Case management in early psychosis intervention programme: Perspectives of clients and caregivers

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Aim: This qualitative study explored the perspectives of clients and caregivers on case management provided by the Singapore Early Psychosis Intervention Programme (EPIP), with the intent to understand the salient aspects of case management from their perspective.

Methods: Clients and their caregivers were recruited from the EPIP outpatient clinics. Focus group discussions (FGDs) were conducted at a community centre outside the hospital with 47 clients and 19 caregivers. Facilitators were experienced researchers who were not involved in the care of the clients and trained in qualitative research methodologies. All FGDs were audio recorded and transcribed verbatim with all participants’ identifiers omitted to protect confidentiality. Qualitative data analysis was conducted using thematic analysis.

Results: There were 11 themes that emerged from the FGDs: therapeutic alliance, holistic monitoring, collaborative role with other care providers, counselling and guidance, crisis management, bridging role, client-centred care, client empowerment and strength building, psychoeducation/education on illness, support and problem solving.

“Problem solving” surfaced only from the client FGDs; the remaining themes were common to both groups.

Conclusions: The voices of clients and caregivers are important to EPIP case management service. This study has provided insights into their perspectives, understandings and lived experiences of case management and its impact on clients and caregivers.

KEYWORDS
caregiver perspective, case management, client perspective, early intervention, psychosis

1 | INTRODUCTION

Case management was introduced in mental healthcare in the 1960s in the United States following de-institutionalization of persons with mental illness from hospital to community care. The goal was to improve their continuity of care by bridging them with needed services, and to improve their quality of life in the community (Amado, McAnally, & Linz, 1989; Stanhope, 2013).

Over the years several definitions of case management have emerged in the human services literature (Intagliata, 1982). Although these definitions were somewhat different, Intagliata (1982, p. 657) observed that “their common theme suggests that case management is a process or method for ensuring that consumers are provided with whatever services they need in a coordinated, effective, and efficient manner.”

The introduction of case management in healthcare has produced favourable outcomes. Outcome studies have found clients receiving case management service to have less rehospitalization days (Bond, Miller, Krumwied, & Ward, 1988) and a reduction in symptom severity (Kim et al., 2015). While qualitative studies that involved clients in focus groups have highlighted that the quality of therapeutic relationship with their case workers served as an important factor in
facilitating their recovery and clients valued the 24-h availability of the service and home visits (Redko, Durbin, Wasylchenko, & Krupa, 2004). Krupa et al. (2005) also highlighted that the focus on client beyond the illness helped in facilitating recovery.

Singapore is a small island city-state in Southeast Asia. The Singapore healthcare system is complex and fragmented (Tan, 2009), which may have been the impetus for the increased case management services being implemented in the recent years. The Singapore Early Psychosis Intervention Programme (EPIP) was initiated in April 2001 with the aim to raise awareness of and reduce stigma associated with psychosis, establish links with primary healthcare providers and collaborate in the detection, referral and management of those with psychosis and improve the outcome of its clients and reduce the burden of care on their families (Yong & Verma, 2013). Case management is a key component of EPIP. Using the phase-specific recovery model, case managers (CMs) conduct bio-psycho-social assessments and provide the strengths based approach and other interventions for clients and caregivers for a period of 3 years. Although its clients’ satisfaction rate has been 80% or more (Verma, Poon, Subramaniam, Abdin, & Chong, 2012), it is unclear what component of case management work has been impactful for its clients. Hence, a team of CMs in collaboration with researchers embarked on this research to access and elicit clients’ and caregivers’ lived experiences, understandings and perspectives of the EPIP case management service. No conceptual framework was adopted in this study. Instead, an inductive approach was undertaken to allow themes to emerge from the study (Thomas, 2006). A qualitative approach was preferred as it provides greater opportunity for the participants to highlight issues of perceived importance from their perspective for their recovery (Carrick, Mitchell, & Lloyd, 2001).

2 | METHODS

The study was approved by the relevant institutional and ethics committee (National Healthcare Group Domain Specific Review Board). Written, informed consent was obtained from all participants.

2.1 | Sample

Inclusion criteria were EPIP clients who were 16–40 years old, Singaporean or Singapore Permanent Resident, those who had been in the programme for at least 1 year to ensure familiarity with the various services, able to speak English and were clinically stable. Caregivers of clients who were in the EPIP programme for at least 1 year and able to speak English were also recruited. Caregivers were recruited irrespective of whether their relative had participated in the study. Client and caregivers were referred from the outpatient clinics by the attending team of psychiatrists and CMs.

A total of 47 clients and 19 caregivers participated in the focus group discussions (FGDs). The participants’ socio-demographic characteristics are shown in Table 1. There were 6 client FGDs and 3 caregiver FGDs conducted from July 2015 to January 2016. Each FGD comprised 6–9 participants which lasted about 1 h in duration. Each participant was given an inconvenience fee of SGD$50 at the end of the FGD.

2.2 | Data collection

The FGDs were conducted at a community centre outside the hospital by 2 team members: a facilitator and a note-taker. The facilitator and note-taker explained the participation processes and ensured that consent forms were signed prior to beginning the FGD. The facilitators (MS and JV) were researchers not involved in client care and were trained and experienced in qualitative research methodologies. An interview guide was developed to ensure uniform data collection across the FGDs. Example of open-ended questions to elicit participants’ perspectives of case management included “Can you describe what case management is to your understanding?”, “What is the process like in case management?”, “How would you describe the role of case manager?”, “Can you tell me a bit about your experience with your/your relative’s case manager in EPIP?”, “What has your/your relative’s case manager done that you found useful?”. The note-taker took detailed notes of the group process and seating arrangement. At the end of each FGD the facilitator and note-taker debriefed immediately to ensure participants’ perspectives were not missed.

There are no general rules on the ideal number of focus groups (McLafferty, 2004). However, some authors recommend that 4 focus groups are generally sufficient and the ideal composition of a focus group is between 7 and 10 people (Nyamathi & Shuler, 1990). This study used the concept of data saturation as a guide to determine the number of focus groups to be conducted (McLafferty, 2004).

The researchers with both clinical and research background met and discussed regularly after the FGDs and after 6 client focus

| TABLE 1 | Participants’ socio-demographics |
| --- | --- | --- |
| **Clients** | **N** | **%** |
| Gender | | |
| Male | 20 | 42.6 |
| Female | 27 | 57.4 |
| Age (mean, SD) | (27.4, 5.39) | |
| Ethnicity | | |
| Chinese | 34 | 72.3 |
| Malay | 9 | 19.2 |
| Indian | 4 | 8.5 |
| **Caregivers** | | |
| Gender | | |
| Male | 6 | 31.6 |
| Female | 13 | 68.4 |
| Age (mean, SD) | (51.21, 14.18) | |
| Ethnicity | | |
| Chinese | 14 | 73.7 |
| Malay | 5 | 26.3 |
| **Relationship with the clients** | | |
| Parents | 14 | 73.7 |
| Sibling | 4 | 21.1 |
| Spouse | 1 | 5.3 |
groups and 3 caregiver focus groups with no new themes emerging, the FGDs were concluded. All FGDs were audio recorded and transcribed verbatim and the facilitators checked the transcripts for consistency. All participants’ identifiers such as names were omitted from the transcripts to maintain confidentiality.

2.3 | Data analysis

A qualitative thematic method was used to analyse the data, which involved identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006). First familiarization with the data was achieved by reading and re-reading the transcripts several times. Based on the narratives of the texts a code list was developed for data analysis (Boyatzis, 1998). Three authors (MS, SS and HHW) coded the same transcripts (2 transcripts in all) using the codebook developed and inter-rater reliability was compared; Cohen’s kappa coefficient was established to be 0.79. The 3 authors then coded the transcripts independently.

Based on the codes, themes were identified and finalized based on an iterative process by the researchers (see examples in Table 2). The data analysis was conducted using NVivo V.10. (QSR International, 2012).

Validity and reliability conceptualized as trustworthiness and rigour in the qualitative paradigm (Davies & Dodd, 2002; Lincoln & Guba, 1985) was ensured by the researchers to eliminate bias and increase truthfulness. This included triangulation (Creswell & Miller, 2000) – accounts of both patients and caregivers were sought and analysed to ensure presentation of different perspectives. Emergent themes were also compared and contrasted with existing literature. Research rigour was ensured by including well-trained neutral researchers who were not part of the clinical team to conduct the FGDs, thereby ensuring that participants could express their thoughts freely. The use of open-ended questions allowed participants to express both their satisfaction and dissatisfaction with the quality of care management service. Coding of transcripts was done by 3 researchers with good inter-rater reliability of 0.79 (kappa coefficient) and a well-documented audit trail of decisions and processes was maintained. Reflexivity was ensured by both the clinicians and researchers by reflecting on their perspectives and the team regularly debriefed to uncover and challenge biases and assumptions (Watt, 2007).

3 | RESULTS

Client and caregiver perspectives are presented in this paper as a combined narrative as they shared many similar perspectives. Besides, CMs were equally in contact with both groups and the CM model of care applies across the 2 groups. The emerging themes from FGDs were classified into 11 broad categories: therapeutic alliance, holistic monitoring, collaborative role with other care providers, counselling and guidance, crisis management, bridging role, client-centred care, client empowerment and strength building, psychoeducation/education on illness, support and problem solving (see Table 3). "Problem Solving" surfaced only from the client FGDs; the remaining were common themes for both groups. The 5 themes that emerged most strongly from the FGDs, that is, emerged in majority of the FGDs, are discussed in further details. Sample quotes for each category are also presented (C—client; CG—caregiver).

3.1 | Emerging themes from FGDs

3.1.1 | Bridging role

This refers to making referrals for participants’ identified needs, which includes services from both within and outside of EPIP. For example, participants said CMs referred them to the peer support specialist for peer support and Club EPIP for sport and recreational activities (see C6 and CG8).

C6: "I wanted to mingle with people so she said ok go club EPIP. I wanted someone that I can talk to... she said ok why don’t you go see psychologist... I told her I have problem with my finances, and then she said ok go see a medical social worker."

CG8: "XXX she will... arrange certain activities like going to peer support ... attend to occupational therapy and art therapies due to her interests in a way like share her interest and introduce her activities..."

3.1.2 | Collaborative role with other care providers

This refers to partnership between the CM and (1) other professionals often as part of a multidisciplinary team and/or (2) the family/non-professional carers aimed at managing the client’s illness and optimizing his/her psychosocial functioning. Clients reported that CMs discussed their care with the psychologist, social workers and psychiatrists (see C7). Caregivers collaborated with CMs by providing feedback on medication side-effects experienced by their family members which was promptly flagged by CMs to the psychiatrists for management (see CG13).

C7: "Even though they are not there, they always discuss with the... psychologist... and then with doctor to see how am I doing lah."

| TABLE 2 | Examples of codes and themes |
|---|---|
| Codes | Themes |
| Case manager (CM) link up client with medical social worker for financial assistance | Bridging role |
| CM referred caregivers to Family Service Centre for family support | Bridging role |
| CM discussed with and received updates from other team members about client | Collaborating role with other care providers |
| Caregiver feedback to CM about client’s medication side-effects profile for attention and management | Collaborating role with other care providers |
3.1.3 | Holistic monitoring
This comprises comprehensive monitoring by CMs to track the progress recovery and well-being of clients and their caregivers. Clients said their CMs sought to understand their “life problems” in addition to their illness and their response to medications (see C7). In addition to making phone contacts with clients, CMs visited them at home, school or workplace to ensure they were coping well. Caregivers said CMs also ensured their well-being so that they can better care for their family members (see CG9).

C7: “When you see doctor, they all want to know do you have any problem regarding your illness. But the case manager is to understand more on your life problem, any problem.”

CG9: “she do check on my sisters, my another sister and my wellbeing also at the same time on the patient.”

3.1.4 | Crisis management
A crisis refers to any emergency situation such as when a client actively feels suicidal or any other situations identified by the client, caregiver or CM as needing immediate attention. Clients said they phoned their CMs when they became suicidal and their CMs calmly talked them out of it (see C6). While caregivers said their CMs’ quick interventions facilitated hospital admissions of their family members (see CG16).

C6: “...when I wanted to kill myself, I called her ... she was really calm... she didn’t panic... she will just talk to me slowly about things... about like 2 hours and I felt slowly like better after that ... the urge to kill myself slowly fade away... thanks to her.”

CG16: “it was a very traumatic experience.... we actually emailed and my case manager replied very promptly. Very very promptly. And she was actually admitted to IMH immediately.”

3.1.5 | Psychoeducation/Education on illness
Participants reported that CMs educated them about their illness and the importance of early symptoms detection for relapse prevention (see CG2). CMs also engaged with them on topics relating to self-care, medication management as well as on diet and exercise to manage weight gain from psychotropic medications (see C17).

C17: “She advises me on how to keep my weight down while I’m on olanzapine coz is known to cause weight gain...”

CG2: “When my husband was 1st diagnosed of this, she came to my place...She explained to me, and to my husband on what he is having...”

4 | DISCUSSION
EPIP clients and their caregivers require the same level of care as reported in previous research in that they often have a wide range of needs and require help from different services (Stanhope, 2013; Watt, Robin, Fleming, & Graf, 2013) and CMs usually link them to these services.

Besides making referrals to needed services, EPIP CMs also work closely with professionals from those services to enhance the quality of care to clients and caregivers. This inter-professional collaboration was achieved by forging a strong partnership that was anchored in effective communication style, shared decision-making and knowledge of professional responsibility (Andvig, Syse, & Severinsson, 2014). EPIP CMs also collaborate with family members as they are often the immediate source of support for clients who live with their families in Singapore. The caregiver CG13 who provided feedback to
CM about her loved one experiencing medication side-effects is a good example where caregivers’ involvement can reduce morbidity and mortality (Lam, 1991), and prevent future client relapses (Sariah, Outwater, & Malima, 2014). Caregivers who engage in collaborative care with professionals may also be better able to preserve their own psychological and physical health (Lefley, 1996).

The emerging theme of “holistic monitoring” by EPIP CMs to ensure clients remain well in the bio-psycho-social-spiritual domains of health is an important one as there are multiple factors that can contribute to clients’ risk of relapse (Sariah et al., 2014; Schennach et al., 2012). Holistic monitoring often involved CMs physically “meeting clients where they are at”, a phrase that is synonymous with case management and many helping professions (Harkey, Sortedahl, Crook, & Sminkey, 2017). CMs visited clients at home, school or workplace to ensure they were coping well. CMs also “meet clients where they are at” by accepting their decision-making and self-identified needs based on their current experiences and perspectives that they may have attributed to their relationship with life and health status. For instance, CMs continue to engage clients who have completely rejected the medical explanation of psychosis and refused all forms of medications. CMs pace these clients at their level of readiness in accepting their illness and will continue to monitor, engage and support them in a holistic way. Sometimes CMs’ support may involve facilitating multiple hospital admissions before clients come to terms with their illness.

During a crisis such as when client becomes suicidal or has an acute relapse of the illness, EPIP CMs help clients and caregivers to regain control of themselves and/or the situation quickly before it spirals out of control. The safety of the client in crisis as well as others who are involved is of priority to CMs. CMs’ support during crisis is important to clients and caregivers as crisis can often induce major stresses leading to loss of self-confidence in their coping ability (Smith, 2006).

The provision of psychoeducation has shown to produce favourable outcomes for clients and caregivers by providing access to information and facilitating skill building and problem solving (Lucksted, McFarlane, Downing, Dixon, & Adams, 2012). A study by Petrikis, Oxley, and Bloom (2012) on family psychoeducation in first-episode psychosis found caregivers to have gained knowledge about psychosis, recovery and relapse prevention. In another study that involved early intervention services (Lavis et al., 2015), the provision of knowledge about psychosis and medications was found to have helped carers to support their relatives. These findings were similarly shared by our caregiver participants.

Some of the emerging themes seemed to overlap with one another. For instance, CMs’ bridging and collaboration roles are often delivered concurrently. When CMs refer their clients to needed services they often engage the service providers in discussion about the clients’ needs. And CMs’ provision of holistic monitoring may help clients to aver or minimize situations requiring crisis management.

This is the first EPIP study to understand the impact of case management from the perspectives of its clients and caregivers. The next step forward is to discern which themes matter most to them so that CMs can channel more time, resources and training to those areas. It may also be beneficial to elicit CMs’ perspectives of case management to understand it from the provider’s perspectives so that a balanced approach can be taken to improve case management in EPIP.

4.1 | Limitations of the study

The use of English language as a medium of communication in FGD may have limited the ability of some of the clients to fully express their perspectives. It is also possible that clients with more negative symptoms may not have participated in focus groups thus limiting their perspectives and understanding of their needs of case management.

5 | CONCLUSIONS

The voices of clients and caregivers are important to EPIP case management service. This study has provided insights into their perspectives, understandings and lived experiences of case management interventions and its impact on them. Clients and caregivers have a range of needs that require CMs to link up and collaborate with other care providers to enhance their quality of care. CMs’ provision of holistic monitoring on clients’ health beyond the illness may help to avert or minimise crisis situations. When in crisis, CMs were there to help clients and caregivers to regain control of themselves and the situations and to keep them safe. CMs will continue to “meet clients where they are at” regardless of their background, beliefs, attitudes and perspectives to support them in their recovery journey.

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