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The impact of patients' chronic disease on family quality of life: an experience from 26 specialties

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Emotional impact

Ninety-two percent of the family members interviewed were affected emotionally by the patient's illness, mentioning worry (35%), frustration (27%), anger (15%), and guilt (14%). Worry was reported when the family members were thinking about the future or the patient's death. Less common psychological effects included feeling upset, annoyed, helpless, stressed, and lonely. Others relied on spiritual and religious input to deal with their emotions.

Twenty percent of the family members found it difficult to find someone to talk to about these feelings. This often resulted in them bottling up their feelings and finding it very difficult to cope, with many describing breaking down in tears when alone.

Several family members found themselves reflecting on what they had done to "deserve" having an unwell family member, developing a "why me?" attitude. One participant whose wife had been diagnosed with lymphoma explained:

You go through sort of like fear, anger the life that you had, you'll never have back because in the back of your mind there's always that worry of "Is it going to come back?"

Daily activities

The negative effect on day-to-day living as a result of having an unwell relative was reported by 91% of the family members. For 38%, this involved aspects of caring, including helping with dressing, personal hygiene needs, assisting with mobility, and providing food. Many reported feeling a burden from caring for the patient, and feeling they had no freedom or time to enjoy their interests. Thirty-five percent reported their hobbies being affected. Forty-seven percent increased the amount of housework they did. The daughter of an elderly patient with osteoporosis described:

I have reverted back to how it was when I was bringing up my children [...] to a certain extent [...] you are housebound [...]. Sometimes I get frustrated that I can't just go out like I once did.

Family relationships

Affected relationships among family members were reported by 69% of participants, with increased stress and tension. Twenty-six percent of family members felt that they had to be with the patient all the time to care for them, leading to them spending too much time with the patient instead of with other family members. This was especially true of patients' mothers who had other well children. Twenty-four percent of family members reported more family arguments. Partners and spouses found the role change to carer challenging, many reporting a negative effect on their sex life. Others reported a decline in their sexual relationship due to the patient's physical condition. A mother hated her diabetic teenage daughter because of the way her illness had affected the family, sometimes wishing her dead. Another said his mother's illness caused his marriage breakdown.

Sleep and health

Sixty-seven percent of participants reported a negative impact on their sleep and health. Sleep loss was caused by worry (32%) and by having to wake to help the patient (38%) for personal hygiene needs or medication. Another reason for sleep loss was feeling the need to wake to check the patient was still alive. Some participants described a decline in their own health: several developed depression. The mother of a teenager with schizoaffective disorder described:

I was living off [...] 2 or 3 hours sleep a night and this was [...] for 18 months and in the end [...] even antidepressants don't help [...] just total anxiety all the time.

Holidays

Problems associated with going on holiday were reported by 62% of family members. The most common was not being able to go on holiday at all (31%) because the patient was too unwell, because of hospital appointments, or worrying about food abroad. The mother of a child with a duplex kidney described:

Getting on a plane where you know your child will disturb other passengers and where she needs the toilet lots [...] up and down the alleyway [...] it's that embarrassment and fear.

Involvement in medical care and support given to family members

Sixty-one percent of the family members described lack of support from friends and other family members. They often felt others did not understand what they were going through and many found it difficult to talk about the patient's illness, through embarrassment or lack of knowledge. Family members needed to remind patients to take medication. Several described being affected by the timing of hospital appointments and not being given enough information about the patient's condition. One family member, whose mother had angina, described:

Half the time people don't want to know [...] I've got [...] brothers and sisters and none of them visit. You feel that they are selfish and they load it all on you.

A few of the family members also talked about how support groups and meeting other family members in similar situations would help them to cope with the impact of the patient's illness. No family members reported having either sought or having received help from professionals such as psychologists or doctors concerning the impact of having a family member with a chronic disease.

Work and study

Fifty-two percent of the family members described how their own work or study was affected. Participants had to take time off work to look after the patient or attend their medical appointments. This caused difficulties with colleagues, and in 9% of cases the family member gave up their job completely. This had a huge financial impact on the families. The husband of a patient with severe depression said:

I just didn't have the time [to work]. There are so many appointments to go to and obviously my wife needed care, it got very difficult to carry on [with work].

Financial impact

The financial impact of disease on the family (reported by 51%) was great. Twenty-six percent reported having to spend money relating to the patient's illness. Areas of financial impact included mobility aids, clothes, transport, holiday insurance, private health care, and the huge impact of the patient or family member giving up work. One family member said:

I gave up a job with very good salary and my husband gave up full time work [...] my parents help us out a lot with money. We couldn't survive without [...].

Social life

Thirty-seven percent of family members reported impacts on their social life (interactions with people, activities, and places) because of lack of money or needing to leave social events early. Eight percent were concerned how strangers would react to their relative's medical condition – especially when visible, eg, skin disease. The wife of a patient with multiple myeloma described:

[...] we used to go out [...] but now we can't do it because with the treatment he doesn't eat properly so [...] why pay all that money if he's not going to eat it [...] and he's lost [...] weight so we don't want people to see him.

Time planning

Fourteen percent of the participants talked about difficulty in being able to plan their time because of attending medical appointments at short notice and the unpredictability of patients' symptoms. Family members also talked about not being able to plan activities in advance, such as holidays and family activities, and complained that they had lost “spontaneity” and “freedom” in their lives. One family member said:

I get really frustrated and a bit angry, it's very unfair of me but I don't seem to be able to plan anything anymore. You know, if someone says “Would you like to come?” and I say “I'll let you know”, because I know damn well that I'll probably have to let them down if I say I'm going.

Positive effects

As well as the negative effects, a small number of positive effects were also identified by family members during the interviews. Thirteen percent of the family member's interviews managed to identify one positive effect of the patient's illness on their life, and these positive effects were only identified under the “Emotional impact” and “Family relationships” themes. In these positive

examples, family members described relationships within the family improving as a result of the patient's illness, with members of the family pulling together to support each other. One family member said:

I suppose it's making our relationship stronger "cause it's making us work through things."

Other family members described overcoming the personal "challenge" of the patient's illness and making them realize how precious their own life is.

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Discussion

The impact of a patients' illness on families is widespread and profound. Family members are affected in multiple ways across all medical specialties. This study has identified the major ways in which family lives can be affected by disease and the commonality of issues across all diseases. This is the first study to identify the similar experiences of family members of patients across the whole of medicine, and the unique findings are relevant to all health care professionals, because all health care professionals who interact directly with patients, whether they realize it or not, are impacting on a close social network involving the family members of each patient. The effect of individual patients' disease on the quality of life of their family members may have major implications on the quality of care and concordance with treatment that the patient receives. In addition, the health care worker arguably may have some responsibility for understanding the impact that the patient's condition is having on their family members, and may be in an ideal position to advise the family member how to seek appropriate support. Even in those specialties where family members are least affected, they still reported being affected by three of the ten themes, demonstrating that the family impact of disease needs to be considered and addressed in all areas of

medicine. Over one-third of the family members reported having to provide care to the patient, although they were not asked whether they were the primary caregiver. Whether or not the patients required family members to provide care, the lives of the family members may still have been affected. Many participants said how grateful they were to talk about the subject, that they had never been asked about it before, and voiced the lack of support they had received in dealing with the effects of the patient's illness.

Family members of patients from all specialties felt a great emotional impact, the most widely previously reported topic.¹² They often felt they had to hide their feelings from the patient in order to provide support – for many this was very difficult. This emotional impact has a major influence on many areas of their lives, eg, on health^{13,14} and sleep. Family members of patients can be more emotionally affected than the patients themselves, particularly in the area of oncology.¹⁵ This may be because attention is mainly focused on the patient and much consideration given to the patient's needs. In contrast, the family member and their concerns are usually ignored or not understood.

The impact of illness on family relationships was extensively described by participants. Optimal chronic disease management depends on good family relationships, but often family members do not know how to emotionally support each other.¹⁶ Partners of patients described the negative impact that the patient's condition can have on their sex life.^{1,17–19} The difficulties faced due to the changing role of the family member in the patient's life have also been reported in a previous study with family members of patients with multiple sclerosis.²⁰

The impact on family finances and employment were major issues. Family members described the financial impact of having to reduce or give up work as a result of the patient's illness, often compounded by the patient also giving up work. Looking after an unwell patient is

expensive.^{21–23} If the 9% of the family members in this study who gave up work was representative, this represents many potentially unemployed. Family members claim carer benefits as they find it difficult to access alternative funding.^{24,25} With adequate social support some of these family members might have been able to continue working. Many of the financial issues reported by family members in this study were similar to those found in a previous study with family members of children with chronic disease,²⁶ including reporting the increased cost of food items and employment problems.

Family members described their own existing medical conditions worsening and several developed depression. This study identifies family members as a hidden “patient” group, with an apparent “ripple effect” of illness; one patient being unwell has the potential to create several more “patients” in the family.²⁷ This can then magnify problems with finances and family relationships, in a vicious cycle. This hidden burden has a potentially huge financial impact on the health care system that could potentially be reduced by appropriate family support.

Patients suffering from more than one medical condition were not excluded from the study as it was felt that including patients with comorbidities would more closely reflect reality. The interviewer found it easy to focus the participant on the effects of the principal diagnosis – any extra information added to the richness and variety of the data.

Although this study focuses on the negative impact on family members’ lives, many participants also described positive effects. Some family members felt closer to the patient through supporting each other in difficult times, and others described making more effort to spend time as a family.²¹ However, these positive effects did not outweigh the huge burdens felt by family members, and many could not identify any positive effects.

Several major areas have been identified where further support is needed for family members. Clinicians should assess the potential impact of decisions on the patient's family, thinking of the ten main themes identified. For example, which treatment course would cause a greater burden to family members? Could a patient's low mood be the result of strained family relationships due to their disease? Does the patient's family need a financial support assessment? With the patient's consent, the clinician should ideally involve the family in discussions about management.¹ Support services for family members should be established to address their problems, ideally with family members themselves identifying and evaluating the services required.²⁸ This study provides evidence for the need for support, particularly emotional support – the area in which family members are affected to the greatest extent. Family support groups for patients with a variety of diseases might be effective as the ways that families are affected are similar across the whole of medicine. Such support might ease the emotional impact on family members, protect their health, and improve family relationships. The results of this study could be used in clinical consultations and to aid the design of family support services and educational programs.

There were limitations to this study. The majority of participants were White British. It is possible that culture and ethnicity could influence the way family members are affected by illness, and some themes could be of greater importance to specific cultural groups. This could be determined by further sampling family members of patients from different ethnic backgrounds. Another limitation is that the range of medical conditions from each specialty was not represented fully. However, physicians were asked to select patients with different conditions best representing their specialty. This expert knowledge and the large total number of interviews carried out beyond the saturation point helped to ensure a representative sample. This study did not consider whether the effects on different family members are

similar; this could be addressed in the future by interviewing more than one family member of each patient.

The coding was carried out by one individual: although using only one coder could be considered a significant limitation, there was regular and active involvement of the other members of the study team during all stages of the coding. Although one individual named the themes (this individual carried out the interviews and so had the greatest understanding of the interview content and played a leading role), the team then met to discuss the naming and definitions of the themes and how they would be interpreted during the coding. In addition, extra efforts were put into place to reduce coder bias: team members listened to a selection of interview recordings, the team met regularly to discuss the naming and definitions of the themes and codes in great detail, and coding was cross-validated manually and using NVivo software.

Sample selection could have introduced some bias. For example, relatives of perceived more compliant patients may have been selected in preference to distressed patients. However, the 26 different recruiting times were likely to have different biases, which may have mitigated against this. In addition, saturation was reached at interview number 40; the rest of the 93 interviews revealed no new themes. Therefore, it is most unlikely that any themes were missed even if there were selection biases. The huge range of different specialties and diseases covered also makes any impact of selection bias much smaller.

The results of this study could be used to inform the development of a larger scale study to draw direct comparisons between the impact of illness on family members across different specialties or different groups of family members. Future studies could determine whether these results are applicable to family members across different cultures. The possibility that unique themes such as dealing with possible death of the patient may be relevant to family members of

specific disease populations could be assessed in future disease-specific studies. Although the key areas of family quality of life have been identified by this study, there is still no established method to measure these for research purposes or for families in clinical settings. The development of a generic family quality of life measure would allow the appropriate assessment of the effect of interventions designed to improve family quality of life.

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Conclusion

This multi-specialty study has demonstrated the huge, yet similar, impacts that illness can have on the quality of life of family members of patients. Family quality of life is a previously neglected critical area of health care that needs to be addressed by all health care professionals in order to provide appropriate support for both patients and family members.

Approximately 35.3 million Americans, young and old, are limited in their daily functioning because of a chronic mental health or physical health condition. For the vast majority of these individuals, family is their first line of healthcare. Whether the member is a child with cystic fibrosis or an adolescent with diabetes, or a parent with multiple sclerosis or a grandparent with Alzheimer's disease, it is the family, first and foremost, that cares for an ill loved one.

One member's chronic illness influences the lives of everyone in the family. Roles and routines change. It may seem as if the medical professionals that care for the ill family member become part of the family. The demands of caregiving must be negotiated. Family members' emotions may be on a continuous roller-coaster ride. On the other hand, families may come together and grow closer. Their lives may take on new meaning. They may find rewards they had not expected on their journey through illness. The only certain thing is that chronic illness is a family experience that is shared by all.

How can chronic illness affect the family?

There are several ways that chronic illness can influence family life:

- Daily routines may change because the limitations of the ill member and the demands of treatment may require that others be more available.

- Families may need to share caregiving responsibilities; this helps all members feel they are contributing to a loved one's welfare and it also protects any single member from caregiver fatigue.
- Family members may experience strong emotions, such as guilt, anger, sadness, fear, anxiety and depressed mood. These are normal reactions to stress. It is useful to talk about these emotions within the family.
- The ill member may need to find ways to be as independent as possible, given the limitations that the illness causes.
- Despite the demands of the illness, families may need to work hard to maintain a sense of "normal" life. This can benefit the ill member, as well; it may help him or her integrate into family life more and may reduce the ill member's sense of guilt regarding the demands the illness places on the family as a whole.

When should the family seek help?

At any time during the life of a chronic illness, family members or the family as a whole may need support from a trained professional, such as a Marriage and Family Therapist (MFT). Signs to watch for include: In any of these circumstances, the family's primary care provider can act as a resource for referring the family to a family therapist who is experienced with illness and collaboration with medical professionals.

What kinds of interventions are common?

Family Therapy