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Mental health professionals and information sharing: carer perspectives

Abstract

Background: The important role played by carers of those with mental health problems is frequently undervalued among healthcare professionals.

Aims: To identify the difficulties encountered by carers in relation to obtaining information from mental health teams.

Methods: Participants in the study included carers or family members of persons with mental illness who were affiliated with a support group in Ireland. Information was gathered using an 18 item self-report questionnaire. This is an amended version of the Carer Well-Being and Support (CWS) Questionnaire for carers of people with a mental health problem or dementia.

Results: One-hundred and fifty-nine carers complete the questionnaire. On average respondents stated that they have been in the role of a carer for someone with a mental health problem for 14.4 years, spending a median of 20 hours caring each week. Despite most carers maintaining that they are generally satisfied with the support offered to them from medical and/or care staff, the majority (56.3%) of respondents stated that they have specifically encountered difficulties accessing information from the treating mental health team. The main reasons given to them by the mental health team for withholding information include: lack of patient consent (46.2%) and unavailability of a team member (46.2%). From a carer perspective, respondents stated that the main reason they feel there is difficulty in accessing information is a lack of concern for their role as a carer in the patient's management (60.5%). More than 75% of all respondents are afraid of negative consequences for them or for the person in their care as a result of information being withheld by the treating team.

Conclusions: Carer involvement is essential for the complete and effective management of individuals with mental illness. Confidentiality should not be used as a reason for completely excluding carers.

Key words: Carers, confidentiality, mental disorder, mental health services, access to information.

Introduction

The significant role played by carers of those with mental health problems is frequently undervalued among healthcare professionals. In a recent survey by the European Federation of Associations of Families of People with Mental Illness (EUFAMI) almost 60% of respondents stated that they felt unrecognised and unengaged by the health care team [1]. Having regular contact and generally being responsible for significant aspects of patient welfare places the carer in an exceptional position. In 2006 “A Vision for Change”, Ireland’s mental health policy, asserted that “family, friends, colleagues, neighbours and community members are important sources of support for service users and have their own unique insight into mental ill health and the provision of mental health services” [2; p.24]. Carers are a valuable source of information as they are often the person most familiar with a patient’s presentation and the first to notice possible signs of relapse. They may also have influence over adherence to treatment and reduce patient relapse rates [3].

Routinely caring for a person suffering from a mental illness can be an isolating and demanding experience. It puts considerable strain on the carer’s own health and wellbeing, particularly when required to provide support for extended periods of time. Research by the British mental health charity Rethink found that of 1,451 carers surveyed, 29% spent over fifty hours per week looking after the individual in their care [4]. Of these, 25% reported moderate to significant impact on their mental and physical health, leisure activities, family relationships, financial circumstances and career progress. Similarly, in a survey of Irish carers, 40.8% reported experiencing stress or nervous tension in the previous twelve months with comparatively high levels of anxiety (22.6%) and depression (17.6%) [5]. The mental state of carers is crucial and affects their ability to offer practical and emotional support to those in their care.

Carers are under additional stress to meet the increasing care needs in the home, whilst maintaining their own health and other family commitments due to the challenges presented by resource constraints. Informal caring activities are of significant economic value to the State. It is estimated that carers save the Government almost €4 billion a year [6]. This means that on average a full-time family carer contributes €62,000 annually to the Irish economy. Government policy formally recognised the carer role in social welfare provisions with the establishment of the Carers Allowance in 1990 as a specific welfare payment for those defined as eligible carers [7]. Social insurance and employment provisions were also introduced with the Carer's Benefit in 2000 and Carer's Leave in 2001. In addition, all full-time carers are eligible to receive a Respite Grant. In 2011 51,666 were in receipt of the Carer's Allowance (including 21,951 who received the half-rate allowance), 1,637 were in receipt of Carer's Benefit and 69,847 were in receipt of the Respite Care Grant [8]. However, as the weekly Carer's Allowance and Carer's Benefit payments are means-tested, many carers do not receive regular financial support in their caring role. Furthermore, the recent cuts in the Budget 2013 reduced the annual Respite Care Grant from €1700 to €1375 [9].

Government policy has developed over the years in response to an increased awareness of the carer role. A social policy report published in 2002 highlighted the mounting demographic pressures that were considered likely to lead to both an increase in the need for care services and a decrease in the supply of those services by the traditional care providers, family members [10]. In 2005, the Equality Authority published the "Implementing Equality for Carers" report which provided practical recommendations to ensure that carers would be adequately supported [11]. The National Development Plan 2007-2013 recognised that respite and day care service places need to be part of a comprehensive community service to give a much-needed break to carers [12]. The National Action Plan for Social Inclusion 2007-2016 acknowledged the role that carers play in supporting the government's policy of caring in the home and community and suggested that carers require a range of supports including financial supports, education and training [13].

It wasn't until July 2012, following lengthy delays, that the first National Carers' Strategy was published in Ireland. This sets out a series of goals aimed at recognising,

supporting and empowering carers [14]. The strategy says that the value and contribution of carers should be recognised and their inclusion in decisions relating to the person they are caring for should be promoted. It acknowledges that carers need more help and support than has been available in the past.

Being involved with a supportive mental health team, with ready access to information, allows carers to feel valued and empowered. Unfortunately, carers do not always regard their interactions with the mental health services in a positive light and often view service providers as hiding behind confidentiality to defend their exclusion from the planning of services and treatment [15]. One carer in our study clearly expressed this view: "Doctor patient confidentiality is taken too far with me as the carer even though I am the mother." Difficulty accessing information can lead to distress and frustration on the part of the carer and a breakdown in their relationship with the treating psychiatric team resulting in compromised patient care.

Previous studies have shown that withholding information from carers is often justified by mental health professionals on the grounds of confidentiality [16-18]. It has long been accepted in convention and law that doctor-patient communication is privileged. The Hippocratic Oath states, "All that may come to my knowledge in the exercise of my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and will never reveal" [19; p.861]. Disclosing confidential information to family members or carers without patient consent is considered fundamentally unethical. However, the Irish Medical Council does allow for disclosure without consent in notable situations such as when the patient or others are at risk of death or serious harm or when directed by a court [20].

In the UK, the General Medical Council has published guidelines on the issue of confidentiality and states that, "If a patient lacks capacity, you should share relevant information...Unless they indicate otherwise, it is reasonable to assume that patients would want those closest to them to be kept informed of their general condition and prognosis" [21; p.26]. Despite this, the remainder of the 52 page document repeatedly refers to the fact that patients have an implicit right to confidentiality. Only in very exceptional circumstances can confidentiality be breached and in doing so, health professionals must be prepared to deal

with the potential consequences: “You are personally accountable for your professional practice and must always be prepared to justify your decisions and actions” [21; p.1].

From the perspective of the mental health professional it is difficult to balance the legal and ethical rights of a patient to a confidential medical relationship against the context of public interest issues that occur as a result of mental illness, particularly the effect of mental illness on family caregivers. This is especially problematic when patients wish to conceal their psychiatric condition from relatives or when competency is an issue. More often than not mental health professionals err on the side of caution when it comes to disclosing information. They are more likely to be reprimanded for breaching confidentiality than for refusing to release information by citing confidentiality. Health care professionals run the risk of being sanctioned by a professional body and may face legal consequences such as a claim for negligence, breach of contract or breach of confidence. Perceived breach of ethical codes may also result in disciplinary proceedings and ultimately, being struck off the professional register.

Rapaport et al [22] pointed to differing opinions between health professionals and service users in respect of the reasons for failing to provide information. They found that 81% of professionals believed that the main reason for carers not receiving information was due to service users withholding consent. However, only 12% of the service users in the study reported being routinely asked by professionals to consent to the sharing of personal information. This is a surprising figure given that patients should be asked on a routine basis who they wish their medical information to be shared with. Good practice in the collection of consent also involves the use of routine ‘disclosure to consent’ forms or advance statements. Another study showed that the expectations of patients and carers differ from those of medical staff. While most carers feel that information should regularly and routinely be shared, the majority of physicians believe that discussions should only occur with the patient’s permission and at the patient’s request [23].

Despite communication between doctors and carers being an imperative clinical issue there is a surprising lack of Irish research in this area and in particular in relation to the determining role of confidentiality. One survey commissioned by the Mental Health Commission in 2003, reported that carers often felt ostracised and excluded from the

care of their family member [24]. However, it did not address carers' explanation for this occurrence or the reasons given by the mental health team for withholding information.

The aim of this study was to determine carer attitudes to the mental health services and the degree to which information and advice were provided to them by the mental health team. We hoped to specifically assess the extent to which confidentiality is viewed as a barrier to information sharing and the perceived consequences of this. The completed questionnaires were examined to determine the difficulties encountered by carers, and the consequences thereof with regard to obtaining information from mental health teams about the person in their care. This included information concerning diagnoses, treatment plans and who to contact in an emergency.

Methods

Participants

Participants in the study included carers or family members of persons with mental illness who were affiliated with mental health support groups in Ireland. The purpose of the study was to survey personal opinions of carers involved with the mental health services. Participation was entirely voluntary. Disclosure of patient details or information regarding specific services was not requested.

Questionnaires

An 18 item self-report questionnaire was used to gather information from study participants. This questionnaire is an amended version of the Carer Well-Being and Support (CWS) Questionnaire for carers of people with a mental health problem or dementia. The CWS is a reliable, valid measure of carer well-being and support, reflecting important aspects of carers' lives [25]. The original questionnaire was developed by the Royal College of Psychiatrists in collaboration with Rethink, the Alzheimer's Society and the London School of Hygiene and Tropical Medicine Health Service Research Unit [26]. We did not include sections A and C of the original version as the questions pertain to the general well-being and needs of the

carer and were not relevant to our study. We wished to specifically examine the relationship between carers and the mental health services. Therefore, only the support scale (section B) of the CWS questionnaire was used (Figure 1). This assesses level of carer satisfaction in terms of information and advice offered, support received and involvement in treatment planning. In addition, several questions specific to difficulties accessing information from mental health teams were included. We also collected general background information about the carers and those in their care including demographic details, diagnoses and social circumstances. Respondents were given the opportunity to comment on any other issues that they felt were important.

Recruitment

Recruitment of study participants was through three national mental health support groups who agreed to take part in the study. For reasons of confidentiality we were not given direct access to member's names or addresses. Each organisation agreed to distribute the questionnaires on our behalf. They were supplied with copies of the questionnaire along with stamped, addressed envelopes for their return.

Shine is a support group for people with mental ill health; addressing the needs of all those affected by enduring mental illness including, but not limited to, schizophrenia, schizoaffective disorder and bipolar disorder. Shine agreed to mail the questionnaire to their 311 members located across the Republic of Ireland. The National Service User Executive (NSUE) is an organisation advocated by the Vision for Change Mental Health Policy to develop and implement best practice guidelines between the user and provider interface. They informed us that they had 1275 members that included both psychiatric patients and carers. All members of the NSUE were indiscriminately mailed a copy of the questionnaire. Patients who received a copy of the survey were asked to pass it on to their carer if applicable. Aware (support group for those affected by depression) did not have a database of their members but were given 50 questionnaires to distribute during their support group meetings.

Prior to distribution of the questionnaires approval for the study was obtained from the Mater Misericordiae University Hospital Ethics Committee.

Statistical analysis

We used PASW statistics version 18.0 for Microsoft Windows to analyse all data.

Results

Sociodemographic

One-hundred and fifty-nine questionnaires were completed and returned by mail between July and September, 2011. We did not receive any responses from patients and all respondents claimed to be carers of those with mental illness. Of those who responded, the majorities are Irish (95.5%) and female (73.5%). Respondents range in age from 20 to 87 years with a mean age of 59.6 (s.d. = 13.6) years. Almost half (48.7%) are from urban areas, 36.4% are from rural areas, and only 14.9% are from semi-urban areas. On average respondents stated that they have been in the role of a carer for someone with a mental health problem for 14.4 years, ranging from 1 to 54 years. The median number hours spent caring each week is 20 hours.

In terms of employment status, 37.7% of respondents are retired, 18.9% employed full-time, and 10.7% employed part-time (Table 1). Some respondents stated that they are unable to work because of their caring responsibilities (6.9%), or due to ill-health/disability (3.1%).

Patient information

The vast majority of respondents care for one person (83.6%), while 10.5% care for two people, and only 5.9% care for more than three people.

Most respondents care for their son or daughter (62.2%). Other relationships include partner/spouse (15.4%), sibling (14.7%), parent (6.4%) and friend (2.4%).

In terms of social circumstances, almost half (47.1%) of respondents do not live with the person they care for. About 38.1% of them live with the person in their care on a permanent basis, while 16.1% only live together for some of the time.

More than half (54.0%) of persons in care live in their own or rented accommodation and 24.0% live in supported accommodation. Eleven per cent of people who are cared for live in hospital, 8.0% live with another family member or friend, and 4.0% live in a care home.

In terms of carer role, 30.6% of respondents stated that they are only caregiver, 36.3% stated that they share responsibilities with others but that they are the main caregiver, 22.3% said that they share equal responsibilities with others, and 8.9% said that someone else is the main caregiver.

More than half of persons cared for suffer from schizophrenia (59.5%) (Table 2). Bipolar disorder and depression are the next most common psychiatric diagnoses.

Satisfaction levels with support received

The majority of carers claim to be generally satisfied with the overall level of information and advice they receive about the person in their care (Figure 2). A reassuring 73.7% of respondents feel that they have enough information to feel confident in their carer role and 76.2% are satisfied with their ability to understand the information. This pertained to information offered by a range of people working in the voluntary and statutory sectors such as general practitioners, social workers, care workers and carer support groups as well as members of the treating mental health team.

In terms of carer participation in treatment and care planning, approximately half (58.0%) of respondents stated that they are satisfied with their level of involvement in important decisions (e.g. in relation to medication and hospitalization) and 50.7% are satisfied with their ability to influence these decisions. Unfortunately this still leaves a considerable number of carers who are unhappy with their level of participation in patient management. A worrying 22% of carers described feeling “very dissatisfied” with both their involvement in and ability to influence treatment decisions.

Overall, most carers are satisfied with the support they receive from medical and/or care staff (Figure 3). However, more than half (52.3%) stated that they find it difficult to get help and support for themselves.

Accessing information from mental health teams (results not shown)

Despite most carers maintaining that they are generally satisfied with the information and support offered to them, more than half (56.3%) state that they have specifically encountered difficulties accessing information from the treating mental health team about the current mental health, treatment plan or medication of the person in their care. More than 75% of all respondents are afraid of negative consequences for them or for the person in their care as a result of information being withheld by the treating team.

Respondents stated that the main reasons given to them by the mental health team for withholding information include: lack of patient consent (46.2%), unavailability of a team member (46.2%), insufficient time (26.2%) and inappropriate setting (6.2%).

From a carer perspective, respondents stated that the actual reasons they feel there is difficulty in accessing information include: lack of concern for their role as a carer in the patient's management (60.5%), doctors uncertainty on how to manage the patient (37.2%), unwillingness of the treating team to reveal or discuss possible mistakes they have made (34.9%) and lack of patient consent (30.2%). Other reasons given by respondents were: lack of interest and empathy on the part of the treating team (9.3%) and constant doctor change over (3.5%).

Carers feel mental health professionals use lack of patient consent as a more common reason for withholding information (46.2%) than is actually the case (30.2%). This suggests that carers view consent as less of an obstacle to information sharing than do mental health professionals.

Carer comments

Respondents were given the opportunity to comment on any specific issues that they felt were important with regard to their interactions with mental health professionals. Confidentiality was a theme that frequently arose. A number of comments made by different carers revealed that it is often perceived as a barrier to communication:

“Patient confidentiality is always a priority, so communication can be very one sided”.

“Rules concerning patient confidentiality in Ireland are too rigid”.

“Patient may not consent due to distorted thinking, so the whole area of communication with psychiatrist becomes a mess”.

Amongst other relevant issues raised (Figure 4), a common concern expressed by carers relates to their sense of isolation and the perceived lack of support available outside of working hours. Many feel that there is a need for consistent and easier access to the psychiatric services, particularly when the person in their care becomes acutely unwell. As one respondent wrote:

“I need 24 hour support. In past crisis”, I have brought my son to A&E to wait for hours for an assessment. Last time we were waiting 4 hours before he left in distress and a psychotic state.”

Some carers also feel that their own perspective and personal mental state is neglected. One respondent expressed her sense of feeling undervalued as a carer:

“I would like to be acknowledged for the important and time consuming role I do. The only people who understand mental illnesses are those who are carers such as myself.”

Another respondent described feeling that her opinion is often overlooked: “(Doctors have) no interest in speaking to me during clinics. Unless I push to be involved they ignore me”. This sentiment was echoed in another comment: “Even with consent, they do not want to engage with me as a parent”.

Other concerns raised by respondents related to poor support outside of working hours or when patients are acutely unwell (11.7%), lack of communication in relation to patient

management/medication (8.7%), poor community services/lack of access to psychologists (7.8%) and unempathetic doctors (5.8%).

Discussion

Our study shows that most carers in Ireland are satisfied with the support they receive from the mental health service. However, a majority have encountered difficulties when attempting to access information resulting in perceived negative consequences. One of the main reasons given by the treating team for this is lack of patient consent.

The results of our study support previous research, showing that carers often feel that their role is undervalued by the medical profession and their needs are overlooked [1, 4-5, 16-18, 24]. The recently published National Carers' Strategy is an important document in recognising the enormous contribution of carers and the vital role they play in our health and social care system. However, the Strategy is weak in some areas, noticeably offering no guarantee to fully protect current income supports and no absolute right to carer assessments. In the UK, the Carers (Recognition and Services) Act 1995 [27], the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004 [28] give carers the legal right to have a separate assessment of their own health and care requirements. Identified needs must then be met with appropriate support and services. Within the Irish policy context there is a noticeable absence of comprehensive assessments of the needs of carers. The movement toward community and family-centred care has brought with it a growing recognition of the need to include an assessment of the carer in the overall assessment of the individual with chronic illness [29, 30]. The Mental Health Reform has stated that there is a duty on the mental health services to assess carers' support needs [31].

Policies in Ireland need to be developed to ensure that the role of carers is recognised. A clear demonstration of this would be the involvement of family representatives in the development of mental health policy-making. Carers should be able to contribute to the design, planning and implementation of mental health services. They should also have

the opportunity to be actively involved in the planning and review of family support and care services.

Government legislation also needs to address the negative financial implications of being a carer. Currently, the Carers Allowance is means tested and worth a maximum of €204 per week [7]. To qualify carers must provide fulltime care. This means that many carers work for much less than the minimum wage.

In addition, strategies to improve support and training services need to be developed. Education and training packages, which teach families and carers about mental illness and its management, help to build coping skills and resilience [32-34]. In Ireland, more resources at a local level need to be allocated to providing support to carers. Involved, supported carers who are able to access the right information and support networks are more effective than carers who are excluded and isolated.

The Recovery Experience Forum of Carers and Users of Services (REFOCUS) has been working with the College of Psychiatry of Ireland to identify ways of improving psychiatric training and the mental health services. The group was established in 2011 and consists of ten service users and ten family members. They aim to improve communication amongst those with psychiatric illness, carers and mental health professionals. A subgroup of the REFOCUS forum recently released a paper looking specifically at the role of the carer [35]. A number of themes were highlighted including the use of patient confidentiality to sometimes justify lack of communication. The paper recommended that a clear discussion on confidentiality and how it can be managed for the particular family should take place at an early stage. Another issue raised related to the need for carer perspective to be incorporated in a structured way into the curricula of trainee psychiatrists and CPD programmes. The College has plans to include members of REFOCUS in the examination process. They also advised that all induction days for trainees should include presentations from carers.

The good practice checklist provided by the Royal College of Psychiatrists specifies that carers should have the right to see a professional on their own and the confidence to voice their views and any concerns they may have [36]. This helps carers to feel like a respected and appreciated member of the treating team. It also affords them the

opportunity to provide information and valuable insight into the mental health of the individual in their care.

Information-sharing is vital and certain aspects of a patient's care could possibly be discussed without explicit consent. A national multi-method study performed in the UK proposed a framework for best practise for information sharing between carers and professionals in the case of a non-consenting service user. They made a distinction between two types of information: General information which can be shared without consent and personal information which is new and specific to the service user and requires consent [37]. Carers may be given information about medication, its effects, evidence of deterioration or regression, and other related material without compromising or revealing communications between the patient and psychiatrist. Confidentiality should not be used as a reason for failing to engage and communicate with carers.

It is hoped that this study will stimulate further research into ways of improving the lives of carers of those with mental illness. Our study looked solely at the attitudes of carers to the mental health service. Further research should be undertaken in order to look at the opinions of Irish mental health professionals in relation to the role of carers.

The main limitation of this study was the low response rate. However, the true response rate is difficult to quantify as questionnaires were mailed arbitrarily to members of the National Service User Executive, meaning that a large number of non-carers were contacted to whom the study was irrelevant. Also, in some cases, respondents may have been members of more than one of the organisations involved and therefore received duplicate copies of the questionnaire. Nonetheless, the total number of respondents (159) represents a large cohort whose views should not be disregarded.

Another limitation of the study is the self-selection of respondents, who may therefore not be representative and may bias the results in one direction or the other. The views of those carers who did not respond to the questionnaire might have been significantly different from those who did participate in the study. The findings may not be generalizable. Therefore, further investigation into the issues from the perspective of carers should be undertaken.

Notwithstanding these limitations, results from this study have identified potentially useful findings about the nature of the relationship between carers and the mental health services. The main strength of this study was that the questionnaire was completed anonymously. Therefore respondents could express their views freely.

Conclusions

Carer involvement is essential for the complete and effective management of individuals with mental illness. Carers require regular contact and information from the treating mental health team in relation to diagnoses, current treatments, availability of community resources, and effective strategies for managing the patient's illness in the community. This is not only crucial for the well-being of the carer themselves but also for the mental health of the individual in their care. Practitioners may feel that legal and ethical principles governing confidentiality prevent them from sharing information with families. However, confidentiality should never be used as a reason for completely excluding carers.

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Table 1. Employment Status of Carers

Employment status	Responses	
	n	%
Employed full-time	30	18.9
Employed part-time	17	10.7
Self-employed	13	8.2
Unemployed	10	6.3
Retired	60	37.7
Student	5	3.1
Unable to work due to caring responsibilities	11	6.9
Unable to work due to ill-health/disability	5	3.1
Other	4	2.5
Missing	4	2.5

Table 2. Psychiatric Diagnoses of those being cared for

Psychiatric Diagnoses	Responses		Per cent of Cases
	n	%	
Dementia	16	8.1%	10.1%
Schizophrenia	94	47.5%	59.5%
Bipolar disorder/manic depression	31	15.7%	19.6%
Depression	30	15.2%	19.0%
Anxiety	13	6.6%	8.2%
other mental health problem	14	7.1%	8.9%
Total	198	100.0%	125.3%

Figure 1. Section B of the Carer Well-Being and Support Questionnaire

Information and advice for carers

In general, how satisfied are you...

1. that you have enough information about the condition/illness of the person you care for to enable you to feel confident in caring for them?
2. that you have enough information about how their condition/illness is likely to develop in the longer-term?
3. that you can get whatever information you need when you need it (e.g. through your doctor or on your own)
4. with how easy it is to understand the information you have?
5. with the amount of advice available to you (e.g. from healthcare workers or other carers)?
6. that you are clear about who to go to for the information and advice you need?
7. that you are clear about who to contact if there is an emergency and you need help right away?
8. that you are clear about who to call if you have a routine inquiry?

Your involvement in treatment and care planning

In general, how satisfied are you with ...

9. your involvement in important decisions (e.g. medication, hospitalisation)?
10. your ability to influence important decisions?

Support from medical and/or care staff

In general, how satisfied are you with...

11. how easy it is to get help and support from staff for the *person you care for* (e.g. to prevent relapse)?
12. how easy it is to get help and support from staff for *yourself* (e.g. advice on how to deal with certain behaviours)
13. the quality of help and support from staff for the *person you care for*?
14. your relationships with key staff who support the *person you care for*?
15. how well the staff you have contact with are communicating with each other (i.e. that they share important information)
16. how seriously staff take what you say to them?
17. the level of understanding staff have of what it must be like to be in your situation?

Note: Respondents were asked to indicate their level of satisfaction based on a four-point scale that includes "very satisfied", "somewhat satisfied", "somewhat dissatisfied" and "very dissatisfied".

Figure 2. Information and Advice for Carers

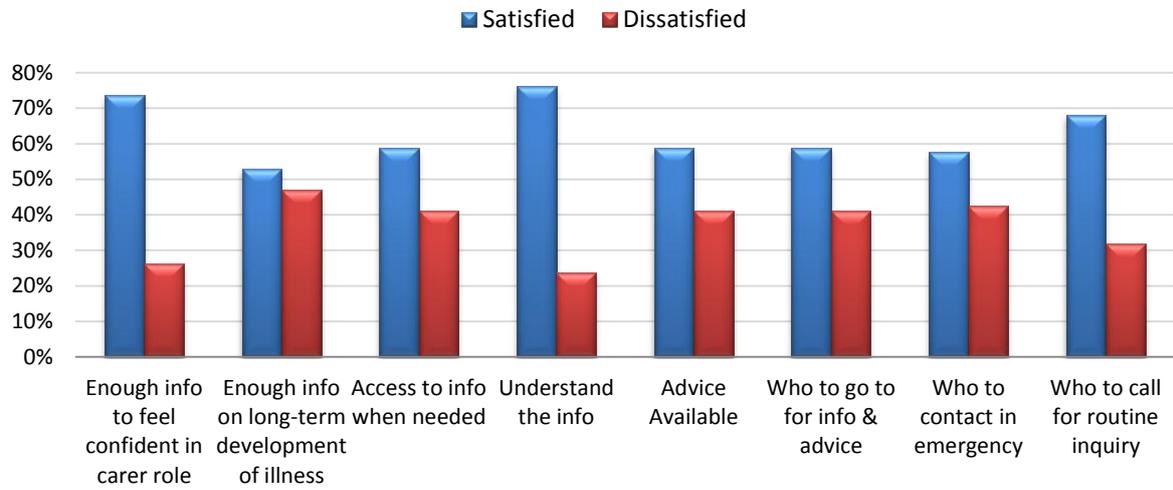


Figure 3. Support from medical and/or care staff

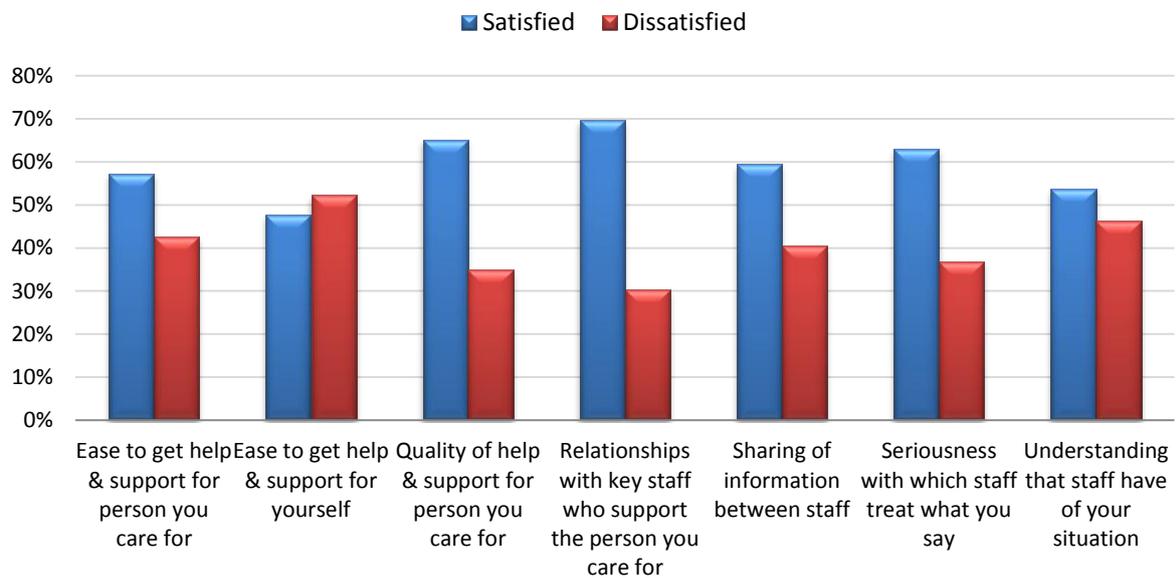


Figure 4. Common Themes Arising in Free Comments Section

