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Engaging hematopoietic cell transplantation patients and caregivers in the design of print and mobile application individualized survivorship care plan tools

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Abstract

Purpose—INSPIRE (Interactive Survivorship Program with Information and REsources) is an online health program that includes a mobile app, website, health action plan, and individualized survivorship care plans for adult hematopoietic cell transplant (HCT) survivors. The INSPIRE program integrates two previously effective randomized control trials that tested an internet-based program and patient-centered survivorship care plans for HCT survivors.

Methods—Three focus groups were conducted with a total of 22 participants (20 patients, 2 caregivers/patient advocates) to explore patient and caregiver preferences and to optimize the patient-centered emphasis of INSPIRE. Adult (age > 18 years at the time of study entry) HCT recipients had to be at least 1-year post-HCT to participate; caregivers/patient advocates were also eligible. Participants had to be able to communicate in English, could have any diagnosis, transplant type, or donor source, and could have had multiple transplants.

Results—All patient participants received an allogeneic HCT; average time since HCT was 8 years (range 2–22 years). The majority of participants were female (77.3%). Overall, the tools were well received by participants in this study, particularly the personalized features of all the tools. Major themes included interest in having the ability to tailor features to individual needs, and an interest in tracking information over time.

Discussion—Engaging patients and caregivers is invaluable to optimize tools designed to improve HCT survivorship care. Print, online, and mobile-based tools, tailored to individual

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Compliance with ethical standards

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patients' treatment history and requisite follow-up care, can provide otherwise unavailable expertise and guidelines for care.

Keywords

Survivorship care plan; Hematopoietic cell transplantation; Patient preferences; Patient-centered; Mobile app

Background

Hematopoietic cell transplantation (HCT) recipients live with risks for life-threatening chronic health conditions including cardiovascular disease, diabetes, osteoporosis, disease recurrence or subsequent malignancies, and other risks [1]. Even more prevalent in HCT survivors are psychological symptoms that inhibit quality of life, specifically cancer-related distress and depressive symptoms [2–6].

Despite their rapidly expanding numbers, the needs of long-term HCT survivors have been understudied. One impediment to addressing needs of HCT survivors is their dispersion around the country, particularly in regions lacking transplant-related clinical expertise. Online programs are an attractive option for HCT survivors as many live far from their transplant center, and many go online seeking information [7–10]. Survivorship care plans (SCPs), currently recommended for all cancer survivors, are another way to help HCT survivors meet their healthcare needs [11–13]. SCPs should include information on (1) the underlying disease, treatments and their potential long-term or late effects, (2) rationale for and schedule of screening and preventive care evaluations, (3) recommendations about lifestyle practices, and (4) information to facilitate communication between health care providers [11, 12].

In a previous work by our group directed at adult HCT survivors in the United States (US), an individualized SCP for post-HCT care was developed in print format using feedback from patients, caregivers, and health care providers [14]. In a multi-center prospective, randomized control trial (RCT), it was effective in reducing cancer and treatment distress and improved the mental health domain of quality of life [13]. An internet-based intervention, INSPIRE (INternet-based Survivorship Program with Information and Resources), was also tested in an RCT, and had a marginal benefit in alleviating distress in an intent-to-treat analysis, although a significant effect on relieving distress in those who logged into the program [15, 16]. In an effort to further improve upon the out-comes of these two approaches, we are combining the individualized mailed SCPs and the INSPIRE intervention in an online health program with an interactive, individualized mobile app and website. This intervention will be tested for efficacy in an RCT at 13 transplant centers in the US, coordinated through the Center for International Blood and Marrow Transplant Registry® (CIBMTR)® and the National Marrow Donor Program®/Be The Match® (NMDP) to centralize identification of patients, medical record data, and out-reach to survivors. The program's aim is to develop and test a sustainable program of survivorship care delivery after HCT. To both inform and optimize the patient-centered emphasis of the SCP, mobile app and web-based content, format, delivery, and implementation, we

conducted focus groups with patients and caregivers, with findings of the focus groups presented here.

Methods

Study population: eligibility and recruitment

A qualitative research design was used to explore patient and caregiver/patient advocate preferences; web-conferenced telephone focus groups of patients and caregivers/patient advocates in the US were conducted. A phone-based screening instrument was used to determine eligibility with a targeted enrollment of approximately 20 participants. Respondents to recruitment efforts were selected sequentially if they met eligibility criteria with no limitations on the number of participants by category. Eligibility included HCT recipients age > 18 years at the time of study entry who were at least 1-year post-HCT with any diagnosis, transplant type, number of transplants, and donor source. Caregivers/patient advocates for a patient at least 1-year post-HCT were eligible. All participants had to be fluent in English. Information collected at the time of screening included transplant type, patient's age at time of transplant, length of time since HCT, diagnosis, whether they were a patient or caregiver/patient advocate, distance-to-transplant center at time of transplantation, level of education, ethnicity, and race.

Participants were recruited via the NMDP Patient Support Center database of HCT survivors through the *Living Now* E-newsletter [17, 18], the Patients Connect Facebook page [19], and flyers at transplant centers that will be sites in the RCT to test the effectiveness of the intervention. Recruitment also took place through use of flyers by NMDP network transplant centers that expressed interest in the qualitative study. Participants received a \$50 Visa gift card as incentive for participation.

Procedures

Focus group preparation—Participants received a sample printed SCP along with mobile app demonstration images via FedEx for review prior to the focus group web-conference. The printed SCP (see supplemental materials) included three parts, first an individualized treatment summary of transplant-specific information (e.g., age at diagnosis, transplant type, cell source type, chemotherapy drugs received, and graft-versus-host disease [GVHD]), populated with data routinely provided by transplant centers to the CIBMTR, an international, HCT clinical outcomes database. The second part of the SCP provided details on tests and health monitoring, including why each is important. This section had suggestions for questions to ask a health care provider and space to make personal notes or add questions. The third section, called “My Health Action Plan” (MAP), contained a summary of the care plan and personalized preventive care recommendations. The MAP included normal ranges for test values and frequency of recommended tests or exams based on published guidelines for long-term HCT survivors, individual exposures to treatment, age, and gender [1, 20, 21]. The MAP was both in the printed SCP and the mobile app. For the mobile app, participants were provided screenshots of what they would see if they were able to access the app. The screenshots included the login and welcome screens, calendar,

and three content domains: mood, heart, and cancer. Participants also viewed samples of the interactive MAP that would be available within the mobile app.

Three focus group teleconferences, held via WebEx (Milpitas, CA), were conducted to obtain feedback on the SCP and mobile app platform. Each focus group consisted of 6–8 participants, and was of 90 minute duration. A discussion guide developed by the study team (see Appendix A) was used to facilitate discussion across the major content areas. Two moderators (KS, ED) with background knowledge of HCT survivorship care issues led the focus groups. Participants provided verbal consent at the beginning of the telephone focus group. Focus groups were recorded and transcribed verbatim for thematic content analysis. This study was conducted under review of the NMDP/Be The Match Institutional Review Board (IRB).

Statistical analysis

Transcript-based analysis was utilized following each focus group to identify saturation of themes across the data [22]. Two experienced reviewers familiar with the area of study and preliminary research (JMP, MM) coded the transcripts using NVivo 10.0 (Victoria, Australia). A kappa statistic of > 0.75 was used to establish inter-coder agreement [23, 24]. The transcribed data was coded by question to examine responses looking for consistencies and differences. Coded textual data were explored inductively using content analysis to generate categories and themes. This step identified hierarchical relationships among codes, creating families of codes that were aggregated, reviewed, and analyzed at an increasingly general levels to saturation of themes [25].

Results

Participant characteristics

Table 1 indicates characteristics of the 22 focus group participants (20 patients, 2 caregivers/patient advocates). While most were white, non-Hispanic race/ethnicity, reflecting a majority of HCT recipients, and 77% were female, participants varied widely in age with 20% young adults (23–39), 45% middle aged adults (40–59), and 35% older adults (age 60 or older). All patients had received an allogeneic HCT. The mean time since HCT for patients was 8.7 years, with a range of 2–22 years. The average distance patients had to travel to their transplant center was 529 mi (range 5 5200 mi). The majority of all participants (77.3%) were female and nearly all had at least a college degree ($n = 21$). All regions of the US were represented, with half of the participants from the Midwest.

Coder reliability

The kappa for inter-coder reliability was 0.85.

Themes

Themes emerged from each of the three major content areas. The themes and accompanying quotes by content area are provided in Tables 2, 3, and 4.

SCP themes—Seven themes emerged regarding the SCPs (Table 2): (1) the care plan is comprehensive and provides helpful information; (2) the care plan is useful as a reminder for what patients need to do, and for discussion with physicians; (3) participants appreciated the inclusion of health issues not generally covered; (4) the care plan should be provided after the second year; (5) additional health information would be helpful in the care plan; (6) the clinic provides similar information; and (7) caregiver perspectives may be helpful in the care plan.

Participants noted that the SCP, including the treatment summary, MAP, and more detailed care plan, was very comprehensive and provided information on what their treatment included and questions they have asked their physicians in the past. Participants agreed that the SCP provided a useful tool for discussions with all providers involved in their care, including transplant, primary care, and specialty physicians, and as a tool for use during annual check-ups. Some participants appreciated that the SCP included health issues they felt were not frequently covered, such as emotional and dental health. Many survivors noted that the SCP should be provided after the first year of HCT, suggesting that if patients saw this at 1 year, it would be overwhelming, and that transplant centers already often provide much of this information.

Participants also noted that they would like additional health information in the SCP, including allergies, immunizations (including live versus inactivated vaccines), diet/nutrition, anxiety, post-traumatic stress disorder, and the intestinal tract. Some participants also noted the need for a place to write questions about specific personal situations.

MAP themes—Six themes emerged from participants regarding the MAP (Table 3): (1) participants had mixed feedback on the utility of the MAP; (2) participants noted that the MAP can be used in multiple ways; (3) participants appreciated a variety of MAP features; (4) participants wanted clarity on the timing of and who completes the MAP; (5) participants noted that additional health information would be helpful; and (6) participants wanted a way to track information over time.

Participants had mixed feedback on the utility of the MAP; with some noting that it would be helpful to be able to use it to talk with their general practitioners and others noting that the information was similar to what they had received from their transplant center in the first year after HCT or what is available from their online records from their primary care providers or oncologists. Participants noted that the MAP could be used in multiple ways, including as a record of events, to help keep both the patient and the caregiver informed, and as a tool to share with their physicians.

Participants appreciated a variety of the features in the MAP, with the preventive care focus, tests, and timing of when those tests should occur noted as especially helpful, and also useful for discussion with physicians. Participants wanted clarity on who completes the MAP, whether patients or their medical team would fill it out, and whether it was a fluid document that could be updated each time they went to the doctor. They also wanted to be able to track information over time.

INSPIRE mobile app themes—Themes that emerged regarding the mobile app were focused in three areas (Table 4): (1) participants had different perspectives on the usefulness of the app; (2) participants were interested in technical aspects of linking, security, and duplication; and (3) participants were interested in a variety of features specific to their individual needs. Participants had differing opinions on whether they thought they would use the mobile app. Participants who noted that they would use the app identified it as a useful tool for anyone who had been through HCT. Reasons for not using the app included its repetition of information received, side effects in the first few years after HCT that inhibited computer use, and personal lack of comfort with computers and mobile apps due to factors such as age. Some patients were interested in integrating and syncing the app with current software and email programs they use to reduce duplication of information and data entry. While some participants were interested in having third party logins to access the app and were not concerned about security, others noted that the login security was important to them. Some participants were also interested in being able to upload medical records to the app.

Participants were interested in a variety of features within the app, and also suggested features be added that were specific to their needs. A number of participants noted that the appointment reminders were a helpful feature. There was a suggestion for the addition of a “remind me later” feature, so that if a patient did not want to do something at that moment, a reminder would pop-up later. Participants liked the ability to track information in the mobile app. They expressed interest in seeing graphs that tracked test results over time, such as for lipids and blood pressure, and in additional health domains, such as tracking GVHD symptoms. They also wanted the app to help them track their medications, including dates a medication started or discontinued, noting that having a complete list of all medications would be helpful. There was a suggestion to include a way to indicate whether a medication was a current or past medication.

Other general comments included interest in the news feature that the INSPIRE app provided, and the addition of a notes feature within the app that would allow patients to write notes during or after appointments. Some participants wanted caregivers to have access to the app, so that the caregiver could access information regarding appointments, as well as to enter data on behalf of the patient. Finally, there was interest accessing the information from a personal computer, not just through the mobile app.

Discussion

This study demonstrates that engaging patients and their caregivers is invaluable to optimize tools designed to improve survivorship care for HCT recipients. Overall, the SCP, the MAP specifically, and the mobile app were well received by participants in this study, particularly the personalized features of all the tools, and the individual adaptability of the mobile app. While not explicitly asked about the timing of the materials, recipients provided feedback that they thought that receipt of the materials at least 2 years post-HCT would be optimal. They were interested in having additional health information added to the SCP and MAP, particularly on allergies and vaccinations. Across all tools, survivors were interested in tracking information over time, such as medications and test results.

There were a variety of features that survivors wanted in an app, with a priority being options to tailor features to individual needs. The ability to allow participants to interact with mobile features is consistent with previous research [26, 27]. Providing options for participants to write in content and complete action plans as part of an online intervention has been shown to have better outcomes (including reduced depression, stress) than those where participants just read online content [28].

Health technologies, such as interactive mobile apps, provide an opportunity to improve survivorship care, but are not yet used widely in delivering survivorship care plans. Our study clearly indicates that patients and caregivers need to be engaged in the process of developing these tools to ensure the technology fits their needs and will be used. This is consistent with previous research, which suggests that patients should be involved in and guide health technology development [26].

There were several limitations to this study. Qualitative studies, by nature, have limited generalizability. Eligibility was not restricted based on current disease status or presence of GVHD, medical care complexity, amount of follow-up with their transplant center, or primary provider for survivorship care. These may be relevant characteristics that could influence responses to the SCP or the app, though a major theme was the need to tailor the app to widely varying individual situations. Having those characteristics of participants may have provided further information on varying responses to the SCP and app as well as how to best personalize the app. While the target population of the INSPIRE RCT is adults 2–5 years post-HCT, participants ranged from 2 to 22 years post-HCT, with an average of 8 years, which limited perspectives of those in the target population closer to completing treatment. However, those who have survived for a longer time since transplant may be able to provide some useful insights into post-HCT needs. Having more caregivers may have provided additional useful perspectives. Participants were primarily white and none were Hispanic or Latino; the majority of participants also had education higher than high school, and only allogeneic HCT patients were represented. Internet access was needed to view the mobile app and participate in the web-based focus groups, and ill patients may not have been able to participate. These factors may limit generalizability to other HCT populations.

Conclusions

To date, most research testing the delivery of a printed SCP, without follow-up to personalize the application of the information to the individual, has not found positive outcomes with regard to health care adherence or distress, although survivors may report feeling positive about having received SCPs [29–43]. Further personalizing the delivery of care plans, allowing interaction and updating of material as care needs change, and provision of action plans with reminders for individuals through online interventions has the potential to make SCPs and delivery of care more efficient and effective [44, 45]. Print, online, and mobile-based tools, tailored to individual patients' treatment history and requisite follow-up care, can provide otherwise unavailable expertise and guidelines for care. The feedback received from these focus groups will be used to improve the SCP, MAP, and mobile app for efficacy testing in an RCT.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1Focus group participant characteristics ($N = 22$)

Characteristic	N (%) or Mean (SD; range)
Role	
Patient	20 (90.9)
Caregiver/patient advocate	2 (9.1)
Age at HCT in years, Mean (SD; range) ^a	43 (16; 12–67)
Age at time of focus group in years, Mean (SD; range) ^b	52 (14; 23–70)
Diagnosis ^a	
AML/MDS	11 (55.0)
ALL	3 (15.0)
CML	2 (10.0)
AA	1 (5.0)
NHL	1 (5.0)
Other leukemia/lymphoma	1 (5.0)
Rare genetic disorder	1 (5.0)
Donor type (all allogeneic) ^a	
Unrelated	12 (60.0)
Cord blood	6 (30.0)
Related	2 (10.0)
Years post-HCT, Mean (SD; range) ^a	8.7 (7; 2–22)
Distance to TC in miles, Mean (SD; range) ^a	529 (1208; 5–5200)
Sex	
Male	5 (22.7)
Female	17 (77.3)
Ethnicity	
Not Hispanic or Latino	22 (100)
Race	
White	20 (90.9)

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Characteristic	N (%) or Mean (SD; range)
Black or African American	1 (4.5)
Asian and White	1 (4.5)
Education	
High school	1 (4.5)
College degree (Associate or Bachelor)	14 (63.6)
Graduate degree	7 (31.8)
Region of US	
Northeast	2 (9.1)
Midwest	11 (50.0)
South	4 (18.2)
West	5 (22.7)

HCT hematopoietic cell transplant, *AML* acute myeloid leukemia, *MDS* myelodysplastic syndrome, *ALL* acute lymphoid leukemia, *CML* chronic myeloid leukemia, *A4* aplastic anemia, *NHL* non-Hodgkin lymphoma, *TC* transplant center

^aTransplant-specific information pertains to patient participants only (*N* = 20)

^bCalculated from age at HCT and time since transplant; available for patient participants only (*N* = 20)

Table 2

Survivorship care plan themes and quotes

Theme 1. The care plan is comprehensive and provides helpful information

- "It was just very comprehensive including every single aspect of recovery from a transplant."
- "I think I'm definitely the longest out, and this section ... is the one I would be finding the most helpful because, you know, I do have to consider long-term care, things that I need to do that maybe my peers may not have to do."

Theme 2. The care plan is useful as a reminder for what patients need to do, and for discussion with physician(s)

- "I see it as a very useful tool on your annual check-ups, and even you know, if not only with your oncologist or your transplant doctor, but also with your primary doctor."
- "I think this is a great tickler file, because you can sit down and look at it every year, and say, 'okay, this is 2018. Have I done this?' You can do it at the beginning of the year or on your transplant birthday, and know that through the course of the year, you need to get these things done."

Theme 3. Participants appreciated inclusion of health issues not generally covered

Emotional

- "I think I was most encouraged to see that emotional health was included, because I see that as a really important part of recovering from a transplant. I know that's one thing I've struggled with as well."

Dental

- "I'm glad to see that you have in this care plan the issue about dental work and possible premeditation...I'm still feeling a little bit uncomfortable about what the actual recommendation is and if it varies because of patient's situations or conditions."

Theme 4. Participants agreed that the care plan should be provided after the first year

- "I thought it was really well put together and being two to five years out, this is an appropriate, an appropriate format for it."
- "... I'm already two years out so I understand it, but if I saw this at one year out of transplant, it would be very overwhelming. It's just-that it's a lot to do."

Theme 5. Additional health information would be helpful in the care plan

Vaccination

- "I thought that something with re-vaccinations could be useful. I don't think I noticed anything with the vaccines that people should be getting post-transplant and the timeline associated with those. And that was definitely something that I had to go back and get a couple times from various doctors, and I think it would be nice to have that in one place."
- "I've run into a few times when I'm going to travel internationally...Conversations with doctors about what vaccines, so yellow fever [for] example, that I can or cannot get. So if there was information even to the detail of the types of vaccines, live versus not live, that might be something."

Allergies

- "I know I'm always asking about allergies, and I only found out some while I was in the hospital and I don't see that on here and I don't know if it's important or not."
- "Allergies was something that changed for me, and I think would be good to include."

Health checklist

- "If the intent here is to have an annual checkup, maybe you could put a checklist in there, to make sure that you're following up every year with this."
- "My thought is to put a checklist in here to make sure you do it or check off that you've done it."

Fertility

- "For the fertility and family planning section, I know this is probably wouldn't apply to everyone, but maybe a section or just a bullet point or two on gene counseling and possibly seeing a specialist in that area."

Diet/nutrition

- "I think it could be good to include foods that that should be avoided, or situations that should be avoided if you're on immunosuppressants...."
- "I do wonder if it's worth referring to a nutritionist. I think nutrition is really complicated and I think every person is complicated, and then if you throw a transplant on top of that, it makes it additionally complicated...."

Emotional health

- "I would like to see anxiety also included... anxiety that just kind of takes over your life and comes in and out is something I think most transplant patients deal with."
- "I feel that [emotional health] does need to be extended upon. Not only with anxiety, but I also would put in post-traumatic stress disorder. I think that, at least in my experience... I've actually had issues where my doctor thinks that I have anxiety, and is not listening necessarily to me. I ended up in the ER having to have an appendicitis shortly after, but I think that the emotional health and what happens to you afterwards—it does play a role."
- "... this many years out. I have a job but, having all [these] appointments and all of these physicians, I have to try to manage all of that with the amount of flex time I have at work. And so, you know, I think kind of juggling all of this later in life is something worth... visiting, maybe not, I'm not sure if it goes under emotional health, but I do think that it could go somewhere, just in terms of a check of, like, you know, how is this affecting you."

Other health information

- "If there could just be a general or miscellaneous section in the back that could pertain to, maybe not common issues, but like for me, I'm almost 4 years out, and my immune system is still very suppressed. I'm basically a hermit. But my doctors need to know that. I mean they do, because they've made me be a hermit, but just to have another section of a miscellaneous, issues section."
- "I also have intestinal issues after the transplant. Those are my biggest issues, so I would echo that for my experience that, that section would need to be added"
- "One of the areas that I didn't feel projected itself but would probably be considered under the endocrine organs is the whole issue of diabetes. Monitoring and tracking, and if it needs to be treated."
- "I think that it should just be open-ended, because each transplant patient is so different.... So just a miscellaneous, where maybe just, you can, instead of checking boxes, you can just type in quickly, you know, a maximum of 100 characters or something, what the issue is."
- "I would like to see maybe a section for your blood test results, or certain areas that are out of range, because I do a CMP [comprehensive metabolic panel] and a CBC [complete blood count] every single month, and- mainly to check on my liver levels. But I'd- I would like to see something that maybe- a little section- and maybe I can just enter it manually, so I can keep track of what the results were for those specific areas that I'm concerned about, such as my liver levels and then I could make a quick comparison when the next test comes."

Theme 6. Participants noted that the clinic provides similar information

- "[My transplant center has an electronic health record] that has a lot of this information in it. They tell me, you know, they list check-ups and things I need to get a year, when I need, even if it's five years out, they've got it listed: colonoscopy or whatever you know immunizations, they just took care of it all."
- "I actually got something similar to this at [my transplant center], and I think what was helpful for me is education that I could read myself, because they tell you a lot of things when you're around, but you really can't remember all of them, and so it's nice to have it all organized like this, where it talks about, 'because you had this treatment, you're more likely to have this'; I think that is a very helpful education for the patient."

Theme 7. Caregiver perspective on emotional health may be helpful in the care plan

- "The only thing that I would add would be under the emotional health, it's asking a lot of questions of how you're feeling today: better, worse than expected. I think there's real value in also getting the caregiver's perspective and feedback here. They've got a unique perspective as the individual patient advocate from day one, and all the way through, especially in those times where the patient could not have otherwise spoken for themselves."

Table 3**My health action plan (MAP) themes and quotes****Theme 1. Participants had mixed feedback on the utility of the MAP**

- "I feel that our transplant center gives us this information which we then... save and we're aware of—but- so it's redundant in some senses, but I guess it is nice to have... a repository other than the binder that we use."
- "for me, my, my clinic center – they're very, very informative. They give us something similar to this as a transplant patient on what we should have-1 month, six months, nine months, one year."

Theme 2. Participants noted that the MAP can be used in multiple ways**Record of events**

- "I thought all of the areas were very nice to have the record of what happened and if I could have kept those as I was going along, it would have been a really nice record to have."

Informs the patient and caregiver

- "I think it's very comprehensive in terms of informing the patient and care partner, I like to say, of current tests- I- and- and medical status." Share with physician
- "I am just three years out, and I found it really helpful because my doctor didn't provide anything like this, and I actually, he just recently told me that I didn't need to come back to the bone marrow transplant clinic, and I was just kind of left on my own. ... I've been trying to do this on my own; put all this information together. And so I found it very helpful personally, like, that you know, what I need to do now going forward."
- "I just see it as something that I would use now if I had had it in the past, since I have moved from my, you know, moved clear across the country, into another town, and starting all over with new doctors, and to have this as a history record, all in one place, I think that would be very helpful that way too."

Theme 3. Participants appreciated a variety of MAP features

- "There's one thing that I really did like is the preventative care. When it talks about, you know, if you're this age you should have a mammogram every eight years or, when you reach this age, you should have... a CT colonoscopy. ... that's stuff that I haven't really discussed or heard of, so I really liked that preventative care in the far future."
- "when I was saying that I've been looking for this information, that's the exact information I've been trying to find: is what tests I need to have, and, cause I'm obviously going to have to coordinate it all myself, and I do see about 10 different doctors, so for me this was like, oh I-I haven't had this test done in a while, I need to do this.... I thought it was really helpful."

Theme 4. Participants want clarity on the timing of and who completes the MAP

- "It does confuse me a little bit. Is this intended for me to do all of these things, get lab tests and then fill it in myself and then hand it back to the doctor? I wasn't clear on that."

- "And also, it says for your yearly physical exam, is- is this something that I would do every year... is the idea that I would be filling one out every year, and then keeping that in a file, providing a copy to my doctors every year, and then at, you know, year five, there's five of them. I just, that's another aspect that's a little bit, that's unclear to me as a patient."

Theme 5. Participants noted additional health information would be helpful in the MAP

- "One thing I think would help is if the patients had any adverse side effects or any allergies to any of the drugs that they had during the transplant process. Maybe if there could be a section for that because for me I had many, and even have one of the drugs that I can never have again in my life. And it's hard to remember all of those- I do have them written down on a little piece of paper in my purse but, as maybe another section that could have a check off that, was this an adverse side effect to X drug, or was it an allergy to X drug?"
- "I might add to that is that maybe whatever important auxiliary diagnosis you get as a result of your bone marrow transplant also be highlighted in the document somewhere."
- "one part of the body that didn't seem to be covered was the intestinal tract."
- "I'm wondering if the document should also record your childhood immunizations that they re-administer after a transplant."
- "For me it would be, and for my doctors, I know it would be helpful if we had blood type listed."

Theme 6. Participants want a way to track information over time in the MAP

- "The one thing I thought because they're yearly exams, if there's a place on that form for the year or the date the test was done so that each year so it's easier to keep track of."

„[definitely agree with the sentiment of having multiple years and multiple columns and maybe just the spreadsheet.“

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Table 4

Themes and quotes related to the INSPIRE mobile app

Theme 1. Participants were mixed on whether they would use the app, noting health issues and age as factors that could affect usage	
Would not use	Would use
<ul style="list-style-type: none"> • "I'm completely computer illiterate. My [spouse], the recipient, is completely computer illiterate. I just wonder if it's generational. On the one hand, I see that it's great having all this information in one place; on the other hand, it seems like it's a lot of work to input all of this information." • "Being a senior citizen, and not really comfortable with apps, I- my first impression was that I doubt very much if I would use the app." • "...the first two years after my transplant, my eyes really bothered me, so I wouldn't have been able to do it... my eyes were terrible, so I had trouble seeing and my eyes watered, so I could not enter into my phone." 	<ul style="list-style-type: none"> • "I do believe that this app is great for anyone who's... been through our kind of situation, and I think it would be very helpful... to keep track of everything with your health as far as the mood, the medications, and the appointments." • "So first, and foremost, I will say that I actually love this, and I have been asking for this for a long, long time, because as someone who's as far out as I am, it is a disaster trying to keep track of all this stuff." • "You guys have done a lot of work. It's a valuable tool that I could see-- Too bad they didn't have it 20 years ago."
Theme 2: Participants were interested in a variety of app features specific to their needs	
Appointment reminders	
<ul style="list-style-type: none"> • "I think the appointment reminder is critical, especially when you're getting further and further out, you don't remember when you're supposed to schedule a certain assessment." • "I know that it's good for me to try to, a couple of days - two or three days prior to whatever appointment I'm going to, to get together to make sure I have the questions I want to ask the doctor, the notes I've made, my changes, just any thing that I need to have, so maybe I wouldn't have... the appointments for the calendar, but I might go in there and set an alert to say - hey check your Google Calendar, you have an upcoming appointment, or you know get your notes ready for Dr. Johnson, and that would- you could do that under a push notification, right?" 	
Medication feature	
<ul style="list-style-type: none"> • "I am looking for something where- I would like to also know what medication I took in the past. Is there some kind of functionality in there, where, you know, I could enter all the different kinds of chemo I had during transplant... where it would there be past medications too, and dates that I took it?" • "You could have a, like, two different colors so you can click to go back and forth between, let's say okay, maybe the green ones are current medications and the red ones are past medications, that I no longer take." 	
Tracking information over time	
<ul style="list-style-type: none"> • "Is there a way to save and graph each of your numbers, like your cholesterol, so you see a graph of it, like you do your mood?" 	
Notes feature	
<ul style="list-style-type: none"> • "Is there a section in there for notes for say, after a doctor's appointment, if there's something that you want to remind yourself to follow up on, or something that, you know, you need to be aware of or, anyway, some type of notes section?" 	
Additional/tailored health domains	
<ul style="list-style-type: none"> • "... I guess right now we're at the point ...years [and] months out with sort of the issues of GVHD so is there a way to track some of the things that are happening in that domain so you keep aware of, you know, keep aware of that, the- the symptoms and, and issues related to GVHD. 'Cause I guess, that's a big consideration for people post-transplant." • "On the drop-down for the types of information that you're going to be keeping track of- How specific is it? Like for me I would be- I would be tracking my immunoglobulins; my CD4s. Are those not something that's included, or can- can there be sections where you can put your own in there, and thus track specifically what you're interested in tracking?" 	
News feature	
<ul style="list-style-type: none"> • "I also wanted to note I really like that news section aspect. That I think I would definitely use that, but maybe making it a little more visible than on that side menu from the home page." 	

Theme 1. Participants were mixed on whether they would use the app, noting health issues and age as factors that could affect usage

Would not use

Caregiver accessibility

- "Would the login credentials here allow a caregiver to enter this data on behalf of their patient?"
- "Would this be something that will be tied together between two different individuals to where, like, the appointments, and some of the stuff going on that, you know, you without having to put it on two separate phones; things like that... she doesn't have to contact me – it's already on there, and she can see it, like you know, then she can make sure she gets off work, or you know, for appointments and that. I think it would, I don't know, I was just curious. Is that something that we'd be able to do on this, to, to be able to tie it together?"

Personal computer (PC) version

- "I was wondering is the mobile app going to be just an app or is it going to be able to be used on a regular PC?"
- "Is there a website interface that we could actually go in, enter a lot of this information that feeds into the app? ... I just don't have a lot of patience for typing away on my little phone versus going onto a website entering everything there and kind of maintaining it, checking it, looking at it via the app."

Theme 3. Participants were interested in linking/syncing with other systems, though some expressed security and duplication concerns

Duplication with what is already used

- "I use [an electronic health record], and... everything just automatically populates in there for me. The appointments get scheduled in there, my medicine is in there, notes from my doctor come through [the electronic health record], so as the app exists right now, I would have to do it all, and so I just would not do it."
- "For me to even think about adding a third point of entry, it's gonna cross check with the two that already exist, makes me dizzy. You know, it's just so much record keeping that patients want to do or have time to do, besides living their life. Integration and Syncing with other programs (e.g., calendars, electronic medical records) Theme 1. Participants were mixed on whether they would use the app, noting health issues and age as factors that could affect usage Would not use
- "So I noticed that the app had a calendar, like a calendar of your dates of appointments, so if I logged in with my Google account, would my Google Calendar and INSPIRE, my doctor's appointment calendar, would those sync together or would those really just going to be completely two separate things?"
- "When you put in the- your scheduled appointments, will that automatically upload to my, like, Outlook calendar or my Google Calendar so that it's all in one place, not just in the app itself?"

Use of third-party logins (e.g., Amazon, Google, Facebook) as a potential security issue

- "I don't like to log in via other things on any website. And I understand it's secure now, but I just worry about in the future, things change, and, and my information is still, you know going through this Facebook, or whatever. It's mainly Facebook that worries me, but that's just me personally. I would be uncomfortable with it."

Ability to upload medical records

- "To have the snapshot of- or be able to take a picture of it, because I know I do have a doctor ... that wants to see the actual results page and not take my word for it or, or what I typed in, so if you could shoot a screenshot of it or, you know, take a picture of it and then be able to upload it, that would also be a very valuable thing."
- "My question is like when I go to [my transplant center] could I take a picture and just upload it, so that way if I just wanted to go from month to month to see the differences, I've just got the picture in there."