

Department of Psychology

Online Support Groups for Family Carers

A Qualitative Study of Care Alliance Ireland Online Support Group

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Acknowledgement of CAI staff
and members of CAI OSG



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“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”

-Rosalyn Carter-

Aim: To understand the relationship between engagement in OSGs and outcomes for family caregivers with a focus on social support and social identity.

Objective: To understand the reasons why family caregivers engage or do not engage in OSGs and the reasons why caregivers receive or don't receive benefits from engagement with these groups

Online Support Groups – A (very) brief history

2010

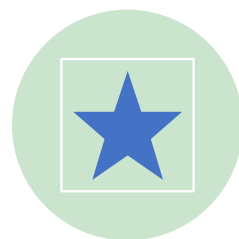
Present



HOW DOES THIS ONLINE SUPPORT GROUP OPERATE?



WHAT WORKS WELL AND WHY?



WHAT BENEFITS (IF ANY) DOES IT HAVE FOR PARTICIPANTS?



ARE THERE AREAS THAT CAN BE IMPROVED?



ARE THERE REASONS WHY THEY DON'T WORK?



ANY RECOMMENDATIONS BY PARTICIPANTS FOR FUTURE DEVELOPMENTS

Care Alliance Ireland Online Support Group



- In March 2020 everything stopped
- Services all ceased – many overnight
- Time of confusion and misinformation
- Other organisations slow to respond
- In response, Care Alliance Ireland pivoted the work of the organisation and founded The Online Family Carer Support Project

Now has over 4,000 members

IT	Level 1	Level 2	Level 3	Level 4	Level 5
THE IRISH TIMES					
Visitors	10 From 3 households	6 From 2 or 3 households	1 Other household	No Visitors permitted	No Visitors permitted
Gatherings	50 Outside your home or garden	6 Indoor 15 Outdoor	No Social or family gatherings	No Indoor gatherings	No Except funerals or weddings
Domestic travel	No Restrictions	No Restrictions	Stay In your county/ religion apart from work/education essential purposes	Stay In your county/ religion apart from work/education essential purposes	Stay At home except to exercise within 5km from home
Public transport	Travel Off-peak hours or walk/cycle, if possible	Peak Hours Essential workers/ purposes only; 50% capacity	All hours Essential workers/ purposes only; 50% capacity	Avoid Public transport; essential workers/ purposes only; 25% capacity	Avoid Public transport; essential workers/ purposes only; 25% capacity

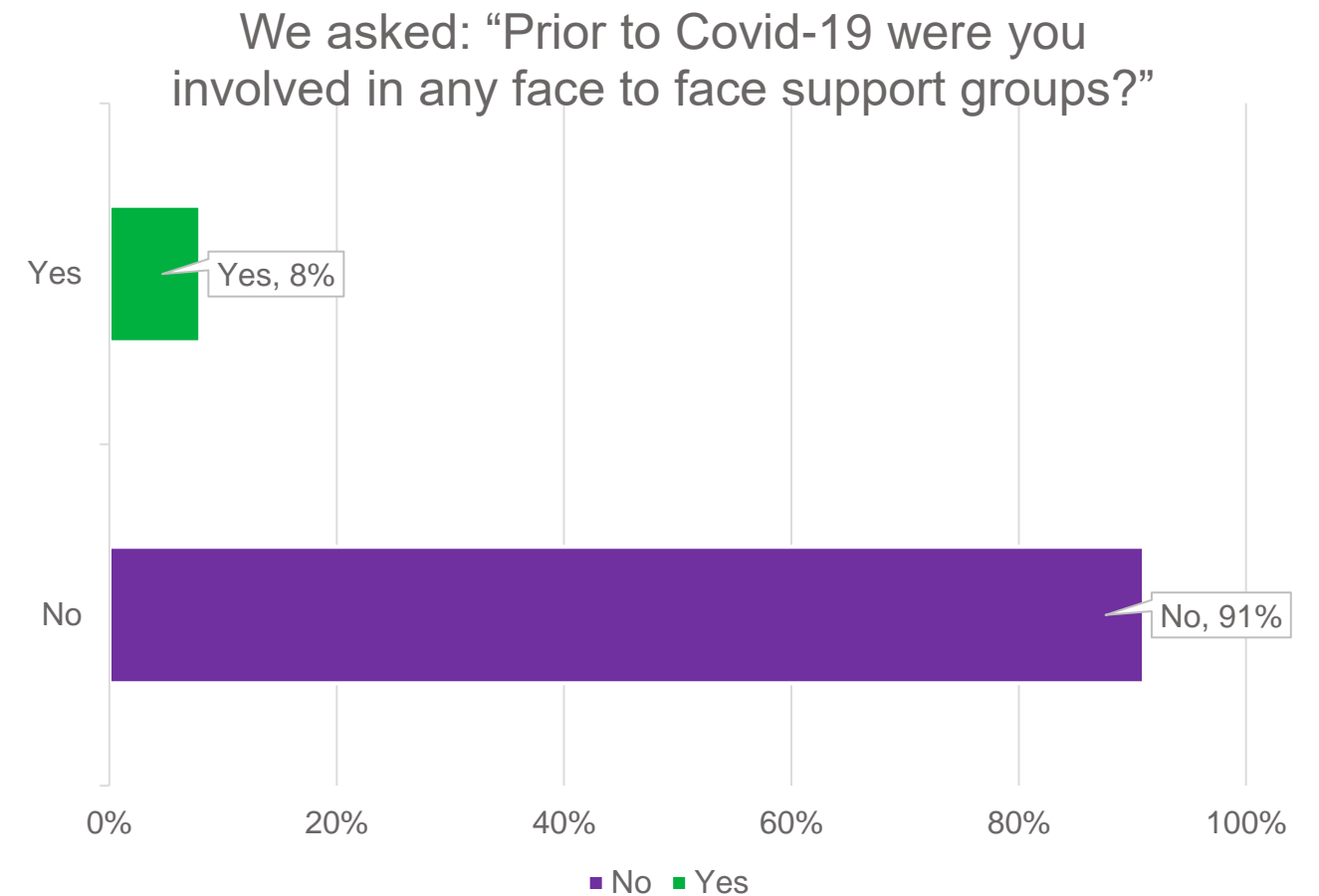
Graphic: Paul Scott/IRISH TIMES GRAPHICS



Use of Facebook as primary medium for engagement



Captured a cohort of family carers who weren't engaged in physical support groups



Methodology

- Semi-structured interviews
- 34 questions refined to 12 key questions
- Transcripts de-identified
- Reflexive thematic analysis
 - (a) deductive
 - (b) inductive
- Generate themes
- Review and refine (this is the stage I am at now)

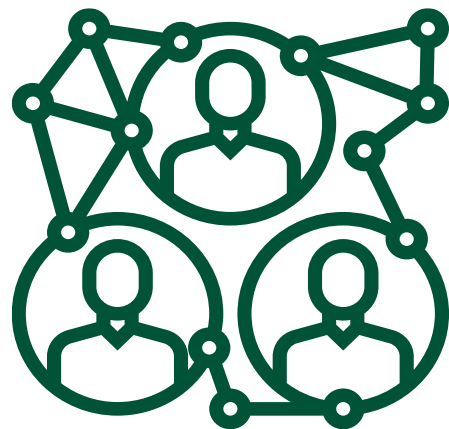
Interview demographics

- 18 interviews – 35 mins to 75 mins (avg = 55 mins)
- 16 F, 2 M, 17 current carers, 1 bereaved
- Age range 39-77, avg = 52
- 10 parent, 3 spouse, 2 sibling/in law, 2 child (3 caring more than one)
- 3 Dublin Urban, 4 urban –other, 6 rural, 4 semi urban/semi rural
- 16 good, 2 not so good
- 16 positive feedback, 2 negative feedback of group
- 5 crashes of internet/Teams during process

Social Support and Social Identity

Types of support in the group

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How strongly identified with the group?



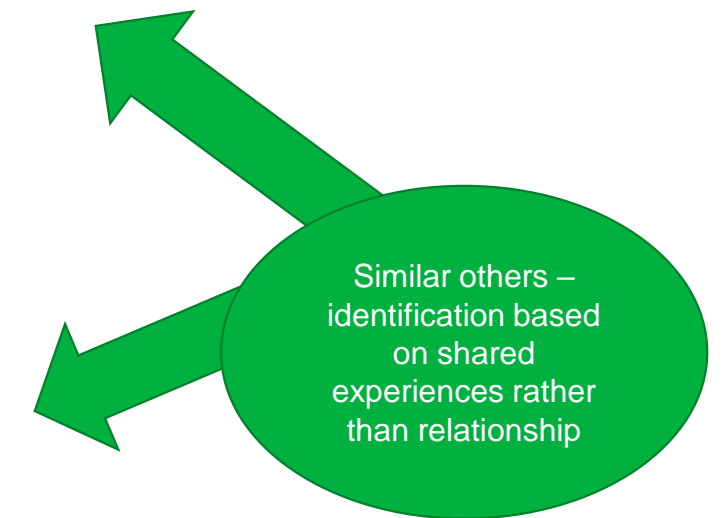
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Inductive Theme: Group is a Tribe and the Tribe “gets it”

“that's what I like about the pages, because even though you don't talk to anyone, you get to read people's experiences and you get to know that you're not the only person paddling. You know there's a whole boat full of us.”

“And it's a non-judgmental forum that you don't get at home, or you don't get from as close to a relative or a partner or a relative or a parent. They just don't get it. So it's nice to have that facility there



Inductive Themes: Just being part of Tribe can be enough

Posts and comments to the group	Direct Message to moderators or other group members	Zoom Activities
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“I would say 90% of the group probably don't interact on it on a regular basis, but it's knowing that that there are people out there that are...voicing your concerns, voicing your opinions, you know...it it kinda helps you know...It's nice to know that that somebody knows we're here.”

Being a Reader can be enough

*“some comments that come up that I would get something out of them, you know or I would feel a bit better or you know like they do you know **even though I'm a reader it does help you know do it.**”*



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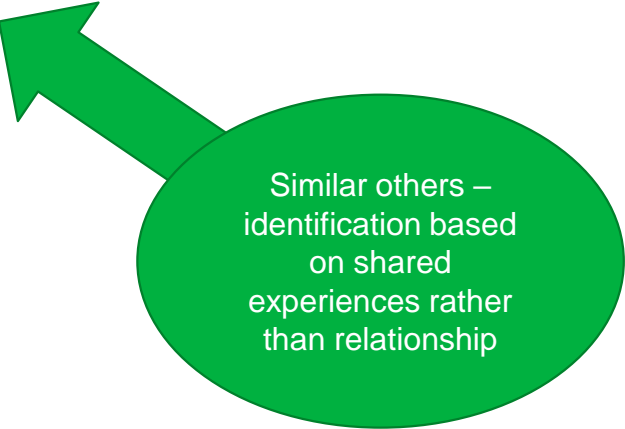
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Inductive Theme: Group as Lifeline and Lifechanging

“I wouldn't be able to cope as well as had been coping. That's what gets me through the day and that's what gets me by.”

“It's such an emotional and practical support. ...many carers unfortunately experienced isolation. And it's a great platform where when you need help, that lived experience, you can identify with the others.”

“Without the support of this group, I would not be able to be as good as a carer and a mum as I am now.... You know some days are bad, some days are brilliant...other days you really, really need someone to talk to. And it's learning to open up and to talk and people say God, you found your voice now haven't you



Similar others –
identification based
on shared
experiences rather
than relationship



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Delivery:

Role of moderators important to creating identity of Tribe

Volunteer moderators from mix of backgrounds with real and/or professional experience of caring

Operate a 7 day rota; training and support from CAI staff

1. All posts are pre-moderated
2. Content is a mix of information and fun
3. Manage Group Dynamics
4. Create Group Safety

“They have to be very special people because they have to be able to make sure while allowing the group users and the group members to put up there, be open and honest. I suppose they have to be careful again that nobody is going to be offended or there’s nothing going off, so I think they take a lot of the responsibility and credit for doing that”



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What helped and what hindered engagement?

Helped	Hindered
Level of anonymity	Social Comparison
Shared what wouldn't normally share in face to face context	Group reinforcing own feelings of isolation/guilt/loneliness
Level of autonomy about how to get involved	Overwhelming – too many people/some cliques in activities
Group rules and privacy understanding	Expectations not being met/different understanding of what group would be
Flexibility of engagement – no pressure	Video Conferencing – not everyone liked it
Always available when carer available	Prefer physical group





Online survey looking at engagement or non-engagement in Online Support Groups

Link to survey: [Survey about Online Support Groups for Family Caregivers](#)

Like and reshare on twitter: @DaynesKearney, @ULPsych, @SASHLab

Email: rosemary.daynes.kearney@ul.ie

If you would like to find more information about Care Alliance Ireland please visit: www.carealliance.ie

Twitter: [@CareAllianceIrl](https://twitter.com/CareAllianceIrl)

If you have any questions about the Online Family Carer Support Project, please feel free to contact:

tara@carealliance.ie



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Thank you



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Reflexive Thematic Analysis (Braun & Clarke, 2019)

- “procedures reflect the values of a qualitative paradigm, centring **researcher subjectivity**, organic and recursive coding processes, and the importance of deep reflection on, and engagement with, data”
 - Generated themes are patterns of shared meaning underpinned or united by a core concept
 - The researcher’s role in knowledge production is at the heart of this approach...implemented with theoretical knowingness and transparency;
 - Themes are analytic outputs developed through and from the creative labour of our coding. They reflect considerable analytic ‘work,’ and are actively created by the researcher at the intersection of data, analytic process and subjectivity.
- Deductive Theme Generation
 - Cutrona & Suhr (1993) Types of social support:
 - Perski et al (2014) context, content, delivery as three interrelated factors that drive engagement in web-based interventions
 - Pearlin et al (1990) role of similar others in social support – linked to social identity
 - Thematic areas identified from Scoping Review (getting ready for submission)
- Inductive Theme Generation
- Making note of things that stood out during interview and transcription process in notebook
- Review and refine (this is the stage I am at now)

Researcher Subjectivity

I'm doing a Ph.D. with the University of Limerick. And my topic is online support groups for family caregivers and looking at it from a kind of a psychological point of view. So why do people engage? What? What makes people join a group? What makes people stay in a group? Why do people leave groups? And what kind of support do people receive when they're in the groups? And what do they like both groups and don't like a group? So it's that kind of perspective. So that's the kind of stuff we'd be talking about today. And also, **just to let you know, I'm a carer myself, so I care for my son and my husband as well. So am I'm coming from it from that point of view as well. So kind of from inside, inside the experience as well.** And so do you have any questions about the I about this at all?

I think that's very important as well that you as a researcher. I know you've to be up to objective, but it's very interesting that you're coming from a...perspective **that you're also a carer and I think that adds a lot of extra value too.**

No, I understand that [I'm] my partner carer and my oldest son's carer as well so at the moment, so yeah, **so I get you.**

If that's great to know, yeah, it's great. Yeah yeah, it's good that's that makes it a bit easier then to talk about it. You know **when you're talking to someone who's in the club is it were,** you know?

How do you get time to do a PhD along with caring for two other people?

Well, it's the yeah. I think it's you know you understand. You know there's the different levels of caring and the different different path, right? Yeah, so I'm in a period now where the caring is reduced down. So we've had intense periods, but it's at a lower level now so thankfully



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Social Support

1. Feel good factor

*“It's just something that **brightens up your day** when you're just having a hard time.”*

2. Provide social, educational and self-care activities

“there is opportunities that you've been, you know to join and offer you something for you which is good. when you're a carer it's all about the person you're caring for and you are invisible so it encourages you to find something”

3. Encyclopedia – information there when you need it

*“And that's a great thing about it is **everybody's experience because somebody else's resource.**”*

4. Inspiring personal growth and change

*Without the support of this group, I would not be able to be as good as a carer and a mum as I am now.... You know some days are bad, some days are brilliant...other days you really, really need someone to talk to. And it's **learning to open up and to talk** and people say God, **you found your voice now haven't you**”*



Types of support in the group



Informational	Emotional	Social Network
<p><i>“It's a comfort to kind of just know that there is a place you could go and ask a question and there is likely to be an answer based on people's experiences...”</i></p>	<p><i>“so I found in the beginning that you just read some of the comments each day. But occasionally I'll stick in a stick in a little comment and say I'm feeling really shitty today...somebody will immediately come back and go. No, you're doing alright or you're entitled...”</i></p>	<p><i>“I've made some fantastic friends, I've got two best friends out with it, and which I've never met. And that's weird to say a best friend, but I speak more to them everyday about my problems.”</i></p>
<p><i>“There's so much advice given on it...but because there's so many different levels of caring on it, like just people caring for small children, people caring for kids and adults with physical disabilities, intellectual disabilities, emotional disabilities, everything like that, and you can always find some little nuggets in it to help you on your way.”</i></p>	<p><i>“I don't reply to all the comments, but sometimes someone will put something in and I go. Oh you poor old thing and I sent a comment on to them, you know and say well hopefully that made them feel better.”</i></p>	<p><i>I really felt, Oh my God, I'm actually making friends and then it got to the stage where I go. Is it Friday yet? [to attend coffee morning]”</i></p>
<p><i>“I've seen my own life reflected on it either now or in 10 years time...you can see it prepares you for what's ahead, whether it's good or bad or hurts. I also find out that the more information you have, the better you're going to have your situation, regardless of what situation is going to be, whether it's going to be a very taxing future or whether it's going to be hard going. If you're prepared for it, you're just you're going to manage better if you know what's ahead...But it's nice to know that there are days that are going to be hard, but you will get through them. And I've seen online people do manage it.”</i></p>	<p><i>that's a conversation piece and just somebody asked me how [my] day went.</i></p>	



What helped and what hindered engagement?



Helped	Hindered
<p>Level of anonymity</p> <p><i>“I don't want to meet local people. I suppose that's you know, UM...It's just the way I am. It's too close to home. you know, people gossip about other people...”</i></p> <p><i>“'cause it's even though your name is there and people can see your page. It's anonymous really...even though they can see your picture...It's just easier”</i></p> <p>Shared what wouldn't normally share in face to face context</p> <p><i>“Sometimes if it's face to face, you tend not to open up as much...you know that you don't actually have to face them people. And so I could say what I need to do again and go about my business. I'm not meeting them downtown...it's from the people that were in town. And I wouldn't. There's no way would open up because we know everybody”</i></p>	<p>Social Comparison</p> <p><i>“And I felt that I really shouldn't be here...because honest to God like I have nothing to complain about compared to that lady whose son is 24 hour care and she can't even get the basic things that he needs”</i></p> <p><i>“a lot of them will be short term carers. You know, they might be doing it for five years or 10 years. Maybe 15 years, whereas the other groups I have you're talking about doing this for 50 years”</i></p>
<p>Level of autonomy about how to get involved</p> <p><i>“The group isn't forcing anything of anybody that they just. Yeah, the group is very active with a lot of you know groups that go with this, like the book and at this like that's another thing. There's something for everybody like OK, you might be above post or you might just like to read and maybe just put up a like are not even do that just to look.</i></p>	<p>Group reinforcing own feelings of isolation/guilt/loneliness</p> <p>Overwhelming – too many people/some cliques in activities</p>
<p>Group rules and privacy understanding</p> <p><i>“ You have to follow them or you are discontinued of the group.”</i></p>	<p>Expectations not being met/different understanding of what group would be</p>
<p>Flexibility</p> <p>Always available when carer available</p>	<p>Video Conferencing – not everyone liked it</p> <p><i>“It's because everybody uses Facebook, but not everybody is comfortable with the zooms... when you have a zoom, you're only talking about a handful of people that can actually be on zoom at the one time and then once the zoom call is over you've had it, but if it's something on Facebook, it's there and you can kind of...Come back at it tomorrow or the next day”</i></p>
	<p>Prefer physical group</p>

