Looking After a Mate

A research report for Student Minds.
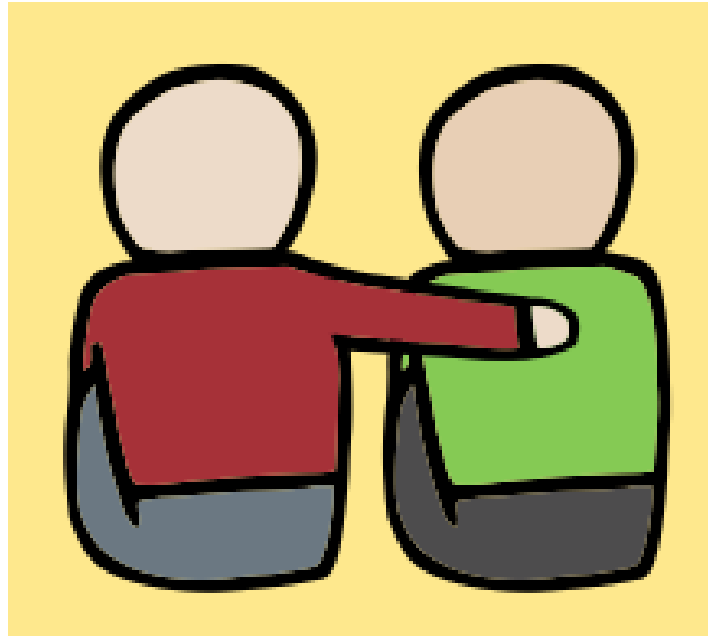
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Acknowledgements

This report has been produced by Student Minds.

Student Minds is the UK's Student Mental Health Charity. We want students to have the skills, knowledge and confidence to talk about their mental health and look out for their peers. We believe in peer support and deliver research-driven training and supervision to equip students to bring about positive change on their campuses through campaigning and facilitating peer support projects. About the Authors

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Contents

Executive Summary

The Looking After a Mate study set out to understand the support for mental health difficulties that student provide to each other. The study looked into the challenges students face in providing support, their needs as supporters, the support they receive and the impact this responsibility has on their lives.

The report sets out details about the student supporters, the friends they are supporting, the supporters' wellbeing, their needs, their experience of providing support and their approach to providing support. The key findings are summarised here.

The level of support that students provide to peers needs to be recognised and provision should be made to support students taking on this role of an informal supporter. In particular, students supporting peers taking time out of university and students supporting a partner, appear to be particularly vulnerable and may benefit from targeted support.

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On average supporters knew 4 individuals with mental health difficulties.

The Supporters

Seventy nine students supporting a friend with mental health difficulties took part in the study. Throughout the report survey respondents are referred to as **supporters** and the friends they are supporting are referred to as **supportees**.

The report indicates that we should be concerned about the mental wellbeing of supporters and suggests that providing support to a friend may reduce the ability to make the most out of the university experience.

Only half of supporters felt able to make the most of their university experience. The quality of life of supporters was lower than expected for a healthy population, but equivalent to that of a student sample. Half of supporters reported current mental health difficulties. This is double what might be expected in a student sample. This is likely to reflect a tendency for students who are experiencing mental health difficulties to reach out to, make friends with and support others experiencing mental health difficulties.

Intensity of Support

Student supporters were providing support to a number of individuals as well as providing a substantive level of support to a specified individual. While supporters were asked to focus on their experience supporting one individual, supporters knew, on average, 4 individuals with mental health difficulties.

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A third of student supporters lived with the supportee. Supporters had known the supportee for between 2 and 5 years. Supporters were seeing the supportee face-to-face several times a week, but were in daily contact via social media, phone or text.

Half of supporters felt they spent most of their time with the supportee talking about mental health and a third felt the supportee's mental health difficulties affected most of the conversations or activities they shared.

Supporters were asked to identify the proportion of support they provided for the supportee, in comparison to all other sources of support; approximately a third of supporters reported providing less than a third of the support, a third of supporters reported providing between a third and two thirds of the support and a third of supporters reported providing over two thirds of the support.

Experience of Caregiving

Student supporters had a comparable experience of caregiving to familial carers. However, they were more likely to identify positive aspects of the relationship than familial carers.

The Role of Student Supporters

Student supporters approach to their relationship with the supportee varied. While some supporters felt that they were able to remain friends, others felt their relationship had changed to one focused on caregiving. Most supporters reported finding it difficult to work out what their role should be and to balance the roles of friend and caregiver.

Student supporters also reported finding it difficult to balance the demands of academic study and providing support; for instance supporters reported having to rush essays or cut back on sleep because they wanted to have time to support their friend or partner. Supporters reported feeling guilty when they prioritise work over providing support.

Student supporters want more information and advice about how to manage their role as a supporter. In particular they want information about how to provide support and advice on finding the balance between being a friend and providing support.

Student supporters might benefit from information about how to apply for extenuating circumstances with university work. Supporters do not currently identify their academic tutor as a source of support. However, the problems supporters are having balancing academic work and providing support suggest that academic tutors may be well placed to provide assistance.

Supporting Supporters

Student supporters completed a needs assessment reviewing information and support needs. This assessment identifies whether supporters need information about where to get advice, support groups, treatment plans and coping strategies, and whether these information needs are met. The assessment also identifies whether supporters feel they need support from a range of individuals and organisations including, family, friends, counsellors and healthcare professionals, and whether these support needs are met.

44%

Of supporters felt that they were the primary source of social support for the supportee.

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> *This is a really necessary study… I think that students should be supported to support each other since we are not only dealing with each other's mental health in a stressful environment, but also things like the loss and grief our friends experience.*

Supporters who identified more unmet information needs and unmet support needs had a more negative experience of caregiving. In particular, supporters who identified more unmet needs were likely to think about the supportee's negative symptoms and the supportee's dependence upon them more frequently. This in turn influenced supporter's subjective impression of their ability to make the most of their university experience.

This indicates that meeting the supporters' information and support needs is an important step to improving the experience of caregiving. Specifically, supporters feel they need support from friends, family, counselling services, GPs and healthcare professionals.

Student supporters described three factors that they felt would make it easier for them to provide support;

- Information and advice for providing support;
- More support for the supportee;
- Support for their own mental health.

We look at the first two of these factors in more detail here.

Information and advice

Student supporters felt that they needed more information about support groups, treatment options, the supportee's current and future treatment plans, the supportee's prognosis, how to meet other supporters to share experiences and what to do in the case of a relapse.

Student supporters reported that they would find training helpful. This may meet some of the supporters information needs.

Training in listening skills and caregiving approach may improve supporters' wellbeing. Student supporters using more skilled levels of listening reported a better quality of life. Supporters adopting highly emotional approaches to caring had a more negative experience of caregiving, lower quality of life and lower ratings of ability to make the most of the university experience. This indicates that supporters may benefit in particular from training in:

- Boundary setting, to provide support without compromising their own needs;
- Balancing friendship with providing support, to help them retain the positive elements of the relationship;
- Coping with their experience of negative symptoms in the supportee, such as the supportee being withdrawn, uncommunicative, uninterested, slow and unreliable about doing things and indecisive;
- Listening skills.

Student supporters felt that they needed support from partners, friends, immediate family, university counselling services, GPs and healthcare professionals. These support needs were, for the majority of supporters, only being met by friends and partners. Improving support for supporters has the potential to improve supporters' experience of caregiving and consequently improve their ability to make the most of their university experience.

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Interestingly, supporters who had sought support from a GP or university counselling service for their own mental health felt that their support needs, as supporters, had been met. This suggests that the problem with unmet support needs, in relation to professional services, may lie in supporters not accessing support from these services.

Support for the Supportee

Over half of the supportees were experiencing complex difficulties including, eating difficulties, psychosis, obsessive compulsive disorder, bipolar, or a personality disorder.

One in five supportees were not receiving any support from professional services. Where supportees were receiving support from professionals, they were most likely to be seeing a professional monthly or less frequently.

As the range and intensity of non-professional support increased supporters reported feeling less responsibility for providing support and consequently, the supportee's mental health was perceived to have less effect on shared activities and conversations. This is particularly important, as reducing the effect on shared activities and conversations, was found to improve the experience of caregiving and increases students' ability to make the most of their university experience. Non-professional support included support from friends, family and peer support. This suggests that it is beneficial for supporters if supportees have a wide network of non-professional support.

We expected that as the range and intensity of professional support increased, the responsibility that supporters felt for providing support might decrease. This was not the case. That is, the range and intensity of professional support that supporters perceive to be available to the supportee did not influence the proportion of support that supporters felt that they provided.

It is of concern that the range and intensity of professional support did not have an influence. This may be because supporters do not feel involved in this relationship.

For example, the majority of student supporters were involved in arranging professional support for the supportee. In particular, they feel responsible for persuading supportees to access support. However, only 5 supporters had had a conversation with or received information from the supportee's treatment provider. In contrast to this, 55% of supporters identified that they would like to receive information from or speak to the professionals providing treatment.

More Problems for Partners

Student supporters identified their relationship with the supportee as a friend, housemate or partner. The wellbeing of partners was lower for than friends or housemates. No specific factor appeared to explain this difference, however partners feel greater responsibility for providing support; they have higher levels of involvement, are more likely to identify as the primary source of social support, feel they provide a greater proportion of all support and identify a narrower range and lower intensity of professional and non-professional support available for the supportee. Partners also spend more time with the supportee and are in more frequent non-face-to-face contact.

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Supportees were not receiving support from professional services.

Introduction

The *Looking After a Mate* study set out to develop our understanding of the form and level of support that students provide to peers experiencing mental health difficulties. Through a combination of qualitative and quantitative measures we sought to assess the challenges that students face in supporting friends and the impact that this responsibility has on their lives. Before focusing on the findings of this study, we provide a brief overview to the context in which this study was conducted.

In 2013-2014 there were 2.3 million students in higher education in the UK[1]. Students are predominantly young adults; half of undergraduate and postgraduate full-time students enrolling in 2013-14 were under 20 years old, with a further 32% aged between 21 and 24 years old[1].

Prevalence of Mental Health Difficulties

Increasingly, the mental health of young adults is becoming a concern[2-4]. 75% of mental health difficulties develop before the age of 25[5-7]. This places students at high risk of experiencing mental health difficulties and a key age group to target with preventative and early interventions. Estimates of the prevalence of mental health difficulties among students range from around 1 in 3[8] to 1 in 5[9].

In addition to age related risks, many additional challenges contribute to the risk of mental health difficulties among students. The Student Minds Grand Challenges[10] project identified that students felt that many common aspects of university life create challenges for maintaining good mental health. These include finding and managing housing, the stress of academic study, the busy student lifestyle, financial pressures, loneliness, lack of sleep and a need to make new meaningful relationships.

Help-Seeking

Low rates of help-seeking are a challenge for all mental health support provision; individuals experiencing mental health difficulties take time to identify that they are struggling and to ask for help[11,12]. While students recognise symptoms of mental health difficulties, only a minority are likely seek support from professionals including a GP (26%) or university counselling service (10%) [13]. Other students report that they would seek support from friends (25%), parents or family (26%) if they felt they were experiencing mental health difficulties[13].

2.3m

Students in Higher Education in 2013-14.

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Access to Professional Support

Once students have asked for help they may face further challenges accessing professional support. The transient nature of student life, with regular moves between university and home, can make accessing support through the NHS challenging[14].

University support services, including counselling services, are reporting increased demand for their services[15]. Services are seeing between 1 in 20 (5%) and 1 in 7 (15%) students in a year, with considerable variability between institutions[15]. Along with increased demand for support, services report seeing students with more severe problems and some services feel that they are unable to provide the necessary intensity of support.[15]

The Role of Friends

When students experience mental health difficulties they often turn to friends for support[13]; 75% of students experiencing mental health difficulties talk to their friends about their mental health[16]. Through the study reported here we sought to understand to what extent students are supporting their peers and what responsibility they feel for providing support.

People close to someone experiencing mental health difficulties may take on an informal care role and can provide extensive support[17-19]. This role has primarily been studied in the family setting. However, as many students live and study away from their family home, friends are likely to be the primary source of support when students are struggling.

Caring can be a strongly positive experience[20], but it is often associated with subjective, as well as objective, burdens[18]. The development of research into the consequences of caring for relatives with mental health difficulties has been divided into four distinctive periods, moving from (1) a focus on the negative aspects of caring, (2) to assessing the burden and (3) the stress of caring through to (4) a focus on the carers' needs and coping styles[21].

Research conducted primarily with families supporting individuals with serious mental health difficulties, often schizophrenia or eating disorders, has identified that caring for a family member with severe and enduring mental health difficulties can be experienced as a burden, is accompanied by substantive stress[22] and carers may feel unable to cope[22-26]. These studies have also identified that carers have a range of information and support needs which are not always met[18,27].

In contrast to the challenges and responsibilities identified, support for carers is limited. Many interventions for individuals with mental health difficulties focus on the service-user.[18]

Research into the challenges of providing care is limited, especially when considering mild to moderate mental health difficulties and to our knowledge the challenges of care provision have not been investigated in the student population. This study aimed to develop our understanding of the experience of student and identify their needs. The study draws on previous research to make comparisons between the experience of familial carers and student carers.

75%

Of students experiencing mental health difficulties talk to their friends about their mental health.

Methods and Analysis

Design

A single survey was developed to assess the consequences of caring. Qualitative and quantitative questions were incorporated alongside standardised assessments of quality of life, experience of caregiving and carers needs. This study had four aims.

Aim 1; to assess the extent to which students are providing support for friends experiencing mental health difficulties and the degree of responsibility they feel for this. This was assessed through qualitative and quantitative questions about subjective experiences alongside questions asking students to assess the number of other individuals involved in providing support and the level of support that they provide.

Aim 2; to assess the impact that caring had on students. This was assessed through specific questions about the students' mental health and qualitative questions about their experience of caring. Students were explicitly asked about their ability to make the most of the university experience. Standard assessments were used, including the Quality of Life Scale (QoLS[28]), the Experiencing of Caregiving Inventory (ECI[29]) and the Involvement Evaluation Questionnaire (IEQ[21]). Scores on the QoLS[28] were compared to a general student sample to assess whether subjective quality of life is lower in a sample of student supporters. Scores on the ECI and the IEQ were compared to published studies of data from family carers, to draw comparisons of the experience of caregiving.

Aim 3; to identify the needs of supporters and assess whether these needs are currently being met. Information and support needs were considered. The Carers Needs Assessment[27] was used to make this assessment and responses were compared to needs identified by familial carers.

Aim 4; the final aim of the study was to assess, through subjective report, students' approach to providing support, including their listening style and their approach to caregiving.

Materials

Quality of Life Scale

The Quality of Life Scale (QoLS) scale has 16 items, each of which can be given a score from 1 to 7 (1 = Terrible; 2 = Unhappy; 3 = Mostly dissatisfied; 4 = Mixed; 5 = Mostly satisfied; 6 = Pleased; 7 = Delighted). The minimum score is 16 and the maximum score is 102. The scale addresses the conceptual categories of material and physical well-being, relationships with other people, social, community and civic activities, personal development and fulfilment and recreation. The QoLS[28] has good internal consistency (α = .82 to .92) and high test-retest reliability (r = .78 to .84)[30].

The Experience of Caregiving Inventory

The ECI conceptualises caregiving within a stress-appraisal-coping framework. The illness, behaviours, disabilities and perceived disruptions of the supporter's life are stressors, appraised by the supporter. As such, the ECI is a measure of the appraisal of caregiving stressors, rather than an objective quantification of stressors. A supporter's personality, quality of relationships and degree of support may all influence the appraisal of stressors. Individuals facing similar stressors may appraise these differently, leading to a different experience of caregiving.

The ECI has been used to understand the experience of caregiving for families supporting individuals with eating difficulties[25,31,32], schizophrenia[33,34] and bipolar affective disorder[35] and as an outcome measure for interventions designed to improve the wellbeing of carers[18,36,37]. The measure identifies negative aspects of

caregiving which interventions should aim to reduce and identifies positive aspects of caregiving which could be enhanced. Szmukler et al (1996) validated this measure both in a large sample of carers predominantly associated with self-help organisations and in a smaller sample of relatives of patients who had recently been discharged from acute care for schizophrenia[29].

The self-report measure asks "During the past month, how often have you thought about/been upset by…" followed by items which are grouped into 2 positive and 8 negative subscales. Responses were given from 1 to 5, where 1 = never; 2 = sometimes; 3 = regularly; 4 = often; 5 = always.

In this study, we chose to use only 6 of the 8 negative subscales. We excluded the subscale of effects on the family as the supporters in this study were not family members. We also excluded the subscale of problems with services as we did not expect that students in our community sample would necessarily have had contact with professional healthcare services.

Supporters in our sample completed items in the following subscales:

- Difficult behaviours (i.e., moody, unpredictable, irritable, inconsiderate, behaving recklessly, suspicious, embarrassing in appearance and behaves in a strange way).
- Negative symptoms (i.e., withdrawn, uncommunicative, not interested, slow at doing things, unreliable about doing things, indecisive).
- Stigma (i.e., covering up his/her illness, feeling unable to tell anyone about illness, feeling unable to hang out together*, stigma, how to explain illness to others).
- Need to back up (i.e., difficulty looking after money, having to support him/her, effect on finances, backing up when s/he runs out of money, setting him/her up in accommodation, s/he keeping bad company).
- Dependency (i.e., unable to do things you want, his/her dependence on you, helping him/her to fill day, s/he's always at the back of mind, feel unable to leave alone)
- Loss (i.e., what sort of life s/he might have had, risk of suicide, have you done something to make him/her ill, s/he thinks a lot about death, lost opportunities, self-harm, whether s/he will ever get well).
- Positive personal experience (i.e., learnt more about self, contributed to others' understanding of illness, become more confident dealing with others, become more understanding of others with problems, become closer to some of my family, become closer to friends, met helpful people, and discovered strengths in myself).
- Good aspects of relationship (i.e., contributed to his/her wellbeing, s/he makes a valuable contribution to the relationship*, s/he has shown strengths coping, s/he is good company, we share some interests, I feel useful).

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*Items were adapted from the original survey to fit with the relationship between friends: feeling unable to have *visitors at home*, was changed to feeling unable to *hang out together*; s/he makes a valuable contribution to *the household* was changed to s/he makes a valuable contribution to *the relationship*.

Involvement Evaluation Questionnaire

The Involvement Evaluation Questionnaire (IEQ; European Version[21]) was developed to cover a broad range of caregiving consequences, including the encouragement and care that the supporter provides, personal problems between the supportee and supporter, and the supporter's worries, coping and subjective burden.

The method of construction of this scale differs from the ECI. While the ECI was developed from interviews with carers, the IEQ was developed from a review of literature, existing instruments and interviews with professionals[21]. In contrast to the assessment of appraisal, provided by the ECI, the IEQ assesses the presence of stressors and as such contains items addressing the frequency of occurrence of concrete events, e.g., how often in the past four weeks has your friend disturbed your sleep?

The self-report measure asks "How often during the past 4 weeks…" supporters have experienced various events. Responses were given on a scale from 1 to 5 (where 1 = never; 2 = sometimes; 3 = regularly; 4 = often; 5 = always). A total of 27 items are grouped into four subscales:

- **Tension** (9 items) – referring to the strained inter-personal atmosphere between supportee and supporter. This subscale includes items relating to disturbed sleep, strained relationship, quarrels, annoyance and threat.
- **Supervision** (6 items) – referring to the supporter's tasks of guarding medicine intake, sleep and dangerous behaviour, including self-harm.
- **Worrying** (6 items) – referring to painful interpersonal cognitions, such as concern about the supportee's safety and future, general health and health care. In contrast to other subscales that predominately ask about the frequency of concrete events, the items in this subscale ask about how often the supporter has worried about a supportee's safety, health and future.
- **Urging** (8 items) - referring to activation and motivation, assessing how often the supporter has encouraged or helped the supportee to take care of themselves, including engaging in activity, eating, taking medicine and attending appointments.

The subscales each have different numbers of items in them. This difference accounts for much of the variation in average total score across subscales.

Van Wijngaarden et al (2000) used the IEQ with relatives (or other significant persons) of patients with schizophrenia, and found it to be a reliable measure across five different sites (Amsterdam, Copenhagen, London, Santander and Verona), suggesting that this is a robust measure of the caregiver experience.

❝❞ *In the same way that I have been a support for them, they have also been a support for me… they bring a lot of happiness to my life, and I'm just glad that I can be the support when they need.*

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Carers Needs Assessment

The Carers' Needs Assessment (CaNAM) [27] was developed to assess the needs of relatives caring for patients with Anorexia Nervosa. The scale was designed to identify needs, assess whether these were being met and what can be done to improve the support for carers. Haigh and Treasure (2003) suggest that meeting the needs of carers will not only reduce carers' distress (which is likely a consequence of unmet needs), but also help them to be more effective providers of support.

The CaNAM[27] was developed through a carer's focus group and is divided into three scales, assessing information needs, support from other people or organisations and ability to seek support for self[27]. Items on the scale have three response options;

- No I haven't received enough information/support and I would like to receive more;
- I don't require information / support in this area;
- Yes, I have received sufficient information / support.

The scale was adapted to suit the student supporter sample; specific questions about managing meal times were removed as the student supporter sample is not exclusively supporting individuals with eating difficulties.

Procedure

Student participants were recruited to take part in the study through Student Minds social media. Students who were currently supporting a friend or friends experiencing mental health difficulties were invited to complete the survey. All participants read the information sheet prior to taking part in the online survey and gave informed consent to participate. The study was approved by Oxford University Central University Research Ethics Committee.

Analysis

Qualitative and quantitative analysis has been used throughout this report. Qualitative analysis was based on grounded theory. Throughout the report quotes have been included, representing a selection of the responses analysed.

We report correlations between survey measures and comparisons between participant groups. Summary data, taken from other published studies of caring, has been used to compare the experience of students to those of familial carers.

Group comparisons have used a combination of parametric and non-parametric tests, with non-parametric tests being used where assumptions of homogeneity of variance were violated. Chi-squared tests have been used to compare categorical data. In all tests a significance level of 0.05 has been adopted, adjusted for multiple comparisons where appropriate. Unless stated otherwise, error bars on figures show standard deviation.

> *It was all-consuming for him so all he ever talked about was how he was feeling, which meant we became less close as friends. It had an impact on my mental health too since it was easy to be drawn in to the way he was feeling and thinking.*

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Participants

Throughout this report survey respondents are referred to as "supporters" and the friends they are supporting are referred to as "supportees."

79 student supporters completed the survey between April and July 2015. As shown in Figure 1, supporters were primarily 18 – 25 years old. Almost all supporters (97%) were current students; with 81% undergraduate students and 16% graduate students. One supporter had recently graduated. Among the undergraduate students, there was a broad distribution of year of study. The majority of supporters (78%) were female.

Relationships

On average, supporters knew 4 (SD = 3.77) people currently experiencing mental health difficulties. For the purpose of this study, supporters were asked to focus on one individual that they felt they provided the most support to or spent the most time with.

Half of supporters were supporting a friend, 25% were supporting a partner and 19% were supporting a housemate and shown in Figure 1.

On average supporters had known the supportee for between 2 and 5 years. However, the full range of relationship duration spanned from less than three months through to over five years.

A third of supporters lived with the person they were supporting, usually in private accommodation (73% of those living together) rather than university halls of residence. While only 15 supporters identified themselves as housemates, 27 supporters identified living with the supportee. Other than housemates, 30% of those living with the supportee identified themselves as a partner while 15% identified themselves as friends.

Analysis of the timeline of the relationship between supporters and supportees indicates that 40% of supporters knew about the supportee's mental health difficulty from the start or early in their relationship.
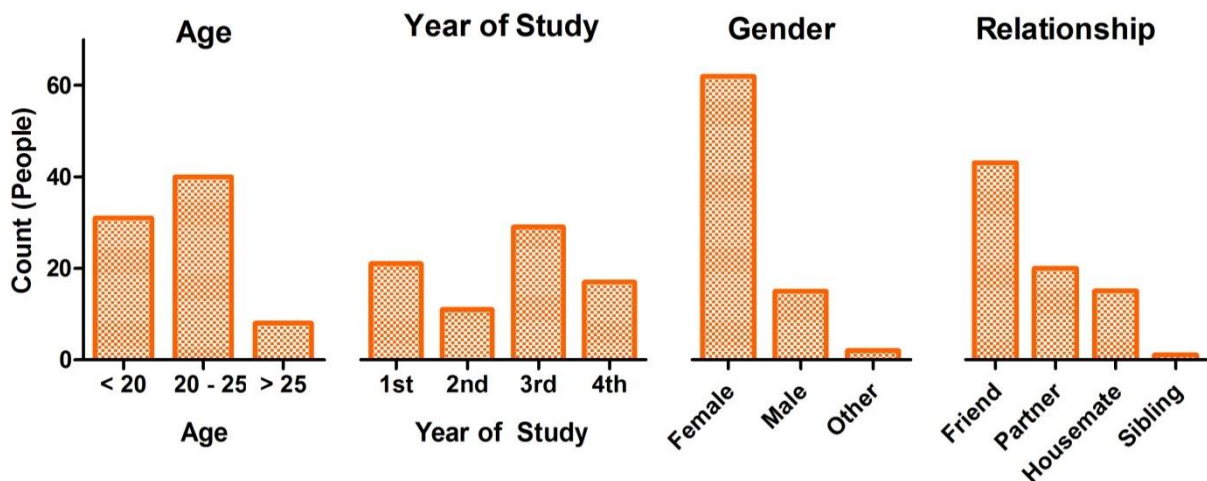

Figure 1: Showing supporters' age, year of undergraduate study, gender and relationship to the supportee.

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Supportees

Information about supportees was collected from the participants completing the survey. The age of supportees was roughly equivalent to that of the supporters (Supportee: X = 21.82 years, SD = 3.77 years; Supporter: X = 21.77 years, SD = 3.47 years). Supportees were predominantly female (66%).

The majority (69%) of supportees were current undergraduate students, with 8% graduate students. A notable 14% of supportees were identified as currently taking time out from work or study due to their mental health difficulties.

Supportees had on average been experiencing mental health difficulties for between 2 and 5 years. As shown in Figure 2, supportees were experiencing a range of mental health difficulties. Many supportees had more than one diagnosis. Approximately half of supportees (43%) were experiencing either anxiety or depression or a combination of the two and no other mental health difficulties. The remaining 57% of supportees had a mental health difficulty other than anxiety or depression, though these difficulties were commonly experienced in combination with anxiety or depression.
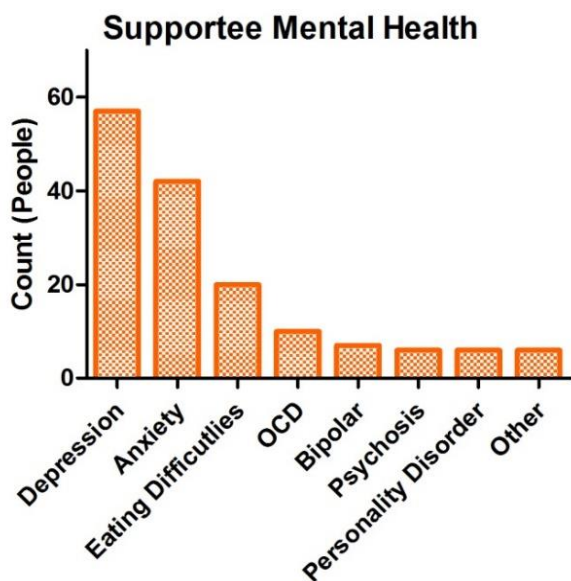

**Figure 2: Mental Health Difficulties Experienced by Supportees**

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Supportees were taking time out from work or study due to their mental health.

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Aim 1:
Responsibility for providing support

The initial aim of this study was to identify the level of support that students are providing for peers and the degree of responsibility they feel for this. Student supporters answered a set of questions about the frequency of contact with the supportee and the extent to which their relationship focused on the supportee's mental health. Supporters were also asked to estimate the proportion of support they were providing for the supportee and the range and intensity of support provided by other professional and non-professional sources of support. We have analysed the relationship between these factors, testing whether increases in the range and intensity of other support reduces the responsibility that supporters feel for providing support.

Figure 3: Frequency of Face-to-Face contact by relationship type
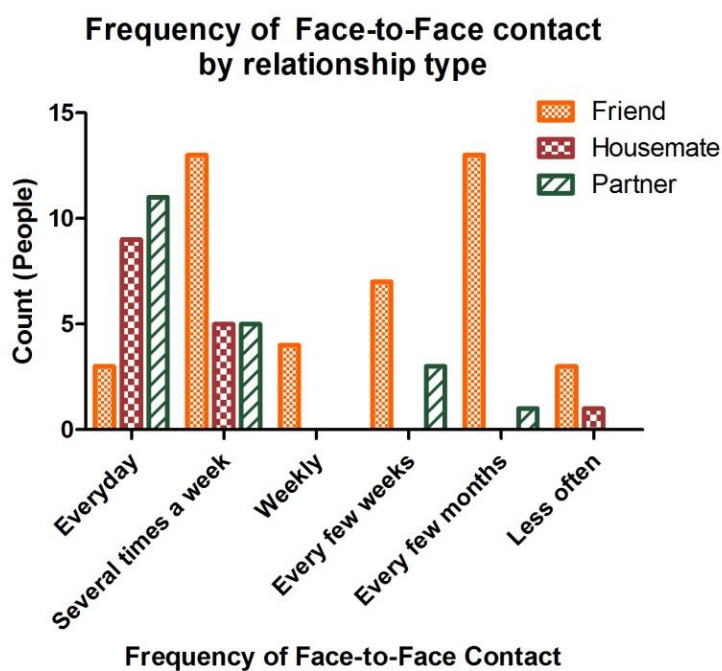
Intensity of Contact

On average, student supporters saw the supportee (face-to-face) several times a week, but were in contact (via phone, text, and social media) every day. The frequency of face-to-face contact varied with relationship, χ^2 (10) = 31.97, p < .001, as shown in Figure 3. While partners and housemates saw the supportee daily, friends saw the supportee less often.

The frequency of non-face-to-face contact (via phone, text or social medial) also varied with relationship; χ^2 (8) = 16.82, p = .032. Partners were in contact daily while friends and housemates were in contact with the supportee via phone, text or social media several times a week.

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Of the time spent together, 45% of supporters stated that they are talking about mental health difficulties most of the time and 35% of supporters identified that the supportee's mental health difficulties affect the activities or conversations they share most of the time. The distribution of response is shown in Figure 4.

While the majority of student supporters (64%) of supporters said that they found it easy to talk about the supportees mental health difficulties, supporters experience was variable.

Some supporters found that it was easy to build a trusting relationship and talk about mental health.

"[We] established a trusting relationship very quickly… they were open about their mental health difficulties…. Therefore our friendship has fairly heavily revolved around talking about mental health difficulties, yet this is not necessarily a negative thing."

Other supporters found it challenging to talk about mental health and felt this put a strain on the relationship.

"If [mental health difficulties are] raised, she feels as if she is being attacked; this has, several times in the past, sent her into psychotic episodes, which terrified me and which have prevented me from trying to discuss it again… I try to make sure that my relationship… is no longer about support, as such, but more about just being a friend… we try to avoid the topic of her mental health and just chat about our day, etc. But her mental health difficulties are always under the surface, and I am constantly aware of them. Sometimes it's like living with a ticking bomb."
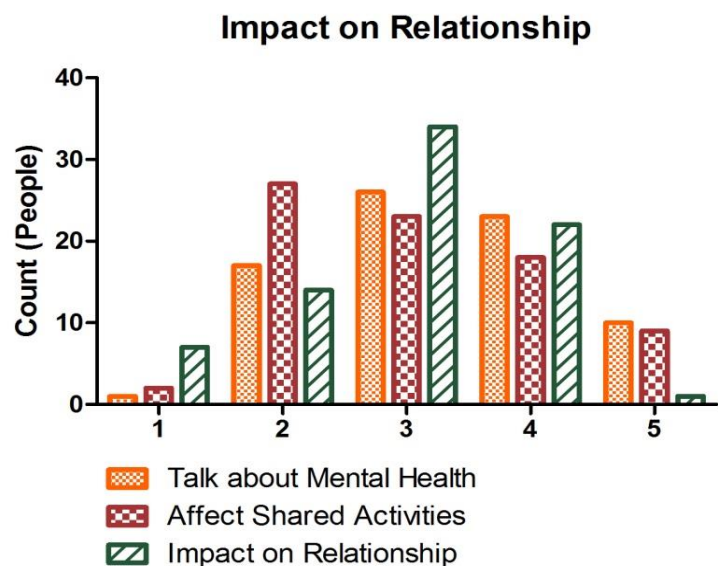
Figure 4: Impact of the supportee's mental health on relationship, showing of the proportion of time spent together, how frequently supporters and supportee are talking about mental health (orange) and how frequently the supportees mental health affects the shared activities and conversations (red); where the scale is 1 = never, 2 = Sometimes, 3 = regularly, 4 = often, 5 = always, and showing the impact that supporters feel the supportees mental health has on their relationship (green); where the scale is 1 = no change, 5 = substantive change.

I feel very responsible for her. The fact that I can't force her into treatment … is difficult to deal with.

Impact on the Relationship

Student supporters were asked to what extent the supportee's mental health difficulties had changed their relationship. Supporters answered on a scale of 1 to 5, where 1 = no change and 5 = substantive change. Responses were normally distributed, as shown in Figure 4.

To further understand the impact on the relationship, supporters answered two qualitative questions about how the supportee's mental health affects their relationship. At different points in the questionnaire supporters were asked "Do you want to tell us anything else about how mental health difficulties have influenced your relationship" and "Is there anything else you'd like to tell us about how the mental health difficulties of the person you are supporting influence your life or your relationship."

Responses to these questions map onto a continuum between acting as a friend and acting as a carer. At one end of the continuum supporters feel that mental health difficulties have brought them closer to the supportee, strengthening the friendship. At the other end of the continuum, a few supporters feel that their friendship has disintegrated into an unbalanced relationship, where they have responsibility for providing care. Many supporters fall somewhere in the middle of this continuum and feel uncertain about their role in the relationship.

A positive effect on a relationship;

Some supporters felt that the support they provide is well received and the opportunity to talk about mental health has had a positive influence on the relationship.

"I think our friendship is stronger now that we have talked about some of her mental health issues."

"I think we may have become closer as a result of having more 'deep' conversations about it, and spending more time together when she's struggling."

Some supporters identified that mental health difficulties could both strengthen and damage the relationship.

"On the one hand, when both of us have not been our best, we have clashed due to the different ways we deal with stress. On the other hand, my help with her difficulties, and her help with mine, have helped us form a stronger bond of friendship."

Balancing friendship and support;

Some supporters feel that while they want to treat the supportee as a friend, they are aware that because of their mental health, they needed to excuse behaviour that they would not normally accept in a friend. Identifying where to draw the boundary of acceptable and unacceptable behaviour is difficult.

"It is hard to discuss relationship issues constructively, as the mental health issues prevent discussions remaining rational or calm. I have to manage the relationship in a different manner to someone without mental health difficulties in order to ensure things aren't misconstrued or taken the wrong way. I have to be calm and reasoned all the time."

Looking After a Mate

Many supporters feel unclear about their role in the relationship. While supporters feel a need to keep friendship and care provision separate, they are unsure of how to balance these roles.

"I would like to have ensured that they get sufficient sleep and drink less alcohol, but they won't listen to my advice. The fact that I have remained a person they trust also hinges on me not pushing those issues too hard."

The strong level of responsibility that supporters feel for the supportee can shape the relationship.

"I worry about how she is doing. She doesn't always get the kind of understanding or support that she needs… so I feel very protective."

Some supporters feel that this responsibility is creating a one-sided relationship.

"We have a very good, strong relationship but it does put a barrier on our friendship as she is often consumed by her difficulties and therefore it is not a two way relationship completely."

The responsibility can put a strain on supporters' mental health.

"Sometimes it is difficult for me to maintain good personal mental health when supporting her, as it can trigger anxieties in myself about whether I am supporting well."

Providing care rather than friendship;

At the other end of this continuum, supporters identified a relationship of care rather than friendship.

"There have been times when I have had to spend a lot of time looking after her; collecting her in taxis from her place when she has been drunk and wanting to self-

harm… taking her to A & E after [hurting herself], begging doctors to see her when she has been suicidal."

Within this, some supporters identified that they are mediating the impact that the supportee's mental health has on other friends.

"A part of her mental health difficulties result in her excluding herself from company, this can cause rifts with our other housemates as they believe she is being rude and ignoring them. I have to defend her but also I don't want to patronise. It can be difficult to balance… she can be inconsiderate, causing a mess in the house that I have to clean up."

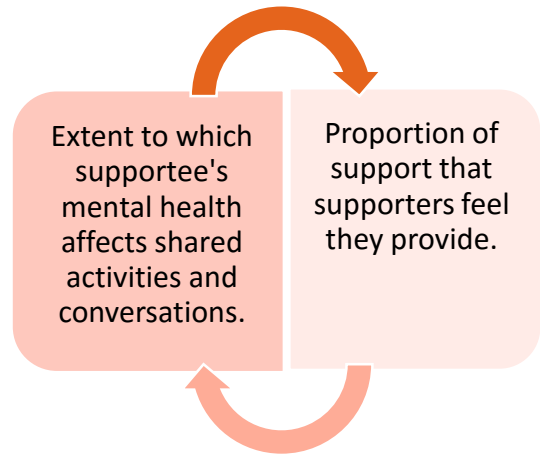**❝ ❞** *It is hard to have a friendship when the person is in a state of emergency, constantly, with no one to help. What can we talk about – shall I ignore that he wants to die, and chat about a football game? He has no energy to care about anything else.*

The Supporters' Responsibility

Student supporters were asked to identify who was the supportees' primary source of social support and in comparison to all other sources of support, what proportion of support they provided. 44% of supporters identified that they were the primary source of social support for the supportee. Supporters varied in their estimates of the proportion of support they provided, with approximately a third of supporters (34%) stating that they provided less than a third of the support, a third of supporters (36%) stating that they provided between a third and two thirds of the support and a third of supporters (30%) stating that they provided over two thirds of the support.

As might be expected, supporters who felt they were providing a higher proportion of support were more likely to feel that the supportees mental health difficulties affected the activities

Extent to which supportee's mental health affects shared activities and conversations.

Proportion of support that supporters feel they provide.

and conversations they shared, $r(79) = 34$, $p = .002$. Surprisingly however, the relationship between proportion of support provided and frequency of face-to-face contact was not significant, $r(79) = .21$, $p = .064$. That is,
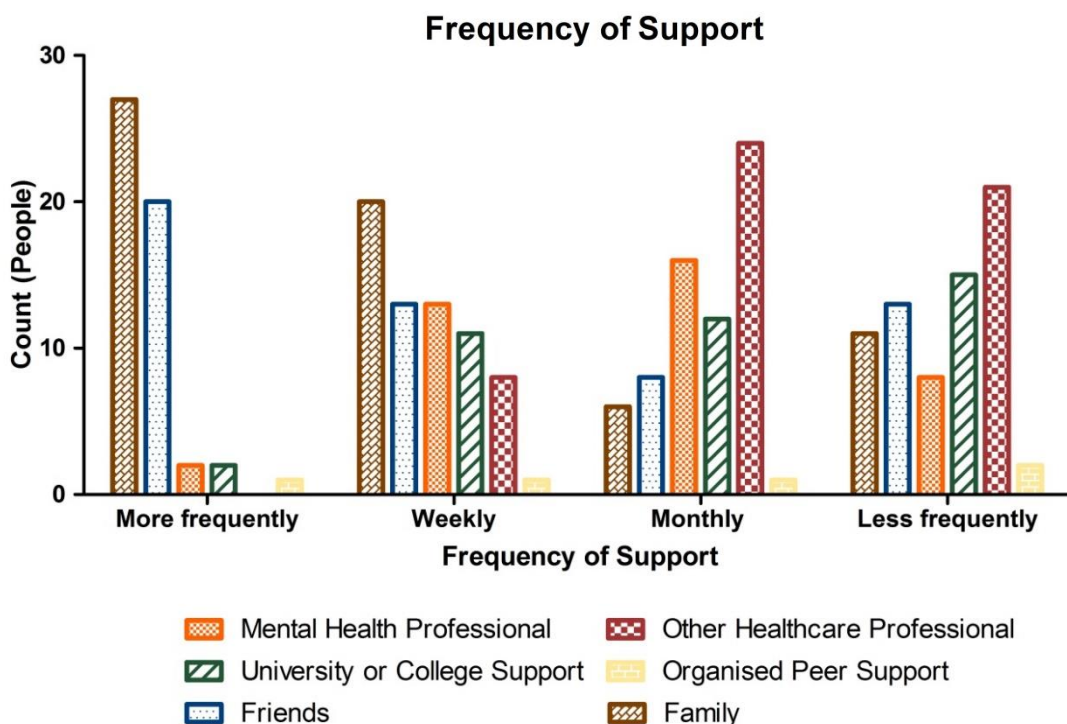

Figure 5: Frequency of support for the supportee provided by professional and non-professional sources of support

Looking After a Mate

> *Thanks for not thinking that I'm a bad person for wanting support too.*

supporters who felt they were providing a higher proportion of support did not spent significantly more time with the supporter than those who felt they were providing a smaller proportion of support.

Access to other support

Access to professional and non-professional sources of support for the supportee and the intensity of support provided by professional and non-professional sources of support might be expected to influence the degree of responsibility that supporters feel.

Supportees were accessing support from a range of professional (mental health professional, other health professional and university support staff) and non-professional (friends, family and peer support) sources.

Professional Support

On average supportees were receiving support from 2 or more professional sources. 50% of supportees were receiving support from mental health professionals. 50% were receiving support from university support staff (including university counselling services, disability service or mental health advisor). 67% were receiving support from other health care professionals (including their GP). However, approximately one in five (18%) supportees was not receiving any support from professional services.

Student supporters estimated the frequency of support provided by different professional services, as shown in Figure 5. To provide a rough assessment of how the level of professional support relates to the other aspects of the

supporters' experience, the *intensity* of professional support was calculated as the sum of frequency of support from all professional services, where frequency is given as: 1 = less than monthly contact; 2 = monthly contact; 3 = weekly contact; 4 = more frequent contact than weekly.

Non-Professional Support

Student supporters estimated the support provided by non-professional sources, including friends, family and peer support. Supporters estimated that 13% of supportees received support from formal peer support, 68% received support from their family and 80% received support from friends. However, 8% of supportees were not receiving support from any informal sources of support other than the supporter. Supporters estimated the frequency of support provided by non-professionals, as shown in Figure 5. As calculated for professional support, the intensity of non-professional support has also been calculated.

8%

Of supporters were providing the only source of informal / non-professional support for the individual they were supporting.

student minds

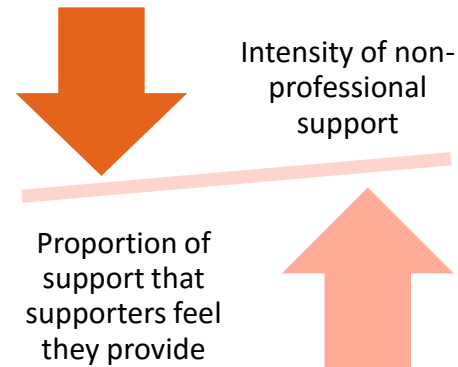## Does access to other support reduce the supporters' sense of responsibility?

While the number of sources of non-professional support available to the supportee and the intensity of non-professional support were related to the proportion of support provided by student supporter, professional support did not have a comparable influence on reducing the supporters' perception of responsibility.

That is, the intensity of non-professional support predicted the proportion of support that student supporters felt that they provided, $R^2 = .27$, $F (1, 77) = 28.33$, $p < .001$, $\beta = -.52$, 95% CI (-.54, -.25). Greater intensity of non-professional support reduces the responsibility felt by supporters. After this, the intensity of professional support did not explain any further variance in the proportion of support provided by supporters, $R^2_{change} = .005$, $F_{change} (1, 77) < 1$, $p = .48$. Further, the intensity of professional support alone, did not predict the proportion of support that supporters felt that they provided, $R^2 = .04$, $F (1, 77) = 2.88$, $p = .09$, $\beta = -.19$, 95% CI (-.41, .33).[†]

55%

Of supporters wanted information from or the opportunity to speak to the professionals supporting the supportee.

[†] The level of professional and non-professional support can also be estimated by the number of sources of support. This approach shows the same pattern. The number of sources of informal support predicted the proportion of support that supporters felt that they provided, $R^2 = .156$, $F (1, 77) = 14.20$, $p < .001$, $\beta = -.40$, 95% CI (-1.81, -.56). After this, the number of sources of professional support did not add

Intensity of non-professional support

Proportion of support that supporters feel they provide

This suggests that the intensity and range of non-professional support available to the supportee relates to the proportion of overall support that supporters feel they are providing. In contrast, the intensity and range of professional support is unrelated. Therefore broadening the network of non-professional support available to supportees may help reduce the level of responsibility experienced by supporters. However at the moment, involvement of professionals does not reduce the responsibility that supporters feel for providing support.

While increasing the range and intensity of non-professional decreases the proportion of support that student supporters feel they provide, it does not directly influence the frequency of face-to-face contact, $r (79) < .2$, $p > .15$ or the extent to which the supportees mental health difficulties affect shared activities and conversations, $r (79) < .2$, $p > .30$. However, the proprotion of support that suppoerters feel that they provide, mediates

anything to the model, $R^2_{change} = .01$, $F_{change} (1, 77) = 1.01$, $p = .32$, and the number of sources of professional support alone, did not predict the proportion of support that supporters felt that they provided, $R^2 = .03$, $F (1, 77) = 2.19$, $p = .14$, $\beta = -.39$, 95% CI (-1.77, -.50).
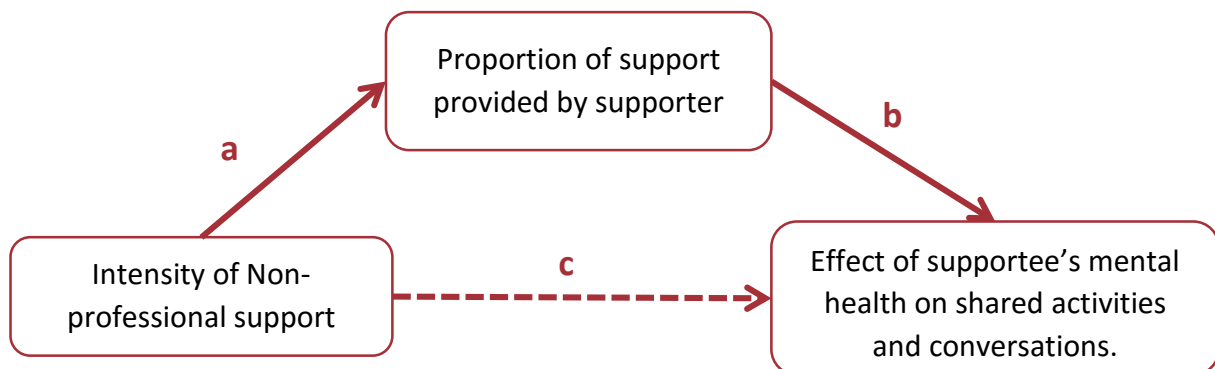
Figure 6: mediated relationship between intensity of non-professional support and effect of supportee's mental health on shared activities and conversations. Solid lines show significant relationships. Dashed lines show non-significant relationships.

an indirect relationship between the intensity of non-professional support and affect on shared activitie sand conversations, as shown in Figure 6; β = - .06, SE = .02, 95 % CI (-.11, -.02):

(a) As the intensity of non-professional support available for the supportee increases, the proportion of support provided by the supporter decreases, β = -.39, SE = .07, 95 % CI (-.54, -.24), t (77) = 5.32, p < .001;

(b) As the proportion of support provided by the supporter decreases, the effect of the supportee's mental health on shared activities and conversations declines, β = .15, SE = .05, 95 % CI (.04, .25), t (76) = 2.84, p = .006;

(c) The intensity of non-professional support did not directly influence effect on shared activities and conversations, β = .01, SE = .04, 95 % CI (-.07, .09), t (77) < 1, p = .805.

Partners feel they are providing more support,

The responsibility for providing support varied with the type of relationship:

🗨 Partners are more likely to be the primary source of social support than friends or housemates, χ^2 (6) = 23.69, p = .001.

🗨 Partners (X = 7.10, SD = 2.22) feel that they are providing a significantly higher proportion of support than friends (X = 4.37, SD = 2.43), t (61) = 4.26, p < .001, or housemates (X = 4.27, SD = 1.98), t (33) = 3.91, p < .001.

The number of professionals providing support, F (2, 75) = 3.96, p = .028, the intensity of professional support, F (2, 75) = 3.94, p = .024 and the intensity of non-professional support, F (2, 75) = 4.07, p = .021, all varied with relationship:

🗨 Partners (X = 1.15, SD = .81) identified **fewer sources of professional support** than friends (X = 1.88, SD = 1.12), t (49.70) = 2.95, p = .005, or housemates (X = 1.87, SD = .99), t (33) = 2.35, p = .025.

🗨 Partners (X = 1.90, SD = 1.74) identified a **lower intensity of professional support** than friends (X = 3.72, SD = 2.75), t (54.99) = 3.18, p = .002, or housemates (X = 3.73, SD = 2.63), t (33) = 2.48, p = .018.

🗨 Partners (X = 3.30, SD = 3.06) identified a **lower intensity of non-professional** support than friends (X = 5.79, SD = 3.38), t (61) = 2.80, p = .007.

" "

I've had to support (go with her) and encourage her to make an emergency appointment with her doctor, since the prospect of having to argue it out with the busy receptionist has scared her off in the past.

Arranging Professional Support

Student supporters were involved in arranging professional support, with 73% of supporters helping to arrange formal treatment for the supportee and 26% accompanying the supportee to treatment. Despite their involvement in arranging treatment, only 5 supporters had had a conversation with, or received information from, their supportee's treatment provider. In contrast with this, 55% identified that they would like to receive information regarding the treatment the supportee is receiving and / or speak to the professionals providing treatment.

Student supporters answered a qualitative question about their role in arranging support for to the supportee: "Is there anything else that you would like to tell us about your involvement with the treatment received by the person you are supporting or how this influences you?"

26%

Of supporters had accompanied the supportee to treatment.

Persuading supportees to access support;

Student supporters feel responsible for persuading supportees to access support. Having taken the role of persuading a supportee to access support, problems accessing support are felt acutely; feeling left out of the loop can be hurtful and supporters feel protective of the supportee, setting high expectations for the support that should be provided.

Persuading supportees to access support can be challenging.

"It can be quite difficult to be insistent on taking someone to counselling, but I only did this when she agreed that she too recognised the need, without coercing her into doing so. I accompanied her to make an appointment but I let her go her own way in following weeks."

Some supporters were resigned, for now, to taking responsibility for support provision in the absence of being able to persuade the supportee to access support from professionals. This illustrates the challenge that student supporters face; if they don't succeed in persuading a supportee to seek professional support, they remain responsible for support provision.

"He takes a long time to open up to people about his mental health and so is very reluctant to talk to a professional. I'm continuing to try my best to encourage him [to seek professional support] as frankly his issues are way beyond what I'm really able to deal with, but it's likely to take a while to build up his confidence to a point where he's comfortable talking to somebody other than me."

Looking After a Mate

In this context, some student supporters may feel the need to break confidence and seek support without the consent of the supportee. Supporters however are aware that this has a substantive cost in terms of trust.

"Often I (and other friends) become aware of problems first. We have previously had to alert my friend's family to relapses or particularly worrying episodes, as we were scared for her well-being and were aware of the fact that no one else knew… one of the things I found hardest about this was that when my friend was still very ill she often resented me for trying to help her in this way and she felt I had betrayed her trust."

Student supporters find the challenges that supportees face accessing professional support distressing. Supporters feel protective over the supportee and worry about the quality of professional support. Problems accessing good quality professional support leave supporters feeling helpless. Supporters are aware that they are filling in the gaps in professional support and where professional support is hard to access or of low quality, supporters feel let down, as they are required to continue to take responsibility for support provision.

"[My friend has] fought to get mental health care from the NHS, but it is hard for them to get anything – medication does not work and the therapy seems sporadic and extremely low quality. They are clearly not a priority, despite suicide attempts and self-harm… I encourage them to get help, but when they get the help, it doesn't change anything and seems more trouble than its worth."

"They are currently trying to access mental health services, with my help, since this is lengthy and complex. They are currently awaiting an appointment following their initial assessment which took about three months… The assessment was disappointing since the therapist was not understanding… and was quite derogatory in a way that was harmful to my friend's mental health… All in all I have to say that I was distinctly unimpressed with the help my friend looks set to receive at the hands of the NHS."

When support has been put in place, supporters feel left out of the loop. While some understand, others feel that more transparency would be feasible and beneficial.

"After health care professionals got involved (social worker, mental health nurses etc.) we were told nothing... I would have appreciated a lot more transparency and advice from the professionals since I had to live with him and was worried [about him]."

"I don't mind that I haven't received information about my friend's treatment from treatment providers, as I understand that it's something that may be very personal for her, and so I'd rather I found out the information from my friend directly so I could be certain she was comfortable with sharing it… However, it would be nice to have more information than I currently do, as I don't always feel total equipped to help her, when I don't know exactly what support she's receiving and how that affects her."

73%

Of supporters helped arrange formal treatment for the supportee.

In view of the challenges in providing support and persuading a supportee to access professional support, supporters feel that more training and more information would help them provide support.

> *"It would be nice to know more about how I could help – I feel so helpless at the moment when he's feeling rough. He also often won't listen to me about his anxiety because I don't have any experience / training, so it would help me to have a more authoritative voice when helping him deal with it."*

> *"It would have been a lot harder if I hadn't received [peer support] training. Because of the training I had a better idea of what signs to look out for and how to better support him in finding the best solution for him."*

Shared decision making

Some student supporters identified a role for themselves in acknowledging the experience of treatment and reported being involved in decision making about treatment.

> *"[I] helped her with decisions regarding whether or not to begin antidepressants."*

> *"He normally tells me how treatment is going, whether or not he's missed doses or appointments and always asks my opinion before starting on something new. I sometimes worry he relies more on what I say than trusting his GP and therapist."*

5

Supporters have had a conversation with, or received information from, their supportee's treatment provider.

Looking After a Mate

Aim 2:
Impact of Caring

The second aim of the study was to assess the impact that caring had on student supporters. Students were explicitly asked about their ability to make the most of the university experience. Standard assessments were used, including the Quality of Life Scale (QoLS [28]), the Experiencing of Caregiving Inventory (ECI) and the Involvement Evaluation Questionnaire (IEQ). To provide comparison to other groups, scores on the questionnaires were compared to a general student sample and data from published studies from family carers.

Throughout the sections below, we assess whether the variables reviewed so far relate to differences in experiences and consequences of providing support.

Specifically, we assessed the influence of the following variables:

- Gender,
- Relationship to the supportee (friend, partner or housemate),
- Cohabitation and location of cohabitation,
- The supportee's diagnosis,
- Whether or not the supportee is taking time out from studies/work due to illness,
- Whether or not the supporter is the primary source of social support or all support,
- Whether the supportee has accessed professional support or informal support,
- The intensity of professional and non-professional support,
- The relative level of support provided by the supporter,
- How frequently the supporter sees the supportee,
- The affect that the supporter feels the supportee's mental health has on their shared conversations and activities,
- The impact of the supportees mental health on the relationship between the supporter and supportee,
- The number of friends experiencing mental health difficulties
- How easy the supporter finds talking about mental health with the supportee.

Throughout the sections below, we report only the significant findings.

66 99

This study has made me feel much better as it shows that someone is interested and cares about informal supporters of people with mental illnesses.

Mental Health of Supporters

Student supporters answered a set of questions about their own mental health. Mental health difficulties were identified by supporters' self-report. The prevalence of mental health difficulties among supporters is higher than would normally be expected among young adults or university students. Half (47%) of supporters reported currently experiencing a mental health difficulty. 72% reported that they had, at some period in their life, experienced a mental health difficulty. Many student supporters reported more than one mental health difficulty, shown in Figure 7.

Of supporters experiencing mental health difficulties (n = 37) 95% reported that they had been experiencing difficulties for two years or longer. The onset of mental health difficulties pre-dated the start of their relationship with the supporter in 65% of cases. This indicates that in the majority of cases, supporters' mental health difficulties could not have been caused by the stress of providing support to this supportee.

While student supporters were more likely to be experiencing mental health difficulties than expected in a student population, they were also more likely to be accessing help for mental health difficulties. For instance, while University Counselling Services report seeing between 5% and 15% of students in a year, 38% of supporters reported having accessed support from their university counselling service. Further, in relation to their own mental health, 81% of supporters with mental health difficulties had accessed support from professional services, including support from their GP (54%), been referred for psychological therapy (32%), or prescribed medication (49%).
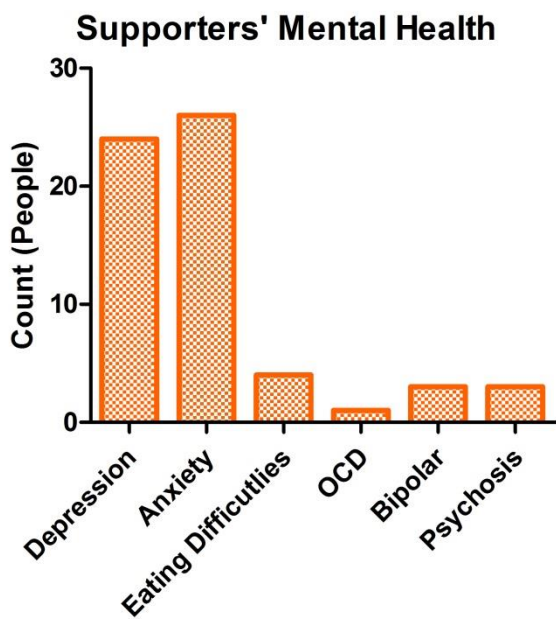

Figure 7: Experience of mental health difficulties among supporters.

47%

Of supporters were experiencing mental health difficulties.

Factors affecting the Mental Health of Supporters

Location of cohabitation had a significant relationship to the supporters' mental health.

Living together

Of the supporters that reported living with the person that they are supporting, they were 10.06 times more likely to be experiencing mental health difficulties themselves if they were living together in private accommodation than if they were living together in university halls.

Qualitative responses indicate that when supportees live in university accommodation, supporters feel less responsibility for the wellbeing and safety of the supportee. Supporters feel that the staff managing university accommodation share some responsibility.

> *"The main thing I've worried about is being able to provide enough support for her next year (as we're planning to live together) when she loses the support from wardens in her halls of residence, particularly as I'm not totally sure if there are things she doesn't share with me."*

"This year she moved back into student accommodation where we have graduate students specially placed in halls who look after vulnerable students. It has been easier on me since she has moved in there. I have had a number I can ring 24hrs a day if I am concerned about her safety. For example, she rang me once to say she had taken [an overdose] – before I probably would have had to go get her and take her to hospital, but I could just ring her hall wardens this time and they took the strain off me."

" " *I would like more information about how to help a friend with anxiety when she is in need. So far I just go with what feels right and what Tumblr posts have told me.*

64%

Of supporters found it easy to talk to the supportee about mental health difficulties.

Looking After a Mate

Supporters' Quality of Life

Student supporters were asked "Do you think that the mental health difficulties faced by the person you are supporting have had an impact on your quality of life?" 59 supporters answered this question and 35 (60% of respondents) identified challenges. Of these, 5 supporters identified that these were occasional or only felt at times of peak stress.

Other supporters reflected that providing support had influenced their quality of life, as it required them to make compromises with their own lives.

> *"I don't always do what I want to do if I feel it will impact him negatively, or I'll do things I don't want to in order to make things easier for him."*

> *"I worry about leaving them alone and I often opt out of nights out or family events to make sure they aren't alone for too long."*

> *"Having caring responsibilities limits the amount of part-time work I can do – this leaves me in financial difficulties that cause stress and affect other aspects of my life."*

The responsibility felt by supporters influences their quality of life. The feeling of responsibility is accompanied by stress and worry.

> *"For a time, every minute spent in my house at university was like living on the edge of a precipice and worrying about my housemates made it very difficult to enjoy parties etc. … I cannot wait to graduate and move away."*

> *"When I was trying to support her it put a huge strain on my confidence and mental health as I felt responsible for her, if I wasn't around to help her and something went wrong it was my fault. Her suicide attempt caused me to have regular nightmares and I stopped eating."*

Some supporters feel they have reached a position where they are managing the relationship and putting boundaries in place to limit their responsibility. While this appears to reduce some of the worry and create space for self-care, some supporters feel guilty about not providing enough support.

> *"I had to learn to draw a boundary and realize that there is not much I can do to help them. I do what I can, the way I would hope someone would do for me if I was facing a life and death struggle with depression. But I also focus on my own happiness. It is a drain on my energy and definitely makes it harder to be positive, but I feel it's something I need to do – or what kind of person and friend would I be?"*

Others supporters feel a sense of loss or feel that due to the mental health difficulties the relationship with the supportee has become destructive, which substantially affects their quality of life. Among these comments, the strain appears to arise from a feeling that, despite being treated poorly or feeling like the relationship is one-directional, they have an obligation to stay in the relationship and provide support. Supporters feel guilty when they are unable to provide the support they feel the supportee needs.

> ❝ ❞
> *I get anxious every time I get a message from them, which is most days. I just know it is going to be something negative again. It feels like a big responsibility and I always worry about saying or doing the wrong thing. It is also a continual worry that they might hurt themselves.*

student minds

"At times I have felt unable to support her… at times I have gotten frustrated at circling the same conversations over and over again and then angry at myself for not understanding… I have felt guilty when I have forgotten to touch base with her. I can be neglectful sometimes, or I can feel I am not providing enough. I have also sometimes felt like I am not appreciated for the support I do give, but that can feel like a very selfish approach, as I don't do it for that."

Many supporters identified that there were positives alongside the negatives. These supporters accepted the challenges. Some felt that things had improved and that they were managing. Some identified that the relationship was bi-directional and the experience of supporting a friend with mental health difficulties may have improved their quality of life.

"Any problems are eclipsed by benefits of having someone to talk to and laugh with about our problems, reward of being able to offer help etc."

"At times yes [her mental health has had an impact on my quality of life]. But I wouldn't change it. I love her like a sister."

66 99

Sometimes I find things hard too, but I feel I can't talk to him about them because I feel like I'm being selfish – I need to be the 'strong' one. Then both he and I get upset that I'm not telling him something.

"[Her mental health difficulties] have had a significant impact and I won't pretend that life wouldn't be easier without her having them, but it's given me the opportunity to prove my love to her, which can only be positive. I'm not greatly inconvenienced by the situation, so I can't complain."

"I have learnt… I have to 'put her in a box', not think about her and get on with my day. This is often to preserve my mental health."

"Once I understood what was useful and what was not, I felt better prepared to help and so there is no major impact on my quality of life."

66 99

I often feel if the person wasn't experiencing mental health difficulties we would get to see more of her personality. Though, I know that mental health is also sort of part of who a person is.

45%

Of supporters feel they most of the time they spend with the supportee is spent talking about mental health.

Quantitative assessment;

Quality of life was measured using the Quality of Life Scale (QoLS[28]). The average quality of life score was 83 (SD = 11.93). The average total score for healthy populations has previously been found to be about 90[30]. This is higher than the quality of life identified in our sample.

However, the QoLS[28] has not been widely used among young people or students. As such, the difference between supporters' quality of life and an average for a healthy community sample may reflect an effect of being a student.

To compare quality of life between supporters and a general student sample, we recruited 80 students at Oxford University. Students participating in a range of unrelated cognitive psychology studies completed the Quality of Life Scale while in the laboratory. This sample of students was not asked about whether or not they

were supporting friends with mental health difficulties, and as such, this sample may contain both supporters and non-supporters. To the extent that the general student sample may include supporters, the comparisons made here may underestimate the impact that providing support has on students' quality of life. Figure 8 show average scores on the items of the QoLS for a general student sample and for the supporters sample. The general student sample was not perfectly matched to the supporters sample.

- The student sample was, on average one year younger than the supporter sample: $X_{student}$ = 20.41 years (SD = 2.34), $X_{supporters}$ = 21.77 years (SD = 3.47); t (157) = 2.90, p = .004.

- There were more men in the student sample: $n_{student}$ = 28, $n_{supporters}$ = 15, χ^2 (2, 157) = 6.80, p = .033.
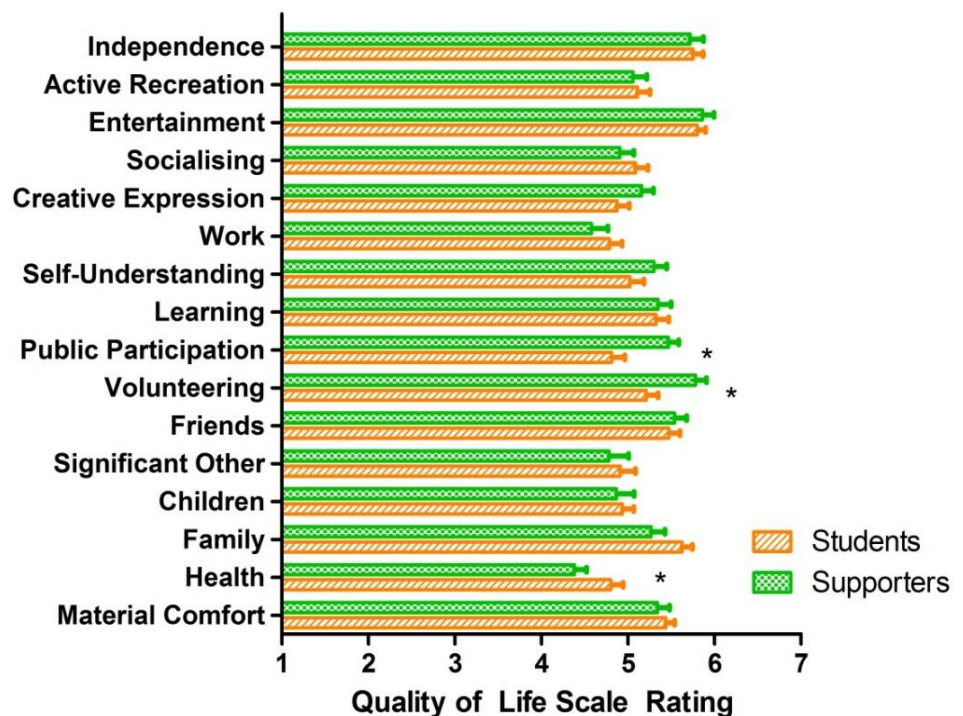

Figure 8: Quality of Life ratings for each item in the scale, for a general student and supporter sample. Note, stars mark the items for which the two samples differed significantly.

The two samples had comparable overall scores on the QOLS: $X_{Student}$ = 82.98 (SD = 11.09), $X_{supporters}$ = 83.41 (SD = 11.93), $F(1, 157) < 1$, p = .814, $\eta_p^2 <$ .001, suggesting that overall, the quality of life of supporters is not different to that of students in general. However, the student and supporter samples differed on certain questions within the scale, $F(15, 2355)$ = 2.72, p = .002, η_p^2 = .02. Specifically, supporters gave *higher* ratings for Volunteering and Public Participation:

Volunteering: $X_{student}$ = 5.21 (SD = 1.22), $X_{supporters}$ = 5.78 (SD = 1.13), $t(157)$ = 3.07, p = .003.

Public Participation: $X_{student}$ = 4.81 (SD = 1.35), $X_{supporters}$ = 5.47 (SD = 1.06), $t(157)$ = 3.40, p = .001.

Factors related to Quality of Life

The supporters' mental health and their relationship to the supportee had a significant relationship with quality of life.

Current and Past Mental Health Difficulties

Quality of life varied with mental health, $F(2, 75)$ = 10.93, $p < .001$, as shown in Figure 9. Supporters with current mental health difficulties (X = 77.77, SD = 11.45) had significantly lower QoLS scores than supporters with no experience (X = 90.59, SD = 9.01), $t(57)$ = 4.51, $p < .001$ or previous experience (X = 86.05, SD = 10.76), $t(55)$ = 2.68, p = .010, of mental health difficulties.

Supportee Relationship

As shown in Figure 14, QoLS scores varied with relationship, $F(2, 75)$ = 4.34, p = .016. Specifically, partners (X = 77.05, SD = 10.69) had significantly lower QOLS scores than friends (X = 85.33, SD = 11.98), $t(61)$ = 2.64, p = .011, or housemates (X = 86.87, SD = 11.03), $t(33)$ = 2.65, p = .012.

While no specific factors appeared to explain the reduced QoLS score for partners many indicators to suggest that partners feel a greater responsibility for providing support and feel there is less support available from other sources.
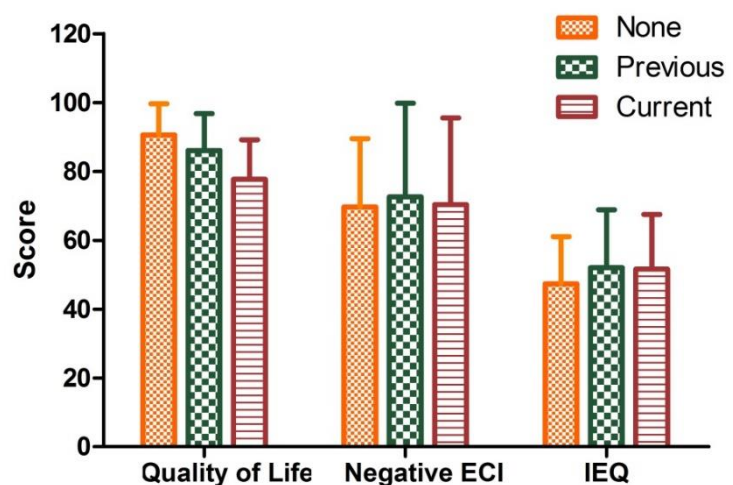

Figure 9: Total Quality of Life Scale scores, Negative Experience of Caregiving Inventory scores and Involvement Evaluation Questionnaire scores for supporters with no experience of mental health difficulties, previous experience and current experience.

Looking After a Mate

Making the Most of the University Experience

Student supporters rated their ability to make the most of their university experience on a 5 point scale ranging from 1 = "I don't feel I'm making the most of my university experience" to 5 = "I feel that I'm making the most of my university experience."

Figure 10 shows the distribution of supporters' responses to this question. Approximately half of supporters identify that they are able to make the most of their university experience.

Student supporters answered a qualitative question about how providing support affected their academic studies; "Do you want to tell us any more about how you balance supporting with your academic studies?" While one supporter identified that studying mental health nursing was helping her support her friend, most supporters identified challenges.

"I don't balance [providing support and academic study] very well, I often find myself stretched between various support roles, and lagging behind on my academic work."

"At the moment, I have not been balancing supporting with my studies very well – I have often had to hand in rushed essays at the last minute before the deadline. I am hoping that this will change as I become more used to providing support."

In the face of the challenge of balancing support and managing academic study, some supporters have become protective over their time to study. However, protecting time and prioritising work appears to be linked to feelings of guilt.

"It has been very difficult recently, as I have been supporting other friends in similar positions. It is mainly difficult because it feels like vicarious stress… I partially dismiss

❝ ❞ *I've tried to create an extended support network for my friend and helped them to attempt to access professional support, so that when I cannot help them, there are others who can.*

*it as 'nothing is happening to **me**.' I have been distracted from my work by supporting multiple other people. It… has affected by own mental health, causing panic attacks, and I got an extension on a piece of work. I can balance to an extent. At the moment it is the holiday and I am home in order to get work done without having to be around people I need to support as much, but I do feel bad about this."*

Other supporters suggest that through experience and self-awareness they have come to manage the balance. These responses suggest that

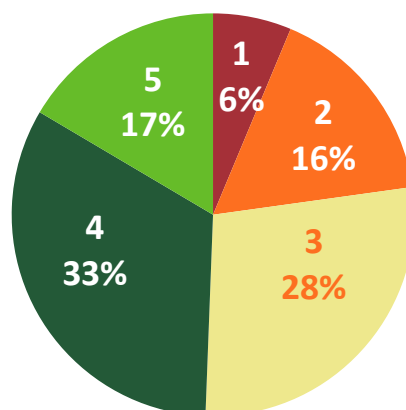### To what extent are you able to make the most of your university experience?

Figure 10: Range of responses to the question, "To what extent are you able to make the most of your university experience?"

“ ” *I haven't had any major problems and I don't think the overall quality of my work has been affected, but my friend often struggles particularly when we have a high workload, which can cause some difficulties with time constraints – I tend to cut down on sleep to finish my work at night, so I can be with her when she needs me.*

considerable planning and commitment to study is required to maintain this balance.

"I've started to put my foot down with him if I have lots of other things going on. I've stopped answering his late night drunk phone calls- he knows to text me first if he really needs to talk – and I make plans with him on my own terms if I'm going through a busy patch."

"I've tried to be as proactive as possible, ensuring that the time I had to myself was used to catch up on my work. I also ensured that I allowed myself some alone time."

For some supporters it is clear that the relationship is bi-directional and the supportee is able to help the supporter maintain the balance.

"I think it's a case of understanding your own stress levels and gauging whether you are in a suitable position to provide support. For example, when I am stressed I know that I won't be very helpful. However, the person I am supporting is a brilliant support for helping me through my academic work. So I guess we each keep each other balanced."

Some supporters identified ways in which managing this balance could be made easier for them. Supporters might appreciate being able to talk to their tutor without feeling judged and could benefit from information about when and how they can apply for extenuating circumstances.

"I would like my tutor to know, but he wouldn't understand why I was helping her and probably just see it as an excuse as to why I was not working and that I should just not have her as a friend."

"I didn't realise I was allowed to record extenuating circumstances during an exam period when my housemate was particularly bad and I spent many late nights with him before exams. I only found out 6 months later."

½

Of supporters felt able to make the most of their university experience.

Looking After a Mate

Factors related to University Experience.

The supporters' mental health, Quality of Life and their relationship with the supportee all related to the ability to make the most of the university experience.

Quality of Life

The ability to make the most of the university experience correlated with QoLS scores; r (79) = .51, p < .001, with ability to make the most of the university experience related to higher QoLS scores.

Experience of Mental Health Difficulties

Supporters' ability to make the most of the university experience varied with experience of mental health difficulties, H (2) = 6.74, p = .034, as shown in Figure 11. Supporters with mental health difficulties had significantly lower ratings of ability to make the most of the university experience (X = 3.03, SD = 1.14) than supporters with no experience of mental health difficulties (X = 3.82, SD = .80), U (22, 37) = 245.50, Z = 2.64, p = .008.

" "

Without my peer support training, I think things would be very different and in general I would have had much less idea of how to deal with supporting my friends, as well as a less positive outlook on supporting people, and I wouldn't have known that it's okay to get support for supporting people.

Supportee Relationship

As shown in Figure 11, the ability to make the most of the university experienced differed with supportee relationship, F (2, 75) = 4.27, p = .017; partners (X = 2.85, SD = 1.04) gave significantly lower ratings than friends (X = 3.67, SD = 1.11), t (61) = 2.80, p = .007.
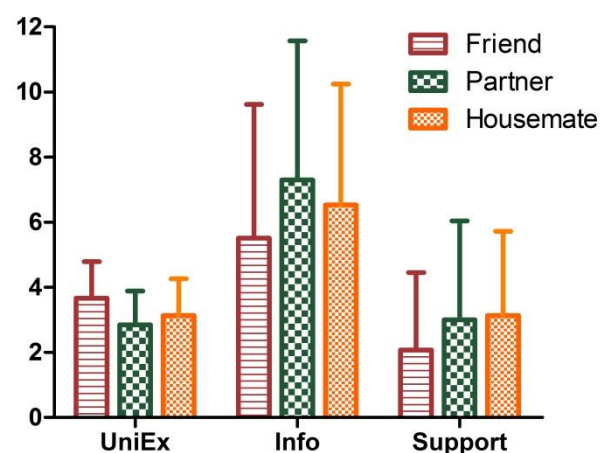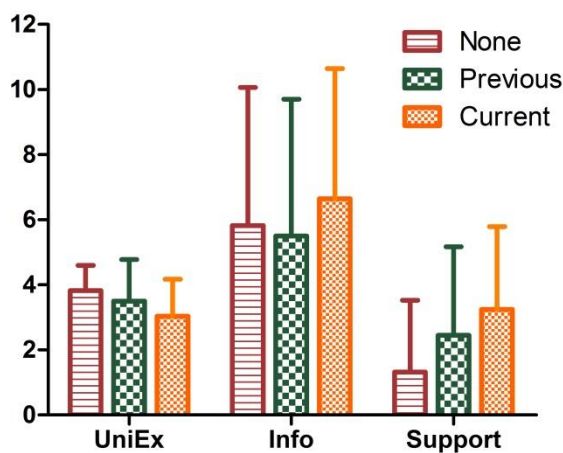

Figure 11: Ability to make the most of the University Experience (UniEx; on a scale 1 - 5), unmet information needs (info) and unmet support needs (support) by experience of mental health difficulties (left) and relationship with the supportee (right).

Experience of Caregiving

Scales have been developed to quantify the experience of caregiving and to assess the impact that caregiving has upon carers. In this survey two different scales were used; Experience of Caregiving Inventory[29] (ECI) and the Involvement Evaluation Questionnaire[21] (IEQ). Though these scales aim to make a similar assessment, they have been developed differently and focus on slightly different aspects of caregiving.

The ECI

Haigh and Treasure (2003) previously used the ECI with a sample of family carers of Anorexia Nervosa patients to assess the experience of caring for a relative[27]. They found that carers reported the greatest number of difficulties in the areas of difficult behaviours, negative symptoms, loss and dependency.

The total scores on each subscale for our sample were compared to the total scores found for family carers, to assess whether experiences of caregiving are different for family members and for students.

As shown in Figure 12, the experiences of caregiving were broadly comparable between familial carers and student supporters. However, compared to family carers, student supporters reported significantly **higher** experiences of stigma, t (105) = 2.71, p = .008.

Student supporters scored significantly **higher** than familial carers on both good aspects of the relationship, t (105) = 4.55, p < .001, and positive personal experiences, t (105) = 2.74, p = .007.
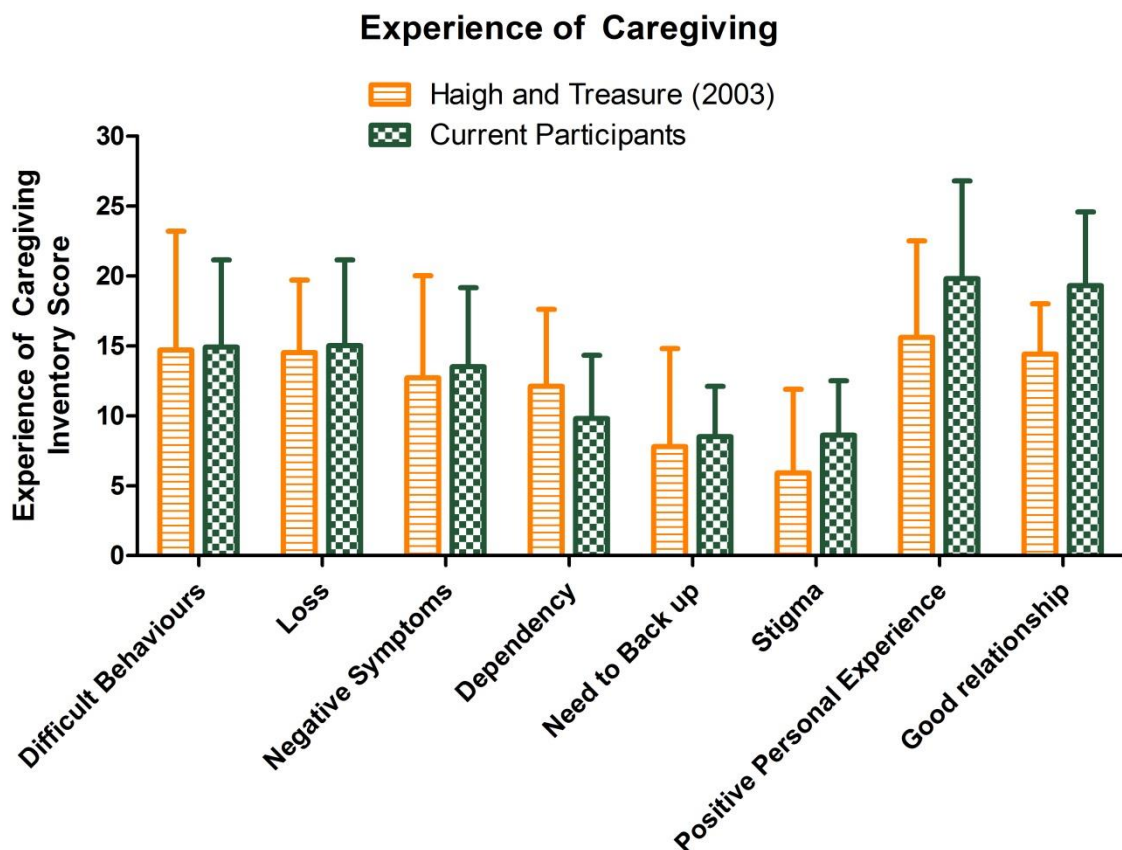

Figure 12: Experience of Caregiving for current participants (green) and parental carers (orange)

The subscales each have different numbers of items in them. This difference accounts for much of the variation in average total score shown in Figure 12. To compare between subscales, we calculated an average response to the subscale, rather than total response. The subscales for which the scores were highest on average in the student sample were:

- 💬 **Positive personal experiences**: X = 2.48, SD = 0.87;
- 💬 **Good aspects of relationship**: X = 2.41, SD = 0.66;
- 💬 **Loss**: X = 2.48, SD = 1.02;
- 💬 **Negative symptoms:** X = 2.25, SD = 0.94.

The subscales for which the scores were lowest on average were:

- 💬 **Need to back up:** X = 1.42, SD = 0.60;
- 💬 **Stigma:** X = 1.72, SD = 0.78;
- 💬 **Difficult behaviours**: X = 1.86, SD = 0.78.

Student supporters had the lowest scores on the **need to back up** subscale, suggesting they are thinking least about issues such as the difficulties the supportee might be having with money or the financial reliance of the supportee on the supporter. This suggests that student supporters see themselves as independent from the individual they are supporting.

The IEQ

We compared the results from the van Wijngaarden et al's (2000) sample with the results for student supporters, to see how the experiences of caregiving differs[21]. This comparison showed no significant difference between the two samples;

- Tension; t (353) = 1.71, p = .088
- Supervision; t (161) < 1, p = .388[‡]
- Worrying; t (134) = 1.97, p = .051[†]
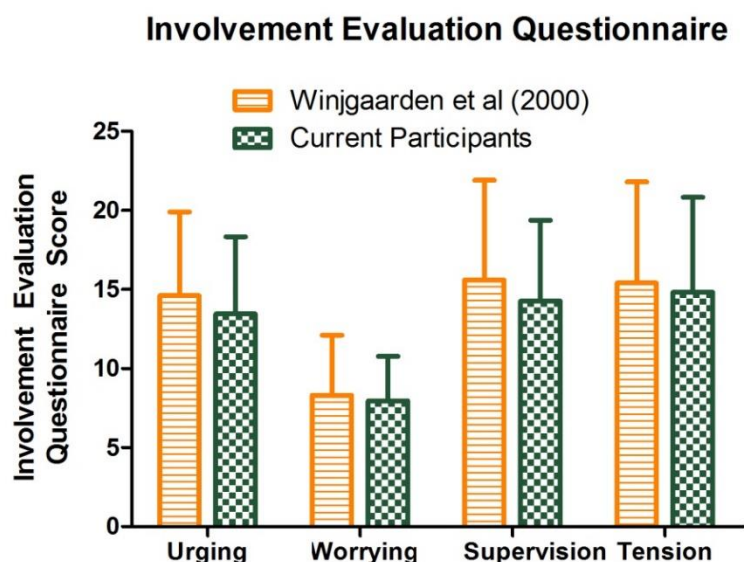- Urging; t (353) < 1, p = .481

Figure 13: Involvement Evaluation Questionnaire Subscale Scores for current participants and Winjgaarden et al (2000).

[‡] Analysis was completed with Welch's correction for unequal variances.

Interdependence of ECI and IEQ subscales;

Scores on the ECI and IEQ subscales were *not* independent. Table 1 shows correlations between the subscales of the two scales, with significance, $p < .001$.

Variation in the Experience of Caregiving;

Scores on the IEQ and negative subscales of the ECI varied with the overall proportion of support that the supporter felt they were providing, frequency of contact, effect on shared activities and conversations, whether or not the supportee was taking time out of studies or work due to mental health difficulties and the relationship between the supporter and supportee.

Supportee Relationship

As shown in Figure 14 the total negative ECI score, $F_{(2, 65)} = 5.70$, $p = .005$, and total IEQ score, $F_{(2, 71)} = 3.73$, $p = .029$ varied with the relationship between supporter and supportee. Specifically, partners had higher scores on the negative subscales of the ECI ($X = 85.28$, SD $= 34.53$) than friends ($X = 63.49$, SD $= 14.69$), $t_{(20.05)} = 2.57$, $p = .018$ and higher scores on the IEQ ($X = 58.07$, SD $= 13.92$) than friends ($X = 46.90$, SD $= 13.50$), $t_{(27.22)} = 2.39$, $p = .024$.

Time out from Work or Study

Students supporting someone who was taking time out from study or work due to illness, had higher scores on the negative subscales of the ECI ($X = 86.00$, SD $= 30.49$) than other supporters $X = 68.46$, SD $= 22.27$), $t_{(66)} = 2.09$, $p = .040$. In particular, they had higher scores on the subscale of experience of loss, $t_{(70)} = 2.55$, $p = .013$.

	Negative symptoms	Stigma	Need to back up	Dependency	Loss	Positive personal experiences	Good aspects of the relationship	Tension	Supervision	Worry	Urging
Difficult symptoms	.70	.45	.47	.70	.60	NS	NS	.71	NS	.70	.52
Negative symptoms		.53	.57	.83	.58	NS	NS	.58	NS	.72	.68
Stigma			.55	.59	.46	NS	NS	.47	NS	.46	.51
Need to back up				.65	.44	NS	NS	.46	NS	.56	.59
Dependency					.55	NS	NS	.58	NS	.69	NS
Loss						NS	NS	.59	.45	.76	.54
Positive personal experiences							NS	NS	NS	NS	NS
Good aspects of relationship								NS	NS	NS	NS
Tension									.50	.67	.50
Supervision										.36	.45
Worry											.72

Table 1: Interdependence of ECI and IEQ subscales, showing correlation between subscale scores (df = 76). NS identifies correlations that were not significant. Correlations of .70 or higher are highlighted.

> **❝ ❞** *Obviously you can choose not to provide support in a given moment, but that's a difficult decision, and you often end up providing support which requires you to be strong and calm when you're actually feeling tired or down yourself.*

Students supporting someone taking time out, also had higher scores on the IEQ (X = 61.78, SD = 17.68) than other supporters (X = 48.94, SD = 14.69), t (73) = 2.40, p = .019. In particular, they had higher scores on the subscale of worry, t (76) = 3.48, p = .001. As noted above, scores on the subscales of loss and worry were highly correlated.

Neither the frequency of contact, t (77) = 1.28, p = .204, proportion of support provided, t (77) = 1.11, p = .272, nor effect on shared activities and conversations, t (77) < 1, p = .486, varied on the basis of whether or not the supportee is taking time out from studies. Regression analysis shows that whether or not the supportee is taking time out from studies continues to explain a significant proportion of variance in negative ECI, R^2 = .04, F (1, 63) = 4.51, p = .038, and IEQ, R^2 = .05, F (1, 70) = 6.46, p = .013, scores after considering frequency of contact, proportion of support provided and effect on shared activities and conversations. This indicates that, independent from other factors related to the experience of caregiving, students supporting someone taking time out of university are likely to have a particularly difficult experience of providing support. Universities may benefit from exploring how to provide targeted support for friends of students taking time out from studies.
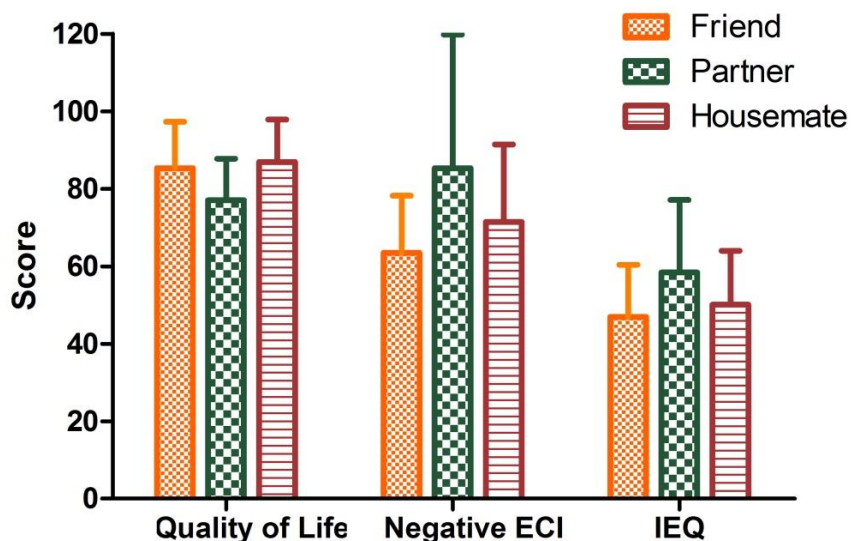

Figure 14: Total Quality of Life Scale scores, Negative Experience of Caregiving Inventory scores and Involvement Evaluation Questionnaire scores for supporters by relationship.

Aim 3:
Meeting the Needs of Supporters

Providing support can be a challenge. The third aim of the study was to identify the needs of supporters and assess whether these needs are currently being met. Information and support needs were considered, using the Carers Needs Assessment[27].

The Challenge of Providing Support:

Student supporters answered a question about the challenges of providing support: "What do you think are the most challenging aspects of providing support?" Their responses can be clustered into four partially overlapping categories.

❝ ❞

Sometimes they need help and sometimes they will want to have their own space to sort things out. Determining the right balance can often be hard if you're worried about the person.

(1) Supporters find not knowing what to do challenging. Supporters worry about whether they are providing too much or too little support and whether the support they are providing is best for the supportee. Supporters are aware that getting the level of support right is important, as mistakes feel costly to the relationship.

(2) Supporters feel helpless because they can't be there all the time, they don't know or understand what is going on, they don't think they are or can do enough. Supporters feel helpless because they can't "do this for the supportee."

(3) The feeling of helplessness contributes to supporters feeling drained and frustrated. When there is no change, they find it hard to be patient. These feelings are tied into a sense of guilt; guilt for not providing enough support, guilt for not providing better support (and thus aiding a more rapid recovery) and guilt for feeling drained or frustrated.

(4) Supporters feel alone and this sense of isolation is challenging. They feel that others don't understand how hard their position is and feel they are left to take more responsibility for support provision than they should.

Looking After a Mate

What should I do?

Many supporters expressed this question simply - they don't know whether their words or actions will help. Knowing what to do seems particularly difficult when the supportee doesn't want help or support.

Student supporters are unsure of their role in the relationship; should they be a friend or a supporter? If they are to be both, when do they play the friend role and when do they play the role of the supporter? The role the supporter adopts affects whether they decide to do what is best for the supportee (as they might do in the supporter role) or what the supportee wants them to do (as they might do in the friend role).

> *"Having the discrepancy between being their friend, and doing what you know they'd prefer and doing what is best for their health [is challenging]."*

> *"Conflict between loyalty as a friend and finding yourself supporting unhelpful behaviours [is challenging]."*

Student supporters feel uncertain about the amount of support to provide; it is difficult to know when to provide support and when to step back and say "you can do this yourself."

> *"I've found it challenging to watch her make bad decisions and not intervene as I know that she does not take this advice well."*

> *"Knowing if what you're saying is the right thing... I don't want to coddle him, but he gets upset if I'm too blunt."*

Uncertainty about what to do and how to manage their role in the relationship is particularly challenging as supporters are aware that their mistakes are costly. Some supporters worry that if they make a mistake it will be detrimental to the supportee's mental health or might ruin the relationship.

" "

It has be challenging to find my 'role' in supporting him: when and how to be helpful and supportive, as well as when not to interfere at all and let him be... it can be selfish wish to be there for him when he doesn't need me in particular situation but rather needs to be alone... it makes me feel better, but it doesn't always help him, and that's hard.

"I have been very unsure as to how I should deal with them. For the most part, things have worked out, but I have made quite a few mistakes which has affected my friend's trust in my ability to cope with her situation."

"[I'm] afraid of not being enough for her, or of doing the wrong thing so she no longer feels comfortable turning to me for support."

"I made mistakes that ultimately lost the friendship – I was worried and continuously tried to give support, however this wasn't received very well and was perceived to have an ulterior malicious motive."

❝ ❞

Not being in that person's head, never fully understanding every aspect of what they're feeling, but still trying to give the best advice and support you can… it's difficult to say the least.

I am helpless

Not knowing what to do contributes to supporters feeling helpless. The sense of helplessness is compounded by being unable to "do this for them" and unable to be there all the time. Supporters identified that their own commitments limit the amount of support that they can provide and with distance they feel particularly helpless.

"Not being able to be there all of the time when they are in a really bad place. Not being able to provide such good support via text / instant messaging as when face-to-face and able to pick up on non-verbal cues."

To an extent the feeling of helplessness is a reflection of the reality that recovery depends on the supportee's own motivation. Supporters are learning to, and often struggling to, manage their role on the side-lines and their desire to simply "do this for them."

"Knowing that no matter what you say / do, an individual will not get better unless they want to."

Feeling helpless is painful, especially when it manifests in being unable to stop the supportee hurting themselves.

"Trying to make her see her potential and how great she is but instead she is consistently harming her body…"

Many supporters feel hold themselves responsible for the lack of change. Supporters feel frustrated by their inability to understand what the supportee is thinking, convince the supportee to listen and see their perspective. In this respect, helplessness is, for some supporters, tied up with feelings of guilt.

"Not knowing exactly what is going on; not knowing exactly what she needs; the knowledge at times there is nothing you can do; the frustration of being unable to help; the irritation of having the same conversations, again and again… and that nothing you say can sink in."

"Feeling a sense of guilt when they aren't seemingly 'getting better.' Which is not accurate, but still lingers."

Providing support is draining and frustrating.

The combination of not knowing what to do and feeling helpless leaves supporters feeling drained and frustrated. In the face of hopelessness and lack of change, supporters can struggle to be patient.

"[The most challenging aspect of providing support is] being patient and understanding when you feel that they are 'not trying hard enough'."

The responsibility that supporters take for the supportee leads many to feel constantly worried, which is draining. In addition to worry, some supporters are overwhelmed by other's emotions.

"Burning out and emotional exhaustion."

"Feeling helpless and getting upset yourself."

"Feeling overwhelmed by the emotions of others, really caring and being completely distracted from what I need to do for my own health."

Looking After a Mate

While supporters feel worried, they also feel a need to both keep their worries to themselves and to remain positive for the supportee. Supporters find it challenging to provide support when they are feeling tired or down.

> *"[The most challenging aspect of providing support is] the need for you to be consistent and a positive influence, even when you don't feel so great yourself."*

Isolation

Supporters identified isolation as a challenging aspect of providing support and felt isolated for a range of different reasons. Some supporters felt isolated and judged by others;

> *"Isolation and the constant worrying… people judging you and telling you, you are not doing enough."*

Some supporters felt isolated because of a need to maintain the confidence of the supportee.

> *"He's spoken to me in strictest confidence so I'm not comfortable talking about his issues with other people as I don't want to break his confidence."*

Some supporters felt isolated because of the lack of understanding and support available for them as supporters.

> *"That no one appreciated how difficult it is to be providing support. There is a range of support for people who have mental illnesses, and so much encouragement to help your friends if they have mental illnesses, but no recognition of how draining and difficult I can be for the supporter. It led to me having another episode of depression."*

> *"Nobody knowns what I'm going through and I am not getting any support."*

Supporters felt that simply the responsibility of providing support was isolating them.

> *"Doing it alone, becoming isolated due to your time and attention being dominated."*

One supporter felt that they were being isolated by professional services.

> *"It has been hard at times when I have wanted and needed support from professionals but they seemed so reluctant to do anything. For as long as I was there, they were okay with me taking the burden… At times I really couldn't cope and her… behaviour was really affecting my health… It was a really difficult time."*

Assessing Supporters' Needs

To assess how well supporters' needs were met, Haigh and Treasure's (2003) Carer's Needs Assessment Measure (CaNAM) was used[27].

Supporters Information Needs

Figure 15 shows student supporters' information needs. Over 50% of supporters identified that they had information needs regarding:

- Mental health difficulties in general,
- Local self-help groups,
- Individual / family support groups,
- Help lines,
- Where to get help and advice,
- Counselling and psychotherapy options,

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Of the information needs identified by supporters were predominately unmet.

- Coping strategies,
- What treatment options are available,
- Current treatment plan,
- Prognosis,
- Plans for future treatment,
- Meeting other supporters to share experiences,
- What to do in the case of a relapse.

Of these needs, supporters were predominantly identifying unmet needs (i.e., significantly more supporters identified an unmet need than a met need) for the following:

- Individual or family support groups, X^2 (1) = 14.54, $p < .001$,
- Current treatment plan, X^2 (1) = 9.62, $p = .002$,
- Prognosis, X^2 (1) = 15.87, $p < .001$,
- Future treatment plan, X^2 (1) = 14.52, $p < .001$,

- How to meet other supporters 'in the same boat' to share experiences, X^2 (1) = 20.55, $p < .001$,
- Different treatment options, X^2 (1) = 21.60, $p < .001$,
- What to do in the case of a relapse, X^2 (1) = 27.56, $p < .001$.

Supporters were asked about other ways information could be passed on to supporters. Supporters reflected that it is very hard to find out what support is avaliable. They felt that there was a general need to normalise mental health to make it easier to share information. Some supporters idenfitied that they would like more information about how to be involved, with consent, in professional treatment, identifying that they would like professionals to share more information with them.

Supporters' Information Needs

Legend: Unmet Needs, Met Needs, No Needs

Helplines
General information about mental health difficulties
Where to get help/advice
Counselling opportunities for you
Individual/family support groups
Current treatment plan
Local self-help groups
Prognosis
Future treatment plan
How to meet others 'in the same boat'
Coping strategies
Different treatment options
What to do/who to contract if relapse

Count (people)

Figure 15: Number of Supporters' information needs that are met or unmet

Looking After a Mate

With regards to recommendations for ways to share information, supporters suggested using:

- YouTube
- E-learning
- Students' Unions.

Support from Others

Figure 16 shows the people and organisations that supporters were asked to reflect upon in terms of support provision and the proportion of unmet support needs. Over 50% of supporters identified support needs regarding:

- Partner or close friends,
- Immediate family,
- Friends,
- University counselling service,
- Healthcare professionals,
- GPs.

Of these support needs, supporters only identified needs to be predominantly met by friends, X^2 (1) = 14.75, p < .001 and partners, X^2 (1) = 25.81, p < .001. Reports of needs being met or unmet were equivocal for support from immediate family, X^2 (1) = 3.45, p = .63, the university counselling service, X^2 (1) < 1, p = .668 and GPs, X^2 (1) < 1, p = .330. Supporters identified significant unmet needs regarding support from healthcare professionals, X^2 (1) = 9.52, p = .002.

While student supporters were, in general equivocal about whether their support needs were met in relation to support from a GP or university counselling service, supporters who had sought support for their own mental health from their GP were 19.58 times more likely to feel their support needs had been met by a GP than those who had not sought support from their GP. Similarly, supporters who had sought support
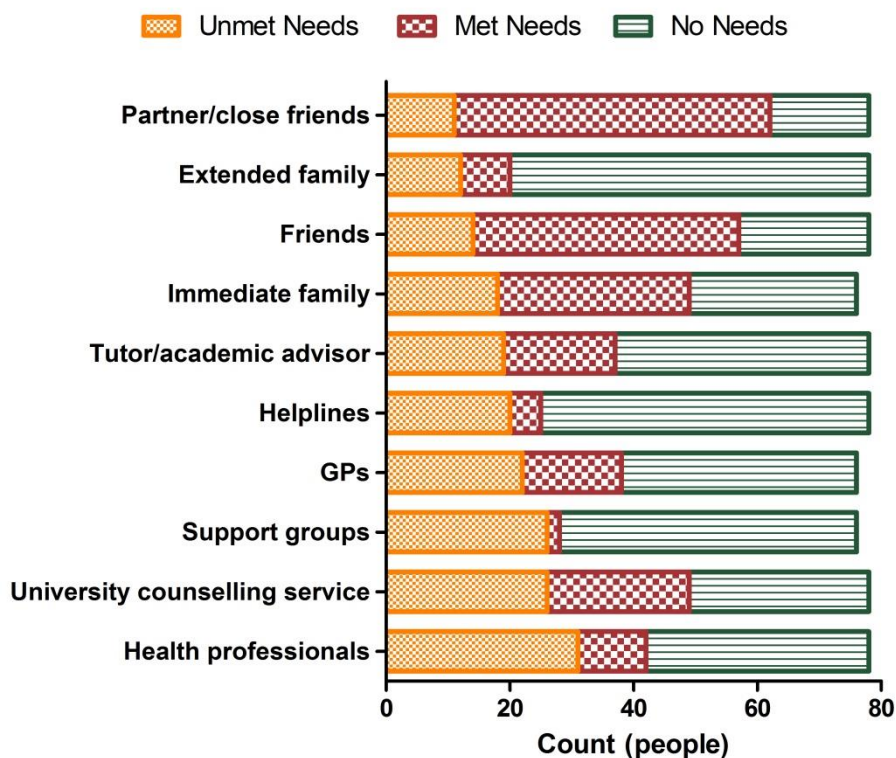

Supporters' Support Needs

Legend: Unmet Needs, Met Needs, No Needs

Figure 16: Number of Supporters' support needs that are met or unmet
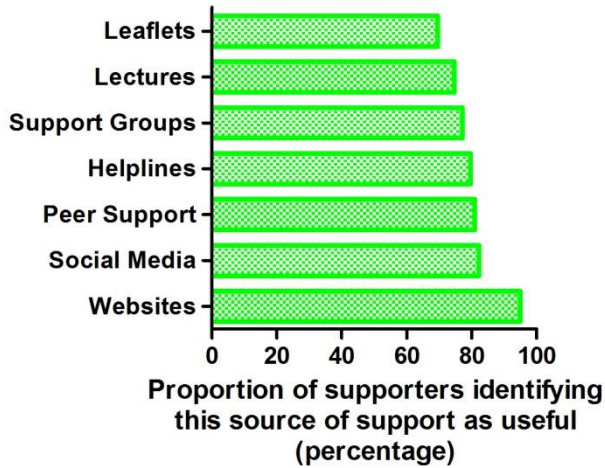
student minds

Figure 17: Supporters' rating of the usefulness of a range of support options

from a university counselling service, were 7.59 times more likely to feel their support needs had been met by the university counselling service than supporters who had not sought support.

This suggests that the challenge in meeting supporters' needs lies in getting supporters to seek help however, where supporters were accessing support from a GP or university counselling service, it was for their own mental health difficulties, rather than for support with their caring role. Given the high rate of mental health difficulties among supporters and the challenges that they face, it would be beneficial for primary care services such as GPs and University Counselling Services to do more to

reach out to support supporters and reassure them that they can access support.

While fewer than 50% of student supporters identified support needs in relation to support groups and helplines, those who did predominantly reported unmet needs for support groups, X^2 (1) = 20.57, p < .001 and helplines, X^2 (1) = 9.00, p = .003.

Student supporters answered a set of questions identifying what they felt to be useful sources of support. Figure 17 shows that supporters felt websites were a useful source of support, alongside social media and peer support.

Supporters were asked whether they were receiving support from any other organisations or individuals, not considered in our survey. Supporters identified the following:

- Students' Union welfare officers;
- Student Minds;
- Training and supervision provided for peer-supporters;
- The Mind Website.

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Of the support needs identified by supporters were predominately met.

" "

I think lots of people want to help but they don't know how and when they do help they often go about it the wrong way. There are many blog posts online about how to support a friend with mental health problems and these are really useful and could be disseminated more.

Looking After a Mate

Self-Support

This scale relates to the ability, as a supporter, to seek support for themselves. Figure 18 shows the self-support items presented in this scale and the proportion of unmet self-support needs for supporters. Over 50% of student supporters identified self-support needs in relation to:

- Seeking professional support,
- Contacting someone in a similar situation for mutual support,
- Meeting others who have recovered / are managing.

Student supporters identified that their need to seek professional support was predominantly met, X^2 (1) = 6.72, p = .010. However this was not the case for contacting someone in a similar situation, X^2 (1) = 2.02, p = .150, or meeting others, X^2 (1) < 1, p = .686.

Making it easier to provide support.

Student supporters were asked whether there is anything that might make providing support easier. Two themes were identified:

(1) A need for more support for supporters, both in terms of support managing their own mental health and managing the role of supporting;
(2) Better support for supportees.

These themes are discussed below.

Supporters also felt that it would be easier to provide support if there was more acknowledgement of how difficult providing support can be.

"The recognition [that providing support is difficult and certainly not always straightforward] is encouraging to try and keep it up."

Some supporters identified that they would find it easier to provide support if the university was more understanding and could be more flexible.

"More support from University. I want and need to be able to offer more time [to support my friend] but my current assessment deadlines are making this extremely challenging."

Supporters' Self Support Needs

Legend: Unmet Needs, Met Needs, No Needs

Figure 18: Supporters' Self Support Needs

Supporting Supporters

Student supporters felt there needed to be more support for supporters. Three categories of support were mentioned: professional advice or information, support for managing personal mental health and the opportunity to talk to others going through the same experience.

Professional advice and information:

In terms of professional advice or information, supporters want training in how to provide support.

"Formal training in support would be very useful, as I would have a better idea of what to do when faced with a difficult situation."

""[It would be easier to provide support if there was] a bit of guidance on how to appropriately distance myself without cutting off contact when things temporarily get too much. A greater understanding of the law regarding preventing someone from harming themselves would be useful."

Supporters want more information and in general thought that it is difficult to find any form of coherent and reputable advice. Information for supporters should be straightforward, coherent and comprehensive.

"[It would be easier to provide support if there was] some professional guidance, not just for him, but for me; just enough to know how to approach things."

35%

Of supporters identified that the supportee's mental health difficulties affect the activities or conversations they share most of the time.

"Online resources are often conflicting."

"[Providing support would be easier with] coherent and complete guides free and easily available, on best methods for support."

Supporters recognised that comprehensive general information may be challenging, as the range of issues experienced by supportees is extensive and some challenges are very specific. Supporters felt it would be helpful to have specific advice. This might either be from a general service or advice from the professionals working with the supportee.

"[Providing support would be easier with] better support for the supporter – having a confidential, anonymous service where you can talk to a professional to check that you're doing the right thing, or if there is anything more you could be doing without compromising your relationship with the person."

"Some of [the supportee's issues] are fairly unusual and that makes it really difficult to know what to do."

Along these lines, some supporters wanted more information to be shared to make it easier to understand, as a supporter, where they could helpfully contribute to support provision.

"[It would be easier to provide support if there was] more openness. We all need to know what has been diagnosed and what she's doing to help it; we need to be told what we can do to help and what we can't do so should bother trying. We need to know when her appointments are and we need to know how she thinks they're going."

Some supporters simply felt it would be nice to meet the professionals involved in supporting the supportee, if only to put names to faces and feel involved.

Looking After a Mate

"It would be nice to meet her counsellor."

"I would like to have more information on the professional support she's getting, i.e. what they do, how it works etc."

Support managing personal mental health;

Supporters felt it would be easier to provide support if they were better supported with their own mental health.

"Coping strategies for my own anxiety would be useful, as I can often overreact or suffer from a panic attack if something happens when I'm stressed and tired."

Opportunity to talk to others;

Supporters felt they would find it easier to provide support if they were able to talk to others in a similar position or access support groups.

"I think it would be easier to provide support if only I had more experience with or knew more people dealing with these issues and that only comes from talking openly I think."

Supporting Supportees

Supporters identified that it would be easier for them to provide support if there was more support available for supportees and if this support were easier to access.

"[It would be easier to provide support it there was] better access to public services for mentally ill people would ease the burden significantly."

"If services other than a GP surgery were more readily available / useful for young people. There is little to no real support at university for those suffering from long-term or severe illnesses and NHS provision lacks massively in our area – it is almost impossible to get any talking treatment other than a 20 minute phone appointment."

One supporter felt it would be helpful if there was support available that they could access with the supportee.

❝ ❞ *We need to know what we're expected to put up with in terms of her behaviour and what is out of order regardless of her mental health difficulties. We need to know what is **scary-but-safe** and what is **dangerous-call-the-police**. The university could help a lot with these last points.*

Diversity in Information and Support Needs

The mental health of the supporter, whether or not the supportee was taking time out from work or study due to illness and the extent to which the supportees mental health was perceived to affect shared conversations and activities were all related unmet support needs.

Current Mental Health Difficulties

Supporters' unmet support needs varied with experience of mental health difficulties, F (2, 76) = 4.07, p = .021. Specifically, supporters experiencing mental health difficulties had more unmet support needs than those with no experience of mental health difficulties, t (57) = 2.94, p = .005.

Taking Time Out Due to Mental Health

Supporters supporting a supportee who was taking time out from university or work due to mental health difficulties identified significantly more unmet self-support needs, t (77) = 2.10, p = .039.

Effect of Supportees' Mental Health on Shared Activities and Conversations

Supporters with more unmet information needs felt that the supportees' mental health had a greater effect on shared activities and conversations, r (79) = .24, p = .032. Similarly, supporters with more unmet support needs felt that the supportees' mental health had a greater effect on shared activities and conversations, r (79) = .31, p = .006. The relationship between unmet support and information needs and the effect that supportees' mental health has on shared activities and conversations remained after controlling for the supporters' mental health and whether or not the supportee was taking time out of university; information needs - r (75) = .236, p = .039 and support needs - r (75) = .293, p = .010.

" "

[It would be easier to provide support if there was] recognition of the fact that [providing support] is hard work. [It would be easier to provide support if there was] more support for supporters – we are not mental health experts but we spend more time with those with illnesses than the professionals, so a helping hand would be nice!

Looking After a Mate

Aim 4:
Approaches to Caring

The final aim of the study was to assess supporters' approach to providing support, including their listening style and their approach to caregiving.

One way to improve students' experience of providing support may be to provide training to help students adopt more positive approaches to caregiving. To understand more about what such training might consider, this study asked student supporters about their listening style and the level of emotion and direction in their approach to caring. The data collected here provides just a summary overview, and the measures of listening style and approach to caring are not sufficient to draw strong conclusions about the relationship between caring approaches and supporter wellbeing. The results reported here however suggest that it might beneficial to investigate these relationships further.

Listening Styles

Fuller and Taylor (2008) identify five levels of listening in a motivational approach to encouraging and supporting individuals to change. These levels build upon each other to a level of listening that develops discrepancies. Listening effectively is central to a motivational approach to caring. However, listening well is a skill. We hypothesised that individuals who felt able to adopt more supportive levels of listening more frequently, might feel better able to provide effective support and find the task of providing support less stressful. This survey assessed listening style roughly, by asking supporters to
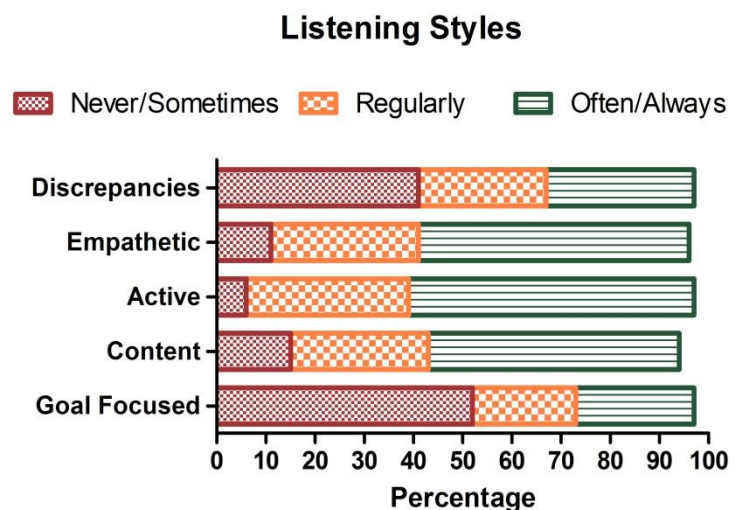

Figure 19: Frequency of use of levels of listening

read descriptions of the levels of listening and self-assess, on a 5 point likert scale, how often they used this style of listening.

The five levels of listening identified by Fuller and Taylor (2008) were:

1. Goal focused listening: Your aim is to solve the problem. You might interrupt, argue or provide advice.
2. Listening to content: taking in the facts that you are being told.
3. Active listening: you move beyond facts to gain understanding, concentrating on what the teller is saying.
4. Empathetic listening: you notice detailed non-verbal reactions and reflect understanding to gain empathy.
5. Listening to develop discrepancies: you reflect back the meaning, feeling and discrepancies that you have to perceived, to check that you have understood correctly.

As shown in Figure 19 supporters were significantly more likely to identify using empathetic and active listening, than goal focused listening; respectively, t (76) = 5.85, p < .001 and t (76) = 7.27, p < .001. Although it would be expected that the different listening styles might be negatively correlated with one another, no significant negative correlations were found between the different listening styles. This may indicate that supporters had limited understanding of the listening levels as described in the survey.

In support of the hypothesis that more advanced listening skills may lead supporters to have a more positive experience of providing support, frequent use of a listening style to develop discrepancies reported higher QoLS scores, r (77) = .27, p = .017, and lower scores on the IEQ subscales of tension, r (75) = .293, p = .011 and supervision r (75) = .300, p = .009.

Direction and Emotion in Caring

Treasure, Smith and Crane (2007) use animal metaphors to set out different approaches to caring. These approaches vary on two dimensions; direction and emotion.

Highly directive caring responses can vary in emotion from high emotion with high levels of sympathy and micro-management (the kangaroo response) to low emotion with too much control and direction (the rhinoceros response). Low directive caring response can also vary in emotion, from too much emotion (the jellyfish response) to too little emotion (the ostrich response).

To make a rough assessment of the use of different approaches to caring, supporters were presented with the six descriptions of caring styles and asked to make an assessment of the extent to which they recognised each style in their own approach to providing support. Ratings were made on a 5 point likert scale. Supporters were given the following descriptions:

The Kangaroo does everything to protect, taking over all aspects of the sufferer's life. They treat the sufferer with kid gloves, burying them in their pouch in an effort to avoid any upset or stress… accommodating all possible demands.

The Dolphin gently nudging him / her to safety, at times swimming ahead and leading the way, and at other times, swimming alongside with encouragement, or even quietly swimming behind.

The Rhinoceros; too much direction and too little warm emotion… fuelled by stress, exhaustion & frustration, or simply one's own temperament, the rhino attempts to persuade and convince by argument and confrontation.

The Ostrich; rather than confronting the difficult behaviour associated with mental health difficulties, the ostrich finds it difficult to cope

with the distress of challenging and confronting and so avoids talking and thinking about the problems at all.

The St Bernard: calm, warmth and compassion involves accepting and processing the pain that is involved with what is lost in the mental health difficulties and developing reserves of kindness, gentleness and love. A St. Bernard responds consistently... unfailing, reliable and dependable in all circumstances.

The Jellyfish: some supporters may become engulfed in intense emotional responses, causing tears, anger and sleepless nights.

As shown in Figure 20, the most frequently used approaches to caring were the balanced approaches; The St Bernard and The Dolphin. The least commonly used approach were the low directive control approaches; The Ostrich and The Jellyfish.

Interdependence between caring styles

In general the frequency with which caring styles were used was not correlated. However it is of interest to note that the Kangaroo caring style and Jellyfish caring style were significantly correlated, r (78) = .26, p = .020. The approaches differ on the dimension of directive control, with a kangaroo approach involving high levels of directive control while a jellyfish approach involves low levels of directive control. Both approaches involve high levels of emotional response.

Relationship between caring styles and experience of caregiving,

To the extent that the ECI and the IEQ provide an indication of how well a supporter is coping with the experience of providing care, we can compare the experience across different caring approaches.

Correlations were observed between total scores across the negative subscales of ECI and both the Kangaroo approach, r (68) = .41, p = .001 and Jellyfish approach, r (68) = .43, p = .001.

Correlations were also observed between total scores of the IEQ and both the Kangaroo approach, r (74) = .40, p = .001 and Jellyfish approach, r (68) = .43, p = .001. Both of these highly emotional approaches to caring appear to be related to negative caring experiences and high involvement.

Supporters identifying with the Kangaroo caring approach, which involves high levels of directional control and warm emotion, had lower quality of life, r (78) = .43, p < .001, and
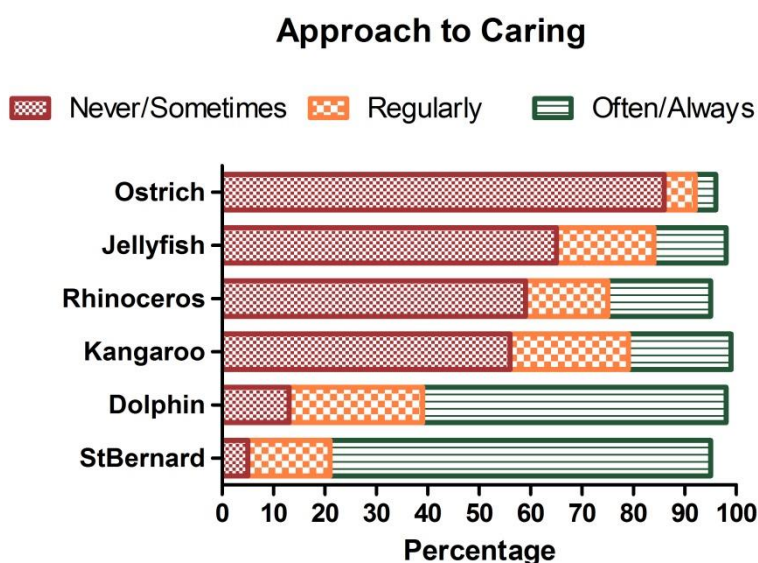

Figure 20: Frequency of use of caring styles

were less able to make the most of the university experience, r (78) = -.41, p < .001.

While the dolphin approach has been identified as a positive approach to caregiving, here the approach was correlated with higher total scores on the negative subscales of the ECI, r (68) = .33, p = .006 and IEQ score, r (74) = .26, p = .029.

This indicates highly emotional approaches to providing support are associated with less positive experiences for the supporter. Information, advice and training for supporters should incorporate emotionality. Skills based training for supporters can equip supporters to adopt a less emotional approach to managing difficult relationship situations.

Interactive effects

Interactive relationships were observed between factors explored across Aims 1 − 4. In particular relationships were found between factors related to the impact of the supportee's mental health on the relationship between supporter and supportee (i.e. frequency of face-to-face contact, the proportion of support provided by the supporter and the extent to which the supportee's mental health affected shared activities and conversations), ability to make the most of the university experience, experience of caregiving, support and information needs and intensity of non-professional support.

As shown in Table 2, there were significant correlations between Negative ECI score, IEQ score and information and support needs and University Experience.

Individuals with higher scores on the subscales of **difficult behaviours**, r (76) = -.33, p = .003, **negative symptoms**, r (74) = -.40, p < .001, **Stigma**, r (77) = -.32, p = .005, **dependency**, r (76) = -.28, p = .015, and **urging**, r (75) = -.32, p = .005, gave lower ratings of ability to make the most of the university experience. This suggests that a negative experience of caregiving has a negative impact on overall university experience.

We look first at the role that the extent to which the experience of caregiving (including the extent to which the supportee's mental health affects shared shared activities and

conversations) plays in mediating a relationship bewteen support and information needs and ability to make the most of the university experience. We then look at these components in further detail, specifying how they fit into a wider picture of providing support.

A Mediated Relationship

A process approach to mediation analysis, using bootstrapping[38], was used to identify the relationship between support and information needs, experience of caregiving (ECI) and the university experience.

	Information Needs	Seeking Support Needs	Support Needs	University Experience	QOLS
Negative ECI	.39	NS	.42	.34	NS
IEQ	.32	NS	.43	NS	NS

Table 2: Correlations between Negative ECI, IEQ and Support Needs, University Experience and QOLS score. All correlations significant at p < .005. NS signifies correlations that were not significant.
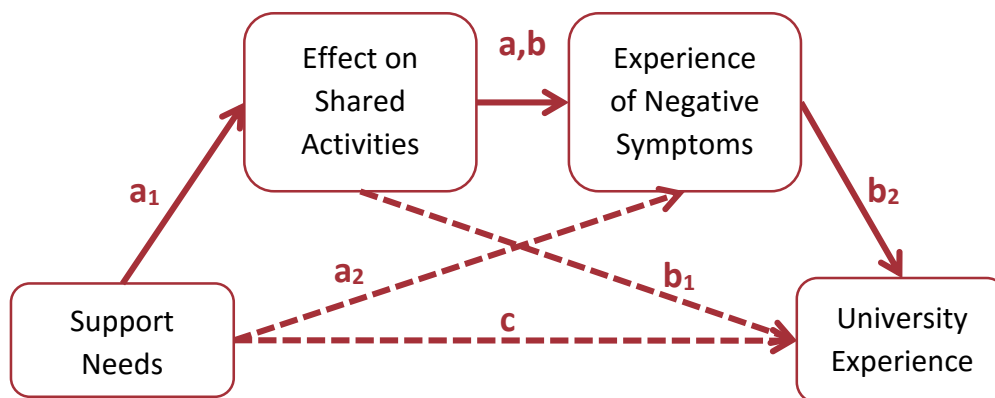
Figure 21: Perceived effect of the supportee's mental health on shared activities and conversations and more generally, Experience of Caregiving (specifically the experience of negative symptoms) mediated the relationship between Information Needs / Support Needs and University Experience. Solid lines show significant relationships. Dashed lines show non-significant connections.

While unmet needs did not, in isolation predict university experience, unmet needs predicted the extent to which supporters felt the supportees mental health affected shared activities and conversations and experience of caregiving which predicted university experience. As such, affect on shared activities and experience of caregiving mediated the relationship between unmet needs and university experience.

Meeting more of supporters' needs, in terms of information and support provision, will reduce the affect that supporters feel the supportees mental health has on shared activities and more generally, improve the experience of caregiving. To the extent that experience of caregiving can improved, meeting more of the supporters' needs will improve university experience.

As shown in Figure 21 effect on shared activities and conversation and experience of **negative symptoms** [§] mediated the relationship between unmet *information* needs and university experience, $\beta = -.02$, SE = .01, 95 % CI (-.05, -.002):

(a_1) As more information needs were unmet, effect of mental health difficulties on shared conversations and activities increased, $\beta = .07$, SE = .03, 95 % CI (.01, .13), $t(72) = 2.23$, $p = .029$

(a_1) As more information needs were unmet time spent thinking about negative symptoms increased, $\beta = .47$, SE = .14, 95 % CI (.19, .76), $t(71) = 3.31$, $p = .002$

(a,b) As effect on shared activities and conversations increased, time spent thinking about negative symptoms increased, $\beta = 2.01$, SE = .53, 95 % CI (.95, 3.07), $t(71) = 3.79$, $p < .001$

(b_1) As effect on shared activities and conversations increased, ability to make the most of university experience **increased**, $\beta = .45$, SE = .12, 95 % CI (.21, .70), $t(70) = 3.68$, $p < .001$.

(b_2) As supporters spend more time thinking about negative symptoms their ability to

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[§] The model is significant for other subscales of the Experience of Caregiving Inventory, including, experience of difficult behaviours, $\beta = -.02$, SE = .01, 95 % CI (-.04, -.001); experience of dependency, $\beta = -.01$, SE = .01, 95 % CI (-.03, -.0002) and experience of loss, $\beta = -.01$, SE = .01, 95 % CI (-.04, -.002).

make the most of the university experience **decreased**, β = - .12, SE = .03, 95 % CI (-.17, -.07), t (70) = 4.85, p < .001.

(c) Unmet information needs, did not predict university experience directly, β = -.006, SE = .03, 95 % CI (-.07, .06), t (70) < 1, p = .85.

As shown in Figure 21 effect on shared activities and conversations and experience of **negative symptoms**[**] mediated the relationship between unmet *support* needs and university experience, β = - .03, SE = .02, 95 % CI (-.08, -.01):

(a$_1$) As more support needs were unmet, effect of mental health difficulties on shared conversations and activities increased, β = .12, SE = .05, 95 % CI (.03, .21), t (72) = 2.49, p = .015

(a$_1$) As more support needs were unmet time spent thinking about negative symptoms increased, β = .61, SE = .23, 95 % CI (.16, 1.07), t (71) = 2.67, p = .009

(a,b) As effect on shared activities and conversations increased, time spent thinking about negative symptoms increased, β = 2.05, SE = .55, 95 % CI (.95, 3.14), t (71) = 3.74, p < .001

(b$_1$) As effect on shared activities and conversations increased, ability to make the most of university experience **increased**, β = .46, SE = .12, 95 % CI (.22, .71), t (70) = 3.77, p < .001.

(b$_2$) As supporters spend more time thinking about negative symptoms their ability to make the most of the university experience **decreased**, β = - .12, SE = .02, 95 % CI (-.17, -.07), t (70) = 4.81, p < .001.
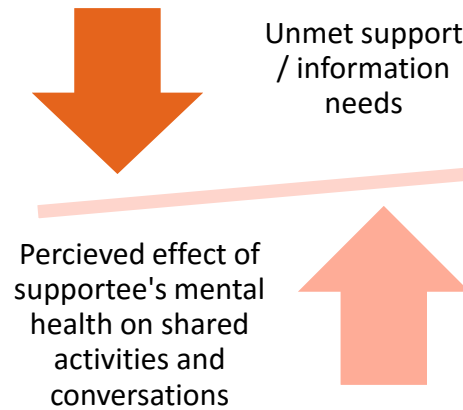
(c) Unmet support needs, did not predict university experience directly, β = -.04, SE = .05, 95 % CI (-.14, .06), t (70) < 1, p = .41.

These models illustrate that the perceived effect of the supportee's mental health on shared activities and conversations, and more generally, experience of caregiving, have an effect on university experience, they are mediating a relationship with support needs. Improving support for supporters should improve their experience of caregiving and in turn their university experience.

Support Needs

The mediated model illustrates an important role for information and support needs. Independent from the mediated model, unmet support and information needs as assessed by the CaNAM[27] related to scores on the ECI and IEQ[21], as shown in Table 2. Specifically, unmet *information* needs related to higher scores on the subscales of **negative symptoms**, r (74) = .43, p < .001, **dependency**; r (76) = .37, p = .001 and **urging**; r (75) = .30, p = .008. Unmet support needs related

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[**] The model is significant for other subscales of the Experience of Caregiving Inventory, including, experience of difficult behaviours, β = - .03, SE = .02, 95

% CI (-.06, -.003); experience of dependency, β = - .02, SE = .01, 95 % CI (-.06, -.004) and experience of loss, β = - .02, SE = .01, 95 % CI (-.06, -.002).

to higher scores on the subscale of **worrying**; r (78) = .32, p = .004.

Importantly, unmet support needs continued to predict scores on the negative subscales of the ECI, after considering the proportion of support that a supporter provides, the frequency of face-to-face contact and the effect that the supportees' mental health has upon shared activities and conversations, R^2_{change} = .06, F_{change} (1, 63) = 5.66, p = .020. A similar, but non-significant, trend was observed for unmet information needs, R^2_{change} = .03, F_{change} (1, 63) = 3.02, p = .087.

This indicates that independent of the intensity of support that the supporter is providing and the level of responsibility that they feel for providing support, meeting their support needs can improve the experience of caregiving.

Proportion of support, frequency of contact and effect on shared activities and conversations.

Neither frequency of contact between supporter and supportee or proportion of support provided by supporter influenced this mediation model as neither factor was related to unmet information or support needs.

However, independent of the mediated model, these factors were related to experience of

caregiving. Each of these factors predicted scores on the negative subscales of the ECI and the IEQ independently. However, the combination of these factors provided a better predictor of score on the negative subscales of the ECI (and IEQ – see below). Combined the proportion of support, frequency of contact and effect on shared activities and conversations predicted variance in negative ECI scores, R^2 = .34, F (3, 64) = 10.87, p < .001[††].

Within this model however, the proportion of support provided by the supporter did not significantly predict negative ECI scores, β = .08, 95% CI (-1.26, 2.74), t (64) < 1, p = .461, while effect on shared activities and conversations, β = .60, 95% CI (6.27, 16.11), t (64) = 4.54, p < .001, and frequency of contact β = .31, 95% CI (-7.70, -1.50), t (64) = 2.97, p = .004, did predict negative ECI scores.

Similarly, the best predictor of score on the IEQ was given by a model containing all three of these variables; R^2 = .42, F (3, 71) = 16.79, p < .001[‡‡]. The analysis shows that proportion of support did not significantly predict IEQ scores, β = -.02, t (71) < 1, p = .83, 95% CI (-1.31, 1.06), however effect on shared activities and conversations, β = .56, t (71) = 5.89, p < .001, 95% CI (5.52, 11.71), and frequency of contact β = .34, t (71) = 3.61, p = .001, 95% CI (-4.88, -1.41), did predict IEQ scores.

[††] Tests to see if the data met the assumptions of collinearity indicated that multicollinearity was not a concern: proportion of support, tolerance = .88, VIF = 1.14; frequency of contact, tolerance = .96, VIF = 1.05; effect on activities and conversations, tolerance = .87, VIF = 1.15. The data met the assumptions of independent errors; Durbin-Watson value = 1.96. The histogram of standardised residuals indicated that the data contained approximately normally distributed errors, as did the normal p-p plot of standardised residuals, which showed points that were not completely on the line, but close. The scatter plot of standardised residuals showed that the data met the assumptions of homogeneity of variance and linearity.

[‡‡] Tests to see if the data met the assumptions of collinearity indicated that multicollinearity was not a concern: proportion of support, tolerance = .83, VIF = 1.20; frequency of contact, tolerance = .95, VIF = 1.06; effect on activities and conversations, tolerance = .87, VIF = 1.16. The data met the assumptions of independent errors; Durbin-Watson value = 2.01. The histogram of standardised residuals indicated that the data contained approximately normally distributed errors, as did the normal p-p plot of standardised residuals, which showed points that were not completely on the line, but close. The scatter plot of standardised residuals showed that the data met the assumptions of homogeneity of variance and linearity.

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