



Keeping Care Complete
International Findings Fact Sheet

Keeping Care Complete examines and raises awareness of the emotional and societal issues associated with the treatment and care of patients diagnosed with schizophrenia, schizoaffective disorder and bipolar disorder.

The program consists of two international surveys addressing complex considerations associated with caring for individuals living with these illnesses.

Keeping Care Complete launched in 2006 with a survey of 1,082 caregivers and continued into 2008 with a survey of 697 psychiatrists. The caregiver and psychiatrist surveys revealed the devastating consequences of relapse and shed light on the importance for doctors to focus on long-term care rather than managing crisis situations. Also, an overwhelming percentage of caregivers and psychiatrists (97% and 96%, respectively) agree that the goal of treatment should be to maintain wellness, defined as the condition of both good physical and mental health.

Keeping Care Complete was developed by the World Federation for Mental Health and Eli Lilly and Company and has surveyed psychiatrists and caregivers in Australia, Canada, France, Germany, Italy, Portugal, Spain, the United States and the United Kingdom.

Key Findings Between the Caregiver and Psychiatrist Surveys

To show the similarities or disparities between caregivers and psychiatrists, key data from each survey is presented below.

The Devastating Consequences of Relapse

Psychiatrists and caregivers both report that relapse, defined as worsening of symptoms and/or acute return of symptoms after apparent and/or partial recovery, can devastate the lives of patients and caregivers.

Comparison of Key Data From The Psychiatrist and Caregiver Surveys	
<u>Psychiatrist Survey</u>	<u>Caregiver Survey</u>
<ul style="list-style-type: none"> • Of 697 psychiatrists who said that their patient experienced relapse, the result was: <ul style="list-style-type: none"> ○ Their patient was unable to work (86%) ○ Their patient attempted suicide (52%) ○ Their patient was incarcerated (30%) 	<ul style="list-style-type: none"> • Of 928 caregivers who said their family member experienced relapse, the result was: <ul style="list-style-type: none"> ○ Their family member was unable to work (69%) ○ Their family member attempted suicide (21%) ○ Their family member was incarcerated (18%)

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| <ul style="list-style-type: none"> ○ Their patient was hospitalized (90%) ○ The life of the family caregiver was disrupted substantially (87%) ○ The family caregiver became more fearful about their family member's condition (87%) ○ The mental and physical health of the family caregiver worsened (68%) ○ The financial situation of the family caregiver worsened (42%) ○ The family caregiver was unable to hold a full-time job (43%) | <ul style="list-style-type: none"> ○ Their family member was hospitalized (65%) ○ Their own lives were disrupted substantially (59%) ○ They became more fearful about their family member's condition and well being (58%) ○ Their own mental and physical health worsened (52%) ○ Their financial situation worsened (26%) |
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Supporting Data from the Psychiatrist Survey

- Of the 697 psychiatrists, 98% said that relapse is a major concern when treating patients with serious mental illness and 93% said that they need more treatment options to address non-adherence and decrease the risk of relapse in patients with schizophrenia

Supporting Data from the Caregiver Survey

- Of the 1,080 caregivers who said their family member's treatment was disrupted due to his/her decision to stop, 37% said that their family member relapsed 5 or more times since becoming diagnosed

Considerations for Selecting Medication and Addressing Non-Adherence

Psychiatrists and caregivers alike say that lack of adherence to medication and treatment disruptions are major causes of relapse.

Comparison of Key Data from the Psychiatrist and Caregiver Surveys	
<u>Psychiatrist Survey</u>	<u>Caregiver Survey</u>
<ul style="list-style-type: none"> • Of the 697 psychiatrists surveyed: <ul style="list-style-type: none"> ○ 99% said that medication discontinuation has led to relapse ○ 94% said that efficacy is a primary concern when considering treatment options for their patients ○ 87% said that patients try 2-5 different medications before finding one that leads to a marked improvement in both their well-being and mental health condition • Of 697 psychiatrists who said their patients found the right treatment and experienced a marked improvement in their condition, patients were able to: <ul style="list-style-type: none"> ○ Perform daily tasks more independently (90%) ○ Stay out of the hospital (88%) ○ Hold a steady job/volunteer (71%) ○ Live on their own (62%) ○ Form a romantic relationship (51%) 	<ul style="list-style-type: none"> • Of the 1,082 caregivers surveyed: <ul style="list-style-type: none"> ○ 91% said that medication discontinuation has led to relapse ○ 91% said that efficacy is their primary concern when considering treatment options for their family member ○ 49% said that their family member tried 2-5 different medications before finding one that led to a marked improvement in both their well-being and mental health condition • Of the 848 caregivers who said their family member had successful treatment and experienced a marked improvement in their condition, family members were able to: <ul style="list-style-type: none"> ○ Perform daily tasks more independently (76%) ○ Stay out of the hospital (70%) ○ Hold a steady job/volunteer (40%) ○ Live on their own (35%) ○ Re-engage with family and friends (80%)

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| <ul style="list-style-type: none"> • Of the 697 psychiatrists surveyed, successful treatment of their patients resulted in wellness and improvement of symptoms and led to: <ul style="list-style-type: none"> ○ Decreased interpersonal tension (92%) ○ Decreased stress levels for their families (91%) | <ul style="list-style-type: none"> • Of the 848 caregivers surveyed, successful treatment of their family member resulted in wellness and improvement of symptoms and led to: <ul style="list-style-type: none"> ○ Decreased interpersonal tension (73%) ○ Decreased stress levels (75%) |
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Supporting Data from the Psychiatrist Survey

- Of the 697 psychiatrists who said that their patients’ treatment was disrupted due to a lack of medication adherence:
 - 84% said a lack of adherence to a medication – either complete or partial – is the number one cause of relapse in patients with schizophrenia
 - 98% said complete or partial non-adherence to medication can be a significant barrier to effective treatment for patients with bipolar disorder, leading to the exacerbation of symptoms and an increased likelihood of relapse
 - 93% said antipsychotic medication in the form of a long-acting injectable can improve adherence and decrease the risk of relapse in patients with schizophrenia

Role of Caregiver Support and Wellness Programs

Psychiatrists and caregivers both agree that support from family caregivers and wellness programs for patients are major factors in helping patients manage their symptoms and maintain wellness.

Comparison of Key Data from the Psychiatrist and Caregiver Surveys	
<u>Psychiatrist Survey</u>	<u>Caregiver Survey</u>
<ul style="list-style-type: none"> • Of the 697 psychiatrists surveyed, key factors, in addition to medication, for keeping their patients well were: <ul style="list-style-type: none"> ○ Family support (96%) ○ Social support (91%) ○ Psychotherapeutic techniques or approaches/therapy sessions (85%) ○ Stable schedules (87%) • Of the 697 psychiatrists surveyed: <ul style="list-style-type: none"> ○ 89% said that programs designed to help patients with their overall wellness (nutrition, physical activity, lifestyle choices) are valuable in helping them manage their symptoms ○ 79% said that they would like to focus more on long-term care rather than predominantly managing crisis situations 	<ul style="list-style-type: none"> • Of the 1,082 caregivers surveyed, key factors, in addition to medication, for keeping their family members well were: <ul style="list-style-type: none"> ○ Family support (74%) ○ Social support (44%) ○ Psychotherapeutic techniques or approaches/therapy sessions (33%) ○ Stable schedules (33%) • Of the 1,082 caregivers surveyed: <ul style="list-style-type: none"> ○ 85% said that programs designed to help their family member with their overall wellness (nutrition, physical activity, lifestyle choice) are valuable in helping them manage their symptoms ○ 76% said that they would like their family member’s doctor to focus more on long-term care rather than managing crisis situations

Supporting Data from the Psychiatrist Survey

- Of the 697 psychiatrists surveyed:
 - 92% said that family caregivers should participate in programs that educate them about the nature of the illness as well as strategies for medication adherence
 - 57% of psychiatrists said that less than 10% of family caregivers who take care of their patients participate in a support group for families of individuals living with a serious mental illness
 - 19% believe there are enough rehabilitation resources available in the community for their patients

Supporting Data from the Caregiver Survey

- 47% of caregivers said that they or a member of their family participates in a support group with other families of individuals living with mental illness
- 52% of caregivers said that they spend more than 10 hours per week caring for their family member

Consequences of Stigma

Both psychiatrists and caregivers agree that discrimination against people with serious mental illness can negatively affect patients' treatment and wellness.

Comparison of Key Data from the Psychiatrist and Caregiver Surveys	
<u>Psychiatrist Survey</u>	<u>Caregiver Survey</u>
<ul style="list-style-type: none">• Of the 697 psychiatrists who said that their patients' treatment was disrupted due to a lack of medication adherence:<ul style="list-style-type: none">○ 81% said that they had a patient struggle with staying on his/her medication due to negative depictions of mental illness in the mainstream media• Of the 697 psychiatrists surveyed, 87% agree that stigma or discrimination against people with mental illnesses make it harder for patients to be well and stay well	<ul style="list-style-type: none">• Of the 534 caregivers who said that their family member's treatment was disrupted due to his/her decision to stop taking medication<ul style="list-style-type: none">○ 64% agree that stigma in society may have influenced their family member's decision to stop taking medication• Of 1,082 caregivers surveyed, 82% agree that stigma or discrimination against people with mental illness make it harder for their family member to be well

Supporting Key Data from the Psychiatrist Survey

- Of the 697 psychiatrists surveyed, 92% said that inaccurate portrayals of serious mental illnesses such as schizophrenia, schizoaffective disorder, and bipolar disorder in the mainstream media can add to the stigma and negatively affect patients' treatment and wellness