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Turkish-Speaking Service-User Experience of Guided Self-Help in an Improving Access to Psychological Therapies Service: Using Discovery Interviews to Improve Services

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Turkish-Speaking Service-User Experience of Guided Self-Help in an Improving Access to Psychological Therapies Service: Using Discovery Interviews to Improve Services

Abstract

Improving Access to Psychological Therapies (IAPT) delivers guided self-help (GSH) interventions in the United Kingdom (UK). A minority service-user group for whom we know little of their engagement with GSH are Turkish-speaking users. The study aimed to better understand Turkish-speaking service-users experience of a GSH intervention in an IAPT service and identify possible service improvements. A discovery interview method facilitated service-users to describe their experience of GSH. Transcripts were analysed thematically. Excerpts of service-user narratives and thematic commonalities across interviews were disseminated in clinical teams and informed service improvements. Participant distress was expressed through somatic complaints, a high level of confusion and inactivity. Engagement with GSH was affected by ambivalent help-seeking and sense of limited self-efficacy. Service improvements aimed to address a widespread sense of confusion and anxiety. Listening to service-user experience provides opportunities for mending communication gaps between services and ethnic minority service-users.

Keywords

IAPT, Guided Self-Help (GSH), Turkish Speaking, Ethnic Minority, Service-User Narrative, Discovery Interview

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Turkish-Speaking Service-User Experience of Guided Self-Help in an Improving Access to Psychological Therapies Service: Using Discovery Interviews to Improve Services

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Improving Access to Psychological Therapies (IAPT) delivers guided self-help (GSH) interventions in the United Kingdom (UK). A minority service-user group for whom we know little of their engagement with GSH are Turkish-speaking users. The study aimed to better understand Turkish-speaking service-users experience of a GSH intervention in an IAPT service and identify possible service improvements. A discovery interview method facilitated service-users to describe their experience of GSH. Transcripts were analysed thematically. Excerpts of service-user narratives and thematic commonalities across interviews were disseminated in clinical teams and informed service improvements. Participant distress was expressed through somatic complaints, a high level of confusion and inactivity. Engagement with GSH was affected by ambivalent help-seeking and sense of limited self-efficacy. Service improvements aimed to address a widespread sense of confusion and anxiety. Listening to service-user experience provides opportunities for mending communication gaps between services and ethnic minority service-users. Key Words: IAPT, Guided Self-Help (GSH), Turkish Speaking, Ethnic Minority, Service-User Narrative, Discovery Interview

Introduction

The introduction of stepped-care access to psychological services can alleviate discrepancies between societal demand and service availability in mental health (e.g., WHO, 2001). In the UK, the introduction of a stepped-care system such as Improving Access to Psychological Therapy (IAPT) services has been successful in this regard (Clark et al., 2009). Mild to moderate mental-health difficulties are managed with low intensity interventions, like guided self-help (GSH) delivered by trained Psychological Wellbeing Practitioners (PWP) who provide psycho-educational and cognitive-behavioural interventions in a small number of contact sessions (National IAPT, 2010; Newman, Erickson, Przeworski, & Dzusz, 2003).

The question of the effectiveness of GSH in primary care has been receiving growing attention with encouraging results (e.g., Gellatly et al., 2007; Hirai & Clum, 2006; Lucock, Kirby, & Wainwright, 2011; Mead et al., 2005; Willemse, Smit, Cuijpers, & Tiemens, 2004;

Williams et al, 2013). Nonetheless, the GSH literature addressing the experience of ethnic minority service-users is in its infancy (e.g., Ünlü et al., 2013). The majority of GSH studies are conducted with English-speaking service-users (i.e., Gellatly et al., 2007), although GSH is also offered to ethnic minority groups (i.e., IAPT, 2009).

Individuals from ethnic minority communities often experience barriers in accessing mental health services (e.g., Dixon-Woods, Booth, & Sutton, 2007; Dixon-Woods et al., 2005; Lamb, Bower, Rogers, Dowrick, & Gask, 2011). Difficulties may arise because services are not available or because the interaction with services deters or diverts help-seeking to ineffective methods (Gask et al., 2012). Understanding the journey of Black and Minority Ethnic (BME) populations in accessing and receiving GSH is important since individuals from differing ethnic and cultural backgrounds could approach mental health services in a dissimilar way and may express distress differently (Molewyk, Landheer, DeGroot, & Warpinski, 2013).

In a qualitative meta-synthesis focusing on “hard to reach” service-user groups, Lamb et al. (2011) concluded that utilisation of services could be affected by many factors including differences in the choice of language for describing mental health problems, practical difficulties in accessing services, different world-views held by users and services or due to the provision of interventions that do not account for one’s culture. Gask et al. (2012) call for services to modify existing interventions to make them more acceptable to poorly served populations such as ethnic minorities.

The UK National Health Service (NHS) has recognised the importance of involving service-users in the redesigning of health-care services (Barnes & Wistow, 1994; Department of Health, 2000; NHS Modernisation Agency, 2004; Robert, Hardacre, Locock, Bate & Glasby, 2003; Wistow & Barnes, 1993). In an extension of this approach, the NHS had introduced an Experience Based Design (EBD) to support a user-informed restructure of healthcare services (Bate & Robert, 2006). This process had the aim of revealing emotive junctures within a service, explore service functionality, and communicate users’ understanding of key treatment moments to service stakeholders and front-line staff (Gage & Kolari, 2002; Greenhalgh, Russell, & Swinglehurst, 2005).

One method used to gain access to service-user narratives is discovery interview—a non-directive, qualitative interview method that aims to help health-care teams understand the experience of receiving care within their service (Bridges, Gray, Box, & Machin, 2008; CHD Collaborative, 2005). This method is usually implemented alongside a series of “Plan-Do-Study-Act” (PDSA) cycles which facilitate the implementation of small, easily evaluated changes by front-line teams (CHD Collaborative, 2005; NHS Modernisation Agency, 2004). Discovery interviews can alter unhelpful staff attitudes and inspire service changes from within (Brown, Griffiths, Wright, Waldmann, & Edwards, 2004; Matrix Consultancy, 2005; Wilcock, Brown, Bateson, Carver, & Machin, 2003). Although this method has mainly been introduced in physical healthcare research (e.g., Bridges & Nugus, 2009; Dawood & Gallini, 2010; Goodman et al., 2009), there is opportunity to be implemented in mental health where the voice of the user is often under-represented (Barnes & Shardlow, 1997; Barnes & Wistow, 1994).

Present Study

There is little research on Turkish-speaking service-users’ experience of GSH interventions despite widespread immigration of Turkish-speaking communities. Turkish-speaking groups (e.g., Turkish, Turkish-Cypriot and Turkish-Kurdish) who immigrated to the UK have primarily congregated around London and specifically in the North and North East London (Yilmaz, 2005).

Research looking at Turkish-speaking immigrants detected a high lifetime risk of depression for women (81%) and men (45%) indicating a need for mental-health service

utilisation (Cicek, 1990). Nevertheless, studies focusing on Turkish-speaking communities in European countries identify factors that could adversely affect successful utilisation of mental health interventions. These include expressed mistrust towards Western medical illness explanations (Bäärnhielm & Ekblad, 2000), an emphasis on communicating distress through bodily symptoms and cultural expectations that could impair the development of collaborative therapeutic relationships (Renner & Berry, 2011; Yazar & Littlewood, 2001). Ünlü et al. (2013) conducted a randomized controlled trial offering internet-based GSH to Turkish migrants in the Netherlands. Their study observed high attrition rates (62% at follow-up) and no significant differences between the experimental and control groups on post-intervention depressive symptoms.

This study implemented discovery interview methodology to understand Turkish-speaking service-users' experience of a GSH intervention. It was conducted in an IAPT service based in a North London borough which has a large percentage (65.3%) of BME groups (Office for National Statistics, 2013). This service has been successful in attracting clients from Turkish-speaking communities, accounting for 16% of referrals. An initiative to explore Turkish-speaking service-users' experience surfaced due to an increase of in-service discussions addressing the question of adapting GSH for this service-user group.

It was important to listen to this group's narrative of their experience of GSH and consider whether and how to adapt service provision. To our knowledge, no qualitative research has examined Turkish-speaking service-users' experience of brief GSH. We assumed an experience-based design and used a discovery interview methodology analysed thematically to arrive at suggestions for service improvements. The aims were consistent with UK's Department of Health's mandate of involving users in services (2000) and NHS' Modernisation agency (2004) initiative of using patient-led discovery interviews to shape services.

Method

Self of the Researcher

The authors of this article were all women, colleagues, employed by the Haringey IAPT service at the time. The first and second authors were counselling psychologists and accredited CBT therapists, both with a White Other minority background. The third and fourth authors were employed as PWP practitioners, were Turkish speaking, and had a Turkish or Turkish-Cypriot heritage. The primary initiative for the project came through an NHS directive for involving service users in redesigning services. The second author had emphasized the importance of introducing the discovery interview project for Turkish speaking service user since she had noticed increased referrals from this service user group. The first author took the lead in organizing the project and during the analysis stage since she had an expressed interest in qualitative methodologies. The third and fourth authors mentioned a special interest due to the project being specifically related to their therapeutic work and cultural heritage. They were both involved in the process of planning the interviews, interviewing service users, transcribing and translating and at the analysis stage. Care was taken that the third and fourth authors did not interview patients that they had previously worked in a therapeutic capacity with.

Participant Recruitment

We identified Turkish-speaking service-users (Kurdish and Turkish) who attended two or more sessions of GSH ($N=34$; male $n=4$; female $n=30$) between October 2010 to February 2011 by searching service records and invited them to participate in the interview process. We sent a letter, written in both English and Turkish, to all eligible service-users asking them to

“talk about their experience of GSH in the IAPT service.” The third and fourth authors followed-up the letter with a telephone-call in the Turkish language. The combined written and telephone recruitment aimed to increase equity and accessibility.

Seven Turkish-speaking ex-service-users initially agreed to participate in the interview process and one withdrew due to their time constraints at a later stage. All of the participants were Turkish-speaking and only one was bilingual. All but one had a Turkish-speaking PWP whilst receiving face-to-face GSH.

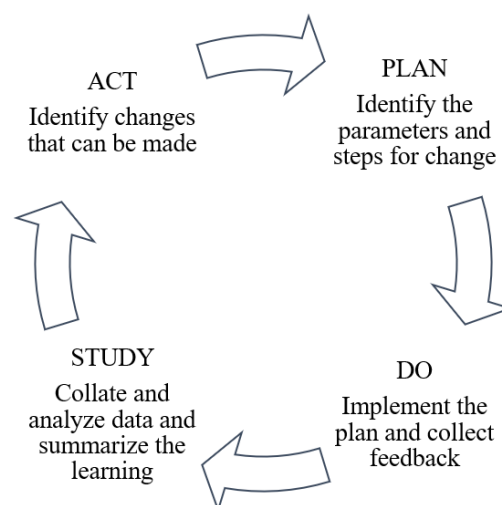
Five of the participants identified themselves as female and one as male, with a mean age of 44 years old ($sd=10,3$). All the participants were identified as having symptoms of either depression or anxiety or a mixture of both diagnoses. All, but one participant, said that they had only had one previous contact with the service. Four out of the six participants had completed the GSH intervention and were either referred on for a further psychological intervention (three cases) or were discharged (one case). Two participants had dropped out of the GSH intervention after having completed at least half of the available sessions (minimum three out of six). The workers that provided GSH for all six participants were either qualified PWPs or in training for this qualification and were supervised by an accredited CBT therapist who had completed IAPT training in PWP supervision.

Confidentiality and consent considerations were outlined in the recruitment letter, discussed over the telephone and at the beginning of the interview. All the participants consented to participation. The project had approval within the ethical guidelines of the Experience Based Design (Baxter; 2010).

Data Collection

We implemented a discovery interview methodology. This involved applying a four-step PDSA cycle (Figure I); collecting the service-users' narratives through semi-structured interviews, communicating and summarising emergent learning, and identifying areas for improvement and implementing changes (NHS Modernisation Agency, 2004). Using the PDSA cycle was a fitting choice since this method provided the avenue for communicating service-user experience to the whole service and facilitate the possibility of change. We aimed to interview six service-users as recommended by the Discovery Interview methodology (One thousand lives plus, 2012).

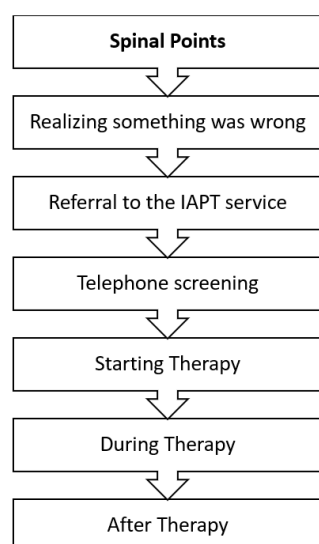
Figure I. Cyclical process of discovery interviews



Note. Adapted from NHS Modernisation Agency, (2004). A guide to using Discovery Interviews to improve care.

Six spinal points were developed to provide rudimentary structure to the discovery interviews. The spinal points represented six key treatment stages that participants would be called upon to discuss during the interview process. The interviewer would present the spinal points to the interviewee both verbally and in written form (presented on cards placed before him) and asked to comment on any points they wanted and, in any order, they preferred. The spinal points were developed in clinical team discussions where all team members participated and represented typical phases through treatment within the service (Figure II).

Figure II. Spinal points in order of presentation



All the interviews were conducted in a quiet, private room in local libraries. Participants were asked to talk freely about their experience using the spinal points as a reference; no pre-set questions were used. Where participants struggled with the non-directive, open format of the interview method, interviewers provided gentle prompting or clarification of a spinal point. For instance, if clarification was needed for the spinal point “realizing something was wrong,” the interviewer would say, “Tell me about what was happening at the time you decided to contact the service.” Further prompting would include phrases such as “tell me more” and “I’d like to understand this better.” The mean interview length was 30 minutes (minimum 20, maximum 50 per interview).

All participants chose to have their interviews in Turkish, their mother tongue. Interviews were transcribed initially in the Turkish language directly from the original audio recordings by the researcher who conducted the interview to maintain contextual information (e.g., pauses, intonation). Transcribing was conducted based on Braun and Clarke’s (2006) guidelines and hence we aimed for a verbatim account of verbal and non-verbal utterances. Translation into English was then conducted as per Birbili’s (2000) recommendation for translating interviews, that is, the researcher who conducted the interview translated word for word while using consultations from the other bilingual researchers and other members of their community. Regular supervision sessions with the whole research team assured that the translated transcripts were reviewed and difficulties with translation resolved.

Analysis

The discovery interview approach does not prescribe the use of a specific qualitative analysis method for approaching interview data; rather the focus is on communicating patient

narratives to clinical teams to inspire service improvements (Ali & Gray, 2006). We proceeded under the assumption that we could achieve a better understanding of service users' experience by a rigorous examination of transcripts and that communicating this material to the service would highlight areas for service improvement. Given the size of the service (approximately 80 clinicians), it was decided to organise the narratives by identifying thematic commonalities and recurrent patterns in the data.

We chose to disseminate all the interview excerpts identified as related to each theme in clinical team meetings. Excerpts reflected participant stories per theme and in some cases cut across several themes. Care was taken that we presented lengthy excerpts from all the interviews. We believed that employing this level of analysis would facilitate communicating service-user feedback to a greater audience and would result in a more productive discussion around areas for service improvement.

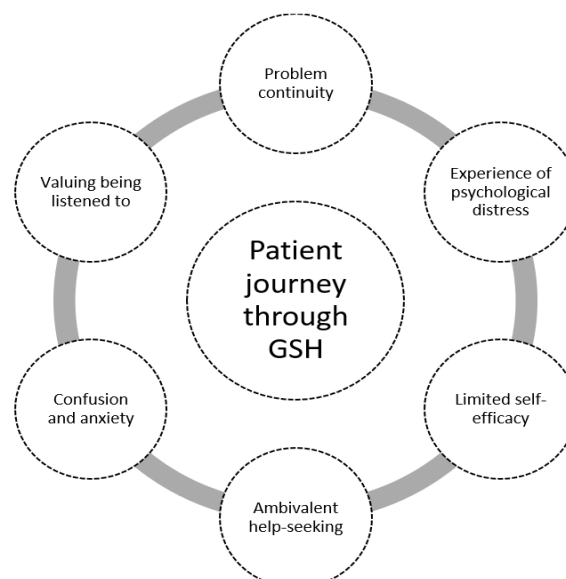
Based on recommendations from literature (Bridges & Nugus, 2009; Goodman et al., 2009), we used thematic analysis as described by Braun and Clarke (2006). This involved generating codes from the narratives and collating them into initial sub-themes/categories and overarching themes. Consistent with disseminating the voice of the service-user (cf. discovery interview), we coded all the narratives at a semantic level and in an inductive way letting commonalities in the data (rather than our original spinal points) guide the coding (Frith & Gleeson, 2004).

Each interview was coded manually by at least two researchers. To facilitate trustworthiness during analysis, one of the two researchers coding the transcripts was the person who conducted the interview and could provide personal reflections of the interview process (cf. Shenton, 2004). The key themes were refined by the first author who reviewed all the interviews; they were then finalised collectively.

Results

The analysis resulted in six key themes (see Figure 3): (1) Service-users' experience of distress; (2) Ambivalent help-seeking; (3) Valuing being listened to; (4) Limited self-efficacy; (5) Confusion and anxiety in the service; (6) Problem continuity. Despite presenting participants with linear spinal points, stories emerged in a disjointed manner with emphasis given to key memorable and emotive experiences.

Figure III. Six key themes



Service-Users' Experience of Distress

This theme reflected a compilation of psychological and physical experiences through which participants described their distress. Components of service-users' experience of distress are reflected under the sub-themes of *psychological distress* and *somatic complaints*.

Psychological distress. It was largely represented as an on-going emotional turmoil. Most associated their emotional "ups and downs" with having a "full head" or overthinking problems and their sleep being badly affected. Participants described "thinking too much" as beyond their control and taking over daily life as shown in the following excerpt:

"...err...I did not feel well, couldn't sleep, hang on to lots of things in my head, used to hang on to them a lot..." (Binnaz)

In addition to overthinking, four participants complained of forgetfulness and of an inability to retain information.

"I am forgetful a lot, memory weakness, I can't remember people; I don't trust myself to go out... because of this..." (Ceyda)

As shown in the previous excerpt, memory problems often triggered practical life challenges and were thought to result in limitations in one's independence.

Somatic complaints. This subtheme was also heavily emphasized. Most participants talked about "giving up" on daily activities and mainly attributed this to physical distress and pain.

"...I only have health problems. I feel tired, like pains, like I have pains in my body, I want to lie down all the time" (Binnaz)

Somatic complaints were often portrayed as the main cause for deterioration of one's mental health as shown in the previous excerpt. A commonality observed across narratives was presenting distress as an all-encompassing and debilitating state. Even when participants made references to symptoms of a more cognitive nature (e.g., overthinking and memory loss), these were often presented as a part of a systemic bodily collapse without a clear distinction between emotional and bodily distress. This sweeping experience of distress seemed to contribute to a persistent sense of helplessness and powerlessness.

Ambivalent Help-Seeking

This theme captured participants decision making process regarding seeking support and their subsequent reluctance in seeking help from a psychological therapies service or their social environment.

Mixed feelings about seeking psychological support. Four of the interviewees expressed such confusion. They doubted they would experience any benefits, whilst still apparently entertaining some hope. For the majority, the catalyst for being referred were steps taken by a family member or their general practitioner (GP), as shown in the following excerpt:

"I have a daughter; she is 25-26 years old. She was pressuring me, asking me to go to a doctor, for me to get treatment. I didn't want to go but she had already booked an appointment on behalf of me." (Ceyda)

Privacy and isolation. The hesitation regarding help-seeking, shown in the previous excerpt, often contained a tendency towards isolation to protect one's privacy in view of a cultural stigma surrounding mental health problems—this was also true when it came to discussing problems during their initial engagement with the service (e.g., IAPT telephone triage session).

"I mean it was just, on the phone it felt very wrong." ... "At the time I had lost my brother. Why do you want to be seen? What are your problems? What is this what is that? A man had asked me all this and I had told him that I was tired of coping with all these things, tired of being strong. It gets to a stage where you feel overwhelmed. Erm but the consultation over the phone did not feel right for me. At the time it felt like they were not taking me seriously." (Leyla).

This excerpt illustrates the difficulty of asking for help (especially through the phone) and specifically the task of balancing the need for *privacy* and the *detachment resulting from isolation*. A similar help-seeking indecision emerged when it came to discussing problems with relatives or friends.

"I mean I told the therapist that the reason I was here was because I didn't talk to others, didn't want to talk to others, if I were to, then maybe. But I'm just not that kind of a person to talk about my problems with people that I know. I don't want people to know." (Afet)

Giving up. Help-seeking ambivalence related to feelings of guilt and shame that reinforced social withdrawal. The decision to seek support was also connected to a pervasive sense of powerlessness that emerged throughout the narratives. This is illustrated in the following excerpt where Emine talks about the period before seeking help:

"My mood was low, I didn't want to open the door to any friends, I didn't want to see anyone; I just wanted to stay inside. I would say I don't want anyone to come around. I think to myself. I go into the garden to sit, I smoke my cigarette." (Emine)

Valuing Being Listened

This theme reflects interviewees satisfaction when effort was made to understand them or accommodate their needs within the service. It is likely that this theme communicates a need to be reminded that they have some control over their life and are not enmeshed with the persona of the "sick" person.

Accommodating requests. This subtheme reflects examples of apparently meaningful requests that were fulfilled by the services such as providing them with a Turkish-speaking PWP and facilitating flexible appointment times.

"When I first started seeing someone at my Doctor's surgery, there was an interpreter who worked there who did the interpreting for me. I told my doctor that I preferred to speak to someone in Turkish, someone Turkish." (Emine)

The above excerpt emphasizes the importance of serving a need to relate to a person from the same culture who is expected to truly listen and understand from the perspective of one's own language and culture.

Talking. Once engaged in GSH, most patients developed positive views about discussing their problems. Talking was presented as means of receiving a sense of relief and the PWP was often described as a supportive, interested listener.

“...when I spoke, when I opened up, I felt like...felt relieved, I felt like there is someone next to me.... That’s how I felt.” (Binnaz)

The importance ascribed to communicating and being truly listened to, as shown in the previous excerpt, was also emphasised by one participant who felt this was lacking. For this interviewee the pre-prepared self-help material became a barrier to feeling individually attended to.

“...she had pre-prepared things which she had to apply to every patient. Like this was something which could be applied to everyone, pre-prepared things.” (Afet)

Afet’s experience emphasizes a fine line between delivering structured GSH and cultivating a supportive therapeutic relationship that carefully considers service-users individuality and cultural characteristics. Allocating sufficient time to develop a therapeutic relationship may be particularly important for this service-user group given their difficulties with ambivalent help-seeking.

Limited Self-Efficacy

This theme encompasses interviewees’ experience and implementation of the self-help element of the intervention as well as their view of their and PWP’s role.

Difficulties with independent action. Interviewees described their PWP asking them to engage in new behaviours. Most said that they had routine-related barriers or increased distress and that, although some effort was made, results were often inconsistent.

“I was telling her that even these small things could make me very happy, but I haven’t got the time to do it and I am very stressed. But even after this, she was still trying to get me to keep a diary... For example, did you have the time to dye your hair today?” (Afet)

In the previous excerpt, the interviewee is recognising the value of behavioural activation and at the same time identifies barriers with the process. She appears to be describing her PWP’s stance as non-understanding.

Behavioural Changes. Nevertheless, three interviewees talked about benefiting from increases in their activity and were able to provide examples of change.

“I go out now, I don’t stay at home. Even if my husband is at home, I don’t stay at home. I give myself to my school, I go there, and Sundays I visit friends.” (Binnaz)

“I mean it is because of this that today I am dressed and have my hair dyed ... I’ve started cooking for my children, because I had given up everything. That is why it was helpful for me.” (Leyla)

The above excerpts indicate that although behavioural changes were not presented as the final step in interviewees’ recovery journey, some spoke about them in a positive light. Given the

fact that many referred to difficulties in independently pursuing changes, it seemed that completion of behavioural steps may largely depend on whether tasks can be meaningfully incorporated into one's daily life.

Hands-on-support. In addition, all the participants talked about the importance of receiving intense practical help from their PWP. They reported wanting their PWP to give them specific advice on how to act and what to do.

"... I would have wanted them to give me more information, like when you go to a doctor and they say drink this, do this, eat this, don't eat that. So, I wanted more information in that way, for psychological, for support. I wanted them to support me like that, to help me". (Binnaz)

Arguably the educative-practical approach requested, apparent in Binnaz's excerpt, is what one would expect within GSH, however there seemed to be a conflict between requesting more instruction from the PWP and scarcely implementing it. Self-reliance in the process of recovery seemed limited and improvement was presented as contingent on input from one's worker. Interviewees seemed to share a belief that their PWP had authority to deal with most requests but that this was not always happening—this arguably could have triggered a sense of unspoken dissatisfaction. This finding could reflect an expectation that their PWP would prescribe solutions from a position of authority. It is likely that in this framework, the meaning of guided "self-help" may be side-lined in service-users' expectations.

Confusion and Anxiety in the Service

This theme reflected prominent emotions that included procedural confusion and anxiety.

Lack of clarify. The interviewees described uncertainty when it came to procedural touch-points such as the referral stage, the waiting periods, being stepped-up for high intensity therapy and being discharged.

"The GP had not told me that he was going to refer me to IAPT or given any names. I didn't know whether I was being referred to you or to another." (Afet)

As the previous excerpt shows, two patients talked about not being clear which healthcare service they were being referred to. Some participants also seemed unclear on the "length of the waiting period for GSH" and for "being stepped up for high intensity work"; this often led to worry and expressed feelings of apprehension as shown in the following passage by Leyla.

"Yes, where I am, how long it will take? I don't even know if I am on that waiting list!" (Leyla)

Feeling abandoned at discharge. Other interviewees reported feeling abandoned after being discharged mainly due to the service not following through with promised post-discharge referrals.

"The other lady said, 'I will look around for schools for you,' and then my case was de-activated. I don't know really." (Ali)

The disappointment echoed in Alis's case reflects an experience of *miscommunication* between Turkish-speaking service-users and the service. Indeed, this was presented alongside strong

emotions in narratives implying a mismatch in the way information was shared between Turkish-speaking service-users and the service.

Difficulties with remembering. Patient confusion was not limited to procedural elements. Interviewees also reported not recalling what was covered in their sessions. Most participants did not describe what their GSH sessions involved and made few mentions of specific interventions.

Participant: "How can I say....err...? I couldn't go anywhere socially, it was a change for me, also they showed those things.... hmmm....it was like an exercise, it was for 'sleep.'"

Interviewer: "So... they showed exercise for sleep?"

Participant: "Yes... they said some stuff, but now... now I can't really remember what they showed...." (Ceyda)

The recall difficulties, reflected in Ceyda's excerpt, may indicate low priority ascribed to the "self-help" element within the intervention or poor understanding of its content. It is conceivable that the PWP was viewed as the primary agent for change and therefore little effort was made to retain information.

Problem Continuity

This theme refers to the way participants spoke about their mental health problems and specifically the fact that they either used the present tense or specified that problems remain.

"As it finished, I mean in those 6 sessions I had made good progress but that has stopped now. I'm stuck where it finished. And sometimes it gets really bad; I mean I still get ups and downs. And I do want more because I'm going through a difficult time. It's very difficult. Like before, I am still stuck in the past." (Leyla)

"I wanted more support, now there wasn't much time. I mean they have only given limited time...." (Binnaz)

As both the above excerpts indicate, participants seemed to expect "something more" from GSH with most perceiving the intervention as too brief and communicating that something had remained unfinished.

Staff Reflections on Patient Narratives

Themes and supporting excerpts were presented to the whole service and to smaller staff meetings. Having listened to excerpts of patient narratives, the staff felt that issues raised were clinically important and accessible for change.

The discussions attempted to grasp the patient journey and explore staff's emotional reaction to topics raised. The focus of this process, consistent with discovery interview methodology, was to brainstorm possible improvements to service provision to this service-user group. The resulting ideas were kept specific and measurable to facilitate further evaluation within PDSA cycles over time. Indicative ideas that were put forward by staff members and ultimately implemented included, the creation and provision of psycho-educational material in Turkish explaining the link between physical and psychological (emotional) difficulties, the formation of group GSH interventions facilitated in Turkish for

long-term conditions (including pain, musculoskeletal problems), the provision of all communication in oral and written form in both English and Turkish and the creation of brief, informational leaflets in Turkish on IAPT and GSH to reduce uncertainty at the referral and ending stage. A review of progress for each step was planned at six months. All six participants were sent a letter summarising the action points requesting their feedback.

Discussion

The experience of BME service-users who receive GSH is currently under-explored and services are uncertain of how these user groups respond to the intervention. This project used a patient-based design to explore Turkish-speaking service-users' experience of GSH in a London-based IAPT service and communicate their narratives to staff members facilitating service improvements.

Six key themes were derived that highlighted participants' experience. The themes can be conceptualised as part of a narrative with a central, overarching structure, "My journey through GSH." Turkish-speaking service-users talked about their *experience of distress* highlighting emotional and cognitive difficulties within a context of physical symptoms (i.e., memory problems, physical pain). Participant descriptions were consistent with those of other ethnic minority groups for whom "thinking too much" and having painful physical symptoms also took centre stage (Muhwezi, Okello, Neema, & Musisi, 2008; Okello & Ekblad, 2006). Indeed, certain communities may be more accepting of physical expressions of distress, with bodily complaints attracting more community support (Arkar & Eker, 1994). In the case of the Turkish-speaking communities, Yazar and Littlewood (2001) suggest that bodily symptoms are culturally accepted as a medium for voicing emotional turmoil and explaining why they featured strongly in participant narratives. This observation has clinical implications for GSH services, suggesting that PWPs need to be aware of the central role of bodily distress in Turkish-speaking service-users' understanding of their difficulties whilst sensitively pursuing evidence-based interventions.

Participants experienced *ambivalence* when it came to disclosing difficulties and seeking help from services, friends, or family. It was suggested that experiencing psychological distress was stigmatising and shameful. Although, similar concerns are generally reported from users of mental health services (e.g., Gask, Rogers, Oliver, May, & Roland 2003) and particularly in BME populations (Lamb et al., 2011), our narratives revealed that Turkish-speaking service-users may be inclined to isolate themselves and conceal their emotional distress. Consistently, in a study interviewing Turkish migrant women, participants emphasized physical complaints as a way of protesting against being labelled "mentally ill," a term that was loaded with a sense of shame and loss of control (Bäärnhielm & Ekblad, 2000). In view of these barriers, it was not surprising that our participants emphasized being listened to and their needs being accommodated by their PWPs. It is likely that being listened to provides a sense of empowerment and assures that one is not out of control. In a qualitative meta-analysis of interviews with hard to reach groups, Lamb et al. (2011) concluded that being listened to can be a powerful way to validate and normalise one's experience and open to receiving support. The importance of being listened to may further explain the high drop-out observed in an internet-based GSH intervention for this group (Ünlü et al., 2013).

Participants spoke of difficulties in completing self-help tasks and implementing activities as suggested by their PWP. Where recommendations were followed by some, these were positively evaluated and involved rediscovering previously enjoyed activities. In a qualitative meta-analysis examining self-help, Khan, Bower, and Rogers (2007) observed that self-help was deemed beneficial when patients continued with activities they had previously found helpful. Nevertheless, there seemed to be tension in the narratives between participants

seemingly requesting additional practical assistance and struggling to implement self-help steps. Similarly, Khan et al. (2007) reported that service-users described self-help as “hard work” and followed recommendations in an eclectic way. In the case of Turkish-speaking service-users, there also seemed to be an expectation for one’s worker to act as an “expert,” a prospect of being “healed” by someone in authority. Interestingly, in a study evaluating the effectiveness of a self-help group for Turkish speaking users, Renner and Berry (2011) recommended that workers take on the role of an expert when working with this group. Arguably, this role may be at odds with the more collaborative, coach like stance of a PWP suggesting that community-level psychoeducational interventions may be helpful.

The intervention did not appear to fully meet participant needs as seen through expressed emotions of confusion and anxiety as well as their discourse of problem continuity. Confusion and anxiety emerged while service-users spoke of uncertainty regarding waiting periods, referral, and discharge processes. Indeed, there was an agreement in team discussions that the narratives indicated dissonance problems between Turkish-speaking service-users and their workers. Given that most interviewees had a Turkish speaking PWP, communication problems appear to extend beyond a language barrier. Lamb et al. (2011) also observed dissonance problems with other “hard to reach” groups and suggested that miscommunications may arise due to service-user difficulty with adapting to professional models of ill health and service procedures. In a set of recommendations for improving access to vulnerable groups, Dixon-Woods et al. (2005) also identified cultural dissonance as a barrier to effective use of services and suggested that this occurs when healthcare organisations hold on to established healthcare cultural norms and expect users to adapt.

Strengths and Limitations

To our knowledge this is the first study to implement a discovery interview methodology to explore the experience of Turkish-speaking services users receiving a GSH intervention. The project benefited from offering the interviews in participants’ native language and therefore prevented challenges that could arise from the use of interpreters (Ali & Gray, 2006). In addition, having Turkish-speaking researchers in our team ascertained good quality translation of transcripts whilst maintaining the cultural integrity of the narratives. An important advantage was that the project had support from key service stakeholders who were willing to cascade service-user stories in the whole service and facilitate service improvements.

In terms of study limitations, five out of six participants were female. Furthermore, three out of the six participants had either requested a re-referral or were waiting for another psychological intervention and it is likely that this affected their willingness to participate. The non-directive format of the interviews seemed challenging for some participants and this may explain a shorter interview length on some occasions. Similar difficulties in using discovery interviews with ethnic minority patients were reported by Ali and Gray (2006). In fact, participants’ difficulty with the non-directive format is paralleled in their preference for a directive format in their GSH sessions.

Conclusion

The narratives indicated a need for developing a definition of GSH and of the role of a PWP to be used with Turkish-speaking service-users. This could also address the ambiguity surrounding the issue of who is expected to be the agent of change. Equally, there seemed to be a need for frequent and clear information sharing at all stages; this includes repeating information, encouraging service-users to ask questions, and getting service-users to repeat information to ensure understanding.

Discussions within the clinical teams and in previous literature (e.g., Lamb et al., 2011) suggest that some of the themes (e.g., confusion, anxiety and limited self-efficacy) might be reflective of other BME users, though further research would be needed before we could extrapolate the findings. Indeed, it would be beneficial if future projects invited service-users from other cultural groups to talk about their experience of GSH to explore cross-cultural similarities or differences in the narratives.

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