

## Online Supplementary Figure 1: Search Strategy

Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily, Ovid MEDLINE and Versions(R): 1946 to May 23, 2018

#	Search	Results
1	((patient* or hospital or spous*) adj4 discharg*) or postdischarg* or ((post or postacute or post acute) adj2 discharge) or survivor*).tw,kf. or Patient Discharge/ or "continuity of patient care"/ or aftercare/ or rehabilitation/ or transitional care/ or Survivors/	222436
2	((family or spous* or primary or informal or survivor*) adj4 (carer* or caregiver* or care giver*)).tw,kf. or exp Caregivers/	37725
3	(interview* or theme* or qualitative or attitude or perspective* or perception*).tw,kf. or exp qualitative research/ or focus groups/ or interviews as topic/ or "surveys and questionnaires"/ or Narration/	1229835
4	1 and 2 and 3	1316
5	limit 4 to (english language and yr="2000 -Current")	1151
6	(pediatric* or teen* or adolescen* or infant* or baby or babies).tw,kf. or child/ or exp child, preschool/ or exp infant/ or exp Pediatrics/	2635582
7	5 not 6	1008
8	remove duplicates from 7	998

**CINAHL via EBSCO May 23/2018**

#	Query	Limiters/Expanders	Results
S7	s5 not s6	Limiters - Published Date: 20000101-20181231; Language: English Search modes - Boolean/Phrase	987
S6	pediatric* or teen* or adolescen* or infant* or baby or babies or (MH "Child+") OR (MH "Infant+") OR (MH "Pediatrics+")	Limiters - Published Date: 20000101-20181231; Language: English Search modes - Boolean/Phrase	483,592
S5	S1 AND S2 AND S3	Limiters - Published Date: 20000101-20181231; Language: English Search modes - Boolean/Phrase	1,189
S4	S1 AND S2 AND S3	Search modes - Boolean/Phrase	1,372
S3	(interview* or theme* or qualitative or attitude or perspective* or perception*) or MH "Qualitative Studies+" OR MH "Surveys" OR MH "Narratives" OR MH "Interviews+" OR MH "Focus Groups" or MH "Questionnaires+"	Search modes - Boolean/Phrase	648,492
S2	(family or spous* or primary or informal or survivor*) N4 (carer* or caregiver* or care giver*) or (MH "Caregivers") or (MH "Caregiver Burden")	Search modes - Boolean/Phrase	30,451
S1	((patient* or hospital or spous*) N4 discharg*) or postdischarg* or ((post or postacute or post acute) N2 discharge) or survivor* or (MH "Patient Discharge+") or (MH "After Care") or (MH "Rehabilitation") or (MH "Continuity of Patient Care") or (MH "Transitional Care") or (MH "Survivors") OR (MH "Cancer Survivors") OR (MH "Polio Survivors")	Search modes - Boolean/Phrase	87,605

**Online Supplementary Table 1: Reciprocal Translation Theme Table**

Domain	Theme	Themes from original papers	Study	Quote
Suboptimal access to clinicians after discharge	Unclear who to call	Whom to call post-discharge	Dossa	Caregiver : I mean, if he's getting sick at nighttime, who do you talk to; who do you call to be able to get a simple answer? Do we just let him sleep it off? Do we give him medication? I mean, I know they do have a primary care doctor, but when the way the hospital works that they have a team that changes from week to week, where my father was seen by the neurology department. I mean, I figured that would be the person that I would want to talk to, not his primary care doctor who hasn't seen him at all since he was in the hospital. I don't know how much she's kept in the loop of things when they get discharged from the hospital. Yeah, she sees him at a certain time afterward. But, in the meantime, who is the person that you go to if there's a problem?
	Unable to reach providers after discharge	Unable to reach either discharging provider or primary care provider for needs	Dossa	Pg. 280 "Yeah, I called there (surgical site). But the people over there, they always tell me I've got to go back to the doctor over in (primary care site). And I'm like—I'm going back and forth just like a yo-yo. You know, I call this one, I call that one. And nobody seems to want to give you what you need for the pain. If they gave me what I needed for the pain, I probably could go in and let them bend my leg. But if I'm in there just on Tylenol or aspirin, that ain't going to do it. And I tell these people, they say, "Well, you know, you've just got to go in and probably have it taken care of." And they're just therapists. And I was just getting a little disgruntled with the hospital; I called about five times, left messages on the phone for the doctor to get a hold of me because I was having problems in therapy. I kept getting their answering services, and then I said, The hell with it. And my girlfriend called a couple of times."
	Desire for a hotline	Program delivery	Blair	Pg 35 I suggest a hotline. Different people may answer and call you back and when they do, they'll listen to whatever your issue is and refer you sometimes.
Overwhelming duties as liaison for appointments and medications	Caregivers responsible for almost all care at home	Caregivers responsible for medications, appointments, transportation, ADLs	Blair	Pg. 33 "I pretty much do everything for him. I give him his medications, take him to doctor's appointments, I drive him everywhere. I pick up his medicines at the pharmacy. Not once has he ever had to make a trip to the pharmacy to get his medications. I do that for him. I cook his food; he can't have salt so I cook without salt

	Managing medications - challenge	Family caregivers feel unprepared and at times overwhelmed by postdischarge medication reconciliation and management	Coleman	<p>Pg 15</p> <p>Then I get him home and try to put his new pills with the ones he is already on and they are different names. They are different colors. They are . . . Oh my gosh! It is so confusing. Why in the world, when you are taking this particular prescription pill, why is it if you order it from this particular outlet, why is it this color? And this shape? But then you go through his mail order and it comes in a totally different shape or color</p>
	Pharmacists - facilitators	Family caregivers feel unprepared and at times overwhelmed by postdischarge medication reconciliation and management	Coleman	<p>Pg 15</p> <p>The pharmacist was my lifeline . . . I mean she sat there (with me) for like 20min on a bench. Other pharmacists are filling things and she's just sitting with me. And that just made all the difference."</p> <p>They (the pharmacists) will tell you anything you want to know about the medication. Why they are on it. Dr. L took Joe off of a pill. I called him (Dr. L) to ask him why but I never heard from back him, so I called the pharmacist and she told me.</p>
Need for information and training at discharge	Discharge information – range of adequacy	Caregivers with many unanswered questions at discharge	Bakas	<p>Pg 244</p> <p>"The only thing they let us know is that he needed to change his diet and go to speech therapy. Well, are there other things that he should be doing totally different? Like, should he stop smoking? Should he be exercising? It seems like if you had a heart attack, they tell you all this stuff, but a stroke is like, I don't know."</p>
		Adequacy of discharge instructions	Foust	<p>Pg 203-204</p> <p>Two caregivers described being satisfied because the instructions were "simple" or "pretty thorough"</p>
	Lack of information about insurance coverage	Family caregivers often assume the responsibility for the sequencing of posthospital care plan tasks and anticipating next steps	Coleman	<p>Pg 17</p> <p>Sometimes the insurance questions too . . . people say we are releasing you and you need to get this, that and the other thing and you kind of don't know, is insurance going to cover it? Do I just go buy it? You just don't really know.</p>
	Discharge training- often inadequate	Caregivers untrained in situations that could arise	Bakas	<p>Pg 244</p> <p>There was nobody there that could tell me [about] bowel movements and things like that... When she got home she was impacted...I was there with her alone. She was in pain."</p>
		Program Delivery	Blair	Pg 35

				Maybe we should be encouraged as caretakers to learn how to take blood pressure, you know, do that for ourselves so that we would know what's going on.
Feeling disregarded by clinicians	Lack of engagement by providers	Patient and caregiver preparation for discharge	Foust	<p>Pg 202 As one caregiver succinctly noted, "when she was released, I was at work. I came home. She was home"</p> <p>"Because I was very upset, I mean very upset. I been going up there, like I said, when I was able to five times while she's been in there and I haven't spoken to anybody. It's weird that, you know, the day I came to get her to take her home, then somebody, the nurse, the discharge nurse, wound up explaining to me, you know, the status and what was happening to her.</p> <p>Pg 203 one caregiver expressed frustration saying "[I] would have liked to have been told more about what was going on to him. Just good to be told anything at all"</p>
		Adequacy of discharge instructions		
		Family caregivers need encouragement to assert their role and identity	Coleman	<p>Pg 16 And then on where the nurses write their name of who is on shift at that time, I wrote my name and my cell phone number and that I have power of attorney. Nobody, not once, called me. Even though decisions were being made and they were asking for input. Not once did somebody call me.</p> <p>And I was . . . really, under the radar in terms of would I be able to participate in a discussion on the discharge process</p>
		Challenges	Blair	<p>Pg 33 One caregiver expressed her frustration with a lack of acknowledgment from the patient's healthcare providers this way: What bothers me is that doctors that I meet here, they ignore the caretakers. Like you can go to the office and the doctor just solely concentrates on the patients, that's wonderful and we sit in a little corner and we are not allowed to say anything if I said something they will just say, "He is the patient; let him say it to me."</p>
	Asserting active role in care	Family caregivers need encouragement to assert their role and identity	Coleman	<p>Pg 16 And usually, believe it or not, I'm an introvert and quiet and shy. But I just had to be massively assertive. So the doctor comes in (and says) you are doing so well, you know. Go home. See me in a month. And I said wait a minute. You can't leave yet. I was hanging on his pant leg practically! You cannot leave."</p> <p>I go in and I see my husband in this state—and the recovery nurse just is beside herself because she can't get him to breathe. And I immediately know what this issue is. He is just</p>

				so scared and she is missing that he is so scared. It is not that he's unconscious. So . . . I just went in and reached deep down inside of him, to bring him up. And he got better right away—she couldn't believe he could talk.
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