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Citation: Batchelor, R., Gulshan, S., Shrivatharan, H., Williams, E., Henderson, C., Gillard, S., Woodham, L. A., Cornelius, V., Elkes, J. & Sin, J. (2021). Perceived acceptability and experience of COPE-support - a digital psychoeducation and peer support intervention: Interview study with carers supporting individuals with psychosis. *Journal of Medical Internet Research*, doi: 10.2196/27781

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Perceived acceptability and experiences of COPE-support - a digital psychoeducation and peer support intervention: Interview study with carers supporting individuals with psychosis

Rachel Batchelor, Sarah Gulshan, Halpana Shrivatharan, Elen Williams, Claire Henderson, Steve Gillard, Luke A. Woodham, Victoria Cornelius, Jack Elkes, Jacqueline Sin

Submitted to: Journal of Medical Internet Research
on: February 21, 2021

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Perceived acceptability and experiences of COPE-support – a digital psychoeducation and peer support intervention: Interview study with carers supporting individuals with psychosis

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Abstract

Background: Digital mental health interventions offer a novel, accessible and self-paced approach to care delivery to family carers, i.e., relatives and close friends who support a loved one with psychosis. We co-produced COPE-support, a psychoeducational intervention delivered via an enriched online environment with network support from professionals and peers. In addition to rigorous investigation of the effectiveness of COPE-support on carers' wellbeing and mental health outcomes, it is imperative to understand carers' experiences in using the digital intervention and its associated online implementation and facilitation strategies.

Objective: This study aimed to explore (1) carers' experience and perceived acceptability of COPE-support and its different components, and (2) how they found engagement with COPE-support affected their own wellbeing and caregiving.

Methods: We conducted a qualitative study, individually interviewing 35 carers after their use of COPE-support for 8 months through an online randomised controlled trial across England. A semi-structured guide with open-ended questions was used to explore carers' experience and perceived acceptability of the intervention, and their ideas to improve the provision. All interviews were conducted remotely through mobile phone or internet communication media, audio-recorded, and transcribed verbatim. We used the thematic analysis framework approach to analyse the data.

Results: Three key themes were identified: (i) remote, flexible and personalised, (ii) impacts on well-being and outlook on caregiving, and (iii) future implementation and integration with existing services. Overall, carers identified COPE-support as a helpful resource for themselves and for their caregiving role. Participants' experiences, usage and activity on COPE-support varied a great deal and differed amongst carers of various ages and level of computer literacy.

Conclusions: Carers found COPE-support a flexible source of knowledge and support from professionals and peers which they can personalise to suit their own needs and convenience. Participants described gaining self-confidence, hope, and a sense of connectivity with others in a similar situation which helped ameliorate isolation and perceived stigma. Most importantly, COPE-support promoted self-care in the carers themselves. While nearly all participants had a positive experience with COPE-support and supported its wider implementation as a beneficial adjunctive support resource for carers in the future, they suggested some improvements. These include having more graphics and visual-audio content materials, improving the navigation and building in

more interactional and customisation options to suit various users' style (e.g. emoji reactions, live online chat, opting in-and-out of updates and choosing frequency of reminders). Any future scale-up of such an intervention should also consider factors pertinent to reaching more carers and integrating the digital resource with other conventional services. Clinical Trial: Current Controlled Trials registration ISRCTN 89563420.

(JMIR Preprints 21/02/2021:27781)

DOI: <https://doi.org/10.2196/preprints.27781>

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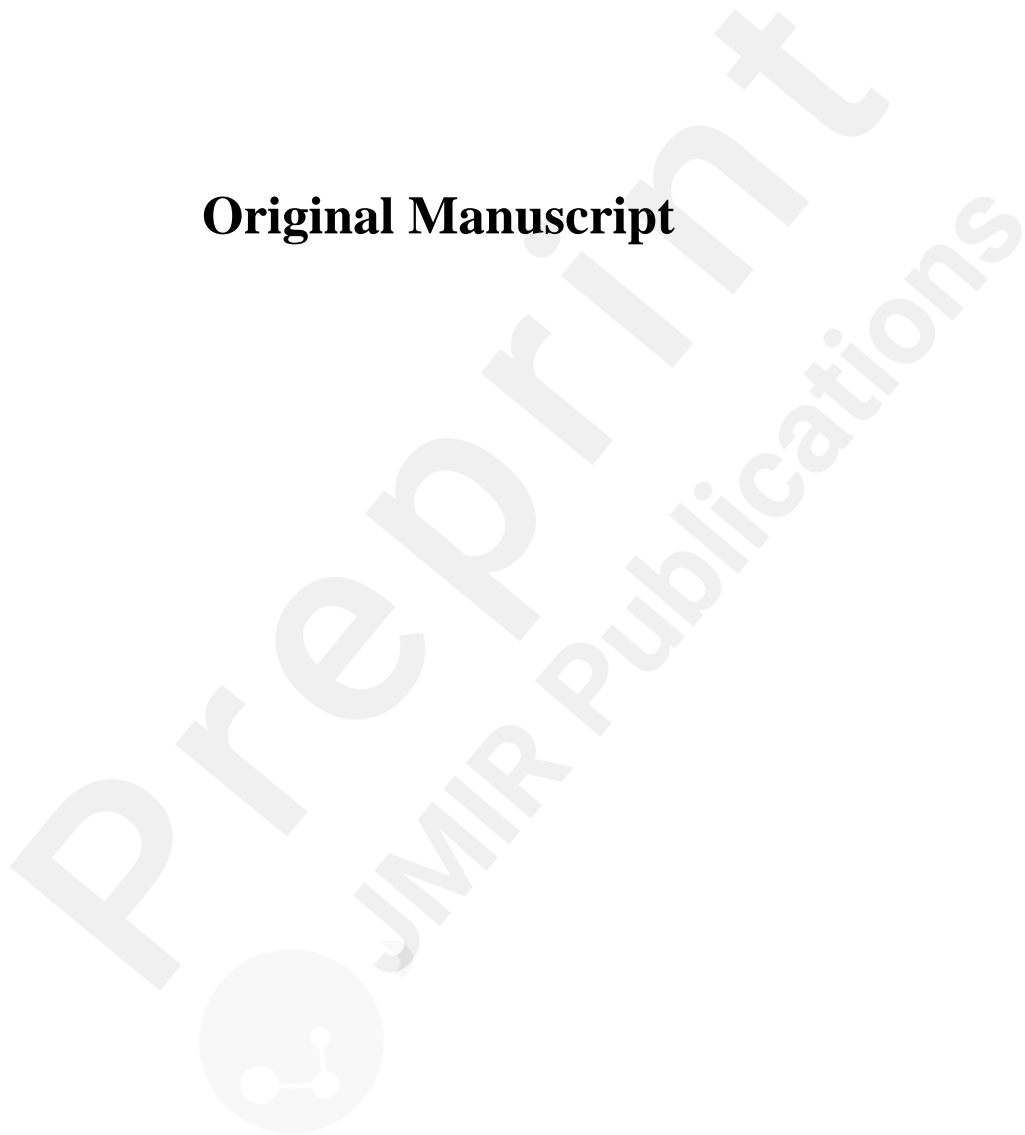
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Original Manuscript



Title: Perceived acceptability and experiences of COPE-support – a digital psychoeducation and peer support intervention: Interview study with carers supporting individuals with psychosis

Abstract

Background: Online mental health interventions offer a novel, accessible and self-paced approach to care delivery to family carers, i.e., relatives and close friends who support a loved one with psychosis. We co-produced COPE-support, a psychoeducational intervention delivered via an enriched online learning environment with network support from professionals and peers. In addition to rigorous investigation of the effectiveness of COPE-support on carers' well-being and mental health outcomes, it is imperative to understand carers' experiences of using the online intervention and its associated online implementation and facilitation strategies.

Objectives: This study aimed to explore (1) carers' experiences and perceived acceptability of COPE-support and its different components, (2) how carers found engagement with COPE-support affected their own well-being and caregiving, and (3) carers' ideas for improving COPE-support and its delivery to inform any future wider implementation.

Methods: We conducted a qualitative study, individually interviewing 35 carers, following their use of COPE-support for 8 months through an online randomised controlled trial across England. A semi-structured guide with open-ended questions was used to explore carers' experiences and perceived acceptability of the intervention, and their ideas to improve the provision. All interviews were conducted remotely through mobile phone or internet communication media, audio-recorded, and transcribed verbatim. We used the thematic analysis framework approach to analyze the data.

Results: Three key themes were identified: (i) remote, flexible and personalized support, (ii) impacts on well-being and outlook on caregiving, and (iii) future implementation and integration with existing services. Overall, carers found COPE-support a flexible source of knowledge and support from professionals and peers which they could personalize to suit their own needs and convenience. Participants described gaining self-confidence, hope, and a sense of connectivity with others in a similar situation which helped ameliorate isolation and perceived stigma. Most importantly, COPE-support promoted self-care in the carers themselves. Participants' experiences, usage and activity on COPE-support varied a great deal and differed amongst carers of various ages and level of computer literacy.

Conclusions: Nearly all participants had a positive experience with COPE-support and supported its wider implementation as a beneficial adjunctive support resource for carers in the future. Any future scale-up of such an intervention needs to take into account carers' feedback and suggestions for further improvement. These included having more graphics and visual-audio content materials, improving the navigation and building in more interactional and customization options to suit various users' style, such as emoji reactions, live online chat, opting in-and-out of updates and choosing frequency of reminders. To ensure successful implementation, we should also consider factors pertinent to reaching more carers and integrating the online resource with other conventional services.

Keywords:

eHealth; family carers; qualitative research; psychosis; peer support; online psychoeducation

Introduction

Background

Family members or close friends supporting a loved one affected by psychosis, i.e., family or informal carers, play a crucial role in promoting the individuals' prognosis and well-being [1-3]. However, the demands and responsibility of caregiving can make carers vulnerable to physical and mental ill health [4,5]. Carers need access to psychosocial treatment for knowledge and support to care for their loved ones and for sustaining their own well-being [6]. In recent years, with the increasing popularity of digital health interventions targeting a wide range of common mental health symptoms among the general population [7], a few clinical trials investigating such provision for carers of people with psychosis have emerged [8-11]. These online interventions tend to be complex multi-component encompassing psychoeducation (i.e., information focused on the health condition and its management) and interactive forums where carers can share emotional support with peers in a virtual 'closed' group (e.g., COPE-support [12], REACT [13]). Indeed, psychoeducation on psychosis and related care giving and problem-solving strategies, especially when integrated with peer support among carers, have been identified in systematic reviews as most desirable ingredients for carer-focused interventions, delivered via the internet or in person [1,14,15]. In previous trials of online interventions targeting carers of people with psychosis, psychoeducation was the most common therapeutic approach used. The online medium enriched information environment allows carers to self-pick information and advice suiting their own needs and go through them in their own pace [8,11,12]. Psychoeducation and peer support can also target difficulties commonly reported amongst carers including isolation, stigma and uncertainty [16].

Online interventions allow for flexible access by carers, minimizing accessibility barriers such as geographic constraints from needing to be in a particular location and time constraints from juggling multiple roles and responsibilities [17,18]. The online medium of delivery also facilitates autonomous use of an individually tailored package of support, i.e., carers can choose how and when to use the content at their own convenience [14,19]. Paradoxically, online interventions typically report much lower adherence and completion rates compared to face-to-face interventions, limiting the evidence about their effects [7,14]. Internet support groups and online peer forums are often highlighted as desirable features of online interventions for promoting social connection and mutual support in mental illness [7,20]. However, their effects, on their own or as part of a complex multi-modal intervention, are inconclusive [21-23]. Although users have often identified a peer forum as an engaging element of online health interventions [24,25], user characteristics and their usage of such forums vary widely [21,26]. Recently, Geramita and colleagues [20] explored the applicability of the 1% rule in a computerized cognitive behavior therapy (cCBT) platform which included a patient support group. The 1% rule originated from the online marketing literature suggesting that 1% of participants in online communities generate approximately 90% of new content [27]. The cCBT study [20], among other online health intervention trials [24,26], identified that it is a small minority of users (about 10%) who post the majority of content in peer forums, and the remainder mainly observe activity. When considering an individual's use of online health tools and services, and subsequent health behavior uptake in general, Powell and Deetjen proposed a new typology [26]. In their study, they identified six types of online health users (learners, pragmatists, skeptics, worriers, delegators and adigitals), prompting considerations into individuals' motivation and orientations behind health-related internet use [26]. Limited evidence to date suggests high engagement levels with peer forum or indeed any discrete elements of complex online interventions (e.g., information, forums) are associated with better health outcomes or subjective satisfaction or acceptability [7,14,20,28-30]. At the same time, these issues highlight the challenge of implementing complex online health interventions which include a peer support forum element with diverse participant profiles and experiences.

While online interventions present a promising opportunity to address a long-standing lack of treatment and support for carers of individuals with psychosis, they can only effect meaningful changes in their users by optimizing their engagement and facilitation strategies to ensure they get the intended benefits. Considering other challenges inherent in developing and evaluating online interventions (such as safety, personalization, trust, reach and uptake) [29], it is imperative to embed qualitative process evaluation within online intervention trials. Although randomized controlled trials are the gold-standard study design to establish clinical effectiveness of an intervention, process evaluation to evaluate participants' experience and perceived acceptability of the intervention and associated facilitation strategies can identify essential contextual factors in outcomes. In the case of online interventions, the contextual factors in question are multiplied as these interventions are designed to be used autonomously by users in their own home. Hence, the Medical Research Council (MRC) complex intervention framework advocates that a thorough process evaluation is needed to understand both the intervention and its implementation process, as experienced by the participants, and to clarify variations in outcomes under the contextual influences [31].

Objectives

This qualitative study explores carers' experiences and perceived acceptability of COPE-support, and its different components, as part of the process evaluation of the COPE-support trial [9,32]. We aimed to understand from the carers if and how using COPE-support had affected their own well-being and the way they provided care for their loved one. With their experience of using COPE-support, carers' ideas for improving COPE-support and its delivery were also invited to inform any future wider implementation.

Methods

Research design and setting

This study used in-depth individual interviews conducted between February 2019 and October 2020, with participants who had been randomly allocated to use the intervention, after final follow-up data collection (i.e., 8 months post-allocation), as described in the trial protocol [9].

For the RCT of COPE-support, a total of 407 family members or close friends who provided at least weekly support for a loved one affected by psychosis across England were recruited [32]. Over the duration of two years (i.e., March 2018 to February 2020), six cohorts each starting four months apart and lasting eight months were scheduled; when participants consented in the trial, they were allocated to the next cohort scheduled to start [9]. This approach allowed us to group an optimal number of participants (i.e., 40 to 120) established from our earlier systematic reviews into each cohort which was "closed" [1,14]. We believe these strategies facilitate peer-group building thus enhanced the interactive elements of the intervention. Half of the participants were randomly allocated to the intervention arm, i.e., access to COPE-support for 8 months, which included being able to post on the peer/expert forums for the initial 4 months (termed the active intervention use period), in addition to usual care. The remaining participants were randomised to receive an online non-interactive information bank as an attention-matched control, also with usual care [9].

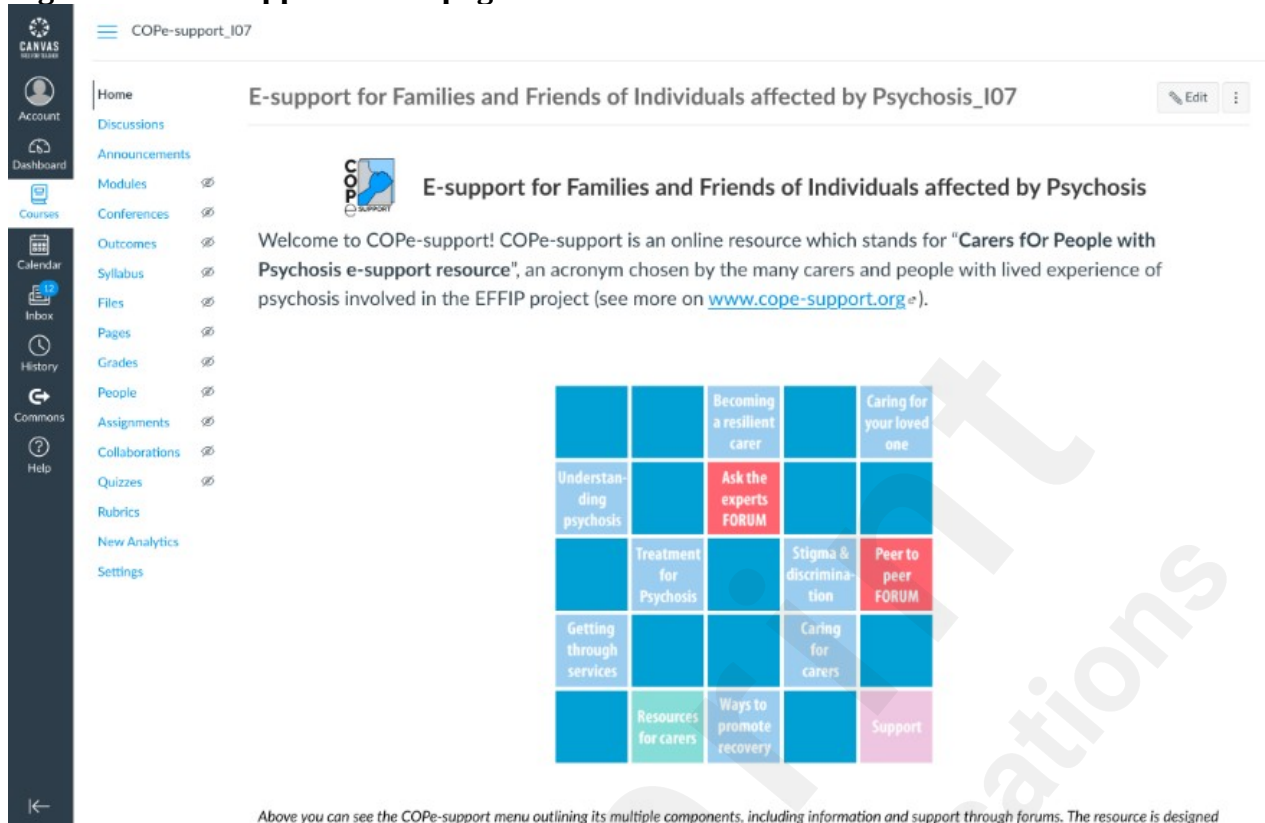
This study as part of the overall RCT has been reviewed and approved by South Central – Oxford C Research Ethics Committee (Reference: 18/SC/0104) and Health Research Authority (Reference: IRAS 240005).

The intervention

The online intervention COPE-support was co-produced using participatory research methodology, as described elsewhere [12]. COPE-support was delivered through an online enriched environment platform which carers could access through a web browser using a computer or laptop, or through an app on smart phones or tablets [9,12]. COPE-support comprised multiple components, including: psychoeducation on psychosis and related caring issues; guidance on well-being promotion information and exercises; a “Resource for carers” section signposting to a wide range of external resources weblinks; and two online forums (one called “Ask the Experts” where participants could post questions for advice from a panel of experts, and the other called “Peer to Peer” for participants to exchange views with one another) (see Figures 1, 2, and 3 for screenshots of COPE-support components). Throughout the study period, an online facilitator (an experienced mental health nurse, JS) monitored and moderated all the interactive functions of COPE-support. A weekly email update was sent through the COPE-support platform to all participants for the first four months of the study period which was regarded as the active use period. For security and confidentiality considerations, participants were required to follow a set of ground rules including using a self-chosen pseudonym and observing confidentiality principles by not sharing any identifying information about themselves and their cared-for person on COPE-support platform. The online intervention platform had an inbuilt usage data recording system for logins, time spent, and number of posts made by each participant.

INSERT FIGURES 1, 2, and 3 HERE

Figure 1 COPe-support Home page



Above you can see the COPe-support menu outlining its multiple components, including information and support through forums. The resource is designed

Figure 2 Ask the Experts Forum webpage

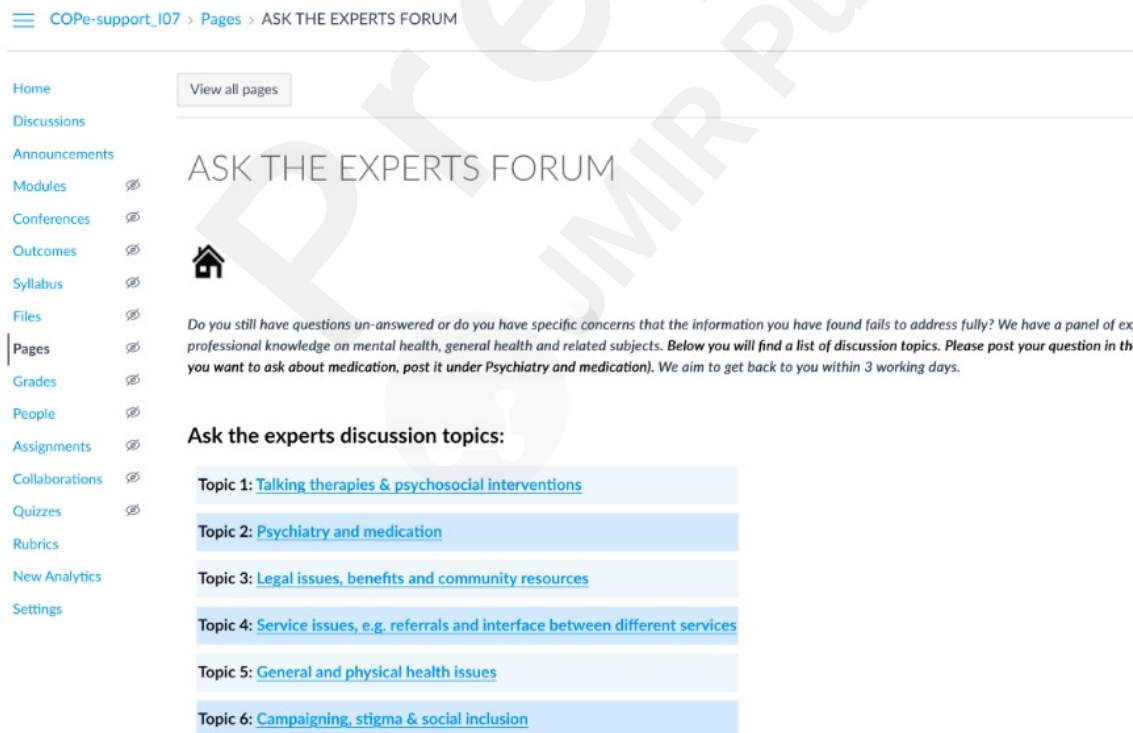



Figure 3 Information on psychosis on COPe-support


- Announcements
- Modules
- Conferences
- Outcomes
- Syllabus
- Files
- Pages**
- Grades
- People
- Assignments
- Collaborations
- Quizzes
- Rubrics
- New Analytics
- Settings

What is psychosis?



'Psychosis' is a term used to describe a set of experiences that are not based on reality, often result in a person's perception, thoughts, mood and behavior are significantly altered. Some common psychotic symptoms include hallucinations, delusions and disturbed thoughts (see sections below for symptoms).

Psychotic symptoms on their own do not make a diagnosis or label of mental illness. However, when such symptoms impact on someone's emotions, functioning and identity, especially in a prolonged and entrenched way, 'psychosis' could also be regarded as a broad category of mental health conditions that have psychotic symptoms as its hallmarks. In the National Institute for Health and Care Excellence (NICE) Guideline on Psychosis and Schizophrenia in Adults - Prevention and Management (NICE, 2014), the term 'psychosis' is used to refer to a set of related conditions, of which the commonest is schizophrenia, and includes schizoaffective disorder, schizophreniform disorder, delusional disorder, the so-called non-affective psychosis, and people who are receiving treatment and support from early intervention in psychosis services (EIPS) for 'early onset psychosis' or 'first episode psychosis'. Psychotic symptoms are also prominent symptoms in those affected by affective psychoses, such as bipolar disorder or unipolar psychotic depression but these are referred to in other NICE Guidelines.



This section covers:

- What is psychosis?
- Possible causes
- Common psychotic symptoms
- Other common co-occurring mental health problems
- Prognosis and recovery

* Attribution: We have devised the information about psychosis and its treatment, in part, based on NICE Clinical Guideline: 178 (@NICE [2014] Guideline on Psychosis and Schizophrenia in Adults - Prevention and Management e). NICE has not checked the use of its content in this product to confirm that it accurately reflects the NICE publication from which it is taken. See the source material [here](#) e and its open license [here](#) e.

Participants

The inclusion criteria for the RCT specified family members, relatives and close friends who: were 18 or over, had at least weekly contact with the carers for person (in any form, ranging from face-to-face to social medical communications, living in England, able to communicate in English in usual online communications, and had daily access to the internet including emails [9]). The inclusion criteria for this qualitative study specified that participants had been (1) randomised to the intervention arm and (2) completed the RCT final follow-up (8-months). Furthermore, purposive sampling was used to identify about 20% of participants in each cohort intervention group from across the two-year study period to ensure representation of those with different demographic factors and different levels of usage of COPE-support. As previous literature shows that female and White participants formed the majority of intervention trials targeting carers for a loved one with psychosis in Western countries [1,3,6,14], we prioritised male carers and those from ethnic minority backgrounds in approaching potential participants. To examine usage, we followed Valentine and colleagues' approach [33] in categorising participants into levels of usage based on the participants' overall number of logins to the COPE-support platform over the 4-month active intervention use period. We categorised participants into three usage groups: (1) non-compliers = participants who had not activated their log-in or only logged in once; (2) moderate users = those who had logged in between ≥ 2 and ≤ 10 times; and (3) high users = those who had logged in > 10 times. Within the usage categories, we also considered whether participants had made forum posts. Thus, participants in the three usage groups were further categorized into: (1) passive users = participants who did not post; and (2) active users = participants who made at least one forum post, in accordance with previous online forum research [34,35]. Participants representing the various demographic considerations and usage levels were then contacted via email and invited to participant in an individual interview. A total of 43 participants were invited – 35 participants agreed, whilst eight did not respond to the invitation with 2 reminders (their reasons for not responding were not provided).

A total of 35 participants gave an interview and were included in this study. The mean age of the

participants was 56 years (standard deviation 13 years, range 23 to 73 years). The majority of the participants interviewed were White (29 White British and 2 other White), while two participants each described themselves as Asian and Black respectively. About two-thirds (22/35) were female and the majority cared for a male person (23/35). Parents comprised the majority of the participants (23/35), followed by partners (7/35), while siblings (2/35) or close friends (3/35) formed the remainder. According to the data on their caregiving roles and activities provided by the participants, the mean age of the cared-for persons was 35 years (standard deviation 14 years, ranged from 17 to 66 years). Just over half of the participants (18/35) reported that their cared-for persons first became unwell with psychosis less than five years ago, while four of them (4/35) described their loved ones had their first psychotic onset over 20 years previously, and the remainder (13/35) had been caring for between five to just under 20 years. About half of the participants lived with their cared-for person (17/35) and 14 carers reported spending over 20 hours per week in caregiving activities. Table 1 provides a summary of participants' demographic, caregiving, and usage data.

Multiple participants from each of the different usage groups across cohorts were interviewed. All participants were interviewed shortly after their access to the intervention platform ceased (i.e., at 8-month follow-up) although their last access to the platform varied widely. Of the 35 participants, 6 were classified as non-compliers. All non-compliers were passive users (passive non-compliers). Most participants (19/35) were classified as moderate users, ten of whom were passive (passive-moderate users) and nine were active (active-moderate users). High users comprised the remaining participants (10/35), all of whom were active within the COPE-support forums (active-high users).

Table 1. Summary of participant usage and demographic information categorised by usage groups

	Pseudonym	Cohort (start-time)	Gender and age of carers	Relationship with Cfp ^a	Gender and age of Cfp ^a	Overall weekly logins ^b	Overall page-views ^c	Posts made
Non-compliers (who have not logged in or only logged in once throughout the 4 months)								
Passive Users (<1 post made)	Mark	October 18	Male / 53	Parent	Male / 27	1	3	0
	Alexandra_1	February 19	Female / 62	Parent	Male / 31	1	8	0
	Ahmed	February 19	Male / 41	Partner	Female / 40	1	3	0
	Aaron	June 19	Male / 23	Partner	Male / 22	1	40	0
	Sally	October 19	Female / 72	Parent	Male / 36	NA ^d	0	0
	Anna	October 19	Female / 50	Parent	Female / 20	NA ^d	0	0
Moderate users (who have logged in between ≥ 2 and ≤ 10 times in different weeks)								
Passive Users (<1 post made)	Fern	June 18	Female / 57	Sibling	Male / 65	4	163	0
	Martin	June 18	Male / 63	Parent	Female / 27	4	83	0
	Summer_2	October 18	Female / 54	Parent	Male / 17	6	238	0
	Faye	February 19	Female / 68	Parent	Male / 38	4	561	0
	Alfred	February 19	Male / 55	Partner	Female / 43	5	263	0
	Sam	June 19	Female / 71	Parent	Male / 42	4	137	0
	Polly	February 20	Female / 70	Parent	Male / 41	8	677	0
	Hamish	February 20	Male / 55	Parent	Male / 30	2	20	0
	John	February 20	Male / 50	Partner	Female / 59	6	482	0
	Edward	February 20	Male / 33	Partner	Female / 30	2	195	0
Active Users (≥ 1 post made)	Katrina	February 19	Female / 62	Sibling	Male / 57	2	533	10
	Alexandra_2	June 19	Female / 72	Parent	Male / 32	6	930	15
	Alexandra_3	June 19	Female / 58	Parent	Male / 20	4	602	22
	Ben_2	June 19	Male / 69	Parent	Male / 35	10	974	11
	Felix	October 19	Male / 42	Step-parent	Male / 17	3	226	3
	Abbie	October 19	Female / 54	Parent	Female / 27	5	212	4
	Molly	February 20	Female / 50	Parent	Male / 17	7	248	4
	Sophie	February 20	Female / 27	Friend	Female / 26	3	63	1
	Louise	February 20	Female / 73	Parent	Male / 40	6	206	2
High users (those who have logged in >10 times in different weeks)								
Active Users (≥ 1 post made)	Matthew	February 19	Male / 46	Partner	Female / 44	15	1125	1
	Flossie	June 18	Female / 58	Parent	Male / 28	13	654	3
	Tony	June 18	Male / 43	Partner	Female / 41	19	2602	31
	Summer_1	October 18	Female / 57	Parent	Male / 25	11	311	3
	Alex	October 18	Female / 56	Parent	Male / 24	15	554	3
	Ben_1	February 19	Male / 66	Parent	Male / 37	13	715	7
	Eleanor	February 19	Female / 63	Friend	Female / 63	13	967	29
	Abby	October 19	Female / 67	Partner	Male / 66	12	354	4
	Maryam	October 19	Female / 67	Parent	Female / 26	11	1154	10
	Imogen	February 20	Female / 62	Parent	Female / 30	14	1227	7

^a – Cared-for person

^b – Number of weeks with logins across the 4-month active intervention use period

^c – Total page-views across the 4-month active intervention use period

NA^d – not activated the log-in

Data collection

All interviews were conducted remotely suiting participants' preference of either phone or internet-facilitated interviews (using Skype or Teams). No face-to-face interviews were used as all participants had joined the online trial of an online intervention, with no requirement for in-person contact. Author JS conducted all interviews. Informed written consent was obtained from each participant through our online study platform prior to the interview. At the beginning of each interview, we asked the participants to confirm their consent orally, including for the interview to be audio-recorded. All interviews were audio-recorded apart from one participant who opted for their interview recorded by written notes instead.

The interviews followed a topic guide which was devised by the Project Reference Group members including individuals with lived experiences of psychosis or caring for a loved one with psychosis, who had been involved in developing the intervention [12]. In line with the objectives of this interview study, the interviewer asked open-ended questions to explore participants' experiences and views of COPE-support, any specific features of the intervention that they liked or disliked, and the barriers and facilitators of their access and use of COPE-support including the facilitation strategies employed. The interviewer asked the participants to reflect on their subjective evaluation of the impact of using COPE-support, on both themselves and their caregiving experiences. Lastly, the interviewer also asked the participants for their views and ideas for plausible wider implementation of COPE-support in the future. The topic guide which includes the semi-structured interview questions/prompts is presented in the supplementary information [S1]. Interview times ranged from 14 to 49 minutes, with a total of 1117 minutes of data transcribed.

Data Analysis

The audio-recordings were transcribed verbatim. Only the transcribed anonymised textual materials were used for analysis. The data was analyzed in four phases using thematic framework analysis [36], with the software NVivo 12 [37]. In accordance with thematic framework analysis, we commenced the data analysis once the first qualitative interview had been completed and transcribed. To ensure the analysis was grounded in the data and the exploration of participants' experiences was driven by the emerging results, the interviews and analysis were performed in parallel so that the identified themes and framework of analysis could be tested and validated in latter data.

In the first analysis phase, the authors (JS, SaG, HS, and RB) familiarised themselves with the data through re-reading the transcripts and noting interesting aspects. In the second phase, two authors (SaG and HS) coded all the data and a third author (RB) coded 20% of the data independently. The data coded by the third author was selected based on user type and demographics, to ensure all groups across the full sample were represented. Open (unrestricted) descriptive codes summarising segments of text were applied across the dataset. Codes were discussed and reviewed between the authors, through several iterations. In the third phase, initial themes and sub-themes reflecting broad units of common ideas were formed by grouping relevant codes together. These were compared and contrasted through reviewing the whole dataset as well as within individual cases. In the fourth and final phase, the authors (RB, SaG, HS, EW, and JS, all female) cross-referenced, discussed and clearly defined the themes and sub-themes and their inter-related links over several meetings. We used a combined inductive and deductive approach in coding and selecting themes throughout the analysis process [38]. Initially we used inductive coding, driven by the data (i.e. participants' experience or the way they

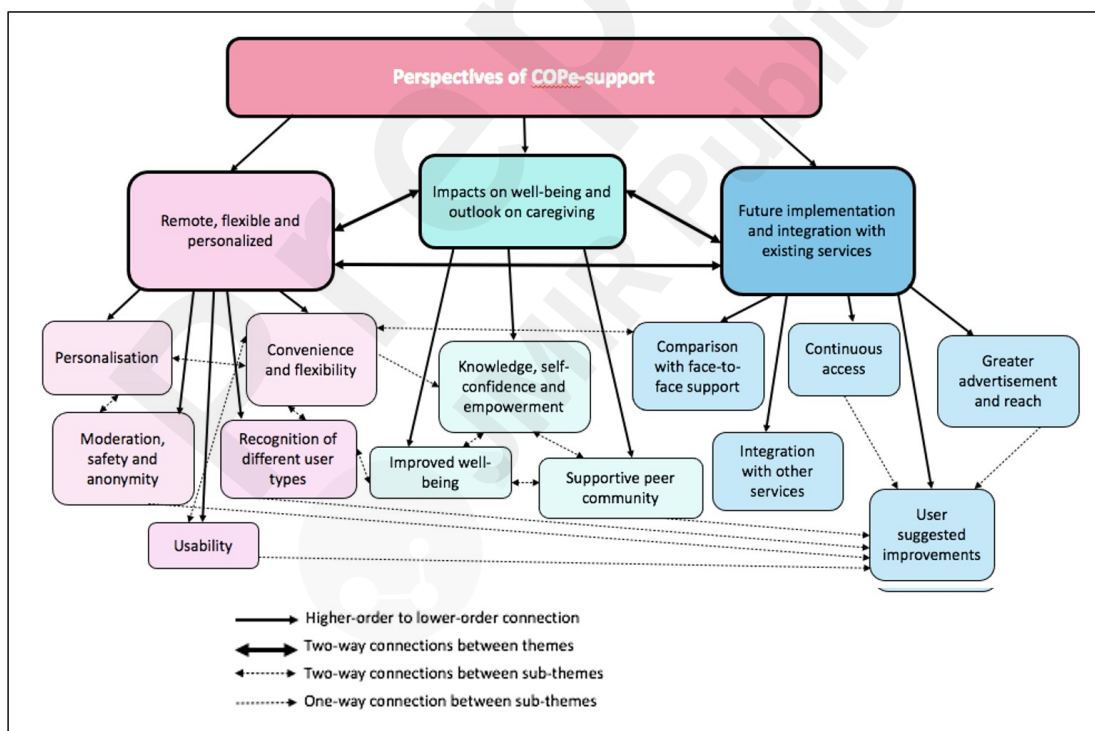
assigned meaning to their perception of using COPE-support). Nonetheless as the study aimed to explore participants' perception of specific elements, functions and facilitation strategies related to the online intervention, we therefore also coded the data deductively with reference to previously reported findings as reported by literature on wider online health interventions and those targeting carers for individuals with a mental illness. These concerned online content, forums, facilitation and perceived safety and security and were explored by questions within our interview topic guide [8,14,24]. Suggested improvements specific to COPE-support were coded deductively, using the ideas generated from our views expressed by the participants. Iterative analysis of the transcript showed that saturation of data was achieved as the final two interview transcripts produced no new themes or sub-themes [39].

Results

In total, three main themes were identified, with each theme divided into sub-themes to comprehensively capture the phenomenon explored. The three main themes were (1) remote, flexible and personalized support, (2) impacts on well-being and outlook on caregiving, and (3) future implementation and integration with existing services (Figure 4). A brief summary of each theme and sub-theme is described in the supplementary information [S2].

INSERT FIGURE 4 HERE

Figure 4 Coding tree summarising the inter-related themes and sub-themes



Remote, flexible and personalized support

This theme covered the experiences and perspectives of carers using COPE-support, with particular regards to navigation, safety, and usability. This theme incorporated five sub-themes, as follows.

Personalization

Carers mostly appreciated that they could choose and focus on specific content on COPE-support, suiting their own circumstances and needs. Several carers also valued being able to choose their own pseudonym. Whilst sharing a common caregiving role, carers recognised that they each have specific interests and needs based on their cared-for person's presentation, treatment, and a range of caregiving factors. For instance, for some carers, information and advice on getting through the benefits system could be a priority at the time, while others were after a summary of research evidence of a new treatment.

“Whereas the stuff from the website was quite helpful and we could tailor it to our own sort of thing. Yes, it was just nice.” – Aaron (male, partner, passive non-complier)

Some carers discussed a preference for having a greater sense of independence and choice regarding the communication in the forums. This included being able to opt in and out of updates and chose the frequency of reminders.

Convenience and flexibility

Many carers appreciated the convenience of having the information and resources they needed in one place, and being able to revisit information and access information any time and place in day-to-day life. Carers particularly valued how flexible their use of COPE-support was. This included having autonomy over their usage/posting without having to adhere to engagement targets, as well as being able to pick out the information that was relevant for them at their own pace. Several carers found revisiting and downloading the information for future reference particularly useful.

“Yes I mean anything that was easier to download and keep for reference, I mean it's always good to have reference material.” – Ben_2 (male, parent, active-moderate user)

Carers particularly appreciated having access to a range of professionals and found it fascinating hearing differing perspectives from experts with a variety of experiences and knowledge. Most carers also appreciated the convenience of expert knowledge on COPE-support. Several considered this as novel and felt it addressed the lack of access to experts in existing services for loved ones. Carers valued the opportunity to ask specific questions at any time and receive prompt and thought-out answers. A couple of carers noted that this was a contrast to their experiences of feeling rushed within appointments with professionals.

“I think looking back to seeing the doctors and the psychiatrists you feel a bit rushed and they haven't got time to think about it much but if it's sent as a question you feel someone has taken time to give you an in-depth answer.” – Abby (female, partner, active-high user)

Moderation, safety and anonymity

Being anonymous helped many carers feel more comfortable interacting on forums. Most carers felt anonymity helped to protect the privacy of their loved one with psychosis and did not affect the community feel on COPE-support.

“Anonymisation probably is quite important because if you are posing questions or comments about your experience as a carer you inevitably have to talk about that person and they might not like you doing that.” – Maryam (female, parent, active-high user)

Carers particularly appreciated the ground rules (e.g., being respectful and not mentioning identifying information) and forum moderation (e.g., checking and approving content), providing reassurance that the forums comprised a safe environment. Some carers expressed appreciation and preference for professional (as utilised in the trial) over hypothetical carer moderation, providing the professional understood the needs of carers, to help increase accuracy of information, dispel potentially misguided beliefs, and manage disagreements.

The weekly emails tended to have a positive impact: carers felt they not only served as a reminder for the intervention but also that someone cared. Some carers described themselves looking forward to or smiling at the emails. Overall, the carers shared a sense of feeling safe and trust-worthy on COPE-support, as reflected as follows:

“It’s having a trusted site to look at and knowing that if you put anything on it it’s a safe place.” – Abbie (female, parent, active-moderate user)

Usability

Mixed experiences were shared regarding the usability of COPE-support. Some carers felt confident due to good computer literacy or previous experience with similar platforms, whilst others described barriers such as age and poor computer literacy knowledge. Carers appreciated accessing COPE-support on different devices (e.g., computers, laptops, mobile phones), with some finding devices with larger screens easier to navigate. Most carers described an adjustment period whereby they initially struggled with navigating the interventions but adjusted and grew in confidence overtime. For example:

“I did start to get a bit more used to [navigating] after a while but to begin with I did find it complicated.” – Summer_1 (female, parent, active-high user)

Recognition of different user types

Many carers expressed an awareness of different user types on COPE-support. Carers tended to distinguish between enthusiastic (active) users whose names frequently appears within forums and other (passive) users who tended to observe. Some active users reported focusing on the peer and/or expert forum and felt these aspects in themselves made COPE-support “powerful” (- Eleanor, female, friend, active-high users, and Alexandra_3, female, parent, active-moderate user). A couple of active users were unaware of being particularly active and felt unsure of how many people were reading their posts. Most passive users were aware they had not posted and found reading what others had to say useful and knowing the forums were there if needed comforting in itself:

“I guess there are some people who are going to be very active on there and discuss things a lot and then there are going to be people who are very quiet on there...It doesn’t mean to say that they’re not taking it all in and getting something from it...I also regret slightly now that I wasn’t a bit more active at the same time.” – Summer_2 (female, parent, passive-moderate user)

Impacts on well-being and outlook on caregiving

There were three sub-themes that represented the impacts on well-being and outlook on caregiving experienced from participating in COPE-support.

Knowledge, self-confidence and empowerment

Many carers felt COPE-support provided comprehensive, relevant and helpful information across a variety of important topics. New carers found the information especially suitable for

their first time learning about psychosis. For others with existing knowledge, the information supplemented resources they had previously accessed. Whilst some felt COPE-support had enhanced their knowledge and skills enough to not require further support, others appreciated the signposting to other sources and local/national services to further support their loved one.

“I’ve got 99% certain I will either get signposted in the right direction or find what I want rather than Googling and going through different websites and trying to find the same information.” – Faye (female, parent, passive-moderate user)

Some carers felt the information quite generic, outdated and repetitive. Moreover, some newer carers initially found the amount of information overwhelming, although reported adjusting and learning overtime, for example:

“It’s also a strength is the fact that once you are in the programme you realise just how comprehensive and detailed it actually is and that this could be a bit daunting initially for people signing up.” – Eleanor (female, friend, active-high user)

Most carers felt the tone of the experts was just right: not pressurising or patronising, yet empathetic, respectful, and comforting. Understandable language (e.g., no acronyms, abbreviations, and technical terms) was also used to explain complex information in an understandable way. However, several carers felt answers were sometimes generic or vague, although appreciated the experts were not aware of their loved one’s full situation and still found suggestions helpful. The information provided and knowledge gained subsequently empowered them to seek further conversations with mental health professionals caring for loved one, as expressed by a participant.

“They’ve not been able to provide really specific answers sometimes because obviously they don’t know our situation but the fact of it is they’ve been able to signpost or suggest something that you maybe hadn’t thought of.” – Alexandra_3 (female, parent, active-moderate user)

Some carers discussed the lack of preparation for caring roles and the ongoing self-doubt surrounding doing the right thing or supporting their loved one in a helpful way. These carers felt by gaining information, resources, and knowledge on COPE-support had better equipped them and also improved their self-confidence in their ability as carers.

“I’m sure it’s given me more confidence as a carer because I’ve got more information and that also becomes a part of how I care for my daughter and talk to the family and others as well.” – Maryam (female, parent, active-high user)

Supportive peer community

One significant benefit carers identified was a sense of belonging to a supportive peer community, without ever seeing or knowing one another. Many carers discussed feelings of loneliness and isolation they had experienced. Reading the resources and forums showed carers that others are going through similar and relatable difficulties, helping the carers feel less alienated, isolated, and detached.

“Sometimes when you are a carer you think you are alone. When you go to these groups or you do these things you realise you are not. It makes a difference.” – Anna (female, parent, passive non-complier)

Carers also reported feeling more connected and having a sense of solidarity and unity with others to proceed on the caring journey. Carers valued having the sense of community, group alliance, and connection which naturally arose from sharing similar experiences/challenges

and feeling mutually understood, something they often lacked in their own lives. This was made explicit by the following: *“Being able to see that people are getting some support and that it normalises the issues that we don’t talk about.”* – Abbie (female, parent, active-moderate user)

Most carers valued being linked with other carers, especially new carers who felt shell-shocked and craved speaking to others in a non-judgmental environment. Many carers appreciated the opportunity to learn from peers, including practical tips, advice, and awareness of differing carer experiences. Some also valued the opportunity to help other carers and the positive feelings that came with that.

“But in the main I found the whole thing quite helpful especially for the first month or so when I could see or read about everyone else’s problems and some were similar to mine and some of the advice they gave if you know what I mean” – Ben_1 (male, parent, active-high user)

As well as creating a community and reducing loneliness, many carers noted that reading posts from other carers also helped to normalise and validate their feelings and experiences. The intervention content and forums also helped to normalise concerns, fears, and often stigmatised psychosis-related topics which carers often found difficult to talk to people in their personal lives about. Such normalisation and validation subsequently helped carers feel less overwhelmed.

“Yes, I think I found it really helpful as well because some of the ways that it was designed with the different subjects helped as well to make me think oh yes well this experience I’m having is normal, which is like there was, how it was set up the programme it had stigma.” – Eleanor (female, friend, active-high user)

Some carers felt the expert and peer support forums provided hope, particularly in instances where carers were able to provide lived accounts and reassurance of particular aspects getting better and situations improving with time. Some carers especially valued reminders that their loved one is still their loved one and reflected that kind words provided ‘light’, led to a feeling of hope. For example:

“In some respects it made me feel a bit better because other people are going through not completely the same as me but very similar as me and they’ve managed to get through it etc.” – John (male, partner, passive-moderate user)

Improved well-being

Carers recognised that COPE-support was specifically designed for them. Some carers discussed how COPE-support not only provided support for their loved one’s well-being but also their own. This included recognising the importance of supporting their own needs, focusing on self-care, and fostering healthier routines such as improving their diet, fitness and sleep hygiene.

“It was just really, really helpful to learn how I can manage my well-being in terms of trying to support myself in terms of trying to help the person I’m caring for ... like I said it has made a really big difference to my well-being and my partner’s well-being and it has been a lifeline.” – Aaron (male, partner, passive non-complier)

“I have actually changed my eating this last few months as a direct result of the site, so that’s quite something.” – Alexandra_3 (female, parent, active-moderate user)

Even the concept that COPE-support had been designed specifically for carers helped carers

recognise their support needs were valid and acknowledged, reducing guilt associated with personal help-seeking. Some carers described how COPE-support had provided personal space and time to reflect on their personal journey as carers, get more in touch with their emotions, and listen to the reflections of others:

“Even just using the questionnaires at times were good for me because it made me sit and focus a little bit on where things were at...and actually think about how I was feeling.” – Alexandra_1 (female, parent, passive non-complier)

Future implementation and integration with existing services

The following sub-themes reflect carers’ perspectives surrounding COPE-support’s future implementation and integration with existing services. This includes suggested improvements for COPE-support.

Comparison with face-to-face support

Compared with face-to-face support for carers, perspectives of COPE-support were mixed. Whilst some expressed a preference for traditional means of delivery, others preferred online-based platforms and ideally a blended approach. Barriers to face-to-face support including geographical factors, family life, funding and time constraints, and the benefits of online delivery in minimising these barriers were discussed by some carers. Other carers considered barriers of online interventions including age and a desire to personally meet carers and be able to sit with others going through similar situation. This is expressed in the following:

“And I think that e-support is definitely a very, very useful, well it’s a very good use of technology for people who have computers or phones and have the confidence to access stuff. You can’t beat that one-to-one when you need it, you can’t beat that.” – Faye (female, parent, passive-moderate user)

Integration with other services

Several carers commented that given the funding restrictions on existing services, implementing COPE-support could ‘only be a benefit’. Some carers highlighted that participating in COPE-support addressed their concerns surrounding interventions for carers and motivated onward utilisation of other services such as face-to-face groups and courses for carers. Whilst some felt the support they had received through COPE-support was sufficient for their needs, others emphasised that COPE-support should serve as adjunctive to existing services rather than a replacement.

“It also encouraged me to join a carers and coping course ...I think it’s made me question why I would find it so hard, ...to sit in a group with other people and hear about what’s been happening to them, so yes I’m definitely looking forward to going to a six-week course at the end of this month.”

– Summer_2 (female, parent, passive-moderate user)

Continuous access

Perspectives on length of time to have access to COPE-support were mixed. Some felt they had received access for just the right amount of time to remain engaged and gain optimal benefits as a carer. However, some desired a longer usage time. Several carers highlighted that as caring can be a long and complex journey, it would be reassuring to be able to revisit information and know they would be able to use it and have instant access to support in the future if new challenges arose (i.e., dip in and out).

“People have different periods of crisis. You would not want to have the sense of support

suddenly be taken away.” – Martin (male, parent, passive-moderate user)

To allow for continuous access suiting carers’ needs, some carers suggested being able to self-refer back into the intervention if necessary or have continual access and be able to opt out when they felt they had used it enough. For instance:

“It was very good, too good hence I asked if I can enrol again...it was a lifeline for me... COPE-support came along and gave me all the help and support I’ve ever wanted.” – Summer_1 (female, parent, active-moderate user)

Greater advertisement and reach

Some carers reflected on coming across COPE-support ‘by chance’ and emphasised a need for greater advertisement to reach more carers if it was to be roll-out widely in the future. Several advertising and promotion routes were suggested including local authorities/social services, charities, GP surgeries, existing services for carers and trust websites, noticeboards, and newsletters. Awareness amongst health and social care professionals, was also noted as important, with potential screening for carers’ well-being and onwards signposting to COPE-support recommended. Suggestions of ways to reach carers include the following:

“When you roll it out into various Trusts and it’s goes further that’s where it needs to be as well. There are a number of options there.” – Mark (male, parent, passive non-complier)

“They always ask at the GP surgery when you register or every so often they’ll say are you caring for anyone and it could be quite helpful to maybe signpost it at that point.” – Aaron (male, partner, passive non-complier)

User suggested improvements

Many carers proposed suggested improvements for COPE-support. Some were about the way information was presented which some found, at times, overwhelming and off-putting (i.e., ‘too much on the screen sometimes’). To reduce confusion, fewer chunks of text and more graphics/visual aids or ‘see more’ drop down options were recommended.

“I suppose what I’m trying to say is even a little, you need to have something – if you want to do mindfulness it needs to have a little picture, it needs to be more visually stimulating” – Molly (female, parent, active-moderate user)

With regard to the forum communications, whilst some described freely writing open posts as cathartic, several carers reflected on an emotional burden arising from posts. At times carers found posts distressing to read and could generate worries. Thus, providing a general warning of content causing potential distress and content warnings for particular comments were recommended.

There were things where, you know there were things that triggered me to think about things and thought this maybe something worth sharing.” – Matthew (male, partner, active-high user)

Moreover, some carers desired more ongoing conversations. Thus, suggestions for a chat room or befriender element were made by a few carers to help build stronger connections. Some carers reported it was hard to relate to others given different life circumstances (e.g., having several children to care for too). Hence, a couple of carers recommended brief profiles with basic, yet non-identifying, information (e.g., gender, caring responsibilities, relationship, living situation) to provide a bit of context would aid with giving advice and support, as well as seeking relatable content. However, when certain forum topics received a good number of posts, one common problem arisen was having to go forwards and backwards between pages and scrolling excessively to see forum comments. This was described by an active user

below:

“I remember the format of the message threads when you had five or six interactions or replies on the same thread it becomes almost impossible to read on the phone because you have to scroll down and the indentation starts going to the right.” – Tony (male, partner, active-high user)

Hence for navigating the forums and the COPE-support content overall, ‘frequently viewed’ and ‘recently viewed’ buttons were recommended by some carers. Some would also like to be able to choose which posts on the forum to expand. Most found the instructions for navigating COPE-support clear, although some would have appreciated an opt-in for 1:1 guidance.

Lastly, to encourage engagement some carers noted that they would have appreciated some additional prompting after periods of inactivity. Several passive users regretted not utilising the forums more and reported barriers for posting including their busyness, mental state, difficulties expressing their feelings, worries surrounding sharing with unknown people, and experiencing hesitation and self-doubt. Some carers suggested having rolling discussion topics and implementing alternative options (e.g., emoji reactions) to facilitate forum engagement. For example:

“If that [thumbs up or other emojis for acknowledgement] feature had been available and I’d seen a couple of thumbs up to the things I’d posted I think that would have been great...And maybe that’s a stepping stone as well they start by just a few reactions, emoji reactions and then it’s small steps. They can do that the first time and then maybe the next time they will write a few words” – Felix (male, step-parent, active-moderate user)

Discussion

Principal findings

The current study aimed to explore (1) carers’ experiences and perceived acceptability of COPE-support and its different components, (2) how they found engagement with COPE-support affected their own well-being and caregiving, and (3) carers’ ideas for improving COPE-support and its delivery to inform any future wider implementation. Notably, this qualitative study is one of the first to explore experiences of carers for individuals with psychosis in using an entirely online psychoeducation and peer support intervention, co-produced by carers and people with experiential expertise. Participants’ experiences were predominantly positive with COPE-support and carers identified a range of benefits from using the intervention. Nonetheless, carers also highlighted some key areas of improvement. Overall, three themes were identified, each addressing one of the study’s objectives: (i) remote, flexible and personalized support, (ii) impacts on well-being and outlook on caregiving, and (iii) future implementation and integration with existing services.

The overall subjective experiences of COPE-support among carers were positive on the whole. In addition to the online gains provided by COPE-support such as improved accessibility, flexibility, and anonymity, participants also reported the intervention as

beneficial in providing access to a rich repertoire of credible information [8,11,12] and fostering personal development by enhancing their self-confidence and understanding. Our results indicate COPE-support was perceived as a crucial resource to reinforce carers' feelings of empowerment while reducing sense of isolation. COPE-support also prompted carers to prioritise their own well-being. These impacts motivated some carers to access further support and engage more with professionals, indicating additional long-term benefits [1,3,6,14,15].

Notably, our themes and sub-themes should be recognised as a set of inter-connected and interacting constructs to be considered in the overall design (e.g., content) and facilitation (e.g., moderation) of online interventions such as COPE-support [8]. For instance, carers would only enjoy interacting on the online forums, provided they felt safe and supported through specific implementation strategies. Carers would be less likely to see the essential intervention contents should the access and navigation be less than facilitative.

Moreover, similar to earlier studies on online interventions with a forum component [20-23,33], we found that carers' usage in terms of numbers of posts and log-ins, does not always align with their perceived acceptability and usefulness of the intervention. While the carers who actively initiated posts themselves were eager to see more exchanges on the forums, many others found benefits in being a passive observer. Some carers identified the anonymous participation on online forums allowed them not to feel pressurised to participate in a certain fashion as in face-to-face group setting. Many carers described finding resonance, connections, and solidarity from the peer and expert forums without making a post themselves, although some identified that they would have made posts if given more time or if a specific question came up.

Future Directions

Participants' experiences seemed partly dependent on factors such as their own demographic profile (e.g., length of time as a carer, age) and preferences for particular delivery formats and computer literacy, as highlighted in previous studies [14,26,40,41]. It is imperative to incorporate these perspectives in considering how best to further refine COPE-support and its facilitation. Upon future implementation, several advertisement routes were recommended to increase COPE-support's reach, as well as a need for greater awareness amongst professionals who have contact with carers. In line with previous research [41], the need for more proactive approaches from professionals and services to identify and refer carers were highlighted, such as potential screening for carers' well-being and ongoing signposting to COPE-support [32].

In any future roll-out of COPE-support, it is imperative to consider the revision and refinement of the content as much as the facilitation of the minimally guided online intervention holistically to keep the participants engaged, so as to induce the anticipated impact [7]. Further scaling-up implementation of COPE-support and similar interventions

also needs to carefully consider what constitutes the optimal group size and set-up for a multi-component online object, including interactive forums catering for a large number of users with varying usage/participation profiles and a more flexible timeframe to suit the ongoing needs of carers. Some participants also highlight a desire for blended services - i.e., COPE-support being adjunctive to, rather than a replacement of, in-person support. Indeed, a blended approach could foster the discussed benefits of both online and face-to-face support, as well as provide carers with options to cater for their needs and preferences.

Strengths and Limitations

We considered the sample of 35 carers interviewed for this study being a strength, as this contributed to wide variation of user experience and usage from carers with different relationships with the individual with psychosis and in different caregiving situations. Having multiple researchers to independently code and analyze the rich data led to the unanimous results and increased the rigour and reflexivity of the study [36,42]. The study results allow us to understand through the carers' perspectives how they engaged with COPE-support, what helped or hindered their engagement, and how using it impacted on themselves. Through these results, we understand that carers' experiences of COPE-support were shaped by a range of demographic and online health literacy factors, in addition to the intervention design and delivery itself. To ensure the users get the intended benefits of the COPE-support in the future roll-out, it is imperative to consider how best to engage a wide variety of users to use all its essential ingredients [7,14].

The study has several limitations. While we aimed to interview carers after completion of outcome data collection at 8 months, some carers had stopped using COPE-support earlier than the study duration and hence found it difficult to recall their experience with the intervention in detail. Although we strived to invite participants with low usage and those from ethnic minority background for the interviews, such populations remained under-represented (in the overall trial and this study) [43,44]. Our interviewees may have been positively biased in their views surrounding the intervention and study. It could be valuable to extend future work to explore reasons for non-enrolment among potential participants within services where the intervention was advertised yet they chose not to take part.

Conclusions

Overall, this qualitative interview study captured carers' experiences of using the online intervention COPE-support. The variation of responses amongst active and passive users captured the user's individual responses of the carer's perception of COPE-support. Notably, support and engagement with peers and experts were appreciated for meeting and validating the needs of carers, and the importance of usability ease, personalization, convenience and safety were discussed. Further work is required to develop COPE-support based on these suggestions and explore steps for optimal implementation.

Declarations

Ethics approval and consent to participate

This study has been reviewed and approved by South Central – Oxford C Research Ethics Committee (Reference: 18/SC/0104) and Health Research Authority (Reference: IRAS 240005). Prior to study participation all participants are required to view and give consent online to the information that was provided in the Participant Information Sheet.

Acknowledgements

The authors thank all the carers who participated in the study.

The authors thank all the input and contributions from the members of the Project Reference Group which provided oversight for the research programme. They are Ellen Harris; Jacqueline Marks; Angela Ryan; Storm Ryan; Lana Samuels; Clive Travis, PhD; Leigh Wallbank; and Dr Elen Williams (see <http://cope-support.org/team/>).

We thank all the members who help run the Ask the Experts forum. They include: Ana Maria Corredor Collazos; David Coughlin; Dr Ranjita Dhital; Sian Evans; Dr Ban Haider; Julia Heathcote; Dr Claire Henderson; Dr Sarah Mansfield; Dr Aileen O'Brien; Mona Qassim; Juliet Sserunkuma; Clive Travis, PhD; and Dr Elen Williams.

For recruiting participants into the study, the project team acknowledges the support of the National Institute for Health Research, through the Clinical Research Network (Division 4).

Contributions of authors

JS conceived the study and initiated the study design with supervision from CH and SG. RB, JS, CH, SG, LW, SaG, and HS further developed the study design and its implementation. RB, SaG, HS, EW, and JS led the analysis and interpretation of results. RB and JS drafted the paper, SaG, HS, and EW supported its further revision. All authors read and approved the final manuscript. JS is the grant holder.

Conflict of interest

This trial, as part of a bigger research programme entitled EFFIP (E-support for Families and Friends of Individuals affected by Psychosis) is funded by the National Institute for Health Research under its Post Doctoral Research Fellowship (awarded to Dr Jacqueline Sin, reference: PDF-2015-08-035). The study was peer reviewed by the funding body.

The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health and Social Care. The funder NIHR had no involvement in study design, collection, analysis or interpretation of data, writing the manuscript, and decision to submit the manuscript for publication.

All authors declare no conflict of interest.

Abbreviations

COPE-support: Carers fOr People with Psychosis e-support

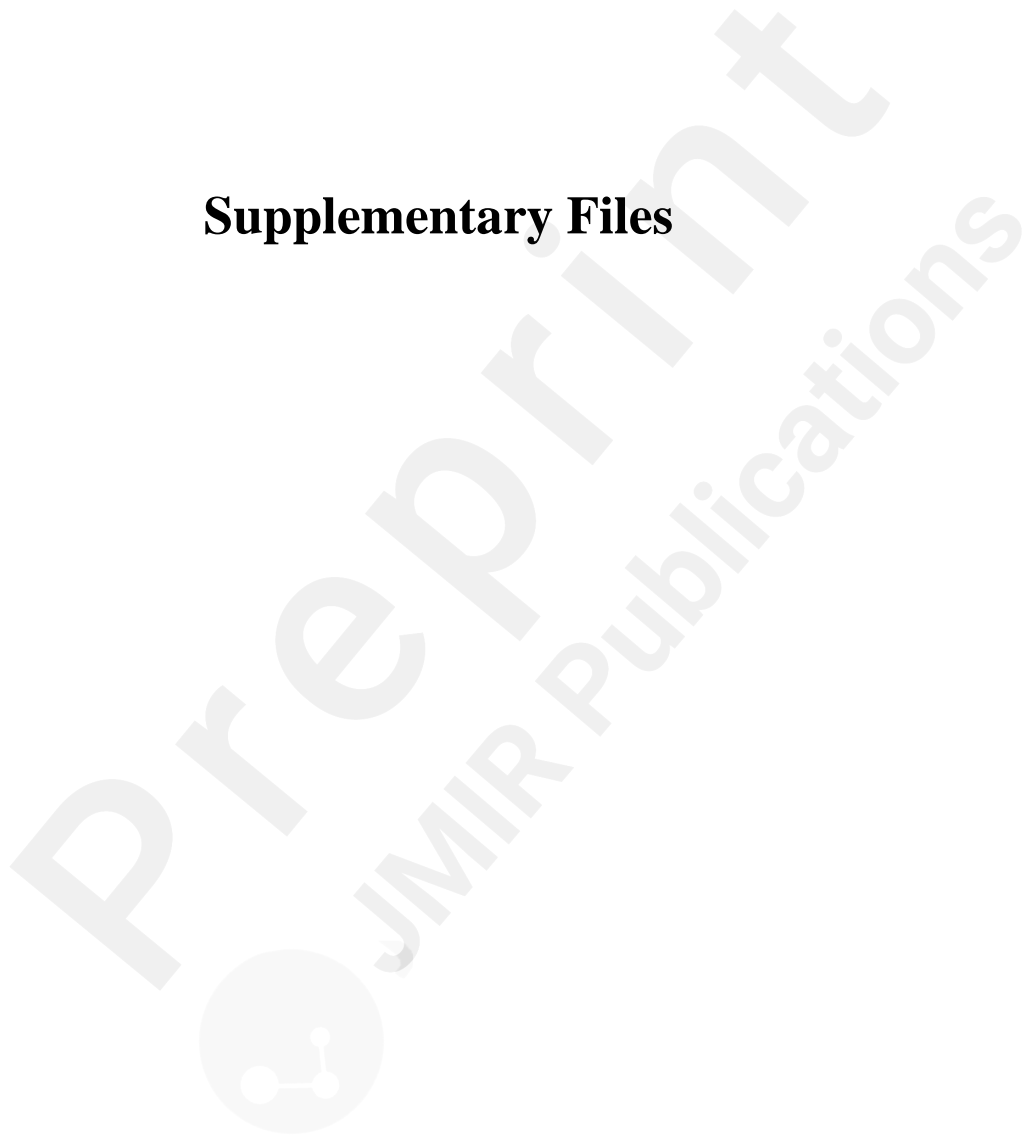
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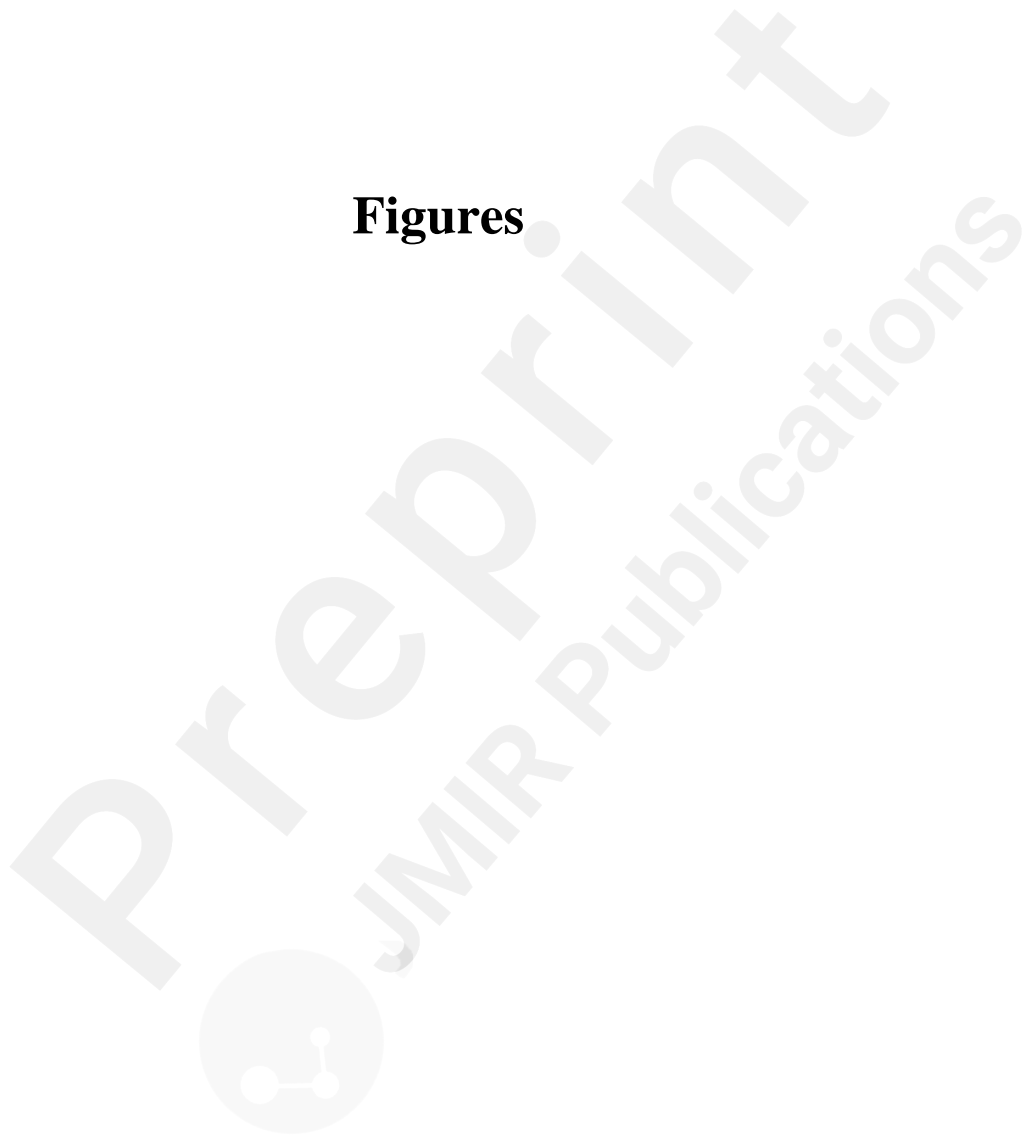
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Supplementary Files



Figures



COPE-support Home page.

COPE-support_I07

E-support for Families and Friends of Individuals affected by Psychosis_I07

COPE-support
E-support for Families and Friends of Individuals affected by Psychosis

Welcome to COPE-support! COPE-support is an online resource which stands for "Carers fOr People with Psychosis e-support resource", an acronym chosen by the many carers and people with lived experience of psychosis involved in the EFFIP project (see more on www.cope-support.org).

		Becoming a resilient carer		Caring for your loved one
Understanding psychosis		Ask the experts FORUM		
	Treatment for Psychosis		Stigma & discrimination	Peer to peer FORUM
Getting through services			Caring for carers	
	Resources for carers	Ways to promote recovery		Support


Below you can see the COPE-support menu outlining its multiple components, including information and support through forums. The resource is designed

Ask the Experts Forum webpage.

COPe-support_107 > Pages > ASK THE EXPERTS FORUM

View all pages

ASK THE EXPERTS FORUM



Do you still have questions un-answered or do you have specific concerns that the information you have found fails to address fully? We have a panel of expert professional knowledge on mental health, general health and related subjects. Below you will find a list of discussion topics. Please post your question in the topic you want to ask about medication, post it under *Psychiatry and medication*. We aim to get back to you within 3 working days.

Ask the experts discussion topics:

- Topic 1: [Talking therapies & psychosocial interventions](#)
- Topic 2: [Psychiatry and medication](#)
- Topic 3: [Legal issues, benefits and community resources](#)
- Topic 4: [Service issues, e.g. referrals and interface between different services](#)
- Topic 5: [General and physical health issues](#)
- Topic 6: [Campaigning, stigma & social inclusion](#)

Information on psychosis on COPE-support.

Announcements

Modules

Conferences

Outcomes

Syllabus

Files

Pages

Grades

People

Assignments

Collaborations


Quizzes

Rubrics

New Analytics


Settings

What is psychosis?



'Psychosis' is a term used to describe a set of experiences that are not based on reality, often result in a person's perception, thoughts, mood and behavior are significantly altered. Some common psychotic symptoms include hallucinations, delusions and disturbed thoughts (see sections below for symptoms).

Psychotic symptoms on their own do not make a diagnosis or label of mental illness. However, when such symptoms impact on someone's emotions, functioning and identity, especially in a prolonged and entrenched way, 'psychosis' could also be regarded as a broad category of mental health conditions that have psychotic symptoms as its hallmarks. In the National Institute for Health and Care Excellence (NICE) Guideline on Psychosis and Schizophrenia in Adults – Prevention and Management (NICE, 2014), the term 'psychosis' is used to refer to a set of related conditions, of which the commonest is schizophrenia, and includes schizoaffective disorder, schizophreniform disorder, delusional disorder, the so-called non-affective psychosis, and people who are receiving treatment and support from early intervention in psychosis services (EIPS) for 'early onset psychosis' or 'first episode psychosis'. Psychotic symptoms are also prominent symptoms in those affected by affective psychoses, such as bipolar disorder or unipolar psychotic depression but these are referred to in other NICE Guidelines.

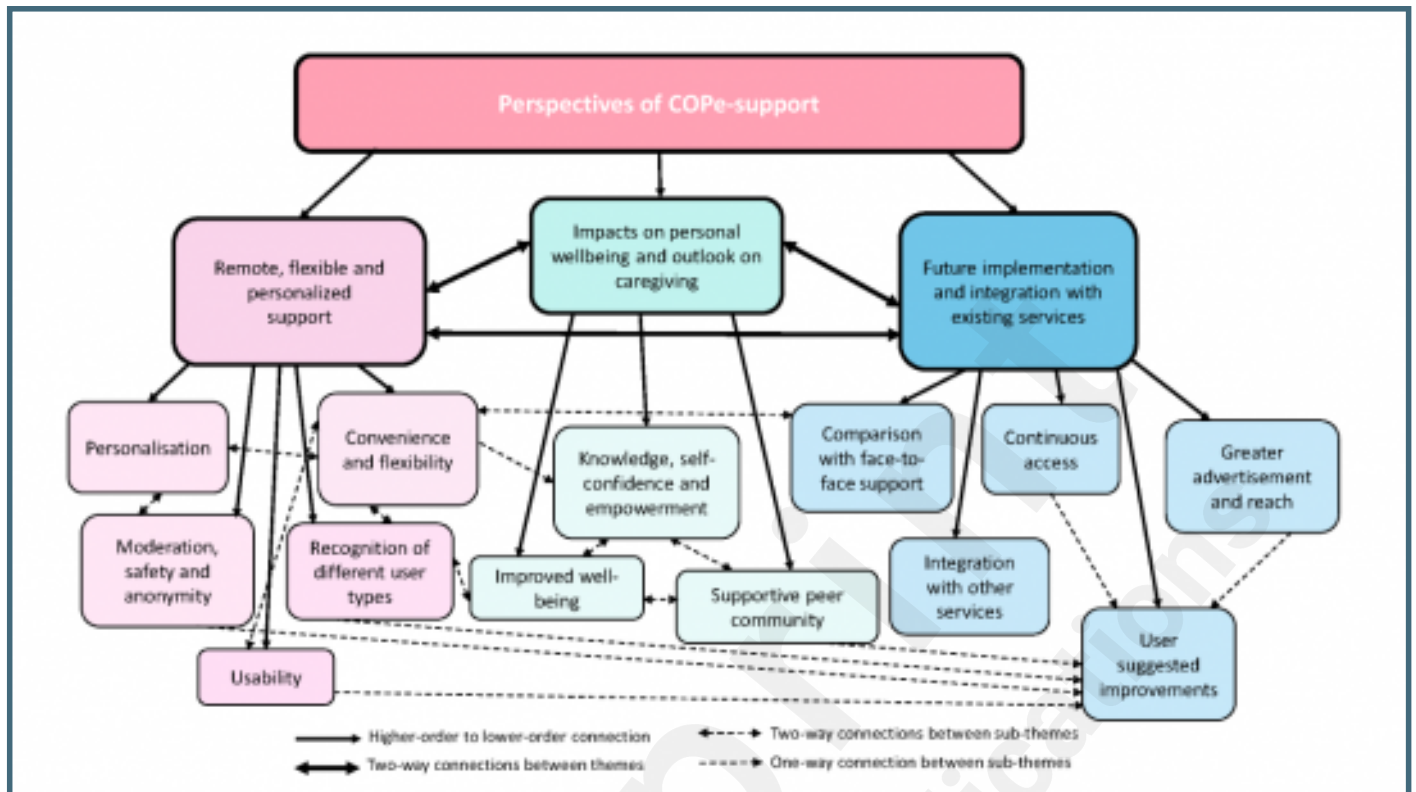


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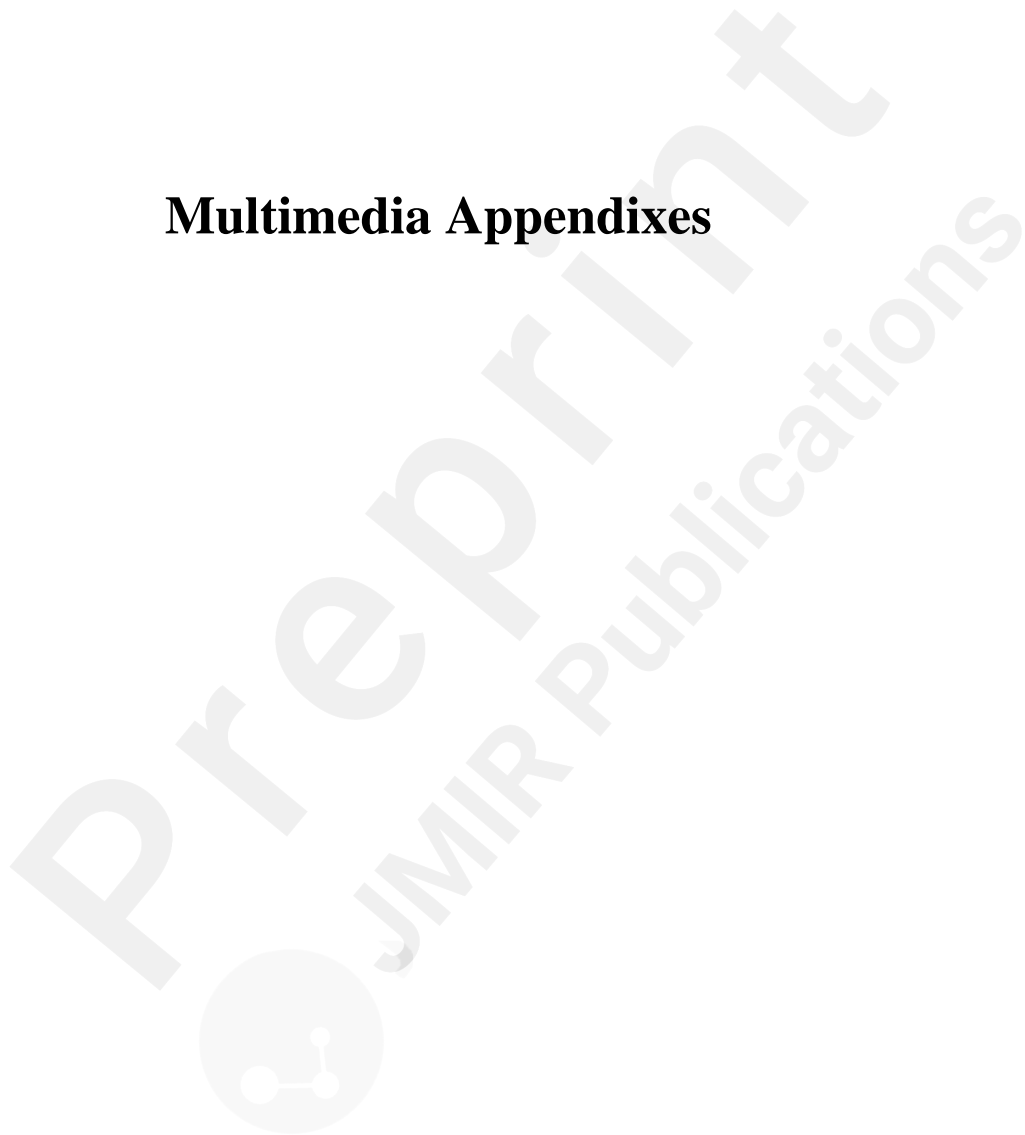
- What is psychosis?
- Possible causes
- Common psychotic symptoms
- Other common co-occurring mental health problems
- Prognosis and recovery

* Attribution: We have devised the information about psychosis and its treatment, in part, based on NICE Clinical Guideline 178 (@NICE [2014] [Guideline on Psychosis and Schizophrenia in Adults - Prevention and Management](#) et.). NICE has not checked the use of its content in this product to confirm that it accurately reflects the NICE publication from which it is taken. See the source material [here](#) et' and its open license [here](#) et.

Coding tree summarising the inter-related themes and sub-themes.



Multimedia Appendixes



Supplementary 1 - Interview topic guide.

URL: <http://asset.jmir.pub/assets/a7feef22f389583565deaa1b5579446.docx>

Supplementary 2 - Summary of themes and subthemes.

URL: <http://asset.jmir.pub/assets/194bf93e9af45c7798fd92241b1590fb.docx>



CONSORT (or other) checklists

COREQ checklist completed for the paper.

URL: <http://asset.jmir.pub/assets/367e5061d122523730948451d8f4cc7f.pdf>