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Authors	McCarthy, Joan;Higgins, Agnes;McCarthy, Bridie;Flynn, Angela V.;Gijbels, Harry
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ORIGINAL ARTICLE

Family members' perspectives of hope when supporting a relative experiencing mental health problems

Joan McCarthy[1] | **Agnes Higgins**[2] | **Bridie McCarthy**[1] | **Angela V. Flynn**[1] | **Harry Gijbels**[1]

[1]School of Nursing and Midwifery, University College Cork, Cork, Ireland

[2]School of Nursing and Midwifery, Trinity College Dublin, Dublin, Ireland

Correspondence
Angela V. Flynn, School of Nursing and Midwifery, University College Cork, Cork, Ireland.
Email: angela.flynn@ucc.ie

Abstract

Current research views hope as a process that plays a positive role in the recovery of individuals with mental health problems. However, little attention has been given to the role of hope in the lives of their families. We aimed to address that gap. We deployed a qualitative descriptive design and carried out individual interviews with nine family members who supported a relative with mental health problems. A cross-comparison of the data generated three major themes: understandings of hope; factors that diminish hope and factors that nurture hope. The participants viewed hope as a positive and productive feeling or attitude that was life-affirming, and empowering. They also associated it with behaviours and dispositions such as attentiveness and empathy and the possibility of a return to a more stable and 'normal' life. The participants experienced hope as initially eroded when their relative was first diagnosed and institutionalized. Hope was further diminished due to the poor communication practices of some mental health professionals and the stress of the caring role itself. On the other hand, hope was nurtured through the support of other family members, friends, neighbours and peers. Acquiring knowledge and understanding about the relative's state of mental health nurtured hope and enabled the participants to have a more meaningful role in their recovery process. Practices of self-care such as independent activities and counselling also strengthened hope and some mental health professionals played a positive role in supporting these. Most striking about the reports of many of the participants was their assertion of their abiding love for their relative. Their account of their ability to see beyond the illness of their relative was an insight that we did not find in other accounts of the experiences of family members. We highlight the need for family members to have timely access to relevant information about their relatives' illness. We conclude that hope is relational at its core because of the interplay of intrapersonal, interpersonal and social factors that diminish or nurture it over time. Specifically, we propose that friends, neighbours and peer support groups as key actors in nurturing the hope of both family members and their relatives.

KEYWORDS
family, hope, information, mental health, recovery

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INTRODUCTION

International trends in mental health services emphasize promoting a partnership approach between service users, families and practitioners within an ethos of recovery. Although interpretations of recovery differ, a key theme running through much of the writing on recovery in mental health is the centrality of hope. Despite the critical role family members play in the recovery journeys of people who experience mental health problems, their voice within the literature on hope is not always evident. In this paper, we report the findings of a qualitative study into family members' perspectives of hope.

BACKGROUND LITERATURE ON HOPE

Hope has been described as an emotion, a cognitive process, a state of being, a disposition, an attitude (Doe, 2020) and within the field of mental health a central tenet (Acharya & Agius, 2017) and 'vital ingredient' of recovery (Watts & Higgins, 2017). Deegan a key figure in the service user movement states that 'hope is not just a nice sounding euphemism' but 'is a matter of life or death' (Deegan, 1996: p. 3). Snyder (1994, 2002), one of the most cited theorists in the area, conceptualizes hope as a future goal-orientated cognitive construct with affective and behavioural implications. Within this theory, hope consists of the person's capability to generate specific plans to reach specific goals (pathways thinking), and the belief that he/she has the energy and ability to implement these particular goals (agency thinking).

Viewed through the lens of people with lived experience of mental health problems, hope is positively associated with self-esteem, quality of life and recovery and incorporates an ability to believe in one's capacity to recover, as well as an ability and flexibility to take action and overcome future obstacles (Hayes et al., 2017; Higgins & McGowan, 2014; Sælør et al., 2014; Slade et al., 2014). Hope is reported to increase motivation, prevents feelings of despair and pessimism and provides positive energy to achieve goals related to the future (Kavak & Yilmaz, 2018). 'Hope and optimism for the future' is one of the five processes identified within Leamy et al.'s (2011) theoretical framework for personal mental health recovery. The key dimensions identified include the following: a belief in possibility of recovery, motivation to change, experiencing hope-inspiring relationships, positive thinking and valuing success, as well as having dreams and aspirations (Leamy et al., 2011).

While much emphasis within the literature is on hope from the perspective of people with self-experience of mental health problems, or on measuring the impact of psychosocial interventions on hope (Hernandez & Overholser, 2021), this emphasis fails, not only, to acknowledge the wider socio-cultural variables that may impact hope, but it ignores the fact that recovery is also a relational process that takes place within a social milieu (Llewellyn-Beardsley et al., 2019). Some consider that it is within, and through, the social milieu of relationships that the 'nutrients of recovery, such as hope, courage, acceptance, warmth and compassionate witness and understanding are available' (Watts & Higgins, 2017: 81). For many people, this milieu includes family members (FMs). While FMs' role in people's recovery continues to be a contested space (Bland & Foster, 2012), it is estimated that many people experiencing mental health problems not only live with FMs but depend on them for a range of supports (Reupert et al., 2015), including what Deegan calls 'surrogate hope' (Deegan, 1994). In other words, FMs not only provide financial, instrumental and emotional supports, but also they are sometimes the holders of hope for people who feel they may have lost all hope in and for themselves.

Although there are several studies focusing on hope in people with lived experience of mental health problems, few studies were located that explored hope from the perspective of FMs. In Duggleby et al.'s (2021) recent systematic review of factors associated with hope in families of persons living with chronic illness, out of the 26 studies included only three studies measured hope in FMs of people with mental health problems. Findings from these studies indicated that hope is negatively associated with maladaptive coping strategies, behavioural disengagement, distress (Friedman-Yakoobian et al., 2009) and caregiving experiences (Marshall et al., 2013). While hope was not associated with the nature of the relationship (parent versus sibling) or living situation (living with person or independent living; Redlich et al., 2010), it was positively associated with caregiver well-being (Marshall et al., 2013). Since Duggleby et al.'s (2021) review, two other quantitative studies have been completed. Han et al. (2022) reported a positive relationship between positive attitudes (i.e. faith in recovery, having hope for the future) and caregiver well-being and Stanley and Balakrishnan (2021) found that hope was a significant predictor of perceived reward in the caring role.

Studies that have taken an emic or qualitative approach to exploring FMs' views of hope are sparse. The FMs living with an individual experiencing depression in Stjernswärd and Ostman's (2008) study described hope as a motivating force for finding effective treatment, a trustworthy physician, a meaningful and productive future and improved quality of life for both themselves and their relatives experiencing mental health problems. Bland and Darlington's (2002) Australian study found that hopefulness was an integral part of the coping process used by FMs. Similarly, Latino FMs of people with a diagnosis of schizophrenia in Hernandez et al.'s (2019) study describe hope as a vital resource in helping them manage stress experienced as caregivers, as well as nurturing the hope of their relatives. Specifically, sustained hope was associated with spiritual connection,

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attendance at a family psychoeducation programme and seeing positive change in their relatives' mental health.

As hope may have different connotations depending on context and given the limited number of studies in this area, exploring FMs' perspectives on hope is critical for a number of reasons. First, FMs are valuable interdependent partners in a person's recovery journey and, as such, they can influence how hope is experienced, as they can either nurture or diminish the person's hope. Second, as FMs navigate the stress and impact of a person's mental health problems on their lives (Fekadu et al., 2019; McCann et al., 2011), hope may be an integral factor or coping strategy within their own experience or recovery journey (Wyder & Bland, 2014). Indeed, for families to be able to hold hope for their relatives, they need to be hopeful themselves. Third, understanding how FMs conceptualize hope and the contextual variables that influence how it is sustained is critical if mental health practitioners are to incorporate hope into the everyday interactions with FMs. Hence, the aim of the study was to explore family members' perspectives of hope when supporting a relative experiencing mental health problems.

RESEARCH DESIGN

We used a qualitative descriptive design informed by Frank's (2010, 2012) writings on narrative and narrative analysis. Emphasis within a narrative approach is on exploring intrapersonal and interpersonal experiences and actions in order to understand how people make sense of their world (Frank, 2010; Riessman, 2007) and is particularly suitable to aid understanding when people's lives have been interrupted by a significant event (Riessman, 2007). Frank (2012) highlights the importance of supporting participants to frame their experiences as a story. Narrative analysis focuses on the characters involved, how they respond to a situation, the meaning they make of it, and how it influences their identity (Frank, 2012). The COREQ 32-item checklist (Tong et al., 2007) was used to support the drafting of this paper.

Recruitment

Participants were recruited via advertisements in national community mental health networks/organizations websites (e.g. Critical Voices Network, Irish Advocacy Network, Family Carers Ireland). Written information about the study outlining the aims of the study, inclusion/exclusion criteria and details about the researcher was provided to the networks/organizations. Participants who volunteered were provided with an in-depth information letter about the study via email including a consent form and the researcher's contact details. Participants were included who met the following inclusion criteria: (i) they self-identified as being supportive of a relative who experienced mental health problems; (ii) they were willing to reflect on their experience of hope in relation to their experience of supporting the family member; (iii) they were over 18. Family members experiencing acute distress at the time of the interview and/or whose English was not fluent were excluded from the study.

Data collection

Data were collected via in-depth, one-to-one, semi-structured interviews from a purposive sample of participants. The interviews were guided by an interview schedule (Table 1), and audio-recorded with participant consent. Interviews were conducted at a time and place that suited the participants and the researcher, such as people's homes and the University where the researcher was based. Data were collected from 1 January to 31 March 2018. One person (MO'D [RIP] See Appendix S1), who was not known to the participants, collected the data. The interviewer was an experienced mental health nurse and lecturer, undertaking the study as part of a Doctorate. One interview was conducted as a pilot study to test the interview schedule, but no changes were made. Even though sample saturation is not a

TABLE 1 Indicative questions.

1.	In terms of hope what has it been like supporting your loved one?
2.	When I say the word 'hope' what comes to mind?
3.	I wonder can you tell me about a time when you felt hopeful?
4.	Were there any turning points?
5.	Were there times when you felt more hopeful than others?
6.	Were there times when you felt less hopeful?
	How do feel in terms of hope right now? (?scale of 1–10)
7.	What helped to give you hope?
	Are there things about you that have given you hope?
	Are there things that happened to you as time passed that have given you hope?
8.	Were there any changes in your FM/loved one that affected your level of hope?
9.	Who supported you to keep hope?
10.	Did you seek help/support?
11.	What do you feel is important to help you keep your hope alive /going?
12.	What are your hopes and dreams?
13.	What advice about hope might you give to other family members about hope?
14.	What would you like nurses /doctors to know about hope?
15.	Is there anything that you would like to add today about hope?

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requirement as participants' stories are unique (Holloway & Freshwater, 2009), Riessman (2007) recommends a sample of between 8 and 12 participants to allow for in-depth analysis. Out of a total of 10 expressions of interest, nine people were interviewed. One person declined due to a family illness. All participants in this study were exceptionally generous in the sharing of what were very intimate, personal and powerful stories. Each interview was a significant length, 60–120 min, responses were probed, and field notes were taken immediately after each interview as recommended by Kvale (1996).

Data analysis

All transcripts were transcribed verbatim and entered into a data management programme NVivo. In Dialogical Narrative Analysis (DNA), there are essentially three stages to the analysis process (Frank, 2012). The first stage is a naïve reading whereby each transcript was read as a whole, and each story considered as a whole. The second stage is coding which involved looking for obvious themes. Coding with the use of mind mapping using Nvivo was used here. The mind map consisted of a diagram to organize and visualize the codes. The third phase involved a more in-depth process of coding, comparison and merging of codes into higher order themes. The content analysis involves identifying themes using participants' own language to describe each theme (Frank, 2012; Hunter, 2010). At each stage, MO'D consulted with JMcC and AF regarding the coding process and the identification of themes but all data were coded by MO'D. Participants were informed that they could review the transcripts if they so wished. One participant availed of this opportunity and confirmed the report of their interview.

Ethical issues

Ethical approval for the study was granted by the Clinical Research Ethics Committee of University College Cork where the researcher was based. All participants received written and verbal information about the study and provided written consent prior to the interviews. Participants were also informed that they could withdraw from the study at any time if they so wished. No participant withdrew from this study. To protect participants' confidentiality, pseudonyms were used.

FINDINGS

Socio-demographic

In total, nine interviews were conducted with seven women and two men living in Ireland (see details in Table 2). There were seven White Irish participants and two White UK participants. These were aged between 45 and 72 years; six of them were aged over 60 years at the time of the interviews. The duration of time that they supported their distressed family member ranged from 5 to 40 years and the median number of years that participants were in the caring role was 20 years.

Themes

We identified three key themes which captured the participants' perspectives of hope in relation to their support of their relatives with mental health problems: (1) Understandings of hope; (2) Factors that diminished hope; (3) Factors that nurtured hope.

Understandings of hope

The sub-themes associated with this theme are (i) hope as positive; (ii) hope linked with behaviours and dispositions and (iii) hope associated with a return to normalcy.

Hope as positive

Many of the participants struggled to articulate what the notion of hope meant to them. In general, they

TABLE 2 Profile of the participants.

Participants/FM pseudonym	Age	Relationship to identified relative	Years supporting relative	Nature of relative's distress	Education level of FM	Employment of FM
Karen	63	Mother–son	15.5	Psychosis	Third-level	Part-time
Tina	47	Daughter–father	5	Depression	Third-level	Self-employed
John	64	Husband–wife	20	Bipolar	Second-level	Retired
Nina	45	Daughter–father Sister–Sister	20	Psychosis anxiety	Third-level	Full-time
Laura	63	Daughter–mother	40	Depression	Second-level	Full-time
Freda	63	Mother–son	30	Psychosis	Second-level	No
Beth	63	Mother–daughter	15	Personality disorder	Second-level	No
Mona	72	Wife–husband	40+	Anxiety depression	Third-level	Retired
David	61	Father–son	10	Psychosis	Second-level	Part-time

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understood hope as a positive, productive and creative feeling or attitude that was life-affirming, healthy and empowering:

> Hope to me is that you're happy, you're optimistic, you're peaceful within yourself and you have empowerment.
>
> (Karen)

David and Mona visualized hope in relation to peaceful and joyful images of nature, music and dance:

> I suppose Spring. It feels hopeful when you see buds breaking on trees, hearing birds singing in the morning, um, sunshine, innocence, childish, childhood innocence.
>
> (David)

> Oh yes, Mozart comes to mind instantly. Yes, I love Mozart. Ahh Mozart, I could dance around the house to Mozart.
>
> (Mona)

Hope linked with behaviours and dispositions

The participants also linked hope with behaviours and dispositions such as gentleness, attentiveness, empathy, patience, eye contact, non-judgement. Some of the participants viewed hope as internal to themselves. Tina saw herself as someone who 'will always have hope'. On the other hand, David viewed hope as external to himself and he struggled to tap into it—'it's something out there rather than in here' (*pointing to his chest*). Whether internal or external, all the participants saw hope as ever-present but lying dormant, available, to be tapped into. Tina described it as a kind of belief or leap of faith:

> This isn't the end of the road, this isn't the end of your life, this isn't the end of their life, that there has to be something, it can't be all, it can't be all negative I think, and it can't be all lost.

Hope associated with a return to normalcy

Hope also concerned the possible restoration of their relatives to 'some kind of normalcy' and the participants' retrieval of their own lives. Many directly referred to hope that their relative might recover a previous sense of 'stability' or have a 'normal life' or 'normal mind' or that they might have a 'proper family' in the future.

> [W]e were never given or the family […] never a millimetre of hope given to us that he would ever recover, um, that we were never given any hope as a family that we'd have a proper family ever.
>
> (Nina)

Factors diminishing and nurturing hope

The participants consistently referred to their experience of hope as dynamic, fluctuating and dependent on others including the relative they supported as well as the wider community and mental health services. Their accounts refer to several different factors that could diminish or nurture hope and these are discussed in the following sections.

Factors that diminished hope

Several factors contributed to diminishing the participants' sense of hope for their relative and for themselves. These are explored under the following sub-themes: i. Admission to mental health services; ii. Poor communication; iii Caring as isolating and stressful.

Admission to mental health services

Many of the participants recounted losing hope when their relative was first diagnosed or when they were first institutionalized. Karen related how her hope was shattered to the point of despair when her son (15) experienced his first admission:

> I mean the worst time I think was when I first had to admit my son. I think that's when I felt the hope was gone and seeing him very highly medicated and not being able to speak, drooling, I couldn't see any hope. I couldn't see him coming back to where he is today.
>
> (Karen)

Similarly, David's hope of his son (19) was shattered when he saw him for the first time, after he was imprisoned for behaviours associated with a psychotic episode. For both Karen and David these were very painful, traumatic experiences underpinned by overwhelming fear and sadness that they had lost their sons, as they knew them, forever.

Poor communication

Mental health professionals and GPs did not provide meaningful information about their relatives' mental health problems and this was a key factor that diminished hope. Beth told the story of how she searched for many years for information and appropriate care for her daughter's mental health problems: 'We kept on asking what, was it bi-polar or was or just depression. We never got really very much help'. Similarly, David 'found it very difficult to find out about medications or even speak to the doctors' regarding his son.

Lack of recognition and understanding on the part of mental health professionals of the traumatic and relational impact of the person's mental distress on the whole family also diminished hope. Participants were not listened to and their knowledge about the person was not

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taken into account or acted upon which further diminished their hope.

> Nobody has ever talked about it with us […]. It's more than just that one person. That person affects all the other people around them and they don't seem to care. And they need to give families more support for mental illnesses.
>
> (Beth)

Caring as isolating and stressful

All the participants reported that the caring role itself undermined their plans and hopes for themselves and led to further isolation. They had to use the energy they had to carry on with the everyday business of caring, not only for their relative, but also, for the rest of the family and their own lives and relationships suffered as a result. Tina, who was caring for her dad, described how she did not have any hopes or dreams for herself and that 'sometimes you do feel like you're a bit of a doormat [a mat in the doorway on which a visitor can wipe their shoes], you do feel like you're forgotten'. For Beth, fear of her daughter harming herself diminished her hope. Her need to adopt a custodial 'caring' role to ensure her daughter's safety meant that her 'normal' nurturing mothering role, along with its associated hopes, was completely overshadowed. The stress of their caring role led them to breaking connections with other family members and friends, and their social circle became even smaller. Both David and John referred to the ending of more intimate relationships due to a lack of energy and the stress of their caring role.

Factors that nurtured hope

Several factors nurtured the participants' sense of hope for their relative and for themselves. These are explored under the following sub-themes: (i) Family and significant others as supportive; (ii) Accessing meaningful information; (iii) Maintaining love for their relative; (iv) Engaging in self-care activities.

Family and significant others as supportive

The role of others was instrumental in the work of nurturing hope. Family, friends and neighbours not only provided psychological and emotional support they also provided instrumental support. Tina's younger sister, for example, who saw that Tina needed a break brought her to a travel agent and 'gave the travel agent her credit card and said, "I don't care where you send her, send her somewhere, send her somewhere"'. While Laura's school friend's mother made her a uniform helping her to be a 'normal' child starting secondary school and not just the child 'with the mad mother'. Mona recalled how a neighbour's encouragement to attend a support group when she was 'in bits' [very emotionally upset] nurtured her hope for a better future.

Accessing meaningful information

Accessing information about their relatives' mental health problems was a powerful factor in nurturing hope. For example, a debate organized by her English teacher helped the adolescent Nina to understand the nature of her father's schizophrenia, developed her compassion and understanding of what might be happening for him and the possibility that her father and her family could manage his ongoing episodes of distress.

> I was thinking maybe I'm the only person in the class because no-one spoke about it back then […] but, yes, so they gave us information and through the library I started reading up on schizophrenia. […] it gave me hope because I understood it more.
>
> (Nina)

The initial intervention by her teacher set Nina on a lifelong path of finding out information about mental health. Similarly, David found first one and then several further education courses on mental health and disability which gave him a vocabulary to better understand his son's mental health and he continues to use educational courses to support other people in distress.

Maintaining love for their relative

Holding on to love for their relative was a further factor that enhanced hope. Five of the nine participants explicitly mentioned their love for their relatives and, when they talked about the person behind the illness, their tone and faces changed and became softer and lighter. At some stage in the interview, all participants spoke in a very caring way about the personhood and humanity of their relative behind the illness/label:

> When I visited him and when he did, um, he was very gentle and loving and I could see the innocent, lovely child that he once was re-emerging in his character.
>
> (David)

Love for the person also helped the participants to endure as Tina stated, 'my father gave me the strength within myself'. John illustrated how love could keep hope alive in the midst of despair:

> I never gave up on her you see. You know you had Jekyll and you had Hyde […] and the real person you see for me was Eleanor […] a very kind gentle person, a very kind-hearted person. […] I could see the real Eleanor. You see somebody from a distance would see, they would see the label.

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Recognizing a positive change, small or large, in the person was also grounds for building hope. For Beth, seeing an improvement in her daughter Lisa's mental health, when she was pregnant, gave her the first glimmer of hope as her daughter was happy again and 'normal'.

> She actually blossomed, she became back to normal, sort of like as normal as you can. […] She bloomed in her pregnancy. Things started going, and I'm going, gosh things, you know things are looking up.
>
> (Beth)

For Laura, change occurred about 30 years into her caring journey when her mother, who was then in her late 1980s, took on a caring role for her grandchild.

> Everybody was gobsmacked, gobsmacked! How could this woman in her eighties look after a special needs child? They can't even understand it. Like she had a role […] like I could move back a small bit like. She had a life. And normally she has no life.
>
> (Laura)

Engaging in self-care activities

The participants' own actions and activities were central to sustaining hope for themselves and their relatives. These were, often, simple everyday activities which were essential to create a calmer space to begin the work of nurturing hope, for example, David cooking, Mona playing bridge, Laura going out on her bike, Freda doing her gardening. Sometimes too, they pushed themselves out of their comfort zone, took a risk, did something different such as taking up yoga or walking the Camino.

> I could say to anybody that if you need to find hope it's a good idea to go on the Camino.
>
> (David)

Activities of self-care such as engaging with one-to-one counselling, peer support groups and psychosocial interventions were pivotal to nurturing the hope of participants and some mental health professionals played an important role in this (though nurses were largely absent from the participants' narratives). David described how availing of the support of a counsellor helped him to understand his confused thoughts and to articulate his distressful experiences with the mental health services.

> Having somebody to talk to. I suppose how I can describe it best is if I can, if my mind is like a rubbish bin, that I have a week's worth of rubbish scrumpled up, notes and that […] I can pour it all over somebody's floor and put it all back, and avail of somebody's support and foresight, it's a huge help.
>
> (David)

Tina, with the support of her psychiatrist, realized that she could help her father more by stepping back. For Karen, the need to step back, to disengage more from her son was also reinforced by a psychiatrist who had a great impact on her: 'I suppose I was very lucky. I had a clinician that turned around and said to me 'to back off' in the nicest possible way'. Undertaking a WRAP (Wellness Recovery Action Planning) course after she had become depressed herself also helped Karen to realize that she was disempowering her son by doing too much for him and not allowing him to make his own decisions.

In short, focussing more on their own self-care enabled participants to gain key insights about their relationships with their relatives. They became re-energized and were able to think more clearly, gain more control of their own lives and, in turn, become more hopeful for their own future and that of their relatives. The hope strengthened through self-care activities encouraged the participants to broaden their friendship and social circles. Many of them also worked with other FMs and supported them to find and nurture hope in different ways and/or advocate to ensure that FMs have a more enhanced role in mental health services.

DISCUSSION

We aimed in this study to explore family members' perspectives of hope when supporting a person experiencing mental health problems. The data generated three major themes: understandings of hope, factors that diminished hope and factors that nurtured hope.

Understandings of hope

Similar to the perception of hope among individuals experiencing mental health problems (Deegan, 1996; Doe, 2020; Hayes et al., 2017; Murphy et al., 2016), all the participants in this study visualized it as a positive, creative and empowering disposition and attitude that was essential for a healthy and productive life.

Hope was understood by some as future-oriented along the lines of Snyder's account of hope as an intentional cognitive state involving goals and agency (2002). Specifically, these participants identified what they hoped for in the future—the recovery of their loved one to some kind of 'normal mind', 'normal life' and 'proper family' and the restoration of some kind of normalcy for themselves. Other participants understood hope as more complex than Snyder's future-oriented cognitive construct and they articulated hope as more relational and contextually construed. Like FMs in the few

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studies available (Hernandez et al., 2019; Stjernswärd & Ostman, 2008), the participants saw hope as concerned with the well-being of their relative as well as themselves and connected with compassionate behaviours and dispositions. They also articulated hope in more indefinite terms which are closer to Ratcliffe's (2012) phenomenological distinction between having specific hopes and having a more generalized sense of hope so that, as Ratcliffe acknowledges, one can 'lose all hopes' and yet retain a 'pre-intentional' or 'existential feeling of hope'. For the participants, this hope was either innate or somewhere 'out there', but never completely lost. As authors such as Ratcliffe (2012) and Scioli et al. (2011) have observed, the assumption that a person might have a residual, innate hopeful core which is present even when all hopes may be lost would enable practitioners to continue to work in a hopeful way even when things appear most hopeless.

Factors that diminished hope

The hope of the participants in this study was eroded from the outset when their relative was diagnosed and hospitalized. This initial trauma was compounded through the withholding of vital information about their relatives' mental health problem, poor communication and the disregarding of the impact that the mental distress of their relative had on them, their well-being, and their capacity to support the person towards any kind of recovery. While the median number of years that participants cared for a relative in distress was 20 years, two of the participants cared for their relative for over 40 years and one for over 30 years. Their accounts bear witness to the essentially traumatic experience of using mental health services in 1970s, 1980s and 1990s Ireland. At that time, mental health services were largely hospital based, the medical model dominated, and FMs were regarded with deep suspicion by mental health professionals (McDaid & Higgins, 2014). The legacy of keeping the families of individuals with mental health problems at a distance still continues into the 21st century as evidenced by several pieces of empirical research that highlight how families feel unsupported by the mental health team (Aass et al., 2022; Hungerford & Richardson, 2013; O'Féich et al., 2019). Currently, one prominent, complex and controversial barrier to engaging with family members is the concern to protect the confidentiality of the individual accessing the mental health services (Hansson et al., 2022). However, as this study demonstrates, the recovery of individuals in mental distress and the well-being of their families are, inevitably, intertwined. The challenge remains for health professionals to develop the skills necessary to engage in supportive conversations with families (Aass et al., 2020; Moen et al., 2021) while doing so in ways that respect the privacy and preferences of their relatives.

The demands and stress of their caring role also led many of the participants to break connections with other family members and friends, their social circles became even smaller, and intimate relationships were disrupted. These findings confirm the findings of two quantitative studies on hope in FMs which indicate that diminished hope is negatively associated with maladaptive coping strategies, behavioural disengagement, distress (Friedman-Yakoobian et al., 2009) and caregiving experiences (Marshall et al., 2013).

Factors that nurtured hope

The hope of the participants was nurtured through access to relevant information about their relatives' illness, and psycho-social interventions. Similarly, the positive impact of education and information on hope, carer burden, coping capacity and problem solving in crisis situations is documented in other studies (Brady et al., 2017; Higgins et al.,2022; Miklowitz & Chung, 2016).

For the participants in this study, like those in Hernandez et al.'s (2019) qualitative study, the support from friends, peers and the wider community played a central role in nurturing hope for their relatives and themselves. In addition, many of the participants reported that they worked with other FMs supporting them to find and nurture hope in different ways and/or advocated to ensure that FMs have a more enhanced role in mental health services. This kind of peer support mirrors the peer support offered to people who experience mental health problems which is well recognized, with a growing number of services employing peer support workers (White et al., 2020). Given Wyder and Bland's (2014) claim that supporting a family's recovery journey requires a move beyond 'seeing families only as potential supports' for their relatives to include the family's needs as well (Wyder & Bland, 2014, p. 193), there is a need for a greater focus on the potential of family peer support, such as the 'Families Helping Families' model developed in Australia, where family peer support workers are positioned in the service assessment area and in the inpatient unit to ensure early involvement (Leggatt & Woodhead, 2016).

Most striking about the reports of the participants was their assertion of their abiding love for their relatives and their openness to the turning points in their relatives' lives, when their situation changed and improved. Their account of their increased capacity for empathy and the ability to see beyond the illness of their relative was an insight that we did not find in other accounts of the experiences of FMs. That many of the participants we interviewed shared the whole of their lives with their relatives demonstrated their deep commitment and love for them.

Finally, activities of self-care led to a greater sense of hope, a vastly improved quality of life and a broadening of friendship and social circles, similar to the reports

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of the FMs in the qualitative research of Hernandez et al. (2019) and Stjernswärd and Ostman (2008).

LIMITATIONS

While the findings from this study help to amplify the often-unheard voices of FMs and highlight important factors influencing their views and experiences of hope, the study has some limitations. The study represents a small number of FMs in one cultural context, namely White Irish (7) and White UK (2) living in the Republic of Ireland, thus findings may not be applicable to FMs in other contexts. As the sample was self-selective, participants were predominantly female (wife, mother, daughters), with only two male participants (husband, father) and an absence of the voices of siblings of all genders. The findings were dependent on memory across significant periods of time, thus, may be subject to recall bias. While collecting data from a diversity of FMs helps to hear a range of opinions on hope, the heterogenous nature of the sample limited an in-depth exploration of how differences in the relationship to the person experiencing mental health issues (husband–wife, father–daughter, sibling–sibling) and other demographics, such as age and gender, might influence the themes identified, suggesting a need for further research that takes account of these limitations. In addition, given that mental health issues impact female family members as much as male members, future studies need to consider developing strategies to recruit male participants as well as more ethnically diverse participants.

CONCLUSION

This study confirms that, from their own perspective and experience, hope is significant in the lives of FMs who are supporting relatives with enduring mental health difficulties. It also draws attention to the complex nature of hope as a positive, dynamic and fluctuating process. It indicates that hope is relational at its core because of the interplay of intrapersonal, interpersonal and social factors that diminish or nurture it over time. The knowledge generated in this study will, hopefully, assist mental health professionals to take a hope-inspiring, recovery-oriented, partnership approach with families, when they are supporting a relative who is experiencing mental distress.

RELEVANCE FOR CLINICAL PRACTICE

- Sustaining hope for their relative and themselves is profoundly significant in the lives of FMs who are supporting relatives with enduring mental health difficulties.
- Access to meaningful information from trusted sources, particularly when a relative is first diagnosed and/or accesses the mental health services, nurtures the hope of FMs and, in turn, their ability to support the recovery of their relative as well as themselves.
- Recognition and acknowledgement of the impact of their relatives' mental distress on the health, sense of self and well-being of FMs encourages FMs to self-care and de-stress and, ultimately, to better cope with their supportive role as well as to realize their hopes and plans for themselves.
- Friends, neighbours and the wider community, as well as peer support groups, are well placed to nurture the hope of FMs for their relatives and themselves and could be resourced by state agencies in more structured and targeted ways.

AUTHOR CONTRIBUTIONS

All authors listed meet the authorship criteria according to the latest guidelines of the International Committee of Medical Journal Editors and are in agreement with the manuscript. The authors' contributions were as follows: Designed study: MO'D (RIP), AVF, AH, JMC. Data collection and analysis: MO'D (RIP), AVF, HG, BMC, JMC. Drafting and commenting on paper: AVF, HG, AH, BMC, JMC.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ETHICS STATEMENT

Ethical approval was granted by the Clinical Research Ethics Committee of University College Cork.

ORCID

Joan McCarthy https://orcid.org/0000-0002-6597-9761
Agnes Higgins https://orcid.org/0000-0002-0631-1884
Bridie McCarthy https://orcid.org/0000-0003-3337-4730
Angela V. Flynn https://orcid.org/0000-0003-0192-3141
Harry Gijbels https://orcid.org/0000-0002-9211-8588

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