists was drawn on a random basis from this frame. In total, 251 rheumatologists participated in this survey.

2 Key Findings

Key Findings

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Patients Don't Fully Express Their Worries About Lupus – Supporters do not necessarily recognize how far patients go to hide from the people who care for them how they truly feel about their lupus. Patients don't disclose the degree to which: they worry about the long-term consequences of their lupus (51% say this describes themselves "very well"); minimize the pain/worry they experience (46%); feel limited by their lupus (43%); and are depressed about not being able to perform everyday activities (40%).

Patients And Supporters Perceive The Doctor/Patient Relationship Slightly Differently – While half of patients "strongly agree" that they can talk freely with their doctors (51%), only one in three supporters say the same about patients (33%). Patients are also much more likely than supporters to "strongly agree" that their physicians understand their symptoms (42% vs. 31%) and have the time and resources to address their lupus (41% vs. 35%).

Key Findings

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Rheumatologists View Themselves As An Important Resource For Patients (87% strongly agree)

Communication gaps about symptoms between doctors and patients – More than half of doctors believe that their patients are open and honest with them about their symptoms (53%). A majority of doctors disagree that patients minimize their symptoms when they talk about their lupus (72% strongly/somewhat disagree).

Supporters Underestimate Symptoms – Arthritis/joint pain and fatigue are the problems about half of SLE patients surveyed struggle with on a daily basis (51% and 46%, respectively, say “everyday”). Supporters recognize these top symptoms, but they underestimate symptoms (19% and 22%, respectively, say arthritis/joint pain and fatigue affect patients “everyday”). When asked to rank which problems patients report most frequently, doctors rank fatigue (50%) ahead of arthritis (35%).

Key Findings

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Assessments Of Patients' Support Vary Greatly By Respondent Type –

While half of patients say their family/friends are “very supportive” (52%), nearly 8 out of 10 supporters describe themselves as “very supportive” of friend/family members with lupus (78%). Doctors, interestingly, are least likely to perceive a patient’s family/friends as “very supportive” (34%).

Lupus Puts Strain On Relationships – Patients and supporters are in agreement that having lupus puts a strain on their relationships. The degree of that strain is also similar. Seven out of 10 patients (68%) agree strongly/somewhat that “lupus affects virtually every relationship a patient has” and a similar number of supporters agree as well (74%). One noticeable difference between the two groups is the perceived degree to which patients with lupus maintain relationships with others who have the disease. Supporters are much more likely to agree that patients have such relationships (72% agree strongly/somewhat compared to 54% of patients).

Key Findings

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Patients Feel Others Sometimes View Them Critically – Two-thirds or more patients “agree” that friends and family think patients can do more than they actually can (75%), think they can improve their condition by eating better (80%) and believe that they can identify with living with lupus (67%). The majority of patients also agree that their family and friends believe that lupus symptoms make patients unmotivated (67%) and that lupus has affected their reliability and dependability (59%).

Lupus Impacts A Patient’s Career – A majority of patients, supporters and doctors report a change in patients’ career plans due to lupus. Two-thirds of patients report reducing the number of hours worked (67%), or quitting work/retiring earlier than planned (63%). Most doctors report that their patients often or sometimes have made the same changes (95% and 78%, respectively).

Key Findings

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More Resources For Lupus Desired By Patients And Especially Supporters –

Both patients and supporters “agree” that they wish there were more resources available to help handle issues that patients with lupus face, but supporters seem more interested (58% “strongly agree,” compared to 48% among patients).

Supporters, overall, take a more active role in seeking out others who have lupus (28% vs. 19% of patients). This desire for information could also be the reason that supporters are more likely to agree that there is a community already available where the lupus patients have a voice and can be heard (34% vs. 26%).

Key Findings

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Men Appear To Be Much More Negatively Impacted By Lupus Than Women

– Men are significantly more likely than women to say “lupus makes them feel flawed as a person” (69% vs. 55%) and “nothing more can be done to help my condition” (60% vs. 46%). They also are more likely to agree they have had someone end a relationship with them specifically due to their lupus (55% vs. 24%), and they would still be married/in a serious relationship if it were not for lupus (55% vs. 38%). Interestingly, men are significantly more likely than women to have tried almost all of the coping mechanisms examined in the survey including yoga (55% vs. 40%) and joining a support group (58% vs. 32%).

Younger Lupus Patients Struggle The Most With Negative Feelings Toward Lupus

– Compared to their older counterparts, lupus patients aged 18 to 34 are more likely to say that they feel depressed, down or hopeless as a result of lupus (84% vs. 77% of those 25 to 54 and 65% of those 55+), that people living with lupus are ignored (64% vs. 56% and 48%), and that people with lupus keep to themselves and would rather be alone (60% vs. 57% and 46%). At the same time, they are most likely to feel their doctor is an advocate for them as well (80% vs. 73% and 69%).

Key Findings

Despite Feeling Limited In Performing Many Everyday Activities, One In Four Patients Still Describe Themselves As Hopeful Or Optimistic – Twenty-four percent of patients who rate themselves as “extremely limited” or “very limited” to at least half of the examined items say they are hopeful or optimistic routinely or most of the time.

Patients Feel Alone And Powerless And Minimize Symptoms So As Not To Upset Their Family – Half (49%) of patients who describe themselves as “feeling alone and powerless” also admit to minimizing the pain or worries they experience because they do not want to upset their families. This compares to only 5% of patients who also feel alone and powerless but don’t minimize their symptoms. Minimizing in order to not upset their family pervades both sub-groups, but is stronger among those who feel powerless.

Key Findings

A Desire For More Resources Is Strong Among Those Who Feel Alone And Powerless – While a high number of patients across the board would like more resources, the desire is significantly greater among those who feel alone and powerless than among those who do not (49% vs. 38%).

Patients Who Feel Alone And Powerless Are Slightly More Likely To Agree They Can Talk Freely To Their Physician About Their Symptoms Than Those Who Don't Have Such Feelings – More than 4 in 10 patients (43%) who say they feel alone and powerless agree (strongly/somewhat) that they can talk freely to their doctor about their lupus symptoms. This compares to 39% of patients who don't describe themselves as feeling alone and powerless. This suggests that the doctor/patient relationship does not negatively affect the patient's feelings.

A Perceived Lack Of Time And Resources By The Doctors Is Not Contributing To Feelings Of Being Alone And Powerless By The Patients – In fact, patients who describe themselves as being alone and powerless (38%) are equally as likely as those who do not (37%) to agree their physician has the time and resources to address their needs.

Key Findings

Regardless Of Being Able To Talk Openly To Their Doctor, High Numbers Of Patients Seek More Resources – Seven out of ten patients (71%) who agree they can talk freely to their physician about their lupus symptoms also wish there were more resources available. This compares to only 16% who say they cannot talk freely to their doctor. Similarly, 65% of patients who would welcome more resources agree their physician does have the time and resources to address their needs. This suggests a communication gap between the doctor and the patient.

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Key Findings

Equal Numbers Of Patients Seek Out More Resources Regardless Of Whether They Feel The Severity Of The Disease Or The Unpredictability Of The Symptoms Is The Most impactful On Their Life – Three in 10 patients (30%) who wish more resources were available feel the severity of the disease is the most impactful part of living with lupus. One in three (34%) who also seek out additional information feel it is the unpredictability of the symptoms that most impacts all aspects of their life, including home and career.

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Reader's Notes

Percentages Not Totaling 100%

- For tabulation purposes, percentage points are rounded to the nearest whole number. As a result, the total percentage in a given table column may be slightly greater or less than 100%.
- All numbers shown on the charts are percentages unless otherwise noted.

Reader's Notes: Significance Testing

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- Significance testing was performed at the 95% confidence level.
- Statistically significant differences are shown in tables by column letters.
 - Differences that are significant at the 95% confidence level are denoted by uppercase letters.
 - Where significant differences occur, the letter that corresponds to the column of the smaller number is placed next to the larger of the two numbers.

▪ Example:

<i>Means</i>	Total (A)	Segment 1 (B)	Segment 2 (C)	Segment 3 (D)	Segment 4 (E)	Segment 5 (F)
Attribute 1	4.2 F	4.3	4.1	4.5 A	4.2	3.9

Compared to segment 5 (column F), other segments (in total) place significantly higher importance on attribute 1.

Compared to all other segments in total (column A), respondents in segment 3 are significantly more likely to agree with attribute 1.

3 Detailed Findings

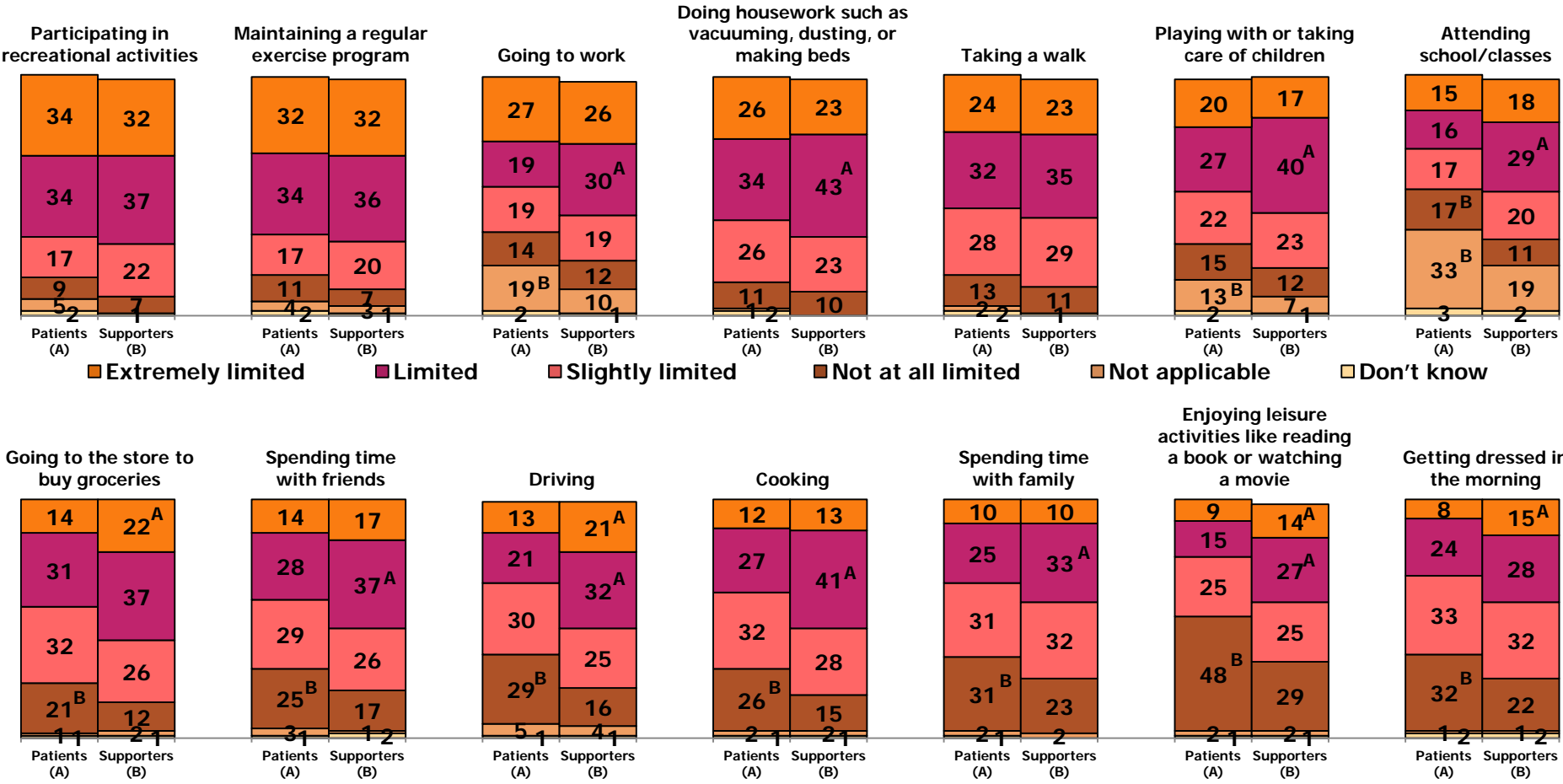
Health & Well-Being

Health & Well Being – At A Glance

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- Patients and supporters are “in tune” when it comes to evaluating the effect lupus has on patients’ everyday activities. They both admit that there are limitations when performing simple tasks such as getting dressed in the morning and going to the store to buy groceries, but interestingly, in many cases, supporters perceive the limitations to be greater than do the patients themselves. This is most notable when asked about how limited patients feel by driving, buying groceries, enjoying leisure activities and getting dressed. Doctors, on the other hand, report “routine” discussions between themselves and their patients more so when their patients feel “extremely limited” by something. Overall, however, doctors do observe that patients do report struggling with performing everyday activities.
- There is a certain “disconnect” between patients and supporters about the perceived degree to which patients experience discomfort from their lupus. More patients report experiencing “fatigue,” “memory loss,” issues with “physical appearance,” “difficulty breathing,” “arthritis/joint pain,” “GI symptoms,” “anxiety,” “depression” and “other kinds of pain” everyday than supporters observing these in patients. Among doctors, the most recognized symptoms are fatigue and arthritis/joint pain.
- Despite the discomfort of lupus, patients seem determined to make the best of their life and are hopeful. They do worry about the long-term health consequences and believe it places limitations on their life, but they admit to downplaying their pain to protect their family. Supporters, in turn, see patients struggling to a lesser degree.
- Long-term health concerns are a frequent topic of conversation between doctors and patients, but what’s interesting is how few doctors (only 2 in 10) say their patients “often report” minimizing their symptoms compared to nearly half of patients saying this statement describes them “very well.”

Supporters Understand Limitations Imposed By Lupus – Supporters generally share patients’ views of the limitations lupus places on patients. When they differ, it is the supporters who feel that patients are “extremely” limited to a greater degree. The biggest disconnect seems to be in terms of driving and going to the store to buy groceries, but also is noted for getting dressed and enjoying leisure activities.



Patients Q1: Following is a list of everyday activities that people do. In your opinion, to what degree have you been limited doing each of these activities due to lupus over the past six months?

Supporters Q1: Following is a list of everyday activities that people do. In your opinion, to what degree has your friend or family member with lupus been limited in doing each of these activities due to lupus over the past six months?

Base: Patients (n=502); Supporters (n=204)



Feeling Alone And Powerless Is Driven By Being Limited In Performing Activities That People Take For Granted – Patients who either feel alone and powerless, or minimize their symptoms, or wish there were more resources/credible information are all significantly more likely than the total sample to be limited in performing most activities.

% saying "extremely limited/very limited"

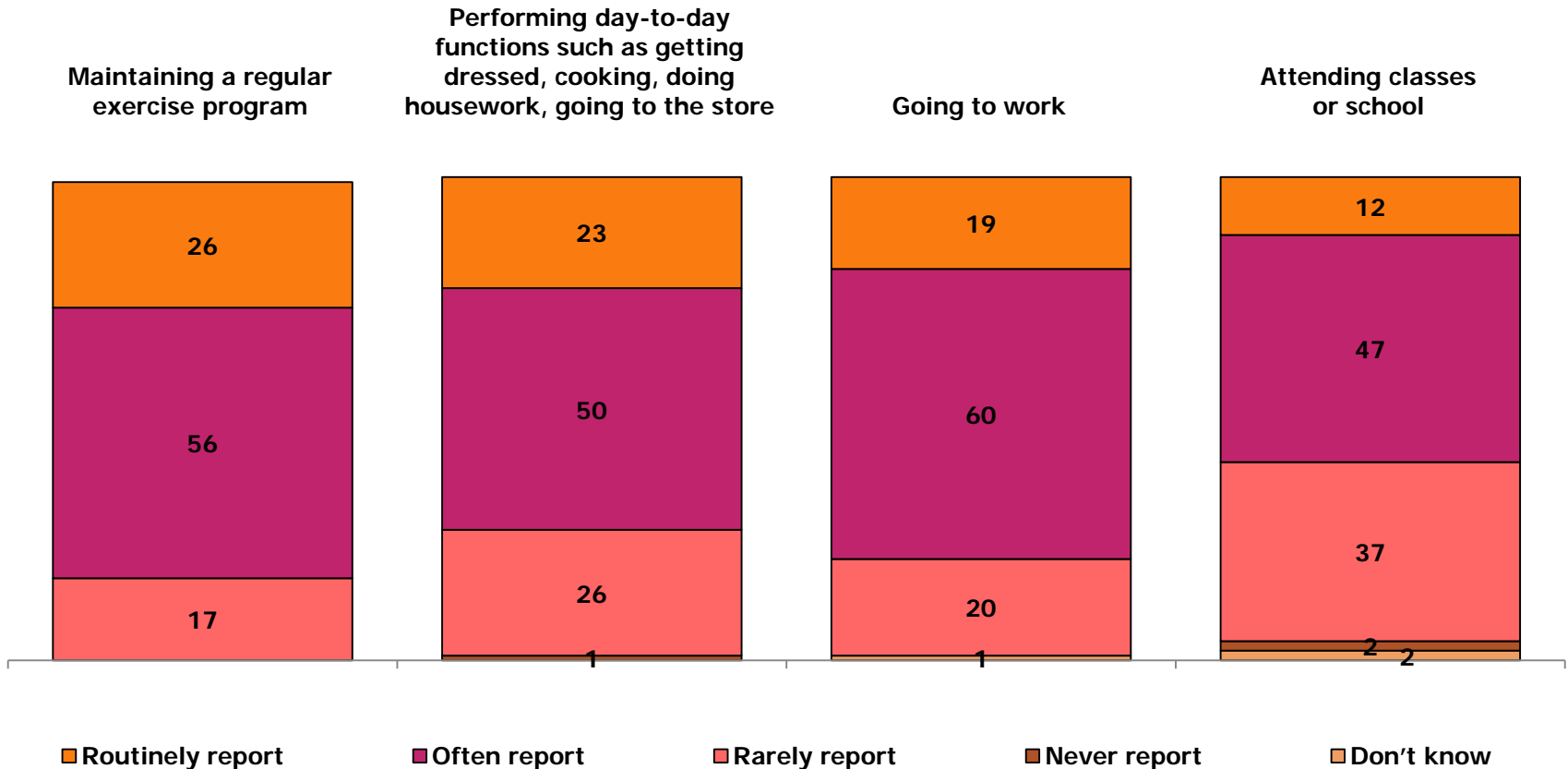
	Total Patients	Limited by 7 or more activities but hopeful and optimistic	Feel alone and powerless and minimize symptoms so not to upset the family	Feel alone and powerless and wish there were more resources	Feel alone and powerless and wish there were more credible information
	(A)	(B)	(C)	(D)	(E)
		N=118	N=244	N=248	N=200
Participating in recreational activities	68	93 ^A	75 ^A	76 ^A	72
Maintaining a regular exercise program	66	91 ^A	75 ^A	75 ^A	75 ^A
Doing housework	59	88 ^A	71 ^A	70 ^A	70 ^A
Taking a walk	56	95 ^A	65 ^A	64 ^A	66 ^A
Playing with or taking care of children	48	80 ^A	57 ^A	57 ^A	55 ^A
Going to work	47	75 ^A	56 ^A	56 ^A	59 ^A
Going to the store to buy groceries	45	85 ^A	57 ^A	57 ^A	59 ^A
Cooking	39	75 ^A	52 ^A	52 ^A	55 ^A
Spending time with friends	42	81 ^A	56 ^A	56 ^A	56 ^A
Driving	34	64 ^A	47 ^A	45 ^A	51 ^A
Spending time with family	34	66 ^A	50 ^A	50 ^A	48 ^A
Getting dressed in the morning	32	65 ^A	43 ^A	43 ^A	44 ^v
Attending school/classes	30	62 ^A	39 ^A	39 ^A	41 ^A
Enjoying leisure activities	24	43 ^A	35 ^A	35 ^A	40 ^A

Patients Q1: To what degree have you ben limited doing each of these activities due to lupus over the past six months?

Base: Patients (n=502)

Patients Talk To Doctors About Difficulties – Most doctors say that their patients do report difficulties related to lupus causing problems with performing everyday activities. Still, doctors say that most patients are not “routinely” reporting difficulties, but are rather “often” reporting them.

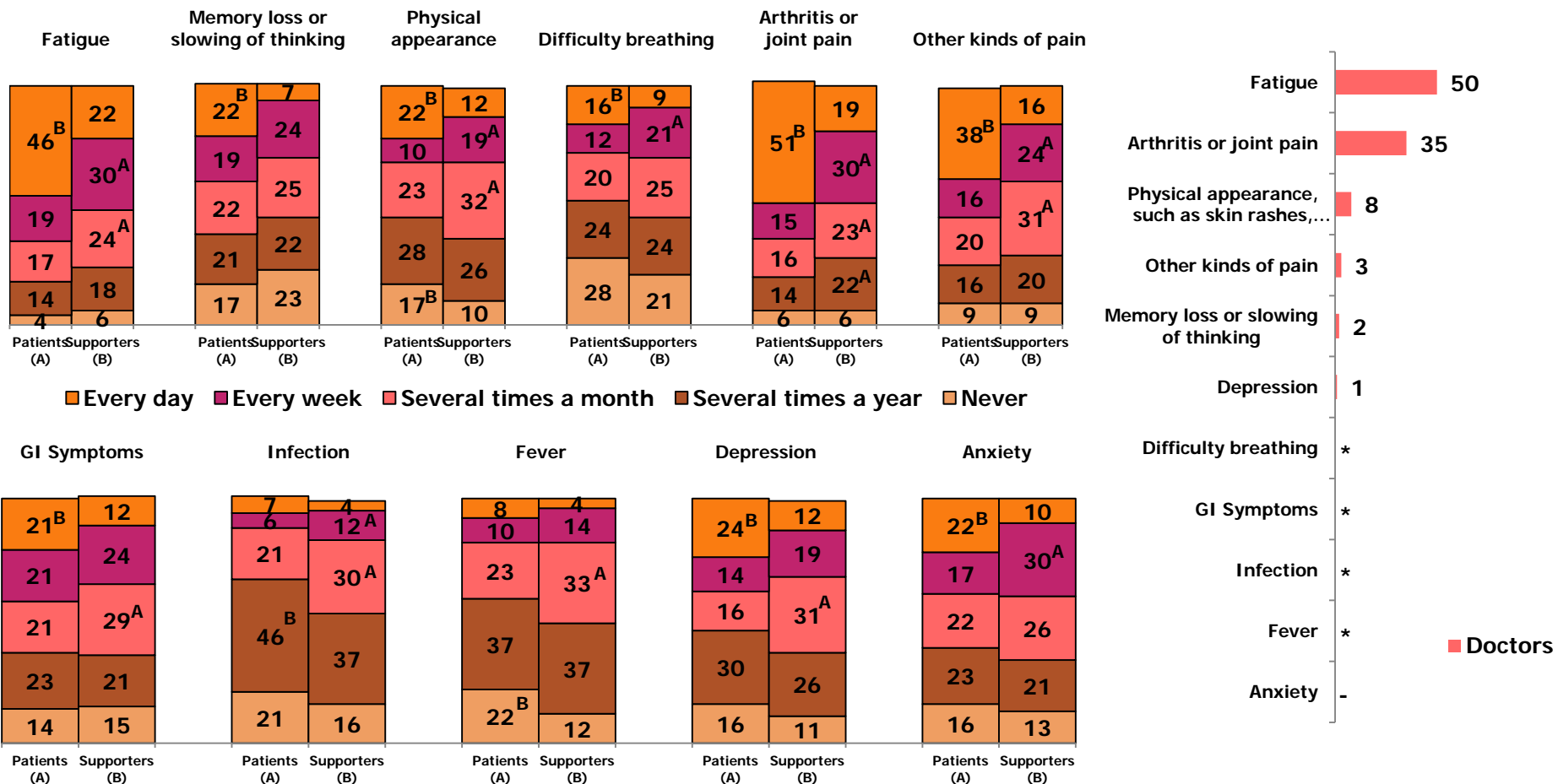
Doctors



Doctors Q1: In general, how often do your lupus patients report difficulty with the following activities due to lupus over the past six months?

Base: Doctors (n=251)

Supporters Underestimate Symptoms – Arthritis/joint pain and fatigue are the problems most SLE patients struggle with on a daily basis. Supporters recognize these top symptoms, but overall they underestimate the degree to which they affect patients. Doctors, when asked to rank the top three most common problems associated with lupus, place fatigue ahead of arthritis, with physical appearance ranked third. Few doctors rank the other symptoms among the “most common.”



Patients Q2: How often, if ever, would you say the following problems affect you?

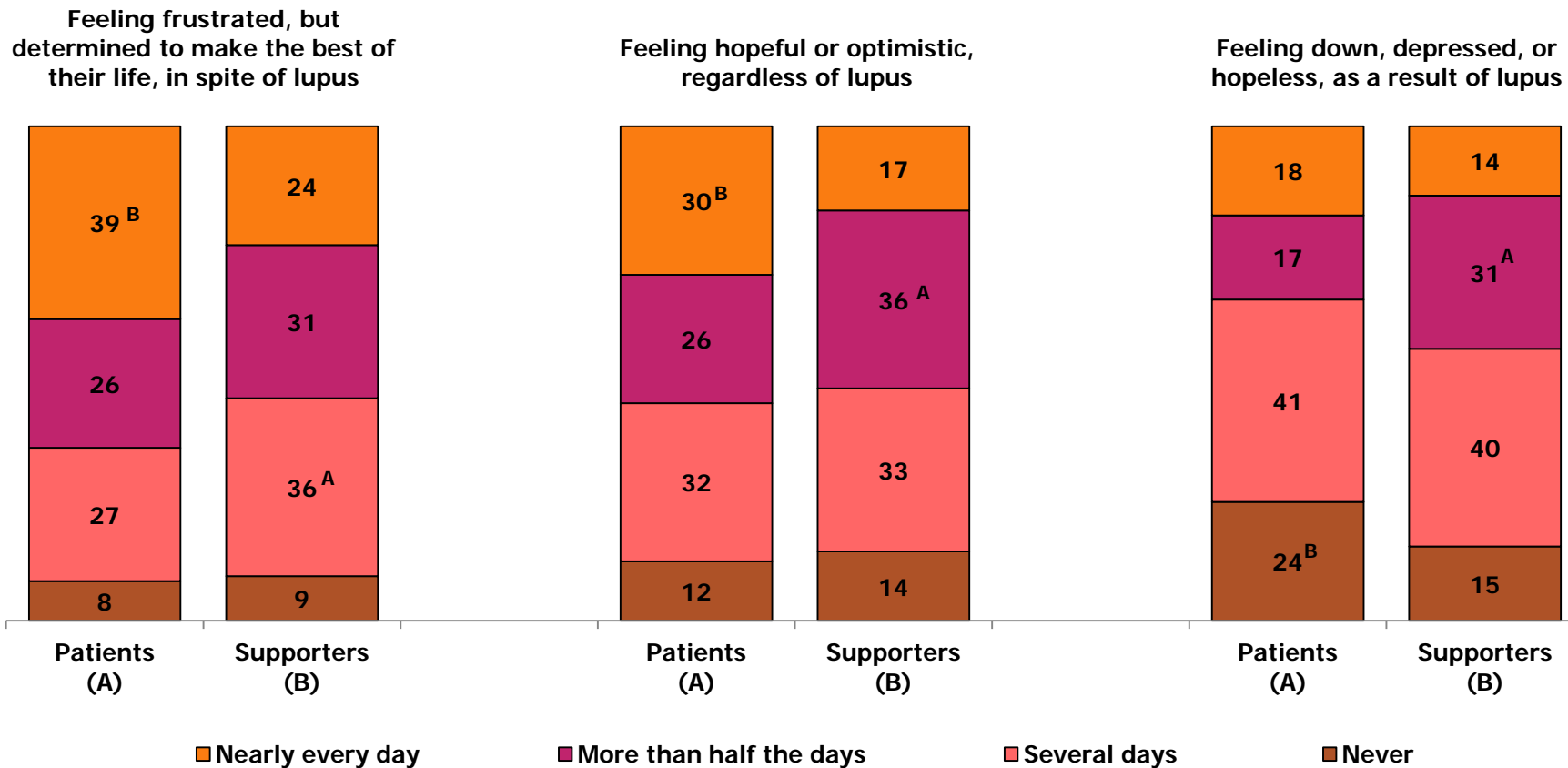
Supporters Q2: How often, if ever, is your friend or family member who has been diagnosed with lupus affected by the following problems?

Doctors Q2: I am now going to read you common problems associated with lupus. I would like you to rank the top three problems starting with the most common. Which one is second most common? Which is the third, most common problem reported by patients?

Base: Patients (n=502); Supporters (n=204); Doctors (n=251)

* =less than 0.5%

Supporters' Differing Assessments Of Patients' Emotional Outlook – Supporters' views of patients' emotional state differ somewhat from the views of the patients themselves. While supporters recognize that patients feel frustrated, they are less likely to see it as a daily occurrence. Yet supporters are also more likely to perceive the patients as being depressed nearly every day/more than half the days than patients themselves. Patients, however, are more likely than supporters to report feeling hopeful or optimistic regardless of their lupus.



Patients Q3: How often in the past month, if ever, have you experienced the following feelings?
 Supporters Q3: How often in the past month, if ever, has your friend or family member with lupus been impacted by these feelings?
 Base: Patients (n=502); Supporters (n=204)



While Women Are More Likely To Feel Frustration, Both Genders Are Equally Hopeful – Almost all women agree that despite feeling frustrated they are determined to make the best of their life in spite of lupus. They also admit feeling hopeful or optimistic nearly everyday or almost all days. Men, despite seeming to struggle more with some aspects of having lupus, also are optimistic most days. Younger lupus patients appear to be struggling most with the disease. A high number say they feel down, depressed or hopeless nearly every day or almost all days.

% saying "nearly everyday/"almost all the days"						
	Total Patients	Gender		Age		
		Men	Women	18-34	35-54	55+
		(K)	(L)	(S)	(T)	(U)
		N=128	N=374	N=168	N=210	N=124
Feeling frustrated but determined to make the best of my life, in spite of lupus	92	88	93 ^K	92	93	90
Feeling hopeful or optimistic, regardless of lupus	88	88	88	87	90	87
Feeling down, depressed, or hopeless, as a result of lupus	76	81	74	84 ^U	77 ^U	65

Patients Q3: How often in the past month, if ever, have you experienced the following feelings?
Base: Patients (n=502)

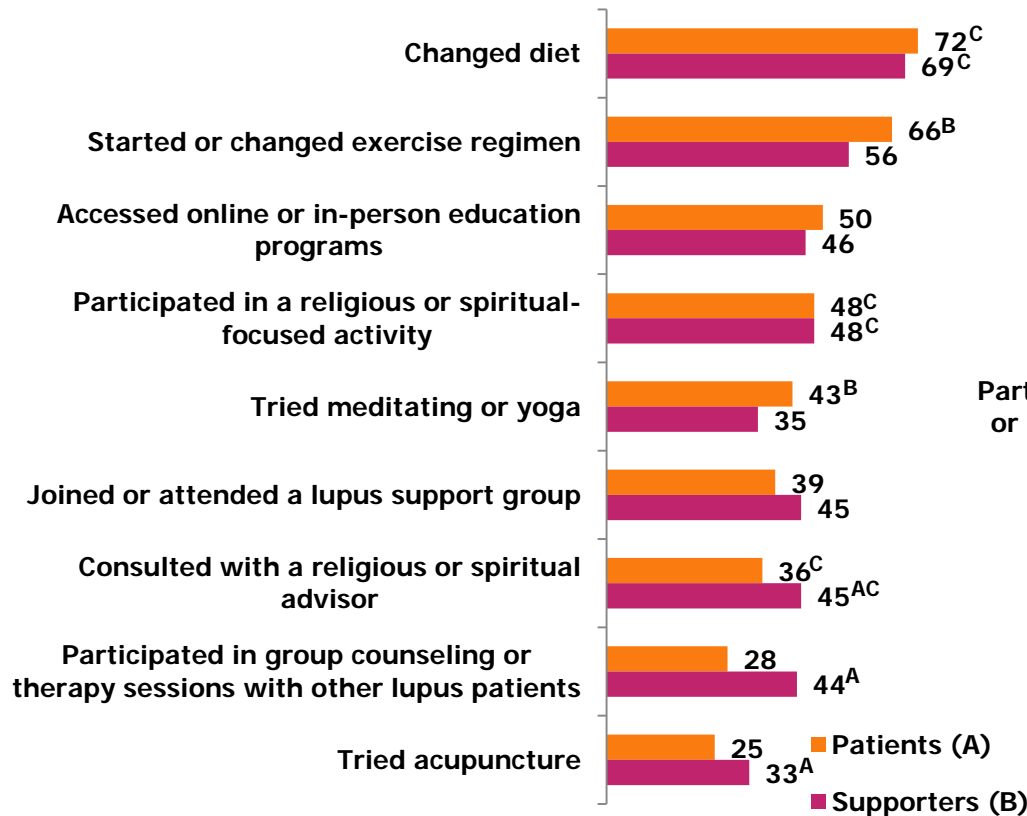
Frustration And Depression Are Higher Among Those Who Feel Alone And Powerless And Wish For More Information And Resources – Again, compared to total patients, those who say they feel alone/powerless or minimize their symptoms or wish for more resources/credible information are much more likely to feel down, depressed or hopeless. They are also more likely to be frustrated but determined to make the best of their situation.

When First Diagnosed With Lupus (%)					
	Total Patients	Limited by 7 or more activities but hopeful and optimistic	Feel alone and powerless and minimize symptoms so not to upset the family	Feel alone and powerless and wish there were more resources	Feel alone and powerless and wish there were more credible information
	(A)	(B)	(C)	(D)	(E)
		N=118	N=244	N=248	N=200
Feeling frustrated but determined to make the best of my life, in spite of lupus	92	97 ^A	96 ^A	96 ^A	95 ^A
Feeling hopeful or optimistic, regardless of lupus	88 ^{CD}	100 ^A	84	85	85
Feeling down, depressed, or hopeless, as a result of lupus	76	90 ^A	92 ^A	94 ^A	93 ^A

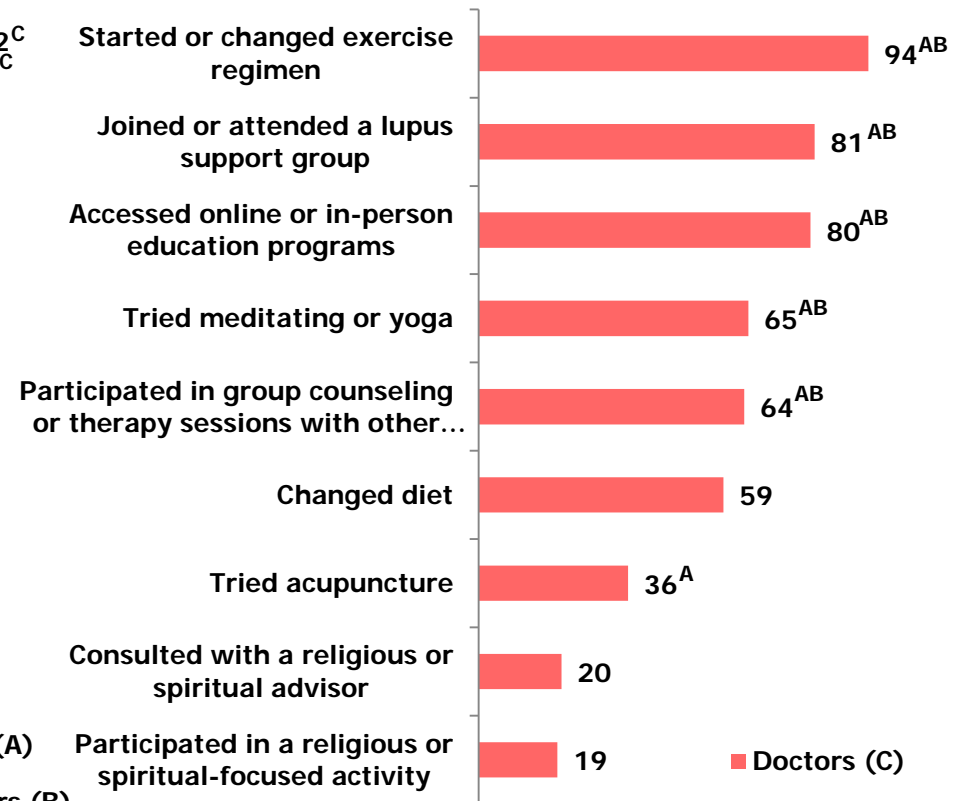
Patients Q3: How often in the past month, if ever, have you experienced the following feelings?
Base: Patients (n=502)

Patients' Coping Strategies Differ From Doctors' Top Recommendations – There appears to be some imbalance between the types of activities patients are doing to cope with their lupus and the frequency in which rheumatologists are recommending them. Both doctors and patients place an exercise regimen near the top of the list, but doctors suggest participating in support groups or counseling sessions and accessing online education programs with much greater frequency than patients are actually doing. Dietary changes and religious or spiritual activities play a much larger role to patients than to doctors.

% Yes



% Yes



Patients Q4: Have you ever done any of the following to help you cope with lupus?
 Supporters Q4: Has your friend or family member ever done any of the following to help cope with lupus?
 Doctors Q3: Do you recommend to patients that they do any of the following to cope with lupus?
 Base: Patients (n=502); Supporters (n=204); Doctors (n=251)

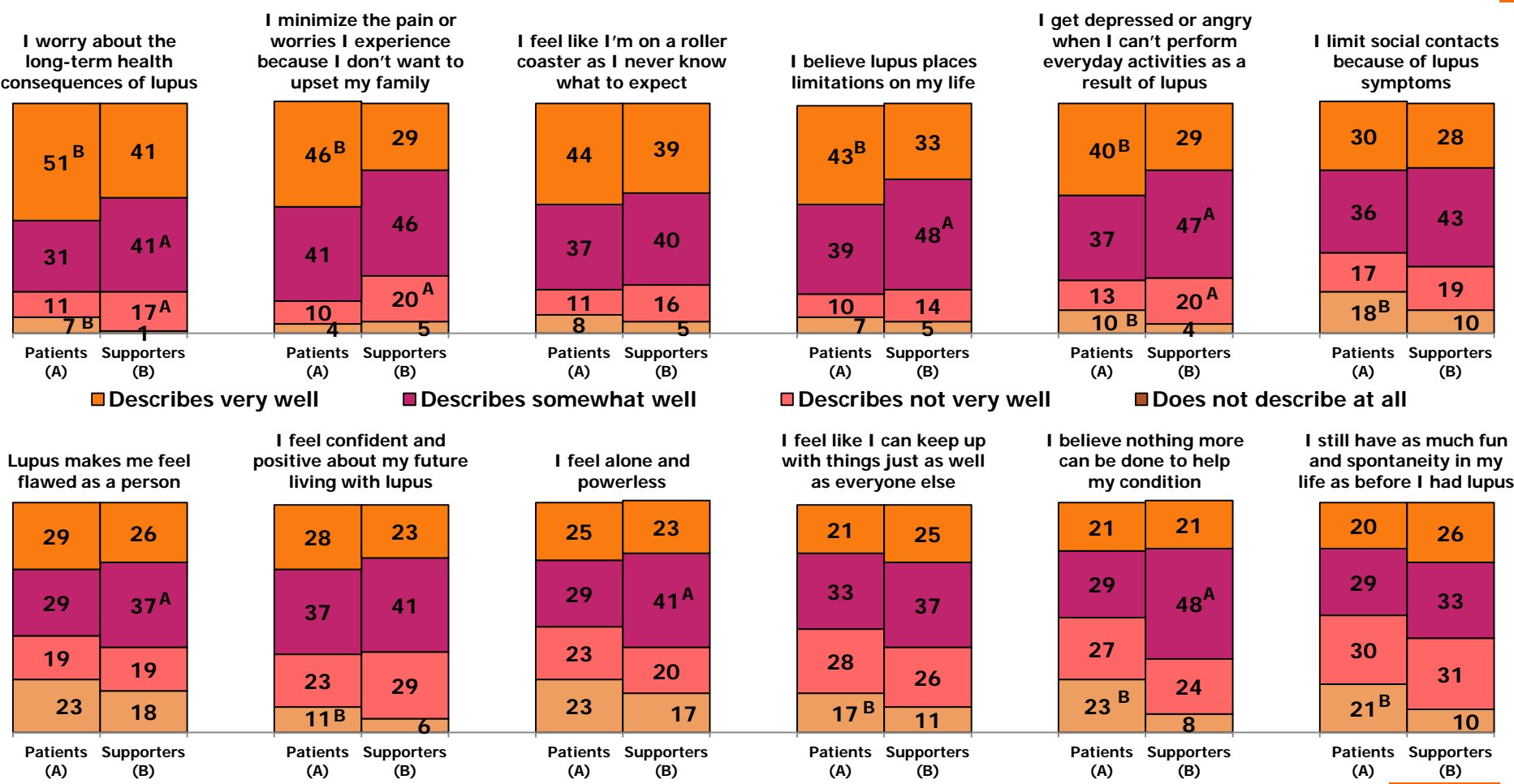


Gender And Age Play A Large Role In The Types Of Things Patients Do To Help Cope With Their Lupus – With very few exceptions, men are significantly more likely than women to have tried both conventional and non-conventional coping mechanisms to help with lupus. The same is true of patients aged 18 to 34 as compared to their older counterparts; older lupus patients are much less likely to have ever done most of the items listed.

% strongly/somewhat agree						
	Total Patients	Gender		Age		
		Men	Women	18-34	35-54	55+
		(K)	(L)	(S)	(T)	(U)
		N=128	N=374	N=168	N=210	N=124
Changed diet	72	72	72	72	73	69
Started or changed exercise regimen	66	73	64	73 ^T	61	65
Accessed online or in-person education programs	50	70 ^L	43	62 ^{TU}	49 ^U	35
Participated in a religious or spiritual-focused activity (e.g. prayer, religious study)	48	57 ^L	45	54	44	49
Tried meditating or yoga	43	55 ^L	40	55 ^{TU}	40	33
Joined or attended a lupus support group	39	58 ^L	32	45 ^U	37	33
Consulted with a religious or spiritual advisor	36	56 ^L	29	44 ^U	34	27
Participated in group counseling or therapy sessions with other lupus patients	28	52 ^L	20	40 ^{TU}	24	19
Tried acupuncture	25	48 ^L	17	37 ^{TU}	17	23

Patients Q4: Have you ever done any of the following to help you cope with lupus?
Base: Patients (n=502)

Patients Don't Fully Express Their Worries About Lupus – Supporters do not necessarily recognize how far patients go to hide from the people who care for them how they truly feel about their lupus. Patients don't disclose the degree to which: they worry about the long-term consequences of their lupus; they minimize the pain/worry they experience; they feel limited by their lupus; and they are depressed about not being able to perform everyday activities.



Patients Q6: How well does each of the following statements describe how you feel about having lupus?
 Supporters Q5: How well does each of the following statements describe your friend or family member with lupus?
 Base: Patients (n=502); Supporters (n=204)



Men Are Less Likely To Let Their Negative Feelings Stand In The Way Of Living Life – Despite a stronger belief that lupus makes them flawed as a person and nothing more can be done, men are also significantly more likely than women to feel they can keep up with everyone else and still say they have as much fun and spontaneity in their life as they did before their lupus diagnosis. Almost all women say they minimize their pain to not upset their families. Younger lupus patients demonstrate the strongest emotions, both positive and negative about living with lupus, especially in terms of feeling alone and powerless.

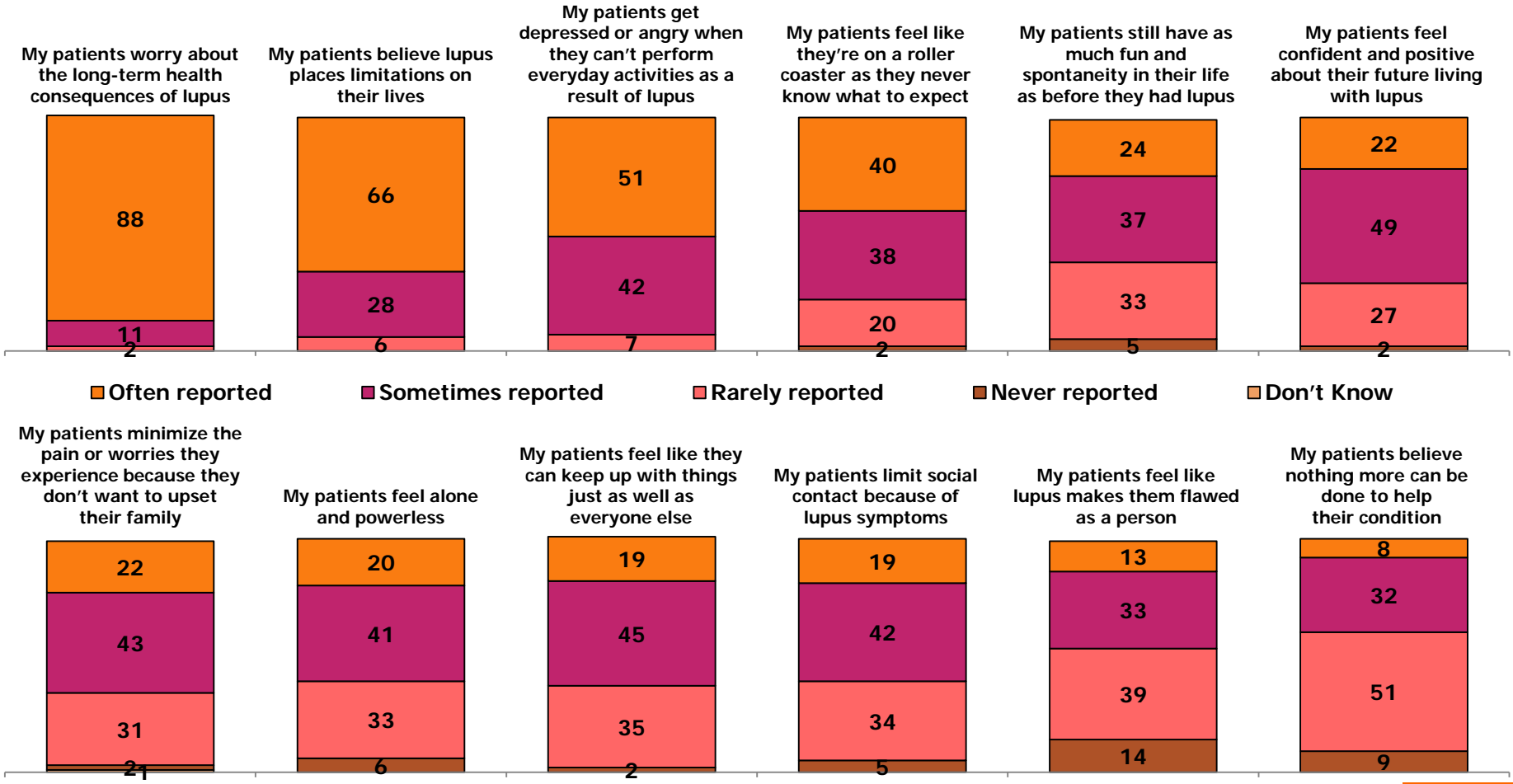
% saying "describes me very well"/"somewhat well"						
	Total Patients	Gender		Age		
		Men	Women	18-34	35-54	55+
		(K)	(L)	(S)	(T)	(U)
		N=128	N=374	N=168	N=210	N=124
I minimize the pain or worries I experience because I don't want to upset my family	86	77	90 ^K	80	93 ^{SU}	83
I believe lupus places limitations on my life	82	78	84	80	85	80
I worry about the long-term health consequences of lupus	82	77	84	85 ^U	85 ^U	73
I feel like I'm on a roller coaster as I never know what to expect	81	81	81	83	84 ^U	74
I get depressed or angry when I can't perform everyday activities as a result of lupus	77	74	78	82 ^U	79 ^U	68
I limit social contacts because of lupus symptoms	66	73	63	71 ^U	67	56
I feel confident and positive about my future living with lupus	66	67	65	63	67	66
Lupus makes me feel flawed as a person	59	69 ^L	55	70 ^U	62 ^U	37
I feel like I can keep up with things just as well as everyone else	54	68 ^L	50	64 ^{TU}	50	49
I feel alone and powerless	54	59	52	66 ^{TU}	54 ^U	37
I believe nothing more can be done to help my condition	50	60 ^L	46	55 ^U	50	42
I still have as much fun and spontaneity in my life as before I had lupus	49	66 ^L	44	59 ^{TU}	44	44

Patients Q6: How well does each of the following statements describe how you feel about having lupus?

Base: Patients (n=502)

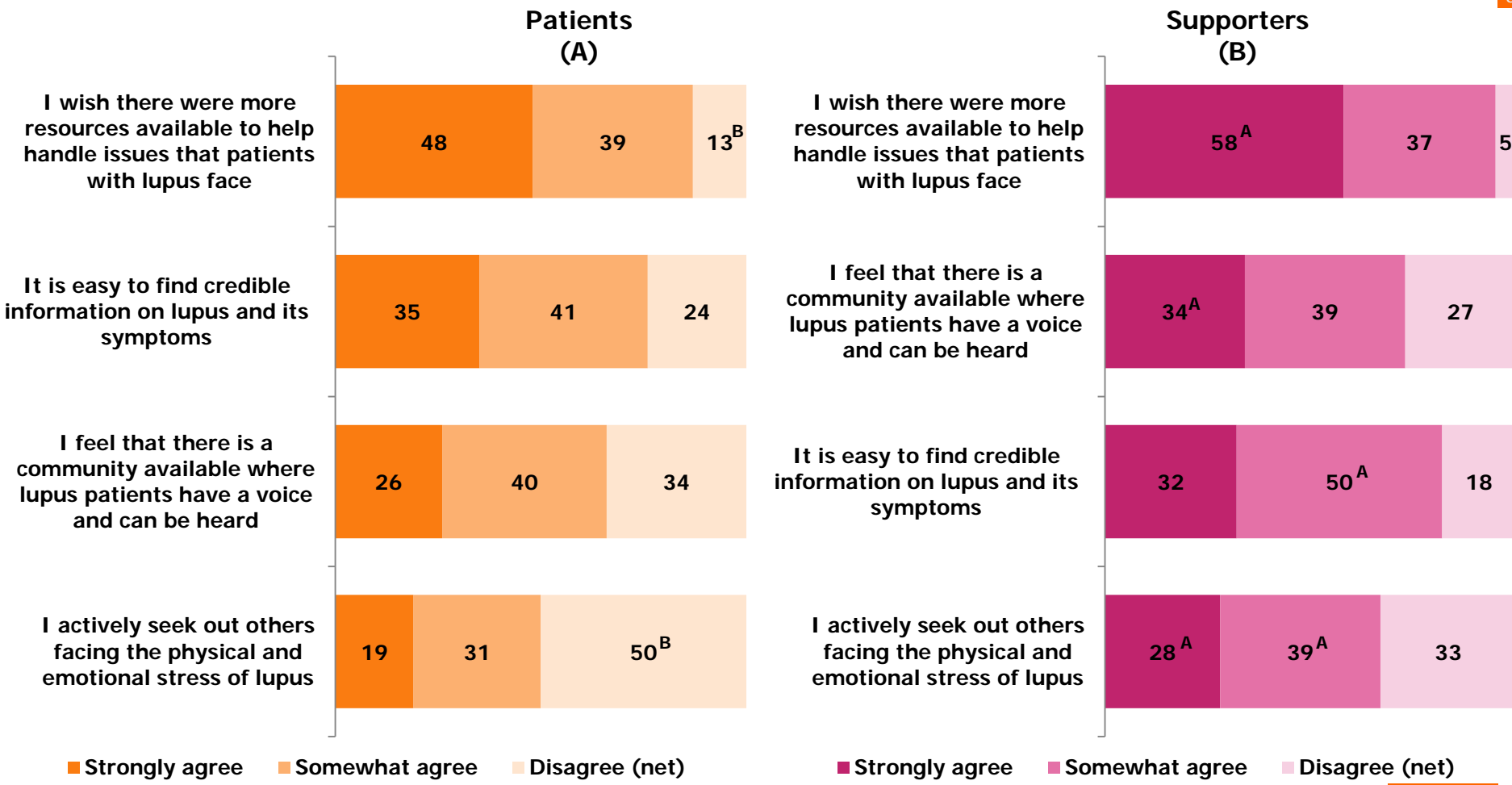
Doctors Report A Range Of Discussions With Lupus Patients – Patients are having a dialogue with their doctors about their feelings toward living with lupus. Doctors report that the most common area of discussion is that of long-term health consequences, which corresponds directly with what patients and supporters are describing as well. Interestingly, however, doctors do not realize the degree to which patients minimize their pain to protect their families. Almost 9 out of 10 patients say they do this, but doctors report these type of discussions are happening much less often.

Doctors



Doctors Q4: How often do your patients report the following statements regarding how they feel about having lupus?
 Base: Doctors (n=251)

More Resources For Lupus Desired By Patients And Especially Supporters – Both patients and supporters “agree” that they wish there were more resources available to help handle issues faced by patients, but supporters seem more interested in such resources. Overall, supporters take a more active role in seeking out others who have lupus. Supporters are also more likely than patients to agree that there is a community already available where the lupus patients have a voice and can be heard.



Patients Q9: How much do you agree or disagree with each of the following statements?
 Supporters Q8: How much do you agree or disagree with the following statements about the availability of information and the community of others living with lupus?
 Base: Patients (n=502); Supporters (n=204)



Men Take A More Active Role In Seeking Out Information And Are More Likely To Believe It Exists – While men and women are equally as likely to wish more resources were available, men are significantly more likely than women to feel it is easy to find credible information and there is a community available for lupus patients. They are also more likely to seek out others with lupus. Patients aged 18 to 34 are twice as likely as those 55+ to say they actively seek out others facing the physical and emotional stress of lupus. Younger patients are also more likely than older patients to feel having lupus is a financial burden.

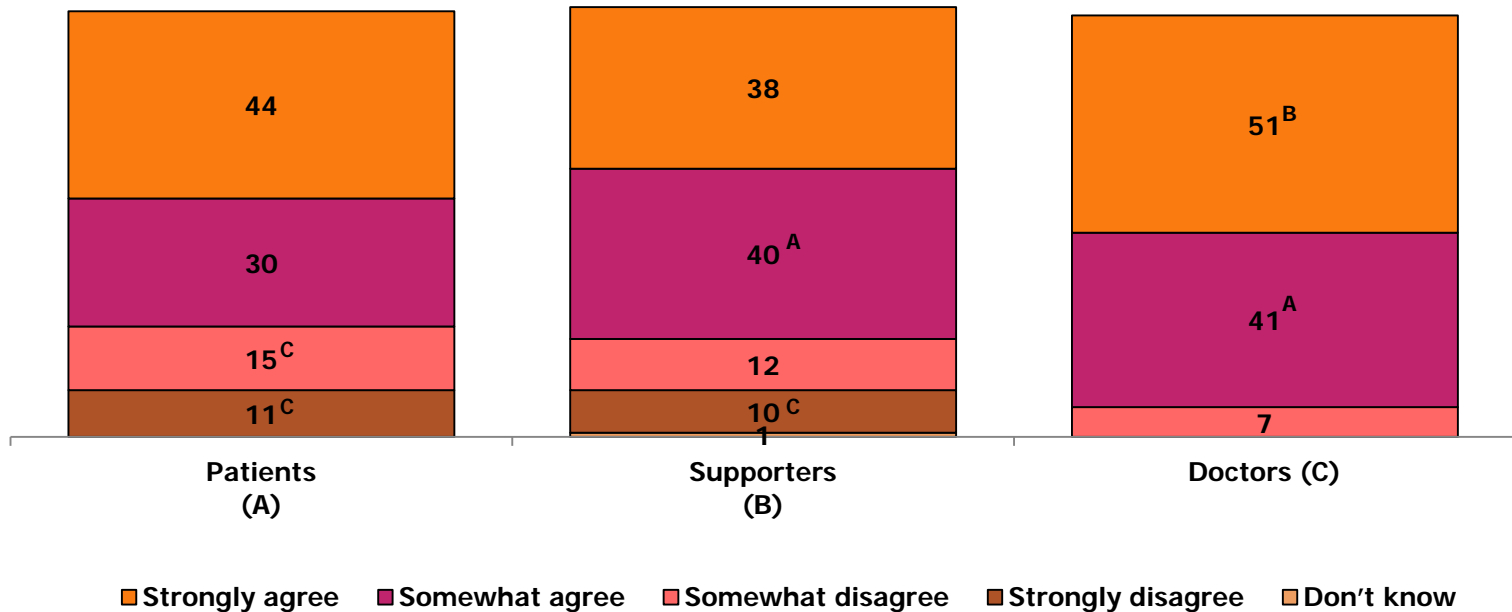
% saying "strongly agree"/"somewhat agree"

	Total Patients	Gender		Age		
		Men	Women	18-34	35-54	55+
		(K)	(L)	(S)	(T)	(U)
		N=128	N=374	N=168	N=210	N=124
I wish there were more resources available to help handle issues that patients with lupus face	87	87	87	85	90	85
It is easy to find credible information on lupus and its symptoms	76	84 ^L	74	77	78	73
For me, having lupus is a financial burden	73	77	72	79 ^U	72	68
I feel that there is a community available where lupus patients have a voice and can be heard	66	82 ^L	60	78 ^{TU}	58	64
I actively seek out others facing the physical and emotional stress of lupus	50	73 ^L	43	68 ^{TU}	46 ^U	33

Patients Q9: How much do you agree or disagree with each of the following statements?
Base: Patients (n=502)

Lupus Seen As A Financial Burden, Especially By Doctors – Doctors are more likely than both patients and supporters to agree that having lupus poses a financial burden. Half “strongly agree” with this statement. It should be noted that 3 out of 4 patients and a similar number of supporters do agree having lupus poses a financial burden.

Having lupus is a financial burden



Patients Q9: How much do you agree or disagree with each of the following statements?

Supporters Q6: How much do you agree or disagree with the following statement?

Doctors Q5: Tell me if you agree, or disagree with the following statement about your lupus patients.

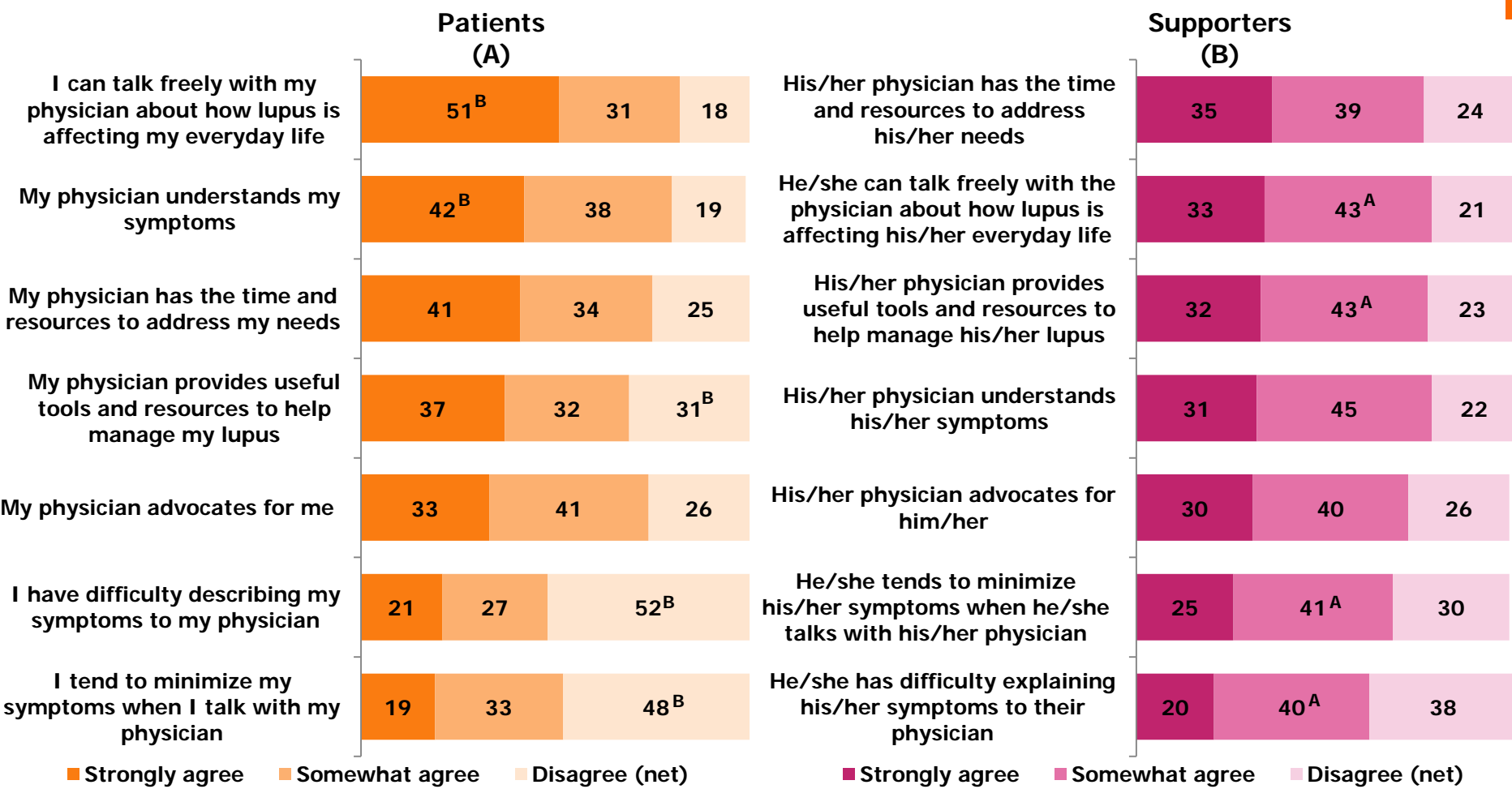
Base: Patients (n=502); Supporters (n=204); Doctors (n=251)

Relationship With Doctors

Doctor/Patient Relationship – At A Glance

- Very few patients describe their doctors' understanding of their struggles of living with lupus as poor. In fact, 3 out of 4 say their doctors have an excellent/good understanding of how lupus affects their daily activities and relationships. Patients also agree that they can talk freely with their physician about how lupus affects their daily lives and feel their doctor understands their symptoms. Yet, despite the positive feelings patients appear to have toward their doctors, only 1 in 3 "strongly agree" that their physician advocates for them.
- Supporters see the doctor/patient relationship a little differently. They are much less likely to "strongly agree" that doctors understand their patients' symptoms and that patients can talk freely to their doctors.
- Even though patients believe they can talk freely to their doctors, they admit to often minimizing their symptoms. Supporters believe patients minimize their symptoms to their doctors even more frequently than patients admit. The majority of doctors, however, disagree when asked if patients do minimize their symptoms when talking with them.
- Almost all doctors see themselves as an important resource for their patients but they do feel frustrated by the limited resources available to educate their patients and agree their patients do expect more resources than are currently available. This possibly explains why only 1 in 3 patients and supporters "strongly agree" their physician provides useful tools and resources to help manage lupus. Doctors prefer printed materials over the Internet when asked which type of resource they use most often to provide information to their patients.

Patients And Supporters Perceive The Doctor/Patient Relationship Slightly Differently – While half of patients “strongly agree” they can talk freely with their doctors, only 1 in 3 supporters say the same. Patients are also much more likely than supporters to “strongly agree” that their physicians understand their symptoms and have the time and resources to address their lupus. Tied back to an earlier finding, supporters are also more likely to agree that patients minimize their symptoms.



Patients Q8: How much do you agree or disagree with the statements below about your relationship with the primary physician managing your lupus?
 Supporters Q7: How much do you agree or disagree with the statements below about your friend or family member's relationship with their primary physician managing their lupus?
 Base: Patients (n=502); Supporters (n=204)



Despite Feeling Their Physician Has The Tools To Help Manage Their Lupus, Men Are More Likely To Both Minimize And Have Difficulty Describing Their Symptoms – Younger patients are also significantly more likely than their older counterparts to also say they minimize their symptoms and have difficulty describing them to their doctors, but they are most likely to agree their physician advocates for them.

% saying "strongly agree" / "somewhat agree"

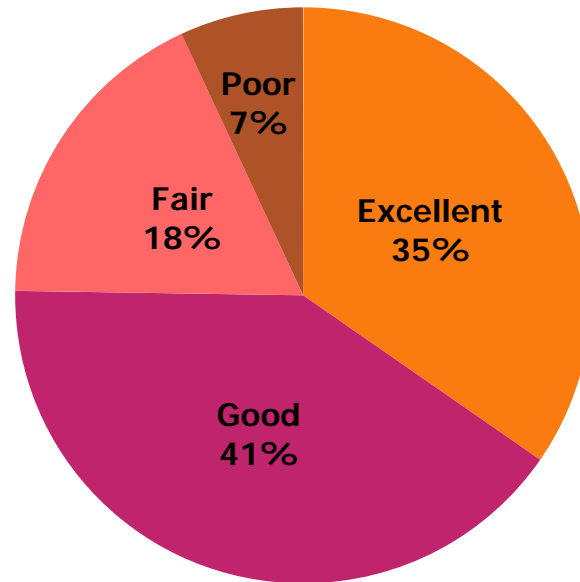
	Total Patients	Gender		Age		
		Men	Women	18-34	35-54	55+
		(K)	(L)	(S)	(T)	(U)
		N=128	N=374	N=168	N=210	N=124
I can talk freely with my physician about how lupus is affecting my everyday life	82	88	80	78	83	85
My physician understands my symptoms	81	83	80	79	84	77
My physician has the time and resources to address my needs	75	82 ^L	73	79	72	75
My physician provides useful tools and resources to help manage my lupus	69	81 ^L	65	72	68	68
My physician advocates for me	74	81 ^L	72	80 ^U	73	69
I tend to minimize my symptoms when I talk with my physician	52	61 ^L	49	65 ^{TU}	51 ^U	37
I have difficulty describing my symptoms to my physician	48	56 ^L	45	61 ^{TU}	48 ^U	30

Patients Q8: How much do you agree or disagree with the statements below about your relationship with the primary physician managing your lupus?

Base: Patients (n=502)

Patients Believe Doctors Have Good Understanding Of Their Life – Patients give their physicians high marks for understanding how their lupus affects their daily activities and relationships, but only 1 in 3 goes as far as saying their physician has an “excellent” understanding of what they are going through.

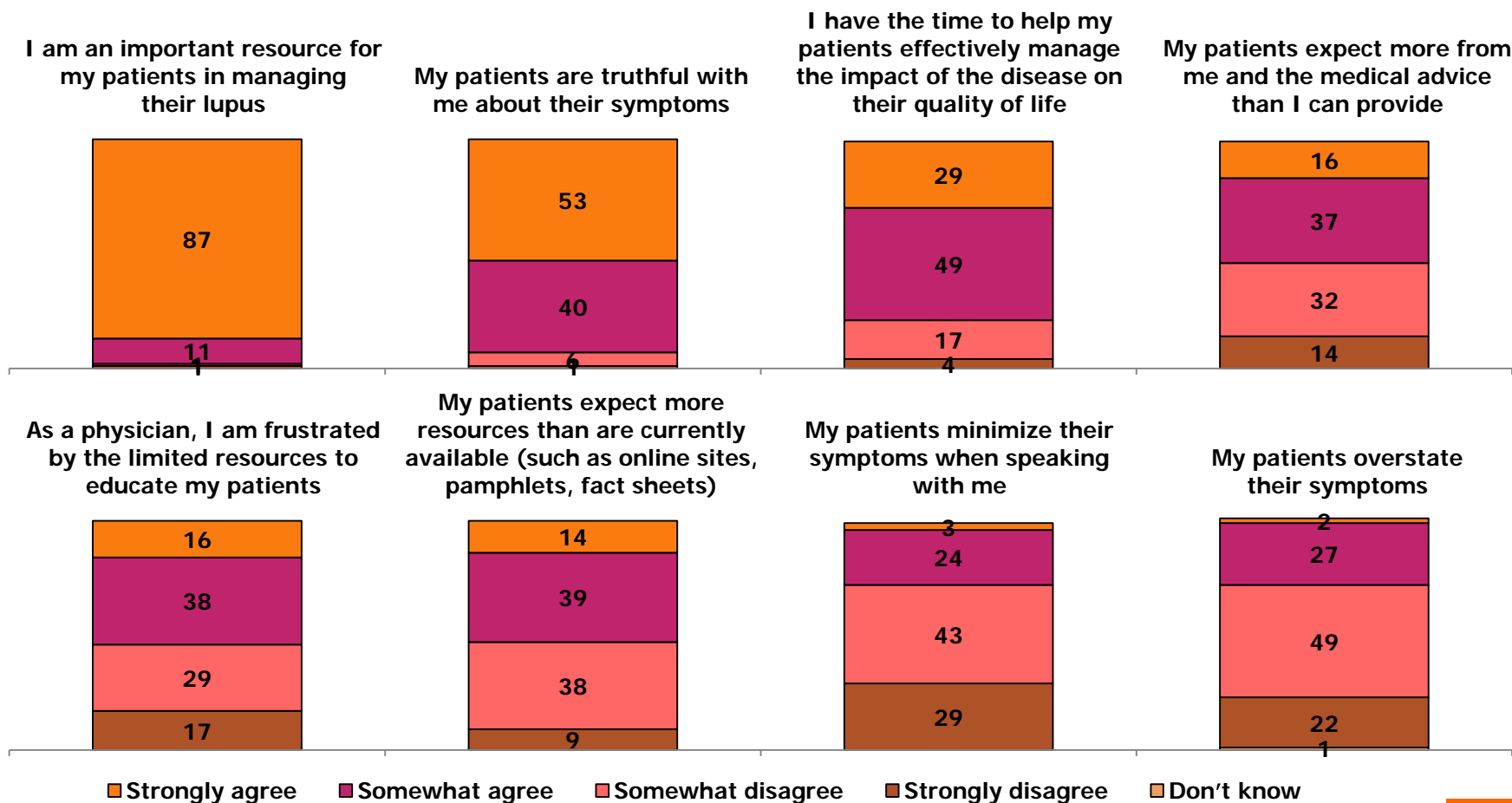
Patients



Patients Q7: How would you rate your physician's understanding of how lupus affects your daily activities and relationships?
Base: Patients (n=502)

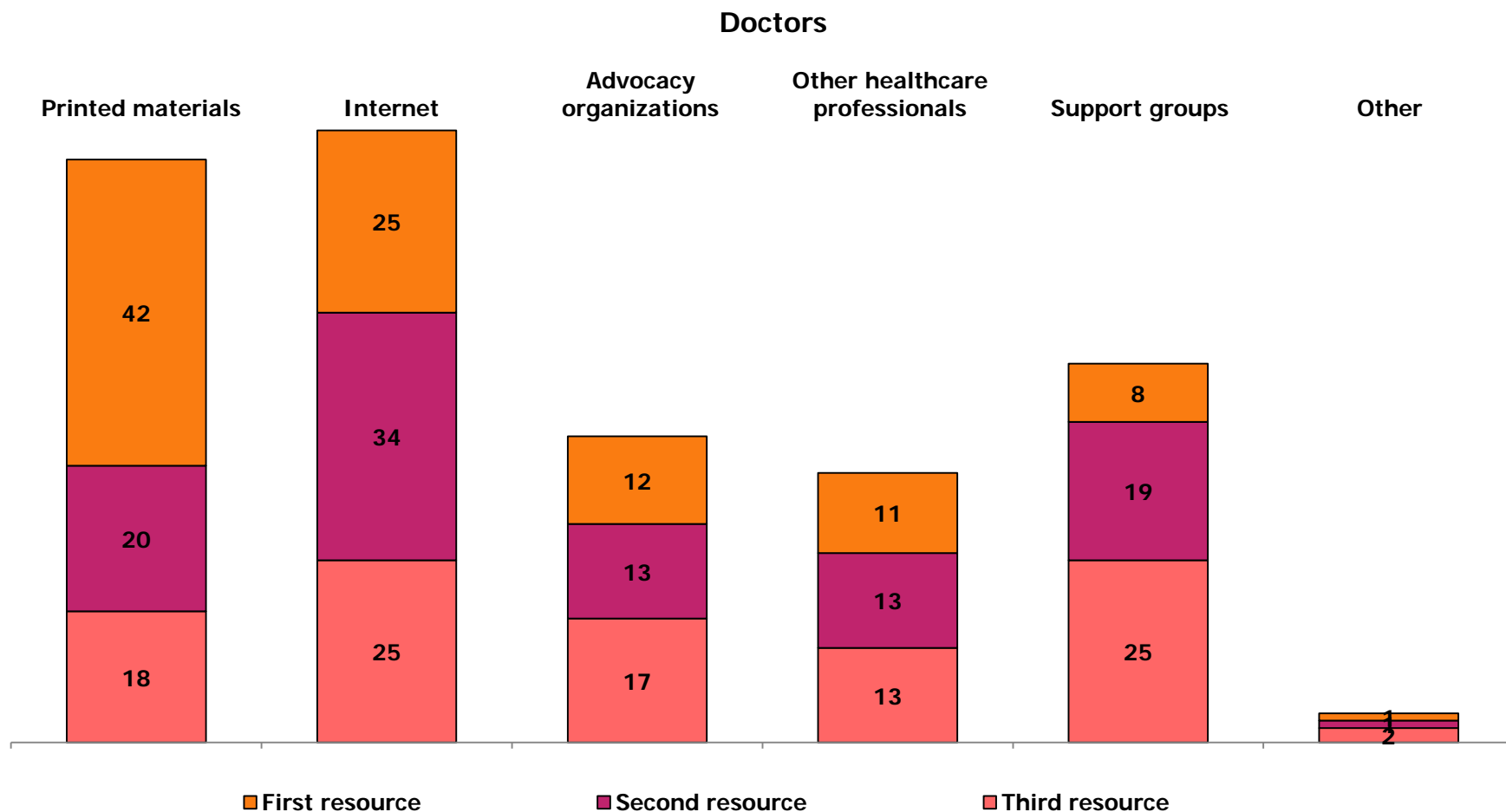
Rheumatologists View Themselves As An Important Resource For Patients – Most believe their patients are open and honest with them about their symptoms. A majority of doctors disagree that patients minimize their symptoms when they talk about their lupus, but as described earlier, this may not necessarily be true.

Doctors



Doctors Q6: Tell me if you agree, or disagree with the following statements about lupus...
 Base: Doctors (n=251)

Printed Materials Top Patient Information Resource For Doctors – When providing information for their patients, doctors most often rely on printed materials as their primary resource. The Internet follows second, with other resources such as advocacy organizations and support groups trailing.



Doctors Q7: I am going to read a list of resources that you might use to provide information to your patients. After I read the complete list, I would like you to tell me which ONE is the resource you use most. Which one is second and finally which one you use third. The list of resources includes...

Base: Doctors (n=251)

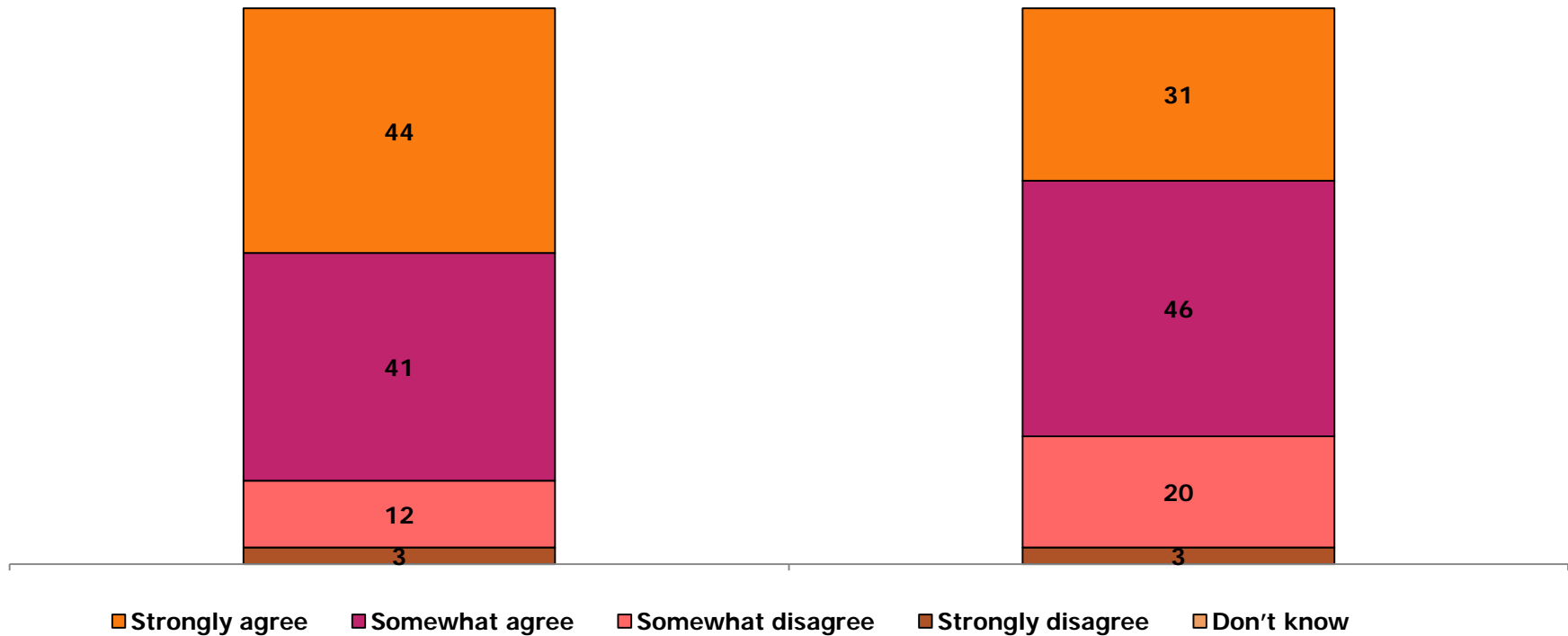
Doctors Feel They Have Limited Resources To Help With Relationships – While most doctors “agree” they are available to help patients navigate the impact of the disease on their relationships, they don’t necessarily feel they have the resources. Fewer than 1 in 3 doctors “strongly agree” that they have such resources.

44

Doctors

I am available to help my patients with the impact of their disease on their relationships

I have the expertise to help my patients manage the impact of their disease on their relationships



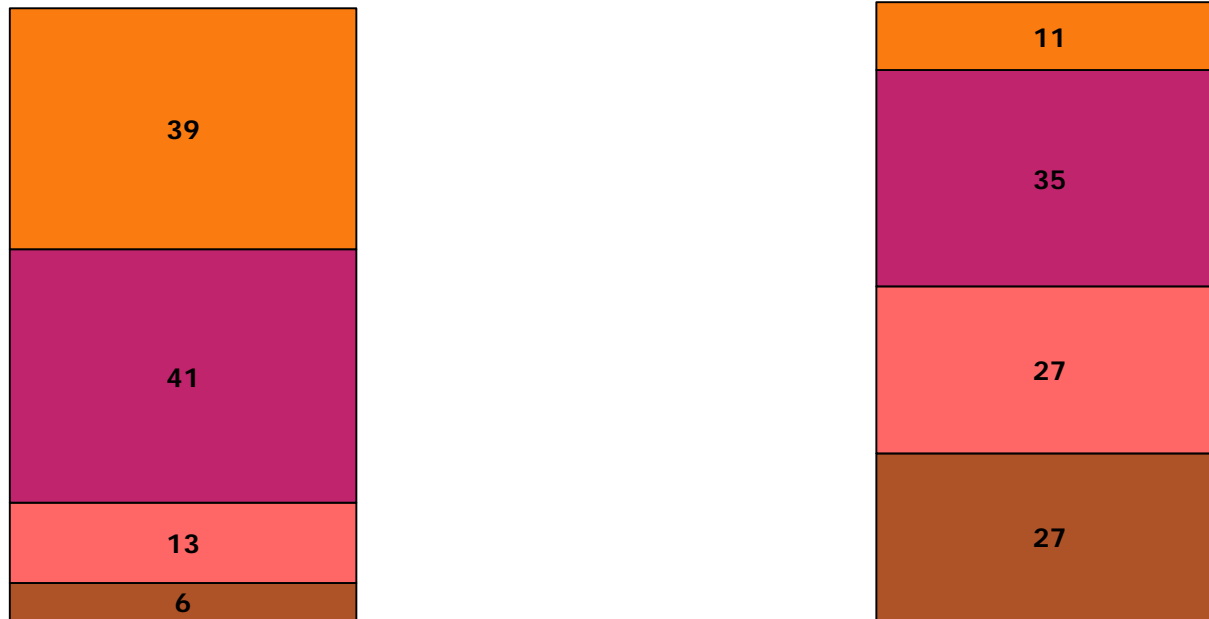
Doctors Q9: Please tell me whether you agree or disagree with each of the following statements.
Base: Doctors (n=251)

Doctors See Lack Of Knowledge As Impediment To Diagnosis – While doctors agree there is an overall lack of knowledge about lupus that impacts the speed of diagnosis, they don't necessarily agree that the complexities of the disease impact their ability to give optimal care to their patients.

Doctors

The general lack of knowledge about lupus impacts the speed of diagnosis of the disease and the prompt referral to appropriate skilled care

The complexities of lupus impacts my ability to give optimal care to these patients



■ Strongly agree
 ■ Somewhat agree
 ■ Somewhat disagree
 ■ Strongly disagree
 ■ Don't know

Doctors Q16: Please tell me how much you agree or disagree with the following. The first statement is
 Base: Doctors (n=251)

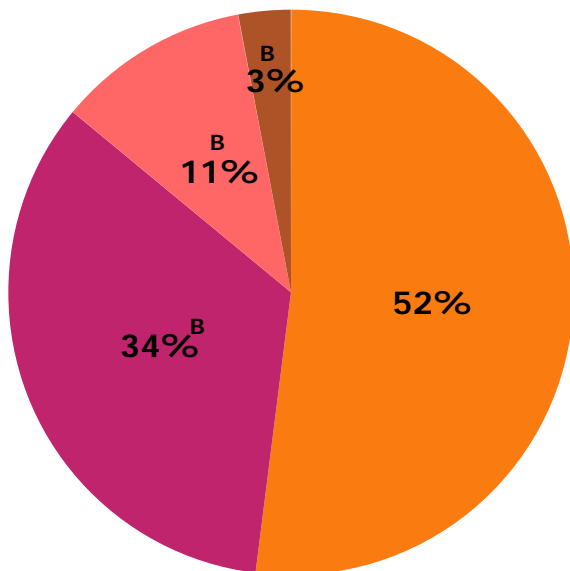
Relationship With Family/Friends

Relationship With Family/Friends – At A Glance

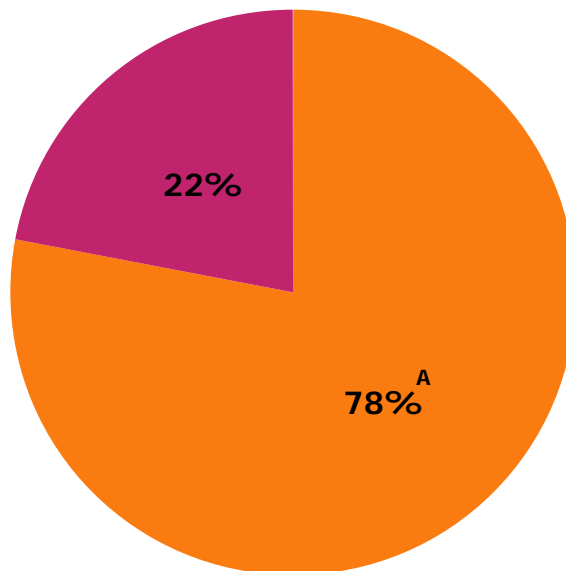
- Supporters take the word “support” to heart with almost 8 in 10 describing themselves as “very supportive” of the lupus patient they help care for. Patients are less likely to describe their friends and family as “very supportive,” though half do make this assessment. Doctors are far less likely to describe the families and friends of their patients as “very supportive.” Only 1 in 3 does so.
- Regardless of how many patients describe their caregivers as “very supportive,” they do feel a certain degree of doubt from their friends and family. Large majorities of patients “agree” that their friends and family think patients can do more than they actually can, they can improve their condition by eating better and having lupus makes them passive and unmotivated.
- Doctors are also much more pessimistic about the impact lupus has on specific relationships. Specifically, patients are twice as likely as doctors to say lupus has had a “positive” impact on their relationship with their spouse/significant other, children, other family members and friends.
- Supporters are in a unique position, since they are juggling care for the family member or friend with lupus and their own friends and family. For the most part, supporters are positive, noting their support of someone with lupus has had a positive impact on their own relationships with their spouse, children, friends and other family members.
- Still, supporters acknowledge that caring for a friend or family member with lupus can strain a relationship.

Assessments Of "Support" Of Patients Varies Greatly By Respondent Type – While half of patients say their family/friends are "very supportive," nearly 8 out of 10 supporters describe themselves as "very supportive" of their friend/family member with lupus. Doctors, interestingly, are least likely to perceive a patient's family/friends as "very supportive" (34%).

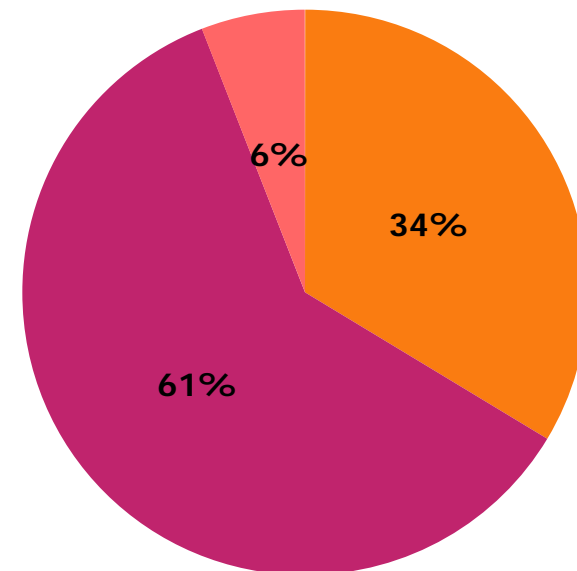
**Patients
(A)**



**Supporters
(B)**



**Doctors
(C)**



- Very supportive
- Somewhat supportive
- Not very supportive
- Not at all supportive

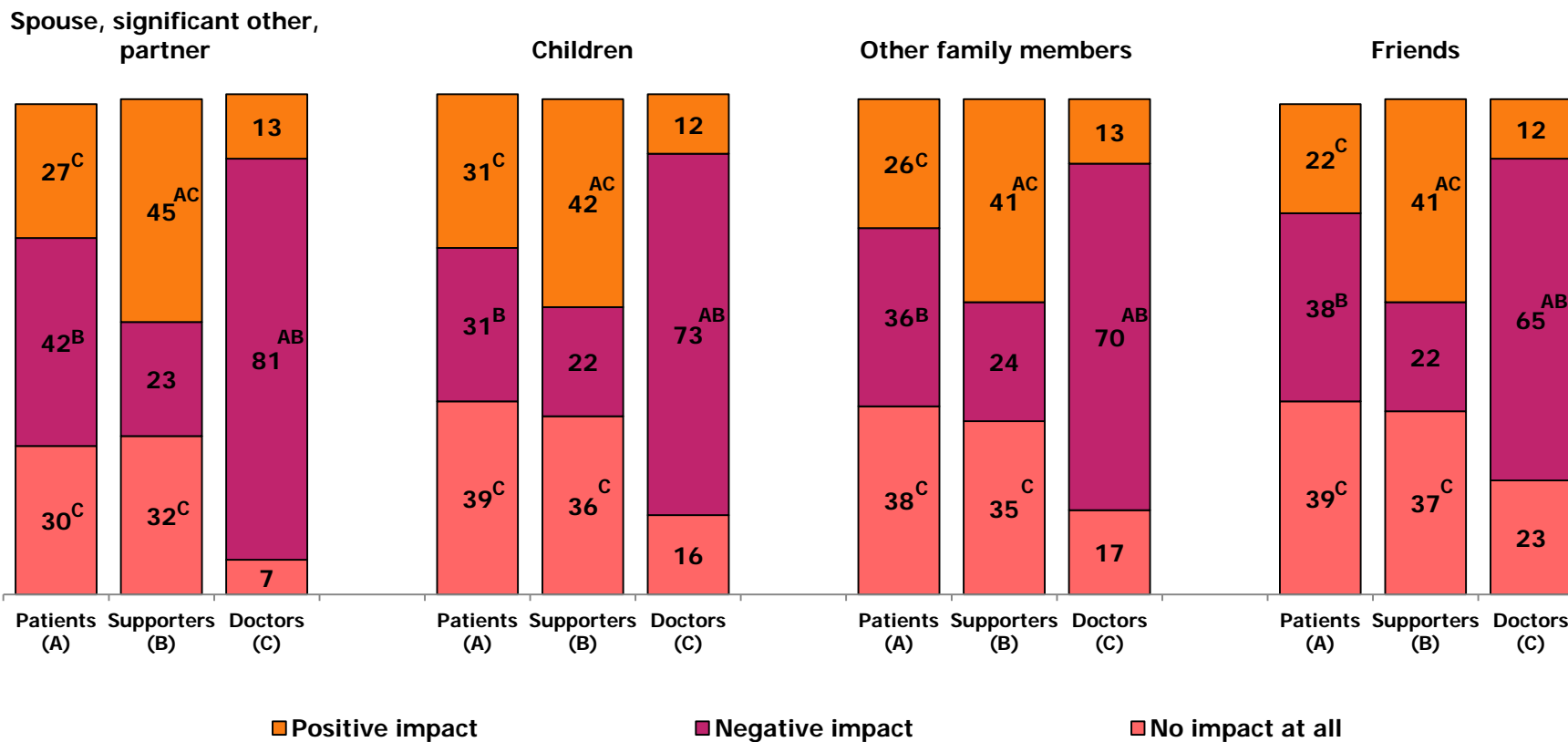
Patients Q14: How supportive would you say your family and friends have been of your illness?
 Supporters Q12: How supportive would you say you are of your friend or family member with lupus?
 Doctors Q12: For most of your patients, would you say that their families and friends are:
 Base: Patients (n=502); Supporters (n=204); Doctors (n=251)

A Perceived Lack Of Support Is More Common Among Those Who Feel Alone & Powerless/Minimize Their Symptoms And Those Who Feel Alone & Powerless/Wish For More Information And Resources – The total sample of patients is significantly more likely than the same segments to feel friends and family are supportive.

Degree of support received from family & friends (%)					
	Total Patients	Limited by 7 or more activities but hope and optimistic	Feel alone and powerless and minimize symptoms so not to upset the family	Feel alone and powerless and wish there were more resources	Feel alone and powerless and wish there were more credible information
	(A)	(B)	(C)	(D)	(E)
		N=118	N=244	N=248	N=200
Supportive (net)	86^{CD}	91	80	81	86
Very supportive	52 ^{CDE}	51	42	42	46
Somewhat supportive	34	40	38	38	40 ^A
Not Supportive (net)	14	9	20^A	19^A	14
Not very supportive	11	8	17 ^A	17 ^A	13
Not at all supportive	3	2	3	2	2

Patients Q14: How supportive would you say your family and friends have been of your illness?
Base: Patients (n=502)

Lupus Seen As Affecting Relationships – Doctors who treat patients with SLE are much more likely than both patients themselves and than supporters to feel lupus has negatively impacted patients’ relationships with their spouse, children, other family members and friends. Patients are more positive than supporters or doctors overall. Supporters were asked how taking care of someone with lupus has affected their own personal relationships and they too are fairly positive; in fact, they are often close to twice as likely as patients to say it has had a positive impact on each of their relationships.

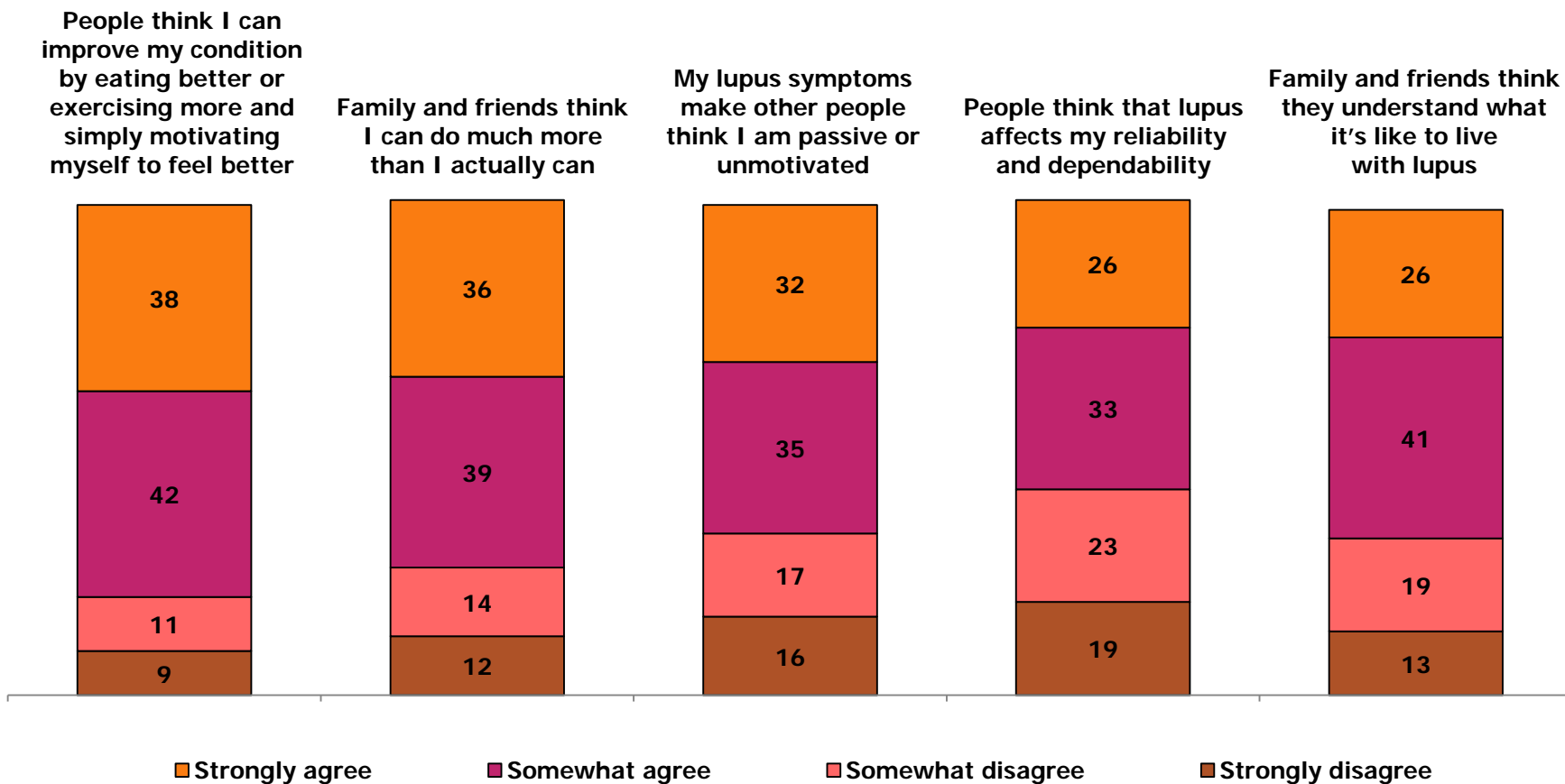


Patients Q13: What overall impact, if any, has lupus had on your relationship with each of the following?
 Supporters Q11: What overall impact, if any, has caring for or supporting a friend or family member with lupus had on your relationship with each of the following?
 Doctors Q10: In general, would you say that the disease has had a positive impact, a negative impact, or no impact on your patients’ relationships with each of the following?
 Base: Varies for each (excludes don’t knows & not applicables)



Patients Feel Others Sometimes View Them Critically – Two-thirds or more patients “agree” that friends and family think patients can do more than they actually can, think patients can improve their condition by eating better and believe that they can identify with living with lupus. The majority of patients also agree that their family and friends believe their lupus symptoms make them unmotivated and that lupus has affected their reliability and dependability.

Patients

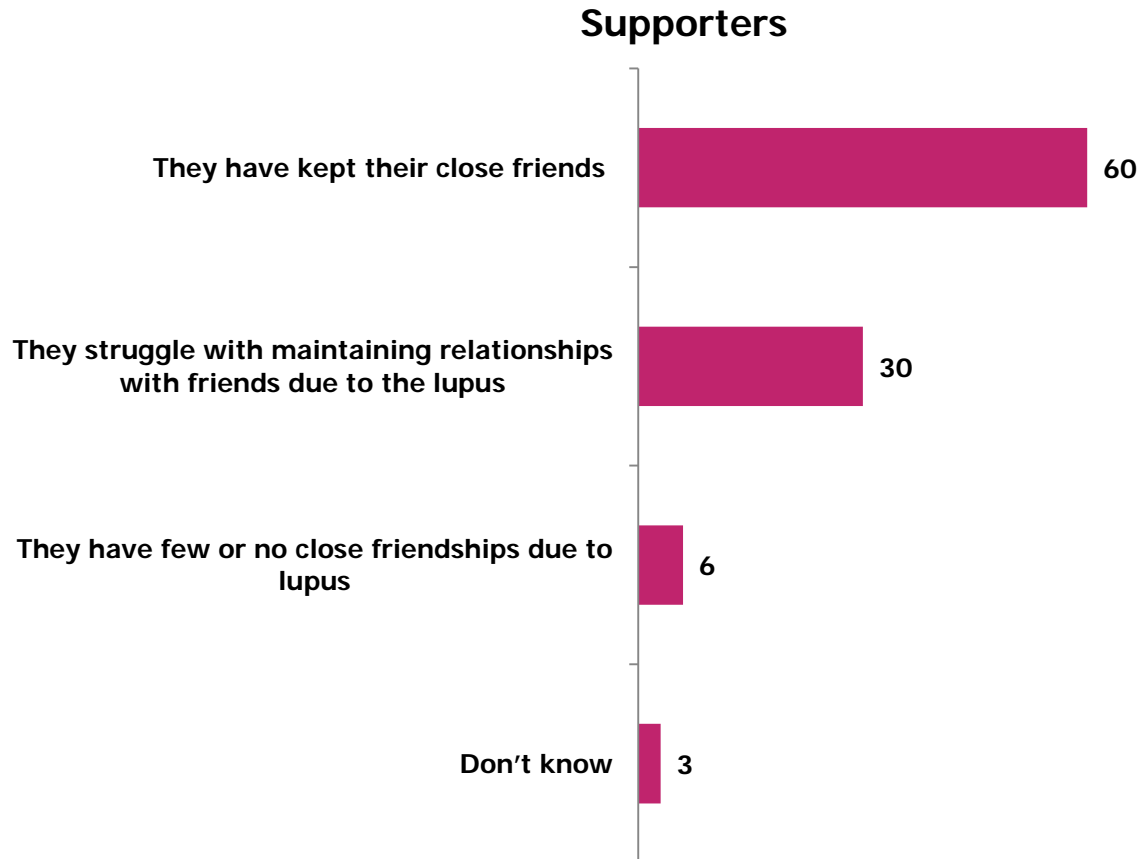


Patients Q5: How much do you agree or disagree with the following statements about having lupus?
 Base: Patients (n=502)



Supporters Perceive Little Change In The Relationship Between Lupus Patients And Their Friends – Supporters are twice as likely to comment that their friend or family has kept their close friends rather than to report that the patient has been struggling to maintain their friendship due to the lupus.

52

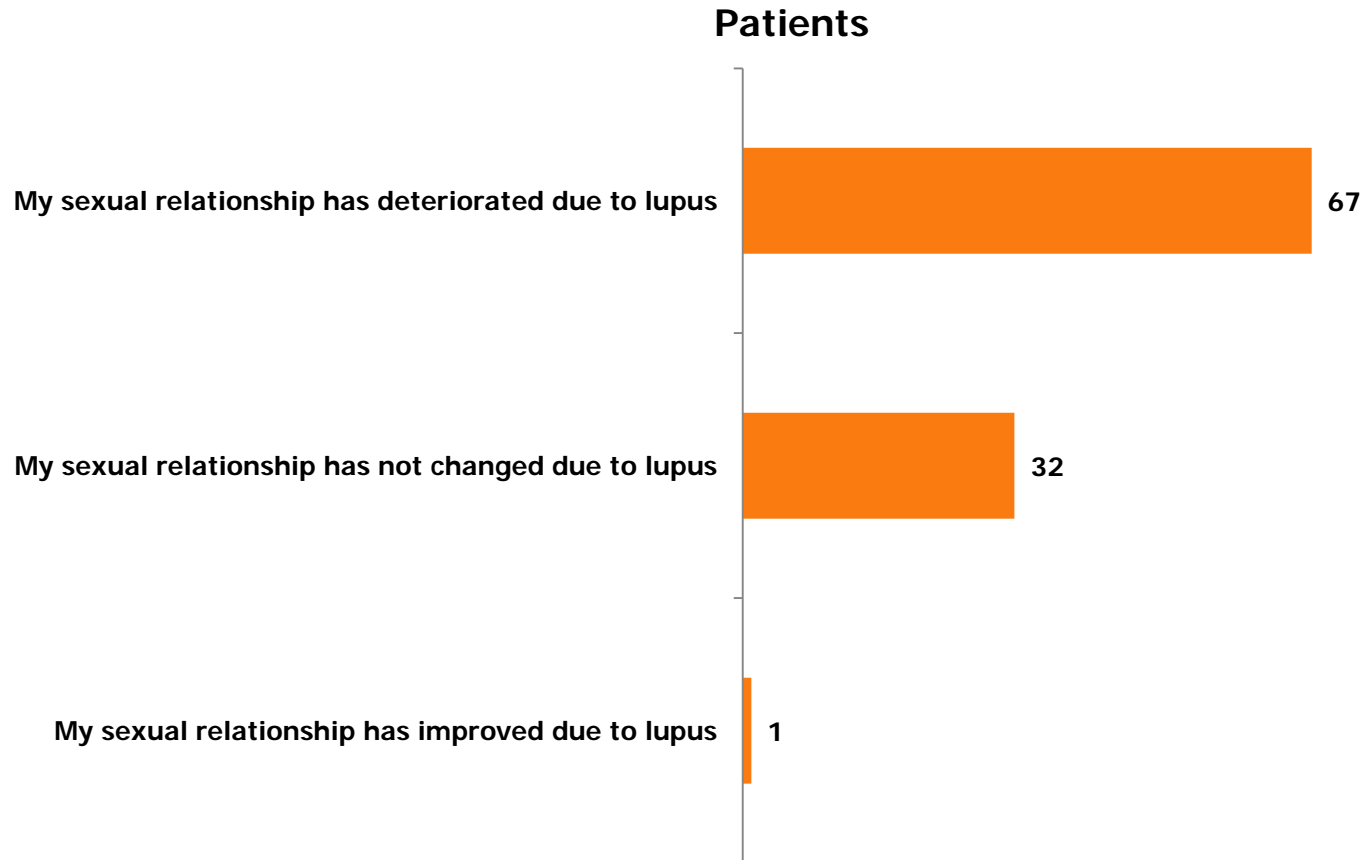


Supporters Q13: Which of the following statements best describes the relationships of your friend or family member with other people since being diagnosed with lupus?

Base: Supporters (n=204)

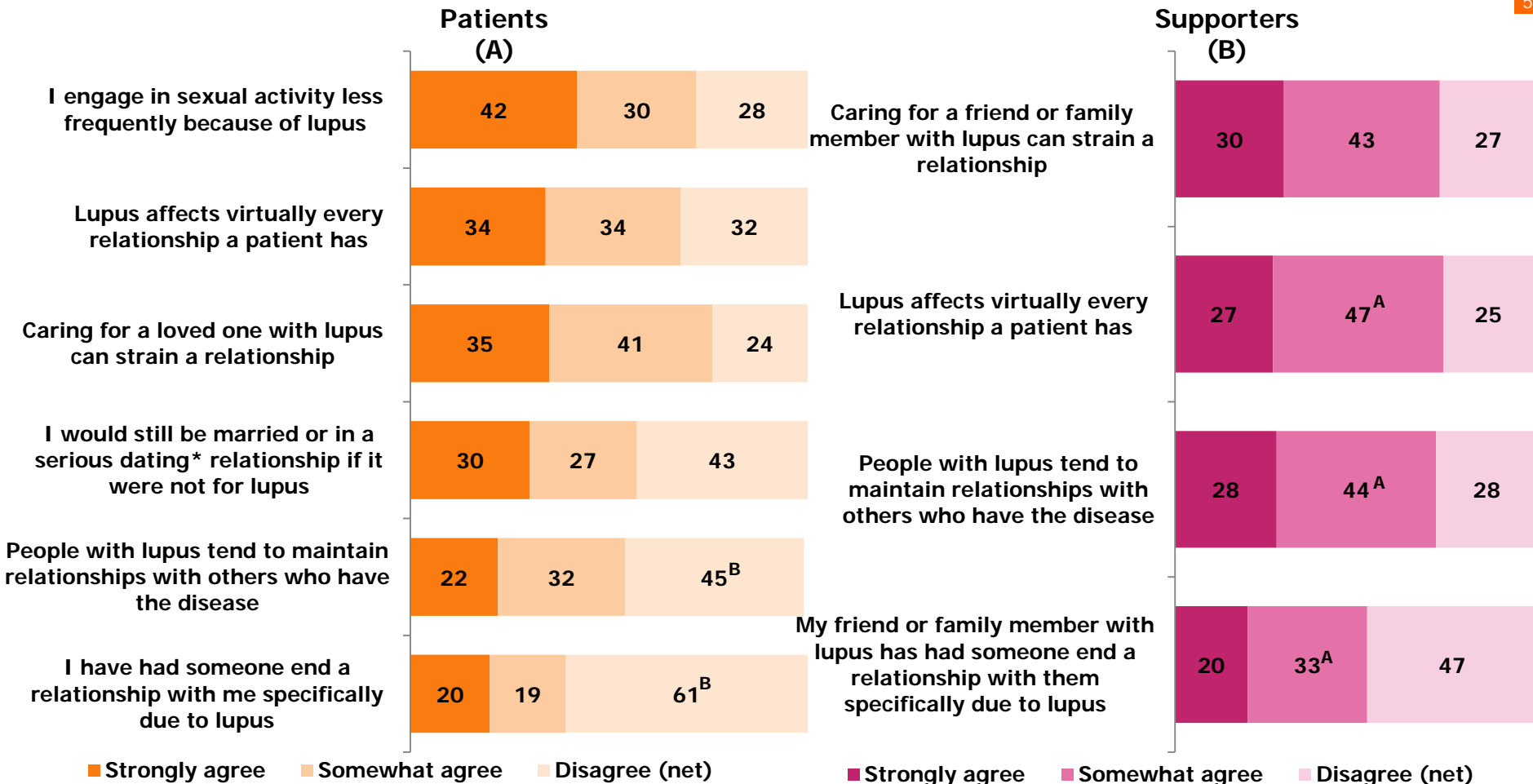
Lupus Appears To Have A Considerable Effect On Patients' Sexual Relationships – Two-thirds of patients say their sexual relationship has deteriorated due to their lupus.

53



Patients Q15: Which one of the following statements best describes your sexual relationship with your spouse or partner?
Base: Patients who did not respond "do not currently have a spouse or partner" or "prefer not to answer" (n=350)

Lupus Puts Strain On Relationships – Patients and supporters are in agreement that having lupus puts a strain on their relationships. The perceived degree of that strain is also similar. Seven out of 10 patients agree that “lupus affects virtually every relationship a patient has” and a similar number of supporters agree as well. One noticeable difference between the two groups pertains to the degree to which patients with lupus maintain relationships with others who have the disease. Supporters are much more likely to agree that they do so.



Patients Q19: In your opinion, to what extent do you agree or disagree with the following statements, when it comes to how lupus affects relationships.

Supporters Q17: In your opinion, to what extent do you agree or disagree with the following statements, when it comes to how lupus affects relationships?

Base: Patients (varies (excludes those who preferred not to answer/not applicable)); Supporters (varies (excluded don't know))

*only asked if patient was single or divorced

Men Have Experienced More “Loss” Due To Lupus Than Have Women – This loss comes in the form of lost relationships, divorce and less frequent sexual activity. Men are also significantly more likely to agree “lupus affects virtually every relationship a patient has” and “people with lupus tend to maintain relationships with others who have the disease.” Younger lupus patients, especially those aged 18 to 34, are similarly much more likely to see lupus having negative effects on their relationships than their older counterparts.

% saying “strongly agree”/“somewhat agree”						
	Total Patients	Gender		Age		
		Men	Women	18-34	35-54	55+
		(K)	(L)	(S)	(T)	(U)
		N=128	N=374	N=168	N=210	N=124
Caring for a loved one with lupus can strain a relationship	68	73	66	71 ^U	70	60
Lupus affects virtually every relationship a patient has	66	74 ^L	63	67	64	66
I engage in sexual activity less frequently because of lupus	57	73 ^L	51	60 ^U	61 ^U	44
People with lupus tend to maintain relationships with others who have the disease	47	67 ^L	40	60 ^{TU}	41	39
I have had someone end a relationship with me specifically due to lupus	32	55 ^L	24	45 ^{TU}	31 ^U	15
IF SINGLE, SEPARATED OR DIVORCED: I would still be married or in a serious dating relationship if it were not for lupus	43 (n=205)	55 ^L (n=60)	38 (n=145)	49 ^U (n=78)	50 ^U (n=76)	24 (n=51)

Patients Q19: In your opinion, to what extent do you agree or disagree with the following statements, when it comes to how lupus affects relationships.

Base: Patients (n=502)

Career

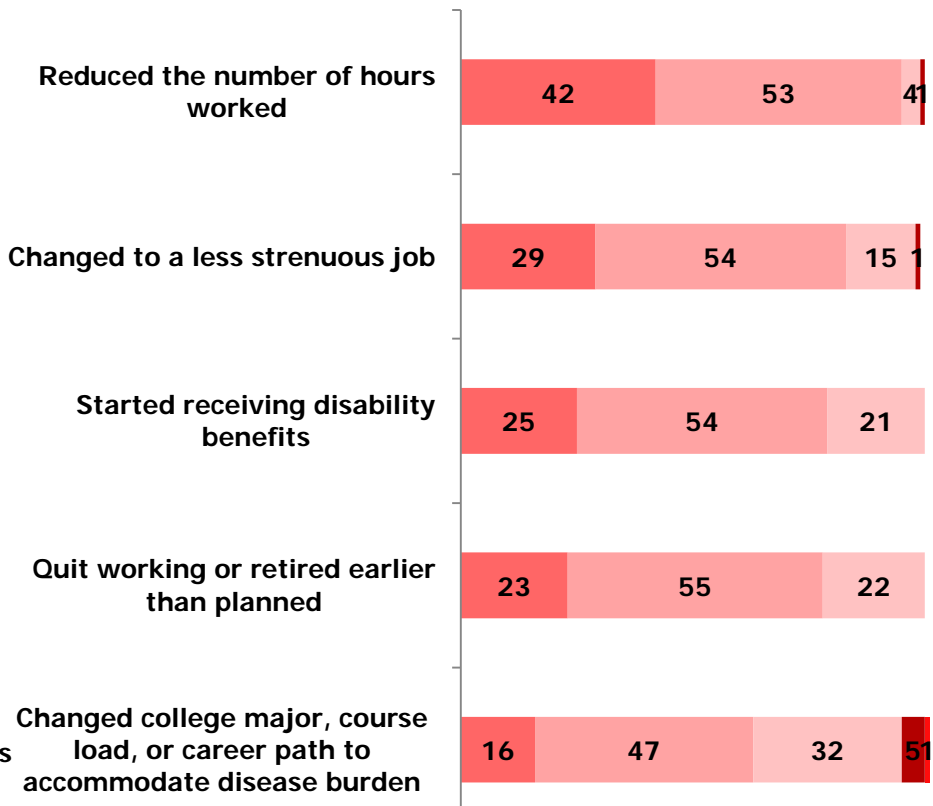
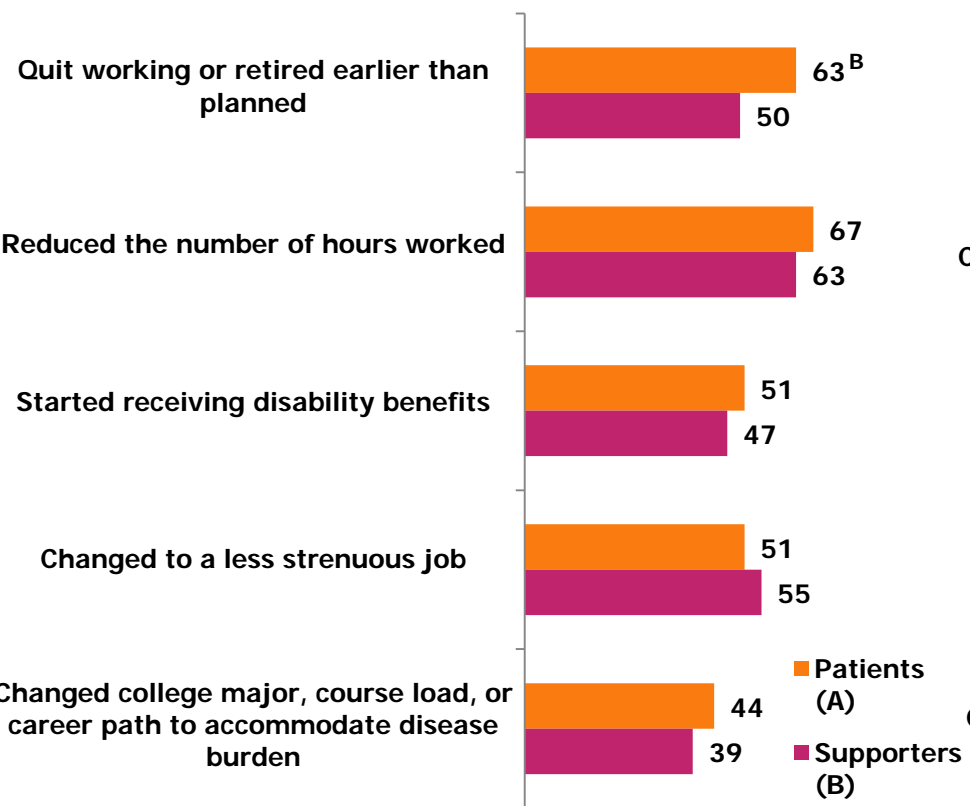
Career – At A Glance

- While the physical symptoms of lupus receive a lot of deserved attention, lupus “complicates” patients’ lives in other areas. Career changes often result from living with lupus, and are not always viewed positively. Half or more patients have quit working or have retired earlier than planned, have reduced the number of hours worked, have started receiving disability benefits or have changed to a less strenuous job as the result of their lupus. Lupus has also harmfully affected their relationships with their co-workers and made them less productive, thus negatively impacting their careers. Supporters and doctors are well aware of the impact lupus has on a patient’s career and for the most part are in agreement as to how often they are having to make changes.
- Career changes play a big role in the emotional aspect of living with lupus. Half or more patients “strongly agree” that they were devastated by having to leave their job, that they miss the social interaction that comes from the work environment, and that not working makes them feel both inadequate and like they are not contributing to their fair share of the household.
- Patients are not the only group whose career changes as a result of the lupus diagnosis: supporters’ careers are also greatly impacted by having to care for lupus patients. Just under half of supporters say they have reduced the number of hours worked, while more than one in three changed to a less strenuous job or started receiving disability benefits.

Lupus Impacts Patients' Career – A majority of patients, supporters and doctors report a change in patients' career plans due to lupus. Close to two-thirds of patients report reducing the number of hours worked, or quitting work/retiring earlier than planned. Most doctors report that their patients often or sometimes have made the same changes.

% saying "yes" to each

Doctors



■ Often ■ Sometimes ■ Rarely ■ Never ■ Don't know

Patients Q10: Have you ever done any of the following due to lupus?

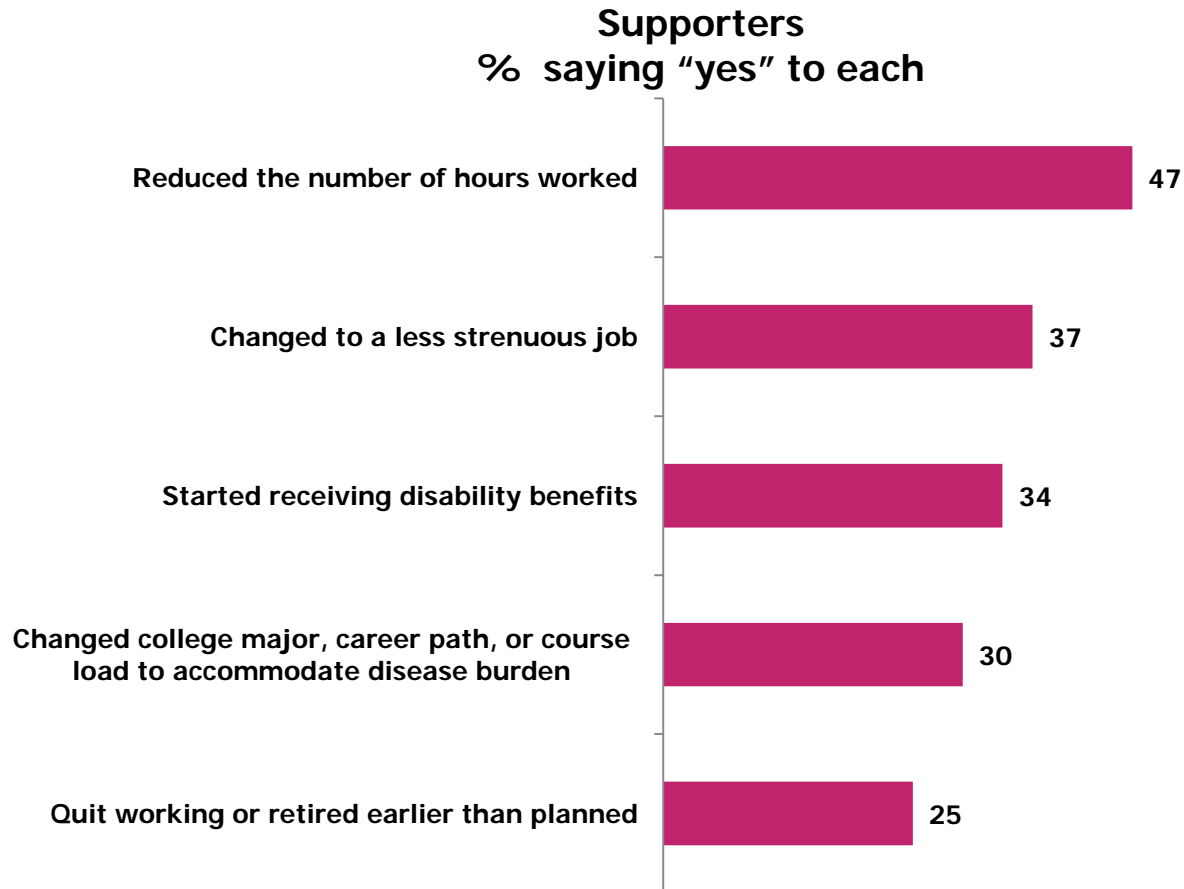
Supporters Q9: Has your friend or family member with lupus ever done any of the following due to lupus?

Doctors Q8: How frequently do you hear reports that your patients have done any of the following due to lupus? Is it often, sometimes, rarely or never?

Base: Patients (n=varies (excludes those who said "not applicable")); Supporters (n=excludes those who said "not applicable"); Doctors (n=251)

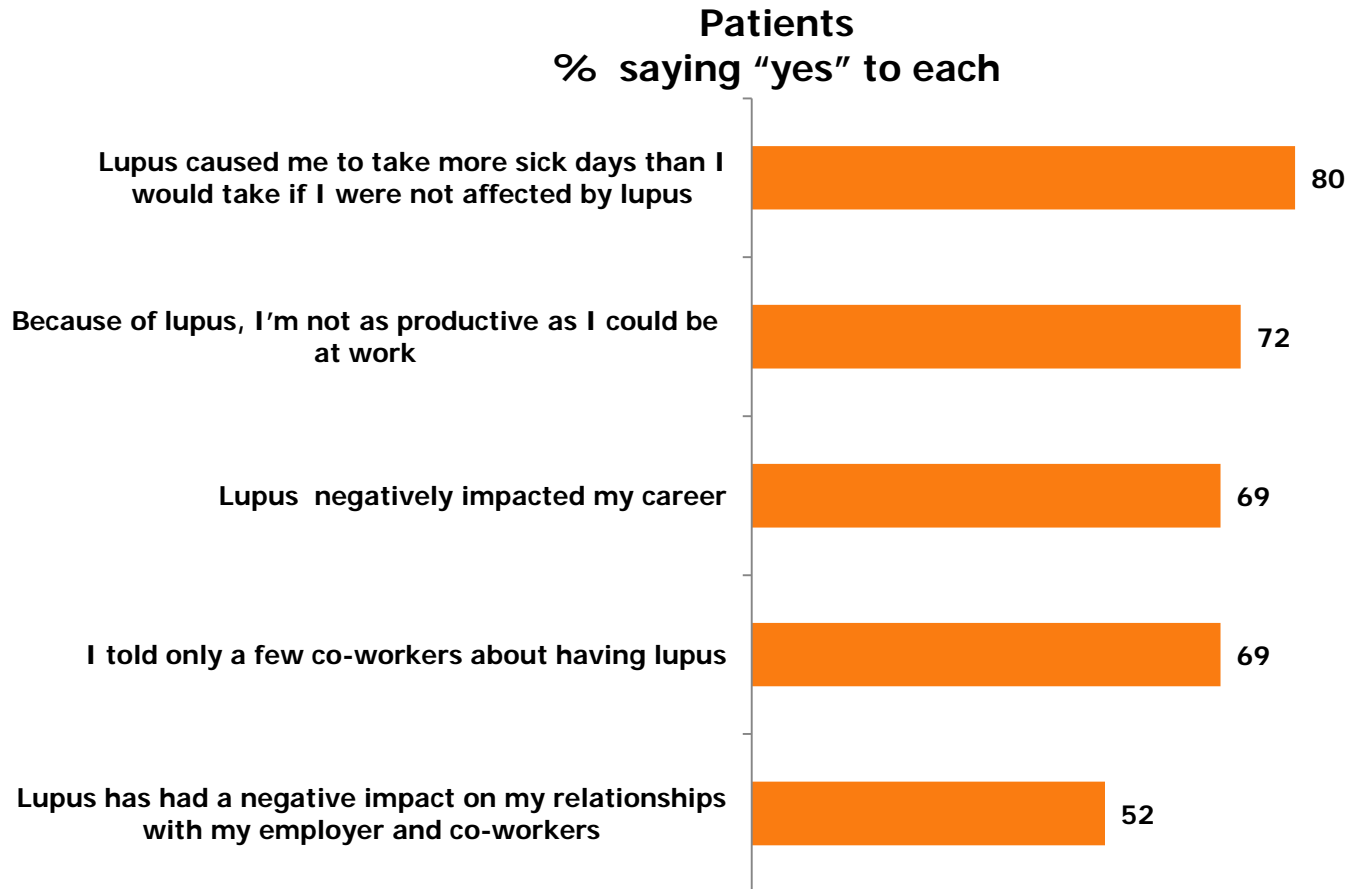


Career Path Of The Supporter Is Also Impacted By Their Caregiving Responsibilities – Just under half of supporters have had to reduce the number of hours they work, while 1 in 3 report having changed to a less strenuous job or started receiving disability benefits.



Supporters Q10: Have you ever done any of the following because of caring for your friend or family member with lupus?
Base: Supporters (varies (excludes those who said "not applicable"))

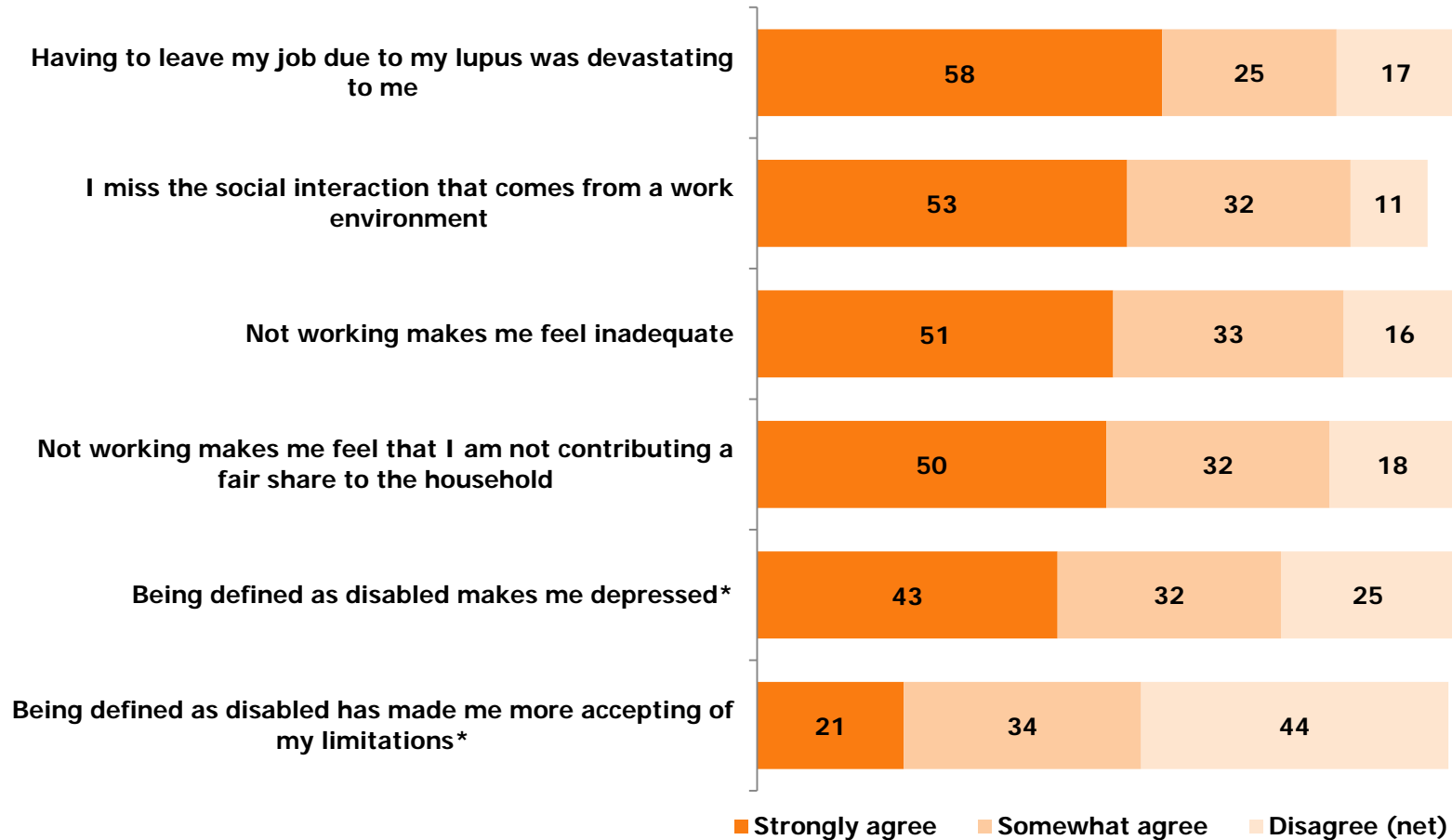
Lupus Impacts Productivity And Has An Undesirable Affect On Relationships With Co-workers – Reduced productivity both through sick days and a general sense of contributing less appears to be another “side-effect” of lupus. Seven out of 10 patients say having the disease has negatively impacted their career. An equal number say they only told a few co-workers about having lupus.



Patients Q11: Do you feel each of the following statements applies to your own experience?
Base: Patients (varies (excludes those those who said “not applicable”))

Inability To Work Is “Devastating,” Making Patients Feel “Inadequate” – Majorities “strongly agree” that having to leave their job was “devastating” and not working makes them feel “inadequate.” The social interaction, which speaks to state of mind, is also greatly impacted by not being able to work. Not contributing also weighs heavily on lupus patients.

Patients



Patients Q12: How much do you agree or disagree with each of the following statements?

Base: Patients (varies (excludes those who said “not applicable to me”))

* Asked only among those patients who reported being on disability (n=114)

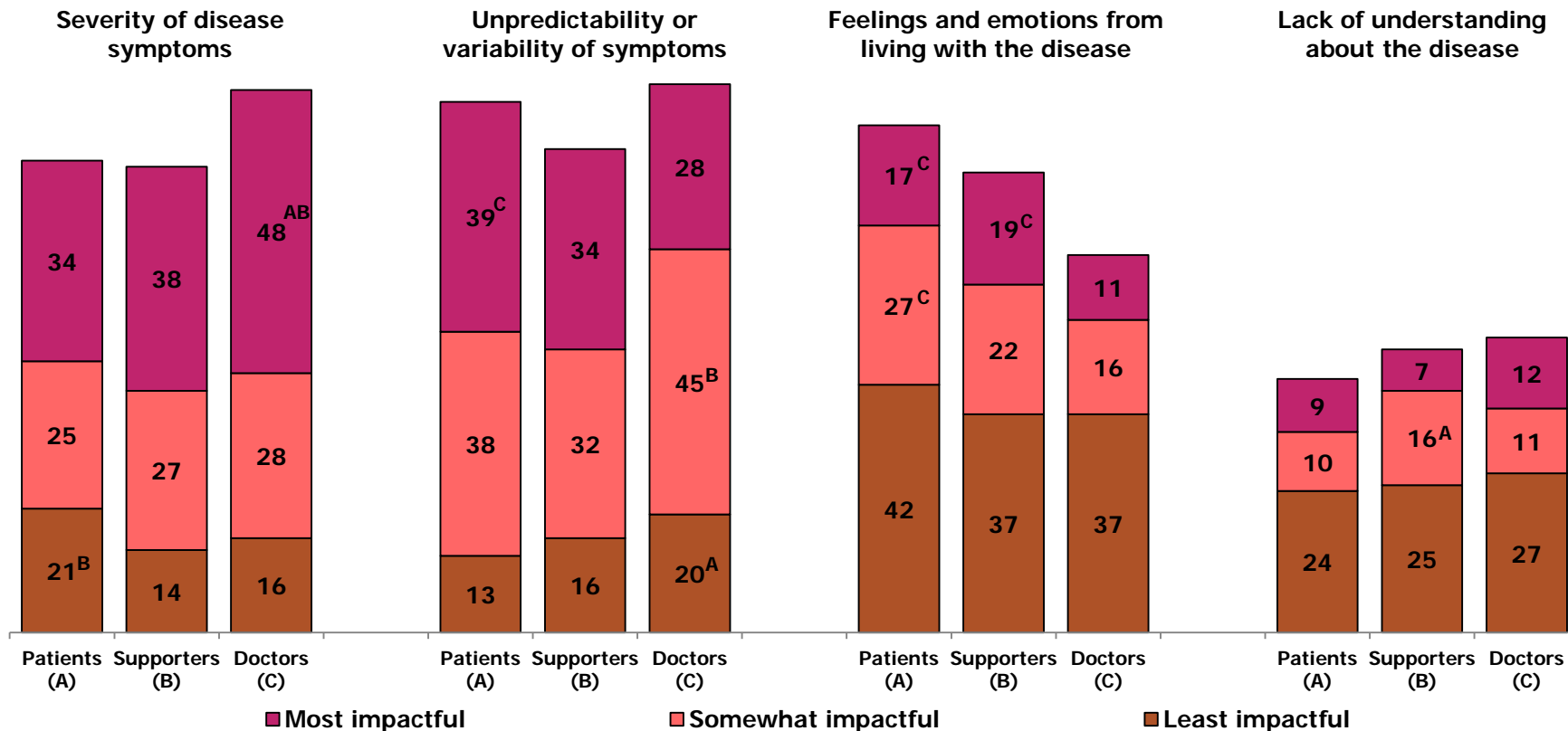


Quality of Life

Quality of Life – At A Glance

- Doctors believe that it is the severity of lupus patients' symptoms that are most impactful to their life, but patients disagree. They comment it is the unpredictability or variability of symptoms that has the biggest impact on their relationships, work and daily function. Supporters are equally as likely to say both are most impactful.
- Mindset is another area in which doctors and patients differ. Patients are twice as likely as doctors to "strongly agree" with the statement, "patients living with lupus are misunderstood." They are also significantly more likely to say they have difficulty communicating what they need from others in terms of support than doctors believe to be true. Perhaps showing the biggest disconnect, only 11% of doctors "agree" that people with lupus are able to have the same quality of life as individuals not affected by lupus, compared to 56% of patients and 60% of supporters.
- Patients may feel they can have the same quality of life as individuals without lupus but the majority admit the disease has significantly affected both their self-worth and their ability to perform their daily responsibilities.

Specific Impact Of Lupus Varies – There is some disagreement as to which aspect of lupus is most impactful. Patients say it is the unpredictability or variability of symptoms, while supporters and doctors believe it is the severity of disease symptoms. The “feelings” and “emotions” of living with the disease are more impactful to patients and supporters than to doctors.



Patients Q16: With regard to the overall impact of lupus on your life (relationships, work and daily function) which of the following items is most impactful? Which is second? And which is third?

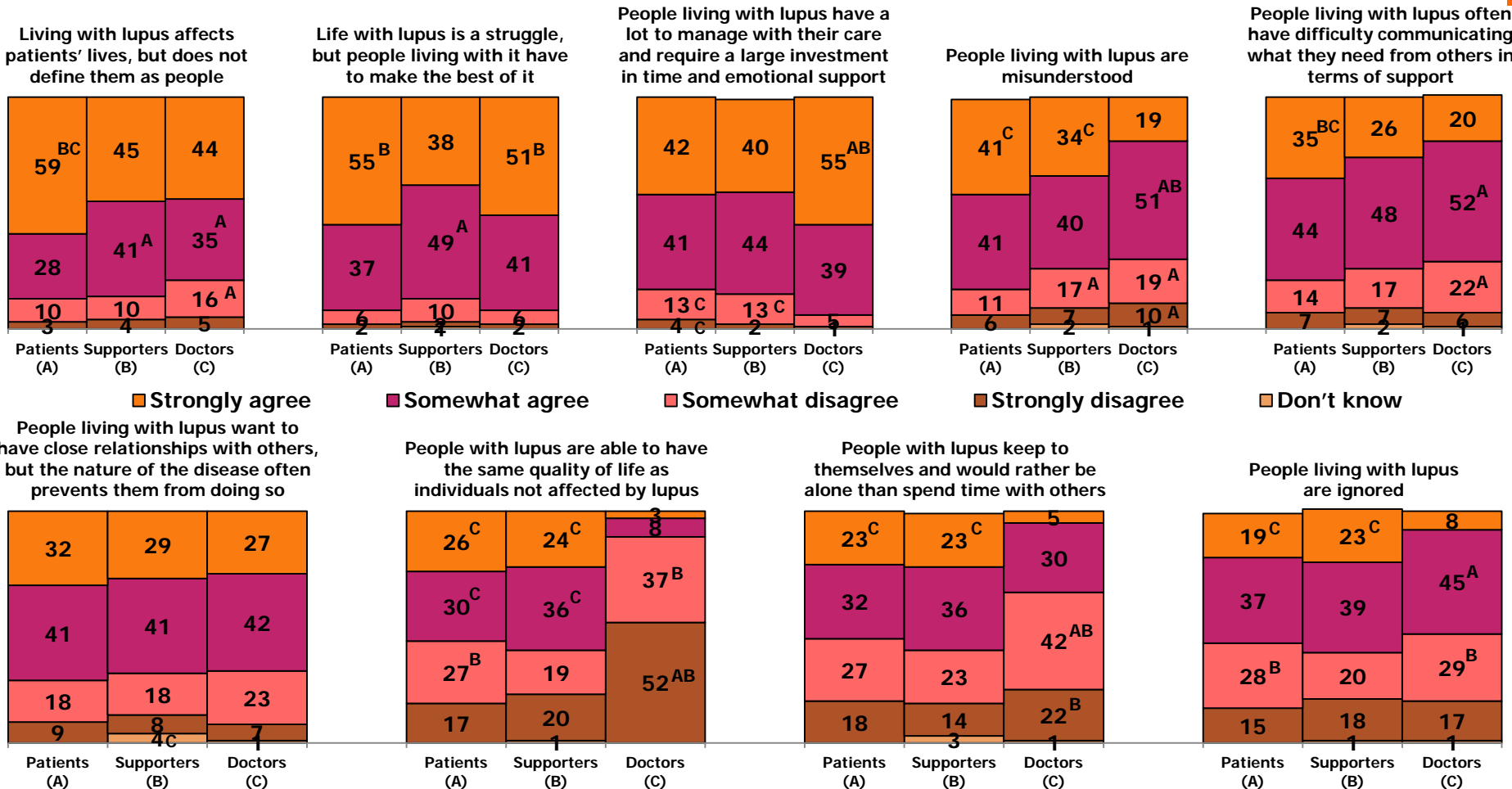
Supporters Q14: With regard to the overall impact on your friend or family member's life (relationships, work, and daily function) which of the following items is most impactful? Which is second? And which is third?

Doctors Q11: With regard to their overall impact on your patients' lives (relationships, work and daily function) which of the following items is most impactful? Which is the second? And which is third? Please let me read the entire list before answering.

Base: Patients (n=502); Supporters (n=204); Doctors (n=251)



Mindset Of Dealing With Lupus Varies – The mindset of someone living with lupus is different from the supporter taking care of them and the doctor involved in their care. Patients do not want the disease to define them and seem determined to make the best of their situation. They do often feel misunderstood but do not necessarily feel ignored. Supporters also do not want the disease to define the patient but recognize the emotional support needed. Doctors appear to focus on the emotional investment but are as likely to agree that patients need to make the best of their situation.



Patients Q17: How much do you agree or disagree with the following statements when it comes to the descriptions about people who have lupus?
 Supporters Q15: How much do you agree or disagree with the following statements, when it comes to descriptions about people who have lupus?
 Doctors Q13: Do you agree, or disagree with the following statements, when it comes to descriptions about people who have lupus?
 Base: Patients (n=502); Supporters (n=204); Doctors (n=251)



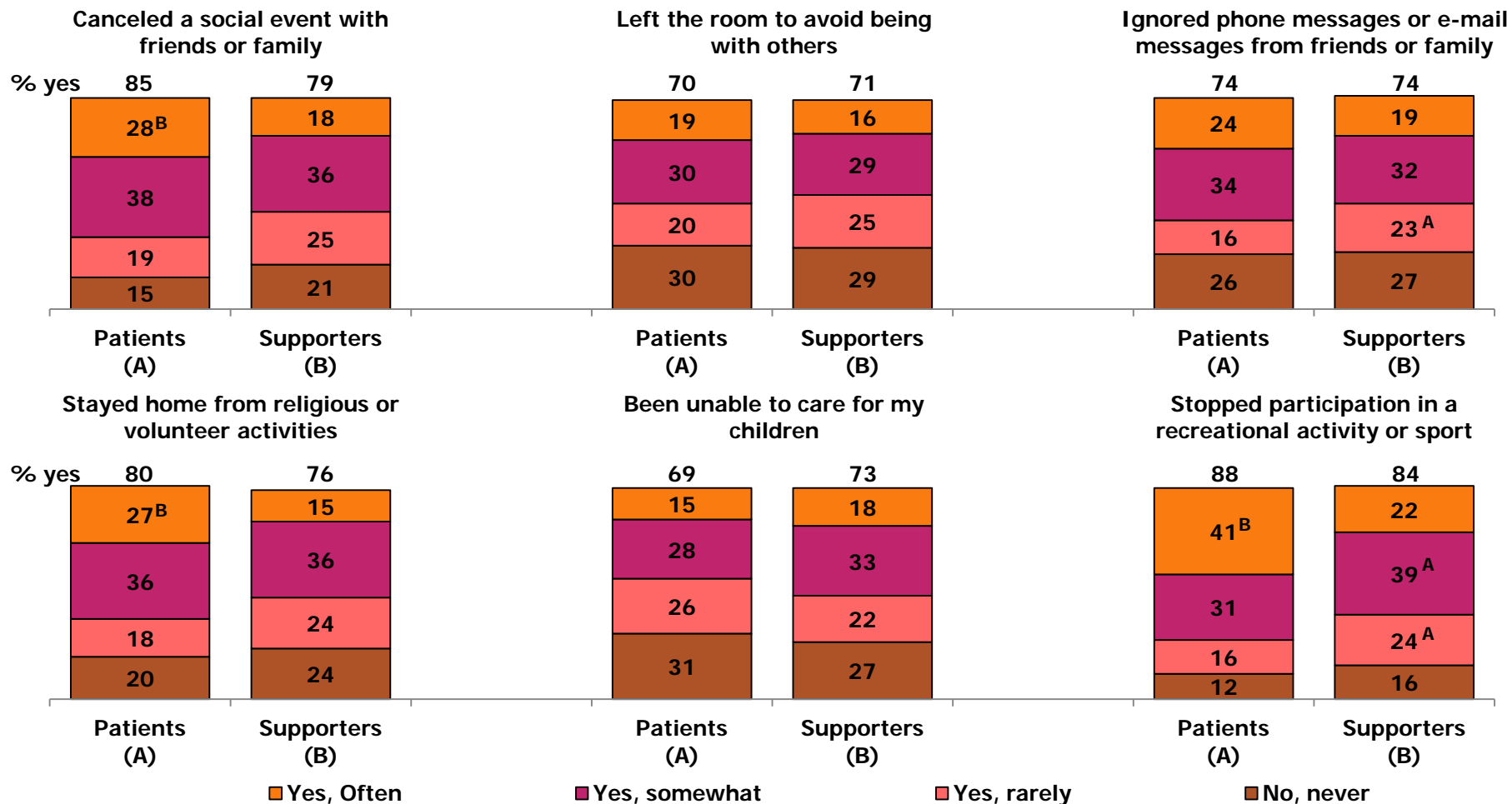
Women Don't Let Their Lupus Define Them, While Men Are More Likely To Keep To Themselves And Feel Ignored –

Men are much more likely than women to agree that “people living with lupus are ignored” and “people with lupus keep to themselves and would rather be alone than spend time with others.” Women, on the other hand, are significantly more likely to agree “lupus does not define them as people.” Patients aged 18 to 34 also appear to be struggling with feelings of being ignored and wanting to keep to themselves.

	% saying “strongly agree” / “somewhat agree”					
	Total Patients	Gender		Age		
		Men	Women	18-34	35-54	55+
		(K)	(L)	(S)	(T)	(U)
		N=128	N=374	N=168	N=210	N=124
Life with lupus is a struggle, but people living with it have to make the best of it	92	88	93	88	93	96 ^S
Living with lupus affects patients' lives, but does not define them as people	87	81	89 ^K	83	90	88
People living with lupus have a lot to manage with their care and require a large investment in time and emotional support	83	81	84	85	83	82
People living with lupus are misunderstood	82	82	83	83	82	82
People living with lupus often have difficulty communicating what they need from others in terms of support	78	77	79	76	82	76
People living with lupus want to have close relationships with others, but the nature of the disease often prevents them from doing so	73	78	71	77	72	68
People living with lupus are ignored	57	68 ^L	53	64 ^U	56	48
People with lupus are able to have the same quality of life as individuals not affected by lupus	56	67 ^L	52	61 ^U	56	49
People with lupus keep to themselves and would rather be alone than spend time with others	55	68 ^L	51	60 ^U	57	46

Patients Q17: How much do you agree or disagree with the following statements when it comes to the descriptions about people who have lupus?
Base: Patients (n=502)

Lupus Interferes With Social Activities And Obligations – For the most part, patients and supporters are in agreement that this interference happens, but the frequency in which it does differs. Patients are much more likely than supporters to say they have “often” canceled a social event, stayed home from religious/volunteer activities and stopped participating in a recreational activity or sport.



Patients Q18: Have you done any of the following due to lupus?
 Supporters Q16: To the best of your knowledge, has your friend or family member with lupus ever done any of the following due to lupus?
 Base: Patients (n=varies (excludes those who said “not applicable”)); Supporters (n=excludes those who said “not applicable”)

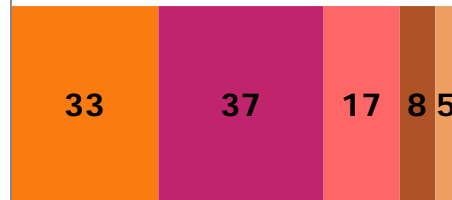


Daily Impact Of Lupus – Seven out of 10 patients say lupus has significantly impacted their ability to perform their daily responsibilities, while half say the same about their self-worth. In addition, well over half of patients “disagree” that the pain from lupus seldom prevents them from their daily routine.

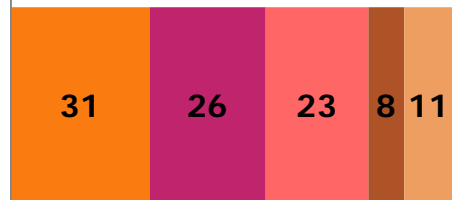
Patients

% How significantly they are impacted

Your ability to perform your daily responsibilities



Your self-worth



I seldom experience pain from lupus that prevents me from my daily routine



- Very significantly
- Neutral
- Not at all significantly

- Mostly significantly
- Mostly insignificantly

- Completely agree
- Agree
- Completely disagree

- Mostly agree
- Mostly disagree

Patients Q21: Please rate your level of agreement with the following:
 Patients Q20: Please indicate how much lupus significantly impacts the following:
 Base: Patients (n=502)



Self-Worth Is Significantly Impacted When Some Degree Of Powerlessness Is Felt – Patients who feel alone and powerless/minimize their symptoms and those who feel alone and powerless/wish for more information and resources say their self-worth is significantly impacted by having lupus.

% saying lupus "very/mostly" significantly impacts self-worth					
	Total Patients	Limited by 7 or more activities but hope and optimistic	Feel alone and powerless and minimize symptoms so not to upset the family	Feel alone and powerless and wish there were more resources	Feel alone and powerless and wish there were more credible information
	(A)	(B)	(C)	(D)	(E)
		N=118	N=244	N=248	N=200
Very/Mostly (net)	58	67^A	78^A	79^A	77^A
Very significantly	31	45 ^A	50 ^A	48 ^A	46 ^A
Mostly significantly	26	22	29	30	31
Neutral	23^{CDE}	21	16	16	18
Mostly/Not at all (net)	19^{BCDE}	12	5	5	6
Mostly insignificantly	8 ^{CDE}	7	3	2	3
Not at all significantly	11 ^{BCDE}	5	2	3	3

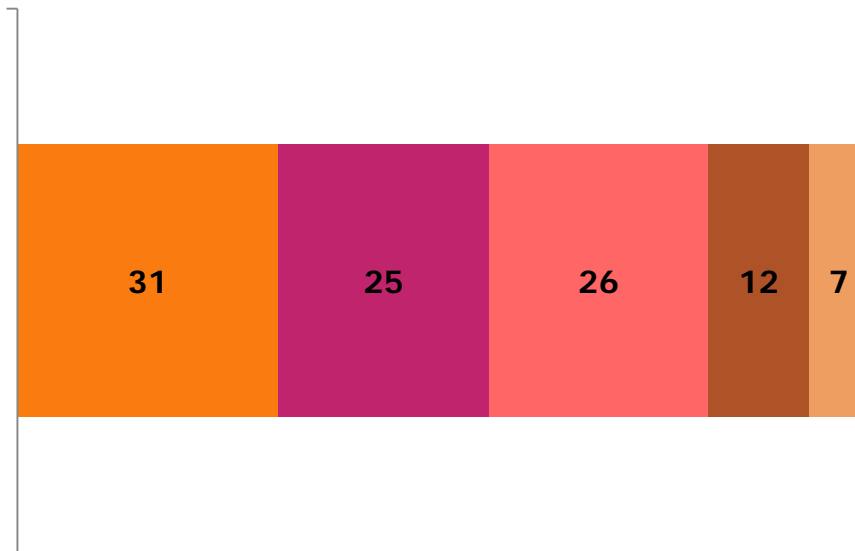
Patients Q20: Please indicate how much lupus significantly impacts the following – your self-worth?
Base: Patients (n=502)

Patients Believe In Healthcare Professionals – Encouragingly, almost all patients agree that their healthcare professionals are the best out there when it comes to managing their lupus.

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Patients

My healthcare professional is the best there is when it comes to managing my lupus



■ Completely Agree ■ Mostly agree ■ Agree ■ Mostly disagree ■ Completely disagree

Patients Q21: Please rate your level of agreement with the following:
Base: Patients (n=502)

Demographics

Demographics – Patients (1/2)

Gender	(n=502)
Male	25
Female	75
Age	
18 to 24	12
25 to 34	21
35 to 44	18
45 to 54	24
55 and older	25
Mean	43.1
Region	
Northeast	18
Midwest	20
South	42
West	21
Community	
Rural (countryside)	22
Suburb	44
City	34

Living Arrangement	
Live alone	20
Live with spouse, partner, or significant other	39
Live with child or children and no other adults	8
Live with children and spouse, partner, or significant other	23
Live with other relative(s) or close friend(s) (not a child/spouse)	9
Live with a roommate	1
Children Below 18 (based on those living with children, n=156)	
1	51
2	29
3 or more	21
Relationship Status	
Single, never married	23
Married	48
Separated	3
Divorced	15
Widowed	2
Living with someone, but not married	9

Employment	
Employed full-time	31
Employed part-time	9
Student full-time	5
Student part-time	*
Self-employed or homemaker	10
Unemployed, collecting disability payments	23
Unemployed, not collecting disability payments	11
Retired	11
Retired Due To Lupus Base: Unemployed/Retired (n=223)	
Yes	69
No	31
Medical Condition	
High blood pressure	50
High cholesterol	41
Diabetes	23
Depression or anxiety	62
Raynaud's disease	33
Sleeping problems	71

Demographics – Patients (2/2)

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Education	<i>(n=502)</i>
Less than high school	2
High school graduate	18
Some college	31
Trade/technical/vocational training	8
College graduate	28
Post graduate work/degree	13
Prefer not to answer	1
Household Income	
Under \$30,000	27
\$30,000-less than \$40,000	13
\$40,000-less than \$50,000	10
\$50,000-less than \$75,000	16
\$75,000-less than \$100,000	12
\$100,000-less than \$125,000	3
\$125,000-less than \$150,000	4
\$150,000 and over	6
Don't Know	1
Prefer not to answer	7

Hispanic	
Yes	10
No	88
Prefer not to answer	2
Race	
Caucasian/White	77
African-American/Black	14
Asian or Pacific Islander	3
Native American	3
Mixed with no major ancestry	4
Prefer not to answer	3

Demographics – Supporters

Gender	(n=204)
Male	53
Female	47
Age	
18 to 24	22
25 to 34	38
35 to 44	22
45 to 54	10
55 and older	8
Mean	34.3
Region	
Northeast	20
Midwest	17
South	40
West	23
Community	
Rural (countryside)	18
Suburb	46
City	37

Education	
Less than high school	1
High school graduate	17
Some college	24
Trade/technical/vocational training	2
College graduate	45
Post graduate work/degree	9
Prefer not to answer	1
Household Income	
Under \$30,000	15
\$30,000-less than \$40,000	14
\$40,000-less than \$50,000	9
\$50,000-less than \$75,000	17
\$75,000-less than \$100,000	15
\$100,000-less than \$125,000	13
\$125,000-less than \$150,000	7
\$150,000 and over	7
Prefer not to answer	3

Hispanic	
Yes	17
No	80
Prefer not to answer	3
Race	
Caucasian/White	75
African-American/Black	12
Asian or Pacific Islander	10
Native American	2
Mixed with no major ancestry	4
Prefer not to answer	3

Demographics – Doctors

Referred To Other Physician	(n=251)
Yes	94
No	6
Lupus Patients Treated For...	
High blood pressure	99
High cholesterol	96
Diabetes	88
Depression or anxiety	98
Raynaud 's disease	94
Sleeping problems	88
Type Of Practice	
Lupus clinical research facility	3
Academic Center or University Facility	16
Private Practice	78
Public Clinic	3

Treating Lupus	
10 years or less	29
11 to 24 years	39
25 years or more	32
Mean (years)	17.9
Number Of Lupus Patients	
Less than 100	28
100 to less than 200	31
200 or more	41

Media Inquiries

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