

Reference

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Abstract

Purpose. Because symptoms are not immediately visible to others, systemic lupus erythematosus (SLE) is often considered an invisible illness. This invisibility can reduce the social support received from network members and adversely affect the quality of life. In the light of this, social support from formal support groups and from medical professionals can be particularly important; however, literature examining support from these sources is scarce. The purpose of this study was to explore the nature and impact of social support from medical professionals and from support groups for individuals with SLE.

Methods. Participants responded to open-ended questions on an online survey administered by Lupus UK and Lupus Group Ireland. Qualitative data from 133 participants (77 % of respondents) were analysed.

Results. Thematic analysis revealed three overarching themes: invisibility, inadequate care, and validation. Respondents felt that their SLE was invisible to social ties and to medical professionals. In addition, treatment and organisational factors in health care contributed to the sense of inadequate care. Finally, validation was derived from informational and emotional support from both support groups, and from some medical professionals.

Conclusions. The findings suggest that individuals with SLE have mixed experiences in terms of contact with medical professionals and involvement with support groups. Furthermore, low public awareness of lupus appears to contribute to feelings of invisibility for patients, leading to loneliness and isolation. Medical professionals might benefit from skills training in terms of managing the psychosocial consequences of lupus.

Keywords. Social support Quality of life Illness Lupus Qualitative Thematic analysis

Systemic lupus erythematosus (SLE) is a complex autoimmune disease of unknown aetiology. Some individuals with SLE experience symptoms including fatigue, fever, and joint pain continually, while others have periods of flares (where symptoms are active) and of remission, where symptoms are less active or under medical control. Because SLE can involve symptoms that are not physically evident to others (e.g., fatigue), it has been described as an “invisible illness” [1], sufferers are vulnerable to negative reactions such as disbelief [2] and unwanted or ineffective social support [3, 4] from social network members. Social support has been defined as “information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligations” [5]. Timely, appropriate, and effective (i.e., high quality) support can have direct and indirect effects on health. For example, support can facilitate positive health behaviours (e.g., medication adherence) [6], and according to the *stress-buffering model* [7], can enhance perceived coping resources, reducing the impact of stress. As such, understanding the social support experiences of individuals with SLE is critical to inform patient care.

Evidence suggests that social support is associated with improved mental health and in some instances, physical function, in SLE [8]. Although support can be beneficial, qualitative and quantitative studies demonstrate that sufferers report dissatisfaction with support both from medical professionals and from their wider social network [9]. For example, Mazzoni and Cicognani [4] found that SLE patients experienced *problematic* support. This incorporated three dimensions; well-intended support that is ineffective because it is focused on the illness, support provided by ties who consider the diagnosis fictitious, and support based on incorrect understanding of SLE. The researchers concluded that patients, even when appreciating others’ supportive intent, can experience deficiencies in support that might be detrimental to quality of life (QoL).

In addition to support from spouses/partners, family and friends, individuals can derive benefit from supportive interactions with medical professionals [10], and/or from membership in formal support groups; however, data on support from these sources is sparse. In one study conducted in the Republic of Ireland, Corcoran [11] reported that patients would benefit from more regional support groups and increased awareness of SLE within the community, as this would assist in tackling problems of understanding, frequently encountered by individuals with SLE. However, besides this, no study has examined formal support groups as sources of potentially beneficial support for individuals with SLE, despite the likelihood that access to support groups has likely improved since Corcoran's study was conducted. Firstly, new support organisations have been founded (e.g., Lupus Group Ireland [2011]), and secondly, the use of social media to facilitate support networks for coping with illness has increased [12].

To address this gap, this study explores perceptions of the quality and the impact of social support for individuals with SLE, with a particular focus on support from (a) medical professionals, and (b) formal support groups.

Methods

Recruitment and Participants

The final open-ended survey questions (Table 1) were administered in an online survey format. These were developed by the authors to address aspects of social support highlighted in the literature as important (i.e., from the medical profession, and from support groups), but that are not captured by well-used psychometric measures of social support in everyday life. Participants were recruited through a study link distributed by Lupus Group Ireland and Lupus UK. The inclusion criteria were: aged 18 and over with a diagnosis of

Lupus; there were no other inclusion/exclusion criteria. Of 172 respondents, 133 (77%) provided qualitative data and were included in the thematic analysis. Over half (54.13%) reported currently experiencing SLE symptoms, 39.85% reported being in remission, and the remainder did not specify their current disease status. Participants modal age range was 45-54 years; the majority ($n = 95$) were resident in Great Britain, 30 were resident in the Republic of Ireland, with the remainder from Northern Ireland (1), South Africa (1), Portugal (1), and the U.S. (2), or did not provide their place of residence (3). Approximately 70% ($n = 93$) of participants reported membership of a support group. Ethical approval was granted by the University of Limerick's Faculty of Education and Health Sciences Research Ethics Committee.

Data Analysis

Thematic analysis was performed in line with Braun and Clarke's [13] guidelines. The nature, meaning, and impact of support for individuals with lupus were concepts that guided the interpretation of the data. Prior to analysis, a theme was said to consist of a recurring aspect throughout the data that represented an important feature of the participants' experiences. The first step in analysis was becoming familiar with the data. Responses were initially reviewed by the first author, and discussed with the second author. Preliminary codes were extracted by the first author; both authors then independently reviewed the transcripts with codes and emergent themes discussed to ensure reliability. Themes were reviewed to identify potential overlap and to ensure all relevant information was included. Themes were finalized based on agreement that these were important in the data and sufficiently distinct as to merit inclusion as different themes. A title was given to each theme to provide a concise representation of its contents. Direct quotations were then identified from the responses which illustrated each theme. Although the frequency with which each theme occurred is

reported quantitatively, it should also be acknowledged that how often a theme is expressed cannot necessarily be taken as a reliable measure of how prevalent or important that view is in the target population [14].

Table 1

Table 2

Results

Three overarching themes were identified, *invisibility*, *inadequate care*, and *validation* (Table 3). Although distinct, themes were also inter-related. Generally, the positive experience of validation (via emotional and informational support from support groups and medical professionals) buffered the negative experience of invisibility buffered the sense of invisibility, but validation was important regardless of this buffering effect. Invisibility also contributed to the sense of inadequate care. Figure 1 provides an overview of the interrelationships between the three themes.

Theme a: Invisibility

Most participants indicated that the invisible nature of SLE profoundly affected social support and supportive outlets. Participants expressed a lack of understanding of SLE by not only the general public and employers, but by family and friends also. Some respondents

referred directly to the “invisible” nature of SLE. Others indirectly noted that looking physically “normal” meant that family, friends, employers, and members of the public responded negatively or disbelievingly to mention of their diagnosis. Respondents felt psychologically invalidated by these reactions and expressed reluctance to be perceived as a “moaner” or someone who “always has some kind of problem”.

“On the outside people think you look well and healthy. Rosy red cheeks, a picture of health. The lack of understanding, consideration, often criticism from non-sufferers means most lupus individuals feel alone, painful, ill and demoralised.”

(England, 45-54)

“...People always say 'you look well', invalidating how you feel, in just one statement.”

(Scotland, 45-54 years)

“More awareness of the condition would be helpful as I really feel family and friends don't understand.”

(Ireland, 35-44 years)

This invisibility caused many respondents to feel lonely and despondent. Some explicitly referred to feeling alone in their illness, with others referring to past feelings of loneliness, or loneliness alleviated by support groups. In some cases, loneliness was attributed directly to the invisible nature of SLE, in that social network members simply could not understand the impact of unseen symptoms and thus failed to provide meaningful support or sympathy to the SLE patient. In other instances, loneliness resulted simply from

not knowing another person or knowing *of* another person with SLE. The perceived lack of understanding from social network members extended to medical professionals, particularly general practitioners (GPs). There was a sense that GPs do not have the specialist knowledge to diagnose or adequately treat lupus, exacerbating respondents' sense of isolation.

“...GP's don't know enough about lupus to help me... I feel very alone living with lupus... it takes a lot to get through every day.”

(Scotland, 35-44 years)

This overarching sense of invisibility and consequent loneliness was echoed by suggestions that enhanced public awareness of SLE would be beneficial. Many participants advocated increasing awareness of lupus to improve the support obtained from social network members, and to improve understanding from the general public, employers, and non-expert medical professionals.

“Social support could be improved for lupus sufferers via a general awareness raising campaign. One of the problems many sufferers refer to is the fact that most people have never heard of SLE, if they have they have limited knowledge which is also often misinformed and results in people commenting you look well , or you don't look ill...”

(England, 45-54 years)

Although some participants reported frustration, guilt, worry, and fear, these emotions were not consistently observed across respondents.

Theme b: Inadequate care

The second overarching theme was *inadequate care*. Respondents overwhelmingly felt that deficiencies in support left individuals with SLE with inadequate support, particularly in terms of medical care. Dissatisfaction with medical care was observed for several reasons, broadly discussed here as *treatment factors*, and *organisational factors*. In addition, a minority of respondents identified inadequacies in support group services that contributed to the sense of inadequate care (*support group factors*).

Treatment Factors

Treatment factors refers to factors directly related to the experience of being treated by the physician, including the quality of communication, feelings about treatment, and support (informational or emotional) received during appointments. Respondents expressed a wish to be treated as a person, rather than in terms of a set of overt physical symptoms. Many reported that subjective symptoms (e.g., fatigue) were not recognised although these were considered particularly impactful by the patient. Because of this, key components of the person's experience with SLE were effectively unseen by the professionals charged with helping alleviate symptoms of SLE. In some cases, respondents reported difficulty adequately conveying symptoms to medics during periods of remission, and felt that this compromised the quality of discussions around treatment. Respondents experiencing a flare reported similar difficulties, observing that symptoms experienced between visits might no longer be present at the time of the appointment. In addition, there was a sense that physicians tended to dismiss all health problems as being lupus-related, or conversely, attribute any potential variation in lupus symptoms to comorbid conditions (e.g., rheumatoid arthritis).

“Consultants are only interested in bloods not symptoms and as long as there's no organ damage they don't seem to care...”

(England, 45-54 years)

“I feel the medical professionals don't listen to me or don't believe all the problems I have related to Lupus. I usually come out of a consultation feeling very deflated and depressed.”

(Ireland, 55-64 years)

“... It would also be beneficial if medical professionals didn't let their frustration and lack of knowledge filter through to the patient in a 'just deal with it' manner.”

(England, 25-34)

Organisational Factors

Organisational aspects of medical care also contributed to the perception of inadequate care within the health service. Many respondents reported insufficient consultation time, insufficient, cancelled, or postponed appointments, lack of follow-up information when medical tests were conducted, and disjointed care involving a revolving series of medical professionals with no central communication between them. In general, organisational factors contributed to the perception that the impact of SLE on the patient was not recognized.

“I think the consultants are so stressed for time with their patients that this affects the care you are given...”

(Scotland, 45-54 years)

“Current rheumatologist says he is unable to do anything for me as I have been 'over-medicated' in the past - he is content to let my renal consultant deal with my problems, however, the renal cons. admits to knowing the bare minimum about lupus, and so refers me back to the rheum. consultant, and so it goes round in circles...”

(England, 45-54 years)

Because there was little continuity in terms of the doctor patients were seen by, patients believed that their medical history was not known in its entirety and felt that they were not receiving comprehensive care. Rescheduled appointments were particularly problematic and impeded everyday function when individuals required new prescriptions, for example. Worryingly, a small number of respondents reported that persistently negative experiences with the health care system lead them to discontinue treatment appointments.

Support Group Factors

This sense of inadequacy also emerged in relation to support groups. Although support groups were described as sources of informational and emotional support, this perception was not universal. Two issues raised were (1) excessive rumination about symptoms, and (2) medical advice dispensed by fellow sufferers who are not medical experts. Although these were raised by a minority of respondents, this theme was recurrent within these responses.

“I do not feel it [support group] has been very useful to me. People tend to go on about symptoms and complain about support available it should be more positive and forward thinking.”

(England, 45-54 years)

This is consistent with perspectives on support as a “mixed blessing”⁽¹²⁾, and suggests that formal support groups can inadvertently facilitate patients focusing on negative aspects of their illness.

Theme c: Validation

The final overarching theme was a sense of validation. Specifically, validation of the diagnosis and its symptoms was experienced through positive and supportive interactions with medical professionals, and through involvement with support groups,

In relation to medical care, some respondents praised the care received, particularly from their rheumatologist and from nurses. Respondents indicated that medical appointments were potential sources of support, information, and validation, and were viewed as opportunities to ask questions and to understand the reasoning behind changes in treatment.

“Having an opportunity to clarify and understand my diagnosis. Feeling that my symptoms have been validated. It is easy to feel that you are a fraud when there are no clear physical signs...”

(Scotland, 45-54 years)

In cases where medical appointments were not perceived as helpful in terms of treating lupus, there was an acknowledgement that the monitoring of lupus symptoms or of medication was also important and reassuring.

“I see a brilliant consultant who is very supportive. He doesn't just look at my blood results and respond accordingly, but also looks at how things like pain and fatigue are affecting me on a daily basis and adjusts my treatment accordingly. I feel that I can talk to him about how I am feeling and he takes time to listen to me. I know I am very lucky to have a Rheumatologist like this!!”

(England, 25-34 years)

Over one-quarter of respondents who were somewhat satisfied with medical support also reported dissatisfaction with some aspects (e.g., positive interactions with rheumatologist, but disbelief from GP). On a positive note, the remainder indicating they were satisfied with support reported no negative feedback.

Informational support was also derived from support groups. Specifically, lupus groups and online forums were viewed as sources of factual information on symptoms, medication, new research, and lupus-related issues, as well as informal advice from other members.

“...our local Lupus group organises talks by medical Lupus experts where we can find out about latest research and ask questions.”

(England, 45-54 years)

Although informational support was important in terms of validating the SLE diagnosis, emotional support was more commonly acknowledged as beneficial. Respondents indicated that support group membership reduced the sense of isolation they experienced, and identified the feeling of being understood by others going through the same challenges. Some respondents also found benefit in providing support to others.

“A problem shared is a problem halved. There is also a positive feeling that comes from extending compassion to another.”

(England, 45-54 years)

The majority of respondents finding benefit in support group membership reported deriving both informational and emotional support from lupus groups. Simply feeling supported helped individuals feel that the impact of their symptoms was important and validated their experiences of SLE.

“Advice from other people with lupus helps me to feel more in control. I can get quick advice about symptoms that helps me to remain calm and not over worry. The emotional side if [sic] the support is invaluable as only others with lupus can fully understand what it is like to have lupus.”

(England, 45-54 years)

“I know I’m not alone, that I’m not mad, I had all these symptoms that no one could see and I thought I was dying. With Lupus Group Ireland I can read that others are like me and I can ask questions or answer questions.”

(Ireland, 35-44)

Communicating with others in the support group provided reassurance, validation, and a sense of being part of a community undergoing a shared experience.

Thus, individuals with SLE experience invisibility and inadequate care as a result of poor support and also derive a sense of validation from positive social support.

Figure 1 shows how disbelief from social network members and limited knowledge

about SLE contribute to feelings of invisibility, which in turn leads to feelings of loneliness, and a desire for greater public awareness of SLE. Treatment and organisational factors, and negative experiences with support groups, contribute to the sense that care for SLE is inadequate. This theme captures the experience of inadequate care independent of the experience of invisibility; however, these themes are inter-related in that experiences of inadequate care are likely influenced in part by perceptions that SLE symptoms are unseen by medical professionals. Finally, informational and emotional support from both support groups and medical providers contributes to a sense of validation, as patients feel their diagnosis and symptoms, and the impact of these symptoms on QoL, is acknowledged and understood.

Table 3

Figure 1

Discussion

The present study analysed qualitative data provided by 133 individuals with lupus, the majority residing in Ireland and the U.K. The findings provide evidence on which to base discussion of challenges faced by individuals with lupus in terms of social support, particularly from medical professionals and from formal support groups.

A key theme that emerged from the analysis was the experience of invisibility as a result of unseen symptoms of SLE. Consistent with prior work on chronic and invisible illness [16], this invisibility generally had detrimental effects on adjustment; in particular, resulting in feelings of loneliness. Individuals with SLE can feel alone and isolated and

negative responses to their diagnosis such as disbelief, or minimizing the problem, might deter them from disclosing or seeking support from others in their social network. Critically, this perception of invisibility was not confined to friends, family, relatives, and the general public. Some respondents suggested that the lack of visible symptoms resulted in negative reactions from GPs. These findings coincide with those of Corcoran [11], who found that low levels of public awareness of lupus creates difficulties for patients in all aspects of their lives. The present findings suggest that the same difficulties remain for patients, some years later. Improving awareness of SLE in the general population, and also, for general practitioners or non-specialist treatment providers might have benefits for SLE patients. In particular, increasing awareness of the subjective symptoms of lupus could help patients feel that their illness is understood by those involved in SLE treatment.

In general, the findings suggest that lupus support groups are a potentially valuable source of informational and emotional support, two forms of support observed as common in other studies of support groups for physical illness [17]. In particular, support groups helped buffer the feelings of isolation brought on by a lack of understanding from patients' other social connections, and thus may especially aid *emotion*-focused coping [18]. However, consistent with the view of support as a "double-edged sword" [19], and theoretical work indicating that the *match* between social support and the recipient's needs is important, the findings also indicate that formal support groups are not necessarily beneficial for all individuals. Some respondents perceived discussion of symptoms as ruminative, while others queried the accuracy of advice dispensed by group members. A few observed that reading about the experiences of others made them feel guilty in cases where their own experiences were less severe, or depressed when their own experiences were perceived as less positive. For these individuals, it seems clear that formal support groups might not be advantageous, reflecting research that has found mixed results for formal support interventions [20]. This

also suggests that social comparison models may be helpful in understanding how support groups can influence QoL, for better or for worse. For example, positively interpreted downward comparison with peers has the potential to improve QoL, while engaging in persistent social comparison can be damaging to QoL [21]. The findings also highlight the possibility that support group discussions on symptoms might reinforce ruminative behaviours and negatively influence QoL. Nonetheless, the majority of respondents derived benefit and validation from involvement in support groups. Indeed, it seems possible that support from support groups might partially compensate for the difficulties SLE patients can have with the social connections that provide support in other circumstances. Because support can increasingly be provided online rather than face-to-face, maximizing positive engagement with online support groups may alleviate the sense of isolation experienced by SLE patients, and thus improve QoL.

In relation to support from physicians, respondents were more likely to report dissatisfaction rather than satisfaction. In particular, the fact that many respondents expressed dissatisfaction with GPs' knowledge of lupus suggests that GPs themselves might have difficulty delivering high-quality care for "invisible" illness that have non-specific symptoms and can be difficult to diagnose. Nonetheless, some respondents were satisfied (and not *dissatisfied*) with the supportive aspects of care they received, suggesting that some treatment providers might be particularly successful in conveying empathy to their SLE patients. Dissatisfaction often stemmed from the perception that physicians were uninterested in subjective symptoms. Therefore, medical professionals might benefit from skills training in terms of managing the psycho-social consequences of lupus. Explicitly acknowledging the less observable impact of SLE and the fact that symptoms can fluctuate over the course of the illness might be one step physicians can take towards improving the quality of interactions with SLE patients.

Limitations

The present study included open-ended questions specifically in relation to social support, and as such, the data are not intended to capture the spectrum of experiences in relation to lupus. In addition, participants were recruited via mailing lists and social media managed by formal support groups in Ireland and the U.K. Therefore, it is possible that the sample over-represents individuals who engage with formal support groups. Nonetheless, as the findings regarding the benefits of support groups were somewhat mixed, the recruited sample represents both positive and negative perspectives. Furthermore, few participants provided data on sex prohibiting consideration of sex in the present analyses (though all respondents providing these data were women, reflecting established rates of SLE [22]). Additional work could consider demographic factors potentially important to the experience of social support (e.g., sex, or race, for which SLE incidence also varies [22]). Finally, although the utility of qualitative data obtained via online surveys has been established [23], the findings might be complemented by semi-structured interviews or focus groups to deepen understanding of the themes observed here. However, to facilitate the discussion of potentially sensitive issues, and because we wanted to obtain data from a large number of individuals and from a geographically-dispersed population, we chose to administer our items online. For this reason also, self-reported SLE diagnoses could not be verified by medical records. Although this study focused on lupus, further research might also consider the potential impact of multi-morbidity in individuals with SLE.

Future Research

The relatively greater satisfaction with informational support received from support groups than from medical teams suggests that additional research on optimal patient-provider

communication about lupus is warranted. For example, researchers [24] have identified practices linked to lower anxiety and depression in cancer patients that resonate with the experiences of the individuals in this study. These practices include providing written information; presenting the information clearly; talking about the patient's feelings; discussing the severity of the situation and how the cancer might affect other aspects of life; and encouraging the patient to be involved in treatment decisions. The findings of this study suggest that these practices are not part of the experiences of many individuals with lupus, and incorporating these into the treatment of SLE and other invisible illness could improve QoL.

Because the responses of social ties were also identified as potentially supportive or negative, additional research should examine how SLE patients disclose their illness to others. According to Joachim and Acorn's [25] theoretical model, patients with invisible chronic conditions can choose not to disclose their illness, or to engage in *protective*, *spontaneous*, or *preventive* disclosure. The latter involves both concealment and disclosure and is considered an appropriate strategy for individuals with an invisible condition that is not under their control. Individuals who practice this are thought to be motivated to avoid stigma or influence the social judgement of others through disclosure, as well as eliciting support, if needed. Relatedly, researchers [4] have suggested that SLE patients themselves are fundamental to the elicitation of positive social support, since patients represent the first source of information about their illness. However, little work has tested whether engaging in preventive disclosure does, in fact, have meaningful benefits for patients with chronic, invisible illnesses. Enabling SLE patients to elicit appropriate support might benefit QoL. Moreover, this is consistent with Street Jnr et al.'s idea of clinicians as moderators of support from other ties [10].

Finally, as involvement in formal support groups was often advantageous for SLE patients, it seems possible that involvement might compensate for lack of support in other domains. For example, Helgeson et al. [26] reported that peer discussion groups were beneficial for women with breast cancer who lacked support from partners or physicians, but were harmful for those with high levels of support. To date, no study has empirically tested whether support group involvement can compensate for support deficits in other domains, for individuals with invisible illnesses. This seems theoretically likely and especially relevant to individuals with invisible illnesses like SLE, and is thus an important avenue for additional research.

Compliance with Ethical Standards:

Conflict of Interest: The authors have no conflict of interest.

This study was conducted in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

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Table 1. *Open-ended questions for which data were analysed.*

1.	Please describe what is (un)helpful or (un)supportive about these visits [to medical professionals].
2.	If yes [to “are you a member of a Lupus support group?”] how has this been beneficial (if it has been beneficial)?
3.	Other than family and friends have you found any other sources of support helpful to you regarding Lupus?
4.	How do you think social support could be improved for individuals with Lupus?
5.	Are there any other comments about your experience with Lupus that you think would be important for researchers to know?

Table 2. Participant characteristics ($N = 133$)

Country of origin	Ireland	22.55% (30)
	England	60.15% (80)
	Scotland	4.51% (6)
	Wales	6.77 % (9)
	Other	3.76% (5)
	Not specified	2.26% (3)
Age group	18-24 years	8.27% (11)
	25-34 years	17.29% (23)
	35-44 years	28.57% (38)
	45-54 years	39.32% (39)
	55-64 years	13.53% (18)
	65+ years	3.01% (4)
Disease status	Flare	54.13% (72)
	Remission	39.85% (53)
	Not specified	6.01% (8)
Current member of support group	Yes	69.96% (93)
	No	30.07% (40)

Table 3. *Overview of themes from thematic analysis.*

Example of codes for each theme	Sample quotations representing each theme	No. participants who reported the theme
<p>Theme a: Invisibility</p> <p>Invisible, unseen symptoms, looking healthy, perception of lack of awareness of lupus.</p>	<p>“On the outside people think you look well and healthy. Rosy red cheeks, a picture of health. The lack of understanding, consideration, often criticism from non sufferers means most lupus individuals feel alone, painful, ill and demoralised.”</p>	<p>65</p>
<p>Theme b: Inadequate care</p> <p>Treating condition not person, treating overt indicators not symptoms, disjointed care (inconsistent treatment providers; rescheduled appointments), rumination, poor medical advice from support groups.</p>	<p>“I have to visit a specialist hospital in London to deal with my lungs which is inconvenient. It also feels as though they are only interested in one part of me and never look at my conditions altogether and me as a whole.”</p>	<p>73</p>
<p>Theme c: Validation</p> <p>Information, advice, understanding, sharing, validation, enjoying good quality relationship with treatment provider(s), reassurance, acknowledgement of symptoms and/or diagnosis.</p>	<p>“It makes a positive difference to be able to talk to people who actually understand how I feel.”</p>	<p>97</p>

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