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First-Time Primary Caregivers' Experience of Caring for Young Adults With First-Episode Psychosis

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Becoming a carer is associated with physical, emotional, and financial hardship, with caregivers often experiencing a maelstrom of emotions as they struggle to understand what has happened to their loved one. While the burden of caring for young people with first-episode psychosis (FEP) has been well documented, much less is known about how carers develop the strength and resilience to continue caring. This qualitative study aimed to understand the experience of 20 first-time primary caregivers of young adults with FEP. Most caregivers were female (85%, $n = 17$) and parents (85%, $n = 17$). The average length of involvement as a caregiver at an FEP service was 14.5 months. Six main themes were identified in the data, highlighting the carers' experience in supporting young adults with FEP. Caregiving is a burdensome responsibility and is characterized as a roller coaster and unpredictable experience. Caregivers often feel responsible for the young person's illness; however, eventually most come to terms with the changes that have occurred in the young person with FEP. As a consequence of the illness, the relationship between caregiver and care recipient frequently becomes closer and deeper, although it is important that they both maintain hope for the future. These findings provide important insights into the experiences of first-time caregivers of young people with FEP, with direct implications for improving the information and support given to caregivers by FEP services, as well as the development of interventions that effectively address the unique challenges caregivers face following the onset of FEP.

Key words: experience/first-episode psychosis/hope/interpretative phenomenological analysis/primary caregivers/qualitative

Background

The symptoms of first-episode psychosis (FEP), coupled with the associated stigma, mean that caregivers are likely to be distressed, confused, and anxious.[1,2] Parents of affected young people in particular face considerable challenges as they struggle to become carers as well as parents, while trying to maintain the well-being of the family unit.[3] They become responsible again for tasks, such as laundry and shopping, that they had relinquished as their child reached adulthood[4] and are often the first to provide emotional and physical "first aid" in the event of an acute psychotic episode.[5] At the same time, they must learn to advocate effectively to ensure that the young person and the family receive the treatment and services they need, while also trying to respect their child's confidentiality and autonomy.[3,5]

Apart from the physical and emotional burden of providing care, caregivers may also experience financial hardship. The direct costs of treatment can be considerable and may not be covered by public funding or medical insurance. As a result, caregivers may have to defer retirement or sell assets. Others may need to give up paid work or reduce hours worked because of the demands of caring, while facing the added costs of an adult child living at home.[4–6]

Caregivers experience a maelstrom of emotions as they struggle to understand what has happened to their loved one. Feelings of helplessness and loss of control are common.[6,7] Parents experience guilt and blame themselves for their child's illness, seeing it as a sign of genetic weakness or poor parenting.[6,7] Others regret not seeking professional help sooner, mistaking psychotic symptoms for normal adolescent behavior.[2] Different emotions emerge as the enduring nature of psychotic illness becomes apparent. In particular, parents start to grieve for the loss of their "normal" child, realizing that the hopes and dreams they hold for the young person are now unlikely to be accomplished.[5,7]

While the burden of caring for a young person with FEP has been well documented, considerably less is known about how carers develop the strength and resilience to continue caring. Huang et al[8] identify 2 cognitive coping strategies, positive thinking and knowledge acquisition, that help to reduce carer burden in schizophrenia.

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For other carers of people with psychosis, behavioral coping strategies, such as keeping busy and pursuing personal interests, have been reported to help.[9] For some caregivers, the upheaval caused by FEP leads to a period of personal growth and a deepening of relationships within the family. Some parents speak about the positive side of their relationship with the young person with FEP, with a sense of increased closeness[5] and a change in the nature of the parent-child relationship: "He's our friend now as well as our son."[9]

Over time, parents slowly manage to gain some control over the chaos that FEP brings into their lives and with this comes a degree of acceptance.[3,6,7] Valuable though acceptance is on its own may not be sufficient to give family members the power and determination to persist in a caregiving role when faced with the pain and uncertainty of FEP. Understanding what combination of cognitive, affective, spiritual, or other characteristics gives carers the strength to keep on caring, as well as documenting associated challenges, is essential in informing the development of appropriate interventions and support services for families with FEP. However, limited research has been conducted in this regard despite substantial research documenting the burden of caring in FEP. Even fewer studies have adopted a qualitative approach, despite the importance of such methodology for providing a deep and rich understanding of carers' unique experiences. Of those undertaken, only one, a small study by Sin et al,[3] has focused on FEP caregivers, and none have been conducted outside the United Kingdom.

This study aims to understand the lived experience of first-time primary caregivers of young adults with FEP, with an emphasis on investigating how they are able to sustain their caring role. A qualitative methodology is adopted because of our focus on the subjective experience of carers, which is a valuable approach for helping to shed light on how carers develop the strength and resilience to continue caring, particularly in under researched areas.

Methods

Interpretative phenomenological analysis (IPA), an interpretative or hermeneutic method based on the Heideggerian interpretation of phenomenology,[10] was used to inform data collection and analysis. The approach necessitates a painstaking scrutiny of the participants' lived experience and how they make sense of their personal and social world.[11] IPA highlights that research is a dynamic, dual process with participants attempting to make sense of their world, while the researcher endeavors to comprehend how participants try to understand their experiences.[10,11]

IPA supports the social constructionist claim that historical, social, and contextual processes have a central influence on how individuals experience and perceive their lives. In particular, its interpretation of social constructionism is attributed more to symbolic interactionism than to poststructuralist thought that inspires most discursive psychology.[12] The IPA approach is also idiographic because it places emphasis on commencing with the individual as the unit of analysis and then progressively working toward general categories or themes.[13–15] IPA is especially appropriate where the problem is new or underresearched, where issues are multifaceted or unclear, and where the researcher seeks to comprehend process and change.[16]

Sample

Participants were recruited through case managers of Orygen Youth Health (OYH), a specialist FEP center in Melbourne, Australia. Twenty first-time primary caregivers to young adults (aged 15–24 y) diagnosed with FEP were recruited. A primary caregiver was defined as the main person (apart from health, social, or voluntary care provider) responsible for helping with activities of daily living, supporting, and advocating on behalf of the young person with FEP. Criterion sampling[17] was used to guide data collection. Inclusion criteria were (1) First-time primary caregiver, (2) being in a caregiving role for <3 years, and (3) ability to communicate in conversational English. Exclusion criteria were (1) receiving specialist family interventions for FEP and (2) current personal history of serious and persistent mental illness.

Saturation of themes and subthemes with "thick" description of the data was achieved when no new data emerged to support the themes. Each theme and subtheme contained thick descriptions and deep, dense, detailed explanations of challenging experiences, which provided a thorough and clear portrayal of caregivers' experiences.[12,18,19] It was this process that determined the actual number of participants in the study, a crucial part of the rigor of the qualitative approach to ascertaining sample size.[20]

Most participants were female (85%, n = 17), with a mean age of 49 years (range = 21–76 y). The majority were parents (85%, n = 17), but the sample included a grandparent (n = 1), spouse/partner (n = 1), aunt/uncle (n = 1), and nearly all lived in the same households as the young people with FEP (90%, n = 18).

The mean duration of caregivers' involvement with OYH was 14.5 months (SD = 8.9, range = 2–35 mo). Participants' highest level of education was university (50%, n = 10), high school (40%, n = 8), and technical and further education (10%, n = 2). The main language spoken at home was English (80%, n = 16), followed by Vietnamese (n = 1), English and Tagalog (n = 1), English and Spanish (n = 1), and English and Romanian (n = 1).

Procedure

Data collection took place at OYH, in participants' homes, or other mutually convenient locations. Semistructured, in-depth, audio-recorded interviews were carried out, using the guidelines suggested by Smith[21] and Eatough and Smith.[12] Interviews lasted approximately 1 hour. The purpose of the interviews was to enable the researcher to ask a range of in-depth questions, so informants could describe their experience of caregiving in *their own* narrative.[17,22] While the semistructured interview approach guided the interview, it did not determine its precise course but gave the researcher flexibility to probe responses.[17,21] The types of questions asked included, eg: "Can you tell me what it is like to be the primary caregiver?" At the end of each key section of the interview, the researcher summarized the content to ensure that the participant's perspective was correctly stated and comprehended, a verification process that strengthened the credibility of the study.[23,24] Ethical approval was obtained from university and local health service research and ethics committees.

Data Analysis

The approach of Smith and Osborn[11,16] was used to guide the data analysis. The first stage involved the transcribed data being read and reread in order to obtain a holistic perspective of participants' experience of caregiving. The second stage entailed the transcripts being closely scrutinized, notes being made in the margins (coding), and the tentative transformation of codes into conceptual themes, which captured the essence of the participants' experience. The third stage consisted of themes being clustered together chronologically into groups of themes and subthemes. At the same time, data reduction took place with preliminary themes insufficiently grounded in the data being omitted. The fourth stage necessitated a more focused analytical and theoretical ordering of themes and subthemes. The final stage involved an independent audit of the process being carried out by another researcher.[11] The iterative and inductive process was maintained throughout the analysis to ensure that the data were suitably represented.[12]

Results

Six competing themes were identified in the data, reflecting the carers' experience of supporting young adults with FEP: (1) burdensome responsibility, (2) roller coaster and unpredictable experience, (3) feeling responsible for their illness, (4) coming to terms with the change, (5) becoming closer, and (6) maintaining hope.

Burdensome Responsibility

Caregiving is perceived as a sad experience because of reflections about the changed life for the caregiver and the care recipient. It is seen as a frightening experience as there are times when some care recipients become verbally aggressive toward caregivers. It is also a burdensome responsibility and obligation, particularly for mothers and other female relatives, trying to balance the demands of caregiving with family, work, and other commitments.

> It's quite a heavy responsibility, because as a mother you feel that it is your role to look after your children, and even if I have my husband and the whole family is involved, you are the main character in this. (interviewee 3)
>
> Personally I've had to take on a leadership role in the family in some ways as it's something that I know more about and picked up on things quicker because of my background. (interviewee 8)

For some, caregiving can be an isolating experience that contributes to the burden of caring. The isolating experience may be due to the stigma of mental illness:

> Some people … they're still judgmental, and that doesn't help, that's not supportive, being judgmental … I've got friends who are the most caring, wonderful people but they just can't deal with it. (interviewee 5)

It also may be attributable to geographical isolation where the caregiver has no immediate family support:

> I have no family in Australia, if I had family maybe they'd come and help me. It's very hard to help me, maybe just friendly talk. (interviewee 2)

For some caregivers, there is also a financial burden associated with caregiving. This is due to direct costs of treatment. For instance, several caregivers initially sought treatment for the young person from private psychiatrists. Indirect costs include, for example, having to relocate from the family home to be closer to an FEP service or to take time off work.

> … we're not actually living in [name of rural location] at the moment …. [Friends said], 'why did you throw a perfectly good job in or take indefinite leave when you could of insisted that … [daughter with FEP] should come back home and you could have cared for her here.' My response was always that there are no support services in … [name of rural locality] …. The strength of the support network here [OYH and Melbourne] is second to none. (interviewee 9)

As a consequence of the burdensome responsibility, caregiving may be physically and emotionally draining, a time of constant worry. It may be a time when constant vigilance is required from the caregiver to be accessible all the time.

> … it's a very physically, emotionally and mentally straining. The stress that it causes me is just too much. It's very hard; you need to be there every time and keep checking her. (interviewee 1)
>
> It's hard work, 24 hours a day, 7 days a week; you're on call in case she has a problem and can't deal with it. (interviewee 7)

Roller Coaster and Unpredictable Experience

FEP is an unpredictable illness and has similar consequences for the demands it places on caregivers. "In my experience it's a roller coaster experience ..." (interviewee 1). The caregiving experience can alternate between phases of relative calm and times where considerable burden is placed on the carer. For instance, when the young person is in an acute phase of illness, it can lead to significant demands being made on the carer, whereas when the person is in the recovery phase the demands are likely to be less, though not necessarily eliminated.

> It's easier now than it was because ... [he is] healthier than he was a year ago .... He's coping with everyday things a lot better, and that's easier. (interviewee 8)

Feeling Responsible for Their Illness

Through a process of self-reflection, several caregivers feel a sense of personal responsibility for the illness, particularly if the care recipient is a son or daughter. This manifests as a generalized feeling of responsibility rather than being attributable to a particular shortcoming in, for instance, parental upbringing. The effect of this is to increase the burden of responsibility of caregivers.

> Just the stress of it all happening at that time. I had a lot of guilt at the time .... (interviewee 18)

Similarly, if other family members blame the primary caregiver when something goes wrong in the everyday life of the young person with FEP, this serves to heighten caregivers' feelings of responsibility and can create conflict in the household.

> You feel responsible for everything that happens in your son's life. So you have all the weight on your shoulders ... it's very hard because when he tried to kill himself my husband blamed me. 'Where were you?' he said. I said, 'What do you mean, where were you? Where were you?' (interviewee 3)

Coming to Terms With the Change

Eventually, most carers begin the process of coming to terms with the young person's illness. There are 2 overlapping subthemes in coming to terms with the change. The first subtheme is *accepting the change* in the young person with FEP. This entails, in some instances, mourning the loss of the previous relationship. It involves accepting the young person's circumstances and, having to be there, to be accessible to the young person.

> I probably mourn the loss in the relationship that I did have with her because it's no longer the same relationship. (interviewee 9)

The second subtheme necessitates *caregivers accepting their circumstances* and coming to terms with the role change from being a parent, spouse/partner, or close relative to a carer. Implicit in this is acceptance that the young person's illness is not a temporary phenomenon, but it necessitates long-term role change, for instance, from being a mother to a caregiver.

> The bottom line is, simply, acceptance of [your] circumstances. Because it's your own children; it's not just ... [his] journal [story], it's also my journal. (interviewee 14)
>
> The role changes because he's 23, he's an adult and so you can be a support person by being supportive, but your role changes in being the carer and a payer of all of his bills and doing all of those support things, to now just being on the edge again. (interviewee 5)

Becoming Closer

For some caregivers, the onset of FEP strengthens existing good relationships with the young person. Other caregivers may not have had such close relationships, and even though the young person's illness presents difficulties to the carer, it helps bring them together in closer, more open, and deeper relationship than previously.

> I guess it has given depth to the relationship. It's been a pretty 'crap' [difficult] time sometimes. There's had to be a bit of honesty and recognition of each other as individuals, and honesty about how both our behaviors have affected the other person. So there's been a closeness, but it's been hard going. (interviewee 8)

Several factors help bind good relationships together, including honesty, mutual trust, the caregiver showing a genuine interest in the young person, being there for them, and attempting to understand their situation.

> The good thing, I think, is that this experience has got me closer to him because before this we didn't talk much. As any boy who is a teenager, they don't talk to the parents and even less to their mother because it's embarrassing to be seen talking to their mother. (interviewee 3)
>
> I am closer to her .... She trusts me a lot more now and she knows I am always there for her, because when she was sick I went to see her every day and I was always there, and these things she remembers .... (interviewee 19)

Maintaining Hope

Despite the unpredictable nature of FEP, and the difficulties in providing care, it is important to focus on, and be optimistic about, the future that things will improve. There are 3 overlapping subthemes to maintaining hope: (1) hope in transition, (2) fostering hope in the young person, and (3) developing hope as a caregiver.

Hope in Transition. Hope is not necessarily a unidirectional concept for caregivers. It is a transitional process, where it may fluctuate between periods of hopefulness or optimism and hopelessness or pessimism, in response to immediate and broader historical, social, and contextual influences. These alternating periods are often determined by the level of well-being of the care recipient. For instance, if the young person is in an acute phase of the illness, the caregiver may perceive a pessimistic future for the young person. However, if the young person is making progress toward recovery, the caregiver may perceive the person's future more optimistically.

> It sounds really negative, but there are positive things. She's a nice girl. Look, I don't know, lots of my friends say it must be nice to have her around the house, but for me at the moment, it's more of a burden. In the last couple of weeks I've been thinking, 'where are the positive things with her?' I joke with her. So, [the] bottom line, at the moment, [is] there is no positive aspect to it [caregiving]. (interviewee 6)

Fostering Hope in the Young Person. Fostering hope for the future of young people with FEP entails frequently reminding them that their situation will improve and that they will have a brighter future than their present circumstance suggests. Adopting this stance may help the young person to endure the present situation. Fostering hope for the future may have a particular focus. For example: "Hopefully, she's going to go for her driver's license when she turns 18, which will give her some independence to get herself to appointments which would take the pressure off me quite substantially. Again, I'd like to try to encourage her to get a job so she's more independent financially." (interviewee 7)

Alternatively, fostering hope for the future may also have a general focus. For instance, "[I] always have to remind them that they will get better. There is a future for them …. I'm happy with him; he's looking towards the future …. [It's] always in my mind that he will get better. There are people who go on with their life, who start working, have friends.' (interviewee 16)

Developing Hope as a Caregiver. Developing hope for the future necessitates caregivers turning hope inwardly on themselves, focusing positively on the future, to strengthen their own resilience. It also involves acknowledging that caregiving demands may not be the only difficulties caregivers are currently facing. Focusing positively on the future helps a caregiver endure the burden of her or his present situation with the young person to see a future beyond their present situation. Fostering hope for caregivers' future may be particularistic as well as general.

> We're going through a really large change. My father passed away last year, and our family member's condition worsened after that …. I guess I can't do more than I'm doing now, just remain inspired, hopeful, supportive and, at the same time, not in deficit financially … it depends on how you look at the half full/empty glass, but I'm inspired by the fact at how some people can recover. (interviewee 15)

Discussion

This exploratory study provides a rich understanding of the underresearched phenomenon of being a first-time primary caregiver of a young adult with FEP, with an emphasis on how carers are able to maintain their caregiving role. The results present 6 rigorously developed competing themes that depict carers' experience of supporting affected young people, including the unique way they adjust to the role, reflected in 4 main findings. First, caregiving is a difficult, demanding, and unpredictable experience, as reflected in the first 3 themes: burdensome responsibility, roller coaster and unpredictable experience, and feeling responsible for their illness. The unpredictable nature of FEP makes it particularly burdensome—physically, emotionally, and financially—for caregivers, especially mothers, as they struggle to provide support against a background of unpredictable behavior, anxiety and worry,[6] and attempt to balance demands of caregiving with family and other responsibilities.[3] The caregivers' roller coaster experience reflects the difficulties they face as they struggle to understand what is happening to their affected children or friends.[6,7] Aligned to this is constant worry about the young person's behavior and the future, consistent with study of Tennakoon et al[25] of caregivers of people experiencing FEP. Another aspect of burdensome responsibility is that caregivers always need to be accessible to the young person to have a presence.[10] Likewise, there are direct and indirect financial implications of caregiving, which can increase the burden of care.[4–6]

Caregivers can also experience guilt and blame themselves for the young person's illness, perceiving it as poor parenting.[6,7] Overall, in the initial period where caregiving is difficult, demanding, and unpredictable, caregivers are at risk of being overwhelmed by the burden of care.[26]

Second, coming to terms with the change highlights that caregiving is a transitional process, characterized as "a change in health status, in role relationships, expectations, or abilities."[27(p108)] The transition reflects caregivers' acceptance of and coming to terms with the change in their child or friend, going through the process of mourning the loss of the person they once knew to accepting the illness, and the effect it has on the person. This transition also has been reported elsewhere, where following the initial shock of the diagnosis, carers grieve for the loss of the child they once knew, recognizing that the hopes and aspirations for the young person are now unlikely to be realized.[5,7] At the same time, the transition necessitates the carer accepting the change from being a parent or friend to that of a caregiver. This may entail taking on responsibilities they had previously relinquished as the young person reached adolescence[4] and, in the case of parents, may signal the return of an earlier, more dependent form of the parent-child relationship.[5]

The transition from guilt to hope necessitates a grieving process,[5,7] with caregivers accepting their situation,[3,6,7] being positive about and coming to terms with the reality that, at least for the foreseeable future, the illness is likely to become an enduring feature of the young person's and their lives.[28] Acceptance and positive thinking about the future have also been identified as important cognitive coping strategies of long-term caregivers and siblings of people with chronic psychotic disorders.[6,8,29,30] Adoption of these constructive coping strategies may also be attributable to the older age (mean = 49 y) of caregivers in the present study and is in line with previous research reporting greater use of these measures with increasing age.[9,31]

Third, becoming closer reflects an unanticipated reward of caregiving. It may mean a period of personal growth and strengthening of an existing good relationship or in some circumstances bring the carer and young person closer together in a more open and deeper relationship than before. This finding is consistent with previous research,[5–7,9] where the predicament of having children, siblings, or friends with FEP brings them together in closer, deeper relationships with the affected person.[32] Overall, becoming closer highlights that first-time caregiving in FEP is not solely a burdensome experience but can be a positive, fulfilling experience.[5,33] Indeed, relationships between caregivers and young people are more likely to be influenced by the burden and the rewards of caregiving than the severity of the young person's symptoms or extent of caregiving involvement.[33]

Fourth, maintaining hope reinforces the importance of caregivers having a realistic outlook for the future and the centrality of hope in giving them strength to carry on caring. The illness experience can leave caregivers enveloped in their current situation, believing that their present circumstance mirrors the future. While there is no "magic bullet"[34] to treat FEP, hope is intrinsic to the process of promoting recovery in affected young people and helps caregivers cope with their situation to focus positively on the future, to see light within the darkness, and to strengthen their own resilience.[35] McCann[35] defines hope as a multidimensional personal construct, with cognitive and affective components that reflect a realistic appraisal of the situation and anticipation of a good outlook. Implicit in this definition is that hope enables psychological comfort and helps caregivers (and by inference, young people with FEP) endure their situation.

Hope is not a dichotomous construct, where the carer either possesses or lacks hope. It is an individual construct comprising degrees of hope.[36] To some extent, hope parallels the Huang et al[8] cognitive coping strategy, positive thinking, and it has affective and, in some instances, spiritual elements,[35] which have been suggested as key coping strategies to help reduce caregiver burden.[6,30] However, while there are claims of a positive relationship between hope and health outcomes, and hope can facilitate coping,[36] in this instance in caregivers, ungrounded hope can contribute to unrealistic optimism about the future.[37] Moreover, hope represents an expression of caregivers coming to terms with their situation,[28] and the ability to foster hope is considered a key expectation of involvement with mental health services.[38,39]

Finally, no differences in themes were identified in the data relating to the experiences of caregivers from cultural and linguistically diverse (CALD) backgrounds, although only 4 such participants were recruited. This preliminary finding suggests that CALD background carers share similar caregiving experiences and is congruent with other studies examining CALD background caregivers.[30,40] However, while this group has similar experiences to other carers, it seems that they encounter some issues, such as stigma, more frequently.[30,40–42]

Limitations

There are 4 main limitations to this study. First, it is a qualitative study, and results are context bound to the participants and the setting in which the project occurred:[43] primary caregivers of young adults with FEP, recruited through one FEP service in Melbourne, Australia. While generalizability is not an essential prerequisite of qualitative research,[23] the results can be verified[44,45] and provide a valuable reference point for primary caregivers, family workers, and mental health clinicians practicing in other FEP settings. Second, recruitment through case managers may have led to an atypical sample of engaged caregivers. Future research might benefit from having caregivers who are not engaged with the service. Third, most participants were female (85%, $n = 17$), similar to the Jungbauer et al study.[5] While this may reflect the fact that most caregivers are women, it limits the findings to one gender, as females may have a different experience of caregiving than other family members.[1] Finally, only a small number of CALD caregivers participated, limiting the generalizability of our findings and highlighting the need for a greater focus on this group in future research.

Conclusion

Caregiving in FEP gives rise to negative and positive experiences, and these competing events are interrelated. These experiences are directly affected by the well-being of the young person with FEP and, in turn, affect the general well-being of caregivers. Our findings have 3 key implications for primary caregivers, family workers, mental health clinicians, and FEP services. First, greater awareness is needed of the contribution, experience, and challenge faced by primary caregivers. Second, FEP services need to develop strategies for staff to incorporate more practical, educational, emotional, and financial support to caregivers within standard approaches to care and treatment. Embedded in these measures is the importance of supporting caregivers to come to terms with the change in the young person as well as the longer term implications of taking on a caregiving role. This involves providing them with sufficient knowledge and ongoing support to help them through the grieving process, to develop positive thinking, and to accept their situation. It also necessitates recognizing that the support caregivers need is dependent on a range of factors, such as what stage they are at in the transition process, as well as cultural and linguistic considerations.

Integral to this process is fostering hope in caregivers so as to strengthen their role in supporting the recovery process. Hope cannot be imposed externally but has to be uncovered, supported, and reinforced in a cooperative approach among family workers, clinicians, and caregivers. It involves uncovering caregivers' beliefs about their future and using their internal and external resources to enable them to fulfill their expectations as caregivers and as individuals. Fostering hope entails consideration of multiple issues, such as appropriate social, psychological, and financial support; reduction in isolation; easy access to mental health staff; education; and for individuals from CALD backgrounds, the provision of culturally and linguistically sensitive care for carers and young people. Ultimately, caregiver hope is intrinsically related to accessible and good quality treatment and support that promotes the well-being of the young person.

Finally, more research is needed to fully characterize the experience of nonengaged caregivers and those from CALD backgrounds, as well as developing and evaluating initiatives to assess the effectiveness of measures to support caregivers and reduce their burden of care.

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