

Supplementary file (A)

Table S1: Example of search carried out in Ovid Medline (1946 to 2021)

	keywords	result
1	Stroke/	107629
2	Cerebrovascular Disease*.mp.	19677
3	Cerebrovascular Disorders/	46868
4	Cerebrovascular accident.mp.	4075
5	brain hemorrhage.mp.	1077
6	Brain Ischemia/	54329
7	CVA.mp.	2530
8	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7	198648
9	limit 8 to (abstracts and english language and humans)	116937
10	Needs Assessment/	31185
11	needs.mp.	343294
12	"Health Services Needs and Demand"/	53907
13	Support.mp.	9569657
14	concern*.mp.	545360
15	demand*.mp.	232715
16	Experience*.mp.	963895
17	wants.mp.	3881
18	Requirement*.mp.	267841
19	Expectation*.mp.	75654
20	#10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19	10872856
21	limit 20 to (abstracts and english language and humans)	5923259
22	Patient Discharge/	31700
23	Discharge.mp.	173477
24	home.mp.	226767
25	long term.mp.	736793
26	long-term.mp.	736793
27	post-stroke.mp.	8065
28	poststroke.mp.	4775
29	Community.mp.	510621
30	#22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29	1552737
31	limit 30 to (abstracts and english language and humans)	1037599
32	Qualitative Research/	61289
33	Qualitative.mp.	215650
34	Interview/	28779
35	interviews.mp.	186431
36	Focus Groups/	31616
37	focus group.mp.	21348
38	mixed method*.mp.	18138
39	case studies/	2032032
40	#32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39	2407668

41	limit 40 to (abstracts and english language and humans)	1225101
42	#9 AND #21 AND #31 AND #41	1245

Supplementary file (B):

Reasons for rejection:

Studies did not explore needs:

1. Alajbegovic, A.; Djelilovic-Vranic, J.; Alajbegovic, S.; Nakicevic, A.; Todorovic, L.; & Tiric-Campara, M. Post stroke depression. *Medical archives*. **2014**, 68(1), 47.
2. Beesley, K.; White, J.H.; Alston, M.K.; Sweetapple, A.L.; & Pollack, M. Art after stroke: the qualitative experience of community dwelling stroke survivors in a group art programme. *Disability and rehabilitation*. **2011**, 33(22-23), 2346-2355.
3. Brookfield, K., ;& Mead, G.; Physical environments and community reintegration post stroke: Qualitative insights from stroke clubs. *Disability & society*. **2016**, 31(8), 1013-1029.
4. Brunborg, B.; & Ytrehus, S. Sense of well-being 10 years after stroke. *Journal of Clinical Nursing*. **2014**, 23(7-8), 1055-1063.
5. Buschenfeld, K.; Morris, R.; & Lockwood, S.; The experience of partners of young stroke survivors. *Disability and rehabilitation*. **2009**, 31(20), 1643-1651.
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7. Ch'Ng, A. M.; French, D.; & Mclean, N. Coping with the challenges of recovery from stroke: long term perspectives of stroke support group members. *Journal of health psychology*. **2008**, 13(8), 1136-1146.
8. Chimatiro, G.; and Rhoda, A. "ENVIRONMENTAL BARRIERS TO REINTEGRATION EXPERIENCED BY STROKE CLIENTS POST DISCHARGE FROM A REHABILITATION CENTRE IN MALAWI." *South African Journal of Physiotherapy*. **2014**, 70(1): 18-23.
9. Clarke, P. Towards a greater understanding of the experience of stroke: Integrating quantitative and qualitative methods. *Journal of Aging Studies* **2003**, 17(2): 171-187.
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11. Croot, E.J.; Ryan, T.W.; Read, J.; Campbell, F.; O'Cathain, A.; & Venables, G. Transient ischaemic attack: a qualitative study of the long term consequences for patients. *BMC family practice*. **2014**, 15(1), 1-8.
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14. da Silva, J.K.; da Silva Carvalho Vila, V. Martins Ribeiro, M. F., & Vandenberghe, L. Survivors' perspective of life after stroke. *Revista Eletrônica de Enfermagem*. **2018**, 18.
15. Danzl, M.M.; Hunter, E.G.; Campbell, S.; Sylvia, V.; Kuperstein, J.; Maddy, K.; & Harrison, A. "Living with a ball and chain": The experience of stroke for individuals and their caregivers in rural Appalachian Kentucky. *The Journal of Rural Health*. **2013**, 29(4), 368-382.
16. DiGregorio, T.; and Matthew, J. Interviewing stroke survivors about experiences of their stroke journey." *British Journal of Neuroscience Nursing*. **2020**, 16(Sup2): S16-S17.
17. Donnellan, C.; Martins, A.; Conlon, A.; Coughlan, T.; O'Neill, D.; & Collins, D.R. Mapping patients' experiences after stroke onto a patient-focused intervention framework. *Disability and rehabilitation*. **2013**, 35(6), 483-491.
18. Doolittle, N.D. *Life after stroke: Survivors' bodily and practical knowledge of coping during recovery*, University of California, San Francisco, **1990**.
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21. Easton, K.L. Post-stroke journey: from agonizing to owning, *Wayne State University* **2001**, 186 p-186 p.
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24. Falkenberg, H.K.; Mathisen, T.S.; Ormstad, H.; & Eilertsen, G. "Invisible" visual impairments. A qualitative study of stroke survivorsexperience of vision symptoms, health services and impact of visual impairments. *BMC Health Services Research*. **2020**, 20(1), 1-12.
25. Falkenberg, H.K.; Mathisen, T.S.; Ormstad, H.; & Eilertsen, G. "Invisible" visual impairments. A qualitative study of stroke survivorsexperience of vision symptoms, health services and impact of visual impairments. *BMC Health Services Research*. **2020**, 20(1), 1-12.
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28. Gustafsson, L.; & Bootle, K. Client and carer experience of transition home from inpatient stroke rehabilitation. *Disability and Rehabilitation*. **2013**, 35(16), 1380-1386.
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32. Ing, M.M.; Vento, M. A.; Nakagawa, K.; & Linton, K.F. A qualitative study of transportation challenges among intracerebral hemorrhage survivors and their caregivers. *Hawai'i Journal of Medicine & Public Health*. **2014**, 73(11), 353.
33. Johnson, M.A. "A qualitative analysis of the lived experiences of African Americans diagnosed with primary stroke. *Dissertation Abstracts International Section A: Humanities and Social Sciences* **2014**, 75(6-A(E)): No Pagination Specified.
34. Leahy, D.M.; Desmond, D.; Coughlan, T.; O'Neill, D.; & Collins, D.R. Stroke in young women: An interpretative phenomenological analysis. *Journal of Health Psychology*. **2016**, 21(5), 669-678.
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37. O'Connell, B.; Hanna, B.; Penney, W.; Pearce, J.; Owen, M.; & Warelw, P. Recovery after stroke: a qualitative perspective. *Journal of quality in clinical practice*. **2001**, 21(4), 120-125.
38. Olofsson, A.; Andersson, S.O.; & Carlberg, B. 'If only I manage to get home I'll get better'- Interviews with stroke patients after emergency stay in hospital on their experiences and needs. *Clinical rehabilitation*. **2005**, 19(4), 433-440.
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44. Visvanathan, A.; Mead, G.; Dennis, M.; Whiteley, W.; Doubal, F.; & Lawton, J. Maintaining hope after a disabling stroke: A longitudinal qualitative study of patients' experiences, views, information needs and approaches towards making treatment decisions. *PLoS One*. **2019**, 14(9), e0222500.

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48. Wiles, R.; Ashburn, A.; Payne, S.; & Murphy, C. Discharge from physiotherapy following stroke: the management of disappointment. *Social science & medicine*. **2004**, 59(6), 1263-1273.
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50. Wottrich, A.W.; Åström, K.; & Löfgren, M. On parallel tracks: newly home from hospital—people with stroke describe their expectations. *Disability and rehabilitation*. **2012**, 34(14), 1218-1224.

Not relevant stage:

1. Alexandrov, A.W.; Brewer, B. B.; Moore, K.; Grau, C.; Beenstock, D.J.; Cudlip, F.; ... & Alexandrov, A. V. Measurement of patients' perceptions of the quality of acute stroke services: Development and validation of the STROKE perception report. *Journal of Neuroscience Nursing*. **2019**, 51(5), 208-216.
2. Henderson, A.; Milburn, D.; & Everingham, K. Where to from here: patients of a day hospital rehabilitation programme perceived needs following stroke. *Contemporary Nurse*. **1998**, 7(4), 211-216.
3. Ing, M.M.; Linton, K.F.; Vento, M.A.; & Nakagawa, K. Investigation of Stroke Needs (INVISION) Study: stroke awareness and education. *Hawai'i Journal of Medicine & Public Health*. **2015**, 74(4), 141.
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5. Olofsson, A.; Andersson, S.O.; & Carlberg, B. 'If only I manage to get home I'll get better'-Interviews with stroke patients after emergency stay in hospital on their experiences and needs. *Clinical rehabilitation*. **2005**, 19(4), 433-440.
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Not relevant design:

1. Andrew, N.E.; Kilkenny, M.; Naylor, R.; Purvis, T.; Lalor, E., Moloczij, N.; ... & National Stroke Foundation. Understanding long-term unmet needs in Australian survivors of stroke. *International Journal of Stroke*. **2014**, 9, 106-112.
2. Boter, H.; Rinkel, G.J.; & De Haan, R.J. Outreach nurse support after stroke: a descriptive study on patients' and carers' needs, and applied nursing interventions. *Clinical Rehabilitation*. **2004**, 18(2), 156-163.
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7. Forster, A.; Brown, L.; Smith, J.; House, A.; Knapp, P.; Wright, J. J.; & Young, J. Information provision for stroke patients and their caregivers. *Cochrane database of systematic reviews*. **2012**, (11).
8. Hermans, E.; Anten, H.W.; Diederiks, J.P.; & Philipsen, H. Use of Care by Home-dwelling Stroke Patients during Three Years following Hospital Discharge. *Scandinavian Journal of Caring Sciences*. **1998**, 12(3), 186-190.
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10. Hotter, B.; Padberg, I.; Liebenau, A.; Knispel, P.; Heel, S.; Steube, D.; ... & Meisel, A. Identifying unmet needs in long-term stroke care using in-depth assessment and the post-stroke checklist–The Managing Aftercare for Stroke (MAS-I) study. *European Stroke Journal*. **2018**, 3(3), 237-245.
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12. Ing, M.M.; Linton, K.F.; Vento, M.A.; & Nakagawa, K. Investigation of stroke needs (INVISION) study: Stroke awareness and education. *Hawai'i Journal of Medicine & Public Health*. **2015**, 74(4), 141.
13. Jerome, D.; Dehail, P.; Daviet, J.C.; Lamothe, G.; De Sèze, M.P.; Orgogozo, J.M.; & Mazaux, J.M. Stroke in the under-75S: Expectations, concerns and needs. *Annals of physical and rehabilitation medicine*. **2009**, 52(7-8), 525-537.
14. Johnson, J.; Pearson, V.; & McDivitt, L. Stroke rehabilitation: assessing stroke survivors' long-term learning needs. *Rehabilitation Nursing*. **1997**, 22(5), 243-248.
15. Lincoln, N.B.; Gladman, J.R.F.; Berman, P.; Luther, A.; & Challen, K. Rehabilitation needs of community stroke patients. *Disability and rehabilitation*. **1998**, 20(12), 457-463.

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17. Martin, B.J.; Yip, B.; Hearty, M.; Marietta, S.; & Hill, R. Outcome, functional recovery and unmet needs following acute stroke. Experience of patient follow up at 6 to 9 months in a newly established stroke service. *Scottish medical journal*. **2002**, 47(6), 136-137.
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20. Moreland, J.D.; DePaul, V.G.; DeHueck, A.L.; Pagliuso, S.A.; Yip, D.W.; Pollock, B.J.; & Wilkins, S. Needs assessment of individuals with stroke after discharge from hospital stratified by acute Functional Independence Measure score. *Disability and rehabilitation*. **2009**, 31(26), 2185-2195.
21. O'Halloran, R.; Worrall, L.; & Hickson, L. Stroke patients communicating their healthcare needs in hospital: a study within the ICF framework. *International journal of language & communication disorders*. **2012**, 47(2), 130-143.
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24. Patchick, E., et al. "The process and outcomes of six-month reviews in care home settings: are we meeting the needs of stroke survivors in care homes? *Clinical Rehabilitation*. **2018**, 32(10): 1413-1413.
25. Post, M.W.; Visser-Meily, J.M.; & Gispen, L.S. Measuring nursing needs of stroke patients in clinical rehabilitation: a comparison of validity and sensitivity to change between the Northwick Park Dependency Score and the Barthel Index. *Clinical rehabilitation*. **2002**, 16(2), 182-189.
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27. Sowtali, S. N., & Harith, S. Educational needs among stroke patients admitted to hospital universiti sains Malaysia: Preliminary findings. *Jurnal Sains Kesihatan Malaysia (Malaysian Journal of Health Sciences)* **2014**, 12(1).
28. Tistad, M.; von Koch, L.; Sjöstrand, C., Tham, K.; & Ytterberg, C. What aspects of rehabilitation provision contribute to self-reported met needs for rehabilitation one year after stroke—amount, place, operator or timing?. *Health Expectations*. **2013**, 16(3), e24-e35.
29. van Veenendaal, H.; Grinspun, D.R.; & Adriaanse, H.P. Educational needs of stroke survivors and their family members, as perceived by themselves and by health professionals. *Patient education and counselling*. **1996**, 28(3), 265-276.

30. Ward, A.; Payne, K.A.; Caro, J.J.; Heuschmann, P.U.; & Kolominsky-Rabas, P.L. Care needs and economic consequences after acute ischemic stroke: the Erlangen Stroke Project. *European journal of neurology*. **2005**, 12(4), 264-267.
31. Yonaty, S.A.; & Kitchie, S. The educational needs of newly diagnosed stroke patients. *Journal of Neuroscience Nursing*. **2012**, 44(5), E1-E9.
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Not relevant population

1. Dalvandi, A.; Ekman, S.L.; Reza Khankeh, H.; Seyed Bagher Maddah, S.; & Heikkilä, K. Rehabilitation experts' experience of community rehabilitation services for stroke survivors in Iran. *Topics in stroke rehabilitation*. **2012**, 19(5), 395-404.
2. Garcia, S.F.; Hahn, E.A.; Magasi, S.; Lai, J.S.; Semik, P.; Hammel, J.; & Heinemann, A.W. Development of self-report measures of social attitudes that act as environmental barriers and facilitators for people with disabilities. *Archives of physical medicine and rehabilitation*. **2015**, 96(4), 596-603.
3. Glickman, L.B. Clients with stroke and non-stroke and their guardians' views on community reintegration status after in-patient rehabilitation. *Malawi Medical Journal*. **2018**, 30(3), 174-179.
4. Hodson, T.; Gustafsson, L.; & Cornwell, P. The lived experience of supporting people with mild stroke. *Scandinavian journal of occupational therapy*. **2020**, 27(3), 184-193.
5. Morris, R. Meeting the psychological needs of community-living stroke patients and carers: a study of third sector provision. *Disability and Rehabilitation*. **2016**, 38(1), 52-61.
6. Visser-Meily, A.; Post, M.; Gorter, J.W.; Berlekom, S.B.V.; Van Den Bos, T.; & Lindeman, E. Rehabilitation of stroke patients needs a family-centred approach. *Disability and rehabilitation*. **2006**, 28(24), 1557-1561.

Studies not in English

- 1- Kim, N.H.; Kwon, Y.S.; Kim, M.; Lee, K. H.; & Kwak, H.W. A study on the nutritional status, symptoms, and information needs in stroke patients with dysphagia. *Journal of Korean biological nursing science*. **2011**, 13(1), 72-80.
- 2- Pedreira, L.C.; & Lopes, R.L.M. Vivência do idoso dependente no domicílio: análise compreensiva a partir da historicidade heideggeriana. *Revista Eletrônica de Enfermagem*. **2012**, 14(2), 304-12.

Low quality studies

1. Garrett, D.; & Cowdell, F. Information needs of patients and carers following stroke. *Nursing older people*. **2005**, 17(6).
2. Kamalakannan, S.; Venkata, M.G.; Prost, A.; Natarajan, S.; Pant, H.; Chitalurri, N.; ... & Kuper, H. Rehabilitation needs of stroke survivors after discharge from hospital in India. *Archives of physical medicine and rehabilitation*. **2016**, 97(9), 1526-1532.
3. McLean, J.; Roper-Hall, A.; Roper-Hall, A.; & Main, A. Service needs of stroke survivors and their informal carers: a pilot study. *Journal of Advanced Nursing*. **1991**, 16(5), 559-564.
4. Vincent, C.; Deaudelin, I.; Robichaud, L.; Rousseau, J.; Viscogliosi, C.; Talbot, L.R.; & Desrosiers, J. Rehabilitation needs for older adults with stroke living at home: perceptions of four populations. *BMC geriatrics*. **2007**, 7(1), 1-17.

Included Studies:

1. Abrahamson, V.; Wilson, P.M. How unmet are unmet needs post-stroke? A policy analysis of the six-month review. *BMC Health Serv. Res.* **2019**, 19, 480.
2. Chen, L.; Xiao, L.D.; De Bellis, A. First-time stroke survivors and caregivers' perceptions of being engaged in rehabilitation. *J. Adv. Nurs.* **2016**, 72, 73–84.
3. Dalvandi, A.; Heikkilä, K.; Maddah, S.S.B.; Khankeh, H.R.; Ekman, S.L. Life experiences after stroke among Iranian stroke survivors. *Int. Nurs. Rev.* **2010**, 57, 247–253.
4. Danzl, M.M.; Harrison, A.; Hunter, E.G.; Kuperstein, J.; Sylvia, V.; Maddy, K.; Campbell, S. "A lot of things passed me by": Rural stroke survivors' and caregivers' experience of receiving education from health care providers. *J. Rural. Health* **2016**, 32, 13–24.
5. Davoody, N.; Koch, S.; Krakau, I.; Hägglund, M. Post-discharge stroke patients' information needs as input to proposing patient-centred eHealth services. *BMC Med. Inform. Decis. Mak.* **2016**, 16, 66.
6. Eames, S.; Hoffmann, T.; Worrall, L.; Read, S. Stroke patients' and carers' perception of barriers to accessing stroke information. *Top. Stroke Rehabil.* **2010**, 17, 69–78.
7. Gard, G.; Pessah-Rasmussen, H.; Brogårdh, C.; Nilsson, Å.; Lindgren, I. Need for structured healthcare organization and support for return to work after stroke in Sweden: Experiences of stroke survivors. *J. Rehabil. Med.* **2019**, 51, 741–748.
8. Hare, R.; Rogers, H.; Lester, H.; McManus, R.J.; Mant, J. What do stroke patients and their carers want from community services? *Fam. Pract.* **2006**, 23, 131–136.
9. Harrison, M.; Ryan, T.; Gardiner, C.; Jones, A. Psychological and emotional needs, assessment, and support post-stroke: A multi-perspective qualitative study. *Top. Stroke Rehabil.* **2016**, 24, 119–125.
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Supplementary file (C):

Joanna Briggs Institute qualitative critical appraisal checklist

1. Is there congruity between the stated philosophical perspective and the research methodology?
2. Is there congruity between the research methodology and the research question or objectives?
3. Is there congruity between the research methodology and the methods used to collect data?
4. Is there congruity between the research methodology and the representation and analysis of data?
5. Is there congruity between the research methodology and the interpretation of results?
6. Is there a statement locating the researcher culturally or theoretically?
7. Is the influence of the researcher on the research, and vice- versa, addressed?
8. Are participants, and their voices, adequately represented?
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Table S2: Joanna Briggs Institute qualitative critical appraisal checklist

	Abrahams on and Wilson 2019	Chen, Xiao and Bellis 2015	Dalvandi et al. 2010	Danzl et al. 2016	Davoody et al. 2016	Eame s et al. 2010	Gard et al. 2019	Garrett, and Cowdel l 2005	Hare et al. 2006	Harriso n et al. 2016	Hartford, Lear and Nimmon, 2019	Jones et al. 2008	Kama lakan nan et al. 2016	Lamo ntagn e et al. 2019	Liddl e et al. 2009
1	Y	Y	Y	Y	N	N	N	Y	N	Y	Y	Y	N	Y	Y
2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
5	Y	Y	Y	Y	U	U	U	Y	U	Y	Y	Y	U	Y	Y
6	Y	U	Y	N	N	N	Y	N	Y	Y	Y	Y	N	Y	Y
7	Y	Y	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	N	Y	Y
8	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
9	Y	Y	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
10	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Total	10	9	10	8	7	7	8	8	8	10	10	10	6	10	10

	Lui, and Mackenzie 1999	Martinsen, Kirkevold and Sveen 2015	McLean et al. 1991	Nordin et al. 2014	Poulin et al. 2019	Reed et al. 2010	Sadler et al. 2014	Schmitz and Finkelstein 2010	Shiley et al 2020	Shook and Stanton 2016	Sumathipala et al. 2012	Talbot et al. 2004	Vincents et al. 2007	White, Magain and Pollack 2009	Wiles et al. 1998	Yeung et al. 2015
1	Y	Y	N	N	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y	N
2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
5	Y	Y	U	U	Y	Y	U	U	Y	Y	U	Y	Y	Y	Y	U
6	N	N	Y	Y	Y	Y	N	Y	Y	N	N	N	N	Y	Y	N
7	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	U	Y
8	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y
9	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	U	Y	U	Y
10	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Total	9	9	4	8	10	10	7	9	10	9	7	7	7	10	8	7

Supplementary file (D):

Table S3

Auth or	First order interpretations (what quotes are used to show what participants say) Second order interpretations (what the authors of articles say).	Codes	Clusters	Themes
Che n et al. 2015	Readiness to return home First-time stroke survivors demonstrated low health literacy in stroke and prevention of stroke recurrence. Their needs to learn more about stroke and rehabilitation programmes were usually ignored in busy clinical settings before discharge from the hospital. Participants perceived that staff members were too busy to explain more detailed information to them and inflexible in caregiver training due to time constraint: <i>They never tell me much about the disease. . . I had very bad experience having a stroke. . . and I said 'Please tell me what I had'. He [the doctor] said, 'Oh I will look into your file'. . . he came back and said, 'Oh you had a LACI'. I said, 'Now what's it short for?', but got no explanation. . . No rehabilitation services information. You got to look up in the phone book and ring them (Adrian, SP8).</i> <i>I also felt pressured as I was told they had to teach ADL, showering, toileting. . . I had to go in 7 o'clock in the morning. . . I couldn't because I was working then. . . it was very traumatic for me. . . (Eileen, CP6).</i> The caregivers also said that they were not involved in discharge education for stroke survivors with cognitive impairment that required a long-term and considerable effort in rehabilitation and adjustment in their daily activities:	The need for information on stroke and recovery programs Providers time restriction Amount of information given The need for rehabilitation programs The need for cognitive support	Needs for info on stroke Factors that influence care experience: accounting for tailoring information need Adequate information delivery Needs for info on rehabilitation program Rehabilitation needs	Limited availability and suitability of information Care experience Limited availability and suitability of information Limited availability and suitability of information Adequate care and services

<i>The only thing I wasn't prepared for was the strategies to manage cognitive changes from the clinical neurologist cos [because] I had not spoken to her until Bill was walking out of the ward (Jane, CP4).</i> Moreover, challenges to manage stroke associated cognitive impairment were compounded by other comorbidities that required caregivers to carefully monitor the effect and side effects of treatment: <i>She [the stroke survivor with cognitive impairment] had no understanding, no insight that she was meant to be on this one [antiplatelet]. . .It certainly has not been explained of medication in the discharge. . .The hospital staff said ' . . we gave you one medication list on discharge' (Jack, CP9).</i> Participants were not aware of side effects of medications that may cause adverse events and contribute to unexpected hospital readmission: <i>The only thing I thought I was a little bit concerned was that he hasn't had a proper drug review. . .The Baclofen was, probably I wasn't aware that it could've been blocking progress. . . (Rebecca, CP11).</i> The participants perceived that knowledge and skills enabling them to maintain activities of daily living, manage ongoing treatments and nursing care for existing chronic conditions were prerequisites for participating in rehabilitation programmes. However, the participants were not fully prepared before discharge from hospital: <i>...it was almost like [being] throwing in the deep end. I've never showered anyone in my life before. . .we just sort of muddled through. . .maybe like when you're leaving rehab</i>	Delayed cognitive education Need for info on treatment side effects Needs for info on medication medication side effects info needs ADL training Self-management training Discharge education plan Training of carer	Rehabilitation needs Needs for info on rehabilitation program Needs for info on rehabilitation program Needs for info on rehabilitation program Needs for info on rehabilitation program Clear and coordinated plan Rehabilitation needs	Adequate care and services Limited availability and suitability of information Limited availability and suitability of information Limited availability and suitability of information Limited availability and suitability of information Adequate care and services Adequate care and services
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<i>inpatient, someone probably should go through with the partner of the person about showering, medications. . . (Judy, CP10).</i> These perceptions of not being prepared and engaged to participate in rehabilitation after discharge from hospital clearly reveal the lack of coordinated discharge planning process among the multidisciplinary team that targets first-time stroke survivors and caregivers' educational and training needs. The consequences of maintaining this status quo would be lack of self-care ability and self-efficacy in managing stroke associated chronic conditions, restoring function and preventing complications during rehabilitation. The nurse's involvement as a discharge planner and coordinator for this patient population may be the better intervention to the situation. Coping with care transition There was a lack of communication and continuity of treatment when the stroke survivors were transferred from one institution to another. Rob expressed his dissatisfaction with unclear care plan when his brother Philip was transferred to a rehabilitation facility. The situation threatened not only the patient's safety but also the outcomes of rehabilitation programme and continuity of care: <i>. . .at that stage, there was a considerable degree of lack of communication where one didn't know what was happening. . .Philip was first transferred to XX [rehab ward]...so that was the transitional period that was difficult for him. . .(Rob, CP12).</i> Transition from acute care to rehabilitation is a difficult time for stroke survivors and their family caregivers, who are still	The need for clear and coordinated discharge plan Consequences of lack of discharge planning Lack of self-efficacy Self-management Restoring function Preventing complication The need for effective communication services The needs for continuity of care The need for clear transferred plan The need for effective communication services	Clear and coordinated plan Clear and coordinated plan effective communication services rehabilitation needs Clear and coordinated plan effective communication services	Adequate care and services Adequate care and services Adequate care and services Adequate care and services Adequate care and services Adequate care and services
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grieving the loss of health and independence and trying to adapt to their changed roles in their lives. During the transfer, stroke survivors were at risk of missed care and even a breakdown in the continuum of care caused by inadequate clinical handover, which posed a threat to patient safety and positive rehabilitation outcomes. Transition from hospital care to home care was a significant step for stroke survivors and caregivers to cope and adjust with daily care activities at home. Stroke survivors and caregivers were facing challenges to adapt to the new role in their life: <i>I don't have that sounding board. . .it puts an enormous weight of responsibility on me in the fact that I don't have his technical expertise to call upon. . .(Jane, CP4).</i> <i>...Sometimes you feel you are left in the limbo...It is just that our bodies both are so tired. . . (Maria, CP3)</i> <i>...It's unfortunate sometimes I hear Maria, I wish I wasn't here anymore. . . (Henry, SP3)</i> The shortened length of stay in an acute care hospital resulted in most first-time stroke survivors being discharged with ongoing treatment and a level of dependency due to physical and mental impairments. Care transition may be compromised if caregivers were not prepared and supported during the transition: <i>I was still in the shock of what happened to Sam, back and forth from the hospital...and they said that we had to take the rented house anyway because it was for him to get transitional care. ...The day they sent him home, I was moving to that place [new rented home]. So it was moving and have him in home...he was home only a week and he ended up in XX [residential facility] because I couldn't cope. It was too</i>	Transitional needs Emotional support Adaptational support Missed care Safety Care continuity Rehabilitation outcomes Training need for carer Patient's Despair Shorter hospital care High dependency Compromised transitional needs Unprepared carers DISCHARGE EXPERIENCE Shock Coping issues Cognitive deficits	Discharge experience Rehabilitation needs Post discharge experience Factors that influence care experience DISCHARGE EXPERIENCE	Care experience Adequate care and services Care experience Care experiences Care experience
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	<i>much...He couldn't understand why he wasn't in his own house (Eileen, CP6).</i> In contrast, provision of education that suits stroke survivors' individual needs, and taking into consideration the home situation and caregivers' emotional endurance, can help smooth the transition from hospital care to home care: <i>I was there [a rehabilitation ward] every day. So I was involved in what he was doing. When we came home, they showed me every- thing. Remember that nurse came out. She told me everything I should be doing. I thought they were very good (Marina, CP8).</i> The variation in the perceptions of care transition is an indicator of a lack of guidelines and a coordinated approach to ensure the continuity of rehabilitation during care transition for all stakeholders involved. Dealing with fragmented rehabilitation services The participants' perceptions of rehabilitation programmes were stated as fragmented and disorganized. They were compelled to undertake coordination with limited support from health professionals. They perceived these fragmented services as challenging during post-discharge rehabilitation: <i>...No rehabilitation services information. You got to look up in the phone book and ring them...This is how we got onto the XX [rehabilitation centre]...There is no coordination in between...you got to pull them [services] all together . . .so this part coordinates with that. . .I think the basis of good rehab is there now, it just has to be tidied up at the ends (Adrian, SP8).</i>	Discharge education/plan: Individualistic Focus on Emotional endurance The need for clear and coordinated discharge plan REHAB EXPERIENCE Fragmented services Limited professional support Limited information on services	Clear and coordinated plan Clear and coordinated plan DISCHARGE EXPERIENCE	Adequate care and services Adequate care and services Care experience
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	The participants identified that if they had a person they could talk to regarding services and other concerns it would benefit their post-hospital rehabilitation journey. They suggested that nurses were in an ideal position to coordinate their rehabilitation: <i>I just had an idea. A sort of discharge rehab nurse that could ring you perhaps two or three times after you were at home...it would be reassuring even if you didn't have a problem, it would be a link, a transition, intermediate, that would be great (Rebecca, CP11).</i> <i>. . .someone to talk to sometimes, I think. Just like a bridge to cross (Michael, SP11).</i> These participants' suggestion about the nurse's role in post-discharge rehabilitation was based on their experiences in working with nurses in rehabilitation wards in hospitals. The lack of engagement of stroke survivors and caregivers in discussing rehabilitation programmes and in making informed decision of the programmes was evident when the rehabilitative interventions were not delivered consistently to a participant with cognitive impairment that caused unnecessary stress to both the participant and his wife: <i>. . .physiotherapist, occupational therapist and speech therapist. . .they make an appointment. . .but they just come when- ever. . .they overlapped on a couple of occasions. . .in James's case, it got to be structured to a certain degree because he gets confused. . .(Sue, CP2).</i> In contrast, participants also talked about how a motivational interview that health professional used increased their confidence and rehabilitation intensity:	The need for post discharge coordinator Discharge nurse Intermediary communicator Consequences of lack of discharge planning Lack of engagement Stress to carers Rehab experiences: Uncoordinated professional visits Motivational interviews Improved confidence	Effective communication services Effective communication services Clear and coordinated plan POST DISCHARGE EXPERIENCE Encouragement and motivation	Adequate care and services Adequate care and services Adequate care and services Care experience Supportive network
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	<i>They asked what my goals were...our driveway at home has got a step down the bottom. I just asked how I should best handle that. . .they talked me through and I tried it at home. . .they've been successful. . .to subconsciously keep you motivated. I look forward to Mondays and Fridays, just to see what's going to happen to me (Andrew, SP10).</i> When rehabilitation interventions engaged stroke survivors in planning and goal setting, they encouraged stroke survivors to take charge of their rehabilitation, a crucial process to develop their self-care and self-management ability in a long-term recovery. Uncertainty about ongoing rehabilitation Participants perceived ongoing changing of rehabilitation goals while they experienced different stages of recovery after stroke. However, they had to wait for a period to commence a new rehabilitation programme once they had been discharged from another: <i>Well, each time we were waiting for different packages, it would be about two or three weeks, you know...yeah it affects our life, cos [because] he wasn't getting nothing. We didn't know what is gonna to happen (Eileen, CP6).</i> The lack of continuity of rehabilitation was an indicator of disengaging stroke survivors and caregivers in goal setting and planning rehabilitation programs in a consistent and coordinated way based on stroke survivor's needs in different stages of recovery. In addition, participants were concerned that the interruption of rehabilitation may	Successful Goal-setting Engagement in goal setting Better self-management Waiting for rehabilitation Needs for continuity of care Rehabilitation delay consequences: jeopardize their recovery	Clear and coordinated plan Clear and coordinated plan Rehabilitation needs Post discharge experience Rehabilitation needs Rehabilitation needs	Adequate care and services Adequate care and services Adequate care and services Care experience Adequate care and services Adequate care and services
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	jeopardize their recovery and hinder them from achieving their rehabilitation goals: <i>Philip's primary goal was to get his right arm working as the best he can...so that was a bit of worry early on because we had the two weeks' gap in between being discharged and starting this program and ...it took a week and a half or something before we actually saw the OT [Occupational Therapist] in here other than on the initial session with XX [therapist's name] identifying goals (Rob, CP12).</i> Stroke rehabilitation aims to enable stroke survivors to adapt to their new life with improved physical, emotional and psychological well-being. Stroke survivors' needs change over time. This study revealed the lack of regular assessment and evaluation of stroke survivors' rehabilitation potential, once the planned rehabilitation programme was completed: <i>No automatic follow up on what I am doing. That's the biggest problem. You've got to have some input...There is no follow up unless you do it yourself (Adrian, SP8).</i> Family caregivers expected that ongoing rehabilitation would prevent stroke survivors from physical and cognitive deterioration and stroke associated complications such as falls. Caregivers also believed that engaging in long-term rehabilitation may alleviate caregiver burden. Jack was caring for Mary who had memory loss post stroke. He shared his story about the difficulty he experienced due to a lack of strategies to manage cognitive impairment and rehabilitation for this condition: <i>Mary and I both got iPad. I have asked around the world for Apps on iPad to help her with her memory...so you know,</i>	hinder them from achieving their rehabilitation goals Waiting for rehabilitation Lack of follow-up services Lack of follow-up services NEED FOR ONGOING REHABILITATION Prevent physical deterioration Cognitive decline Reduce caregiver burden Support for cognitively impaired survivors.	Post discharge experience Follow up services Rehabilitation needs Rehabilitation needs	Care experience Adequate care and services Adequate care and services Adequate care support
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<i>cognitive things, I did ask [therapists], I had no information from them (Jack, CP9).</i> The participants revealed that inadequate education about how to prevent and manage falls contributed to readmission to hospital for stroke survivors and added stress for caregivers: <i>It [wheelchair] moved with brakes on it and he slipped down there. I didn't even think about the breakage. The next morning I noticed his leg was sticking out to the side like that...he was there [hospital] for three weeks (Eileen, CP6).</i> The above examples indicate that the family caregivers were not well prepared to care for stroke survivors due to lack of ongoing caregiver education and support about management of stroke-related complications. The long-term commitment to caregiver role without adequate caregiver support also resulted in social isolation: <i>I am always here to help him. Assist in the shower, personal care. If I happen to go out, I always set up all his lunch before I go...I am just around most of the time. I don't go out very often (Marina, CP8).</i> The consequences of social isolation without interventions include depressive symptoms, high levels of caregiver burden and low levels of quality of life. Social isolation is also an indicator that the social reintegration based on stroke survivors and caregivers' psychosocial and spiritual needs is largely overlooked in rehabilitation.	Fall prevention info needs Training need for carer before discharge	Information needs on stroke Rehabilitation needs	Limited availability and suitability of information
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