

**A Fine Balance:
Mental Health and Family Caring**

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Executive Summary

This report highlights the findings and policy recommendations of a research project funded by the Irish Research Council, New Foundations Grant Scheme 2014. The purpose of this research project was to examine specific experiences and lived contexts of family carers who are caring for family members, whose caring requirements have come about as a result of their mental health difficulties, and on the experiences of care recipients in these contexts. The project partnership is a continuation of the relationship between the School of Applied Social Studies and the Carers Association, Cork¹, in carrying out research and informing policy on the lives and experiences of family carers in the region; a community / academic relationship has been on-going since 2007.

In conjunction with Family Carers Ireland, a participatory research project on family caring, where caring needs arose because of mental health issues, was undertaken between March and October 2016. Following a detailed review of the literature on care and policy frameworks framing familial caregiving and mental health in Ireland, twelve depth interviews were conducted with family carers and family care recipients in the Cork region.

The findings highlight the experiences and issues raised by carers and recipients separately and then interdependencies between both are examined. The manner in which family carers reconstruct household and personal priorities and practices in the context of support needs are discussed. Attention is brought to the invisibility of care in these contexts.

Patterns and practices of daily living become normalised, and obstacles encountered tend to compound the invisibility faced in accessing welfare supports that recognise family members as carers. We also see how family carers' experiences can lead to their becoming knowledgeable on the specifics of illnesses their family members face. We see how carers engage actively in management of issues, and consider the individual type of supports that they consider useful. Some go on to become involved at more political and advocacy levels in attempting to affect change for others. For others, the work involved in the support they offer and in rearranging their lives takes all the time and effort they have.

The experiences and issues raised by care recipients highlight the loneliness and isolation often experienced by them, as well as their ongoing efforts to engage and re-connect with social, employment, voluntary and education opportunities. The findings alert us to the obstacles to such engagement - brought about by the structure of treatment interventions, and the nature and level of supports. Sometimes supports meet their specific needs and at other times, they are distanced from them. These findings highlight the reality of living with gaps in services and strategies used to negotiate these gaps. We see how beneficial and positive considered support can be and participants identify key supportive family and professional

¹ In 2015 the Carers Association voted to merge with Caring for Carers. They both now form a new organisation, and operate under as Family Carers Ireland. Further reference will be made to Family

relationships. Their value and insight as advocates cannot be overstated, as they move on to dismantle obstacles they faced, in the hope that others coming after them will have more positive experiences overall. Some research participants continue to face stigma – from within their extended families, from friends and in the community. Others find support and acceptance and support from these places and people.

In particular, the findings highlight ambiguity that is associated with family caring in mental health contexts and which frames caring relations. Invisibility intersects with the nature of mental health issues and the reconstruction of daily lives. It also intersects with a multiplicity of factors that together understate the financial, social and personal costs associated with on-going caring. In restating the centrality of ambiguity and invisibility surrounds these caring contexts it then goes on to make specific recommendations to address issues encountered. Specifically recommendations arising from the research findings include the following:

- Family carers, caring for relatives with mental health issues, are included in the criteria for carers allowance.
- Community services are adequately funded to help recognise, address and support the interdependent nature of family care.
- The voices of carers and care recipients are included in the development of strategies and services, in a grounded way.
- The development of easily accessible avenues for carers and care recipients to articulate their experiences.
- It be clearly demonstrated how their experiences are to be taken into account in the development of policy and practice.
- A range of community services that facilitate engagement of young people with mental health issues, in social activities and that are cognisant of individuals' needs and dispositions be developed.
- Work be continued to increase the visibility of mental health and to challenge stigma.

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Members of Headway provided further perspectives and insights on living with more invisible health issues in the community and commented on the initial findings of the research.

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1 Introduction

PURPOSE OF THE CHAPTER

This chapter provides the rationale for this research project which explores participants' experiences of living with and constructing caring relations in contexts of mental health issues. It details the research context, objectives and methodology used in the study. It also describes the key findings, research contributions and limitations before presenting an overview of the report structure.

BACKGROUND

Since 2007, the UCC-Family Carers Ireland (Cork) collaboration continues to provide an on-going academic/civil society exchange and has resulted in several research initiatives and public policy recommendations. To date, research completed through this collaboration includes studies on experiences and supports available to carers in Cork², as well as studies on experiences of loss and reconstruction of lives for former carers.³ The combined contributions of this ongoing research collaboration have helped make the experiences of carers in the south western region of Ireland more visible. The research conducted has also advanced the work of the Family Carers Ireland in advocating for policy changes at government level in order to address some of the unmet needs of carers and the people for whom they care, which the various research studies have highlighted.

AIMS AND OBJECTIVES OF THE RESEARCH UNDERTAKEN

This current project was funded through the Irish Research Council, New Foundations Grant Scheme 2014⁴. Its specific focus was to examine, with family carers and care recipients, experiences of caring/care giving and receiving, where the need for care arose from mental health issues. This research objective emerged from both from a gap in the literature in relation to the experiences of families living with and caring for members with mental illness, as well from the concerns of members of Family Carers Ireland (Cork) and the Cork Carers Forum. They identified this particular group of carers and care recipients as particularly invisible, both in the community, and to policy makers and healthcare professionals.

² O'Riordan Jacqui and Feilim O'hAdhmaill (2014) *Hearing Family Carers: Going from Bad to Worse*, School of Applied Social Studies, UCC. Available at: <https://cora.ucc.ie/handle/10468/1725>.
Kelleher, Carol (2015) *Life after care: Carers' experiences of loss on cessation of the caring role*, UCC Community Action Research Links (CARL) report for the Cork Carers Association. Available on request from carol.kelleher@ucc.ie

³ Barrett, Trisha (2015) *Life After Care: Transitional Pathways, Reconstruction of Life Post Care and Outcomes for Former Carers*, Master of Social Work Research Thesis, School of Applied Social Studies, UCC. The report is available at this website: <http://www.ucc.ie/en/scishop/tr/>

⁴ Further information on this grant scheme is available at this website: <http://www.research.ie/scheme/newfoundations2014>

OVERVIEW OF RESEARCH

The research focus was informed, in the first instance, by discussions and negotiations with carers. Concerned with gaining an understanding of the lived experiences of carers, its direction was informed through on-going dialogue between carers, the research team and research participants. The qualitative study followed an interactive reflexive research pathway (Ponic, Reed and Frisby, 2010) in that it incorporated information exchange as an integral part of the process. The research that was carried out involved in-depth dialogue with a small number of participants on their own experiences, trajectories, supports available to them and their perceptions of these supports. Specifically, this study, through the integration of experiential, academic and policy based perspectives, characterises the experiences of family carers who care for family members who have mental more than physical care needs, as well as the experiences of those in receipt of care in these contexts. It is a small-scale qualitative study aimed at giving visibility to one particular group of carers and care recipients in the Cork area. It, therefore, speaks to their particular experiences and to the local environment. However, while having this local focus, the manner in which these issues are also identified in national and international literature suggests that their experiences are also more generalizable to a wider population of care contexts

KEY FINDINGS

The key findings of the research draw attention to a particular ambiguity that is associated with family caring in mental health contexts and which frames caring relations. Invisibility intersects with the nature of mental health issues and the reconstruction of daily lives. It also intersects with a multiplicity of factors that together combine to understate the financial, social and personal costs associated with on going caring.

For purposes of clarity the research findings are presented in two sections; the first section outlines the experiences and concerns of family carers, while the second section focuses on the experiences and concerns of care recipients within the family. While similar issues often arose throughout the research process, they did so in slightly different ways, and detailing them separately facilitates the discussion of these particularities. In relation to carers, ambiguity often arose as a key backdrop to caregiving. This ambiguity was associated with the episodic nature of mental health issues and manifestation, as well as the associated difficulties in planning of personal, caring, livelihood and household activities. Family care giving took the form of quite visible support at times of crisis to very invisible, but very necessary ongoing support, in the intervening periods. Care recipients often feared having to live with mental health issues for the rest of their lives. They also experienced a lack of adequate and individualised medical support and assistance, especially at the onset of illness,

when they were particularly unfamiliar with the issues involved. Poor and suboptimal communication between patient and medical staff was also common. For example, the communication of diagnoses was often delivered with little or no explanation, requiring care recipients and their carers to carry out their own research in informing themselves about issues arising for them.

The findings also reveal the complex relationship between family caring and mental illness. Suicide also emerged as an underlying issue, exposing the stress under which both carers and care recipients often found themselves as well as the actual difficulties of achieving a fine balance within the dynamics of the caring process.

In relation to further research, the findings suggest that there is a need for research looking particular at the stress of caring for both carers and care recipients and how society might be able to more fully support the caring relationship and promote better mental health for all concerned. The findings also identify a possible association between an understatement of such interdependencies and levels of suicide.

DISSEMINATION

The knowledge produced through this project is now in a position to facilitate the elucidation of specific issues facing this sub-set of family carers and those for whom they care.

Furthermore, in addition to guiding the way for further research / interventions directed towards meeting these challenges, the research has the potential to give voice to the specific experiences of these family carers and those for whom they care. This knowledge, which is grounded in their lived experiences, will be an invaluable contribution to our understanding of the dynamics and nature of care located within the family, and set in the context of local and regional conditions.

REPORT STRUCTURE

The report comprises six chapters, which are outlined in detail below:

In *Chapter 1*, the *Introduction* to the report, we provide a brief overview of the research rationale, research objectives, research methods and key findings. We conclude with the structure of the report and dissemination of the research to date.

In *Chapter 2*, *Family caring in mental health contexts*, we review and synthesise some of the contemporary discourses and debates amongst scholars in relation to family caring in mental health contexts. This chapter is divided into two sections. In the first section we focus on issues identified in the literature pertaining to family carers and thereafter we discuss issues arising for care recipients.

In *Chapter 3, Mapping the policy landscape*, we review and synthesise two key policy frameworks that are central in guiding policy development in this area: *The National Carers Strategy – Recognised, Supported, Empowered*, first published in 2012 and consequent progress reports thereafter, and *A Vision for Change* published in 2006, which is the current health strategy document guiding mental health services in Ireland. Its term spans from 2006-2016. Our focus in this section is to highlight the specific provisions in each that pertain to supporting family caring relations in the context of mental health issues.

In *Chapter 4, Research approach, process, influences and methods employed*, we outline the research philosophy, design, and methodological choices underpinning the research conducted.

In *Chapter 5, Family caring and mental health: findings of the research undertaken*, we present the research findings. This chapter is divided into three sections. The first focuses on the experiences and issues raised by carers. A section that presents issues raised by care recipients follows this. The third section examines interdependences highlighted throughout the research process.

The final chapter of the report, *Chapter 6, Conclusions and recommendations*, brings together the key conclusions of the research, focusing on those issues of particular concern to family caring and mental health. In restating the centrality of ambiguity and invisibility surrounds these caring contexts it goes on to make specific recommendations to address issues encountered.

2 Family caring in mental health contexts: insights from existing literature

INTRODUCTION AND OVERVIEW

This chapter provides an overview of issues arising in the literature on family caring, with specific focus on mental health contexts. Research in this field has contributed to making the lives and experiences of family carers and care recipients more visible. The literature highlights the interrelationships and interdependencies that exist in such contexts, as well as articulating characteristics of care and other-centred work and orientations (Tronto 1993; Kittay 2002; Lynch et al 2009; Held 2006). Many studies highlight that caring relations are socially constructed, seek to develop theoretical understandings of care and caring relations, and situate caring and care giving at the centre of human activity. The care literature also highlights the extent of work and skill that is involved in providing care and support offered, the interactions between familial roles and relationships in constructing environments of care, and give voice to the views of both carers and care recipients in such contexts.

Embedded within the move away from institutionalised care and a concurrent shift of emphasis to care in the community, driven by ideologies and policies of ‘aging in place’ are societal norms and expectations that family members will take on increased care roles. However, expectations about family caring, while tacitly present are often not clearly articulated or supported in healthcare and social policies. Such factors contribute to the increased difficulties in fulfilling caring roles and highlight a gap between service assumptions and the realities of community/family caring contexts (Colombo et 2011; O’Riordan and O’hAdhmaill 2013; Dalton-O’Connor et al 2014). We see that, in general, once treatment for acute symptoms of mental illness is complete, patients are discharged from hospitals/ clinics with the assumption that they return to their lives in their communities. Should they require further more long-term care, it is assumed that family members/community supports will fulfil those needs and that some level of support will be available. According to Census 2011, 182,884 carers are caring for their family members in Ireland. This population of carers are largely unpaid and generally provide substantial amounts of care over extended periods of time (Census 2011; Care Alliance 2015). Family care giving contexts range from caring for family members who have become frail, have had some form of disability, and/or suffer from a range of chronic conditions (Foley 2008; O’Riordan and O’hAdhmaill 2013).

COMPLEXITY OF LIVING WITH MENTAL ILLNESS IN THE FAMILY

A smaller and more focussed body of literature draws attention to the very complex nature of living with and supporting family members with mental illness. This literature offers further insight into issues such as care burden and the difficulties in identifying and addressing the needs of these carers (Lloyd and Carson 2005, Kuipers et al 2006). Other themes addressed in this literature include: information sharing and confidentiality (Pinfold et al. 2007, Slade et al 2007, Gray et al 2008), participation in decision-making (Roulstone and Hudson 2007), and relationships with practitioners (Krupnik et al 2005; Clarke 2006; Wilkinson and McAndrew 2008). Furthermore, assumptions about the roles of families in caring for loved ones with mental illness and expectations about their knowledge base and availability intertwine with family members' own interpretations of their familial roles. This presents further challenges to understanding and articulating expectations and moving towards supporting them. Furthermore, and not surprisingly, there is a health-oriented focus in much of the research in this area and research has a tendency to be oriented towards identifying/refining possible health service interventions/supports, as opposed to addressing family care needs in relation to caring for members with mental health difficulties more generally. Therefore, specific issues arising in caring for a family member with, for instance, depression, schizophrenia, bipolar and intellectual disability draw attention factors that are associated more particularly with these condition oriented contexts, offering insight into more particular issues arising in these specific contexts.

LOCATING PERSONAL EXPERIENCES OF MENTAL ILLNESS WITHIN THE FAMILY AND COMMUNITY

Focusing on the experiences of those living with serious mental illnesses in the United Kingdom, Lester and Tritter (2005) found that participants in their study described it as 'impossible to ignore their impairment, the impact of the illness itself and others' reactions to their diagnosis on their individual identity, on their wider relationships with friends and family'. They contended that those who were living with mental illness were lonely and isolated in their communities, often feared interacting in the wider community and generally had few opportunities for interaction and development of friendships. While support was found in families and voluntary groups, 'care in the community was equated with a solitary existence outside the mainstream, with little hope of living a 'normal' life (p. 660). Similar experiences were also observed in the Irish context. For instance, Dalton O'Connor et al (2014) investigated experiences of those living with acquired brain injuries in Ireland and found that outside of immediate family members and specific voluntary support, people had very limited interaction with and support in their communities. Immediate family members

were often key supports for them, in accessing information regarding their conditions, working with them to identify potential services, negotiating medical bureaucracies and in day-to-day care and companionship. However, such support sometimes presented challenges in negotiating dynamics of power and control, and unobserved, could be open to manipulation. Finding the balance between levels of dependency, interdependency and autonomy was always experienced as a post-injury journey towards a new conceptualisation of self and newly emerging interdependencies. Sometimes it was a difficult and protracted one and involved compromises and a re-negotiation of ideas of self and others over a period of time.

STRUCTURE OF DISCUSSION

In order to bring clarity to the specificity of these contexts and the perspectives of those involved in these particular caring relationships, as well as the complexity of interdependencies that emerge and evolve, this chapter first discusses issues arising and experiences of carers. A section then follows on the experiences and perspectives of care recipients.

Perspectives of Family Carers

INTRODUCTION

Our synthesis of the literature on family carer perspectives revealed the following overarching themes:

- The complexity and ambiguity of family caring contexts in mental health
- Articulating and recognising care in mental health contexts
- Communication with services and supports
- Balancing divergent needs within households

The discussion of issues arising is structured under these themes and thereafter followed by a brief conclusion

THE COMPLEXITY AND AMBIGUITY OF FAMILY CARING CONTEXTS IN MENTAL HEALTH

The family caring context in relation to caring for family members with mental health difficulties can often be very complex. For instance, Wales and Prymachuk (2009, cited in Rowe 2012: 74) found that carers caring for family members with mental health difficulties had different needs to those caring for a relative with physical problems. They suggest that caring for family members with mental health difficulties can have adverse impacts on carers own sense of worth (Wilkinson and McAndrew 2008) and that sustaining care in such contexts is generally unsupported and requires a steep and sustained learning curve (Gray et al 2009). McCann et al (2015) undertook research into experiences of carers for older people who have severe mental illness with the aim of identifying what helped them to sustain their caring roles. Similarly, they found that such caring was often difficult and demanding, and had adverse emotional, physical, social and financial effects on carers.

The ambiguity of living of mental illness -its ups and downs- and balancing differing family and household concerns within this ambiguity was identified by Rose et al (2002) as a defining characteristic of family caring in this context. This ambiguity relates to unpredictability of behaviour, and associated tensions and feelings of being consumed by concerns related to the illness. Drawing on research they undertook with family carers on their experiences, they argue that '[f]amilies described an enduring stance of watching and waiting. They worked to figure out the subtleties of symptoms and worried about what they meant' (p. 526). In this, they draw our attention to the nature and background environment in which such caring contexts work themselves out: one where the particular illness/associated behaviour/patterns and issues arising, form a intense backdrop to everyday life and make up an environment of watching, waiting and unpredictability.

Providing support for a family member who suffers from mental illness is often initially accompanied by a sense of crisis, with family members attempting to come to terms with and understand conditions, find answers to their questions and concerns, and identify sources of support, while simultaneously attempting to maintain normalcy in their lives. Rose et al (2002: 517) suggest that [f]amily members become caregivers, providing ongoing support and practical assistance while grappling with their lack of understanding of the mental illness itself' and they group responses of family carers into three categories: (a) keeping watch/losing trust, (b) being consumed by the illness, and (c) making sense of behaviours as illness symptoms. They go on to suggest that '[i]n the early stages and during many repeated hospitalizations, family members described a sense of crisis and an urgent need to find answers to help them to manage the crisis' (p. 527). They suggest that this period can then be followed by a stage of attempting to secure some control over the illness, for those suffering symptoms of mental illness, other family members, and themselves. This process can include dealing with feelings loss and grief, management of conditions and negotiations on responsibility for symptom management; negotiations that can be stressful, conflict-ridden and sometimes violent. Sometimes, over time, this ambiguity become an unbearable burden. As Rose et al state

Relationship patterns shifted at this stage as families experienced the ebb and flow of waning and resurging hopes from periods of calm and episodes of crisis and acute exacerbations of the illness. Families considered shutting the patient out, sometimes physically, as one mother did by locking her ill son out of the house. Families reached breaking points in their tolerance of patients' behaviors, such as when the patient became physically threatening or began drinking alcohol to excess (2002: 528).

Other times, changing patterns and behaviours are incorporated into the "new normal" of family life through a complex set of negotiations between all involved. Sometimes breaking points, as discussed above, provide a catalyst for further negotiations on supports needed and those offered to individuals. Wynaden (2007) undertook research on carers' experiences in Australia in the context of a growing move to community support for people with mental health issues. She found that when participants in her study began caring, they were often 'overwhelmed by the role and consumed by what was happening to the ill family member, to themselves, and to their family' (p. 381). In attempting to understand carers experiences in a conceptual manner and thus, contribute to developing analytical tools to deepen this understanding, Wynaden (2007) conceptualised such feelings as 'being consumed' following a family member's illness and consequent need for care. She suggests that in managing the process of being consumed by care, carers then tried to achieve a balancing of commitments of the particular family member and other household and personal commitments. Achieving this balance requires attention to the unpredictability of mental health issues arising within competing personal and familial and household patterns. Over time, Wynaden (2007) suggests, high levels of commitment to the family member with mental health difficulties

could lessen and become proportionate to other commitments, obligations and responsibilities.

Family roles, relationships and expectations

A number of articles focus on changing familial relationships and expectations. Some examine the feelings of loss, in particular, that parents have in coming to terms with and supporting their children. Parental care in such contexts is often experienced as life long and interspersed with 'on going grief, sorrow and losses interpreted as chronic sorrow' (Pejlert 2001:199). It intersects with both conflict between family members and professional care systems and support from same, as well as experiences of stigma and public shame. Harden (2005) suggests that parents reconstruct narratives to fit the dual roles they adopt as parents and carers in attempting re-interpret experiences and hopes for the future for the family member being cared for. An associated issue is what is described as living with feelings of 'complicated grief' (Jones 2002), in which the carer holds ambivalent feelings towards their relative with severe mental illness. This can result in feelings of betrayal, hostile responses at times, and a longing for 'what was once' or what 'might have been'. A small number of articles examine gender differences and expectations in caring for partners and children, highlighting the gap between the realities of the lived experience and idealized gendered notions of care. Moller et al (2009) found that women carers 'experience higher levels of burden and depression and lower levels of subjective well-being and physical health than men' (p. 157). Bottorff et al (2014) draw on a gender relations approach (Connell 1987) in their study of women caring for their male partners with depression. Their study offers insights into how women partners interacted with gendered caring roles, sometimes accepting and sometimes challenging such assumptions. They suggest that gender relations be included as a key consideration in developing successful care management and in understanding family and relationship care dynamics. Slade et al (2007) in their policy synthesis on carers in these contexts found carers provided effective and safe care, and generally they did the job well.

ARTICULATION OF AND RECOGNISING CARE

Family caring in the context of mental health difficulties is characterised by its long-term nature (Rapaport et al 2006) is associated with high levels of invisibility, and involves the adoption of particular roles that intersect with familial obligations. Banton 1965 (cited in Rowe 2012: 72) suggests that these caring roles 'can be explained as sets of obligations and rights, where obligations denote what is expected of the role holder and rights are those elements that enable fulfilment of obligations'. Lyons et al (2009) suggest that family caring only becomes recognised at crisis points and at acute times when medical professionals are involved, often at breaking points in a relative's illness. Furthermore, Wilkinson and

McAndrew (2008) argue that carers want to be involved in decision-making, and contribute their relative's care but are often excluded and isolated from formal care discussions.

Rowe (2012), in a review on the role of family carers in cases of severe mental illness, summarises what the obligations of a family carer entails. He suggests that they are comprised of providing/developing safe care as well as balancing involvement, risk, management, information sharing and knowledge acquisition. Providing care reduces carers own free time and reduces time and social activities (WHO 2003; Fiorillo et al. 2011). It involves the emotional and physical work of sustaining caring, comfortable and loving relationships. It can also involve more instrumental support, such as engaging in shared activities, accompanying a family member socially, and to medical and support service appointments/events and so on.

McCann (2015) found that carers found their roles to be emotionally and physically demanding and that stress increased if their family member was heavily sedated or was admitted into residential care. Increased levels of stress were also associated with criticism of other family members. Radfar et al (2014) explored the experiences of family members caring for relatives suffering from depression and highlighted the economic as well as social costs of care. Their participants reported that planning everyday life was often difficult. This related to the sporadic or episodic nature of their relatives' illnesses, which then also had adverse impacts on their ability to continue working and earning. Similarly, Gray et al (2009) advise that care is often undertaken out of consideration of familial duties and has a tendency to be sporadic and unpredictable.

COMMUNICATION WITH SERVICES AND SUPPORTS

The expertise that family carers hold was foregrounded by Wilkinson and McAndrew (2008) who suggest that they are an important source of knowledge and are expert in knowing the person behind the illness. Despite this, it is suggested that professionals often see carers as challenging and can be suspicious of them. This, in turn, can have adverse effects on relationships and communications between carers and professionals. Interestingly, Lowcyk et al (2004) point out that only a minority of those caring in these contexts look for support from services. Such indicates high levels of carer invisibility and forms a more general backdrop.

In attempting to clarify expectations on the roles and obligations of family carers, Rowe 'aimed to find out what professionals expected of family carers and what family carers expected of themselves' (2012: 70) and found that health care professionals made assumptions on the moral obligation of family members 'to support effective care, but that the rights to enable carers to fulfil these obligations were not consistently upheld' (p. 70). They further suggest, with reference to the UK, that mental health professionals expected

caregivers to act in the best interests of their relative, but not in their own best interests.

This assumption is critically discussed in the Australian context by Winch (2006) who suggests that the family carer is being constructed through a state imposed morality of care. Winch (2006) examined the moral and ethical expectations constructed by the state and imposed on family carers of older people in Australia. Her analysis is a timely warning on how assumptions about natural orientations to care in close personal relationships, can be distorted to become oppressive agents of social control in an environment dominated by neoliberal thought. She details the manner in which the professional health care service, the state and health care workers enforce codes of behaviour

in relation to the care recipient and [the family carer] is seen as a blend of selfless helpmate and professional entity...In general, carers have to work in the best interests of the care recipient, but not necessarily in their own best interest. The carer is then constructed as a person who is compassionate, empathic, merciful and selfless (Winch 2006: 14).

Where family members do not match these assumptions, they are then constructed as problematic and defined as having 'complex needs', in effect they are denounced because they do not adhere to imposed sets of behaviours. On the other hand, Chen and Greenberg (2004) identify information sharing and collaborative interactions with professionals as significant supports for family carers.

BALANCING SUPPORTS AND NEEDS? CARE BURDEN AND DEVELOPING RESILIENCE

An amount of research on family carers and care giving focuses on what is termed a care burden, often identifying the negative impacts that high caring involvement has on the physical and mental well being of carers themselves. What is also sometimes referred to as family burden is defined 'as the presence of problems, difficulties or negative events that influence the life of the family member of the psychiatric patient (Lowyck et al 2004: 395).

Thus, it is known that caring over long /intense periods can have adverse impacts on the physical health of a carer; that carers frequently suffer from depression associated with isolation and priority given to the needs of others; and are often adversely impacted upon financially. Lowyck et al (2004) go on to state that '[f]amily members of schizophrenic patients experience burden on a practical, financial and emotional level and the extent of the burden is closely linked to the amount of symptomatic behaviour of the patient' (p. 395).

Thus, they draw our attention to the interaction between levels of burden and behaviour of a family member owing to the problems they are experiencing.

In the caring literature more broadly, the concept of family burden has also been further broken down into objective burden and subjective burden (Hoenig and Hamilton 1966, cited in Baronet 1999). Objective burden refers to 'negative effects of the illness on the household and the caregiving demands placed on family members', whereas subjective burden 'refers to

the caregiver's or family member's personal appraisals of the situation and the extent to which individuals perceive they are carrying a heavy load' (Baronet 1999: 820). In a review of literature on caring for family members who were caring for family members with mental health issues in Canada, Baronet found that objective burdens were experienced in:

providing transportation, help in money management, housework and cooking, need for constant supervision, restrictions in caregivers' personal activities and providing financial help' [whereas] the '[h]ighest SB [subjective burden] was reported for issues of safety and possible violence of the ill individual toward self and other, excessive demands and high dependency toward caregiver, night disturbances, embarrassing behaviors, symptomatic behaviors, worries about the future, and uncooperative attitude leading to conflicts and family hardships (819-20).

Other studies suggest that examining care/family burden at different stages in the process of caring, incorporating its objective and subjective elements, is more useful in understanding people's lived experiences (Lowyck et al 2004). All are helpful in assisting us to come to an understanding of the different aspects of care or family burden, in separating out the objective task oriented type of burden from its more subjective aspects, as well their interaction with one another along a continuum of care.

Due to the focus on burden within the care literature, it has frequently been criticised for unduly focussing on the negative aspects of care. It is important to point out that there are other, more positive, aspects to the caring relationship /journey, despite difficulties encountered. Lowyck et al (2004: 401) point out that, in their study of family carers caring for relatives diagnosed with schizophrenia, '[s]ome respondents pointed out that they often got something out of caring for the patient, such as a much more solid relationship with their family member than before the onset of the illness'. They argue that in considering care /family burden, it is important to keep this in mind and not be overly focused on burden to the neglect of other aspects of evolving relationships. Similarly, McCann et al (2015) found that, over time, carers develop resilience in caring, which helps sustain them in their role. They suggest that through considering caring as purposeful and satisfying; harnessing social support from others; and maintaining their own well being, carers develop this resilience.

CONCLUSION

From the above discussion, we see that family caring for family members with mental health difficulties is multifaceted. It is associated with high levels of invisibility and, while often long term, is generally sporadic in nature. It is associated with high levels of stress, related to its very nature, as well as complexities involved in managing and balancing changing and sometimes, unpredictable needs. Communication with services can be challenging, although support from mental health professionals, when available, can also be a source of support for carers. Motivators behind the construction of the 'selfless carer' are important factors in developing a comprehensive understanding the interaction between structural and cultural influences. Caring intersects with familial roles, assumptions and obligations, and carers often experience feelings of loss that interact with their own expectations of themselves, as family

members as well as those constructed by the wider society in which they live. While burdens of care can be high and connected with exhaustion, carers can also develop strategies of resilience over time.

Perspectives and experiences of care recipients

The literature on the experiences of care recipients is more limited than that of carers, and is often focused on engagement with service providers rather than support within family/household contexts. Nevertheless, through our synthesis of issues examined in this literature the following themes were identified, and shed light on the issues that intersect with household/family support.

- Physical and emotional impacts of living with mental illness
- Medication, treatment and support
- Gender identity, education and employment

Discussion in this section is structured under these headings and thereafter followed by a brief conclusion.

PSYCHOLOGICAL AND EMOTIONAL IMPACTS OF LIVING WITH MENTAL ILLNESS

Living with mental illnesses is often an on-going part of people's lives encompassing periods of strength and confidence and those of instability. For instance, Martin (2000) describes living with schizophrenia as a continuous process of 'riding the storms of good times and bad times' (p.138). It can be frightening, isolating, and difficult to communicate to others and not very well understood. Lester and Tritter's (2005) study of peoples' experiences of serious mental illness draws attention to how frightening such experiences can be and how they can also be impossible to describe to those who have not experienced mental health difficulties.

[t]he experience of mental illness was almost universally described as frightening for the individual, their family and their friends, particularly during the build-up to a 'crisis'. It was also acknowledged as something that was almost impossible to describe to someone who had never experienced it, and difficult to appreciate for those with no lived experience of mental illness (p. 657)

Discussing stigma associated with particular mental illnesses, Harrison and Gill (2010: 242-43) even suggest that a diagnosis of schizophrenia brings with it 'a 'second illness': the reactions of the social environment and the stigma associated with the disorder [leading] to social isolation, limited life chances and delayed help-seeking behaviour'. The label alone can bring a life of stigma with it and consequent isolation can then lead to feelings of depression. Lester and Tritter (2005) also discuss difficulties people with mental health difficulties have in accessing health services, and associated lack of confidence, especially for those suffering depression. Furthermore, their findings indicate that people considered that they needed to appear rational if and when accessing services; something that those with psychotic diagnoses found adds to their stress and fears. Finding ways to fill one's time with meaningful activities has also been identified as an issue for those with mental health issues, even for those who interacted with support organisations (Rankin 2005) and those who were supported by family members (Dalton-O'Connor 2014). Taken in tandem with the invisibility of mental health /ill-

health, these factors highlight important issues concerning the experiences of living with mental illness, as well as the dynamic interdependencies of family care giving.

Lester and Tritter (2005) found that some of their research participants went a little further in embracing their mental health 'conditions', thus giving legitimacy to an associated alternative rationality. This group of people 'believed that it was important to 'own' their impairment and indeed to feel positive about embodied irrationality rather than ignoring it or being ashamed' (Lester and Tritter 2005: 658). In doing this, they give more credence to their voices and challenge more hierarchical expert-led communication about mental illness.

However, feelings of disempowerment, shame or stigma are more common experiences of those who are with living with mental illness (ibid). They also suggest that a cultural bias exists in society at large regarding mental illness, which people who are diagnosed /suffer from mental health problems internalise. Harrison and Gill (2010: 244) suggest that

[i]ndividuals who are diagnosed as mentally ill accept the shared knowledge and internalize the cultural norms and rules. They accept the validity of the diagnosis of schizophrenia, their health status or the need for treatment, which may lead to accepting the negative identity assigned to them, which can be disputed and leads to internal stigma.

Weiss (1994) claims that stigma associated with mental illness develops from early childhood and then continues throughout the life course, while more recently it is argued that such stigma can and is being challenged with greater awareness and understanding of mental health /illness (McGuffin and Neilson 1999).

EXPERIENCES OF MEDICATION, TREATMENT AND SUPPORT

Medication, while addressing some aspects of mental illness, can also raise difficulties with regard to sustaining social interactions and livelihoods. Side effects of medication, including tiredness and low levels of concentration, are common. For example, Lester and Tritter (2005) suggest that weight gain, commonly associated with medication, adversely impacts on women. They state that '[t]he side effects of medication, particularly weight gain for women and tiredness and blurry vision, were frequently raised as difficult to live with, a situation made worse by the relative lack of discussion and information from health professionals' (p. 658).

Tambyerzer and Van Audenhove (2013) point to the importance service users attach to actively engaging in decisions about their mental health, treatment, and care plans, highlighting the importance care recipients/service users attach to equal partnerships in the care and treatment of their conditions. They state that '[s]ervice users mainly value receiving chances for involvement, participating in treatment decisions and being treated as equal conversation partners, as do the family carers (p. 678).

In contrast to this perspective, making reference to nurses and their interactions with patients who have been diagnosed with schizophrenia, Martin (2000) observes that health

professionals appeared to have only a minimal understanding of what it is like to experience hearing voices, thus limiting their potential for understanding experiences of patients. His recommendation was that health professionals should focus more on developing an enabling environment and less on the details of diagnosis, thus placing the emphasis on developing a supportive, open environment in which such understanding could be encouraged and people's experiences could be expressed and articulated as much as possible.

In experiencing the contexts of treatment/accessing services, it was found that people also identified limited health care resources and a concentration on psychotropic treatment as limiting their ability to engage in full discussion /exploration of treatments /interventions appropriate to their needs (Mechanic 1994, cited in Harrison and Gill 2010). Harrison and Gill (2010) further argue that limited resourcing of health care budgets can be seen as a form of discrimination against those with mental illnesses, in that the low priority given to such services impact on people's abilities to participate fully in society. They quote Mechanic (1994) in suggesting that 'the way in which resources are given to the mental health services affects not only patient's recovery, but their quality of living as well' (Mechanic 1994 cited in Harrison and Gill 2010: 243-44).

What is clear from the above range of issues is that engagement and full participation in decisions about their well being are important to people who are experiencing difficulties in maintaining their mental wellbeing. However, service users commonly experience stigma and discrimination in the community, drawing on prejudices that are sometimes developed from early childhood, that are evident throughout the life course, and across all sectors of society, including the level of resourcing that goes to mental health services. In turn, experiences of stigma and discrimination lead to marginalisation of people who are diagnosed with mental illness and serve to contribute to their silencing. At the same time, people with mental health difficulties develop their own strategies to enable them to give voice to their experiences.

GENDER IDENTITY, EDUCATION AND EMPLOYMENT

Gender identity

A small number of articles examine gender dimensions of living with mental illness. They draw attention to interactions between gender identity, expectations around roles and relationships and again, draw attention to the invisibility of mental health issues, which leads to lack of recognition of changing interdependencies within the family.

Johnson et al (2012) argue that male care recipients' conceptions of themselves and their masculine identities, as well as those of the societies of which they are a part of, influence how men who are suffering from depression, seek out support. They undertook a qualitative

study in Canada that investigated how men sought help for depression, their perceptions about their depression and the types of assistance and support they sought. Their findings reveal that '[m]any men suggested, with acute awareness, that their reluctance to seek help [for depression] was tied to their sense of masculinity (p. 350). They also noted that men found it more acceptable to seek help from family members rather than professionals; a strategy that maintained their sense of self and confidentiality around their well-being. The majority of men who participated in their research 'invoked manly self-reliance in a number of ways as they tried to position their depression as a minor personal problem that could be handled alone. The notion that "manly" men do not seek help was a key feature of this discourse.

In an Irish study which explored female experiences of care, Dalton-O'Connor et al (2014) found that women with acquired brain injury, particularly when the effects of their post injuries were less visible, found it difficult to ask for support and were sometimes expected to continue to fulfil gendered family /relationship roles as they had pre-injury. They state that these women 'seemed to experience a particular lack of understanding from others as their injuries were quite 'invisible' and so others generally assumed that they were now fully recovered – back to their 'old selves''. Once past a stage of acute medical intervention, expectations were that life would return to normal, i.e. as before, particularly in the absence of physical manifestations of an injury; the invisibility of mental injuries and associated limitations such as tiredness, lack of memory, sensory difficulties as well as the frustrations of dealing with them, that the woman might have post injury, were often not fully taken into account or understood, and sometimes were just dismissed.

Education and Employment

Accessing employment can be difficult for those with mental illness, with obvious consequences for quality of life, finances and feelings of self worth, particularly when living in a society where one's worth is often equated with one's employment and level of education; increasingly normalised expectations in modern societies (Evetts 2003; Sweetman 2003). Gill and Harrison suggest that 'patients have their jobs terminated because of aspects of their illness (2010: 243-44) and cite an earlier study by Tsang et al (2003) in the UK where it is argued 'that employment and financial burden also had a major impact on the quality of life of patients' (cited in Gill and Harrison 2010: 243-44). Similarly, Dalton et al (2014) found that for most participants in their study, employment and /or education opportunities had become much more restricted and their financial positions had deteriorated considerably post injury. A small number of exceptions to this pattern, whereby employers' re-formulated positions to facilitate their employees conditions post diagnosis, offered some level of optimism for more informed and open employment. Harrison and Gill (2010: 248) argue for a

‘greater public awareness, reporting of mental illness by media, change public view of mental illness and support people in employment and promote employment as an option for others who are unemployed’.

Related to this and interacting with age, continued participation in /re-accessing education can be difficult for those with mental illnesses. On-going issues arise in re-entering education programmes, re-training and attaining qualifications that are increasingly a pre-requisite for employment. For instance, it may not be possible to meet normal expectations of curricula, examinations might bring with them high levels of stress and education programmes that are based on full-time participation can be too inflexible. Obvious problems then arise for younger people whose education is interrupted and who then find themselves without qualifications and thus at a disadvantage in accessing employment as a result.

CONCLUSION

In summary, existing research suggest that living with mental health issues can be a long-term part of a person’s life and that symptoms are often experienced as frightening and as having significant impact on quality of life, education and employment opportunities. Added to this comes stigma and limited understanding and /or capacity of those who do not experience symptoms to understand the embodied experiences of living with mental illness. Isolation, limited interaction with community and low levels of public awareness are common. Limited employment and education opportunities are usual as are limited accommodation for changing norms and practices in employment and education. Support from family members seems important in researching and interacting with health professionals and in every day living. This support intersects with gendered roles and expectations and it can be particularly difficult for women to be understood as needing sustained familial care support. Such support brings with it new interdependencies and challenges in personal relationships. For people who experience mental health issues that require on-going support, being heard and fully participating in strategies/interventions to address issues arising seems to be critical.

3 Mapping the Policy Landscape

INTRODUCTION

In order to contextualise our findings, it is necessary to provide a brief overview of national social and healthcare policies which impact the provision and experiences of mental illness in Ireland, as well as caring (including family care) more generally. Policy developments in the areas of family caring and mental health have a long and often separate history. Both policy domains are not integrated, which in turn impacts on families' experiences of mental health. In this overview, we specifically focus on two current key drivers in each area: the *National Carers Strategy – Recognised, Supported, Empowered*, first published in 2012 and consequent progress reports thereafter and *A Vision for Change* published in 2006, which is the current health strategy document guiding mental health services in Ireland. Its term spans from 2006-2016. Specifically, we highlight the provisions in each policy that pertain to supports (or hinders) family caring relations in the context of mental health issues.

NATIONAL CARERS STRATEGY – RECOGNISED, SUPPORTED, EMPOWERED

The Carers Strategy was published in 2012 (Department of Health, 2012) and focuses on outlining the policy framework that recognises and supports unpaid carers in the community who provide significant levels of caring for family members, neighbours and /or friends. Within this document, a carer is defined as 'someone who is providing significant levels of care to a person who is in need of that care in the home due to illness or disability or frailty' (p.8). The strategy emphasises the importance of recognising, supporting and empowering carers. It includes four national goals addressing priority areas that were co-identified by carers and organisations representing them, as well as being informed by issues arising internationally. Each priority includes a number of goal-specific objectives, itemising the overall vision of the policy into forty-two practical and measureable undertakings.

The four priority areas highlighted are as follows:

1. Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for.
 2. Support carers to manage their physical, mental and emotional health and well-being.
 3. Support carers to care with confidence through the provision of adequate information, training, services and supports.
 4. Empower carers to participate as fully as possible in economic and social life.
- (Department of Health 2012:10)

While all four priorities are relevant to family carers, caring for family members with mental health issues, some sub-objectives under each goal are of particular relevance. These we now outline below:

Under *Goal 1*, key objectives include:

1.2 Including carers in planning and decision making for those that they care for.

Under *Goal 2* key objectives include:

2.1 Promote the development of supports to protect the physical, mental and emotional well-being of carers.

Under *Goal 3*, key objectives include:

3.1 Promote the availability of user friendly and timely information and advice.

Under *Goal 4*, key objectives include:

enabling carers to access respite (4.1) and retain contact with the labour market (4.2).

Since the publication of the Carers Strategy in 2012, the Department of Health has produced Annual Progress Reports detailing progress on each of these goals and the Carers Association has also followed progress through publication of a *Family Carers' Scorecard* (2014).

In their 2015 progress report, the Department of Health point to the following as progress in *Goal 1, 1.2*:

The establishment of working groups to inform reform of disability services in which carers views are to be taken into account; the development of a National Dementia Strategy; co-operation across agencies in rolling out Meitheal – a community based model for working with vulnerable children and young people – as well as the organisation of a Health Consultation event 2014, at which carers were represented. (Department of Health, 2015: 4).

Progress in actions under *Goal 2, 2.1* was recorded by the Department of Health (2015) as including:

Discussion on carer needs in primary health care meetings, meetings at which it states carers can attend, when appropriate and with the permission of the care recipient (p.14)

For actions under *Goal 3*, under actions under 3.1, they state that they developed a section on carers on the Department's website and give examples of how this information is making information accessible (p25-26).

Under progress on *Goal 4.2*, they focus on care leave provisions for staff in the Department of Health as well as their policies on family friendly workplaces.

On the other hand, in *Scorecard* (2014)⁵, the Carers Association states that '[o]n the whole, the level of progress across the strategy is poor' (p.6). With regard to the specific

⁵ Progress on the Strategy was monitored by a monitoring group set up by the Carers Association and comprised family carers, representatives of the Carers Association and Care Alliance.

goals/actions mentioned above, this *Scorecard* details each goal, objective and actions to be followed in achieving progress. It reports the following:

‘No Progress’ on *Goal 1, 1.2*,

‘Initial but slow Progress’ on *Goal 2, 2.1*,

‘No Progress or/Initial but Slow Progress’ on actions under *Goal 3, 3.1*, and

a range from regressive progress to initial but slow progress on actions under *Goal 4, 4.2*.

In summary, while the development and publication of a National Carers Strategy does represent a positive step in recognising carers, the realisation of its vision requires resourcing and particular attention to their evolving experiences and their interaction with broader societal trends. The divergence in perspectives on level of progress in meeting the priorities and objectives identified remains worrying. It is arguable that the detail of the Department of Health’s focus seems to be at a preparatory rather than an implementation level and thus, likely to be a little distanced from the reality carers face in their daily lives. The detail included in the *Scorecard* is more grounded in practical measures, and these practical measures provide considerable room for progress as well as concrete avenues towards achieving it.

A VISION FOR CHANGE

The second policy document impacting on family caring in Ireland is *A Vision for Change*, which was published in 2006 (Department for Health). This is the guiding document framing the shape and development of mental health services in Ireland. It states that ‘[i]t proposes a holistic view of mental illness and recommends an integrated multidisciplinary approach to addressing the biological, psychological and social factors that contribute to mental health problems (p.8). It emphasises the importance of person-centred care to be ‘evolved and agreed with service users and their carers. (p.8) and it makes particular reference to the importance of including service users⁶ and their carers in all levels of service intervention. With regard to recovery from mental health difficulties, it states that [i]nterventions should be aimed at maximising recovery from mental illness, and building on the resources within service users and within their immediate social networks to allow them to achieve a meaningful integration and participation in community life (p.8).

This framework includes provision for the development of community-based teams of clinicians, across several local health catchment areas, with populations of between 250,000 and 400,000 people. It proposes that services that are geared towards serving particular population groups and adopts, what it terms, a lifespan approach. This is aimed at ensuring

⁶ Terminology used in the document under discussion.

services are developed to meet particular age /ability groups in the population for each health service catchment area. Services to be developed for particular population groups are: child and adolescent services, general adult services, rehabilitation and recovery services for people with severe and enduring mental illness, mental health services for older people, for people with intellectual disability as well as a range of other specialist services. The development of community based health supports provided by multi-disciplinary teams is at the centre of this strategy, as is the involvement of service users and carers. A specific emphasis is also placed on supporting recovery through care plans that are to be developed in line with an individual's particular needs and networks. The vision outlined is that '[s]ervice providers should work in partnership with service users and their families, and facilitate recovery and reintegration through the provision of accessible, comprehensive and community-based mental health services (p.14). The policy document also prioritises the meaningful involvement of carers in planning and delivery of care and recognises potential emotional, financial and social costs for carers. It promotes the idea of partnership in care, involving service users, family members, carers and community networks and suggests that user involvement policies be developed by health service providers. Furthermore, it highlights the differences between categories of service users and cautions against considering them as interchangeable.

In summary, it would be reasonable to expect, as a result of publication and implementation of a *Vision for Change*, that existing mental health services and supports for family carers and care recipients in Ireland would emphasise communication, ensure the availability of holistic community-based services, geared towards the needs of particular groups in the population, and work to meet the individual needs of their clients. One would also expect clear methods and avenues of communication as well as communication across services themselves, in the interests of their service users. Regrettably however, reports on progress made in involving service users and family carers paint a mixed picture of progress and differ across the country. There is, however, some evidence that service provision and inclusion has become more inclusive of user and family views, and carer forums have been established across the country. However, it seems that progress is driven by key individuals at local levels and dependent on them, rather than evidenced in more systemic change throughout the country, which would ensure parity and fairness in relation to the provision of services and supports for all citizens. In assessing the implementation of the policy, Mental Health Reform (2015: 5) in their review of progress on this strategy state that

It appears that some professionals are adopting a partnership approach welcomed by service users and family supporters, while others are not listening enough. Peer advocacy services are available for adults accessing inpatient mental health services across the country, however these services are unable to provide a comprehensive advocacy service in the community and there is no national advocacy service for children and adolescents under the age of 18 years.

Their analysis highlights the continuing gaps between the vision developed within the strategy and development of services on the ground.

CONCLUSION

In the recent and not most recent past, there have been several policy developments in the areas of caring and mental health. This report does not engage in a comprehensive discussion of such developments, as they are comprehensively examined and analysed elsewhere. However, an overview of two key policy developments: *The National Carer Strategy* and *A Vision for Change* which most directly impact of family carers of family members with mental health difficulties are outlined, together with assessments on what has been achieved or not, to date. It is argued that both policy documents are central to understanding the more structural policy environment under which family care dynamics operate and, therefore, offer a contextual overview of what might be expected in terms of support for them. Drawing on both policies, there are legitimate expectations that family carers would be recognised and valued and that care recipients who have mental health issues, would have access to individualised treatments and care plans, throughout the full duration of their illnesses. It is also reasonable to expect that communication with care recipients, carers and health services would be ongoing, clear and comprehensive, that family carers and care recipients have access to community-based services, that their different needs would be recognised and that they are actively involved in treatment and long term care plans. It remains to be seen however if such is evidenced in the lives of the participants in this research project.

4 Research approach, process, influences and methods employed

RESEARCH AIMS AND OBJECTIVES

The aim of this research is to explore the specific experiences and lived contexts of family carers who are caring for family members whose caring requirements have come about as a result of their mental health difficulties, as well as the experiences of care recipients in this context. It is a continuation of the joint community-academic collaboration between the School of Applied Social Studies and the Family Carers Ireland, (Cork), which has been ongoing since 2007.

Family care needed in the context of mental health difficulties is multi-faceted and comprises many challenges including:

- The nature of the mental health issues that have led to increased necessity for family care.
- The extent of the care required, including its nature, regularity and time spent caring.
- The formal and informal supports available to the person being cared for and the carer regarding their condition and associated needs.
- Assumptions and perspectives encountered in the community regarding the care contexts.

The objective of the research was to get to an in-depth knowledge of the breadth and nuances of issues faced in these particular family care contexts through giving voice to both family carers and care recipients. It was argued that illuminating the experiences of both family carers and care recipients would facilitate participant-led development of recommendations to address issues identified and explained, that are grounded in lived experiences, and that are embedded in perspectives current in local communities and levels of service provision. The research itself was conducted in Cork city and county and while the issues identified arise in this locality, the nature of experiences can be generalised to a broader population of family carers in Ireland.

RESEARCH PROCESS

The research process followed an interactive reflexive research pathway, in that it incorporated information exchange as an integral part of the process. In this, it attempted to produce a democratic relationship dynamic; what has been termed a ‘power-with’ partnership (Ponic, Reed and Frisby, 2010) whereby the research participants become active agents in directing the process, and the process is designed to respond to priority issues identified by participants. The research focus and direction was informed through on-going dialogue between the Family Carers Ireland (Cork), Cork Carers Forum, the research team, and research participants.

Following this, in line with good practice and in recognition of potential vulnerabilities of some of the participants, ethical approval was sought for the project from the Social Sciences Ethical Committee (SSEC), UCC, and the project was given ethical approval. The original plan was to convene two focus groups to inform the project and elicit relevant experiences of family carers and care recipients. However, the opinion of the SSEC was that such a forum might not be advisable for care recipients because of their possible increased levels of vulnerability. This was agreed and the research process then took the following pathway:

(i) At the outset a focus group of carers was convened, drawn from the database of the Family Carers Ireland (Cork). A central aim of this forum was to begin a process of identification and discussion of issues arising in the context of this particular care dynamic for those at its centre.

(ii) Thereafter, a process of identifying and contacting research participants for one-to-one in-depth interviews was initiated using the database of the Family Carers Ireland (Cork) as well as contact with the Cork Carers Forum, Cork Mental Health Forum, Shine and Headway. It proved more difficult to source research participants who were in a position to engage with the research than had been anticipated at the outset. A number of factors contributed to these difficulties. These included i) a slight delay in the commencement of the project which resulted in research fieldwork overlapping more participants' time commitments and responsibilities, including their own holiday arrangements, family holidays, school holidays etc. ii) The nature of the particular caring contexts sometimes meant that the timeframe of the project coincided with 'crisis events' and increased tensions, resulting in some potential participants' non-availability. ii) The nature of language used in discussing mental health contributed to potential participants, whose contexts would render them eligible as participants, according to the broad conceptualisation employed by the project, ruling themselves out. In the end, twelve in-depth interviews were carried out with carers and care recipients. The bulk of interviews took place between May and June 2015. However, the final interview was undertaken in October 2015, at which this particular participant was ready and available to partake in the process.

Participants included family carers and care recipients ranging in age from their early twenties to mid seventies. Carers were and /or had been caring for children, siblings, parents, partners, relatives, and neighbours. Care recipients found that they needed care because of a range of conditions /issues that impacted on their mental wellbeing. Some had been diagnosed with depression, schizophrenia, autism, Asperger's and intellectual disability. In other cases, there was no specific medical diagnosis. Generally, issues were long term and over the course of their lives there were times when carers became care recipients and care recipients became carers, indicating that the area is set in the context of a complicated and evolving set of

interdependencies. In the context of this complexity the table below offers some sense of the detail of the participants and their roles.

	Participant role/s	Family Relation	<i>Primarily caring and /or being cared for /by</i>	Age range
1	Carer	Parent/Child	Son/daughter	40-60
2	Carer	Parent/Child	Son/daughter	40-60
3	Carer	Sibling/Sibling	Sibling	40-60
4	Care Recipient	Sibling/Sibling	Sibling	40-60
5	Carer	Partner/Spouse	Partner/Spouse	40-60
6	Carer	Parent/Child	Son/Daughter	60+
7	Carer	Parent/Child	Son/Daughter	20-40
8	Carer	Partner/Spouse	Partner/Spouse	60+
9	Carer and Care recipient	Child/Parent	Parent	60+
10	Carer and Care recipient	Parent/Child	Son/daughter	40-60
11	Carer and Care recipient	Child/Parent	Parent	20-40
12	Carer and Care recipient	Child/Parent	Parent	20-40

Prior to the interviews, the aim and focus of the research was explained to participants and their consent to recording and, thereafter, using data for analysis were requested. All participants signed consent forms and were made aware that they could withdraw their consent if they so wished. A copy of research materials used is included in appendices to this report.

All interviews were recorded, transcribed, and reviewed. Thereafter, research participants were contacted and offered copies of transcriptions, an offer that some participants accepted. Further meetings were then arranged with participants where they reviewed their transcripts and their use with the researcher. Depending on the progress of research findings, where possible, findings developed were also discussed with participants at this point.

As previously mentioned, Headway⁷, an organisation that works to support people living with acquired brain injuries, was also contacted with regard to identifying potential research participants. None of those using their support services wished to partake in one-to-one interviews. However, in discussions about the project it was suggested that a group of service users be presented with initial findings and engage in a discussion about overlaps /interconnections with their own experiences. Therefore, such a forum was arranged and proved to be both a valuable dissemination forum as well as one where input could be given from care recipients' perspectives, from the positions of a group of people who also live with

⁷ See <http://www.headway.ie> for further information on Headway.

largely invisible, and not very well understood conditions. This forum can be conceptualised then as part of both the research and dissemination elements of the project. A separate forum for carers to present initial findings was also convened, as was a larger public meeting to present initial findings. Feedback from these fora was incorporated into the final report.

Finally, engagement with a Loss and Resilience workshop⁸ was discussed with participants as well as representatives of the Family Carers Ireland (Cork) and Headway and it was agreed that such was relevant and would be very useful. Three members of the project team attended this four-day workshop and plans are being developed to present the learning from the workshop to carers and care recipients, in smaller time slots, to suit their schedules. The learning from their workshop fed into the final analysis.

ANALYSIS

All transcripts were analysed thematically through several close readings and using Nvivo 10, a qualitative data analysis software package. Initial issues arising were identified, organised and discussed between the research team, resulting in the identification of overarching themes in order to provide a framework through which the nuances and complexity of the experiences could be recounted. Findings are presented in the following chapters, first separately from the perspectives of carer and care recipient perspectives, and then the interdependencies between both perspectives are discussed and highlighted. Key recommendations are detailed in the final section to this report.

The knowledge produced through this project is now in a position to (i) facilitate the elucidation of specific issues facing this sub-set of family carers and those for whom they care (ii) as well as guiding the way for further research / interventions directed towards meeting these challenges.

The outcomes of the project give voice to the specific experiences of family carers and those for whom they care, where the need for care arises because of mental illness. Where reference is made to transcripts of interviews undertaken, sources refer only to research participant, in order to forefront the issues raised, and contribute towards securing anonymity. This knowledge which is grounded in their lived experiences, will be an invaluable contribution to our understanding of the dynamics and nature of care located within the family, and set in the context of local and regional conditions.

⁸ See <http://abrpo.org/program/resiliency-initiative/> for further information.

5 Family caring and mental health: findings of the research undertaken

INTRODUCTION

The research was concerned with exploring family caring in the context of mental health issues in general, and where additional care was required because of some sort of mental rather than physical issue. For purposes of clarity and in order to give visibility to the different perspectives of carer and care recipient, the research findings are now discussed below in three separate sections. We first focus on the perspectives of family carers. In identifying and examining the issues that arise for them we were alerted to experiences that warrant examination on a larger scale. While they share much in common with experiences shared by the broader body of carers, these participants also portrayed a context of caring that raises further issues related to the manner in which care and care support is understood and conceptualised. In the following section, we discuss the experiences and issues arising for care recipients, and highlight the range and diversity of issues they face in dealing with the difficulties they encounter. Together, these sections bring our attention to issues faced by carers and care recipients, they encompass interrupted education, restricted opportunities to participate in employment, the context of and build up to crises in people's lives and on-going struggles in maintaining themselves, interacting with family members, and in engaging with the wider community. They also highlight the, sometimes, hazy boundaries between giving and receiving support. In the final section in this chapter, we focus on the interdependencies between family carers and care recipients, highlighting their centrality in understanding and sustaining care, as well as the very concerning issues that arise when attention and support is not directed towards the interdependent nature of caring relations.

Experiences and perspectives of family carers

OVERVIEW

This section outlines the experiences of ten participants who are or have been caring for their spouses/partners, children and siblings, parents, who have different mental health issues, some of which were definitively diagnosed by medical professionals, others which were more ambiguous and not so clearly defined. Sometimes, they were already caring for or had previously cared for other family members in their nuclear or extended family network. While not intending to detract from the more general issues that arise and which they share with the wider body of carers, this section focuses on those specific care related issues that were highlighted by participants as being more particular to these contexts and is, thus, structured under the following headings.

- Experiencing mental health issues within the family
- Living with mental health issues
- Support/Caregiving
- Communication with medical services
- Services and supports: access and communication
- Advocacy and awareness

EXPERIENCING MENTAL HEALTH ISSUES WITHIN THE FAMILY

And it is not nine-to-five job. It is a twenty-four hour care, Monday to Monday. There is no time off (Research Participant 6)

Experiencing mental health issues within a family context took many forms and interacted with the specifics of relationships within a particular household. Depending on which family members were experiencing difficulties – father, mother, child, sibling, as well as their age, gender and the roles they played within their families and so on – experiences differed. Recognising and supporting a family member with mental health difficulties always involved a re-negotiation of family relationships, roles and household practices, as is also identified in the wider literature (Rose 2002; Harden 2005; Rowe 2012). Often family caring experiences in such contexts had a strong influence on the structure of family carers' daily lives and that of the households in which they lived.

[date], my life changed from being a mum to being a mum and a full time carer for my daughter. The emotional impact affected all of us, each one of the family (Research Participant 1)

For instance, the extract above draws our attention to the difference between being in a mother/ daughter relationship where lives are intertwined with the usual school, work, outings, other family members, friends, activities and so on, and the mother-carer/ daughter relationship; a more intense, emotional and involved relationship. It also reflects other

contexts encountered where common household patterns and relationships changed to prioritise the needs of a particular family member experiencing mental difficulties, reflecting issues raised in the literature on the reconstruction of relationships, expectations and narratives (Pejlert 2001; Jones 2002; Harden 2005).

In recounting their situations, some family carers identified a specific crisis/event as a turning point for them and their families.

[] went to school and then we got a phone call 'collect [] back here' and when we saw her it was not the same [] (Research Participant 1)

I was going to work and I got a phone call. I got a phone call, this is one of the top doctors in GF⁹. [...] I said GF, who is GF, never dealt with it before? Oh! the mental health, they said, up in the Regional (Research Participant 6)

For others, the transition from family member to family carer was a more gradual one, often precipitated by a mother/ partner/ spouse gradually noticing something about their family member.

But at the start he was very withdrawn, he was very insular, he wouldn't go out, he was afraid to go out. At this stage I didn't realise he was still on a high with the drugs and it was only when he came off the drugs [I could see] how paranoid he had got (Research Participant 10)

For example, it could be that a mother noticed something about a child that she considered warranted attention, or perhaps a spouse/ partner gradually realised that patterns of behaviour were not quite as expected. A parent, often mothers, might then act on these perceptions on behalf of a young child, or might encourage older children to seek help. Wynaden's (2007) concept of 'being consumed' with the changed environment resonated in such instances. Similarly, a spouse might notice something. Sometimes, they would then encourage their partner to change their behaviour and seek help, engaging in support and management of the illness, as also identified in the literature (Rose et al 2002; Rowe 2012). This support interacted with gender role expectations of care associated with family roles and power dynamics, as highlighted by Johnson et al (2012).

When she was younger she would have outbursts, she was frustrated, tantrums, she would lose her temper and I started to bring her to [psychologist], [...] and he diagnosed her learning difficulties (Research Participant 7)

Always and forever, I knew there was something wrong, something for want of a better word, amiss (Research Participant 2)

There were certain warnings you know, sometimes... kind of, paranoia, you know, that kind of way...before we got married [] got bad ... and then just a couple of years ago...(Research Participant 5)

For all family carers interviewed, their caring contexts were long term, and are characterised by the provision of emotional and practical support that is geared towards the individual needs of their family member, which is also corroborated in the wider literature (Rapaport et al 2006; Rowe 2012). The provision of support became naturalised and, therefore, can be quite invisible. As one family carer stated, 'very much you are constantly tiptoeing around'. Furthermore, because much of the support offered, as also identified elsewhere (Rose et al 2002; Lyons et al 2009), takes place in between 'crisis events', where there is generally

⁹ Locally the psychiatric unit in Cork University Hospital is referred to as GF.

interaction with health services, on-going care and support tended to become camouflaged within the daily interdependencies of family /household life, part of 'getting on with life'. Sometimes family carers did not fully identify with their roles as carers within the family. It was only as a result of thinking about and participating in the research, openly discussing their roles within the interviews we undertook, did they themselves gain more clarity. This could be interpreted as reflecting of the ambiguity of the environment (Rose et al 2002;) and as well as relating to a tendency for care in these environments to impact on people's sense of worth (Wilkinson and McAndrew 2008). At other times, family carers were not recognised as carers, for instance, under the eligibility criteria for receiving welfare support allowances or Carers and Disability support payments. This can, perhaps, be interpreted as reflective of structural assumptions on the intersection of care and family roles and obligations (Rowe 2012). Although the caring tasks performed by family carers were onerous, time consuming, and long term, they were recognised by carers as being critical in sustaining the well-being of family members and support for them.

LIVING WITH MENTAL HEALTH ISSUES

A key factor that was associated with living with mental health issues as a carer in a family context, was the manner in which experiences of living with mental health formed a constant backdrop to household routines, schedules, priorities, resulting in 'being consumed' (Wynaden 2000). Due to its often, episodic nature, periods of calm were interspersed with periods of intense crisis.

... But a couple of them [periods of crisis] - the knife was a bad time. I locked the kids in the house in another room (Research Participant 5)

For examples, in times of crisis, family members would be called upon by health professionals and /or the Gardaí to provide background information on behaviour, medication, patterns and so on. During such interactions, family carers were viewed as important sources of knowledge (Wilkinson and McAndrew 2008). Conversely, family members themselves called on the same professionals as well, as a means of protection and assistance.

She went out around the house with a knife one night and we had to get the guards and everything (Research Participant 5)

They [medical professionals] locked the doors on him, I called the guards, three guards came (Research Participant 10)

Family carers also experienced periods where a loved one would be hospitalised, or accompanied family members to medical appointments where they performed the emotional and instrumental work of caring (WHO 2003; Rowe 2012).

I have to have my phone switched on basically nearly twenty-four hours ... He has got panic attacks during the night now and they have had to ring me and I have had to get up during the night and go down and take him, one a couple of weeks back where he couldn't breathe at all after this particular panic attack. We had to take him to South Doc (Research Participant 6)

You have to look after her all of the time ... So you kind of have to be there for her all the time for her, do you know what I mean. Or if I am not there you, kind of, need somebody that will be around her (Research Participant 3)

Recovery, when it was embarked upon, could also be a winding rather than a clear-cut process, with multiple ups and downs, stresses, hopes and fears. Recovery often involved a constant re-balancing of interdependencies, a balance that could be difficult to achieve and maintain.

I am kind of delighted in a way because she is, kind of, after improving since she is on the tablets, do you know, what I mean? (Research Participant 5)

You know so it was just a matter of pulling back to let him empower himself you know to kind of which was very, very difficult because as a mother you don't class yourself as a carer, you are a mother. I realised how toxic I was for him because I was doing everything for him (Research Participant 10)

It hasn't happened now in about two months and fingers crossed it won't happen for a while or it won't happen at all, but she will hit me, pull my hair, try and bite me, throw things at me, scream at me and it will all happen (Research Participant 7)

And so far like it is May now and nothing going on from January to a couple of weeks ago in April when he was in and out again (Research Participant 6)

At other times there would be little or no acknowledgement by those encountering difficulties that there was a difficulty, or of a necessity for recovery. In such cases, patterns of behaviour would continue, with different degrees of intensity and accommodation, over long time periods and were interspersed with periods of intense crisis.

You would have to, kind of, know her to understand what I mean. It is like she can be two, like she is schizophrenic so there is two people anyway and then if there are a load of people around, she acts different then again (Research Participant 3)

Constant, constant like you never know when you are going to get a phone call or when he is going to come in the door saying 'I need to go here or I need to go there' you don't know what is going on (Research Participant 6)

And [] happens to have a very short fuse and dealing with him at the best of times is difficult but when he was suffering very, very badly from mental health, depression, ... it was even harder. It is still hard because even now he cannot cope with anything really that crops up (Research Participant 8)

The uncertainty associated with this tension leads to quite ambiguous situations, making caring sporadic, unpredictable and emotionally and physically demanding (McCann 2015), with carers unsure as to what to expect (Radfar et al 2014). Some family carers revealed that they could identify warning signs, which tended to lead up to periods of crisis. Then they would attempt to prepare themselves in anticipation. Others generally lived with the uncertainty and hoped that more calm times would continue.

Living with this ambiguity was a difficult but constant issue in the lives of family carers. It is thought that attaining and maintaining mental well-being requires regular and sustained attention with regard to the emotional and psychological aspects of self care; aspects of care which are often not prioritised (Rose et al 2002; Wilkinson and McAndrew 2008; Rowe 2012). The nature of mental health well-being and conversely, illness, is that it can often be episodic in nature and often is associated with a complex set of issues and concerns pertaining to the individual, and the nature of relationships with school /work, family, friends, community, colleagues and peers. All of these relationships are dynamic, divergent and can include competing obligations and responsibilities that conflict as well as merge with one

another: Realising and maintaining mental well being involves achieving a fine balance that, in itself, can be difficult to achieve, sustain and reconstruct.

During the course of the research, family carers referred to the difficulties that they faced in maintaining this delicate balance and in supporting their family members. For instance, maintaining balance might have required adjustment and accommodation from family carers with regard to the evolving relationship they had with their family member, in examining and reviewing in turn the impact they might have on their son /daughter /brother /partner /sibling (Pejlert 2001; Rose et al 2002).

Through this, kind of, first five years I had with him I wasn't allowed look at him a couple of times when he was paranoid because I was sucking the brains out of him, I would have to close my eyes when I was actually talking to him. And then trying to find out what at all was going on yourself, it was, kind of, where do I go from here?
(Research Participant 10)

As can also be understood from this quote above, not knowing what to do, and coming to terms with what can be a nebulous situation, leaves family carers in a fearful and uncertain position.

At the same time, other family carers highlighted the necessity of maintaining a sense of security and openness as a key central of their perceived role. In accommodating the needs of their family member who was in need of support, they found a sense of purpose and were often resolute in achieving this.

I firmly believe that feeling good comes from the inside out. At that time our home was a safe space for all of us. People who came to our house came into that and knew [x] was our priority and had to have respect for that. We were advised to treat our home as a hospital (Research Participant 1)

We'll say like that now even though it [specific activity] is going to cost two hundred and fifty quid for two weeks, I want him to do it because it will teach him more social skills, do you know what I mean (Research Participant 2)

so [x] is a survivor of paranoid schizophrenia right and he is experiencing that and for the last five years he has been out of hospital (Research Participant 10)

Yeah, she finds going out too much maybe or something yeah. It would be nice if there was some kind of place you could go that would be maybe not so hard or something (Research Participant 5)

This process is reflective of building resilience and finding purpose in the caring environment (Lowyck et al 2004; McCann 2015). As time passed this determination could change according to changing circumstances and, at times, continued reflexivity on their situations and roles. Over the course of the research, some participants spoke about plans they were making to take holidays, often for the first time since the onset of illnesses, a process also identified by Wynaden (2007). While they looked forward to these necessary breaks, they were often apprehensive as to whether, in reality, they would turn out to be a good idea or not. Others spoke about coming to a time when they considered that the more intensive support they had been giving, had come to an end. At this point, they began to separate themselves from more routine aspects of support, as a means of strengthening independence. In some cases, often, deeper more interdependent and close relationships followed. Sometimes, as is

discussed in more detail in the next section, relationships could evolve so that a care recipient, over time, could become the carer.

... and when I suffered depression, ... so then I became the service user, the carer became the service user and the service user became the carer. That was both part of our recovery plus the fact that I had forgotten he was a man, he wasn't a child anymore ... So we now have a very happy balance, I respect him, he respects me, if he needs time out we don't talk, if I need time out we don't talk (Research Participant 10).

It is hard to say you see because [x] would always have been in denial around ... his behaviour generally (Research Participant 8)

In other cases, the nature of their relationships and the constraints under which interdependencies had evolved over the years implied that little change could realistically be expected and the ambiguity, and ups and downs, could be expected to continue unabated.

SUPPORT/CAREGIVING

Support was given in the context of the relationships participants had with their family members, as is characteristic of family caring in general. Also, caring interacted with the nature of that relationship and associated normative expectations (Rose et al 2002). Partners /spouses /parents /siblings /children were living and caring both in the contexts of loving supportive relationships or they might be living and of fraught and burdensome relationships, or anything in between. Parents sometimes felt guilty about the difficulties their children faced and experienced loss regarding their potential futures. For instance, mothers often took on quite intensive and presence oriented caring roles; a wife /husband /partner might take on roles and responsibilities they would previously have expected a husband / wife /partner to play. They might have had to develop coping strategies to deal with household matters without the contributions they might have assumed would come from their partner/spouse and feel an associated loss. Family members might find themselves 'stuck together' in closely interdependent relationships, from which they could see no way out, apart from abandoning their child /sibling /partner and mutual social /financial factors could make it difficult to envisage any other relationship construct. What seemed to be most important, however, for family carers, was that they were recognised and visible.

For me, it was very important to be recognised in my caring role in order to feel supported in what I was doing [...] Also the lack of support from mental health professionals, advice and information, comfort, hope, left us isolated, stigmatised and very vulnerable (Research Participant 1)

Interviewer: And has there been anything to support you in doing this? Interviewee: Is it pure mad you are! (Research Participant 2)

In terms of actual caring, it could take many forms but being present and maintaining household relations to suit the anticipated needs and wishes of a care recipient seemed to be important. Carers accompanied family members to appointments, researched medicalised conditions and treatments and were on call in emergency situations. Often, post an intense period, or after a first traumatic crisis, presence was very important. This could mean high levels of presence, spanning twenty-four hours or require family carers to be on call all or

most of the time. For parents, it could mean accompanying their child to school, hospital and other appointments and organising households to around meeting the needs of one child.

Sometimes homes were organised so that they divided into separate living spaces; some directed specifically to the needs of the particular individual requiring care and other spaces that were geared towards other members of a household. Alternatively, in some households different family members simply used different spaces, which they viewed as specifically theirs; for activities such as listening to TV, radio, music, reading, eating and so more or less separately.

Often family carers were unable to continue with their previous employment and so the focus and patterns of their lives changes completely, as did their financial contribution to their households, highlighting the adverse social and financial aspects of caring (Wynaden 2007). Where their financial contributions to the household was high, this came with consequent adverse financial consequences.

She slept with me for the first year, I would say, because anytime her eyes would close the devil was there to get her. The continuation of support and reassurance that there is hope was something we had to do every day. I left my job the day my daughter got sick ... my husband lost his job, maybe a month later ... (Research Participant 1)

You are trying to upkeep everything and you are trying to keep an even keel in the house... And, kind of, covering up basically, as well and that is, all kind of, very invisible as well... Keeping quiet and I would almost sometimes look into the sitting room there and it is thickened glass to see you know (Research Participant 8)

Stigma

A number of family carers felt that living with mental illness continues to be stigmatised, and their experiences had resulted in distancing of friends, neighbours and family members. A common strategy to counter stigma was not to mention any mental health diagnosis, associated medication or health support, except to those they were absolutely sure would not be prejudiced.

Researcher: So you think there is more stigma to schizophrenia?

Interviewee: Oh definitely even if [x] and I are out now and someone says something about it, I say, do you know now, look after number one, number one is, I have to say that, like, she has to look after herself (Research Participant 1)

People, I keep saying to people [x] has paranoid schizophrenia and I remember telling them when he was first diagnosed, I remember telling my [] friends and one of them stood back and kind of went 'whoa', and I, kind of, went 'it is not contagious' (Research Participant 2)

Oh, I think there is stigma Jacqui, I don't know, people wouldn't overly express, but I think there is around mental health (Research Participant 8)

[x] now drives me a bit mad alright because she would be saying 'is [x] alright, is [x] alright and everything' [...] but I mean she would be more nosey now than anything else but the rest are lovely (Research Participant 1)

Well, I tell you now a lot of people put it under the carpet, you know (Research Participant 5).

This adds a further dimension to living with mental illness; namely retreating from the threat and reality of prejudice and bias and hiding it as much as possible. Associated consequences include increased isolation and fear as well as heightened attention to the views and biases of others, for those caring and for those in need of care.

No, there is no stigma whatsoever (Research Participant 3)

Other family carers indicated that they did not experience stigma and spoke of the support they received from friends, neighbours and the communities in which they lived. In these cases, the absence of stigma for them was positive, as all indicated that they were aware that it was a possibility and that mental health was sometimes not understood well in general. It was one thing that they did not have to deal with.

COMMUNICATION WITH MEDICAL SERVICES

What was evident was that, whichever was the case, in approaching/ interacting with health professionals, diagnoses were given, interventions were initiated and often a process of finding out more about these opinions/interventions followed.

Diagnostic labels didn't always make a lot of sense to participants, and did not always coincide with their own views or observations. While offering an identifiable label and then perhaps reasons for problems their family member had been encountering, they could also be confusing. Family carers often followed up with their own research find out more for themselves and their family member, so that they could be more informed on what was considered to appropriate support.

Professionals might assume the assistance of family members and their involvement and co-operation expected, reflecting literature on assumptions by professionals on carers actions and priorities (Wilkinson and McAndrew 2008). However, what form this assistance might take was often not articulated clearly. Family carers might also be placed at a distance from services, indicating a level of suspicion or mistrust of carers (Wilkinson and McAndrew 2008; Rowe 2012). Such encounters generally left family carers in ambiguous situations; with partial or limited information. This went hand in hand with assumed but often unarticulated, expectations based on their familial roles, and little or no recognition of them as individuals, who might have different and divergent commitments.

The three of us went to CAMHS the day my daughter got sick. My daughter was in one room and my husband and I in another with a psychiatrist. The psychiatrist asked us had anything different happened that day. With that, after speaking with her for 20 minutes we were given a prescription, and she said if anything happens after five o'clock, ring CUH (Research Participant 1)

When we went to the GP, he called me outside the door and he says '[] has schizophrenia' ... and I looked at him and I said 'I don't even know what that is'. And he said 'we will ring CAMHS' and I said, 'who are CAMHS?' (Research Participant 10)

One of the doctors up in [psychiatric health facility] then told me, one day, she took me in and she told me he has paranoia, schizophrenia, psychotic psychosis ...so she said the paranoia would be about people. Now, she said there are loads of schizophrenia but he is the schizophrenia of the self-harming one... (Research Participant 6)

While, as mentioned above, having a diagnosis offered some rationale for issues faced and behaviour encountered, this diagnosis could also be restricting and somehow reductionist, as is articulated in the quote below. Below, the family carer discusses the accuracy of a diagnosis of schizophrenia. In the process we are given a glimpse into an on-going process of

separating traits associated with the label itself, as they attempt to identify elements of the condition evident in the behaviour of a family member diagnosed with schizophrenia, and those they do not see as relevant to him.

We still debate about that, he maintains he doesn't have schizophrenia but he has all the traits of it right and he has definitely got the traits of paranoia when he is non-compliant (Research Participant 10)

Comment following a diagnosis of a participant's child: I tore strips of them, [teachers] well politely, tore strips off them. I said 'hang on now, has he changed from when he started here in first year'? 'No'. I said, 'well, why treat him as if he has, he is still the same young fella. Yeah, he does have his moments' (Research Participant 2)

Arguably, such remarks can be interpreted as a challenge to a tendency to reduce a person to the diagnostic label given to them, based on the symptoms with which they present, and associated reductionism. It can also be viewed as emphasising the importance of the individual and attention, in these instances, to more specific concerns, issues, behaviour, influences and so forth. Given the tendency to view and stereotype people, in particular in the context of this study, those who experience mental health problems, it is an important strategy of resistance. In challenging reductionist tendencies these remarks seek to clarify what exactly the label means and in identifying elements associated with it, takes the conversation away from expert led one and onto a one that is grounded in people's own observations, dialogue and experiences. At the same time, a diagnosis offers the potential for support and access to services, as articulated below.

Because, like I said to [support worker], she said how do you feel now that he has got a diagnosis? [...] all I want to do now is get the help he should have been getting all along but because he is eighteen, he is grand while he is still in school, he will get the help and thank god he will be in school for another twelve months (Research Participant 2)

SERVICES AND SUPPORTS: ACCESS AND COMMUNICATION

As part of their lives as family carers, they access services and supports with and sometimes on behalf of their family members or themselves, as carers. In their interaction with services they expressed a wish to be recognised, as also reflected more broadly (Wilkinson and McAndrew 2008). Family carers expressed a wish that their own needs and those of their family members would be addressed, and that they be clearly communicated to, and supported, by access to relevant services. Supports mentioned during the course of the research included that of various medical professionals; GPs, psychiatrists, counsellors, hospital A&E units, community mental health services aimed at adults and children and families, social workers, the Gardaí, as well as housing and social welfare supports, occupational therapists, psychologists, family therapists, teachers and special needs assistants in schools. In accessing these services they had a range of experiences of professionals, some of which they found to be communicative and supportive and others less so.

While not wanting any special recognition for the efforts they made, family carers did want to be recognised and their opinions and insights taken on board.

I had to think about different ways of doing things, like, but I had to get on with it and nobody listens to the parents. That is the biggest problem; nobody listens to the person looking after, like, it has to be your doctor said, or he is the professional not you, you don't know what you are on about (Research Participant 2)

For me to be recognised is vital, as it brings an awareness of mental ill-health difficulties and it shows how very important family members are in the care of a loved one, and how we need to be supported (Research Participant 1)

As a parent you have no rights in mental health. If the service user does not want you to know anything about his condition and they shove it down under this confidentiality thing which they push a lot, but you are not allowed in there but I have to go in because Patrick wouldn't remember you know what was going on (Research Participant 10)

However, the opinions of family carers were often not taken on board, something also identified by Wilkinson and McAndrew (2008). Parents and partners /spouses felt that they might be viewed negatively or that their opinions would be simply ignored while siblings' views were generally even more invisible. Furthermore, services aimed at children often did not include parents, sometimes leaving them in unclear as to how best to support their children. One family carer stated that having an understanding of why her child acted in a particular way and ideas on how ways to support would be very helpful to her.

Because we, personally, don't understand why she gets like this. So what makes it hard is that we can't get somebody to come up and say 'look this is what is going on can you deal with it this way, can you do it that way, can you try it that way?' and give us ideas of what to do, because we don't know (Research Participant 7)

However, they found that community services dealing specifically with children had a more general parenting course for parents, which she and her partner then attended. However, this course was not of much help to them in their particular situation; attendance was more to keep contact with the services than for any insight it could offer to the specifics of their situation.

We did the parenting course, which is the last thing you do before you get your case closed. So they did help us a lot in our relationship, in everything to do with us [...] But the child was still the same (Research Participant 7)

So while, as is indicated above, engagement with this service was positive, it did little to inform /help with the issues the child faced. This is reflective of the structure of services, which are aimed at particular groups following a life course approach (Department of Health, 2006). However, it highlights a gap in services support that involve interdependencies across generations/groups.

In some instances, over time, carers developed relationships with the medical professionals who treated their family members, and within the confines of the professional /client relationship, became part of a triad of care, whereby some communication spanned professional, care recipient and carer. Family carers recognised and appreciated the efforts these professionals went to and such efforts contributed towards alleviating their own stress and isolation.

Now the head one there, the second time we went up, she asked me would it be alright if she brought the head one down to talk to [x] like, to talk to us. Within two hours she told me exactly what was wrong with the young fella' (Research Participant 2)

Some days I talked to the psychiatrist. Oh, I went in to the doctors another day, I brought her down to the doctor's in [x], she ran out the doctor's. Doctor [x] he followed her, he caught her (Research Participant 5)

Such support wasn't always available, however, and some indicated that they had no support and no recognition. Parents spoke about a constant and long-term struggle to access support

systems for their children, sometimes from when their children were very young; others from the time their older children had started to experience difficulties.

You knew there was something wrong with him as a small child, and the Montessori teacher knew there was something wrong, and it took until he was seventeen years old [for child to be diagnosed] (Research Participant 2)

Anyway, I rang the speech therapist and she wasn't there, and I got through to another lady, and she told me to ring a social worker or somebody, I got through to this lady, and she said ring your GP (Research Participant 1)

In articulating their struggles to access support for themselves and / or their children, these parents found that some services were client /child oriented or condition oriented. While dealing in such specificities, the wider context of family care and sustainability remained unaddressed and / or the struggle might be to achieve a particular diagnosis in order to access specific services. Additionally, some family carers believed that diagnoses were not very considered and then associated services didn't really fit, but were just available. Arguably, their experiences are reflective of poor development and resourcing of such services.

I had murder with them for putting him up there [secure psychiatric unit] but they said they had to because they were afraid in case he would do something (Research Participant 6)

Well, she was the assessor, she knows what she is talking about! Hello, like, she spent what, an hour with him. (Research Participant 2)

Carers spoke about having to 'play the system', so that they and their family members could access services. This could mean a number of different things, such as asking medical professionals to support them in their applications for assistance for carers allowance, encouraging one professional to prolong a professional relationship with their family member until they accessed a follow-on service, availing of a service themselves, just to maintain contact, and making someone homeless in order to access community and housing services. At times, these actions and routes were taken in conjunction with the professional they had contact and were often conceptualised as, perhaps drastic, but the only means they had of obtaining support for themselves and their family member.

Well, I had to get [x] into the system because they weren't helping me, so I made [x] homeless (Research Participant 10)

No, but she [Counsellor] kept seeing him until he got an appointment for the other place purely because she could see he needed something (Research Participant 2)

It seemed as though family carers and care recipients had to fit into the construction of services, that wider caring contexts were not really taken into account by them; leaving many gaps, which then had to be filled within families and households as creatively as possible.

Family carers also stated that they built up resilience over the years, which also helped them to deal with the vagaries of their realities.

I have very, very good survival skills and I always maintain tomorrow is a new day so you know let the other part go of it, shit happens, leave it there, don't worry about it, move on (Research Participant 10)

I suppose I am good at coping, I know I am good at coping because [...] I wouldn't have survived if I wasn't, you know (Research Participant 8)

However, sometimes there was a fine balance between coping and not coping. Family carers indicated that they felt overwhelmed, isolated and undervalued and that they needed their own

needs to be recognised, understood and addressed, again highlighting isolation experienced by carers more generally (Lowcyk et al 2004; Wilkinson and McAndrew 2008, Rowe 2012).

There is a very fine line from being well one minute to being very unwell the next, and none of us are immune from mental health difficulties. At that time we got very isolated and then, I take tablets for depression, and obviously, they are higher now. That shows that the carer gets unwell and the only response from the mental health professional is medication (Research Participant 1)

Sometimes they just needed someone to talk to, someone who had some understanding of what they were going through, and who provided a safe space for them to express their own feelings. Other family carers revealed that they needed some respite from their daily lives or perhaps, medication to alleviate their own conditions and symptoms. For those who had such access, they found it invaluable to them an external source of strength that helped them to continue to provide care.

So when I met her [support professional] she just looked at me and she said 'are you okay?' and I said 'I just want a hug' so I had a big cry and left it out, which I hadn't done in a year...But you need to do it, because if you don't it all gets caught up and then you become you become tired, you become resentful, you become sharp when you shouldn't be sharp or, you know, it seeps out, it has to seep out some way, it has to, it has to (Research Participant 1)

I went away for a week last year because the boys gave it to me for my birthday [...] but when I came back he was in [secure medical unit] and crying all the time for his mother and his grandmother [...] It did me no good to go away anyway, I shouldn't have gone, to be honest with you (Research Participant 6)

Sometimes, however, attending to their own needs had repercussions, as in the example above, leading family carers to question the decisions that they made regarding their own needs were the ones they should have made.

ADVOCACY AND AWARENESS

Some family carers went on to become involved in support and advocacy groups. They might first come into contact with a support group though looking for support for themselves in their role of carer or their family member and then increase their involvement, in contributing to advocacy /campaigning work of that organisation. Alternatively, family carers' experiences and reflections led some carers to become politicised at a broader social level and led to them questioning the societal norms and practices related to care and the treatment of mental health they would have heretofore accepted.

But I had the courage to talk about it, where a lot of parents won't, a lot of parents are embarrassed and where the stigma is coming from is from the parents and from the person that has it. It's not coming from the outside because if you look at the generation now with suicide and depression they are all talking, there is not a lot of stigma there but it's the group between the thirties and the sixties, when we had no back up and no support 'we couldn't tell anybody, the embarrassment' (Research Participant 10)

Depending on the time that they had available to them, some family carers became involved in advocacy work, ranging from involvement in carers support groups, mental health support and campaigning groups, arts and drama initiatives aimed at increasing awareness of caring and mental health as well as campaigning groups on a range of issues not directly related to either caring and mental health. Such involvement offered family carers a way of channelling their experiences to effect change in the hope that they might be able to contribute to easing the way for others.

CONCLUSION

In this section, we have identified and highlighted the experiences that family carers face in caring for their family members who face mental health issues. We are offered a glimpse into those issues that arise when they first encounter a crisis event in their families and their subsequent immersion in the more specific issues they face in dealing with medical personnel, diagnoses of illnesses and negotiation of support for their family member. We get an idea of how family carers reconstruct household and personal priorities and practices in the context of support needs. Some face stigma in their extended families, friends and in the community, others find support and acceptance there. As care becomes normalised, it can become difficult to see oneself as a carer and obstacles encountered tended to compound the invisibility they face in accessing welfare supports that recognise them as carers. We also see how family carers' experiences can lead to become knowledgeable in the specifics of the illnesses their family members face, engage actively in management of issues, and consider the individual type of supports that are useful; some go onto become involved at more political and advocacy levels in attempting to affect change for others. For others, the work involved in the support they offer and in rearranging their lives takes all the time and effort they have.

Experiences and perspectives of care recipients

INTRODUCTION AND OVERVIEW

This section focuses on experiences of research participants who encountered difficulties in their mental health that in some way necessitated some level of support from family members, additional to that which would be more usually expected in the course of household /domestic relationships. They might also have interaction with mental health services, advocacy and community supports and might have been diagnosed with a psychiatric condition.

Our findings in relation to care recipients' experiences of mental illness draws mainly on four participants, and while this number is small the range of issues highlighted offers an insight into the breadth of issues people face in coming to terms and coping with the difficulties they face. Three of the participants were diagnosed with a mental health condition following a crisis event in their lives while the fourth had a range of physical conditions that over the life course intersected with mental capacity and wellbeing. Their experiences bring our attention to issues faced as younger and older adults. These encompass interrupted education and associated employment options, the context of and build up to crises in peoples' lives and ongoing struggles in maintaining themselves and participating in society. They also highlight the blurred boundaries between giving and receiving support. Due to the small number of care recipients interviewed, reference to gender and age is not made specifically when referencing particular circumstances. However, as these are key social dividers in society in general and intersect with care and health, the section on gender and age considerations identifies and attempts to delineate issues arising.

Specifically, we categorised care recipients' experiences under four themes, which we outline in detail below:

- Physical and emotional impacts of living with mental illness
- Medication, treatment and support
- Gender identity, education and employment
- Countering invisibility - Advocacy and awareness raising

PHYSICAL AND EMOTIONAL IMPACTS OF LIVING WITH MENTAL HEALTH ISSUES

In line with Lester and Tritter (2005), some care recipients experienced living with mental health issues to be ever present, frightening, disturbing and episodic. Others experienced their conditions as scary, horrible and relentless.

Complete hopelessness, helplessness, despair, you know, and you are fighting, you can't get up out of the bed. You can't sleep at night. You are waking at the dawn and you are tossing and you are turning and you are having cold sweats at night. Oh, there is no more horrible place in the world (Research Participant 9)

Yeah, that is the hardest part because like it affects me nearly every day in some way (Research Participant 11)

For others, experiences of mental illness went hand-in-hand with hearing voices, feeling high levels of anxiety, depression and /or hopelessness, being either separated from peers and /or feeling pressure to conform to peer culture and practices. For instance, one care recipient, in explaining what it was like to hear voices stated:

It is very weird. It is very strange because it feels like there is someone right there, but I know, obviously, they are not. But it does feel like there is someone very, very close to my ear and they are saying all this stuff. It is always negative (Research Participant 11)

Such feelings and experiences can bring on a heightened awareness of oneself and simultaneously block communication with others, thus increasing isolation and contributing to accentuating feelings of not feeling well, becoming more anxious and feeling overburdened and unable to cope.

Onset of illness

For the participants in this research, the onset of mental health difficulties was particularly salient and poignant. For instance, some care recipients revealed a history of being isolated and criticised by a particular colleague /peer /partner, work commitments might have build up over time to become overwhelming and could then negatively intersect with personal obligations and demands. Eventually, the pressure of these contexts seemed to give rise to a crisis of some sort. This crisis generally marked the beginning of a care recipient's interaction with mental health services and led to increased support from family members, while also, at times, leading to a distancing from others: friends, colleagues, neighbours and sometimes extended family members. Care recipients remembered this time in their lives as significant and marking a considerable change in their life courses.

I basically burnt out and ended up down in [psychiatric] health care facility] for six or eight weeks... house, home, habitation, marriage, sanity, job, the lot, you know. [...] Oh, it was building up for months but there was no one taking any notice of it (Research Participant 9)

... I was breaking doors in the houses, you know, with my fists, I was getting angry, getting upset [...] At its worst, before I ended up in hospital, I had this appalling dry retching that I couldn't talk, it was horrible to do and it must have been obnoxious for anyone to be around me. I was constantly dry reaching, your guts were clenching you know, your throat was clenching (Research Participant 12)

I was very unwell, because I fainted one day [...] and then when I came home, then I wasn't the same. I felt different. I was hearing voices a lot and seeing things that weren't there. [x] was just always mocking me [...] saying I was a loner and then everyone just didn't like me [...] and I just didn't have many friends (Research Participant 11)

From this time on, the stresses and burdens placed on care recipients and the resulting symptoms of mental distress or illness became the focus of medical interventions. Some family members provided additional support, while others distanced themselves, as care recipients themselves set about coming to terms with and managing their lives under these new sets of conditions and interdependencies.

Experiences of stigma, loneliness and isolation

Across the group, care recipients found living with mental health issues to be an on-going lonely business that was very difficult to overcome. As indicated, for many different reasons, friends were lost, sometimes they moved away, and lives followed different trajectories, leaving people with little to do and with a lot of time on their hands.

... lost nearly every single one of them [friends] [...] they didn't put in any effort with me when I needed them most so I just didn't bother reconciling the friendships when I got better (Research Participant 12)

Younger care recipients felt the loss of school friends and peers acutely, which exacerbated feelings of hyper-invisibility and low self-esteem. For some, experiences of teenage isolation was difficult, and these difficulties continued into adulthood.

And I couldn't do stuff all my friends could do, I couldn't go out to discos or and when I did go out, I didn't have a good time (Research Participant 11)

As highlighted by Harrison and Gill (2010), the reactions of the social environment and the stigma associated with mental illness further contributes to social isolation. While loneliness seemed to be more of an issue for the younger care recipients, it raises a noteworthy issue in the context of boundaries of friendships. Friendships seemed to fade away as people were faced with dealing with very difficult issues in their lives. Living over a long time with emotional needs seemed to exacerbate isolation, particularly if mental health issues were combined with decreased levels of mobility and availability to independently engage socially. Consequences include having little or no social outlets and having a lot of time to fill, by oneself.

It is hard I really don't like being off, it is so boring because I am just at home most days [...] It is because I always have to do things myself, walk myself to the estate, walk back up, it has to be me myself and then I go to bed early then, because I have nothing else to do (Research Participant 11)

Having to be silent and 'pass' as 'normal' was also evidenced in the research. This might be in the form of not reacting to, for instance, as in the extract below, hearing voices, in public. It might also be in making considerable efforts to re-engage in activities, so as to have something to talk about and, just generally, to be involved.

Interviewer: And do you feel that it is a secret that you have to keep to yourself?

Research Participant: Yeah, it is. Because I could be on the bus and I could hear voices and no one would know. I would be upset in my own head and no one would understand because they don't hear voices (Research Participant 11)

So, I started getting back into snooker, I started playing five-a-side soccer, I started watching the sports again on television, interacting through, you know, social media, basically (Research Participant 12)

Long stays in medical facilities are associated with a concentration on medicines, getting the medical intervention and level correct, and it was pointed out that on returning to the community, one can then be left with nothing to talk about.

There is nothing. No, with me if you start losing your friends throughout something as difficult as I went through it is very hard to cope back in the real world because you have to start all over again, at the end of the day I started realising I cannot keep talking about the same stupid content I was going on about (Research Participant 12)

Care recipients lost touch with the activities /topics /practices that ease communication, for example involvement in sport, talk about a television programme that friends /colleagues generally watch and then discuss, mutual interests in music and so on, as they become distanced from friends and acquaintances. Becoming distanced from the everyday, one is not aware of updates /twists /turns in conversations and quickly becomes an outsider. While new friendships were built up through re-engagement in organisations /activities /education, this could be a slow process.

I love walking a lot. I like going for a walk especially when it is sunny, I like going early because then I don't really see that many people out. But when I do go for a walk I like listening to music, I love music, I am always watching music channels and getting up all the latest music videos (Research Participant 11)

So we see here the loneliness of living with mental health issues. We see how assumptions of community support and involvement are not really supported in the experiences of these participants: they recount loss of friendships, loss of social. Importantly, these experiences also alert us to the interaction between long stays in residential facilities and loss of contact with social activities and social currency. After a long residential stay, where illness and medical interventions dominate conversations, participants literally had little else to talk about. Setting about re-engaging meant reacquainting themselves with issues of interest to their potential friendship cohorts and re-skilling themselves in social activities that would facilitate the development of new friendships. However, these reconstructions of life are done in the context of the ongoing issues faced by care recipients, of their fears and experiences of exclusion and as they attempt to build up their coping strategies and resilience.

MEDICATION, TREATMENT AND SUPPORT

While medication may be often necessary in treating certain aspects of mental illness, the side effects can also add to care recipients' negative experiences of mental illness and reduce quality of life. Care recipients spoke about their experiences of medication, how they reacted to treatments as well as their fears of being treated for mental health issues. They emphasised the importance of family members in supporting them and acting as advocates for them, especially when they were under the influence of strong drugs that rendered them unable to speak for themselves. They also highlighted the importance of professionals who listened to them and understood them and the issues they faced, as well as identifying a range of supports within the community that aided their recoveries.

Medication

Participants reported that they were sometimes prescribed drugs that were very strong, which rendered them unable to function, which had serious side effects that were not communicated well to them, and they were sometimes at a loss to what was meant by a diagnosis placed on them.

They are making me tired and they make me cranky sometimes, even though I am on two relax tablets because I get very cranky if I am in pain (Research Participant 4)

I was doped out of my mind [...] I couldn't do nothing, my mother told me one day she saw me, she was going to the shop and she came back and my head was just down on the window with drool all over my mouth, coming out of me, I was that heavily medicated, you know (Research Participant 12)

I get very hungry with my medication; it makes me hungry all the time. Like, I could have a roast dinner, ice cream, biscuits and tea and I would still be hungry (Research Participant 11)

Furthermore, diagnoses given were sometimes not explained fully, leaving them with a label for their symptoms, but with little or no understanding of what that really meant, expect that it was a recognisable label.

They diagnosed me with paranoid schizophrenia, but I didn't understand it myself, I still don't understand it today, you know I take my meds, I go every month, I have to get a blood test every month and take tablets (Research Participant 12)

These findings are in line with Lester and Tritter's (2005) study, which highlighted that sufferers of mental illness found the side effects of many medications difficult to live with, which was exacerbated by lack of information from and consultation with health professionals.

While Tambyerzer and Van Audenhove (2013) highlight the importance of service users' active involvement in decision making in relation to their mental health, treatment, and care plans, care recipients did not feel that they were part of an equal partnership with medical professions in terms of planning their treatment and care. In the current research, being in a position to get some clarification or to have more in-depth discussions with psychiatrists was sometimes seen as not being an option, as they were perceived to be busy people and to take up too much of their time would mean taking time away from other patients.

Research Participant: She [psychiatrist] does [listen]. But it is a very quick appointment time. I am only in there for, like, ten minutes and I am home again.

Interviewer: That is not very long really is it?

Research Participant: No, but you see, there would be people waiting for her. She is usually quite busy, so I am only in there a few minutes (Research Participant 11)

I would have to go to the facility in [x] every week and get an injection and the stuff didn't work at all, it was terrible (Research Participant 12)

It seems from the first extract above that care recipient takes on the worry about taking up the time of the health professional, in this case, a psychiatrist, who is considered as a busy person, with a lot of patients to see. Taking time is constructed as taking time away from other patients, and the limited health support offered is set in this context, the emphasis being placed on the time of the professional over the needs of the patient. The second extract indicates an on-going situation whereby injections were being administered on a regular basis, leading us to question priorities again: in this latter case it would seem that the priority coming through is on the maintenance of system of administration of medication, rather than a concern with its efficacy. Certainly, at least, the participant wasn't consulted about their experiences of the administration of the drug in question or its effects. Eventually, the

participant, with the support of a mother's involvement, changed to another more suitable medicine regime.

Treatment

Frequently, participants' memories of their first admission/interaction with health services, while highlighted as significant for them, was a little vague. If admitted to a residential facility, generally they little or no idea of what to expect and could find this process, in itself, a frightening one.

Interview Participant: We saw a consultant there [hospital] and interview, and I was admitted within the first hour that I was up there.

Interviewer: How did you feel about that?

Interview Participant: It was scary (Research Participant 12)

... I don't know what happened. I felt very upset and I was miserable, and they didn't know what was wrong with me, for the first few days and then, some parts of it, I only remember when I was unwell (Research Participant 11)

While intervention at this point was welcome and necessary, it could also be confusing.

Communication with health service personnel was often vague, not very clear, and sometimes seemed to be deflective rather than informative.

Because you know ... at that time the only thing I knew about mental health units was, I didn't know the word unit or health, I was thinking mental asylum, you know, they were going to put me in here and I was never going to get out again. [...] I only thought I would be in there a small while and every time I saw a psychiatrist they would be telling me 'oh you will be out soon, you will be out soon' you know (Research Participant 12)

Not knowing how the health service worked, what to expect and being frightened about what was happening to them, increased feelings of vulnerability. This reflects [Lester](#) and Tritter's (2005) findings in relation to the difficulties care recipients experience in accessing health services, and associated the lack of confidence. As outlined above, such feelings are particularly acute at the onset of an illness when neither the care recipient nor family member understands what is happening.

On the other hand, meeting with an interested and communicative consultant who could engage and knew the context of a person's life, concerns and livelihood, was always helpful in supporting a person to see the issues they faced, from a fresh perspective.

...I was suffering from anxiety, there was severe strain on the marriage, there was as much strain as work so the way [consultant] put it to me, when I was dealing with him, he basically sat me down and said 'I have been listening to you for a couple of months and you are not the devil with hoops and horns that you try to make yourself out to be and you have been riding around on your white horse saving the world since you were twelve. The horse died two years ago and you won't last much longer unless you listen to me' (Research Participant 9)

Such personnel were remembered warmly and their role in acknowledging and supporting participants through difficult times was valued. This corroborates Lester and Tritter's (2005) study which found that care recipients 'believed that it was important to 'own' their impairment and indeed to feel positive about embodied irrationality rather than ignoring it or being ashamed' (Lester and Tritter 2005: 658) and challenge more hierarchical expert led communication about mental illness.

Care recipients also identified a number of support services that were of assistance to them including Shine¹⁰, the Foyer¹¹, Out and About¹², The National Learning Network¹³ as well as the teaching and learning initiatives that were offered in residential centres that helped some to fill gaps in interrupted education and others to up-skill /reskill themselves. What was important to care recipients, in addition to the supports offered by these initiatives, was that the services offered by these organisations fitted their needs and levels of ease /unease with being part of a group. Some preferred smaller, more individualised treatment, education and training interventions, while others were more comfortable in larger group settings.

Sometimes, close family members worked with care recipients, social workers and other health service personnel to research and identify services appropriate to their needs, may have provided transport to and from groups and classes and provided supported to continue participation in classes. Support services were also identified by peers in residential psychiatric centres through a peer network that formed through engagement with these residential services.

From the care recipients perspectives, family members were also seen as playing important roles in gathering and accessing information, negotiating with health service providers and for general companionship; this is an important factor in the context of increased isolation, something experienced by all. In one instance, a participant pointed out a mother's sensitivity to the negative effects of medication. Her subsequent research and discussions with medical personnel was important in the recovery process. This care recipient stated

Without her I probably I would either be stuck to a bed now, completely doped up to my mind, no use to anybody
(Research Participant 12)

Support

The supports that care recipients felt they need most from family members was often emotional in nature. Sometimes they needed to rest for a considerable amount of time. At other times, care could also involve close family members carrying out research in identifying appropriate services/ information/ training and into the conditions that they had been diagnosed with, as well as possible interventions. Their needs varied depending on people's levels of anxiety, depression and associated ability to engage with family, the wider society and services. Overall, in the context of care within the family, for most participants, regardless of diagnosis, what emerged as important was that family support was reliable,

¹⁰ See <http://shineonline.ie> for further information on Shine and its range of services in Cork

¹¹ See <http://www.corkfoyer.ie> for further information on The Foyer, and its range of services in Cork

¹² See <http://www.oandaireland.ie> for further information on ONADA, Out and About Association

¹³ See <http://www.nln.ie/Home.aspx> for further information on the National Learning Network

flexible, and sensitive to the individuals' situations and needs. Care recipients wanted to feel accepted and wanted the difficulties they were facing to be acknowledged.

Principally, care recipients lived in their original familial homes, with siblings, or by themselves, but with close interaction with family members, particularly with mothers. In some instances, adaptations were made in the maternal home, to create more communal as well as individualised living spaces that would help meet the needs of all co-residents, requiring the co-operation of all members of the household. Care recipients identified specific members of their family who provided support for them: mothers were in the forefront followed sometimes by fathers, siblings and grandmothers in providing a place to stay, comfort, company and sustenance. Move back into a maternal home, having left it many years beforehand, emerged for some as an option that provided a place to live, away from the stresses that had built up in education /work and personal relationships. For example, one participant recounted the following:

I moved back to live with my mother at the time [...] and at that time I suffered quite a bit with depression, despair, anxiety and all the rest of it, and for a year or two, while that was going on, it was my mother minding me (Research Participant 9)

Another care recipient commented on the importance of a supportive family, who provided constant support and security.

Oh, I have a great family. I have a loving family, they are always there for me and I love my house as well (Research Participant 11)

These examples indicate the importance of having a safe and secure place to live, where there is some reliability regarding daily routines and some understanding that the person him /herself needs time to recuperate.

All participants spoke about the importance of having supportive family members/ supportive families in helping them through their difficulties. At the same time, they might not always agree with one another and sometimes they felt that family members just didn't understand them.

We would always go together [with a sibling]. We would get half an hour and we would be fighting sometimes, and other times you wouldn't, like, but you wouldn't be normal if you didn't fight sometimes (Research Participant 4)

In other cases, families were also the source of some of the issues people faced. For example, difficult family circumstances contributed to one care recipient's difficulties, in the lead up to a crisis, which was partly related to close personal relationships. Another participant, while acknowledging the critical role played by family, found living with their parents /siblings stressful and so, after some time, moved out, while maintaining close relationships thereafter.

I just couldn't deal with the stress at home and [sibling] there as well, which we never really had a good relationship (Research Participant 12)

So we see the very complex set of contexts around which participants interact in accessing treatment for the issues that are affecting them. Prior to involvement with medical services,

knowledge of such services can be cursory and participants were sometimes fearful about what was happening to them. Their participation in decision making about interventions was not all that evident and perhaps, intersected with their feelings that mental health consultants and professionals are busy people, whose time they should not infringe upon too much. Family support, while welcome and offering levels of security and stability, intersected with levels of understanding and closeness /distance of relationships.

GENDER IDENTITY, EDUCATION AND EMPLOYMENT

Gender Identity

Age and gender interacted with the supports needed by and available to care recipients. Younger care recipients mentioned being offered services where they perceived that they had little in common with other users, were aware of being one of a very few or the only young person. They found that such groups had little to offer them and even contributed to making them feel even more isolated. Comments about appearance and body image were mentioned by female participants, which seemed to align with societal expectations about women and girls and gendered presentation of self. Coming to terms with difficulties in adulthood, having completed an education, secured employment, perhaps formed close personal relationships and so on - having lived normative adult lives - seemed to lead more to a re-assessing of identities, priorities and decisions made.

Education and Employment

Finding ways to fill one's time with meaningful activities has also been identified as an issue for those with mental health issues, even for those who interacted with support organisations (Rankin 2005) and for family members (Dalton-O'Connor et al 2014). Employment and education not only offer a way of making a living; they give one a schedule, an identity, company and a place to go. Education offers more than the subject matter of the programme, it fills a day and takes time and energy. Accessing education, for those whose education was interrupted, was viewed as an important part of the journey towards recovery and maintaining their wellbeing. Care recipients were motivated to develop existing skills or learn new skills, viewed participation in education and employment as a means out of loneliness and into more full engagement with society, and ways and meet new people.

There was about twenty of us in my class and they were all young people so I was delighted and I could do anything and they were so nice and I got my FETAC ... award there (Research Participant 10)

However, returning to employment full-time, to employment /education that had previously been part of a build up of burden and stress, was not an option for many.

This seems to align with Dalton et al's (2014) assessment of the difficulties experienced by those living with acquired brain injuries in finding and keeping employment, and with Gill and Harrison's (2010) observation that 'patients have their job terminated because of aspects of their illness' (p. 243-44). Finding ways to participate in employment/ voluntary work and alternative forms of education where one could start anew, on terms that did not induce burden, seemed to work best and helped to build up esteem and confidence. However, finding such routes was not always easy and care recipients spoke about times when they felt their anxiety levels rising, were becoming more depressed and/or finding it more difficult to cope.

So the benefit of [education] has just opened up my horizons different people, different cultures you know different religions, races everything (Research Participant 12)

... kind of my life [was] closing down into kind of like a funnel. And I don't quite know what changed, maybe it was getting on top of this place, but all of a sudden it was the other way around, it was opening up and opening up (Research Participant 9)

Nevertheless, finding an interest /education course /work brought hope for the future and offered much in terms of developing a new education /work identity that incorporated strategies and made sense of associated pressures, and ways of working that participants found helped to maintain their well-being.

There is a lot of pressure [...] and I am judging my anxiety levels and my tiredness levels and I am definitely tired out from it, and I am saying 'do I need to check with my doctor to see if I am alright,?' Should I, with the winter coming in now, should I think about taking a course ... (Research Participant 9)

Care recipients were mindful of their own wellbeing and considered their activities in the contexts of their interaction with it. In this they draw our attention to the on-going nature of living with mental health issues, high and low levels of anxiety and depression, maintaining wellbeing, and the importance of continually sustaining support mechanisms that could meet the ebbs and flows of their lives.

Countering invisibility – advocacy and awareness raising

The experiences of mental health and associated ongoing struggles, coupled with the complexity and difficulties in negotiating the health system, to identify and access services, developed a strong sense of activism, advocacy and the importance of awareness raising amongst some participants. It seemed that as care recipients had to fight for and against so much, their resolve to fight for services, for both themselves and others, increased.

Contributing to assisting others to not become isolated and, rather, be able to access appropriate support, emerged as important. Participants reflected on their time in residential centres and commented on the boredom they encountered, as well as how being in a residential centre, with a concentration on medicine and health interventions, simultaneously distanced them from the everyday communications that often forms the basis of dialogue with others. They had very practical suggestions on how everyday life in such centres could be

improved and how, for instance, physical exercise and simple but appropriate activities, could be incorporated into residential care environments.

Eventually, they took my idea on [...] and they bought a small little pool table [...] they put a treadmill in there [and] at least, if you had a little gym in there you could get your health up, and afterwards, then you would have that experience of a gym, if you never went to a gym, and it would be through their health process that you joined and got fit and meeting people there would be music on in the gym (Research Participant 12)

Here we see the way a participant viewed the importance of physical and mental wellbeing and could clearly see how the incorporation of a fitness regime, initiated within a residential centre, could become part of a health intervention. This could also be beneficial in the longer term as one re-integrated into the community. To this participant, it just made sense that recovery meant getting physically fit and mentally well.

To the participant below, getting help meant having someone to talk to and someone with whom to be friends. Recognising the nature of mental health, association with mental illness and loneliness as well as the importance of individualised responses, could be interpreted a first step.

Research Participant: It is very unfair, especially if someone got sick tomorrow, you would want to make sure that they got help.

Interviewer: And what do you think would be the most important thing if somebody, what would be important to have if somebody got sick, say, like you did now?

Research Participant: Like friends, someone to talk to, because it gets very lonely (Research Participant 11)

Giving voice to their experiences and the wish to make a positive difference to others who might come after them was also a key factor that motivated some participants to partake in this research.

CONCLUSION

The experiences and issues raised highlight the loneliness and isolation experienced by these care recipients, as well as their ongoing efforts to engage and re-connect with social, employment, voluntary and education opportunities open to them. It alerts us to the obstacles to such engagement - brought about by the structure of treatment interventions, and the nature and level of supports, that sometimes meet their specific needs and which, at other times, are distanced from them. They highlight the reality of living with gaps in services and strategies they use to negotiate their way through these gaps. Through the experiences encountered some of these gaps are identified. We see how beneficial and positive considered support can be and participants identify key supportive family and professional relationships. Their value and insight as advocates cannot be overstated, as they move on to dismantle obstacles they faced, in the hope that others coming after them will have more positive experiences overall.

Caring relations and interdependencies

INTRODUCTION

An issue that is interweaved throughout the research findings is that of complex interdependencies. From the first experiences of mental health issues within a family, the household and personal spaces and priorities changed for carers and care recipients. There was contact with acute medical services at times of crisis and this was generally followed with regular/ semi-regular contact with mental health professionals. Formal and community support services were organised around support for carers and for care recipients, each with their more specific focus.

In between more acute medical interventions, normal household life was constructed and re-constructed to meander around recovery and in accordance with the needs of the individuals involved. Within these conditions, care and caring relations became largely invisible, as they meshed into the everyday – in many this is necessary in order to reconstruct lives within the evolving environment. In many ways also this is not only necessary but also welcome: caring relations that are suited to the resources, needs and priorities of all concerned are, arguably, those that are most sustainable and supportive of care recipients and carers alike.

However, throughout the research process, it became evident that enmeshed within the reconstructed normal lives were issues that, when not recognised and addressed, remained unresolved and which led to on going difficulties. In the first instance, the absence of external support in the reconstruction of these new interdependencies was an issue. Secondly, embedded within these reconstructions were differing perspectives on ways forward, which again, unaddressed, remained as unresolved tensions. Furthermore, lives were often then lived in isolation, within and outside of homes and communities. It is not surprising that within such isolation, the issue of suicide arose several times in interviews with carers and with care recipients. Arguably, this can be linked to the isolation and tensions people lived with in their daily lives. On the other hand, the new and evolving interdependencies can also form the basis of deeper and meaningful relationships, alerting us to their more positive aspects and changing trajectories.

RECOGNISING AND SUPPORTING CARING?

As identified within this research and in the wider literature on caring, family caring has financial implications. Carers' and care recipients' participation in employment and opportunities to engage in further education /training was curtailed by the circumstances in which they found themselves. The particular contexts of caring in the context of mental health issues, its largely invisibly nature, feeds into the assumption that the reconstructed household

and caring relations are freely made choices and not the business of caring support schemes. This was evident in carers experiences of being refused access to social welfare allowances and also of considering themselves, that they would not be entitled to them, irrespective of the amount of caring they did.

'They [social welfare] said she is not, what way did they put it, she don't need really need care, but she does... and then when you are out... you don't know if something is wrong or not' (Research Participant 4)

'they [social welfare] called me and told me because he was in rehab I wasn't entitled to my money' (Research Participant 6)

I never put in for the Carer's [allowance]. I only put in for it this year. I don't know if I will get it' (Research Participant 5)

This is despite the ways that the research participants had re-arranged their lives to match their caring obligations; some had given up their employments to focus entirely on caring, others had switched to working part-time or occasional hours. The non-recognition of their caring places further burdens and tensions on carers and on care recipients and sometimes, places impossible burdens on them.

Somebody would need to be up in the social welfare department in the places where they are passing you and not passing you...I think that they should have somebody that just does the mental health issues' (Research Participant 6)

As expressed above, one suggestion to help address this was to include personnel in offices where social welfare allowances were assessed who have an understanding of living with mental health in the community.

WHO'S RIGHT AND WHO'S WRONG?

A related issue is the manner in which differing and often opposing perspectives and ideas can become embedded into reconstructed daily lives and caring relations. While daily lives are often lived in such circumstances, embedded and unresolved conflicts and viewpoints can contribute to isolation and increase burdens of giving and receiving care. During the course of the research, family carers commented that they lived with family members who were unwilling to acknowledge and address issues they faced. Care recipients commented that their family members just didn't understand them, and in response, they retreated and isolated themselves. Unacknowledged and unaddressed, these issues make any discussion of them difficult, if not impossible. They can result in all involved constructing their lives so that they have as little interaction as possible with one another. Yet, simultaneously dependencies remain central. While support continues to be segregated into carer and care recipient /client /patient groups it is difficult to see how support to address such issues can be developed.

SUICIDE

However, while these issues remain unaddressed it can be expected that tensions and increased isolation continue to be part of the environment. As mentioned above, in such

contexts it is not surprising, although it is a matter of grave concern, that suicide was raised several times through this research process. In all, four participants recounted several attempts of suicide pertaining to their contexts. Both those caring and those who were care recipients recounted attempts of suicide. When making reference to their family members, participants expressed concern, were watchful, and sometimes feared the possibility of further attempts of suicide. Attempts of suicide were seen within the context of the mental health issues that they faced themselves, that their family members faced, and were related both to the onset of mental health issues in the household and associated burdens of care.

she tried to kill herself, yeah. She jumped out of one of those windows (Research Participant 4)

Attempt suicide was described as the being the only viable option to exit a stressful situation, for the person themselves, their family and having made this decision a participant recounted how it was then impossible to reach them.

'I made an attempt on my life and threw myself in the river ... basically, I was so happy and relaxed that it was going to be all over' (Research Participant 9)

'The time I took it was of a Sunday... [partner] was saying to me, you know, you are doing okay, but it was like I had gone into another room, he couldn't get to me even though he was just there, there was no looking back and no one could have, could have come in, do you know what I mean? (Research Participant 1)

That this issue was raised by participants themselves, independently, and recounted as a simple matter of fact within their experiences of caring, suggests that it is an underlying issue, in these caring contexts, that needs to be addressed more directly. This research indicates that living with suicide attempts is a very real part of the environment, and that it is connected with the build up of tensions and isolation people experience. While further research into this is warranted, arguably, assuming reconstructed interdependencies are self-supporting contributes to it.

CHANGING PLACES?

At the same time interdependencies can have more positive outcomes. In time, dependencies change. Interest and involvement in the trajectory of a person's health issues could also become the basis of close and deep familial-based friendships and trust, as is evident in the interview extracts below:

Because she [mother] would know me better than anyone, really (Research Participant 12)

As time passes and interdependencies of close living and attention to the other evolve, care recipients could adopt the role of carer, without really ever quite seeing the change happening.

... as I came back to myself, I found myself that my mother became incapacitated and was confined to bed. Or perhaps, even with mental health issues, and took to the bed to some degree and she may have suffered from depression herself but never showed it, it she was always bright and cheerful (Research Participant 9)

Such might also be recognised and acknowledged by their extended family members, before the person themselves could see the level of interdependencies evolving. This is well illustrated in the extract below, where siblings identified the changing and interdependent role played by the care recipient as carer for their mother. That they lived together interchangeably as carer/ care recipient was evident to this participant's siblings before being recognised by the participant.

And they [siblings] said to me 'you never told us you were away, you know, you were away from Friday to Monday and, you know, you didn't tell us'. I said 'you know, I was glad to get away and leave my mother alone and get out from under her feet'. [They said] 'but sure, look, we needed to check on our mother' and I said 'but it is she is minding me' and they said 'Oh, they said, she needs minding, she needs checking on every day, you took a load off our back when you moved in there' (Research Participant 9)

CONCLUSION

Together, what these issues remind us of is the complexity and divergence in family relationships: Familial /personal relationships aren't always supportive, couples split up and make up, siblings, parents and their children argue and don't always understand one another, relationships change and are made up of very often discordant elements. It is in this context that family support takes place and negotiations around members' needs are sorted out. We are reminded of Kittay's (2002) stance on the centrality of supporting interdependencies and those people who are central to them as well as Lynch et al's (2009) contention on the importance of affective equality in sustaining primary care relations. Focusing on the experiences and perspectives of carers and care recipients, as we have done in this research, alerts us to the importance of giving voice to each of these perspectives as well as to the very centrality of interdependence in family caring relations.

6 Conclusions and recommendations

CONCLUDING COMMENTS AND RECOMMENDATIONS OF THE RESEARCH

While this is a small scale study and focused on the experiences of carers and care recipients living in one geographical area in Ireland, Cork, it nevertheless offers us important insights into the lives and experiences of family caring in mental health contexts. The generosity of those who participated in the research in sharing their realities, hopes and interactions, makes the issues they face in their everyday lives a little more visible. Where there is more visibility there is a hope of appropriate intervention and support. Their involvement and engagement with the research process is indicative of the role, highlighted in the research, which they play in advocacy and a reflection of their aspirations to dismantle obstacles for those who follow in their paths.

The range of experiences and issues raised throughout are complex and cover a wide breadth. In attempting to synthesise them we now view them from the perspective of the pathway from onset of illness to recovery and advocacy.

MENTAL HEALTH IN THE FAMILY: THE ONSET OF CARING

Experiencing mental health issues in the family, for carers and care recipients often came hand in hand with a venture into the unknown and was imbued with crisis and fear. Access to acute services was often quick; sometimes diagnoses were offered quickly. At other times, this took many years, with many appointments with various consultants as, for instance, parents attempted to access supports for their children. However, explanation of diagnoses, when diagnoses were given, and communication about what to expect, seemed to be vague. At least from the perspectives of those at the receiving end of those communications, the messages about what to expect in living with or supporting, for instance schizophrenia, was not at all clear. Families learnt as they lived with the diagnosis; as those suffering from it and as those caring for them. As time went on and families became more knowledgeable about particular medical conditions, they looked to how particular symptoms associated with them reflected what they experienced or not, and participants engaged more actively in managing their conditions and those of their family members. The latter could be interpreted as a process of ‘owning’ of one’s condition, perhaps also representing an alternative way of viewing mental illness /wellbeing and incorporation of associated factors into life courses and patterns.

FAMILY CARING AND MENTAL HEALTH

Family caring in the context of mental illness took a multiplicity of forms, from being present, re-prioritising of household environments, researching medical conditions and interventions and available supports in the community, accompaniment to appointments and intersected with familial roles and relationships. Those experiencing mental health issues generally appreciated their support, even if they differed on ways to recovery at times. Significantly, being heard and fully participating in strategies /interventions to address issues arising seems to be critical to all.

Care recipients also emphasised the importance to them of having family members' support in acting as advocates for them, especially at times when they unable to speak for themselves. However, because of its episodic nature and the manner in which care becomes incorporated into the invisibility of daily living, ongoing caring and caring needs tend to become normalised. This is despite the social, financial and personal costs associated with it. Removing the cloak of invisibility and challenging assumptions about the 'selfless carer', would seem to be pre-requisites to supporting and sustaining these caring relations.

Living with mental health issues can be long-term and the research suggests that stigma continues to be an issue. Furthermore, participants highlighted its embodied nature as well the loneliness and isolation they experienced and the limited employment and education opportunities open to them. Such leaves carers and care recipients living with little support around them and bearing the financial and social costs of limited understanding and flexibility. Strategies to counter such isolation were identified as participants reconstructed their lives and sought out ways and means of interaction. Participants reacquainted themselves with issues of current interest to enhance their chances of forging acquaintances and friendships and engaged in social activities, advocacy and voluntary work. The value and insight of carers and care recipients as advocates cannot be overstated, as they engage in identifying challenges they faced and work towards dismantling these obstacles.

Communications with services indicate that aspirations of inclusion in decision-making and development of holistic services, as envisioned in the *National Carers Strategy* and the *Vision for Change*, are not well developed. Having services differentiated by gender and age and which are activity-based were emphasised as being particularly important for younger participants. Age and gender specific activity-based services could offer young care recipients support in meeting someone with similar feelings and with whom one could actively engage, outside of a health related environment.

There was some evidence that the suggestions of some participants are making a contribution to changing conditions in residential centres. Nevertheless, outside of the recognition and

support of some professionals and engagement with community services, for some, daily life continues, largely, passing for ‘normal’, and in silence. Together, the pathway from onset of illness to living with and engaging with the range of medical and community supports as well as interactions with friends, family and the wider community alerts us to the interdependencies inherent in their contexts. The issues raised reinforce the importance of recognising and supporting these interdependencies. The research undertaken identifies a possible association between understatement of such interdependencies and levels of suicide, an issue that warrants further research.

RECOMMENDATIONS ARISING FROM THE RESEARCH

A key step in supporting such recognition is to move from a strategy that envisions more holistic, carer and care recipient service, towards one where such becomes a right. Support elements identified in this research that warrant such recognition include:

1. Family carers, caring for relatives with mental health issues, are included in the criteria for carers allowance.
2. Community services are adequately funded to help recognise, address and support the interdependent nature of family care.
3. The voices of carers and care recipients are included in the development of strategies and services, in a grounded way.
4. The development of easily accessible avenues for carers and care recipients to articulate their experiences.
5. It be clearly demonstrated how their experiences are to be taken into account in the development of policy and practice.
6. A range of community services that facilitate engagement of young people with mental health issues, in social activities and that are cognisant of individuals’ needs and dispositions be developed.
7. Work be continued to increase the visibility of mental health and to challenge stigma.

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Appendices

INTERVIEW SCHEDULE: CARERS.

Housekeeping and consent:

- Re-cap on introduction to and origin of the research.
- Previous collaborations between Cork Carers Association and researcher, including associated research reports and activities.
- Consent forms explained and distributed.
- Recording / note-taking and transcriptions explained fully.
- Contact details of Carers Association / researcher distributed.

Focus group discussions guide:

- Mental health issues generally as experienced by participants in group.
- Range of mental health issues leading to increased necessity for family care by participants.
- Impact on family, carer and care recipient.
- The types care/support required, including its nature, regularity and time.
- Formal and informal supports available to individuals and families.
- Possible care alternatives and issues arising.
- Assumptions and perspectives encountered locally/nationally related to care/caring supports.
- Ideal care solutions and enablers (group perspective)

INTERVIEW SCHEDULE: THOSE REQUIRING INFORMAL CARE SUPPORT

Housekeeping and consent:

- Re-cap on introduction to and origin of the research.
- Previous collaborations between Cork Carers Association and researcher, including associated research reports and activities.
- Consent forms explained and distributed.
- Recording and transcriptions explained fully.
- Details of Carers Association / researcher distributed.

Individual interviews will follow the narrative of the participant, drawing on the intersections between the caree's experiences of the mental health issues concerned, their intersection with personal relationships, the need for increased care and the particular care context in which the participant finds themselves.

It is envisaged that these interviews, while focusing on broadly similar issues to the focus groups, will facilitate people in discussing their own particular contexts and experiences in more detail. This form of semi-structured interviews follows the participants' areas of interest / priorities. It is process driven, responsive to issues arising, and facilitates in-depth discussions of specific experiences in the care journeys of individuals and families. At the same time, its focus on care attempts to guide the discussion towards care experiences, needs and supports, which is the focus of the research.

General issue guide

- The nature of the mental health issues that have led to increased necessity for family care for participants.
- The extent of the informal care required by them and offered to them, including its nature, regularity and time involved.
- Impact on family, caree and carer from the perspective of those needing care support.
- The formal and informal supports available to support caring needs of the participant.
- Any possible care alternatives that were considered and issues arising.
- Assumptions and perspectives encountered in the community regarding the care contexts.
- Ideal care solutions and enablers for individual contexts.

LETTER OF INTRODUCTION

Experiences and Challenges Faced for Family Caring in Mental Health Contexts

We are contacting you with regard to a research project that has been developed in collaboration with the Carers Association Cork and UCC. It is focused upon getting a better understanding of issues facing individuals and families in the Cork area, who have caring needs, and where that need arises because of mental health issues generally. This can include any mental health issue that has given rise to the need for increased informal care support in your family context.

The hope is that, through discussions with carers and those for whom they care, specific issues arising for these family caring contexts in the Cork region will be identified. The information gathered will be written up in a report, which we hope, will be useful in making the issues you face more clear to policy makers.

We are, therefore, looking for participants to co-operate in a focused group discussion, and/or in-depth interview. We envisage that this discussion will last for up to two hours and, with your permission, will be recorded. Throughout this time we will generally discuss the following:

- Mental health issues generally that lead to increased necessity for family care.
- Carer/Care recipient and families experiences and other issues arising at the outset of these issues.
- The types care/support required, including its nature, regularity and time.
- Formal and informal supports available to individuals and families.
- Assumptions and perspectives encountered locally related to care / caring needs/supports.

If you think that you would be interested in participating in this research, please contact the Carers Association at [] and we can discuss details of the research and your participation further.

Many thanks for your support and co-operation.

[signatures]

CONSENT FORM:

Experiences and Challenges Faced for Family Caring in Mental Health Contexts

Thank you for agreeing to take part in this interview. It is part of a small number of in-depth interviews focused upon getting a better understanding of issues facing individuals and families in the Cork area, who have caring needs/provide such care, and where that need arises because of mental health issues.

It is understood that the nature of the research and its purpose has been explained to you by the researcher / Carers Association Cork. Briefly, this research has been suggested through on-going discussions between the researcher, the Carers Association Cork and the Carers Forum Cork. It is funded by the Irish Research Council, New Foundations Funding Scheme. This is a research funding scheme that supports collaborations between voluntary/community groups and researchers working in higher education institutions in Ireland. As a research collaboration, it follows previous research collaborations in 2008/2009 and 2012/2013 that investigated supports available to and experiences of informal carers in Cork. This project now, is focused on gaining more nuanced knowledge of the experiences, challenges and concerns pertaining to informal caring, where the need for care arises in the context of mental health issues, in general, and with a focus on attempting to elucidate specific issues arising for these family caring contexts in the Cork region. With your consent the interview will be recorded. After this, it will be transcribed and the transcription will be given to you for review. At this time you can make further clarifications / adjustments that you think appropriate and your personal identifying features will be removed in order to assist keeping your information confidential.

It is not envisaged that there will be any adverse consequences to your participation in this research and the extent to which you choose to share any information is entirely up to you.

You can withdraw your consent/conclude your participation at any time during the research process and prior to the development of a final report, allowing time for the report to be completed. It is proposed to carry out the research beginning in March 2015 and it is envisaged that a report will be produced by December 2015. If you wish to withdraw your consent please contact the researcher – contact details are provided below.

Having agreed on a final version of your interview transcription, your name on the transcription will be changed in order to help keep your information anonymous. However, this procedure has limitations. In writing up of information thereafter, issues of confidentiality will continue to be considered and every effort will be made to keep your information confidential. This might mean that, in instances where it is considered that confidentiality could be breached in explaining an issue, by making specific comment on your situation, that issue will be discussed in more general terms.

Data will be stored on the internal hard drive with a back up copy on the external hard drive of the researcher's computer, which is password protected and, according to policy requirements of UCC, will be stored for seven years.

Name of Participant:

I agree to participate in the 'Experiences and Challenges Faced for Family Caring in Mental Health Contexts', research study.

The purpose of the study has been explained to me and I understand it.

I am participating voluntarily.

I give permission for [my interview/focus group] to be recorded and such personal details as I have provided to be kept on record.

I understand that I can withdraw from the study, without repercussions, at any time whether this is before it starts or while I am participating.

I understand I can withdraw my permission to use the data up to a month following agreement on a final transcription of my interview, in which case the material I have provided will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity and thereafter issues of confidentiality will continue to be considered in writing up data.

I understand that extracts from the finalised transcription may be quoted in any subsequent publications if I give permission below.

☐ I agree to quotation/ publication of extracts from my data

☐ I do not agree to quotation/ publication of extracts from my data

Signed: _____ Date: _____

[Researcher Contact Details included]