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Title	First time stroke survivors' perceptions of their health status and their goals for recovery
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Publication date	2011-02-28
Original Citation	Hartigan, I., O'Connell, E., McCarthy, G. and O'Mahony, D. (2011) 'First time stroke survivors' perceptions of their health status and their goals for recovery'. International Journal of Nursing and Midwifery, 3 (2):22-29.
Type of publication	Article (peer-reviewed)
Link to publisher's version	http://www.academicjournals.org/journal/IJNM/article-abstract/6CC9C59887
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Download date	2026-11-15 15:00:40
Item downloaded from	https://hdl.handle.net/10468/3869

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International Journal of Nursing and Midwifery Vol. 3(1), pp. 22-29, February 2011
Available online http://www.academicjournals.org/ijnm
ISSN 2141-2499 ©2011 Academic Journals

Full Length Research Papers

First time stroke survivors' perceptions of their health status and their goals for recovery

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Accepted 28 December, 2010

Stroke is an intensely individual, complex and life changing experience. Stroke recovery has many dimensions, and perceptions of health status are thought to affect recovery. The purpose of this qualitative study was to describe patients' perceptions of their health status and their goals for recovery from early post stroke. Following ethical approval, semi structured interviews were conducted with patients (n=10) diagnosed with a first incident of stroke. Time following stroke onset ranged from 4 to 7 days. Gender difference was equal, and mean age of participants was 77 years. Participants considered themselves to be active and in excellent health prior to the stroke onset. All participants perceived that their health had declined since the stroke onset, but they were hopeful for the future. Two distinct themes emerged; "sudden fear and helplessness" and "regaining control in life". Participants reported wanting to quickly return to doing everyday things and identified individual goals for recovery. The patients' experience should be considered early post stroke to provide a complete picture of their role in recovery. Participants believed that the greatest challenge would be testing themselves at home. This study reinforces the importance of engaging with patients early post stroke so that recovery goals are identified that help restore meaning through the re-establishment of previous activities. Patient goals for recovery need to be discussed and devised in conjunction with health care professionals.

Key words: Stroke, health status, goals, recovery.

INTRODUCTION

Stroke kills nearly 6 million people in developed countries every year and is the leading cause of death for those over the age of 60 years (Mackay et al., 2004). Stroke remains the leading cause of long-term adult disability globally and by 2015, the World Health Organization (WHO) estimates that over 50 million healthy life-years across the globe will be lost as a result of stroke (WHO, 2005). Stroke represents a considerable burden on Irish healthcare resources (Hartigan et al., 2009). Population projections for the occurrence of new stroke challenges health care providers, and the complexity of stroke recovery is evident (Anderson and Myers, 1993; Vanhook, 2009). There are numerous factors that potentially could affect stroke recovery which can not be explained from a single approach (Salter et al., 2008). The onset of stroke presents survivors with various degrees of personal and physical limitations and the best methods for characterising recovery following stroke are elusive (Duncan et al., 2000).

Rehabilitation therapy is the mainstay of care for stroke patients (Saxena et al., 2006). According to the European Collaborative Evaluation in Rehabilitation of Stroke project, great differences exist in stroke management and outcomes across Europe (Putman and De Wit, 2009). Rehabilitation services in Ireland vary for stroke survivors some hospitals provide offsite rehabilitation in units which cater for patients with other conditions, whereas,

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others provide rehabilitation as part of the elderly services (HSE, 2009). Stroke survivors' progress is often evaluated using benchmarks relating to physical functioning whilst stroke survivors themselves frame their progress using activities that have a wider social meaning (Burton, 2000a). Social roles and responsibilities are often not addressed in the early stages post stroke (Pajalic et al., 2006). Psychological, social or environmental needs are given minimal attention during rehabilitation (Bruton, 2000b).

Medical and nursing literature accentuates the functional impact of stroke (Bendz, 2003; Clarke, 2003; Dowswell et al., 2000) and less is known in relation to stroke survivors perceptions of recovery. Health perceptions have a significant role in determining recovery. A poor perception of health post stroke is associated with lower functional abilities (Hanger et al., 2000; Paul et al., 2005) and influences mortality (Idler and Kasl, 1991). Understanding patients' perceptions of their health status provides a broader picture of how their perceptions of their health impacts on their recovery (Bugge et al., 2001; Spertus et al., 2002).

Perceived or subjective health is defined as "an individual's experience of mental, physical and social events as they impinge upon feelings of well being" (Hunt, 1988: 24). Health status measures are repeatedly used to quantify patients' perceptions (Bugge et al., 2001) and there are a very limited number of qualitative studies exploring patients' perceptions of their health status post stroke and none early post stroke. The literature highlights that health care providers are not sufficiently aware of stroke survivors' own model of recovery and of their perceptions of their health early post stroke (Bendz, 2003; Pajalic et al., 2006). For this reason, it is important to investigate patients' perceptions of their health early post stroke and their model of recovery. The aims of this study were twofold. Firstly, to describe patients' perceptions of their health status pre and post stroke. Secondly, to identify patients' goals for recovery and their role in achieving them.

METHODOLOGY

The purpose of this qualitative study was to uncover patients' perceptions of their health status and their goals for recovery from early post stroke. A qualitative descriptive methodology was employed to achieve the research aims. The chosen methodology facilitated data collection and analysis in a naturalistic fashion, allowing the researcher to completely focus on the individuals involved in the study and their experience in post stroke.

Sample and setting

Ethical approval to conduct the study was granted by the local Research Ethics Commitee thus ensuring that the principles governing medical research were adhered to (Gelling, 1999). Individuals who presented to the Emergency Department (ED) of a large teaching hospital within a week of a first stroke incident, confirmed by computed tomography, and who were not acutely ill were identified as potential study participants.

For the purpose of this study, stroke was defined as "rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer with no apparent cause other than of vascular origin" (W.H.O., 1980). Permission to access the ED admissions record book and approach potential participants was obtained from the relevant Consultants and Nurse Managers. Once eligible patients were identified, the researcher informed the Clinical Nurse Manager who agreed the suitability of the patients, and introduced the researcher to the patients. Participants' autonomy was respected throughout this study. All participants were given verbal and written information pertaining to the study. The researcher returned 1 to 2 days later and if the patient agreed to participate in the study, written consent was signed. Subsequently, 10 patients consented to participate, 5 male and 5 female patients with an average age of 77 years and all within 4 to 7 days of their stroke. All participants were informed that they could withdraw from the study at any time. Confidentiality was ensured by withholding names and coding all data. The data collected and the arrangement of the findings did not identify participants.

Data collection

Data were collected using in-depth semi-structured interviews. To guide the interviews the researcher developed a set of questions which were not asked in any fixed order. Participants were asked to give their perspectives on their recovery. Examples of questions include, "Can you describe your health before you were admitted to hospital?" and "How would you describe your health today?" as well as "What are your goals for the future and how will you achieve these?" Indeed, incoming information raised by the interviewee could be followed up in more detail by probing questions. Demograhic data were also collected detailing each participant's age and sex. Additional data collated included participants residual deficit and living arrangments prior to hospitalisation. All interviews were recorded and conducted in a private room in the hospital by the nurse researcher. The nurse researcher documented field notes in a diary throughout the research process taking into consideration personal biases and descriptions of participants'emotional expressions.

Data analysis

Demogrphic data pertaining to each participant were collected, thus enabling conclusions to be reached about the transferability of the study findings. The participants that consented to this study were interviewed at a time suitable to them and all interviews were between 40-90 min in duration. Following interview, all audio recordings were transcribed verbatim and accuracy was checked by listening to the recordings twice. The researcher used Burnard's 14 stage framework to conduct this method of content analysis (Burnard, 1991). This framework for data analysis is modified from Glaser and Strauss' grounded theory approach and from various other works on content analysis (Burnard, 1991). The aim of the analysis was to produce a detailed account of the themes and issues addressed in the interviews.

The researcher read the transcripts and incorporated relevant field notes into each transcript. All transcripts were read several times and meaningful units were identified and codes were attached. The researcher and a colleague validated the findings. Lists of categories were discussed and adjusted as necessary. Transcripts and categories were examined to ensure the data related to each category. Data was linked to category headings and agreement was unanimous. As central themes emerged from the

Table 1. Demographic profile of participants.

Code	Age	Gender	Discharged to	Living situation	Residual disability
P1	70	Female	Home	alone	Left sided weakness
P2	82	Male	Home	alone	Expressive dysphasia and blurred vision
P3	83	Female	Rehabilitation	With spouse	Slurred speech, ataxia
P4	80	Female	Home	alone	Right sided facial weakness and dysphasia
P5	78	Female	Home	alone	Left lower facial weakness and dysarthia
P6	79	Female	Home	alone	Left upper limb weakness
P7	71	Male	Home	alone	Right hand weakness and sensory deficit
P8	83	Male	Rehabilitation	alone	Slurred speech, diplopia and right side weakness
P9	76	Male	Rehabilitation	With spouse	Expressive dysphasia and left visual field defect
P10	79	Male	Rehabilitation	With spouse	Right sided weakness and dysphasia

Table 2. Examples of participants' perceptions of health pre and post stroke.

Participant	Health status pre stroke	Health status post stroke
2	My health was good…excellent	I feel the same as I was before, perhaps my health is not as excellent as before…I suppose that I wouldn't know
4	Um fine, we actually just got back from a two week holiday. Very good level of health	Shock….well below par. It takes you by storm
6	Excellent	Sorta cooling down quietly
8	It was good because I could go into town and do everything. My health is o.k. Well up to Friday everything was alright.	After Friday, I don't know. I would use a very bad word to describe it (my health).

data, further discussion led to consensus and concrete illustrations of each theme were identified.

RESULTS

The majority of stroke patients admitted to hospital were excluded as they either had a diagnosis of vascular dementia or impaired cognition, as documented in their medical case notes, or were acutely unwell or previously diagnosed with a chronic disease such as Parkinson disease, Diabetic ulcers, or a previous history of Cancer. These patients were excluded as other illness may influence their perception of their stroke recovery. All participants understood that they were admitted to hospital because they had a diagnosis of a stroke and were able to describe its meaning. There is no dedicated stroke unit or stroke specific service available from this large acute teaching hospital. Four patients were discharged to an offsite short stay rehabilitation hospital and the remaining participants were discharged to home. Table 1 presents the demographic profile and residual disability of all participants.

Perceptions of health status pre and post stroke

All participants (n=10) expressed how they perceived their health pre and post stroke. All but one of the participants described their health as excellent or very good prior to stroke. The majority of participants (n=6) stated that they felt their health had deteriorated as a result of the stroke. Examples of participants' perceptions pre and post stroke are presented in Table 2.

Recovery goals

All participants were asked to identify their most important goals for recovery. These are listed in Table 3.

Two distinct themes emerged; "sudden fear and helplessness" and "regaining control in life". All participants described the stroke event and the emotions experienced as a result. All participants were optimistic about returning home and regaining control over their lives. Participants identified realistic goals based upon their previous performance and health prior to their stroke.

Table 3. Participants goals for recovery

Participant	Goals for recovery
1	To be independent Keep improving at all times
2	To be able to check the cows To work and care for collie dogs.
3	Use the computer again Write computer programmes To be able to walk and talk again
4	To recover 100% of my speech To get home To do some gardening
5	To get back to where I was last week To learn everything I can about stroke
6	To keep my mind going To be able to get up and get dressed myself
7	To travel with my wife To be able to use my (right) hand To be able to play golf
8	To be able to speak properly To be able to do normal things
9	To get home To drive and play golf
10	To be able to walk and talk To get home

Theme 1: Sudden fear and helplessness

All participants spoke about their feelings when the stroke occurred. Initially they expressed feelings of shock and fear related to loss of bodily control which later manifested as anger, frustration and guarded optimism. Participants were astonished that they received a diagnosis of stroke as they had generally being feeling well prior the event. One participant spoke of the shock experienced and another of the loss of control.

"I kinda felt lifeless, it was uncomfortable you know, it was as if my life tumbled apart I was shocked….My mind was perfectly lucid, lucid the whole time" (P6).
"I felt things outside began to move, I don't know what happened or came over me" (P8).

Confusion and anxiety were expressed by participants as they described the stroke incident. Mild to moderate sudden changes accompanied the stroke and this is how two participants describe their loss.

"I suppose, it was indescribable. I went looking for words and they were muddled….. I suppose now I am fortunate that it was so obvious and I caught it quickly. I went to my doctor before it deteriorated" (P2).

"I was feeling very weak, very wobbly, but mostly while I was speaking to him on the phone I knew my voice had gone funny….. I was anxious to be honest about it (P5).

On the surface, participants were calm and appeared to be coping with their situation. However, as the interviews progressed, other emotions were evident and one participant expressed how she was anxious about falling as the evening she got the stroke she had a fall. Emotions of fear and anger emerged from the interviews. Fear was associated with the diagnosis of stroke. One participant spoke about the fear he felt when he heard the word 'stroke'. This fear was related to his previous experience of knowing somebody who had suffered a stroke.

"When the doctor mentioned stroke, I got a fright....a man I know...he had a stroke. Initially he just sat at the window of his house looking sad, cut himself off altogether and now he is in a nursing home. I am scared" (P7).

Fear was also expressed as an emotional response to participants' loss of control. Fear was stimulated by the environment and their ability to adapt. The excerpt below describes how fear inhibits this gentleman's identity as he has lost control over his speech and mobility.

"I was feeling very weak and wobbly when about the house, with this, I dread most of all speaking cos I know my voice is gone funny" (P5).

Initial feelings of shock and fear were replaced by anger and frustration. Anger and frustration were amplified by a lack of independence. Anger and frustration was most often directed at a non-functioning limb:

"It's a nuisance (her hand) because you could be going someplace and it won't go" (P9).
"I mean I can't get out things you know, I try to get them out but I make a mess out of them. Messy mixing words" (talking about expressive dysphasia) (P9).

The behaviours and emotions expressed by participants were a reflection of their stroke injury. Consequently, loss of personal control results in anger and frustration. Feelings of frustration were reinforced as patients made comparisons with their pre-stroke life. One participant

expressed frustration related to arthritis of her knee which sometimes hindered from doing ordinary activities and now as a result of the stroke items fall out of her hand.

“I have arthritis in my knee and that sometimes hinders me…. I suppose, it is at home you would really have to test it, my hand seems grand but everything falls out of it, I can’t control that” (P1).

Frustration was expressed by many of the participants as they were unsure if they could return to pre-stroke activities. Despite this, several participants had a positive outlook on their recovery post stroke. This highlighted their personality traits of motivation and determination;

“Mental attitude is the only way that you can defeat strokes. Good mental attitude will help you in any stroke” (P3).
“I just want to get started again….. I would never give in” (P1).

For others it appeared to be linked to the expectation that old age was often accompanied by decreased physical functioning;

“One of the most important things in life is being able to let go....Life is not perfect you know, at my age you expect a few years and no more” (P3).

This theme *sudden fear and helplessness* gives insight to the emotional trajectory stroke survivors experience early post stroke. Fear and anxiety were associated with their ability to adapt to the impairments of post stroke. Lack of control confounded feelings of anger and frustration. Evidence of frustration was predominately related to impairments in physical and social functioning. Participants yearned to remain optimistic for the future and motivated to accomplish normal activities of everyday life.

Theme 2: "Regaining control in life".

The participants spoke about the importance of returning to the ‘normal’ life they had before their stroke incident. This involved regaining autonomy in everyday life. Normal life was related to regaining control in three areas; personal care, everyday responsibilities and social functioning.

“To do the usual things and that’s it…. to fix breakfast and you know what that entails and doing normal things about the house….” (P10).
“I am living on my own and I do all the house work……washing, cleaning, cooking for myself, shopping, so I need to be active again” (P5).

Participants felt that progress in relation to these three areas would only be accomplished when they arrived home to practice activities;

“I would not be doing much here.. Dropping things to pick them up…I really think I need to test my independence at home. I think it (independence) will come easier when you’re on your own…. It’s when you go home that you worry something might happen to you…No, at home I do it my own way and at my own pace. See you have to have your own familiar things to figure it out don’t you really. It’s very hard to explain it” (P1).

Participants looked forward to being able to return to their pre-stroke responsibilities;

“I’m not fully sure till I get home…I am feeling good right now and want to do those things (jobs on the farm) I’ll know more when I’m there and see can I do the jobs… Of course being away from the job itself would mean a little relaxation. A little, not being forceful….Just keep trying to get back to square one (P2).

Health was described as more than just physical. One participant spoke about the importance of well-being as sometimes people “*can walk themselves to a hard place”.* Self-belief and confidence were identified as significant for re-engagement in activities;

“Well to get back where I was last week. I was certainly will make every effort as I have been. I would like to learn everything in my power to get over the stroke. I’ m determined, strong willed. If I need to do something,. I wouldn’t be putting it aside. I would do it. I wouldn’t leave it till tomorrow or day afterward. I would do it. I would be methodical in that sense. So I guess the main thing is to get back to where I was last week” (P5).

Hope and self-belief emerged as a category during data analysis from a number of participants. One participant summed it up as follows;

“I’d say it would be alright, you just have to get used to it…then get started again. I would never give in and to be able to do my own jobs. Keep improving all the time” (P1).

All participants were not acutely ill and described their circumstances as lucky. The majority of participants believed that they were fortunate as they had mild residual disability and believed their recovery would be determined very much by themselves;

“When I’ll go out for a walk outside and I’ll see how able I am. See if I can talk to somebody as usual…I think I just have to achieve what I am doing myself” (P3).

Another participant reinforced this with the emphasis on testing himself at home;

“I’d say I have to get use to it now….I just want to get

started again….. I would never give in. Good mental attitude will help any stroke….Because when you are in your own environment you know how you can deal with it (P3).

A sub theme emerged relating to how participants would test their recovery at home. The majority of patients believed that they would truly know the extent of their stroke once they returned home.

"I would love to be at home to try it out, I really feel like you are under observation here, you would love to do things for yourself like, see how I go…It is at home you would really have to test it……" (P1).
"At home you know exactly where the chairs are and know which ones you can touch. It is actually more difficult in hospital, the beds are moving and chairs are moving. You are conscious that you are in the presence of strangers all the time" (P3).

DISCUSSION

Medical and nursing literature accentuates the functional impact of stroke; little attention is given to qualitative studies that offer insight to patients views on recovery. Participants in this study gave detailed accounts of how they perceived their recovery and their health post stroke. Participants compared their health to expectations that often accompanied old age. The majority of participants perceived their health had deteriorated somewhat post stroke. However, health was described as more than just physical and the importance of well-being was elaborated on by a number of participants. Health was evaluated according to their ability to engage in personal care and social activities. Four participants judged their health according to their attitude on life and felt that a positive mindset could help overcome the physical limitations post stroke. Self-belief and confidence were identified as significant in gaining a full recovery.

The social complexity in which stroke occurs has been previously identified in the literature (Jones and Steward, 2002; Sturm et al., 2002). Early recognition and understanding of the person's perception of recovery is an important determinant for progress. Health status has been shown to be predictive of important outcomes such as the use of health services and ways of coping (Johnson and Wolinsky, 1993; Krokavcova et al., 2008; Miilunpalo et al., 1997). As health care providers, it is important to understand patients' perceptions of their health and how this influences rehabilitation. This reinforces the findings of previous studies highlighting the interrelated nature of physical and social activities as well as emotional well-being in facilitating recovery from stroke (Dowswell et al., 2000).

Previous studies demonstrate the focus of recovery is predominantly related to physical functioning and determined by health care providers (Bendz, 2003; Doolittle, 1994; Kaufman, 1988). The findings highlight the importance of physical functioning however participants discuss their recovery by giving meaning to everyday functioning or routines which in turn influences their recovery goals. It is importance for nurses to engage with patients in the early stage post stroke to gain an understanding of patients emotional, physical and social health so that recovery goals are identified that allow patients to restore meaning through the re-establishment of old activities. Nurses are ideally placed to discuss concerns with patients so that barriers to recovery can be recognised and support provided to achieve activities of daily living (Vanhook, 2009). Identification of patients' recovery goals is not trivial and assumptions about the patients' wishes and expectations should not be taken for granted (Wade, 2009). Although all patients had identified their own goals for rehabilitation they had not discussed them with any members of the multidisciplinary team. A qualitative review reported similar findings in that individuals often have very clear personal goals of their recovery which they may not have had the opportunity to disclose to healthcare professionals (Hafsteindottir and Grypdonk, 1997). This study highlights the importance of recovery goals which motivates stroke survivors to actively participate in recovery. Patient "devised goals" need to be integrated into their care plan to ensure a meaningful recovery. Limited understanding of the personal impact of stroke renders nurses helpless in educating patients in how to adapt to their new lifestyle.

Rehabilitation services should commence early in the acute hospital to actively include patients and their goals for leisure, occupational and social activities as well as physical functioning. As stroke affects every aspect of life, it is important for health care providers to understand patients' perceptions of their health status post stroke, how this influences their recovery and informs their goals. Furthermore, the patient's experience of suffering a stroke should be considered at an early stage post stroke to give a comprehensive picture of their role in recovery and to alleviate fears. Individuals experience a variety of emotions post stroke such as shock, anxiety and fear that may compromise the rehabilitation process and affect their adaptation post stroke. The emotional trajectory described in this study gives insight to feelings and beliefs of participants early post stroke. Previous research investigating patients' experiences of stroke have shown that stroke is an intensely personal experience (Burton, 2000b) associated with a significant impact on emotions (O'Connell et al., 2001; Murray and Harrison, 2004; Salter et al., 2008). Fear expressed by the participants' mirrors findings by Burton (2000b), as fear was related to uncertainty about the future. Feelings of anxiety and fear were associated with loss of control and related to how participants will adapt when they return home. Despite this fear, participants were determined to return home and regain autonomy in everyday life. Although participants' residual disability after the stroke was mild, they strongly believed that the disruption caused by the

stroke would resolve when they returned home as only then could participants' test their abilities by re-engaging in everyday activities and responsibilities. Participants were passive recipients of care while in hospital and much time was spent idle. This is an opportunity for nurses to engage with patients early post stroke to gain an understanding of their recovery. It is necessary to discuss emotions of anxiety and fear in the acute stage to reduce the patients' personal anguish and provide optimal outcome. Participants were anxious about returning home but considered it as an important step in recovery as they would be able to test themselves at home and regain control. Participants' optimism overshadowed their impairments and the difficulties they may encounter at home. The concept of returning home to facilitate recovery is not new to the literature (Becker, 1993) and older adults tend to use strategies tied to their past experiences to judge their recovery (Kaufman, 1988).

Self efficacy and locus of control are central to how an individual performs activities following stroke (Johnston et al., 1999). Participants in this study believed that their role in recovery would begin when they returned home, as there, they would be in control and be able to test their abilities. As the home environment is one of familiarity and security, participants stated that this would allow them to make judgements on how to perform activities and provide opportunities to be active. Gradual adaptation to impairments mainly occurs at home and this allows patients to regain control, confirming their recovery to them (Olofosson et al., 2005). Stroke represented a discontinuity with a previous way of life and there are a variety of obstacles to re-adjustment (Dowswell et al., 2000) however many of these may not be evident for participants in this study until they return home. The results of this study are tentative in terms of generalisability however the findings do provide insight of first time stroke survivor's perceptions of their recovery from early post stroke. Further research is needed in other settings and with larger stroke populations of varying degrees of severity if challenges are to be explored in greater depth and to inform rehabilitation service planning and priorities.

Conclusion

Stroke is a sudden crisis for those experiencing it. This study is the first of its kind to interview patients early post stroke giving insight to patients' perception of their health status and goals for recovery. Patients often do not realise the implications of their situation while in hospital. Participants in this study were optimistic about their recovery and expected only when they returned home they would be able to test their recovery. Individual participants had very clear personal targets in relation to their recovery which they did not have the opportunity to discuss with health care professionals. The findings of this study are consistent with previous qualitative studies in that participants associated recovery in terms of their pre-stroke self and abilities. Long term disability or paralysis is common post stroke so patients' recovery goals need to be identified early and need to have meaning for each individual. The readjustment to life after stroke is difficult for patients to understand early post stroke. Therefore it is important for nurses to be aware of patients' perception of their recovery post stroke to inform patient care, as well as provide patient education and consultation. Nurses have the opportunity to engage with patients early to identify factors associated with successful re-integration, assist patients to regain independence and return to a meaningful life.

ACKNOWLEDGMENTS

The authors wish to thank all the patients who participated in this study. The research on which this article is based was supported by the Noel Hickey Research Bursary honoured by the Irish Heart Foundation.

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