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CLINICAL TRIAL

Sharing in care: engaging care partners in the care and communication of breast cancer patients

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Abstract

Purpose Family is often overlooked in cancer care. We developed a patient–family agenda setting intervention to engage family in cancer care communication.

Methods We conducted a pilot randomized controlled trial (NCT03283553) of patients on active treatment for breast cancer and their family "care partner." Intervention dyads ($n = 69$) completed a self-administered checklist to clarify care partner roles, establish a shared visit agenda, and facilitate MyChart patient portal access. Control dyads ($n = 63$) received usual care. We assessed intervention acceptability and initial effects from post-visit surveys and MyChart utilization at 6 weeks.

Results At baseline, most patients (89.4%) but few care partners (1.5%) were registered for MyChart. Most patients (79.4%) wanted their care partner to have access to their records and 39.4% of care partners reported accessing MyChart. In completing the checklist, patients and care partners endorsed active communication roles for the care partner and identified a similar visit agenda: most (> 90%) reported the checklist was easy, useful, and recommended it to others. At 6 weeks, intervention (vs control) care partners were more likely to be registered for MyChart (75.4% vs 1.6%; $p < 0.001$), to have logged in (43.5% vs 0%; $p < 0.001$) and viewed clinical notes (30.4% vs 0%; $p < 0.001$), but were no more likely to exchange direct messages with clinicians (1.5% vs 0%; $p = 0.175$). No differences in patients' MyChart use were observed, but intervention patients more often viewed clinical notes (50.7% vs 9.5%; $p < 0.001$).

Conclusions A patient–family agenda setting intervention was acceptable and affected online practices of cancer patients and care partners.

Keywords Health information technology · Electronic health records · Consumer health information · Health literacy · Breast cancer

Introduction

Family (as defined by each patient) plays a vital role in cancer care. Family assist with daily activities, schedule and attend medical visits, coordinate care, manage complex treatments, and participate in routine and high stakes

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decisions [1]. Although patients commonly value, desire, and rely on family to help manage the demands of cancer care [2, 3], interpersonal dynamics are variable and perspectives are not always aligned [4, 5]. As family is not routinely identified or supported in care delivery, their information needs often remain unmet [6]. The actions of poorly supported family affect patients, who are at heightened risk for anxiety, unnecessary suffering, and higher utilization of unwanted and burdensome care [7–9]. Few cancer care interventions explicitly engage family at the point of care [1, 10, 11].

The patient portal is a personal health record tethered to an electronic health record through which patients may view test results and sections of their medical record, perform health management tasks, and communicate with clinicians using secure messaging [12, 13]. Many health systems allow patients to share access to their patient portal account through a registration process in which "care partners" receive their own identity credentials (login/password) [14]. Emerging evidence suggests that engaging family care partners through shared access to their records improves communication and increases patient and family confidence in their ability to manage care [15–17]. The intense longitudinal demands of cancer care and heavy reliance on family suggest that shared access may be particularly helpful in the context of cancer care. However, little is known about cancer patients' electronic information sharing preferences or whether preferences may be elicited and supported within routine care [18].

To address these gaps, we developed a patient–family communication intervention, "Sharing in Care" for patients who regularly attend oncology visits with a family or other unpaid care partner. The intervention sets forth a structured process to establish a shared visit agenda and clarify expectations about the role of family during in-person and electronic interactions with the care team. In two prior trials, we found patient–family agenda setting increases the patient-centeredness of face-to-face communication in primary care, but this work was limited to the examination of communication during a single visit [19, 20]. Given increasing reliance on electronic communication and the particular importance of family in cancer care, we conducted a two-arm randomized trial to examine effects of the Sharing in Care intervention on online practices and cancer care communication among patients receiving active treatment for breast cancer. Here, we report information sharing preferences and practices at baseline, and intervention acceptability and short-term effects at 6 weeks.

Methods

Overall design

We conducted a two-arm single-blind randomized trial of a behavioral intervention at two academic oncology clinics that have a well-established integrated Epic (Verona, WI) and MyChart[1] patient portal. Medical oncology physicians and nurse practitioners were recruited between June and September 2017 and patient–family dyads were enrolled between August 2017 and November 2018. The patient–family dyad was the unit of analysis and randomization. All study procedures, consents, and surveys were approved by the institutional review board of the Johns Hopkins University School of Medicine (IRB00129995), and the study was registered in clinicaltrials.gov (NCT03283553).

Study procedures

Oncology clinicians at participating clinics were eligible and provided informed consent. Patients of participating clinicians who were in active treatment for early stage or advanced breast cancer were mailed letters describing the study 3 weeks before their next scheduled visit. Patients who did not "opt out" by mail were contacted by research staff to discuss study procedures and administer a screening interview. Patients undergoing active breast cancer therapy that required frequent clinic visits (at least once every 3 months) were eligible if they reported regularly attending appointments with a family or unpaid care partner who then also agreed to participate. Eligible patient-care partner dyads who expressed interest met a member of the research team at the clinic 30 min before the patient's visit. Each patient and care partner dyad provided informed consent and was randomized using stratified, blocked randomization with alternating block sizes of 4 and 6 for each clinician. Dyads assigned to the intervention were asked to complete the checklist immediately before the visit without instruction from research staff. Dyads assigned to the control group waited for their visit as usual.

Clinicians, patients, and care partners completed brief written surveys in the clinic suite immediately after the visit. Patients and care partners completed baseline telephone interviews 1 week post-enrolment. MyChart use was assessed at baseline and six-weeks post-enrolment. Follow-up continues up to 12 months assessing patterns of MyChart use and surveys of patients and care partners at three time points.

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[1] *MyChart® is a registered trademark of Epic Systems Corporation.*

Intervention

Agenda setting is a strategy to improve the effectiveness of patient–clinician interactions by establishing relational "ground rules," identifying priorities, and negotiating conversational focus [21]. Agenda setting is aligned with a broader set of patient-directed engagement strategies that have been successfully used to clarify goals in cancer care [22–24]. Few existing patient engagement strategies address the reality that persons with cancer commonly navigate health system demands with the help of family care partners [2, 25]. To address this gap, we developed a three-step patient–family agenda setting checklist (Fig. 1) to guide patients and care partners through a structured process to prepare for a medical oncology visit. The first step clarifies the role of the care partner during visit interactions by prompting discussion and selection of desired behaviors from those previously identified as being helpful [26, 27]. The second step prompts patient and care partners to individually identify concerns about the patient's health and decide together which to discuss with the clinician. The third step prompts patients to consider preferences for accessing their electronic medical record by registering the patient, care partner, or neither for MyChart. All text is in 14-point font and readability of the checklist on the Flesch-Kincaid grade level is 8.7. After the visit, patients and care partners were offered instruction on how to access MyChart and clinical visit notes [12].

Measurement

Acceptability and short-term outcomes

Checklist acceptability was assessed from written, post-visit surveys that were administered to patients, care partners, and clinicians using questions from our formative work [19, 20]. Patient and care partners' utilization of MyChart was assessed at baseline and 6-weeks post-enrolment using date—and time-stamped audit trails of patient portal actions extracted by the Clinical Research Data Acquisition Core of the Johns Hopkins Institute for Clinical and Translational Research.

Intervention process

Care partner roles and patient preferences were decided together and visit priorities were identified separately from responses to the agenda setting checklist. Patient-care partner agreement regarding the visit agenda was examined on the basis of whether each health issue was selected as a priority by patient only, care partner only, neither, or both (Fig. 1).

Participant characteristics and perspectives

Patient and care partner socio-demographic factors, health status, and employment were assessed from baseline telephone interviews. Symptoms of depression and anxiety were assessed using established cut-points of 3 or more from responses to the PHQ-2 [28] and GAD-2 [29, 30]. Health literacy was assessed using a validated single-item screening question [31]. Patient quality of life was assessed using the FACT-B [32]. Disease stage was assessed from the electronic health record by study staff at the time of the enrolment visit. Perspectives regarding the role of the care partner [33] and patient and care partner online practices and preferences were assessed from baseline telephone surveys. Clinician characteristics were assessed from written surveys administered at the time of informed consent.

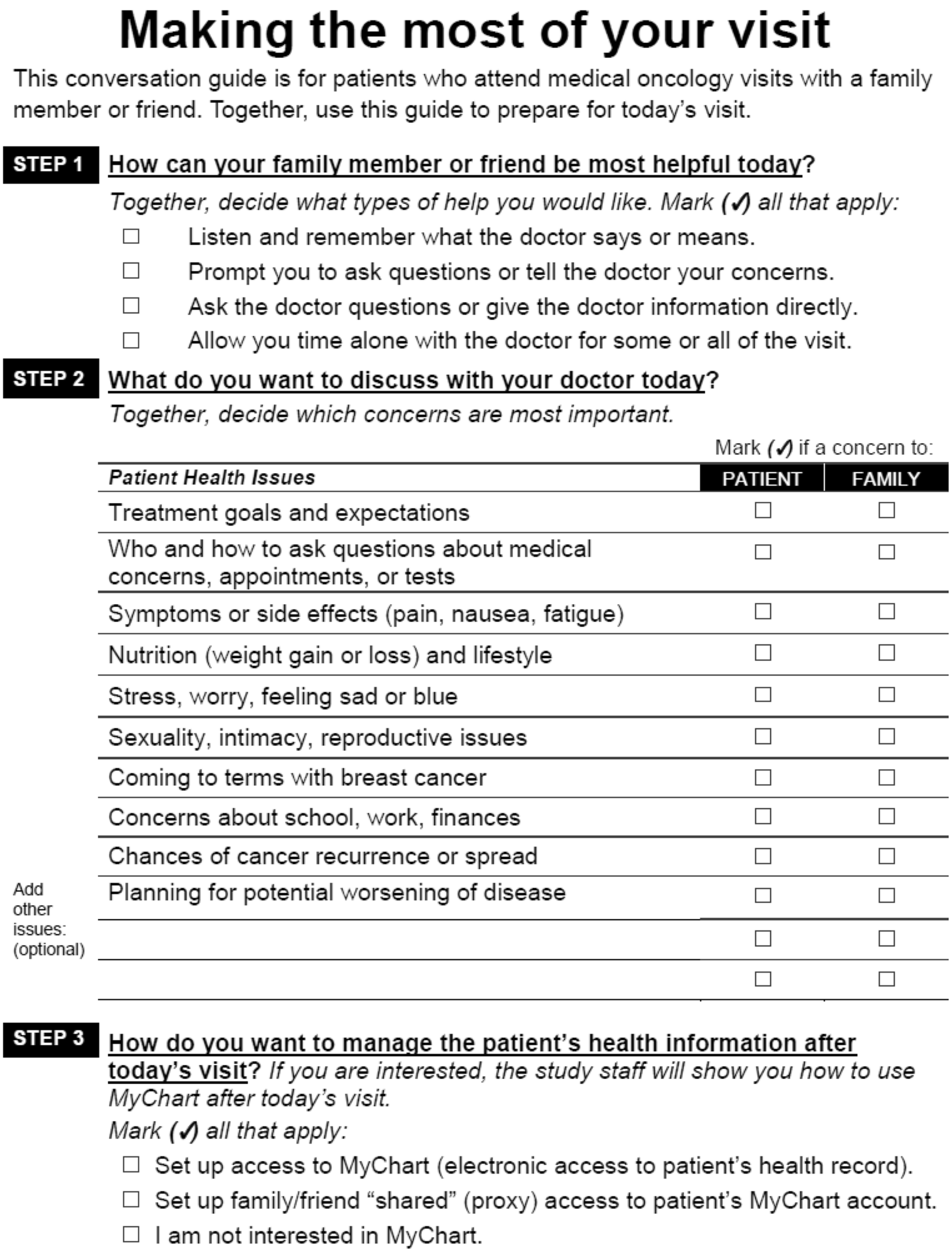
Analysis

Simple statistics (frequency distributions, group means) were used to assess differences between potentially eligible patients and patients who were enrolled, intervention and control participants, and process measures relating to agenda setting completion. The statistical significance of patient and care partner agreement regarding care partner roles and priorities for the visit agenda was assessed with McNemar's test. Intervention effects on MyChart utilization at 6 weeks were examined in regression models in which the main independent variable was group assignment and the patient-family dyad was the unit of analysis. We assessed the statistical significance of between-group differences from regression models that included intervention and control group assignment and patient-level covariates that were found to be different at baseline by group assignment. Statistical tests were two-sided with a significance level of 0.05. Analyses were performed in SAS statistical software, version 9.4 (SAS, Cary, NC).

Results

Study sample characteristics

All ten clinicians (three nurse practitioners and seven physicians) who met eligibility criteria agreed to participate and provided informed consent. Clinicians were on average 50.3 years of age (SD 9.5; range 38–67), more than half were female ($n=7$), and more than half had been practicing 15 or more years ($n=6$).



Making the most of your visit

This conversation guide is for patients who attend medical oncology visits with a family member or friend. Together, use this guide to prepare for today's visit.

STEP 1 **How can your family member or friend be most helpful today?**

Together, decide what types of help you would like. Mark (✓) all that apply:

☐ Listen and remember what the doctor says or means.
☐ Prompt you to ask questions or tell the doctor your concerns.
☐ Ask the doctor questions or give the doctor information directly.
☐ Allow you time alone with the doctor for some or all of the visit.

STEP 2 **What do you want to discuss with your doctor today?**

Together, decide which concerns are most important.

Mark (✓) if a concern to:

Patient Health Issues	PATIENT	FAMILY
Treatment goals and expectations	☐	☐
Who and how to ask questions about medical concerns, appointments, or tests	☐	☐
Symptoms or side effects (pain, nausea, fatigue)	☐	☐
Nutrition (weight gain or loss) and lifestyle	☐	☐
Stress, worry, feeling sad or blue	☐	☐
Sexuality, intimacy, reproductive issues	☐	☐
Coming to terms with breast cancer	☐	☐
Concerns about school, work, finances	☐	☐
Chances of cancer recurrence or spread	☐	☐
Planning for potential worsening of disease	☐	☐
Add other issues: (optional)	☐	☐
	☐	☐

STEP 3 **How do you want to manage the patient's health information after today's visit?** *If you are interested, the study staff will show you how to use MyChart after today's visit.*

Mark (✓) all that apply:

☐ Set up access to MyChart (electronic access to patient's health record).
☐ Set up family/friend "shared" (proxy) access to patient's MyChart account.
☐ I am not interested in MyChart.

Fig. 1 Patient–family agenda setting checklist

Figure 2 shows the flow of patient and care partner participation. Recruitment letters were mailed to 361 patients of participating clinicians. Of these patients, 20 (5.5%) returned a mailed card to the study team indicating that they were not eligible ($n = 11$) or declined participation ($n = 9$); 21 (5.8%) could not be reached. Screening calls were fielded to 320 (88.6%) patients, of whom 139 (38.5%) were not eligible, 49 (13.6%) refused participation, and 132 (36.6%)

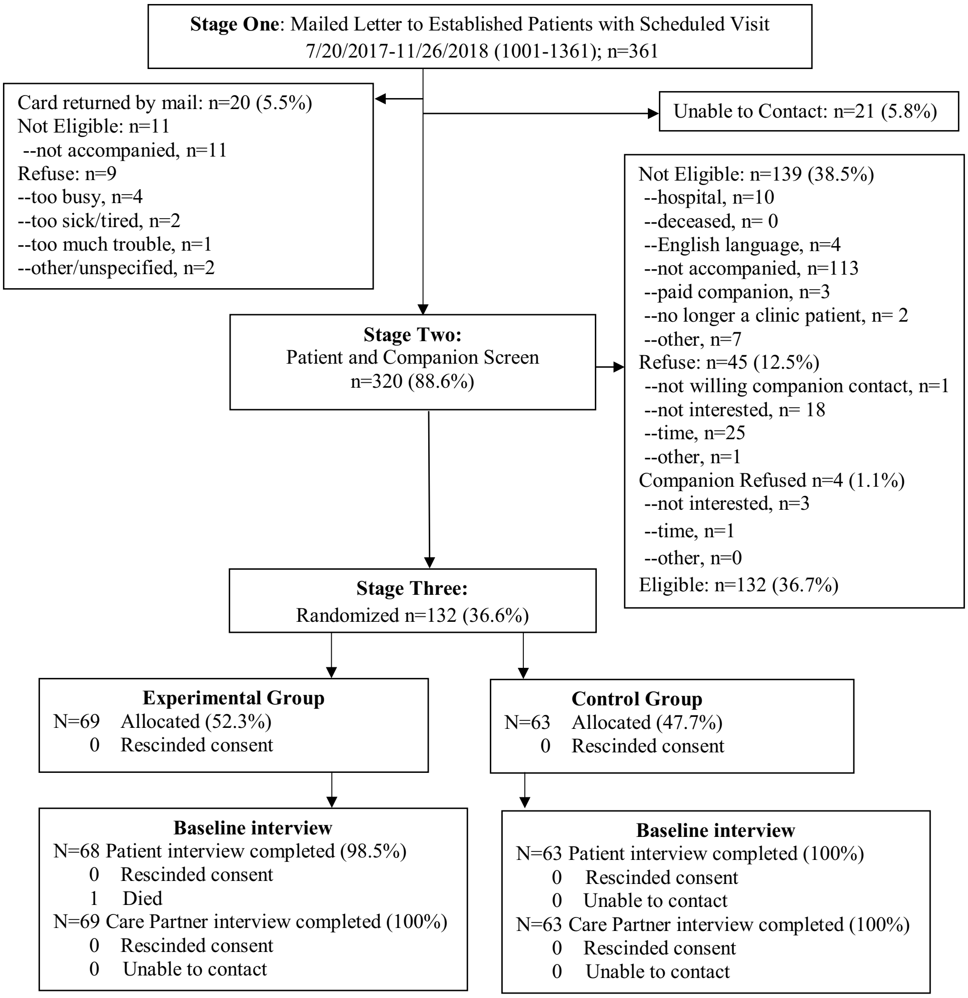


Fig. 2 Sharing in care CONSORT diagram weeks 1–68

patient-companion dyads were eligible and agreed to participate. Each dyad was randomized to the control ($n=63$) or intervention group ($n=69$). With the exception of 1 patient who died shortly after enrolment, enrolled patient and care partners completed telephone interviews at baseline. Relative to patients who did not participate in the study, enrolled patients were younger (53.9 vs 56.8 years; $p=0.045$); no other group differences were observed by gender, disease stage, baseline patient portal registration, or clinic site (data not presented).

Most enrolled patients were female (99.2%) with more than high school education (85.6%; Table 1). Just under half were diagnosed with metastatic disease (45.5%). Care partners were most often men (65.2%) and were spouses/partners (59.9%), adult–children (15.2%), or friends or other relatives (25.0%). The nearly two-thirds (61.4%) of care partners who reported working in the past week worked an average of 38.4 h– and among this group 64.2% reporting being absent in the past week to help the patient. These care partners missed 7.7 h of work on average. Patients and care partners reported symptoms of depression (16.0% and 9.1%, respectively) and anxiety (17.6% and 13.6%, respectively). Intervention patients were more likely than control patients to have more than high school education (92.8% vs 77.4%; $p=0.01$) but no other statistically significant between-group differences in patient characteristics were observed.

Patient and care partner perspectives on care partner role

Patients and care partners were generally in agreement about the role of the care partner (Table 2). Patients and care partners reported the care partner attends oncology visits for reasons relating to information exchange, decision-making, emotional support, and logistics (top panel), including: to hear about diagnosis and treatments (93.9% and 95.5%), remember clinician advice and instruction (85.5% and 89.4%), communicate concerns (78.6% and 85.6%), and help with medical decisions (74.8% and 81.1%). In reflecting on decision-making, patients and care partners stated the patient most often considers family opinions (51.1% and 64.1%) or makes decisions together (31.5% and 19.1%); few reported

Table 1 Study participant characteristics by group assignment

	Intervention ($n=69$)	Control ($n=63$)	Total ($n=132$)	p value
Patient characteristics				
Mean age (SD), years	55.1 (13.4)	52.9 (14.5)	54.1 (13.9)	0.359
Female gender, *n* (%)	68 (98.6)	63 (100.0)	131 (99.2)	0.338
Nonwhite race or hispanic; *n* (%)	17 (24.6)	21 (33.3)	38 (28.8)	0.270
Beyond high school education, *n* (%)	64 (92.8)	49 (77.8)	113 (85.6)	0.014
Suspected of low health literacy, *n* (%)	9 (13.0)	5 (8.1)	14 (10.7)	0.357
Married; *n* (%)	46 (66.7)	44 (69.8)	90 (68.2)	0.696
Metastatic disease, *n* (%)	34 (49.3)	26 (41.3)	60 (45.5)	0.356
Positive for depressive symptoms, *n* (%)[a]	11 (15.9)	10 (16.1)	21 (16.0)	0.977
Positive for symptoms of anxiety, *n* (%)[a]	11 (15.9)	12 (19.4)	23 (17.6)	0.608
FACT-B Score (SD)[b]	114.6 (22.1)	114.2 (22.7)	114.4 (22.3)	0.907
Care partner characteristics				
Mean age (SD), years	54.0 (13.8)	54.0 (13.5)	54.0 (13.6)	0.995
Male gender, *n* (%)	41 (59.4)	45 (71.4)	86 (65.2)	0.148
Beyond high school education, *n* (%)	63 (91.3)	50 (79.4)	113 (85.6)	0.051
Suspected of low health literacy, *n* (%)	16 (23.2)	19 (30.2)	35 (26.5)	0.365
Relationship to patient, *n* (%)				
Spouse/Partner	40 (58.0)	39 (61.9)	79 (59.9)	0.752
Adult Child	12 (17.4)	8 (12.7)	20 (15.2)	
Other (e.g. parent, sibling, friend)	17 (24.6)	16 (25.4)	33 (25.0)	
Worked in the past week, *n* (%)	39 (56.5)	42 (66.7)	81 (61.4)	0.232
Mean hours worked in past week (SD)[c]	38.6 (10.1)	38.3 (14.2)	38.4 (12.3)	0.919
Missed hours from work in past week, *n* (%)[c]	20 (51.3)	32 (76.2)	52 (64.2)	0.020
Mean hours missed from work to help patient (SD)[c]	6.3 (4.0)	8.5 (5.1)	7.7 (4.8)	0.106
Positive for depressive symptoms, *n* (%)[a]	5 (7.3)	7 (11.1)	12 (9.1)	0.440
Positive for symptoms of anxiety, *n* (%)[a]	9 (13.0)	9 (14.3)	18 (13.6)	0.835

[a] Symptoms of depression assessed using cutpoint of 3+ from PHQ-2; Symptoms of anxiety assessed using cutpoint of 3+ on GAD-2

[b] Quality of life measured using FACT-B: higher values = higher QOL (total score of 164)

[c] Among care partners who reported hours worked; mean hours missed limited to those who missed work

making decisions with little or no family input (13.9% and 14.5%). Nearly 4 in 5 patients (79.4%) stated they would like their care partner to have electronic access to their health information. Nearly 2 in 5 (39.4%) care partners reported logging into the patient's portal account to view medical information or test results in the prior year, of whom most (78.8%) used the patient's identity credentials. Nearly half (48.1%) of care partners who logged in to the portal account using the patient's credentials reported exchanging direct messages with the medical oncology team.

Agenda setting process

In completing the checklist, intervention participants endorsed an active communication role for care partners: in listening and remembering (94.2%), asking the clinician questions or giving information directly (76.8%), and reminding patients to ask questions or tell their concerns (75.4%). Two-thirds (65.2%) endorsed all three behaviors. Less than one in five dyads selected a role for the care partner in allowing patients time alone with the doctor for some or all of the visits (17.4%). Three in four intervention patients (75.4%) noted they would like the care partner to have shared access to MyChart and one in four (24.6%) were not interested.

Patients and care partners prioritized similar concerns for the upcoming visit (Fig. 3). Topics most frequently selected were discussing treatment goals and expectations (75.4% and 66.7%, respectively), symptoms and side effects (73.9% and 62.3%), and chances of cancer recurrence or spread (49.3% and 44.9%). Nearly two in five patients and care partners stated they would like to discuss planning for potential worsening of disease (37.7% and 36.2%). Patients and care partners were less often in agreement in concerns about nutrition (39.1% and 24.6%; $p = 0.02$) and symptoms and side effects (73.9% and 62.3%; $p = 0.03$).

Table 2 Patient and care partner perspectives about care partner role at baseline

Role of care partner	Patient ($n=131$)[a]	Care partner ($n=132$)	*p* Value
Reasons for attending oncology visits			
Emotional support			
Company and support, *n* (%)	128 (97.7)	131 (99.2)	0.157
Informational support and decision-making			
Hear about diagnosis and treatment options, *n* (%)	123 (93.9)	126 (95.5)	0.480
Remember advice or instructions, *n* (%)	112 (85.5)	118 (89.4)	0.251
Help communicate concerns, *n* (%)	103 (78.6)	113 (85.6)	0.083
Help make medical decisions, *n* (%)	98 (74.8)	107 (81.1)	0.117
Instrumental support			
Transportation, *n* (%)	104 (79.4)	109 (82.6)	0.414
Coordinate care, *n* (%)	57 (43.5)	80 (60.6)	<0.001
Involvement in medical decision-making[b]			
Patient makes decisions with little or no input from family, *n* (%)	18 (13.9)	19 (14.5)	0.136
Patient makes decisions after considering family opinion, *n* (%)	67 (51.5)	84 (64.1)	
Patient and family make decisions together, *n* (%)	41 (31.5)	25 (19.1)	
Family makes the decisions, *n* (%)	4 (3.1)	3 (2.3)	
Patient preferences for sharing access to patient portal			
Patient prefers care partner to have access to their electronic health information, *n* (%)	104 (79.4)	–	
Care partners' reported online practices			
Care partner reports viewing medical information or test results in prior year, *n* (%)		52 (39.4)	
Care partner reports logging in using the patient's identity credentials, *n* (%)[c]		41 (78.8)	
Care partner reports direct messaging with medical oncology team, *n* (% accessed)[c]		25 (48.1)	

[a] One patient died between enrolment and baseline interview

[b] *p*-value computed for 129 dyads with complete responses (item nonresponse for $n=1$ patient and 1 care partner)

[c] Computed for subset of $n=52$ care partners who reported viewing medical information or test results in prior year

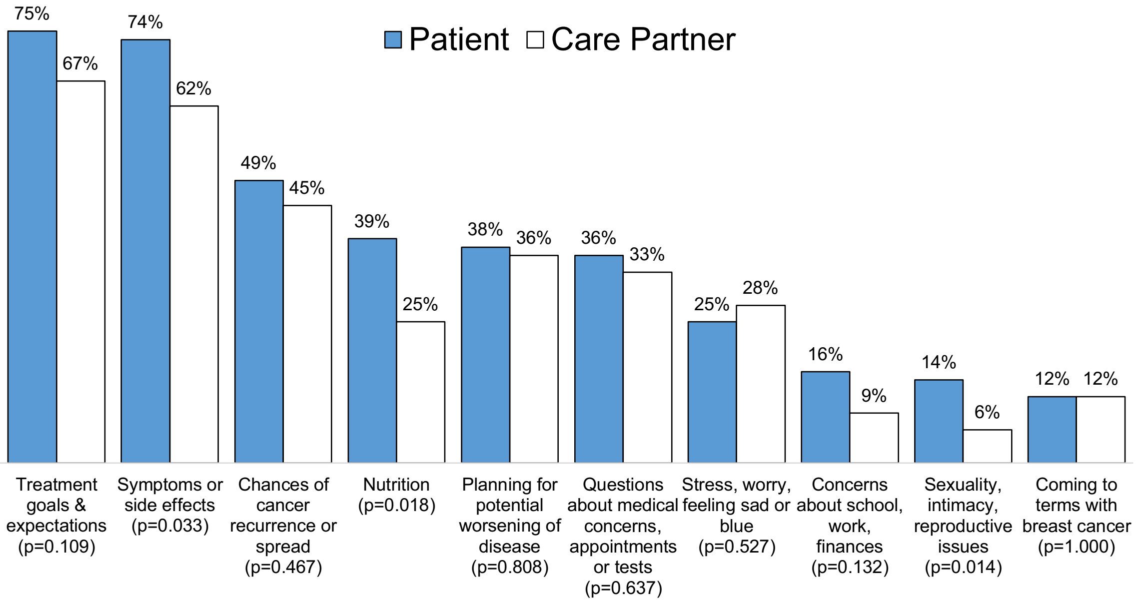


Fig. 3 Patient and care partner-identified visit priorities from agenda setting checklist. Intervention group only ($n=69$). *p*-values reflect statistical test of difference in whether each health issue was a priority for the visit (patient only, care partner only, both, neither)

Table 3 Short-term effects on patient and care partner registration and use of the patient portal

	Patient			Care partner		
	Intervention $n=69$	Control $n=63$	p value[a]	Intervention $n=69$	Control $n=63$	p value
Registered for patient portal						
Baseline	63 (91.3)	55 (87.3)	0.636	1 (1.5)	1 (1.6)	0.948
Six weeks	66 (95.7)	55 (87.3)	0.149	52 (75.4)	1 (1.6)	<0.001
Logged into patient portal						
Baseline	63 (91.3)	54 (85.7)	0.456	1 (1.5)	0 (0.0)	0.338
Six weeks	64 (92.8)	55 (87.3)	0.434	30 (43.5)	0 (0.0)	<0.001
Viewed clinical notes in patient portal						
Baseline	11 (17.5)	5 (7.3)	0.095	0 (0.0)	0 (0.0)	–
Six weeks	35 (50.7)	6 (9.5)	<0.001	21 (30.4)	0 (0.0)	<0.001
Exchanged direct message in patient portal						
Baseline	40 (58.0)	31 (49.2)	0.313	0 (0.0)	0 (0.0)	–
Six weeks	40 (58.0)	30 (47.6)	0.234	2 (1.5)	0 (0.0)	0.175

[a] Adjusted for group differences in patient education

Intervention acceptability and short-term effects

Intervention patients and care partners unanimously agreed or strongly agreed that completing the checklist was easy (100% for both), useful (97% and 93%, respectively), helped in preparing for the visit (86% and 81%), clarified the role of the care partner (91% and 81%), and helped them feel more in control of their care (80% and 84%). Most patients and care partners recommended the checklist to others (97% and 96%), stated they would like to continue to use it in the future (88% and 84%), and that the amount of time it took to complete the checklist was "just right" (97% of both).

No differences in global visit satisfaction were observed for intervention and control patients (87.0% and 84.1%), care partners (78.3% and 74.6%), or clinicians (94.2% and 96.8%). "Excellent" visit communication was reported by similar proportions of intervention and control patients (91.3% and 85.7%), care partners (84.1% of both), though less by clinicians (55.1% and 61.9%).

We did not observe differences between intervention and control patients' registration (95.7% and 87.3%) or use (92.8% and 87.3%) of MyChart at 6 weeks, but intervention patients were more likely to view oncology visit notes (50.7% vs 9.5%; $p<0.001$) than control patients (Table 3). Intervention care partners were more likely to be registered for MyChart (75.4% vs 1.6%; $p<0.001$) and have accessed (43.5% vs 0%; $p<0.001$) the patient's information at 6 weeks: 30.4% of care partners viewed clinical visit notes, and 1.5% engaged in direct messaging using the proxy MyChart account. Of the 30 intervention care partners who accessed MyChart between baseline and 6-weeks, 20 (66.6%) reported accessing MyChart in the prior year (data not shown).

Discussion

This study examines the acceptability and short-term effects of a low-cost, scalable strategy to engage family care partners in cancer communication. At baseline, most—but not all—patients reported involving family in medical decision-making while 4 in 5 patients stated they would like their care partner to have access to their electronic health information. Few (< 2%) care partners were registered for MyChart at baseline, although 4 in 10 reported viewing patient's electronic health information in the prior year using the patient's credential. Within this context, we found that a brief, self-administered patient–family agenda setting checklist was endorsed as being helpful to patient and care partner pre-visit preparations, led to striking increases in care partner registration and use of the patient's MyChart account, and led to more intervention patients viewing oncology visit notes at 6 weeks.

Our study fills an important evidence gap in establishing the feasibility and relevance of increasing engagement of family at the point of care. That 3 in 4 intervention dyads elected to register the care partner for shared access to MyChart is notable for both the high uptake and strong alignment with baseline information sharing preferences of patients in both arms of the trial. That 4 in 10 intervention care partners accessed the patient's MyChart account by 6 weeks indicates a high degree of engagement and the perceived value of shared access functionality. It may be reassuring to some clinicians that care partners who obtained their own access to MyChart tended to use it for viewing information rather than sending direct messages to clinicians, as it suggests that shared access functionality does not necessarily translate to additional time demands for clinicians. In addition, given that nearly 1 in 5 care partners at baseline reported direct messaging clinicians in the prior year, shared access may confer advantage to clinicians in affording greater ability to differentiate with whom they are messaging: the patient or their care partner.

Studies to date have primarily documented the challenges of cancer caregiving [1] or trialed psychosocial interventions to address caregiver burden [6, 10, 11]. Emerging interventions to increase engagement of families in decision-making about cancer care [22, 24, 34] have largely focused on a specific decision and been conducted outside care delivery. Our study supports the importance of better supporting care partners as we find that symptoms of depression and anxiety among cancer care partners are common. That most caregivers were working and nearly 2 in 3 working caregivers reported missing an average of a full day of work due to caregiving in the past week contributes to emerging concerns about a need to more broadly assess and address financial toxicity in cancer care [35, 36].

Results are subject to limitations. Our study was not designed nor powered to detect differences in intervention effects for patients with early versus advanced breast cancer. While the study was conducted in two separate clinics within a single academic institution, additional research is necessary to determine whether findings generalize to mainstream oncology community care. Because the study protocol involved research staff distributing the checklist to intervention participants, we cannot yet comment on how the protocol would be adopted in routine practice. The widespread use of MyChart by patients in this study is higher than previous reports of modest registration and use in general primary care and oncology populations [37] and may be due in part to the high levels of educational attainment among study participants.

Our current study contributes to a broader literature establishing the importance of longitudinal communication in serious illness [38–40]. Timely, comprehensive, and accurate information about prognosis and treatment is valued by patients [41] and families [42–44], and is foundational to disease understanding, decision-making, and delivery of care that supports patient wishes [9, 45, 46]. The accelerating spread of health information technology, increasing complexity of therapeutic regimens, and heavy reliance on family to help manage the demands of cancer care support the need for practices that respect patient preferences and family contributions in co-managing the delivery of safe, clinically appropriate, person-centered care. Follow-up of patients and care partners in this study is ongoing to examine longer-term effects for quality of communication, symptoms of depression and anxiety, satisfaction with cancer care, and illness understanding.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards Informed consent was obtained from all individual participants included in the study.

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