Using a treatment partner and text messaging to improve adherence to psychotropic medication: a qualitative formative study of service users and caregivers in Cape Town, South Africa

S Mall¹, G Sibeko², H Temmingh², DJ Stein², P Milligan², C Lund²

¹Alan J. Flisher Centre for Public Mental Health, Department of Psychiatry and Mental Health, University of Cape Town, Cape Town, South Africa ²Department of Psychiatry and Mental Health, University of Cape Town, South Africa

Abstract

Objective: Poor adherence to medications, including psychotropic medications contributes to the burden of disease. Mental health service users (MHSU) may also not attend follow-up appointments at their health care facilities where they could discuss adherence with their health care provider. This paper reports on preliminary qualitative research preceding a randomised controlled trial that aims to improve adherence to psychotropic medication and to follow up treatment visits. The intervention will entail the support of individuals with serious mental disorder by a treatment partner and short message service (SMS) text messaging. Methods: The preliminary research reported in this paper aimed to extract views about the intervention from both mental health service users (MHSU) and caregivers through focus group discussions and individual interviews. Data were analysed using ATLAS TI qualitative software. Results: The caregivers interviewed were all mothers of MHSU who took measures to encourage adherence. They held mixed opinions on whether the treatment partner should be a family member. Most participants expressed the view that due to living conditions, family members were natural treatment partners, but others stated that they would prefer a treatment partner who was not a family member. Similarly, while most MHSU supported the idea of a treatment partner, a minority were concerned that a treatment partner may potentially be too controlling and compromise their autonomy. The vast majority of participants supported SMS text messaging as a means of reminding MHSU to take their medication and attend followup appointments. One participant mentioned the importance of broader social inclusion issues that should be incorporated in the intervention. Conclusion: Qualitative research may provide useful insights for the design of interventions of this nature related to social inclusion randomised control trials with its focus on adherence.

Keywords: Mental illness; Treatment partner; Social inclusion; Community care; Mobile phones

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Introduction

Globally and in South Africa, the burden of chronic diseases such as HIV/AIDS, diabetes and mental illness is substantial. ¹⁻³ In South Africa, stakeholders have engaged in various measures to encourage adherence to medication. ⁴ Non-adherence to medication contributes to adverse outcomes and

Correspondence

Or S Ma

Alan J. Flisher Centre for Public Mental Health, Department of Psychiatry and Mental Health, University of Cape Town, Cape Town, South Africa email: Sumaya.mall@gmail.com

increased costs. Barriers to medication adherence include structural barriers such as poverty and individual barriers such as poor health literacy.⁵

In low and middle income countries (LMIC) where the burden of infectious diseases is substantial, several initiatives have been applied to the HIV/AIDS and tuberculosis (TB) epidemics to encourage adherence to drug regimens. For example Directly Observed Treatment Short course (DOTS), a strategy recommended by the World Health Organization, has been promoted in the public health sector of South Africa to improve medication adherence in TB.6 This process entails a trained or lay health care provider or caregiver e.g. a family

member or friend issuing the patient with their medication and then observing them swallowing each dose. There is evidence that when DOTS is rigorously implemented, it helps patients adhere to their drug regimen, prevents transmission to those in their close proximity and reduces transition to multi drug resistant (MDR) TB.7 Similarly, antiretroviral (ARV) adherence efforts have in some public health care facilities included the appointment of a 'treatment partner'. Hlophe (2010)⁴ found that ARV clients in the Free State province of South Africa reported that access to a treatment partner not only improved their ARV adherence but also offered a mechanism for psychosocial support. More recently, to target integrated TB and HIV/AIDS treatment, the Western Cape Provincial Department of Health has proposed a policy framework for adherence support. This framework entails training of adherence counsellors and identification of treatment buddies.8

Scott & Pope⁹ describe lack of adherence to psychotropic medication as a serious issue that can lead to relapse, rehospitalizations, homelessness, stigmatization as well as violent episodes. Data from a large psychiatric hospital in Cape Town, South Africa indicate that re-admission within the first three months after discharge is common, and the most likely precipitant for episodes of psychosis is non-adherence, among both high and low frequency service users. 10 Therefore there should be significant interest in developing interventions to improve medication adherence in psychotic disorders. 11,12 Faroog et al¹³ developed an adherence intervention for people living with schizophrenia in Pakistan, based on DOTS for TB control in the region. This study found that training a relative or friend to act as a treatment partner was beneficial, with adherence to psychotropics improving substantially. The introduction of a treatment partner can also serve to foster social inclusion advising and dealing with issues of social and occupational integration¹⁴ while improving adherence: "There is a creative synthesis between recovery and social inclusion. Recovery both requires and allows social inclusion and social inclusion helps to promote recovery. Both are key concepts for modern consultants and psychiatric practice" (Royal College of Psychiatrists, 2009: 12).15

Despite the potential of treatment partners to strengthen adherence to psychiatric medication and foster a mechanism for social inclusion, there is also the possibility that they could compromise patient autonomy if their adherence efforts become coercive or extreme. Decisions to implement public health strategies where patient autonomy is compromised can only be justified if the public health goal is legitimate. The intervention also has to be the least restrictive means to achieve the public health goal. ¹⁶

Van Heerden, Tomlinson & Swartz report that global penetration of cell phones has reached 87%. The Mapham Reports that mobile phones in South Africa are an increasingly useful mechanism for encouraging adherence to chronic medication with over two-thirds of the adult population having access to a mobile phone. He describes a short message service (SMS) system operated by clinic staff at a health facility in Johannesburg, South Africa. Patients attending the ARV programme receive SMS reminders of clinic appointments. These reminders have reduced the loss to follow up rate of this clinic substantially.

The current study reports on formative qualitative research in

the form of focus group discussions and individual in depth interviews to inform a randomised controlled trial (RCT) of the proposed intervention. Qualitative research may be a useful process in designing and implementing complex interventions. ^{19,20} It can also facilitate in-depth exploration as well as an understanding of underlying social and contextual issues.²¹

The current study aimed to explore the feasibility and acceptability of a social inclusion intervention for improving medication adherence for people with severe mental illness in Cape Town. The proposed intervention will include adherence support for people with mental disorders and their family or elected support networks, collectively to be identified as treatment partners. Furthermore the intervention will monitor and facilitate adherence to treatment by people with severe mental disorders during the first three months after discharge from in-patient hospital care. To our knowledge, this study is unique as it proposes the incorporation of a SMS messaging system to encourage adherence to follow-up appointments.

Methods

Study site

The study site was Valkenberg hospital, a psychiatric hospital for adults located in Cape Town, South Africa. The hospital has 215 acute beds, serving a population of 1.34 million in the Western Metropolitan area of Cape Town.

Development of measuring instrument

A literature search for studies on social inclusion in relation to mental illness as well as more general studies on adherence conducted in South Africa was undertaken. The latter search mainly retrieved studies of adherence in HIV/AIDS and TB . We developed our interview guides for the different categories of participants (i.e. the caregivers and MHSU) , incorporating issues emerging from the literature search. The interview guide addressed participants' understanding of mental illness and diagnosis, adherence issues and more specific characteristics of what the treatment partner relationship and intervention should entail. We also collected clinical and demographic details from participants such as age, diagnosis and employment status. See Table 1 at the end of the manuscript.

Sampling procedure and data collection

The sample was recruited through a purposive sampling procedure for individual in depth interviews and focus group discussions (FGD). The decision to conduct a combination of individual in depth interviews and FGD is to triangulate the data. This makes several contributions to the research including generating different perspectives of the research question. ²² Lambert & Loiselle²³ indicate that a reading of the nursing literature provides three main rationale for this combination: (1) pragmatic reasons; (2) the need to compare and contrast participants' perspectives (parallel use) and (3) striving towards data completeness and or confirmation (integrated use).

Mental health service users (MHSU) who were admitted to Valkenberg with a diagnosis of schizophrenia, bipolar mood disorder and schizoaffective disorder were included in the sample. Nursing staff and the research team approached MHSUs in the pre-discharge ward or who were attending the outpatients department (OPD) at the time that the study was

being conducted . We conducted 4 focus group discussions of six to eight participants each. The first FGD consisted of caregivers (all of whom were mothers of patients with mental illness), the second of mental health service users (MHSU) attending the outpatient clinic (male and female), the third of male MHSU (pre-discharge inpatients) and the fourth of female MHSU (pre-discharge inpatients). While the participants for the caregiver FGD were recruited with the assistance of a clinical psychologist at the hospital who was familiar with this population, the MHSU participants were recruited with the assistance of nursing staff. The individual interviews were conducted with both inpatient and outpatient MHSU. Six participants were currently inpatients and four participants were outpatients. All the FGD were co-facilitated by the two first authors (SM & GS), one of whom is a medical doctor and research officer in psychiatry (GS) and the other a PhD graduate and public health researcher (SM). The in depth individual interviews for female service users were conducted by the female interviewer (SM), while the male interviewer (GS) conducted the individual interviews with male service users. A clinical psychologist assisted with the recruitment and co-facilitation of two FGDs.

Data analysis

Focus group and individual interviews were transcribed by an independent transcription service. The analysis phase followed and consisted of different stages: 1. Familiarization with the data; 2. Identifying a thematic framework; 3. Indexing; 4. Charting; 5. Mapping and interpretation. ²² Familiarization refers to the process during which the researcher becomes familiar with the transcripts of the data collected and gains an overview of the collected data.²² In the process, the researcher becomes immersed in the data by reading and re-reading the transcripts, and becomes aware of key ideas and recurrent themes which then led to a formalized coding process. The transcribed data were then coded by the first author and discussed with the research team. The transcriptions were then analysed using thematic analysis to identify categories, themes and sub-themes. The qualitative data analysis software ATLAS TI was used to manage and analyse the data.

Ethics

Informed written consent was provided by all participants. There were no consequences if a participant declined to participate. All recorded information was kept confidential. Ethical approval was obtained from the Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town (REC REF 511/2011).

Results

Table I presents demographic details (mean age, diagnosis (for mental health service users) and employment status) of the FGD participants (mental health service users and caregivers).

A number of key themes emerged from the analysis of the responses of the different groups of respondents: (1) participants' current approach to adherence; (2) participants' suggestions for essential characteristics of a treatment partner; and (3) participants' suggestions for the design of the intervention.

1) Participants' current approach to adherence.

The caregiver participants described their current approaches to encouraging adherence to psychiatric medication in their children. Five of the six participants seemed to adopt an active approach whereby they regularly reminded their children to take their medication. One mother described herself as a 'policeman' as she made sure that her son took his medication every day. Attitudes of different caregivers are encapsulated in the quotes below:

my son is not willing, but I must remind every now, you know I put the tablets next to his phone because that's the first thing he see.. (mother 1)

it's only weekends that T struggles to (take his medication), because he knows it's going to clash with his addiction, he wants to drink weekends, alcohol and I need to, to make him understand that your body's more important than whatever your social life it's very important to explain to him... (mother 2)

my son takes his meds regularly, but I put it next to his plate of food or I'll put his packet of cigarettes with it, then he has, then he knows he has to take it... (mother 3)

One participant described a contrasting experience to that of her co-participants. She explained that her son understood his illness and the importance of adherence already. She explained that a treatment partner would not be of benefit to him at all:

> since he understood that he has an illness, and since he understood that he, that he needs to take his medication to stay healthy, he has been taking his medication without fail. He would, I bought

Table I			
Category of participant	Mean Age of group	Diagnoses of individual patients	Employment status (Percentage employed)
Caregiver	53.3		57% employed
Male inpatients and outpatients.	32	65% Schizophrenia 12% Bipolar mood disorder 23%Schizoaffectivedisorder	0% employed
Female inpatients and outpatients	33.8	62% Schizophrenia 38% Bipolar mood disorder	15% employed

him a little box where he puts his medication, his, his tablets in, the amount of tablets, puts that tablets in. If he goes anywhere he takes that with him and, but then I would, if he goes, maybe sometimes he does odd jobs with my brother-in-law, my own brother, whoever, then I would ask them – please just remember to remind him to take his medication. But then they would say to me – no, by the time when I asked him, he's already taken it, so... (mother 4)

In the out-patient and in-patient FGD, service user perspectives of adherence support were also well described:

it's also my mom, since my brother tried to OD [overdose] in 2005, she's been in control of the medication um, so she puts them out and then I've just got to try and remember to take it and if she sees it there she'll come and remind me – oh you haven't taken your medication yet... (female MHSU –outpatient 1)

my Dad put a notice in the kitchen...saying have your medication, so that every time I walk past, I see it... (male MHSU outpatient 1)

my fiancé is very supportive, he checks even when I've had it, then I tell him, no look I've already taken my medication, I'm responsible enough, except for the time that I started to default, then I would pretend that I already took it and I just be in denial about this stupid medication... (female MHSU inpatient 1)

A caregiver and a male MHSU (inpatient) both described participation in a counselling group focused on adherence. The caregiver reported that her son became despondent about participating in the group as fellow members remained negative about their illness and this had made her sceptical about the concept of treatment partners in general:

my son attended the group for a long time which he enjoyed at the time, and then afterwards, he became fed up with the rest of the group. he said that it's almost like they don't want to get better, they want to stay like that and they want to complain and they want to ... and he just doesn't have time for them anymore. So I, I have to be honest about it, that is how my son felt at the time, so I don't know really... (mother 2)

A female MHSU described her participation in the group as helpful and recommended the experience for helping patients overcome barriers to adherence:

you sit as a group and then we all talk and then we say stuff and then we say staff that are very important and stuff. yes, then you tell them maybe what you, what's happening at home...(female MHSU –inpatient 1)

A male MHSU, currently an inpatient, also supported the idea of a support group to assist with adherence issues.

going to the clinic, meeting up with other mental ill patients and we sit in a group before, or between or after the discussion, I mean before or after (male MHSU-inpatient 1)...

There were participants who believed they were adequately taking responsibility for their own adherence and therefore did not require assistance from anyone. Although this view was reflected in a minority of interviews, (n= 5), it was a view that emanated from different categories of participants (i.e. inpatients and outpatients, males and females). A female MHSU (outpatient) explained:

I know that I have to take it to keep me stable. There have been times when I was much younger that I came off my medication, I thought I was better and I went into a hyper-active state um, but since then I've been fine. I've always taken my medication and you talk about a treatment partner but I'm in such a routine in my life that I actually don't need a treatment partner. I take my medication absolutely regularly and routinely... (female MHSU –outpatient 1)

2) Participants' views on treatment partners.

Participants' expectations of the qualities of a treatment partner included that they should be accessible, 'dependable', 'compassionate' and have in-depth knowledge of mental illness and of patients' needs.

A female MHSU (outpatient) reported that family members become natural treatment partners given the structure of households, where outpatients tend to reside in the same home as parents or siblings:

because family is always there, they're around you all the time, you might want to try a friend but your friend lives at their house and they're not going to necessarily phone you or sms you every day to remind you at a certain time, your family's there, they're around you...(female MHSU outpatient 2)

A male MHSU, currently an inpatient explained that as his sister is also living with mental illness, she was a great help to him. If her clinic appointments could be scheduled on the same day as his, this would help him greatly:

my sister's also at the day hospital and how I'm going to remind me, the day she's going to go, I'm going to go then... (male MHSU inpatient 2)

Others commented on the personal qualities of the treatment partner regardless of whether he or she is a family member or not:

the person must have patience, understand the illness, the one day the (patients are) difficult, one day they, they're co-operative...(mother 5)

A male MHSU attending the outpatient clinic suggested that the appointed treatment partner be someone with a mental disorder currently taking medication:

> it would be easier if it was (another patient) because then they can just have a joint medication session... (male MHSU outpatient 2)

Two participants held exceptional views and believed that a treatment partner should not be a family member. One of them was a mother who spoke of her son's relationship with an occupational therapist whose intervention he had benefitted from. She saw how this association could develop into a treatment partner relationship:

in the beginning when T started with his medication at home, then he got connected with one of the occupational therapists, I will phone her and ask her, he needs motivation and needs this, but then it comes from her and I see it helps a lot. (mother 1).

Her views were also reflected in that of a female MHSU who also felt strongly that a treatment partner should not be a family member:

my mother was helping me. trying to be controlling what you do, what you don't do, where you go, where you don't go, controlling everything. did you take your medication, take your medication – and it's like I, I am taking my medication – take your medication, I want to see, you don't take your medication alone, I want to see, I want to see... (female MHSU inpatient 2)

One caregiver participant explained that she had experienced health problems as a result of the stress of caring for her son with mental illness and therefore could benefit from contribution from a treatment partner:

I also had a nervous breakdown, I couldn't understand, I couldn't, but since I had that attitude. I developed a high blood pressure from worrying and my health deteriorated... (mother 3)

A male outpatient was sceptical of the concept of a treatment partner:

I mean I don't know what you're asking, what, like open a person's mouth and shove the pills down or what, I don't know what... (male MSHU outpatient)

3) Participants' suggestions for the design of the intervention. The interviewers discussed the mechanisms through which a treatment partner should contact the participants i.e. through SMS, notes or phone calls, and asked participants what they would find most helpful. The following quotes illustrate some current practices that participants agreed could form structure of the intervention:

my mommy writes it down, put a reminder on a phone... (male MHSU inpatient)

probably visit, that's how I would do it, visit each other's homes... (male MHSU inpatient)

In particular, there was overwhelming support for SMS text messaging as a reminder to take medication or attend follow up visits, based on accessibility and every day use of cell phones:

sms's will help yes, because you do get the message on your phone...(female MHSU outpatient)

the whole thing with medication and treatment at an out patients or any doctor, is to get it into your routine and remind, there're cell phones, there're diaries, there're lots of things that remind you of appointments ... (female MHSU outpatient)

One female MHSU, currently an outpatient said that SMS reminders to comply with medication regimen would be alongside consistency in clinic appointments. She meant that clinic appointments should always be the same day of the week so MHSU can easily remember to attend:

with regards to clinic appointments it helps that it's the same day at the same time, if it was different days then it would be less easy to remember... (female MHSU outpatient 3)

Other participants gave technical suggestions for a potential SMS intervention e.g. how often SMS reminders should be sent. Responses regarding how often the SMS reminders should be sent from once or twice a week to as regularly as twice a day (when the patients are due to take their medication) are presented below:

it depends on the patient you know, I wouldn't need it every day or every time, but maybe twice a week... (male MHSU outpatient 3)

maybe even once a week, just to come find out when he takes his medication or what, not really to be a watch dog...(male MHSU inpatient 3)

One participant, a female MHSU and currently an outpatient explained that although SMS communication could be useful, it would be important for the treatment partner to also make face to face contact:

maybe a face to face every now and then so that they can actually physically see how you're doing because you can always lie in an email, but you can't really lie face to face, if they see that you're experiencing these symptoms, obviously you haven't taken your meds...(female MHSU outpatient 3)

This view was corroborated by a male MHSU (inpatient):

(a visit to) see if you're all right, how's your, how is your health doing, are you taking your medication, did you go and fetch your pills, what does the doctor say, you know making, making him understand, giving him a conversation to talk about also... (male MHSU inpatient 4)

One participant, a female MHSU (inpatient) suggested that the treatment partner should also offer support with regard to broader social inclusion issues such as employment and relationships.

the treatment partner should ask if the patient is taking their medication) and are they having any problems with it...(they must ask) are you coping, in society, in your marriage... (female MHSU inpatient 4)

Discussion

Several themes have emerged from the triangulated data giving a contextual base as well as technical advice for the design of the intervention. Current approaches to medication adherence include an active role from caregivers (in this case all mothers) in promoting adherence. These mothers had naturally taken the role of treatment partners as they reside in the same house as their children. MHSU tend to be receptive to reminder messages from caregivers which ranged from notes to verbal face to face messages. MHSU also described the attitudes of relatives who lived in the same house who had naturally taken the role of treatment partners. While some MHSU suggested they were competent with regard to taking their medication and did not require assistance, others were comfortable with a family member supporting them. Some MHSU did not think a family member was an optimal treatment partner. There were participants who were worried that a treatment partner may become abusive or too controlling. Overall participants from the different groups supported SMS text messaging to remind them to take their medication.

The caregivers' overall experiences of caring for their adult children with mental illness are not unusual. Seltzer et al²⁴ compared coping strategies of mothers of adult children with mental illness to that of mothers of adult children with intellectual disability. They found caregivers' of children with mental illness were engaged in daily tasks including encouraging adherence. This was not an easy task considering the burden of care and their own aging process. Similarly, in our study caregivers reported that they thought that a treatment partner's help would ease the burden of care . Although a natural response to the threat of poor adherence is for family members residing in the same household to take the role of a treatment partner, there should be consideration of a separate individual (who is not a family member) taking this role. This could ultimately lessen the disproportionate burden of care on family members and improve social support and inclusion for people who use mental health services.

Characteristics of treatment partners reported by caregivers were knowledge of mental illness and of individual

users' needs, empathy and compassion. The MHSU also supported the potential contribution of a treatment partner. Generally, the feeling among participants was that a treatment partner could help facilitate better adherence.

Various views of the role of the treatment partner were proposed, ranging from reminders to take medications and to attend clinic appointments to broader contributions to social inclusion. A broader role is reminiscent of the initial treatment programmes designed by Paul Farmer and colleagues in Haiti where ARV clients received home visits from an 'accompagnateur' (treatment partner). Not only did these treatment partners provide DOT for ARV clients, they also provided moral support and listened to family concerns. Adherence to ARV treatment in Haiti has generally been strong with recipients of the 'accompagnateur' service reporting weight gain and better quality of life or functioning.

Suggestions for the design of the intervention included SMS reminders sent as often as medication needs to be taken, visits and phone calls. The overwhelming support for the mobile phone technology is also not surprising in view of the wide use of these technologies in the South African setting.⁸ Previous studies conducted in South Africa and other countries have also indicated that mobile phone technology is not only widespread²⁵ but it is also effective for dealing with psychiatric illness^{26,27} and for adherence to ARV therapy.²⁸

The issue of the possibility of treatment partners becoming too coercive in their approach to adherence is a critical one, given the danger of compromising patient autonomy. However, the approach that our caregiver participants describe where they take an active role in encouraging adherence is probably not unjustified. One mother described her worry when her son who has schizophrenia drinks alcohol excessively. In South Africa, there are high rates of substance abuse including cannabis and alcohol which could induce mental illness or worsen the progression. ²⁹ However, it is still important that individual rights are taken into account when designing public health interventions. It would be in the best interest of treatment partners and MHSU if the treatment partner respects the autonomy of the patient but does not undermine the impact of poor adherence.

There are several limitations to this study. One of the interviewers (GS) was known to some of the MHSU. The clinical psychologist who helped with recruitment of participants for two of the FGD works at Valkenberg Hospital and was also known to some of the participants. This may have biased some of the results. It was challenging for many of the MHSU to participate in the study as they find concentrating and participation difficult particularly when symptoms of severe mental illness are heightened. However, it is vital that MHSU have an opportunity to contribute to the design of interventions which could benefit them. Their participation is a step closer to contributing to social inclusion. A final limitation is that the sample of caregivers was limited to mothers of MHSU, and a wider group of caregivers is likely to have introduced additional perspectives.

Conclusion

The qualitative research conducted has provided useful information for the design of the social inclusion RCT with its focus on adherence. The recommendations for the proposed RCT and perhaps for other interventions to support

medication adherence are that: (1) the intervention should comprise regular SMS to MHSUs to remind them to take their medication and attend follow-up appointments; (2) family members are, in most instances, well placed to be treatment partners, but MHSU should be given the option to select nonfamily members if they choose to; (3) treatment partners should adopt a collaborative, non-coercive approach; (4) opportunities for building social inclusion and other social support should be sought; and (5) care should be taken to ensure that family members do not carry a disproportionate burden of care.

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