

Research paper

LIVING WITH GUILLAIN-BARRÉ SYNDROME

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Abstract. The potential long-term symptoms associated with Guillain-Barré syndrome (GBS) have been made evident in various studies. The purpose of the current investigation was to explore the meaning of living with GBS in a Maltese community setting following discharge from hospital. The study adopted a Heideggerian phenomenological approach. Four Maltese female participants were identified through purposive sampling, two to four years following their diagnosis. The women had all been treated in the Intensive Therapy Unit (ITU) of a Maltese general hospital at the acute stage of their illness. They were interviewed twice in their own environments. Data analysis led to the identification of three super-ordinate themes, namely Lost at Sea, Propelled into Change and The Aftermath. Participants spoke about the long-term symptoms related to GBS which left them feeling worn out most of the time. Subsequently, they were induced to delegate strenuous everyday roles to others, typically close family members. Participants highlighted a feeling of indebtedness towards their relatives, although at times they also felt ‘suffocated’ due to being over-protected. The women were very grateful for the professional care they received as hospital in-patients. However, when back in the community they felt that health care professionals failed to empathise with their needs. Participants described GBS as a “shot out of the blue” that totally transformed their lives. Although GBS changed their outlook on life, they never gave up hope of having a better future. However, in trying to re-integrate themselves in society, they were faced with various environmental obstacles and ‘human barriers’ that led them to social isolation. A key recommendation of the study is the need for an effective discharge planning programme intended to help these patients make a smooth transition as they return back to the community.

Keywords: Guillain-Barré syndrome, lived experience, phenomenology, hermeneutics, community, intensive care

1 Introduction

Guillain-Barré syndrome (GBS) is an infective disorder of the nervous system involving the spinal roots, peripheral nerves and, occasionally, the cranial nerves (Bokhari & Zahid, 2010). In about two-thirds of affected patients, the presence of a preceding acute viral or bacterial illness is reported one to three weeks prior to onset (Atkinson et al., 2006). A definitive cause of GBS has still not been identified. The treatment options available, namely intravenous steroids, immunotherapy, plasma exchange and cerebrospinal fluid filtration, solely aim to decrease the duration and severity of the disease (Haldem & Zulkosky, 2005). While treatment may prove to be effective, it does not exclude the patient from requiring months or even years of rehabilitation (Haldem & Zulkosky, 2005). GBS affects around two persons in every 100,000 annually (Lugg, 2010; Sulston 2001), with literature even quoting figures of up to four persons per 100,000 annually (Akbarayam et al., 2011). In Malta, a total of 54 patients have been admitted to the state general hospital with GBS between 2012 and 2015 (S. Distefano 2016, personal communication, 6th June).

The suffering endured by patients diagnosed with GBS goes beyond the acute phase. Forsberg, Ahlstrom and Holmqvist (2008) report that during the acute stage of the illness, patients with GBS were already informed of possible long-term effects by their physicians. Fatigue has been cited as one of the most common and distressing long-term effects of GBS (Drory et al., 2012; Garssen, Koningsveld & Van Doorn., 2006). The physical symptoms also impact other aspects of life, particularly social activities. For example, following GBS, patients have had to temporarily suspend or end their job (Bersano et al., 2006; Bernsen et al., 2005).

The presence of psychological illness has also been associated with living with GBS, with Haldeman and Zulkosky (2005), Kogos et al. (2005) and Gregory (2003) reporting depression. Post-traumatic stress disorder, as well as living in constant fear of possible recurrence, has also emerged in the literature (Bernsen et al., 2002; Chemtob & Herriott, 1994). Additionally, Bernsen et al. (2002) reported patients to suffer from emotional instability, as well as concentration and/or memory disturbances.

While the research literature has described a number of long-term effects of GBS, there seems to be a lack of documentation related to individuals’ experiences of living

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with GBS in the community. Here, the term ‘community’ implies independent living at home. The present study aimed to gain insight on what living with GBS in a Maltese community setting actually means to affected individuals.

2 Methods

2.1 Design

A qualitative design using the Heideggerian hermeneutic phenomenological approach was used. Hermeneutic phenomenology was considered as an ideal approach for this study as it addresses the intricacies of individual experiences (Robertson-Malt, 1999). Heideggerian phenomenology is based on the premise that an in-depth understanding of a person cannot take place unless the person’s world is also considered. Therefore, it adopts a ‘being-in-the-world’ approach to enquiry (Walters, 1995), with its fundamental aim being to gain an understanding of the meaning of Being.

2.2 Participants

A homogenous purposive sample of four Maltese female participants was recruited for the study. Pseudonyms were given: Mary, Grace, Joyce and Rita. Due to the fact that a purposive sampling method was adopted and participants meeting the inclusion criteria were limited, it was coincidental that all participants were female. All women were married with children. Mary and Joyce were employed whilst Joyce and Rita were full-time housewives. This sample size was considered as being appropriate as it allowed for an in-depth view into the participants’ experiences (Smith, Flowers & Larkin, 2010). The study’s inclusion criteria required the participants to be Maltese speakers who may have been making use of hospital out-patient services but were not being treated as in-patients. Other criteria were previous admission to the Intensive Therapy Unit of a general acute hospital and living in the community at the time of data collection. The participants were aged between 44 and 68 years and had been admitted to ITU with GBS between 2009 and 2011. Their involvement in the study took place two to four years following their diagnosis.

2.3 Procedure

Each participant was interviewed twice by the first author. All interviews were held in Maltese and took place in locations chosen by the participants. An intermediary period of six weeks between the first and second interview was used to listen and re-listen to the audio-recordings and transcribe them. Transcripts were also read over and re-read. Following this, a new set of questions for each participant was prepared to address issues that were felt to require clarification or further discussion. In fact, new concepts emerged from the second interview. All interviews were audio-recorded with the participants’ consent.

2.4 Ethical considerations

Ethical approval to carry out the study was granted by the University of Malta Research Ethics Committee. Potential participants were identified via the ITU patient database of a Maltese state general hospital by a proxy, who was a senior ITU nurse. The proxy passed on an information letter to the potential participants that provided details regarding the nature of the study and time requirements. The letter also stated that participants had the right to withdraw from the study at any point. Those persons who expressed their willingness to participate were then contacted by the first author and each individual was provided with an opportunity to clarify any queries. Those individuals who expressed their willingness to proceed were then asked to sign a consent form.

2.5 Data analysis

The interviews were transcribed and analysed by the first author using Van Manen’s (1990) approach. Accordingly, the first and second analytic stages included the reading and re-reading of the transcripts several times to allow immersion in the data. During the third stage, transcripts were re-read to identify emergent themes and distinguish them from the non-essential themes. A story for each participant was then written, in order to bring out the essential aspects of their experiences. This was followed by a joint review by all authors, together with agreement on a final set of themes. Following an in-depth analysis of the stories, three themes were created. These were then put together into one thematic statement, which eventually formed part of the study’s conclusion. Finally, participants’ stories were verified. Each participant was sent her story and was given one week to read and reflect on it, following which she was contacted by the first author for feedback.

2.6 Credibility and trustworthiness of the study

The framework outlined by Yardley (2000) was applied to ensure trustworthiness of the current study. Yardley’s (2000) framework is based on four aspects: sensitivity to context, commitment and rigour, transparency and coherence, as well as impact and importance. Sensitivity to context was ensured by making the participants’ voices heard through accurate descriptions of their story. Stories are a good way to preserve the context and meaning of the experience (Johnson, 2000). The issues of commitment, rigour, transparency and coherence relate to the expectations of thoroughness in data collection, analysis and reporting in research (Yardley, 2000). These aspects were addressed by keeping a field journal as suggested by Wall et al. (2004) in order to provide a record of personal feelings, thoughts, ideas and biases, feedback and information gathered throughout data collection. Hence, the research process was described in detail and a rationale was given for all decisions and actions taken. The final criterion of impact and importance

was addressed by thoroughly documenting the meaning of the experience of living with GBS for the participants.

3 Results

Three super-ordinate themes emerged from data analysis. These were Lost at Sea, Propelled into Change and The Aftermath. Living with GBS was perceived by participants as a sudden loss. All the participants described how GBS made them feel at a loss, to the point where they felt the loss of their identities. This constituted the first super-ordinate theme, Lost at Sea. Propelled into Change describes the changes that participants experienced in their lives following the diagnosis of GBS, mainly the fact that they could not plan for the future, as well as the effect that these changes had on the family. The final super-ordinate theme, The Aftermath, highlights the impact of the illness on the participants' social relations. Each super-ordinate theme comprised sub-themes which are outlined in Table 1.

Findings are presented with verbatim extracts from participants' interview responses to illustrate each theme. The insertion of ellipses (.....) in the excerpts indicates removal of segments for editorial reasons. Brackets indicate information added for further clarification.

Super-ordinate themes	Sub-themes
Lost at Sea	Sudden onset Loss of identity Out in the cold
Propelled into Change	From a player to a spectator The after-effects of the storm Taking life day by day
The Aftermath	Social isolation Hoping for a better future

Table 1. Super-ordinate themes and sub-themes concerning the experience of living with GBS

3.1 Lost at Sea

3.1.1 Sudden onset

The women in this study spoke about their personal feelings after their diagnosis of GBS, and metaphorically described themselves as feeling “lost at sea”. Joyce distressingly recounted:

“It is like I am lost at sea.”

This feeling was also shared by Rita who, with a blank face, commented:

“Following GBS I feel like I am a lost person.”

The feeling of loss attributed to GBS was exacerbated by the sudden, inexplicable onset of the illness. The onset of GBS disrupted the participants' entire life in an instant. Mary stated:

“It just happened overnight, like a shot from the blue. There were no signs or signals. It was not gradual... I was washing the dishes and I could not stand up properly.....until I had swollen up so much that I could not take off my clothes.”

Furthermore, two years following onset, Rita described how she still could not believe what had happened or how the illness had struck her.

“I could not believe how bad and how sudden it was. One minute you are healthy and the next, that's history.... I was out at a restaurant with my husband and his colleagues..... The next morning, I tried to get out of bed and my legs felt dead.”

3.1.2 Loss of identity

Loss of identity was perceived by the women as the result of their diminished ability to carry out one or more of their major roles, particularly those related to their occupation. The loss of roles was attributed to the physical and psychological residuals of the condition. Participants described how the loss of roles, or major alterations in them, made them feel no longer the same. For example, Joyce claimed:

“I had to stop working. I used to work a 12-hour shift and sometimes even 16. Certainly, I cannot do that now! When you have been working for 22 years, it is no joke suddenly finding yourself not working.... It is not just the money. It is your routine of getting up in the morning and meeting someone.”

Rita and Grace never worked away from home and fulfilled the role of full-time housewives. Following GBS, they felt they could not fulfil this role the way they used to. For example, Grace said:

“I still feel that sense of disappointment, that I do not keep the house in good order as I used to... I am always at home. Before (GBS) I used to do everything myself; dusting, cleaning windows etc. but now I have to get help. What a big difference!”

3.1.3 Out in the cold

All participants further reported that their experience of feeling “lost at sea” was further exacerbated by the fact that they felt that their needs as individuals living with GBS in the community were not understood by health care professionals. Participants expressed their gratitude for the care they received in hospital. However, in the community they felt that, as opposed to in-patients in the acute phase of illness, these same health care professionals failed to understand them, or even listen to their concerns. This made them feel as if they were literally left out in the cold. For example, Joyce, with a sense of resentment in her voice, said:

“Whenever I went to hospital they (medical team) used to tell me that if I was walking I was fine. Then I stopped going. Do not get me wrong, I agree with them because I was practically dead, and the medical care I was given in hospital was excellent..... but in my case it left symptoms.”

Mary also expressed her disappointment at the fact that after being discharged back home, no one followed up her case.

“I never got any letters for a follow-up appointment, since I was out of hospital!”

Grace, on the other hand, acknowledged her regular appointments on out-patient basis, but she perceived such appointments as not having much significance. She stated:

“Today, for example, I had an out-patient appointment. I spent more time waiting rather than being seen by the medics. I would barely have the time to tell them how I am feeling.”

3.1.4 Propelled into change

Change is defined as a transition or transformation (Farlex Inc., 2016). Change was represented in participants’ attempts to move away from loss in the best way they could, although this was not always possible. Their changes in roles, relationships and abilities brought a sense of new direction.

3.1.5 From a player to a spectator

GBS brought about changes in the participants’ family dynamics and roles. All participants were responsible for housework, including those who were in full-time employment. In the present study, GBS brought limitations on participants in such a way that they were not even able to fulfil the role of a housewife any longer. Other family members, usually the husband or children, had to take on these roles, in addition to their other responsibilities. For example, Rita described how her daughter took over some of the housework duties which belonged to her prior to her illness.

“My children suffered too. That is how my daughter got sick. She had too much to do. She used to do everything, cook, clean the entire house for us.... The medical consultant told her she was taking on so much.”

Furthermore, Joyce said:

“My children’s life has changed due to my illness, even the fact that I still depend on them to do certain errands.”

Like Joyce, Grace depended on her daughter to go out.

“I now depend on my daughter to go anywhere.”

In order to decrease the burden on their family, the women reported that they tried to hide their pain and deal with its limitations by themselves. For example, Mary said:

“I try dealing with GBS myself. I have a son who is nineteen. I hide from him that I am in pain because I know he worries about me.”

Similarly, Grace also hid her worries from her daughter because she did not want to cause her extra burden over and above her work responsibilities.

“My daughter needs to go to work. I cannot depend on her for everything.”

All the women in this study expressed gratitude and appreciated the support they received from their families. Joyce fondly spoke about the support she received from her children.

“I am so grateful to my children. I cannot imagine how I would have coped without them!”

However, the same women revealed that, at times, they found this attention to be rather suffocating. For instance, Grace spoke about her regret on the fact that she had to refrain from carrying out certain household chores after her family insisted on this.

“My neighbours saw me sweeping the pavement in front of my house. They panicked and went to tell my brother about it. He was really cross at me! He was really worried that I would fall and hurt myself. Still, I used to feel good sweeping a little, as I used to feel that I can do the same work as before.”

Joyce also expressed her wish to get out of the house to do some paid work, even for a few hours a week. Like Grace, she tried to reclaim some of her ‘lost identity’. However, her children stopped her from doing this in good faith.

“Sometimes, I wish I could go and help someone, even for a few hours a week, like wash a few dishes... but my children won’t hear of it!”

3.1.6 The after-effects of the storm

All participants shared how they had to learn to live with the residuals of the condition, lamenting that GBS had left some form of permanent disability in their lives. Mary, for instance, recounted that:

“Recently a physiotherapist told me that my hand lacks strength and GBS has affected it.... There are days when I need to rub my right leg... or my arm as they feel stiff, especially at night when I come to roll over in bed.”

The residual symptoms were still experienced by the participants even two to three years after they had been living back in the community. For example, Grace, in an annoyed voice, said:

“If I spend a certain amount of time on my feet during the day, I get very tired.”

Similarly, Joyce felt fatigue which still caused several limitations in her life, even three years after diagnosis.

“When I left hospital I was still very tired and I am still so very tired. I cannot be on my feet for long. Two hours is the limit. After that my legs hurt a lot. It is like electric shocks.”

The ongoing residual effects of GBS also had an impact on the person’s body image, especially when incontinence and impaired bladder control were experienced. For example, Rita poignantly discussed how distressed she felt when making use of a diaper. Grace also said that she did not feel comfortable showing her legs in public. She lifted up her skirt and showed her legs, which were still emaciated due to muscle loss caused by immobility brought over by GBS. She further revealed that she always wore trousers outside, even during the hot summer months.

Another psychological aspect and after-effect that some of these women were dealing with on a daily basis was the ongoing fear that GBS may haunt them again, possibly with worse outcomes. With a worried expression, Mary said:

“I feel that GBS is always there, it is always asleep, and maybe it will re-emerge.”

Grace also lived with the same fear, but this was mainly exacerbated when she was having a bad day of excruciating pain.

“I have good moments and not so good moments... On a bad day, I am frightened that GBS will re-emerge.”

Furthermore, participants were still living with the memories of being patients in ITU. Rita spoke about how her stay in ITU still haunted her even in her dreams.

“Many times, two years later, I still dream I am still in ITU....I still get visions of a young child I remember dying over there.”

Mary had similar recollections, although in her case she preferred to avoid talking about these distressful memories.

3.1.7 Taking life day by day

The fact that GBS struck the participants suddenly made them realise the fragility of life and ultimately changed their outlook on it. They stopped making long-term plans and started taking life day by day, appreciating it more. Mary said:

“These days I accept the fact that I have a condition I need to live with. Before, I did not use to accept certain things. I used to say ‘But why me?’.... After the condition, this attitude taught me to live day by day, whatever happens.”

Taking life day by day also meant that these women became more thoughtful of the people around them. Rita acknowledged how she started to value her husband more.

“Today I appreciate much more how much he (husband) has done for me during my illness, and he still does. Following my illness, I started to appreciate him more in my life.”

3.2 The Aftermath

Re-integrating into society after this experience was, most of the time, not easy for the participants. Although these women took conscious actions to adapt to their new way of being, some still hoped that their residual symptoms may one day disappear.

3.2.1 Social isolation

The social isolation that the participants faced was evident through their poignant narratives of the numerous environmental obstacles and ‘human barriers’ that they encountered on a regular basis. Grace expressed this frustrated anger by saying:

“I need to spend a day in Gozo but I cannot do it. How can I go to Gozo and do my errands? For instance, I like to go to Ta’ Pinu Sanctuary, but there are steps there... I am scared I might trip.”

It was therefore evident that inaccessibility to certain places was isolating these persons, as they felt that, due to the obstacles, they would prefer to stay in the comfort of their homes, without facing more problems. This was further exacerbated by the fact that the women had to plan in advance where to go. As Joyce explained:

“You have to plan your life to do all you need to do. Although I walk, if I am walking and come across a high pavement, it is very difficult for me to go up.”

Indeed, what came to light when talking to these women was that, although they found the physical barriers distressing, they were more upset when they had to face ‘human barriers’. Some friends stopped talking to Rita during and following her illness, the reason being that they were unsure of how to console her without upsetting her. With tears in her eyes she said:

“What hurt me most was the fact that when I started to go out to the grocer’s shop to do my shopping, I used to realise that my friends were avoiding me.... I used to ask myself ‘But why they are not talking to me?’ By time I got to know... that they used to avoid me as she (friend) said I was so weak and frail and they were lost for words of what to tell me, and were afraid to speak to me.”

3.2.2 Hoping for a better future

Despite the fact that society did not make it easy for them to re-integrate, the participants still remained very positive in life as they hoped for a better future. With enthusiasm, Mary said:

“I always look forward to the future, and hope for a better future.”

Grace said that her hopes and expectations for a better future were kindled when she met other patients who managed to overcome similar hurdles.

“Sometimes I think I might be well again, at least well enough to do away with this (walking frame). When I used to go for therapy, it was encouraging to see the other patients. One of the patients used to tell me ‘You will be just fine. You will get better. I went through it myself.’”

4 Discussion

This study provides an in-depth exploration of adults living with GBS. Following GBS, participants started to feel “lost at sea”. The women in the study attributed the loss to the sudden inexplicable onset of the condition, this being a common phenomenon in GBS (Forsberg et al., 2008). It was in fact described as a “shot in the blue”. This sudden onset took away the normality of participants’ lives, leaving them to wonder what might have been the actual cause of the illness. As a result of this, it was discussed how the women started to hypothesise on what might have caused GBS, even comparing it to more commonly known illnesses such as cancer, in spite of the fact that the pathologies of the two illnesses are completely different. Heider (1958) viewed lay people as naive psychologists trying to make sense of the social world. Fiske and Taylor (1991) asserted that the social perceiver, that is, the lay individual, uses information to arrive at causal explanations for events, when individuals find themselves in difficult and uncertain situations. Furthermore, according to Clow (2001), the use of symbolic language helps affected people to derive meaning from their experience.

Participants in this study felt that they were not the same individuals they were prior to GBS onset, for different reasons. It was debated how, prior to their illness, work gave the women a chance to socialise. Furthermore, it made them feel they were ‘useful’ to society. These findings corroborate those obtained by Shaw et al. (2002), who looked at return to work behaviours of individuals following long-term disability leave. The participants in the latter study stated that work gave them an identity and a sense of attachment to what they did. Moreover, in the present study, being a housewife gave the women a sense of pride in being in charge of a family. Indeed, within the traditional Maltese nuclear family, the role of housewife is a crucial one.

Furthermore, GBS made these individuals give up their leisurely activities, as was also evident among participants in Bernsen et al.’s (2002) study. Additionally, the participants perceived health care professionals as entities that further contributed to their loneliness, as they failed to understand their needs as individuals living in the community. They were sidelined by those health care professionals whom they had thought highly of when they were still in-patients. This insensitivity on behalf of health care professionals caused distress in participants’ lives.

Similar findings were reported by Forsberg et al. (2008). A different study carried out by Forsberg, Cuesta and Holmqvist (2006), which partly looked at satisfaction of 42 GBS patients in relation to health care services, concluded that patients were mostly dissatisfied with not being provided with adequate information with regard

to their rehabilitation. However, participants in Forsberg et al.’s (2006) study reported dissatisfaction with the information given throughout their care, including during the acute phase. In contrast, the women in the present study expressed satisfaction with the care given to them, including the information provided, while they were being cared for as in-patients.

The long-term effects of GBS were also the main reasons participants had to delegate their social roles to significant others. The women described guilt feelings of being a burden on the family. Bernsen et al. (2006) looked at the effects of GBS on close relatives during the first year of illness. Findings revealed that GBS had a psychosocial impact on relatives. Bernsen et al. (2006) highlighted the fact that, as relatives assumed new roles, they could not perform their own work properly due to psychological stress. However, in addition to what Bernsen et al. (2006) reported in their study, participants in the present study also expressed feelings of guilt. The latter feeling resulted from the fact that they felt like a burden on their children and family. In spite of all this, the women in the present study reported that the delegation of such roles brought family members closer together but also caused a feeling of ‘suffocation’.

Long-term effects which participants had to live with included fatigue and pain. Such long-term barriers hindered the women from regaining their independence in basic daily living activities. The presence of long-term fatigue related to GBS is also evident in the literature. Garssen, Koningsveld and Van Doorn (2006) looked at the issue of fatigue and reported that 60% of their participants reported severe fatigue two years following GBS. Furthermore, Garssen et al. (2006) concluded that fatigue was more common in female GBS patients who fell in the age bracket of 50 years and older, similar to the demographics of the participants in the present study.

Psychological long-term effects were also present in the women’s lives as they were still dealing with post-traumatic stress related to ITU admission even two or three years later. A study carried out by Russell (1999), which explored perceptions, memories and experiences of 298 patients in an intensive care unit, showed that participants were still battling with the traumatic experience of being admitted to intensive care even six months after their discharge. The disparity of experience between the present study and Russell’s (1999) is that distressing experiences for participants did not last for six months but for over two years, although no specific dynamics could be attributed to this outcome. The women also lived in constant fear of recurrence of GBS. Similar experiences of living in fear of GBS recurrence have also been reported in Chemtob and Herriott’s (1994) case study. The age difference between the young woman aged 24 years in the latter study and the women in the present study does not seem to have an effect on the experience. Therefore, the fact that the women in this study were older did not grant them the ability to deal better with feelings of worry and fear associated with the possibility of GBS re-emerging. Nonetheless, the women took conscious actions that helped them to move on. Participants started to choose alternative ways of filling their lives, such as strengthening their faith in

God. These women's experiences fit the ones presented in a review carried out by Koenig, Larson and Larson (2001), where the overall conclusion was that when people become physically ill, many rely heavily on religious beliefs to relieve stress and maintain hope.

This study also revealed how the women tried to re-integrate themselves back in society following their illness, and encountered considerable challenges due to several environmental barriers and societal attitudes. These barriers actually made them feel disabled and in turn kept them 'trapped' in their homes, where they felt more safe and protected. These experiences are echoed in detail in the Social Model of Disability, theorised by Oliver (1990). 'Human barriers' were also acknowledged by the participants, whereby friends or long-term employers started to avoid them or even failed to empathise with them. This is a common occurrence among people faced with serious illness (Buckman, 2012). It was also seen how the participants always hoped for a better future when their condition would improve, and the day when they would be totally free of GBS residuals. The importance of a GBS support group was also mentioned, particularly as sharing their concerns with people who went through a similar experience would have made them feel better.

4.1 Limitations

A potential limitation of the present study is the fact that a third brief interview was not carried out. This would have been beneficial, as it might have elicited more in-depth experiences. In fact, a heightened sense of trust in the interviewer was already felt by the second interview. Moreover, although all interviews were carried out in Maltese, interview transcripts were then translated to English. This might have led to the risk that, at times, the essence and meaning of a sentence or phrase might have been lost during the process of translation. To minimise this shortcoming, translations were carried out by an independent translator and it was agreed that when untranslatable words were present in the text, the original Maltese word was to be written in brackets next to the translation. This was done so that, as much as possible, the meaning would not change.

5 Conclusion

This study addressed the experiences of Maltese individuals living with GBS in the community. In conclusion, living with GBS was found to involve a continuous battle to reintegrate into society while trying to accept the resulting sudden losses, together with the tough and lifelong changes the condition brings. The study's findings generate a number of recommendations for practice. In order to help such individuals address challenges, they must continue to obtain necessary support following discharge from hospital. This support could be provided through further community services delivered by a multi-disciplinary team. Participants spoke emotionally about the environmental barriers they had to face while dealing with the illness. Diminishing

these would enable individuals with GBS to cope better psychologically and socially on a long-term basis. The various environmental restraints, such as the absence of ramps, need to be effectively addressed by the respective authorities. Addressing such barriers would enable these individuals to look forward to going out rather than having them dread the hurdles they have to face outside their homes.

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8 Conflicts of interest

The authors report no conflicts of interest.

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