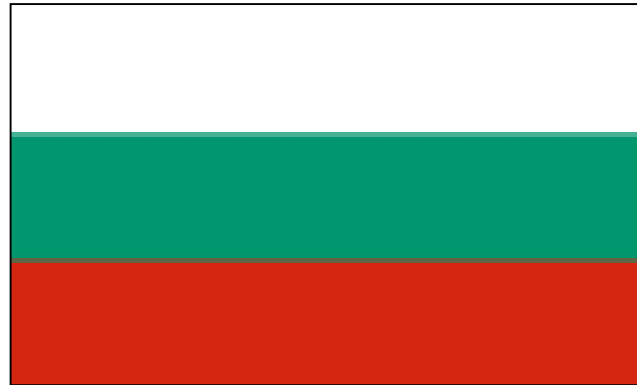


2018 Global Patient Survey on Lymphomas and CLL

Bulgaria



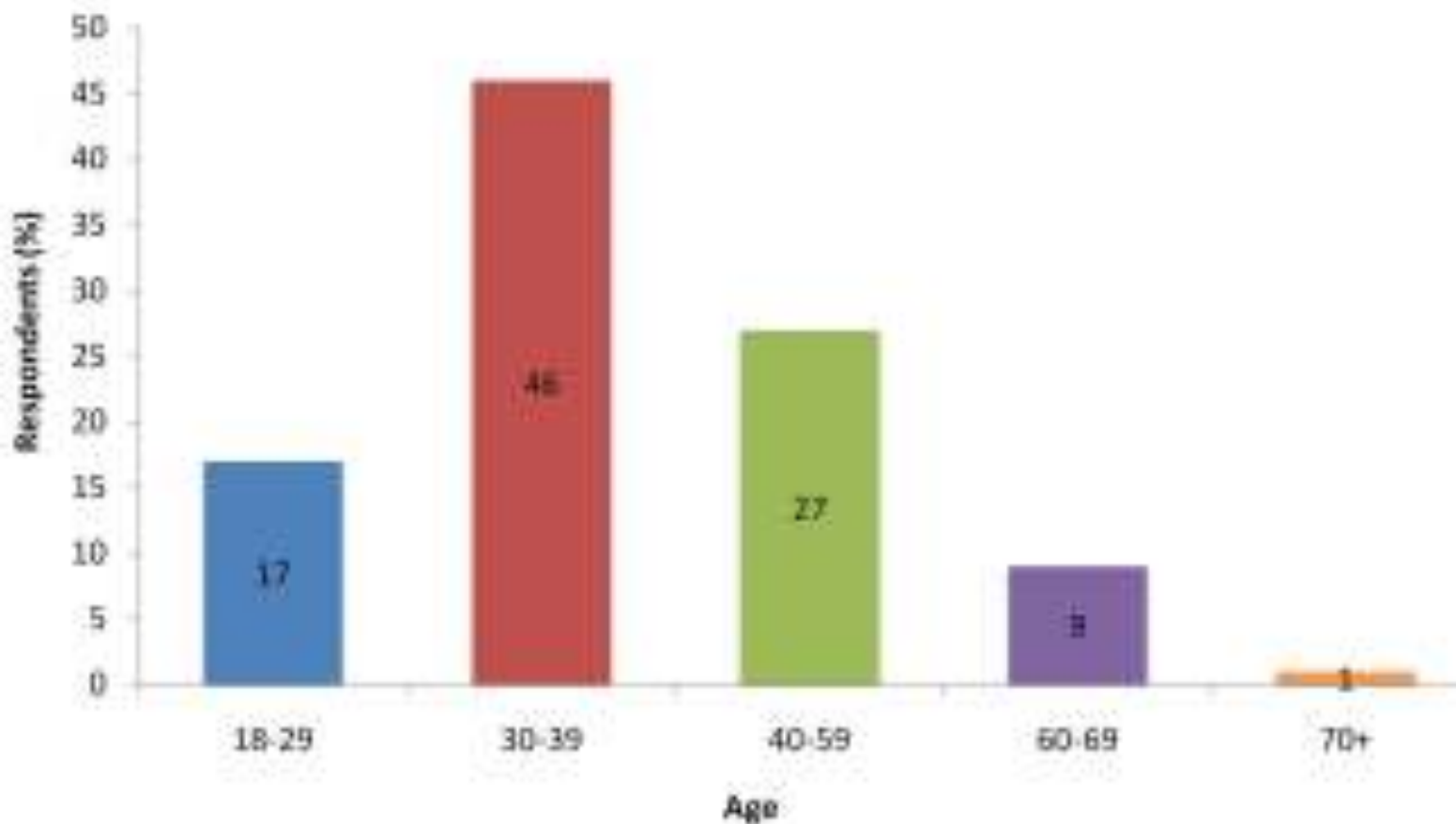
2018 Global Patient Survey on Lymphomas and CLL: Overview

1. Demographics
2. Patient information, guidance and support
3. Fear of relapse
4. Fatigue
5. Living with side effects
6. Barriers & Impediments

I) Demographics

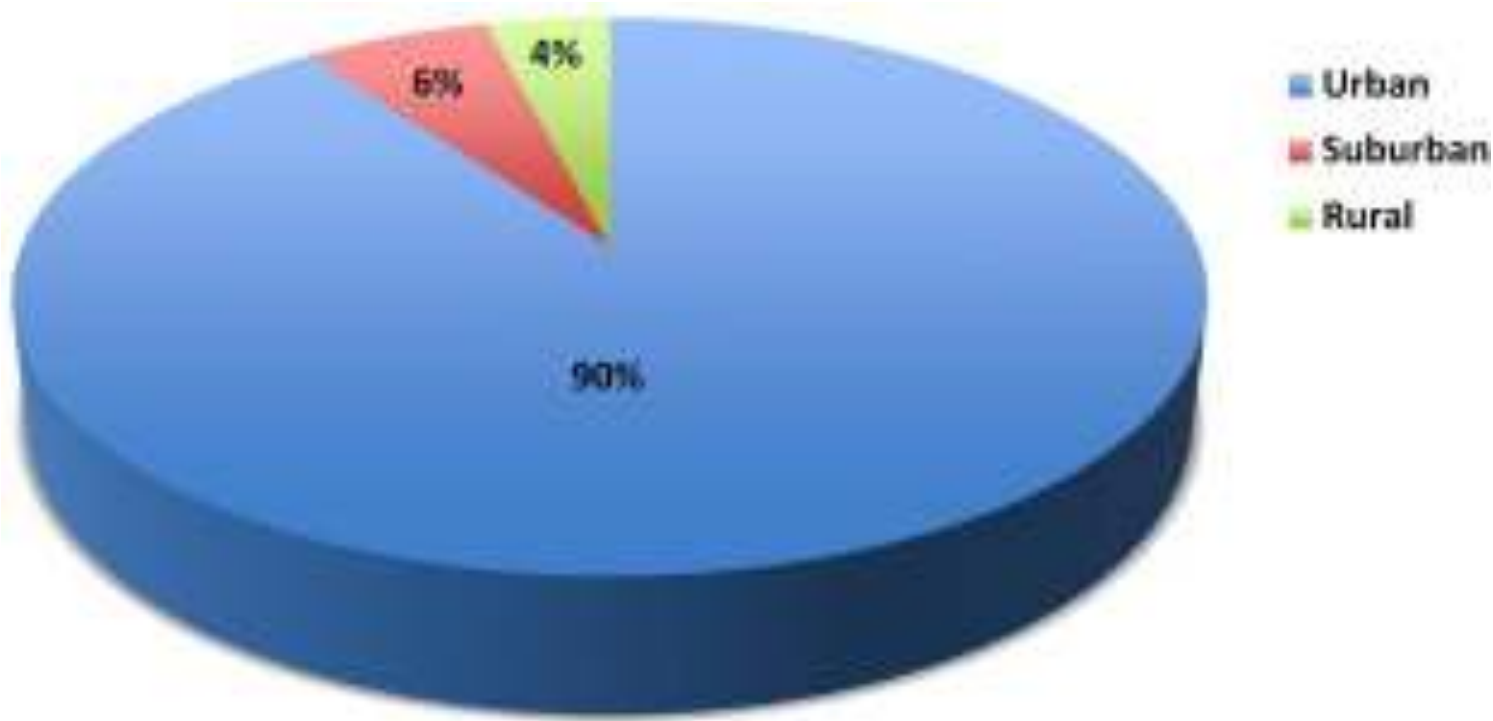
Respondents Demographic Profile

- A total of 184 (3% of total survey respondents) individuals from Bulgaria answered this year's Global Patient Survey
- 49% were male and 51% were female
- 46% of the respondents were between 30 -39 years old



Respondents Demographic Profile

- 89% of the respondents reported that their year of diagnosis was after 2010
- 90% lived in an urban area



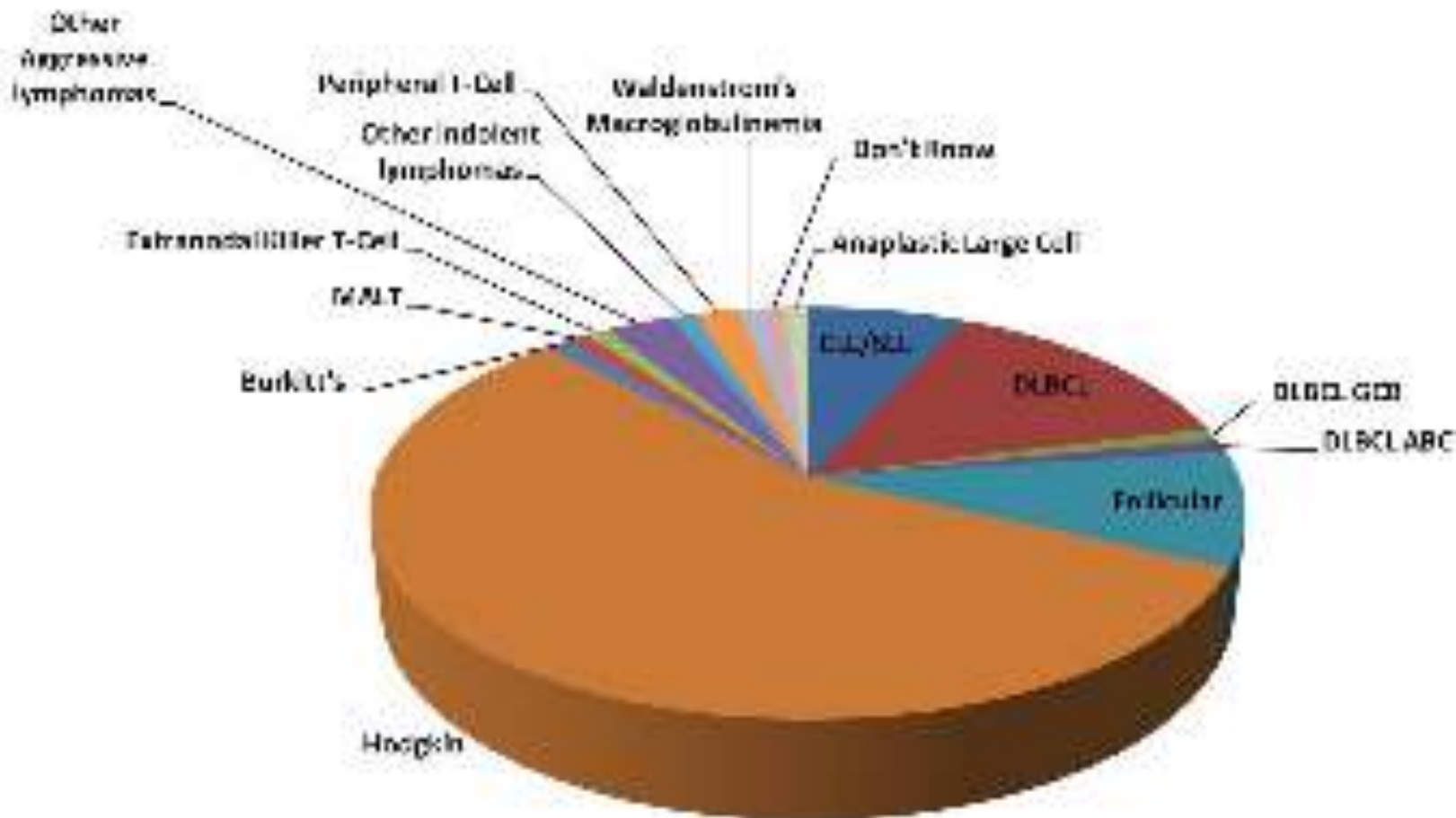
Distribution of Lymphoma Respondents in Bulgaria

Lymphoma Subtype	% of Lymphoma Respondents
Hodgkin	56
DLBCL if not told what specific type	14
DLBCL GCB type	1
DLBCL ABC type	1
Follicular	9
CLL/SLL	7
Other Aggressive lymphomas	3
Peripheral T-Cell	2
MALT/MZ	1
Don't know	1
Other Indolent lymphomas	1
Waldenstrom's Macroglobulinemia	1
Anaplastic Large Cell	1
Burkitt's	1
Extranodal Killer T-Cell	1

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Abbreviations: CLL, Chronic Lymphocytic Leukemia; SLL, Small Lymphocytic Lymphoma; DLBCL, Diffuse Large B- cell Lymphoma; GCB, Germinal Centre B-cell; ABC, Activated B-cell; MZ, Marginal Zone; MALT, Mucosa Associated Lymphoid Tissue

Distribution of Lymphoma Respondents in Bulgaria



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Abbreviations: CLL, Chronic Lymphocytic Leukemia; SLL, Small Lymphocytic Lymphoma; DLBCL, Diffuse Large B-cell Lymphoma; GCB, Germinal Centre B-cell; ABC, Activated B-cell; MZ, Marginal Zone; MALT, Mucosa Associated Lymphoid Tissue

Stage of Lymphoma Experience

- 2% were newly diagnosed
- 25% had been diagnosed and were in treatment
- 2% had been diagnosed and had been told treatment is not yet needed
- 20% were in remission and had been treatment free for 2 years or less
- 24% were in remission and had been treatment free for 2 to 5 years
- 9% were in remission and had been treatment free for more than 5 years
- 3% had relapsed for the first time and were in treatment
- 2% had relapsed more than 2 times and were in remission
- 4% had relapsed more than 2 times and were in treatment
- 7% had finished treatment and were in maintenance therapy
- 2% had transformed

II) Patient Information, Guidance and Support

Respondents Understanding after their Initial Diagnosis

Meeting with the Doctor

- Respondents in Bulgaria had the most difficulty understanding the characteristics of their particular subtype 44% and side effect management (42%) (responses 1+2)

Issues Around Diagnosis and Care	Respondents' Level of Understanding*						
	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Don't know (%)	N/A (%)
Diagnosis	15	10	19	10	41	4	1
Characteristics of the particular subtype	27	17	17	11	17	9	2
Different medical treatment options	28	12	18	9	24	8	1
initial treatment if started right away	14	11	14	14	37	7	3
Potential side effects of treatment options	19	15	23	14	20	7	2
Side effect management	26	16	18	16	16	6	2
Process and stages of care	13	17	20	18	21	7	4
Active surveillance ('watch and wait') if applicable	16	12	15	13	15	9	20

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*Respondents' Level Of Understanding: 1 is the lowest, 5 is the highest

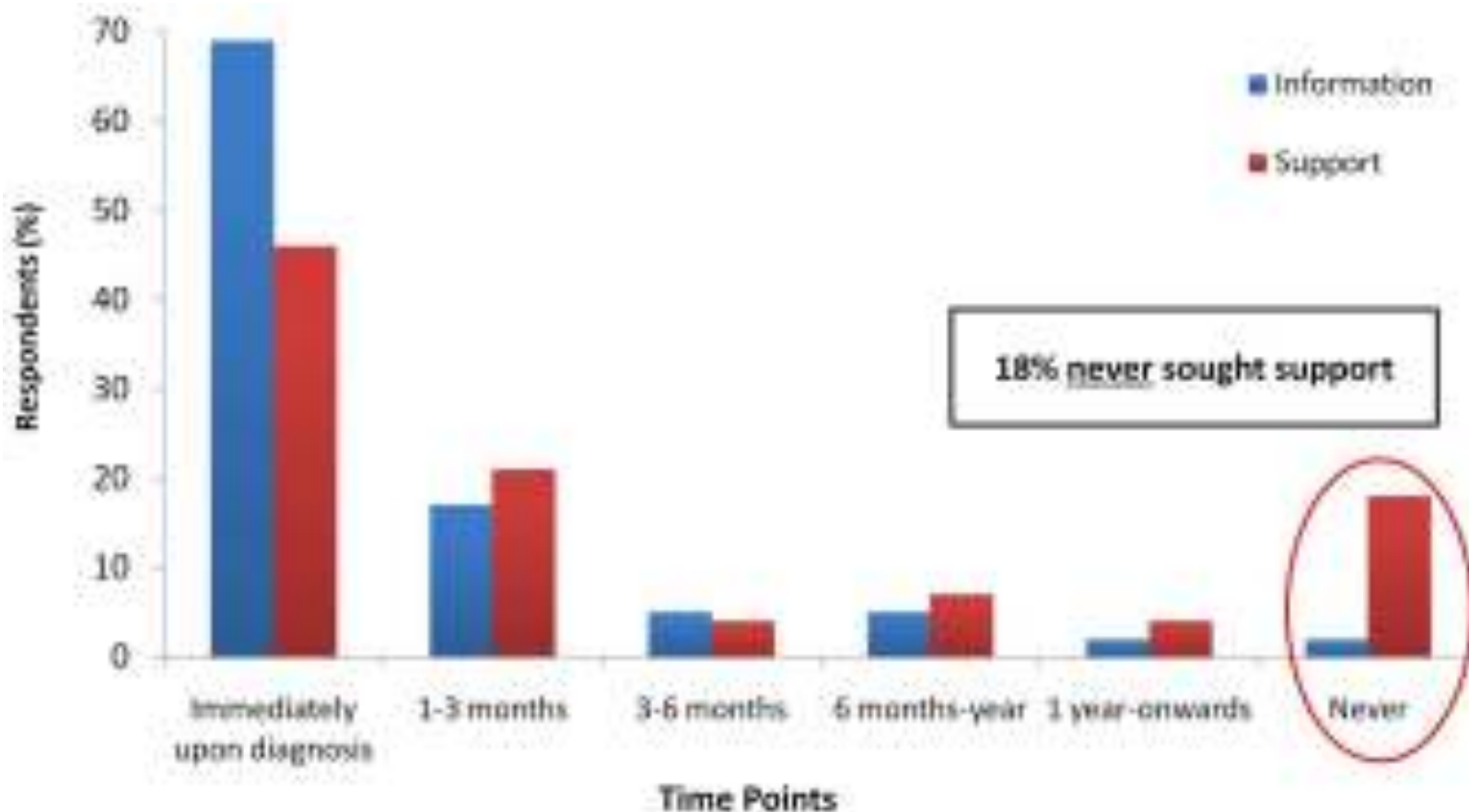
Need for Additional Medical or Associated Support Information

When asked if they would have liked to receive additional medical or associated support information at their initial diagnosis meeting with the doctor:

- 65% would like to receive additional information
- 21% received enough information
- 11% felt overwhelmed and did not want more information as it was too much to take in at the time
- 3% did not want additional information

Respondents' Information and Support Seeking

- Seeking more information was very important to most respondents. They were most active in seeking information and support immediately upon diagnosis and 1-3 months after diagnosis



Main Sources of Information



Doctor 56%



Patient Organisations 17%



Nurse 15%



Websites 64%



Online blogs/
social media 59%



Family/friends 29%

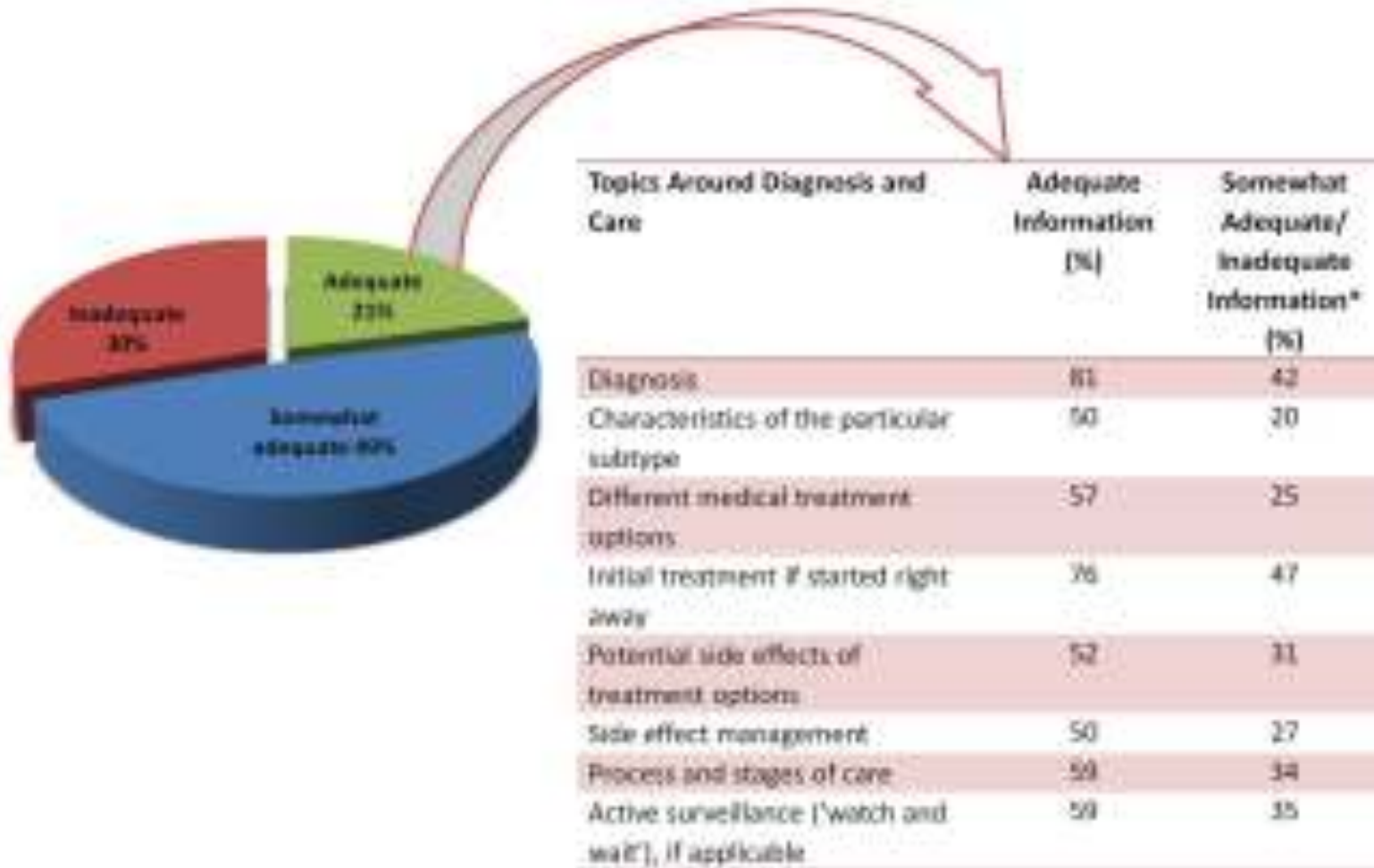


Other 3%

2018 LC Global Patient Survey

Perceived Information Level

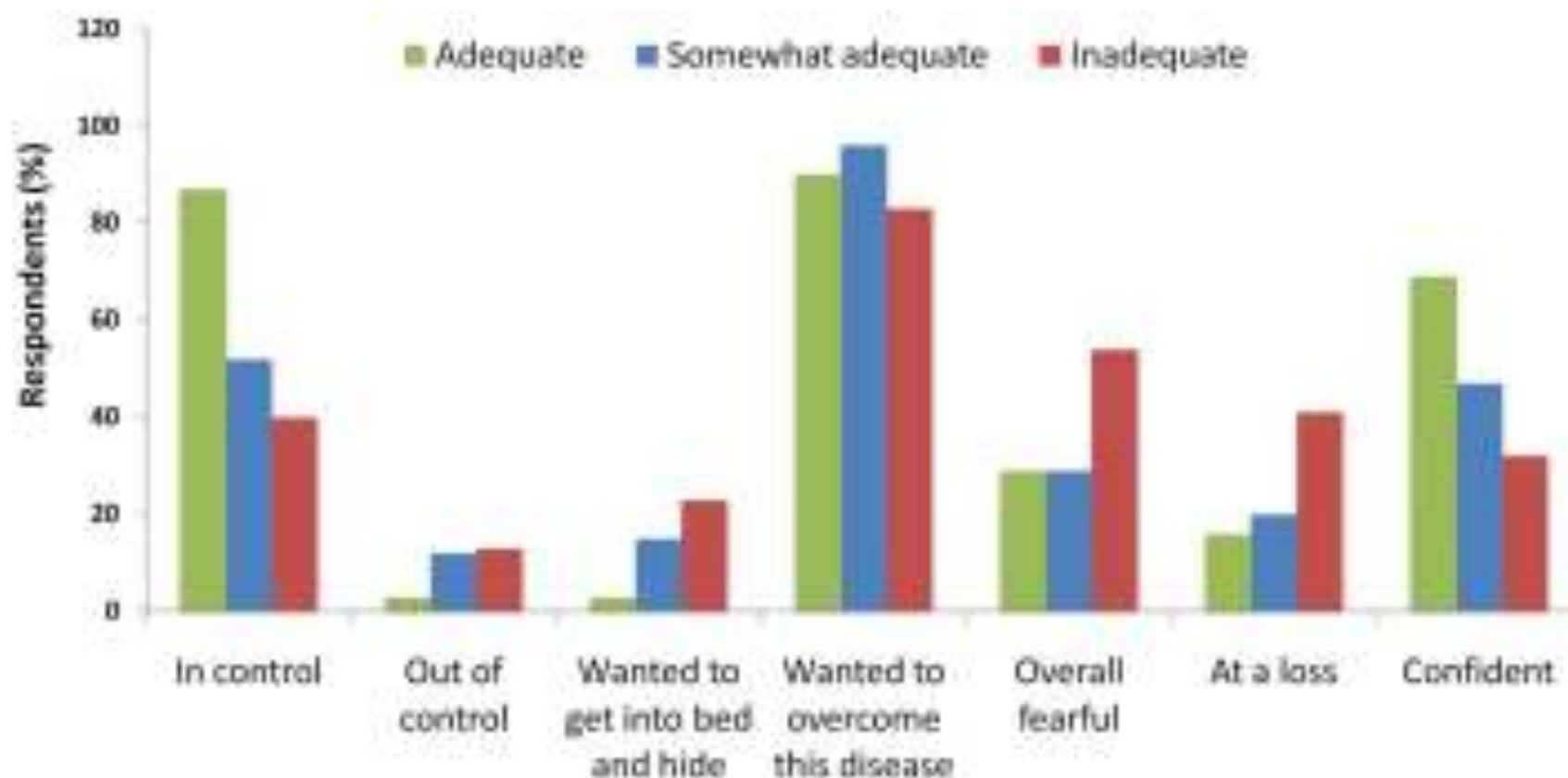
- Respondents who felt they had adequate information reported a greater understanding of all topics surrounding diagnosis and care after the initial visit to the doctor



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**Somewhat and Inadequate groups were merged together for analysis*

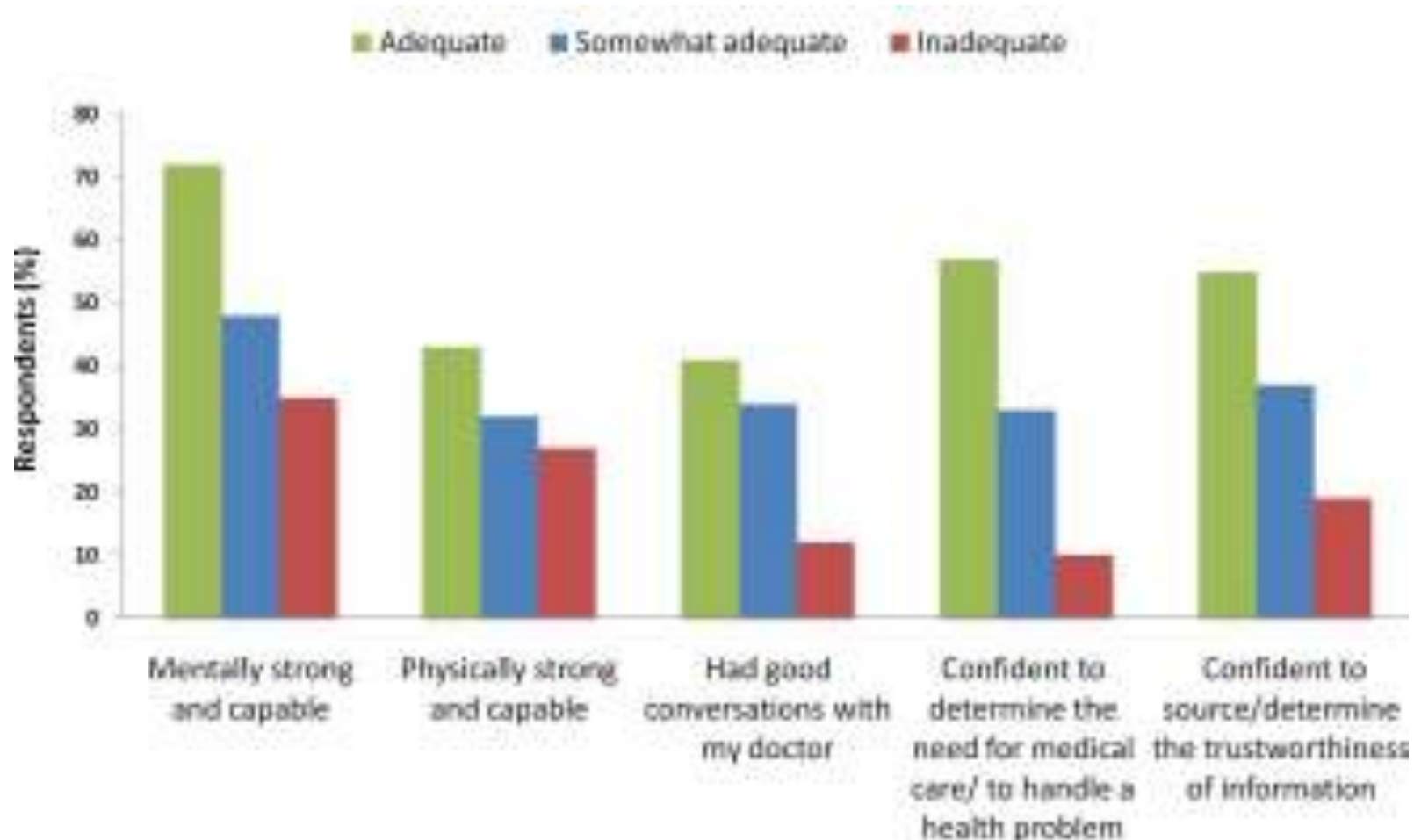
Feelings Experienced by Respondents with Different Perceived Information Levels 'Most Days'



Feelings Experienced By Respondents 'Most Days'

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Feelings Experienced by Respondents with Different Perceived Information Levels 'Most Days'



Feelings Experienced By Respondents 'Most Days'

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Feelings Experienced by Respondents with Different Perceived Information Levels 'Most Days'

- Respondents who considered themselves to be adequately informed wanted to overcome the disease (90%), felt in control (87%), were confident (69%) had good conversations with their doctors (41%)
- *Respondents who were somewhat adequately and inadequately informed felt in control to a lesser extent (52% and 40% respectively). They also had good conversations with their doctors less frequently (34% and 12% respectively)*
- 'Most days', adequately informed respondents were confident they could determine if they needed medical care or could handle a health problem on their own (57%) , as well as determine the trustworthiness of information about their health condition and treatment choices (55%)
- *Somewhat adequately informed and inadequately informed respondents felt less confident in these same two areas (33% and 37%; 10% and 19% respectively)*

Communication with the Doctor

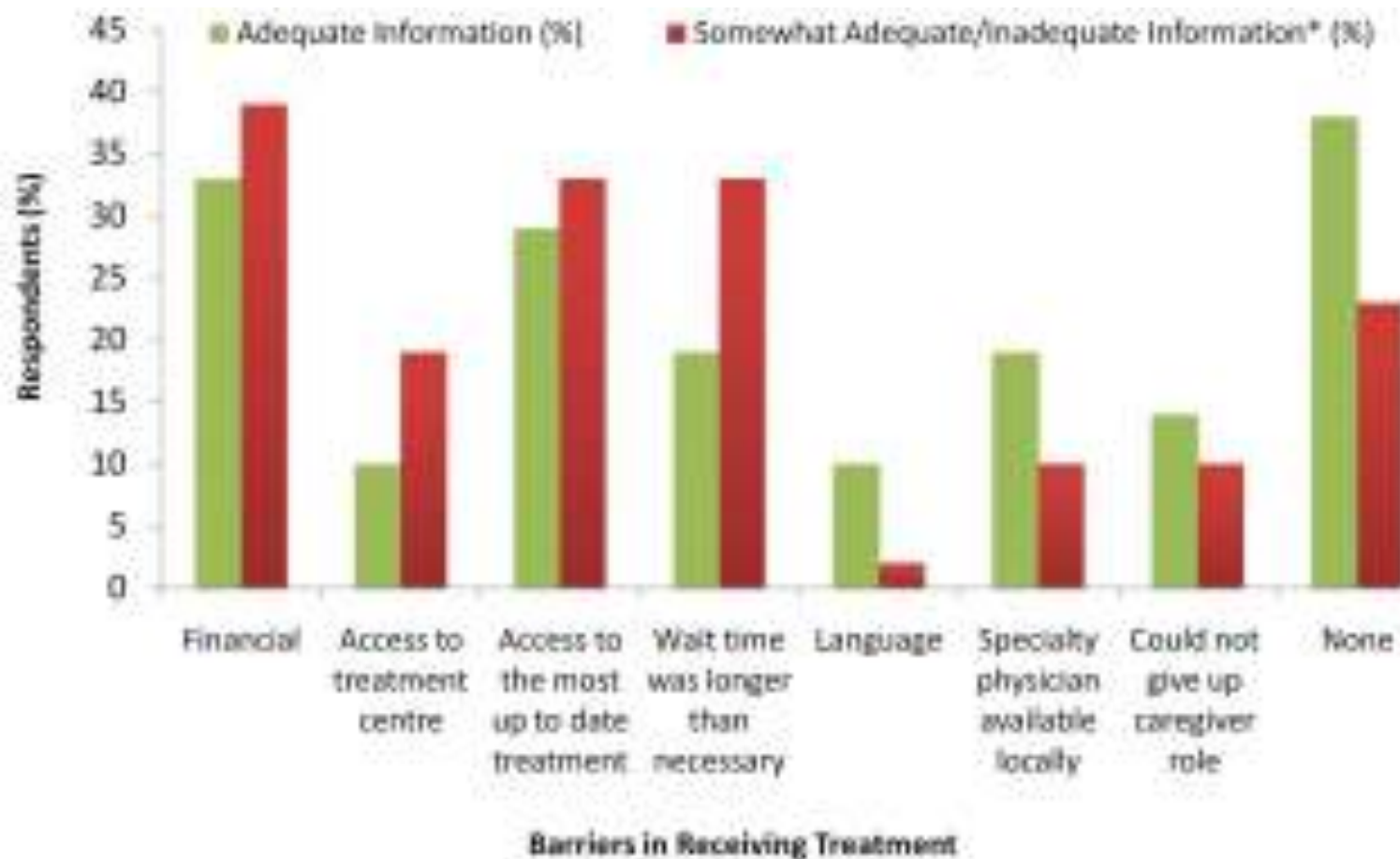
Communication with Doctor on Topics Concerning the Patient Experience	Responses			
	Yes	Somewhat	No	N/A
	(%)	(%)	(%)	(%)
Have you communicated any of your physical and/or medical issues to the doctor?	61	31	5	3
Was the doctor able to help?	25	67	21	7
Have you communicated any of your emotional issues to the doctor?	23	25	47	5
Was the doctor able to help?	11	29	45	19
Did you bring forward questions about side effects?	76	10	11	3
Was the doctor able to answer your questions?	41	36	19	4
Was the doctor able to help you cope with your side effects by providing medication or other support?	35	39	23	3
Did you seek clarification on things you did not understand?	73	18	4	5
Was the doctor able to answer your questions?	39	43	13	3
Did you discuss your fear of relapse with your doctor?	32	19	38	11
Do you feel that it helped to alleviate the fear?	13	30	37	20
Did the doctor or nurse refer you to further support you were able to use?	26	18	50	6
Did you feel confident/comfortable voicing your concerns to your doctor?	35	27	34	4
If you experienced fatigue issues, did the doctor or nurse refer you to further support or information that you were able to use?	19	20	50	11
Did you feel you had the right to take the doctor's time to discuss any of the above during your visits?	50	30	12	8
Did the doctor encourage discussion with you on any of the above?	18	28	47	7

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Communication with the Doctor

- A large proportion (61%) of respondents reported communicating their physical and/or medical issues to the doctor, however only 25% reported that the doctor was able to help
- Respondents were much less likely to communicate their emotional issues to the doctor; only 23% reported doing so, and only 11% reported that the doctor was able to help
- Of those who experienced fatigue issues, only 19% were referred onto further information or support (by a doctor or nurse), 50% were not referred

Barriers in Receiving Treatment By Information Level



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* For the purpose of analysis, somewhat and inadequate information levels were grouped as a comparator against adequate information

Respondents' Interest in Different Services

Service Type	Interest of Total Respondent Population (%)
Complementary nutrition/fitness information	99
Treatment information	97
Downloadable materials	96
Information on patient organisation services	91
Patient organisation support	90
Fatigue support	89
Credible website links	89
Clinical trial options	87
Online chats	85
Financial support	85
Professional emotional support	83
Hard copy materials	82
Professional physical support	73
Support in navigating the insurance system	80
In person support groups	77
Live education sessions	75
Phone-line support	63

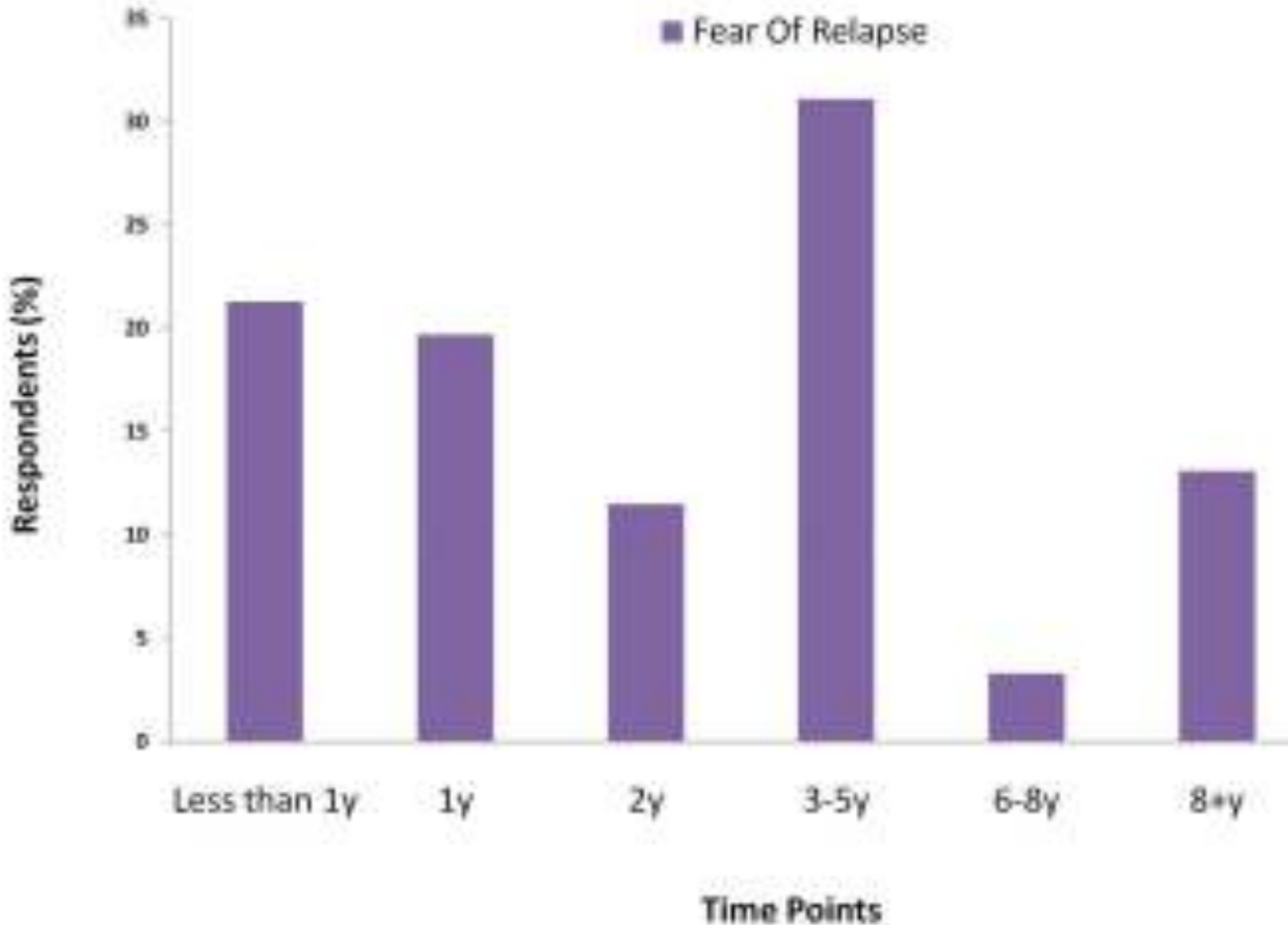
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III) Fear of Relapse

Fear of Relapse

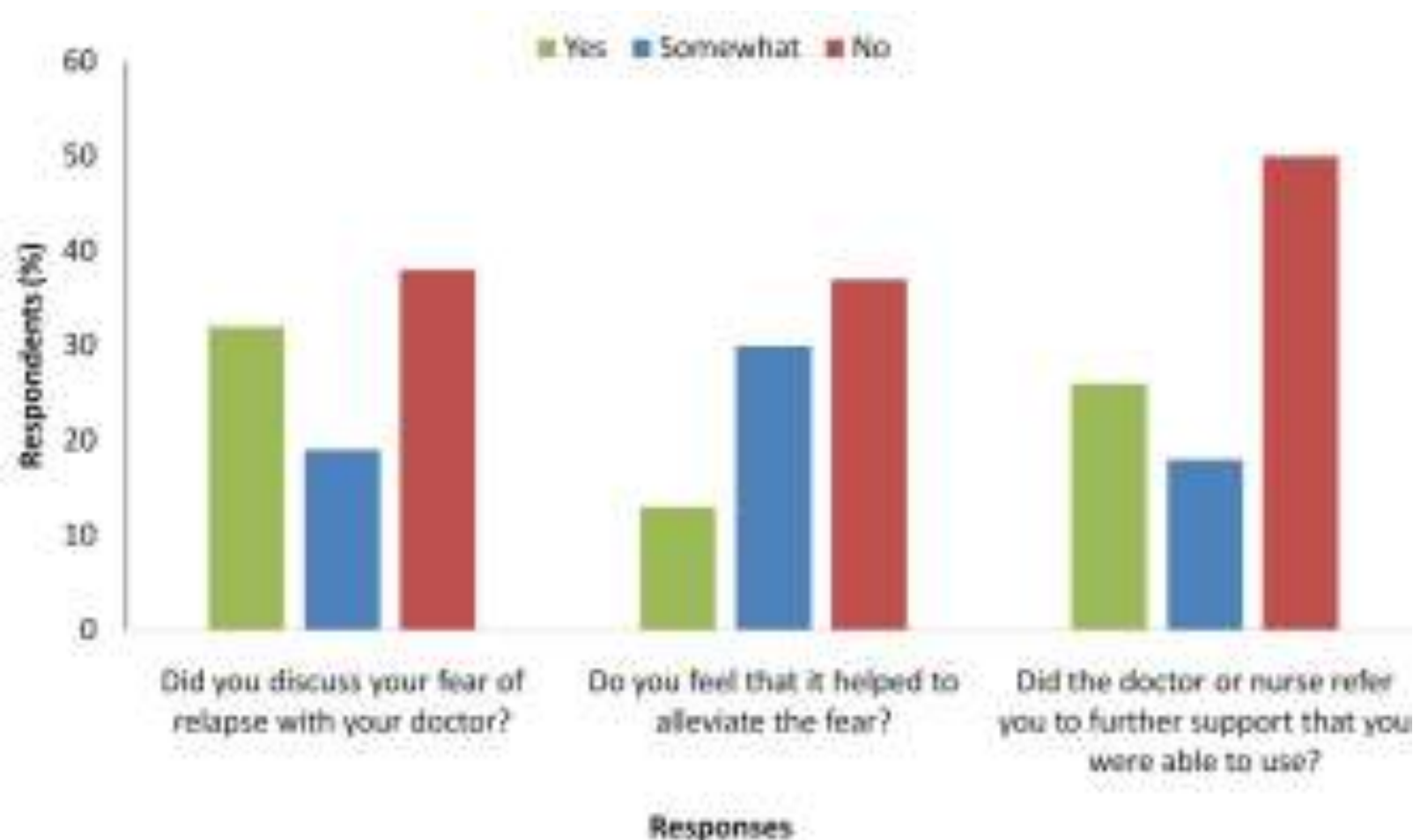
- Fear of relapse was present both during and after treatment, showing an increase from 44% during treatment to 82% after treatment
- Respondents' reports of fear of relapse peaked around 3-5 years after treatment, and it was reported by some respondents to continue for 8+ years
- Among those with fear of relapse, 11% had adequate information, 58% had somewhat adequate and 31% had inadequate information

Fear Of Relapse at Different Time Points



Fear of Relapse: Discussion with the Doctor

Of those who experienced fear of relapse, 32% discussed and 19% somewhat discussed this fear with their doctor. Only 13% felt this helped and 30% felt it somewhat helped. However, 37% did not feel it helped alleviate the fear



Fear of Relapse and Feelings of Isolation/Depression/Anxiety

Respondents who reported experiencing fear of relapse also reported experiencing feelings of isolation, depression and anxiety either during treatment or after treatment

Feelings Among Respondents Who Reported Fear of Relapse	During Treatment (%)	I Have Discussed It with My Doctor (%)
Isolation	71	4
Depression	62	9
Anxiety	80	5

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These feelings were rarely discussed with their doctors (both during and after treatment)

Feelings Among Respondents Who Reported Fear of Relapse	After Treatment (%)	I Have Discussed It with My Doctor (%)
Isolation	23	3
Depression	27	3
Anxiety	38	2

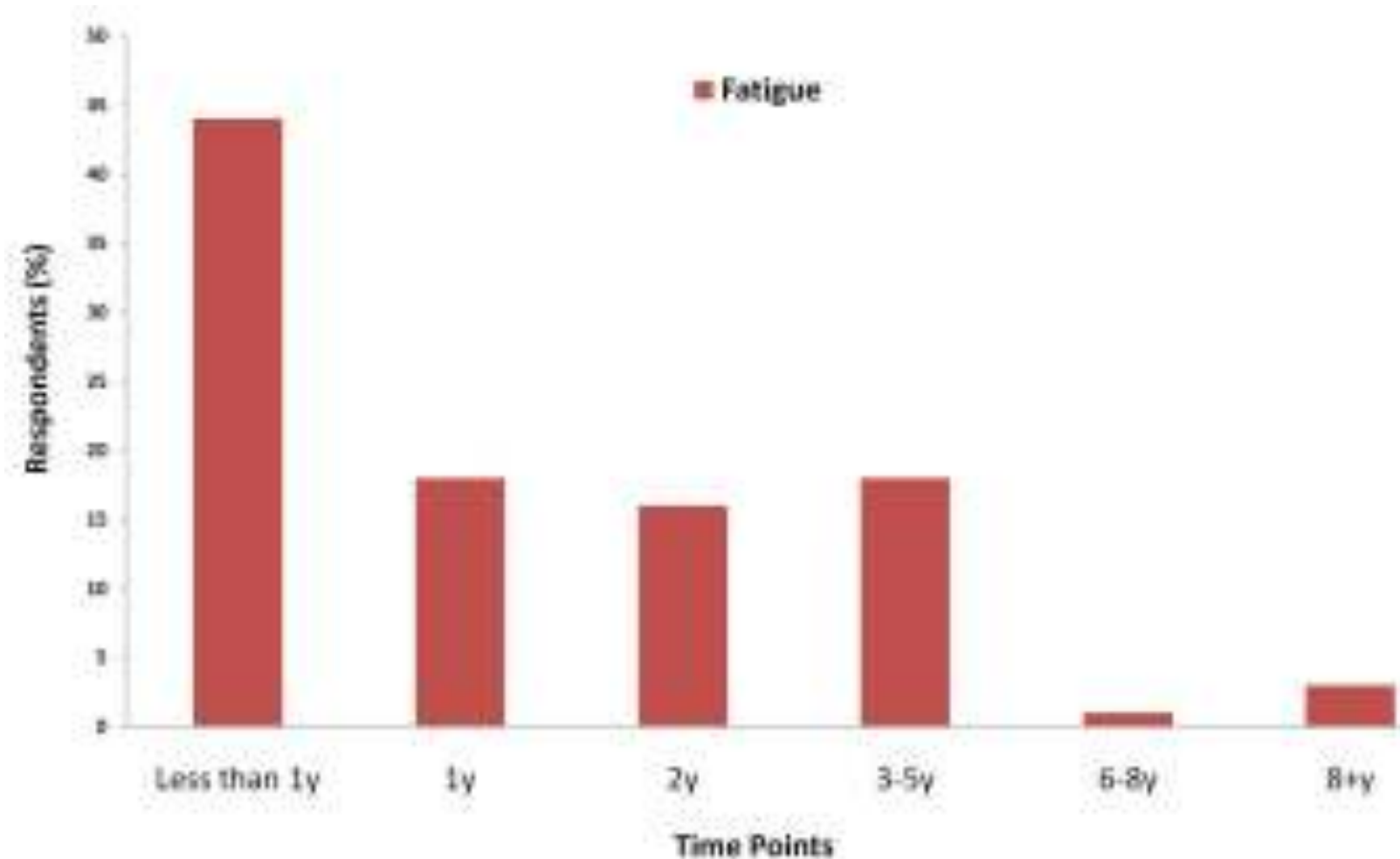
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IV) Fatigue

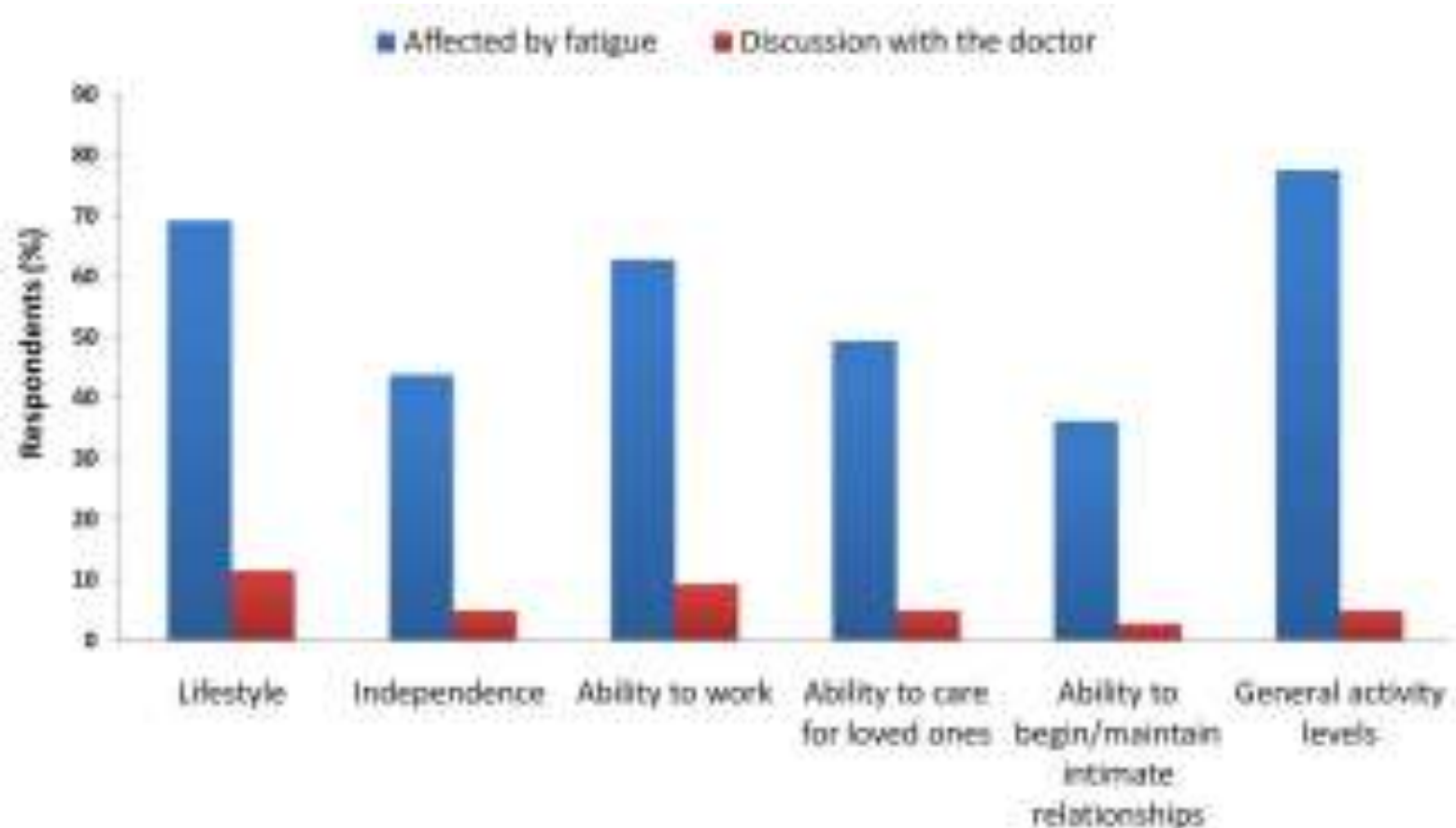
Fatigue

Fatigue was the most frequent physical condition (79%) affecting respondents' sense of wellbeing since diagnosis. Fatigue peaked immediately following treatment and some also reported it even 8+ years after treatment



Fatigue: Life Changes and Discussion with the Doctor

Fatigue affected respondents' independence but more so their lifestyle, with general activity suffering the largest impact. Respondents also reported that life has changed (49%) or moderately changed (79%), or that they sleep well but the fatigue does not go away (43%)



Life Changes And Their Discussion With The Doctor

Fatigue and Psychosocial Issues

Psychosocial Issues Affecting Wellbeing During and After Treatment Amongst Respondents with Fatigue	Treatment	
	During (%)	After (%)
Changes in relationships with loved ones, friends or co-workers/social life	41	18
Stress related to financial issues	36	15
Loss of self-esteem	21	8
Concerns about body image/physical appearance changes	39	14
Loss/reduction in employment	32	14
Isolation	35	13
Depression	32	13
Anxiety	41	20
Fear of relapse	28	37
Difficulty on the job or in school	21	15
Problems getting health or life insurance coverage	9	5
Difficulty working effectively through the healthcare system	26	13
None	2	2

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V) Living with Side Effects

Living with Side Effects

- **Top reported physical condition(s)**

Fatigue(79%) and hair loss (65%)

- **Top reported medical conditions**

(i) During treatment: Stomach-related issues (53%) and numbness (39%)

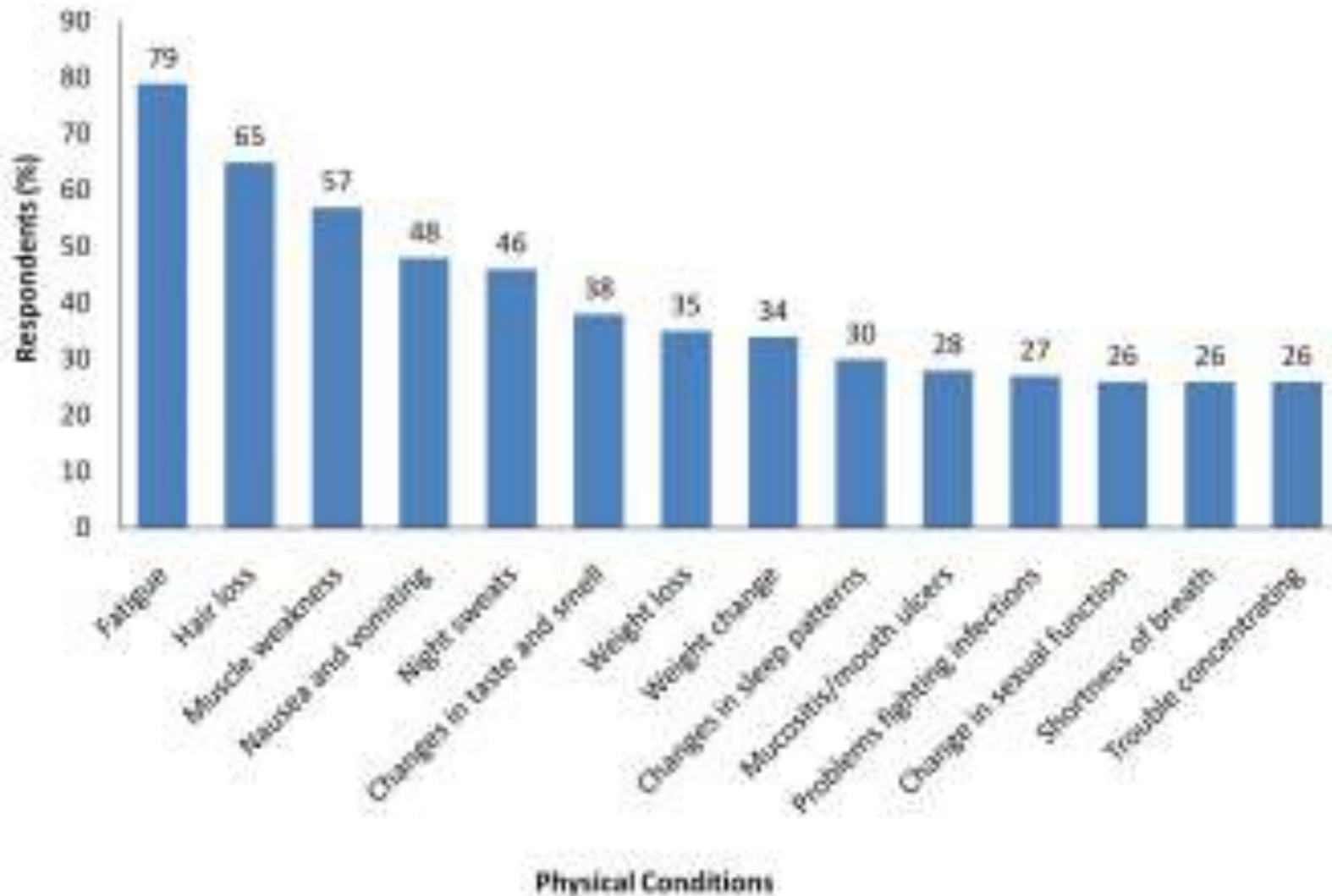
(ii) After treatment: Tingling, numbness (39%) and eyesight issues (32%)

- **Top reported psychosocial issues**

(i) During treatment: Fear of relapse (44%), changes in relationships with loved ones, friends or co-workers/social life (35%) and concerns about body image (35%)

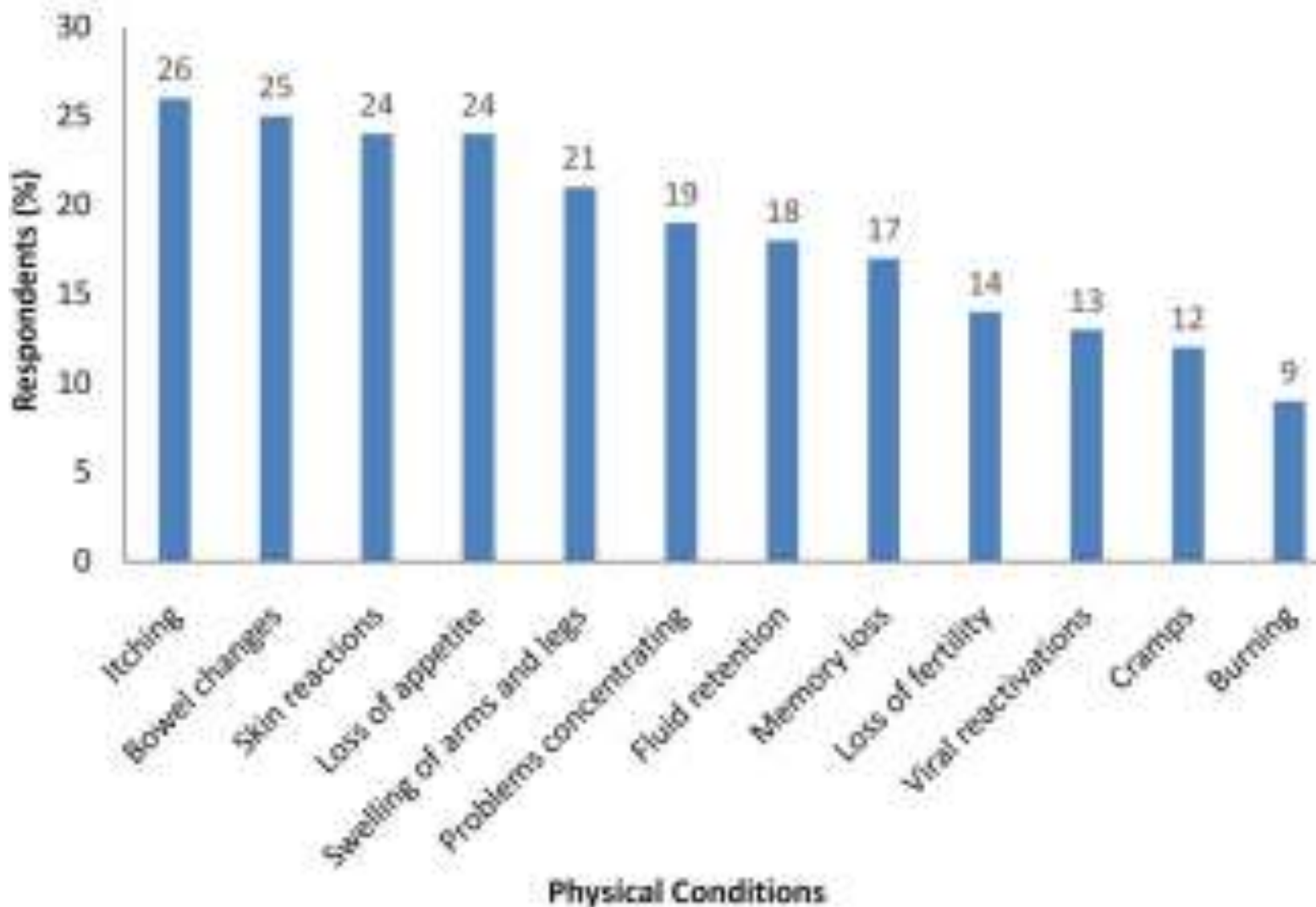
(ii) After treatment: Fear of relapse (82%)

Physical Conditions Affecting Sense Of Wellbeing



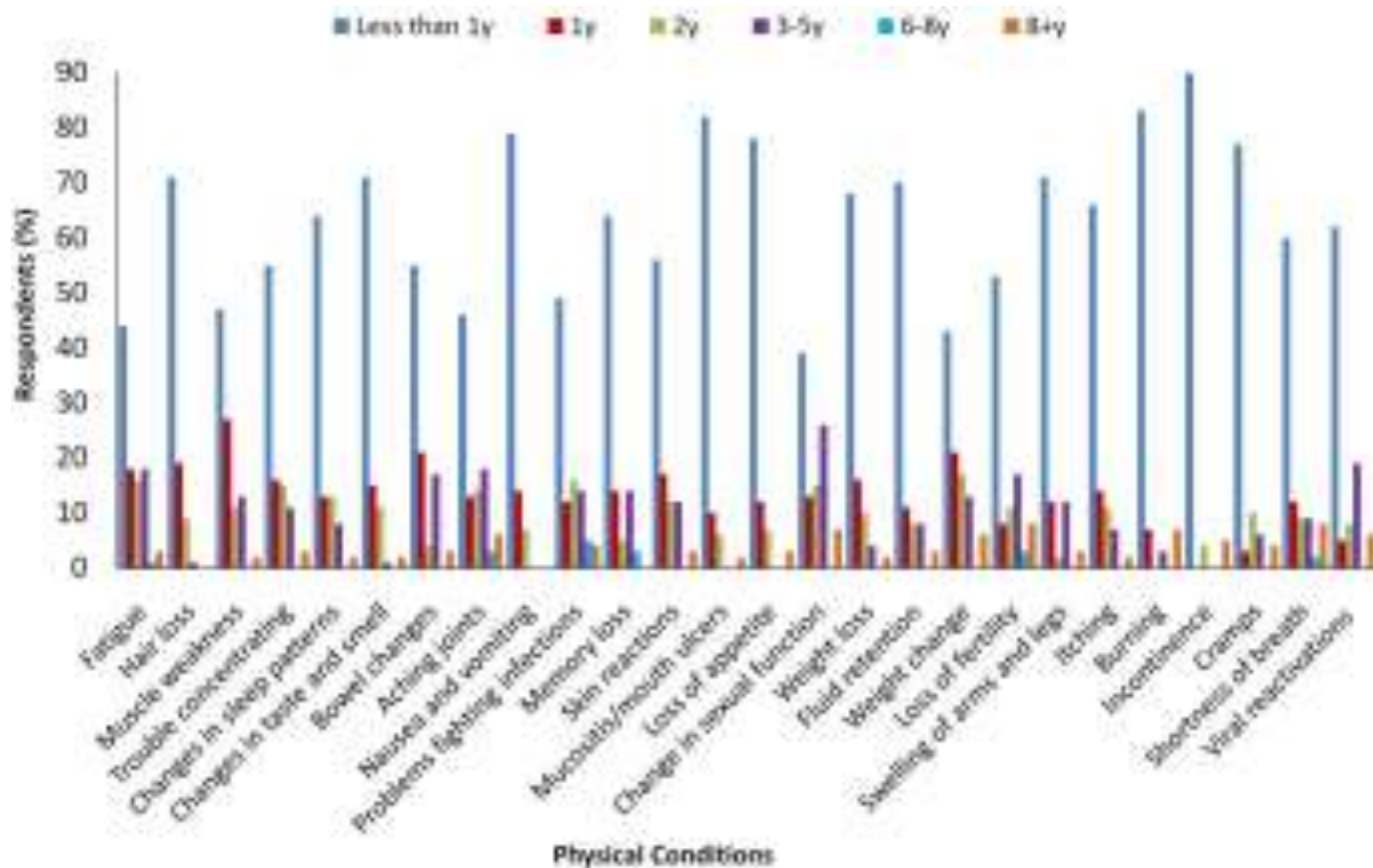
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Physical Conditions Affecting Sense Of Wellbeing Cont.



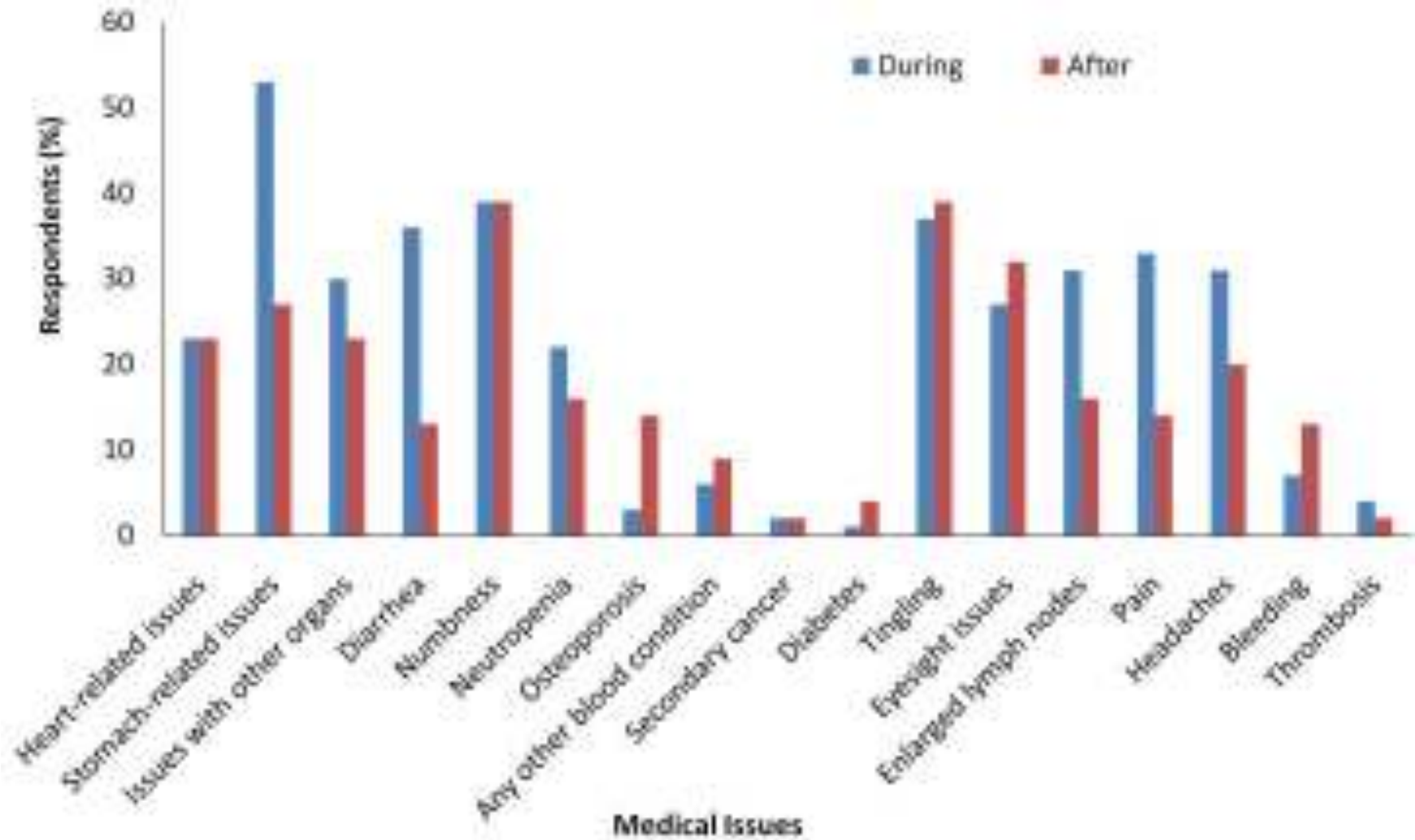
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Duration Of Physical Conditions Following Treatment



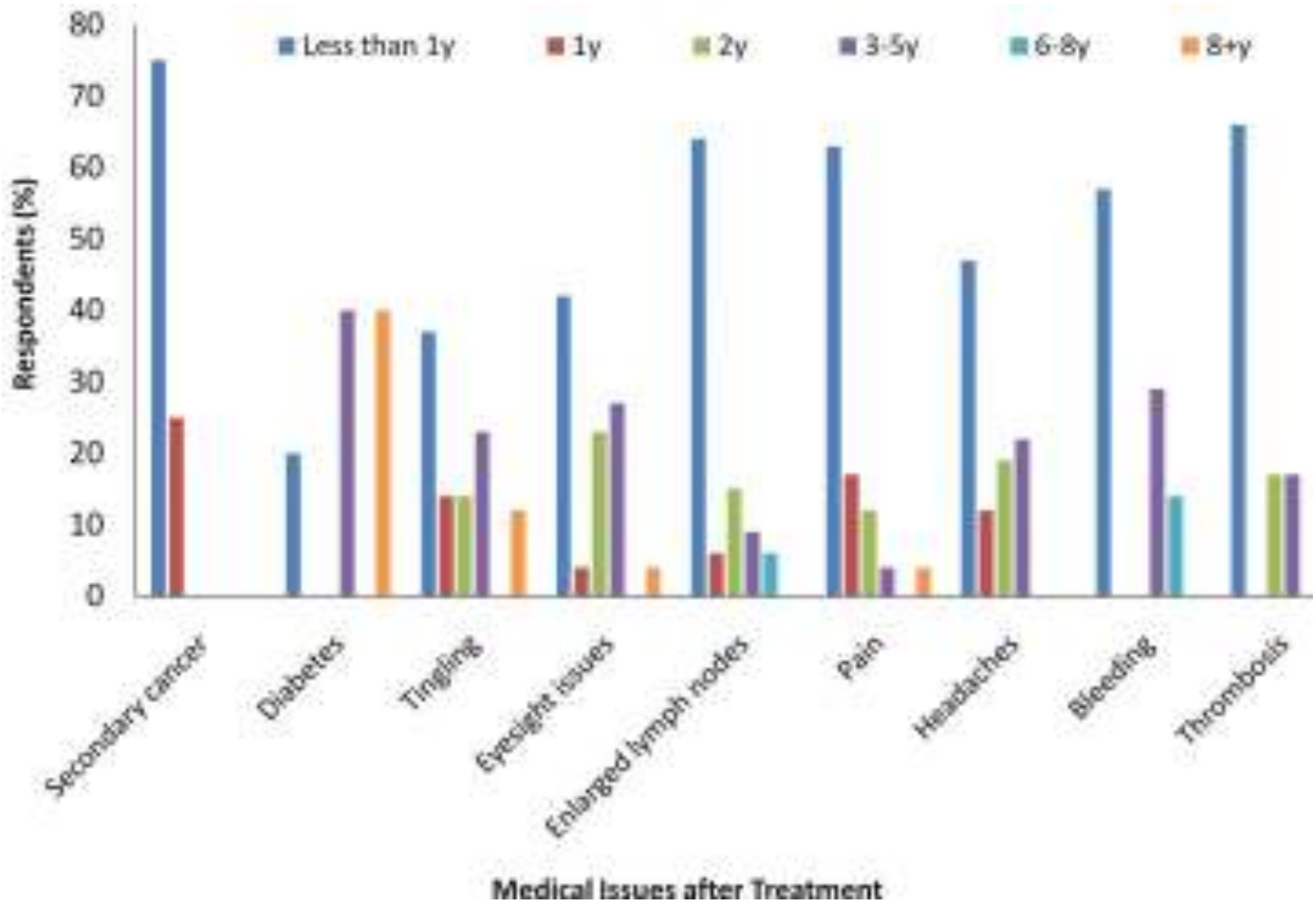
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Medical Issues During And After Treatment



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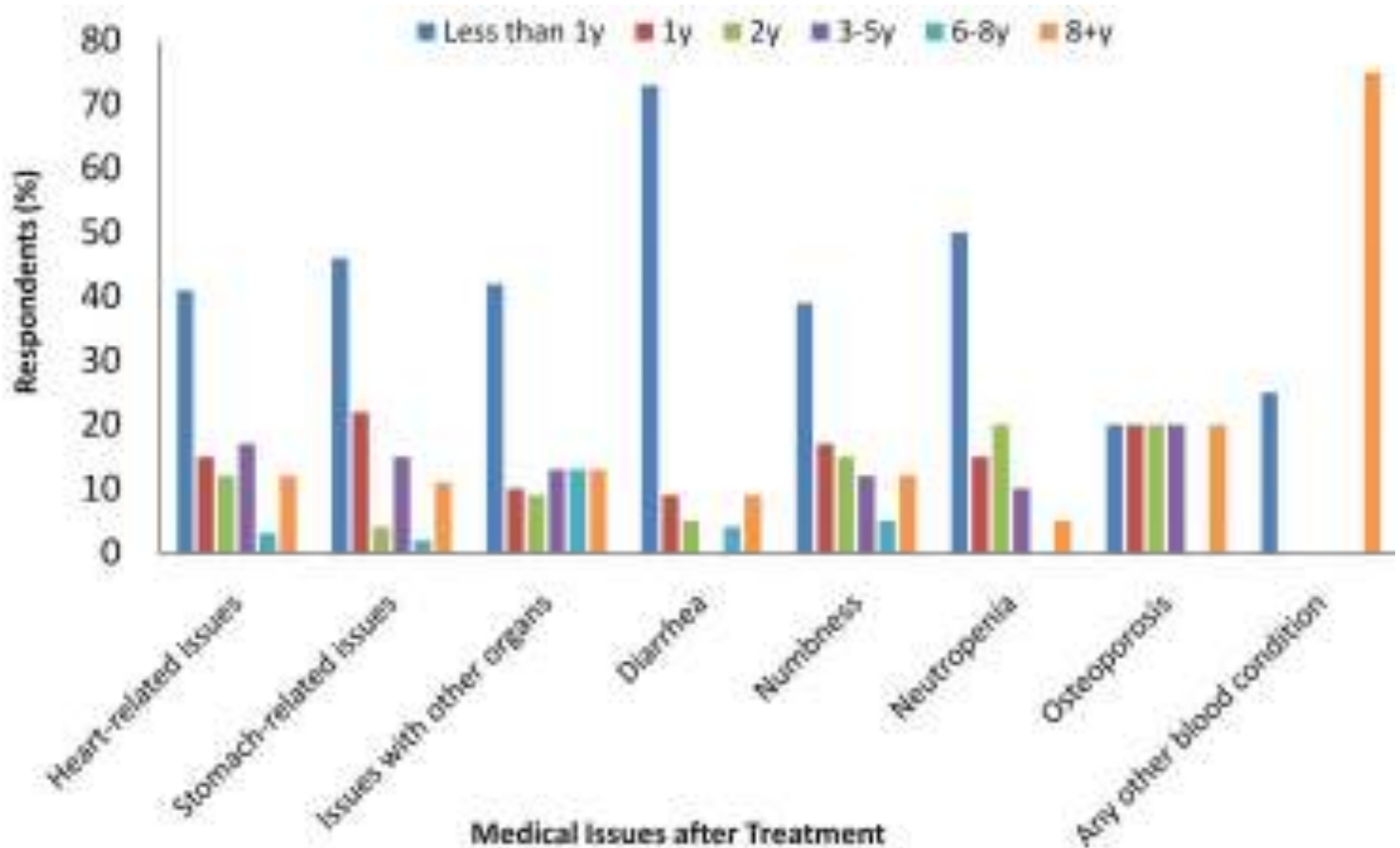
Duration Of Medical Issues Following Treatment



Having no bars in a category means that there is no reported incidence of a medical issue at a particular time point.



Duration Of Medical Issue Following Treatment Cont.

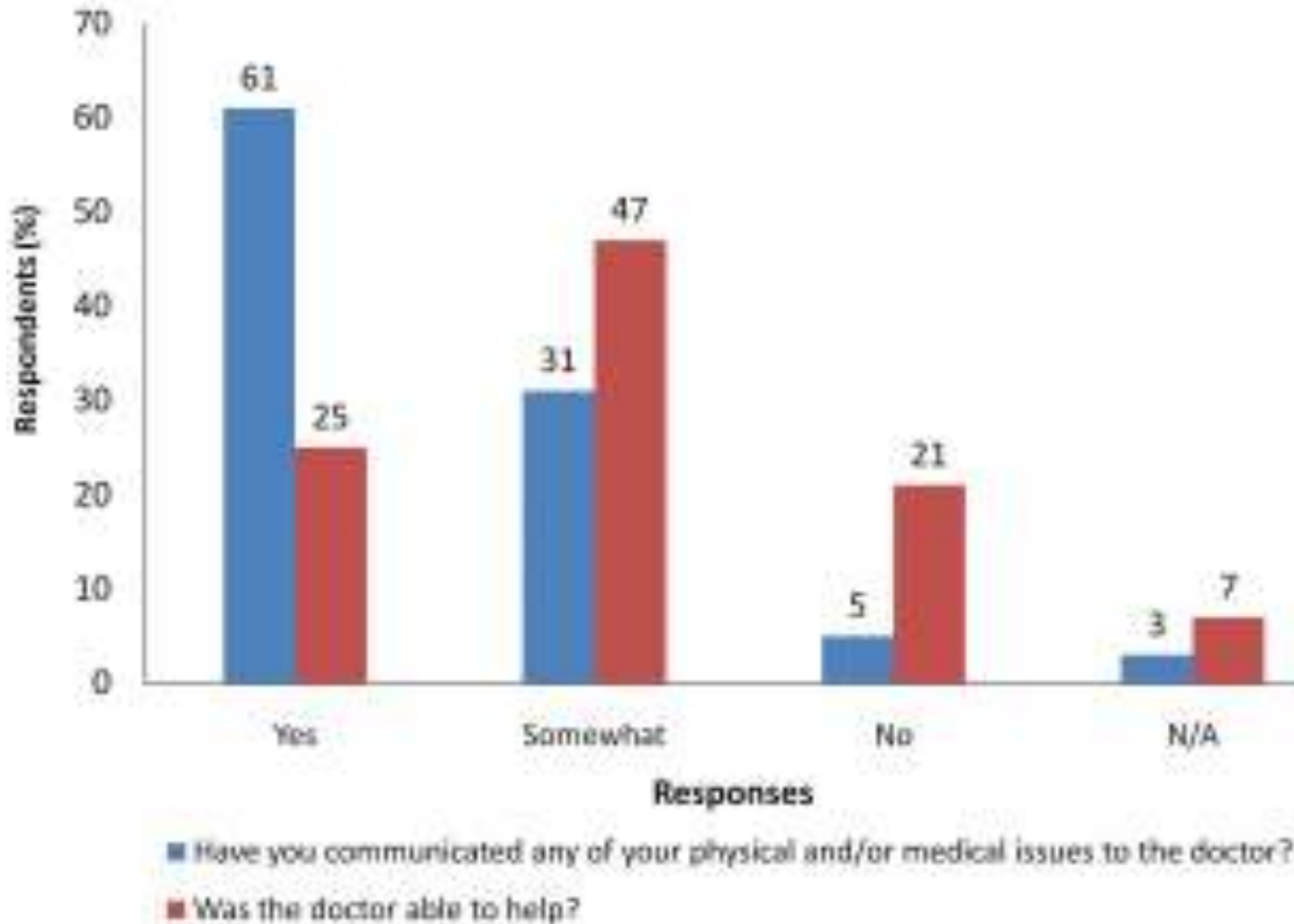


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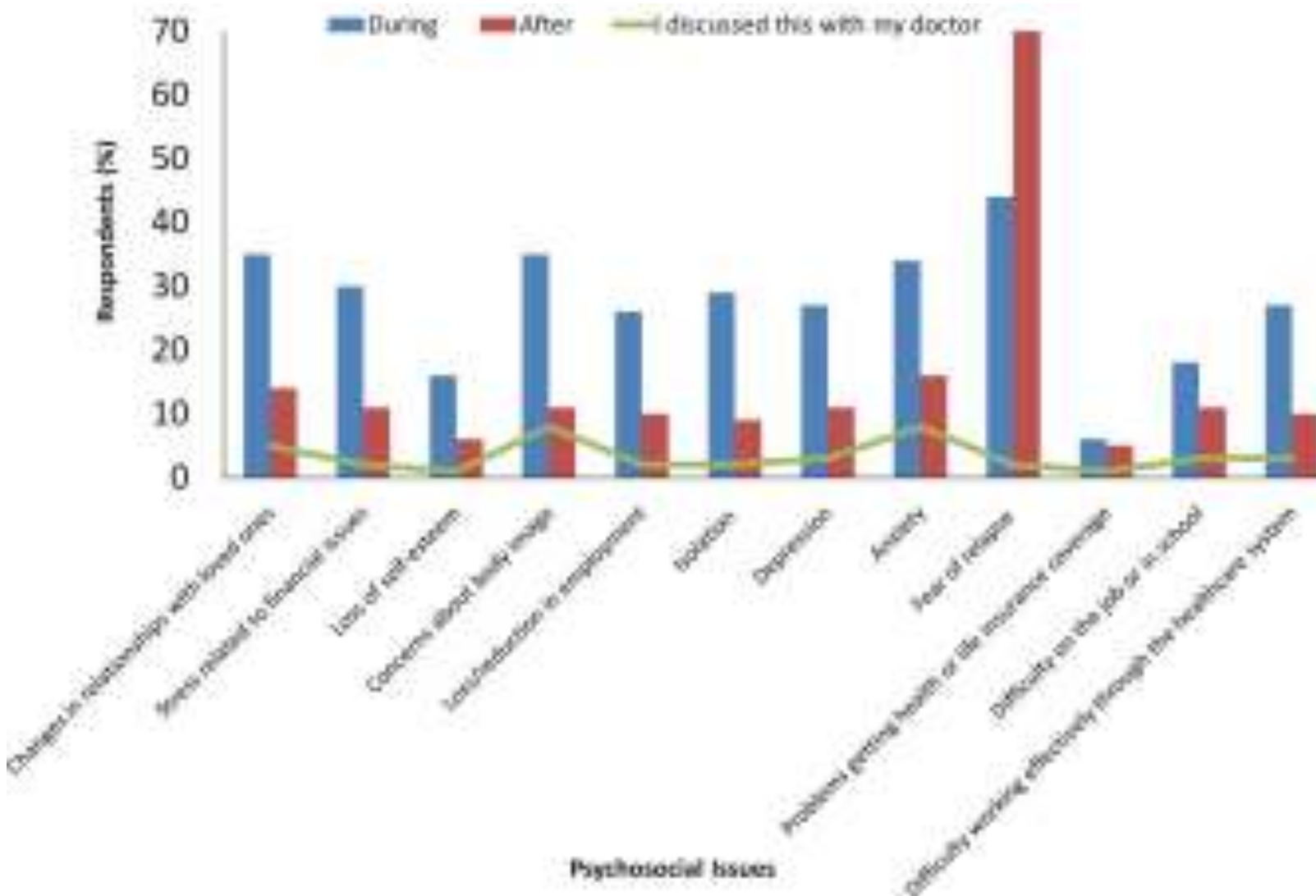
Having no bars in a category means there is no reported incidence of a medical issue at a particular time point.

Communication with the Doctor

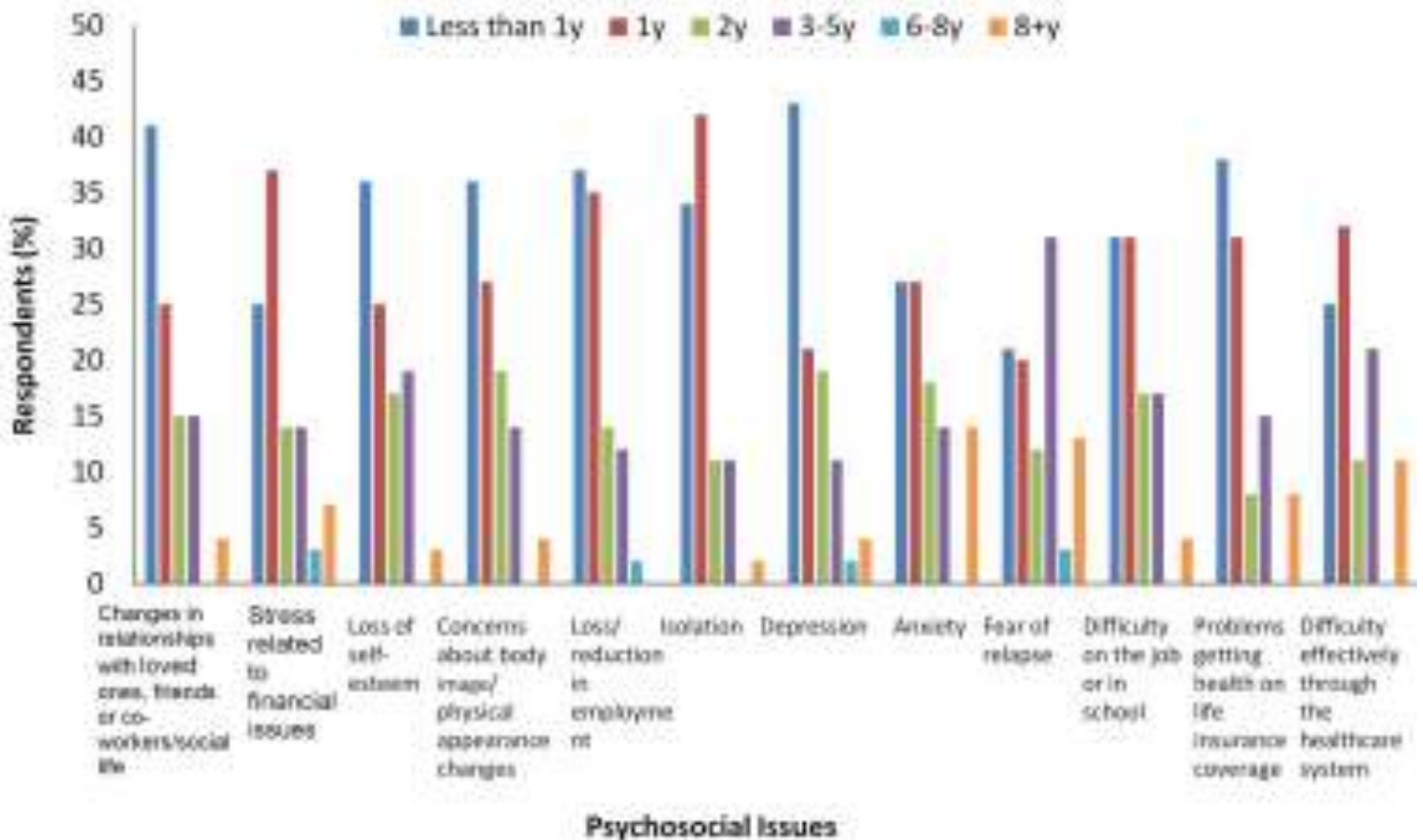
Respondents communicated physical/medical issues to the doctor in 61% of cases and indicated that the doctor was able to help in 25% of cases and to somewhat help in 47% of cases



Time Points (During /After Treatment) Respondents Were Affected By Psychosocial Issues and Discussion with the Doctor

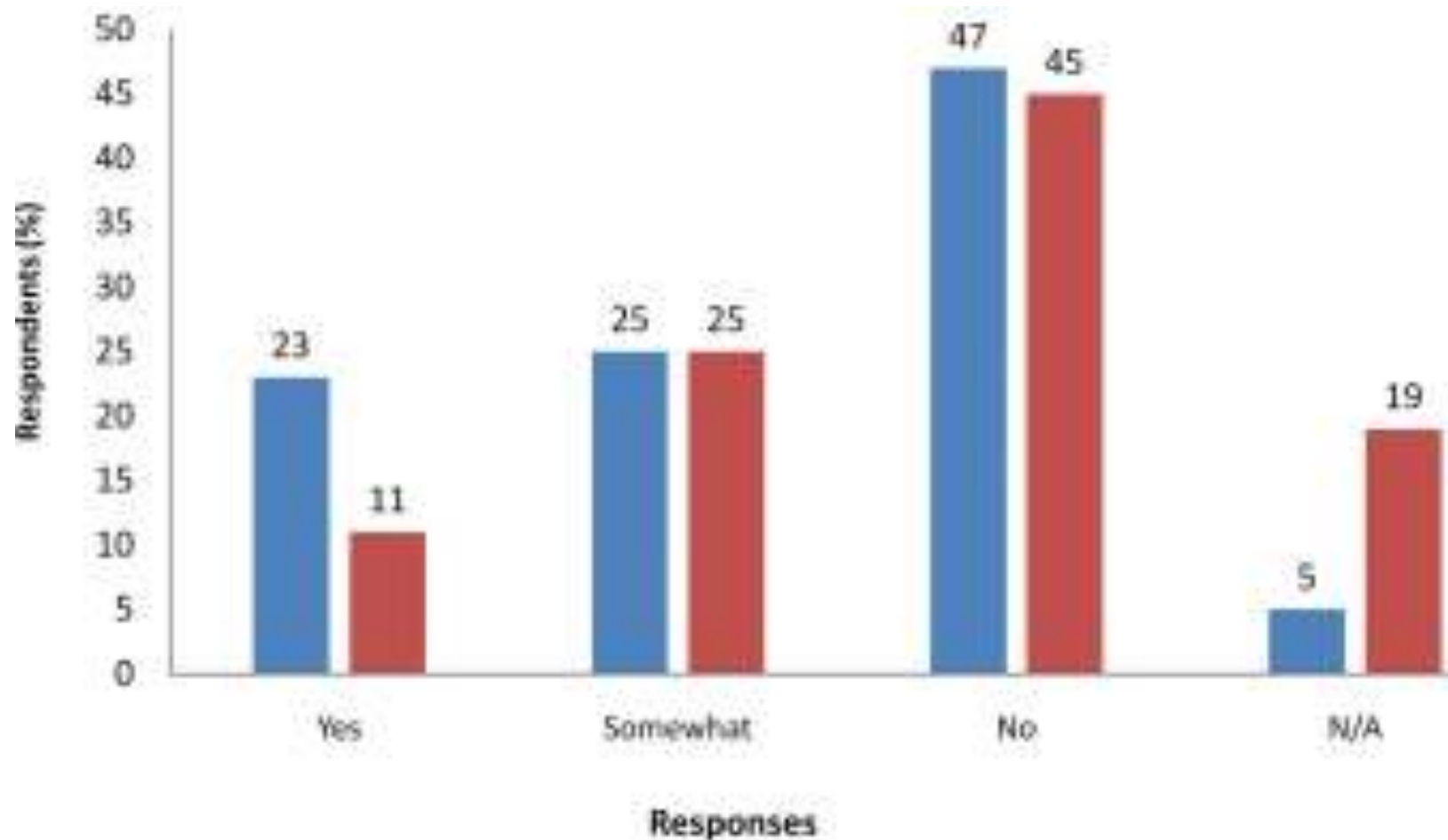


Duration of Psychosocial Issues



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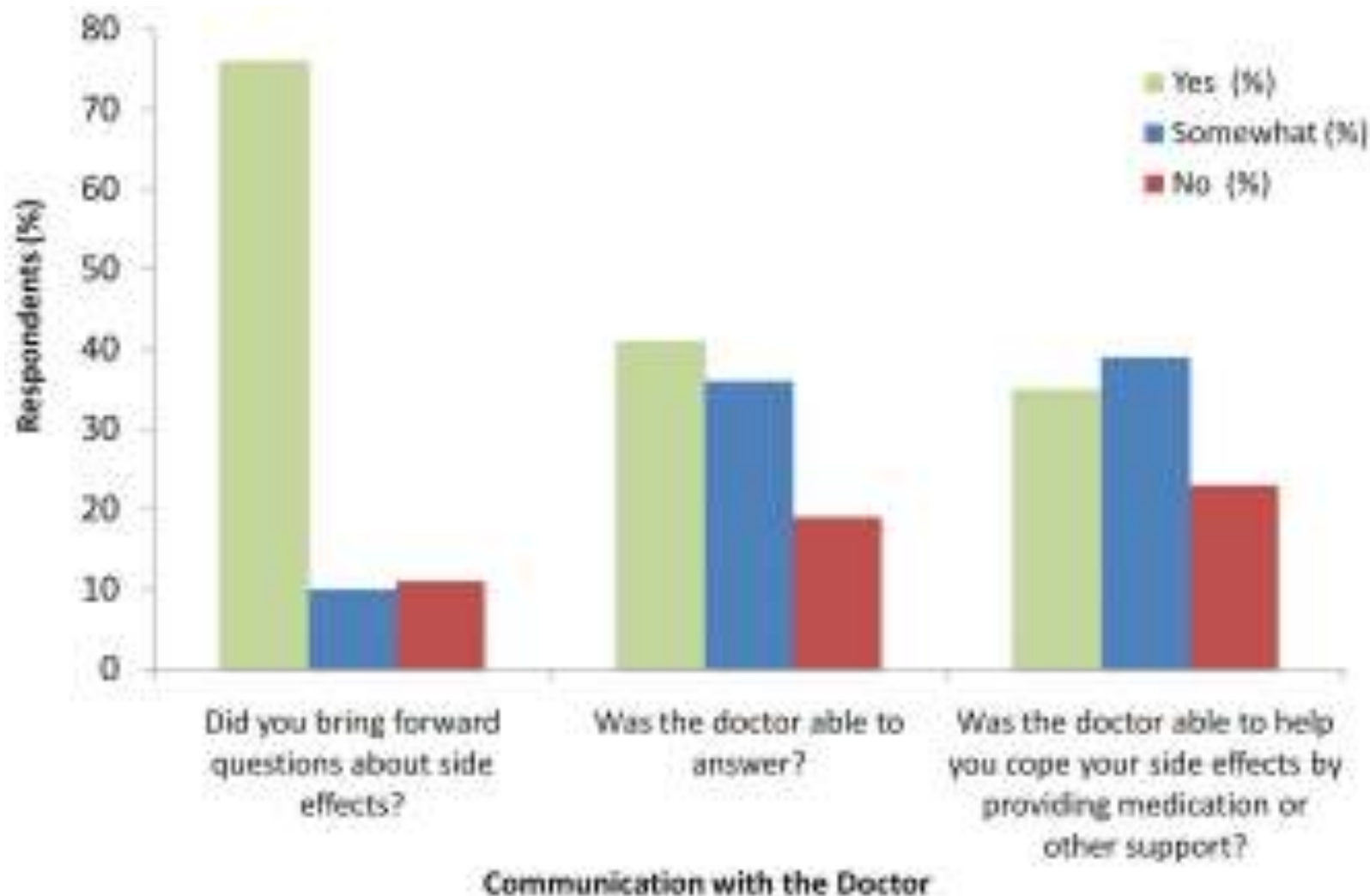
Communication with the Doctor



- Have you communicated any of your emotional issues to the doctor?
- Was the doctor able to help?

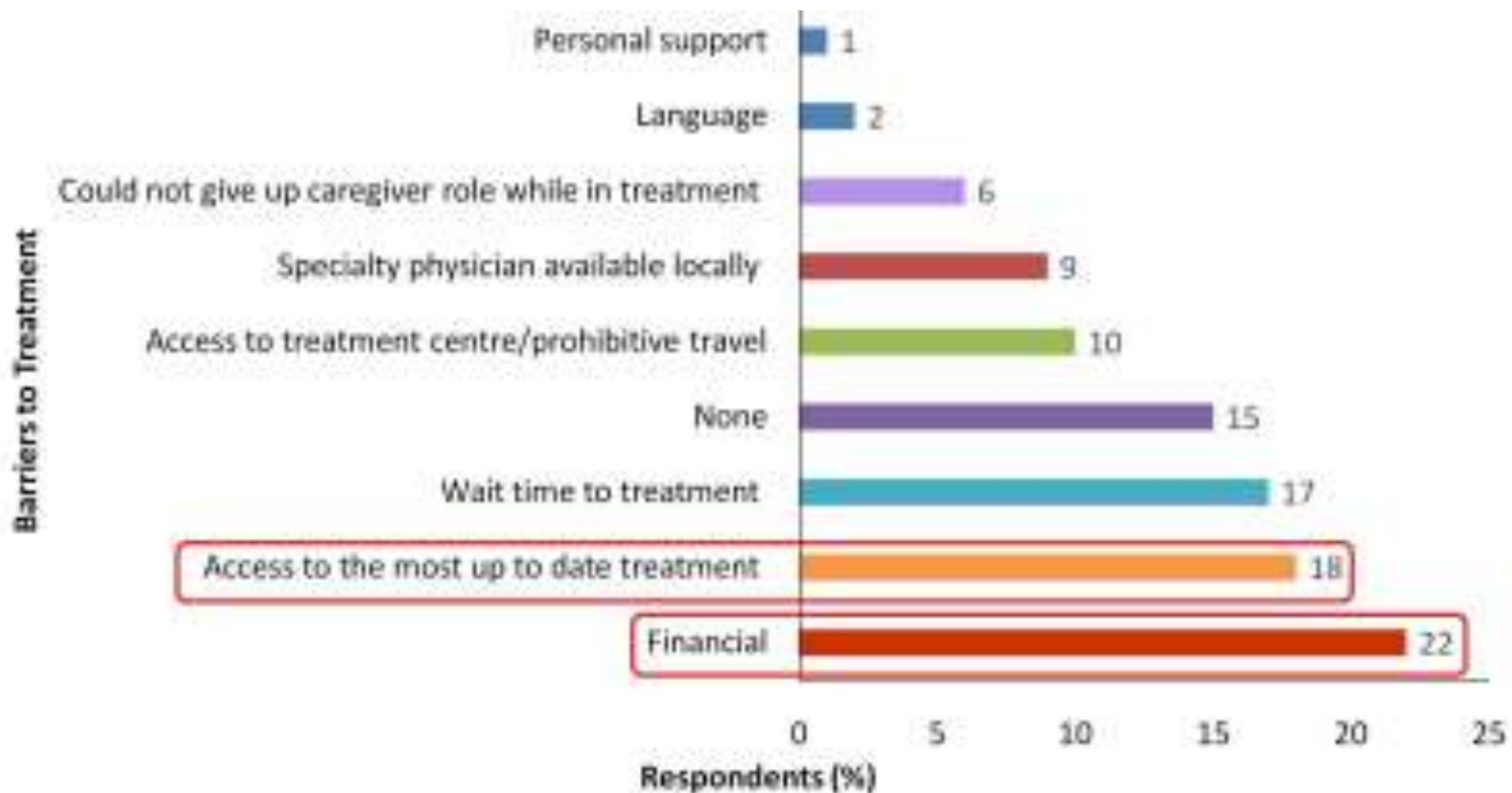
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Communication with the Doctor about Side-Effects (General)



VI) Barriers and Impediments

Barriers in Receiving Lymphoma Treatment



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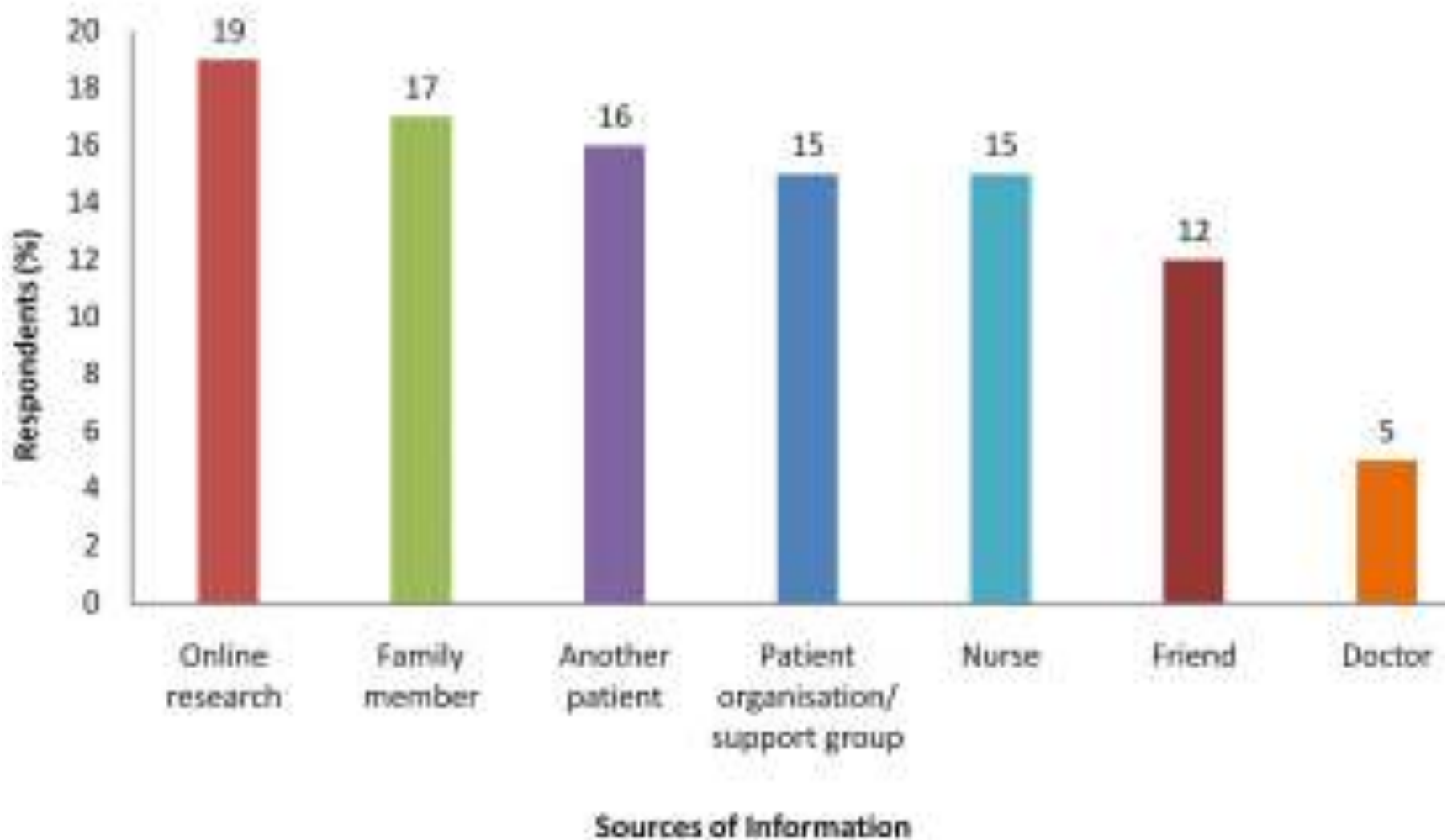
Evaluation of Services in Bulgaria

Patient organisation/support groups and spiritual support were the services respondents in Bulgaria reported to be the most helpful

Types of Services	Evaluation of Services (1 lowest rating - 5 highest rating)							
	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Don't know (%)	Not available in my country (%)	N/A (%)
Social worker	20	5	4	-	3	23	31	14
Patient organisation/ support group	7	3	8	17	35	15	5	15
Dietician/nutritionist	15	-	5	4	12	20	21	23
Counsellor/psychologist	16	3	5	8	12	18	18	20
Spiritual support	14	5	3	8	31	12	10	17
Physical therapy	14	3	7	6	4	22	13	31
Pain management	14	-	9	5	8	21	12	31
Complementary therapist	15	-	4	6	7	18	19	31

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Sources of Information about Services in Bulgaria



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- 9% of respondents were not provided with information about services

Barriers to Treatment Based on the Area of Residence

Financials were reported as the most frequent barrier by respondents in rural and urban areas. Access to up to date treatment and wait time to treatment were barriers identified by respondents in suburban areas

Types of Barriers to Treatment	Area of Residence		
	Rural (%)	Urban (%)	Suburban (%)
Financial	100	36	38
Access to treatment centre/prohibitive travel	25	16	25
Language	-	4	-
Access to the most up to date treatment	-	32	50
Wait time was longer than necessary	25	27	50
Personal support	-	1	-
Specialty physician available locally	-	15	38
Could not give up caregiver role (child, parent, disabled person) while in treatment	-	10	25
None	-	27	13

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Barriers to Treatment and Communication with the Doctor

Respondents who ‘most days’ or ‘sometimes’ had good conversations with their doctor did not identify any barrier in 35% and 31% of cases respectively, in contrast to only 13% of those who never had good conversations with their doctors

Good Conversation	Barriers to Treatment						None (%)
	Financial (%)	Access to treatment centre/ prohibitive travel (%)	Access to the most up to date treatment (%)	Wait time was longer than necessary (%)	Specialty physician available locally (%)	Could not give up caregiver role while in treatment (%)	
Most days	31	14	17	10	7	10	35
Sometimes	36	14	28	31	25	8	31
Never	39	22	48	48	17	13	13

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